LETTERS TO THE EDITOR

The Family Fund database – an underused research resource

EDITOR,—I wish to bring to the attention of paediatricians, and other health and social workers interested in childhood disability, the existence of a unique source of information with great research potential.

The Family Fund (now known as the Family Fund Trust for Families with Severely Disabled Children) was established in 1973 to provide grants to families with one or more children whose disabilities cause very severe handicap. Funding is provided by the Department of Health. Until 1995 the administration of the fund was under the direction of the Joseph Rowntree Foundation, but it is now a free standing registered charity. The fund is available to families with disabled children up to the age of 16 years who are resident in the UK (England, Wales, Scotland, and Northern Ireland). Applications can be initiated by parents as well as by health and social work professionals.

The qualifying medical condition is the degree of disability rather than the specific medical diagnosis. In order to make the best use of the funds available, grants are not normally available to families that can afford the relevant costs. Although the award of a grant requires that the medical and economic criteria are both satisfied, and that the items requested are appropriate, all children whose families apply for help are included in the computerised records. The database is in no sense a comprehensive register of all disabled children in the UK, nor is it necessarily representative of them. It has been estimated that 50–75% of eligible families apply to the fund for help. Selection bias arises principally from:

- Local awareness of the existence of the fund. However, at regional level, application rates tend to reflect known differences in the prevalence of disability.

- Professional awareness of the Family Fund criteria for making grants. Medical and social work staff who are experienced in the use of the Family Fund will not waste time on fruitless applications.

- The fund restricts its grants to families whose gross income is below the national average wage. Although applications are sought as widely as possible, this restriction tends to be known by medical and social work staff making referrals or recommendations to the fund.

The fund's register holds data on over 150 000 applicants. New applications are now approaching 10 000 annually. It is therefore self evident that the main strength of the database is its sheer size, which is reflected by very large numbers of children with common disorders and substantial numbers of relatively rare conditions. For example, data are held on approximately 30 000 cases of non-specific mental handicap (learning difficulties), 20 000 cases of cerebral palsy, 12 000 cases of Down's syndrome, 7000 cases of deafness, 4000 cases of childhood malignancy, 2000 cases of metabolic disease (other than diabetes), 2000 cases of cystic fibrosis, 1000 cases of

disabilities caused by head injury, 700 cases of juvenile chronic arthritis, and 500 cases of brittle bone disease.

For the large majority of cases there is a detailed social work report. The main weakness of the database for medical research purposes is that doctors' reports exist for only a minority of children. For reasons of confidentiality, names and addresses cannot be given to researchers without permission of the parents concerned. However, Family Fund staff are prepared to approach parents on behalf of researchers to request permission for medical records to be studied, and experience has shown that the great majority of parents are only too happy to help in this way.

For further information about using the Family Fund as a research resource, please contact: Dot Lawton (Research Fellow), Social Policy Research Unit, University of York, Heslington, York YO1 5DD; tel: 01904-433608, fax: 01904-433618.

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Cellular profile of bronchoalveolar lavage fluid in pulmonary tuberculosis

EDITOR,—Bronchoalveolar lavage (BAL) has been used to study the immunopathogenesis of several respiratory diseases. The aim of our study was to determine the inflammatory changes occurring at the site of a tuberculous lesion in the lung in children.

Eighteen children (mean (SD) age 5.1 (3.2) years, range 1.5–12 years) attending the tuberculosis clinic at the Institute of Child Health and Hospital for Children, Madras who had signs and symptoms suggestive of pulmonary tuberculosis with a persistent radiographic abnormality had early morning gastric lavage and bronchoscopy and BAL done under local anaesthesia. The bronchoscope (3.5 mm Pentax) was wedged into the involved segment and BAL was performed by instilling 2 ml/kg sterile saline in three equal aliquots. There were no complications encountered and informed consent was obtained from the parents. The study was approved by the institutional ethics committee.

The total cell count showed wide variation between cases and the mean (SD) total count (74 (45) × 10⁶/100 ml) was not significantly different from reference values (80 (84) × 10⁶/100 ml).¹ The percentage of macrophages was significantly reduced in those with tuberculosis compared with reference values (56 (25)% v 84 (8)%; *p* < 0.01). The BAL fluid from cases of tuberculosis compared with reference values had a greater mean number of lymphocytes (22 (17) v 10 (6) × 10⁶/100 ml, *p* = 0.02) and eosinophils (10 (17.5) v 0 × 10⁶/100 ml, *p* < 0.001). Bronchial epithelial cells accounted for 6 (4.5)% of total cells. Due to the obvious ethical limitation of enrolling controls, we have used the BAL data on healthy children of Ronchetti *et al* for comparison.¹

Several studies looking at BAL cellular profile in adults with pulmonary tuberculosis have demonstrated increased lymphocyte counts.^{2,3} Nowakowski *et al* found that the CD4/CD8 lymphocyte ratio was decreased in BAL fluid but increased in blood in children with pulmonary tuberculosis.⁴ In this study, we have found a relative lymphocytosis and eosinophilia at the site of the lesion in children with pulmonary tuberculosis. There was a proportionate decrease in the percentage of alveolar macrophages in BAL fluid. More research into the local immunopathology of tuberculosis is required.

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Screening for biliary atresia

EDITOR,—Having discussed this issue with colleagues several times over the past year without a clear consensus emerging I welcomed the recent article by Mowat *et al*.¹ Obviously nobody would seriously argue with the proposition that it is beneficial if children with biliary atresia are identified and treated early, certainly by 40 days after delivery. However there are a number of questions that need to be answered. How good is the screening test proposed in detecting cases of biliary atresia at 2, 3, and 4 weeks and what percentage of the normal population are still slightly jaundiced at these ages? Every paediatrician seeing small infants will frequently see infants of 2 weeks of age who are still slightly yellow, thriving, often breast fed, with normal yellow breast milk stools.

Probably equally difficult for me, in the case being advanced for screening, was the cost benefit analysis attempted. While allowing for a certain amount of advocacy can you seriously introduce a national screening programme involving someone at least looking or checking on the degree of yellowness of every infant at two weeks after delivery and in addition obtain a urine sample from those thought to be still jaundiced, without any additional personnel? I seriously doubt it. The logistics involved in effectively screening a population are considerable and well documented. I enjoyed the two five minute phone calls to track results and don't believe any laboratory test costs £3.50 (for direct bilirubin) in the real world where heating, lighting, insurance and salaries, travel expenses, etc have to be