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Dear Reader,

Thank you for taking an interest in EFNA and our work in 2017.

As you may remember, 2016 had been 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 Member of the European Parliament Interest Group on Brain, Mind and Pain; EFNA was hugely pleased with the implementation of our annual workplan 2016. Therefore, 2017 was to be a year of adding, refining and improving on these keynote projects – as well as working on our internal governance and external communication.

We spent a lot of time reviewing a new constitution and set of associated by-laws, as well as beginning a lengthy (and ongoing) process of updating our existing policies and procedures. This work was kicked-off by a workshop – open to all our members – on Governance and Transparency, highlighting EFNA’s commitment to good governance. We also built a new website and overhauled our branding – introducing a new logo and improving the appearance of our various promotional materials.

Our MEP Interest Group continued, with three meetings in 2017. This was supplemented by various activities aimed to boost our advocacy evidence base. These included EFNA involvement in the Value of Treatment project, led by the European Brain Council, and the EFNA-led project to map neurology patient engagement in Health Technology Assessment (HTA).

Patient empowerment work via our Training Initiatives for Neurology Advocates (TINA) grew to incorporate one pan-European event in Brussels and three national workshops in Bucharest, Valencia and Warsaw. These covered a wide variety of topics relevant to the respective patient communities in each country.

Given this expansive range of activities (summarised further below), and EFNA’s small staff of three, thanks must be extended to the EFNA Board and wider membership for their active commitment to our cause. Of course, the staff must also be thanked for going above and beyond the call of duty to ensure the delivery of the workplan for 2017. This includes the national coordinators for our TINA events who are key to ensuring their success.

More detail on all of these activities can be found in the following pages. We have endeavoured to keep this document concise: full reports, presentations and other materials can be found on the relevant websites, should you wish to know more. And, of course, you can get in touch with me at: executivedirector@efna.net. For now, happy reading!

[Signature]
ABOUT EFNA

The European Federation of Neurological Associations [EFNA] is an umbrella group representing pan-European neurology patient groups. Our slogan ‘Empowering Patient Neurology Groups’ encapsulates our goals as an Association. We strive to add capacity to our members – allowing them to be the most effective advocates possible in their own disease specific areas. EFNA embraces the concept of ‘Partnership for Progress’ – working at a high level with relevant stakeholders from the fields of policy, medical, scientific/research, industry, patient partners and other key opinion leaders.

OUR VISION

A better quality of life for people in Europe living with a neurological disorder.

OUR MISSION

• To influence policy makers and legislators in Europe (and particularly in the European Union) to prioritise resource allocation to reduce the burden for people living with a neurological disorder.

• To communicate with our members to achieve positive change and to ensure that our actions both represent and provide added value to their own concerns and activities, and ensure that patients are empowered and encouraged to participate in relevant decision-making processes.

• To establish strong partnerships and alliances with relevant stakeholders in the scientific, clinical, political and corporate arenas to help us to reach our goals – partnership for progress.

OUR VALUES

• Trustworthiness and transparency – we will be open, honest and ethical in all we do.

• Respect and democracy – we respect one another’s differences and contributions.

• Sustainability – we will make best use of our resources to bring about changes that produce permanent benefits for our members and will plan our activities to ensure EFNA’s future.

EFNA’s aims are to improve the quality of life of people with neurological disorders, their families and carers, by working in four strategic areas:

Awareness  Advocacy  Empowerment  Engagement
MEMBERS
ADHD-Europe
Dystonia Europe
Euro-Ataxia
European Alliance for Neuromuscular Disorders Associations
European Alliance for Restless Legs Syndrome
European Headache Alliance
European Huntington’s Association
European Multiple Sclerosis Platform
European Myalgic Encephalomyelitis Alliance
European Myasthenia Gravis Association
European Parkinson’s Disease Association
European Polio Union
International Brain Tumour Alliance
International Bureau for Epilepsy
Pain Alliance Europe
Retina International
Stroke Alliance for Europe

BOARD MEMBERS 2017
Ann Little
Vice-President
President
International Bureau of Epilepsy
Euro-Ataxia
European Huntington’s Association
International Brain Tumour Alliance
Stroke Alliance for Europe
European ME Alliance
European Alliance for RLS
Dystonia Europe
Cathalijne van Doorne
Treasurer
Bea de Schepper
Secretary-General
Jenny Baker
Joke Jaarsma
Monika Benson
Monique Lindhout
Nancy Van Hoylandt

STAFF 2017
Donna Walsh
Heather Clarke
Elizabeth Cunningham
Executive Director
Senior EU Policy Officer
Communications Coordinator

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Follow us on Twitter:
@EUneurology
Find us on Facebook:
/EFNA.net
And on Instagram:
/EUneurology
SUMMARY
ACHIEVEMENTS UNDER EFNA’S STRATEGIC AREAS

ADVOCACY

- MEP Interest Group on Brain, Mind and Pain: Three meetings in 2017 at the European Parliament
- Coordination of research project on neurology patient engagement in Health Technology Assessment
- Participation in the Value of Treatment project – led by the European Brain Council – to generate advocacy data and evidence
- Participation in the Brexit Health Alliance and associated activities
- Input into consultations on the European Social Pillar and EU Cooperation on HTA, with ongoing monitoring of progress in this area
- Ongoing collaboration with other partners in the field, to which EFNA adds the neurology patient perspective
- Active involvement in the Societal Impact of Pain symposium under the auspices of the Maltese Presidency of the EU
- Involvement in the steering committee for the inaugural Brain, Mind and Pain Grant
- Participation in EFNA member and partner advocacy initiatives and events at the European Parliament and elsewhere
- Involvement in discussions on off-label medicine use, value added medicines, animal research, Strategic Policy Committees, etc.

AWARENESS

- Continuation of EFNA’s Together Under the Umbrella campaign
- Creation of new EFNA website and content
- Development of new branding for EFNA
- Improvement of EFNA’s newsletter and increasing presence online via social media
- Raising visibility amongst external audiences e.g. booth and photo opportunities at EAN Congress
- Support of members’ and partners’ communication and awareness raising activities
EMPOWERMENT

- **Training Initiatives for Neurology Advocates – National Workshops:**
  - Romania
  - Spain
  - Poland
- **Training Initiatives for Neurology Advocates – Pan-European Workshop on:**
  - *Effective External Ambassadorship*
- **EFNA Member’s Workshop on Governance and Transparency**

ENGAGEMENT

- Ongoing external representation at relevant organisations/activities
- Increased participation in EFNA Member General Assemblies, events, activities, etc.
- Strengthened engagement with European Academy of Neurology – with signing of Memorandum of Understanding
- Annual Partners’ Meeting

Above: The out-going EFNA Board, June 2017. L-R: Monika Benson (Dystonia Europe), Cathalijne van Doorne (Euro-Ataxia), Manuela Mussmer-Wullen (SAFE), Joke Jaarsma (EARLS), Ann Little (IBE), Bea de Schepper (EHA), Klaus Knopps (EMSP), Nancy Van Hoylandt (EMEA), Jenny Baker (IBTA) and Donna Walsh (EFNA)
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 Member of the European Parliament 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.

2017 was a busy year for us with three meetings in the European Parliament. Each meeting was held in partnership with other key players in the field.

Below you will find a short summary of each meeting, and the actions arising. The full reports can be obtained at: www.brainmindpain.eu

**MEP INTEREST GROUP 2017 – IN FIGURES**

3 x meetings

150+ multi-stakeholder attendees from key partners and institutions

10+ individual disease areas profiled

15+ European Policy Makers (from the European Parliament and European Commission) actively involved
TOPIC 1:
OPTIMISING THE EUROPEAN SOCIAL PILLAR TO #MAKETHEWORKWORK FOR THOSE AFFECTED BY BRAIN, MIND AND PAIN CONDITIONS

MARCH 2017, EUROPEAN PARLIAMENT, BRUSSELS
HOST: MARIAN HARKIN MEP
PARTNER: MEP INTEREST GROUP ON MENTAL HEALTH AND WELLBEING

SUMMARY

In 2016, the MEP Interest Group focussed on access to employment for those affected by brain, mind and pain disorders. Therefore, the group was encouraged by the work of the European Commission on the European Pillar of Social Rights – which was seen as a new mechanism to lever more equitable opportunities in the labour market for those the group represents. Two of the 20 key pillars are key:

- 16 - Healthcare: Everyone has the right to timely access to affordable, preventive and curative health care of good quality.
- 17 - Inclusion of people with disabilities: People with disabilities have the right to income support that ensures living in dignity, services that enable them to participate in the labour market and in society, and a work environment adapted to their needs.

The meeting gave the Interest Group and its partners further insight into the development of the Pillar and ideas on how to best optimise its contents and ensure its implementation in the future.

Raquel Cortés Herrera (European Commission, DG EMPL) said:

“The Commission aims at adopting the Social Pillar in the Spring and will then look at how to make its principles operational, by means of a variety of tools it has at its disposal, i.e. legislation, non-legislative proposals, funding, etc. The adoption of the Pillar is the beginning of a process rather than the end.”

The full report of the discussion can be found on the website.

ARISING ACTIONS:

The Interest Group pledged to host another meeting on this topic to assess progress and inform next steps.

MEP Marian Harkin said that she would take the conclusions and recommendations arising and ensure they were brought up in the ongoing discussions.
“One of the most pressing and social priorities is the need to develop a supportive working environment for patients. Patients can face stigma or discrimination at work at various stages which prevents them from entering/remaining in the labour market. Ensuring that workplaces offer support for patients is crucial to achieve Europe2020’s goal of ‘smart, sustainable and inclusive growth’.”

- Katie Gallagher, Policy Officer, European Patients’ Forum

“The EU and its Member States must acknowledge that accurate, early diagnosis and appropriate treatment/management are necessary to enable those with chronic conditions to optimise the social acquis covered by the European Social Pillar. Improving Europe-wide access to existing treatments and supporting the development of innovative medicines to better treat these conditions is an important part of supporting employment and economic productivity amongst patients and carers. The European Social Pillar must span and be embraced throughout all relevant EU Commission DG’s and underpin all aspects of its work.”

- Donna Walsh, Executive Director, EFNA

Bottom of page, left - right: Dolores Gauci (GAMIAN-Europe) and Marian Harkin MEP; Raquel Cortés Herrera (European Commission, DG EMPL) and Sam Kynman (European Pain Federation EFIC).
TOPIC 2:  
THE VALUE OF EARLY INTERVENTION IN BRAIN, MIND AND PAIN CONDITIONS

JULY 2017, EUROPEAN PARLIAMENT, BRUSSELS  
HOST: JANA ZITNANSKA MEP  
PARTNERS: EUROPEAN BRAIN COUNCIL AND MEP INTEREST GROUP ON MENTAL HEALTH AND WELLBEING

SUMMARY

In June 2017, the European Brain Council released a policy White Paper on the Value of Treatment [VoT]. This VoT study examined health gains and socio-economic impacts resulting from best health interventions (pharmacological and psychosocial) in comparison with current care, or – in some cases – comparison with no treatment at all. Care pathways were mapped for each specific disorder along the whole care process from prevention, prodromal, early diagnosis to disease management in order to identify the major unmet needs and causes for treatment gaps (both those needing research and better evidence to inform treatment decisions and those needing better organization of services).

Throughout 2017, EFNA was actively involved in the project, with many of its members taking part in the disease-specific case-studies which formed the basis for VoT.

One of the clear findings from this study was the benefit of early intervention in the field of brain, mind and pain disorders. This was the topic to be addressed during this Parliamentary event, highlighting the usefulness of the MEP Interest Group as a vehicle through which new studies and data can be disseminated to a political audience and interested stakeholders.

As well as giving an overview of the project and its results, representatives from four disease areas spoke about the findings in their specific fields (stroke, multiple sclerosis, restless legs syndrome and schizophrenia). This was followed by presentations from the areas of chronic pain, ataxia and myalgic encephalomyelitis – who were not included in the study – but proposed for inclusion in the next phase.

All speakers stressed the growing prevalence and burden of brain, mind and pain disorders, emphasising the benefits of early detection and intervention or, where possible, prevention.

It was clearly stressed, that although changes to services need to be funded and driven at the national level, the EU is vital to develop Europe-wide guidelines and accreditation, increase opportunities for Continuing Medical Education and/or training in cutting edge techniques, facilitate the exchange of expertise and knowledge between centres and continue to support research.

It was agreed, therefore, that dissemination of the findings was now key – exploring the individual disease areas, but also looking at specific countries and the development of national strategies.

Five MEPs spoke during the event – Marek Plura, Michal Boni, Jana Zitnanska, Brian Hayes and Nessa Childers. MEP Boni stressed the benefits of new digital health technologies to detect and manage brain, mind and pain disorders – and leading to a more integrated approach to healthcare.
“There is clearly a need for more research to address the gaps identified by the Value of Treatment study, especially in relation to early diagnosis and intervention. The European Commission is convinced of the need for more research to address those gaps. Other stakeholders, such as the Member States, will also need to be convinced and encouraged to coordinate their research efforts.”

- Stephane Hogan, Head of Sector, Neuroscience, DG Research

ARISING ACTIONS:

EFNA will continue to work with the European Brain Council on the dissemination actions arising from the VoT white paper, and the development of the next phase.

EFNA will work via the Interest Group and partners to push for increased priority for brain, mind and pain research in the upcoming HorizonEurope funding framework – including a meeting in 2018 once the first draft is available.

The Interest Group will take a more active role in the monitoring of the digital health agenda.

Below, left - right: Patrice Boyer (EBC), Paul Arteel (Gamian), Jana Zitnanska MEP and Joke Jaarsma (European Alliance for Restless Legs Syndrome)

Bottom of page, left - right: Stéphane Hogan (DG Research, European Commission), Paola Giunti (University College London) and Frédéric Destrébecq (EBC); Ann Little (President, EFNA) and Nancy van Hoylandt (European ME Alliance).
TOPIC 3: ENSURING EQUITABLE ACCESS TO HIGH-QUALITY TREATMENT IN BRAIN, MIND AND PAIN DISORDERS

NOVEMBER 2017, EUROPEAN PARLIAMENT, BRUSSELS
HOST: LIEVE WIERINCK MEP
PARTNERS: EUROPEAN ACADEMY OF NEUROLOGY AND EUROPEAN PAIN FEDERATION

SUMMARY

“The right to health is a basic social right enshrined in the Charter of Fundamental Rights of the European Union - yet it is still not a reality for all of us. Large health inequalities persist in the EU and many patients do not have access to effective treatment for neurological and pain disorders. Uncontrolled symptoms worsen the personal and economic impact of these disorders, new and better treatments are urgently needed.

- Lieve Wierinck, MEP

The above quote set the scene for this meeting, which was organised in partnership with the European Academy of Neurology and European Pain Federation, to discuss issues in access to treatment across the EU for patients with brain, mind and pain disorders.

Representatives from these medical societies gave examples of their work in the areas of Stroke, Parkinson's Disease and Chronic Pain which showed that patients can have difficulty accessing treatments and specialist services depending on where they live in the EU. This was followed by a panel discussion, chaired by Nicola Bedlington of the European Patients' Forum [EPF]. Nicola spoke about how EPF is working with member organisations towards universal achievement of Sustainable Development Goals by 2030. It has set up a Patient Access Group to monitor each country's progress against the Goals. A multi-stakeholder approach to integration at national level with country specific objectives is promoted. The Interest Group will engage with this work.

Four patient advocates then spoke about the issues in their individual disease areas: Dystonia, Huntington's Disease, Chronic Pain and Rheumatic/Musculoskeletal Diseases. Similar issues were seen across the board: delays in diagnosis, long waiting lists to see a specialist, treatment not reimbursed in all countries, lack of treatment, need for further investment, etc. The need for patient empowerment, awareness and advocacy was emphasised by all.

The meeting finished with a discussion on the impending Brexit and consideration of whether this might result in a worsening of issues around access to treatment. Elisabetta Zanon of the NHS Brussels Office said:

“A big concern is that the relocation of the European Medicines Agency (EMA) may cause disruption and capacity issues. And future trade barriers and diverging regulatory systems could lead to delays for patients in accessing innovative therapies, some medicines or devices becoming unavailable in some countries plus possible higher costs.”
She also reminded the audience that the UK was a leading partner in the *EU Joint Programme in Neurodegenerative Disease Research* and has the highest number of pan-European trials for both rare and childhood diseases. She said that policy makers and patient organisations should press for health issues to be prioritised in the negotiations.

The meeting was closed by British MEP, Rory Palmer who also called on patients to mobilise for health to be prioritised. He pledged to continue to work to secure the best possible outcome for patients, researchers, healthcare workers and citizens across Europe.

**ARISING ACTIONS:**

EFNA has joined the Brexit Health Alliance to keep informed of development and to add a neurology patient perspective to the ongoing discussions.

EFNA supports the EPF campaign on Universal Access to Healthcare, and contribute to its associated activities.

EFNA to work with the European Academy of Neurology on its Neurocare Project to map the disparities in access to essential neurology healthcare services across the EU, and disseminate the results once available and advocate for change.

EFNA to build on its project to map neurology patient engagement in HTA, with a Phase 2 to provide recommendations for future action (see below)

Left: Robert Palmer MEP (UK)  Right: Elisabetta Zanon (NHS Brussels)
Below, left - right: Nicola Bedlington (EPF), Ann Little (EFNA), Monika Benson (Dystonia Europe) and Neil Betteridge (EULAR)
An EFNA-commissioned mapping exercise of neurology patient engagement in Health Technology Assessment, was carried out in 2017 and showed uncertainty in how the provision of a patient perspective impacts final decisions.

Covering six countries – France, the UK, Spain, Sweden, Germany and Poland – the arising report suggests that although there are more and more ways for a patient perspective to be provided, it is unclear how this influences the result.

EFNA commissioned Pharmerit International to carry out Phase 1 of this project, which was based on desk research aiming to elucidate the systems and practices that are currently in place to support patient engagement in HTA processes.

According to the report: The lack of voting rights, funding to support advocacy group efforts and transparency regarding the content of discussions that take place at HTA meetings make it difficult for patients to influence HTA decisions in many countries.

Donna Walsh, EFNA Executive Director, said:

“The results are not surprising. We have been running training workshops on HTA for many years, and we hear from participants that whilst they are now upskilled and ready to be more involved – they feel that Patient Relevant Outcomes Measures and their own personal testimony is not adequately integrated into the decision-making process.”

“This is particularly important in the field of neurology where patients are living with chronic, often life-long, conditions where they are more concerned with improvements in overall functionality than the more easily measured improvements in individual symptoms.”

The report concludes that further research involving patients and other stakeholders is needed to gain a better understanding of how patient groups or patients with neurological disorders can improve the HTA decision-making process.

EFNA will now commission Phase 2 of the project which will include face-2-face interviews with patient advocates and payers in the six countries. This should be completed by mid-2018.

“We hope that these interviews will provide greater context, clarity and insight to the Phase 1 report,” says Donna, “And we plan to use the results to advocate for more meaningful involvement and to develop tools to communicate the important specifics of neurological disorders which can be impactful and beneficial to patients.”

You can read the full report at: https://www.efna.net/efna-commissioned-report-neurology-patient-involvement-hta-shows-difficult-patients-influence-hta-decisions-many-countries/
A NEW LOOK FOR EFNA

In mid-2017 EFNA revised its branding and brand guidelines, with the intention of developing a more modern and professional appearance, appropriate to the organisation. A new logo was created with a design that reflects exactly what EFNA is – a network of neurology associations.

Central to our updated look was the redevelopment the EFNA website. The new-look platform provides visitors with user-friendly and mobile-accessible pages where they can find out about EFNA’s core activities and EFNA’s members can easily access all information and publications required.

EFNA’s digital newsletter was updated to reflect our new look and provide the best way of sharing both our news and news of our member and partner organisations.

If you don’t currently receive the newsletter and would like to, please click here: http://eepurl.com/oPRML

2017 also saw an increase in both social-media presence and activity, with the addition of a new Facebook page. You can visit us at: www.facebook.com/EFNA.net

TOGETHER UNDER THE UMBRELLA

In 2016, EFNA rolled-out its first pan-European awareness campaign: Together Under the Umbrella. The campaign asks the patient community and general public to take and share pictures of themselves under an umbrella using the hashtag #UnderTheUmbrella.

The aims of this campaign were:

- 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’

Given the enthusiasm shown by patient organisations and other partners in the sector for the initiative during 2016, EFNA decided to harness this momentum and continue the campaign in 2017, broadening its scope. The campaign moved away from its initial viral focus and expanded to (i) share patient stories and (ii) share information about brain disorders - all under the symbol of the umbrella.
BRAIN AWARENESS WEEK

During Brain Awareness Week (March 13th-20th), we invited you to share a photo or video of yourself #UnderTheUmbrella and then tag a friend or organisation to ‘pass’ the umbrella to them. We planned to see how far the umbrella could travel!

WORLD BRAIN DAY

World Brain Day takes place annually on July 22nd. The main objective of this day of the brain is to increase public awareness and promote advocacy related to brain health.

As part of EFNA’s Together Under the Umbrella campaign, organisations and individuals were encouraged once again to take a photo under an umbrella and share it to social media to raise awareness, mentioning the neurological disease area they are either affected by or represent.

Hundreds of photos were shared on social media from across the world throughout the Day.

In addition to these images, in 2017 EFNA recorded a series of interviews with patients/patient advocates from seven different disease areas. You can watch the videos here: http://undertheumbrella.eu/category/your-stories/

Speaking on the Day, EFNA President, Ann Little said:

“By continuing to work together we can maximise the visibility of brain disorders as a whole and ensure we can access the resources required to tackle the enormous burden these diseases pose.”
EAN CONGRESS 2017

The annual congress of the European Academy of Neurology took place in Amsterdam in 2017. EFNA shared a stand at EAN 2017 with the European Brain Council. The stand promoted EBC’s ‘I Love My Brain’ campaign while also providing an opportunity to get together #UnderTheUmbrella! Visitors could access information on both organisations and our members, whilst also having some fun by taking part in the ‘Great Brain Puzzle’ or colouring in a mandala.

My Voice Matters

From the 21st-24th November 2017 EFNA participated in the My Voice Matters exhibition at the European Parliament in Brussels. The exhibition was an initiative of Medicines for Europe and was launched by Lieve Wierinck MEP (ALDE, Belgium).

The objective of the exhibition was to provide a platform for patient groups and representatives to raise awareness of their needs, the importance of a healthcare agenda, and how to integrate the patient preference within a range of therapeutic areas.

The exhibition featured information stands from EFNA, Value Added Medicines, Active Citizenship Network and the European Huntington Association (an EFNA member). EFNA used the opportunity to further our work on access to employment.

The overarching message from all groups is “my voice matters” – the need for patient centricity in healthcare & EU policy.
SOCIAL MEDIA REPORT

5,595 visitors to the EFNA website
1,403 Followers on Twitter (+535)
201 Followers on Facebook (+201)
796 Subscribers to the EFNA newsletter

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Twitter: @brainmindpain

TOGETHER UNDER THE UMBRELLA
Web: www.undertheumbrella.eu
Twitter: @UnderUmbrellaEU
Facebook: /UnderUmbrellaEU/
TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES

For many years EFNA had run workshops on HTA 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: for example, 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 2016.

In 2017, we built on the learnings from our first year of activity and built an even bigger programme of training and capacity building events at both the national and pan-European level.

Details of the events organised in 2017 are below.

**TINA IN NUMBERS:**

5 WORKSHOPS IN 5 COUNTRIES

7 DAYS OF TRAINING

100+ PARTICIPANTS

20+ NEUROLOGICAL DISORDERS REPRESENTED – and even more individual organisations!

15+ NATIONALITIES

20+ HIGH LEVEL SPEAKERS AND FACILITATORS
PAN-EUROPEAN EVENT

The first TINA event on 2017 was held in Brussels and led by communications expert, Bettina Hausmann – with the focus being on helping participants increase their advocacy impact through more hard-hitting communications. The emphasis lay on external (and oral) communications with a selection of priority audiences.

In an increasingly complex medical, public policy and media environment, patient advocates can find it hard to get their voice heard. So, this workshop brought together representatives from different European neurological associations and patients, all of them wanting to learn more about Effective External Ambassadorship.

Over two days, Bettina guided the participants on how to:

- Develop and control messages that resonate with different priority audiences
- Act as proactive ambassadors, e.g. through effective external presentations and interviews

The interactive workshop allowed participants to gain new insights, tips and tools; exchange best-practice; and rehearse different communications situations in an experimental, ‘safe’ space.

At the end of the workshop, a number of advocates agreed to be interviewed on camera and these videos were used by EFNA on World Brain Day to showcase the impact of living with a neurological disorder on those affected. You can watch these videos here: [https://www.youtube.com/playlist?list=PLHXd94iOcyi8OHNNHpGpWjEWDXlynodjM](https://www.youtube.com/playlist?list=PLHXd94iOcyi8OHNNHpGpWjEWDXlynodjM)
NATIONAL EVENTS

The pan-European event was supplemented by three national workshops.

ROMANIA

Following a hugely successful first workshop in Romania in 2016, a second event took place in 2017 due to demand. This workshop was scheduled to coincide with World Brain Day (July 22nd).

Entitled *Science, Communication and Social Affairs*, the workshop focused on understanding how various neurological diseases affect the brain and current developments in research. Participants learned to what extent these conditions are disabling and took part in an informative and open discussion on the rights of people with disabilities and what support can be implemented in Romania.

The session on story telling showed participants new ways of communicating more effectively within the current healthcare system, how to convey the message with more power and how to better engage stakeholders to support their cause. One of the outcomes of these trainings was also to find new opportunities to collaborate between neurological patients’ associations in Romania.

The event was held in partnership with the National Association of Patients with Neurodegenerative Disorders (APAN Romania). Speaking at the event its President, Dragos Popescu said:

“APAN Romania wants to become the main voice of people with neurodegenerative diseases in Romania and to ensure that patients have a strong voice in setting their own goals and priorities.”

These TINA workshops are facilitating the APAN to achieve this goal, and another meeting will be organised in 2018 on a regional level.

There were a total number of 45 participants at the workshop. All major neurological associations in Romania were present at the meeting, and extensive media coverage followed.

Feedback for the TINA workshop was very positive and participants reinforced their desire to continue these events as they contribute to a stronger, more empowered patient community in Romania.
Our inaugural workshop for Spanish patient groups took place in Valencia in October 2017, facilitated by Elena Ruiz de la Torre, President of European Migraine and Headache Alliance. 30 different patient associations participated in the workshop, which focused on HTA.

Topics covered included an introduction to pricing, access and reimbursement, the importance and implications of patients involvement in HTA, best practice multi-stakeholder collaboration in influencing decision-making and the EMA process of medicines approval.

Communications specialist Denis Costello explained how social media use can be optimised to influence decision-makers. Social media can help organisations raise awareness and reach both existing and new audiences. It also provides a platform to generate and disseminate evidence.

Participants noted that significant discrepancies exist in Spain with regard to how and for whom medicines are financed and treatments made available.

They described a lack of accessible information on the medicines approval process and the ways patient associations are involved, with many attendees being previously unfamiliar with the term ‘HTA’.

Participants found the workshop very useful and left feeling better able to advocate for the rights and interests of the patients they represent. They also expressed gratitude for the opportunity to participate in a pro-active initiative and to know that there are organisations working on their behalves at European level.
POLAND

A workshop for Polish patient organisations representing those affected by brain disorders took place in Warsaw on December 1st 2017, in partnership with NeuroPozytywni (Polish patients with neurological diseases advocacy group).

Participants represented a wide range of brain advocacy and support groups, from Alzheimer’s Disease, Parkinson’s Disease, childhood epilepsy, MS and mental health, to the rare neurological disorder AHC.

In the first session Prof. Maria Barcikowska of the Polish Brain Council provided an overview on how the brain works, and we saw a beautifully illustrated ‘brain atlas’, authored by Prof. Wieslaw Nowiński.

The workshop, focusing on enriching advocacy skills for patients, also included speakers involved in the areas of policy and governance. Polish Ombudsman Mr. Adam Bodnar talked about many areas where brain health forms part of his work, including nomination of a mental health coordinator who is now part of his team. He also reiterated that we need to fight for a language that will not further stigmatize people affected by ill brain health. This is particularly true in the area of mental health, where inappropriate and stigmatizing language is still used.

Member of the European Parliament Mr. Bogdan Wenta, one of the best handball Polish players of all time, described his work in the area of promoting health, including brain health, and in promoting the involvement of people with disabilities in sport. He emphasised that patients need to know that they are not alone and they are not different.

Workshops that followed focused on three areas that have been identified by Polish patients as priorities: i) HTA, ii) creating effective awareness campaigns and iii) building partnerships for progress.

The event was very helpful in cementing the cooperation between the different disease areas represented and resulted in a joint call reiterating the need for a Polish Brain Plan with patients’ needs at its centre.

Videos from this event can be accessed on YouTube: https://www.youtube.com/channel/UCOq58dXDY9HjDtYIApkjaiw

EFNA MEMBERS’ EVENT

A two-day workshop on Governance and Transparency was held by EFNA in Dublin from March 22 – 23rd for its members. Noémi Ambrus (right), Senior Trainer with Civil Support, Budapest hosted the workshop. Here, EFNA members were invited to learn more about the Role of the Board, the Responsibilities of Board Members, the Transparency and Accountability of Patient Organisations and the Engagement of our Members. This event was held in the framework of EFNA’s updating of its existing constitution and the creation of new, associated by-laws. This new constitution was formally approved and published in 2017.
Throughout 2017, 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. These included:

- European Brain Council
- Patients and Consumers Working Group at the European Medicines Agency
- EFPIA Think-Tank
- Europa-Bio Patients BioForum
- Patient-MedTech Dialogue
- European Alliance for Access to Safe Medicines
- Alliance for Safe Online Pharmacy
- European Patients Forum
- European Society for Radiology – Patient Advisory Group
- Societal Impact of Pain
- Medicines for Europe including My Voice Matters initiative

More details on these groups can be found on the EFNA website.

EFNA also works closely with our health professional partners at the European Academy of Neurology – having signed a Memorandum of Understanding to enshrine our cooperation. On the following page we tell you more about this partnership, as an example of best practice collaboration between patients and health professionals.

**WORKING TOGETHER WITH EAN**

In 2017, EFNA, once again participated actively during the annual congress of the European Academy of Neurology; this year taking place in Amsterdam.

As well as building a booth in the Exhibition Centre – in partnership with the European Brain Council (read more on page 20) – we also had an extensive programme of activities at the Congress, where we were invited to label selected sessions as ‘Patient Choice’.

This included a *Professionals and Public Meeting on Palliative Care*. Here, national and international experts came together to explore a series of questions relating to the palliative care of neurology patients, with examples from the fields of: brain tumour, dementia, Parkinson’s disease and motor neurone disease.

We also organised a special session on *Shared Decision-Making* – which was well attended by an audience of both neurologists and patients. The session explored the theory of SDM, techniques to improve communication and the usefulness of digital tools.

The EFNA General Assembly took place during the Congress, allowing our members to participate in relevant congress activities – in many cases attending the sub-speciality scientific panels in their own disease areas. These panels are responsible for the development of clinical guidelines and submission of suggested topics to future Congress programmes so it is important for our patient advocates to be involved.

Selected EFNA Board Members also attended meetings of the EAN Training & Education and Liaison Committees, as well as a bilateral meeting with the EAN leadership to discuss future collaboration on areas of mutual interest.

Of course, this involvement extends beyond the Congress, with reciprocal involvement in each other’s ongoing activities. We look forward to growing cooperation in the future!
A WORD FROM OUR TREASURER

On behalf of EFNA, as Treasurer, I would like to acknowledge support from the following corporate partners in 2017. 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 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 2017 and our budget for 2018. 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/ORGANISATIONS WHO HAVE SUPPORTED US IN 2017:
## EFNA Annual Accounts: 31/12/2017

### Training Initiatives for Neurology Advocates

**Project Income**
- MSD: 15000
- Merck Serono: 45000
- Genzyme: 10000
- Teva: 20000
- Biogen: 6660
- UCB: 10000
- Pfizer: 15000

**Total Project Income:** 121660

**Project Expenditure**
- Venue Costs incl. accommodation: 31010.29
- Delegate/Speaker Travel Expenses: 12343.09
- Steering Committee/Planning Meeting incl. APM: 6000.18
- Meeting Coordinator Costs: 18202.55
- Printing/Promotional materials: 489.94
- TINA Filming Costs: 796.67
- TINA Miscellaneous Costs: 1938.6
- EFNA 20% admin cost: 25332
- EFNA Project Manager (6 days per month): 25200

**Total Project Expenditure:** 121313.32

**SUB-TOTAL SURPLUS:** 346.68

### MEP Interest Group on Brain, Mind and Pain

**Project Income**
- Pfizer: 30000
- Grunenthal: 25000
- Merck Serono: 30000

**Total Project Income:** 85000

**Project Expenditure**
- Senior Policy Officer: 24878.8
- Interest Group Meetings: 15916.21
- Written Declaration Costs: 483.03
- Planning Meetings and External Representation (policy): 9323.39
- Communication/Promotional Materials incl. website: 274.7
- Other Advocacy Costs: 6096.41
- EFNA 20% admin cost: 17000
- EFNA Project Manager (2.5 days per month): 10500

**Total Project Expenditure:** 84472.54

**SUB-TOTAL SURPLUS:** 527.46

### Under the Umbrella - Awareness Campaign

**Project Income**
- Teva: 20000
- Pfizer: 30000

**Total Project Income:** 50000

**Project Expenditure**
- Communications Coordinator incl. VAT: 32408.28
- Printing/Promotional Materials: 1059.22
- Launch Event - European Parliament: 3267
- Keynote Campaign Events incl. stand at EAN Congress: 2496.96
- Participation at associated events: 182.4
- EFNA 20% admin cost: 10000
- EFNA Project Manager (1.5 days per month): 6300

**Total Project Expenditure:** 55713.86

**SUB-TOTAL DEFICIT:** -5713.86

### General Assembly incl. Participation at EAN Congress

**GA Income**
- European Academy of Neurology: 20000
- Membership Fees: 3150

**Total GA Income:** 23150

**GA Expenditure**
- Accommodation: 14210.2
- Travel Expenses: 7884.1
- Promotional materials, equipment hire, etc.: 834.3
- Catering: 1690.15
- Shipping: 215.25

**Total GA Expenditure:** 24834

**SUB-TOTAL DEFICIT:** -1684

### Administration and Other

**Project Administration Charges**
- Janssen: 10000
- Reimbursements: 3353.73
- Other income: 77.27

**Total Admin/Other Income:** 65763

**Total Admin/Other Expenditure**
- Unallocated fee of Executive Director (non-project) incl. VAT: 28777.4
- Other Fees: 753.2
- Other Overhead: 435.4
- Website, Telephone, Internet (non project): 822.79
- Accounting Fees: 8515.85
- Membership Fees: 1915

**Total Admin/Other Expenditure:** 41219.64

**SUB-TOTAL SURPLUS:** 24543.36

### Overall Accounts

**TOTAL INCOME:** 345573

**TOTAL EXPENDITURE:** 327553.36

**TOTAL SURPLUS:** 28019.64
2018 – WHAT’S TO COME?

ADVOCACY

• 3 x meetings of the MEP Interest Group on Brain, Mind and Pain
• Phase 2 of the EFNA project to map neurology patient engagement in HTA, associated roundtable and development of White Paper
• Neurology Advocacy Awards 2018

EMPOWERMENT

• 2 x pan-European TINA workshops
  Value: Patient Perspectives and Preference @ Champalimaud Foundation, Lisbon
  Science for Advocates @ FENS Forum, Berlin
• 1 x regional TINA event
  The Future of Healthcare in the EU, Bucharest

AWARENESS

• Focus on Young People living with Neurological Disorders
• Survey of the issues affecting young people (18-35) living with neurological disorders – with launch during Brain Awareness Week and dissemination on World Brain Day
• Associated #BrainLifeGoals campaign
• Workshop for young advocates on Patient Advocacy in a Digital World
• Focus on GDPR compliance and development of associated communications strategies and policies