The lack of funds for clinical epilepsy research in the UK

ABSTRACT—This is a survey of annual research funding for clinical epilepsy projects from major medical charities and the MRC from 1987 to 1989 (taking the latest available annual figures). The MRC provided between £70,000 and £166,000, the medical charities £173,000, and the epilepsy charity £84,000. This equates to between £0.90 and £1.2 per person with epilepsy in the UK per year, which compares unfavourably with funding for other conditions, and by international comparison. There is serious underfunding of epilepsy research in the UK.

The shortage of research funds is a substantial headache for all clinical academic researchers in the UK [1–6]. In recent years, government (central) funding for universities has been heavily cut and the allocation of direct government funds appears to be dictated by short-term or political expediency. Application to the MRC, shorn of funds as it is, results in tortuous procedure, long delays, and failure to fund projects given alpha ratings, and there is a widely held perception that the allocation of MRC funds is biased and unfair [2,3]. Research workers are thus increasingly forced to rely on other sources for funds, principally the medical charities and industry. These considerations prompted this survey into the current funding of clinical epilepsy research in the UK. The findings are disquieting.

Epilepsy is perhaps the most common serious neurological condition. There are about 30,000 new cases a year and over 350,000 persons with active epilepsy in the UK. It is a condition with potentially severe medical and social consequences, and one in which basic and applied research work is most certainly required.

Method and findings

A survey was carried out using published data (the annual reports of charities and the 11th edition of Charity trends) [7], and personal enquiry into the funds made available for clinical epilepsy research from 1987 to 1989 (taking the latest annual figures available from each source).

S. D. SHORVON, MA, MD, FRCP Senior Lecturer in Neurology, Institute of Neurology; Consultant Neurologist, National Hospitals for Nervous Diseases, London Medical Director, Chalfont Centre for Epilepsy

The Medical Research Council (MRC)

The MRC, in the financial year 1988–89, believes it devoted £166,000 to clinical research. This figure requires closer scrutiny, however. It comprises 11 items, but only one is for a research project specifically for epilepsy. The others are for an epilepsy component in the funds either for established MRC units which support research in all areas (eg the MRC Biostatistics Unit, MRC National Survey of Health and Development Division) or for projects which appear to have little directly to do with epilepsy (eg non-genetic biological studies of autism, the application of behavioural memory tests for use in children, long-term outcome after first-ever stroke). Thus, the real MRC involvement in epilepsy is probably nearer to £70,000 than its own estimate of £116,000.

Major research charities

The Wellcome Trust is the largest medical research charity in the UK, and its grant provision now exceeds that of the MRC. In 1988, the Wellcome Trust spent £80,000 on three clinical research projects on epilepsy. In 1988 or 1989 eight other charities known to support work in the area of neurology and epilepsy devoted a total of £93,000 annually to four epilepsy projects.

Epilepsy charities

Another source of income for medical research is the medical charities devoted to specific diseases (‘single-disease charities’). For epilepsy in the UK, only the British Epilepsy Association Research Foundation (BEARF) has a research fund which invites research applications; it gave a total of £84,000 in research funding in 1988–89.

Industrial research support

The pharmaceutical and (to a lesser extent) the medical instrumentation industries carry out clinical research in epilepsy, but the amounts spent on this were not made available for this survey. It seems likely that the figure extends into hundreds of thousands of pounds, and is undoubtedly more than that specifically allocated by the government or the charities. This research is essential but is almost always tied to specific commercial or even marketing topics and often takes the form of a simple drug trial of a new compound.
Discussion

It is difficult to identify the amount of money spent by agencies supporting epilepsy research. The MRC apportions percentages of each grant notionally to specific conditions; thus its figure for epilepsy includes proportions in grants which have only a tenuous relationship to epilepsy. Its contribution to projects in which epilepsy is a major component is small. Conversely, the other charities do not make such an apportionment, and it may be that some epilepsy funding is ‘hidden’ in apparently non-epilepsy projects (however, it is unlikely that this accounts for large sums of money). Nor has it been possible to quantify the contribution for epilepsy research from the block grants from the universities. Even in ‘well found departments’ (ie where senior staff and back-up facilities are provided) carrying out epilepsy research, most clinical projects still need to obtain specific grants from non-university sources. Assuming that only the university departments receiving specific project grants from the medical charities surveyed are in fact carrying out clinical epilepsy research, then fewer than ten departments appear to be active in such research. It is also possible, but unlikely, that I have omitted major funding from a charity not surveyed. Industry funds, in the clinical field at least, are usually restricted to projects immediately relevant to commercial interests (eg drug trials), and although industry probably supports clinical epilepsy research to a greater degree than any other source, the money is narrowly channelled. This survey has been restricted to clinical research. Basic scientific research is also funded from all the above sources (especially industry). Because the potential applications of basic research often cross clinical boundaries, the amount of epilepsy-specific work is difficult to determine, but comments from colleagues involved in basic research lead one to suspect that basic science research funding in epilepsy is also scarce.

In the field of epilepsy, a particular problem is the lack of research funds available from the charities specifically devoted to the condition. It is interesting to compare what might be called the ‘research quotient’, defined as the annual research expenditure by a single-disease charity for every individual in the country with the condition (calculated by dividing the annual research expenditure of the single-disease charity by the prevalence of the disease in the UK population). In the neurological field the research quotient is about £250 for muscular dystrophy, £160 for motor neurone disease, £140 for multiple sclerosis, but only £0.23 for epilepsy! Enquiries made of the Commission of the European Communities reveal that no EEC money is currently allocated to epilepsy research projects.

Non-neurological single-disease charities also spend large sums on medical research. In 1989 the British Diabetic Association (BDA, the largest of several single-disease charities for diabetes) spent over £2-million on clinical research; over £14 million was spent by the British Heart Foundation, and £1.1 million by the National Asthma Campaign. To emphasise the importance of single-disease charities, the BDA made a detailed study of overall medical research for diabetes in the UK, and found that 26% of all support for medical research in diabetes was provided by the BDA. This gives a research quotient of over £13 per diabetic from all sources.

In summary, the situation in the UK is intensely worrying. On the basis of the above figures, the total amount granted by all charitable and MRC sources is only between £0.90 and £1.2 per year per patient (the lower figure being based on a MRC contribution of £70,000, and the higher figure on an MRC contribution of £166,000). This is less than that spent on other neurological and non-neurological conditions, and the failure of central or MRC funding causes special concern in the absence of a large single-disease charity supporting medical research in epilepsy.

UK research funding is also low by international comparison; in the US, for instance, annual expenditure from the government, via the National Institutes of Health, for the epilepsy program is US$ 5.5 million, and the major (but not the only) disease-specific charity (the Epilepsy Foundation of America) allocated over US$1,000 million annually for epilepsy research and fellowships. Although not exactly comparable, these figures undeniably show a much greater degree of investment in epilepsy research, and provide a stark contrast with the UK position. Indeed, it seems remarkable that research in epilepsy is of the quality and quantity that it is, considering the poverty of funds, and that there is a high level of scientific publication [1]. One wonders whether this essentially unstable situation can be sustained. This problem is probably not confined to epilepsy, and the future of medical research in this country should be the subject of urgent debate.

References

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Address for correspondence: Dr S. D. Shorvon, Institute of Neurology, National Hospitals for Nervous Diseases, Queen Square, London WC1N 3BG.