LETTERS TO THE EDITOR

Cystic fibrosis identified by neonatal screening: incidence, genotype, and early natural history

EDITOR,—Commenting on our paper, which described an apparent halving in the incidence of cystic fibrosis in East Anglia,¹ Dr Coles and colleagues suggest that during the last three years of the reported study, a substantial number of patients with cystic fibrosis might have remained undiagnosed because of over reliance on the efficiency of the screening test.² This is an implausible explanation for our observations. Such an occurrence would require either a drastic deterioration in the analytical performance of the assay, which is not supported by the results of the external or internal quality control procedures conducted throughout this period, or an abrupt change in the pathophysiology responsible for the raised blood immune reactive trypsin (IRT) concentrations in the newborn who have inherited cystic fibrosis during this later period. Furthermore, there is no evidence to suggest that East Anglia's paediatricians have, over the years, become complacent about achieving the earliest possible diagnosis in that small percentage of cystic fibrosis patients not detected by screening. We are confident in this assertion from the number of inquiries received from every ward and clinic in the region seeking to confirm that routine neonatal IRT screening has been carried out on infants and children presenting with symptoms, in conjunction with the continuing usage of the excellent sweat testing facilities throughout the region, and more recently with the increasing use of the facility to test for the more common cystic fibrosis genotypes on DNA extracted from stored neonatal blood spots.

Secondly, all the cases were diagnosed by IRT assay. Dr Coles and colleagues refer to the figure of 68% of cases being identified by IRT assay alone. The remainder of cases had clinical features which might have led to the diagnosis, in addition to an abnormal IRT assay.

There is thus no evidence to suggest that under ascertainment explains the declining incidence. We agree that it will be important to continue monitoring the incidence of cystic fibrosis in East Anglia.

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1 Green MR, Weaver LT, Heeley AF, et al. Cystic fibrosis identified by neonatal screening: incidence, genotype and early natural history. *Arch Dis Child* 1993; 68: 464-7.

2 Coles EC, Dodge JA, Morison S. Cystic fibrosis identified by neonatal screening: incidence, genotype and early natural history (letter). *Arch Dis Child* 1993; 69: 470.

Parental participation in case conferences

EDITOR,—In child protection work the focus of professional endeavour should be the welfare of the child and as children live (usually) in families, their carers must clearly be involved in any assessment and longer term plans. So what is the function of the child protection conference? In the past information was collected concerning possible abuse and an assessment of the child and family at least started. Now the conference has altered, it is held at the end of an investigation usually jointly planned by the police and social services and reports are focused and tend to look at the incident rather than attempt to look at the concerns in the context of the family. The presentation may be further modified by previous strategy meetings where the professionals have met and discussed in some depth the gathered information. It is then the task of the case conference to consider whether inclusion on the child protection register is to be recommended, a key worker and core group is identified.

The parents will usually work with the various professionals and their attendance at the conference is a logical extension of this work. But what of the difficult cases where parents strongly deny the concerns and do not accept the need for professional involvement? As colleagues increasingly recognise child sexual abuse they will meet more denial. A 3 year old girl told her mother of the 'games' she plays with Daddy on her weekend access. Social services and the police investigate, the medical reveals a torn hymen and Daddy denies any wrong doing. Although the professionals feel there is substance in the story the Crown Prosecution Service do not take the case forward. At the conference are the estranged parents, the mother may have worked closely with the professionals, the father asserts it's all an attempt by his malicious ex-wife to stop access. Do we have the skills to handle all the issues presented here in the conference, attended by the parents' two solicitors who may advise their client not to talk?

It may be argued that the above case is unusual: this depends upon the geographical area and the willingness of professionals to engage in complex work. Each is different, if the girl in the scenario above was 13 years would she want her father, who may be her abuser, to have details of her medical report (and her teacher, etc ...).

Working Together does not expect that professionals can always work with parents to achieve child protection.¹ Cooperation may develop but true cooperative 'partnership' is not achieved instantly. A working relationship with parents may be a better description of the longer term expectation.

In recent papers in the journal *Sheehy Skeffington* is right to suggest caution and keep the focus on the child's needs and welfare²; Hutchinson is overly optimistic of parenting behaviour given our increasing knowledge of the dynamics of abusive relationships and behaviours.³

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1 Home Office. *Working together under the Children Act 1989*. London: HMSO, 1991.

2 Sheehy Skeffington F. Parental participation in case conferences: the case against. *Arch Dis Child* 1993; 69: 457-8.

3 Hutchinson T. Parental participation in case conferences: the case in favour. *Arch Dis Child* 1993; 69: 455-7.

EDITOR,—We write in full support of parent participation at case conferences as presented by Dr Hutchinson.¹ We would however like to draw attention to some recent problems.

On one occasion the parents were accompanied by all four grandparents all wanting to voice their opinions against the medical diagnosis of non-accidental injury and give character references of the parents. Chairing such a conference proved extremely difficult. One parent appeared inhibited by their presence and only went on to give relevant information after the conference ceased and the group dispersed.

At another case conference a solicitor accompanied the parent and took copious notes using the occasion to 'interrogate' the doctor on the significance of her medical findings in a 'court trial format'; the conference lasted five hours.

On another occasion a female friend accompanied the mother for support. Her surname (given on introduction to the conference) was the same as the alleged perpetrator's alias, although she claimed not to know him. She was, in fact, his sister and after the conference was in a position to give him some valuable information regarding the investigation. The health visitor was clearly anxious about stating her concerns for the family openly. The mother without warning suddenly lost her temper and attempted to physically assault the health visitor who was left extremely shaken by the incident and later had time off work.

We recommend that a time limit is imposed on conferences. The number of supporters should be limited. They should be there purely in a support rather than a contributory role. Information on them should be checked before the sharing of such confidential information especially if an investigation is still proceeding.

It is our general experience, however, that parental participation promotes partnership and good practice and should continue.

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1 Hutchinson T. Parental participation in case conferences: the case in favour. *Arch Dis Child* 1993; 69: 455-7.

Sudden infant death syndrome

EDITOR,—A high degree of heat production has been identified as a risk factor in the causation of sudden infant death syndrome (SIDS) by several studies.¹ It has been suggested that one reason why sleeping prone may increase the risk of SIDS is that it restricts the loss of heat from the infant to the environment.¹ Concern has thus focused on factors that may increase heat production, such as febrile illness, or limit heat loss, such as excessive thermal insulation of clothing or high environmental