ANNUAL REPORT 2018

EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

An opening word from the Executive Director

Dear Reader,

Thank you for taking an interest in EFNA and our work in 2018.

As you'll see, this year we continued to build on some of our ongoing projects – such as our MEP Interest Group on Brain, Mind and Pain and our Training Initiatives for Neurology Advocates.

However, in 2018, we began to work more with younger people affected by neurological disorders, for the first time.

This started when we conducted a survey of those living with a neurological disorder in Europe, aged between 18-35. The results showed us that much needed to be done to highlight and address their needs, as well as better facilitating and equipping them to engage in health advocacy.

This led us to our latest awareness campaign: #BrainLifeGoals – which you can read more about on Page 19, as well as to the coordination of a workshop, specifically targeted at this demographic, on the theme of: Health Advocacy in the Digital World. You will also see that one of our Interest Group meetings tackled the theme of how the EU can #MakeWorkWork for young people with a neurological disorder.

This new focus, we feel, will lead us nicely to our next Strategic Plan (in 2020) in which we will strive to ensure that the needs of this younger generation are reflected, as well as ensuring opportunity for them to better engage with and influence our work.

As usual, we have divided our activities into the strategic focus areas of Advocacy, Awareness, Empowerment and Engagement – so do read on to find out more about what else we have been up to in each area in 2018.

As you'll see, we've been busy! And I would like to thank all/any of you who have been part of this. With our hard-working (but small!) staff and a dedicated Board, we can do a lot. But we depend on our members, partners and supporters to enable us to fully roll-out our annual workplan – as detailed over the coming pages.

We have endeavoured to keep this document concise so full reports, presentations and other materials can be found on the relevant websites – should you wish to know more.

And, of course, you can also get in touch with me at: executivedirector@efna.net.

For now, we hope you will browse through the pages and see what we have been up to in 2018. Thanks for reading!

Donna Walsh

Donna Walsh
EFNA Executive Director

A quick note from our President

Dear Reader,

As will be clear from the pages below, EFNA's activities in 2018 have been many and manifold. I congratulate the EFNA team and Board on this solid achievement. I am even more convinced now that campaigning for what matters most to our patients and making neurology an issue higher on the various stakeholder agendas is of the utmost importance and needs to be continued. Thus, our professional approach to creating alliances and good working relations with European Institutions will have renewed emphasis and our focus on what matters to patients will remain.

The support received from our various stakeholders has been essential, and I hope this will continue and increase, in order to create an even greater impact of our work.

Joke Jaarsma
EFNA President

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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

BOARD MEMBERS 2018

Ann Little	**President until June 2018**	International Bureau of Epilepsy
Joke Jaarsma	**President from June 2018**	European Alliance for RLS
Cathalijne van Doorne	**Vice-President**	Euro-ataxia
Bea de Schepper	**Treasurer**	European Huntington's Association
Jenny Baker	**Secretary-General**	International Brain Tumour Alliance
Monique Lindhout	**Board Member**	Stroke Alliance for Europe
Nancy Van Hoylandt	**Board Member**	European ME Alliance
Monika Benson	**Board Member**	Dystonia Europe

STAFF 2018

Donna Walsh	**Executive Director**
Heather Clarke	**Senior EU Policy Officer until March 2018**
Tadeusz Hawrot	**Senior Advocacy Coordinator from August 2018**
Elizabeth Cunningham	**Communications Manager**

MEMBERS

ADHD-Europe
Dystonia Europe
Euro-ataxia
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
Pain Alliance Europe
Retina International
Stroke Alliance for Europe
European Alliance for Neuromuscular Disorders Association

SUMMARY

ADVOCACY

- MEP Interest Group on Brain, Mind and Pain:
  - Three meetings in 2018 at the European Parliament (see more detailed reports below)
- Coordination of steering committee on the future of the MEP Interest Group and work on the updated and new policy documents and associated collateral.
- EFNA Advocacy Awards 2018 – see winners on Page 15
- Coordination of research project – PHASE 2 – on neurology patient engagement in Health Technology Assessment, and two roundtables to discuss results and next steps.
- Participation in the Brexit Health Alliance and its arising activities.
- Participation in the EU Health Summit and arising EU Health Coalition, with an active role in the Policies for Health sub-group.
- Joined Chrodis+ work package 8 on Employment and Chronic Disease as a collaborating partner.
- Involvement in the steering committee and judging panel for the inaugural Brain, Mind and Pain Grant.
- Contribution to the Societal Impact of Pain framing paper and joint statement, as well as participation on the Societal Impact of Pain steering committee
- Contribution to the framing paper and joint statement on Improving the employment of people with chronic diseases in Europe
- Continued involvement in the European Brain Council's Value of Treatment project – as well as contributing the neurology patient perspective to their advocacy efforts for a Brain Mission
- Increased cooperation with European Academy of Neurology on policy actions with EFNA representation on their European Affairs Sub-Committee and contribution to their Neuro-Care project (mapping neurology healthcare services in Europe)
- Participation in EFNA member and partner advocacy initiatives and events at the European Parliament and elsewhere

AWARENESS

- Survey of young people, aged 18-35, living with a neurological disorder in Europe
- Pilot launch of arising #BrainLifeGoals campaign
- Work on GDPR compliance for EFNA and its members
- Continuation of EFNA's bi-monthly newsletter and building our online presence
- Support of members' and partners' communication and awareness raising activities

EMPOWERMENT

- **Training Initiatives for Neurology Advocates – Workshops:**
  - Pan-European Meeting: 'Value – patient preferences and perspectives', in partnership with the European Brain Council, Champalimaud Foundation, Lisbon, April 2018
  - Pan-European Meeting: 'Science for Advocates' – in partnership with the Federation of European Neuroscience Societies, FENS Forum, Berlin, July 2018
  - Regional Meeting: 'Future of Healthcare in the EU' – in partnership with the Alliance for People affected by Neurodegenerative Disorders [APAN], Bucharest, October 2018
  - Workshop for Young Advocates, November, Brussels

ENGAGEMENT

- **Ongoing external representation to relevant organisations/activities**
- **Participation in EFNA Member General Assemblies, events, activities, etc.**
- **Annual General Assembly and Annual Partners Meeting**

Advocacy →

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

Since 2015 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.

2018 was a busy year for us with three meetings in the European Parliament – building on successes to date, but also looking to the future as we approached the EU elections in 2019.

These MEP Interest Group meetings serve a number of purposes. Primarily, they allow us to:

- **RAISE AWARENESS of the challenges facing those living with neurological disorders or chronic pain conditions amongst policy makers, key opinion leaders and other relevant stakeholders – with the aim of, indirectly, influencing policy and decision-making at the EU institutions and beyond.**
- **ENGAGE with policy-makers, but also other organisations with similar policy goals – building connections for future collaborative actions outside of these meetings, allowing their work to inform our activities or simply providing a platform for our members and partners to promote and disseminate relevant work.**
- **Directly IMPACT POLICY!**

Given these three goals, we have divided each meeting report into such sections to showcase how we tried to achieve our objectives via the meetings in 2018.

The full reports can be obtained at: www.brainmindpain.eu

FEBRUARY MEETING 1: 'HOW CAN THE EU #MAKEWORKWORK FOR YOUNG PEOPLE AFFECTED BY BRAIN, MIND AND PAIN CONDITIONS?'

The first meeting of 2018 – chaired by MEP Marian Harkin – returned the group to a very familiar topic: Access to Employment. However, this time the focus was on Young People – linking in with EFNA's work with this demographic during 2018 (see 'awareness').

AWARENESS

Two powerful opening testimonies from Peter Boyd – living with arthritis – and Jacobo SantaMaria Barral – living with multiple sclerosis – set the scene for the discussion to follow.

PARTNER ENGAGEMENT

The remainder of the event featured presentations by organisations also working on this topic – in an attempt to align our efforts. These were:

European Network of Independent Living – Youth

European Patients' Forum – Youth Group

European Brains @ Work

European Chronic Disease Alliance

POLICY IMPACT

MEP Jana Zitnanska attended the meeting and explained that she was the rapporteur on a new report entitled: Pathways for the reintegration of those recovering from injury and illness into quality employment.

She said that she would be presenting the draft report at the Parliament's Employment and Social Affairs committee the next day and asked the MEP Interest Group to feedback on its content, whilst also assuring the group that she had listened to the discussions with interest.

She mentioned that as well as reintegration, the report would also look at prevention and early intervention. She said that she would ensure the sharing of best practices was included but made it clear that support from the Member States would be required to ensure that the report could be leveraged and optimised.

POLICY IMPACT

MEP Rory Palmer also attended and said he, too, was open to ensuring feedback from the Interest Group was factored into the discussion of the report – in his role as shadow rapporteur.

He also spoke about a new initiative which he is coordinating – a focus group on Dying to Work, which was hoping to create legislation to protect the employment status of those with a terminal illness. The Interest Group will support this initiative moving forward.

POLICY-MAKER ENGAGEMENT

As well as the MEPs mentioned above, there was a keynote address from Emmanuelle Grange, Head of Unit Disability and Inclusion, DG Employment, Social Affairs and Inclusion, European Commission.

Ms Grange informed the group of a number of Commission initiatives, which the Interest Group will follow up during the next mandate (under the thematic area of 'Fighting Stigma, Isolation and Discrimination') – these include:

- **Pushing for the implementation of the European Pillar of Social Rights, possibly via the European Semester Process**
- **Influencing the passing of the EU Accessibility Act and the update of the Disability Strategy**
- **Leveraging EU funding via the structural funds, European Programme for Social Innovation, etc.**
- **Being part of a joint DG EMPL and DG JUST awareness campaign, targeting employers, on discrimination at work, as part of the 'EU Empowers' programme.**

JUNE MEETING 2:

AWARENESS

The aim of this meeting was to showcase how what matters most to patients should be better reflected in policy and decision-making, but also in research and development.

Cathalijne van Doorne, a person affected by ataxia, set the scene by giving some examples of how what matters most to patients is not always the same as what matters most to researchers. She spoke about how the distance walked was used as an outcome measure when testing the effectiveness of an ataxia treatment. However, she said, that patients are more concerned with the ability to talk.

PARTNER ENGAGEMENT

The discussion that followed allowed partners to give their perspective on the topic. These included:

- **Pharmerit International**
- **European Brain Council**
- **Pfizer Inc.**
- **European Patients' Forum**
- **Pain-Out Project**

The consensus was that it is important to understand the priorities of patients in terms of the outcomes of their treatment and management – this can also save our healthcare systems time and money. There are already good examples of how this can and should be done. However, this requires political will from policy-makers, regulators and payers. The EU could support this by investing more in digital technologies but also data registries, to better collect, analyse and share such outcomes. The EU could also ensure that the patient perspective is adequately included in the research it funds – which led into the next discussion. Panellists here included:

- **European Pain Federation**
- **EFPIA**
- **Grunenthal**

The discussion centred around what the EU can do to better fund and support patient relevant research and development. IMI – particularly projects like PREFER and PARADIGM – was promoted as a best practice example. However, it was also noted that the pharmaceutical industry itself is making strides to better integrate patient reported/relevant outcomes and this should be replicated in publicly funded research.

This topic will be taken forward by the Interest Group in the 2019-2024 mandate under the thematic area of 'Promoting patient empowerment for increased involvement and engagement'.

POLICY-MAKER ENGAGEMENT

However, before the discussion, there was an address from Anna Graca, Project Officer from DG RTD who presented the proposed Horizon Europe funding framework.

POLICY IMPACT

Here, there was an opportunity for Joke Jaarsma, EFNA President to put forward the requests of EFNA and the Interest Group. She said:

- **We welcome the improvements suggested in the "Horizon Europe" proposal, including increased funding, but we believe that this is not enough to meet global challenges, as well as to address the historically low success rate that is currently seen in Horizon 2020 – particularly in the field of brain, mind and pain disorders.**
- **We would like to see a new budget of at least 120 billion euro to meet the ambitions formulated in the FP9 proposal.**
- **We are concerned about the provisional budget of 7.7 billion euro allocated to the "Health" cluster under Pillar II. We believe that adopting the proposal as it stands will be insufficient to effectively address the societal challenges associated with healthcare in the field of brain, mind and pain disorders.**
- **We are encouraged by the increased budget for the European Social Fund [ESF+]. However, this is to be spread across a wider range of activities – and we need to ensure that actions in the area of health are supported and the instrument promoted at member state level for this purpose.**
- **We realise that health remains a national competence but we would like to see ongoing and increased support for health-related actions where cross-border cooperation brings added value e.g. work in the area of chronic diseases, HTA, etc. This should be reflected in the proposal.**

NOVEMBER MEETING 3: FUTURE OF HEALTHCARE IN EUROPE – WHAT NEXT FOR BRAIN, MIND & PAIN?

The final meeting of the MEP Interest Group for 2018 took place on the 21st of November in Brussels. Thoughts turned to the future of the group, with a presentation of the proposed new thematic areas which the group would cover during the 2019-2024 mandate. These would be:

- **Fighting stigma, isolation and discrimination**
- **Ensuring equitable access to treatment, services and supports across the EU**
- **Promoting patient empowerment for increased involvement and engagement**

PARTNER ENGAGEMENT

There was widespread agreement in the room that these cross-cutting themes were of relevance to the wider Brain, Mind and Pain community. Presentations were made from the areas of:

- **Alzheimer's Disease – White Paper on Driving the Policy Agenda to Optimise Care for People with Alzheimer's Disease in Europe**
- **Stroke – Stroke Action Plan for Europe 2018-2030**
- **Chronic Pain – Societal Impact of Pain Framing Paper and Joint Statement**

These presentations highlight how the Interest Group has been used to promote, showcase and disseminate related disease-specific initiatives.

This meeting was also used to set the scene in terms of understanding the challenges faced by patients living with neurological disorders and chronic pain conditions; but also to showcase the disease-specific policy work that is being undertaken and to discuss how the Interest Group can support and align.

The discussion was chaired by Kaisa Immonen of the European Patients' Forum, as a way to ensure that the future work of the group was aligned with the broader patient advocacy movement, and contributions were sought from organisations such as the European Academy of Neurology, European Brain Council, IMI and so on.

POLICY-MAKER ENGAGEMENT

From a policy perspective, Ortwin Schulte, Health Attaché, German Permanent Representation to the EU gave an address – providing advice on how to link with future EU Presidencies – and MEPs Merja Kyllonen, Mady Delvaux, Tilly Metz and Marian Harkin contributed.

POLICY IMPACT

After the meeting, work got underway to update the central policy document of the Interest Group – The Book of Evidence, to reflect the new policy areas. The new document would build on the successful work of the Interest Group to date, include the latest research and statistics and contain concrete policy recommendations to be pursued in the coming years.

The final documents will be launched in 2019, following a meeting of neurology patient advocates to contribute to the documents and discuss their dissemination.

See www.brainmindpain.eu to read the follow reports of all these meetings, and to check our new policy documents for the next mandate!

In and Out @ EFNA

In March 2018, Heather Clarke left EFNA as our Senior EU Policy Officer. We wish Heather good luck with her future plans and thank her for her enormous work on the MEP Interest Group since its launch in 2015!

In August 2018, Tadeusz Hawrot joined the team in the, renamed, role of Senior Advocacy Coordinator. Below, Tadeusz tells us about how he plans to take the advocacy work of EFNA forward in the future.

Dear Reader,

It is with real pleasure and a sense of great responsibility that I joined EFNA last summer in my new role, coordinating our advocacy and policy work. Coming from a decade long experience in the field of EU policy and brain health allowed for a smooth and quick transition.

Right from the start, I have been greatly impressed by the amount of activities and recognition that EFNA has achieved with limited resources, owing to an impeccable internal management and work done by the staff and Board Members.

I joined EFNA less than a year ahead of European elections, therefore my immediate focus became building on EFNA successes achieved during the current European Parliamentary term and supporting the team in developing a strategy of engagement with MEP candidates. This is particularly important given that more than half of current co-Chairs of EFNA's MEP Interest Group on Brain, Mind and Pain (IG) will not be running in the 2019 elections. Therefore, as we work on re-constitution of the Interest Group, it will be crucial to identify new neurology champions that connect with our mission, and who are influential and action driven.

As the new leadership of the European Commission will be established in the months following the elections, I will be also working with my colleagues to make sure that the voice of neurology patients is taken into account by new leaders.

This work will be complemented by an increasing involvement with countries taking up the rotating EU Presidency, the Member State-led EU Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases (NCDs), as well as EU Health Policy Platform.

In parallel with an EU focus, in 2019 we plan to increasingly get involved in raising the profile of neurological health and the voice of neurological patients at the global level. It is important to appreciate here that global health priorities have been actively shaping the course of policy at the EU and Member State level. This is especially visible in dossiers addressing NCDs, Sustainable Development Goals as well as Universal Health Coverage. So far neurology has not been adequately prioritized in these global policies and we will strive to address this next year.

I am so excited to work on these projects with my EFNA colleagues, Board, Members and Partners!

Tadeusz Hawrot, EFNA Senior Advocacy Coordinator

Advocacy Awards 2018

On the evening of Tuesday, November 20th 2018, EFNA held its third Advocacy Awards Ceremony, at the Fondation Universitaire in Brussels.

These awards recognise the contribution of individuals or groups to the development and promotion of advocacy for people with neurological disorders in Europe. This year, to coincide with EFNA's focus on young people, the awards were given to young advocates – with a Lifetime Achievement award also bestowed on the evening.

YOUNG HEALTH PROFESSIONAL/RESEARCHER

Winner: Dr Giorgos K Sakkas **Nominated by:** European Alliance for RLS (EARLS)

For his work in researching the condition of Restless Legs Syndrome, but also his genuine interest and warmth in his interactions with patients. His work includes a large study on RLS in pregnant women, participation in an RLS case-study as part of the Value of Treatment project, development of a proposal for a COST action on RLS and the exploration of novel treatments.

YOUNG DIGITAL ADVOCATE

Winner: Poppy Ellis-Logan **Nominated by:** ADHD Europe

For her work in launching a national campaign on ADHD in the UK, entitled: Attention UK (attentionuk.org) to highlight the problems facing adults with ADHD. She was also instrumental in the development of instant messaging software for students with mental health problems to access high quality support at Cambridge University, where she became Welfare Rights Officer, despite her own challenges with ADHD.

YOUNG VOLUNTEER ADVOCATE

Winner: Dr Ramona Moldovan **Nominated by:** European Huntington Association (EHA)

For her work in Romania which has led to the creation of the Romanian Huntington Disease [HD] Association, the coordination of a national HD week, the development of a team at the University hospital in Cluj offering a multi-disciplinary service and the availability of free-of-charge genetic laboratory analyses for Romanian patients.

YOUNG POLICY-MAKER

Winner: Jeroen Lenaers MEP **Nominated by:** Pain Alliance Europe (PAE)

For his work as a Member of the European Parliament and co-chair of the MEP Interest Group on Brain, Mind and Pain.

LIFETIME ACHIEVEMENT

Winner: Prof. Wolfgang Oertel

For the first time EFNA presented the special achievement award to a scientist. With the scientific and patient communities working together more closely, the EFNA Board felt this would be timely. The award this year goes to Professor Wolfgang Oertel of Germany, in gratitude for his broad and multifaceted career in neurology. Professor Oertel was part of a few seminal discoveries and performed instrumental work in movement disorders. For this magnificent model career he was awarded the Hertie Sr professorship, the most prestigious award in Germany. Professor Oertel's broad vision on science, his tireless work in the European institutions, all combined with an active interest in neurological patient advocacy, make this award a special one.

Awareness →

AWARENESS – SECTION 2

2018 saw a dramatic increase (39%) in visitors to the EFNA website and in the numbers following our social media channels.

The bi-monthly EFNA Ezine provides news from EFNA and our member and partner organisations. Share your news with communications@efna.net for inclusion!

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

SOCIAL MEDIA REPORT

Visitors to the EFNA website: **7,973** (+39%)

Followers on Facebook: **659** (+458 / +69%)

Followers on Twitter: **2,395** (+992 / +41%)

Followers on Instagram: **NEW! 252**

GDPR – ENSURING COMPLIANCE AND ADOPTION OF BEST PRACTICE AT EFNA

The General Data Protection Regulation 2016/679 is a regulation in EU law on data protection and privacy for all individual citizens of the European Union and the European Economic Area. It also addresses the export of personal data outside the EU and EEA areas. The GDPR came into effect on May 25th 2018.

Following a period of extensive research, EFNA developed an updated Privacy Policy, relating to how EFNA will use personal information that is collected via the EFNA website, and a new Data Protection Policy, providing a concise policy statement regarding the organisation's Data Protection obligations.

Developed in conjunction with these were an associated Subject Access Request procedure, a Data Retention and Destruction Policy, a Data Retention Periods List and a Data Loss Notification procedure.

EFNA are committed to protecting and respecting your privacy.

2018 - A FOCUS ON YOUNG PEOPLE

In 2018 EFNA chose to focus on young neurology patients, with specific attention on young adults aged between 18 and 35 years. Our goal was to identify the issues that most affect this group and to create a programme that would assist young people in becoming advocates for their own disease areas.

Those living with chronic illness face a number of additional burdens as young people. Often they are unable to complete their education, unable to take a place in the workforce, fear they will not find a romantic partner or have to watch their peers participate in activities they cannot access. Comorbidity between neurological diseases and mental health disorders such as depression and anxiety is common. These comorbidities increase disease burden and stigma – issues acknowledged across our membership.

SURVEY OF YOUNG EUROPEANS AFFECTED BY NEUROLOGICAL DISORDERS

EFNA conducted a survey to explore the problems faced by young neurology patients, as well as their feelings around levels of understanding of their disorders and their engagement in advocacy work or patient groups.

Between March 12th and May 15th 2018, 1368 responses to the survey were received from 39 countries.

Almost 80% of the respondents were female, with the majority of the responses coming from the below disease areas:

- **Multiple Sclerosis**
- **Myalgic Encephalomyelitis**
- **Chronic Pain**
- **Migraine**

Interestingly, all of the aforementioned conditions are largely 'invisible illnesses' with symptoms such as pain and fatigue featuring prominently. It is no surprise, therefore, that two of the biggest issues for respondents are 'isolation' and 'stigma'. This could be attributed to the lack of public understanding of brain disorders. Overall, respondents placed understanding of both brain disorders (in general) and their conditions (specifically) at 2.5 – on a scale of 1-10, with 10 being full understanding. A lack of understanding was also clearly shown amongst family, friends and employers.

Interestingly, the top ranked issue was 'access to medication/treatment'. This is despite the fact that over 70% of respondents take prescribed medication, and just under 70% see a specialist/neurologist. However, when asked what changes could improve the lives of respondents, many listed: a cure, more effective medication or medication with fewer side-effects. This seems to suggest that although these young patients have access to treatment it is often not optimal. The need for increased advocacy and awareness is therefore clear.

Encouragingly, although almost two-thirds of the respondents had never taken part in an awareness campaign, approximately the same number indicated that they would be interested in doing so. Similarly, although the majority were not a member of a patient organisation, most were interested in learning more about how they could get involved. We hope that, in partnership, we can take these findings and improve the quality of life of young people living with neurological disorder.

You can read the complete survey report here: www.efna.net/efnayoungpeoplesurvey/

THE BIGGEST ISSUES

These are the biggest issues facing 18 - 35 year olds living with neurological disorders in Europe today, according to our survey.

2. ISOLATION

1. ACCESS TO MEDICATION/TREATMENT

STIGMA 3.

EDUCATION

16% of respondents have obtained a Masters Degree

MS: 22%
ME: 8%
Migraine: 14%
Chronic pain: 11%
Epilepsy: 7%

MEDICATION

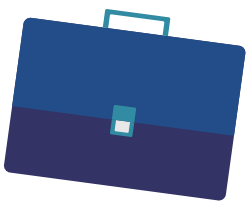
72% of respondents take prescribed medication for their condition

MS: 90%
ME: 41%
Migraine: 70%
Chronic pain: 63%
Epilepsy: 95%

EMPLOYMENT

34% of respondents are in full-time employment

MS: 43%
ME: 8%
Migraine: 22%
Chronic pain: 16%
Epilepsy: 37%



SPECIALIST CARE

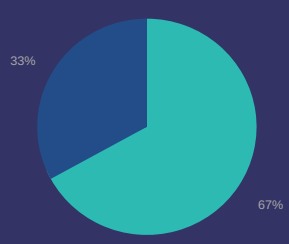
67% of respondents are under the care of a specialist doctor or neurologist

MS: 95%
ME: 19%
Migraine: 45%
Chronic pain: 43%
Epilepsy: 95%

ENGAGEMENT AND ADVOCACY

38% are members of patient organisations

58% are interested in learning more about patient organisations



67% are interested in taking part in awareness raising activities

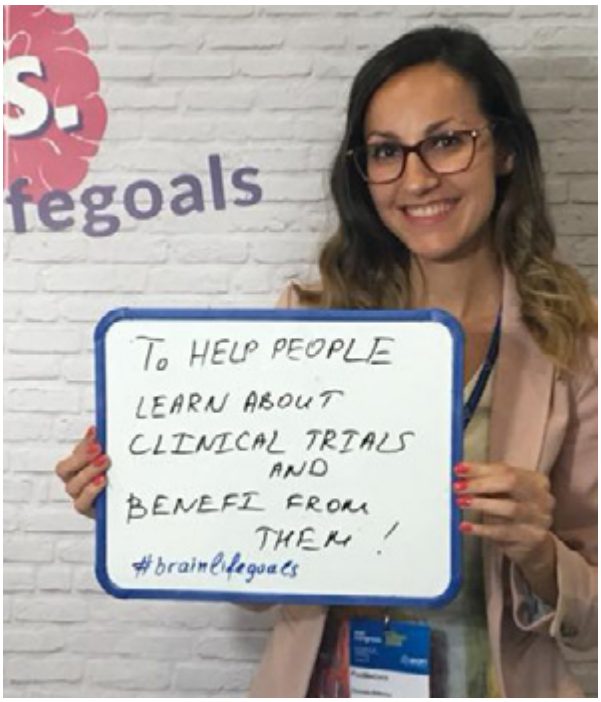
RAISING AWARENESS AT THE EUROPEAN ACADEMY OF NEUROLOGY CONGRESS IN LISBON

EFNA's stand at the EAN Congress in 2018 was themed around young people living with a neurological disorder. Initial results of our recent survey of 18 – 35 year olds were presented through posters and flyers. Direct quotes from survey participants were used to highlight the things that would most improve their lives. We are calling these #BrainLifeGoals! Visitors to the stand had an opportunity to take a photo and share their #BrainLifeGoals with us.

This idea will be expanded into an awareness campaign during 2019, providing a platform for neurology patients across Europe to raise awareness of the issues that affect them.

Assisting us at the stand were three fantastic young patient advocates; Adam Kalinowski (Board Member at Dystonia Europe), Barbora Jones (Fieldworker at Epilepsy Connections) and Helen Chandler (MS Advocate, representing EMSP). Helen gave a presentation entitled 'Health, Wealth and Workability; Young People and MS' at the Scientific Theatre during the Congress.

Adam Kalinowski, Dystonia Europe



Daniela Shikova, Find Me Cure

Representatives of the Glut1 Deficiency Foundation

Empowerment →

EMPOWERMENT – SECTION 3

TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES (TINA)

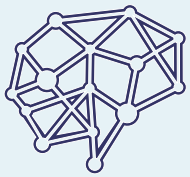
For many years EFNA had run workshops on Health Technology Assessment and, lately, Pharmaceutical Policy – Pricing, Access and Reimbursement at the London School of Economics.

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: For example, through the development of communication, advocacy and campaigning skills and the generation of patient evidence or patient reported outcomes.

Also, EFNA was 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.

Details of the events organised in 2018 are below, when we built our biggest ever programme of training and capacity building events at both the regional and pan-European level!



TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES

TINA IN NUMBERS:

4 WORKSHOPS IN **4** COUNTRIES

7 DAYS OF TRAINING

200+ PARTICIPANTS

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

20+ NATIONALITIES

30+ HIGH LEVEL SPEAKERS AND FACILITATORS

LISBON

EFNA's first pan-European workshop of 2018 took place at the Champalimaud Foundation in Lisbon on April 17th and 18th under the topic of: Value – Patient preferences and perspectives.

The agenda explored patient engagement in Health Technology Assessment across Europe, with a focus on the most Patient Relevant Outcome Measures and how these can be better integrated and reflected in the decisions taken to reimburse new treatments.

Speakers included:

- **Dr Iñaki Gutierrez Ibarluzea (Vice-Chair HTAi & Knowledge Manager, Osteba, Basque Office for HTA, Ministry for Health, Basque Government) who spoke about value beyond cost effectiveness and shared examples**
- **Prof. António Vaz Carneiro (Head of the Centre for Evidence Based Medicine & International Consortia for Health Outcomes Measurement [ICHOM], Cochrane Portugal) who discussed developing and integrating Patient Relevant Outcome Measures in research**
- **Prof. Mondher Toumi (Professor of Public Health, Aix-Marseille University) who spoke about Value Added Medicines**

Day Two of the workshop featured a joint session hosted by EFNA with the European Brain Council (EBC). This was moderated by John Bowis (former British Conservative MP and MEP).

Patrice Boyer (Vice-President, European Brain Council) presented the Value of Treatment for Brain Disorders project and posed the question 'How do we foster a new paradigm in value based, innovative, patient-centred healthcare?'

This was followed by views from:

- **Flora Giorgio (Head of Sector Health Technology Assessment, European Commission), representing the European Policy-Maker**
- **Nuno Silverio (Director of Market Access & Governmental Affairs, Merck), representing Industry**
- **Donna Walsh (EFNA Executive Director) representing the Patient**
- **Maria do Céu Machado (President, INFARMED – National Authority of Medicines and Health Products) representing The National Regulator**

The workshop finished with a group exercise; mapping next steps for our Training Initiatives for Neurology Advocates (TINA), with feedback on TINA initiatives to date and an assessment of the current training/capacity building needs of neurology patient groups.

BUCHAREST

On October 15TH and 16TH 2018, the EFNA Autumn Academy of the Training Initiatives for Neurology Advocates [TINA] took place. 30 participants from neurology patient groups from CEE countries gathered in Bucharest to discuss the future of healthcare in the EU in the context of the upcoming EU elections, as well as how patient groups can achieve better financial sustainability.

On Day 1, participants discussed the issues that mattered most to patients in their disease-specific community/country and how these could be addressed by EU policy. The first presentation was from the upcoming Romanian Presidency of the EU – and centred on how such Presidencies can be leveraged to ensure that issues of relevance to the neurology patient community are visible on the agenda. This was followed by a presentation by the European Public Health Alliance on the potential scenarios for health as an EU competence after the 2019 elections, and a contribution from EFNA on our advocacy priorities at the EU Institutions and beyond during the next mandate.

On Day 2, the focus shifted to how patient organisations could benefit from EU support – including funding to push their national agendas forward. Presentations were given by Frederic Destrebecq (European Brain Council) and Carla Finocchiaro (CF Consulting) on the proposed Horizon Europe funding framework and how patient organisations could get involved. This was followed by Rosa Castro from the EU Funds 4 Health project who spoke about how structural funds could be used for health-related initiatives in the EU member states.

The day continued with the interactive workshop of Peter Gustafik, from PCDS. Here participants were invited to think about what makes a successful fundraiser and ideas for novel approaches to fundraising.

The meeting also announced the launch of the Romanian Neurological Disorders Coalition, to ensure a better representation of those affected by these conditions. Patient groups involved include Multiple Sclerosis, Parkinson, Alzheimer, Epilepsy, Myasthenia Gravis, Stroke, Huntington, Dystonia and Spinal Muscular Atrophy.

BRUSSELS

The 'Patient Advocacy in the Digital World' workshop took place in Brussels from Monday, November 19 – Wednesday, November 21, as part of EFNA's Training Initiatives for Neurology Advocates [TINA] programme. This workshop was open to 18 – 35 year olds from around Europe who are affected by brain disorder.

Sessions on Day 1 included a series of talks from inspiring patient advocates on 'How to Influence Change and Lead in Your Community'.

Emma Lawton, Parkinson's campaigner & author, spoke on the power of storytelling. In a powerful presentation Emma explained how she strives to find a balance between expressing the reality of an often dark and difficult situation with positivity and humour.

George Pepper, Founder of Shift.ms, discussed his experience of building an online community. Shift.ms is a social network for young people with MS run by its users, where people can meet, share experiences and support each other.

Louis Gustin, a stroke survivor affected by aphasia, introduced S'adapter – an awareness campaign he has initiated to raise awareness across Europe.

To conclude Day 1, Elisabeth Kasilingam, MD of European MS Platform, joined us to discuss working with patient organisations. Elisabeth explored the added-value patient organisations can offer, through capacity building around education, policy, with service providers and R&D, and through peer support.

Elisabeth then facilitated a discussion around the group's expectations of patient organisations and how we can encourage young people to get involved in the patient advocacy movement.

Day 2 focussed on eHealth and Technology-enabled Solutions. Goncalo Carrico, Political Adviser, Innovation, Technology and Digital Policy Issues, European People's Party discussed Artificial Intelligence and what it means for health policy and patients in Europe. Kim Baden-Kristensen, Co-founder & CEO at Brain+, gave a presentation on digital applications being developed for neurology patients. Finally Marcello Ienca, of the Health Ethics & Policy Lab at the Department of Health Sciences and Technology, ETH Zurich, explored the ethical and policy issues associated with new and emerging technologies in healthcare.

Participants were also given the opportunity to attend the Brain, Mind and Pain MEP Interest Group at the European Parliament.

Following the workshop, participants were tasked with completing a digital advocacy project as part of the #BrainLifeGoals campaign, to launch in 2019.

BERLIN

This workshop took place as a satellite session to the FENS Forum in Berlin on July 6th and 7th. The FENS Forum is a basic neuroscience conference, organised by the Federation of European Neuroscience Societies.

Exploring the theme of 'Science for Advocates', the workshop drew over 30 patient advocates to learn how to better access, understand and communicate basic neuroscience.

Day 1 featured four keynote speakers. Opening proceedings, Monica di Luca – President of the European Brain Council – spoke about the impact of brain disorders in Europe; focussing on cost and burden. She stressed the need to continually advocate for increased resources to create better treatments and – perhaps eventually – cures. She said patient organisations could play a key role by calling on the European Institutions to ensure that brain research is prioritised in the upcoming EU Funding Framework (Horizon Europe).

The next presenter was Gaia Novarino of the FENS Kavli Network of Excellence. She presented some concrete examples of recent advancements in the field of brain research, focussing on autism spectrum disorders. She stressed the importance of patient organisations and the research community to work together to communicate science – dispelling myths – to wider society.

The third presentation was a timely focus on neuroethics. This compelling lecture was presented by Marcello Ienca who gave a background to the topic, before moving on to discuss four case studies in the areas of data mining, neuroprosthetics, brain implants and experiments with human brain tissue. He called for responsible, patient-centred innovation – balancing research innovation with subject safety.

The final presentation of the day was on another controversial topic – animal research. This was given by Kirk Leech of the European Animal Research Association. He predominantly focussed on how we can improve transparency and communication on animals used for scientific research.

Day 2 focussed more on interactive sessions – led by Punch Consulting. These were:

- **Find Science. Find Quality**
- **Build a Strong Foundation**
- **Turn Evidence into Action**

The group were tasked with using their newly acquired skills to design a political or public awareness campaign, based on a controversial issue in neuroscience.

The feedback from all was overwhelmingly positive and discussions are already planned to explore how this 'Science for Advocates' approach can be further pursued in partnership with FENS in future.

Engagement →

ENGAGEMENT – SECTION 4

Throughout 2018, 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. Here, some of our Board Members tell us more about their work in this area.

JOKE JAARSMA – PRESIDENT

Throughout 2018, my work as Treasurer and member of the Executive of the European Brain Council has involved many things; there is much synergy between the work done by EBC and EFNA, which makes working on both Boards rewarding.

During 2018, the Value of Treatment Project Phase 2 was started after the successful launch of the first round of case studies. This time working groups on dystonia, ataxia and phenylketonuria have begun to map the patient journey and identifying gaps and unmet needs. The project will continue throughout 2019 and launch is expected in late 2020. Patient participation in the working groups is ongoing.

A major research project at EBC is EBRA, the European Brain Research Area. Coordinated by EBC, EBRA aims to promote co-operation and exchange between brain research projects and networks, and thus enable or enhance international collaboration and the emergence of development of clusters in all areas of brain research, in line with EBRA's aim to foster new, and extend existing, transnational research cooperation of European countries, and to support coordination of research efforts. EFNA is represented on the General Assembly of this ambitious project.

In June 2018, the European Commission submitted proposals for a mission-oriented and impact-focussed Framework Programme for 2021-2027, entitled Horizon Europe. The proposals introduced the concept of a R&I mission which would have to be bold, inspirational, targeted and have measurable goals that should be reached within a given timeframe. EBC has launched various initiatives aimed at raising awareness of the societal benefits of adopting a brain mission and has published the statement "Understand – Fix – Enhance: The space race of the 21st century" which provides guidance to decisionmakers on how to design a mission on the brain. To date, it is still not clear where Brain Research will fall under the new EU Commission's work.

Our work with the European Academy of Neurology has intensified in 2018. In addition to the memorandum of understanding, many of our members participate in Scientific Panels, and we are represented on the Education Committee, the European Affairs Sub-Committee and the Guidelines Production Group. At the 2018 Lisbon Congress, Patient Choice sessions were on the program. As in previous years, we had a booth in the exhibition area featuring the #BrainLIfeGoals campaign, a special session on the Value of Treatment and presentations were given in the Scientific Theatre. We familiarized ourselves with EAN's Neuro-Care project, and are much looking forward to participating in this important study and in organizing associated joint events.

During 2018 there has been contact with the International Consortia of Health Outcomes Measurement (ICHOM). EFNA presentations were held and discussions on inclusion of neurological diseases in ICHOM's work are ongoing.

CATHALIJNE VAN DOORNE – VICE PRESIDENT

As Vice-President of EFNA I am involved in quite a number of activities. I have synopsised these below.

I am a member of the Patients' and Consumers' Working Party (PCWP) of the European Medicines Agency. This platform is essential for the exchange of information and discussion of issues of common interest between EMA, patients and consumers.

I also represent EFNA at some industry forums. These include the EuropaBio Patients Bio-Forum. Here patients and representatives of the biopharmaceutical industry come together three times per year to discuss common topics like registries, access to orphan drugs, Biosimilars, European Reference Networks etc. And, of course, there is also the EFPIA Think-Tank – meeting four times a year to discuss topics like principles for engagement with industry, remuneration of patients, patient empowerment and involvement, and so on. It is important that EFNA is visible here to represent the voice of the neurology patient community.

After four years of being the patient chair, this year I stepped down from this role at the European Alliance for Access to Safe Medicines (EAASM). I will stay on the Board, however, and to see further progress on key projects like off label use, common logo and improving patient safety with the Falsified Medicines Directive (FMD).

NANCY VAN HOYLANDT – BOARD MEMBER

As an EFNA Board Member, I undertake many external representation assignments.

In 2018, I was the delegate to the AGM of the European Patients' Forum – a group to which EFNA is an associate member. It is very important for us to work with EPF on topics of common concern for the wider community of patients with chronic diseases. This allows us to then focus on what is specific to our disease area… neurology.

One of the other groups that we are actively involved in, because of its relevance to our community, is the European Society of Radiology, where I represent EFNA on the Patient Advisory Group (ESR-PAG)

This group brings together patients, the public and imaging professionals in order to positively influence advances in the field of medical imaging to benefit patients in Europe.

EFNA joined the ESR-PAG to raise the voice of its members to enable neurological patients to make informed decisions about their care options and increasing empowerment through equality and understandable information. We have been actively involved in their special sessions at the annual European Congress of Radiology, their work on audits and standards, the survey on value-based radiology and so on. We also contributed to the new strategy of the group: 'ESR-PAG: a Strategy for 2019 and Beyond'.

MONIKA BENSON – BOARD MEMBER

EFNA continues to be actively involved in the Societal Impact of Pain Initiative, but in 2018 we also had representatives on the Steering Committee of the Brain, Mind and Pain Grant. This Patient-Centred Innovation Grant has been initiated by Pain Alliance Europe and supported by Grünenthal the Group, with the main aim of encouraging patient-centred innovation having, as a result, the improvement of the living conditions of pain patients.

The first edition of the Grant was awarded to three projects (MyBrainNet, ASPERGA, Master Your Pain) in June 2018. The theme was "Overcoming problems in access to treatments".

The second edition of the grant 2019-2020 call for proposals will start 1 July 2019.

Patients, and the people associated with them, will know that there is a need to raise awareness of the social and psychological impact they will experience regarding the various aspects of living with chronic pain or neurological conditions.

The theme of the 2019-2020 grant is "STOP Stigma! Reduce stigma to improve quality of life for brain, mind, and pain patients." As an EFNA Board Member, I look forward to being involved again!

The BMP Grant team will be supporting innovative ideas designing new solutions to meet the need for a more understanding society.

More details on these groups, and our other external representation activities, can be found on the EFNA website.

MONIQUE LINDHOUT – BOARD MEMBER

I became an EFNA Board Member in 2016, representing the Stroke Association for Europe (SAFE).

As board member of both organisations, I always try to link the EFNA activities with those of SAFE and vice versa. I strongly believe that working together that way will strengthen all organisations involved in EFNA.

In November 2018 I presented the Stroke Action Plan for Europe during a meeting of the MEP Interest Group Brain, Mind and Pain at the EU Parliament, connecting this disease specific plan with challenges faced by all patients living with neurological disorders. The plan also includes consideration of the family, friends and others who provide support for people with the neurological disorder and whose own quality of life is potentially affected.

Within SAFE I always drew attention to EFNA's activities, asking SAFE members to give input into plans and projects and encouraging them to take part in some of the many activities EFNA has developed. I see this as one of the most important tasks of a board member: linking EFNA's activities at European level with those of its national members and ensuring that what EFNA does supports and aligns with its membership. Together we are stronger!

Finance & Governance →

A word from our Secretary-General

Jenny Baker, EFNA Secretary-General

Good governance matters in all organisations and sectors. But in non-profits like EFNA it is fundamental; our members, partners and associates, other stakeholders and the public will expect EFNA to 'be good', as well as to 'do good', to be accountable and transparent about our work and how we spend our money - and our impact.

In pursuit of our commitment to good governance, in 2018 the EFNA Board decided to supplement our new Statutes with new By-Laws. We updated existing policies and developed new ones – with a particular focus on compliance with the new General Data Protection Regulation GDPR(EU)2016/679. We also held a Strategic Review workshop with an external facilitator (Noemi Ambrus) to review our current strategic plan, Board roles and responsibilities, etc. All are available on EFNA's website.

A word from our Treasurer

Bea de Schepper, EFNA Treasurer

On behalf of EFNA, as Treasurer, I acknowledge support from the following corporate partners in 2018. Our relationships with all sponsors/funders are regulated carefully by our updated "Funding Statement" available here: https://www.efna.net/about-us/finance-funding/

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 – with a new structure in place for 2018. 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 2018 and our budget for 2019. For ease of reading, we have built the accounts around our central projects – on which the work of EFNA is based. VAT is included in costs/fees, where applicable. As you will see, we made a very small surplus in 2018, and the Board is committed to building our reserve in future years to ensure the sustainability of the organisation. Please do not hesitate to get in touch should you have any questions.

Once again, thank you!

ANNUAL ACCOUNTS 2018

EFNA Annual Accounts: result 31/12/2018

INCOME		EXPENDITURE	
Training and Capacity Building			
Merck Serono	20,000.00	Venue Costs incl. accommodation	25,345.58
MSD	16,666.67	Delegate/Speaker Travel Expenses	21,949.34
Biogen	20,000.00	Meeting Coordinator Costs	23,753.27
Teva	20,000.00	Other Training Costs	860.51
Ipsen	15,000.00	20% EFNA project management fees	18,333.33
Project Income	91,666.67	Project Expenditure	90,242.03
SUB-TOTAL SURPLUS/DEFICIT	**1,424.64**		
General Assembly incl. Participation at EAN Congress			
European Academy of Neurology	20,000.00	Accommodation	4,217.79
		Travel Expenses	9,829.18
		Promotional materials, equipment hire, etc.	150.90
		Exhibition Stand	3,126.69
		Catering	1,759.20
		Shipping	844.61
Meeting Income	20,000.00	Meeting Expenditure	19,928.37
SUB-TOTAL SURPLUS/DEFICIT	**71.63**		
Health Advocacy and Young People			
MSD	8,333.33	Communications Coordinator	39,710.70
Sanofi Genzyme	35,000.00	Advocacy Workshop	33,376.23
Novartis	40,000.00	Survey Costs - incl. dissemination	581.83
		Printing/Promotional Materials	50.56
		Planning Meetings	727.06
		Advocacy Awards	3,151.08
		20% EFNA project management fees	16,666.66
Project Income	83,333.33	Project Expenditure	94,264.12
SUB-TOTAL SURPLUS/DEFICIT	**-10,930.79**		
MEP Interest Group on Brain, Mind and Pain incl. neurology patient engagement in HTA research			
Teva	20,000.00	Senior Policy Officer	36,417.15
Grünenthal	25,000.00	Interest Group Meetings	16,498.31
Sanofi Genzyme	35,000.00	Policy Documents/Promotional Materials	4,471.52
Merck Serono	20,000.00	Planning Meetings	3,545.03
Novartis (HTA)	24,000.00	External representation: Policy	3,456.59
Merck Serono (HTA)	30,000.00	20% EFNA project management fees	26,360.00
Pfizer	15,000.00		
Roche (HTA)	30,000.00		
Mapping tool: deferred income	-67,200.00	Mapping tool amortizations	26,391.48
Project Income	131,800.00	Project Expenditure	117,140.08
SUB-TOTAL SURPLUS/DEFICIT	**14,659.92**		
Administration and Other			
Janssen	10,000.00	Fee of Executive Director	70,000.00
Membership Fees	3,300.00	Printing and Publishing Costs	622.24
Payment differences	5.20	Office Supplies	55.43
Exchange rate differences	1.71	Website	36.29
Other income	2,181.20	Teleconferences/Webinars/etc.	686.75
		Internet	224.99
20% admin fees received	61,359.99	Governance/Legal Fees	1,815.00
		Accounting Fees	6,670.04
		Membership Fees	1,367.64
		Shipping and Postage	6.66
		Equipment	26.26
		Other Overheads	539.63
Income	76,848.10	Expenditure	82,050.93
SUB-TOTAL SURPLUS/DEFICIT	-5,202.83		
TOTAL INCOME	403,648.10	TOTAL EXPENDITURE	403,625.53
ACTUAL INCOME (minus project management fees)	342,288.11	ACTUAL EXPENDITURE	342,265.54
OVERALL SURPLUS/DEFICIT 31/12/2018	22.57		

Thanks to the following companies who have supported us in 2018:

2019 – WHAT'S TO COME:

- Development of new policy documents: Book of Evidence, key messages and advocacy guide
- Organisation of associated advocacy workshop for neurology patient advocates
- 2 x MEP Interest Group meetings
- Promotional event in Strasbourg to engage incoming/returning MEPs in our work
- Joint meeting with EAN in the European Parliament
- Development of a multi-stakeholder coalition and strategy to engage with the global campaign on non-communicable diseases
- 2 x TINA workshops – on access and involvement, respectively
- Awareness campaign to be led by and focussed on young people affected by neurological disorders in Europe, themed around #BrainLifeGoals campaign
- Active participation at EAN 2019 – including special session, public day, exhibition booth, patient participation in scientific panels/committees, GA, etc.
- Ongoing external representation, engagement with and communication to members, partners and supporters
- Roll-out of strategic review and development of Strategic Plan 2020-2024
- Election of new Board Members and continued focus on good governance

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