Clinical genetics in practice

A survey of the clinical facilities for the management of familial cancer in Europe: details of the current status

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We have set out to evaluate the current status of services for inherited breast cancer in different European countries, with the following specific aims.

(1) To determine the provision of clinical services for inherited breast cancer in relation to the population served, in different European countries.

(2) To evaluate the progress of service development in these countries, with particular emphasis on the use of genetic counsellors for the delivery of such services.

(3) To assess the provision of educational and career structures for such nurses and counsellors for each country in relation to their perceived roles.

(4) To determine the provision of educational materials on cancer genetics in European countries, in the context of general public education and awareness.

(5) To identify factors which have an impact on the development of such services.

A questionnaire about cancer genetics services was devised and sent out to all BIOMED participating centres (see Annexe) and to selected professionals in all European countries. A second questionnaire and reminder were sent out about one year later, requesting broader information about such services in these countries, and replies were analysed. Personal contacts were made at international conferences such as the European Society of Human Genetics meeting in Portugal in 1998, and posters were presented and discussed at the European Society of Human Genetics meeting in Geneva in 1999, and the American Society of Human Genetics meeting in Denver, Colorado in 1998.

The information received was drawn into a comprehensive report. Detailed data are shown in table 1. It should be noted that this is a "snapshot" of services at one point in time and the situation is changing rapidly. In addition, since only selected authors were chosen for each country, we cannot exclude bias or incompleteness of reporting.

Information received indicates a wide variability in the level of services in different countries, depending on many factors, including the following.

(1) The level of general awareness in the population about cancer genetics, which affects the demand for such services, and media interest in the subject.

(2) The background level and tradition of genetic services in the country.

(3) The interest in cancer registries and genetic registers.

(4) The tradition of integrated health care networks in the country (influenced by size of country) and strategies for primary care.

(5) The acceptance and recognition of genetic nurse/counsellors as part of the team for service delivery and the educational and career structures available for such counsellors.

(6) The economic level of the country and the proportion of GNP spent on preventative health care.

Countries in which cancer genetics services are well developed, and in which genetic counsellors are integrated into service delivery, are the United Kingdom, Norway, Finland, The Netherlands, and Israel. In Denmark, nurses are being deployed to assess family histories and prioritise referrals for genetic counselling.

Countries with comprehensive, well established cancer genetic services, but where genetic counsellors are not accepted as playing a significant role in service delivery, include France, Germany, and Sweden. Others, where genetic counsellors play a limited role, include Belgium.

Active development of an integrated service is being promoted in Italy, Austria, Switzerland, Portugal, Poland, and others. There are as yet few cancer genetic services in Spain, Turkey, Estonia, Latvia, Greece, Lithuania, Romania, and Hungary. In Russia there are some services, but these are not as an integrated network. Genetic nurses are also accepted as helping to provide the cancer genetic service in Belarus, Croatia, the Czech Republic, Ireland, and Hungary.

Most countries have some form of cancer registry. Registers for familial polyposis and other single gene disorders tend to form the prototype for genetic cancer registries and are

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Table 1 Survey of cancer genetics services in 89 centres from 34 European countries (includes data obtained from Concerted Action on Genetic Services in Europe[7]

Country	*Population (×10⁶)*	*GNP/cap (×10³)*	*Recognised speciality*	*Genetic counsellors*	*Integrated service*	*Cancer genetics services*	*Genetic registers*	*Recognised training in cancer genetics*	*Audit and evaluation*	*Discussion fora?*	*State funding?*	*Cancer charities?*
Austria	8.0	20.9	1994	Few	Yes	Comprehensive	No data	No data	No data	Soc Hum Genet	Yes	Yes
Belarus	No data	No data	No	Yes	No data	No data	Yes	No data	No data	No data	Yes	Yes
Belgium	10.1	20.8	No	Some	Yes	Comprehensive	Yes	Developing	Yes	Yes & website	Yes	Yes
Bulgaria	8.4	4.6	1985	Yes	No data	Limited	No data	Developing	Yes	Yes	Yes	Yes
Croatia	4.8	3.9	No	Some	No data	Limited	Yes	Developing	Some	Some	Yes	No data
Cyprus	0.7	11.6	No	Some	No data	No	Yes	Outside Cyprus	Yes	Yes	Some	Yes
Czech Republic	10.3	21.5	1980	Yes	Yes	Limited	Yes	Developing	No	Yes	Yes	Yes
Denmark	5.2	26.0	1996	Yes	Yes	Comprehensive	Yes	Yes	Yes	Yes	Yes	Yes
Estonia	No data	No data	No data	No data	No data	No data	Yes, cancer	International only	Yes	Yes	Yes	Yes
Finland	5.1	17.1	1981	Yes	Yes	Comprehensive	Yes	Developing	Yes	Yes	Yes	Yes
France	58.1	20.0	1995	Few	Yes	Comprehensive	Yes	Yes	Yes	Yes	Yes	Yes
Germany	81.6	20.4	1992	No	Yes	Comprehensive	Not integrated	Yes	Yes	Yes	Yes	Yes
Greece	10.6	11.7	No	Some	No data	Limited	No data	No data	No data	Little	Yes	Yes
Hungary	10.2	6.6	1978	Few	Yes	Limited	Yes, cancer	No data	Some	Yes	Yes	No data
Iceland	No data	No data	No data	Developing	Developing	Developing	Yes	Yes (in Sweden)	No data	Yes	No data	No data
Irish Republic	3.58	16.43	No	Yes	Yes	Developing	Yes	Developing	Yes	Developing	Yes	No data
Israel	5.5	15.7	1986	Yes	Yes	Comprehensive	Yes	Yes (including MSc)	Yes	Yes	Yes	Yes
Italy	57.3	19.5	1940	No	Developing	Developing	No data	Developing	Yes	Yes	Yes	Yes
Latvia	2.5	3.3	No data	No	Developing	Limited	Yes	Developing	Developing	Developing	Yes	Yes
Lithuania	3.7	4.0	1991	Yes	Only 1 centre	Limited	No data	Developing	(Yes)	No data	Yes	No data
Netherlands	15.5	19.3	1987	Yes	Yes	Comprehensive	Yes	Yes	Yes	Yes	Yes	Yes
Norway	4.4	23.2	1971	Yes	Yes	Comprehensive	Yes	Yes	Yes	Yes	Yes	Yes
Poland	38.6	5.5	1998	Few	Yes	Developing	Yes	Yes	Yes	Yes	Yes	No data
Portugal	9.9	12.8	Yes	Few	Developing	Developing	Yes	Developing	Yes	Yes	Partly	Yes
Romania	22.7	4.3	1997	No data	No	Limited	Some	Developing	No	(Yes)	Yes	No data
Russia	148.1	4.4	1988	Few	Not integrated	Limited	Local only	Developing	Developing	Yes	Yes	No data
Serbia	10.5	0.4	No	Yes	Yes	Limited	No data	Yes	No data	Developing	Yes	Yes
Slovenia	2.0	10.7	No	Few	Yes	Developing	Yes	Developing	Yes	Yes	Yes	No data
Spain	39.2	14.2	No	No	Partly integrated	Limited	Yes, cancer	No	Developing	Yes	Yes	Yes
Sweden	8.8	18.2	1991	Developing	Yes	Comprehensive	Yes	Developing	Developing	Yes	Yes	Yes
Switzerland	7.0	24.4	No data	No	Yes	Developing	Developing	No	No	Yes	Partly	Yes
Turkey	62.5	5.6	1990	No	Partly integrated	Limited	Developing	No	Developing	Yes	Yes	Yes
Ukraine	51.5	2.4	1993	Yes	Yes	Comprehensive	Yes	Developing	Yes	Yes	Yes	Yes
United Kingdom	58.3	18.4	1970	Yes	Yes	Comprehensive	Yes	Yes	Yes	Yes	Yes	Yes

particularly renowned in Belgium, the United Kingdom, Denmark, The Netherlands, Finland, and Ireland. There are national networks for genetic registers in France, The Netherlands, and Germany. Registers also exist in Sweden, Slovenia, Poland, and Lithuania.

Audit of cancer genetic services is under way, or being initiated, in Denmark, The Netherlands, the United Kingdom, France, Germany, Italy, Norway, Poland, Sweden, and Israel. Most countries have some educational facilities for cancer genetics, although this is variable.

Factors shown to influence the level of cancer genetics are, in detail, the following.

(1) The recognition of genetics as an official speciality (21 of 29 European countries for which data were available).

(2) There is a rough correlation between Gross National Product (GNP) per capita and the level of cancer genetics services in the country, but other factors also influence the development of these services. These include the existing status of genetics as a recognised specialty (which enables career structures and education in genetics to be developed and formalised), which in turn is dependent upon political and historical factors. The best networks for genetic services may exist in the former Eastern Bloc countries and in Scandinavia, but lack of funding prevents implementation of these networks in less affluent countries. The proportion of the population with access to medical services depends on geographical, economic, and traditional factors.

(3) Balance between national and private health services. Eleven countries have government funded services alone. Many have variable amounts of research funded services and others partly use health insurance and private practice. In countries where private and national health services operate concurrently, there may be conflict between the two strategies, and coordination of services and audit may be hampered.

(4) Cancer genetics service development is predicated upon coordination of strategy and maintenance of an evaluation of service outcomes in order to provide data for health service policy makers in strategic service development. In the United Kingdom, cancer genetics networks have been set up using the framework of the network of clinical genetics services, divided into Regions served by a Regional Genetics Centre. Plans are being made for selecting high risk patients in primary care and clinics in cancer units, possibly jointly by trained genetic counsellors within the cancer clinics. "Moderate risk" people can be referred for screening locally, provided that there are facilities for central recording of surveillance outcomes allowing long term audit of the service. High risk subjects may be referred to the Genetics Department for specialised counselling and predictive testing, possibly in conjunction with "Calman" cancer centres. A network of cancer genetics clinics in

France has been developed after the research interests of the group in Lyon led to increasing demands for genetic counselling for breast cancer susceptibility. In 1987 the service became part of the Centres against Cancer (CLCC), supported by a French charity, the League against Cancer. In France there is a network on cancer predisposition known as the Genetics and Cancer Group of the Féderation Nationale des Centres de Lutte Contre le Cancer (FNCLCC), which gathers together oncologists, radiotherapists, surgeons, and geneticists involved in the field, from which has sprung the concept of an "oncogeneticist". In The Netherlands a similar process led to the development of a national registry of hereditary breast cancer families managed by the Foundation for the Detection of Hereditary Tumours, and family cancer clinics were set up in several Dutch medical centres. A multicentre interdisciplinary network for the management of hereditary breast cancer has been set up in Germany and Deutsche Krebshilfe is funding a research programme to investigate HBOC management. Active development of an integrated service for cancer genetics is being promoted in Italy, Austria, Switzerland, Portugal, Poland, and other countries. There are, as yet, few cancer genetics services in Spain, Turkey, Estonia, Latvia, Greece, Lithuania, Romania, and Hungary, but these are being actively promoted. In Russia, there are some services, but they do not constitute an integrated network.

(5) Tradition of primary health care is important, since coordination between primary care and referral centres for surveillance and management is fundamental to this type of service.

(6) Features of the health system facilitating the development of genetic cancer services include the presence of existing genetic screening programmes for common genetic conditions with an important impact on public health, such as thalassaemia in Mediterranean countries, and established genetic registers for specific genetic conditions which predispose to cancer, such as the Danish register for familial adenomatous polyposis. This establishes a framework upon which general cancer genetic services can be modelled.

(7) The tradition of service audit in place in the country influences how this can be adapted to evaluate cancer genetics services. For instance, specific audit of cancer genetic services is under way in Denmark, The Netherlands, the United Kingdom, France, Germany, Italy, Norway, Poland, Sweden, and Israel. Audit of the outcome of surveillance is vital for this service, but is very difficult to achieve because of the coordination and data retrieval required. Confidential databases able to store such data are invaluable, but require considerable manpower for data retrieval and input.

(8) Since much of cancer genetics services depends upon an efficient identification and assessment of subjects at raised genetic cancer risk in the community, with appropriate referral strategies, countries where the role of genetic counsellors in service delivery is accepted have an advantage. Genetic counsellors may be nurses or graduates having received a training in genetic counselling (such courses are being developed, particularly in the United Kingdom). They have an important role in obtaining and assessing pedigree data, estimating cancer risks, counselling, and organising appropriate surveillance. However, training and career structures for them are still being developed. The recognition of Genetic Counsellors as having an acceptable role in the delivery of genetic services is important, because the large scale required to deliver such a service to the population requires considerable organisation and manpower.

The education of genetic nurses and counsellors in the delivery of cancer genetics services is being developed. Plans include education courses on pedigree evaluation and genetic counselling in cancer genetics for nurses and other genetics associates (for example, those with an MSc in Genetic Counselling and a science degree) to work as "gatekeepers" in primary care. A randomised study of the role of genetic counsellors in providing educational and supportive links with primary care in the management of cancer family members is under way in Lothian (Scotland), and there is an increasing appreciation of the need to develop a system for the development of a network of primary care gatekeepers to prioritise people for referral to genetics and screening services. It is important to have guidelines available for primary care and to have ongoing educational input, and to ensure uniformity of standards for the education of the gatekeepers.

Countries in which cancer genetics services are well developed and in which genetic counsellors are integrated into service delivery are the United Kingdom, Norway, Finland, The Netherlands, and Israel. In Denmark nurses are being deployed to assess family histories and prioritise referrals for genetic counselling. Countries with comprehensive, well established cancer genetics services, but where genetic counsellors are not accepted as playing a significant role in service delivery, include France, Germany, Austria, and Sweden. Others, where counsellors play a limited role, include Belgium. Genetic nurses are accepted as helping to provide the cancer genetic service in Belarus, Croatia, the Czech Republic, Ireland, and Hungary.

(9) Most countries have some form of cancer registry. Registers for familial polyposis and other single gene disorders tend to form the prototype for genetic cancer registries and are particularly renowned in Belgium, the United Kingdom, Denmark, The Netherlands, Finland, and Ireland. There are national networks for genetic registers in France, The Netherlands, and Germany. Registers also exist in Sweden, Slovenia, Poland, and Lithuania. Such registers provide a template for the development of registers for cancer which could allow at risk relatives to be identified appropriately.

(10) Public awareness of cancer genetics has a fundamental influence on the demand for services for cancer genetics, reflected in rapid increase in such demand recently. Some coun-

tries have taken the initiative to set up museum exhibitions, and have extensive media coverage of these issues, but the discipline of genetics can in some countries have unpleasant historical connotations, which detracts from its popular image. World Wide Web sites are being developed rapidly and disseminate much information about cancer genetics. Patient support groups for genetic conditions exist in a few countries (notably the United Kingdom, The Netherlands, and France), but those specifically concerned with cancer genetics are still relatively uncommon.

The provision of educational material on cancer genetics

With increasing awareness of the public health implications of cancer genetics, the provision of educational material is being developed at several distinct levels in all the countries represented. The aim of such material is largely to satisfy demand from the public and professionals for appropriate information and guidelines to ensure that those at increased genetic risk of developing cancer can be identified and counselled, and given options for appropriate preventative measures to reduce their cancer risks. This carries profound public health implications, so health care economists require appropriate information to guide future planning in this area. There is particular need to provide as much proof of the efficacy of cancer genetic services as possible, and to "demystify" the subject for groups for whom this is new information.

The "targets" for such educational material need to be defined, as the background knowledge of genetics and the outcome aims will differ for the different target groups.

"Opportunity groups" for educational material include: the public, via the media; consumer associations and self-help groups; primary health care professionals; genetic nurses and associates (with a background in nursing or academic science, with additional clinical genetics training); other professionals (surgeons, oncologists); industry, pharmaceutical companies; opinion leaders and government.

Many of the above services will be sympathetic to the aims of genetic services, but possible "Hurdle Groups" may include: certain aspects of the media; health care purchasers and government agencies; insurance companies; pressure groups.

Current activities

Information was collected from the BIOMED II contributing centres about their current activities. All centres were providing information to patients, usually as personalised letters, and most were also developing educational leaflets for the patients seen in the genetics clinics. Half of the centres responding stated that they were helping to produce seminars and support group information. All were developing provisional referral guidelines and supporting publications and training for primary health care, and 87% were providing such guidelines for medical consultants. As evidence for the benefits of surveillance and prophylactic measures accumulates, these provisional guidelines are being disseminated more widely.[1–3] Chapters and books on cancer genetics are proliferating, mainly addressing scientific and psychosocial aspects, directed at physicians working in the field. However, agencies such as the Progress Educational Trust and the Wellcome Trust are producing booklets aimed at a lay audience which address genetic issues and include aspects of cancer genetics (for example, *The Progress Guide to Genetics* by Marcus Pembrey) for primary care workers and the public.

Professor M Steel's group (Scotland) has developed video material and uses nurses' groups to disseminate information. Other groups are developing computerised packages appropriate for use in primary care (for example, the Imperial Cancer Research Fund and the Cancer Research Campaign[4]). Information is being disseminated through the Foundation for the Detection of Hereditary Tumours in The Netherlands, the League Against Cancer (Centres Against Cancer) in France, the Cancer Family Study Group in the United Kingdom, and through the Danish Breast Cancer Collaborative Group in Denmark.

Patient support groups specially for cancer genetics are only just beginning to form; in the United Kingdom there is an active group being developed in Manchester (run by W Watson), and information may be channelled through Cancerlink and the Genetic Interest Group.

Cancerlink and Cancer Bacup provide more general information and support for cancer sufferers, but are beginning to advise people with a family history of cancer, as demand for information grows, and articles about genetic testing for cancer susceptibility are being published, for example in *Bacup News*.[5]

The cancer charities provide some information about cancer genetics in their publications and pharmaceutical companies mention the issue in their publications for patients (for example, the *Sussex Breast Cancer Guide*, Glaxo). There is as yet little such information from the minority groups, notably the Ashkenazi Jewish organisations, for whom the issue of hereditary breast cancer is of particular relevance.

In Norway there are national referral guidelines being distributed by the cancer charities and medical associations.

Lecture courses are being developed, notably the Cancer Genetics module of the MSc course run by the Royal Marsden Hospital (London) and the Cancer Genetics module in the BSc course on genetics for nurses at Queen Margaret College (Edinburgh).

The Cancer Genetics Group in the United Kingdom has grown up as an organisation for discussion about research into cancer genetics, for geneticists and other professionals involved in offering these services. This group is forming a nucleus for national and international collaboration; other, more specialised, international collaborative groups include the International Collaborative Group for the Study of Hereditary Non-Polyposis Colon Cancer (ICG-HNPCC) and the European Group for

the Study of Familial Adenomatous Polyposis (EUROFAP).

There is increasing interest in the media about hereditary cancer and many programmes are being produced, mainly focused on personal dilemmas and the psychological and family impact of issues surrounding predictive testing and management of familial cancers. Geneticists may be asked to help with the scientific background of these programmes, but their role is mostly reactive.

Museums in the United Kingdom are producing exhibitions about genetics in relation to medicine and cancer genetics receives a high profile. The recent "Genetic Choices" exhibition at the Science Museum, funded by the Wellcome Trust, had a significant emphasis on cancer genetics, and a new and much larger exhibition, funded with Lottery money, is planned at the Science Museum for the year 2000.

The Wellcome Trust is actively involved in developing educational packages about genetic issues, particularly for schools. These activities may be summarised as the following.

(1) Educational research, for example, a project recently undertaken at the University of Leeds, on young people's understanding of and attitudes to the "New Genetics".

(2) Theatre in Education production, "The Gift", for secondary school students, now produced as a CD-ROM disk. There is also a video, "Perfectly Normal", exploring ethical and social dilemmas of genetic issues.

(3) LabNotes: research updates for secondary school teachers.

(4) Workshops for Students in the Lifelab space at the Wellcome Building, run by PhD students trained in science and communications skills.

(5) Teacher training in molecular biology.

(6) Exhibitions such as the travelling show "Genes R U", which has appeared at shopping centres throughout the country and "Nature Nurture" in September 1997.

(7) Meetings to discuss the ethical issues surrounding genetic testing, such as a debate held in March 1997 entitled "Human Genetics: the People Decide", which attracted national television news coverage.

Similar projects are being developed in other European countries, for instance, a major exhibition entitled "Mensch und Gene" was held in the Exhibition Hall in Bonn in 1998.

In the United Kingdom, a "Gene Shop" was set up at Manchester Airport, providing general information about genetics direct to the public, and a "Gene Dome" is being built in Newcastle, which is to be a museum of genetics for the general public, including a good deal of information about cancer genetics.

The Wellcome Centre for Medical Science has developed a "Theatre in Education" programme, including a presentation entitled "Lay Genetics: Creating the Debate", for lay audiences, which was shown at Fringe theatre locations in 1996. A video produced from this production was used for teaching purposes. Another educational performance was a play produced with the help and advice of the Yorkshire Regional Genetics Services, entitled "Mental", and there is a video of this, entitled "Perfectly Normal", exploring some of the ethical and social dilemmas of genetic issues.

All the countries surveyed are developing teaching courses, including cancer genetics, for medical students, general practitioners, other professionals, and the specialist colleges, and some education about cancer genetics is being incorporated into the medical students' clinical teaching curricula.

A specialised one week summer course in Cancer Genetics is organised jointly by the Istituto G Gaslini (Genoa, Italy) and the International Agency for Research on Cancer (Lyon, France) for PhD students, geneticists and other medical specialists, genetics associates, and genetics nurses, and a course in genetic counselling has just been added to this.

The World Wide Web now has several sites which address cancer genetics issues. These include the following.

(1) What is Genetic Screening? (BIOSIS) http://www.scicomm.org.uk/biosis/human/whatis/html

(2) Understanding Gene Testing (European Initiative for Biotechnology Education - resources for teaching aimed at 16-19 year olds) http://134.225.167.114:8001/EIBE/preview.html

(3) Advisory Committee on Genetic Testing - draft code of practice (BIOSIS) http://www.scicomm.org.uk/biosis/acgt/ACGT2.html

(4) There is a London based website, BIONEWS, which scans media articles for details of the latest developments in human genetics and biotechnology and e-mails subscribers weekly. This can be found at http://www.progress.org.uk/News/BioNews/index.html

(5) An internet based newsletter, the "Gene Letter" (established by the Shriver Center, with a grant from the US Department of Energy/ELSI programme), aims to educate consumers and professionals about advances in genetics and to encourage discussions about emerging medical, ethical, legal, and policy dilemmas in this area. Further discussions about the newsletter appear on http://www.geneletter.org

(6) The National Cancer Institute (NCI) has a web site, "Cancer Facts", on CancerWeb, which supplies information for cancer patients, their families, and the public, and backs this up with a telephone advice service: http://cancerweb.www.graylab.ac.uk/cancernet/600349.html

(7) As part of the Cancer Genome Anatomy Project, funded by the NCI, American Vice President Al Gore recently unveiled a website at http://www.ncbi.nlm.nih.gov/ncicgap with the aim of having "all the pieces together in the same place".[6]

It is to be hoped that this "'snapshot" of cancer genetics services in different European countries will provide baseline evidence for the factors influencing their development and allow comparisons to be made over time as these services develop.

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1 Eccles DM, Evans DGR, Mackay J, on behalf of the UK Cancer Family Study Group (UKCFSG). Guidelines for a genetic risk based approach to advising women with a family history of cancer. *J Med Genet* 2000;**37**:203-9.
2 Eisinger F, Alby N, Bremond A, Dauplat J, Espie M, Janiaud P, Kuttenn F, Lebrun JP, Lefranc JP, Pierret J, Sobol H, Stoppa-Lyonnet D, Thouvenin D, Tristant H, Feingold J. Recommendations for medical management of hereditary breast and ovarian cancer: the French National Ad Hoc Committee. *Ann Oncol* 1998;**9**:939-50.
3 Vasen HF, Haites NE, Evans DG, European Familial Breast Cancer Collaborative Group. Current policies for surveillance and management in women at risk of breast and ovarian cancer: a survey among 16 European family cancer clinics. *Eur J Cancer* 1998;**34**:1922-6.
4 Emery J, Walton R, Coulson A, Glasspool D, Ziebland S, Fox J. Computer support for recording and interpreting family histories of breast and ovarian cancer in primary care (RAGs): qualitative evaluation with simulated patients. *BMJ* 1999;**319**:32-6.
5 *Bacup News* 1997;**29**:7-10.
6 Ehrenstein D. Your complete web guide to tumors. *Science* 1997;**277**:762.
7 Harris R, ed. Genetic services in Europe: a comparative study of 31 countries by the Concerted Action on Genetic Services in Europe. *Eur J Hum Genet* 1997;**5**(suppl 2):1-220.

Annexe

ALBANIA

Genetic services

There is one genetics centre in Albania, but this does not offer a service for familial cancers.

CANCER GENETICS SERVICES

There is as yet no centre offering a molecular diagnostic service for familial cancers; the current approach to the care of families with a strong history of breast cancer involves annual screening from the age of 30 years (mammogram, ultrasound, and clinical examination), with a further clinical and ultrasound examination every six months.

The University Hospital Center in Tirana runs a breast clinic as part of its oncology service, and a second clinic is run by the Public Health Service. These clinics offer a diagnostic and screening service, with specialist surgical, radiological and cytopathological staff, and offer imaging by mammography and ultrasound.

Training

There is no specialist training currently available.

TRAINING OF CANCER GENETICISTS

There is no specialist training in cancer genetics and the country lacks the specialist equipment necessary for a routine cancer genetics service.

Audit and evaluation

There is no provision for audit, evaluation, or surveillance at present.

Discussion fora

There is a discussion forum for the consideration of genetic blood disorders.

SPECIFIC CANCER DISCUSSION GROUPS

There is no specific cancer discussion group at present.

Education

No details are available.

Registers

There is a cancer epidemiology register.

Support

CANCER CHARITIES

No details are available.

PATIENT SUPPORT GROUPS

No details are available.

Persons responding

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AUSTRIA

Genetic services

Genetic services in Austria, and the historical difficulties attending their implementation, have been summarised by Utermann[1]: following

1945 there were no university departments of human genetics, and departments of "medical biology and genetics" developed into de facto Institutes of Human Genetics. Today there is no organised network of genetics services at either a national or a regional level. In order to function, genetics centres have to be approved by the Ministry of Women's Affairs and Consumer Protection, but no centre has yet been accorded such approval (for example, the Innsbruck Centre has still not been approved despite at least three applications in eight years). There are two genetics centres (Graz, Innsbruck), which offer a comprehensive service with counselling, diagnostic testing, cytogenetics, and molecular genetics, and operate their own diagnostic laboratories, while a number of other centres (in particular the Allgemeines Krankenhaus, Vienna) provide services for particular disorders. There is no biochemical genetics service, although, for instance, neonatal screening for phenylketonuria is available. Screening programmes (for example, for cystic fibrosis) exist at a local level in some parts of the country, but there is no organised national service. Genetic services are generally funded by the social health insurance system; however, Utermann[1] states that more than half of all genetic services in Austria are privately funded (for instance, two private laboratories in Vienna offer cytogenetic analysis).

Utermann[8] estimates that there are between 12 and 15 trained medical geneticists currently working in Austria (a figure of approximately two geneticists per million of the population). There are no genetic counsellors or nurses and in Vienna, at least, there is no provision for genetic associates/nurses (either general or specialists) to take part in the provision of a genetics service.

CANCER GENETICS SERVICES

There are five familial breast cancer clinics in Austria (which also deal with sporadic cancers). Each is state funded and run by a doctor. Testing is available for familial breast/ovarian cancer, but not for FAP. Innsbruck and Graz offer molecular testing for *BRCA1/2*, *hMSH2*, *hMLH1*, and *APC* mutations, and services are also available for Li-Fraumeni syndrome and the multiple endocrine neoplasias. Vienna offers *BRCA1/2* testing.

Training

There are no recommendations for the teaching of genetics in medical schools, either at undergraduate or postgraduate levels, and none of the three Austrian medical schools (Vienna, Innsbruck, Graz) teach genetics as part of their curriculum. This lack of genetic knowledge among non-geneticists hampers access to genetic services.

Genetics was recognised as a subspecialty in 1994, but there is no provision for the training of medical geneticists, and the major centres have no teaching posts: the Ministry of Health and Consumer Protection has not yet recognised it as a separate specialty. According to Utermann[1] there are 12 physicians who have qualified in the subspecialty of human genetics: of these, five are gynaecologists involved in prenatal diagnosis, not general geneticists. It is possible for physicians who have specialised in gynaecology, dermatology, histology and embryology, hygiene and microbiology, internal medicine, paediatrics, medical biology, laboratory medicine, neurology, pathology, and psychiatry to qualify as subspecialists in medical genetics.

There are no training courses for genetic associates or nurses and genetics is not included as part of the nursing curriculum. Laboratory technicians receive "hands on" training "on the job", but there is no broader training scheme in operation.

TRAINING OF CANCER GENETICISTS

Vienna runs a two day course on familial breast/ovarian cancer for MDs annually.

Audit and evaluation

There is no system for the auditing or evaluation of genetic services, although they are nominally under the surveillance of the Ministry of Women's Affairs and Consumer Protection.

Laboratories carrying out carrier testing for recessive disorders, or predictive testing, using molecular diagnostic techniques must be accredited by the Ministry of Health and Consumer Protection, although this is not necessary once symptoms have developed. Accreditation is the responsibility of a Scientific Council for Gene Analysis and Gene Therapy (set up in accordance with the Gene Technique Law), but there are as yet no criteria for approval, although a considerable number of applications are pending.

Discussion fora

The Austrian Society of Human Genetics was founded to remedy the lack of genetic services and awareness from which Austria suffers.

SPECIFIC CANCER DISCUSSION GROUPS

The Austrian Cancer Society, the Austrian Society for Surgical Oncology, and a number of other groups hold discussions from time to time.

Education

The lack of genetic awareness among non-specialist physicians hampers public access to genetic services, and there is lack of awareness of the availability of genetic services within the profession.

Vienna does not supply information leaflets to patients, but post-counselling they are given leaflets by the Austrian Cancer Society. There are no information videos for patients.

Medical genetics issues enjoy a very low profile in Austria, for a variety of reasons, historical and otherwise. There are very occasional television programmes, for instance an upcoming TV programme on breast/ovarian cancer.

Registers

There are no genetic registers in Austria.

Support

CANCER CHARITIES

Austrian Cancer Society

PATIENT SUPPORT GROUPS

The Austrian Cancer Society offers information leaflets to patients post-counselling.

8 Utermann G. Genetic services in Austria. *Eur J Hum Genet* 1997;**5**(suppl 2):31-4.

Persons responding

Dr Teresa Wagner, Vienna.

BELARUS

Genetic services

Genetics services in Belarus are in their infancy. Public knowledge of hereditary factors in breast cancer, to give one example, and interest in genetic counselling or screening, was non-existent. A sustained effort has been made to educate both health care professionals and the public about genetic issues and the situation is improving, although there is still considerable need for further development.

CANCER GENETICS SERVICES

There is one familial breast cancer clinic at the Institute of Genetics and Cytology of the National Academy of Sciences in Minsk. This is a research institute, not a medical institute, and so does not have a specialist clinician: it operates with three research associates (two research funded, one half funded by the Government Health Service), who analyse and estimate individual risks of developing cancer, and two genetic nurses (research funded), who gather information, family histories etc, from cancer patients. The service has been operational since 1990, but because this is a research institute the personnel are not authorised to provide a specialist service and are not medically qualified. It is hoped, in the future, to introduce molecular genetic methods into the service, and to develop a programme for the genetic screening and subsequent monitoring of breast cancer families. Since 1996 there has been close collaboration with the Minsk State Oncological Clinic (one clinician and one nurse, government funded), and members of families presumed to have hereditary breast cancer are seen by both a geneticist and an oncologist. However, this service has not yet spread to other genetics and oncology clinics.

Training

No general information on genetic teaching in the medical curriculum is available. There is a Chair of Genetics in the biology department at Minsk State University, and lectures on medical genetics form part of the curriculum at the Minsk State Medical Institute, at medical colleges, and at Minsk State Pedagogical University.

TRAINING OF CANCER GENETICISTS

Cancer genetics is in its infancy and there is no specialist teaching for cancer geneticists. Only a few hours are devoted to cancer genetics in special courses run by the biology department of the State University and the State Pedagogical University. The situation with regard to teaching of cancer genetics in medical institutes and colleges is similar. The first training course in cancer genetics for oncologists, which took place in the summer of 1998, formed part of the Annual Seminar for Physicians.

Genetic associates should have a PhD in biology and specialist training at university level. Nurses require specialist training at university or medical college level, the former being preferable.

Audit and evaluation

No details are available.

Discussion fora

No details are available.

SPECIFIC CANCER DISCUSSION GROUPS

No details are available.

Education

The Minsk Centre sends a special letter to cancer patients regarding familial breast cancer. Since 1998, Minsk has also offered awareness lectures to the general public. There are no educational videos available, but some educational material has been produced for public consumption. There are no known websites.

Registers

Since 1990, a familial breast cancer genetic register has been run by the Minsk Centre: this covered the areas contaminated by radiation from Chernobyl (Brestskaya, Gomelskaya, Mogilevskaya) and was extended in 1997 to cover the Minsk population.

Support

CANCER CHARITIES

No details are available.

PATIENT SUPPORT GROUPS

Currently (1999) two support groups for women with breast cancer are being set up. The first, "Together against Cancer", forms part of a Russian organisation, while the second, "Women for Life", is intended to focus on the social rehabilitation of breast cancer patients. The two groups have not yet been registered officially, but this is anticipated, and in the meantime they are already very active.

Persons responding

Dr G Porubova and Dr E Ekimova, Institute of Genetics and Cytology, National Academy of Sciences of Belarus, Akademicheskaya Str 27, Minsk 220072, Belarus.

BELGIUM

Genetic services

Genetic services in Belgium have been reviewed by Cassiman.[9] Since 1973, eight genetics centres have been licensed by the Ministry of Health and funded to provide genetic services: these are Leuven (two separate centres), Brussels (two separate centres), Loverval, Liège, Gent, and Antwerp. The establish-

ment of these centres is regulated by law. Licensed centres must be affiliated to a university or university hospital. They must have a qualified team of geneticists and allied personnel (although the conduct and training of their personnel are not regulated) and an appropriate diagnostic laboratory infrastructure, and must carry out scientific research in the field of human genetics. The services provided by the genetics centres are freely accessible to all and are reimbursed by the health care system. Traditionally, all counselling is provided by clinical geneticists or by paramedical specialists (nurses, social workers, and psychologists) within the centres. However, a limited number of private practitioners also offer genetic counselling (not reimbursed as such by the health care system), and there are an increasing number of non-clinicians becoming involved. Some genetic testing is performed outside the genetics centres, but the cost of this is not covered by the health care system. Collaboration between the different centres is increasing gradually; for instance, Leuven, Gent, and Antwerp operate a common protocol for presymptomatic testing for Huntington's disease. In 1997, the eight genetics centres were staffed by 34 physicians trained in genetics and a further 11 trainees, together with 22 cytogeneticists, 36 molecular geneticists, and 22 genetic nurses/counsellors.

Also in 1973, the Ministry of Public Health established a Higher Council on Human Genetics, made up of representatives from the centres, to provide advice on matters relating to genetics. The Council also has a role in coordination, development, and public education regarding genetic issues.

CANCER GENETICS SERVICES

Belgium has eight health service funded cancer genetics clinics. These are largely organised by the genetics centres, on a local basis with no unifying national structure, but function in a multidisciplinary setting, with input from other relevant specialties. In the past they have provided a limited leukaemia cytogenetics service in conjunction with departments of haematology, and cytogenetic analysis of solid tumours. Currently each genetic centre provides counselling for a number of different hereditary cancer syndromes. Testing for these is usually provided through a clinical service: while presymptomatic testing for breast/ovarian and colorectal cancer is presently being implemented, there is no access to testing without previous counselling. In addition, some centres are adopting a more integrated, multidisciplinary approach. In some molecular diagnostic laboratories, the analysis is limited to a search for common or recurrent mutations, while in others extensive screening of the responsible gene is undertaken.

Training

The level of general genetic education for medical students, nurses, and midwives is inadequate; there is little in the way of organised teaching. Genetics is not included in the common core curriculum; some universities offer a basic preclinical genetics course, with some clinical education at a later stage, while others omit genetics altogether. However, the proposed introduction of a PhD course in medical sciences, available to all postgraduates (medical and otherwise), should result in a series of formal courses in human genetics. In addition, there is an increasing demand for genetic input from specialists in allied disciplines. Genetics is not a recognised specialty. Most, if not all, clinical geneticists are certified in one of the classical medical specialties (generally paediatrics, obstetrics and gynaecology, or internal medicine), following which they receive specialist training (leading to a PhD) in one of the genetics centres or abroad. However, there are no national training guidelines and training is said to be poorly assessed.

Genetic counsellors and genetics nurses learn "on the job". There are a number of research based genetic counsellors (nurses, social workers, psychologists), some with degrees, and some nurses and other paramedics are also beginning to be involved in counselling, home visits, and follow up. There is considerable interest in establishing a formal training programme.

TRAINING IN CANCER GENETICS

Consultants in cancer genetics are recruited from among the general pool of clinical geneticists; some are oncologists or specialists in internal medicine, with some genetic training (this may be via a doctoral thesis in cancer genetics).

Audit and evaluation

The genetics centres discuss and review common problems through the regular sessions of the Higher Council on Human Genetics. There are currently no quality assurance schemes for cytogenetics or for clinical and molecular genetics (it is the view of the government that the university affiliation of the centres obviates the need for independent quality controls). Metabolic screening centres are supervised by the Higher Council on Human Genetics. Presymptomatic and diagnostic testing for late onset disorders and cancer genetics are based on international guidelines.

There are no formal national or regional mechanisms for evaluating the uptake of genetics services. Leuven monitors some aspects of the service (for instance, the impact of prenatal testing for neural tube defects and Down syndrome). In addition, a form is completed one year after testing for all women referred for prenatal diagnosis, which provides limited data on the targeting, effectiveness, outcome, etc of prenatal diagnostic services.

We are not aware of any organisation taking action to evaluate the cancer genetics service/audit surveillance measures in Belgium.

Discussion fora

The genetics centres hold a joint bimonthly dysmorphology meeting and there is an annual European Dysmorphology meeting in Strasbourg.

At present there is little direct collaboration between the genetics centres, but this is starting to change, as different centres collaborate in the collection and management of specific genetic disorders.

There is a website, BelNDA, which lists the molecular genetics tests available at the different centres.

SPECIFIC CANCER DISCUSSION GROUPS

No details are available.

Education

The Higher Council on Human Genetics is charged with educating the public about genetic services and increasing public awareness of genetic issues.

Registers

EUROCAT Register: some centres, for example, Loverval, collect congenital malformation data for this register.

Belgian Polyposis Register (coordinator: Dr Lucy Edwards, FAPA, 217 Rue Royale, Brussels). This participates in the EUROFAP network involved in FAP and HNPCC research.

Support

CANCER CHARITIES

There is a national association, FAPA (Familial Adenomatous Polyposis Association), which runs a genetic register.

PATIENT SUPPORT GROUPS

Clinical geneticists are very active in this area and there are a number of patient support groups (for example, for cystic fibrosis, Huntington's disease, Prader-Willi and Angelman syndromes, neurofibromatosis, Williams syndrome, fragile X syndrome, etc).

9 Cassiman JJ. Genetic services in Belgium. *Eur J Hum Genet* 1997;**5**(suppl 2):35-40.

Persons responding

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Dr Eric Legius, Centre for Human Genetics, Gasthuisberg O and N6, University of Leuven, Herestraat 49, B3000 Leuven, Belgium.

Dr Geert Mortier, Centrum Medische Genetica, Universiteit Gent, Universitair Ziekenhuis OK5, De Pintelaan 185, B-9000 Gent (tel: 32 9240 3603; fax: 32 9240 4970).

BULGARIA

Genetic services

Genetic services in Bulgaria have been reviewed by Simeonov and Kremenski.[10] After a painful transition period, and slow movement towards democracy from 1989 to 1997, Bulgaria is now well integrated into the European political and economic structure, with its recognition of private initiative, a market economy, and the importance of human rights. The former highly centralised state health care system is being abandoned, and a decentralised system with some provision for private practice is being introduced. A health insurance system has been legally constituted and will be introduced at the start of the year 2000. In 1986, the Ministry of Health approved a national programme for genetic prevention, which is currently being updated. There are now five university affiliated regional genetic centres (Sofia, Plovdiv, Varna, Pleven, Stara Zagora), 20 clinical genetics units, and three specialist genetic counselling units (ophthalmology and otorhinolaryngology in Sofia and ophthalmology in Stara Zagora). The clinical genetics units, which consist of a clinical geneticist and a nurse or midwife, are intended to collaborate closely with various field specialists, collect and register new families, provide genetic information in simple cases, or refer these to one of the regional genetics centres, act as a community genetics service. They take part in the registration of congenital abnormalities in neonates and operate other screening programmes. Some genetics services are also now being provided by private practitioners. Laboratory services are provided by six regional, three specialist, and three district cytogenetics laboratories, and by the Laboratory of Molecular Pathology in Sofia. This laboratory, together with the Paediatric Endocrinology Laboratory (Paediatric University Hospital, Sofia), also provide a biochemical genetics service, including population screening for phenylketonuria and congenital hypothyroidism.

In 1997 there were a total of 90 people (doctors, trainees, nurses, and midwives) involved in the provision of a clinical genetic service, of whom 26 were specialists in clinical genetics. There were 36 scientific workers and 28 coworkers.

Funding is usually not sufficient to maintain the service without supplementation and most consumables and equipment are therefore obtained via international organisations or research grants.

CANCER GENETICS SERVICES

A well organised cancer genetics service does not exist in Bulgaria. Cancer cytogenetics research started in the 1970s, when the chromosome 14 marker and the t(8;14) found in Burkitt lymphoma were reported by the Cancer Cytogenetics Laboratory at the National Centre of Oncology in Sofia. There is no provision for presymptomatic or predictive testing for persons at high risk of cancer and this is currently seen as a low priority. The first family cancer clinic was set up in February 1999 by the clinical genetics section of the Higher Medical School in Sofia, together with its molecular diagnostic service. The clinical psychologist attached to the clinic has received further training in Rotterdam to provide psychological support for patients with familial

breast/ovarian cancer, both affected and presymptomatic. The Sofia centre has launched a joint predictive testing programme in collaboration with the National Centre of Oncology.

Training

Medical genetics has been included in the student curriculum since 1919, when the Medical Faculty of Sofia was founded. During the Communist era, it was strongly discouraged, resulting in poor undergraduate education, lack of specialist training, and almost complete ignorance of genetic issues. Recently, great efforts have been made to reverse this. Medical students receive 56 hours of teaching (half lectures, half seminars) on the main problems of medical and clinical genetics, and the 5th year paediatrics course contains eight hours of clinical genetics.

At a postgraduate level, clinical genetics is an integral part of the three month general and short term specialist paediatrics and obstetrics courses.

Medical genetics became a recognised medical specialty in 1985. Specialists must have had four years of clinical practice and have attended a three month course run by the University Department of Medical Genetics, Sofia, culminating in a state run examination.

Laboratory specialists (cytogeneticists, biochemists, and molecular geneticists) obtain their professional training and experience "on the job": there is no official recognised programme of accreditation or assessment. An intensive introduction to molecular biology for teachers in the medical faculties of Sofia and Plovdiv was organised through the TEMPUS programme in 1995, and the encouraging feedback from this course suggests that it will be repeated in future.

Beginning in 1996, nurses and midwives in Sofia had received 16 hours of genetics teaching in the last year of their training. In 1997, this was extended to all 14 colleges in Bulgaria. All nurses now receive 30 hours of obligatory lectures (16 hours for midwives) and 14 hours of seminars.

TRAINING OF CANCER GENETICISTS

No details are available.

Audit and evaluation

Since 1986, the Bulgarian Ministry of Health has a National Programme for Genetic Prevention, due to be revised and updated in the light of information regarding projected need, uptake of services, financial resources, etc, during 1999.

Discussion fora

The genetic centres work in close collaboration and hold regular exchanges of information. The Society of Human Genetics holds regular meetings and two National Clinical Genetics meetings have been held in the last few years. The Sofia Genetics Centre provides a consultation and diagnostic service for other centres as necessary and acts as a coordinator and facilitator for training, obtaining consumables and equipment, etc.

The Bulgarian Society of Human Genetics exists to further the recognition of genetic prevention as a priority field of the health care system in Bulgaria (together with cancer, cardiovascular disease, and environmental medicine).

SPECIFIC CANCER DISCUSSION GROUPS

No details are available.

Education

Throughout the Communist period there was almost complete ignorance of modern genetics, and even today the level of genetic knowledge among professionals and the public alike remains very low, although steps are being taken to remedy this. The general public is surprisingly accepting of new advances in genetics. However, access to genetics services is limited by ignorance of genetic issues in the medical profession: attempts to combat this are being made through improved medical education and by the clinical genetics units, which operate at a local level and play an important role in genetic diagnosis and prevention. The Bulgarian Society of Human Genetics is lobbying to raise the profile of genetics.

Registers

Registration of congenital anomalies began in 1985. Since 1996 a EUROCAT-type register of congenital anomalies has existed in Sofia.

Support

CANCER CHARITIES

There are at least two newly emerged foundations which provide support to children with malignancies and their families, and one foundation, "Fighting Cancer", for adult sufferers.

PATIENT SUPPORT GROUPS

PKU Society.
Cystic Fibrosis Society.
Bulgarian Association of Mental Retardation.
Autism Society.

10 Simeonov E, Kremenski I. Genetic services in Bulgaria. *Eur J Hum Genet* 1997;**5**(suppl 2):41-5.

Persons responding

Dr E Simeonov, Section of Clinical Genetics, Department of Paediatrics, Higher Medical School, 11 D Nestorov Str, Sofia 1606, Bulgaria (tel: 3592 517 264, 3592 598 161; fax: 3592 2 521 650; e-mail: emil@medfac.acad.bg).

CROATIA

Genetic services

Genetic services in Croatia, and the effects of war conditions, lack of funding, etc, on these, have been well reviewed by Baric *et al.*[11] The health care system is centrally organised: all genetic services are officially free and funded by government health insurance schemes (although there are an increasing number of private practitioners). In practice this leads to difficulties in reimbursement for work carried out and to difficulty in funding new developments. The Ministry of Science and Technology provides some additional funding, but this is almost entirely for research purposes. Genet-

ics services arose within the university departments of paediatrics, initially through the provision of prenatal diagnosis, followed rapidly by genetic counselling and the introduction of neonatal screening programmes. Human molecular genetics was introduced in Zagreb in 1990.

A full scale specialist service is available in Zagreb, Split, and Rijeka. There are seven genetics centres offering a genetic counselling service (five in Zagreb, one in Split, and one in Rijeka). In 1997, they had nine clinicians, one trainee, 14 cytogeneticists (in eight cytogenetics laboratories), and five molecular geneticists. There are two laboratories in Zagreb offering a biochemical genetics service. Three laboratories offer a molecular diagnostic service. There are regular joint medical/genetic clinics, and shared care of patients by appropriate specialists.

A limited service is provided in some smaller cities by paediatricians with a postgraduate training in medical genetics. A much larger group of paediatricians, gynaecologists, neurologists, biologists, molecular biologists, biochemists, and statisticians are involved with limited aspects of medical genetics.

Genetic nurses are not recognised as a profession in Croatia.

CANCER GENETICS SERVICES

There is one cancer genetics clinic, in Zagreb, funded jointly by charitable and research funds and by the government health service. This functions in a multi disciplinary fashion: a patient with medullary thyroid cancer will have a blood sample tested by the Division of Molecular Medicine (Rujder Boskovic Institute), following psychological assessment and clinical genetic consultation at the Clinical Hospital "Sestre milosrdnice". Oncologists, radiotherapists, and general practitioners are all involved in formulating a care package. Currently four laboratories provide a cancer cytogenetics service.

A molecular genetic service with particular emphasis on cancer genetics was introduced by the Institute Rudjer Boskovic in Zagreb in 1990. Three laboratories, all in Zagreb, currently offer diagnosis for familial adenomatous polyposis and multiple endocrine neoplasia type 2, and research into breast and ovarian cancer, and *RET* proto-oncogene related diseases is under way. It is hoped to introduce diagnostic services in these areas.

There is no systematic test programme for families with hereditary cancers; currently these are managed on an individual basis, but attempts are being made to develop specialist family services for hereditary thyroid cancer, multiple endocrine neoplasia, familial adenomatous polyposis, hereditary non-polypotic colon cancer, and breast/ovarian cancer.

Training

Genetics has been a formal part of medical education since 1976, as part of the cell biology and paediatrics curriculum, although it has tended to have little influence on medical education.

Undergraduates receive basic instruction in cell biology as part of the preclinical course, and a few lectures and one week of practice in the paediatrics curriculum (5th year), followed by 20 hours on ethical issues in genetics (6th year). Students of "defectology" are taught medical genetics as a separate subject. Medical genetics also forms part of many postgraduate courses in different specialties (for example, ophthalmology, orthopaedics, antenatal and perinatal medicine, paediatrics). It is very difficult for non-specialists to obtain up to date information on medical genetics following graduation, although attempts are being made to improve this situation.

Medical genetics is not a recognised specialty and there is as yet no formal training programme, although a number of informal ones exist. The Croatian Society of Human Genetics has recommended that a period of postgraduate specialist study and five years of practical experience should be necessary to quality as a medical geneticist. Currently the Ministry of Health requires previous specialisation in paediatrics, followed by two years of academic (university based) training, and a postgraduate scientific course on one of a broad range of related topics, in order to specialise in genetics (over four semesters).

For laboratory geneticists, the Faculty of Natural Sciences and Mathematics offers a four year course in molecular biology for about 30 students a year (this is likely to constitute a good source of medical molecular geneticists in future). The Department of Molecular Medicine at the Institute Rudjer Boskovic in Zagreb offers twice yearly courses for those with an interest in non-clinical and molecular genetics.

Nurses and midwives receive some genetics teaching from specialists as part of their basic training, with lectures and case studies for primary care staff during later specialisation. Rijeka offers some specialist training in genetics for nurses.

TRAINING OF CANCER GENETICISTS

Consultants in cancer genetics are trained during their regular medical education. Zagreb organises annual meetings at which they may meet and have discussions with foreign specialists (for example, A Gal, E Petty, B Ponder). Currently, Croatia does not offer any official training for counsellors in cancer genetics.

Audit and evaluation

The Ministry of Health organises and supervises the health care system, with the National Board of Health acting in an advisory capacity. Coordination of joint strategies and new developments in genetic services is poor, and attempts to improve this hampered by war conditions and lack of funding. Following representations by interested specialists, the Croatian Ministry of Health will shortly begin an evaluation of cancer genetics services.

On a personal level, there is no regular system for assessment of training or continued medical education in the field and few opportunities to obtain up to date information. The Croatian Chamber of Medical Doctors

has been set up to facilitate monitoring of practitioners and dissemination of knowledge in all areas of medicine, including genetics, and to develop criteria for acceptable practice. The Croatian Society of Human Genetics also aims to monitor standards and activities.

Discussion fora

There are (infrequent) local clinical and laboratory genetics meetings. The first Croatian Congress of Medical Geneticists with international participation was held in 1994.

Croatian Society for Human Genetics (founded in 1972). This also admits associate members from other professions with an interest in genetics.

SPECIFIC CANCER DISCUSSION GROUPS

Zagreb organises discussion meetings on cancer genetics, with the input of foreign specialists, but these are infrequent, taking place once or twice a year.

A National Group for Cancer Genetics Professionals is in the process of being set up.

Education

In general, access to genetics services is hampered by lack of awareness of genetic issues among primary health care workers and the general public. However, the general attitude to genetic services and research is favourable, and attempts are being made to improve genetics education.

Registers

The Children's Hospital in Zagreb operates a register of congenital anomalies as part of the EUROCAT network.

There is a national cancer registry. Attempts are also under way to set up a registry for hereditary cancer/predisposing conditions, based in Zagreb.

Support

CANCER CHARITIES

No details are available.

PATIENT SUPPORT GROUPS

These exist for phenylketonuria, cystic fibrosis, and Duchenne muscular dystrophy, and, in association with international organisations, for galactosaemia, spinal muscular atrophy, and the mucopolysaccharidoses.

11 Baric I, Barisic I, Begovic D. Genetic services in Croatia. *Eur J Hum Genet* 1997;5(suppl 2):46-50.

Persons responding

Prof Dr Kresimir Pavelic, Division of Molecular Medicine, Rudjer Boskovic Institute, Bijenicka 54, Hr-10000 Zagreb, Croatia.

CYPRUS

Genetic services

Cyprus has both a public and a private health service. The primary health care system plays an important part in implementing genetic programmes, such as the thalassaemia project, and the neonatal screening programmes for phenylketonuria, hypothyroidism, and Duchenne muscular dystrophy. There is a long tradition of such public health programmes in Cyprus. Genetic services in Cyprus have been summarised by Angastiniotis and Middleton[12] and their complexity will not be detailed further here. Essentially, Cyprus has a long history of genetics services, beginning with the Thalassaemia Control Programme which was set up in 1972. This has expanded into a network of thalassaemia centres, referring patients and diagnostic samples to the Thalassaemia Centre in Nicosia, offering a preventative, diagnostic, and therapeutic service for affected persons and their families. Affiliated to the Nicosia Centre is a general and prenatal diagnostic service based at the Makarios Hospital (a genetic counsellor assists the clinician here and may also see patients independently). Limassol has a Centre for the Prevention of Mental Retardation (which runs the national neonatal screening programme for mental retardation and Down syndrome). Lastly, the Cyprus Institute of Neurology and Genetics is a bicommunal institution which aims to provide specialised medical care, in collaboration with other local institutions, and to provide research and postgraduate education. Clinics (two neurogenetics and one general genetic clinic each week) are directed by a US qualified specialist on a multidisciplinary basis with input from gynaecologists, oncologists, a behavioural scientist, and a molecular geneticist. It is funded by a variety of different sources, including the government of Cyprus, the United States, and the United Nations.

In 1997, the four genetics centres were said to have four genetically trained physicians, two trainees, 10 cytogeneticists, 22 molecular geneticists, and six genetic nurses/counsellors, with access to cytogenetics, biochemical, and molecular genetics laboratory services. In 1998, we were informed that there were two clinical geneticists, one genetic counsellor, and several molecular geneticists. Other physicians (for example, obstetricians and paediatricians) are also directly involved in the clinical management of patients and preventive programmes for genetic disorders; they routinely perform a basic genetic work up, while referring cases onwards for specialist care.

CANCER GENETICS SERVICES

The first cancer genetics clinic in Cyprus was set up in June 1998, after much lobbying, on charitable/research funding. The clinic is based at the newly established Bank of Cyprus Oncology Centre and offers a multidisciplinary service, run by a specialist laboratory scientist and a specialist in clinical genetics (a trained genetic counsellor) with input from gynaecologists, obstetricians, oncologists, geneticists, a behavioural scientist, and a molecular geneticist. *BRCA* mutation screening is available and the Institute also has access to a leukaemia cytogenetics service (FISH is available for some types of cancer). Various other screening programmes (for example, mammography, cervical cytology) are operational.

Training
Cyprus does not have a medical school. High quality training programmes are organised both locally and abroad by the Ministry of Health, the Cyprus Institute of Neurology and Genetics, and the Paediatric Society of Cyprus, among others.

There is only one specialist clinical geneticist who is qualified to provide genetic counselling (Dr Tanos). There are no training facilities for genetic counsellors in Cyprus. Specialist clinical laboratories are directed by scientists with postgraduate degrees or a PhD, supported by postdoctoral and MSc workers. Laboratory technicians require a BSc.

TRAINING OF CANCER GENETICISTS
There is one trained genetic counsellor. Oncologists would be included.

Audit and evaluation
Coordination and integration of genetics services is furthered by regular meetings, joint clinics, and by the widespread awareness of genetic issues among both health care professionals and the public following many years of educational programmes.

The Cyprus Institute of Neurology and Genetics has strict quality control procedures, including regular clinical and laboratory meetings, regular performance evaluation, and provision for site visits by international experts, to carry out a regular scientific/medical audit.

The cancer genetics clinic has only recently been established. There are plans for continuous audit and evaluation of its data and performance (through its publications). The results of this process will be used to formulate new strategies for gynaecological cancer prevention in Cyprus.

Discussion fora
The Cyprus Institute of Neurology and Genetics organises regular scientific lectures and "public awareness" lectures (four in 1997, with further lectures planned).

SPECIFIC CANCER DISCUSSION GROUPS
No details are available.

Education
There is a high level of awareness and acceptance of genetics as a result of the success of the thalassaemia prevention programmes.

All three genetics centres provide both written and oral information on genetic issues to persons consulting them. There are a wide range of leaflets available on most kinds of cancers.

Registers
General registers for genetic disorders are beginning to be set up. The Cyprus Institute of Neurology and Genetics has a database containing clinical, pathological, and genetic data on breast cancer patients diagnosed since 1990. More than 130 high risk families have been identified to date.

Support
CANCER CHARITIES
Anti-Cancer Society.

PATIENT SUPPORT GROUPS
Attempts are being made to increase psychosocial support for affected persons and families, but this is being hampered by lack of funding.

Pan-Cyprian Association of Cancer Patients and Friends.

Thalassaemia Association.

12 Angastiniotis M, Middleton L. Genetic services in Cyprus. *Eur J Hum Genet* 1997;5(suppl 2):51-7.

Persons responding
Dr K C Kyriacou, Cyprus Institute of Neurology and Genetics, PO Box 3462, 1683 Nicosia, Cyprus (tel: 357 2 673 340; fax: 357 2 673 305).

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CZECH REPUBLIC

Genetic services
These have been reviewed by Kucerova *et al*.[13] Like many other eastern European countries, the Czech Republic is moving slowly towards a western pattern of health care provision, but with attendant difficulties with regard to funding, infrastructure, medical education, etc. In general, genetic services in the Czech Republic are relatively good, and clinical genetics has been a recognised part of the health care system since 1970. The first genetics centres were instituted in the 1960s in Brno and Prague, followed by Olomouc, Ostrava, Usti nad Labem, Ceske Budejovice, and Hradec Kralove. There are now 12 genetics centres (all in large hospitals, four in Prague alone), including laboratory services, and a small number of private services. General genetic clinics are provided in all the bigger cities. The average centre has three to five trained clinicians (who provide a genetic counselling service), with four to seven laboratory geneticists; in 1997 there were 37 trained clinical geneticists, eight trainees, 48 cytogeneticists, 15 molecular geneticists, and 30 genetic nurses in the public sector, and a further 35 persons engaged in private practice in various capacities. There are no genetic associates. Clinics are often multidisciplinary in nature, with input from other interested specialists in gynaecology, obstetrics, etc. There is a relatively good network of genetics centres, with close cooperation between physicians, clinical geneticists, and laboratory staff, and, again, good collaboration between the various specialist laboratories, which are each able to provide DNA diagnoses of selected monogenic disorders.

CANCER GENETICS SERVICES
Cancer genetics is a newly emergent discipline. All large hospitals have departments of oncol-

ogy, and most of them also have specialist cytogenetic laboratories, although they do not offer genetic counselling for cancer families. They are beginning to refer such families to specialist centres, but still very rarely. Cancer genetics counselling mainly takes place during general genetics clinics. These are provided in all the bigger cities. Counselling for high risk families is provided in four specialist cancer genetics centres (three in Prague, at Charles University and the Thomayer University Hospital, and one at the Masaryk Memorial Institute in Brno), funded by a mixture of research, government health service, and health insurance funds, but only the Brno centre has a specialist genetic counsellor involved in counselling these families.

There are no multidisciplinary clinics in the Czech Republic, although the Masaryk Institute in Brno is planning to establish a multidisciplinary clinic for high risk cancer families. It already operates a genetic programme for such families.

The Institute of Biology and Medical Genetics (2nd Medical Faculty, Charles University, Prague) has a special interest in Li-Fraumeni syndrome. A database of germline *p53* mutations is in the process of being set up (accessible via the Institute's website at: http://www.lf2.cuni.cz). The Institute also offers a genetic counselling and molecular genetic diagnostic service for families with familial adenomatous polyposis, Lynch syndrome, and von-Hippel-Lindau disease. It is also engaged in an experimental study of cancer therapy in collaboration with the Czech Academy of Science, of which details are published at the Institute's website.

The Department of Oncology and the 2nd Institute of Medical Chemistry and Biochemistry (1st Faculty of Medicine, Charles University, Prague) offer a molecular diagnostic and therapeutic service for breast cancer (*BRCA1*), pancreatic cancer, and hepatobiliary cancers (*K-ras*, *c-myc*, *TP53*), and provide a telephone enquiry service.

Training

There are seven medical schools, but no standard curriculum. The curriculum of the 1st Faculty of Medicine (Charles University, Prague), for example, is considered directly comparable to the American medical curriculum and accredited accordingly, but the quantity and quality of clinical education varies. The basics are taught during the preclinical course. At some medical schools, further genetics teaching (clinical and molecular genetics, molecular genetic techniques, etc) is compulsory for 5th year students. There is currently widespread lack of awareness of genetic issues among GPs and internists.

Systematic postgraduate education in genetics was introduced in the late 1960s by the Postgraduate Medical School in Prague, and this has since been expanded and developed. Genetics became a recognised specialty in 1980, since when it has expanded considerably. The Universities of Prague, Brno, and Olomouc, and the Institute for Postgraduate Medical Education all have Chairs in Medical Genetics. The Institute for Postgraduate Medical Education now supervises the training of all clinical and laboratory specialists in genetics. Clinicians must have a primary attestation in a clinical specialty (such as paediatrics, gynaecology, or internal medicine) and a further three years of specialist training in clinical genetics, before they can offer genetic counselling. The training includes both theory and practice, together with cytogenetics and molecular genetics, culminating in Board examination and attestation. In addition, the department organises intensive short courses on different topics in medical genetics four to six times a year, and there are one to two week training courses in genetic counselling, cytogenetics, and molecular genetics for interested parties (these also constitute continuing medical education in genetics). This has been obligatory for all licensed medical staff since 1998, when the Czech Medical Board programme of continuing medical education was introduced (this includes training in medical genetics and oncology).

Specialist genetics laboratory scientists must be graduates (mainly in the biological sciences) with a specialty attestation in medical genetic laboratory techniques. Only attested workers can sign laboratory reports.

Genetic nurses have a three year specialist training programme in medical genetics, ending with a Board examination. There are seminars for nurses and laboratory personnel. Genetic nurses keep a registry of patients and obtain history and details and assist doctors with blood samples and examinations. Within a genetic department, they can progress from staff nurse to head nurse.

TRAINING OF CANCER GENETICISTS

There are a few consultants in cancer genetics, who are recruited from among the consultant geneticists. There is no specialist training in cancer genetics, simply that which is acquired during the course of general training for consultant geneticists.

Audit and evaluation

The Society of Medical Genetics has organised pilot schemes for the external evaluation of cytogenetic and molecular diagnostic laboratories twice in recent years, with feedback to the laboratories concerned, but there is no organised national scheme.

Discussion fora

The Czech Society of Medical Genetics and the Society for the Prevention of Genetic Disease (to which genetic nurses are also admitted) both organise regular workshops and seminars.

The Society of Biology has a cytogenetics section.

Clinical geneticists, oncologists, etc, hold scientific conferences, with the collaborative participation of speakers from other countries or other disciplines.

SPECIFIC CANCER DISCUSSION GROUPS
Clinical geneticists, oncologists, etc, hold scientific conferences, with multidisciplinary and international participation.

Education
Awareness of genetic issues among non-specialist physicians is recognised as inadequate, and efforts are being made to improve this situation through regular discussion meetings, continuing medical education, etc, although, as with all former Eastern Bloc countries, this is hampered by lack of funding.

Information about familial cancer is very rarely available; what there is mostly supplied by geneticists. There are some information leaflets available about cancer, but these are mostly about treatment. The Brno Institute is in the process of producing information leaflets on cancer genetics/heredity for their patients. The League against Cancer and other organisations such as ARCUS, EMASH, and the State Institute of Health of the Czech Republic also produce some publications on cancer risks and prevention.

Letters giving detailed information about hereditary cancer syndromes, summaries, and recommendations for preventative measures are sent to patients following a genetic consultation. Basic information about heredity, risks, and basic cancer genetics is given to the patient by the consultant.

The Thomayer University Hospital in Prague has produced a video for patients with breast cancer, giving limited information on familial cancer.

Registers
There is a National Register of congenital malformations, run by the National Statistics Institute, to which notification is obligatory. This also contributes to the ICBMS and EUROCAT programmes.

A National Cancer Registry has existed since 1951. There is no central register of cancer predisposing conditions, although some local ones exist. Each of the four centres (three in Prague, one in Brno) dealing with high risk cancer families has its own. The Prague centre (Institute of Biology and Medical Genetics, 2nd Medical Faculty, Charles University/ University Hospital Prague Motol) has a patient register.

Support
CANCER CHARITIES
There are some support groups for breast and colon cancer patients throughout the country, but very few charities. Diana, Jantar, and Mamma are some of the familial cancer support organisations in existence. The League against Cancer supports some cancer prevention activities and is able to sponsor some small research projects.

PATIENT SUPPORT GROUPS
The Czech Republic already has support groups for Turner syndrome, cystic fibrosis, Down syndrome, mental retardation, DMD/BMD and other muscular dystrophies, and Huntington's disease.

Diana is a support group for women with breast cancer. The League against Cancer provides supportive publications.

13 Kucerova M, Gregor V, Santavy J. Genetic services in the Czech Republic. *Eur J Hum Genet* 1997;**5**(suppl 2):58-64.

Persons responding
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Prof Dr Maria Kucerova, Genetics Department, Thomayer University Hospital, Videnska 800, 140 59 Prague 4, Czech Republic.

DENMARK

Genetic services
These have been reviewed by Brøndum-Nielsen[14] as part of the Concerted Action on Genetic Services in Europe. Clinical genetics services evolved through the University Institutes of Human Genetics (Copenhagen, Århus, Odense) and the Rigshospitalet Departments of Paediatrics, Gynaecology, and Obstetrics. In addition, the John F Kennedy Institute in Glostrup has a longstanding interest in the genetics of mental retardation.

The government has plans to extend genetic services in Denmark. In the meantime, there are currently six clinical genetics centres in Denmark, at Århus, Vejle, Odense, and three in Copenhagen (Rigshospitalet, Panum, John F Kennedy Institute), offering a genetic counselling service with a variable degree of laboratory back up. There are five cytogenetics laboratories offering prenatal analyses, and a number of specialist laboratories offering a particular molecular diagnostic service (for example, for Menkes syndrome at the John F Kennedy Institute, or Huntington's disease at the University of Copenhagen). Others offer analysis on a research basis.

Most counselling is carried out by clinicians, not genetic associates, although their training and responsibilities have yet to be clarified. It is hard to quantify the number of people involved in the provision of genetic services, since not every clinic has a health service funded doctor, and some providers of clinical services are researchers working on a part time basis, or non-specialists (paediatricians, gynaecologists, midwives) backed up by telephone access to specialist advice. Around 20 people were involved in genetic counselling and laboratory testing, at an academic level, in 1997, while the

average genetics centre had three health service funded doctors and no genetic nurses. Currently, Odense has two to three health service funded clinicians, one to two genetic associates, and one genetic nurse. The Rigshospitalet in Copenhagen also has one genetic nurse. Århus has a technician and a secretary in training. On the academic side, Århus has four health service funded consultants, all qualified specialists in clinical genetics.

Genetic associates (laboratory scientists) are also involved in the provision of genetic services, but this is still on an informal basis, although there are plans to change this. Odense, for instance, has a technician with a special education in genetics. Genetic associates carry out genetic analysis and laboratory projects (not counselling).

Genetic nurses have, with one exception (a specialist genetic nurse at the Rigshospitalet, Copenhagen), no formal training programme (although a Pan-Nordic scheme is under consideration) and no career structure. Their role has still to be clarified, but they are seen as pivotal, for instance, in peripheral clinics, making contact, taking family histories, diagnostic samples, and arranging for onward referral to a specialist genetics centre where appropriate. There may be four to five nurses involved in genetic counselling in this way in all Denmark.

CANCER GENETICS SERVICES[15]

Cancer genetics services in Denmark are still not very well organised, with the exception of Copenhagen (APC/FAP) and Odense (mainly breast cancer). In Copenhagen, genetic counselling for hereditary cancers of the gastrointestinal tract is being moved from the Rigshospitalet (where the laboratory work is carried out) to Hvidore University Hospital, where it will coexist with the HNPCC Register. All six genetics centres run cancer genetics clinics (funded by a mixture of research and health service monies), but cancer genetics counselling is concentrated in four of them. All the centres collaborate with other clinical specialties (oncology, neurology, etc); some hold multidisciplinary clinics, but mostly contact is via meetings and conferences. At Århus, all cancer genetics services have been centralised, and are provided by an Onkogenetisk Klinik, run by a consultant in clinical genetics and two genetic associates (training). This clinic is concerned with all types of (suspected) familial cancers, and evaluates risks according to pedigree, or via mutation analysis (performed mainly in Copenhagen and Odense), and refers persons to cancer screening programmes as appropriate; the annual caseload is currently expected to be around 100 family referrals per year.

Predictive testing is offered to all persons at risk in families with known mutations in *APC*, *BRCA1*, and *BRCA2*, and the genes for HNPCC and von Hippel-Lindau disease. Country wide screening programmes for FAP and HNPCC follow the guidelines issued by the Polyposis and HNPCC registries at Hvidore Hospital, screening being offered every year or every two years, respectively. The FAP screening programme has been in operation since 1978, and at risk subjects are screened between the ages of 10 and 60 years. Screening and mutation analysis for von Hippel-Lindau disease are available in Århus and Copenhagen, and probably nationwide.

In 1998, the Danish Breast Cancer Group (DBCG) started a parallel registry for familial breast cancer, and has issued guidelines for screening and clinical management, based on a research programme which investigated the relationship between genetic status, effects of treatment, and prognosis before the large scale introduction of presymptomatic DNA diagnosis. It is expected that all Danish counties will shortly accept these guidelines. The DBCG also organises a national counselling service for high risk women, involving all the clinical genetics centres in Denmark. Lastly, a family study is being carried out in collaboration with the National Cancer Institute, which aims to evaluate the risk of breast cancer in ataxia telangiectasia carriers. Regular screening for hereditary breast/ovarian cancer is still the subject of debate; it is not yet fully integrated into the health service system in Denmark, and is currently only available on a small scale, in a research setting.

Training

The basic medical school curriculum teaches cell biology during the preclinical course. The University of Copenhagen gives 30 hours of lectures on human genetics and 25 hours on clinical genetics. The Århus course includes two hours on cancer genetics. Following graduation, all specialties undergo 18 months basic training before postgraduate specialisation.

Clinical genetics was recognised as a medical specialty in 1996, and a new, six year training programme in clinical genetics was introduced, based within the clinical genetics centres and leading to recognition. This involves 36 months of clinical training (including counselling), with a bias towards either paediatrics, gynaecology and obstetrics, or internal medicine and neurology, and a further 36 months of cytogenetic and molecular genetic laboratory training. In due course, it is intended that only qualified specialists will provide genetic counselling. Doctors wishing to undertake specialist training must apply for a training post, and it is anticipated that those who already have a PhD in an appropriate subject will have an advantage here.

The National Board of Health offers an annual one week course in clinical genetics (mostly attended by specialists in paediatrics or gynaecology/obstetrics), and it is planned to expand this into an intensive interdisciplinary training course for clinical genetics and other specialties.

Genetic associates must have a doctorate in medical or biological sciences, but there is as yet no formal career structure and no specific training programme.

A Pan-Nordic specialist training programme for genetic nurses is under consideration, but

again, there is as yet no formal training programme or career structure.

TRAINING OF CANCER GENETICISTS

Specialists in cancer genetics are primarily recruited from among consultants in clinical genetics. Specialist courses in cancer genetics are available, for clinicians only, but there is no recognised subspecialty. There are also cancer genetics courses for specialists in other, related, disciplines (biochemistry, surgery, etc) and for PhD students.

Audit and evaluation

The Danish National Board of Health provides guidelines and recommendations for clinical and laboratory practice (for example, for prenatal diagnosis) from time to time. It also supervises all health care professionals.

There is no national audit/evaluation programme, but Odense is planning to set up its own local evaluation. Cancer genetics services in Denmark are still under development. Copenhagen has a very well organised service for colorectal cancers (APC/FAP/HNPCC) and the guidelines issued by the FAP/HNPCC registers in Copenhagen are followed throughout the country. Odense also has a well developed service, involving mainly breast cancer.

All specialist laboratories have, or are developing, informal quality control programmes. The Danish Society for Medical Genetics is exploring the possibility of centralising and rationalising genetic counselling and laboratory analysis for specific diseases.

The charity Kraeftens Bekaempelse has a subcommittee for management of inherited cancers, based within the Odense department.

Discussion fora

Poor coordination between genetics centres, or between clinical and laboratory geneticists, has hampered the development of genetics services, although it is hoped that this situation will improve with the recognition of clinical genetics as a specialty in its own right. Attempts are also under way to remedy the situation through regular conferences and meetings with other specialties. The Danish Society of Medical Genetics is actively working to promote this.

The National Ethical Council exists to initiate discussions on ethical issues in genetics and publishes regular reports on these topics.

SPECIFIC CANCER DISCUSSION GROUPS

An All-Centre Cancer Genetics Group exists.

There is an HNPCC group which has been set up to discuss patients, management, etc.

The Danish Society of Medical Genetics has a cancer genetics working group.

There is a Danish Breast Cancer Collaborative Group, which has for more than 20 years maintained a bank of tumour tissue samples and data from all Danish women treated for breast cancer, as a research resource.

Education

There is widespread ignorance concerning genetic services among GPs, among health insurance administrators (who have to authorise referrals for specialist testing, which GPs cannot make on their own initiative), and among the general public. Lack of funding, the inability of GPs to access specialist analysis direct, and funding/training limitations have all contributed to this ignorance, and there are insufficient specialists to reverse this trend.

After counselling, patients receive a summary letter covering the consultation, test results, proposed management, etc. The HNPCC and polyposis registers have patient information brochures, and Kraeftens Bekaempelse provides limited information about breast cancer, and is preparing a general information leaflet. Odense produces general information leaflets for GPs and regional hospitals and information about hereditary cancers for patients referred to them.

There are no videos as far as we know.

Registers

There is a national congenital malformation register and a separate register of all terminations of pregnancy. Funen has a congenital malformation register which forms part of the EUROCAT programme.

There is a central cytogenetics register which records all analyses, both pre- and postnatal.

There are registers for HNPCC (for example, at Hvidore University Hospital, Copenhagen, set up in 1990), FAP (first set up in 1971 and extended nationally in 1976), von Hippel-Lindau disease, and retinoblastoma. A register for familial breast/ovarian cancer began operation on 1 October 1998.

A multiple endocrine neoplasia working group is establishing registries for MEN 1 and MEN 2.

Support

CANCER CHARITIES

Kraeftens Bekaempelse (the Danish Cancer Society; tel: 45 35 25 7500) is a large national organisation, raising funds for research and information/education about cancer and breast cancer.

PATIENT SUPPORT GROUPS

Kraeftens Bekaempelse has local branches to provide information and support groups; these focus mainly on affected persons and their relatives and less on educating persons who may be at risk.

There are no support groups for minority or high risk groups, for example, Ashkenazim. No such groups have been identified in Denmark.

14 Brøndum-Nielsen K. Genetic services in Denmark. *Eur J Hum Genet* 1997;**5**(suppl 2):64-8.
15 Bourret P, Koch L, Stemerding D. DNA diagnosis and the emergence of cancer-genetic services in European health care. In: Wheale P, von Schomberg R, Glasner P, eds. *The social management of genetic engineering*. Aldershot: Ashgate, 1998:117-38.

Persons responding

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ESTONIA

Genetic services

There appear to be 14 health service funded doctors devoted at least part time to the provision of genetics services. There are no genetic nurses yet, although this may be planned development for future.

The recent setting up of a non-profit making organisation, the Genome Center Foundation, by a group of Estonian geneticists, may foreshadow other developments in genetics. The Foundation proposes to create a national genetic database, both to identify disease genes and to allow individual Estonians access to their own data so that they can benefit from the personalised medicine of the future. The proposal has been endorsed by the Scientific Council of the University of Tartu and accepted by the Estonian government as one of three large scale national projects which will receive state funding in the year 2000. This will allow the preparation of a formal proposal to be laid before the Estonian parliament, and will also enable the creation of a public debate about its merits and defects.

CANCER GENETICS SERVICES

There are no specialist genetic associates in cancer genetics.

There is a comprehensive cancer centre, which runs a cancer genetics clinic, funded by government health service sources. Oncology centres appear to run two clinics specialising in familial breast cancer, and the first molecular diagnostic service for familial breast cancer is now operational.

Training

There is one medical faculty, at the University of Tartu. Non-medically trained genetic gounsellors: no specialist training.

TRAINING OF CANCER GENETICISTS

Consultants in cancer genetics are trained via international courses. There is no specific cancer genetics course, but molecular genetics, including cancer genetics, is a part of the general course.

Audit and evaluation

No details are available.

Discussion fora

No details are available.

Education

We are not aware of any educational measures, videos, etc. However, the need for education concerning genetic issues is clearly recognised and it is expected that media discussion of the issues involved in creating a national genetic database will lead to greater professional and public awareness.

Registers

There is a 25 year old Estonian Cancer Register. There are no registers of cancer predisposing conditions. There are also proposals, now well advanced, for a gene bank run by the Genome Center Foundation, along the lines of the Icelandic and Swedish models. It is hoped that this will catalogue information on the health status and genetic make up of more than 70% of the Estonian population of 1.4 million people, over a period of 10 years. The resultant database would be used for research purposes as well as for individual health care purposes, and it is expected that more than half the costs would be met by companies buying rights to use the data for genetic research.

Support

CANCER CHARITIES

There are several foundations devoted to cancer in general, but nothing specifically targeting cancer genetics or familial cancers.

PATIENT SUPPORT GROUPS

There are a number of these, including a breast cancer patients' support group. General advice is to see a doctor more frequently and in a specialist oncology clinic.

Persons responding

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FINLAND

Genetic services

Genetic services in Finland were reviewed by von Koskull and Salonen[16] as part of the comparative study carried out by the Concerted Action on Genetic Services in Europe. Because Finland is recognised as having a high frequency of (often unique) genetic disorders, historically medical genetics has had a high profile in Finland. The first genetics centre was established in Helsinki in 1971, as the result of a collaboration between the Family Federation of Finland (a state funded union of associations dealing with social, family, and population affairs) and the Department of Genetics at the University of Helsinki (which established the first Chair of Medical Genetics in 1972, although the first professor was not nominated until 1974). There are a total of eight government health service funded genetics centres, all of which include cancer genetics as part of their general service. Four (Helsinki, Tampere, Kuopio, and Oulu) are tertiary centres providing clinical and molecular genetics and cytogenetics services. The university

hospitals in Helsinki and Turku only have genetic counselling units; however, they work closely with the corresponding university departments.

Vaestoliitto and Folkhalsan provide genetic counselling outside the hospital system, but in close collaboration with the university departments. There are 11 cytogenetic laboratories (seven public, four private; one of these is supported partly by public funds, while the other three are commercial). There are 13 molecular genetics laboratories (three of which are private) and five biochemical genetics laboratories.

Average staffing levels are two to three clinicians and one to two genetic nurses; these perform preliminary interviews with patients, collect family data and samples, and organise follow up. In most departments they also provide counselling before prenatal diagnosis. In 1997 there were 17 clinical geneticists and 10 trainees, nine hospital geneticists and six trainees, 60 technicians, and 23 nurses.

CANCER GENETICS SERVICES

There is one well organised cancer genetics centre in Helsinki (the only HNPCC centre). There are seven centres offering counselling and predictive testing for breast cancer: a national centre at Vaestoliitto, and another at Folkhalsan, which serves the Swedish speaking population, together with the five university hospitals (Helskini, Turku, Tampere, Oulu, and Kuopio). Predictive testing is available for hereditary non-polyposis colon cancer, on a research basis, but studies on other hereditary cancers (for example, breast/ovarian cancer and multiple endocrine neoplasia) have only just begun. Long term follow up is not systematically organised country wide, but is beginning to be run on an individual basis, for the benefit of their own patients, by some specialists, including medical geneticists, paediatricians, neurologists, or surgeons working with colorectal cancer.

The Cancer Society of Finland runs a network of 12 to 14 clinics in all big city centres, where a nurse can take family histories and act as "triage". It has six polyclinics and six laboratories, which inspect the majority of samples generated by municipally funded mass screening programmes. The provincial cancer societies also have their own centres, which offer a limited cancer counselling service. They also offer "mole" clinics, which screen persons concerned about the risk of skin cancer or melanoma.

Training

Preclinical genetics teaching comprises lectures, laboratory demonstrations, and clinical teaching, provided by professorial departments. In those medical faculties without a professorial department, and in clinical departments, genetics teaching is integrated into their own teaching programmes.

Genetics became a recognised specialty in 1981, and the medical faculties of Helsinki, Turku, and Oulu run postgraduate training programmes in medical geneticists. These must be approved by the boards set up by the universities to run the specialist training programmes, as must the trainees themselves.

Since 1990 the University of Helsinki has run a four year training programme for non-medical "hospital geneticists". These are natural scientists or biologists who already have an MSc in which genetics was the major topic, and which contained a specified amount of human genetics teaching. Following the course, they are approved by the National Board of Medico-Legal Affairs (part of the Ministry of Social Affairs and Health). They are then qualified to run specialist genetics laboratories and usually sign laboratory reports.

There are no genetic associates in Finland.

There is no organised special training for genetic nurses, who obtain in service training in the course of their work in the genetics centres. The Cancer Society of Finland offers informal courses for nurses working in their network of clinics.

TRAINING OF CANCER GENETICISTS

There are no formal training courses in cancer genetics for specialists. The Cancer Society of Finland takes part in education programmes for the medical profession and organises training days on different themes, and the Finnish Association for Cancer Patients offers training to health personnel and other interested persons.

Audit and evaluation

Medical genetics, as a recognised specialty, is regulated, and the rights and responsibilities of medical geneticists are laid down by law.

There is no organised programme of quality control, but the Society for Medical Genetics has proposed and updated recommendations for this. Only the cytogenetics laboratories operate a quality assessment scheme, and laboratories from Norway and Lithuania have also participated in this.

The Cancer Society of Finland and the Finnish Society for Medical Genetics are drawing up plans for an evaluation of cancer genetics services in Finland.

Discussion fora

The Finnish Society for Medical Genetics was founded in 1976. Today its main purpose is to organise scientific meetings.

Geneticists in Health Care was founded in 1983, with the intention of establishing the training programme for hospital geneticists, and to make this a recognised (non-medical) specialty.

Both of these organise meetings and courses for scientific and practical training at least twice a year. Informal meetings for patient reviews, discussions of current clinical practice, laboratory problems, and the evolution/evaluation of guidelines also take place once or twice a year.

SPECIFIC CANCER DISCUSSION GROUPS

The Cancer Society of Finland takes part in international collaborations, principally with

the Nordisk Cancer Union (NCU, made up of Cancerfonden, Den Norske Kreftforening, Krabbameinsfelagid Islands, Kraeftens Bekaempelse), the European Cancer League (ECL), and the International Union Against Cancer (UICC). It also participates in the Europe Against Cancer programme and European Cancer Week.

Education

The general public is well disposed to genetic testing issues. The Cancer Society of Finland produces good quality, well illustrated information leaflets on a variety of cancer related topics, including the risk of familial cancers and familial breast cancer. It publishes a medical journal seven times a year to provide reliable and up to date information on cancer related diseases. It also produces brochures, posters, and videos related to cancer and health education, which are available for a small charge. It also participates in education programmes for the medical profession and organises training days on different themes. The Finnish Association for Cancer Patients offers training to health personnel and other interested persons.

There is a website maintained by the Cancer Society of Finland, which gives general information about cancer (in Finnish and English): http://www.cancer.fi

Registers

All genetics centres have their own patient registers. The National Research and Development Centre for Welfare and Health keeps some national registers and a Finnish Register of Congenital Malformations has been in existence since 1963. There is a well established register of cancers, operated by the Cancer Society of Finland, and based at the Institute for Statistical and Epidemiological Cancer Research in Helsinki. It gathers information on the occurrence of cancers in Finland, and produces annual cancer statistics, for instance, on the epidemiology of hereditary non-polyposis colon cancer. It is also actively engaged in statistical and epidemiological cancer research.

Support

CANCER CHARITIES

The Cancer Society of Finland embraces 12 provincial cancer societies and four patient organisations; it strives to support the public through health promotion, education about cancer issues, organisation of screening programmes and clinics, and by supporting diagnostic services and scientific research. It also operates three homes for the terminally ill, in Helsinki, Tampere, and Turku.

The Cancer Foundation and the Cancer Research Foundation (which includes the President J K Paasikivi Fund) support scientific research into cancer.

The Foundation for the Finnish Cancer Institute operates as a national collaborative body as well as a research fund. It was established in 1986 by all the institutions involved in cancer research in Finland (the five university medical schools, all university hospitals, the National Public Health Institute, the Institute of Occupational Health, the National Research and Development Centre for Welfare and Health, the Ministry of Health, and the Ministry of Education). It exists to develop cancer prevention and treatment, and to improve understanding of the causes and biological factors involved in cancer, by supporting research.

PATIENT SUPPORT GROUPS

In addition to a wide range of lay organisations for many different disorders, the following specifically cancer oriented organisations exist.

The Finnish Association for Cancer Patients.

The Association of Parents of Children with Cancer.

LE-Invalids.

The Finnish Association of Prostate Cancer Patients.

The Cancer Organisations operate a national helpline, Cancer-contact, which offers telephone consultations with health care professionals (in Finnish and Swedish), to support patients and their relatives in coping with cancer, and to distribute information about prevention, diagnosis, treatment, rehabilitation, the operations of the cancer organisations, and other forms of support. Cancer related consultations in Finnish and Swedish are also available via e-mail. They also organise supportive courses for patients and their relatives, to help in coping with cancer, and the changes in every day life it can cause. There is also a Support Person service, similar to the American "buddy" system: this began with the LE-Invalids service for persons with laryngeal cancer, and was extended to include breast cancer in 1978.

16 von Koskull H, Salonen R. Genetic services in Finland. *Eur J Hum Genet* 1997;**5**(suppl 2):69-75.

Persons responding

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FRANCE

Genetic services

Genetic services in France were reviewed by Aymé *et al*[17] for the comparative study carried out as part of the Concerted Action on Genetic Services in Europe. Most genetic counselling services were set up in the 1960s, at first within other departments (for example, paediatrics, neurology), although some were attached to cytogenetics laboratories. Since 1994 government policy has endorsed the creation of multidisciplinary centres for prenatal diagnosis. Regional genetics centres are not formally planned. There are as yet very few such

centres, and their place is filled by local networks of genetic clinics; in 1997 there were 62 of these, with 125 clinical geneticists seeing patients.

There is good access to diagnostic laboratories; from 1980 onwards these were funded by the Association Française pour le Dépistage et la Prévention des Handicaps de l'Enfant, so that biochemical and molecular tests incurred no costs, but in 1992 cytogenetic analyses were recognised as routine investigations and became directly chargeable against health insurance, and biochemical and molecular genetics followed in 1996. In 1997, there were 53 molecular biology laboratories offering tests for 171 different conditions. There were 98 cytogenetics laboratories, with a total of 200 cytogeneticists, and 31 biochemistry laboratories.

Uptake of genetic services is low when measured against the expected number of patients requiring diagnosis/counselling, but this may be explained by the low level of public knowledge concerning genetic issues.

In 1997, there were 125 genetically trained physicians (with an intake of 30 trainees each year), 200 cytogeneticists, and 100 molecular geneticists. There are no genetic nurses involved in the operation of genetics clinics, owing to opposition from medical geneticists, and no plans to alter this situation.

CANCER GENETICS SERVICES[18]

Since 1986, a well developed network of cancer genetics clinics has developed (separate from the general genetics clinic network), initiated by a group in Lyons with research interests in hereditary breast/ovarian cancer. The original intention was to provide a clinical resource for research, but the need to provide a clinical service for the families ascertained has led to the development of a network of clinics in centres of the Fight against Cancer; in 1987 the first clinical service in Lyon was funded by the League against Cancer, which now funds all such services. There were 33 of these in 1997, forming a national federation. Some funding is also now made available through government funding/social insurance sources; if a clinic is limited to consultation, both full and part time salaried consultants are supported by government funds, but laboratory activity is generally funded from charitable sources.

Cancer genetics clinics are often multidisciplinary and located in specialist centres, giving ready access to many different disciplines. Counselling is most often done by clinicians, usually medical consultant oncologists or radiotherapists, whose genetic activity is on a part time basis, for one, two, or three days per week. Genetic counsellors and genetic nurses are not involved. There are approximately 30 such clinics, each with approximately one clinician. A Working Party of INSERM (National Institute of Health and Medical Research) has recently agreed guidelines for the management of families with an inherited susceptibility to breast and breast/ovarian cancer, and a number of screening programmes have been set up.

Training

Undergraduates receive approximately 30 hours of genetics teaching in the first year of the preclinical course; this was sometimes provided by the Faculty of Science rather than the Faculty of Medicine, but genetics is now taught either by specialist medical geneticists or by physicians who are engaged in the provision of genetic services. The first Chair in Medical Genetics was established in 1981 and today 29 of the 37 faculties of medicine have a Professor of Medical Genetics.

From 1981 onwards, a competency certificate in medical genetics could be obtained. Medical genetics became a recognised subspecialty in 1983 (although one in which it was not possible to qualify until review boards were set up in 1990). Diplomas in molecular biology and human cytogenetics (the latter only available to those who were already specialists in medical biology, gynaecology and obstetrics, haematology, internal medicine, paediatrics, or oncology) were instituted in 1988 (before that time, the only higher degrees available to would-be specialists were MSc courses in cytogenetics or human genetics). Medical genetics became a full specialty in 1995, and there are plans to increase the number of trained specialists to 400 by 2005, although the funding for this is not yet clear. Guidelines for genetics teaching or training do not exist.

Nurses and psychologists receive no training in genetics. The profession of nurse/counsellor does not exist.

With the recognition of medical genetics as a specialty, clinical, molecular, and cytogenetics programmes have been set up for laboratory geneticists.

TRAINING OF CANCER GENETICISTS

Specialists are drawn from the ranks of oncologists, geneticists, or public health specialists with a special interest in cancer genetics. Most are already specialists in medical oncology or radiotherapy (a few are trained in biostatistics applied to oncology), who receive a year's general training in genetics (including cancer genetics), but about 30% of consultants have three to four years specific training in genetics. There is no specific cancer genetics training programme available.

Audit and evaluation

There are no specific professional guidelines governing professional practice, evaluation, or audit. Centres offering prenatal diagnosis require a licence from the Ministry of Health.

There is no quality assurance scheme for laboratories offering genetic diagnoses (although there is a scheme adopted by half the laboratories offering serum screening). Diagnostic laboratories are licensed to carry out specific activities on a five yearly renewable basis.

Cancer genetics services are at present evaluated within the hospitals/centres themselves, but it is planned to introduce National Health Authority approval in the near future. In March 1998, an ad hoc committee coordinated by the Institut National de la Santé et de

la Récherche Médicale (INSERM) published recommendations for the management of women with a predisposition to hereditary breast/ovarian cancer.

There is a National Consultative Ethics Committee for Health and Life Sciences, which issues regular reports on genetic issues, available from http://62.160.32.15/ccme/

Laws exist to regulate some aspects of genetic services, together with confidentiality and infringements of liberty. Other laws cover the use or exchange of cells and biological material of human origin, and the collection of human biological samples for research purposes (population genetics is categorised as research, and is not considered to be of direct benefit to the subjects studied).

Discussion fora

SPECIFIC CANCER DISCUSSION GROUPS

There is a French network for oncogenetics (Groupe Génétique et Cancer of the FNCLCC (Féderation Nationale des Centres de Lutte Contre le Cancer), secretary Dr Catherine Nogues, Centre Rene Huguenin, 35 Rue Dailly, 92210 Saint-Cloud, France), which was set up in 1991 to foster nationwide collaboration in the conduct of genetic counselling, screening, and research into hereditary breast/ovarian and other cancers. It has recently agreed guidelines for the management of cancer families. It organises two to three meetings per year, usually on a specific theme, for example, Li-Fraumeni syndrome or predisposition to different types of cancer.

Education

Genetic awareness has a very low public profile; the better educated enjoy better access to genetic counselling and diagnostic services, and many attempts are being made to improve public knowledge of genetic issues, through television programmes, articles in specialist and popular journals, and by the government.

Since 1997, the Ligue Contre le Cancer (LCC) has offered a short leaflet on predisposition and genetic risk; this explains what will happen at a genetic consultation. Plans are also well advanced for an information leaflet on breast/ovarian cancer, which will be given to patients following the first consultation; this is a translation and adaptation of that produced by Annie Jackson (Cambridge). Both the LCC and the ARC newsletters regularly carry information on cancer predisposition.

To improve referrals and provide a source of high quality information to physicians and the public, a database has been established jointly by the Ministry of Health and INSERM at <http://orphanet.infobiogen.fr>. There is also an on-line service, Allogene, for practitioners and the public, sponsored by the Ministry of Health and the Association Française contre les Myopathies (AFM).

There is a toll free telephone line delivering information on genetic diseases and services for health care workers and the general public.

Registers

France has national registers for cystic fibrosis and sickle cell anaemia and there are four population based registers of birth defects. There is as yet no national cancer registry or registry of those predisposed to genetic cancers, although there are some regional registers. There are plans for a breast/ovarian cancer register (as part of a *BRCAX* carriers cohort study), and for national registers for *BRCA* and *MMR* carriers, but not for a systematic, exhaustive registry. The *BRCA* register will be anonymous at a national level, but will hold confidential personal identity data on a local basis. An FAP register is planned for the Rhone/Alpes region.

Support

The Association Française contre les Myopathies (AFM) is a major charity supporting medical genetics.

CANCER CHARITIES

There are two main cancer charities, the Ligue Contre le Cancer (LCC) and the Association de la Récherche contre le Cancer (ARC). The Société Française Transgene is funding research into gene therapy for mesothelioma.

PATIENT SUPPORT GROUPS

There are no support groups for specific groups, for example, Ashkenazi Jews. Information on lay associations can also be obtained from: http://orphanet.infobiogen.fr/associations

17 Aymé S, Briard ML, Mattei JF. Genetic services in France. *Eur J Hum Genet* 1997;**5**(suppl 2):76-80.
18 Bourret P, Koch L, Stemerding D. DNA diagnosis and the emergence of cancer-genetic services in European health care. In: Wheale P, von Schomberg R, Glasner P, eds. *The social management of genetic engineering*. Aldershot: Ashgate, 1998:117-38.

Persons responding

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GERMANY

Genetic services

Genetic services in Germany have been reviewed by Nippert *et al*.[19] They have enjoyed a chequered past, for a variety of historical reasons, including, most recently, the reunification of East and West Germany in 1990. In the early 1970s, a joint initiative by university based geneticists and obstetricians and the Deutsche Forschungsgemeinschaft led to the establishment of 41 University based genetics centres in what was then West Germany. By 1995, there were 105 departments offering

genetic counselling and diagnosis (roughly half of which were private and half university based). At the end of 1996, 441 specialists were certified, and there were over 440 medical and non-medical specialists engaged in the provision of genetic services. Every medical school, with the exception of the Universities of Cologne and Mainz, has a university based genetics centre attached; these combine genetic counselling with specialist diagnostic and research laboratories, and access to specialist obstetric and paediatric university services. Göttingen offers genetic counselling, but does not operate an on site molecular diagnostic service; instead DNA samples are referred to other laboratories as appropriate and results reported back to Göttingen. Historically, emphasis had been placed more on prenatal testing and diagnosis, but more emphasis is now being placed on genetic counselling. Counselling costs are usually only reimbursed by the insurance organisations if it is provided by a specialist in medical genetics or a holder of the special medical education certificate (Zusatzbezeichnung). Most genetic counselling is provided by specialists, but there are some private practitioners. Social workers are involved in the provision of genetic services at Freiburg (Institute of Human Genetics) and at Heidelberg.

CANCER GENETICS SERVICES

In Germany there is no formal network of cancer genetics glinics. However, since 1994 a number of multidisciplinary clinics have been set up within university hospitals. Different disciplines (for example, gynaecology, oncology, human genetics, psychotherapy, and molecular biology) may be involved in their operation, with counselling provided by a specialist medical geneticist and information on treatment, prevention, etc, provided by an oncologist who is a specialist in the particular type of cancer (breast, ovarian, colon, etc). Where predictive testing is possible or desirable, a psychotherapist may also be involved. On average such a service would involve two specialist geneticists, two oncologists, a radiologist, a psychotherapist, a biologist, and a laboratory technician.

In addition to these multidisciplinary clinics, there are also some specialist centres involved in ascertainment, counselling, and surveillance for specific cancers, for example, breast or colon (HNPCC, FAP) cancer or multiple endocrine neoplasia.

Breast cancer genetics

Before 1995, there were no specialist breast cancer clinics and familial breast cancer was ascertained and treated in regular gynaecology departments. In 1995, a network of research workers and clinicians involved in familial breast cancer was set up (but not funded) as part of the Ministry of Health Cancer Programme and instituted a German *BRCA* Consortium. At the end of 1996, Deutsche Krebshilfe set up and funded 10 centres (later increased to 11, with the further addition of a centre for pathology and a centre for data management and genetic epidemiology in 1998) in medical schools throughout Germany, as part of a large multidisciplinary prospective study on familial breast/ovarian cancer, to provide standards for genetic counselling, testing, treatment, and the management of high risk patients, and to assess different methods of service provision and their effects. Each centre was allocated 1 million DM for three years, to allow them to develop a comprehensive service structure, including counselling and molecular diagnostics. These centres are free to decide how to use their own money and internal resources, but as regards patient counselling they have to take a multidisciplinary approach, involving gynaecology, human genetics, and psychology. For example, the Bonn centre involved a collaboration between the gynaecology clinic and the Institute of Human Genetics. It is staffed by a specialist medical geneticist (mainly involved in genetic counselling and *PTT* mutation analysis), a gynaecologist (involved in surveillance), a graduate biologist, and a technician involved in direct sequencing for mutations and other research topics. It also has a number of part time staff: a second gynaecologist, a radiologist, a psychotherapist, a human geneticist, and some students doing research work, mainly in the laboratory. The Institute for Human Genetics in Göttingen operates a service for breast cancer, in collaboration with the Department of Gynaecology.

Colorectal cancer genetics

There are six multidisciplinary clinics for hereditary colorectal cancer and seven centres with a special interest in FAP (Berlin, Bonn, Dusseldorf, Freiburg, Heidelberg, Homburg/Saar, and Münster). The Deutsche Krebshilfe has recently decided to fund six colorectal cancer centres, at the Universities of Bochum, Bonn, Dresden, Dusseldorf, Heidelberg, and Munich/Regensburg, to the tune of 1.3 million DM per year for the next three years, following criteria similar to those for the breast cancer project. The Institute for Human Genetics in Göttingen operates a service for colon cancer in collaboration with the Department of Surgery there.

Training

Genetics is taught in conjunction with basic biology during the preclinical course (although the amount and extent of such teaching varies from university to university). It is also taught during the clinical course, with an obligatory written examination, and future curriculum changes are expected to emphasise it still further.

In 1978, medical genetics was acknowledged by the Certification Boards of the different states: appropriately trained clinicians could obtain a Zusatzbezeichnung (special medical education certificate). In 1992, the Deutscher Arztetag (general assembly of German physicians) acknowledged human genetics as a new specialty, "Facharzt für Humangenetik". Specialists in both medical and human genetics are certified through the Landesarztekammern, rather than centrally through the German

Board of Medical Genetics. Following graduation, a five year training period leads to specialisation (Facharzt für Humangenetik); in most states this requires a two year subspecialisation (Fachkunde) in either cytogenetic diagnosis or molecular laboratory diagnostics. Alternatively, to obtain the Zusatzbezeichnung Medizinische Genetik, it is necessary to have had four years of clinical practice or previous recognition in a different medical specialty, and to follow this with two years of training in clinical genetics and genetic counselling. These requirements may vary slightly from state to state.

Genetic associates (non-medical geneticists) take a first degree in biology or biochemistry, followed by five years of specialist training leading to the title of Fachhumangenetiker/in (instituted by the Society for Human Genetics in 1993). This makes provision for further specialisation in molecular genetics, biochemical genetics, cancer genetics, or teratology and mutagenesis. Genetic associates are not generally involved in clinical or counselling work, although they do make cytogenetic and molecular diagnoses. Non-medically qualified personnel may be involved in research projects on genetic disorders.

Genetic nurses do not exist in Germany. There is one social worker in Würzburg who is involved in home visits for patients with muscular disorders and two in Heidelberg. If a suitable training programme structure and qualifications were available, this might alleviate the workload of clinicians, who do the bulk of German genetic counselling at present.

TRAINING OF CANCER GENETICISTS

There is no formal training programme for consultants in cancer genetics; most practitioners acquire their expertise through contact with colleagues and superiors, "on the job". Most are drawn from specialists in the university hospitals.

Audit and evaluation

The university departments of medical genetics in Baden-Wurtemberg collaborate on general genetic service policy matters,and have developed plans for the future provision of genetics services in their state.

The Bundesarztekammer (German Physicians' Board Association) has published guidelines for the proper interdisciplinary counselling and treatment of patients with hereditary cancer and for predictive cancer diagnostics. Several task forces exist to promote collaboration between different disciplines. The Ministry of Health Cancer Programme and Deutsche Krebshilfe cooperated on the latter's national *BRCA1/2* research funding scheme, to set up centres in medical schools throughout Germany. The Deutsche Kresbhilfe funds research to evaluate the utility of cancer genetics and to set standards of practice for hereditary colon cancer and hereditary breast/ovarian cancer (Mildred Scheel grant). The German breast cancer genetics networks are participating in the BIOMED-2 programme on familial breast cancer.

Fifty five cytogenetics diagnostic laboratories and 73 molecular diagnostic laboratories are currently taking part in a national evaluation of quality assurance programmes orchestrated by the Board of Medical Genetics.

Discussion fora

Board of Medical Genetics (founded in 1988): this issues professional guidelines, provides quality control, and publishes a journal, Medizinische Genetik, in conjunction with the Society for Human Genetics.

Gesellschaft für Humangenetik (German Society for Human Genetics).

Arbeitskreis fur Molekulargenetik in der Frauenheilkunde (Molecular Genetics in Obstetrics and Gynaecology).

Bavarian Research Association of Human Genetics.

Other than these, there are no formal discussion fora, although there are a number of informal discussion groups, collaborations, and study groups. Collaborative/cooperative links are usually at state or regional level, via the university departments of human genetics.

SPECIFIC CANCER DISCUSSION GROUPS

An HNPCC interdisciplinary study group, with around 150 members, has been in existence since 1994; it has a website and a twice yearly newsletter.

The Deutsche Krebshilfe centres hold regular meetings to discuss methodology, ethics, and surveillance issues, and other matters.

The Deutsche Krebsgesellschaft has organised an initiative for the coordination of efforts in the field of hereditary cancer (registration, counselling, prevention, screening, ethics), to constitute a forum for improving education/communication. It is planning a national meeting for broad participation.

An International Congress on Hereditary Cancer Diseases took place in August 1998 in Dusseldorf (Nordrhein-Westfalen), organised by the Gesellschaft zur Bekampfung der Krebserkrankungen (the Cancer Society of Nordrhein-Westfalen) (with some financial support from the Deutsche Krebsgesellschaft).

Education

The Deutsche Krebshilfe centres provide comprehensive information material for patients and clinicians (based on the information sheets produced by Professor Bruce Ponder's department, Cambridge, UK); it is intended that this information should be standardised across all 11 centres for familial breast/ovarian cancer. Some of the leaflets produced include: Familiarer Brust- und Eierstrockkrebs - Schwerpunktprogramm der DKH: (1) Ausfuhrliche informationen für Patienten; (2) informationen für Patienten; (3) informationen für Arzte.

Other leaflets which are made available by various centres include:

Frauenklinik, Heinrich-Heine-Universität Dusseldorf (Dr M Beckmann): Informationsblatt uber die untersuchung zur familiaren haufung von brust- und eierstockkrebs.

Zentrum für Familiaren Brustkrebs Universität Bonn: Schwerpunktprogramm der Deutschen Krebshilfe "Familiarer Brustkrebs" - Kurzinformation für betroffene Familien.

Rheinische Friedrich-Wilhelms-Universität Institut für Humangenetik/Medizinische Klinik Allgemeine Innere Medizin: Studie zum autosomal-dominant erblichen Dickdarmkrebs (HNPCC) - Kurzinformation uber Autosomal-dominent erblichen Dickdarmkrebs (Lynch-Syndrom; HNPCC) (different versions for doctors and patients).

Various pharmaceutical companies also produce leaflets.

The HNPCC Study Group has a twice yearly newsletter and a patient information booklet, distributed nationally.

There is a high degree of public awareness of and interest in predictive testing for late onset disorders owing to the Human Genome Project and to a high profile in the media. The public is well informed about cancer related issues, and consequently demands a high level of service.

A major exhibition on genetics, "Mensch und Gene", was held at the Ausstellungshalle, Bonn in 1998.

From time to time there are special TV transmissions on familial cancer (for example, in a general series on medicine)

There is an HNPCC study group website with hotlines for doctors and patients. The German *BRCA* Consortium also plans a website, but this is not yet operational. Other cancer charities and various university hospitals also have websites, but details are not available.

Registers

There is no official, all embracing national register, for a variety of reasons (for example, the question of data protection and confidentiality). The importance of registers of cancer predisposing conditions is stressed in many professional guidelines and recommendations (for example, those for Security in Work, declarations of the Berufsgenossenschaften, etc). There has been a national HNPCC study group register since 1994, and others are being set up for MEN 1/2 and hereditary pancreatic cancer. There are also local registers for hereditary breast cancer, FAP, HNPCC, MEN, von Hippel-Lindau disease, and NF1/2. Some states, for example Bavaria, have passed laws requiring the registration of cases of cancer (including hereditary cancers), but others, for example, Nordrhein-Westfalen, have not.

Support

CANCER CHARITIES

Deutsche Kresbhilfe (Deutsche Krebshilfe eV, Thomas-Mann-Strasse 40, 53111 Bonn, Germany).

PATIENT SUPPORT GROUPS

In addition to the help offered by the Deutsche Kresbhilfe centres, the HNPCC Study Group has a hotline website open to patients as well as doctors, a twice yearly newsletter, and a patient information booklet, distributed nationally. There is a patient support group for FAP and hamartomatous polyposis syndrome, which produces *Polyposis Post*, a twice yearly newsletter.

There is an umbrella organisation, Selbsthilfegruppen und Humangenetiker eV, which exists to bring together professionals and patient groups.

19 Nippert I, Horst J, Schmidtke J. Genetic services in Germany. *Eur J Hum Genet* 1997;**5**(suppl 2):81-8.

Persons responding

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GREECE

Genetic services

Genetic services in Greece have been reviewed by Bartsocas,[20] as part of the Concerted Action on Genetic Services in Europe. The first services arose out of the population screening and prevention programmes for thalassaemia and sickle cell anaemia, and in 1997 there were 13 genetics centres in Greece (mostly affiliated to university departments), offering a variable range of services, with a further two private clinics in Athens. However, there are not enough centres to provide adequate access to genetic services in all parts of the country. The number of geneticists with formal training is not known.

In 1997, there were two genetic counsellors.

There are eight molecular genetics laboratories (six in Athens, one of them private, and two elsewhere), 11 cytogenetics laboratories (two of them private), and five biochemical genetics laboratories (one of these, at the Institute of

Child Health, provides a national neonatal screening service for phenylketonuria, hypothyroidism, G6PD deficiency, and galactosaemia).

CANCER GENETICS SERVICES

There are two main centres: the Anti-Cancer Hospital Ag Savvas has one at least. On average each has two to three doctors, no genetic associates, and one genetic nurse, funded by government health service sources. There are multidisciplinary clinics for tuberous sclerosis and NF (with neurologists etc) and for familial breast cancer.

Training

Genetics teaching in medical schools is inadequate and receives insufficient time in the curriculum.

Postgraduate genetics teaching is under development, but is hampered by the fact that medical genetics is not recognised as a separate specialty. Accordingly, most geneticists train abroad, with the aid of generous funding from the State Scholarship Fund, the Onassis Foundation, and the Greek National Health Service. Seminars in clinical genetics (covering various topics and subspecialties) are organised by the National University of Athens (Prof C S Bartsocas) every three years, with international participation.

The School of Dentistry and the Faculty of Nursing (University of Athens) both offer genetic counselling as an elective postgraduate course. There is a Master's degree in Clinical Nursing, with the emphasis on genetic counselling, the demand for which greatly outstrips the places available. Graduate nursing students can also learn counselling through practical application.

TRAINING OF CANCER GENETICISTS

There is no formal training/recruitment system for consultants in cancer genetics. The Hellenic Society of Nursing Studies and the Hellenic Anti-Cancer society offer a joint course in cancer genetics for nurses.

Audit and evaluation

None. The lack of checks on clinical practice and of quality assurance schemes for genetic counselling or diagnostic laboratories lower the quality of the genetics services available in Greece. National guidelines only exist for certain disorders (for example, the haemoglobinopathies). The Hellenic Association of Medical Geneticists and the Demokritos Research Centre operate a voluntary quality assessment scheme for laboratory methods.

Discussion fora

Hellenic Association of Medical Geneticists

None. There is poor communication and collaboration between clinical geneticists and between genetics laboratories.

SPECIFIC CANCER DISCUSSION GROUPS

No details are available.

Education

Efforts to remedy the lack of genetic education among health care professionals and hospital administrators are hampered by the shortage of suitably trained geneticists and the perennial lack of funding. The general public is reasonably aware of genetic issues, although the tendency to conceal genetic disorders, or refrain from seeking help, where this may have disadvantageous consequences for oneself or one's family, remains. However, screening programmes for thalassaemia and sickle cell anaemia have been well accepted and have ensured a basic level of genetic knowledge.

Registers

In 1997, there were no general genetic registers or registers dealing with cytogenetic and congenital abnormalities, terminations of pregnancy, or hereditary cancers. It is thought that the Department of Cancer Cytogenetics (Aghios Savvas Anti-Cancer Hospital) has a register, but this has not been confirmed.

Support

CANCER CHARITIES

The Greek Anti-Cancer Society.

PATIENT SUPPORT GROUPS

Some exist (for example, tuberous sclerosis, "Floga", "Elpida" for children with neoplasias).

The Greek Anti-Cancer Society provides support and education for patients and health care professionals.

20 Bartsocas CS. Genetic services in Greece. *Eur J Hum Genet* 1997;5(suppl 2):89-92.

Persons responding

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HUNGARY

Genetic services

Genetic services in Hungary have been reviewed by Czeizel,[21] as part of the Concerted Action on Genetic Services in Europe. The health care system has been in a state of flux since 1990 and the gradual onset of democratic reforms. A new health care structure and a system of health care insurance have been introduced. In Hungary, genetics services do not seem to have suffered unduly from the lack of interest or positive discouragement experienced in some other countries of the former Eastern Bloc, although they nevertheless operated under a cloud. The first genetic counselling service was set up in 1963. By 1997, there were 16 genetics centres (six of them in Budapest, 10 elsewhere), with a total staff of 17 specialist clinicians (seven medical geneticists, six gynaecologists, two paediatricians, and one specialist in internal medicine) and 14 trainees, and 23 genetic nurses/counsellors. Difficulties in obtaining funding or reimbursement, and lack of genetic knowledge among physicians, are factors limiting access.

There were 16 cytogenetics laboratories, with 16 genetically trained physicians, 13 cytogeneticists, and 47 genetic nurse/counsellors; 12 of these worked directly with genetic counselling clinics.

There were 14 molecular genetics laboratories (including three well established biochemical laboratories mainly involved in medical genetics), with 14 genetically trained physicians (and six trainees), 16 molecular geneticists, and 49 genetic nurse/counsellors. There were also nine fetal diagnostic centres, with nine genetically trained physicians, six cytogeneticists, four molecular geneticists, and 28 genetic nurse/counsellors, a grand total of 54 genetically trained physicians, 20 trainees, nine cytogeneticists, 20 molecular geneticists, and 147 genetic nurse/counsellors.

In Hungary, genetic associates carry out the scientific component of the service, while genetic nurses are mainly concerned with administration. Both associates and nurses must be graduates in biology or genetics, but there is no formal career structure.

CANCER GENETICS SERVICES

Twenty three percent of Hungarians die of cancer and this rate is increasing. Cancer genetics services are in their infancy, but there is increasing awareness of their importance. An international collaborative study carried out by the National Institute of Oncology in Budapest has shown the usefulness of genetic testing in people from families at high risk of developing breast/ovarian cancer, but at present this is only available on a research basis.

With regard to breast/ovarian cancer, the study indicated that the spectrum of mutations in *BRCA1* and *BRCA2* did not appear to differ greatly from that found in western Europe. There is one familial breast cancer clinic in Hungary, health service funded, with two doctors, two genetic associates, and two genetic nurses.

Semmelweis Medical University (Budapest) houses the National Registry of Childhood Cancer and has special clinical and genetic services for its patients.

Three cytogenetics laboratories are involved with tumour cytogenetics. Debrecen Medical University has a research interest in the cytogenetic aspects of childhood cancer.

Collaborative links are being developed between oncology and cancer genetics services, mainly in the area of childhood cancers.

The Family Planning Clinic in Budapest has a special genetic counselling unit to assist in family planning for cancer patients.

Training

Four undergraduate and one postgraduate medical universities undertake basic medical education, which involves a six year course. The principles of molecular biology form part of the biological course in the first year of the curriculum. A clinical or medical genetics course (two to 24 hours) is taught by geneticists, paediatricians, or obstetricians in the fifth year, but only two universities set examinations in genetics; the other two include it as part of paediatrics or obstetrics. Genetics teaching at undergraduate level is inadequate and unsatisfactory, resulting in inadequate knowledge among medical graduates, and difficulty in filling training posts in genetic counselling services.

Following qualification, a further four to five year training period, with some obligatory courses, leads to primary specialisation. There is little genetics teaching at a postgraduate level; no postgraduate course in medical genetics has been offered in the past 15 years, although postgraduate courses in other specialties, such as paediatrics, dermatology, obstetrics and gynaecology, and oncology, have some genetic content in their 60 hour curriculum.

Since 1978, medical genetics has been a recognised specialty, but there is no specific training programme, and certification in genetics can be obtained from the Board of the Postgraduate Medical University without examination (this is not the case for the majority of specialties). The minimum requirements for qualification are four years of practice post-qualification, and this otherwise depends upon references, CV, and publications.

There are no training programmes for others involved in the provision of genetics services, for example, cytogeneticists or genetic nurses. The OFPS (Periconceptional Optimal Family Planning Service) offers a two week course with an examination for nurses working in its network of clinics.

TRAINING OF CANCER GENETICISTS

There is no formal training programme in cancer genetics, although there is some genetics teaching in postgraduate courses in oncology. The European School of Oncology ran a training course in molecular genetics in November 1997.

Audit and evaluation

National Guidelines for Fetal Diagnosis are issued by the Board of Medical Geneticists and the National Institute of Obstetrics and Gynaecology. Prenatal and neonatal screening programmes are monitored by the Hungarian Congenital Abnormality Register, and this reviews the records of the nine centres offering fetal diagnosis.

There is no system of checks on quality of clinical practice, and no quality assurance schemes for laboratories offering genetic diagnosis.

Discussion fora

Regular clinical/laboratory review meetings do not take place.

The Hungarian Society of Human Genetics.

SPECIFIC CANCER DISCUSSION GROUPS

No details are available.

Education

No patient information leaflets, videos, etc, are available. No media interest.

Access to genetic services is governed chiefly by education and socioeconomic status. The Hungarian media's generally favourable cover-

age of genetic issues has led to a reasonable degree of public awareness, and there are ongoing public education programmes on topics such as family planning, genetic counselling, the prevention of congenital anomalies, and ethical issues. Following the birth of a baby with congenital malformations, the Hungarian Congenital Abnormality Register notifies the Centre for Congenital Anomaly Control, which sends the parents information on possible causes, available care and medical treatment, and recurrence risks. However, pre-1990 attitudes still linger and genetic disorders are often considered rare and untreatable. Medical policy makers are often unaware of genetic issues.

Registers
National Registry of Childhood Cancer (Semmelweis Medical University, Budapest).

Support
CANCER CHARITIES
No details are available.

PATIENT SUPPORT GROUPS
No details are available.

21 Czeizel A. Genetic services in Hungary. *Eur J Hum Genet* 1997;**5**(suppl 2):93-9.

Persons responding
Dr Peter Bosze, Budapest (e-mail: bosze@mail.matav.hu).

Dr Edith Olah, National Institute of Oncology, H-1525 Budapest 114, Pf 21, Hungary.

ICELAND

Genetic services
There are two breast cancer screening/mammography services, based in Reykjavik and Akureyri, and one mobile unit. No details of staffing are available.

Genetic associates do not have a role in the provision of genetic services.

CANCER GENETICS SERVICES
There are no cancer genetics or familial breast cancer clinics in Iceland and no multidisciplinary clinics with a genetic component.

Training
For consultants, training must be sought abroad. No plans currently exist for this in Iceland.

There is no training programme for genetic associates or nurses, but the Nordic School of Public Health in Gothenburg, Sweden, is planning formal training courses for the future, as part of a Nordic Network.

TRAINING OF CANCER GENETICISTS
There are currently no specialist cancer genetics consultants working in Iceland. Training in this field is undertaken exclusively through clinical genetics and oncological training programmes abroad.

Audit and evaluation
There are no provisions for audit of cancer genetics services or audit surveillance measures.

Discussion fora
There are no formal general genetics discussion groups.

SPECIFIC CANCER DISCUSSION GROUPS
Samhjalp kvenna, an association of breast cancer patients, has held a symposium on familial breast cancer, but this is not an established group.

Icelandic Cancer Society (Prof H Tulinius).

UUS-Biosciences (Dr R Arngrimsson).

Nordisk Cancer Union (NCU: made up of Cancerfonden, Den Norske Kreftforening, Krabbameinsfelagid Islands, Kraeftens Bekaempelse).

Education
Neither the Iceland Cancer Society nor other organisations have produced any leaflets on familial breast cancer. There are no videos and no websites. However, one of the benefits of the active debate regarding the generation of a database containing the medical records of the entire population is that it has raised public awareness of the issues of inherited disease susceptibility, and genetic issues generally enjoy a high profile.

Registers
The Icelandic Cancer Registry has records of cases of breast cancer diagnosed in Iceland since 1910; there are approximately 2000 families. The Cancer Society has a collection of blood samples and clinical family history information from consecutive cases with breast cancer diagnosed in Icelandic hospitals since 1987.

On 17 December 1998 the Icelandic Parliament granted an exclusive licence to deCODE Genetics, a biotechnology company based in Reykjavik, permitting them to construct an electronic database of the medical records of the entire Icelandic population (approximately 270 000 persons). While this is not a register as such, it is a particularly valuable resource for research into the genetics of common disorders, because of the completeness of these records and the isolated nature of the Icelandic gene pool, which will allow correlation of genetic and genealogical data. deCODE also has exclusive rights to the commercial exploitation of this database for 12 years. The company has entered into an arrangement with Hoffman-La Roche, allowing the latter to access the database for research into the genetics of 12 common diseases. There is active public debate concerning the ethical implications of such a database, and a correspondingly high public level of awareness of genetic issues such as inherited cancer susceptibility, which, in this context, is bound to influence demand for cancer genetics services. The government has stated that information contained on the database will not be identifiable, although there are concerns that guaranteeing anonymity is

not possible (currently there is provision for people who do not wish their details to be included on the database to opt out). Many clinicians have indicated that they will not enter patient data, and much of the objections raised come from this group, although it could be argued that it will provide substantial benefits for the population of Iceland.

Support

CANCER CHARITIES

Icelandic Cancer Society.

PATIENT SUPPORT GROUPS

Samhjalp Kvenna is an Association of Breast Cancer Patients. There is also an Icelandic organisation for the parents of children with cancer.

Persons responding

Dr Reynir Arngrimsson, Senior Lecturer in Clinical Genetics, Medical Genetics Unit, Faculty of Medicine, University of Iceland, Medical School Building Valnsmyrarvagur, 101 Reykjavik, Iceland.

IRELAND

Genetic services

Genetics services in the Republic of Ireland have been reviewed by Barton,[22] as part of the comparative study carried out by the Concerted Action on Genetic Services in Europe. State funded genetics services are delivered through the National Centre for Medical Genetics in Dublin, which aims to provide a comprehensive clinical and laboratory service for all patients and families affected by or at risk of a genetic disorder. The centre includes an academic department of medical genetics, part of University College Dublin, with a strong research interest, and has strong links with the national neonatal screening service. It is staffed by a Professor of Medical Genetics, a second consultant appointed in 1998, a registrar, and a nurse counsellor (with plans for expansion), with approximately nine cytogeneticists and six molecular geneticists. A further 12 persons are engaged in the provision of genetics services in other parts of the country. There is one clinical geneticist in private practice, offering a limited service.

There are nine cytogeneticists attached to the National Centre, with a further seven working elsewhere, and six molecular geneticists, with a further four elsewhere. According to Barton,[15] there are cytogenetics laboratories at University College Galway (which has a Professorial Chair in Cytogenetics) and Trinity College Dublin has cytogenetic and molecular genetics laboratories; there are also molecular genetics laboratories at University College Cork (research only) and the long established National Screening Centre in Dublin (which offers the only biochemical genetics laboratory service). In addition to these, the Smurfit Institute of Genetics at Trinity College Dublin (Dr David McConnell) has an established international reputation for genetics research.

CANCER GENETICS SERVICES

There are two cancer genetics centres in the Republic of Ireland. The first, at St James's Hospital, Dublin (Prof P Daly) has been in place for several years; the second is run as part of the National Centre for Medical Genetics and is included in the regular service.

The National Centre is actively developing contacts with cancer specialists from other disciplines, to improve and coordinate patient care in the light of recent advances in cancer genetics. There are ongoing research collaborations with colleagues in the UK (Prof M Stratton, Prof J Peto, Dr D Easton, and others). In an effort to bridge the gap between research and service delivery, a group led by Prof A Green and Dr D Barton made a successful application to the Health Research Board for a programme grant to study the implementation of genetic testing in families with hereditary breast cancer. This programme is now under way, the participating centres being the National Centre for Medical Genetics, the Departments of Medical Oncology at St James's and Mater Misericordiae Hospitals, and the Departments of Surgery and Oncology at St Vincent's and St Luke's Hospitals, all in Dublin (for logistical reasons). A research nurse in cancer genetics and a part time secretary/data manager have been recruited. Cancer genetics clinics have been established at the different centres with input from local staff and Prof A Green. All molecular analysis is carried out in the laboratory of the National Centre. This programme will last for four years, and it is hoped that it will lead to the emergence of a structured service in this area.

Since 1992, there has been a research focus on familial breast cancer at St James's Hospital, Dublin, in collaboration with Trinity College Dublin. This group has formed a number of collaborations (notably with Prof M Stratton, Institute of Cancer Research, Sutton, Surrey) in the UK and elsewhere to add to the international resources being concentrated in this area. Irish families, being large, are especially suitable for linkage analysis, and this was particularly helpful in the localisation of the *BRCA2* gene. In addition, the Department of Clinical Oncology at St James's Hospital has set up a research unit, funded by the Health Research Board, to explore gene therapy and its uses in treatment of cancer, under the direction of Prof D Hollywood.

The cytogenetics laboratory attached to the National Centre offers a cancer cytogenetics service, with particular reference to leukaemias and lymphomas. The molecular genetics laboratory also has an interest in the diagnosis of inherited forms of cancer.

In addition to this, an All-Ireland Cancer Agreement has recently been instituted in collaboration with the American National Institutes of Health. This will take advantage of the harmonisation of government regulations and improved communication to bring the Republic and Northern Ireland together in the fight against cancer. It is intended to enhance and coordinate tumour registries throughout Ireland, to improve informatics in the support of

clinical trials, and to provide for improved education in the field.

Training

All university medical schools teach basic genetics, but the content varies widely. The National Centre for Medical Genetics participates in undergraduate genetics teaching at University College Dublin and at the Royal College of Surgeons of Ireland. Some postgraduate genetics teaching is also provided for other specialties.

Genetics is not a recognised specialty. There are no published recommendations for teaching, and postgraduates must look to the UK or the USA for specialist training and service guidelines. Trinity College Dublin runs postgraduate courses on genetics and molecular biology in clinical medicine, and offers an MSc course in molecular medicine for clinicians and scientists.

Genetic counsellors receive training "in house"; there is no organised career structure.

TRAINING OF CANCER GENETICISTS

No specific training is available in Ireland; specialists (which would include oncologists and cancer geneticists) are recruited via international advertisement. The recent All-Ireland Cancer Agreement aims to provide a further education exchange programme for cancer specialists.

Audit and evaluation

The National Centre for Medical Genetics carries out internal audit, and prepares an annual report on its activities.

Its molecular genetics laboratory participates in the UK NEQAS scheme for molecular genetics and its cytogenetics laboratory in the equivalent scheme for cytogenetics, as well as the American College of Pathologists QA scheme. Other molecular genetic diagnostic laboratories do not appear to do so.

Discussion fora

No details are available.

SPECIFIC CANCER DISCUSSION GROUPS

The 12th meeting of the Breast Cancer Collaborative Group took place in Dublin in September 1998.

The new All-Ireland Cancer Agreement is intended to foster improved communication and discussion both within Ireland and with other countries, to take advantage of improved communication systems and the globalisation of scientific research.

Education

For a variety of reasons, including religious principles, genetics has not formed a major part of the curriculum in Irish medical schools, and therefore knowledge of genetic issues among both general practitioners and the general public is very patchy. However, this situation is changing rapidly.

Registers

There is a National Cancer Registry, based in Cork (with a website at Cancereg@indigo.ie). The National Centre for Medical Genetics has a register of cancer predisposing conditions. The NCI-All Ireland Cancer Agreement, which was recently set up, aims to enhance and coordinate tumour registries throughout Ireland (north and south).

Support

CANCER CHARITIES

No details are available.

PATIENT SUPPORT GROUPS

Ireland has numbers of these, but none specifically relating to hereditary or other cancers. There is an umbrella group, the Inherited Diseases Organisation, which lobbies the government on genetic issues.

22 Barton DE. Genetic services in Ireland. *Eur J Hum Genet* 1997;5(suppl 2):100-4.

Persons responding

Dr Ruth Barrington, Chief Executive, Health Research Board, 73 Lower Baggot Street, Dublin 2, Republic of Ireland (Validator) (tel: 353 1 6761176; fax: 353 1 6611856; e-mail hrb@hrb.ie).

Prof Peter Daly, Hope Directorate, Haematology, Oncology and Palliative Care Service, St James's Hospital, James's Street, Dublin 8, Republic of Ireland (tel: 353 1 453 7941 ext 2164/2165; fax: 353 1 453 0557).

Prof Andrew Green, National Centre for Medical Genetics, Our Lady's Hospital for Sick Children, Crumlin, Dublin 12, Republic of Ireland.

ISRAEL

Genetic services

Genetic services in Israel have been reviewed by Chemke and Zlotogora,[23] as part of the Concerted Action on Genetic Services in Europe. The first genetic counselling service was set up in Jerusalem in 1964, and medical genetics services in Israel have undergone constant development since that time. A national programme for the detection and prevention of birth defects has been in operation since 1980, established by the Ministry of Health. In 1997 there were 13 medical genetics centres (all but one in university hospitals), each with a genetic counselling clinic and at least a cytogenetics laboratory, with 17 consultants (and three trainees), 32 cytogeneticists, 19 molecular geneticists, and 16 genetic nurses. All main centres have at least one Board certified medical geneticist and another physician, who is also often Board certified. The clinical team in most clinics includes at least one genetic nurse/counsellor, who shares genetic counselling with the clinician.

All centres provide genetic counselling, with multidisciplinary management of complex disorders, and there is a good degree of coordination with other centres and specialties. All centres also have access to diagnostic laboratory facilities, either in house or within other

departments. In addition, there are a number of specialist centres involved in population screening, coagulation disorders, neuromuscular disorders, and lysosomal storage diseases. Because of the nature of the Israeli population, specialist centres also exist to carry out screening for disorders known to occur more frequently in certain population groups, such as Tay-Sachs disease in the Ashkenazi population and β thalassaemia in Jews from Kurdistan and Israeli Arabs. The Bedouin population, with a very high rate of consanguinity, also suffer from a wide range of disorders more often than the average, and the Genetics Institute of the Soroka Medical Centre has a specialist outreach/primary care programme targeted to this group.

CANCER GENETICS SERVICES

Multidisciplinary cancer genetics services are being developed in the major medical centres, in conjunction with oncology services. Usually, an oncology social worker participates in counselling, while molecular genetic investigations are performed in the laboratories attached to the genetics centre. There are also five centres for cancer genetics, with trained genetic counsellors who take family histories and refer on as necessary. Nurses have a clear role in delivering services, including risk evaluation on pedigree data. There is a Consultative Service for Hereditary Cancer, operated by the Tel-Aviv Medical Centre.

Breast cancer genetics services are well organised. Since 1994, a colon cancer service has been operated by Dr Paul Rozen, to provide clinical consultation, screening, and follow up for most known FAP, HNPCC, JP, and Peutz-Jeghers families. All are offered genetic counselling and mutation analysis is routine for FAP and some HNPCC families.

Training

There are four medical schools. Medical genetics forms part of the preclinical curriculum in all universities; it is also included in paediatric, gynaecological, and haematological lecture courses, and there is a common final examination for all students.

Medical genetics became a recognised specialty in 1986. To specialise, physicians who are already certified in internal medicine, paediatrics, or obstetrics and gynaecology can undertake a two year training programme (including 18 months of clinical training and six months in a genetics laboratory). This must be in one of four fully approved medical genetics centres, which must have two certified clinicians, as well as cytogenetic, biochemical, and molecular genetic laboratories (a further two are approved for partial training), and leads to Board examination and certification. By 1994, there were 23 Board certified medical geneticists (14 paediatricians, seven gynaecologists, and two specialists in internal medicine), of whom seven were practising.

The Ministry of Health has recently recognised cytogenetics, and biochemical and molecular genetics, as specialties in health care, and has defined professional criteria for them, but there are still no formal training courses, and many people now working in Israel took a Masters degree in genetic counselling in the USA.

Since 1997, the medical school of the Hebrew University in Jerusalem has offered an MSc course in genetic counselling, in association with the medical school at Hadassah, Ein Karem. Students must be biology graduates with a course average of 85% or more, psychology graduates who have taken a year of biology studies, or nursing school graduates, and all must have taken a course in genetics and human genetics. The two year MSc programme covers clinical genetics and counselling, cytogenetics, genetics of metabolic disorders, basic psychology, and a period of laboratory experience. Students attend weekly seminars in the Department of Human Genetics and are required to give a talk annually. One semester per year is spent in clinical experience in a genetic counselling clinic. The course offers 30 credits per year; following completion, students are required to work under supervision in a clinical genetics service in order to obtain recognition by the Ministry of Health. It should be noted that this is not a research degree. Students who wish to obtain such a degree, which is a prerequisite for undertaking a doctorate in Jerusalem, are required to carry out a research project.

Nurses receive medical genetics lectures as part of their training, and have a well established role in genetic counselling. There is also a national course for public health nurses.

TRAINING OF CANCER GENETICISTS

No details are available.

Audit and evaluation

The Societies of Medical and Human Genetics work together, and recommend policies to the Ministry of Health (inter alia they identify genetic disorders to be recommended for carrier screening). The Ministry, which has an advisory committee on genetics to recommend policies and guidelines for the provision of genetic services, is responsible for the maintenance of standards together with the National Programme for the Prevention of Birth Defects. The Ministry also carries out cost benefit analyses from time to time.

Laboratories and departments involved in prenatal diagnosis under the auspices of the Ministry of Health must be certified and are evaluated by a quality assessment committee.

Discussion fora

Association of Medical Geneticists.
Israeli Society of Human Genetics.

SPECIFIC CANCER DISCUSSION GROUPS

No details are available.

Education

No details are available.

Registers

There are national registers for congenital malformations and Down syndrome and others are planned.

Support

CANCER CHARITIES

No details are available.

PATIENT SUPPORT GROUPS

No details are available.

23 Chemke J, Zlotogora J. Genetic services in Israel. *Eur J Hum Genet* 1997;**5**(suppl 2):105-11.

Persons responding

Prof P Rozen, Consultative Service for Hereditary Cancer, Department of Gastroenterology, Tel-Aviv Medical Centre, 6 Weizmann Street, Tel-Aviv 64239, Israel (tel: 972 3 697 4297; fax: 972 3 697 4622; e-mail: rozen@ tasmc.health.gov.il).

Dr Michal Sagi, Genetic Counselling Clinic, Hadassah University Hospital, Kiryat Hadassah, POB 12000, IL-91120, Jerusalem, Israel (tel: 972 2677 6329; fax: 972 2643 4434; e-mail: sagi@vms.huji.ac.il).

Dr Ruth Shomrat, Genetic Institute, Tel Aviv Medical Centre, 6 Weizmann Street, Tel Aviv, Israel (fax: 972 3697 4555).

ITALY

Genetic services

Genetic services in Italy have been reviewed by Dagna Bricarelli *et al*,[24] as part of the Concerted Action on Genetic Services in Europe. A general guide is also available on the internet. Italy has 20 health regions and the provision of genetic services, formal or informal, varies from one to the next, for reasons of funding or capability. Currently, 16 regions have genetic centres, but in general the level of provision of genetics services is informal, with no organised secondary or tertiary referral mechanism, although several centres accept regional or national referrals for particular disorders, for example, the National Cancer Institute in Milan (INT). Liguria, which enjoys a high level of genetic services, is organising a regional medical genetics centre in Genoa, the first such in Italy, to coordinate these services within the region, and to serve as a model for other regions, a group of which are attempting to set up a network of genetics centres, coordinated by INT. However, it has proved difficult to fund this initiative.

Every region has access to at least one cytogenetic laboratory and 16 regions have molecular biology laboratories, and common genetic disorders are diagnosed therein, while rare disorders are referred to centres with a particular expertise. Biochemical genetics is organised along similar lines.

Genetic associates are usually biologists with a PhD or some other training in medical genetics, involved with the laboratory services; they may occasionally take part in counselling sessions about the tests that they perform; however, this is the exception rather than the rule, and they have no formal role in counselling.

There is no tradition of participation by genetic nurses/counsellors and no formal training programme or career structure exists, although some local initiatives are under way.

CANCER GENETICS SERVICES

Cancer genetics clinics are not formally recognised by the Health Department, although all staff members involved are paid by the National Health System (with a few exceptions they have other duties in addition to cancer genetics clinics, depending on their professional background). Clinics are mainly organised on a local basis, for example, a cancer centre (or a research centre specialising in cancer genetics). Most cancer genetics services do not include a medical geneticist or a genetic associate/genetic nurse, and counselling is provided by the consultant specialising in the particular field of interest (for example, a gynaecologist or a gastroenterologist, usually with a particular interest in hereditary cancer; in Modena, for instance, the service is provided by an internist with lengthy experience of colorectal cancer, who provides a full counselling service for all hereditary gastrointestinal cancers). Alternatively, counselling for inherited cancers is provided by medical geneticists as part of the regular genetics service. Wherever possible clinics are multidisciplinary, but a few specialise in more than one type of hereditary cancer.

Local practices with regard to the division of responsibilities/counselling/management varies from centre to centre. Genetic associates, for instance, may deal with interviews, before consultation, but they do not make decisions.

The Associazione Italiana per la Ricerca sul Cancro (AIRC) is organising, coordinating, and funding a network of cancer genetics clinics and laboratories, aimed primarily at the diagnosis and prevention of colorectal cancer and of breast/ovarian cancer.

It is thought that there are about 10 cancer genetics clinics in Italy (not all have a genetic consultant), funded from Government health sources. The distribution varies between regions.

Liguria has six specialist cancer genetics clinics, as follows:

(1) Neurofibromatosis 1 (one consultant, one dermatologist, one psychologist), Medical Genetics Division, Ospedale San Martino, Genoa.

(2) Von Hippel-Lindau disease (one consultant, one psychologist), Medical Genetics Division, Ospedale San Martino, Genoa.

(3) Familial malignant melanoma/FMM (one consultant, one dermatologist, professor with special interest), Medical Genetics Division, Ospedale San Martino, Genoa.

(4) Hereditary breast cancer (one consultant, one psychologist, one clinician with special interest), Breast Cancer Unit, Istituto Nazionale per la Ricerca sul Cancro (IST)/Ospedale San Martino, Genoa.

(5) Hereditary colorectal cancers: FAPP (one consultant, one psychologist, one gastroenterologist); HNPCC (one consultant, one psychologist, one gastroenterologist, two doctors with special interest). Ist, DIMI.

(6) MEN (one consultant, one surgeon, one doctor with special interest), Istituto G Gaslini.

Rome (Catholic University) has three specialist clinics, other cancer predisposition

syndromes being dealt with by a medical geneticist, who coordinates input from other specialties/psychologists.

(1) Colorectal cancer (one consultant, one gastroenterologist).

(2) Breast/ovarian cancer (one consultant, one clinician with a special interest, one psychologist).

(3) Neurofibromatosis type 1 (one consultant, one dermatologist).

The various centres collaborate informally. The newly established Ligurian Department of Human Genetics will develop a family cancer clinic where these different activities can be integrated. Each of the current Ligurian centres provides counselling, including cancer risk estimation, information about present and future genetic studies, offers advice on cancer screening and prevention (when appropriate) to subjects and their families with a specific history, and offers diagnostic genetic testing, but so far only for NF1, VHL, FAP, and MEN. Molecular analysis for HNPCC, FMM, and HBC is only offered on a research basis.

Modena and Bari have a research interest in colorectal cancer, Pisa in breast/thyroid cancer, and Florence in endocrine cancers.

Regions offering a cancer genetics diagnostic service

Family breast/ovarian cancer: Abruzzo, Campania, Emilia-Romagna, Friuli-Venezia Giulia, Lazio, Lombardia, Toscana, Piemonte, Puglia, Veneto, Liguria.

Medullary thyroid carcinoma: Lazio, Liguria, Lombardia, Toscana.

Leukaemia: Piemonte, Puglia, Veneto.

Li-Fraumeni syndrome: Lazio, Piemonte, Puglia.

Melanoma: Lazio, Liguria.

Multiple endocrine neoplasias/*RET* mutation analysis: Friuli-Venezia Giulia, Lazio, Liguria, Lombardia, Toscana.

Neurofibromatosis: Lazio, Liguria, Veneto (NF1); Toscana (NF2).

FAP: Abruzzo, Friuli-Venezia Giulia, Liguria, Puglia, Toscana.

HNPCC: Abruzzo, Friuli-Venezia Giulia, Lazio, Lombardia, Puglia.

Von Hippel-Lindau disease: Liguria, Veneto.

WAGR: Lombardia, Toscana.

Training

There are no published recommendations for the teaching of genetics to medical students, resulting in a low level of genetic knowledge. The Regional Genetics Centre of Liguria is planning to address this, by instituting education programmes in genetics for GPs.

Medical genetics has been a recognised specialty since 1970. There are no published training programmes for medical or laboratory geneticists, and no national certificate of competence. Two types of courses leading to specialisation are possible: (1) a PhD or (2) a four year postgraduate course in medical genetics offered by the High Schools of Medical Genetics (including compulsory training in genetic counselling). These courses are open to both clinicians and biologists (they also constitute the only official qualifications for laboratory geneticists). There are a number of fellowships and scholarships available for both clinicians and biologists.

No genetic nurses are employed within the existing (research based) services, although some may be involved in the collection of family data. There are no courses for them and no published recommendations for their training.

TRAINING OF CANCER GENETICISTS

There is no formal curriculum for consultants in cancer genetics, who are recruited by centres as needed, either via CV evaluation and interview, or via the PhD programmes in the High Schools of Medical Genetics. Six of these (Genoa, Milan, Rome, Florence, Catania, Padua) offer short specialist courses in cancer genetics (molecular oncology, genetic counselling in oncology). The schools of oncology also offer short courses in cancer genetics as part of their specialist training. Most medical geneticists deal with cancer genetics as part and parcel of general genetics.

The European School of Medical Genetics (Sestri Levante, Genoa) organised cancer genetics (and general genetics) courses open to all physicians and molecular geneticists (PhDs, MScs), but these are attended mostly by consultant geneticists and oncologists.

Postdoctoral biologists and medical doctors without a doctorate in medical genetics can gain experience by attending alternative national and international courses in cancer genetics. They must have a degree in biology and a PhD in medical genetics.

There are no courses for genetic associates or genetic nurses.

Audit and evaluation

There are published guidelines for genetic testing and counselling, which can also be accessed via the Istituto Superiore di Sanita (http://www.iss.it). There are no extant national guidelines for the regulation or distribution of medical geneticists, and no published audit reports relating to genetic services, inspection of training centres, accreditation of specialists, or laboratory quality assessment. The Italian Medical Cytogenetics and Medical Genetics Associations have prepared guidelines for genetic diagnosis, but these are informal. The National Ethical Council is also publishing audit recommendations.

The National Cancer Advisory Board recommended that cancer genetics counselling (and genetic testing) be offered only in specialised centres in which a multidisciplinary team (geneticists, oncologists, psychologists) operated. An official report is due to be published.

People who wish to know more about genetic testing and who perceive themselves to be at risk of cancer because of family history can refer themselves. Cancer genetics services currently belong to academic and basic research institutions according to the research interests of particular groups. The shift from research to clinical practice (for example, funding for molecular analysis and genetic counselling) is

still in progress. Timing/protocols will vary between regions, as health care services are planned and funded on a regional basis.

Discussion fora

The Italian Association of Medical Genetics (AIGM), the Italian Association of Medical Cytogenetics (AICM), and SISMME (Inborn Errors of Metabolism) became affiliated, in 1980, into the Italian Federation for the Study of Inherited Diseases (FISME), which is being subsumed into the Italian Society of Human Genetics (SIGU). SIGU organises discussion fora/working groups etc.

The Italian Association of Genetics (AGI) is concerned with general, not medical, genetics.

SPECIFIC CANCER DISCUSSION GROUPS

The Associazione Italiana per la Ricerca sul Cancro (AIRC) is organising, coordinating, and funding a network of cancer genetics clinics and laboratories, aimed primarily at the diagnosis and prevention of colorectal cancer and of breast/ovarian cancer.

The Italian Association of Medical Oncology and the Italian Society of Oncology both organise discussion fora through working groups.

Education

The Regional Genetics Centre of Liguria is planning to address the poor level of genetic education among medical practitioners by instituting education programmes in genetics for GPs.

There is a high level of public awareness concerning cancer, in particular following the recent publicity given to Prof Di Bella and his treatment for cancer.

Genoa and Rome (Catholic University) both send written summaries following consultations, but do not have formal information leaflets.

Respondents were not aware of any videos, or any particular media interest, with the exception of the recent interest in the unorthodox cancer treatment of Prof Di Bella.

A consortium composed of the Italian Scientific Associations and the Ministry of Health sponsors a genetics centre network, on www.genet.it.

Registers

Cancer genetics registers are kept by laboratories on a local basis, and in some cases a laboratory acts as the national referral centre for a particular disorder.

Cancer registers include (1) Registro Italiano Tumori Colorettali Ereditari/inherited colorectal tumours (Istituto Tumori, Milan); (2) neurofibromatosis (Parma); and (3) familial malignant melanoma (not yet activated; no further details). Pisa is in the process of establishing a hereditary breast/ovarian cancer register.

Support

CANCER CHARITIES

The Associazione Italiana per la Ricerca sul Cancro (AIRC) is organising, coordinating, and funding a network of cancer genetics clinics and laboratories, aimed primarily at the diagnosis and prevention of colorectal cancer, and of breast/ovarian cancer. It does not produce any information material, however.

PATIENT SUPPORT GROUPS

There is a patient support group for neurofibromatosis type 1, based in Parma.

24 Dagna Bricarelli F, Dallapiccola B, Provedel R, Romeo G. Genetic services in Italy. *Eur J Hum Genet* 1997;**5**(suppl. 2):112-15.

Persons responding

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LATVIA

Genetic services

Genetic services in Latvia were reviewed by Krumina and Lugovska,[25] as part of the Concerted Action on Genetic Services in Europe. The overall responsibility for health care rests with the Department of Health of the Ministry of Welfare, and the health care system is in the process of changing from a centralised Soviet-type system to a health insurance based system.

A (limited) clinical genetics service was first introduced in Latvia in 1971, by the Riga Medical Institute and the Marriage and Family Consultation Centre. Currently, the Latvian State Medical Genetics Centre, founded in 1986 within the State Children's Clinical Hospital "Gailezers" but financially independent from it, provides a service comprising genetic counselling, laboratory investigations, training, and research, with a staff of seven specialist clinicians, seven cytogeneticists (three clinicians, four biologists), and four (part time) molecular geneticists. The State Medical Genetics Centre introduced a molecular service in 1997, and there are three others (two belonging to Latvia University and one at the Medical Academy of Latvia). These institutions (with the exception of one cytogenetics laboratory and one immunogenetics laboratory) are centrally funded. The Biomedical Research and Study Centre

offers a diagnostic service for phenylketonuria, Down syndrome, and fragile X syndrome, but there is no breast cancer programme.

Non-specialist counselling can be offered in the first instance by referring physicians (mostly paediatricians and gynaecologists). There are no nurse/counsellors. There is a well established system for giving counselling advice by telephone.

CANCER GENETICS SERVICES

There are no clinics specifically devoted to cancer genetics.

There is a Latvian Oncology Centre in Riga and two cancer hospitals in smaller towns. The Latvian Oncology Centre provides histopathology services and some examination of patients, and the Biomedical Research Centre in Riga provides molecular genetic characterisation of tumours. Testing for cancer susceptibility genes is not available, except on a research basis.

The four molecular genetics laboratories carry out analyses for leukaemia (mainly chronic myeloid leukaemia). Testing for cancer susceptibility genes is not possible in Latvia. However, preliminary studies indicate that there may be a raised frequency of *BRCA1* mutations in the Latvian population.

Training

There are no published recommendations for genetics education. Since 1995, medical students get 38 hours of lectures and 38 hours of laboratory work in the Department of Medical Biology and Genetics, but medical geneticists are not directly involved in teaching.

Genetics is recognised as an additional medical specialty, but there are no accredited training programmes. All specialists directly involved in providing genetic services must be certified as medical geneticists. This requires the passing of an examination which includes questions covering all branches of the discipline. Currently there are 15 trained people (five genetic counsellors, three paediatricians, and two gynaecologists).

TRAINING OF CANCER GENETICISTS

Training courses for GPs and other doctors on breast cancer, but not particularly in familial breast cancer, organised by the Latvian Oncology Centre.

Audit and evaluation

The Central Ethical Council was established by the Department of Health in 1994, but issues involved in medical/clinical genetics have not yet been considered.

Latvia has no laws regulating the provision of genetic services, although the Department of Health has issued some instructions concerning the operation of the service (for example, regarding the need for obligatory neonatal screening, ultrasound screening for fetal defects, and the registration of birth defects). All health care professionals are subject to surveillance by the Department of Health and can be disciplined for poor practice.

To date there is no quality assessment scheme covering clinical genetics services, or the performance of cytogenetic, biochemical, and molecular genetics laboratories. Exceptions to this are the external control programme for neonatal screening, and the quality assurance programme for metabolic disorders.

Discussion fora

No details are available.

SPECIFIC CANCER DISCUSSION GROUPS

The study of familial breast cancer is only just getting under way, as part of a national programme on the study of malignant tumours.

Education

There are some articles in the press about cancer generally, and also familial breast cancer in particular. The Latvian Cancer Foundation is promoting educational initiatives in the field of cancer prophylaxis. The Latvian Oncology Centre organises courses on, for example, breast cancer, for GPs and other doctors.

Registers

Latvia has had a national population based cancer registry since 1963. This was computerised in 1978.

In 1993, a separate Latvian cancer registry group was established; it is responsible for the registration, recording and processing of cancer data. Legislation passed by the Latvian Health Department makes it the responsibility of every practising physician, including pathologists and specialists in forensic medicine, to notify each primary cancer case. Twice a year, cancer registry data are compared with death certificates (to include haematological and neurosurgical data).[26]

Support

CANCER CHARITIES

The Latvian Cancer Foundation raises additional funds for the State Programme Against Cancer, promotes educational projects on cancer prophylaxis, and supports further development of cancer services in Latvia.

PATIENT SUPPORT GROUPS

The Latvian Oncology Centre has a support group for breast cancer patients; it meets once a week and is in touch with similar groups in Sweden.

There are national societies for phenylketonuria, cystic fibrosis, and Down syndrome. None have any influence over the decision making process in developing or operating genetic services.

25 Krumina A, Lugovska R. Genetic services in Latvia. *Eur J Hum Genet* 1997;**5**(suppl 2):116-20.
26 Stengrevics A. Cancer-registry data in Latvia. *Lancet* 1997; **350**:523.

Persons responding

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LITHUANIA

Genetic services

Genetic services in Lithuania have been reviewed by Kucinskas,[27] as part of the Concerted Action on Genetic Services in Europe.

There is only one genetics centre in Lithuania, the First Clinic for Genetic Counselling (composed jointly of the Human Genetics Centre of Vilnius University and the Human Genetics Centre of Vilnius University Hospital); this was founded in 1971 and is funded jointly by research and government health service sources. The Human Genetics Centre holds multidisciplinary clinics in a variety of areas. In 1997, there were eight clinicians and four genetic nurses.

CANCER GENETICS SERVICES

There is as yet no specialist cancer genetics centre/clinic, apart from the Lithuanian Oncology Centre in Vilnius. Patients with familial/inherited forms of cancer are counselled at the Human Genetics Centre, as for any other inherited or congenital disease, but in fact they usually consult oncologists not geneticists.

Training

Since 29.4.91, clinical genetics has been a specialty recognised by the Ministry of Health, and special training programmes have been introduced by the HGC/University. Following six years in medical school, and one year of (primary) residency, followed by a further two years (secondary) specialised residency, a two year tertiary residency is taken up in special training in clinical genetics or laboratory medicine (genetics).

The Medical Faculty of Vilnius University provides training in human and medical genetics. The HGC is responsible for genetics teaching for medical students, residents, postgraduates, and PhD students, and for carrying out scientific research in human and clinical genetics. Since 1990 there has been an organised course for medical students, with a 16 hour introduction to genetics, 16 hours of human genetics theory, and 32 hours of teaching group practice in the eighth semester, and 32 hours teaching group practice in clinical genetics for sixth year students. The latter two courses include lectures on genetic assessment and counselling, classification of congenital and hereditary diseases, aspects of teratology, and specialist lectures on congenital eye diseases, the genetics of mental retardation, congenital endocrine system disorders, and model approaches to cystic fibrosis, as well as group teaching on the most important points of chromosomal and single gene disorders, congenital malformations, prenatal diagnosis, the Lithuanian Registry of Inherited Diseases and Congenital Anomalies, and biomedical ethics.

Regular postgraduate education, by attendance at courses, is seen as essential.

Nurses receive three months training in general genetics.

TRAINING OF CANCER GENETICISTS

This involves an additional two years of specialist training. There are as yet no specialised consultants in cancer genetics. Oncologists (after a period of secondary training) can do a specialist residential course in clinical genetics.

Audit and evaluation

The Research Council of Norway carried out an evaluation of research in Lithuania in 1996.[28]

Discussion fora

No details are available.

SPECIFIC CANCER DISCUSSION GROUPS

No details are available.

Education

No details are available.

Registers

There are registers for FAP (Dr N Samalavicius, Lithuanian Oncological Centre) and a general register of cancer cases in Lithuania (Lithuanian Oncology Centre). There is also a Lithuanian Registry of Inherited Diseases and Congenital Anomalies.

Support

CANCER CHARITIES

No details are available.

PATIENT SUPPORT GROUPS

No details are available.

27 Kucinskas V. Genetic services in Lithuania. *Eur J Hum Genet* 1997;**5**(suppl 2):121-4.
28 Research Council of Norway. *Panel reports. Evaluation of research in Lithuania*. Oslo, 1996:495.

Persons responding

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THE NETHERLANDS

Genetic services

Genetic services in The Netherlands were reviewed by ten Kate,[29] as part of the Concerted Action on Genetic Services in Europe. In the 1960s, clinical genetics services in The Netherlands began to be offered by university departments of human genetics and paediatrics (for example, from 1968 onwards the Departments of Cell Biology and Genetics and Obstetrics and Gynaecology of Erasmus University, Rotterdam offered a cytogenetic and biochemical genetics service, including prenatal diagnosis). In 1977, the Health Council (an independent board advising the Ministry of Health on the evaluation, implementa-

tion, cost-benefit, and ethical and psychosocial implications of developments in medical technology) recommended funding for a limited number of clinical genetics centres affiliated to university hospitals and university departments of genetics. In 1979, the Dutch Association of Sick Funds, the Sick Funds Council, and private medical insurance companies, supported by the Ministry of Public Health, decided to reimburse cytogenetic diagnosis, metabolic screening, and amniocentesis, and to finance genetic counselling and clinical enzymology for genetic metabolic diseases. This resulted in the organisation of eight regional clinical genetics centres, set up in association with university hospitals. Their funding was open ended (although annual growth was tightly controlled) and ceased in 1996. In 1999, negotiations began regarding a more restricted budget system, to accommodate future growth in view of the increasing clinical demand for genetic risk assessment and DNA analysis for cancer and multifactorial diseases in adulthood. At present (1999) the annual budget of DFl 85 million covers the annual cost of laboratory analyses, genetic counselling, and prenatal diagnosis associated with a risk of congenital disorders. It also funds the training requirements. However, there is a clearly recognised need to provide for future growth in genetic services, as late onset disorders and cancers are included.

Today there are eight clinical genetics centres (two in Amsterdam and one each at the Universities of Groningen, Leiden, Maastricht, Nijmegen, Rotterdam, and Utrecht). In 1997, they were staffed by approximately 55 clinicians, with a further 20 in training, and six genetic nurses. There are three regional subcentres (Arnhem, Eindhoven, Enschede), and a number of peripheral hospitals where clinical geneticists from the centres provide diagnosis and counselling. Most clinical genetics centres hold joint clinics with other specialties (for example, familial tumour, neuromuscular, craniofacial, and other clinics).

Since 1994, DNA diagnostics and cancer genetics activities have increased dramatically, and are predicted to increase still further. Clearly, future demand for genetic risk estimation cannot be met by the genetics centres alone. In 1998, a National Health Council committee produced a report on DNA diagnostics, which considered future developments in genetic testing. The report proposed an optimal organisation of services for the future, with the creation of networks linking clinical and laboratory groups which, it was felt, would enable essential coordination of existing activities, and would facilitate the transition from research to clinical diagnostic facilities, as new developments were brought into service. This approach would permit more efficient use of resources and expertise, which will be essential to cope with, for example, the predicted doubling of the DNA test workload over the next five years, to about 20 000 tests a year, largely because of requests from people with a family history of breast or bowel cancer.

An important change in the organisation and clinical management of genetics services was the introduction of genetic associates to perform specific tests. In presymptomatic testing and counselling, genetic nurses became expert in taking family and personal histories, and in family management, while medical supervision guarantees consistency.

CANCER GENETICS SERVICES[30]

The eight clinical genetics centres all offer cancer genetics counselling. Clinics are generally multidisciplinary (or planned to become so). Genetic associates/nurses have an important role, and psychological support is available in several centres. Two supraregional cancer institutes are active: the Netherlands Cancer Institute in Amsterdam (Prof Dr P Borst) and the Daniel den Hoed Cancer Centre in Rotterdam. These centres provide a multidisciplinary service; they have one to two specialist clinical geneticists, with one to two medical residents in genetics, and one to three genetic nurses. Funding is variously from charitable, health insurance reimbursement, or research sources.

Mutation analysis in various forms of hereditary cancer is carried out by the laboratories of the clinical genetics centres and by one supraregional institute. Oncology and clinical genetics centres collaborate closely; in Amsterdam the diagnostic testing is carried out in the Cancer Centre, with counselling provided by the Clinical Genetics Centre. Patients are referred from medical specialists or by the oncology centres. There is also close cooperation with oncologists via the Committee for Medical and Genetic Counselling, as in the Rotterdam Committee.

During the past three to four years, cancer genetics diagnostic requests have shown an annual increase of 25-30%, compared to all clinical genetic activities, and it is possible that the future demand for genetic cancer risk estimations cannot be met by the eight genetics centres alone.

There is a national cancer screening programme for familial adenomatous polyposis.[31] First degree relatives at risk are offered colonoscopy every two years from 10 to 12 years until they reach 60 years. Similar screening programmes exist for hereditary non-polyposis colon cancer, hereditary breast/ovarian cancer, and some other hereditary cancers. Screening programmes are monitored and promoted by the Foundation for the Detection of Hereditary Tumours (Stichting Opsporing Erfelijke Tumoren).

Training

Medical and clinical genetics teaching forms a variable proportion of the undergraduate medical curriculum in different centres, both in terms of the ground covered and of the time allocated to this subject in the curriculum. In general, insufficient time is allocated to impress upon students either the general importance of medical genetics, or its rapidly increasing relevance to virtually all fields of medicine. The amount of cancer genetics teaching varies between the different medical schools.

For GPs and medical specialists, genetics forms part of the postgraduate training programme and of the residency course for obstetricians and paediatricians.

Clinical genetics became a recognised medical specialty in 1987. There is a national curriculum for clinical genetics residents. Training is available following accreditation by a committee of the Royal Dutch Medical Society involving peer review and site visits (to qualify, a centre must have access to the great majority of medical specialties, formal cooperation with a department for fundamental research, and a minimum of 300 patients counselled/year, 500 cytogenetic and 300 molecular analyses). All the genetics centres offer training programmes for clinical geneticists, taking four years (including four months training in each of cytogenetics, and molecular genetics). At any time, there are probably 20 residents in training. In addition, the Erasmus University (Rotterdam) offers a summer programme with regular courses in human genetics and related disciplines.

As in other medical specialties, certification must be renewed every five years, with checks on the extent of clinical work, participation in postgraduate education, attendance at meetings, etc.

Genetic assistants/associates follow a national, four year curriculum. In 1997, the Dutch Society of Clinical Genetics set up a training programme. This involves a four year course in a clinical setting, with participation in genetic counselling, and includes cancer genetics. There is as yet no formal career structure, but graduates from this course can function as genetic nurses in clinical genetics departments. In the future, they may work in other departments which are engaged in genetic studies. Genetic associates may be recruited from a number of different educational disciplines (nursing, dietetics, etc). The training of genetic nurses is organised and funded centrally, with a study programme lasting two years.

For laboratory workers, certification programmes and accreditation schemes exist for certification in cytogenetics and molecular genetics, under the auspices of the Dutch Society of Human Genetics. An accreditation scheme for molecular geneticists or molecular biologists engaged in DNA diagnostic work, who will be designated "clinical molecular geneticists", is under development.

TRAINING OF CANCER GENETICISTS

A limited number of doctors receive cancer genetics training as part of their in house training in clinical genetics. Every genetics centre has one or two senior geneticists who specialise in cancer genetics services. At least three of the centres collaborate with oncologists from the two supraregional cancer hospitals in The Netherlands. There is as yet no formal genetics training programme for oncologists, but in every specialist area (breast/ovarian cancer, colorectal cancer, etc) Multidisciplinary National Working Committees ensure that there are sufficient opportunities for education and exchange of information.

In addition, the Dutch Cancer Society (DCS) has a fellowship programme for promising young researchers wishing to specialise in cancer research/treatment, to train either in institutes in The Netherlands or abroad.

Dutch institutes regularly invite foreign workers to visit/lecture.

The training programme for genetic nurses includes elements of cancer genetics.

Audit and evaluation

Audit of the multidisciplinary cancer genetics clinics is in place.

The clinical genetic services have a number of regulatory safeguards built in: clinical activities are audited and feedback mechanisms exist to control development/growth (for example, the Ministry of Health has the power to limit or restrict certain activities, and the health insurance system also has regulatory powers).

Genetic testing is limited by law to the genetics centres. All clinical genetics centres submit annual reports to the Ministry of Health, Welfare and Sports as part of an audit programme.

The Department of Health has a Committee on Population Genetic Screening.

A Committee for Explorations on Cancer, which collects data necessary for policy development in the broad field of combating cancer, ranging from prevention and early discovery to treatment and patient care, was set up by the Dutch government in 1997 to make policy recommendations to itself and other organisations, including the DCS.

The Dutch Societies of Human and Clinical Genetics operate quality control systems.

The Dutch Cancer Society (DCS) evaluates its large scale educational campaigns in cooperation with the University of Maastricht.

Discussion fora

Genetics receives wide and frequent attention on television and in the written media. Increasingly it is being introduced into the secondary school curriculum and education. Possible community/educational involvement is fostered by the recently formed Dutch Society of Community Genetics, an expert group working alongside the Dutch Society of Human Genetics and a Dutch Society of Clinical Genetics, which seek to further discussion and development in the specialty. Clinical geneticists and trainees have monthly national meetings to discuss new developments and case histories. During the last three years (1996-1998), there has been considerable development in involving general practitioners and social workers at the community level in the dissemination of genetic information.

The DNA diagnostic network has a national working group, Landelijk Overleg DNA-diagnostiek (LOD), which coordinates service related issues, such as quality assessment, funding, and new diagnostic developments. The participants are molecular geneticists and molecular biologists from the different diag-

nostic laboratories. The LOD newsletter serves as an update on rapidly evolving diagnostic developments for clinicians.

SPECIFIC CANCER DISCUSSION AND RESEARCH GROUPS

The Foundation for the Detection of Hereditary Tumours (Stichting Opsporing Erfelijke Tumoren) was established in 1983, under the sponsorship of the Ministry of Health, with the aim of increasing awareness of the involvement of genetics in cancers, promoting screening programmes, and providing a source of data for research into these disorders. The Foundation also collaborates with the working groups which have been active in every major area of cancer (breast/ovarian, colorectal, etc) for the past 10 years, and assists in coordination of preventive and research efforts.

A special forum, the Landelyk Overleg Borsttumoren (LOB), exists as a discussion platform for research and management of hereditary breast cancers, including *BRCA* mutation screening, and the molecular genetic techniques relevant to this. Members of the LOB exchange data on new mutations in *BRCA1*/*BRCA2*, and collaborate in the validation and improvement of test protocols.

Groups from Leiden and Erasmus University belong to an International Collaborative Group on HNPCC which includes the Dr Daniel Den Hoed Cancer Clinic. DCS publishes an annual overview of the research projects it is supporting, and belongs to the International Union for Cancer Control (UICC); it also supports the European Organisation for Research on the Treatment of Cancer (EORTC).

Education

The multidisciplinary cancer genetics clinics offer leaflets to patients, with information about hereditary breast/ovarian cancer.

Since 1979, as part of a government initiative, the DCS has been responsible for the initiation and coordination of education and information on cancer in The Netherlands. It produces leaflets and brochures for doctors and those involved in health care, covering the entire field of combating cancer (prevention, early detection, treatment, and helping patients and their families), updated every two years.

The DCS runs an information centre where people can go for a personal interview and to consult publications, and operates a service whereby expatriates living in The Netherlands can obtain leaflets from sister organisations in other countries. There is a free help/information telephone line giving immediate access to the DCS (more than 40 000 people a year make use of this).

The DCS also mounts large scale education campaigns, set up and evaluated in cooperation with the University of Maastricht.

The DCS organises courses for patients and those close to them, in cooperation with patient associations. These are independent, but the DCS can provide financial and practical support to them, through the coordinating organisation Nederlandse Federatie van Kankerpatienten-verenigingen (Dutch Federation of Cancer Patients' Associations). It also subsidises other groups undertaking projects in the field of information or patient support (for example, those of the Integrale Kankercentra, the comprehensive regional cancer centers).

The DCS also provides information on alternative treatments.

There are a number of videos giving patient information: Nijmegen University Hospital's Department of Radiotherapy produces a video on breast cancer and another is in preparation.

The DCS has a website at http://www.dutchcancersociety.org

Registers

Local registers are maintained by clinical genetics departments.

There are national obstetrics and neonatal registries, for the registration of congenital anomalies, and via EUROCAT in two regions of The Netherlands (north, south west).

The two National Oncology Hospitals (Amsterdam, Rotterdam) maintain registries.

The Netherlands Foundation for the Detection of Hereditary Tumours manages central registers for a number of familial cancers. The FAP registry, which was the first to be set up, in 1985, monitors screening programmes and arranges referrals to the clinical genetics centres for genetic counselling, and also encourages registered people to avail themselves of regular screening. More recently, registers for other hereditary cancers have been instituted, for instance, a national registry for HNPCC families was set up in 1991, and one for hereditary breast/ovarian cancer families in 1993.

Support

CANCER CHARITIES

Charities like LOTTO/TOTO engage in public fund raising, with a separate annual fund raising session for cancer research.

The Dutch Cancer Society, Nederlandse Kankerbestrijding (Stichting Koningin Wilhelmina Fonds Nederlandse Organisatie voor de Kankerbestrijding): (1) produces information leaflets (for example, "This is the Dutch Cancer Society", describing its activities); (2) funds scientific cancer research (annual budget of some 60 million Dutch gilders); (3) supports training of specialists through a fellowship scheme; (4) since 1979, the DCS has had an initiating/coordinating role, on behalf of the Government, re information on cancer in The Netherlands, and cooperates in this with other national organisations.

The Netherlands Foundation for the Detection of Hereditary Tumours (Stichting Opsporing Erfelijke Tumoren).

The Breast Cancer Association.

PATIENT SUPPORT GROUPS

The Dutch Cancer Society produces information leaflets.

There are general patient associations for breast and colon cancer.

The Breast Cancer Association is planning a section for genetic breast cancers.

There is a strong federal patient and parent association in the field of congenital and genetic disorders.

29 ten Kate LP. Genetic services in the Netherlands. *Eur J Hum Genet* 1997;**5**(suppl 2):125-29.
30 Bourret P, Koch L, Stemerding D. DNA diagnosis and the emergence of cancer-genetic services in European health care. In: Wheale P, von Schomberg R, Glasner P, eds. *The social management of genetic engineering*. Aldershot: Ashgate, 1998:117-38.
31 Stemerding D, Koch L, Bourret P. (1998) DNA diagnosis and the emergence of cancer genetic services in European health care. *Eur J Hum Genet* 1998;**5**(suppl 2):25-30.

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NORWAY

Genetic services

Genetic services in Norway have previously been reviewed by Tranebjaerg *et al*,[32] as part of the Concerted Action on Genetics Services in Europe. There is a well organised health service, under the aegis of the Ministry of Health and Social Affairs, operating at regional, county, and district levels.

Currently there are four regional genetics centres.

Ulleval Hospital, Oslo.

Haukeland Hospital, Bergen.

Nordnorsk Avdeling for Medisdinsk Genetikk, Tromsø.

The Norwegian Radium Hospital/National University Hospital, Oslo.

In addition, there is a small cytogenetics service associated with a research laboratory for occupational and environmental genetics, at Skien District Hospital, southern Norway. Most biochemical diagnostic tests are performed by the Department of Clinical Chemistry, National University Hospital, Oslo. Prenatal testing for Huntington's disease is carried out at Ulleval Hospital, Oslo.

In 1997, there were 11 specialist geneticists (out of a total of 18 specialist posts) and three nurses (by 1998 this had risen to four).

CANCER GENETICS SERVICES

In general, cancer genetics services are conducted according to national consensus, managed by the regional genetics centres, and validated by an interdisciplinary group involved in breast/ovarian, gynaecological, colorectal, and prostate cancers.

Since 1989, there has been a specialised genetic oncology service at the Norwegian Radium Hospital, Oslo. Counselling for cancer families was first funded in 1995 and the Hospital now constitutes a complete multidisciplinary centre for hereditary cancers. The bulk of cases seen are breast, ovarian, and colorectal cancers. The service has two specialist and two trainee clinicians, and three genetic counsellors. There is a research laboratory with long term experience in cytogenetics, molecular biology, and mutation screening, and a diagnostic laboratory engaged in genetic testing.

Ulleval Hospital has a consultant specialising in cancer genetics and a DNA diagnostic laboratory (main interests colorectal and breast cancer)

Haukeland Hospital (Bergen) has a consultant specialising in cancer genetics, a genetic nurse, and a DNA diagnostic laboratory. There is a breast centre (with a surgeon, a radiologist, an oncologist, and a pathologist).

Training

Medical students are taught both human and clinical genetics late in the clinical course in all universities. They receive a total of approximately 40 lectures. There are a limited number of postgraduate medical genetics courses for GPs and other clinical specialists.

Medical genetics was recognised as a specialty in 1971. Formal training lasts for four years, with a further compulsory year in some other clinical specialty; it includes two years of genetic counselling (including prenatal counselling; one year of this may be cancer genetics), one year of molecular diagnostics, and one year of cytogenetics, leading to government approval (via the Board of Medical Genetics, which supervises training). There is a requirement to attend 120 hours of theoretical teaching. There is no formal examination and approval is given by the national Board of Medical Genetics (which was set up by the Norwegian Medical Association to supervise and approve training). As part of the formalised training programme in medical genetics, an obligatory 21 hour course in cancer genetics is given every third year.

Genetic nurse/counsellors have been informally involved in cancer genetics services since 1998. They can offer counselling and carry out data collection, documentation of diagnoses, etc. There are currently four such positions based in two different centres.

TRAINING OF CANCER GENETICISTS

All cancer genetics consultants must be approved medical geneticists and must have

taken the cancer genetics course. This course also serves as an update for specialists and is in addition open to interested persons from other specialties, as well as to genetic nurses and associates.

Since 1998, genetic nurse counsellors have been involved in the management of inherited cancers, but there is no formal training programme. To date, they must have a university degree and are then trained "in house"; they have been recruited from among trained nurses or people educated abroad. However, their involvement is not yet widely accepted.

Audit and evaluation

Genetic testing is centrally regulated by government bodies, under separate legislation.

The Norwegian Parliament enacts laws relating to general operational matters, for example, the "Act relating to the application of biotechnology in medicine" (Act No 56, 5 August 1994), and sets out general guidelines for, for example, assisted reproductive technology applications, research on embryos, preimplantation and prenatal diagnosis, genetic testing after birth, and gene therapy. It also specifies the conduct of institutions making use of these techniques, and lays down requirements regarding regular reporting (for example, for establishments offering predictive testing). Norway has very strict laws regarding the disclosure of genetic information, most notably with regard to the results of predictive testing.

The Medical Technology Advisory Panel is charged with the evaluation and implementation of medical biotechnology, and the Advisory Board of Biotechnology gives advice to the government on questions relating to genetics and ethical issues.

The Directory of Health Services supervises health care provision and the setting of criteria for the proper provision of services within the genetics centres.

The regions collaborate closely in the provision of services, shared protocols, etc, and are evolving national guidelines.

There is no accreditation scheme for genetics laboratories, but the Biotechnology Act is intended to ensure that all laboratories fulfil good laboratory practice, and quality assurance programmes for cytogenetics and molecular genetics are being developed.

Discussion fora

Representatives of the genetics centres meet once a year.

The Norwegian Association for Medical Genetics (a subgroup of the Norwegian Association for Medical Doctors).

The Advisory Board of Biotechnology Advisory Board arranges open meetings for the public and publishes a journal, *Gen Etikk*.

With these exceptions, fora are regional.

SPECIFIC CANCER DISCUSSION GROUPS

The Norwegian Cancer Society funds an inherited cancer group, to which all geneticists working with cancer families belong. This discusses, among other matters, national health programmes and their evaluation.

Interdisciplinary groups for the treatment of breast, gastroenterological, prostate, and gynaecological cancers all include a geneticist.

Education

There is strong public awareness of genetic issues, particularly with regard to termination of pregnancy, screening for genetic disorders, in vitro fertilisation, and preimplantation diagnosis.

The public is gradually becoming aware of genetic/familial cancers. Several patient support organisations have produced genetic leaflets in collaboration with medical geneticists.

The Government Advisory Body on Predictive Testing has produced a booklet on this subject.

The Bergen Genetics Centre, and the other groups/departments with which it collaborates, produce a leaflet on familial breast cancer which is given out at counselling sessions.

The Advisory Board of Biotechnology has produced an information leaflet on predictive genetic testing, which is given to each person seeking predictive testing at the Norwegian Radium Hospital.

The Norwegian Radium Hospital and Haukeland Hospital (Bergen) operate websites with home pages giving information on familial cancer. In addition, there are ongoing newsgroups on the internet. A website with national guidelines became operational early in 1999.

Registers

The medical birth registry produces an annual report.

There are no national cytogenetic or prenatal cytogenetic registers.

The cancer registry: this contains a register for autosomal dominant polyposis families, and routines are being developed to provide information to all at risk persons concerning clinical follow up and genetic counselling.

The medical records of departments function as registers. The computerised patient records of the three cancer genetics centres contain data on some 15 000 persons who are either "at risk", or who belong to cancer families.

All registers are subject to Norway's very strict laws regarding confidentiality and disclosure.

Support

CANCER CHARITIES

All cancer charities are subsumed into one powerful national umbrella organisation.

PATIENT SUPPORT GROUPS

Public awareness of genetic/familial cancers is growing, but there are as yet no separate support groups for inherited cancers. There are a large number of patient and family organisations supporting specific groups of genetic disorders, and several of these have produced information leaflets in collaboration with medical geneticists. None of these, apparently, deal with genetic cancer predisposition.

The Frambu Helsesenter provides regular courses on neuromuscular disorders, Usher syndrome, fragile X syndrome, and other rare disorders for patients and their families, and provides a strong baseline for well informed consumers.

There is no specialist support group for minorities, for example, the Ashkenazi Jewish population.

32 Tranebjaerg L,Børresen-Dale A, Hansteen IL, Heim S, Kvittingen EA, Møller P. Genetic services in Norway. *Eur J Hum Genet* 1997;5(suppl 2):130-4.

Persons responding

Dr Jaran Apold, Avdeling for Medisink Genetikk, Haukeland Sykehus, N-5021 Bergen, Norway.

Dr A L Børresen-Dale, Department of Genetics, Institute for Cancer Research, University Clinic, Norwegian Radium Hospital, Montebello, N-0310 Oslo, Norway.

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POLAND

Genetic services

Genetic services in Poland were reviewed by Zaremba,[33] as part of the Concerted Action on Genetics Services in Europe. The following is a brief summary of his findings, with some updated information. Clinical genetics in Poland arose in the 1960s, when the Institute of the Mother and Child and the Institute of Psychiatry and Neurology, two research institutes in Warsaw, began to offer a service. Until recently, such services have been sparse (for various historical reasons), and as a result awareness of genetic issues among, for instance, primary health care practitioners and the general public is very poor. In 1974, a Department of Human Genetics was set up by the Polish Academy of Sciences in Poznan (initially on a research only basis), and genetics centres are now being set up in many different cities. In 1997, there were 21 genetics clinics, with 12 molecular genetics laboratories, 24 cytogenetics laboratories, and three biochemical genetics laboratories working in close collaboration with them. Clinical genetics is centrally funded by the Ministry of Health and Welfare (80%), while the State Research Committee provides some funding (20%) for genetics centres attached to medical schools. In 1994, there were some 96 clinicians, 139 biologists, and 100 technicians working in the field. The average staffing level now includes three to seven government funded clinicians, 10 research and four government funded genetic associates (who carry out molecular analyses). Genetic counselling is provided by clinicians with specialist training, or by (post-doctoral) laboratory scientists. There are very few specialist genetic nurses working in the field of general or cancer genetics, although Szczecin has three non-specialist nurses working with their registry, counselling unit, and offices, etc. There are a number of specialist centres offering long term follow up for particular disorders, for example, cystic fibrosis or Wilson disease. In general, multidisciplinary genetics clinics do not exist. In general, the better educated enjoy better access to genetic services (patients can refer themselves directly), but poor funding for the health service generally, together with the lack of genetic specialists, are other limiting factors.

CANCER GENETICS SERVICES

Bydgoszcz, Gdansk, Gliwice, Kraków, Lódz, Poznán, Szczecin, and Wroclaw all have centres for cancer genetics (defined as separate units providing counselling and surveillance for high risk families). Szczecin, which has operated a registered service for some years now, is the leading hereditary cancer centre, but the others, while still small, are growing and a national programme, initiated and coordinated by Prof J Lubinski, exists to support their further development. Szczecin surveys around 6000 families yearly and about 700 preselected patients are examined and diagnosed. Surveillance is extended to around 100 patients/month, mostly for hereditary breast cancer, but also for breast/ovarian and colorectal cancers. There is a staff of eight clinicians (the national average being three to seven), one secretary cum administrator, six PhDs, and four technicians (DNA/RNA testing). Szczecin is alone among the hereditary cancer centres in having three nurses (registry and counselling unit, offices, etc). It is funded by the Medical University, the Oncology Hospital, and by both national and international (National Institutes of Health, USA; European Commission) research grants.

In Gliwice, the breast cancer counselling service has two clinicians, one nurse, and three researchers carrying out DNA testing (two PhDs, one MSc). It is hoped to extend the service to include other hereditary cancer syndromes, especially for hereditary colon cancer. These patients are treated at the Oncology Centre, so it would be easy to ascertain families at risk and counsel them, although a more detailed molecular analysis would have to be carried out by the Hereditary Cancer Centre at Szczecin.

Molecular diagnosis is currently carried out for *BRCA1* (Szczecin, Poznán, Warsaw, Gliwice), *BRCA2* (Szczecin, Poznán), *hMSH2* and *hMCH1* (Szczecin), *APC* (Poznán), Von Hippel-Lindau syndrome (Szczecin), *Rb-1* (Szczecin), *RET* (Gliwicz, Lódz, Warsaw), and *p53* (Warsaw, Wroclaw). Following a meeting held at the Hereditary Cancer Center in Szczecin, it has been agreed that in future molecular analyses of genes involved in rare hereditary diseases, such as *HNPCC*, *FAP*, *VHL*, *MEN2* and *Rb-1*, should be referred to a single specialist laboratory, to decrease the cost of these analyses. However, the affected families will remain under the care of the Centre of Oncology, as regards intensive follow up.

Training

For historical reasons, undergraduate genetics teaching has been poor (although biology students received a much better grounding) and has varied substantially between universi-

ties. Poland has 11 civilian medical schools, but there are few trained lecturers and nine of the 11 medical schools (the exceptions being Gdansk and Poznán) have no professorial chair. In 1995, the Polish Academy of Sciences appealed for an improvement in this situation, and this has led to the adoption of a minimum uniform programme of medical genetics for all undergraduates, and a required minimum of 30 hours (maximum 75 hours) lectures and practicals. Essential genetics is taught during the preclinical course, and medical genetics in the fourth and fifth years of study.

Genetics became a recognised specialty in 1998, following the programme of specialisation introduced by the Commission of Medical Genetics of the Polish Academy of Sciences and the drawing up of legal regulations for the specialty. Only qualified specialists are permitted to provide genetic counselling.

Other specialists (paediatricians, obstetricians, gynaecologists, and neurologists receive regular updates on clinical genetics at postgraduate courses organised by the Centre for Postgraduate Medical Teaching. The Institute of the Mother and Child and the Institute of Psychiatry and Neurology also provide postgraduate teaching.

Genetic associates (laboratory workers) require a doctorate and some on the job training, but are independent scientific workers.

There is no genetics content in the nursing curriculum.

TRAINING OF CANCER GENETICISTS

Undergraduates receive 10 to 20 hours on cancer genetics during their education.

The Hereditary Cancer Centre in Szczecin runs postgraduate updates/specialist courses; these include a yearly three day training programme for cancer genetics professionals, which covers the latest advances with regard to hereditary tumours, and an annual three day training course for family doctors. There are other, unspecified, courses for oncologists and persons offering genetic counselling (either molecular biologists or doctors who have already done specialist training on inherited cancers); these include lectures on genetic epidemiology and hereditary predisposition to cancer.

Consultants in cancer genetics are recruited from among geneticists or oncologists.

There are no specialist training courses for nurses in cancer genetics.

Audit and evaluation

The Institute of the Mother and Child, Warsaw, and the Institute of Psychiatry and Neurology conduct nationwide supervision in their respective specialties, provide a supervisory board, and act as advisors to the Ministry of Health and Social Welfare. The Institute of the Mother and Child has been carrying out an evaluation of the effectiveness of genetic counselling.

A cost-benefit analysis of prenatal diagnosis was carried out in Warsaw between 1981-1984.

In 1994 the Collegium for Laboratory Diagnostics was set up to maintain the standard of laboratory tests. The Collegium has established a Working Group for Clinical and Molecular Genetics, although this is not yet operational, owing to lack of government funding.

The Institute for Mother and Child supervises the national screening programme for phenylketonuria. It also collaborates with European and American quality assurance programmes.

There is no established audit network for the cancer genetics service, but this is in process of formation. However, Szczecin has been auditing its work since 1992.

Approximately 6000 cancer families, all randomly selected, are checked yearly for cancer family history.

Approximately 700 preselected probands/families are seen, examined, and formally diagnosed by the Genetic Counselling Unit

Surveillance is extended to around 100 patients/month: approximately 40 families with marker germline mutations; around 200 families with hereditary breast/ovarian cancer; a few dozen early diagnosed and appropriately treated tumours of the bowel, breast, ovaries, kidneys, and brain.

To date there are no systems for the assessment of counselling and other genetic services provided by non-geneticists.

Discussion fora

Commission of Human Genetics, Polish Academy of Sciences.

Polish Genetical Society.

Polish Society for Human Genetics.

A yearly scientific meeting is held in one of the Polish academic centres, coordinated by the Hereditary Cancer Center in Szczecin: in 1997 in Szczecin, in 1998 in Gdansk, and in 1999 in Bydgoszcz. Regular local review meetings in clinical and laboratory genetics have not yet been organised.

SPECIFIC CANCER DISCUSSION GROUPS

A yearly scientific meeting is held in one of the Polish academic centres, coordinated by the Hereditary Cancer Center in Szczecin: in 1997 in Szczecin, in 1998 in Gdansk, and in 1999 in Bydgoszcz.

Education

All families with hereditary cancers are in contact with their own doctor. Szczecin particularly ensures that they make personal contact with patients from hereditary cancer families, and is proposing the formation of an association of hereditary cancer families.

Patients referred to genetics centres, and their referring physician, may receive an information card giving details of test results, diagnosis, and details of genetic risk, indications for prenatal diagnosis, and recommendations (if any) for treatment.

Newspaper and journal articles, radio programmes, etc, are quite common, and the press is receptive to cancer related issues.

Registers

A register for congenital malformations was set up in 1997 to serve western and central Poland.

Szczecin already operates an oncological register of hereditary tumours. Szczecin, Bydgoszcz, Gdansk, Poznán, Lódz, Gliwice, Kraków, and Wroclaw have agreed to set up computerised databases of families with hereditary cancers of different types. In general, centres or clinics collect their own information. They appear to cooperate with other groups to provide access, but details remain confidential.

Support

CANCER CHARITIES

No details are available.

PATIENT SUPPORT GROUPS

There are no groups interested in cancer genetics in minorities, for example Ashkenazim, but Szczecin is proposing to organise associations of families with a genetic predisposition to cancer.

33 Zaremba J. Genetic services in Poland. *Eur J Hum Genet* 1997;**5**(suppl 2):135-9.

Persons responding

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PORTUGAL

Genetic services

Genetic services in Portugal have been reviewed by Santos *et al*,[34] as part of the Concerted Action on Genetic Services in Europe. Karyotyping had been available in Portugal since 1959 and informal genetic counselling since 1963, but formal genetics services in Portugal began in the 1970s, with the setting up in 1975 of a clinical genetics and counselling service by the Paediatric Service of Santa Maria Hospital (Lisbon), and the opening of a cytogenetics laboratory service, also in Lisbon, in the following year. Hospital based genetics Centres are few, and the infrastructure still leaves something to be desired, but over the last two decades the situation has expanded rapidly, as real progress has been made in integrating medical genetics into the work of other specialties. In addition to the public services, there is one private laboratory in Lisbon, offering a full range of clinical, genetic, and molecular diagnostic services (set up in 1990), and two other private laboratories operating in Porto. These latter accept samples from pathology laboratories for testing.

There are now three major genetics laboratories: IPATIMUP-Porto, Istituto de Genetica Medica Jacinto de Magalhaes-Porto (both in Porto), and the National Institute of Health (Lisbon). On average, each has one clinician and two genetic associates (biologists) and is funded by a mixture of charitable/research and government funds. Further university and hospital based laboratories are now operating within the Portuguese Institute of Oncology (at their Porto and Lisbon centres) and the Department of Human Genetics at the New University of Lisbon. These centres offer a variety of specialised consultations and counselling for different aspects of medical genetics, some nationally (for example, for phenylketonuria). Counselling is carried out either by recognised "specialists" (for example, at the Children's Hospital in Coimbra or in Lisbon) or by "counsellors" who are experienced but without official recognition in medical genetics; there are too few of them, however, and as yet very few nurses. Screening for late onset disorders (for example, FAP) and cancer is therefore often provided by other specialists (neurologists, oncologists) without genetic counselling support.

There are a number of ethical and practical concerns about the provision of genetic counselling services, for example, the predictive testing of children or adolescents and the provision of prenatal diagnosis (which is not acceptable to many doctors and may not be offered even if practicable).

Testing for carrier status (for example, for CF, the haemophilias, and haemoglobinopathies) can be requested directly by the patient's GP or by other specialists (for example, gynaecologists, paediatricians, etc) without referral via a geneticist. Screened persons may sometimes simply be given a card listing their status, without counselling, or guarantees that this information will not be used to discriminate against them, genetic "awareness", the safeguarding of patient confidentiality, and patient rights.

On a national basis, Portugal has a specialist genetic service for Machado-Joseph disease, coordinated from Porto; this includes a national programme of predictive testing and counselling. There is a central service (17 staff) with regional teams in Vila Real (five staff), Porto (seven staff), Coimbra (six staff), Lisbon (six staff), Ponta Delgada (five staff), and Angra do Heroismo (four staff). Each of these teams includes a genetic counsellor.

CANCER GENETICS SERVICES

There are no real cancer genetics clinics with appropriately trained personnel to offer genetic counselling (with the exception of tumour genetics services at the university hospitals in Coimbra and Lisbon), and no Portuguese hospital has a specialist consultant in cancer genetics. What cancer genetics services there are have largely resulted from the interest of clinicians in various specialties, rather than from government initiatives, with the result that services, for instance with regard to familial breast/ovarian cancer, are variable in quality and scope. Inherited gastrointestinal cancers constitute the major focus of cancer genetic research and services.

Three cancer institutes (Coimbra, Lisbon, Porto) offer a service and have attached genetic laboratories, but they have no formal genetic counselling support. Counselling in cancer

genetics is a multidisciplinary area, provided by any of the following: neurologists, oncologists, gastroenterologists, surgeons, pathologists, and other specialists involved in the care of patients, or by geneticists from other institutions (for example, paediatric clinical geneticists working in general hospitals) to which patients have been referred. In Porto the Professor of Medical Genetics is not formally attached to the staff of the Cancer Institute, and counselling for inherited cancers is provided by the oncologists of the Cancer Institute. The Coimbra Medical School and the Lisbon Medical School (Classical University) have professors of medical genetics, but their main role, although they do carry out some service based work, is in teaching and research.

Training

Clinicians. All medical students have received some genetics teaching since 1970, although this will vary from faculty to faculty; the syllabus for medical students at Coimbra and Porto does not include genetic counselling, for instance, nor does it cover ethical or psychosocial aspects of genetic testing. However, some teaching on ethics is included within the discipline of medical genetics. At Lisbon genetics has been a whole year subject since 1984. Medical training takes eight years (undergraduate and intern). The Coimbra Medical School and the Lisbon Medical School (Classical University) have professors who engage in genetics teaching and provide some genetic services to medical centres, but their main programme is dependent on the teaching and research objectives of the universities.

Following partial recognition ("granting of competence") in 1979, genetics was recognised as a specialty by the National Executive of the Portuguese Medical Boards in May 1998,[35] and details of the rules regarding certification were published in November of that year (Portuguese Medical Boards Bulletin 9 (Oct/Nov), p29). To date, however, no specific training programmes have been set up.

Training ranges from five to seven years; at Coimbra it requires three years of practical clinics and two (full time) or four (part time) years of specialist training in a genetics department with clinical practice. The trainee must see 300 patients and have undergone 20 hours of specific courses and seminars.

The University of Porto offers a Masters degree course in genetics.

IPATIMUP (Instituto Patologia e Immunologia Molecolar da Universidade do Porto) offers postgraduate courses on genetic topics. In 1997, a PhD programme was set up.

The Medical Faculty of Coimbra University offers an annual postgraduate course on biomedicine, which includes molecular biology for clinicians and genetics. This is equivalent to a Masters degree and is officially recognised. The Department of Medical Genetics in Coimbra offers courses on molecular genetics in clinical practice.

Genetic associates. These do laboratory work and must be graduates in biology, pharmacy, or biochemistry.

Genetic nurses. Some (untrained) nurses do now take part in genetic consultations, but there are no specialist, trained genetic nurses in Portugal. They are only just "starting".

TRAINING OF CANCER GENETICISTS

Most cancer genetics consultants come from the university genetics departments, but some are geneticists who have decided to specialise further following their certification.

IPATIMUP offered a Masters class in oncobiology from 1991 to 1996.

Every two years, the Institute of Oncology of the Centre of Portugal offers a postgraduate course on genetics and oncology. The fifth of these will take place in 1999. Some 60 people attend each course, which is run by a professor of medical genetics.

Audit and evaluation

In 1996, negotiations took place between the Ministry of Health and the Portuguese Medical Board to discuss the needs of genetic services and improved training and accreditation. This has led to new interest/recommendations.

All the genetics centres, large and small, operate in full compliance with international recommendations on quality control.

Discussion fora

The Portuguese Society of Human Genetics was set up in 1997. Both the Gastrointestinal Society and the Genetics Society hold conferences/congresses.

SPECIFIC CANCER DISCUSSION GROUPS

There are no specific organisations for cancer genetics.

Education

Some public health information leaflets exist, for example, warning about the importance of avoiding sunburn.

The Institutes of Oncology (Coimbra, Lisbon, Porto) provide leaflets for the general population and others are planning to do so in future.

The Institute of Oncology in Lisbon produces a comprehensive booklet on FAP for patient/family information and education, in collaboration with the Portuguese League against Cancer.

The central registry produces leaflets concerning hereditary colorectal cancer, but we are not aware of others dealing specifically with cancer genetics or for minority groups.

The Portuguese League against Cancer has produced videos, and there have been television programmes.

Registers

There is a central Portuguese cancer registry. This operates on a regional basis (north, central, and south), and attempts are being made to register inherited cancers (for example, FAP, Lynch syndrome/HNPCC), under the aegis of the three oncology centres. This process is farthest advanced at the Portuguese Institute of Oncology in Lisbon.

Portuguese Institute of Oncology (Av Prof Lima Basto, 1070 Lisbon, Portugal; tel: 351 1 7266727) or the Ethical Commission of the Portuguese Institute of Oncology (tel: 351 1 7868376) may be able to provide further information.

Support

CANCER CHARITIES

Portuguese League Against Cancer (branches in Coimbra, Lisbon, Porto).

PATIENT SUPPORT GROUPS

These exist, but no information is currently available. Two (non-cancer) groups are: CEDEMA (the association of parents and friends of adult mental deficients, Praca de Londres, 9-4°E, 1000 Lisbon, Portugal) and APPACDM (same address).

34 Santos H, Cordeiro I, Nunes L. Genetic services in Portugal. *Eur J Hum Genet* 1997;5(suppl 2):140-4.
35 Harris R, Oliveira JP, Santos HG. Formal recognition of the speciality of medical genetics in Portugal. *Eur J Hum Genet* 2000;**8**:3.

Persons responding

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Prof Maria-Cristina R Pinto, Department of Human Genetics, Faculdade Medicina de Lisboa, Rua Amilcar Cabral 21-R/CH, 1700 Lisbon, Portugal.

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ROMANIA

Genetic services

Genetic services in Romania have been reviewed by Maximilian *et al*,[36] as part of the Concerted Action on Genetic Services in Europe. Romanian genetics has had an unfortunate history, like many other countries of the former Eastern Bloc. Until relatively recently, medical genetics was strictly limited in its scope, and genetic services were sparse, while medical education was gravely hampered by the lack of contact with mainstream western European medicine. Those few people who were permitted to travel abroad to obtain further training seldom returned, for various reasons including the lack of funding, infrastructure, and opportunities for development both technical and personal, a situation which has not altered significantly despite the recent changes in government. The health care system is virtually unchanged since the Communist era. Lack of policy direction and prospects for medical and social improvement mean that the infrastructure is drastically undersupplied. Combined with the poor level of knowledge concerning genetic issues, Romania's unfortunate recent history has meant that even today the importance of genetics in modern medicine is not recognised.

There is no national network of genetics services in Romania and only three genetic counselling clinics, although many scientific institutes, such as the Haematological Institutes (Bucharest, Cluj, Timisoara), the Endocrinology Institute, and the Institute for Mother and Child (both in Bucharest), and the Oncology Institutes in Bucharest and Cluj, have an interest in genetic disorders, and many university clinics and children's hospitals offer some counselling. There are eight university centres with some 45 people involved in genetic counselling and laboratory testing, but there are only 10 trained specialist medical geneticists recognised by the Health Ministry and no specialist genetic nurses. Funding is very scarce; the government makes a contribution to the salary of geneticists (about US $100 per month in 1997), but laboratories must be financed by their parent institutions, and modern equipment and consumables are both costly and very difficult to obtain.

A medical genetics department was recently set up at the Institute of Legal Medicine "Mina Minovici" in Bucharest, which will become operational in a few months. The newly created genetics department, which has all the relevant equipment, is designed to function as the national medical and forensic diagnostic reference centre for both cytogenetic and molecular analysis. The medical diagnostic service will concentrate mainly on the diagnosis of inherited disorders and of several genetically inherited cancers (including familial breast cancer). The scientific staff of the new department have transferred from the Victor Babes Institute of Human Genetics and Pathology, also in Bucharest. Before the setting up of the new department, cytogenetic analysis was not widely available in Romania; only 15 laboratories could provide even a basic service, and even some major centres did not have access to a laboratory service, a situation which is set to improve dramatically as the new department becomes operational.

CANCER GENETICS SERVICES

These are limited to cytogenetic investigations, almost entirely for leukaemias. Solid tumours are rarely examined because of technical difficulties (lack of funding; FISH is not currently available for this reason). Few haematology or oncology centres have shown interest in the genetic aspects of cancers, and none of the eight university genetics centres specialises in cancer genetics. There are two oncology institutes (Bucharest, Cluj) and several oncology/haematology clinics (Bucharest, Cluj, Iasi, Timisoara, Oradea, Constanta, Craiova). They do not have their own cytogenetic laboratories, but occasional collaborations have been set up with suitable cytogenetics units (for example, the Victor Babes Institute in Bucharest has a particular interest in cancer cytogenetics). However, karyotyping is not practised systematically, mainly because of lack of medical interest.

Owing to the extreme lack of funding for genetic laboratory services, molecular genetics testing for inherited cancers is not carried out.

There is no action being taken over familial breast cancer services, either officially, by the Health Ministry, or in other centres.

Training

Undergraduates receive one semester of genetics teaching in the first or second year of medical school. As a result, the level of genetic knowledge in the medical profession is low, and this impedes access to genetic services. There are no guidelines for the teaching of medical genetics to undergraduates.

Genetics became a recognised specialty in 1997. Since January 1998, formal training schemes for medical/clinical genetics have been in place, leading to accreditation as a specialist in medical genetics, but these are hampered by lack of funding for new posts and services. There are no guidelines for professional training for clinicians or for laboratory geneticists, and no training programmes for genetic nurses or associates. Genetic nurses are not recognised as a specialty.

TRAINING OF CANCER GENETICISTS

No details are available.

Audit and evaluation

There are no published audit reports regarding genetic services, no professional guidelines for training or practice, and no quality assurance schemes.

Discussion fora

There are no regular public debates on genetic issues, and no publications designed to increase the level of awareness of such issues, or the general level of genetic knowledge, despite its relevance to Romania's heterogeneous population.

Romanian Society of Medical Genetics.

SPECIFIC CANCER DISCUSSION GROUPS

No details are available.

Education

Very little information is available for patients.

Registers

National registers have been established for some genetic disorders (for example, sickle cell anaemia, β thalassaemia, congenital malformations), but these are hampered by poorly organised screening programmes. There are regional registers for hereditary colorectal cancer, but not for other common cancers (gastric, lung).

Support

CANCER CHARITIES

No details are available.

PATIENT SUPPORT GROUPS

No details are available.

36 Maximilian C, Stefanescu D, Calin G. Genetic services in Romania. *Eur J Hum Genet* 1997;**5**(suppl 2):145-7.

Persons responding

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RUSSIA

Genetic services

Genetic services in Russia have been reviewed by Baranov and Ginter,[37] as part of the Concerted Action on Genetic Services in Europe. As with many other countries, the chaotic economy and government ructions have severely reduced health care services from the ideal of free access to health care guaranteed for all and funded by the state. More and more medical care facilities are obliged to charge for their services, in order to keep even a minimal level of service operating under very difficult circumstances, and the ever increasing costs sharply reduce the scope of the available services. To date, they have remained mostly free for all families at high risk of genetic disease, but this situation may change with the move to a health insurance system and the introduction of private practice. The major difficulties facing the system are funding shortages (which limit the provision of, for instance, biochemical diagnostic services or laboratory investigation), and the lack of genetic education among health care professionals and the general public (so that, for instance, the importance of a correct diagnosis following the birth of a malformed infant is not recognised).

Medical genetics has a long history in Russia, the first Institute of Medical Genetics (in Moscow) being founded in 1932 to study the genetics of common disorders, and the first genetic clinic in St Petersburg in 1934. This latter offered a service for hereditary neurological disorders and pioneered genetic counselling with trained nurses in a primary role. However, this promising initiative was effectively halted in the 1930s, with the rise of Lysenko, when the specialty was officially defined as eugenic and racist. It was not until the 1960s that medical genetics began a slow recovery, with the establishment of a medical genetics laboratory in St Petersburg, and the re-establishment of the first Institute of Medical Genetics in Moscow. Genetic counselling was reintroduced into the health care system and the number of clinics gradually increased. A second institute was founded in Tomsk in 1985. In 1990, the Moscow Institute became the Research Centre of Medical Genetics, composed jointly of the Institute of Human Genetics and the Institute of Clinical Genetics.

In general, for the reasons given earlier, genetics services are poorly organised, with inadequately trained geneticists. Genetics services are provided through a three tier system. At the most basic level, there are around 70 units located in paediatric departments or policlinics, where primary genetic consultations are carried out, and patient referrals organised as appropriate. At the next level, 10 regional medical genetics centres (for example, Novosibirsk) deal with all types of prenatal diagnosis, neonatal screening programmes, and maintain

regional genetics registers. At the highest level, there are five federal medical genetics centres (for example, Moscow, St Petersburg, Tomsk), affiliated to pre-existing institutes and linked to specialist medical genetics clinics. These offer a molecular diagnostic service for 40 or 50 different genetic disorders. All federal and regional medical genetics centres have cytogenetic laboratories. Collaborative links between the various centres are being established.

Most counselling is carried out by clinicians specially trained in genetics. The average centre has two (research funded) genetic associates, who are usually graduates in biology or a similar subject, and undertake diagnostic laboratory studies.

CANCER GENETICS SERVICES

There are two familial breast cancer clinics. The average staff includes seven health service doctors, two (research funded) genetic associates (who carry out cytogenetic studies), and one (health service funded) genetic nurse. Individual family members are each given specific appointments for physical examination, mammography, and ultrasound. There is very little predictive testing for cancer susceptibility, and what there is mostly provided on a commercial basis. Oncology centres may provide counselling for families at high risk, but this is usually carried out by oncologists with some special training in genetics, not by geneticists.

Training

All medical schools provide approximately 30 hours of human and clinical genetics in the first year of the preclinical curriculum (including cell biology). There are four Chairs of Medical Genetics at the Institutes for Medical Genetics (Moscow, St Petersburg, Tomsk), tasked to emphasise the input of medical genetics into clinical disciplines, and so improve the lack of genetic education among physicians.

Clinical genetics was recognised as a medical specialty in 1988, and two primary training programmes have been set up, for clinicians and scientists, overseen by a special Department of Medical Genetics of the Russian Medical Academy for Postgraduate Study. Each lasts seven months and covers basic genetic knowledge. Most clinicians have a clinical background in paediatrics or obstetrics and gynaecology, but some are neurologists or specialists in internal medicine. Scientists usually have a degree in biology or a similar qualification. There are three postgraduate departments of medical genetics which oversee such training. They also offer periodic refresher courses in genetics; it is recommended that genetic counsellors undertake these every three years.

Genetic teaching for nurses is inadequate.

TRAINING OF CANCER GENETICISTS

No details are available.

Audit and evaluation

Overall responsibility for the medical genetics services rests with the Advisory Committee on Medical Genetics of the Department of Mother and Child Care, Ministry of Health. This is charged with determining strategies and policies for the service (for example, for prenatal diagnosis or medical genetics education). It also issues guidelines and manuals for medical genetic staff.

External quality control for medical genetics does not exist, but legislation for certification of diagnostic laboratories and screening programmes is in preparation.

Discussion fora

The Interregional Society of Medical Genetics.

Ethical issues in medical genetics have been discussed under the aegis of the Research Centre for Medical Genetics in Moscow, and a number of reports on specific issues published.

SPECIFIC CANCER DISCUSSION GROUPS

The Research Centre for Medical Genetics (Moscow) has published a report on predictive testing for inherited cancers.

Education

This is recognised as a problem area, and considerable efforts are being made to ameliorate the situation through seminars for the medical profession and improved teaching and training opportunities. The Advisory Committee on Medical Genetics is charged with furthering medical genetics education. It issues the Bulletin of the Interregional Society of Medical Genetics, to introduce information on developments in medical genetics nationally and internationally.

Contacts are being forged with patient support organisations, and the institute in St Petersburg has conducted a survey of patients' wishes. They are developing information leaflets for patients. There are occasional television and radio programmes and articles in the media about cancer genetics, but no videos or websites.

Registers

There are as yet no federal registers, although the Advisory Committee on Medical Genetics is considering them. The regional medical genetics centres maintain local (computerised) registers for genetic diseases (which include all handicapped children and families at high risk of genetic disorders). The federal centres also operate DNA databanks on these patients and their families. There is a National Register of Chromosome Disorders and many local registers of congenital malformations. Work is ongoing to computerise these and create a national register.

Support

CANCER CHARITIES

No details are available.

PATIENT SUPPORT GROUPS

These exist for a number of disorders (cystic fibrosis, neuromuscular disease, blindness, etc). The Invalids Association is the most prominent sponsor of medical genetic services in Russia.

37 Baranov VS, Ginter EK. Genetic services in Russia. *Eur J Hum Genet* 1997;5(suppl 2):148-53.

Persons responding

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SERBIA

Genetic services

These have been reviewed by Micic,[38] as part of the Concerted Action on Genetic Services in Europe. Serbia (part of the former Yugoslavia) enjoyed an organised system of genetic services, with referral from primary health care providers to specialist centres, responsibility for which rested with the hospital, and the Ministry of Health. The first genetics services began in 1968, with karyotyping for the mentally handicapped, and the institution of a Down syndrome register; cytogenetics laboratories were set up in 1970 at Belgrade and Novi Sad, and these developed into the two regional clinical genetics centres at Belgrade and Novi Sad (later followed by three others in regional hospitals), while a network of genetic counselling services in local health care centres and hospitals was staffed by trained paediatricians. In 1997, there were a total of 11 trained clinicians (with a further 11 in training), 25 cytogeneticists, 10 molecular geneticists, and six genetic nurse/counsellors involved in the provision of a genetic service. Specialists in other disciplines (for example, paediatrics, gynaecology and obstetrics) could also access specialist genetic advice where required. Smaller towns also enjoyed some access to clinical/laboratory genetic services. However, genetic services, and the health service as a whole, have suffered greatly during the ongoing civil strife, and this has meant an end to international collaborative ventures in clinical and cancer genetics, which has gravely reduced the services available, so that they are scarcely recognisable under recent conditions. The genetics centre in Novi Sad, for instance, has been reduced to offering counselling and basic cytogenetic analyses, while two other cytogenetics laboratories have closed. The screening programmes for phenylketonuria and hypothyroidism have lapsed for lack of funds, and two molecular genetics laboratories in Belgrade, which were working on cystic fibrosis and Duchenne muscular dystrophy, ceased to operate. Work continues, with extreme difficulty, priority being given to prenatal diagnosis and cytogenetics services.

CANCER GENETICS SERVICES

There are three cancer genetics clinics in Serbia, each with an average of one doctor, three genetic associates, and three genetic nurses, funded by government health service sources. The first 20 patients have been screened for mutations in *BRCA1*/*BRCA2*, and screening for *p53* mutations is available. Collaborative links have been set up with UICC (Lyon) and Budapest, and there is a fellowship training scheme in operation. However, development of a molecular diagnostic service is hampered by the high cost of chemicals and consumables, and the current political situation. The Institute of Oncology (Belgrade) has a cytogenetics laboratory which studies around 600 bone marrow analyses per year and around 100 solid tumours (using cytogenetic and molecular techniques).

Training

Undergraduate medical studies include biology and human genetics in the first year, when students get 60 hours of theoretical and 45 hours of practical work.

Following graduation, it has been possible for clinicians (and a few molecular biologists) to follow a two year course in human genetics leading to a MSc, which involves theoretical and practical education in all fields of human genetics. Examination, and the presentation of a thesis, leads to a certified diploma "Master of Medical Genetics", which qualifies them to work as specialists in medical genetics in their own field. The medical faculty of the University of Belgrade has now introduced a two year specialty course in medical genetics (resembling the postgraduate course but with further training in different fields of clinical genetics), which will lead to legal recognition as a specialty.

Novi Sad offers a one year course in clinical genetics for paediatricians, gynaecologists, physiologists, and some other specialties. Continuing medical education programmes in genetics are provided by university medical faculties.

Genetic associates (geneticists working in clinical laboratories) must have a qualification in molecular biology. They can undertake further training courses, for example, in cancer genetics.

There are no official educational requirements for genetic nurses, although some training in genetics is planned.

TRAINING OF CANCER GENETICISTS

The Department of Molecular Biology offers courses in cancer genetics, in order to recruit consultants. Oncologists are not yet included in this.

Geneticists play a part in training oncologists. They also carry out testing and counselling. They must have a specialist training in cancer genetics/have undertaken a course.

Audit and evaluation

Responsibility for the genetic services and for their organisation lies with the Ministry of Health. All medical and dental professionals are subject to quality assessment, but there is no formal audit or quality assessment scheme for genetics. There is no official inspection of training centres or standards.

Discussion fora

There is no established collaboration between centres and collaboration mostly depends upon personal connections. Informal genetic discussion groups are just beginning to be formed.

The Society of Human Genetics (which embraces clinical and molecular geneticists and cytogeneticists) holds regular meetings, but there is no professional organisation for biochemical geneticists or coworkers.

SPECIFIC CANCER DISCUSSION GROUPS

No details are available.

Education

In general, public awareness of genetic issues is low and uneven; inhabitants of the big cities enjoy much greater access to genetic services. Lack of funding and genetic education, and poor organisation and coordination, hamper efforts to improve this situation.

The Novi Sad Centre runs a telephone enquiry service providing information on harmful agents in pregnancy; this operates on a national basis, with a database of known teratogenic agents.

Information leaflets are in preparation (no details, but presumably being prepared by the Institute for Oncology and Radiology and similar organisations).

There is a Serbian Society against Cancer, which produced many leaflets (on chemotherapy, nutrition, radiation, clinical trials, etc), but none on gene testing.

There are no videos specifically about cancer genetics, although their use for patient information is common. Recently, there has been media coverage of genetic facilities and information.

No websites are known.

Registers

Novi Sad houses the national register of congenital malformations (linked to EUROCAT, although unrecognised). A cytogenetics register has existed since 1970.

Support

CANCER CHARITIES

The Serbian Society against Cancer.

PATIENT SUPPORT GROUPS

There are no patient support groups at present.

The Serbian Society against Cancer produces information leaflets on chemotherapy, nutrition, radiation, clinical trials, etc.

38 Micic M. Genetic services in Serbia. *Eur J Hum Genet* 1997; 5(suppl 2):154-8.

Persons responding

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SLOVENIA

Genetic services

These have been reviewed by Peterlin,[39] as part of the Concerted Action on Genetic Services in Europe. The Slovene system of health care is funded by a national health insurance scheme (although people can supplement its provisions with private schemes), and is based on a widespread network of primary, secondary, and tertiary health services. Most health care workers are government funded, but some private practitioners and laboratory services exist. Genetics services have a long history, beginning in the late 1950s with the establishment of a laboratory based cytogenetic service. The Department of Obstetrics and Gynaecology of Ljubljana University set up a cytogenetic service in 1966; this developed into the Division of Medical Genetics, a tertiary referral centre offering a genetic counselling and laboratory service. A number of other centres have also provided some genetic counselling services in the past, but currently the Division of Medical Genetics is the only government funded provider of genetic counselling services in Slovenia. There are three cytogenetics laboratories and four molecular genetics laboratories providing a diagnostic service, but a shortage of laboratories offering a biochemical genetics service. There is also one privately funded centre, which offers genetic counselling and a cytogenetic diagnostic service.

Most counselling is provided by the Division of Medical Genetics, but some is still carried out by paediatricians (for example, for haemophilia) or gynaecologists (for prenatal and neonatal cytogenetics tests). There are joint neurogenetics and dermatosis clinics, shared with the appropriate specialists.

CANCER GENETICS SERVICES

Cancer accounts for some 23% of all deaths in Slovenia. The majority of Slovenian cancer patients are concentrated in the Institute of Oncology. In 1998, a Joint Working Group of the Division of Medical Genetics/Institute of Oncology developed a protocol for a service for breast cancer patients and this will become operational during 1999.

The Division of Medical Genetics (Ljubljana) operates a government funded cancer genetics clinic, in close collaboration with the Institute of Oncology and the Department of Obstetrics and Gynaecology. One genetic counsellor is involved in counselling for cancer families, but while trained in clinical genetics, this person has no formal training in cancer genetics. The molecular genetics facilities in Slovenia cover the diagnosis of T and B cell lymphomas and *BRCA1*/*BRCA2* mutation analysis in inherited breast/ovarian cancer. However, DNA samples are still regularly referred to other centres in Europe for analysis.

Training

Undergraduates receive 15 hours of genetics teaching in the second year (jointly taught by the Division of Medical Genetics and the Institute of Cell Biology), and some further teaching in the later part of their training, during the paediatric, neurology, gynaecology, and obstetrics courses.

Since 1972, the Institute of Cell Biology (Ljubljana) has run a two year training programme in medical genetics, in collabora-

tion with the Department of Medical Genetics. Following the recognition of medical genetics as a subspecialty in 1997, the Institute has also been involved in developing the proposed new five year course for clinical geneticists, in collaboration with the Slovenian Association of Human Genetics. This will involve two to three years common training in genetics, and will then split into clinical genetics (mostly doctors) and molecular genetics (others, mostly PhDs) moieties. Previous specialisation in a branch of clinical medicine (for example, paediatrics, neurology, internal medicine) will be required for entry to the course, which will include basic human genetics, cytogenetics, cancer genetics, molecular genetics, and syndromology, together with some practical training in both clinical and laboratory genetics (this will also include genetic aspects of other disciplines such as paediatrics, neurology, gynaecology and obstetrics, ophthalmology, dermatology, and oncology. The programme is currently awaiting ratification by the Slovene Medical Society and the Slovene Medical Chamber. A separate subspecialisation programme is being prepared for medical cytogenetics and medical molecular genetics. Until the proposed five year training programme comes into operation, clinical cytogeneticists and clinical molecular geneticists can take one year training courses. A diploma in biology, chemistry, pharmacology, medicine, or veterinary medicine is required for entry to these, and the training programmes are technically oriented, with the emphasis on quality control and genetic counselling implications.

The Slovenian Association of Human Genetics is also preparing teaching courses for some other specialty training programmes.

TRAINING OF CANCER GENETICISTS
No details are available.

Audit and evaluation
A board of specialists from the Division of Medical Genetics, the Institute of Oncology, and the Department of Obstetrics and Gynaecology are evaluating the cancer genetics services available in Slovenia.

The National Board of Health is responsible for the professional regulation of all health care workers, and legislation to regulate laboratory diagnostics and gene therapy is in preparation. A national quality assurance scheme for genetic counselling and diagnostic services is also being prepared.

Discussion fora
The Slovene Association for Human Genetics.

The Slovene Association for Obstetrics and Gynaecology.

SPECIFIC CANCER DISCUSSION GROUPS
Slovene Association for Oncologists.

Collaboration between the Division of Medical Genetics and other tertiary medical institutions is relatively good.

Education
Public awareness of genetic services and issues is relatively poor. The genetic knowledge of non-specialist medical practitioners is also somewhat limited, although steps are being taken to combat this.

Registers
The Division of Medical Genetics operates a register for patients or families with an increased risk of severe genetic disorders.

The Institute of Oncology has kept the Slovenian Cancer Registry since 1950. However, it contains no family data, and is therefore of no use for molecular diagnostic purposes. Specialised registers (containing family data) are in preparation (for example, breast cancer register, HNPCC (started in 1995), MEN 2 (started in 1994), MEN 1 (started in 1996), etc).

Support
CANCER CHARITIES
No details are available.

PATIENT SUPPORT GROUPS
These exist for groups of disorders (neuromuscular disorders, mental retardation, blindness). They engage in joint initiatives with the Division of Medical Genetics, to provide up to date information (for example, on new diagnostic techniques), and to improve the general awareness of the management and prevention of genetic diseases among patients, their families, and the general population, as well as among health care professionals.

39 Peterlin B. Genetic services in Slovenia. *Eur J Hum Genet* 1997;5(suppl 2):159-62.

Persons responding
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SPAIN

Genetic services
Genetic services in Spain have been well summarised by Ramos-Arroyo *et al*,[40] as part of the Concerted Action on Genetics Services in Europe. Genetics began to be incorporated into medical care in the mid 1960s, with the introduction of cytogenetic diagnostic services in a number of health centres. These developed further in 1980 and 1987, when a National Plan for the Prevention of Handicap was drawn up, to consolidate the existing centres into a network supplying genetic services nationwide, and to institute neonatal screening programmes for certain disorders. Sadly, this programme was never fully funded, and development of genetic services continued on a piecemeal basis without an overall unifying strategy. Today, genetic services are mainly provided by the large public sector hospitals in

each region (under the overall umbrella of the Instituto Nacional de la Salud), and the corresponding costs are (mainly) met by the national or regional health services, which cover the costs of all medically indicated genetic studies. However, inadequate funding hampers the implementation of molecular diagnostic techniques, and essential basic research. Some of this shortfall has been made up by research funding from various sources (mainly the Fondo de Investigacion Sanitaria) and DGICYT, which have played an important role in technological development. Research funds also help ameliorate the manpower shortage caused by lack of recognised specialty status and appropriate career structure, by funding would-be trainee specialists. However, the diagnostic overload means that research and education suffer while these trainees assist with the clinical work of the genetics centres.

In 1997, there were 37 genetics centres (not including private or research groups), with around 150 trained geneticists (approximately half clinicians and half laboratory scientists), and around 145 laboratory staff; 17 of these centres had around 80 students, supported on research grants, who took part in diagnostic work as part of their training. Almost all genetic counselling in Spain is done by (non-specialist) doctors; there are no genetic counsellors or genetic nurses to share or reduce the workload. Almost all centres provide genetic counselling services, 83% provide prenatal cytogenetic analysis, and more than half provide molecular diagnostics (access to biochemical genetics laboratories is less good, with only 10 laboratories offering a diagnostic service, and 21 carrying out neonatal screening for phenylketonuria and hypothyroidism). However, consultation is often limited to prenatal diagnosis, and only about 10 centres were offering a complete service with diagnosis, counselling, and follow up. At least 20 of the centres could provide counselling by a competent specialist if they had appropriate facilities and funding. There are no specific arrangements for the linking of clinical genetics, cytogenetics, and molecular genetics, although in practice this tends to occur.

Clinical genetics services are often organised on a multidisciplinary basis, with the involvement of paediatricians, neurologists, haematologists, gynaecologists, and other specialists as well as clinical geneticists, and there is a high degree of regional (though not yet national) coordination and cooperation. Coordination at a primary care level is virtually non-existent. There is general agreement that genetic services must include appropriate counselling as well as diagnosis, and that only medical geneticists and others having competence in medical genetics should have the authority to provide genetic testing (in practice many centres carry out analyses requested by professionals without genetic training, and counselling cannot be guaranteed).

CANCER GENETICS SERVICES

There are no dedicated cancer genetics clinics in Spain. Cancer genetics is largely concerned with haematological disorders. There are some groups working on familial breast cancer, colon cancer, and MEN which provide genetic counselling as or when necessary. Experience of predictive testing for cancer is very limited. A few centres have started prospective studies on people with a genetic susceptibility to breast cancer, FAP, and MEN who had previously been ascertained for research purposes.

Training

Genetics is not a recognised specialty and there is no accreditation. Few funded posts are available, and much of the development of genetics in Spain has been driven by the personal interest and motivation of a few workers, mainly research funded.

Until 1990, genetics was not taught at all. Since then medical schools have been required to include human genetics in the curriculum (varying from 10 to 60 hours at different universities).

There are no official training programmes in clinical genetics, cytogenetics, or molecular genetics, although some doctoral courses in medicine and biology include human and medical genetics. The lack of recognition and official training programmes means that would-be specialists cannot gain access to a genetic centre through the National Training Programme for Medical Specialists. Training has to be provided unofficially (without audit or evaluation), most frequently on research funds, but the diagnostic overload, with which trainees assist as part of their specialist education, limits opportunities for training and research. Since 1995, the University of Alcala de Henares and the Department of Medical Genetics, Hospital Ramon y Cajal (Madrid) have offered a course in medical genetics leading to a certified degree, for clinicians with or without a specialty, and non-clinicians. This includes basic concepts of human genetics, a broader approach to clinical genetics, and its possible application to different fields of medicine.

In the area of laboratory genetics, biology students fare better than medical students, with around 150 hours of basic genetics teaching and other optional courses in specific areas such as cytogenetics, human genetics, population genetics, and molecular biology. There are no Masters programmes, although different universities regularly offer short courses in cell biology and molecular genetics.

There are no training programmes for genetic counsellors or genetic nurses.

TRAINING OF CANCER GENETICISTS

These are recruited from the general clinical genetics services and there are no specialist training programmes in cancer genetics.

Audit and evaluation

Quality assurance schemes for genetic services are practically non-existent. Only laboratories performing neonatal screening work have a national quality assurance scheme, controlled by the Sociedad Espanola de Bioquimica Clinica y Patologia Molecular. Seven bio-

chemical genetics laboratories collaborate with the European Network for the Evaluation and Improvement of Screening, Diagnosis and Treatment of Inherited Disorders of Metabolism. There are no organisations responsible for the maintenance of standards in clinical genetics, cytogenetics, or molecular diagnostics. In 1994, a Committee for Accreditation and Quality Control of Cytogenetic Laboratories was set up, and this has recently introduced standardised criteria for accreditation and quality control. Plans to develop quality standards for clinical and molecular genetics are under way.

Discussion fora

The Spanish Association of Human Genetics.
The Spanish Association of Prenatal Diagnosis.

SPECIFIC CANCER DISCUSSION GROUPS

ASEICA.

Education

Lack of awareness of genetics among the public and health professionals means that consumers with higher social and educational levels have easier access, and there is considerable need for more widespread education about these issues. There is considerable media interest in and discussion of genetic developments, and open discussion of scientific and ethical aspects of genetics, which is improving the general level of public knowledge.

Registers

There are at least five registers of congenital malformations and inherited disorders, including the Spanish Collaborative Study of Congenital Malformations, and four population based registers. There are also cancer registers (mostly of colon cancer) in different communities, and a "White Book" produced by the Spanish Association Against Cancer. There are no registers of cancer predisposing conditions.

Support

CANCER CHARITIES

Asociocio Espanola Contra el Cancer.

PATIENT SUPPORT GROUPS

No details are available, but the numbers of such organisations has significantly increased in recent years.

40 Ramos-Arroyo MA, Benitez J, Estivill J. Genetic services in Spain. *Eur J Hum Genet* 1997;**5**(suppl 2):163-8.

Persons responding

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SWEDEN

Genetic services

Genetics services in Sweden have been reviewed previously by Kristoffersson,[41] as part of the Concerted Action on Genetic Services in Europe. Services are centred on each of the six health care regions, based at the University Hospitals in Stockholm, Gothenburg, Linkoping, Lund, Umeå, and Uppsala. The departments of clinical genetics are university affiliated and provide excellent research opportunities. Lund, Stockholm, and Umeå have professors of clinical genetics; Gothenburg, Linkoping, Uppsala, and Umeå have preclinical Chairs in medical genetics parallel to the clinical genetics departments. The centres are well staffed: Stockholm has five consultants, Lund has four, Uppsala three, and Umeå and Gothenburg two each, while Linkoping has one. Besides clinicians, centre staff usually include hospital geneticists and laboratory technicians. In addition, all centres except Linkoping have a part time nurse, usually with an oncological background, attached to the cancer genetic clinic.

The university oncological departments are organised in a similar way and supplemented by 16 units located at central county hospitals. However, no genetic service is offered at these departments.

Much genetic counselling is provided by non-genetic specialists based at district hospitals and primary care units (paediatricians, gynaecologists, and midwives). In particular, midwives or gynaecologists usually perform genetic counselling for prenatal chromosome disorders, while the main role of the clinical geneticists is to keep them up to date. However, experience in cancer genetic counselling is rare outside university units.

Cancer genetics services

The cancer genetic service is multidisciplinary. Geneticists and oncologists provide counselling, but specialists from many other specialties with a particular interest in cancer genetics (such as surgeons, gynaecologists, radiologists, and pathologists) are involved in patient care.

Specialist cancer counselling and diagnostic services are organised jointly by the departments of clinical genetics and oncology; patients usually see both a geneticist and an oncologist at the same consultation. There are currently six cancer genetics clinics, one at each university hospital, funded from government health service sources.

A national research based laboratory service for the investigation of breast, colon, and other cancer associated genes, accessible by all clinics, is offered by Lund, Stockholm, and Gothenburg. Lund also provides a laboratory service for large areas of Denmark.

Training

There are six medical schools, one at each university. The medical licence course takes 5½ years, followed by 21 months of internship. Medical genetics is usually taught in a one week course in the first part of this training,

supplemented with lectures and workshops on specific topics, integrated into other courses during the latter half of training. There is a national consensus among medical and clinical geneticists as to what should be taught, but there are still great variations locally and present tuition is insufficient. Clinical genetics became a specialty in 1991. Specialist training is regulated by the National Board of Health and Welfare. Board certification takes a further five years following licensing. Currently some 20 doctors, specialists and residents, are working in clinical genetic departments.

Specialists in oncology undergo a similar educational programme. Undergraduate training is divided into two parts: a three week preclinical course on neoplasia and a two week course in the last part of the medical licence course.

Genetic nurse posts are rare in Sweden; there are five "ad hoc" educated specialist nurses at present, all affiliated to the oncogenetic service. The Nordic School of Public Health in Gothenburg is, together with the University of Gothenburg, planning a Masters programme in genetic counselling, mainly for nurses and social workers, based on the Manchester programme. A shorter pilot course, for people with previous experience, is to be held in May 1999, and these persons will serve as tutors on the first Masters course, to be held in the year 2000.

Training of cancer geneticists

There are no formal training programmes. Geneticists, oncologists, or nurses joining the staff of the cancer genetics clinics are trained on an "ad hoc" basis.

The Southern Swedish Health Care Region has undertaken an educational programme for one surgeon, one gynaecologist, one nurse, and one social worker from every county (secondary) hospital within the region. These now constitute a local network for handling follow up and patient selection. Similar training programmes are planned, or under discussion, in the other health care regions.

Other opportunities for limited specialist training also exist; for instance, the clinics offered a three day course for residents in oncology or genetics in Gothenburg in 1997 and a further course is planned for Spring 2000. Members of the teams repeatedly participate in local courses or national postgraduate courses.

Audit and evaluation

The Ministry of Health and Social Affairs is responsible for developments in areas such as health care, social insurance, and social issues. It draws up terms of reference for government commissions and drafts new legislation.

The National Board of Health and Welfare (NBHW) is the government's central advisory and supervisory agency for health services, health protection, and social services. It evaluates the services provided to ensure that they correspond to government policy and licences medical staff. The NBHW has recently issued a directive that all health care units must have a quality assessment programme. Because of this directive, the Federation of County Councils has decided to introduce a quality assessment programme (QUL) based on the European Federation for Quality Management (EFQM) programme.

In 1993, the Swedish Society of Medical Genetics (affiliated with the Swedish Society of Medicine) issued recommendations on quality assurance for clinical genetics centres (including guidelines for cytogenetic and molecular diagnostic laboratories, as well as for genetic counselling). The Society is deliberating on other audit and surveillance measures within the profession.

In 1994, the Oncogenetic Clinic Planning Group was formed. This is a national planning group partly supported by grants from the Swedish Cancer Society. In 1999, it will issue national guidelines for clinical cancer genetic services, including follow up programmes, in collaboration with the National Board of Health and Welfare.

The Oncogenetic Clinics in Lund and Stockholm are currently evaluating different aspects of the psychosocial impact of the counselling process.

Discussion fora

There is no formal cooperation between the different genetic centres, but there are close contacts and information exchanges, and informal cooperation in the diagnosis of rare disorders.

The Swedish Society of Medical Genetics (affiliated with the Swedish Society of Medicine) organises doctors and scientists within the broad field of medical genetics and has about 100 members. The Society also includes specialists in clinical genetics, and functions as a branch of the national trade union, the Swedish Medical Association. Its Board holds a voluntary specialist exam, and has issued recommendations on quality assurance for clinical genetic laboratories. It meets annually.

The Swedish Society of Oncology (affiliated with the Swedish Society of Medicine) organises doctors and scientists within the broad field of medical oncology and has about 300 members. Its Board holds a voluntary specialist exam. It meets twice yearly and also organises courses on relevant topics for its members.

SPECIFIC CANCER DISCUSSION GROUPS

The Oncogenetic Clinic Planning Group, which is part sponsored by the Swedish Cancer Fund, meets twice a year. Currently it is preparing National Guidelines for Cancer Genetics Counselling and Follow up.

Education

There is quite a high degree of general genetic awareness in the country and public acceptance of genetic advances is good. There is an ongoing media debate on the impact on society of the advances in molecular genetics.

Families may experience difficulty in accessing information on particular disorders, but various support groups are springing up to combat this.

The Board of Social Health and Welfare has recently allocated funds to produce documentation for lay persons on rare disorders, including several genetic diseases. Some lay organisations are providing information sheets on the specific disorders they represent.

Registers

The National Board of Health and Welfare administers four registries of interest for cancer genetics, to which reporting is compulsory.

Medical Birth Registry.

Swedish Registry of Congenital Malformations.

Cause of Death Registry.

Swedish Cancer Registry.

There are regional cancer registries at the university hospitals.

A national database of familial cancers has been constructed from the Swedish Cancer Registry: this includes some 6 million people, with more than 30 000 cases of cancers in offspring diagnosed between the ages of 15 and 51 years and their parents.[42] A particular advantage of the database is that the contribution of both parental lineages to cancer risk can be examined.

There are many other national and regional registries operated for research and clinical purposes, such as the national register for polyposis coli, and semiofficial registers for MEN 1 and MEN 2. In Stockholm, a local HNPCC register has been developed and the introduction of a nationwide register is currently under discussion.

Support

NATIONAL CANCER CHARITIES

The Swedish Cancer Society.

The National Association for Cancer and the Traffic Injured.

PATIENT SUPPORT GROUPS

The National Association for Cancer and the Traffic Injured.

There are lay associations for breast and other types of cancers, but they have no specific information on hereditary cancers. People are instead advised to contact the genetic centres.

Most of these lay organisations provide information sheets on the specific disorders they represent.

41 Kristoffersson U. Genetic services in Sweden. *Eur J Hum Genet* 1997;**5**(suppl 2):169-73.
42 Hemminki K, Vaittinen P. National database of familial cancer in Sweden. *Genet Epidemiol* 1998;**15**:225-36.

Persons responding

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SWITZERLAND

Genetic services

Genetic services in Switzerland were reviewed by Pescia,[43] as part of the Concerted Action on Genetic Services in Europe. The health service is based on a federal system, with each of 23 cantons responsible for the operation of its own health services, and is funded one third by government sources, one third by insurance schemes, and one third payable by the consumer. Care of those with congenital malformations, inborn errors of metabolism, etc, is funded through invalidity insurance. Medical genetics as a profession began in the 1940s, and by the 1960s all five university hospitals (Basel, Bern, Geneva, Lausanne, and Zurich) had institutes of medical genetics. By 1997, these had evolved into the five present day medical genetic centres, which offer counselling, diagnostic, and laboratory services at six public centres (with a staff of 14 clinicians, 10 trainees, 13 cytogeneticists, 13 molecular geneticists, and 70 trained laboratory technicians). There were nine DNA laboratories and six cytogenetics laboratories. In addition, there were four private cytogenetics laboratories, affiliated to university centres (with one clinician, four cytogeneticists, and 23 laboratory technicians). Specialist genetic counselling is carried out by clinicians, but often primary counselling (for example, about prenatal diagnosis) is performed by obstetricians, or, less frequently, by general practitioners. Nurses are not involved in genetic counselling, although they may assist clinicians, particularly with paediatric cases. There are no specially trained genetic nurses or genetic counsellors.

There is a national neonatal screening programme for phenylketonuria, hypothyroidism, and galactosaemia, which operates independently of the genetics centres.

CANCER GENETICS SERVICES

The Division of Medical Genetics (Lausanne) is the national referral centre for the cytogenetics of malignant haemopathies.

There are three familial breast cancer clinics, one at the University Hospital in Basel (two gynaecologists, three medical geneticists, one nurse, one to two oncologists, others; health service funded with research projects), one at the University Hospital in Geneva (Department of Oncology), and one at the Centre for Tumour Detection and Prevention in St Gallen. Average staffing levels for a clinic are: two oncologists, one geneticist, one nurse, one psychologist, and one technician (all part time). Other clinics are being developed, as is predictive testing for cancer susceptibility genes. Several studies are under way to investigate the attitudes of patients and their families towards specific cancers (for example, breast/ovarian and colorectal cancers).

Training

There is no national agreement concerning the teaching of genetics to medical students, and therefore wide variation exists between university centres.

At a postgraduate level, the Swiss Society of Medical Genetics and the University Institutes of Medical Genetics operate training courses in genetics for clinicians and postdoctoral workers. Medical/clinical genetics is not a recognised specialty, and there is no formal training

programme. The FMH hopes to introduce one, granting (clinical) specialty status in medical genetics. The Swiss Society for Medical Genetics and the Swiss Academy of Medical Sciences are discussing training options.

There is no defined training for clinical or laboratory scientists.

There is no formal programme for nurses and no career structure, and only a few nurses are involved in the provision of genetic services (almost entirely in the field of cancer genetics). There are very distinct roles for nurses and doctors, and physicians are abundant, so it is unlikely that this situation will alter in the future.

TRAINING OF CANCER GENETICISTS

None is yet available. Short courses (apparently for clinicians and genetic associates) are to be offered in future by the European School of Oncology's German speaking section. Such courses are also offered on an irregular basis by the Department of Medical Genetics, Basel University, and by the Swiss Cancer League.

There is no formal cancer genetics training programme for nurses. Those few who are involved in the provision of a service are academically prepared and carry out pedigree evaluation and risk assessment, and must have experience in cancer care and counselling.

Audit and evaluation

There are as yet no national standards for genetic counselling. The Swiss Academy of Medical Sciences supervises the quality of genetic services, and, for instance, publishes guidelines for prenatal and postnatal genetic testing. There is a quality control scheme for diagnostic laboratories, run by the Swiss Society of Medical Genetics, and the Society also publishes guidelines on ethical practice.

Discussion fora

The university centres regularly organise postgraduate lectures on specific topics in medical genetics, and there are regular meetings and seminars (for example, at the University of Basel).

The Swiss Society of Medical Genetics organises regular multidisciplinary meetings in collaboration with other specialties (for example, paediatrics, obstetrics and gynaecology, neurology, ophthalmology).

There are four annual dysmorphology meetings.

There are strong research collaborations with other countries (for example, France, The Netherlands, the UK, and the USA).

SPECIFIC CANCER DISCUSSION GROUPS

The UICC Breast Cancer Meeting, which took place in Lucerne at the end of April, was devoted to the psychosocial impact of breast cancer.

There is a spirited national debate on DNA technology under way.

Following previous successful meetings in St Gallen in 1985 and 1998, the next consensus meeting on Adjuvant Therapy in Breast Cancer will take place in St Gallen from 21-24 February 2001.

An international conference, Tumor Prevention and Genetics 2000, was held in St Gallen (17-19 February 2000).

A new task force, dealing with cancer predisposition and counselling at a national level, is currently being established.

Education

The Swiss Academy of Medical Sciences produces brochures on topics such as genetic engineering for lay audiences.

The Swiss Society of Medical Genetics, the Swiss Cancer League, and others offer information to patients and their relatives (for example, the Swiss Cancer League produces a leaflet on chemoprevention for breast cancer). The St Gallen Centre is also starting to produce information leaflets for patients on familial breast cancer.

There are no known videos or exhibitions and little media interest. The Swiss Cancer League has a website at <http://www.swisscancer.ch>; it also operates a twice yearly newsletter to update its members on the various genetic services available.

Registers

The medical genetics centres at the Universities of Lausanne and Zurich operate the registry of congenital malformations for their cantons, and the centre in Lausanne runs EUROCAT-Switzerland. There is no national genetics register. Some cantons operate familial cancer registers (for example, for FAP and retinoblastoma). Currently, a service offering cancer genetic testing (*BRCA1* and *BRCA2*) with pre- and post-test counselling is being established by the Stiftung Tumorbank Basel, in collaboration with the Center for Tumor Detection and Prevention, St Gallen. In this context, a data bank for *BRCA1* and *BRCA2* mutations in Switzerland will be set up.

Support

CANCER CHARITIES

Schweizerische Krebsliga (Swiss Cancer League).

PATIENT SUPPORT GROUPS

No details are available, but a large number (concerned with, for example, Huntington's disease or cystic fibrosis) do exist and the university centres regularly take part in public debates, lectures, and meetings dealing with issues in modern medical genetics.

43 Pescia G. Genetic services in Switzerland. *Eur J Hum Genet* 1997;5(suppl 2):174-7.

Persons responding

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Prof Hans-Jakob Muller, Department of Medical Genetics, University Children's Hospital, CH-4005 Basel, Switzerland (tel: 41 61 691 2626; fax: 46 61 691 2676).

TURKEY

Genetic services

Genetic services in Turkey have been reviewed by Tuncbilek,[44] as part of the Concerted Action on Genetics Services in Europe. The system of health care provision is confusing, with two policy making organisations (the Ministry of Health and the State Planning Organisation) and input from other organisations (university hospitals or organisations involved in health insurance). Health services are administered by provincial health directorates and split into two types: health centres provide free services and a network of midwife stations ("health houses") offering maternal and paediatric health care operates in parallel. Access to genetic services is free, but is hampered by lack of education concerning genetic issues, and by the lack of trained specialists. Funding is provided through a mixture of health insurance, the general state budget, and private funding. To supplement this, there is a system of research funding, provided by various governmental or international agencies on a project basis.

The first medical genetics units were established in the 1960s at Hacettepe University (Ankara) and Cerrahpasa University (Istanbul), originally in paediatric departments, and were initially concerned with clinical genetics and cytogenetics. In the 1980s, molecular genetics was introduced, but the importance of genetics to public health only began to be recognised at the end of the 1980s, when the development of molecular diagnostic techniques and treatment possibilities during the late 1990s led to the official recognition of medical genetics as a specialty.

In 1997, 22 of the 26 medical genetics centres in Turkey were university based. They were staffed by 14 trained clinicians (with 20 to 30 trainees), 49 cytogeneticists, and 28 molecular geneticists. There are no genetic associates or genetic nurses/counsellors involved in the provision of genetic services (including pre- and postnatal diagnosis, population screening for thalassaemia and phenylketonuria, etc). Genetics centres often operate multidisciplinary clinics, for example in conjunction with neurologists and haematologists.

Laboratory facilities vary greatly between centres. There are 25 major cytogenetics laboratories and four major molecular genetics laboratories, based in university departments, and in addition to these there are seven private cytogenetics laboratories and two molecular genetics laboratories. There is no specific biochemical genetics diagnostic service, but both Hacettepe and Istanbul Universities carry out a limited range of enzyme tests, especially for neurodegenerative disorders.

These numbers are likely to alter in the near future. The Ministry of Health has recently taken responsibility for the control of all genetics centres, whether private or university based, engaged in providing clinical, cytogenetic, or molecular genetic (including cancer genetics) services, under the agreement Regulation of the Centers for the Diagnosis of Genetic Diseases. A Ministry of Health Commission is responsible for the maintenance of a directory of approved centres, and for the quality of the services they provide, according to guidelines published in the directory. New centres must be authorised before work can begin, and the Commission has the power to cancel this authorisation if acceptable standards are not maintained.

CANCER GENETICS SERVICES

There are no specialists in cancer genetics, although there is considerable interest in this area, and no specialist cancer genetics units in oncology/cancer hospitals. Most cancer genetics services operate within medical genetics centres or in close collaboration with them (private cancer genetics centres do not exist). Multidisciplinary clinics do not exist as such, but informal collaboration between clinicians and geneticists, haematologists, surgeons, biochemists, and oncologists exist. Oncologists who are interested in cancer genetics collaborate with cancer genetics specialists, but increasingly the oncologists themselves are seeking some genetic training abroad. Few university based genetics departments have cancer genetics sections. The Oncology Institutes of Istanbul and Ankara Universities are carrying out screening and research studies with cancer patients. A few haematology departments are concerned with genetic aspects of haematological malignancies, and Turkey is a participant in the European Fanconi Anaemia Research Project (EUFAR). Most cytogenetics laboratories carry out cancer cytogenetic analyses (for example, for leukaemia), and a limited number of laboratories are carrying out research into familial cancers. Technical and laboratory facilities for screening cancer patients are available at the Oncology Institutes of Hacettepe University (Ankara) and Istanbul, and in some other major cities, but there is no population screening programme.

There are a number of medical genetics departments involved in different aspects of cancer genetics.

(1) Cancer Genetics Section, Department of Medical Genetics, Osmangazi University Medical Faculty, Eskisehir (performing cytogenetic and molecular diagnosis).

(2) Hacettepe University Oncology Institute/Basic Oncology Department, Ankara (performing cytogenetic and molecular diagnosis, carrying out screening and research studies on cancer patients).

(3) Bilkent University has a molecular genetics laboratory specialising in cancer genetics.

(4) Ankara University Haematology Department.

(5) Akdeniz University.

(6) Medical Genetics Department, DETAM.

(7) The Genetic Diagnosis and Research Centre, GENTAM (Eskisehir) has a cancer genetics section.

(8) Istanbul University Oncology Institute (carrying out screening and research studies on cancer patients).

Eight to ten of these centres perform cytogenetic analysis on solid tumours and for haematological malignancies. The remainder all deal with molecular aspects of cancer, particularly haematological malignancies.

Training

Medical training takes six to seven years and leads to an MD. There are no details concerning undergraduate genetics education and no standard curriculum.

Genetics has been a recognised specialty since 1990, although there is as yet no formal postgraduate training programme, and for this reason a number of people leave Turkey to train, before returning to practice. In addition, with the exception of Ankara, Istanbul, Izmir, and Eskisehir, provincial training centres may be inadequately funded and staffed, and the shortage of specialist teachers means that genetics training is not of the high quality desired. Ege, Dokuz Eylul, Hacettepe, and Capa include medical genetics sections within their institutes of child health. Eskisehir, Konya, Samsun, and Antalya have medical genetics departments, while all other university medical genetics services are organised within medical biology departments. The one exception is Capa medical faculty's medical genetics section, which forms part of the Department of Internal Medicine.

The Scientific and Technical Research Council of Turkey has indicated that genetics, molecular biology, and biotechnology areas are priority areas for funding, and has launched scholarship programmes in an attempt to improve the situation. Currently, only eight universities are authorised to offer MSc and PhD programmes, although there are 52 medical faculties in Turkey.

Clinicians generally have six years of medical training and two or more years of specialist training in genetics (to include the giving of seminars on appropriate subject matter, and participation in counselling sessions, as well as cytogenetics, molecular genetics, population genetics, and prenatal diagnosis) before they are authorised to provide genetic counselling (which they alone can provide). A number of different specialist training programmes in medical genetics exist.

Specialist PhD programmes are available within the university medical faculty based departments at Eskisehir, Cerrahpasa, Ankara, and Gulhane.

PhD programmes in medical genetics for clinicians are taught by four university paediatrics departments (Istanbul, Hacettepe, Ege, and Ankara), supervised by the Institute of Child Health and by the Department of Medical Biology (Ankara).

PhD programmes in medical biology are offered by 23 medical biology departments, operated under the institutes of health sciences (each university faculty of medicine has such an institute, tasked with coordinating postgraduate education in the basic medical sciences).

There is a two year course, with a national entrance examination set by the Universities Selection and Placement Centre, for medical graduates, but no standard curriculum.

There is no official certification programme for cytogenetics or molecular genetics, and most people working in these areas have no formal training. Cytogenetics and molecular genetics are mostly taught in formal speciality and PhD programmes, as is the subject of cancer genetics, both practical and theoretical aspects. There are no genetic associates or genetic nurses/counsellors in Turkey, and no official training programme for them, or for primary health care staff, nurses, and midwives.

TRAINING OF CANCER GENETICISTS

Cancer genetics is very new in Turkey and only a few departments of medical genetics provide any training (informally). There are virtually no experienced specialists and as a result there is no formal specialist training programme. Those who offer such a service do so either through personal interest, or because they have had access to specialist training abroad. There is an increasing trend for oncologists who are interested in cancer genetics to seek such training for themselves, rather than to operate in collaboration with specialists in cancer genetics.

Audit and evaluation

The Ministry of Health controls oncology hospitals and health centres. It is also responsible for licensing medical and other health care professionals and laboratories, but, once licenced, there is no quality assessment scheme. Departments operate their own internal guidelines and quality control schemes.

The Ministry of Health is also responsible for all genetics centres providing clinical, cytogenetic, or molecular genetic (including cancer genetics) services, under the agreement Regulation of the Centres for the Diagnosis of Genetic Diseases. A Ministry of Health Commission is responsible for authorisation and quality control.

The Turkish Medical Genetics Association controls the genetic work of the centres. Standardisation and quality control schemes are under development, but are not yet well organised.

There are constant efforts to improve the situation. The numbers of persons training abroad in cancer genetics should effect a significant improvement on the situation in Turkey at present.

Discussion fora

General conferences and groups are being organised on a local basis. Within departments and joint haematology/genetics groups meet regularly to discuss their work.

SPECIFIC CANCER DISCUSSION GROUPS

The Haematology and Cancer Genetics Section of GENTAM hold regular clinical discussion meetings.

Education

There is intense interest in cancer generally, and a rapidly developing interest in cancer

genetics as a result. There are frequent programmes on television and radio, seminars and conferences on patients' rights, and ethical studies. Considerable effort is being expended in raising the level of genetic knowledge among the medical profession and the general public.

Registers

Since 1992, a register has been under way; the types of cancers and incidences are registered by the health centers in each city. The project aims to determine cancer predisposing conditions by examining the incidences of each type of cancer in each region of the country. It is also looking at the effect of local or regional carcinogenic agents.

Support

CANCER CHARITIES

The Turkish Leukaemia Association and the Turkish Cancer Research Association are actively engaged in the organising of meetings to discuss cancer and in fund raising to promote treatment.

PATIENT SUPPORT GROUPS

A number of societies have been established to support research into and family support for genetic disorders (for example, Down syndrome, phenylketonuria, and Duchenne muscular dystrophy). Parents'organisations are most active in the education of mentally handicapped children.

44 Tuncbilek E. Genetic services in Turkey. *Eur J Hum Genet* 1997;**5**(suppl 2):178-82.

Persons responding

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UKRAINE

Genetic services

Genetic services in the Ukraine have been summarised by Arbuzova,[45] as part of the Concerted Action on Genetic Services in Europe. The Ukraine is divided into seven regions. Healthcare is 98% government financed, under the overall supervision of the Ministry of Health, and there is a network of government hospitals. A major factor in health care provision generally, and medical genetics services in particular, has been the 1986 Chernobyl catastrophe, which exacerbated already strained demographic and ecological circumstances. Increased infant mortality in recent years has been attributed directly to this, and it is also though to explain a general decline in public health. People are very aware of the possible genetic effects of radiation, and there is an intense awareness of the importance of public surveillance measures.

Medical genetics has been in existence since the end of the 1960s, under the coordination committee on medical genetics of the USSR Department of Health. The Institute of Medical Genetics, under the control of the USSR Academy of Sciences, was the scientific leader and coordinator. Following independence in 1991, medical genetics services came under the joint umbrella of the Ministry of Health of the Ukraine, the Research Institute of Hereditary Pathologies (Lvov), and the Ukrainian Scientific Centre of Medical Genetics (Kiev). Today, the Ukraine has seven interregional medical centres (Donetsk, Kharkov, Kiev, Krivoi Rog, Lvov, Odessa, Simferopol), and a smaller network of 19 regional and 57 district medical institutions of medical genetics. District institutions provide primary counselling and make referrals, and are also responsible for submission of data to the national registries. The regional institutions provide counselling and some laboratory investigations, carry out prenatal ultrasound screening, and organise referrals to the interregional medical genetics centres. Each of the interregional medical genetics centres provides genetic counselling and a wide spectrum of laboratory services, including prenatal diagnosis; they also conduct mass neonatal screening programmes and supervise regional registers. In 1997, these seven IMGCs had 346 clinicians, of whom 272 were genetically trained (together with 74 trainees), 133 laboratory geneticists, and 286 nurses. Coordination is relatively good and other specialties refer patients to the interregional medical genetics centres for specialist genetic assessment. Funding varies between regions, and although the level of services offered by the interregional medical genetics centres is broadly equal, there are some variations; for instance, funding difficulties have held back maternal serum screening in some areas. Lack of funding has impeded both routine clinical testing and the introduction of new developments, largely because of the high cost of chemicals, consumables, and equipment, and because it inhibits international contacts and collaborations.

Laboratory diagnostic services are available in all the interregional medical genetics centres, and some of the regional institutions. Some carry out specialist analyses; for example, the Laboratory of Molecular Genetic Diagnostics (Institute of Molecular Biology and Genetics, Kiev) carries out molecular diagnostic tests for cystic fibrosis, neuromuscular disorders, haemophilia, and phenylketonuria, but this is mostly on a research basis.

CANCER GENETICS SERVICES

After Chernobyl, an increase in paediatric cancers and adult leukaemia has been reported. There are obligatory annual preventative specialist examinations, which are intended to identify early cancers and persons at high risk.

Training

All seven regions of Ukraine offer some training in genetics for medical students. The Medical Institute of Lugansk has established a Department of Clinical Genetics and Clinical Immunology to teach genetics to medical students. Each of the regions also offers

lectures and practical sessions in medical genetics as part of the specialty training programmes for gynaecology and obstetrics, paediatrics, neurology, and neopathology. The interregional medical genetics centres also provide some medical genetics training for general practitioners and clinicians working in general purpose clinics, in the form of seminars, conferences, and lectures.

Medical genetics became a recognised medical specialty in 1993. Before this, it had been provided by specialists from other disciplines (for example, paediatrics, gynaecology, obstetrics, neurology) who had developed a particular interest in genetics. Currently, two departments of medical genetics, at the Institutes of Advanced Studies in Kiev and Kharkov, provide training in medical genetics, and only clinicians who have followed these courses are permitted to practice in the interregional medical genetics centres.

Laboratory geneticists working in the interregional medical genetics centres must have completed advanced training in the appropriate department (cytogenetics or biochemistry) in Kiev or Kharkov.

TRAINING OF CANCER GENETICISTS

No information.

Audit and evaluation

Medical genetics services are regulated by the Ukrainian Ministry of Health. Quality control (both clinical and laboratory genetics) is provided by the Coordination Council on Medical Genetics.

Discussion fora

The Ukrainian Ministry of Health regularly sponsors local and national conferences on medical genetics and related specialties, for purposes of continuing medical education. There is an active research community, producing regular publications (for example, cytology and genetics), and regular collaboration with other disciplines and scientists working in related fields. Academic institutes, such as the Institute of Molecular Biology and Genetics, the Institute of Biochemistry, the Institute of Human Physiology, and other centres, with modern equipment which is not available to the interregional medical genetics centres, act as the base for medical research.

There is a Society of Medical Geneticists, based in Lvov, which acts as an umbrella for specialists in both general health care and scientific institutions, to promote discussion and development.

SPECIFIC CANCER DISCUSSION GROUPS

No information.

Education

As a result of the Chernobyl disaster in 1986, there is widespread public awareness of genetic disease. However, the population is generally ill informed about genetics, mainly because of social problems. There is intensive educational activity on the part of the medical genetics institutions, in an attempt to combat this ignorance.

Registers

There is a State Registry of Congenital and Hereditary Pathology, supported by the network of medical genetics institutions. All births of malformed infants are reported to the registry and all data submitted are examined by the interregional medical genetics centres, who will assess risks, inform about diagnostic possibilities, and offer counselling where relevant. Following the Chernobyl disaster in 1986, inherited tumour syndromes are registered by the interregional medical genetics centres and used to identify high genetic risk groups. There is a Prenatal Cytogenetic Registry for disorders detected prenatally. The Ukrainian Scientific Centre of Medical Genetics, based in the Research Institute of Hereditary Pathologies (Lvov), supervises the national registries.

Support

The Supreme Council of Ukraine has funded a state governmental programme, "Children of the Ukraine", which exists to expand medical genetic help to children through positive funding and increased support of medical genetics services.

CANCER CHARITIES

The Chernobyl Society is particularly concerned with improvements in medical, and especially medical genetics, assistance for the victims and their children.

PATIENT SUPPORT GROUPS

A number of these have been formed by the parents of children with phenylketonuria, cystic fibrosis, and other disorders: they cooperate actively with the interregional medical genetics centres.

45 Arbuzova S. Genetic services in the Ukraine. *Eur J Hum Genet* 1997;**5**(suppl 2):183-7.

Persons responding

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UK

Genetic services

These have been well reviewed by Raeburn *et al*,[46] as part of the Concerted Action on Genetics Services in Europe.[47] The National Health Service is the principal provider of free health care services, through general practitioners offering primary care to a network of district and regional or university teaching hospitals. Medical genetics has a long history in the UK, although it was not recognised formally until the 1970s. Initially most genetic clinics were developed by paediatricians, and, later, by neurologists, before the appearance of clinicians with a specialist training in medical genetics. Genetic services have evolved over the past 20 years, not least as the result of two major reorganisations of

the National Health Service. Regional genetics centres, providing an integrated clinical and laboratory service, have been established for many years, and there are varying degrees of cooperation and collaboration both between centres and between centres and health care purchasers or consumers in the regions they serve. Most regional genetics centres also operate "outreach" clinics at satellite hospitals, or dedicated clinics (for example, for neurogenetic or ophthalmological disorders, or for inherited cancers) in collaboration with the appropriate specialists. Currently, there are 25 regional genetics centres, each serving a population of 3-6 million; in 1997 they had 79 specialist clinicians (with 55 trainees) and 107 genetic nurses (also known as nurse counsellors).

In the UK, genetic counselling is offered by consultant clinical geneticists (with specialist training), supported by specialist registrars in clinical genetics (training posts) and genetic nurses or counsellors. The involvement of such genetic counsellors varies greatly from country to country; since the 1970s the UK has had several attached to each regional genetics centre. Their roles include interviewing probands, constructing pedigrees, confirming diagnoses, and stratifying risk estimates. They maintain screening protocols, organise clinics, liaise with other health professionals, and may undertake home visits to maintain links with patients. In many centres, they provide full genetic counselling for many conditions, with the support of a discussion departmental framework. They may also obtain samples for research studies and coordinate such research. They are involved in the provision of educational material for patients and health professionals, and may help in the development of patient support groups. Genetic counsellors are valuable members of the clinical genetics team, who play a considerable role in the provision of counselling services, thereby reducing the workload of consultants and registrars, who can then target particular aspects of the service.

There is a degree of underfunding, for a variety of reasons, including changes in the funding of health care services, and reorganisation of the basis upon which this is calculated. Current staffing levels generally fall short (sometimes by as much as 60%) of the recommended levels[48] for clinical provision, but the level of staffing is now being increased. Laboratory staffing levels are somewhat better, at 70% of the recommended level, but the ever increasing cost of modern diagnostic techniques, their provision for a growing number of conditions, and the consequent upsurge in demand, are additional problems. This shortfall in genetic expertise will increase if expansion in the fields of cancer genetics and dysmorphology, to name but two growth areas, continues at its present rate.

Laboratory diagnostic services are integral parts of the regional genetics centres and form national collaborative networks through their professional bodies, which are also responsible for training and quality control. In 1997, there were 408 cytogeneticists (with 106 trainees) and 101 molecular geneticists (with 31 trainees) providing a laboratory diagnostic service to these regional genetics centres, and a well developed network of biochemistry laboratories providing a biochemical genetics diagnostic service. There is now a clear process of laboratory accreditation. The UK network of molecular genetics centres has rationalised testing for mutations in specific genes in certain centres only, by agreement. Thus, 17 centres currently test for breast/ovarian cancer (*BRCA1*/*BRCA2*), 13 for familial adenomatous polyposis, nine for multiple endocrine neoplasia type 2, five for hereditary non-polyposis colon cancer, five for von Hippel-Lindau syndrome, four for multiple endocrine neoplasia type 1, three for neurofibromatosis type 1, three for retinoblastoma, two for Beckwith-Wiedemann syndrome, two for neurofibromatosis type 2, two for Cowden disease, and one each for Gorlin syndrome, tuberous sclerosis types 1 and 2, hereditary pancreatitis, Denys-Drash syndrome, juvenile polyposis, *p53* mutations, and Peutz-Jeghers syndrome. However, the patenting of genes such as *BRCA1* and *BRCA2* is likely to have a profound impact on the costs and management of cancer genetics services, and could result in "rationing" of tests to very high risk families only.

CANCER GENETICS SERVICES

With increasing awareness of, and publicity about, cancer genetics, such referrals have increased greatly over the last 10 years, such that they now comprise approximately half of the genetics referrals in many centres. The impact of developments in the field of cancer genetics is a matter of importance to health service planners, and the Department of Health, which commissioned the recent review of cancer genetics services from a working group under Prof Peter Harper in 1996.[49] The report of this group has stimulated negotiations to increase funding for cancer genetics services. A similar report was published in 1998 by the Scottish Office (Department of Health), covering cancer genetics services in Scotland. Both reports recommend the establishment of regional cancer genetics centres, offering services on the basis of agreed risk criteria (judged by family history). Subsequently, a Scottish Office Advisory Group on Cancer Genetics (chaired by Prof N Haites) has been set up to review developments, including audit of the existing services. A similar review of genetics and cancer services in Northern Ireland is pending. The Department of Health has announced that it will spend £2.5 million to investigate whether to set up a national screening programme for bowel cancer. This will fund two pilot studies (one each in England and Scotland), over a period of three years, during which time screening by faecal occult blood testing will be offered every two years to persons aged from 50 to 69 years, the ages between which the disease is most likely to occur.

Northern Ireland, together with the Irish Republic, has recently become a party to the All-Ireland Cancer Agreement, in collaboration with the American National Institutes of

Health. This aims to enhance and coordinate cancer registries throughout Ireland, to improve support for clinical trials, and to promote educational exchange programmes.

Currently, most specialised genetic counselling for familial cancer is organised by the regional genetic centres. Most run designated cancer family clinics or operate multidisciplinary clinics in conjunction with other specialties. Initially, many of these were developed on an ad hoc basis, funded from research sources, but NHS funding is now replacing this. The Imperial Cancer Research Fund provides some support, including genetic counsellor salaries, to the cancer family clinics at St Mark's and Guy's Hospitals in London, and in Leeds, Liverpool, Cardiff, Oxford, Newcastle, and Edinburgh. Increasingly, NHS funded consultant posts in cancer genetics are being created, notably in Southampton, Bristol, Leeds, Cardiff, Birmingham, and Manchester, and at Guy's Hospital and Northwick Park Hospital in London. The service is becoming more integrated and cohesive with the benefit of discussion fora, such as the Cancer Family Study Group, and management guidelines are being developed. In addition, it is increasingly being recognised that general practitioners and specialists in other disciplines have an important role to play in the initial recognition of patients and families in need of referral for specialist genetic counselling. It is intended that specialised cancer care be centralised to the specialist units dealing with the care of breast/colorectal cancer, etc, catering for some 150-250 000 people, according to guidelines laid out in the Calman-Hine Report (1995).[50] People at moderately increased risk will be managed in this way, and only high risk subjects in whose families it is probable that a genetic predisposition is segregating will be seen in the regional genetics centres themselves (serving a population of 3-6 million). Genetic counsellors will play an important role in evaluating risks for prioritising referrals and coordinating screening. They are also likely to provide a "gatekeeper" role in primary care. Audited follow up is crucial for evidence based review, facilitated by a fully documented confidential database recording pedigree data and surveillance outcomes. This requires dedicated data managers and preferably a coordinated surveillance network. Specialised genetic counsellors might also fill this role.

It has been suggested that specialist cancer nurses (for example, breast cancer nurses) with training in some aspects of genetics might undertake the annual follow up of high risk women from the breast cancer genetics clinics, carry out clinical examinations, and enquire about further developments in family history, but this is still the subject of discussion.

Genetic counsellors thus have an important role to play in delivering the cancer genetics service and maintaining computerised databases. The Cancer Family Study Group and the ICRF Cancer Genetic Nurse Support Group and the Macmillan Nurse network help support the activities of these professionals and maintain uniformity of standards.

Northern Ireland has one cancer genetics clinic (not multidisciplinary), with a part time consultant and genetic counsellor, and no genetic associate (funded jointly by charity/research sources and ad hoc NHS funding, pending the outcome of the Department of Health review). However, it is anticipated that the recent All-Ireland Cancer Agreement will significantly enhance cancer services in Northern Ireland. As part of this, the American NCI's clinical trials information system, which will become available to all academic institutions in 2001, is to be piloted in Belfast.

Training

Undergraduate genetics teaching forms part of the clinical curriculum, within the GMC problem based curriculum, in all UK university medical schools.

Following graduation, those wishing to specialise in clinical genetics can undertake a training programme which is supervised by the Clinical Genetics Specialist Advisory Committee (jointly formed by a group of the Royal Colleges, the bodies overseeing postgraduate training and professional standards in various different disciplines). The CGSAC inspects centres offering training programmes and the teaching content of their courses. On behalf of the Joint Committee on Higher Medical Education, it controls enrolment on training courses and accreditation. Since 1997, it has offered a Certificate of Completion of Specialist Training. Training is structured over a seven year period, in conformity with practice in other European countries, and is intended to lead to inclusion on a specialist register.

It is clearly recognised that improving the genetic knowledge of general practitioners and specialists in other disciplines is an essential part of a cancer genetics service. Computer packages for primary care, to help evaluate pedigree data and prioritise referrals based on cancer risk estimates, are being developed and evaluated in a research context. The Genetic Interest Group runs a human genetic awareness programme for primary health care workers, and the Royal College of General Practitioners is currently debating ways of improving education for primary care practitioners, and various other organisations are involved in educational initiatives (for instance, the Genetic Interest Group runs a Human Genetics Awareness Programme for primary health care workers). The Public Health Genetics Network also plays a part in genetic education.

Genetic counsellors, until recently, have usually been nurses, midwives, or health visitors (occasionally social workers) who have received specialist training in genetics (often in house). However, increasing numbers of graduates without a nursing background, but who have pursued a course in genetic counselling, are coming into the profession. MSc courses in Genetic counselling for such subjects are available at the Universities of Manchester and Cardiff, and at Northwick Park Hospital, London. There is a cancer genetics module in the Queen Margaret College (Edinburgh) Specialist Practitioner

Qualification BSc course for nurses. Short, two week courses in cancer genetics are being developed for nurses (for example, for ENB approval in London and Manchester), and cancer genetics is available as a module in the Royal Marsden Hospital's postgraduate courses on cancer and palliative care. A working party of their professional body, the Genetic Nurses and Social Workers' Association, is currently developing a competency based training and accreditation programme for non-medical genetic counsellors. There is a question of training specialist cancer nurses in some aspects of genetics (for example, annual follow up of high risk women from the breast cancer clinics), but this is still the subject of discussion.

The training of laboratory geneticists (cytogenetics, molecular geneticists, biochemical geneticists) is overseen by their respective professional bodies.

TRAINING OF CANCER GENETICISTS

Standard UK guidelines.

Accreditation in clinical genetics or oncology.

Accreditation of oncologists (and specialists from related disciplines) and clinical geneticists in cancer genetics are currently being considered by the Royal Colleges, and the appropriate training for specialist registrars in oncology and genetics wishing to be accredited in cancer genetics is under consideration by the relevant specialist advisory committees.

The Harper report emphasised the need to build up expertise at the level of the Calman Centres, which will provide specialised cancer care, under the direction of the regional genetics centre.

Some UK centres now offer modules in cancer genetics, as part of their genetics or nursing curricula.

The training of laboratory geneticists (cytogenetics, molecular geneticists, biochemical geneticists) is overseen by their respective professional bodies.

There are a number of pilot training programmes for disease specialist nurses (colorectal, breast) to undertake initial risk assessment and refer appropriately to the regional genetics centre, while reassuring those who are at less than moderate risk.

The All-Ireland Cancer Agreement aims to augment scholastic exchange programmes in the field of oncology and cancer research.

Audit and evaluation

There are a large number of advisory and statutory bodies which address issues such as human fertilisation and embryology regulation, genetic testing, and scientific advances in genetics. The House of Commons Science and Technology Committee has reviewed genetic issues, and when the government failed to make an adequate response to their 1995 report, they applied pressure (with the backing of many professional and public recommendations) which resulted in the establishment of the Human Genetics Advisory Commission, the Gene Therapy Advisory Committee, and the Nuffield Bioethics Forum.

All regional genetics centres must undergo regular audit of their services, judged against preset quality standards. The Department of Health is funding ongoing enquiries into the management of disorders such as Down syndrome, thalassaemia, or neural tube defects, to name but three, in an attempt to formulate national standards, in collaboration with the Genetic Enquiry Centre (Manchester) and the Royal College of Physicians of London. The Royal College of Physicians also has a Clinical Genetics Committee, which reports on genetic service provision. All regional genetics centres are required to hold monthly audit meetings to maintain existing quality standards. A new checking system of clinical governance is also being initiated. In Scotland, the Scottish Office Advisory Group on Cancer Genetics is tasked with audit of the existing cancer genetics services.

Specialist training is overseen by the Clinical Genetics Specialist Advisory Committee.

Genetic testing is overseen by the Department of Health Advisory Committee on Genetic Testing. The appropriate professional bodies operate quality assessment schemes in cytogenetics, molecular, and biochemical genetics. Lastly, all specialist diagnostic laboratories are encouraged to join in the official accreditation scheme.

The Cancer Family Study Group and the ICRF Cancer Genetic Nurse Support Group are charged with maintaining uniformity of standards for genetic nurses involved in cancer genetics services.

In 1997, a new organisation, the Public Health Genetics Unit (PHGU), was set up within the Anglia and Oxford office of the NHS Regional Executive. The prime focus of the PHGU is the NHS itself. Its aims are: to keep abreast of developments in molecular and clinical genetics, and their ethical, legal, social, and public health implications; to provide a link between academic research, clinical practice, and the development of policy within the NHS for genetics and genetic services, including the implications for funding, development, staffing, organisation, and provision of these services; to establish mechanisms for dialogue within the NHS between geneticists, physicians, public health and primary care professionals on matters related to genetics, molecular medicine, and genetic services; and to provide an epidemiological and public health perspective on NHS policy development for genetic and related services, including criteria for evaluating genetic testing and screening programmes.

Discussion fora

The British Society of Human Genetics (formed in 1996) is made up of the Clinical Genetics Society, the Association of Clinical Cytogenetics, the Clinical Molecular Genetics Society, and the Genetic Nurses and Social Workers Association. There are a number of meetings of the various organisations annually,

and the BSHG holds an "umbrella" meeting in York every autumn.

There are a large number of discussion groups with various special interests (for example, the London Dysmorphology Group).

The Public Health Genetics Network of the PHGU exists to establish mechanisms for dialogue within the NHS between geneticists, physicians, public health and primary care professionals on matters related to genetics, molecular medicine, and genetics services.

SPECIFIC CANCER DISCUSSION GROUPS

Cancer Family Study Group.

National Cancer Forum.

ICRF Cancer Genetic Nurse Support Group.

Northern Ireland Regional Advisory Committee on Cancer.

The All-Ireland Cancer Agreement aims to improve communication in this field between north and south and internationally.

Education

Genetics enjoys a particularly high profile in the UK, with a high level of public interest acting as a driving force for better development of future genetic services. There is considerable debate about genetic issues and developments in the media, and there are a large number of independent bodies, such as the Nuffield Council on Bioethics and the King's Fund, which participate in the evolution of genetic service philosophies.

The Public Health Genetics Unit (PHGU) established the Public Health Genetics Network, with the aim of disseminating knowledge and understanding of genetics, and debating and discussing the implications for the NHS, via twice yearly meetings. It sets up working groups to investigate specific topics more closely. In order to encourage communication on a continuing basis, a website has been set up (http://www.medinfo.cam.ac.uk/phgu). In addition to a publicly accessible area containing news and information about developments in genetics from a public health perspective, the site has a password access section where members of the PHGN can post documents, exchange information about current activities and plans, and participate in discussion on topics of interest.

Museums in the UK are now producing exhibitions about genetics in relation to medicine, and cancer genetics receives a high profile. The recent "Genetic Choices" exhibition at the Science Museum, funded by the Wellcome Trust, had a significant emphasis on cancer genetics, and a new and much larger exhibition, funded with Lottery money, is planned at the Science Museum for the year 2000. Dr M Super has developed a "Gene Shop" at Manchester Airport, providing information about genetics direct to the public, and Prof J Burn has obtained funding for a "Gene Dome" in Newcastle upon Tyne; this will be a museum of genetics for the general public, and will include a good deal of information about cancer genetics.

The Wellcome Centre for Medical Science is developing a "Theatre in Education" programme, including a piece entitled "Dramatic Genetics - Creating the Debate", for lay audiences. This was shown at fringe theatres, and a video of the production was used for teaching purposes. Another educational performance by a fringe theatre, on a genetic topic, is also available on video.

The Scottish Breast Cancer Family Clinics have also produced a number of videos.[51]

All centres send letters summarising consultations, and giving information about results, diagnostic possibilities, etc. There are a large number of self help and patient support groups providing similar information in the form of leaflets, journal articles, and via websites (for example, the Cancer Research Campaign (CRC) has a web site at www.crc.org.uk). There are several other websites, including:

"What is genetic screening?" (http://www/scicomm.org.uk/biosis/human/whatis/html).

"Understanding gene testing" (European Initiative for Biotechnology Education - resources for teaching aimed at 16-19 year old students) (http://134.225.167.114:8001/EIBE/ preview/html).

Advisory Committee on Genetic Testing - Draft Code of Practice (BIOSIS)

(http://www.scicomm.org.uk/biosis/acgt/ACGT2.html).

An internet based newsletter, "the Gene Letter", aims to educate consumers and professionals about advances in genetics, and to encourage discussions about emerging medical, ethical, legal, and policy dilemmas in this area. This was established by the Schriver Center, with a grant from the US Department of Energy/ELSI programme, and further details can be accessed via www.geneletter.org

In Northern Ireland information leaflets are currently only available for FAP/HNPCC, not breast cancer. Many educational videos have also been produced.

Registers

The Edinburgh RAPID register (Register for the Ascertainment and Prevention of Inherited Disease).

The Dysmorphology Database.

There are a number of local, regional, and national registers for particular disorders, for example, the National Down Syndrome Register.

CANCER REGISTRIES

Many regional genetics centres have registries for specific genetic conditions, including some monogenic cancer predisposing conditions, such as Gorlin syndrome, von Hippel-Lindau disease, Cowden disease, neurofibromatosis types 1 and 2, *BRCA1*, *BRCA2*, and HNPCC mutation positive families. Some also have registries for families with a cancer family history.

Thames Cancer Registry.

St Mark's Hospital, London, has a polyposis register.

Northern Ireland has registers for HNPCC, MEN 2A, MEN 2B, FMTC, NF 1/2, von Hippel-Lindau disease, Cowden syndrome, and FAP. One of the principal aims of the recently instituted All-Ireland Cancer Agree-

ment is to enhance and coordinate cancer registries, in collaboration with the American National Institutes of Health.

A Scottish Breast Cancer Genetics Database, funded by the Scottish Office Chief Scientist's Office and the Melville Trust, is already functioning but still under development. This is not exactly a register, but will also permit interrogation for epidemiological research, audit of clinical outcomes, etc.

Support

CANCER CHARITIES

Action Cancer.
Cancer Research BACUP.
Cancer Research Campaign.
Imperial Cancer Research Fund.
Ulster Cancer Foundation.

PATIENT SUPPORT GROUPS

There are over 150 self-help organisations. There are no known patient support groups for cancer genetics in Northern Ireland.

GIG (Genetic Interest Group) is an umbrella organisation representing more than 100 genetic charities, which acts as a pressure group, lobbying for the provision of adequate resources for affected families, and for service providers.

46 Raeburn S, Kent A, Gillott J. Genetic services in the United Kingdom. *Eur J Hum Genet* 1997;**5**(suppl 2):188-95.
47 Harris R, ed. Genetic services in Europe: a comparative study of 31 countries by the Concerted Action on Genetic Services in Europe. *Eur J Hum Genet* 1997;**5**(suppl 2):1-220.
48 Harper PS, Hughes HE, Raeburn JA. Clinical genetics services into the 21st century (summary of a report of the Clinical Genetics Committee of the Royal College of Physicians). *J R. Coll Phys Lond* 1996;**30**:296-301.
49 Department of Health. Genetics and cancer services. Report of a Working Group for the Chief Medical Officer, Department of Health (Harper report), 1966.
50 Department of Health and Welsh Office. A policy framework for commissioning cancer services. A report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales (Calman-Hine report)], 1995.
51 Cull A, Miller H, Porterfield T, Mackay J, Anderson EDC, Steel CM, Elton RA. The use of videotaped information in cancer genetic counselling: a randomized evaluation study. *Br J Cancer* 1998;77:830-7.

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