



MEETING
BOARD WANDA
KUSADASI, TURKEY
28th MAY 2004

Apologies: Lee Leith, Mayana Zatz, Alex Mackenzie, Andy Esworthy
Observer: Reinhard Rudel (former president of WANDA), Allan Bretag

1. Opening & welcome by the president

A special welcome for Allan Bretag from Australia and WANDA- former president Reinhardt Rudel.

The recent resignation of Andy Esworthy -- due to a change in personal circumstances -- as Secretary General and Treasurer and also as acting representative for Australia & New Zealand, was felt a great loss for the Alliance. The president expressed her great appreciation for the track record of services of Andy . The many achievements of Andy were recapitulated since the founding of the alliance in 1990.

The progress since the 4annual meeting in Munich and in particular since the meeting in Vancouver were reviewed (attachment A w86shworkplanshterm.vanc & w86shworkplanlongterm.vanc). The structure had been upgraded, the constitution amended, the website established through which transparency and visibility had been increased. Also a strong alliance with the G.Conte Academy had been established leading to a workshop in Kusadasi and to develop a website of which the first phase has been realised (ww.worldmuscleforum.org).

The communication with International NMD- specific groups has been given a lower priority as communication turned to be complex

2. There were no comments on the minutes of the previous meeting

3. Policy determination and workplan

www.wandaweb.org

a. international activities and representations

There was report about the various international affairs

in which WANDA played an initiating, stimulating or participating role:

International Genetic Alliance

www.egaweb.org/iga

BioVision Global Life Sciences' Forum (Lyon)

www.biovision.org

World Alliance Organisations for Prevention & treatment of
Genetic & Congenital Conditions

communication with

WHO - non communicable diseases

WFN – rare neurological diseases

UNESCO- bio ethical committee

b. continental policy and activities

The situation in all continents was reviewed and discussed.

The differences turned out to be enormous.

This was the reason why earlier (Vancouver- assembly) a continental approach was agreed to.

Each continent will

determine its own policy, priorities and activities following a common format (YP)

get an own sector in the wandaweb catering for the needs in their area. (YP)

liaise and contribute as much as possible to international affairs

c. liaison scientific community and contributions to research

Representation in relevant organisations

It was agreed that

WANDA Conte Academy Forum

Allan Bretag from Australia

MSM and WMS

Piraye Serdaroglu from Turkey

IGA, WAO and BioVision

Ysbrand Poortman from The Netherlands

AOMC & ENMC

Allan Bretag From Australia and Piraye Serdaroglu from Turkey

UNESCO bio ethics committee

Ekram Abdel- Salam from Egypt

National scientific NMD- networks

It was agreed to seek contact and communication and mentioning on the website

d. Ethical, legal & social affairs were considered important and

the options were discussed for a constructive contribution and as such were mentioned:

to stress and promote the importance

to open a sector on the subject in the website

to refer to practical and high quality information

(to be worked out by PS)

4. Constitutional affairs

Legal entity

It was decided to register the alliance

after the legalisation of the WANDA Conte Academy Forum..

Secretary General and Treasurer

There was no option for a successor for Andy Esworthy at the moment

Acting representative for Australia and New Zealand

Allan Bretag was co opted for this function up till the assembly meeting in 2006

5. Management affairs

Secretariat and database

There was no option for a take over of the secretariat from Andy Esworthy

The database will be maintained in Baarn, The Netherlands

6. Websites

The maintenance and further development of the site should go in conjunction with the activities for the worlmscleforum site.

7. Preparation 5th assembly in Istanbul

The 5th quadriennial assembly will take place in Istanbul from 2- 8 July 2006.

WANDA will organise a full day program:

a. business meeting

b.3 focussed sessions

* “from (lab. + clin.) diagnosis to therapy”

(SMA was thought to be the best model)

* genetics/proteomics/genomics/biotechnology and NMD

horizon/future, prevention,

* NMD in developing countries

Moreover meetings are scheduled of the

a. WANDA- board

b. board of directors of the WANDA Conte Academy Forum

c. the scientific advisory board of the Forum (if needed)

First announcement

This needs to be soon to enable the members to prepare the trip and the meeting.

WANDA proposes two projects

a. a glossary of terminology to contribute to harmonisation and better understanding

b. survey of the NMDAs in the world (AB to send a model)

The various plans for the assembly will be worked out in more detail

in electronic communication with the members of the board.

8. Any other business

Newsletter

On the basis of a format each board member will contribute.

The newsletter will be sent out electronically and pasted on the website

A publication on translational research, following the Vancouver workshop *, was considered still relevant.

The plan will be further developed and candidate authors approached.

News in the Acta

Deadline 30 September 2004

Next meeting

Possibly: June 2005 Napels

Meetings

1-4 Sept.	2004	Goteborg	Sweden	WMS
June	2005	Napels	Italy	GCA
28 Sept.-1Oct	2005	Iguassu Falls	Brazil	WMS
Febr.	2006	Tozeur	Tunis	WMS
2-8 July	2006	Istanbul	Turkey	IC-NMD
	2006	Istanbul	Turkey	WANDA