LETTERS TO THE EDITOR

Chronic idiopathic bronchiolitis of infancy

EDITOR,—We read with interest the report by Hull *et al* on chronic idiopathic bronchiolitis.¹ However, it is not totally correct to state that clinically, chronic bronchiolitis is a previously unreported respiratory entity. We have recognised the existence of this syndrome for many years and reported eight children with this condition in our percutaneous lung biopsy series.² It is our impression that chronic bronchiolitis in infants is not a distinct entity, but rather a non-specific response of the small airways to a variety of different insults. In some children this condition is familial and may have an autoimmune component.³

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Confidential inquiry into families with two siblings with cystic fibrosis

EDITOR,—Lane and colleagues¹ confidential inquiry into families with two siblings with cystic fibrosis was essentially to determine whether couples with one child were offered prenatal diagnosis before a second pregnancy. There are several misconceptions with reference to the Northern Ireland population. The statement “clinicians and/or clinical geneticists did not offer prenatal diagnosis to a significant proportion of the couples . . . 56% of those in Northern Ireland”, does not reflect the actual situation. Since 1990 there has been a policy that when a child with cystic fibrosis is diagnosed, the paediatricians refer the family for genetic counselling. Most referrals are accepted and the genetic counselling session always includes information on prenatal diagnosis and appraisal of all possible reproductive options. When a couple embark on a further pregnancy, they can contact directly the regional genetics service responsible for coordinating the regional prenatal diagnostic clinics. These clinics, which are staffed by obstetricians and clinical

geneticists, provide chorionic villus biopsy and early amniocentesis from 12 weeks' gestation.² All obstetricians are aware of these clinics in Northern Ireland.

The statement that “the Abortion Act does not apply there and this may affect uptake of prenatal counselling” is incorrect. While the 1967 Abortion Act does not apply to Northern Ireland, terminations for fetal abnormality have been and continue to be performed here based on case law, as was the case in England before 1967. There is no problem about discussing prenatal diagnosis at these clinics. The relevant questions that need to be addressed are primarily whether the couple want to come to the clinic or whether they are referred by their obstetrician, general practitioner, or other practitioner. This referral may not be made because of differing views on prenatal diagnosis by medical practitioners and their possible directive counselling, but this has been discussed in detail elsewhere.^{3,4}

The reason given for not offering prenatal diagnosis was “Northern Ireland” in two cases and “not clearly documented” in the other cases. This is an inadequate response and needs to be addressed. If parents are offered prenatal tests by general practitioners or obstetricians but decline the offer, this refusal may not be documented in their notes and usually there is no referral. The key messages of the study are that options should be given to the couple, and that parents should be free to make an informed choice, but patients may decline tests that have already been explained to them carefully.

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Dr Lane *et al* comment:

We applaud the system set up in Belfast in 1990 that refers families for genetic counselling once a child has been diagnosed with cystic fibrosis and which aims to make all obstetricians aware of the existence of prenatal diagnostic clinics. However Dr Morrison and colleagues miss several important points about the inquiry, which is part of a larger exercise primarily concerned with the work of non-geneticists who deal with the bulk of the clinical management of patients regardless of whether they have obviously genetic disorders. The chief aim of the inquiry is to raise standards and to encourage good clinical record keeping. In connection with second children with cystic fibrosis, as with the other

arms of the inquiry, we were seeking written evidence that parents had been given adequate information and counselling on available options to allow them to make their own considered decisions. Genetic events are potentially very important to individuals and they may affect generations to come. Keeping adequate records of genetic consultations is as important as keeping those of the more familiar informed consent, surgical procedures, and prescribing.

Our inquiries were inspired by the confidential inquiries into maternal deaths and perioperative mortality, and this cystic fibrosis study once again benefited from exemplary cooperation. We had detailed replies from more than 95% of the obstetricians, paediatricians, and general practitioners who had dealt with families with two or more affected children, where at least one affected child was born between 1 January 1991 and 30 June 1995. The data we received on what was recorded in the notes have been accurately reported in our paper. There were 45 cases in all and we received data from obstetricians for nine of the 10 from Northern Ireland. We were told that four of these couples had been offered prenatal diagnosis in the second affected pregnancy (two accepted, two declined). Hospital notes did not indicate that the other five were offered prenatal diagnosis. No reason was given in three but in the remaining two the reason was given as “Northern Ireland”, presumably a reference to different attitudes compared with the rest of the UK. Consistent with the policy outlined by Morrison *et al*, paediatricians reported that all 10 cases were referred to clinical geneticists (only five attended) after the diagnosis of the first affected child. This study looked for documented evidence that a specific referral for prenatal diagnosis was made during the second affected pregnancy. Morrison *et al* acknowledge that “. . . if parents are offered prenatal tests but decline . . . this refusal may not be documented”. Without documentary evidence, the assumption was made that prenatal testing was not offered and this is reflected in the results. The inquiry does not accept that individual patients have benefited from policies unless there is written evidence in records of their application to that patient. The data show a difference (albeit on small numbers) between Northern Ireland and the rest of UK and the non-application of the 1967 Abortion Act, which no doubt reflects local demand, may be a relevant factor.

We do not suggest that specialist genetic services in Northern Ireland are deficient, far from it, but there are improvements to be made throughout the UK. This is particularly important in the recording of the offer and content of counselling, the offer of prenatal diagnosis, communication between professionals, and communication between professionals and patients. One will have confidence that parents actually have been able to make informed choices if these and the parents' decisions are routinely recorded in the obstetric, paediatric, and primary notes. This is the gold standard of medical genetics.