

**FOUNDING MEETING OF THE INTERNATIONAL ALLIANCE OF
ALS/MND ASSOCIATIONS
SOLIHULL, BIRMINGHAM. 4-6 NOVEMBER, 1992.**

This meeting took place following the 3rd International Symposium on ALS/MND. Representatives at this meeting were from organisations from the following countries -

New Zealand, France, Italy, U.S.A., Ireland, Scotland, South Africa, Sweden, Canada, Japan, Spain, Switzerland, Denmark, Uruguay, Croatia, United Kingdom, and Australia.

The delegates were addressed by Her Royal Highness the Duchess of York, who stated her wish to continue her work in support of the Alliance.

As Australia's representative, I was invited to respond on behalf of the gathering, thanking Her Royal Highness for her attendance, and her continued support which means so much to so many MND people worldwide. A presentation was made of the insignia of the meeting.

BUSINESS SESSIONS.

Responses to the Consultative Document which MNDAA had made earlier input, were as follows -

1. OBJECTS: These were AGREED as follows:

- * to increase awareness of ALS/MND worldwide.
- * to exchange and disseminate information relating to -
 - Patient Care and Disease Management
 - Research
 - Effective organisation.
- * to stimulate and support research.
- * to provide an international identity.
- * to improve the quality of care.
- * to support the development of new associations.

2. MEMBERSHIP: This was AGREED as follows: Membership of the Alliance will be open to non-profit, independent associations not subject to any other body, with a defined constituency, whose objects are in accord with those of the Alliance, and which accept the objects of the Alliance. The Executive Committee will, on behalf of the general council, approve applications for membership; all founding members will be eligible for full membership.

For organisations or individuals not wishing, or not eligible to become full members, there will be the special status of Corresponding Member, with entitlement to receive publications and attend meetings of the General Council as observer, but without the right to speak or vote.

Membership criteria will be specified by the General Council.

3. VOTING: Each member, regardless of size, resources, population or number of members, should have only one vote in the General Council.
4. REPRESENTATION: There should be provision for the appointment of national representatives where there is more than one association within a country, and of regional representatives for several countries, but these should not attract double voting rights.
5. GENERAL COUNCIL: The Alliance should be governed by a General Council consisting of all members meeting annually or by special requisition. Members unable to attend meetings should be able to express their views and vote by post/telecommunications. A quorum should be set in the constitution.
6. EXECUTIVE COMMITTEE: The Executive Committee should consist of 7 members and should act to implement the policy of the General Council. Members will act in their personal capacity rather than as representatives or delegates, and will serve for up to three years, retiring in rotation 2/2/3, and eligible for re-election. The General Council will endeavour to ensure a regional spread of Executive Committee members. Meetings should be in person, with a quorum of three, and views and votes of those not attending should be by post/telecommunications when the quorum is met. The executive committee should have the power to appoint sub committees as necessary.
7. TIME LIMITS: The constitution should specify time limits for setting meeting dates and circulating agendas. Annual meetings should be within 18 months of the previous one.
8. PATRONS: It was AGREED that Professor Stephen Hawking be approached to become the first the first patron of the Alliance.

NOTE: I am pleased to inform you that Professor Stephen Hawking has since accepted the invitation.

Participants were asked to nominate prestigious individuals, with some connection with ALS/MND, who the provisional committee could invite to act as patrons. A broad geographical/cultural spread should be the aim.

Patrons would be non executive.

9. SUBSCRIPTIONS: The MNDA UK representatives explained that the work which it was now carrying out and which it offers to continue under the auspices of the Alliance, was funded from its main funds, and through the 'Stephen Hawking Fund For International Information Exchange on ALS/MND' which consists of donations from outside the UK.

Discussions showed that a subscription of say \$100.00 which in some countries would be a very small token, would in others represent more than the monthly salary of a senior doctor. It was therefore AGREED that though provision should be made in the constitution, no subscription would be required at present.

It was also AGREED that when a subscription is fixed, there should be provision for associations to sponsor the subscription of bodies unable to afford it.

10. SERVICES: The services to be provided by the Alliance are:

- information exchange through The Bulletin and other media.
- international conferences, including the International Symposium on ALS/MND
- representation to international governmental and non-governmental bodies.
- international support for research.
- other services as appropriate.

The Alliance should be able to co-operate or act in concert with other bodies on matters of common concern.

11. SECRETARIAT: The offer by MNDA UK to provide the Secretariat until review in November 1993 was ACCEPTED with thanks. It was Agreed that the secretariat should be under the direction of the Executive Committee on behalf of the General Council.

The composition and location of the Secretariat would be agreed by the Executive committee, on behalf of the General Council, with the host organisation.

12. REGISTRATION/INCORPORATION: It was agreed that the Alliance should be registered as a non profit organisation (charity) in the UK, and that the advice of the lawyers should be taken on the need for formal incorporation as a legal company.
13. WINDING UP: It was AGREED that legal advice should be followed.
14. NAME: Subject to the advice of the designer on a short name for publicity purposes, it was AGREED that the name should be The International Alliance of ALS/MND Associations, or as correctly translated in the language of each member.
15. CONSTITUTION: It was AGREED that the registration should take place in the U.K. and that the brief to lawyers be that the constitution be based upon the consultative document.

The provisional committee should approve the resulting draft and supervise the ensuing process.

The associations, as defined by the membership criteria, should then be invited to give their assent to the constitution as a pre requisite for membership.

Associations should aim to be represented at each meeting by the same individual.

16. WORK PROGRAM: Discussions took place on a work program to be undertaken by the Alliance under the following headings, Awareness, Meetings (including 4th Symposium), Membership, and Fundraising.
17. COMMUNICATION. Directory and Exchange Bulletin.
 - 17.1 It was felt that the Directory could be expanded to include a description of the association, approximate numbers of members with MND, and details of research funded by the association.
 - 17.2 The Exchange Bulletin to provide the main forum for communication within the Alliance.

Audience: primarily lay associations, but associations should redistribute material to members and researchers as they feel is appropriate.

Subjects covered by the Exchange Bulletin: patient care, research, international organisation news, administration of voluntary organisations, current awareness section, details of published papers etc.

Format: One document with different subjects in different sections for ease of photocopying by associations. The main language will be English.

Assessment of contributions: Scientific articles should be assessed by peers within the same field.

Reports and Standardised Information: The Alliance may be the forum for producing reports on the needs of people with MND to use as lobbying material in individual countries. In addition, agreed standards for information on patient care would ensure that all members were consistent in the information which they provide.

18. DESIGN. Discussions took place with a designer for a design for the Alliance. Observations included, target audience; that the name of the disease is important; the design should appear authoritative and elegant, but also friendly and accessible; it should be one colour, capable of photocopying and faxing clearly, and should be compatible with widely available computer software.

19. ELECTION OF PROVISIONAL COMMITTEE. The following were elected -

Chairman - Eithne Frost - Ireland.

Members - Wendy Fisher - USA.
- Mavis Gallienne - Australia.
- Diane Husband - South Africa.
- Yukio Matsuoka - Japan.
- Carlo Pasetti - Italy.
- Jim Tew - U.K.

Secretary General - Peter Cardy U.K.

Editor - Ruth Carlyle U.K.

In conclusion, I should also report that there was a great feeling of co operation amongst all participants at the meeting. Through international understanding we must surely hasten our goal to conquer MND, and in the meantime provide better information and services to MND people who require our assistance now. I was pleased to be joined by Norm Minton, Motor Neurone Society - Newcastle Hunter Region during part of the proceeding, thankyou Norm for your support. It was a honour to have represented MNDAA at this meeting.