

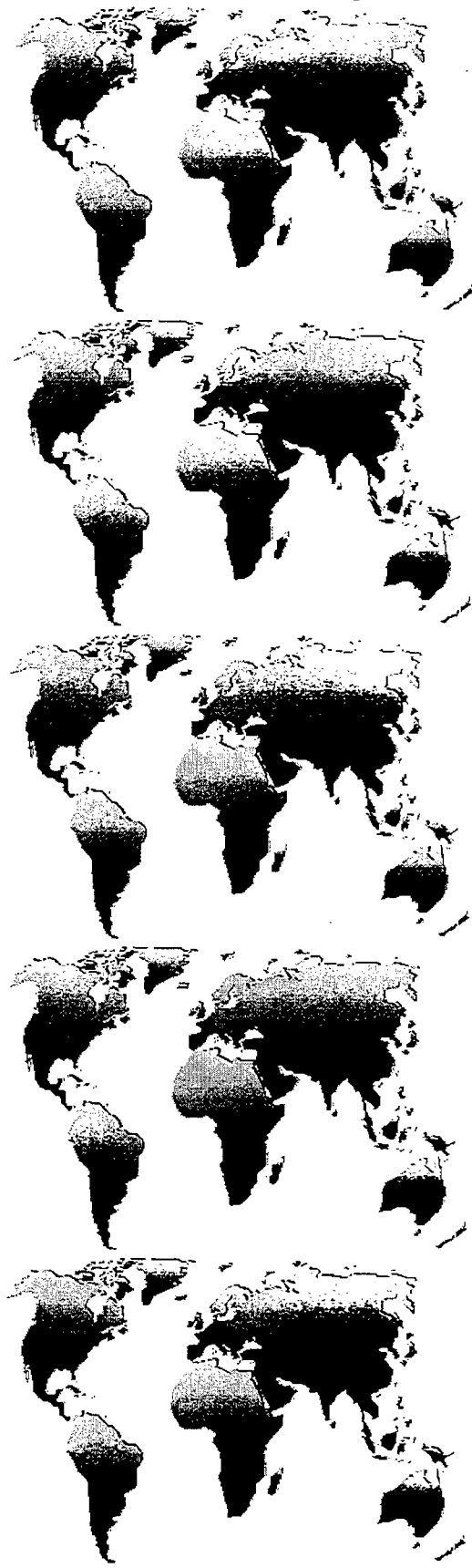
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**Second Meeting  
of the WHO  
Working Group  
on Multiple  
Sclerosis**

**Report**



Department of Mental Health  
Social Change and Mental Health  
World Health Organization  
Geneva



## **SECOND MEETING OF THE WHO WORKING GROUP ON MULTIPLE SCLEROSIS**

**Zürich, 4-5 June 1999**

### **REPORT**

This meeting reviewed the ongoing WHO activities related to Multiple Sclerosis and discussed new projects to be undertaken in this field. A timetable of future activities was produced and specific projects were assigned to those members of the Group responsible for their completion.



**Department of Mental Health  
Social Change and Mental Health  
World Health Organization  
Geneva  
2000**

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## SECOND MEETING OF THE WHO WORKING GROUP ON MULTIPLE SCLEROSIS

### Report

#### 1. INTRODUCTION

Dr L. Prilipko, Coordinator, Neuroscience and Neurological Disorders, Department of Mental Health, opened the meeting and welcomed the participants, explaining that the objective of the meeting was to review progress on the items decided upon during the WHO Working Group on Multiple Sclerosis' first meeting in Geneva on 4 December 1998 and to decide on future actions. A total of 10 of the 12 advisers invited to attend were present (Professor W.I. McDonald and Professor J.H. Noseworthy were unable to attend).

Professor O.R. Hommes, representative of the European Charcot Foundation (ECF) was introduced by Dr Prilipko as an observer to the meeting, the aim being to allow an exchange of views. Professor D.W. Paty (Vancouver, Canada) endorsed the attendance of Professor Hommes at the meeting. Professor A.J. Thompson (London, UK) expressed his preference to continue discussions within the Working Group and suggested that Professor Hommes only be present to deliver his presentation on the Charcot Foundation activities. Furthermore, Professor Thompson expressed his concern regarding the Working Group's confrontation with a *fait accompli* as well as the last minute changes in the agenda. The agenda and list of participants are attached as Annexes I and II of this report. In order to prevent any irregularities with respect to procedural matters in the future, the Working Group unanimously decided to conduct its meetings according to the strictly implemented procedures.

Dr A.N. Boiko was unanimously approved as the Working Group's secretary to assist in the coordination of the planned activities, and Martin Hardens was confirmed as rapporteur.

The Group agreed to a change in the agenda to allow Professor Hommes to present the activities of the European Charcot Foundation as the first agenda item.

#### 2. INITIATIVE OF THE EUROPEAN CHARCOT FOUNDATION

The main objectives of a recent data-based initiative of the European Charcot Foundation (ECF) are the development and implementation of a standardized European database of multiple sclerosis (MS) guidelines/data. The ECF has its own task force related to establishing a standardized electronic medical record, forming an essential data set for the database, establishing the computer adaptation and finally implementing the database. In order to achieve the above outlined objectives, several requirements were identified:

- Establishing the monitoring procedures and EDS requirements
- Establishing and omitting the non-essential data

- Defining the duration of data collection
- Establishing the compatibility of the data-set with the existing database
- Defining the optimal case for optimal care
- Defining the critical event that indicates the purpose
- Establishing the rules for the use of the WHO dictionary.

Recognition that an essential data set is required led to a discussion of the essential data-set for MS and the EDS was established as follows:

1. Increasing irreversible deficit
2. Spasticity
3. Chronic ataxia
4. Chronic pain
5. Congestive dysfunction
6. Depression
7. Fatigue
8. Bladder dysfunction
9. Sexual activity

The essential data set is based on educated guesses and a decision algorithm approach will be employed. This approach will be based on a pathogenic pathway, results of studies, and clinical experience. The likely use for this data set will be for monitoring, risk assessment, intervention, and intermediate outcomes. The database system will be tested on twenty centres, which will each provide 50 patients, requiring a software adaptation to all existing database systems. The centres have not yet been identified.

Minutes of the ECF meeting on 29 October 1999 will be published as a supplement in the journal "Multiple Sclerosis" in two months and the algorithms will be presented at the European Clinical Trial Research Investigation of MS (ECTRIMS) in Basel in September 1999.

It was discussed that the second recommendation in the WHO brochure on MS conforms to the ECF initiative. Dr H.-P. Hartung suggested that the Working Group take notice of the work of the ECF and to help promote the initiative. Professor Thompson commended the ECF and indicated that it should be seen as one among many similar initiatives, such as the Cockrane and MS-Connect collaboration currently under consideration by member organizations of the International Federation of Multiple Sclerosis Societies (IFMSS). Professor Thompson emphasized that the Working Group remains completely independent and expressed his concern over the non-evidence-based approach of the ECF, proposing that the Working Group be more pro-active by steering the efforts of the individual initiatives.

Professor Kesselring thanked Professor Hommes and stated that the Working Group is open for discussions about this initiative. At that point, Professor Hommes left from the meeting.

On this particular subject the following recommendations were agreed by the Working Group:

- To involve the IFMSS in the ECF pilot project
- To monitor the progress of the ECF pilot project
- To obtain more information on the ECF project
- To limit the number of presentations of individual initiatives to one per meeting

### **3. THE FACT SHEET FOR MULTIPLE SCLEROSIS**

The target for the fact sheet on MS was confirmed as being journalists. The objective is to have the document published in time for the ECTRIMS/ACTRIMS starting on 12 September 1999. The deadline for Professor Thompson to complete the final manuscript of the fact sheet is the end of June 1999, for submission to the other members of the Working Group. After submission of the final manuscript, the additional delay for publication is five weeks. Both Professors Paty and Thompson were commended for their work to date on the fact sheet.

The following recommendations were put forward for Professor Thompson to take action on:

- Inclusion of a paragraph on the "Burden of Disease"
- Inclusion of comments on the rise in Multiple Sclerosis in developing countries
- Incorporation of a statement highlighting that it is not clear whether improved diagnosis is responsible for the increase in prevalence in Multiple Sclerosis
- Better definition of the symptoms of Multiple Sclerosis
- Need to emphasize the particular burden on young females
- Emphasize the "clinical diagnosis" (should be a separate heading before "social implications" and after "symptoms")
- Include a section on the cause of Multiple Sclerosis: (such as "it is widely accepted that tissue damage aggravates the immune response")
- Multiple Sclerosis represents a spectrum of symptoms. Under symptoms add:
  - Sexual and bladder disturbance
  - Gait
  - Mood disturbance
- Emphasize the disease course and predictors of the disease.

### **4. THE BROCHURE ON MULTIPLE SCLEROSIS**

The objective of the brochure on Multiple Sclerosis is to represent a recommendation to WHO by the Working Group. Mr Hardens was reconfirmed as editor of the brochure. The deadline for Mr Hardens to produce the new version and distribute this to participants is the end of June 1999. Comments on the new version are required within 7 days after receipt. The target is for Dr Prilipko to receive the comments by 15 July.

The following additions were recommended for the brochure:

- A section on direct and indirect costs, using the introduction from “Outcomes Data and Epidemiology”
- Early and accurate diagnosis, for example by a specialist
- A concluding section.

## 5. GUIDELINES ON DIAGNOSIS AND THERAPY

The following guidelines were identified and discussed:

- The MERITS guidelines document<sup>1</sup> was distributed and its value acknowledged; it was remarked that this document would gain from the addition of other forms and the treatments of the disease (rehabilitation).
- The guideline by the Multiple Sclerosis Council for Clinical Practice Sclerosis were presented: The guidelines for fatigue and the bladder have already been published, whereas guidelines for vaccination and spasticity, and immuno-modulating agents were in the last stages of preparation. Establishing guidelines for pregnancy, depression and mood changes are planned for the future.
- Guidelines are also provided by the Cochrane Collaboration, which use an evidence-based approach, employing a systematic review of published literature.
- Professors Noseworthy and McDonald are planning to undertake a project on data collection in collaboration with IFMSS.

Dr Prilipko advised that the number of guidelines in Multiple Sclerosis is much larger than in other neurological indications, suggesting that the Working Group should function as a commentator on all guidelines, rather than producing its own. All were in agreement on the Working Group's role to review new guidelines and comment on their applicability.

The validation of existing guidelines is a two-step process, involving (1) acknowledging the existence of guidelines, followed by (2) reviewing the updates. The two tasks of the Working Group were ascertained as ensuring the applicability of the guidelines on a worldwide basis and the clinical usefulness of the guidelines.

### 5.1 Recommendations

The recommendations in relation to establishing guidelines on diagnosis and therapy of MS were agreed as follows:

- The Working Group will create a list of available guidelines and initiatives by proactively approaching other groups with the request to provide a half-page description of their initiative. An editorial or publication in a peer

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<sup>1</sup> European Journal of Neurology, Volume 6, Supplement 1, April 1999.

reviewed journal on individual efforts in guidelines will be produced by the Working Group.

- Professor Thompson to contact the Cochrane Collaboration and the Multiple Sclerosis Council
- Professor Thompson to assess timing implication for Multiple Sclerosis Journal.
- Contact needs to be established with the national neurological societies in order to query which guidelines are being produced.
- Research needs to be done on whether the newsletter of the WFN, at the occasion of the World Federation of Neurology (WFN) meeting (London, 2000), can be used to raise awareness about the Working Group on MS.

## **5.2 Actions**

It was decided that in order to achieve the recommendations with regard to guidelines, the Working Group needs to perform a number of tasks and objectives. The first step, which was to establish appropriate guidelines, was discussed as involving the review of existing guidelines. There are several revised tasks and objectives for reviewing other guidelines, including:

1. A questionnaire to request which ongoing initiatives should be dispatched. The secretary of WFN can provide a list of national neurological societies, with individual members of the Working Group covering a specific geographical location. The designated countries together with the members assigned to cover them are as follows:
  - Americas: Professor D.W. Paty
  - South Asia and Asia mainland, Eastern Mediterranean: Dr B. Singhal
  - Middle East and Africa: Professor A. Siva
  - Central and Eastern Europe and CIS: Dr L. Prilipko
  - Western Europe: Professor A.J. Thompson
  - South East Asia: Dr E.W. Willoughby
2. A draft letter to Multiple Sclerosis Societies and Neurological Societies will be prepared by Mr Hardens and sent along with the draft minutes to Dr Boiko. The letters together with the brochure will be sent at end of August 1999.

## **6. FUTURE ACTIVITIES OF THE WORKING GROUP**

### **6.1 Publication of documents**

The "Epidemiology of Multiple Sclerosis" (author: S. Warren) will be published as soon as possible by WHO, at the request of the author. The introduction is to be written by Professor J. Kesselring (Chairman of the Working Group) and endorsed by the Working Group. WHO will require data on epidemiology in the near future and it is hoped that the publication will provide a good first source.

Publications for the use by patients should be the responsibility of the IFMSS and not of the Working Group. Dr E.W. Willoughby is to contact Peter Sheridan of IFMSS about improvement of patient materials. "Frequently asked questions in Multiple Sclerosis" for mainstream neurologists is available on the IFMSS web site. The Working Group also discussed reviewing Quality of Life although only in the future (it was noted that a consortium of Multiple Sclerosis Centres has produced a new scale for the evaluation of Quality of Life). There was a general statement that only properly validated instruments should be used.

## **6.2 Teaching courses in various regions**

Relating to the discussion on teaching courses, there was an agreement on seven specific activities to be performed:

1. Trainee-ship at MS clinics
2. Teaching courses, including:
  - Bedside teaching
  - How to run a clinic
  - Data collection methods
3. A visiting faculty at annual meetings of neurologists in developing countries
4. Participation in regional meetings to increase awareness using the WHO Regional Offices (e.g. in December 1998 in Heidelberg 100 neurologists convened to discuss epilepsy). The schedule is one region per year; the first region will be Europe (and linked to Dublin 2000) and there will be a declaration of the issues discussed in the meeting.
5. Dissemination of travelling seminars and teaching courses whereby WHO sends experts to various countries to educate the local neurologist. There is a requirement for such educational efforts and it is believed that members of the Working Group would be prepared to accept trainees to their centres.

## **6.3 Collaboration with IFMSS/ECTRIMS/ACTRIMS/RIMS, Guideline Panel**

The major issue is the care of young disabled, which is the focus of WHO across different departments. In this respect, collaboration with the World Bank and UNICEF should be contemplated. The issue of care of young disabled will be primarily approached as an awareness programme.

### **Recommendations**

- To establish links with other WHO initiatives (e.g. brain injury)
- To promote the adaptation of the MERITS guidelines in each of the participating countries to raise awareness.
- To organize regional meetings as separate events and invite representatives of the Ministries of Health of the participating countries.

However, concerns were voiced about the independence of the Working Group. Dr Prilipko was encouraged to raise funds from other sources, rather than relying solely

on pharmaceutical companies. The involvement of IFMSS may be required to launch the fund-raising efforts.

#### **6.4 “Therapeutic Claims”**

The publication “Therapeutic Claims” is still in progress. It is to be published as “endorsed by the Working Group on MS” and will be finalized on 15 July 1999. Dr Prilipko cautioned the use of logos on the publication and will verify the procedure of use.

### **7. OTHER BUSINESS**

It was noted that the ICD-10 classification on MS is very inadequate and the Working Group will need to ensure that the next ICD version is modified. The involvement of the Working Group in the update of the list of Essential Drugs was accepted at Dr Prilipko’s encouragement.

#### **Recommendation**

Dr Prilipko is to notify the Essential Drugs Committee and establish contact between the WHO Expert Committee and the Working Group on MS.

### **8. CLOSURE**

It was decided that working group meetings are usually held once a year for two days, however, it is believed that they should convene more frequently, particularly in view of the target date, tentatively scheduled for Friday, 11 February 2000.

## ANNEX 1

### AGENDA

1. Welcome and discussion on procedures
2. Activities carried out by the Charcot Foundation
3. Discussion on "The Fact Sheet for Multiple Sclerosis"
4. Discussion on "The brochure on Multiple Sclerosis"
5. Guidelines on diagnosis and therapy
6. Books on Multiple Sclerosis under the auspices of WHO
7. Future Activities of the Group
  - Publication of documents
  - Teaching courses in various regions
  - Collaboration with IFMSS/ECTRIMS/ACTRIMS/RIMS, Guideline panel
  - The International Multiple Sclerosis Week in Basel, September 1999
  - Support by pharmaceutical groups
8. Closure

## ANNEX 2

### LIST OF PARTICIPANTS

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\* Invited but unable to attend.

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