

reviews

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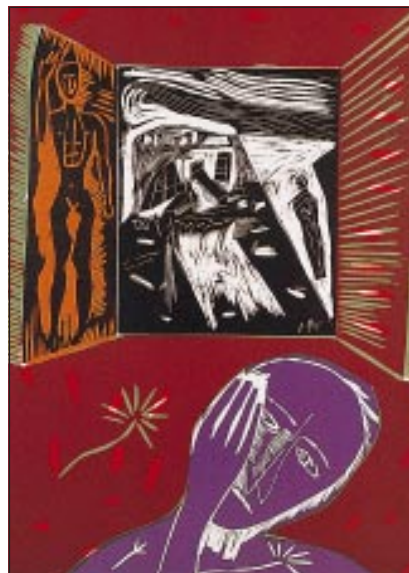
ART

Artists for Médecins du Monde

Hart Gallery, London, 25 May to 1 June.
Moving to Munich and Milan

Médecins du Monde provides health care to the victims of war, natural disasters, or political repression, treating both physical wounds and psychological trauma. International volunteers, including about 700 medical staff, carry out relief programmes all over the world. They are also involved in domestic projects, providing health care for socially disadvantaged people in France. As an independent organisation funded largely through charitable donations, Médecins du Monde is able to help “forgotten populations” who have often been overlooked by the media and “official” sources of humanitarian aid.

Relief programmes include emergency projects to bring immediate aid, rehabilitation projects to help restore sanitary conditions, and long term projects to mitigate the effects of poverty. The organisation is active in 52 different countries, often war torn areas such as Nigeria, East Timor, and Latin America. A map showing their



© Mimmo Paladino, *Sans titre*



© Tom Wesselman, *Monica in robe with motherwell*

current projects is available at <http://www.nirvanet.net/warvictims/>, and further details are available in French. Since the outbreak of hostilities in former Yugoslavia the organisation has been particularly active in the Balkans.

In 1994, 23 well known artists from around the world each produced an original limited edition print for Médecins du Monde. The aim was to raise funds from sales of the prints and to highlight the plight of people in Sarajevo. The collection was first presented in Paris in 1994, since when it has travelled around the world to cities as far apart as Vancouver and Tokyo. Last week it was shown at the Hart Gallery in London, and it will be moving on to Munich and Milan.

The collection is a fascinating range of work from a diverse group of artists united by a readiness to help a good cause. The pieces are artistic interpretations of the conflict in Sarajevo or classic examples of the artist's work. Mimmo Paladino and Antoni Tàpies have submitted brooding portraits of a stricken city. More upbeat pieces are recognisable as work by Roy Lichtenstein, the father of pop art, and Tom Wesselman has submitted a picture of Monica, his favourite model, in his typical style.

Each print is one of a limited edition. Prints are produced by silk screen printing or lithography, in which a design is etched on to a zinc or stone plate, which is then inked to create a print. After 50 prints the lithograph is destroyed to prevent further copies being made. Prints cost £200-5000,

with a full set available for £19 500. Over 40 sets have been sold so far, and all the money raised goes towards Médecins du Monde's current projects in Kosovo.

Judging by reports from their doctors, the altruism of the artists who have helped raise funds is matched by the dedication of Médecins du Monde's medical personnel. Reports of conditions in makeshift field hospitals, often on the frontlines of battlezones, put working conditions in the West, into perspective. Dr Pierre Pradier, honorary president of Médecins du Monde speaks of working “with our hands covered in blood, our feet deep in mud, and fear in our guts, under threat from assassins on all sides.”

The organisation has been working in Kosovo since July 1998. Since the start of the air strikes by NATO it has been conducting emergency projects to help refugees in Macedonia, Albania, and Montenegro. Medical staff based in emergency healthcare centres provide immediate help for refugees crossing the border. The organisation also supports local facilities, supplying drugs and surgical equipment and providing water and shelter.

The principles of Médecins du Monde are “to help, to care, and to bear witness,” and the organisation collects testimonies from victims of human rights abuses. It regards this aspect of its work as crucial in stimulating political action and preventing humanitarian aid from becoming a substitute for political solutions.

Richard Harling, *BMJ*

Inherited Susceptibility to Cancer: Clinical, Predictive and Ethical Perspectives

Ed William D Foulkes, Shirley V Hodgson



Cambridge University Press, £60, pp 471
ISBN 0 521 56340 2

Rating: ★★★

As its title suggests, this book comprehensively marries the clinical, predictive, and ethical issues that arise from identifying genes that indicate increased risk of cancer. It also effectively

Reviews are rated on a 4 star scale (4=excellent)

and in an accessible manner conveys the criteria for genetics testing and what is known of the biology underlying most known inherited cancers. The book is timely in its scope. As knowledge about inherited susceptibility to cancer increases and additional susceptibility genes are identified, there seems to be a greater need for multidisciplinary teams to care for the medical and psychological needs of families with hereditary cancer syndromes.

The growing access to genetic information has left society at large in a state of anxiety over its consequences. As Knoppers and Godard and Nelkin point out, if genetic susceptibility tests become freely available they may have repercussions in many spheres of our lives. On the one hand, public demands and expectations for treatment and cure of disease are increased, but, on the other, information about individuals' inherited susceptibility to cancer could severely limit their access to health care, life insurance, etc.

Although genetic tests are available for some inherited cancers, our increased understanding of genetic disease does not necessarily lead to benefits beyond the ability to predict. The next hurdle is translation of biological understanding of the disease

to its treatment. As the chapter on "late-breaking developments" shows, we are far from effective treatment for these cancers. It is to be hoped that formation of counselling programmes for familial cancer will not only offer a suitable context for testing susceptibility but could also serve as a framework for technological advances to follow in every aspect of cancer care—surveillance, diagnosis, treatment, and follow up.

Although this book deals with highly penetrant inherited cancers, it is likely that most cases of cancer occur because an individual has been exposed to certain carcinogenic and environmental agents and that inherited factors have rendered them more susceptible to the effects of these agents. Genes conferring a small increased susceptibility to cancer will be much more difficult to identify, and counselling of people found to have such a susceptibility will be difficult. Nevertheless, the book makes a good attempt at marrying different disciplines in a good overview of genetic testing for inherited cancers.

Feyruz Rassool, lecturer in haematological medicine, King's College Hospital, London

A book that changed me

Our NHS: A celebration of 50 years

Ed Gordon Macpherson

BMJ Books, £25, pp 227
ISBN 0 7279 1279 8
Reviewed *BMJ* 25 July 1998

For me, this book turned a vague intuition into a focus for action in the future: rarely before can the gulf in the NHS between "top down" aspirations and local experience have been charted with such directness and honesty.

There is a deep contrast in this volume, with its 30 contributions, between the repeated powerful endorsement of the NHS as a national institution and the troubling personal experience of some contributors. The NHS appears as an organisation that has been kept in place by negatives—the blind, even pathetic, loyalty of patients and the desire of politicians to avoid trouble about funding. Much of the personal experience has been highly disquieting, and the BMA itself appears as a body that has been far more adept at manipulating these political forces than at leading towards professional models to meet this disquiet.

The book will outlast much else from the 50th anniversary by the sheer immediacy of many of its papers from key NHS contributors, helped by excellent editing so that the papers are short and graphic. Among the "local"

contributors, Gilmour's tribute to his uncle's work at St Charles' Hospital for the London County Council and at Lewisham Hospital Group stands out. The "great camaraderie" of the London County Council hospitals was lost, but John Howard Simmons used the NHS as an opportunity in "forging the Lewisham Hospital Group into a committed and well organised service to its large catchment area."

Rosemary Rue also gives a fascinating memoir, although for her the tale of public health under the NHS is mainly one of dissipation of an inheritance. "By the time I became a medical student as the war ended, there was widespread general knowledge of preventive health and a good deal of confidence in the country's ability to maintain and deliver health services, including those of public health."

Melanie Phillips writes of the lost dream and finds she has been writing the same story about the NHS for almost a quarter of a century: from waiting lists out of control in Hemel Hempstead in 1974 to a chronic shortage of community care in London in 1994. Particularly poignant are the experiences of James Stoddart as a student fighting off "depersonalising jargon" as he clerked a long waiting, grateful patient in the "sun lounge" (or corridor); of Peter Plumley as a fed up surgeon fighting managers in Hastings; and of Abdul Jaleel seeing the behaviour of his colleagues when he was seeking a consultant appointment.

I was not surprised to find that most of the positive tributes to local initiatives

came from general practice. David Williams, his father, and partner (father, son, and holy spirit) were able to transform their practice in Flintshire. Irvine and Godber report how a successful mix was achieved between national aspiration and local innovation with the family doctor charter—but only just in time. There are also positive accounts by Weatherall and Wade of the role of the NHS in medical research. Britain lost an early world lead in medical trials that had led the young Food and Drug Administration to speak of it with "awe and envy."

For the future, Macara sees the NHS as likely to survive in some guise to the "last syllable of recorded time." Ham and Robinson call for reappraisal, with more use of private finance and a more responsible and managed approach to evaluation. There is little good said about the 1989 reforms, but time may well change this verdict, and some testimony from a successful fundholder (and there were plenty of them) would have been useful. For me, this book has been a source of a New Year resolution to contribute constructively to the debate on the longer term future of the NHS. I don't want to see another generation go through the same mill. There must be a better way.

Nick Bosanquet, professor of health policy, Imperial College, London

We welcome contributions for "A book that changed me" of up to 400 words.



Skin cancer: in your face

In 1999 in the United States there will be over a million new cases of skin cancer, and, whereas the incidence for all other cancers in the United States has stabilised or declined, the incidence of melanoma continues to rise, especially for white men. Since 1985 the American Academy of Dermatology, a non-profit organisation with 12 000 physician members, has run a skin cancer control programme aimed at promoting awareness of melanoma and persuading people to practise sun protection. This year the association has worked with Campbell Mithun Esty, an advertising agency, to develop a particularly striking message about preventing skin cancer.

The new advertisement, being shown on television, uses a case history of a man with deforming skin cancer to emphasise the importance of sun protection. It adopts what has come to be known as the "tombstone approach," which is characterised by a generalised threat of death or destruction from a particular type of behaviour. This approach has been used in smoking campaigns in the past decade, though with only varying levels of success because people have defensively avoided the message, selectively perceived the message in ways that reduced the threat, or discounted the message source.

In recent years, however, case histories have persuaded viewers to change attitudes. The testimonies of real people with real stories have had a strong impact because they put a face on seemingly remote dangers and show the worst that can happen. In Massachusetts, for example, a decline in smoking among middle school students has been linked to documentary style commercials, the most dramatic of which centres on a woman dying of emphysema (*BMJ* 2 January 1999, p 66). In a recent study of antitobacco advertisements by the firm Teenage Research Unlimited the three adverts that tested best with teenagers featured patients, including the California advert with a woman smoking through a hole in her neck.

The American Academy of Dermatology has built on these recent experiences in motivating teenagers to design a public service announcement that threatens teenagers with something they might consider even worse than dying—the possibility of living with skin cancer and its highly destructive results. The 1999 programme, "Skin Cancer Can Kill You. And now the Really Bad News," features the example of Don Biederman, an entertainment attorney who had squamous cell carcinoma of the nose treated with more than 30 operations. In 1996 he had a resection of the nose and left cheek that resulted in his wearing a prosthesis. This brave man was willing to narrate the announcement about his experience with childhood sunburns of the nose, which led to his skin cancer, in the hope that he could prevent others from having a similar experience.

The advertisement uses clips from home movies shot in Super 8 film showing Biederman as a toddler playing on the beach and



CAMPBELL MITHUN ESTY, MINNEAPOLIS

Don Biederman and his facial prosthesis

his now dead father reclining shirtless on a lounge chair. The family scenes at the beach are juxtaposed with close-ups of Biederman as he narrates his transformation from sun worshipper to cancer patient. To emphasise that skin cancer is not a minor annoyance, he is shown in profile view removing his prosthesis. The concept was tested in focus groups, who did not find it "repulsive" but rather were moved by this man's experience and were motivated to take sun protection precautions with their children.

In April 1999 the academy released the advertisement to television networks and 925 local stations. The ABC network rejected the segment as too graphic to broadcast nationally; an official at ABC described it as the "rip your face off" advert. The opinions of station managers ranged from "powerful and provocative" to "so graphic that people will switch to a different station." The stance of some television station managers was criticised by radio commentators because, while they refused to show the advert, they were, at the same time, broadcasting gruesome news footage of the high school shooting in Littleton, Colorado, and of massacres in Kosovo. Interestingly, by refusing to air the advertisement, ABC created a controversy that was discussed in prime time and may have increased public awareness of the dangers of unprotected sun exposure more than if they had taken the video and simply left it on the shelf or relegated it to time slots late at night, when it would not compete with paid advertising.

Other countries have had forthright approaches in their media messages regarding skin cancer. Australian television has shown surgical removal of skin cancer and an in depth portrayal of a person dying of melanoma, who advised people to protect themselves from the sun. While some viewers in the United States may not yet be ready to see such frank presentation of the morbidity of skin cancer, we only regret that some of the public was denied the opportunity to see a sensitive treatment of the story of a brave man who wanted to prevent others from getting skin cancer.

June K Robinson, professor of medicine and pathology, Loyola University, Chicago, and **Darrell S Rigel**, clinical professor of dermatology, New York University, USA



WEBSITE OF THE WEEK

www.nuffield.org/bioethics/index.html As you wander through the infrastructure of medicine, you cannot help but notice that Nuffield pops up a lot. This week it is the Nuffield Council for Bioethics, which has produced a report that is broadly in favour of continuing development of genetically modified crops (p 1506). Thanks to the wonders of Google (www.google.com) it is the work of moments to discover the site, the full text of the report, and all about Lord Nuffield (the usual: left school at 15, worked hard, became rich, was frugal, became a philanthropist, died). There's even a nice picture.

The Nuffield Foundation is still seriously rich—and its website is extremely well put together. The foundation is admirably transparent about its workings: investments of £220m generate an income of £8m a year, which is then used to fund projects that advance education or social welfare. One such project is to fund, jointly, with the Wellcome Trust and the Medical Research Council, the Nuffield Council for Bioethics.

This typically British arrangement has the advantage of assuring a degree of independence from the government, and the composition of the expert panel is there for all to read, including job titles. Now, in the midst of the controversy about the release of genetically modified organisms into the environment and feeling less sanguine than the report, I find myself wanting to look for conflicts of interest. Naturally, I am reassured that "the report is grounded in liberal, scientific values and takes a broadly utilitarian approach to ethics, a starting point which is shared by most people in the United Kingdom." But how much effect does being Unilever research professor (www.ex.ac.uk/biology/Alternate/sgh.html) or director of the John Innes Centre (www.jic.bbsrc.ac.uk/welcome.htm) have on your views about genetically modified organisms?

Douglas Carnall
BMJ

PERSONAL VIEW

Iceland's database is ethically questionable

Last December the Icelandic parliament, Althingi, passed an act on a health sector database. The legislation was instigated by a Delaware corporation, deCODE, a biotechnology company operating in Iceland (2 January, p11).

The company will receive an exclusive licence to construct a database containing the entire country's health records and permission to combine and analyse them with genetic and genealogical data.

The Icelandic government and deCODE maintain that the project will uphold patients' rights and conform to international obligations and will serve as a model for similar databases elsewhere (20 March, p 806).

Few geneticists dispute the usefulness of databases. Rather, the debate focuses on how deCODE, through the act, has been permitted to break fundamental principles of scientific conduct: the requirement that research plans should be evaluated and approved by independent ethics committees before recruiting patients for studies. Without submitting a research plan, deCODE convinced the Icelandic government that it should pass a law which avoided the necessity for review by the bioethics and data protection committees, the official regulatory bodies. While the government asked for the opinion of these committees after the bill was written, their recommendations on key issues, such as consent and exclusivity, were not followed.

deCODE has also been allowed to preclude patients' second line of defence by not obtaining informed consent from participants. The implementation of informed consent in the strictest sense may be difficult for the database envisioned by deCODE. However, it seems fair to require a general consent outlining the type of information entered and its potential use, benefits, and risks.

We have been repeatedly told that the database will be anonymous (non-personally identifiable); the main argument for avoiding informed consent. However, old medical records, which might otherwise never have been examined, will now be read and the data entered into the database; at that stage there will be no anonymity. Also, while identity will be encrypted after the data have been entered, individuals will be easily identifiable in our small society. More importantly, health data on individuals will be added in "real time," and, to permit this, the identity of individuals will be encrypted, not anonymised. Thus, a key linking Icelanders' names to their database information will be in continuous use, and despite one way coding the owner of a par-

ticular set of health information can be quickly found by sequentially entering the names of Icelanders.

What if studies using the database reveal that some Icelanders carry mutations predisposing them to serious diseases for which preventive measures are available? It seems fair that patients contributing to the database should be able to obtain potentially lifesaving information from the database. Doctors and scientists involved with the database should also be obliged to provide this information, provided that an individual wants to know and ethics committees deem contacts appropriate. Therefore, it is troubling that deCODE and the Icelandic government maintain that the database is anonymous when it is clearly not.

Much has been made of the so called "opt out" clause allowing Icelanders to decline participation. But the mechanism is crippled because patients who halt participation are not allowed to withdraw their data after entry into the database.

As justification, deCODE and the government claim that the act results from an informed democratic decision. But only 13% of the nation considered themselves to have a good grasp of the bill, according to a Gallup survey in November 1998.

deCODE, helped by Iceland's former president, Mrs Vigdis Finnbogadottir, and prime minister, Mr David Oddson, swayed public opinion and pushed the act through parliament before the public understood the issue. While the decision was democratic, if defined as a majority vote in parliament, such a decision should not supersede individual consent when it comes to participation in human investigations. The history of unethical state sponsored research that fulfills this criterion emphasises the obvious fallacy of deCODE's argument. Clearly, some issues, including the ethical evaluation of research and databases, should be left out of politicians' hands.

We have to embrace attempts to attract foreign capital. But it seems only fair that the company should submit its plan, for example, to institutional review boards affiliated with Harvard University in the Boston area in the United States where major shareholders are located. Plans analogous to the Icelandic database would never be approved in the United States. Neither should the expatriate activities of deCODE in Iceland.

Bogi Andersen, *assistant professor of medicine, University of California, San Diego*, and **Einar Arnason**, *professor of evolutionary biology and population genetics, University of Iceland*

Dr Arnason serves on the national bioethics committee and is a member of Mannvernd, Icelanders for ethics in science and medicine.

"Some issues ... should be left out of politicians' hands"

SOUNDINGS

New England journal

Sunday: United States immigration officials are scary. In my student days they sniffed my toothpaste—or was it the Customs? The huge shoulder badges still intimidate me, even here in Shannon airport where the lady with the stamp tries to inject world weary gruffness into her west of Ireland brogue.

Monday: "Grand rounds" suggests big processions from bed to bed, or a series of cases with obscure Bostonian diagnoses to challenge the visiting professor. It actually means a lecture. What is grand is that at 7 30 am people actually turn up. Interns in theatre pyjamas munch takeaway bagels. Should a talk be different at this hour, I wonder, like the morning's laid back weather forecast compared with the evening's?

Tuesday: Going to Harvard the taxi driver speaks in Russian into a mobile phone. "Where are you from?" we ask. "St Petersburg," he replies sadly. "Very beautiful," we say. Long pause. "Yes," he murmurs. Chekovian despair fills the cab.

Wednesday: Boston has umpteen centres of excellence. I express envy, and a local doctor smiles wryly. "I think of us," he says, "as a care centre for people who are still trying to prove something to their mothers."

Thursday: Another state, another bagel. I've adjusted to early rising—or remained on British summer time. And I've learnt that jokes are acceptable over breakfast. American medicine, unlike ours, still has a sense of humour.

Friday: Downtime. In Newport, Rhode Island, near the church where the Kennedys were married, is a street of empty chateaux. A lady from the Preservation Society shows visitors the marbled opulence built by Gatsby-style fortunes. "Before unions," mutters a man in a check shirt.

Saturday: Salem's tourist industry is based mainly on hick witchcraft, with palmists and models of crones on broomsticks. A judge in the 1692 trials is buried here and on adjacent ground is a memorial to the people he hanged. There is a posy on each of 19 stones, and carved quotations: "O Lord, help me. I am wholly innocent." The surrounding tackiness makes it all the more moving. Arthur Miller compared the Salem witch hunts to McCarthyism, but each generation makes the same mistake in a different way. Ours has its own martyrs to political correctness. I suppose we should be pleased we have not hanged them.

James Owen Drife, *professor of obstetrics and gynaecology, Leeds*