in reducing the first occurrence of neural tube defects.[4]

ANDREW E CZEIZEL

Department of Human Genetics and Teratology,
National Institute of Hygiene,
WHO Collaborating Centre for the Community Control of Hereditary Diseases,
Budapest,
Hungary

BERNADETTE MODELL

WHO Collaborating Centre for Community Control of Hereditary Diseases,
Department of Obstetrics and Gynaecology,
University College London,
London WC1E 6HX

1 Abelin T, Bracainak ZJ, Carstairs VDL, eds. *Measurement in health promotion and protection.* Copenhagen: WHO Regional Office for Europe, 1987. (WHO regional publication, European series No 22.)
2 Modell B, Kuliev AM. A scientific basis for cost-benefit analysis of genetic services. *Trends in Genetics* 1993;9:46-52.
3 MRC Vitamin Study Research Group. Prevention of neural tube defects: results of the MRC vitamin study. *Lancet* 1991;**338**: 131-7.
4 Czeizel AE, Dudás I. Prevention of the first occurrence of neural tube defects by periconceptional vitamin supplementation. *N Engl J Med* 1992;**327**:1832-5.

Screening for diabetes during pregnancy

EDITOR,—R J Jarrett expresses many concerns about the existence of gestational diabetes.[1] One difficulty not mentioned arises from the definition of gestational diabetes, which includes abnormal glucose tolerance arising in or first detected in pregnancy. A consequence of this is that women with undiagnosed non-insulin dependent diabetes, which is potentially as risky for the pregnancy as insulin dependent diabetes, are lumped together with women who have abnormalities of glucose tolerance that are trivial so far as the index pregnancy is concerned.

This is not an important issue for women of European origin, in whom non-insulin dependent diabetes is quite uncommon during their childbearing years, but in other ethnic groups it is a concern. In our clinic we have managed 262 pregnancies in 203 women with diabetes over the past five years, 143 of whom had non-insulin dependent diabetes. Of these, 85% were of Maori, Pacific Island, or Indian origin: these are ethnic groups with a high prevalence of non-insulin dependent diabetes.[2] Screening for gestational diabetes is practised in Auckland, and of the 143 women with non-insulin dependent diabetes, 87 were first found to have diabetes on screening in pregnancy; the disease was confirmed after delivery.

Using a composite score derived from factors significantly associated with the persistence of diabetes after delivery, we can now distinguish, with a high degree of certainty, women with non-insulin dependent diabetes from others with "gestational diabetes" at the time gesational diabetes is diagnosed (A Knox *et al*, New Zealand Society for the Study of Diabetes, 1992). We believe, therefore, that for communities like ours, in which unrecognised non-insulin dependent diabetes is fairly common in young people, screening for gestational diabetes is justified. Furthermore, at risk pregnancies can be defined accurately and treated accordingly; thus the requirements of a good screening test are fulfilled.

CRAIG McBRIDE ALISTAIR ROBERTS
ANDREW KNOX TIM CUNDY

University of Auckland Medical School,
Auckland,
New Zealand

1 Jarrett RJ. Gestational diabetes: a non-entity? *BMJ* 1993;**306**: 37-8. (2 January.)
2 Scragg R, Baker J, Metcalf P, Dryson E. Prevalence of diabetes mellitus and impaired glucose tolerance in a New Zealand multiracial workforce. *NZ Med J* 1991;**104**:395-7.

Management after life threatening events in young children

EDITOR,—Martin P Samuels and colleagues' paper on diagnosis and management after life threatening events in infants and young children who received cardiopulmonary resuscitation suffers from the fact that the hospital provides a tertiary referral service and probably sees problematic cases.[1] Since 1977, when a detailed inquiry into child deaths was instituted in Gwynedd, no children admitted for life threatening events in the first four years of life have subsequently died (apart from two children with known epilepsy who have died during fits). Some of our children classified as having died of the sudden infant death syndrome may have been suffocated, but none of them presented to hospital before their death if that was so. And people who strangle their infants, thus causing their admissions, must give up the practice thereafter. Samuels and colleagues seem to have been especially unfortunate in their experience of babies with prolonged expiratory apnoea (blue breath holders). I am not aware of any deaths of babies with prolonged expiratory apnoea in Gwynedd although over 30 cases a year are seen in wards or outpatient clinics (the child population of Gwynedd is about 45 000 with 2800 births a year).

R H DAVIES

Tregarth,
Gwynedd LL57 4PW

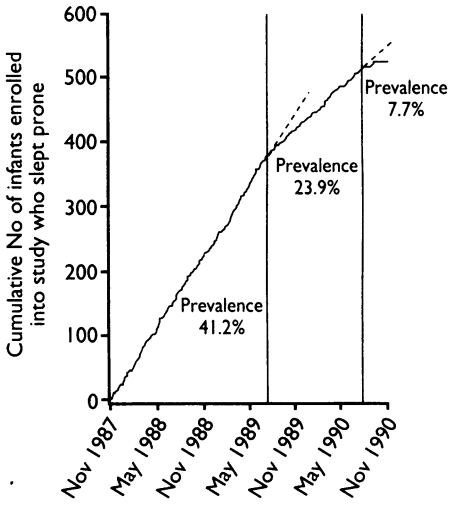
1 Samuels MP, Poets CF, Noyes JP, Hartmann H, Hewertson J, Southall DP. Diagnosis and management after life threatening events in infants and young children who received cardiopulmonary resuscitation. *BMJ* 1993;**306**:489-92. (20 February.)

Publicity and infants' sleeping position

EDITOR,—The rate of the sudden infant death syndrome in Scotland fell before the national campaign aimed at reducing the prevalence of the prone sleeping position.[1] A survey in Scotland found that 87% of health visitors had changed the advice given to parents about the syndrome and that 54% stated that this change occurred before mid-1991.[2] This preceded the national campaign in the United Kingdom, which began in November 1991. Furthermore, these health visitors cited journal articles and the mass media as the most important influences for changing advice. Data from the New Zealand cot death study show that the prevalence of the prone sleeping position decreased before the campaign in New Zealand and suggest that other publicity, such as that generated by fundraising campaigns, may have had an influence.

The New Zealand cot death study was a nationwide case-control study carried out from 1 November 1987 to 31 October 1990. Altogether 1800 control infants were randomly selected from all births in the study regions. The figure shows the cumulative number of these infants placed to sleep prone. The prevalence of the prone sleeping position was relatively constant at 41% until August 1990, was 24% for the next 12 months, and was about 8% for the final three months of the study. The two changes in infant care practice had a temporal relation with mass publicity accompanying fund raising for the Cot Death Association.

The association's first "Red Nose Day," in September 1989, emphasised the size of the problem and the devastating effect on parents. The fundraising part of the campaign was accompanied by items on television, in magazines, and on radio. Some of these would have included the suggestion that sleeping prone might not be safe for babies.



Prevalence of prone sleeping position among subjects enrolled into study. Vertical lines indicate times when prevalence of prone sleeping position changed; broken lines indicate prevalence before the changes

By 1990 unpublished data from the New Zealand study confirmed the increased risk of the sudden infant death syndrome if an infant was placed to sleep prone. In July 1990 a television advertisement by the Cot Death Association advised against placing infants to sleep prone. Publicity for its 1990 Red Nose Day in mid-August used television, radio, popular magazines, newspapers, and pamphlets to spread messages about reducing the risks, particularly "sleep baby on the side."

The wide publicity surrounding these two Red Nose Days and the change in the prevalence of the prone sleeping position preceded the national cot death prevention programme, which was formally launched in February 1991.[3] The change in the prevalence of the prone sleeping position has been associated with a 40% fall in the rate of the sudden infant death syndrome in New Zealand.[6] This analysis illustrates the potential health educational value of mass publicity surrounding fundraising activities.

E A MITCHELL

Department of Paediatrics,
School of Medicine,
University of Auckland,
Private Bag 92019,
Auckland, New Zealand

SHIRLEY TONKIN

Cot Death Association,
5 Clonburn Road,
Remuera,
Auckland

1 Gibson A, Brooke H, Keeling J. Reduction in sudden infant death syndrome in Scotland. *Lancet* 1991;**338**:1595.
2 Scott A, Campbell H, Gorman D. Sudden infant death syndrome in Scotland. *BMJ* 1993;**306**:211-2. (16 January.)
3 Mitchell EA, Aley P, Eastwood J. The national cot death programme in New Zealand. *Australian Journal of Public Health* 1992;**16**:158-61.
4 Mitchell EA, Ford RPK, Taylor BJ, Stewart AW, Becroft DMO, Scragg R, *et al.* Further evidence supporting a causal relationship between prone sleeping position and SIDS. *Journal of Paediatrics and Child Health* 1992;**28**(suppl 1):S9-12.

Mothers' consent to screening newborn babies for disease

EDITOR,—Neonatal screening for Duchenne muscular dystrophy has been introduced in Wales with close monitoring, social evaluation, and a continuing education programme.[1] This should result in uptake of the test being based on informed consent. Once a test becomes routine, however, the same care is unlikely to be taken. Even in this demonstration project one of the nine families with a positive diagnosis apparently entered the programme in ignorance. Routine Guthrie testing has

been carried out for phenylketonuria since the mid-1970s and testing for hypothyroidism since the mid-'80s. Our recent data on new mothers' knowledge of these tests suggests that ignornce is widespread.

As part of the Cambridge prenatal screening study, 1387 women from nine hospitals in four regions completed a postal questionnaire six weeks after giving birth.[2] All but eight women knew where the test had been done (1209 at home and 163 in hospital, with more primiparous women tested in hospital). Most women (951) said that the test had been fully explained and 222 "knew about it already." The extent to which women thought that they were informed, however, was not reflected in the answers to a question about which disorders this blood sample was tested for (table).

Mothers' responses to question "Which of the following was your baby tested for?"

	Yes	No	Don't know
Cystic fibrosis (n=1232)	348	163	721
Cerebral palsy (n=1202)	183	218	801
Phenylketonuria (n=1293)	584	45	664
Haemophilia (n=1183)	114	230	839
Muscular dystrophy (n=1187)	118	223	846
Hypothyroidism (n=1217)	247	111	859
Diabetes (n=1186)	125	227	834

Older, more educated women were more likely to answer the questions correctly, but only 51 of the 150 most educated women correctly identified hypothyroidism and 105 phenylketonuria. Multiparous women were no more likely to answer these questions correctly than primiparous women. Twenty one women answered "yes" for all of the disorders; these women all stated that the Guthrie test had been fully explained, as did 250 of the 489 who answered "don't know" for all of the disorders.

Phenylketonuria was the disease that was most commonly identified correctly, but still by only 45% of the sample. Only 20% identified hypothyroidism, even though this condition is more likely to be detected (three cases in our study). Six of the districts used the Guthrie spot to test for cystic fibrosis, and in these districts 306 (37%) of the 964 women identified cystic fibrosis (correctly), compared with 42 (10%) of 409 in the other hospitals, who did so incorrectly.

Most new mothers do not know what the Guthrie test is for: a considerable number incorrectly believe that it will detect more disorders than is the case. These results clearly challenge any notion that women are giving informed consent for their babies to be tested, even though they believe themselves to have been informed.

HELEN STATHAM
JOSEPHINE GREEN
CLAIRE SNOWDON

Centre for Family Research,
Social and Policital Sciences Faculty,
University of Cambridge,
Cambridge CB2 3RF

1 Bradley DM, Parsons EP, Clarke AJ. Experience with screening newborns for Duchenne dystrophy in Wales. *BMJ* 1993;**306**: 357-60. (6 February.)
2 Green JM, Statham H, Snowdon CM. *Pregnancy: a testing time. Report of the Cambridge prenatal screening study.* Cambridge: Centre for Family Research, University of Cambridge, 1993.

Medical management of Duchenne muscular dystrophy

EDITOR,—James E Bowman states that patients with Duchenne muscular dystrophy are bedridden by the age of 12.[1] This should not be accepted as adequate medical management in the 1990s. Most patients with Duchenne muscular dystrophy lose their independent mobility and may be confined to a wheelchair by the age of 12, but many spend some time standing with a suitable support. Patients become bedridden only when they are terminally ill or if they are allowed to develop progressive scoliosis which results in intolerance of sitting. This last can be prevented by modern orthopaedic treatment,[2] but, unfortunately, many patients are still referred to a suitable orthopaedic clinic too late.[3]

Not only does spinal stabilisation for early scoliosis in patients with Duchenne muscular dystrophy maintain sitting balance but it is also associated with a slower deterioration in lung function.[2] It is a major procedure in these patients, and, unfortunately, not all patients are fit enough for surgery at the time of referral. Of 169 patients with Duchenne muscular dystrophy referred to the orthopaedic muscle clinic at the Royal Manchester Children's Hospital, 117 already had a scoliosis at the time of referral; three patients had a curve between 80° and 100° and eight patients had a curve in excess of 100°.[3] Some of the patients with a curve in excess of 100° were no longer able to sit because of the pelvic obliquity consequent on the scoliosis; they were bedridden not because of the Duchenne muscular dystrophy itself but because they had been allowed to develop such extensive spinal curves before referral to an orthopaedic muscle clinic.

C S B GALASKO

Department of Orthopaedic Surgery,
University of Manchester,
Hope Hospital,
Salford M6 8HD

1 Bowman JE. Screening newborn infants for Duchenne muscular dystrophy. *BMJ* 1992;**306**:349. (6 February.)
2 Galasko CSB, Delaney C, Morris P. Spinal stabilisation in Duchenne muscular dystrophy. *J Bone Joint Surg [Br]* 1992; 74:210-4.
3 Galasko CSB, Delaney CM. The effect of prolonged standing on scoliosis and lung function in patients with Duchenne muscular dystrophy. *Muscle Nerve* (in press).

Working with adult survivors of child sexual abuse

EDITOR,—Does the surgical senior registrar who seems to have performed an unnecessary internal examination under anaesthesia without consent before an appendicectomy[1] realise how lucky he is not to have been charged with battery?[2,3] According to the patient, she had made patently clear her refusal to allow him to perform a vaginal or rectal examination because of a history of child sexual abuse by her doctor father.

If the ideal course of action is not possible doctors must use their ingenuity to find another. This was not a difficult patient, rather a difficult medical problem. The surgeon apparently did not listen to his patient or respect her bodily integrity.

A defence of acting in her best medical interests fails: he could have tried to find a female gynaecologist, and, indeed, his female house officer had already examined the patient; a pelvic mass could have been shown by ultrasonography; if it was necessary to exclude pelvic disease a laparoscopy could have been performed before the appendicectomy; it is doubtful whether the examination under anaesthesia served any purpose as tenderness could not be elicited; and, finally, he could have asked the patient first whether an examination under anaesthesia was an acceptable compromise.

This patient was bound to be extremely distressed at finding that a male doctor had forcibly touched her intimately. Waiting until she was anaesthetised and had no control over events re-enacted and reinforced the abuse begun by her father. The examination under anaesthesia without consent is inexplicable (unless it was to punish her for having refused examination when conscious). The surgeon also abused the patient, and it was a misuse of professional privilege that he did so.

SUSAN BEWLEY

Department of Obstetrics and Gynaecology,
University College and Middlesex School of Medicine,
London WC1E 6HX

1 Anonymous. Working with adult survivors of child sexual abuse. *BMJ* 1993;**306**:395-6. (6 February.)
2 Kennedy I, Grubb A. *Medical law—text and materials.* London: Butterworths Legal, 1989:171-229.
3 Bewley S. The law, medical students and assault. *BMJ* 1992;**304**: 1551-3.

Mothering skills of women with mental illness

EDITOR,—The mothering skills of women with mental illness are important for the physical and mental health of their children.[1] Certain crucial issues are, however, confused in Louis Appleby and Chris Dickens's editorial. On the one hand there is severe mental illness in mothers, possibly psychotic and requiring admission to specialist units. Although the incidence of psychotic illness in women is significantly greater after delivery than at any other time, it is still relatively rare (about one or two cases per thousand). On the other hand, there is postnatal depression, which is extremely common, occurring in 10-20% of mothers.[2] This condition is mostly dealt with in the community, which often means that it is not dealt with at all. In inner cities the prevalence of depression among mothers of young children is even greater.

We now know that babies whose mothers are depressed continue to be affected even after the mother has recovered. They tend to be more clingy and less competent, both socially and intellectually. This was well summarised by Murray *et al.*[3]

Many different factors contribute to the neglect and invisibility of maternal depression, not least the confusion between a rare psychotic illness and a common condition. To deal with it and to prevent its persistent effects on children, doctors and nurses need more training to develop their psychological awareness and their counselling skills. The ready availability of a screening questionnaire that mothers at risk can complete under supervision in a few minutes is potentially useful,[4] but only if health workers and others can rise to the needs of depressed mothers. This is a damaging epidemic which remains politically invisible but socially evident.

STANFORD BOURNE
EMANUAL LEWIS
SEBASTIAN KRAEMER

Tavistock Clinic,
Tavistock Centre,
London NW3 5BA

1 Appleby L, Dickens C. Mothering skills of women with mental illness. *BMJ* 1993;**306**:348-9. (6 February.)
2 Cooper PJ, Campbell EA, Day A, Kennerley H, Bond A. Non-psychotic psychiatric disorder after childbirth: a prospective study of prevalence, incidence, course and nature. *Br J Psychiatry* 1988;**152**:799-806.
3 Murray L, Cooper PJ, Stein A. Postnatal depression and infant development. *BMJ* 1991;**302**:978-9.
4 Cox AD, Holden JM, Sagovsky M. Detection of postnatal depression: development of the 10 item Edinburgh postnatal depression scale. *Br J Psychiatry* 1987;**150**:782-6.

Screening for hypertrophic cardiomyopathy

EDITOR,—We strongly support A L Clark and A J S Coats's conclusions that screening for hypertrophic cardiomyopathy is not justified at present and that more research is needed on both the effectiveness of early treatment and the natural course of minor abnormalities detected by screening.[1] We have recently been concerned by prominent publicity in the media in Wales relating