EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

ANNUAL REPORT 2016

EMPOWERING PATIENT NEUROLOGY GROUPS

A WELCOME FROM DONNA WALSH, EFNA EXECUTIVE DIRECTOR, AND ANN LITTLE, EFNA PRESIDENT

Dear Reader,

Thank you for taking an interest in EFNA and our work in 2016.
We've been busy this year with three flagship initiatives, which fit within the various focus areas of our strategic plan:

MEP Interest Group on Brain, Mind and Pain - *See: ADVOCACY – page 6*

Together Under the Umbrella awareness campaign - *See: AWARENESS – page 14*

Training Initiatives for Neurology Advocates - *See: EMPOWERMENT – page 17*

Thanks must be expressed to our small but committed team at EFNA who continually go beyond the call of duty to ensure that the above projects are successful. Our Communications Coordinator, Elizabeth Cunningham, is the driving force behind our awareness campaign, whilst Heather Clarke, our Senior EU Policy Advisor, ensures the ongoing roll-out of our Interest Group and its associated advocacy activities.
With the roll-out of additional activities at the national level this year, we have also been dependent on partners and volunteers across the EU to:

- *Help plan country-specific workshops (in Romania and the Netherlands in 2016)*
- *Contact national MEPs and policy-makers to promote our Written Declaration and additional policy asks*
- *Host localised #UnderTheUmbrella events*

Thanks to everyone who got involved – in many cases, led by our own Board Members who continue to represent us so effectively externally.

Over the next pages you can read, in more detail, of our activities in 2016 – grouped under the headings of 'Advocacy', 'Empowerment', 'Awareness' and 'Engagement'. If you've only got a minute, then take a look at our quickfire summary overleaf, and also check out the Table of Contents so you can find what's of most interest to you quickly.

Happy reading!

Donna and Ann

BOARD MEMBERS 2016

Ann Little	***President***	International Bureau of Epilepsy
Audrey Craven	***Past President***	European Headache Alliance
Cathalijne van Doorne	***Vice-President***	Euro-Ataxia
Bea de Schepper	***Treasurer***	European Huntington's Disease Association
Joke Jaarsma	***Secretary-General***	European Alliance for Restless Legs Syndrome
Manuela Messmer-Wullen	***Board Member***	Stroke Alliance for Europe
Nancy Van Hoylandt	***Board Member***	European Myalgic Encephalomyelitis Alliance
Klaus Knopps	***Board Member***	European Multiple Sclerosis Platform
Jenny Baker	***Board Member***	International Brain Tumour Alliance

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Visit us at: www.efna.net | www.undertheumbrella.eu | www.brainmindpain.eu
Follow us on Twitter: @EUneurology | @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 Myalagic Encephalomyelitis Alliance
- European Network for Research in Alternating Hemiplegia in Childhood
- European Polio Union

- European Myasthenia Gravis Association
- 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

Find out more about our members at

www.efna.net/members

2016 EFNA ACTIVITIES EXPLORED IN THIS ANNUAL REPORT:

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Below: A flashmob 'Jumps for Dystonia' Under the Umbrella at Dystonia Europe's D-Days event in Oslo, April 2016. Photo by Stephan Röhl.

SUMMARY

2016 was a busy year for EFNA, with the launch of some of our biggest-ever, independent projects – for example: our *Training Initiatives for Neurology Advocates* and the ***Together Under the Umbrella*** awareness campaign. Coupled with the continuation of existing central activities such as the MEP Interest Group on Brain, Mind and Pain, EFNA was hugely pleased with the implementation of our annual workplan 2016.

ADVOCACY: MEP INTEREST GROUP ON BRAIN, MIND AND PAIN

- Four meetings in 2016 at the European Parliament.
- Focus on access to employment for those affected by neurological disorders and chronic pain conditions, including the launch of a Written Declaration on this topic.
- Following a large scale promotional campaign, including meetings with leading MEPs, almost 180 sign the Written Declaration – giving us a platform to build on for future work on this and related topic.
- Input into consultations on the European Social Pillar and EU Cooperation on HTA.
- Additional areas covered included patient involvement in research.
- Ongoing collaboration with other partners in the field, to which EFNA adds the neurology patient perspective – e.g. European Patients Forum, European Brain Council and so on.

AWARENESS: TOGETHER UNDER THE UMBRELLA

- EFNA's first pan-European awareness campaign
- Campaign aims:
  - To educate society on the wide range of neurological and other brain/brain-related disorders.
  - To raise awareness of the impact and prevalence of these disorders.
  - To 'brand the brain' by grouping these disorders under a common symbol.
- Numerous successful offline events were organised by EFNA, our members and supporters.
- July 22nd, World Brain Day, saw hundreds of people around the world share selfies along with the hashtag #UnderTheUmbrella.
- Focus on awareness of invisible disabilities and symptoms with a campaign drive during *Invisible Disabilities Week 2016* in October.
- Fantastic feedback for our Together *Under the Umbrella* '12 Days of Christmas' Facebook competition which had 180 participants.

EMPOWERMENT: TRAINING INITITIATIVES FOR NEUROLOGY ADVOCATES

TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES

- One pan-European workshop at Trinity College Dublin in October 2016 on *Putting the Neurology Patient Perspective at the Heart of Research and Beyond*.
- Speakers drawn from the fields of academia, clinical practice, neuroscience, health economics, patient advocacy and IT.
- Overwhelmingly positive feedback but emphasis on the need for more practical training in communicating the patient perspective. This will be addressed in 2017.
- Two national workshops – the first in Bucharest, Romania and the second in Utrecht, The Netherlands.
- Hugely positive feedback from the Romanian event, with a follow-up planned for 2017.
- Over 100 patient advocate participants across the three workshops, drawn from across the spectrum of neurological disorders.

Below: Marian Harkin MEP hosts a meeting of the Brain, Mind and Pain Interest Group at the European Parliament
Bottom: A selection of pictures shared on social media as part of the Together Under the Umbrella campaign on World Brain Day.

AWARENESS

1

At EFNA, we are ongoingly seeking ways to influence policy and achieve concrete outcomes.

Since late 2014 we have provided a policy platform for our members and partners to highlight their concerns, work and examples of best practice via the MEP Interest Group on Brain, Mind and Pain – which we coordinate with our colleagues at Pain Alliance Europe [PAE].

The group 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.*

2016 was a busy year for us with four open meetings in the European Parliament, bi-lateral meetings with dozens of MEPs and a huge call for MEP signatures to support improvement in access to employment for those affected by neurological disorders and chronic pain conditions.

Much of our work in 2016 focussed on the issue of **employment** as you will see in the meeting topics listed, and the arising actions – including the launch of a Written Declaration on Access to Employment for those affected by neurological disorders and chronic pain conditions.

"WORK IMPACTS ON SOCIAL COHESION AND ON PEOPLE'S QUALITY OF LIFE. THUS IDENTIFYING FIRST AND THEN CARING ABOUT WORKERS WITH NEUROLOGICAL DISORDERS COULD BENEFIT EMPLOYERS, THANKS TO TAILORED INTERVENTIONS. A HEALTHIER WORK ENVIRONMENT CAN BE A FACILITATOR, AND NOT A BARRIER, IN HELPING TO PREVENT INCREASES IN THE LEVELS OF DISABILITY EXPERIENCED BY PEOPLE AFFECTED BY NEUROLOGICAL DISORDERS."

DR. CHIARA SCARATTI, BESTA NEUROLOGICAL INSTITUTE, ITALY.

"THERE ARE HUGE UNMET NEEDS IN THE AREA OF NEUROLOGICAL DISORDERS AND CHRONIC PAIN CONDITIONS. MORE RESEARCH IS NEEDED – FROM BASIC TO CLINICAL TO TRANSLATIONAL. HOWEVER, DUE TO THE COMPLEXITY OF THIS RESEARCH, THE HIGH FAILURE RATES AND THE LENGTHY DEVELOPMENT TIMES (COMPARED TO OTHER DISEASE AREAS), MANY COMPANIES ARE DOWNSIZING OR CLOSING THEIR OPERATIONS IN THIS AREA. WE CALL ON THE EU TO ENSURE THAT PUBLIC FUNDING THROUGH H2020 AND THE IMI BRIDGES THIS GAP."

DONNA WALSH,
EFNA EXECUTIVE DIRECTOR.

MEETINGS 2016

Topic 1: Neurological and Chronic Pain Disorders at Work

February 2016, European Parliament, Brussels
Host: Jeroen Lenaers MEP

Associated outcome:
Plans for the launch of a Written Declaration on access to employment for those affected by neurological disorders and chronic pain conditions
(See below for more details on this initiative.)

Topic 2: Patient Involvement in Research – How and Why those with Brain, Mind and Pain Disorders must be involved

June 2016, European Parliament, Brussels

Host: Marian Harkin MEP

Associated outcome:

Launch of EFNA's *Training Initiatives for Neurology Advocates* as an attempt better to enable patient involvement in decision-making.
(See page 17 for more details on this initiative.)

Topic 3: #MakeWorkWork - Launch of Written Declaration

October 2016, Working Breakfast, European Parliament, Strasbourg

Host: Heinz Becker MEP

Associated outcome:

Official launch of a Written Declaration on access to employment for those affected by neurological disorders and chronic pain conditions – and the development of a workplan to generate support e.g. development of promotional materials, activation of membership, schedule for MEP meetings, creation of contact database, etc.
(See below for more details.)

Topic 4: #MakeWorkWork for those affected by Neurological Disorders and Chronic Pain Conditions

November Breakfast Meeting, European Parliament, Brussels

Host: Jeroen Lenaers, MEP

Associated outcomes:

- Usage of content to develop responses to EU consultation on Social Pillar and HTA (see below
- Further promotion of Written Declaration
- Building of connections with organisations active in the field of employment e.g. Fit for Work, EU-OSHA, etc.

"WE KNOW INTEGRATING PEOPLE WITH A CHRONIC PAIN OR BRAIN CONDITION IN EMPLOYMENT IS SOCIO-ECONOMICALLY BENEFICIAL. GETTING PEOPLE WHO WANT TO WORK BACK TO WORK DECREASES THE VOLUME OF DISABILITY ALLOWANCE AND EARLY RETIREMENT PAYMENT."

HEINZ BECKER, MEP.

"GOOD WORK HAS BEEN SHOWN TO IMPROVE HEALTH OUTCOMES, AND GOOD HEALTH ENABLES PEOPLE TO BE PRODUCTIVE WORKERS. HOWEVER, THERE IS A LACK OF INTEGRATION BETWEEN HEALTH SYSTEMS AND EMPLOYMENT AND WELFARE POLICY– WHICH MUST BE ADDRESSED.."

ANTONELLA CARDONE, EXECUTIVE DIRECTOR, FIT FOR WORK.

MORE INFORMATION ON OUTCOMES...

In 2016, the *Written Declaration on access to employment for those affected by neurological disorders and chronic pain conditions* was co-authored by Members of the European Parliament (MEPs): Elena Gentile, Jean Lambert, Ivo Vajgl, Glenis Willmott, Biljana Borzan , José Blanco López, Eva Kaili, Jutta Steinruck , Brian Hayes, Roberta Metsola , Miroslav Mikolášik, Sirpa Pietikäinen, Sofia Ribeiro, Cristian-Silviu Buşoi, Karin Kadenbach, and Merja Kyllönen.

Knowing that:

- Brain disorders and chronic pain conditions are two of the leading causes of long-term sick leave and are growing in their impact as Europe's workforce ages.
- Best practices for the retention and reintegration of people with chronic conditions are widespread.
- Integrating people with chronic conditions such as these into employment is socio economically beneficial-

We called upon MEPs to add their support to our call for:

- The Commission to use the EU Semester's country-specific recommendations to encourage Member States to implement cost-effective retention, reintegration and rehabilitation actions.
- The Commission (DG SANTE, DG EMPL, DG REGIO and DG ECFIN) to collaborate on consolidating and consistently implementing EU legislation that will ensure equal access to employment for those affected by neurological disorders and chronic pain conditions.
- The Commission, in close cooperation with the Member States, to work, together with their social partners, to clarify patients' rights, highlight successful workplace adjustments and reintegration actions – e.g. flexible working hours – and promote the use of the European Social Fund for such actions.
- The Commission and Council to encourage the Member States to acknowledge that accurate early diagnosis and appropriate treatment and management are necessary to enable employees affected by these chronic conditions to enjoy equitable employment opportunities.

The Written Declaration provided many opportunities for working with our members and developing our very active advocacy role within the European Parliament.

We had bi-lateral meetings with dozens of individual MEPs to gather support for our policy work including:

- **Vice Chair of the Employment Committee**
- **Vice Chair of the Environment & Health Committee**
- **Vice Chair of the Women's Committee**
- **Co-ordinators of the Employment and Environment & Health Committee**

These were supplement by:

- **Regular meetings with additional MEPs and assistants**
- **Weekly door-knocking and pigeon-holing of MEPs and assistants – supported by many of our members and supporters who gave their time voluntarily to be in Brussels or Strasbourg to promote the work**
- **Creation, translation and distribution of promotional materials but on and offline, including via social media**
- **Building of a comprehensive contact database for all MEPs**
- **Ongoing updating of www.brainmindpain.eu and associated social media channels**

We finished the year with almost 180 signatures supporting our call to improve access to employment for those affected by neurological disorders and chronic pain conditions.

Although this was not enough to see the Declaration passed by the European Parliament, the exercise provided us with an increased network of MEPs supporting our work, raised awareness of the impact of the disorders we represent on employment and provided a platform for future advocacy work in this area.

The Declaration has now been renamed as our '**Call to Action - #MakeWorkWork**' and can be found on the website: www.brainmindpain.eu

We encourage our members, supporters and partners to continue to pursue the Declaration's asks as we strive to see better retention and/or rehabilitation and reintegration in the workforce for those we represent.

FURTHER OUTCOMES...

Monitoring policy developments and seeking to influence

In 2016, the MEP Interest Group responded to various European Commission consultations by drawing on the content of our *Book of Evidence* and recent outcomes from the Brain, Mind and Pain MEP Interest Group.

These included detailed responses to consultations on:

- ***European Social Pillar of Social Rights*** **- this high level, cross-cutting initiative focuses on needs and challenges in employment and social policies. Our response emphasised that the priority must be on the implementation of existing legislation, rather than the creation of new legislative texts. This would not only benefit patients, but wider society from a socio-economic perspective. This could be achieved via the EU Semester's country-specific recommendations, through encouraging Member States to implement cost-effective retention, reintegration and rehabilitation actions.**

- ***Health Technology Assessment*** **– We called for the societal impact and indirect cost-savings of treatments be incorporated in the economic modelling of HTAs to reflect patient preferences, in a harmonised manner. We also called for the development of a framework which would better facilitate patient involvement and would facilitate the quantifying of real-world evidence and patient reported outcomes measures as part of the overall cost-effectiveness calculations.**

You can find the full responses on: www.brainmindpain.eu.

STRENGTHENING PARTNERSHIPS FOR POLICY

We worked closely with many other organisations as we aimed to provide solutions to the challenges raised at the interest group meetings. These included the European Patients' Forum, the European Brain Council, the Besta Neurological Institute, GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks-Europe), the European Academy of Neurology, the European Pain Federation and many more.

We are also present on the Societal Impact of Pain platform [SIP], where EFNA has played an increasingly more active role in recent years. In 2016, EFNA – via its Executive Director – moderated a session on Pain as a Quality Indicator for Health Care. Many of the recommendations from SIP are ongoingly taken up by the Interest Group.

FOLLOWING UP ON 2015

In 2015, we held an MEP Interest Group meeting on the topic of stigma. One of the recommendations arising from this meeting was the need to raise awareness of the prevalence and impact of brain disorders. With this in mind, EFNA launched – in 2016 – its *Together Under the Umbrella* campaign.

This campaign was launched at the European Parliament where 50 MEPs were photographed **#UnderTheUmbrella**; pledging their support to our cause.

You can read more about the campaign on page 14.

"THE WRITTEN DECLARATION WAS AN IMPORTANT INITIATIVE WHICH RAISED KEY POINTS THAT COULD REALLY MAKE A DIFFERENCE IN THE LIVES OF PATIENTS WITH NEUROLOGICAL DISEASES. FOR PATIENTS WHO ARE STILL ABLE TO WORK A FEW HOURS PER WEEK IT MEANT THE DIFFERENCE BETWEEN ISOLATION OR BEING PART OF SOCIETY AND BEING TREATED AS EQUALS."

NANCY VAN HOYLANDT, EUROPEAN ME ALLIANCE

COMMUNICATIONS

The www.brainmindpain.eu website was maintained in 2016 by staff of both EFNA and PAE, who ensured the news and events sections were updated, as well as the audiovisual content and extensive resources made available to MEPs and other supporters of the Written Declaration.

The Written Declaration was promoted widely using the @brainmindpain Twitter account, which offers a way of directly engaging with MEPs and other EU organisations, using the hashtag **#MakeWorkWork**.

A number of print and web materials were designed to promote the Declaration. These included a special **#MakeWorkWork** graphic suitable for sharing through social media.

HELLO FROM OUR SENIOR EU POLICY OFFICER

Hi, I am Heather Clarke and I work as the Senior EU Policy Officer at EFNA. My main task is in coordinating the MEP Interest Group and its associated activities, as outlined above. However, there are many other advocacy activities in which we are involved and where I am actively representing EFNA and its members. This includes, for example, the European Patients' Forum where I am member of their Policy Advisory Group. Indeed, we are ongoing contributors and supporters of EPF's policy work in areas such as access, empowerment, etc. – providing the neurology perspective to their more generic approach. I ongoingly try to be a visible presence at relevant events to our membership inside and outside the European Institutions; building connections and developing partnerships with those with whom we share mutual interests. And I am always available to our members, supporters and partners to discuss EU policy and related work. So don't hesitate to get in touch! You can contact me at: euaffairs@efna.net

IN 2016, EFNA HELD – ONCE AGAIN – ITS NEUROLOGY ADVOCACY AWARDS.

These awards recognise the contribution of an individual or group to the development and promotion of advocacy for people with neurological disorders in Europe.

This year's winners were presented with their awards at a Gala Dinner in Dublin on October 13th.

EUROPEAN POLICY-MAKER 2016: MARIAN HARKIN MEP

The winning European Policy-Maker for 2016 was Marian Harkin MEP. She was nominated for her award, jointly, by the International Bureau for Epilepsy and Pain Alliance Europe.

Marian is currently a co-chair of the MEP Interest Group on Brain, Mind and Pain – but has been long-term champion of health issues in the European Parliament. She was presented with her award by last year's winner – Gay Mitchell, former MEP.

Left to right: Ann Little - Executive Director, International Bureau for Epilepsy, Marian Harkin MEP, Gay Mitchell, former MEP.

EUROPEAN HEALTH PROFESSIONAL 2016: PROFESSOR PAOLA GIUNTI

The second award of the evening was for European Health Professional, and went to Professor Paola Giunti.An ataxia specialist, Prof. Giunti was nominated for her work in the field – including the establishment of a specialist ataxia centre – a bespoke health service made in partnership with patients.

Speaking on the evening, Cathalijne van Doorne of Euro-Ataxia commended Prof. Giunti for her voluntary work with patient organisations and the wider patient community.

She was presented with her prize by judge Prof. David Vodusek – representing the European Academy of Neurology.

Left to right: Cathalijne van Doorne, Vice-President of EFNA, Professor Paola Giunti, Dr. David Vodusek

European Patient Advocate 2016: Alistair Newton

The final award of the evening was presented to Alistair Newton – the winning European Patient Advocate. Not only was Alistair involved in the foundation of Dystonia Europe but also in organisations such as EFNA and the European Brain Council.

Explaining why he was put forward for the award, Monika Benson of Dystonia Europe said:

> "WE THANK ALISTAIR FOR HIS DEDICATED WORK AND ALL HIS EFFORTS OVER THE LAST 30 YEARS, A TRUE PATIENT ADVOCATE WHOSE MISSION HAS STIMULATED FRUITFUL COLLABORATION AND CREATED MANY SUCCESSFUL PARTNERSHIPS TO BENEFIT PATIENTS WITHIN NEUROLOGY, ESPECIALLY DYSTONIA."

Left to right: Monika Benson of Dystonia Europe, Alistair Newton and Frédéric Destrebecq, European Brain Council.

LIFETIME ACHIEVEMENT AWARD 2016: AUDREY CRAVEN

Audrey Craven, Past President of the European Federation of Neurological Associations [EFNA] was presented with a Lifetime Achievement Award; acknowledging her long-time commitment to the cause.

This was presented by Eveline Sipido of the European Academy of Neurology, last year's winner, who said:

> "IN ALL THESE YEARS AND IN SPITE OF THE CONDITION SHE LIVES WITH, AUDREY NEVER LOST THE GOOD SPIRITS NOR GAVE UP SO I THINK THAT WITH OSCAR WILDE'S HELP I CAN PERFECTLY SUMMARISE WHAT SHE DID:
> ***THE WORLD IS DIVIDED INTO TWO CLASSES, THOSE WHO BELIEVE THE INCREDIBLE, AND THOSE WHO DO THE IMPROBABLE."***

Left to right: Eveline Sipido of the European Academy of Neurology and Audrey Craven, Past President of EFNA.

AWARENESS

2

In 2016, EFNA rolled-out its first pan-European awareness campaign: Together Under the Umbrella.

It is our hope that the campaign will lead to an increase in public, political and scientific support for all brain and brain-related disorders, resulting in reduced stigma. The campaign asks the patient community, general public, and high profile figures to take and share a picture of themselves under an umbrella using the hashtag **#UnderTheUmbrella**.

The aims of this campaign are:

- To educate society on the wide range of neurological and other brain/brain-related disorders
- To raise awareness of the impact and prevalence of these disorders
- To brand the brain by grouping these disorders under a common symbol to create a unified and identifiable 'brand'

2016 CAMPAIGN ACTIVITIES

A number of successful events in 2016, both online and offline – organised by EFNA, our members and supporters ensured that the campaign had a wide-ranging impact and reach.

The *Together Under the Umbrella* campaign was officially launched at the European Parliament in Brussels during Brain Awareness Week with a cocktail event, hosted by Marek Plura MEP.

Eight MEPs attended on the night – including Helga Stevens, Chair of the EP Disability intergroup.

This event was the culmination of a two-day promotional visit to the European Parliament to build support for the campaign. Forty MEPs, the Belgian Health Minister and well-respected leaders in the field – such as Richard Morris OBE, Brain Prize winner – were photographed 'under the umbrella'.

The Together Under the Umbrella campaign is supported by many organisations, including the European Brain Council (EBC), the Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN) and the European Patients' Forum (EPF).

The campaign provides opportunities for neurology patient organisations to work together at a national and European level, whilst also allowing them to further promote their individual disease areas through awareness-raising, fundraising and advocacy activities. This aligns with EFNA's aims in its strategic plan 2015-2020 re. working with national neurological alliances across the EU Member States.

TOGETHER UNDER THE UMBRELLA

2016 CAMPAIGN ACTIVITIES CONT.

On July 22nd, in celebration of *World Brain Day* 2016, individuals, companies, institutions and organisations were encouraged to take a photo under an umbrella and share it via social media to raise awareness of the wide range of brain disorders. We were overwhelmed by the response.

Hundreds of people from around the world – including patients, carers, pharmaceutical companies, health professionals and more – came together and shared hundreds of images throughout the day on the various social media platforms; using the hashtag **#UnderTheUmbrella**.

A special Facebook Event page was set up and the posts shared reached an audience of 3,400 people. Other organisations including Dystonia Europe and Fundazione Neuromed set up their own event pages.

Companies such as Abbvie, Eirgen and Pfizer got involved with onsite photoshoots, whilst Medtronic encouraged all their national affiliates to participate – resulting in many photos from as far afield as Mexico.

Other highlights of the campaign in 2016 included a special *Together Under the Umbrella* photo booth at the EAN Congress, a social media awareness drive during *Invisible Disabilities Week* and our *Together Under the Umbrella - 12 Days of Christmas* competition. The competition ran for 12 days, from Monday 12th to Friday 23rd December. Each day a new question relating to the brain or brain disorder was posted on the Facebook Event page and the public were invited to share their entries. Prizes were selected at random and included campaign merchandise, gift vouchers and an iPad as star prize. Feedback from the competition was extremely positive with many participants commenting on how much they had learned over its duration.

Together Under the Umbrella events were also held by both European and National level patient organisations during the year, including Dystonia Europe's D-Days event, *European Huntington Association's Awareness Day* and *Restless Legs Awareness Day.*

Pictured Together Under the Umbrella next page:
Top left: Cathalijne Van Doorne and Manuela Messmer-Wullen at European Academy Neurology (EAN) Congress 2016, Copenhagen.

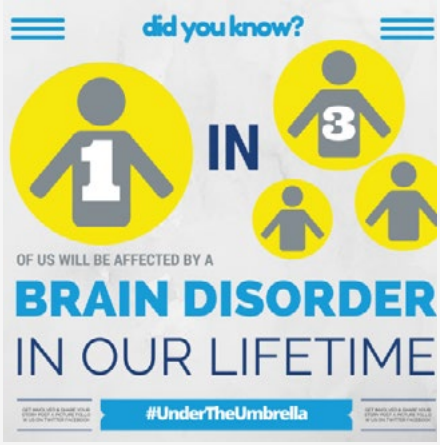
Top right: Elna Harris (RLS UK) and friends shared this picture on Facebook to raise awareness of Restless Legs Syndrome on World Brain Day.

Bottom left: Staff of the EAN office during Invisible Disabilities Week in October.

Bottom right: Stroke Alliance For Europe (SAFE) and MERZ event held in December to raise awareness of spasticity.

"IN DYSTONIA EUROPE WE HAVE OUR OWN AWARENESS CAMPAIGN- *JUMP FOR DYSTONIA.*
WHEN EFNA LAUNCHED THE UNDER THE UMBRELLA CAMPAIGN WE THOUGHT IT WAS A GREAT OPPORTUNITY TO COMBINE THE TWO CAMPAIGNS. BY ENCOURAGING MEMBERS AND OTHERS TO JUMP FOR DYSTONIA UNDER THE UMBRELLA WE RAISED AWARENESS OF BOTH DYSTONIA AND OTHER BRAIN DISORDERS AND REACHED OUT TO A LARGER AUDIENCE."

MONIKA BENSON, DYSTONIA EUROPE



HELLO FROM OUR COMMUNICATIONS COORDINATOR

Hi, my name is Elizabeth Cunningham and I work as the Communications Coordinator at EFNA.

My primary focus in 2016 has been the development and roll-out of the *Together Under the Umbrella campaign* but it is a broad role with technical, design, content and administrative aspects.

I update and maintain the www.EFNA.net, www.undertheumbrella.eu and www.brainmindpain.eu websites as well as managing a number of social media accounts for the organisation on an on-going basis. This provides an opportunity to engage directly with patients; listening to them and sharing their stories.

The role involves a considerable amount of original design work. The Together Under the Umbrella campaign required its own branding and extensive materials including a campaign toolkit. My design responsibilities also included The Brain Mind and Pain group's Written Declaration campaign resources, the EAN 2016 exhibition stand, EFNA's 2015 Annual Report and other promotional items.

Bi-monthly I compile and send the EFNA Ezine – an email newsletter featuring the latest news from our members, associates and the EFNA team. If you would like to receive the newsletter, or if you have news to contribute, please write to me at communications@efna.net.

Remember to connect with us on Twitter, Instagram and Facebook!

TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES

For many years EFNA had run workshops on *Health Technology Assessment* and lately, *Pharmaceutical Policy – Pricing, Access and Reimbursement* at the London School of Economics.

However, feedback from participants indicated that patients now needed to be equipped to use the theoretical knowledge gained on these processes, and the wider research and development cycle, in a more practical way, such as through the development of communication, advocacy and campaigning skills and the generation of patient evidence or patient reported outcomes.

EFNA was also eager to ensure that our training activities are targeted to the neurology sector and the specific obstacles faced therein. Working with other stakeholders in the field e.g. neuroscientists, neurologists, industry, regulators and payers was, and is, also part of our envisaged way forward.

This approach led to the launch of our *Training Initiatives for Neurology Advocates* in autumn-winter 2016, with a pan-European workshop in Dublin and two associated national workshops in Bucharest, Romania and Utrecht, The Netherlands.

These workshops were broad-ranging in terms of topics covered but were aligned to the overarching theme of creating and communicating patient based evidence to support patient reported outcome measures – as part of the Research and Development process, and beyond in decision/policy-making.

PAN-EUROPEAN EVENT

The pan-European meeting took place on October 13th and 14th 2016 and was entitled: Putting the Neurology Patient Perspective at the Heart of Research and Beyond.

This meeting was hosted by Trinity College Dublin and featured presentations from members of the faculty, as well as experts from further afield.

PAN-EUROPEAN EVENT SPEAKERS

Neuroscience – What Patients Need to Know
Prof. Orla Hardiman, Professor of Neurology, Trinity College Dublin

Integrating Patient Reported Outcomes into Neuroscience Research and Beyond: The Role of the Patient Advocate
Prof. Melanie Calvert, Professor of Outcomes Methodology, Institute of Applied Health Research, University of Birmingham

Generating Evidence to measure Patient Report Outcomes: The Role of e/m-Heath
Dr. John Dinsmore, Health Innovation Lead & Deputy Director, Centre for Practice and Healthcare Innovation, Trinity College Dublin

Beyond Research: How do we value care? vs. How should we value care?
Prof. Charles Normand, Edward Kennedy Professor of Health Policy & Management at Trinity College Dublin

Moving Forward as Empowered Patients
Camille Bullot, Membership & Stakeholder Relations' Manager, European Patients' Forum (EPF)

In addition to the above speakers, we were delighted to welcome over 50 patient advocates to Dublin from a wide variety of neurological disease areas – both national and European – to participate in the event.

As well as benefitting from the presentations detailed above, these participants were invited also to join a series of interactive, break-out workshops as detailed below:

WORKSHOP 1: *Exploring Patient-Generated Evidence*

Facilitator: Dr Derick Mitchell, CEO, Irish Platform for Patient Organisations, Science and Industry

WORKSHOP 2: *Optimising Social Media to Communicate a Patient Perspective*

Facilitator: Marie Ennis-O'Connor, Social Media Strategist and Digital Engagement Professional

WORKSHOP 3: *Guiding Principles for Patient Partnerships with Relevant Stakeholders*

Facilitator: Audrey Craven, Past President, European Federation of Neurological Associations

"I WOULD LIKE TO THANK EFNA FOR THE WORKSHOP OPTIMISING SOCIAL MEDIA TO COMMUNICATE A PATIENT PERSPECTIVE FROM DUBLIN!!! MRS. MARIE ENNIS-O'CONNOR GAVE ME THE COURAGE AND THE POWER TO TELL MY STORY AND TO TALK ABOUT MY INVISIBLE DISABILITY."

ALINA SAVU, EUROPEAN MYASTHENIA GRAVIS ASSOCIATION

NATIONAL EVENTS

UTRECHT, THE NETHERLANDS – November 2016

Focus on: *Patient Reported Outcomes and Patient-based Evidence*

This national workshop was designed to equip and empower neurology patient advocates with the information and skills needed to influence decision-making during the Research & Development [R&D] process and beyond, in areas such as pricing, access and reimbursement.

With a focus on patient reported outcome measures and patient based evidence, the course explored why the engagement and involvement of patient advocates from the neurology sector is particularly important, and how this can be achieved.

BUCHAREST, ROMANIA – October 2016

Focus on: *Political Decisions and Patient Involvement*

The 'Political Decisions and Patient Involvement' Workshop was organised with the support of the Association of Patients with Neurodegenerative Diseases in Romania (APAN). The theoretical and practical aspects of Health Technology Assessment (HTA) were examined.

"The theoretical knowledge gained in R&D processes must be put into practice. With their help the voice of the patients will be stronger and will play an important role in decisions on pricing, market access and reimbursement of medicines. At the same time, it is necessary to develop communication and advocacy skills, as well as campaigns to change health policies where needed," said Andreea Antonovici, Public Affairs European Platform for Multiple Sclerosis and Vice-President of APAN Romania.

ENGAGEMENT

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At EFNA, we are ongoingly active in aiming to engage with other organisations with common goals. With a small staff of three, this is only possible through the commitment of our Board who represent us externally throughout the year. Below we hear from some of our Board Members who tell us where they have worn their EFNA hat in 2016!

My name is Ann Little and I am EFNA President. In 2016, I was also the EFNA nominated Board Member to the European Brain Council [EBC]. The EBC is a non-profit organisation gathering patient associations, major brain-related societies as well as industries. Its mission is to promote brain research in order to improve the quality of life of those living with brain disorders in Europe. 2016 saw the launch of many important and interesting EBC projects and initiatives in which EFNA has been actively involved, from the patient perspective. These include: the *Value of Treatment* project and a *Call to Action* on the development of brain plans.

In 2016, EFNA also enjoyed a very productive working meeting with the leadership of the **European Academy of Neurology** which resulted in the signing of a Memorandum of Understanding between both our organisations. This formalises and consolidates the wonderful partnership that we have created over recent years, which has allowed for:

- EFNA participation on the Training/Education Committee and Liaison Committee
- EFNA members participating in relevant sub-speciality, scientific panels
- Increased EFNA activity at the EAN Congress including a booth in the exhibition centre, special session and public day
- EAN involvement in EFNA's advocacy, awareness and training activities throughout 2016

My name is Nancy van Hoylandt and in 2016 I continued 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'm Cathalijne van Doorne. I am currently EFNA Vice-President with special responsibility for **Science and Research**. In 2016, I continued my position as **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.

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 2016.

In the early part of 2016, I also represented EFNA on the **Patient and Consumer Working Party and the European Medicines Agency (EMA)** – before handing over to my colleague Cathalijne van Doorne, later in the year. This 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.

I am Manuela-Messmer Wullen. In 2016 I participated in the **European Society of Radiology [ESR] – Patient Advisory Group**. 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. In 2016, EFNA was once again represented on the programme at the ESR Congress when myself and the EFNA Executive Director addressed the audience on the importance of good communication between health professional and patient.

A WORD FROM THE TREASURER

On behalf of EFNA, as Treasurer, I would like to acknowledge support from the following corporate partners in 2016. 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 EMA activities.

I would also like to thank our health professional colleagues at the European Academy of Neurology who, once again, supported our projects financially – but, also, through in-kind contributions via the sharing of their expertise in many of our initiatives and also the provision of facilities and equipment to allow our active participation in their annual Congress.

Once more, our members have contributed to our core income in the form of membership fees. We are very grateful for your commitment – financially and otherwise.

I would also like to acknowledge the work of our accountants at SBB who we engage to support us in the preparation of our accounts throughout the year and also advise us in the areas of VAT, insurance, etc.

Below you will find the final results of 2016 and our budget for 2017. Please do not hesitate to get in touch should you have any questions.

Once again, thank you!

Bea de Schepper
EFNA Treasurer

Thanks to the following companies who have supported us in 2016:

MSD
UCB
SANOFI GENZYME
TEVA PHARMACEUTICAL INDUSTRIES LTD.
NOVARTIS
MERCK
Pfizer
GRÜNENTHAL
Biogen
janssen
NOVARTIS IRELAND
MENARINI

ANNUAL ACCOUNTS

INCOME

Income from sponsors	206,838.69
Grant from European Academy of Neurology	20,000
Membership Fees	2950
Bank Miscellaneous	1441.88
20% Project Overheads Accumulated	***38,767.74***

TOTAL INCOME: 269,998.31

(= income of 231,230.57 + project overheads of 38,767.74)

EXPENDITURE

Training and Capacity Building	
Venue Costs incl. accommodation	*13,401.16*
Delegate/Speaker/Steering Committee Expenses	*18,164.78*
Consultant Costs: Training Coordinator & Exec. Dir.	*19,053.32*
Printing/Promotional and other materials	*133.25*
Catering costs (incl. advocacy awards dinner)	*1,565.70*
20% overhead cost	*15,767.74*
Project Expenditure	68,085.95
Advocate for Brain, Mind and Pain Workshop	
Consultant Costs: Senior Policy Officer & Exec. Dir.	*34,584.52*
Interest Group Meetings	*14,361.33*
Written Declaration Costs	*9,764.48*
Planning Meetings	*1,145.18*
Communication/Promotional Materials incl. website	*1,500.00*
Other Advocacy Costs	*1,106.39*
20% overhead cost	*13,000.00*
Project Expenditure	75,461.90
Under the Umbrella - Awareness Campaign	
Consultant Costs: Communications Coordinator & Exec. Dir.	*31,161.54*
Printing/Promotional Materials	*4,541.24*
Launch Event (European Parliament) and other events	*1,454.69*
Translation	*162.00*
UTU Stand at EAN Congress (including shipping)	*2,123.57*
20% overhead cost	*10,000.00*
Project Expenditure	49,443.04
General Assembly incl. Participation at EAN Congress	
Accommodation	*14,175.73*
Travel Expenses	*5,202.18*
Promotional materials, equipment hire, etc.	*764.22*
Catering	*1,424.04*
Project Expenditure	21,566.17
Administration and Other	
Fee of Exec. Dir. (unallocated to projects and overheads)	*23,656.86*
Website, Telephone, Internet, Office Supplies, etc.	*744.10*
Accounting Fees	*5,431.25*
Membership Fees	*1,700.00*
External Representation	*2,886.39*
Corporate Partners Meeting	*2,987.79*
ADV Previous Financial Year	*5,583.78*
Other Overhead (banking costs, …)	*233.96*
Core Expenditure	43,224.13

TOTAL EXPENDITURE: 257,781.19

(= expenditure of 219,013.45 + project overheads of 38,767.74)

OVERALL SURPLUS 2016 ***12,217.12***