Personal remarks by EFNS Scientific Panel chairs (collected in 2008)

Michael P. Barnes, Chair of the EFNS Scientist Panel on Neurorehabilitation (1991-1997)

‘I became Chair of the Scientific Panel on Neurorehabilitation in 1991. We had a very active and interested panel and the majority of country members took part in our meetings. We held a focus workshop in Rome – on the management of spasticity and the use of botulinum toxin and in Seville a joined Meeting of the Scientist Panel and the IRMA. The main task for the panel in these few years was to produce EFNS guidelines on aspects of neurorehabilitation. We produced guidelines on minimum standards in neurological rehabilitation – along with the Multiple Sclerosis Scientific Panel.

The key members of the group were part of the initial, larger, group of individuals who went on to form the World Federation for Neuro-Rehabilitation, which is now a global body representing professionals involved in the field (www.wfnr.co.uk). There are still very strong and close links between the EFNS Scientific Panel and the WFNR. I remain President of the WFNR (until September 2008) and the current Chair of the Scientific Panel (Professor Volker Hömberg) is also the Secretary General of the WFNR. These links have produced an excellent collaboration and a number of sub-speciality specific teaching courses, regional meetings and conferences around the world.’

Professor Michael P Barnes MD FRCP
Newcastle upon Tyne
United Kingdom
I was Chairman of the EFNS Scientist Panel on Autonomic Nervous System Disorders from 1999 to 2005. It was a tiring but very interesting and gratifying experience: tiring because I had to keep in touch with a lot of people in different countries with different needs and coordinate proposals and organization during EFNS congresses. My task was to bring together the Main Topic, Teaching Course and Focused Workshop, bearing in mind not only the special interests of experts involved, but also the need to arouse the curiosity of young neurologists and attract new forces to study the pathophysiology of the autonomic disorders which so often complicate the lives of our neurological patients. I hope I succeeded in my task of meeting the needs of all those involved in meetings I helped to organize:

2001 (5th WFN and EFNS meeting London): Symposium on “Autonomic disorders”
2002 (6th EFNS meeting Vienna): Focused Workshop on “Laboratory evaluation of autonomic function in neurological practice”
2003 (7th EFNS meeting Helsinki) Focused Workshop on “Vestibular-autonomic interactions”
2004 (8th EFNS meeting Paris) Focused Workshop on “Clinical and research value of spectral analysis of heart rate variability in autonomic disorders”
2005 (9th EFNS Congress Athens) Teaching Course on “Disorders affecting the autonomic nervous system - clinical evaluation, investigation and treatment”

My work for the Task Force on “Diagnosis and management of orthostatic hypotension” was especially stimulating. Two years of intense virtual meetings with colleagues via e-mail yielded the “EFNS guidelines on the diagnosis and management of orthostatic hypotension”.

Lastly, I would like to emphasize how positive my experience as Chairman was from a human standpoint. Chairing the EFNS panel I had the opportunity to meet many leading experts and colleagues in the field. They never failed to offer their help, and above all their friendship. To them I offer my grateful thanks, undying esteem and admiration.

Prof Pietro Cortelli
Università di Bologna
Bologna (Italy)
Valery Feigin, Chair of the EFNS Scientist Panel on Neuroepidemiology  
(1995-2005)

The Neuroepidemiology Scientist Panel was one of the first Scientist Panels set up by the EFNS. The Panel was established in 1995 and I was honoured to lead this Panel over the next 10 years.

Over that period of time the Neuroepidemiology Scientist Panel has grown up from just a dozen to over 30 members and it has been established as an integral and important part of the EFNS activities. All members of our Panel shared a common vision that neuroepidemiology is a basic science for all clinical studies of neurological disorders, and as such deserves a wider recognition in the scientific community of neurologists. Within our Panel activities, we managed to set up an EFNS Task Force for Teaching Neuroepidemiology in Europe and published our findings in the European Journal of Neurology.

We also actively participated in all EFNS Congresses by holding our workshops and being involved in other panel/committee activities. I dare to believe that our Panel activities have contributed and will continue to contribute to the scientific community and best practice in neurology. For me personally, heading this Panel enriched and extended the scope of my organisational and research expertise, the value that I especially treasure now in my present role as Editor-in-Chief of Neuroepidemiology, the only international journal devoted to the study of neurological disease distribution and determinants of frequency in human populations.

I am proud to say that the EFNS Neuroepidemiology Scientist Panel activities I was involved in for almost 10 years has lead to the First International Congress on Clinical Neuroepidemiology which is scheduled to take place in Munich, Germany in 27-30 August 2009.

Valery Feigin  
Auckland Mail Centre,  
Auckland, NEW ZEALAND
The panel had initially to be established with at least one member responding and accepting to take active part from each EFNS country. The number grew steadily to more than 30 such members, around ten of them being the driving forces of the panel. Main aims were to establish task forces on relevant topics and to contribute to the scientific congress program. Eight guideline documents appeared from task forces initiated by the panel during this period. A cornerstone in the panel work was the cooperation with other panels, especially regarding task forces. Our panel had the ambition to influence research and research priorities in Europe. Together with relevant scientific organisations we made successful impact on EU framework programmes and the building of research networks. An experience from the panel work is that research and project cooperation facilitates and promotes all other cooperation as well.

Nils Erik Gilhus
Bergen, Norway
Recent progress in molecular genetics has greatly improved our understanding of the molecular basis of many monogenic as well as multi-factorial neurological diseases. The chromosomal position of a large number of genes is now known, which when mutated can cause neurological disorders. This increasing wealth of knowledge has allowed the reclassification of a number of formerly heterogeneous clinical syndromes, provides novel diagnostic possibilities, and allows characterization of the pathologic gene products, thereby providing further insight into the molecular pathogenesis of these disorders and eventually opening up new approaches towards therapy and prevention.

The EFNS Scientist Panel on Neurogenetics consists of members from most European countries. The aims of the panel is to disseminate good neurological practice throughout European countries, assist the EFNS congress programme committee, assist EFNS in training neurologists and promote research collaborations in the field of neurogenetics.

The Scientist Panel on Neurogenetics has earlier formed a task force to develop guidelines and a directory to molecular diagnosis of neurological diseases in Europe, and published “Guidelines for the molecular diagnosis of inherited neurologic diseases” in a two-part article in the European Journal of Neurology in 2001. An update of these guidelines will be completed in 2008. These guidelines include some generally accepted principles of molecular diagnosis as well as some minimal diagnostic criteria that should be met to make molecular diagnosis useful. The directory provides information on the state of the art and the availability of diagnostic procedures.

The panel holds regular meetings at the EFNS congresses, where also suggestions for EFNS congress topics are prepared. For both recent and planned congresses proposals from our panel has been accepted every year.

Hanne Flintstad Harbo, Chair of the EFNS Scientist Panel of Neurogenetics (2007-2009)

Hanne Flintstad Harbo
Ullevål University Hospital
Oslo, Norway

My name is Irena Hausmanowa-Petrusewicz. I was and I am neurologist and clinical electro physiologist. My field of interest are muscle diseases. I was connected with EFNS from the very beginning and attended the first Congress in Vienna. The person who contacted me on behalf of EFNS was mainly Prof. Gerstenbrandt.

When Dr Scarlatto (Italy) resigned from function of chairman of Muscle Panel. I was asked to take this function and I chaired Muscle Panel more than 6 years until Dr Heinz Reichmann from Germany took it. During his chairmanship I still tried to collaborate with him contributing to annual meetings. During my chairmanship I organized two focused seminars both on Emery-Dreifuss dystrophy (laminopathies) one in Prague, another in Vienna. I was very enthusiastic and pleased when the EFNS started and considered it as a first symptom of European Union. Later on I became a disappointed because of bureaucratic character of EFNS administration (maybe it was just my impression). I was unable to understand why they prepare the program of meetings two years ahead which exclude very unexpected, really important scientific news. In spite of that I am still very interested in EFNS.

Irena Hausmanowa-Petrusewicz
Poland

I became involved with the EFNS when I was Head of the Finnish Neurological Association. We tried to find members for the scientist panels. I became nominated as a member of the “Alcohol Panel” since then, I am a member of EFNS Scientist Panel on “Alcoholic Effects on the Central and Peripheral Nervous System” and Head of the panel 1994-2000. I was also a member of Editorial Board of EJoN 1994-2004 and am at present Co-Editor-in-Chief of EJoN.

A little anecdote:
I was rewarded by Henry Barnett because of his remarkable activity in recruiting patients to the NASCET trial. Henry passed me a bottle of wine without knowing that I was a temperance man and belonged to the Scientific Panel of Alcoholic Effects, and that the most recent patient he had recruited was an alcoholic (see photo).

In the beginning, my first impression of the EFNS was that this is a club of very old and distinguished European neurologists, mainly coming from the east.

Matti Hillbom
Finland
David Hilton-Jones, chair of the EFNS Scientist Panel on Muscle disorders (2009-2013)

We are trying to support the EFNS through proposals for Main Topics, Teaching Sessions and Focussed Workshops. Currently two Task Forces are developing guidelines for the "Diagnosis and Management of Idiopathic Inflammatory Myopathies", and "HyperCKemia". Our intention is to promote understanding of primary muscle disorders and to liaise with other relevant Panels, notably Peripheral Nerve and Genetics.

I am Clinical Director of the Muscular Dystrophy Campaign supported Muscle & Nerve Centre in Oxford. I am particularly interested in bringing the latest research developments to the clinic, and involving clinic patients in research. I write and teach extensively in the field of neuromuscular disorders and am joint editor of "Disorders of Voluntary Muscle", a standard textbook in the field.

David Hilton-Jones
John Radcliffe Hospital
Oxford, UK
I was delighted and privileged to be Chairman of the EFNS Scientist Panel on Infections including AIDS 2000-2007. The most interesting and exciting aspect was the interaction with neurologists from so many different European counties who always brought their own particular viewpoint and perception of the subject. It was particularly good to see such good representation from Eastern Europe.

Like many other Chairs, I found that of the 26 or so members the bulk of the panel’s work was carried out by about 12 people with perhaps 6-8 of those being exceptionally active and committed. The most frustrating aspect of the job was constantly failing to receive replies from a few panel members even when I had contacted them multiple times. Accordingly, about half-way through my tenure I carried out an extensive restructuring exercise replacing completely inactive members with newer and more active individuals. That proved to be a productive thing to do. Up to 6 panel members usually attended Panel meetings at the annual EFNS meetings.

The most important aspect of the panel was the setting up and driving of the Task Forces to write neurological guideline documents for publication in the EJN. I set up and oversaw 4 of these, namely the management of viral encephalitis, the management of the neurological aspects of HIV infection, management of bacterial meningitis and most recently neuroborreliosis. The first two have been published, the third is submitted for publication and the fourth is well in progress. For virtually every year my panel contributed to focussed workshops or other sessions at the EFNS meetings, generally on neurological infections of global importance. I was succeeded by one of the most active of the panel members, Prof Israel Steiner. I was also appointed the official ABN delegate to the EFNS.

Peter GE Kennedy
Institute of Neurological Sciences
Glasgow, UK
Albert Ludolph, chair of the EFNS Scientist Panel on ALS and Non-dementing Degenerative Disorders (2009-2011)

I was given the Chair of the Science Panel ALS and Non-dementing Degenerative Disorders since I got Chair Elect of the European ALS-MND-Group in 2007. I hope our small group contributed. I think we had an advantage since the organization of the EFNS-Group and the European ALS-Group is very similar and communication is easy. The guidelines for treatment and the internal rules are complementary to each other. It was a great pleasure for me to get into contact with Nils Eric Gilhus and also my respected colleague Deflef Kömpf during the time I worked in the EFNS.

Albert Ludolph
Germany
Edgar Lukáš, Chair of the EFNS Scientist Panel on Environmental Neurology and Neurotoxicology (1995-1997)

The idea of establishing the EFNS Scientist Panel on Environmental Neurology and Neurotoxicology emerged at the 5th International Congress on Industrial and Environmental Neurology, which took place in Prague in 1990. Prof. Gerstenbrand, who was invited as a member of the Honorary Committee of the Congress, brought the inspiration. After then, Czech neurologists took an active part at the Second Congress of the Paneuropean Society of Neurology (Vienna 1991), and at the Meeting of the EFNS in Berlin 1993. In 1995, assoc. prof. Edgar Lukáš, M.D. DSc., chair of the Section on Occupational Neurology of the Czech Society of Neurology, was invited by Prof. Gerstenbrand to chair the Scientist Panel on Environmental Neurology and Neurotoxicology of the EFNS.

Among the main activities of the Panel in the reported period 1995-1997, there was cooperation during the 2nd Congress of the EFNS in Rome 1996 and especially in the Congress Program Committee of the EFNS Meeting in Prague in June 1997. (Prof. Olesen, Prof. Gerstenbrand). During the latter Congress, a special workshop on Neurotoxicology, Occupational and Environmental Neurology was organized, which was held on June 7th.

Edgar Lukáš
Czech Republic
Neuroimaging had been my great interest while I worked in the United States, from 1972-2000. My fellowship in Neuropathology at the Harvard Medical School in 1976 served to interest me in the powerful tools that were becoming available to study the structure and function of the alive, working human nervous system. I continued my research on neuroimaging at the Albert Einstein College of Medicine, in New York. While chairing the Department of Neurology at the New York Medical College (1991-2000), I dedicated time to neuroimaging research, education, and professional organizations. In 1994 I became the President of the American Society of Neuroimaging. I was a member of the Appropriateness Criteria Panel of the American College of Radiology and chaired the Neuroimaging Section of the American Academy of Neurology. So, it was only logical that I would become involved in neuroimaging in Europe when, in 2000, I took over the chairmanship of the Department of Neurology and Neurosurgery at the University of Navarra, in Pamplona, Spain.

The opportunity came in 2002, when I was kindly invited to lead the EFNS Scientist Panel in Neuroimaging. I was preceded in this position by an outstanding physician-scientist and good friend, Prof. Jean-Claude Baron. Under the leadership of Prof. Baron, of Cambridge University, the Scientist Panel on Neuroimaging had a distinguish record of activity, with the production of several research papers and practice guidelines, as well as a very active participation at the EFNS annual meetings. Prof. Baron and Prof. Isabel Illa, delegate to the EFNS from Spain, suggested my candidacy, which I was delighted to accept given the excellent reputation of the EFNS and the Panel.

A number of outstanding physicians were already among the Panel members. In 2003 we were lucky to incorporate other superb neuroimaging physicians, such as Professors Massimo Filippi, Karl Herholz, Paul Matthews, Patrizia Pantano and Philippe Scheltens. A year later, the chairman of the Research Committee, Professor RAC Hughes, combined the Neurosonology and the Neuroimaging panels into a single panel, the Neuroimaging-Neurosonology Panel. The very active members from the Neurosonology community further energized the Panel.
The Panel continued its active tradition. It produced two practice guidelines, “Neuroimaging of Multiple Sclerosis”, led by Prof. Massimo Filippi and “Guidelines for the use of imaging in acute stroke,” which I led. Prof. Philippe Scheltens wrote the neuroimaging portion of a guideline, chaired by Prof. Gunhild Waldemar, dealing with the work-up of dementia. These guidelines were published in the European Journal of Neurology and the European Handbook on Neurological Management. An average of four neuroimaging activities have been present at the EFNS annual meeting. The Panel has issued several position statements to the Research Committee on the practice and research of Neuroimaging in Europe.

The workings of the Neuroimaging-Neurosonology Panel were tremendously facilitated, indeed made possible, by the highly skilled and very helpful staff of the EFNS.

Joseph C. Masdeu
Spain
Since January 2006 the Chairmanship of the EFNS Panel on Parkinson’s disease and other movement disorders has been a joint panel of the EFNS and MDS-ES.

Dr. Martin Horstink took over chairmanship from Prof. Andrew Lees in 2000, and in 2001 Prof. Albanese was invited to form a separate Special Task Force on dystonia.

In 2000 the PD panel started a number of meetings during EFNS and MDS congresses, discussing uniform rules for the diagnosis and assessment of PD, because uniformity is a prerequisite for European co-operation on PD and multicenter clinical trials. This resulted in a very well attended focused workshop on ‘Assessment of PD in clinical practice’ in Helsinki 2003 with the faculty AJ Lees (chair), CG Goetz (general overview), P Martinez Martin (assessment ADL), MWIM Horstink (assessment with timed motor tests) and WH Oertel (DaT-SPECT).

From the early days of the Panel, attempts were made to co-ordinate a number of European societies promoting movement disorders, namely the European Neurological Society (ENS), the Federation of European Neuroscience Societies (FENS), the European Section of the Movement Disorders Society (MDS-ES), and the European Federation of Neurological Societies (EFNS). In 2002 a formal collaboration between the EFNS PD panel and MDS-ES was established, and the PD panel was represented on the board of MDS-ES with Martin Horstink, the Panel chair, becoming an ex-officio member of the MDS-European Section Executive Committee. In 2003 MDS-ES took responsibility for all Movement Disorders programming at the EFNS Annual Congress. With effect from 1st January 2006 the Chair of the Scientist Panel has been the current Chair of the Movement Disorder Society’s European Section and the Panel was renamed: Parkinson’s disease and other movement disorders; an EFNS/MDS-ES panel. From 1st January 2006, Prof. Niall Quinn chaired the panel, and from 1st January 2007 Prof. Wolfgang Oertel has been the chair.
The Panel membership list is co-ordinated by the EFNS Office, and the work of the Panel is supported by Karen Henley, Associate Executive Director of MDS, who runs the MDS-ES Secretariat in London.

In 2004 the EFNS started to prepare the European Handbook of Neurological Management. From 2004 to 2006 combined EFNS and MDS-ES taskforces wrote reviews of the therapeutic management of early (uncomplicated) and late (complicated) PD, and MDS-ES provided financial and administrative support for this initiative. These guidelines were published in the European Journal of Neurology in 2007, and will be updated in 2009 for republication in 2010, working in association with the MDS Task Force on Evidence Based Medicine. Guidelines on the diagnosis and treatment of primary (idiopathic) dystonia and dystonia plus syndromes, were also partially supported by MDS-ES funding, and were published in the European Journal of Neurology (2006). In 2008 we will be creating a European consensus document on therapies for Advanced Parkinson’s Disease for publication in the European Journal of Neurology.

The Panel has looked at the criteria for recognition of Parkinson’s disease centres in Europe, and although for legal reasons it will not be possible to establish a formal recognition system, we do expect to issue recommendations for good practice and optimum service provision, which Panel members have confirmed will be of great value to them in creating and improving local Movement Disorders centres.
Heinz Reichmann, Chair of the EFNS Scientist Panel on Muscle Disorders (1999-2007)

The Muscle panel consisted of specialists from many European countries and met regularly during the EFNS meetings. In particular we developed the “The interesting case” session which always attracted many congress participants. During these sessions special cases were presented by muscle specialists and discussed by the auditorium. After Professor Hausmanowa-Petrusevicz had given the chair to me I tried to attract new members to the panel and to refresh the activity of many old members. We discussed to establish guidelines for myositis and dystrophies. On the focus of our panel were metabolic and dystrophic myopathies, congenital and inflammatory myopathies.

Heinz Reichmann
Universitätsklinikum Carl Gustav Carus
Dresden, Germany

Per Soelberg Sorensen, Chair of the EFNS Scientist Panel on Demyelinating Diseases and Multiple Sclerosis (2004-2009)

I have been a member of the EFNS Scientist Panel on Demyelinating Diseases and Multiple Sclerosis from 1993 and became chairman in 2004. During 2006 many members of the Scientist Panel were exchanged and many new active scientists joined the Scientist Panel. We have produced Guidelines on the use of anti-interferon-beta antibodies measurements in Multiple Sclerosis and Guidelines for treatment of multiple sclerosis relapses. These guidelines were included in the Handbook of Neurological Management. At each EFNS Congress multiple sclerosis has been one of the main topics, and several focused workshops have been held including epidemiology of multiple sclerosis, genetics of MS and neutralizing antibodies against interferon-beta. Teaching courses, either full day or half day, on multiple sclerosis have been recurring at each EFNS Congress. A collaboration with the European Committee for
Treatment and Research in Multiple Sclerosis has been established to produce guidelines on the use of immunomodulatory therapy in MS

Per Soelberg Sorensen
Copenhagen, Denmark