

**WORLD ALLIANCE OF NEUROMUSCULAR DISORDER ASSOCIATIONS**  
**Board Meeting Held at the Corfu Palace Hotel**  
**Friday 24<sup>th</sup> May 2002**

**1. Present:** A Esworthy- President, Y Poortman, A Mackenzie, M Zatz and H Kaiya

**2. Apologies:** L. Leith

**3. Previous**

**Minutes:** The minutes of the previous meetings held on the 30<sup>th</sup> September 2000 and the 1<sup>st</sup> October 2000 in Capri, the minutes of the 21<sup>st</sup> April 2001 in Naples and the minutes of the joint meeting between WANDA and the Gaetano Conte Academy were confirmed as true and accurate records.

**4. Business arising from previous minutes:** Covered under the following business.

**5. Other**

**Business:** **1. WCAF Update**

A. Esworthy and Y. Poortman reported on the meeting of the Board of WCAF held just prior to this meeting and stated that the Conte Academy are still supportive of WANDA and that they stated there was now 23,420 euro's available for the 2002 budget out of which the cost of this meeting would be met. This sum included 8 million lira remaining from the 2001 budget. It was noted that although there was a separate budget for the WCAF web site, that this would now have to be met out of the WANDA budget as Professor Negro had intimated that funds were at present tight.

**2. WANDA Constitution**

A Esworthy reported that a new draft of the constitution had been circulated to A McKenzie and Y Poortman for a meeting held in Canada a few weeks ago. Copies to be given to M Zatz and H Kaiya for discussion tomorrow.

One change to the Constitution that was discussed was the representation on the WANDA Board. There was agreement that there should be up to 9 Board Members consisting of delegates from the following continents: North America, South America, Australia and New Zealand, Europe, Middle and South Africa, Asia and Middle East and North Africa. In addition to the seven continental delegates, there is provision to have a separate President and Secretary General. This would allow flexibility to appoint a President and Secretary General who is not a continental delegate thereby spreading the workload as much as possible. This format was agreed to. It was also agreed on the suggestion of Y Poortman that Ms Abdel Salam should be approached to be the Continental Delegate for the Middle East and North Africa. A. Esworthy and Y. Poortman to approach during this meeting.

**3. WANDA Web-site**

It was agreed that WANDA web-site should have a new domain name as the current one is difficult to navigate. It was requested that all Board Members give this some thought and send their suggestions to A Esworthy. There was also discussion to have a private area for Board Members to access correspondence such as board minutes and other private papers. Y Poortman to establish for those Board Members who wish to access this service.

#### **4. ICNMD Vancouver**

A McKenzie outlined the program for WANDA's meetings in Vancouver in association with ICNMD as follows-

##### Wednesday 10<sup>th</sup> July

11:00 am- 1.00 p.m.: WANDA General Assembly

1:30 p.m.- 4.30 p.m.: Scientific program on translational research for DMD, MYDY, FSH and SMA.

4:30 p.m.: Reception.

A McKenzie to send agenda ASAP to A. Esworthy for inclusion in a promotional letter to be sent immediately following this meeting.

##### Saturday 13<sup>th</sup> July

Family Meeting

Following this family meeting, the Board of MDA Canada have invited the Board of WANDA for dinner.

It was also agreed that WANDA should be on the program for the opening session. A McKenzie to follow up.

It was noted that there would be no charges to WANDA for the cost of hosting the Board Meeting and Scientific meeting at ICNMD Vancouver.

#### **6. Future structure**

##### **of WANDA** **1. President**

It was noted that it was necessary to find a new President following ICNMD Vancouver and that A Esworthy and Y Poortman had proposed to MDA Canada that they take over this role which at the time included the Secretariat. Since that time, it was agreed that the Secretariat need not travel with the President. It was therefore felt a counter offer following the refusal of MDAC to accept the initial proposal could be made outlining the changes agreed to today. A McKenzie felt that Brian Kellor, a past President of MDAC, would make a good President but that it may take sometime to reverse the current situation. He also suggested that George Karpati would make a good President and following discussion it was agreed that such an approach could be made following the ICNMD Vancouver. It was also noted that M Zatz declined a request as did Y Poortman. MDA Japan indicated they would consider such a request and that this issue should be placed on the agenda for the Vancouver Board Meeting.

##### **2. Secretariat**

A Esworthy informed the meeting that as he was retiring in July, he was prepared to maintain the Secretariat in the short term providing basic admin costs are met. However, it was felt that it was more appropriate that the Secretariat should reside with an active MDA who could fund same. This offer was accepted.

##### **3. Corporate Image**

It was agreed that there was a need for some professional publications such as a case statement folders, brochures, letterhead, business cards etc. Such professionally produced items would include achievements to date plus the vision for the future and would show the professionalism of WANDA to potential supporters. It was agreed that A Esworthy would design appropriate stationary. Y Poortman agreed to write the words for the brochure etc and H Kaiya agreed to pay for printing and mailing.

#### **7. Fundraising**

It was agreed that fundraising should take place only to International Companies and not on any local or national basis. Such approaches could be made to the Diagnostic industry, Pharmaceutical industry, World Bank and other such Institutions. Y Poortman agreed to produce a two-page paper on fundraising which will be circulated to Board Members for discussion.

## 8. News Bulletin

### June 2002

H Kaiya informed the meeting that he had already received two manuscripts and that the responsibility for other articles rested with Board Members who agreed to complete their responsibilities within the next 10 days. All articles should be e-mailed to Yoshi Kaiya ASAP together with photos. Y Poortman agreed to send a list of addresses of MDA's where the News Bulletin should be posted plus the numbers for each Association.

### News Bulletin Autumn/Winter 2002 (Northern Hemisphere)

H Kaiya agreed to fund a second issue of the New Bulletin in 6 or 8 months time. It was agreed that further discussion on the content and format should be held in Vancouver.

The meeting adjourned at 4.30 p.m. It was agreed to meet again at 3.00 p.m. on Saturday 25<sup>th</sup> May.

### The meeting resumed at 3.00 p.m. Saturday 25<sup>th</sup> May 2002

Also present at the meeting Beatrice McKenzie.

### **News Bulletin June 2002 (continued)**

The responsibilities for articles for the fourth coming News Bulletin were reiterated. It was also agreed that A McKenzie would prepare a brief report on the epidemiology workshop.

## 9. WANDA Continental Delegates

A Esworthy and Y Poortman reported that they had discussions with Professor Abdel Salam who agreed to co-operate on behalf of the Middle East and North Africa. Y Poortman to send information and previous minutes.

## 10. Constitution

A copy of the Constitution was pre-circulated. A Esworthy explained that items 4.3, 4.5, 4.6 and 6.2 needed slight amendments to reflect that WANDA works on a International level and would not cut across national Association's responsibilities. It was noted that the Constitution should be a guiding/working document and the need for comment from Board Members was requested. Please send comments ASAP to A Esworthy. The document will then be presented to a Solicitor for comment at prior to registration. Y Poortman agreed to look at tax implications prior to registration.

## 11. Focus Disorder

The current focus disorder, SMA, was now coming to the closing stages. It was agreed that there was a need to have a concluding strategic meeting and then prepare the final paper. A McKenzie suggested Y Poortman should visit the "Fight SMA Group" in Baltimore in the coming weeks. This to be arranged between A Mackenzie and Y Poortman

## 12. WANDA Links

A discussion took place with regard to links with organisations such as W.M.S, I.C.M.D, W.F.N, E.N.M.C, WHO and Unesco. Y Poortman reported on discussions he has had with Professor Dubowitz of WMS. The desirability was discussed for a strategic meeting with the first four groups. **Y Poortman agreed to prepare a statement** on this topic. There was also discussion about the importance for WANDA to have its own strategic plan before meeting with other International groups and that it would be useful to find out what each of their platforms was. B McKenzie agreed to search for this information.

**13. Common** It was agreed that all NMD Association contact details would be placed on the web-site for all to access, plus  
**Location for** the Vice Presidents contact details would also be posted. Please provide photographs and the contact details  
**Address List:** you would like revealed on the web-site.

**Additional** **Constitution**  
**Business:** There was further discussion regarding the Constitution and the fact that we would like our Constitution to be complementary, yet different from other organisations such as WMS etc. B McKenzie agreed to try to obtain copies of other relevant organisations' Constitutions.

**Date of Next** The next Board Meeting of WANDA will be held in Vancouver on Wednesday 10<sup>th</sup> July 2002 at 11.00 am,  
**Meeting:** venue to be advised.

There will also be an additional WANDA Board Meeting to be held in Rotterdam on or about the 6<sup>th</sup> October simultaneously with the World Muscle Society Meeting.

Meeting closed at 4.30 p.m.

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