

WORLD ALLIANCE OF NEUROMUSCULAR DISORDER ASSOCIATIONS

4th INTERNATIONAL ASSEMBLY- DELEGATES MEETING

VANCOUVER CONVENTION CENTRE- WEDNESDAY, 10TH JULY 2002

VANCOUVER, CANADA

Present:

Denise Ganley, Hisanobu Kaiya, Shizuko Kawabata, Alex MacKenzie, Ruth McKenzie, Dr. Maruta Naudina, Ysbrand Poortman, Yves Savoie, Boris Struk, Dr. Oscar Vincent, Mayana Zatz, Chang-Oing Zhu

Regrets:

Andy Esworthy (Australia), Dinggho Shen (China), Piraye Serdaroglu (Europa), Lee Leith (South Africa), Ekrim Abdel Salam (Middle East)

1. Welcome & Introduction

In the absence of the president, Andy Esworthy, Ysbrand Poortman welcomed all present and in particular Mrs. Kawabata from the JMADA (foundermember of WANDA) and the new representatives from China, Latvia and Mexico.

He stated that all continents were represented except for the representative from Africa who was ill and unable to attend the Assembly.

He thanked Yves Savoie of the MDAC for hosting the successful WANDA-dinner and for the invitation for attending the national MDAC- conference later that week.

He reminded the audience to the WANDA- scientific conference on translational research later that afternoon.

WANDA focus is on supporting the establishment of new and of emerging MDA's, with the ultimate goal of having MDA's in all countries. WANDA is not only about North America and Europe working together as evident in the representation of Board members from all continents.

He requested that each person introduce themselves and so happened.

Oscar Vincent from Uruguay handed over the flag of his country and the respects of his NMDA.

Ysbrand Poortman called the meeting to order at 11.15 a.m. on 9 July, 2002.

2. Confirmation of the Minutes of the Previous Meeting held in Adelaide, Australia 2nd September 1

The chairman paraphrased the minutes of the previous meeting in Adelaide so that they could be read into the record. Some of the items covered were the name change, internet and newsletter. There were no comments from the audience. The minutes will be posted on the web for people to react through that forum.

3. Approval of Agenda

The agenda was approved. Papers were circulated on June 25th but many of those present had not received the information.

4. Constitutional affairs

4.1. Introduction.

The chairman introduced the subject by recalling the discussion in the previous assembly and the as yet limited means of the alliance demanding simple and adequate structure and procedures. Moreover he expressed the need for a legal identity as WANDA was maturing and getting involved in various joint ventures and cross border projects.

The present continental structure was based on practical and principle factors and agreed to at the meeting in Kyoto in 1994.

Representatives of a continent were supposed to be dedicated and highly respected people in the field of NMD and well known in their area, with extensive networks including well established contacts with the various NMDAs and/or parent/patient groups, agreeing with the objectives of WANDA and with the will, capacities and abilities to contribute to the achievement of these objectives. Moreover they are all supported by their national or continental NMDAs.

In earlier assemblies it had been determined:

- a. for reasons of equity, pragmatism and management to focus on equal and best representation of all continents in the board
 - b. to focus on research and development as a priority also because the work in the disability and handicap area are of a more general nature and not NMD specific and more relying on national infra structure and legislation. Moreover with the present means WANDA would be unable to work successful in this area.
- Important topics to be discussed were the continental structure, the composition of the board and the acceptance of International Neuromuscular Disease Specific Groups (INDSG) as members and the option for subscription in kind.

4.2. Discussion on the Constitution

The 3rd draft for a constitution was submitted to the assembly and was subject of much discussion.

4.2.1. Continental structure

The continental structure is an important principle anchored in the document and which was thought for the coming years the most pragmatic concept given the priorities for influence of as many countries as possible and for stimulating research for diagnosis and treatment.

It was stated from the audience that by having continental representation, you miss a lot of richness from specific national associations.

The relationship was discussed between the continental vice president and the NMDAs in his/her area. It turned out that each continent was very different in number, size and program of NMDAs and that the role of the NMDAs in the various continents was not quite clear.

To address the specific needs of the different continents and to follow the ideas/wishes of the various NMDAs in these regions was considered a challenge for the vice president of that continent.

The consensus was that continental mechanism is one that works today, with a long-term view to have all the national members being a member and involved in the Governance of WANDA.

There were unclarities towards the position of New Zealand. The representatives of New Zealand suggested representation as a distinct unit, to be separate from Australia. With satisfaction was taken notice about various developments in South East Asia and Oceania.

4.2.2. Board

The Board is composed of dedicated, respected, influential people with extensive networks from each continent serving for a 4-year period.

The audience agreed with the proposal to have additional to the vice presidents of the six continental areas

- a. an additional overall president
- b. a secretary general (and treasurer)
- c. a vice president for the area North Africa and Middle East.

Andy Esworthy did not stand for prolonging his presidency but was willing to stand for election as Secretary General.

The audience appreciated this option and appointed Andy Esworthy as Secretary General.

There was not a proposal for the newly created position of an overall president.

Ekrim Abdel Salam from Egypt was welcomed as vice president for the middle east region.

The audience agreed with the re appointment of the sitting board members and the appointment of Alex MacKenzie in the place of Michael Brooke of Canada and of Lee Leith as the successor of Joop de Venture (who left for family reasons)

4.2.3. Membership

Membership is open to all associations and with equal rights and regardless size, budget or program. NMDA (US) has the same rights as NMDA (Uruguay) or NMDA (Latvia).

There was extensive discussion on the position of international disorder-specific organisations. There was a proposal for a policy that provides a class of membership for international disorder-specific associations, as long as they recognize the umbrella role of the national umbrella associations (NMDAs) and undertake to work in good collaboration. There was consensus for this proposal, with a need to have it integrated into the Constitution.

4.2.4. Membership fee / subscription

It was agreed that for the short term membership fee was voluntarily and could be paid in kind and that executive activities could be delegated to members paying in this way their subscription towards WANDA

5. WANDA- focus disorder

Previously WANDA had focussed on Pompe disease and at present worked on SMA. (see WANDA-news bulletin.).

WANDA aims at raising on a global level awareness for this disease and to produce an analysis of the strong and weak point on the road of this disease to therapy. Moreover it strives to scientific contributions in the format of bringing together (potential) interested groups and more specific in the field of genetic epidemiology.

A question was then raised as to the appropriateness of FSH as an area of focus for the next 4 years.

There was a discussion on this subject as towards the criteria for selection and the fact that FSHD was not considered to be in a turbulent stage needing support. Moreover there was already an International FSHD-group. It was agreed to make contact with this group and discuss the WANDA- options and activities for FSHD and the planned activities of the IFSHD). It was concluded that FSHD could be the third WANDA-focus disease and that feedback would be given through the web..

6. Future directions

The chairman presented a short term and, as an option, a long term program.

6.1. Short term program

A. improve the present infra-structure of WANDA

- * secretariat, visibility & profile, website, presentation materials
- continental representation and function
 - strengthening the formation of continental alliances
 - supporting the formation of new NMDAs
- fundraising

B. international NMD- specific groups

- finish program on SMA
- orientation on FSHD as a next focus disease

C. WANDA- Conte Academy Forum (WCAF)

To further carry out the activities as indicated in the charter

- research focussed website (worldforum)
- subject bound workshops
- disease specific workshops
 - concluding workshop on SMA
 - workshop on FSHD?
- genetic epidemiology
- implementation of (ENMC) diagnostic criteria

D. strengthening emerging NMDAs and supporting initiatives for new NMDAs in countries where so far none exist

E. Other joint ventures with groups, companies or institutions sharing objectives of WANDA

F. Extending of contacts with

- WFN- working group on NMD, org. committee Xith ICNMD, (Istanbul-congress)
- WMS (education and news in JNMD)
- ENMC (coordination and support for implementation of agreements)

- GCA (WCAF, education, news in AM)
- MSM (communication)
- G. Participation and representation in global organizations
 - WHO, (department of non communicable diseases)
 - UNESCO, (bio ethic committee)
 - IGA (International Genetic Alliance of parent/patientgroups)
 - IAPO (International Alliance of Patient Organisations)
 - WAOPBD (International Alliance of Organisations for the Prevention of Birth Defects)
- H. Policy development on strategic issues
 - Role disease specific patientgroups
 - Support to global joint ventures (trials)
 - Pathways to therapy
 - Joint ventures with industry
 - Dismantling of false hope treatments

6.2. Long term program

- member representation on the national, regional & continental level
- differentiation towards needs of small and of big NMNDAs towards global issues
- educational services and exchange programs for underserved countries
- strategic alliances with industry
- disease specific programs

7. Any other business

It was repeated that communication within WANDA was poor and that the subject needed much attention. Yves Savoie noted the need to be more prepared for the next XI ICNMD- congress and WANDA- assembly so that advance communications and emails could start sooner. There was no other business tabled.

8. Close of Meeting

The meeting close at 3.40 pm.