

EFNA

Annual Report 2011

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Message from the Board



At the General Assembly 2011 Dr Mary Baker (President) and Alistair Newton (former Secretary-General), both founding members of EFNA, will leave the organisation. Both Mary and Alistair will be sorely missed. They have shaped the organisation that EFNA has become and have contributed enormously to its success in a large number of projects and initiatives from its foundation in 2000 to the present day. EFNA is extremely fortunate that links with Mary and Alistair will remain strong through its membership of the



European Brain Council on which board both serve.

The other board members...



Audrey Craven
Vice-President

President of the European
Headache Alliance (EHA)



Balthasar Schaap
Secretary-General

Represents Euro-ataxia



Bea De Schepper
Treasurer

President of the European
Huntington's Association



Irem Hattat
Member at Large
President of the European
Sexual Health Alliance
(ESHA)



Manuela Messmer-Wullen
Member at Large
President of SHÖ –
Schlaganfallhilfe
Österreich

EFNA's team of advisors.

We are grateful to EFNA's advisors who give of their time and expertise and are unfailingly resourceful and available.



Stephan Pickard
Legal Advisor



Jean Mossman
Policy Advisor



David Sinclair
Finance and Governance
Advisor

[Jean Mossman](#) has more than two decades of health care advocacy and clinical research experience. From 1995 to 2000, she was chief executive of CancerBACUP (now merged into MacMillan Cancer Support). Jean serves as a member of the National Coordinating Centre for Health Technology Assessment Public Involvement Steering Group and is a member of the Health Technology Assessment International Patient/Citizen Interest Group.

[David Sinclair](#) has been EFNA's advisor on matters of financial administration and governance since his appointment in 2009. David also works as a volunteer for the Camden Branch of the Multiple Sclerosis Society of Great Britain and Northern Ireland where he was a trustee and Honorary National Treasurer for three years to 2008.

[Stephen Pickard](#) was president of the European Parkinson's Disease Association (EPDA) from 2006 to 2009 and is currently Legal Advisor to the Board of EFNA and EPDA. His father had Parkinson's disease and he has worked in the voluntary sector on neurological diseases for many years. Stephen is an English solicitor based in Brussels where he specialises in lobbying the European Institutions for a number of clients and interest groups and practises EU competition, trade and anti-dumping law.



Amanda Worpole
Executive Director

Executive Director

In February 2011 Amanda Worpole was appointed Executive Director of EFNA. Amanda qualified and practised as a Speech and Language Therapist before her appointment as Education and Training Officer at the Parkinson's Disease Society (now PUK). In her subsequent career she held various senior roles within the pharmaceutical industry, notably with Servier and GSK. She joined Quintiles in 2009, working with clients to drive market development strategy. She was invited to join EFNA as Executive Director in 2011 to steer the organisation's initiatives, partnerships and projects.

Thank you

The board and Amanda would like to extend their very grateful thanks to the following people for ably supporting the activities of EFNA by their competent administration behind the scenes: **Pat Robertson**, PA to Mary Baker; **Milly Lemos** of EHSA, and the newest member of the team **Sarah Titcombe** who works with Amanda. Pat will be sorely missed as is Milly who left EFNA in July this year after spending many years with EFNA in various capacities. We would also like to thank **Eveline Sipido** of EFNS and EBC for her continuing support.

Partnerships for Progress

Health Technology Assessment (HTA) training course.

In partnership with the London School of Economics (LSE), EFNA has taken a lead in informing and educating patient organisations to enable effective participation in the process of Health Technology Assessment (HTA). The course has now been run twice a year since 2010 and has a growing reputation for its rigorous academic level and high quality lectures.

The goals of the course are:

- ☉ To improve the way in which the patient and informal caregiver experience is incorporated and considered as part of the HTA process;
- ☉ To improve patient groups' understanding of the HTA process;
- ☉ To develop patient groups' expertise in providing evidence as part of the HTA processes;
- ☉ To strengthen partnerships among patient groups and with participating stakeholders.

This work has been supported enthusiastically by a number of pharmaceutical companies who have been invited to nominate delegates for inclusion on the course.

The Patient Academy

The success of the HTA initiative has led EFNA, under the leadership of Mary Baker, towards the establishment of The Patient Academy. This new collaboration with the LSE will build upon the success of the HTA model and offer more courses to enhance the skills base of the patient organisation community. It will see patient groups contributing to the research agenda of the newly formed Medical Technology Research Unit based at LSE. The range of training courses will increase and patient groups will be encouraged to participate directly in research. The Patient Academy will be up and running in 2012. We are looking forward to the launch of what will be an enduring legacy of the successful partnership of EFNA and the LSE.

Multiple Sclerosis coalition

This coalition is a project that aims to increase the length of time a person diagnosed with MS can stay in the workplace. It is a great example of partnership for progress and the sharing of information. Microsoft brings knowledge about accessibility tools for work; the Employers' Forum on Disability knows about the employer issues; Merck Serono brings its therapeutic expertise and, more importantly in this context, is an organisation that already supports all of its employees with long-standing incapacitating conditions; and EFNA has the voice of the people living with the neurological condition and their carers.

European Year of the Brain 2014 (EYOB)

In partnership with EBC, EFNA has been lobbying and co-ordinating the responses of the three EU Institutions to achieve agreement on EYOB which we believe will be approved for 2014.

Initiatives

Quality Of Life Instrument for Carers of People with Parkinson's disease (The PDQ-C)

The report on the Carer's Quality of Life study was launched at the EFNA Awareness session at the EFNS Annual Congress 2011 in Budapest.

The purpose of the study was to develop a reliable and valid measure of carer quality of life in Parkinson's disease. Scores over 60 suggest caring has regular and frequent impacts on the

carer's quality of life and a brief overview of the results shows that the percentage of respondents scoring over 60 on domains of the PDQ-C were as follows:

- ⦿ Personal and Social Activities: 33.8%
- ⦿ Anxiety and Depression: 26.6%
- ⦿ Self care: 12.2%
- ⦿ Stress: 23.3%

These results indicate that the role of carer can have substantial effects on quality of life for a high proportion of PD carers. EFNA anticipates that this questionnaire will be used alongside the PDQ-39 which is the most widely used Parkinson's disease specific measure of health status. It contains thirty nine questions, covering eight aspects of quality of life. The blueprint now exists to conduct research into the impact of caring on those who care informally for people living with other neurological diseases. We believe that high-quality standardised measures to assess carer burden and quality of life will facilitate a move to a more holistic assessment of the impact of diseases and the treatment regimes aimed at them.

Science & Society

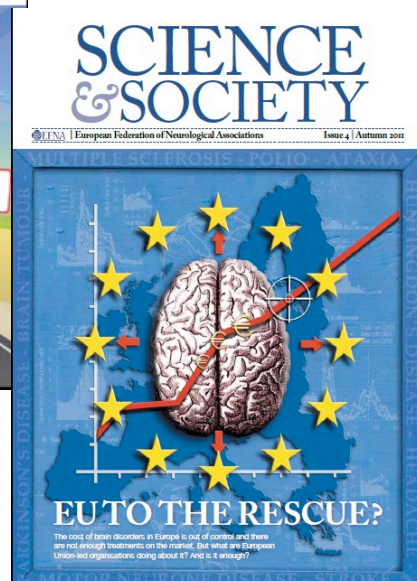
EFNA is proud to have launched Science & Society, published three times a year and distributed to all 732 MEPs and EFNA stakeholders.



Science & Society has covered important and diverse topics such as HTA, the threat to MRI scanning, medical records, the EMA...



Music and the brain, the cost of brain disorders, cross-border healthcare and much more...



Events

Pain Alliance Europe

For several years, EFNA has been planning a project to bring together pain patient organisations into a European alliance. The need for such a platform at the European level has been pointed out by a number of people in the EU institutions and among the pain groups themselves. EFNA has been successful in obtaining support for this project from the Medtronic Foundation, Grunenthal and Pfizer, all of whose sponsorship is gratefully acknowledged. This year, the plans will become reality as a result of a great deal of hard work from Mary Baker, Alistair Newton and Evelyn Sipido who have guided the process of the formation of this new and important organization alongside representatives of more than 20 organisations representing people living with pain in 11 countries across Europe.

EFNA is delighted to announce the imminent foundation of the Pain Alliance Europe (PAE) which will launch at the European Parliament on November 29th 2011. The enthusiasm to establish this group comes not only from the patient organisations involved but also from policy makers in Europe and the pharmaceutical industry. The mission of PAE is to improve the quality of life of people living with chronic pain in Europe.

EFNS Annual Congress

This year at the EFNS 2011 Annual Congress in Budapest, EFNA organised two very successful special sessions. The Awareness Session featured presentations on:

- ⊙ 'Treatment strategies of Parkinson's disease' from László Vécsei, Professor of Neurology, University of Szeged, Hungary;
- ⊙ 'Legal rights for employees with disabilities' Caoimhin MacMaolain, Director of Research, School of Law, Trinity College, Dublin;
- ⊙ 'Development of a quality of life instrument for carers of people with Parkinson's disease (the PDQ-C)', Crispin Jenkinson, Professor of Health Services Research, Oxford University, England;
- ⊙ 'Mindfulness Based Interventions for people with decreased health related quality of life.' Gabor Fazekas, MBSR instructor, Hungarian League against Cancer, Hungary.

"The Good Life" Special Session presented a virtuoso piano recital by Olga Bobrovnikova who lives with MS. As she played, we saw a video clip of Functional magnetic resonance imaging showing a brain's response to a Chopin Waltz and the music of Franz Liszt. E K Avenue performed a set of jazz songs with a specially written piece called flying through the Storm. Finally, the string quartet Bowjangles illustrated the notion that performing music at a professional level requires the integration of multimodal sensory and motor information and precise monitoring of the performance via auditory feedback.

Other Activities

- ⊙ Counterfeit Medicines – Working in a partnership to stop the supply of counterfeit and sub-standard medicines in Europe.
- ⊙ Advanced Therapies - Lobbying European Parliament and Council of Ministers to ensure the views of patients are heard.
- ⊙ European Medicines Agency (EMA) – EFNA is represented on the Managing Board and on committees (Patients' and Consumers' Working Party, Pharmacovigilance Working Party).
- ⊙ JPND (Joint Programme in Neurodegenerative Diseases) - participation in stakeholder meetings contributing to the the drafting of a Strategic Research Agenda (SRA) for neurodegenerative disease and construction of EFNA/EBC database of stakeholders.
- ⊙ PSURs: The forum 'trusted third party' for collaboration between the pharmaceutical industry and regulatory bodies has been established.

2012 and beyond...

- ⊙ Brain and Pelvic Organs - a proposal to improve management of bowel, bladder and sexual dysfunction in neurological disease.
- ⊙ Palliative Care – in partnership with King's College London, working to identify good practice in palliative care for patients with neurological diseases.
- ⊙ Patient Reported Outcomes – in partnership with the University of Oxford. To develop a short patient reported outcome measure designed specifically to assess participation in society, activities and level of dependency.

**EUROPEAN FEDERATION OF
NEUROLOGICAL ASSOCIATIONS**

**STATEMENT OF FINANCIAL ACTIVITIES
for the year ended 31 December 2010**

	2010 €	2009 €
INCOMING RESOURCES		
Incoming resources from generated funds		
Donations and other voluntary income	469,583	299,961
Investment income	<u>3,595</u>	<u>3,645</u>
Total incoming resources	473,178	303,606
RESOURCES EXPENDED		
Expenditure in achieving its aims	368,929	144,353
Membership subscription of EBC	1,525	1,500
Meeting costs	32,796	95,482
Governance costs	14,472	19,596
Other resources expended	<u>19,265</u>	<u>20,294</u>
Total resources expended	436,987	281,225
	—————	—————
NET INCOMING/(OUTGOING) RESOURCES	36,191	22,381
RECONCILIATION OF FUNDS		
Total funds brought forward	335,391	313,010
	—————	—————
TOTAL FUNDS CARRIED FORWARD	<u><u>371,582</u></u>	<u><u>335,391</u></u>

Members and Affiliates of EFNA

- ⊙ Euro-Ataxia
- ⊙ European Alliance for Restless Legs Syndrome (EARLS)
- ⊙ European Alliance of Neuromuscular Disorders Associations (EAMDA)
- ⊙ European Dystonia Federation (EDF) European Headache Alliance (EHA)
- ⊙ European Huntington's Federation (EHF)
- ⊙ European Multiple Sclerosis Platform (EMSP)
- ⊙ European Network for Research in Alternating Hemiplegia in Childhood (ENRAH)
- ⊙ European Parkinson's Disease Association (EPDA)
- ⊙ European Polio Union
- ⊙ European Sexual Health Alliance (ESHA)
- ⊙ Guillain-Barré Support Groups - Europe (GBS-E)
- ⊙ International Brain Tumour Alliance (IBTA)
- ⊙ Motor Neurone Disease Association (MND - Europe)
- ⊙ Progressive Supranuclear Palsy Association - Europe (PSP-Europe)
- ⊙ Stroke Alliance for Europe (SAFE)
- ⊙ Trigeminal Neuralgia Association UK

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Abbott, Amgen (Europe) GmbH, Baxter, Bayer, BMS, Celgene, Lilly, F Hoffman-La Roche, GE Healthcare, Genus, Genzyme, Grunenthal, GSK, J & J, Janssen-Cilag GmbH, Medtronic, Medtronic Foundation, Merck Serono, MSD, Norgine, Novartis, NovoNordisk, Pfizer, Pierre-Fabre, sanofi-aventis, Takeda, Vifor Pharma AG.



European Federation of Neurological Associations

Working for people living with brain disorders

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