



ANNUAL REPORT

2015

FOREWORD

A WELCOME FROM EFNA EXECUTIVE DIRECTOR, DONNA WALSH



Hello and welcome to our Annual Report 2015. Firstly, I'd like to thank you for your interest in learning more about EFNA and our work.

In 2015, EFNA took time-out from certain projects to review and refocus, whilst introducing some new flagship initiatives to strengthen our advocacy work in Europe.

It was also a time when EFNA built new relationships or strengthened ongoing partnerships and we are now ready to play a larger part in the central workplan of these important organisations.

2015 also saw a change in EFNA President with Audrey Craven stepping down after more than 3 years of work in steering the organisation as we undertook our new strategic direction. The role is now filled by Ann Little, representing the International Bureau of Epilepsy. Read on, to hear more from both ladies.

Once again, this report is divided into the four pillars that form the basis of our Strategic Plan:

- » **Advocacy**
- » **Empowerment**
- » **Awareness**
- » **Engagement**

Please get in touch if you have any questions or comment – we would value your input and feedback. Thanks again for reading!

A GOODBYE FROM THE PAST PRESIDENT

Audrey Craven stepped down as EFNA President in June 2015. Here she reflects on her time in post; highlighting her key milestones and hopes for the future.

Looking back on my term in office the focus was to ensure that all those affected by brain disorders receive the priority they deserve. To achieve this we needed to form a ‘coalition of the willing’ whereby all stakeholders – scientists, researchers, health professionals, policy makers, industry, patients and other key opinion leaders – speak with one voice. We know that by successfully adopting this approach in other disease areas such as cancer and heart, significant improvements have been achieved. EFNA has aligned ourselves closely with key partners who – during my term in office – were also undergoing changes of their own.

EFNA has a long history of working closely with our neurologist partners in the European Federation of Neurological Societies. However, in 2014, the EFNS merged with the ENS to become the European Academy of Neurology [EAN]. We worked hard to ensure that this relationship with our health professional colleagues was maintained and expanded upon in terms of even greater cooperation with the new organisation. From the outset, it was clear that the EAN – led by its President, Prof. Guenther Deuschl and a dedicated Board – could see the value of patient participation. A highlight of my Presidency was seeing the level of patient engagement at the first EAN Congress in 2015 (see page 17) – giving us a platform upon which we can come together in future.

Our colleagues at the European Brain Council – under the leadership of President, David Nutt and Executive Director, Frédéric Destrebecq – have also reviewed their strategy in recent years as the main promoters of brain research and beyond in Europe. As a Board member, EFNA has engaged extensively in this process; positioning the role of the patient in all aspects of research. The importance of partnering with all stakeholders; industry and major brain related scientific societies cannot be over-emphasised.

The distribution of scarce resources will always be challenging for those ordering priorities. However, it is vital that they are apportioned fairly to reflect the economic and societal burden on all those affected. ‘Empowering Patient Neurology Groups’ became the EFNA slogan during the early part of my Presidency. We have a long track-record and continuing focus on up-skilling and building capacity amongst neurology patient advocates, so that we can fulfil our role to represent patients effectively. This requires a huge level of dedication and commitment from everyone, many of whom give their talent and expertise on a voluntary basis.

EFNA has worked hard to give these equipped and empowered advocates a platform on which they can influence policy-making. During the early part of my Presidency, we launched the EFNA Pledge to Protect Neuroscience Research and Neurology Patients. This advocacy work at the EU-level led to my involvement in European Month of the Brain - May 2013. Here, I served as the only patient representative on the scientific steering committee for the European Commission’s ‘Healthy Brain: Healthy Europe’ conference, held during the Irish Presidency of the European Union. This resulted in recommendations that highlighted the central role of patients in all stages of research and healthcare. The next step for EFNA’s advocacy was the creation – with our colleagues at Pain Alliance Europe – of an MEP Interest Group on Brain, Mind and Pain (see page 7). Almost 50 MEP’s and the European Health Commissioner have signed a Register of Supporters. Again, this gives us a strong platform on which to build in future years.

The current Board of EFNA is determined to meet the challenge of representing members at a very high level where we are seen by the European Institutions as a respected partner, responsible advocate and the “go to” organisation for a neurology patient perspective.

The role of patient organisations is increasingly moving towards centre stage. I feel privileged to have been a part of this exciting journey and I wish Ann, Donna and all the team the best of luck in the future. Sincere gratitude to all who worked so hard to make a difference. There is nothing we cannot achieve if we speak with one voice!



A HELLO FROM THE CURRENT PRESIDENT

Ann Little is the current EFNA President, taking on the role in mid-2015. Here she speaks about the organisation she 'inherited', her involvement to date and plans for the coming months.

When I took over the privileged role of EFNA President in mid-2015, I realised that I had some pretty big shoes to fill. Audrey Craven had been an incredible source of dynamic leadership for EFNA for the previous three years, sailing the ship with flair, diplomacy and vision. So, when she 'weighed anchor' on her presidential term, she passed over a craft that was more than 'ship shape' having completed many very successful and visionary voyages.

For the past year, Audrey has very kindly stayed on board as Past President to ensure a smooth handover and to support me as I grew into the role. For that help, I will be forever grateful to Audrey. Now that it is my turn to steer the rudder, I am pleased that I won't be doing so alone but will have the assistance of a wonderful crew. The EFNA board members (see page 4) continue to commit to giving of their time voluntarily and selflessly in acting as the EFNA reference point in a number of partnership and collaboration activities in which EFNA is involved. I would like to thank each one for their continuous commitment to EFNA.

Those who know Donna Walsh are forgiven the sin of envy at our having her as EFNA's Executive Director. Her dynamism, knowledge, drive, devotion to cause, and her ever-ready willingness to help makes her EFNA's greatest asset. She is due a huge 'Thank You' and I am always grateful for her support to me. Thanks are also due to Heather Clarke, our Senior EU Policy Officer, and to Elizabeth Cunningham, our Communications Coordinator, for their great work.

Audrey has spoken of the incredible advances that EFNA has made over the past three years, a breathless list of achievement. As I begin my term, I would like to mention briefly the EFNA activities in the second half of 2015 and the programme in place for 2016.

The focus in the latter part of 2015 was on putting plans in place for the launch of our year-long Together Under the Umbrella campaign, with a scheduled launch in March 2016. The aim of this campaign is to raise awareness of all disorders which fit under the 'neurology umbrella'. In other words, we are ambitiously attempting to 'brand the brain'.

A first step was to bring together patient advocates from across the continent to participate in a workshop designed to build enthusiasm and interest in the campaign. Over 50 delegates attended and actively contributed, resulting in a toolkit for supporting organisations – available from: www.undertheumbrella.eu

During this workshop we also held a gala dinner to honour the winners of our inaugural Advocacy Awards. This became a remarkable display of togetherness and goodwill amongst all stakeholders in the neurology sphere. I congratulate the winners, thank the judges and commend the nominating organizations for their participation. Read more on pages 10 - 11.

Following on from this workshop, all participants then travelled to the European Parliament for a meeting of our MEP Interest Group on Brain, Mind and Pain; the focus, on this occasion, being stigma- something so many of those in attendance know too much about! This was a pertinent reminder to us all of the work we still have to do to eradicate the discrimination and isolation felt by so many suffering from neurological disorders.

These initiatives will continue and grow throughout 2016, whilst new projects will also be rolled-out at EFNA. This includes our Training Initiatives for Neurology Advocates which will focus on empowering and equipping patient representatives to better influence decision-making. We will also work with the European Brain Council to produce the evidence we need to enable our advocacy activities. This will take the form of the Value of Treatment project which will show policy-makers that funding treatment is an investment, not a cost – especially important in the cost-cutting environment in which we operate today.

Implementing much of our workplan also requires the engagement and support of our multi-stakeholder partners and so we would like to thank all of you who worked with us in 2015 and encourage you to get involved again in 2016, when we host our Annual Partners Meeting.

As you can see, these are exciting times for EFNA as we sail forth with fair winds, always focussed on our destination – a better quality of life for people in Europe living with a neurological disorder. I hope that, when my term as captain comes to an end, the ship will have moved a few leagues closer to that 'Treasure Island'.



Board Members 2015

Ann Little	<i>President</i>	International Bureau of Epilepsy
Audrey Craven	<i>Past President</i>	European Headache Alliance
Cathalijne van Doorne	<i>Vice-President</i>	Euro-Ataxia
Bea de Schepper	<i>Treasurer</i>	European Huntington's Disease Association
Joke Jaarsma	<i>Secretary-General</i>	European Alliance for Restless Legs Syndrome
Maggie Alexander	<i>Board Member</i>	European Multiple Sclerosis Platform
Manuela Messmer-Wullen	<i>Board Member</i>	Stroke Alliance for Europe
Nancy Van Hoylandt	<i>Board Member</i>	European Myalgic Encephalomyelitis Alliances

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Visit us at: www.efna.net | www.undertheumbrella.eu | www.brainmindpain.eu
 Follow us on Twitter: [@EUneurology](https://twitter.com/EUneurology) | [@UnderUmbrellaEU](https://twitter.com/UnderUmbrellaEU)

Our Members

- » [Dystonia Europe](#)
- » [Euro-Ataxia](#)
- » [European Alliance for Neuromuscular Disorders Associations](#)
- » [European Alliance for Restless Legs Syndrome](#)
- » [European Headache Alliance](#)
- » [European Huntington's Disease Association](#)
- » [European Multiple Sclerosis Platform](#)
- » [European Myalgic Encephalomyelitis Association](#)
- » [European Network for Research in Alternating Hemiplegia in Childhood](#)
- » [European Polio Union](#)

- » European Myasthenia Gravis Association
- » European Sexual Health Alliance
- » Guillain-Barre Support Groups - Europe
- » International Brain Tumour Alliance
- » International Bureau for Epilepsy
- » Motor Neurone Disease Association
- » Pain Alliance Europe
- » Progressive Supranuclear Palsy Association
- » Retina International - Europe
- » Stroke Alliance for Europe
- » Trigeminal Neuralgia Association UK

2015 EFNA ACTIVITIES EXPLORED IN THIS ANNUAL REPORT:

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**BRAIN
MIND
PAIN**



ADVOCACY

MEP Interest Group on Brain, Mind and Pain

EFNA has consolidated its advocacy activities into its MEP Interest Group on Brain, Mind and Pain. This is a joint initiative with Pain Alliance Europe (PAE). The group was launched in Brussels in February 2015 at an event with over 100 attendees; composed of patient advocates, health professionals, policy-makers, industry representatives and many more. It is co-chaired by MEPs Marian Harkin, Jeroen Lenaers and Daciana Sarbu (all pictured below).

The Member of the European Parliament Interest Group on Brain, Mind and Pain works:

To encourage research into and access to innovative treatments, promote prevention and self-management approaches, decrease stigma and work together to improve quality of life for people living with these disabling conditions.



Daciana Sârbu MEP



Jeroen Lenaers MEP



Marian Harkin MEP

We will contribute to innovative, efficient and sustainable health systems by providing a forum to share and exchange best practice, encourage debate and discussion, and lead to tangible actions in the areas outlined in the Interest Group mission statement above.

From the outset it was important to provide a sound policy base and work towards positive policy outcomes. A Book of Evidence was commissioned by EFNA & PAE in order to inform and support the activities of the MEP Interest Group. It summarises evidence in four focus areas, along with case studies of positive activities from around Europe, and recommendations for action. The data was collated via literature reviews, focus groups with national and pan-European patient organisations, interviews with industry, health professional and other stakeholder groupings, etc. The Book of Evidence, which can be downloaded from the website, is divided into 4 pillars:

- » **Stigma - Visible and Invisible**
- » **Quality of Life - Education and Employment**
- » **Improving Investment in Research**
- » **Patient Involvement**

For more information and to download the Book of Evidence, please visit: www.brainmindpain.eu.

Influencing the policy makers

We were delighted when Vytenis Andriukaitis, the EU Commissioner for Health, agreed to meet us and sent a message of support to our launch meeting :

'I welcome the intention of the Interest Group on Brain, Mind and Pain to focus on supporting concrete action. Today's presentation of the "Book of Evidence" is an important step to map priorities for action and to launch a call for action...'

You can read the full statement of support from the Commissioner on page 9.

After the official launch event a subsequent meeting in the European Parliament focussed on **Health Promotion and Prevention**. Dr Jenny Barnett revealed that many neurological disorders which are deemed 'unpreventable', can be prevented – at least in part – through simple lifestyle modifications. She used the example of Alzheimer's Disease in which approximately 50% of the risk for developing the disease is attributable to seven modifiable risk factors. This was supported by Prof. Wolfgang Oertel of the European Academy of Neurology who said that good sleep patterns – for example – could not be underestimated, and supported Dr. Barnett's call for more education and awareness raising of these facts. Both emphasised the need to target young people, saying many of these diseases begin to develop during our youth, even if they do not obviously manifest until later life. References to the papers/ research cited above, along with additional information, can be found in a presentation available here: <https://goo.gl/L5056n>

Prof. Giustino Varrassi of the European League Against Pain then explained ways in which musculoskeletal disorders could be prevented, with a focus on the workplace – again through mostly simple, low-cost adaptations. Full presentation also available here: <https://goo.gl>

Stigma is another issue which unites many patients, and for our next meeting we joined up with the Interest Group on Mental Health, Wellbeing and Brain Disorders - hosted by MEP Damian Dragichi. Following some powerful patient testimonies neurologist Prof. Matilde Leonardi informed the audience of the outcomes of a Patient Experience Survey of almost 5,000 patients.

One of the main findings was that 57% of the sample feels stigmatised at least occasionally and persons who think that their condition should have been diagnosed earlier perceive a significant higher workplace and social stigma and a worse overall well-being compared to persons who think that their condition was diagnosed on time.

Michael Hübel, (European Commission, DG SANTE) underlined that if we want to truly tackle the issues around chronic disease, we need to look at mental as well as at physical health.



Above: Joop van Griensven, President Pain Alliance Europe with Vytenis Andriukaitis the EU Commissioner for Health and Former EFNA President Audrey Craven



Left to right: Prof. Giustino Varrassi, Dr Jenny Barnett, Audrey Craven, and MEP Damian Dragichi

The European Commission's message resonated with ours:

'Three quarters of EU health care cost are related to chronic disease and the proportion of brain disorders and mental health conditions within this is huge. This does not only relate to the direct costs of the conditions, but also to indirect costs, due to long term absence and early retirement. If awareness of these facts does not increase and if policy makers and service providers cannot be convinced that this is a serious issue, a situation where people will not reach their full potential will continue.

'Stigma is a very important aspect in this respect. It often relates or leads to outright discrimination. There are several tools, such as the Convention of the Rights of People with a Disability, to which the EU has signed up. The Commission's Mental Health Pact, the Joint Action on Mental Health and the work carried out to address mental health in the work place are all useful actions taken by the EU level.

'The workplace would seem to be an ideal setting to promoting mental health and well-being, because so much time is spent there. In terms of the organisation of health services, the general trend towards community care based services should be seen as an opportunity to bring mental and physical health services together. However, the philosophy upon which these services are based will determine how they deal with and combat stigma. Brain disorders can be prevented and we need more investment in policy and research.'

A Policy Outcome

The workplace, therefore, was a common theme of all meetings in 2015 and thus – as an outcome – we contributed to the EU Strategic Framework on Health and Safety at Work report. We were delighted the amendment we worked on was passed on 25 November. It *'draws the attention of the Commission to the increased number of workers affected by chronic illness in the workforce; takes the view that accessible and safe jobs should be available for people affected by terminal illnesses, chronic and long-term conditions and disability; urges the Member States to focus on retention and integration of people affected by chronic diseases as well as to support reasonable adaptation of workplaces, which will ensure a timely return to work; calls on the Commission to promote integration and rehabilitation measures for people with disabilities and to support Member States' efforts by raising awareness and identifying and sharing good practices on accommodations and adjustments in the workplace;*' The report will be passed to the Council and the Commission. We are grateful for the support of MEPs Harkin, Willmott and Lenaers throughout.

BUILDING ON 2015 SUCCESS

In 2016, there will be three further Interest Group meetings. These will focus on Access to Education and Employment and Patient Involvement in Research & Beyond. Building on our successful policy outcomes in the area of employment in 2015, we will also launch a Written Declaration on Access to Education and Employment for those affected by Neurological Disorders and Chronic Pain Conditions.



STATEMENT OF SUPPORT FROM THE HEALTH COMMISSIONER

Dear Members of Parliament, Ladies and Gentlemen,

I fully support the new Interest Group on Brain, Mind and Pain.

We all know that brain disorders and chronic pain are common, disabling and costly chronic disorders. Brain disorders can affect people all over their lives and drastically reduce their quality of life and ability to participate in society, at school and at work.

Brain disorders are still surrounded by stigma; and people experiencing such disorders do not always receive the support they need.

This is a challenge for society as a whole. A study suggested that, in 2010, brain disorders generated close to 800 billion Euros in costs paid by citizens, health and social systems.

In this context, I welcome the intention of the Interest Group on Brain, Mind and Pain to focus on supporting concrete action. Today's presentation of the "Book of Evidence" is an important step to map priorities for action and to launch a call for action. This is indeed what Europe is about: Identifying what works in one part of the EU, sharing knowledge, encouraging and supporting evidence-based policies.

I share your concern with mental health and brain disorders and look forward to co-operating with the interest group in the years to come.

Inaugural EFNA Advocacy Awards

In 2015, EFNA ran its first Advocacy Awards. Members were invited to submit nominations in four categories: Patient Advocate, Policy-Maker, Health Professional and Media. These were assessed by our esteemed judging panel: Nicola Bedlington (European Patients Forum), Mary Harney (former Irish Health Minister), Nick Ross (former BBC Journalist), Lynne van Poelgeest (EPPOSI) and David Vodusek (European Academy of Neurology). Read more from the winner, judges and nominating organisations below.



The Awards took place on the evening of Tuesday October 13th at the Thon Hotel in Brussels, Belgium. The night was hosted by Nick Ross, Broadcaster and Journalist, and also facilitated by Audrey Craven, Past-President at EFNA.

The Awards provided an opportunity to recognise some of the excellent efforts made by particular individuals to better the lives of many living with neurological disorders in Europe.

In 2016, EFNA will once again hold these awards. There will be a new category of Employer.

Policymaker Award Winner: Gay Mitchell

The first award of the evening was our Policymaker award. The nominating organisation was The International Bureau for Epilepsy (IBE) whose Executive Director, Ann Little had the pleasure of introducing the award to Former MEP, Gay Mitchell. It was presented by former Irish Health Minister, Mary Harney.



Ann explained that The International Bureau for Epilepsy nominated Gay Mitchell, for the Policymaker award, on foot of his consistent and dedicated campaigning for people with epilepsy in the European Parliament for more than 10 years.

“Gay Mitchell opened doors for us in Europe, and provided us with direction, which have been instrumental in raising epilepsy on the political agenda.”

He launched the first European Epilepsy Day in the European Parliament in 2011 and hosted the event until retirement from politics. Also, he created the European Advocates for Epilepsy MEP Group in 2011, which submitted a Written Declaration on Epilepsy that achieved one of the highest ever numbers of MEP signatures.

Thanks to the exposure that epilepsy received from these activities, research on epilepsy was defined as a priority in the final FP7 Call in 2012. On retirement from politics, Mr Mitchell joined Epilepsy Advocacy Europe – the task force that coordinates IBE’s EU-related activities.

Health Professional Award Winner:

Prof. Cristina Tassorelli

The award for Health Professional was explained by David Vodusek, Chair of the Liaison Committee of the European Academy of Neurology. The nominating organisation was the European Headache Alliance, whose President Audrey Craven had the honour of presenting the award to Professor Cristina Tassorelli.

Prof. Cristina Tassorelli served voluntarily as Medical Advisor for 9 years to the European Headache Alliance – an organisation of which she was a founder member.

Throughout all these years her clinical and research work has benefited countless patients and so many others affected by headache disorders. Her genuine passion and commitment in her role as a Neurologist with a special interest in headache disorders, has served both the scientific and patient community well and she has worked tirelessly to bring stakeholders from industry and patient groups together. She has demonstrated great awareness of the importance of having evidence based data to influence those ordering priorities to advocate for more resources whilst ensuring the patient perspective is respected.



Media Award Winner: Jeroen de Schepper

Mary Lynne Van Poelgeest-Pomfret, Patient Advocate and President, European Platform for Patient Organisations, Science and Industry [EPPOSI], introduced the candidate put forward by the European Huntington Association (EHA) in the Media category of the EFNA Advocacy Awards 2015. Jeroen succeeded in raising awareness through the media of a very serious neurological disorder – Huntington’s disease.

In Belgium he held a press conference in cooperation with Prof. Ann De Paepe, Rector of the University of Ghent and was featured on the VRT’s main news programme – as well as on different local TV channels, newspapers and radio stations. His ‘crosscountry4huntington’ initiative was not just profiled by the Belgian media but also by media outlets all across Europe. He travelled throughout the continent by bike: cycling over 12,000km in four months.

In each country he visited, he met either families affected by Huntington’s Disease or called to nursing homes and local Huntington Associations. These meetings were reported on by TV, radio and newspapers in each country. He also kept a blog to report on his trip which was read by many people. All of this raised so much awareness and understanding of Huntington’s Disease and not just from amongst those affected by HD, their family and caregivers, and health professionals – but also with the general public. According to Jeroen:



“I don’t have the time to tell all the stories off my trip but one year later the story still continues. Together with my girlfriend we crossed Bulgaria by bike from the Black Sea to Sofia. The recognition for the disease in Eastern Europe is non-existent. The President of the new Bulgarian Huntington Association invited us to draw attention. She is trying to make the government recognize the disease. We ended the trip with more media than we expected and hope it is another step towards the recognition. But there is still a lot of work and I’m happy that I could contribute.”

Patient Advocate Winner: Shana Pezaro

The European Multiple Sclerosis Platform (EMSP) were the nominating organisation for the Patient Advocate award, which was outlined by Nicola Bedlington, Secretary General of the European Patients Forum [EPF]. As Nicola could not be with us on the evening she was represented by her colleague Camille Bullot. Maggie Alexander, Executive Director of EMSP was delighted to announce Shana Pezaro as the winner of this award.

Shana is 36 and has Intermittent Relapsing MS. She was finally diagnosed eight years ago but has had MS since childhood. Shana sold her business during diagnosis, was signed off work permanently and divorced due to the pressure MS placed on her marriage. With emotional and



practical support from her MS Nurse, Neuro-Rehabilitation Team, Physios and Fatigue Management OTs, Shana has been able to rebuild her life. She is now dedicated to helping other people with MS to do the same.

She has become a Trustee for the Brighton & Hove Federation Centre For Independent Living and works voluntarily with the Campaigns, Press and PR departments of the National MS Society and EMSP. Shana also politically campaigns around health, welfare and social care reform on a local and national level and has many successes in implementing policy change.

She is involved in initiatives both in the UK and with EMSP in Europe to support disabled people to maintain paid employment. Shana has won the UK MS Society’s ‘National Campaigner Award’ and the ‘National Olympic Champions Community Award’. Shana organises social events for young people with MS and has run a very popular pub-afternoon event for the past 6 years in Brighton. Shana is particularly interested in the impact of MS and disability on sexuality and self-esteem.

Maggie explained:

“EMSP is fortunate to work closely with many outstanding patient advocates and they are at the heart of everything we do. However, Shana is really exceptional not only for her energetic and persistent lobbying on behalf of people with MS (despite the frequent bouts of acute fatigue and mobility restrictions imposed by her condition), but also for her ability to change the hearts and minds of key decision-makers, healthcare professionals and funders. Shana achieves this by uniquely combining disarmingly candid accounts of the impact of her condition with highly informed experience and evidence in support of her arguments for greater health equality for all those affected. This, together with her pioneering work with young people affected by MS is the reason for EMSP’s unequivocal support for Shana to receive this excellent new award.”



EMPOWERMENT

Patient Advocate Workshops at the London School of Economics [LSE]

There is increasing emphasis on ‘patient centred healthcare’ and greater involvement of patient groups in policy setting at all levels. However, it is clear that not all patient groups are sufficiently skilled to take full advantage of the opportunities offered to them to contribute effectively to developing policy.

The LSE and EFNA have worked together for four years to deliver training to patient groups on health technology assessment (HTA) and, more recently, Pharmaceutical Pricing, Access and Reimbursement – which was the theme for the course which took place during February 2015.

Almost 30 patient advocates came to London for two days to participate in this important initiative which was aimed at equipping them with the knowledge and skills they need to be actively involved in influencing regulatory decision-making in relation to medical technologies/pharmaceuticals.

By attending this course, participants obtained insights on: (a) how pharmaceuticals fit within the overall health care system; (b) how different countries in Europe and beyond pay for pharmaceuticals; (c) what are the most salient regulations addressing coverage/access and how these affect patient access; (d) how stakeholders – including patients – participate in the decision-making process. Topics included:

- » Rate of Return Regulations
- » Price Referencing and Tendering
- » Patient Access Schemes
- » Generic Pharmaceutical Policy
- » Risk Sharing
- » Adherence to Medicines
- » Value Based Pricing
- » Prescribing Policies and Incentives

The course was run by Prof. Panos Kanavos of the London School of Economics. Prof. Kanavos is Reader in International Health Policy and is an economist by training. He coordinates the activities of the Medical Technology Research Group at LSE and works closely with the wider stakeholder community (government, patients, industry, etc.). His research interests comprise health systems analysis and reform, health technology assessment and the economics of medical technology.



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AWARENESS

3. AWARENESS

Together Under the Umbrella is an innovative pan-European campaign which will launch during Brain Awareness Week, March 2016.

A year-long initiative of the European Federation of Neurological Associations [EFNA], the campaign aims were decided at our 2015 Advocate for Brain, Mind and Pain workshop in Brussels. These are to:

- » Educate society on the wide range of neurological and other brain/brain-related disorders
- » Raise awareness of the impact and prevalence of these disorders
- » Brand the brain by grouping these disorders under a common symbol to create a unified & identifiable 'brand'

Almost 50 representatives from pan-European and national patient organisations attended this workshop, organised by EFNA from October 12 to 14th 2015 in Brussels. We strived to enable, equip and inspire our member organisations to become involved in the campaign.

EFNA provided opportunities for training with experts in new and traditional media and from the fundraising and advocacy sectors. The workshop was open to patient advocates drawn from a mix of disease areas and European countries. Those who registered to participate were asked that they return to their own organisations/countries and work with EFNA to roll-out the campaign on the ground.



To find out more about the campaign see: www.undertheumbrella.eu

During the campaign EFNA will advance the wider Call to Action 2015 of our partners at the European Brain Council in calling for:

The European Commission to come forward with a European strategy to tackle brain disorders in a collaborative, integrated and comprehensive manner, as well as to further support European Union Member States and associated countries in their efforts to combat the impact of brain disorders.

European Union member states and associated countries to implement public health programmes addressing brain health in a systematic way, making the best possible use of available resources in order to stimulate more and better co-ordinated brain research, and to foster strategies for prevention, early detection, diagnosis and adequate treatment.



ENGAGEMENT

4. ENGAGEMENT

EFNA works closely with the European Academy of Neurology (EAN)

The EAN was born in 2014 following the coming together of the EFNS and ENS, and its first congress was held in Berlin – a city symbolising unification!

With over 6,000 participants from across Europe and the world, EFNA used the opportunity to raise awareness of our work.

Along with our Members, we held a Patient Corner in the Exhibition Centre where we distributed information and networked with interested neurologists.

While EFNA was represented on the Liaison and Training & Education Committees of the EAN, many of our members were invited to sit on the relevant sub-speciality panels where they provided the patient perspective.



An awareness day on Headache and Sleep Disorders – organised jointly by EFNA and the EAN – was also held for German Patients.

And, our Corporate Partners Meeting with interactive sessions for the EFNA membership and our sponsors capped five successful days of activity.

All of the above was made possible due to the respect the leadership of the EAN shows to the patient voice but also because of the support of the EAN's Liaison Officer Eveline Sipido – who has championed EFNA and its work for many years. Eveline was presented with our first Lifetime Achievement Award in 2015.

Above: Eveline Sipido, EAN Liaison Officer



EFNA also works closely with the European Brain Council and the European Patients Forum in Brussels

In 2015, various members of the Board represented EFNA at the European Brain Council (EBC). The focus of EBC is in fostering cooperation and promoting dialogue between scientists, industry and society. This is clearly important for EFNA as we strive to ensure that a patient perspective is central to such partnerships. The EBC has a long track-record and continues to undertake scientific research which can strengthen our advocacy – e.g. Cost of Brain Disorders in Europe 2010 and the current Value of Treatment project in which many EFNA members are represented.

The European Patients Forum is an umbrella organisation that represents the interests of an estimated 150 million patients in public health and health advocacy across Europe. The EPF works on cross-cutting issues, which allows us to focus on the specific concerns of the patient community we serve. EPF also gives us an opportunity to exchange ideas, concerns and best practices with our colleagues in the patient community.



Throughout 2015, the EFNA Board and Staff represented the organisation (and patients more broadly) as speakers, chairs and participants at many meetings of key stakeholders and partners in the field of neurology. Below our Board Members/Staff tell us more about these organisations and their roles therein.

I'm Cathalijne van Doorne. I am currently EFNA Vice-President with special responsibility for Science and Research. I am the Patient Chair at the **EuropaBio Patients BioForum**. This is a platform for an exchange of views and expertise between patient organizations, EuropaBio and its members on issues of common concern related to the field of healthcare biotechnology. For EFNA and its members the BioForum is an excellent opportunity to bring a patient-relevant topic to the table and to discuss it from our perspective with other stakeholders in the field. Examples of topics are: "Involvement of patients in clinical development - how to make it happen" and "Biosimilars: what are they and what do patients need to know?"

I also represent EFNA at the **BioPontis Alliance for Rare Diseases**. The aim of this alliance is to fill a gap in the discovery and development pathway by raising money from charities, companies and individuals to fund preclinical discovery projects in rare diseases and advance programmes to the point where they are de-risked and can be fed into the end of the clinical development pipelines of pharma companies. The current focus is on rare neurological disorders.

Finally, I am the current chair of the **European Alliance for Access to Safe Medicines (EAASM)**. This is an independent, pan-European initiative dedicated to protecting patient safety by ensuring access to safe and legitimate medicines. Its key activities include campaigning for the safer use of unlicensed or off-label medicines and also the exclusion of counterfeit and substandard medicines from the supply chain. This is important for EFNA as many neurology patients are prescribed off-label medicines, and some resort to counterfeit drugs because of cost, stigma and – often – ineffective treatment options.



I'm Joke Jaarsma, I serve as Secretary-General of EFNA and have special responsibility for Training and Education. In this role, I sit as a patient representative on the Training and Education Committee at the European Academy of Neurology. This committee discusses neurology education in the broadest sense, from education of young neurologists to neurology in the developing world. Patient representation is valued by the team and has resulted in -for example - sessions being nominated "Patient Choice" on the annual congress scientific programme. Suggestions for specific symposia/ special sessions have been taken on board and will result in a joint session at the 2016 Congress entitled – Open Dialogue: Let's Talk about Sleep, Stress and Sex.

In 2015, I also represented EFNA on the **Patient and Consumer Working Party and the European Medicines Agency**. The quarterly group meeting is a joint event with representatives from patients, consumers and healthcare professional organisations. The delegates discuss issues in relation to their involvement in EMA's activities, with particular focus on pharmacovigilance legislation, communication and information. EFNA's presence at the meetings allows for disease specific information to reach the EFNA membership at an early stage, and for participation in specific hearings – for example in the clinical trial process.





My name is Nancy van Hoylandt, the newest EFNA Board Member. In 2015, I began to represent EFNA externally at the **EFPIA Think-Tank**. This is a platform that brings together both EFPIA members, who are the European pharmaceutical industry, and European patients' organisations. In these meetings the objective is to build an open discussion which increases mutual understanding on the approach of each to EU policy, strategies, goals, etc. The group is also involved in planning towards the annual Health Collaboration Summit. It is important that EFNA is represented in the Patient Think Tank to ensure that the specific concerns of neurology patients are reflected in the discussions.

I am Manuela-Messmer Wullen. In 2015, I participated in the Patient Advisory Group on **Medical Imaging at the European Society of Radiology (ESR-PAG)**. As a stroke survivor and patient advocate, I have both professional and personal experience and interest in radiology. Indeed, radiology is a discipline that many neurology patients encounter and so it is important for us to be represented here. EFNA's involvement in this group resulted in the International Day of Radiology 2014, focussing on Brain Imaging. This active involvement has continued into 2015 with EFNA contributing to the development a Driver Diagram and Change Package on Delivering Patient-Centred Care in Clinical Radiology, and being asked to present at the annual European Congress of Radiology in Vienna on this topic.



A WORD FROM THE TREASURER

On behalf of EFNA, as Treasurer, I would like to acknowledge support from the following corporate partners in 2015. Our relationships with all sponsors/funders are regulated carefully by our "Code of Practice". This is available on our website, along with a more detailed breakdown of funding received to meet the requirements for participation in European Medicine Agency activities.

I would also like to thank our members who paid membership fees in 2015 for the first time. This is important to diversify our income but also to show the commitment and engagement of the membership we serve. Thanks, too, go to the European Academy of Neurology who have again supported us financially this year.

I would also like to acknowledge the contribution of our accountants at SBB who work with us closely to prepare and accurately present these figures, as well as providing advice and assistance on all financial – and legal – matters when required.

Of course, fundraising is becoming increasingly difficult and so a final thank you to all those who continue to support our cause, and who have allowed us to coordinate and run all the activities outlined in this report. We hope to work with you again in 2016.

Thank You!



Bea de Schepper
EFNA Treasurer



Income	Amount
Income from Sponsors	250,000
Membership Fees	3,000
Other Bank Income	954.47
Total Income	253,954.47

Expenditure **Amount**

Advocate for Brain, Mind and Pain Workshop

Venue Costs incl. accommodation and gala dinner <i>incl. room rental, equipment hire, accommodation, awards gala dinner, etc.</i>	39,038.71
Delegate/Speaker Travel Expenses	9,519.76
Communications Officer	9,087.66
ADV Costs - Previous Financial Year	8,515.25
Admin/Overhead Provisions	10,500.00
Project Total Expenditure	

Brain, Mind and Pain MEP Interest Group

Venue Rental	162.39
Corporate Partners Meeting	2,200.00
Senior Policy Officer	31,084.63
Interest Group Meetings	6,393.13
Planning Meetings incl. Promotional Visit to Strasbourg	2,046.77
Website and Online Publishing	2,180.00
Printing and Publishing Costs	2,666.86
Equipment and Supplies	2,044.99
Admin/Overhead Provisions	10,500.00
Project Total Expenditure	

General Assembly incl. Participation at EAN Congress

Accommodation	6,459.69
Travel Expenses (incl. Board Meeting 2)	7,334.59
Promotional materials, room and equipment hire, etc.	2,318.37
Exhibition Stand	1,938.00
Meals and Catering	2,217.16
Shipping	210.00
Admin/Overhead Provisions	3,000.00
Project Total Expenditure	

Training and Capacity Building Workshop at London School of Economics

LSE Fee	79,866.57
Accommodation	6,871.94
Delegate Travel Expenses	3,746.01
Admin/Overhead Provisions	13,500.00
Project Total Expenditure	

Other Running/Admin Costs

Additional payments to consultants	5,637.94
Website Hosting, Telephone and other miscellaneous admin costs	1,005.74
VAT returns/reimbursements/etc.	-3,061.67
Accounting Fees	5,675.00
Membership Fees	1,750.00
External Representation	5,469.32
Other Financial Overheads	2,969.64
Project Total Expenditure	

Total Expenditure **282,848.45**

Deficit in income over expenditure 2015 **-28,893.98**

CASH AT BANK 130,480.37

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www.brainmindpain.eu

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EFNA is registered in Belgium as an Association Sans But Lucratif (ASBL) #0543319269