



**THE WORLD FEDERATION OF  
NEUROSCIENCE NURSES  
EXECUTIVE COMMITTEE**

**President**

Herman Ubachs, RN  
Mispadstraat 19  
3600 Genk, Belgium  
Email:  
Herman.Ubachs@pi.be

**Vice President**

Peter Hagell, RN  
Department of Nursing  
Faculty of Medicine  
Lund University  
PO Box 157  
SE-221 00 Lund  
Sweden  
Tel: +46 46 222 1937 (w)  
Email:  
Peter.Hagell@omv.lu.se

**Secretary**

Rochelle Firth, RN  
C/- Level 7  
Royal North Shore Hospital  
St.Leonards NSW 2065  
AUSTRALIA  
Phone: (61 2) 9926 6163  
Email:  
rfirth@doh.health.nsw.gov.au  
Fax: (61 2) 9437 5172

**Treasurer**

Virginia Prendergast, RN  
Masferrer Neurosurgical  
75 Printers Parkway,  
Suite 145  
Colorado Springs, CO 80910,  
USA  
Fax: +1 719 448 9080  
Email:  
vprender@hotmail.com

# INTERNATIONAL BRAIN WAVES

The Official Newsletter of the World Federation of Neuroscience  
Nurses

Volume 13, Number 2

June, 2005

## *From the President*

- After the meeting in Sydney, I had contacts with the President and the Secretary of the World Federation of Neurosurgical Societies and with the President of the Organizing Committee of their next world Congress. Because there was no possibility to organize our Congress at the same place and time and because there is no Neuroscience Nurses Association in Morocco, the risk to organize a Congress in Morocco was too high and Sitges, Barcelona was proposed and accepted as the venue of the next WFNN Congress.
- Had many contacts with the President and Past-President of the Spanish Association regarding the next WFNN Congress in 2005. The WFNN Executive Committee had a meeting in Sitges to discuss the 2005 WFNN Congress and we met with the local arrangement representatives and visited the Congress site.
- Together with the other members of the WFNN Executive Committee, we compiled and developed the contents and contributed to the design of the new WFNN website.
- Maintained contacts with other neuroscience organizations and attended several international Neuroscience-Congresses to promote the WFNN.
- Attended in December 2001 and 2002 in the name of the WFNN the yearly meeting of the Nongovernmental Organizations concerned with the Prevention and Treatment of Neurological Disorders at the World Health Organization in Geneva. There was a report of these meetings in our Brainwaves and you will find the summary of the 2002 meeting at the end of this report.
- There were also many e-mail contacts between the members of the Executive Committee (>600) about the new WFNN website, the next WFNN Congress, international contacts, International Brainwaves and other ongoing business.
- The book that I reviewed in the name of the WFNN: "Common neurological symptoms and conditions: a guide for non professionals", was published end 2002 (ISBN 1-904251-02-1). The WFNN is mentioned in this book as scientific organization that provides information and support to patients with neurological symptoms.

## *From the President*

- I want to thank the members of the Executive Committee, Virginia Prendergast and Peter Hagell for the splendid cooperation this last 2 years. I want to thank in particular Vicki Evans, who has decided not to stand for Secretary, due to commitments with her new baby. It was wonderful working with her and we hope that she will get involved again in the WFNN in the future. Thanks Vicki.
- And finally, I also want to thank all the members of the WFNN for their confidence in our organization and for their unselfish dedication. I hope that the WFNN will grow further the next years and that we keep more in contact, also thanks to our new website. I hope to meet a lot of you and of the members of your organizations at our next World Congress in Sitges in 2005.

Respectfully submitted,

Herman Ubachs  
President WFNN

### **MEETING OF NONGOVERNMENTAL ORGANIZATIONS CONCERNED WITH MENTAL AND NEUROLOGICAL DISORDERS**

**17-18 December 2002, WHO Headquarters, Geneva**

#### **A Summary of Discussions and Agreements**

The meeting was opened by the Executive Director of the WHO Cluster Noncommunicable Diseases and Mental Health (NMH), Dr D. Yach, who welcomed participants, outlined the main achievements of WHO in the year 2002 and pointed out that next year would bring a new Director-General to WHO. The Director of the WHO Department of Mental Health and Substance Dependence, Dr B. Saraceno, also welcomed participants and summarized the purpose of the meeting and its expected outcomes. After adopting the Agenda of the Meeting (see Appendix I), participants briefly introduced themselves and the NGOs they represented (see Appendix II). This was followed by Dr Saraceno's presentation of key recommendations of the WHO World Health Report 2001 (devoted to mental health) and a summary of the main WHO projects and activities carried out by the Department. After a brief discussion, the meeting continued with a series of short presentations of successful joint WHO/NGO projects including The Global Campaign Against Epilepsy by Ms H. de Boer, IBE; Identification and Management of Dementia in the Community by Ms E. Rimmer, ADI; Other Examples of Positive Collaboration in the Area of Neurology by Dr L. Prilipko, WHO; Collaboration Within Areas of Psychiatry and Mental Health by Dr J. Bertolote, WHO; and WHO Atlas Projects on Country Resources for Mental and Neurological Disorders by Dr A. Janca, WHO Temporary Adviser.

At the beginning of the afternoon session, Dr B. Saraceno presented the WHO mental health Global Action Program (mhGAP) and summarized its objectives and strategies as follows: (i) to increase governments' awareness and responsiveness to mental health issues; (ii) to enhance quality and effectiveness of mental health services; (iii) to reduce stigma and discrimination; (iv) to reduce the risk factors and burden of mental and physical disorders, and (v) to enhance the mental health of the population.

Dr Saraceno's presentation was followed by a round table discussion - the main theme of which was how the WHO mhGAP objectives and strategies could be incorporated into a collaborative framework between WHO and the NGOs. It should be noted that during their discussions numerous participants congratulated Dr Saraceno on his clear and stimulating presentation of the mhGAP project. The rapporteur was asked to record verbatim the following statement shared by many discussants: "The mhGAP is the most important WHO initiative in the past 5-10 years".

The specific points made during the round table discussion were as follows:

- The mhGAP strategies and objectives to a great extent fit the overall programmes of work of many NGOs present at the meeting. Consequently, several discussants emphasized that there should be no difficulties in establishing a common WHO/NGO platform for launching specific collaborative projects in the context of WHO mhGAP. Several overlapping areas between the WHO mhGAP and the NGO programmes of work were singled out, including the development of health information systems, integration of policy and service development, advocacy and research.
- In view of the preliminary findings of the Neurological Atlas project and in line with recommendations of last year's meeting of NGOs Concerned With Prevention and Treatment of Neurological Disorders, it was recommended that the following neurological disorders and conditions should be considered for inclusion in the WHO mhGAP initiatives: stroke and other cerebro-vascular disorders; headache and other pain syndromes; and head injuries. Production of separate sections of the Neurological Atlas (or separate WHO Atlases) covering these disorders should also be considered.
- In response to the point that the above-mentioned disorders and conditions also fall under the responsibility of other WHO units and programmes, several participants emphasized that the WHO organizational structure should not be an obstacle for their inclusion in the mhGAP and Neurological Atlas projects.
- Several participants stated that the focus of mhGAP should be much broader and include mental and neurological disorders that are not particularly frequent but, nevertheless, represent public health problems from a prevention point of view (neurocysticercosis and some genetic and malnutrition-related conditions were given as examples).
- A substantial part of the round table discussion covered the ways in which the NGOs could be of immediate and practical help to WHO in carrying out its mhGAP activities. Particular emphasis was put on education and training of primary care and other health workers in developing countries, involvement of families and carers, reduction of stigma, ethics and human rights of people suffering from mental and neurological disorders. It was agreed that the NGOs would send lists of existing educational programmes in these areas including detailed specifications of all already available simple teaching and training manuals which might be included in the mhGAP in the immediate future. To facilitate collection of such an educational and training programme inventory, WHO agreed to send a brief questionnaire to NGOs specifying the needs of developing countries and giving examples of educational materials that might be of relevance to the planned mhGAP initiatives. It was agreed that this questionnaire should be sent to NGOs by the end of February 2003.
- Many participants commented on the importance of the Neurological Atlas project. In addition to the assistance already provided by the WFN, several other NGOs expressed their interest in providing WHO with names and contact details of potential respondents and contributing some suitable data on specific neurological disorders for this project. To facilitate this WHO/NGO collaboration, a list of non-responding countries and a copy of the WHO Neurological Survey Questionnaire were distributed to all the participants in the meeting. In the course of this discussion, a number of specific comments and suggestions related to the presentation of the Neurological Atlas data were made, including collection of more detailed information on models of good neurological practice, health economics and quality of life of patients with mental and neurological disorders; additional analysis of the Neurological Atlas data, taking into account gender issues; inclusion of information on relatively rare but severe neurological disorders that require specific public health action, prevention or intervention.
- At the end of the round table discussion, there was unanimous agreement that the mhGAP initiative offers new possibilities for collaboration between WHO and the NGOs – both those present at this meeting and many others that share the same interests and concerns. It was recommended that the latter group of NGOs should be approached by WHO and provided with information about mhGAP.

The second day of the meeting started with the presentations by Dr M. Menken and Dr N. Sartorius, who gave their views and comments on the results of a WHO Meeting on Mental vs. Brain Disorders, which had been organized on 7 January 2002 at the WHO Headquarters in Geneva. Dr Menken's presentation was accompanied by an illustrative talk on neuropsychiatric aspects of stroke, given by

Dr J. Bogousslavsky.

The last session of the meeting was chaired by Dr Saraceno, who asked participants to focus their final discussions on the specific aspects and components of mhGAP in which the NGOs would be fully committed to start collaboration with WHO in the not too distant future. At the end of this session, Dr Saraceno summarized the agreements reached as follows:

1. The main areas of collaboration between WHO and NGOs in carrying out the mhGAP project are education and training; collection of data on mental and neurological disorders (for Atlas and other projects); involvement of families and carers; reduction of stigma and discrimination; and human rights of people suffering from mental and neurological disorders. In order to establish an inventory of available educational and training materials already produced by NGOs, WHO will develop and circulate a brief questionnaire summarizing country needs and types of materials required.
2. There is a need to increase and improve collaboration between WHO and the NGOs and to better define specific areas of such collaboration. In this regard, it was agreed that the NGOs would send lists of specific interests and concerns to WHO for their inclusion in the mhGAP and other WHO global projects and activities.
3. There was broad agreement on supporting the development of a WHO Manual of Comorbid Dimensions of Health. NGOs were committed to assist WHO in producing such a multidisciplinary document, which would aim to address multiple dimensions of population health.
4. NGOs agreed to assist WHO in organizing a major Meeting of Donors that would involve governments, foundations and the private sector aiming to raise substantial funds for WHO and NGO projects and activities on mental and neurological disorders. A set of background documents will have to be produced for such a purpose and WHO will inform the NGOs about the ways in which they can contribute to this fund-raising endeavour.
5. There was general agreement on the proposal to produce a joint NGO position statement on the importance of mental and neurological disorders that could be read at the forthcoming meetings of DOHA and/or the World Health Assembly. WHO agreed to provide assistance to the NGOs in producing such a statement but, in view of the approaching change in the leadership of WHO, it was agreed that production of this statement should be done after the appointment of the new WHO Director-General.
6. In order to facilitate further development of the productive relationships between WHO and the NGOs, it was agreed that WHO would circulate a new set of rules for the establishment of working relationships with NGOs, which will be finalized and adopted by the WHO authorities in early January 2003.

At the end of the meeting, Dr Saraceno thanked everyone for their participation and contributions to the meeting and expressed his sincere wishes for a prosperous and successful New Year.

---

## ***Annual Activity Reports***

### **American Association of Neuroscience Nurses (AANN)**

#### **2001-2003 Summary to the WFNN**

1. Approximately 3,000 members.
2. Revised AANN Core Curriculum for Neuroscience Nursing in the publication process.
3. Other products to assist the bedside neuroscience nurse are in the development process.
4. The annual meetings each had approximately 900 attendees.
5. The *Journal of Neuroscience Nursing* and the Synapse newsletter were each published six times per year.
6. AANN is represented at the Brain Attack Coalition, Council of State Neurosurgical Societies, American Nurses Association's Call to Action, and the WFNN.

7. AANN held first ever nursing symposium titled, "Discogenic Low Back Pain: Surgical Treatment Options for the Non-physician" at the AANS/CNS Section on Disorders of the Peripheral Nerves and Spinal Disorders Annual meeting
8. Neuroscience Nursing Foundation awarded the following:
  - 2001
    - a. 10 travel grants for AANN members to attend the annual meeting
    - b. 4 scholarships
    - c. Research Grant: "Thermoregulatory Sequela of Traumatic Brain Injury"
    - d. Fellowship: "Family Management of Parkinson's Disease Across the Lifespan"
  - 2002
    - a. 10 travel grants for AANN members to attend the annual meeting
    - b. 2 scholarships
    - c. Research grants for the study:
      - i. "Mild Traumatic Brain Injury and Psychiatric Patients"
      - ii. Cognitive and Behavioral Responses to Acute Activation of the Immune System"
  - 2003
    - b. 10 travel grants for AANN members to attend the annual meeting
    - c. Research grants for the study:
      - i. "Understanding Adaptation to Spinal Cord Injury: A Qualitative Study".
9. American Board of Neuroscience Nursing:
  - a. accredited by the American Board of Nursing Specialties
  - b. administered CNRN exam to over 150 neuroscience nurses in April 2003

Respectfully Submitted,

Andrea Strayer  
President, AANN

**Canadian Association of Neuroscience Nurses (CANN)  
Association canadienne des infirmieres et infirmiers en sciences  
neurologiques (ACIISN)**

WFNN Report May 2003

At present our association has over 300 members and eleven chapters across the country. The annual scientific conference and Annual Meeting is scheduled for June 18-20, 2003 in Quebec City, Quebec, CANADA. Abstract submissions were received from Canada, and internationally. This venue includes two and a half days of plenary or concurrent educational sessions. Poster presentations are done in conjunction with the Canadian Congress of Neurological Sciences who also hold their annual scientific meeting during this time. The collaborative date and city with neurologists and neurosurgeons across Canada provides an opportunity for networking and learning across disciplines. Consider attending!

CANN also distributes the Neuroscience Bursary (The Jessie Young Award-named after the founder of our association) for educational support at the Annual Scientific Conference. The Codman Award and Brain Tumour Foundation Award papers are also selected and presented. A pre-conference neurovascular workshop is being offered this year on June 17, 2003 featuring an overview of the latest diagnostic imaging and treatments of cerebral aneurysms and arteriovenous malformations.

CANN publishes a peer-reviewed journal quarterly. The journal publishes scientific articles of interest to neuroscience nurses and local chapter updates. Axon, L'Axone is indexed in Cumulative Index to Nursing and Allied Health Literature, International Nursing Index (INI) and Nursing Citation Index. Information regarding our Association can also be found on the web. [www.cann.ca](http://www.cann.ca).

CANN also provides research funding of \$1, 000 annually. This year, the award was

given to Pat Gallagher for the research project "The Emotional Journey of Stroke Recovery".

CANN also liaises with the Canadian Nurses Association (CNA) and other professional groups on behalf of neuroscience nurses across Canada. CNA provides the opportunity for neuroscience nurses to be certified in their speciality.

For CANN, at the Board of Directors level, the last year has been one of operationalizing the strategic plan and moving ahead with discussions and ideas regarding fiscal responsibility.

Unfortunately, I will not be able to be present at the EANN meeting in Copenhagen. I will be anxious to read the reports, as they become available. Congratulations on an excellent website, and remember, should anyone visit London, Ontario be sure to give me a call or e-mail Wilma.Koopman@lhsc.on.ca.

Respectfully submitted

Wilma Koopman  
CANN

## **DUTCH ASSOCIATION OF NEUROSCIENCE NURSES (NVNV) Annual report 2002**

### **Membership**

At the end of the year 2002 the NVNV had 450 members. The number of members is slowly increasing.

### **Board of directors**

In 2002 the Dutch association changed the organization. We now work with special focus groups. Already existing are focus groups on neurorehabilitation (120 members) and Parkinson Disease (20 members). A new group is founded on MS. Each focus group has a representative in the BOD. In this way the Dutch association was able to recruit new board members.

### **Meetings**

In October there was a successful congress in Amsterdam on Neuro-oncology and Parkinson's disease. Speakers were neuroscience nurses, nurse practitioners and physicians. There were 225 attendees.

In November there was a meeting in Nijmegen again on Parkinson disease. At this meeting the national guidelines for caring for Parkinson patients were presented to the presidents of the Parkinson's Patient Association and the NVNV.

The workgroup Neurorehabilitation (120 members) had a spring meeting and an autumn meeting.

The workgroup Parkinson's Disease (15 members) had three meetings.

A new workgroup was founded: the workgroup MS.

### **Journal**

The NVNV publishes the journal together with our Belgian colleagues. The outfit changed in 2001 and the new outfit is a great success. It seems the new journal stimulates nurses to write more articles. The journal was published 5 times.

### **International co-operation**

7 members of the focus group on neurorehabilitation presented a preconference workshop at the annual meeting of the AANN in Chicago.

### **Other activities**

The Dutch association started a national project to introduce the new Parkinson guidelines into nursing care. The project is financed by the AVVV, the Dutch national association for nurses and the Parkinson's Patient Association. In this project two courses are developed. There is a two day course for the introduction of the guidelines and a four day course for the training of nurse specialists on Parkinsons.

The NVNV published the Function profile of the neuroscience nurse. The main part of

the Function Profile is based on three areas of care: multi system impairments, neurorehabilitation and neuropalliative care. Furthermore for the development of the profile the ICF was used. A special focus group is now working on a national education plan for neuroscience nurses based upon the function profile.

In 2002 there was a meeting of the delegations of the NVNV and the National Association of Neuro Physicians to discuss the problem of the shortage of nurses.

#### **Finances**

The activities of the NVNV are financed by membership fees (€ 28), advertising and sponsoring, and by project financing by the National Association of Nurses in the Netherlands (AVVV).

Paul van Keeken  
NVNV

### **WFNN: Japanese Report May 2003.**

#### **JANN Organization**

We have approximately 300 nurses. Our core membership is about 100. The newsletter is a biyearly publication. We have 9 local societies and each have members of 100~300. There is a study meeting every year. Recently, during our business meeting which local directors attended, we discussed reorganizing JANN. It was decided to separate the Board of Directors and the Executive Committee of the Annual Study Meeting. The Executive Committee are elected each year and incorporate the 9 local societies.

The 29th Annual meeting was held in November 2002, in Shizuoka-city. There were 210 attendees. The nursing program included oral presentations/lectures with discussions given by a doctor & 3 nurses. Topics covered nursing risk management, bed sore care, restraints, care of the unconscious patient, care of the terminal patient, rehabilitation and care of the neuro patient at home.

The other program was focussed on the Nutrition Support Team (NST). This included not only a doctor and nutritionist, but also all professional staff collaborating with using per intestinal nutrition in the early stage unconscious patient. Merits of this approach are to stimulate the intestine and autonomic nervous system. Therefore, patients step to early recovery and shorten medical costs.

We shared thoughtful time even though it was only a one-day seminar.

#### **JANN Study meeting 2003**

This year the annual meeting will be held November 15th at the Yamaguchi-prefecture.

The chairman is the director of the Yamaguchi local society (Nerosurgery Ward at the Yamaguchi University Hospital).

Respectfully submitted by:  
Teiko Yumi