

distress. This test, with a positive predictive value of less than 3%,⁴ will generate many false positive results. Women who receive a positive result from a screening test are entitled to much greater support than they now receive. The costs of such a service would, however, outweigh the benefits of routine screening. Districts now considering the introduction of such a programme should bear in mind the maxim quoted by Marteau: "first do no harm."⁵

GERRY WALDRON

East Surrey Health Authority,
Redhill,
Surrey RH1 5RH

E S WILLIAMS

Croydon Health Authority,
Croydon CR9 2RH

- 1 Statham H, Green J. Serum screening for Down's syndrome: some women's experiences. *BMJ* 1993;307:174-6. (17 July.)
- 2 Williams ES, Waldron GJ. Screening, ethics, and the law. *BMJ* 1992;305:1433.
- 3 Connor M. Biochemical screening for Down's syndrome. *BMJ* 1993;306:1705-6. (26 June.)
- 4 Wald NJ, Kennard A, Densem JW, Cuckle HS, Chard T, Butler L. Antenatal maternal serum screening for Down's syndrome. *BMJ* 1992;305:391-4.
- 5 Marteau TM. Psychological consequences of screening for Down's syndrome. *BMJ* 1993;307:146-7. (17 July.)

... but time consuming and expensive

EDITOR.—Like Michael Connor, I welcome biochemical screening for Down's syndrome and look forward to newer tests with higher detection rates.¹ I agree that the NHS should fund and provide screening. My concerns are what constitutes informed consent for people who undergo screening tests, especially tests with low detection rates; the extra work needed to counsel people to gain their full informed consent; and the threat that this extra work poses to other educational tasks in the antenatal consultation.

As a general practitioner, I have had to visit distraught families who have been informed of a positive result of a screening test and who—despite knowing vaguely what the test was—really knew nothing. In counselling a woman who is to have a screening test for Down's syndrome a doctor must explain what Down's syndrome is and how it varies, how it is detected by the test, and what probability is and what the positive predictive value of a positive result is, and must discuss what options exist if the result is positive. It can take more than 45 minutes to explain the test properly. Anything less than an understanding of these issues does not enable the woman to give informed consent and leads to unnecessary anxiety in the event of a positive result. The alternative to a full explanation is to give limited information, hope that the woman does not inquire too closely, and hope too that her result is negative. Is that the kind of informed consent we would want for ourselves?

Cost-benefit analysis of biochemical screening programmes usually compares the savings from the care of affected children with the tertiary costs of the screening programme but does not estimate the effect on workload.²

If counselling is not resourced adequately other tasks in antenatal care must be neglected in order to include it. Either informed consent is not gained—which lowers compliance, detection rates, and the success of the new screening programme—or assertive middle class patients, who rightly wish to know exactly what such tests do and mean, are counselled at the expense of unassertive single young mothers (an example of the inverse care law). Alternatively, all women are counselled at the expense of other activities in the consultation. Thus the true costs of offering the test may include less advice about smoking or less time to discuss breast feeding. Such prioritisation will undermine other aspects of health education, with expensive sequelae, such as increased rates of premature delivery, which are not considered in the simple cost-benefit analyses described above.

Resources are scarce—so we are told—and must be used efficiently and wisely. There is no room for new services if they are resourced inadequately and stop us from providing the old ones with no professional or public debate about which is the more economically, quantitatively, and qualitatively valuable.

J MIBISON

London SW12 9HE

- 1 Connor M. Biochemical screening for Down's syndrome. *BMJ* 1993;306:1705-6. (26 June.)
- 2 Bhatti N, Mackie A. Antenatal screening for Down's syndrome. *BMJ* 1992;305:770.

Private screening is problematic

EDITOR.—In his editorial on biochemical screening for Down's syndrome Michael Connor says that NHS screening is preferable to private screening because of the inequality of access inherent in private medicine.¹ Although this is a major socio-political consideration, there are more serious concerns about the provision of screening tests for Down's syndrome.

Screening for Down's syndrome is relatively new and uses the concept of risk.² Interpreting risk is difficult and highly personal—for example, people may be prepared to risk money in a transaction that has a 95% chance of making a profit but would be unlikely to risk flying if there was a 5% chance of crashing. It is therefore important that the obstetric services to which a woman who has been tested privately presents herself know what the estimate of the risk of Down's syndrome means and are able to perform any further investigations that are required.

If screening is organised locally clinics can be reorganised so that results suggesting a high risk are not given out at the end of a week—as recommended by the Royal College of Obstetricians and Gynaecologists working party on Down's syndrome screening.³ This may not be possible if the result of a test performed privately is returned direct to the patient. Further problems may arise when a patient has both NHS and private tests: what procedure should be followed if the results are discordant?

The gestational age is crucial to the accurate determination of risk.⁴ It is easier for the laboratory in a local NHS programme to contact the antenatal clinic to confirm the gestational age when results are unusual than for a remote private laboratory to do so. It is also easier for the antenatal clinic to contact a local laboratory if the gestational age is revised and the risk must be recalculated.

T M REYNOLDS

Royal Gwent Hospital,
Newport,
Gwent NP9 2UB

- 1 Connor M. Biochemical screening for Down's syndrome. *BMJ* 1993;306:1705-6. (26 June.)
- 2 Reynolds T, Penney M. The mathematical basis of multivariate risk analysis: with special reference to screening for Down's syndrome associated pregnancy. *Ann Clin Biochem* 1990;27:452-8.
- 3 Royal College of Obstetricians and Gynaecologists Scientific Advisory Committee Working Party. *Biochemical detection of Down's syndrome*. London: RCOG, 1993.
- 4 Reynolds T. Practical problems in Down syndrome screening: what should we do about gestation dating? What is the effect of laboratory imprecision? *Communications in Laboratory Medicine* 1992;1:31-8.

Widening the programme would be costly

EDITOR.—Michael Connor rightly calls on the Department of Health to coordinate screening for Down's syndrome within the NHS¹ as the resource implications of offering serum screening for this condition to all expectant mothers extend beyond the cost of the biochemical reagents.

The aim of the screening programme is to find affected fetuses and offer abortion. A recent study

showed that a substantial proportion of parents refuse the screening test, decline definitive investigations if the result of the test is positive, and refuse abortion if the fetus is cytogenetically abnormal.² While these ethical decisions must be respected, they raise the question of whether current methods of pretest counselling are adequate.³

In my district an analysis of the costs and benefits of changing from a selective policy (based on age) to a screening programme for all expectant mothers showed that an adequate counselling service would be the greatest single cost (followed by the increased resources needed for accurate gestational dating). The marginal opportunity costs of such a change would be greater than suggested,² and as all districts already offer age related screening,⁴ careful consideration must be given to the efficient use of resources when only marginal benefits can be expected.⁵

Providing a service with inequality of access need not be an issue as it is a duty of all who work in the NHS to ensure that resources are used effectively. In this instance the biochemical screening tests that are used currently are more sensitive in older mothers.²

The identification of biochemical markers as risk factors for Down's syndrome has been a major development in obstetric care, but their place in antenatal diagnosis needs to be established in the context of advances in the availability and techniques of ultrasound scanning. We now need to consider how to combine these screening tools efficiently without denying resources inappropriately to other NHS users.

ADRIAN PHILLIPS

Department of Public Health Medicine,
Dudley Health Authority,
Dudley DY1 2DD

- 1 Connor M. Biochemical screening for Down's syndrome. *BMJ* 1993;306:1705-6. (26 June.)
- 2 Wald NJ, Kennard A, Densem JW, Cuckle HS, Chard T, Butler L. Antenatal maternal serum screening for Down's syndrome: results of a demonstration project. *BMJ* 1992;305:391-4.
- 3 Parsons L, Richards J, Garlick R. Screening for Down's syndrome. *BMJ* 1992;305:1228.
- 4 Wald N, Wald K, Smith D. The extent of Down's syndrome screening in Britain in 1991. *Lancet* 1992;340:494.
- 5 Cuckle H. Maternal serum screening policy for Down's syndrome. *Lancet* 1992;340:799.

Existing tests not good enough

EDITOR.—Michael Connor suggests that the NHS should provide biochemical screening for Down's syndrome and describes the controversies surrounding the issue.¹ But he reaches his conclusion only by ignoring some of the crucial problems, although these have been documented in extensive correspondence in the *BMJ* and elsewhere.^{2,5}

In particular, Connor trivialises the psychological and emotional costs, making only a passing reference to the difficulties with counselling experienced by all districts and health boards. Counselling is essential: "failure to obtain informed consent for a screening procedure is not only ethically unacceptable but also exposes the health authority to the risk of litigation." It is necessary to inform patients, before blood is taken, of the false positive rate (about 65 false positive results for every true positive result, or about one pregnancy in 20), the false negative rate (around 40%), the necessity for amniocentesis to make diagnoses, and the ultimate aim of termination. The practical difficulties of doing this have disrupted antenatal services. If counselling is done properly most women reject the offer of biochemical screening.⁵ If counselling is not done properly many women reject the offer of amniocentesis.⁵ In this case patients' autonomy leads to results not desired by the advocates of screening; we suggest that the values of the patients should have priority.

These values may reasonably be shared by

professionals. Keatinge and Williams have calculated that over 10 000 women need to be told of the possibility of their fetus having Down's syndrome for one extra case to be detected and termination performed. The psychological and emotional consequences of introducing all pregnant mothers to the possibility of their fetus having Down's syndrome are probably the most important cost. Of course, many women are not bothered or are reassured by their low risk on screening, but an important minority are deeply disturbed by the suggestion, making comments such as "Before they told me about this test I was quite happy about the baby. Now I'll be worried until I can see that it's all right." Correctly, much attention has been given to women with false positive results, who suffer considerable psychological trauma and may lose a normal fetus owing to amniocentesis, but these make up only about 5% of all pregnancies.¹ Over 40% of all women are incorrectly given negative results on screening, and the clinical impression is that the birth of a baby with Down's syndrome is much more traumatic if it follows the false reassurance of a negative result of screening.

Financial issues may seem trivial by comparison, but, as previously calculated, the extra costs of counselling and testing the entire pregnant population outweigh any financial savings from aborting fetuses with Down's syndrome.² Connor incorrectly suggests that there will be a saving on diagnostic tests. No such saving is likely: most previous advocacy has simply assumed that the number of amniocenteses (and consequent abortions) will stay the same but that more cases of Down's syndrome will be detected.

Simplistic "cost effectiveness" analyses are thus doubly flawed: they omit most of the important costs and overestimate the likely benefits. The only appropriate form of economic evaluation is comprehensive cost-benefit analysis, which describes and weighs up all the relevant costs and benefits within the ethical requirement to promote autonomy.

Given these facts it is not surprising that a recent discussion of the published evidence among public health physicians in Wales concluded that while research should be encouraged, the existing tests are simply not good enough for use on younger mothers.

RICHARD KEATINGE
CERILAN ROGERS

Department of Public Health Medicine,
Gwynedd Health Authority,
Bangor, Gwynedd LL57 4TP

- 1 Connor M. Biochemical screening for Down's syndrome. *BMJ* 1993;306:1705-6. (26 June.)
- 2 Keatinge R, Williams ES. Prenatal screening for Down's syndrome. *BMJ* 1991;303:54-5.
- 3 Correspondence. Prenatal screening for Down's syndrome. *BMJ* 1991;303:468-9.
- 4 Correspondence. Antenatal screening for Down's syndrome. *BMJ* 1992;305:769-70.
- 5 Correspondence. Screening for Down's syndrome. *BMJ* 1992;305:1228.
- 6 Statham H, Green J. Serum screening for Down's syndrome: some women's experiences. *BMJ* 1993;307:174-6. (26 June.)

Health of children born prematurely

Antenatal factors may be important

EDITOR,—Ann Johnson and colleagues' data on the abilities at four years of age of children who were born before 29 weeks' gestation will be useful to obstetricians and neonatologists when counselling parents. The authors correctly avoided any reference to outcome, focusing instead on "health status in infancy and childhood," because outcome implies a cause and effect relation, which may not be valid.¹

This paper, however, provides no lessons to

improve clinical practice. Further information from this cohort could help in the management of pregnancies that end before term and preterm babies. Firstly, what proportion of babies at each gestational age was born by spontaneous rather than iatrogenic labour? Secondly, were any antenatal factors associated with a better or worse health status at 4 years?

South East Thames region is conducting a study of low birthweight babies (<2500 g) with the aim of determining the effect of antenatal factors, such as the detection of fetuses that are small for gestational age, and neonatal factors on subsequent health status. Data from the first three months indicate that only 35% of babies that are small for gestational age are detected antenatally. Knowledge of the effect of detection, and possible antenatal intervention, on health status would provide obstetricians with evidence of their influence on longer term health status. Such data would also begin to answer some of the questions posed by the work of David Barker *et al* on the early origins of adult disease.¹

A minimum dataset has been recommended to be used nationally for the follow up of very low birthweight babies (<1500 g).² As neonatal care will inevitably continue to improve, data on health status will need constant revision. Researchers will need to ensure the conformity of their dataset, as proposed by the Audit Commission and by Johnson and colleagues.

RICHARD H B DE COURCY-WHEELER
JONATHAN D GOODMAN
CHARLES D A WOLFE

South East Thames
Low Birth Weight Study,
St Thomas's Hospital,
London SE1 7EH

- 1 Johnson A, Townshend P, Yudkin P, Bull D, Wilkinson AR. Functional abilities at age 4 years of children born before 29 weeks of gestation. *BMJ* 1993;306:1715-8. (26 June.)
- 2 National Perinatal Epidemiology Unit. *Collecting information on perinatal morbidity (health status in infancy and early childhood)*. Oxford: Oxford Regional Health Authority, 1993.
- 3 Barker DJP, Meade TW, Fall CDH, Lee A, Osmond C, Phipps K, *et al*. Relation of fetal and infant growth to plasma fibrinogen and factor VII concentrations in adult life. *BMJ* 1992;304:148-52.
- 4 Audit Commission. *Children first. A study of hospital services*. London: HMSO, 1993.

New treatment reduces risk of blindness

EDITOR,—Ann Johnson and colleagues' article on the functional abilities at 4 years of children born before 29 weeks' gestation presents important data but paints an unnecessarily gloomy and outdated picture with regard to vision.¹ The authors report total blindness in nine of the 35 children with severe disability. Though aetiologies are not discussed, I assume that much of this could be attributed to retinopathy of prematurity, perhaps even in the three children with cerebral palsy who were blind. Although the details are not given, a small proportion of the 64 children with mild and moderate disabilities probably also suffered loss of vision due to retinopathy of prematurity.

The study was undertaken during 1984-6—that is, two years before cryotherapy was reported to reduce the unfavourable outcome for severe retinopathy of pregnancy by just under 50%.² This encouraging preliminary result of the American multicentre trial of cryotherapy for retinopathy of prematurity has been borne out by subsequent reports,³ and, most importantly, visual function is much better in treated babies. Thus in the time between the Oxford study being carried out and published clinical practice has changed dramatically. Screening preterm neonates at risk of retinopathy of prematurity is now recommended as at last there is an effective treatment for this potentially blinding condition.^{4,5}

The main sensory handicap in the children with a severe disability was visual.¹ It is encouraging that in this respect considerable advances have

occurred; hopefully, many fewer extremely low birthweight neonates will become visually impaired.

ALISTAIR R FIELDER

Department of Ophthalmology,
Birmingham and Midland Eye Hospital,
Birmingham B3 2NS

- 1 Johnson A, Townshend P, Yudkin P, Bull D, Wilkinson AR. Functional abilities at age 4 years of children born before 29 weeks of gestation. *BMJ* 1993;306:1715-8. (26 June.)
- 2 Cryotherapy for Retinopathy of Prematurity Cooperative Group. Multicenter trial of cryotherapy for retinopathy of prematurity: preliminary results. *Arch Ophthalmol* 1988;106:471-9.
- 3 Cryotherapy for Retinopathy of Prematurity Cooperative Group. Multicenter trial of cryotherapy for retinopathy of prematurity: one year outcome. *Arch Ophthalmol* 1990;108:1408-16.
- 4 College news: ROP screening duty. *Quarterly Bulletin of the College of Ophthalmology* 1990;autumn:6.
- 5 Fielder AR, Levene MI. Screening for retinopathy of prematurity. *Arch Dis Child* 1992;67:860-7.

Serum lipid testing

EDITOR,—Stuart Handsides reports that *Effective Health Care* argues against indiscriminate screening of cholesterol concentrations.¹ The public's current enthusiasm to know their "cholesterol number" has resulted in a vast increase in laboratory requests for measurement of cholesterol concentration, prescriptions, and needless anxiety, often in patients who are at low risk of developing coronary heart disease.

In an attempt to stem the ever rising numbers of requests received in the laboratory an audit of 2000 requests for measurement of lipid concentrations was carried out over three months. Of these requests, 540 were part of opportunistic screening, 1040 were for high risk patients being screened, and the remaining 420 were for patients being monitored during treatment of hyperlipidaemia by diet or drugs. In the high risk group 177 (17%) of the 1040 patients were aged over 65 and 21 (2%) were over 70. In the treatment group 97 (23%) of the 420 patients were over 65 and 42 (10%) were started on diet or drug treatment after the age of 65, with no evidence of ischaemic heart disease.

The pattern of requests varied considerably among clinicians, from requests being made for almost all new patients to requests being made only for those with severe established coronary heart disease. Three patients were considered to be receiving inappropriate treatment.

The patients who benefit most from lowering of their cholesterol concentration are young and middle aged people who are at increased risk of coronary heart disease.² The benefit of treating patients aged over 65 is less clear, and hence in general the policy of screening patients aged over 65 must be questionable in the present economic climate.

Practical guidelines on the management of patients with hyperlipidaemia are urgently needed; these should preferably be prepared by a national expert body along the lines of the national cholesterol education programme in the United States.³ The policy of selective cholesterol testing to target people who are at increased risk is not advocated by some expert bodies and carries with it the disadvantage of missing heterozygous patients with familial hypercholesterolaemia.^{2,3} This highlights the importance of taking a history from all patients to avoid missing these cases.

Laboratories would do well to concentrate their efforts on improving the quality of measurements of total and high density lipoprotein cholesterol concentrations to help reduce the drug bill.⁴ Clearly, there is considerable scope for savings and those looking to wield the axe ought to be looking here.

S BULUSU

Department of Chemical Pathology,
Newham General Hospital,
London E13 8RU