

Correspondence

Sir,
The Sub-Committee for Research of the Arthritis and Rheumatism Council has recently given moral and financial support to enable a National Case Register of the less common rheumatic diseases to be established and maintained at a clinical rheumatological centre. The need for such a Register springs from paucity of understanding of rare connective tissue diseases because in most rheumatology units so few cases of any one condition are seen that the acquisition of information and skill in management is often anecdotal. Many rheumatologists, perhaps wisely, refrain from publishing single cases, so unless experience is amalgamated useful knowledge is unlikely to result.

The object of the register is to increase knowledge and understanding of the identification, natural history, and management of less common rheumatic diseases by establishing a National Case Register of patients suffering from these diseases. This register would provide a pool of clinical material suitable for detailed study.

Interested clinicians who agree to participate will be asked to record simple identification data on suitable cases. These records will be collected and collated by Dr. Hilary Hill at Stoke Mandeville Hospital, Aylesbury, Bucks., and will form the National Register. The scope of the cases to be registered, the details to be recorded, and the means by which the register is to be maintained and exploited will be controlled by the undersigned who form the A.R.C. Case Register Sub-committee.

Conditions to be registered are:

Behçet's disease
Dermatomyositis
Felty's syndrome
Lesch-Nyhan syndrome
Polymyositis
Relapsing polychondritis
Systemic sclerosis
Wegener's granuloma
Whipple's disease

and any connective tissue disease (other than RA) exhibiting features of more than one clinical entity. For example, dermatomyositis plus calcinosis, sicca syndrome plus primary biliary cirrhosis, and any other very rare condition encountered.

Participation in this scheme implies only the provision of data which will be handled by Dr. Hilary Hill at Stoke Mandeville Hospital. The data requested will be of the simplest so as to preserve confidentiality between each consultant and his patient and to minimize the burden of

record keeping. The data would be limited to naming the consultant, the hospital which the patient attended, the patient's name (this is optional), date of birth, hospital and NHS number, and the condition from which the patient suffers.

Application for access to data concerning a particular disease on the Register will be made to the A.R.C. National Case Register Sub-Committee. Each applicant will have to show that he has already done background research into the problem, has a genuine interest, sufficient time and financial support to enable him to complete the project. When access to the list pertaining to a particular disease has been granted, each participating physician would be notified of the applicant's name in writing. The applicant would be supplied with data from the Register (and this would normally not include the NHS number so as to make it impossible for the applicant to trace the patient on his own and the patient's name would only be revealed if the physician-in-charge so wishes). The applicant would be required to make personal contact with each physician who has contributed cases for permission to gain access to his case records and to arrange to see patients where appropriate. The NHS number is necessary only so as to be able to trace patients who have moved from the Area Health Authority and this would be done by Dr. Hilary Hill as co-ordinator to maintain confidentiality. Progress reports would be made to all participants at regular intervals.

The significance of this National Case Register is that it should lead to a greater understanding of the diagnostic problems, treatment, and management of patients. No single unit is likely to see sufficient cases of any one disease to enable a balanced assessment to be made. The establishment and maintenance of a National Case Register would be the first step towards pooling individual cases and extending medical knowledge in an admittedly small, very specialized, but important field. In the long term this Register could benefit rheumatologists and their patients on a national and possibly international scale.

Readers of this journal who are interested in contributing to the scheme please contact Dr. Hilary Hill (co-ordinator) at the address below.

W. CARSON DICK,
HILARY HILL (co-ordinator),
VERNA WRIGHT, and
PHILIP H. N. WOOD

*A.R.C. National Case Register of
Rheumatic Diseases,
Stoke Mandeville Hospital,
Aylesbury,
Bucks. HP21 8AL.*