

MEDICAL RESEARCH COUNCIL

CJD WG 78/1

Circulation
Members of Working Group

WORKING GROUP ON CREUTZFELDT-JAKOB DISEASE

Meeting to be held at 2.00pm on Friday 6 October 1978
in room G10, 20 Park Crescent, London W1N 4AL

AGENDA

1. Chairman's opening remarks
2. Confirmation of proposed terms of reference (CJD WG 78/2)
3. Consideration of arrangements to be made to implement the recommendations made at the meeting on 9 March 1978. These might include the following:

Retrospective analyses

- (a) What data should OPCS be asked to provide? (see Dr Adelstein's letter)
- (b) Who will receive the data and who will analyse it?
- (c) (i) Will Professor Matthews and his staff compare the OPCS data with his own, to discover how many of the same patients are involved?
(ii) If diagnoses are to be confirmed from case notes in at least a sample of cases, will Professor Matthews liaise with OPCS on this problem?
- (d) Mr P Smith has agreed to analyse the combined data from OPCS and Professor Matthews for clustering at a cost of £100-£200. He will require names and addresses, with dates of diagnoses or death. When might this be provided to him?
- (e) If data provided by the Doll/Hill study of 34,000 doctors on the medical register in 1953 is to be analysed for excess death rates from C-J etc. among certain specialist groups, should Sir Richard Doll be asked if this could be carried out by his staff, provided the Council pays the expenses involved?
- (f) Who will collate the information obtained under (a) - (e) and write up?

Prospective studies

- (g) If OPCS are asked to collect prospectively notifications of all deaths from C-J etc., to whom will they send this information, how often and for how many years?

S503/11

.../

78/10.06/1.1

(h) Immunological/genetic studies:

(i) HLA status. (Professor Batchelor has provided addresses of 13 tissue typing laboratories in different parts of the UK.)

(ii) General genetic screening.

(iii) Storage of serum samples for future study of antibody profiles.

How will these activities be organised and who will act as co-ordinator?

4. Timetable and arrangements for future meetings*

5. Any other business

BACKGROUND PAPERS

Recommendations for action which might be taken, made at the meeting on 9 March 1978 (CJD WG 78/3)

Letters commenting on some of the above recommendations from:

- (a) Dr Adelstein (CJD WG 78/4)
- (b) Professor Batchelor (CJD WG 78/5)
- (c) Professor Vessey (CJD WG 78/6)

* Members are requested to bring their diaries to the meeting so that dates for future meetings may be agreed.

Working Group on Creutzfeldt - Jakob Disease Membership List

Professor J N Walton TD MD FRCP (Chairman)
Regional Neurological Centre
Newcastle General Hospital
Westgate Road
Newcastle Upon Tyne NE4 6BE

Tel. 0632 738811

Dr A M Adelstein MD FRCP
Chief Medical Statistician
Office of Population Censuses and Surveys
St Catherine's House
10 Kingsway
London WC2

Tel. 01-242 0262

Mr K Burns (ARC Observer)
Agricultural Research Council
160 Great Portland Street
London W1N 6DT

Tel. 01-580 6655

Professor C O Carter DM FRCP
MRC Clinical Genetics Unit
Institute of Child Health
30 Guildford Street
London WC1N 1EH

Tel. 01 242 9789

Professor W B Matthews DM FRCP
Department of Clinical Neurology
The Churchill Hospital
Headington
Oxford OX3 7LJ

Tel. 0865 64841

Peter Smith
Department of Social and Community Medicine
8 Keble Road
Oxford OX1 3QN

Tel. 0865 511293

Dr A Smithies (Health Departments' Observer)
Alexander Fleming House
Elephant and Castle
London SE1 6BY

Tel. 01-407 5522 x 6863

Professor B E Tomlinson MD
Newcastle General Hospital
Westgate Road
Newcastle Upon Tyne NE4 6BE

Tel. 0632 38811

Professor M P Vessey MD MRCPed FFCM
Department of Social and Community Medicine
8 Keble Road
Oxford OX1 3QN

Tel. 0865 511293

78/10.06/1.3

MEDICAL RESEARCH COUNCIL

WORKING GROUP ON CREUTZFELDT-JAKOB DISEASE

Proposed terms of reference

CJD WG 78/2

1. To consider the practicalities of implementing the recommendations made at the meeting on 9 March 1978 on the feasibility of carrying out epidemiological studies on Creutzfeldt-Jakob disease.
2. To co-ordinate action as appropriate.
3. To report to the Neurosciences Board annually, making at least an informal report at some stage in the 1978/9 session.

MEDICAL RESEARCH COUNCIL

WORKING GROUP ON CREUTZFELDT-JAKOB DISEASE

CJD WG 78/3

Recommendations for action which might be taken - extract from minutes of meeting on 9 March 1978

The following suggestions were made about action which might be taken:

- (i) OPCS might be asked to provide data on the occupations listed for all deaths due to dementia and the other diseases with which C-J might be confused recorded within, say, the last three years.
- (ii) OPCS might be asked to collect prospectively notifications of all deaths from C-J disease, the dementias and other diseases with which it might be confused.
- (iii) The data provided by OPCS might be correlated with that obtained by Professor Matthews (confirming diagnoses from case notes etc. in at least a sample of these cases) to see how many of the same C-J patients were involved. These data should be analysed for evidence of clustering.
- (iv) Data provided by the Doll/Hill study of 34,000 doctors on the medical register in 1953 might (with the authors' agreement) be utilised to see if any excess death rates from C-J disease, the dementias or other disease with which it may be confused, could be identified among certain specialist groups.
- (v) HLA status of C-J patients should be determined.
- (vi) General genetic screening might be undertaken of patients with C-J disease.
- (vii) Samples of serum from C-J patients should be stored for future study of antibody profiles.
- (viii) Although technically outside their remit the meeting recommended that good work should be encouraged on the isolation, characterisation, distribution in the body, routes of infection and methods of destruction of the C-J agent.

78/10.06/1.5