EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

2020 ANNUAL REPORT

EFNA

EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

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The artwork on the front cover of this report is entitled 'In Water I am Free' and is by Melanie Hobday. This was one of the runners-up in EFNA's #BrainLifeGoals art competition. Read more about the competition on page 20.

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A MESSAGE FROM EFNA'S PRESIDENT

2020 started on a positive and optimistic note.

On February 18th, we organised a meeting in the European Parliament entitled: "Brain health as a global priority – Time for the EU to start now". As reported in last year's Annual report, we had stepped beyond Europe because we had realised that EU priorities were being guided by those at an international level. We needed to ensure that neurology was not overlooked, and that this would translate into prioritisation and action at EU level. So, with this event, we began our journey into the international setting.

The room was packed with over 100 people, among which a significant number of MEPs. With high level speakers from the European Commission, World Health Organisation and Global Public Health NGOs – this became a memorable event, which was followed by a workshop with many of the key stakeholders that very same afternoon where we started preparing for the remainder of 2020...

And then there was Covid-19.

Everything shut down. And when, after a couple of weeks, we could only conclude that we needed to be resourceful and start working within the virtual reality all of us found ourselves in, we pushed ahead with our advocacy efforts at accelerated speed!

Going back into my 2020 agenda, and as you will read in this report in detail, the world discovered Zoom and the number of meetings steadily increased: Team meetings, Board meetings, Covid webinars, our MEP Interest Group conference, new e-learning modules; the beginning of the OneNeurology Initiative and so much more… we look back on an exceptionally productive year!

All of this work was possible thanks to our dedicated team, Board Members and sponsors – as well as the commitment of our members and partners. Thank you all for your support in 2020. We look forward to continuing to work together in the years to come, in which it will become increasingly important for all of us to speak with one voice.

Do get in touch should you require more detailed information on any part of our work. We value your interest and we hope you'll enjoy this report.

Joke Jaarsma
EFNA President

EFNA MEMBERS

BOARD MEMBERS 2020

Joke Jaarsma
President
European Alliance for RLS

Cathalijne van Doorne
Vice-**President**
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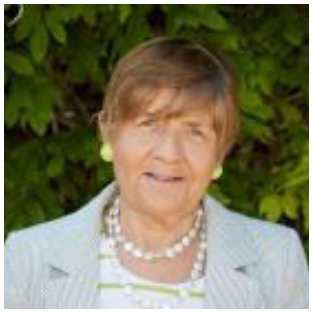

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Klaus Knopps
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STAFF 2020

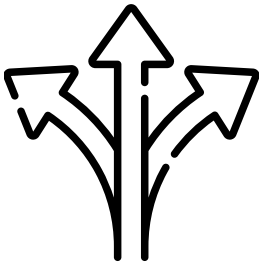
Donna Walsh
Executive Director

Tadeusz Hawrot
Senior Advocacy Coordinator

Elizabeth Cunningham
Communications Manager

SUMMARY OF 2020 ACTIVITY

Work hasn't stopped because of Covid. In fact – it's been busier than ever! So, scroll down to see some highlights from what's been happening this year and then, if interested, flick through the report for more details...



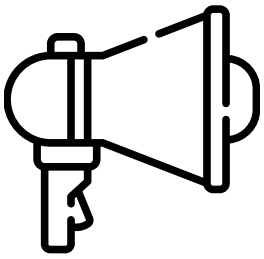
A NEW DIRECTION...

In the early part of 2020, governance and strategy took a front seat for EFNA, with work underway on an **updated Constitution** to ensure full compliance with new Belgian legislation. This coincided with the creation of EFNA's **new Strategic Plan** 2020-2025, which was approved by a virtual meeting of our General Assembly in May.

EFNA also organised **two webinars on the topic of Covid-19**, the first exploring the impact of Covid on the neurology community and the second focusing on how we can advocate to ensure the challenges and opportunities faced by our members are addressed. These high-level webinars included representatives from the World Health Organisation, European Commission and well-known advocacy groups. We've got recordings available if you missed them!

EFNA is also the only patient organisation represented at the global **Neuro-Covid Forum** of the World Health Organisation and is actively participating in the working group on the continuation of essential services. We've also been working with our colleagues at the European Academy of Neurology to capture the views of our members of the impact of Covid-19 via **surveys**.

Of course, we have also been actively representing our membership in virtual meetings, events and consultations to ensure the voice of neurology patients is heard during and after the pandemic.



RAISING AWARENESS...

#BRAINLIFEGOALS CAMPAIGN

Our **#BrainLifeGoals awareness campaign** continued this year. The focus in 2020 has been 'Stigma' and during Brain Awareness Week in March we launched a **major survey** to identify how and when the neurology patient community experiences **stigma**. With over 1,300 responses, this eye-opening survey will inform our work on this topic in the years to come. The results of the survey were published on World Brain Day.

Following on from the survey results, we launched a call to collect examples of best practice in 'Action on Stigma'. Selected projects will receive the **EFNA Advocacy Award** in 2021!

Also, as part of the campaign this year, EFNA's #BrainLifeGoals **grants scheme saw 10 projects receive funds of €3,000 each** to support their work on the topic of 'access'.

We announced the winners of our **Photo Competition** in January and, to finish the year, we launched our Art Competition – the winners of which grace the pages of this report!

CONTINUED ADVOCACY...

MEP INTEREST GROUP ON BRAIN, MIND AND PAIN

Unfortunately, the **MEP Interest Group on Brain, Mind and Pain** was unable to meet in 2020. However, we took this opportunity to review our approach. A steering committee, with support from Weber Shandwick, performed a **landscape analysis** to assess policy challenges and opportunities in the public health sphere – which has changed due to the pandemic. The group approved a two-year **Roadmap to Action** which was launched at a **virtual meeting** of the Interest Group on November 10th.

MAKING NEUROLOGICAL HEALTH A GLOBAL PRIORITY

Building on meetings with the World Health Organisation in 2019, this year EFNA really stepped up efforts to push for neurological health to become a global priority.

This started with a **meeting at the European Parliament in February**, which had the patronage of influential MEPs from across the political spectrum. We also enjoyed high level participation in a full plenary room – including a presentation from the Director of WHO's Department on Mental Health, Substance Use and Neurological Disorders.

Following this event, **a multi-stakeholder workshop** was convened to discuss how we can advance neurology as a public health priority. The outcome was a call for coordinated action. So, throughout the summer, with the help of a Communications Consultant and a Policy Specialist, we worked hard on our **advocacy messaging and strategy**. A two-year strategy, along with an associated advocacy toolbox, was then launched at a **virtual working conference** on November 27th.

EFNA has also written a number of **open letters and articles** on this topic in 2020.

ONLINE CAPACITY BUILDING...

TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES

Unable to host our planned face-to-face workshops, EFNA built a **series of e-learning modules** that were launched in November 2020 and focused on 'effective advocacy in a virtual world'.

Our planned workshop at '**The Power of the Patient-Physician Partnership**' became a **virtual session** during our General Assembly and the outputs will now be taken forward as part of a joint EFNA-EAN Taskforce on Patient Involvement.

AND LOTS MORE...

PUBLICATIONS

In 2020, EFNA published two position papers spinning out of our Training Initiatives for Neurology Advocates workshops in 2019. These focused on:

- Optimising patient involvement in neuroscience research
- Advocating for access to treatment, services and support

EXTERNAL REPRESENTATION

We have maintained our ambitious programme of external representation – even if now virtual!

Check out the list on page 26.

COVID

"I have had MS for many years. Decreased cognition is one of my main symptoms. MS is different for everyone. For me, next to my cognition problems I also have difficulty walking. Sometimes I can't find the right words, I also forget a lot. My brain feels like a maze in which I continuously am searching for the right direction."

Danielle Sysmans, Belgium

COVID

Like so many patient organisations, a new workstream was added to the EFNA activities in 2021. This, of course, was addressing the impact of Covid-19 on our community.

RESOURCE HUB

As a first step, EFNA created a Covid-19 Resource Hub on our website – aggregating neurology disease specific information from amongst our member organisation. We also included the latest scientific data from our colleagues at the European Academy of Neurology, World Health Organisation, etc.

WEBINARS

EFNA also organised a series of webinars to discuss the impact of Covid-19.

The first was entitled: **Covid-19 – Shaping the future of neurology advocacy.** Through this webinar we aimed to collect the concerns and recommendations of our members and partners to influence our future advocacy actions in line with our three themes of:

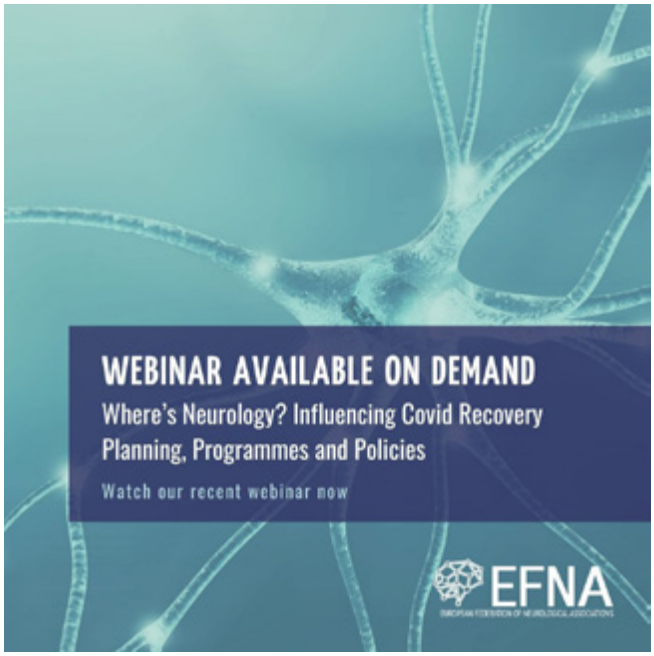
- **Fighting stigma, isolation and discrimination**
- **Ensuring equitable access to treatment, services and support**
- **Promoting patient empowerment for more meaningful involvement and engagement**

Participants shared their experiences and expertise as we discussed how we shape our future neurology advocacy to best support our community during and after the Covid-19 pandemic.

As a follow-up to our first webinar, EFNA organised a second virtual event entitled: **'Where's Neurology? Influencing Covid Recovery Planning, Programmes and Policies.'**

Here, we brought together a fantastic line-up of speakers from the World Health Organisation, Non-Communicable Disease Alliance, European Commission and Parliament – as well as colleagues from the global patient advocacy community.

We discussed how they are planning to support those affected by neurological disorders in the months ahead, but also gathered their thoughts on what we can do – as the neurology patient community – to ensure that our voices are heard loud and clear in influencing their agendas and plan.



Following these events, EFNA produced an initial statement on the impact of Covid-19 on those affected by neurological disorders – with recommendations for policy-makers.

This statement will be updated in 2021 as new evidence becomes available. EFNA was involved in generating data via two collaborations:

SURVEYS

Firstly, we worked the European Academy of Neurology on a survey to better understand how care pathways were reconfigured for the neurology patient community during the first wave of the pandemic. However, more importantly, we want to capture recommendations to ensure that any future changes to service delivery are made in the interests of the patients – rather than, solely, in the interests of the healthcare system. This will result in a published paper.

Secondly, EFNA was invited to join the **WHO's NeuroCovid Global Forum** where we actively participation in the Essential Services working group. Here, EFNA led the dissemination of a survey to gather feedback on disruption to neurology services globally and the mitigation actions that were put in place to address this.

ADVOCACY

"For many years I suffered terrible basilar migraines which totally disrupted my life. As well as headaches and sickness I experienced fragmentation of vision, twinkling, pulsing of colours and shapes, overlaying of images and my vision becoming two dimensional or 'flattened'.

Through a series of chance opportunities I met researchers in visual disturbance and learnt more about them and their impact on my artwork. In fact I was told my paintings displayed migraine aura many years before I began to experience migraine. I discovered my choice and distribution of colours were actually causing photosensitivity and break-through migraines on top of hormonal ones. I didn't realise that I was painting the 'twinkling, pulsing' aura effect in my work. I was fortunate to collaborate with experts in 'migraine art' and discover how I could paint, use the colours I love and not trigger migraines.."

Debbie Ayles, United Kingdom

MEP INTEREST GROUP ON BRAIN, MIND AND PAIN

LANDSCAPE ANALYSIS AND UPDATE OF POLICY DOCUMENTS

Due to the travel and meeting restrictions in 2020, EFNA was unable to organise its face-to-face MEP Interest Group meetings. However, this gave us the time to take a step back to review the structure of the Interest Group, but also to think about the impact of Covid-19 and our advocacy work moving forward.

Repurposing our funding, EFNA engaged Weber Shandwick to come on board and to conduct a landscape analysis of the current trends in the area of EU public health, as well as surveying our members on what was now most important for them. The result of this work culminated in the creation of appendices to our central policy document – the Book of Evidence, but also a draft Roadmap to Change which laid our a new strategy and direction for the Interest Group moving forward.

These were presented and discussed at a virtual meeting – replacing the face to face parliamentary events which had been planned.

MEP INTEREST GROUP VIRTUAL MEETING

On 10 November 2020, the MEP Interest Group on Brain, Mind and Pain (BMP) organised a virtual event on the future of BMP advocacy. Given the current context, which is increasingly impacting the healthcare policy landscape, the main objective of the event was to identify and leverage public health priorities and actions for those affected by neurological and chronic pain conditions.

The event also sought to provide an overview of the Interest Group's new policy direction, and was an opportunity to launch a set of appendices to update the group's central policy document – the Book of Evidence. It also aimed to gather feedback on its Roadmap to Change, which is a plan for action for the next two years.

The virtual meeting brought together key stakeholders from the BMP community, other disease specific groups and relevant third-party organisations. High level policy makers also attended, including: Dr Bente Mikkelsen – World Health Organization, Mr Stefan Schrek – European Commission, Katarzyna Ptak – European Commission, MEP Isabel Wiseler-Lima (Luxembourg, EPP), MEP Cristian Busoi (Romania, EPP), MEP Tilly Metz (Luxembourg, Greens/EFA) and MEP Marisa Matias (Portugal, GUE/NGL). MEP Sirpa Pietikäinen (Finland, EPP) and MEP Kateřina Konečná (Czech Republic, GUE/NGL) also shared their input and sent video messages.

The opening plenary was an opportunity to better understand and discuss the place of BMP disorders in non-communicable disease policy, as well as their position within the EU health and research priorities post-pandemic. Following this session, three parallel breakout sessions took place that allowed for more interactive discussions focusing on the core themes of the Interest Group: stigma, access and patient empowerment.

You can read more about the key takeaways at the website: www.brainmindpain.eu

Based on the feedback received during the event, the BMP Interest Group has finalized the Book of Evidence appendices, as well as the Roadmap to Change, which are now also available on the website.

Additionally, as part of its Training Initiatives for Neurology Advocates [TINA], EFNA launched its first e-learning module at the event: 'EU Advocacy for the BMP Community'.

This provides an overview of how the EU institutions work, how patient groups can influence policy-makers of get involved on EU level. You can download this module at: www.efna.net/elearning and you can read more about this new platform on page 23.

ONGOING EU ADVOCACY

A REPORT FROM TADEUSZ HAWROT, EFNA SENIOR ADVOCACY COORDINATOR

2020 was a critically important year for EFNA due to EU negotiations on the next EU health programme 2021-2028. Against the backdrop of Covid-19, the EU4Health Programme received an unprecedented 11-fold budget increase as compared to its predecessor.

To ensure neurology was featured prominently, EFNA organized a number of parliamentary meetings with the involvement of DG SANTE, hosted personal meetings with SANTE officials, sent open letters and, even, issued a Parliamentary Written Question. However, despite this activity, in its initial legislative proposal, the European Commission did not include neurology as one of the NCD priority areas. Therefore, we concentrated further on engaging with the two: the European Parliament and Council. Eventually, we were successful in mobilizing the Members of the European Parliament which resulted in circa 20 parliamentary amendments to the EU4Health proposal, adding neurology as a priority area. We have been equally successful in securing the necessary amendments from the 27 EU member states, all of whom we addressed on several occasions with formal letters and informal approaches. As a result, the final text of the EU4Health Programme now lists neurological disorders alongside other major NCDs: cancer, cardiovascular diseases, respiratory diseases, diabetes and mental health. This is a major breakthrough for the neurological community.

In our advocacy, we have been helped by the timely publication of the European Academy of Neurology's study, which provided much-needed data on the disease burden of neurological disorders in Europe, reporting that they are the 3rd leading cause of death and the 3rd leading cause of Disability-Adjusted Life-Years (a combination of disability and mortality) in Europe.

Throughout the year, EFNA has been actively engaging in civil society initiatives. We are members of the EU Health Coalition as well as the EU4Health Civil Society Alliance. Additionally, we participated in health-related initiatives and virtual meetings organized by organizations like the European Patient Forum, European Chronic Disease Alliance, Patient Access Partnership, Science Business, EFPIA, ECPC's cancer comorbidities initiative, European Public Health Week, POLITICO Healthcare Summit, and many more!

One of the outcomes of note from our external representation took place at a hearing of *the expert panel on effective ways of investing in health*, regarding its opinion: "The organisation of resilient health and social care following the covid-19 pandemic". Following our oral and written interventions, neurology was added to the document.

We also continued with our involvement in the EU project CHRODIS +.

In terms of specific consultations, EFNA:

- **Contributed to the Patient Access Partnership (PACT) joint statement on COVID-19 – Leaving no-one behind, now and in the future.**
- **Coordinated input to the EU project led by EBC: Shared European Brain Research Agenda**
- **Contributed to EPF's Response to the EU's Beating Cancer Plan Public Consultation**
- **Submitted amendments proposals to the EU4Health legislative proposals**
- **Submitted a statement to the WHO European Programme of Work**

We continued with our monthly Policy Bites newsletter - a resource for EFNA members (and their members) with a focus on important policy developments in our field. Additionally, we launched a new section on EFNA's website with editorial pieces on various policy developments relevant to EFNA: https://www.efna.net/category/advocacy/.

ONENEUROLOGY: MAKING NEUROLOGY A GLOBAL PUBLIC HEALTH PRIORITY

2020 timeline

January

EFNA joins the NCD Alliance.

EFNA meets with the WHO Rehabilitation Team and nominates patient representatives to its taskforces on TBI and PD.

Preparations for the WHO Executive Board (EB) meeting: EFNA develops a brain health concept note calling for the inclusion of other neurological disorders in discussions on epilepsy. This is circulated to all EB members, and followed by calls with selected Geneva missions.

EFNA works closely with IBE and ILAE on its advocacy in relation to its push for a resolution on epilepsy and other neurological disorders – acknowledging their crucial efforts on the global stage.

February

EFNA participates in the NCD Alliance global forum in Dubai.

Success! WHO EB Decision requests WHO to expand the scope of its technical report on epilepsy by adding a new section on "synergies in addressing the burden of epilepsy and other neurological diseases".

EFNA orchestrates a meeting in the European Parliament with support from EAN and EBC: "Brain Health as a Global Priority – time for the EU to act now". Read more below.

This resulted in an editorial in Lancet Neurology!

EFNA organizes a multi-stakeholder workshop to discuss how the neurological community can better join efforts internationally.

March

EFNA submits feedback as part of consultations on the WHO Mental Health Plan.

April

With Covid-19 having now put most of Europe into lockdown, EFNA starts to build its advocacy actions to better understand the impact and mitigation actions needed.

May

Success! WHO publishes a report on "Synergies in addressing the burden of epilepsy and other neurological disorders" – featuring 5 pages discussing neurology specifically.

June

EFNA joins the WHO's Neuro-Covid Global Forum.

EFNA provides feedback at the WHO Europe briefing on WHO European Programme of Work.

July - August

EFNA engages a Communications Consultant and a Global Public Health Policy Specialist to advance its global advocacy ambitions.

WHO Brain Health team takes shape and the official WHO Brain Health website is launched – EFNA meets with Dr. Tarun Dua, head of this new unit.

EFNA joins a new NCD Alliance network: PLAN – focusing on an inclusive NCD agenda, where we present our policy work on neurological health to the global community.

September

EFNA takes part in WHO public consultations on Mental Health Global Action Plan.

EFNA takes part in the UN General Assembly side event on brain health.

Start of informal consultations among WHO member states on a resolution on Epilepsy and its neurological synergies to be approved at the World Health Assembly (WHA) in November. EFNA teams up with EBC and EAN and sends letters to missions calling for support to place neurology centrally in the Resolution.

October

EFNA develops a memo on "Neurology - an overlooked NCD with the highest toll" and distributes it to WHO member states. Engagement intensifies with approaches to nearly 70 health attaches in Geneva UN missions. As a result, a number of follow-up calls are scheduled in the following weeks.

November

Success! WHA adopts a renamed resolution: "Global Actions on epilepsy and other neurological disorders". Out of 38 formal co-sponsors, there are all 27 EU member states. The Resolution requests development of a 10-year Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders.

EFNA organizes a working conference on making neurology a global public health priority. Read more below.

December

EFNA celebrates a great year and begins preparations to launch its OneNeurology Initiative with its global partnership in 2021!

Throughout the year, EFNA representatives took part in various virtual meetings organised by NCD Alliance and WHO as part of the NCD Hard Talks series. This included:

- **WHO event on NCDs & COVID-19**
- **WHO NCD Biggest Burden, Where's the Money?**
- **WHO building back better after COVID-19: The research agenda**
- **UN General Assembly side event**
- **World Health Summit**
- **WHO-NCDA leaving no-one behind- the need for a person-centred, inclusive NCD agenda**
- **WHO Global Coordination Mechanism NCDs**

And many more!

PARLIAMENTARY WRITTEN QUESTION

With support from 17 MEPs, EFNA submitted a Parliamentary Written Question on January 23rd.

The question called for the European Commission to acknowledge the burden of neurological disorders and to see better integration of neurology within the Commission's portfolio of work on non-communicable diseases (NCDs). It also called for the development of a unified EU brain health strategy.

Unfortunately, the response received from the Health Directorate, DG Sante – on April 22nd – effectively confirmed that there is no coordinated effort to address neurological health from a public health perspective at EU level.

SANTE also confirmed that there are no plans to include neurology in the work of its Steering Committee on Health Promotion and Prevention on Non-Communicable Diseases – even though it is recognized at the global level as the 5th main NCD (along with mental health).

With this in mind, EFNA organised a series of external and internal meetings with the European Institutions over 2020 to ensure that neurology was featured in the new EU4Health programme – see updates below.

MEETING AT THE EUROPEAN PARLIAMENT - *FEBRUARY*

To capitalise on the global prominence of neurology, EFNA – along with the European Academy of Neurology and the European Brain Council – organised a meeting at the European Parliament on February 18th.

The meeting was entitled: "Brain Health as a Global Priority – time for the EU to act now" and was attended by more than 100 participants from leading organisations in the field of brain health. It brought together policymakers, clinicians, scientists, healthcare companies, patient advocates and carers to share knowledge and perspectives on brain health and urge the EU to act on this issue.

The event was hosted by MEP Jaroslaw Duda, under the patronage of five members of the European Parliament across five different political groups:

- **Ewa Kopacz, Vice President of the EP, European People's Party [EPP]**
- **Miriam Dalli, Vice-Chair, Group of the Progressive Alliance of Socialists and Democrats [S&D]**
- **Frédérique Ries, Vice-Chair, Renew Europe [Renew]**
- **Kateřina Konečná, European United Left–Nordic Green Left [GUE/NGL]**
- **Tilly Metz, Group of the Greens/European Free Alliance [Greens - EFA]**

Speakers included: Dr Dévora Kestel, Director of Mental Health and Substance Use at WHO and Mr John Ryan, Director of Public Health, Country Knowledge and Crisis Management, DG Santé.

The meeting heard the latest statistics from the Global Burden of Disease Study, highlighting how neurological disorders are the leading cause of disability worldwide, and the second leading cause of death.

Later presenters highlighted the global trends mentioned above, and how these could be leveraged at EU level. Some concrete examples from the field were also discussed; including successful global advocacy work on epilepsy and national efforts to create a Norwegian Brain Plan.

The event made for a clear and strong signal to EU policy makers that our efforts need to be urgently stepped up. The event's co-patron and Vice-President of the Parliament Ms. Ewa Kopacz said "*We need to act fast and we need to act together!*"

High-level representatives from the European Parliament, European Commission and EU Presidencies also reiterated opportunities for this international activity to be reflected in EU initiatives.

At the meeting a Call to Action prepared by organizers and endorsed by supporting MEPs was announced. The document calls for EU policy makers to acknowledge and use latest data on burden of brain disease, give a higher priority to neurology as well as brain as a whole, develop European and national plans addressing brain health and sustain adequate level of brain research.

In the afternoon, a workshop was convened with invited participants to begin planning an advocacy strategy for neurology in the context of these new opportunities.

VIRTUAL WORKING CONFERENCE - *NOVEMBER*

A few weeks after a critical milestone for the neurology community, with the adoption – by the World Health Assembly – of the resolution on Global Actions in Epilepsy and Other Neurological Disorders, 60 invited participants attended this virtual working conference on November 27th.

This meeting, entitled **Making Neurology a Global Public Health Priority – An advocacy roadmap for change**, was organised jointly by the European Federation of Neurological Associations [EFNA] and the European Academy of Neurology [EAN] – in partnership with the European Brain Council [EBC].

It was also well supported by the World Health Organisation through the involvement of ADG, Access to Medicines and Health Product, Dr Mariangela Simao and Head, Brain Health Unit, Dr Tarun Dua.

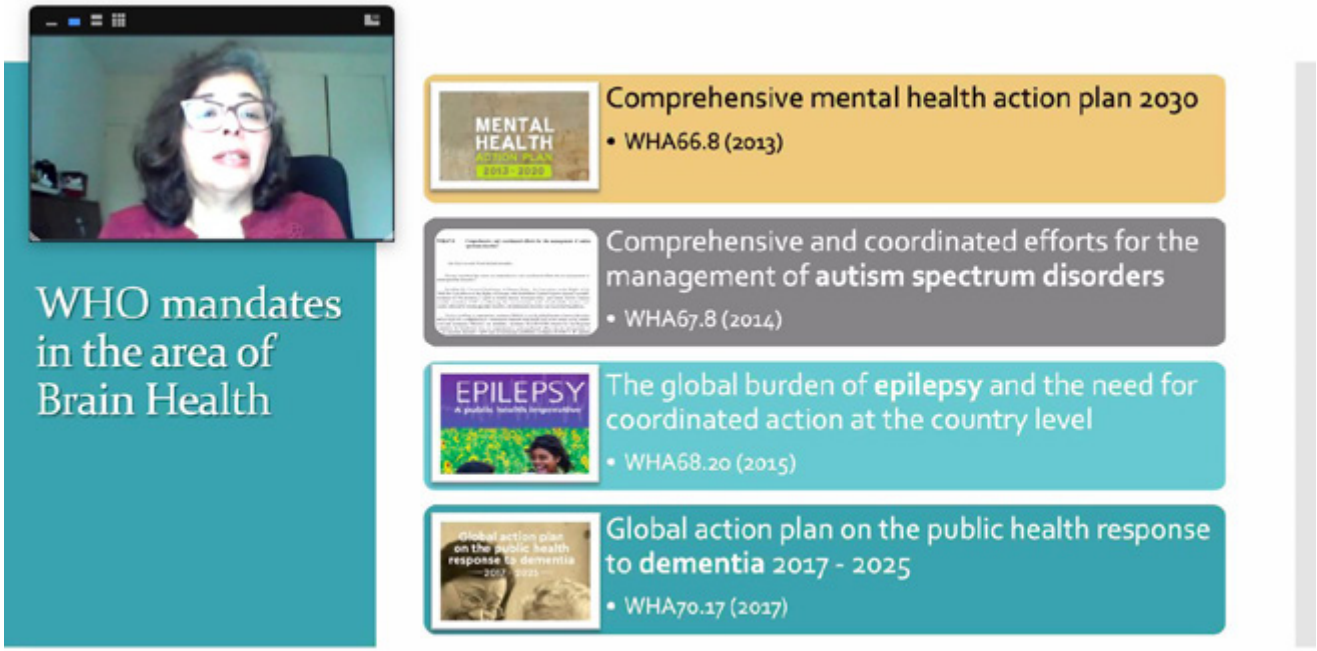
All the discussions converged towards a significant conclusion: The current policy momentum at global level for neurology – in line with an increased awareness of neurological disorders, their prevalence, burden, etc. – represents a critical opportunity for the neurology community. We must unite, coordinate and be ready to collaborate with WHO and policy-makers worldwide to build an integrated response to neurology across the life course within healthcare systems to improve patients' lives.

This could be made possible through the development of a new 10-year intersectoral Global Action Plan on Epilepsy and other Neurological Disorders as called for in the aforementioned resolution.

Presentations were made on behalf of the National Health Ministries of Iceland and Russia – via Dr. Anna Lilija Gunnarsdóttir and Prof. Alla Guekht – outlining the process and the opportunities for us to influence this work.

The cornerstone of the workshop was the presentation of a proposed strategy to make neurology a global public health priority. This strategy focuses on building a multi-stakeholder umbrella initiative representing the neurology community through a single voice, developing an integrated response to neurology and leveraging the advocacy momentum at all levels: global, regional and national.

This was how the OneNeurology Initiative was conceived. Look out for exciting developments ahead!



"It is important that we take an integrated approach as there are synergies between the neurological disorders."

Dr. Tarun Dua, WHO Brain Health Unit.

AWARENESS

"Just one of the many symptoms of the complex debilitating condition known as ME is cognitive impairment. It often feels like my brain is a wall of marshmallow and the thoughts that I have and the words I want to speak are somewhere right at the back behind it all and they are all jumbled."

Stacy Hart, United Kingdom

#BRAINLIFEGOALS

The #BrainLifeGoals campaign is an initiative that aims to raise awareness of the impact of neurological disorders. Kicking off in 2019, the campaign continued in 2020 with the activities listed below:

GRANTS SCHEME

EFNA once again provided grants to support work on one of our chosen advocacy themes. In 2020, the focus was on: Ensuring Equitable Access to Treatment, Services and Support for Neurology Patients and their Carers.

Access to treatment is one of the central #BrainLifeGoals of many neurology patients, and we wanted to help make that a reality across Europe! EFNA provided 10 grants of €3,000 each to selected organisations, working to address this theme.

26 applications were received from across Europe, all featuring exciting projects.

We were delighted to announce that the following organisations and their projects were chosen as #BrainLifeGoals Project Grant recipients in 2020:

#brainlifegoals

PROJECT GRANTS 2020

+ **Dystonia Europe**
#JumpforDystonia2020

+ **ADHS Deutschland e.V.**
Raising Awareness about Undiagnosed ADHD in Women

+ **European Huntington Association**
Healthe-rnd communication

+ **The Brain & Spine Foundation (UK)**
#BrainCareNow

+ **Neurological Alliance Of Ireland**
Making Our Asks A Reality' – A Three part Documentary Series

+ **EPIONI – Greek Carers Network**
Caring for Carers: Access to services and support for family caregivers

+ **European Parkinson Disease Association (EPDA)**
Awareness Initiative for Healthcare Professionals

+ **ADHD Ireland**
ADHD Understanding for Educators

+ **Federacion Espanola de Parkinson**
Training programme for engagement in research

+ **Hellenic Alliance/Action for Stroke**
FAST 112 HEROES: Patient engagement in educational stroke awareness for kids in the Greek language.

SURVEY ON STIGMA AND NEUROLOGICAL DISORDER

Eradicating stigma is also a major #brainlifegoal of many within the neurology community.

Therefore, in 2020, EFNA carried out a survey to better understand how those affected by neurological disorders perceive stigma, where it is most felt and what can be done.

1373 responses to the survey were received from 37 countries. Responses came from a diverse range of neurological conditions, with the greatest numbers coming from the areas of Myalgic Encephalomyelitis (ME), dystonia, migraine or headache and chronic pain. The results were published to mark World Brain Day 2020.

92% of respondents report feeling affected by stigma on account of the neurological disorder they live with. Lack of understanding is seen as the biggest cause of this, followed by myths/misconceptions about these disorders and their invisible nature.

74% felt they did not receive adequate treatment because a medical professional did not believe the severity of their symptoms.

35% have avoided seeking medical advice because they felt embarrassed.

The issue of stigma has proved most problematic during interactions with medical professionals. 74% felt that a medical professional did not believe the extent or severity of their symptoms and the same percentage feel they did not receive adequate or appropriate treatment because a medical professional did not take them seriously.

Stigma is also prevalent within families and in social situations. 49% say their families sometimes make them feel that they exaggerate their condition and, sadly, 32% of respondents with children have been made to feel that they are inadequate parents.

Almost half of respondents who lived with a neurological disorder during childhood found it difficult to make friends or maintain friendships at school, and a similar number were excluded from school events on account of their condition.

The full results can be found in a report on the EFNA website.

Building on this stigma focus, EFNA also launched its Advocacy Awards 2021 on this theme with two categories; one for individuals, and the second for organisations.

32% have been made to feel they are inadequate parents

Over 30% have been denied insurance or a mortgage on account of their condition

ADDITIONAL AWARENESS RAISING

Also on World Brain Day, we invited our members, sponsors, health professional colleagues and other stakeholders to tell us why goal-oriented healthcare is so important.

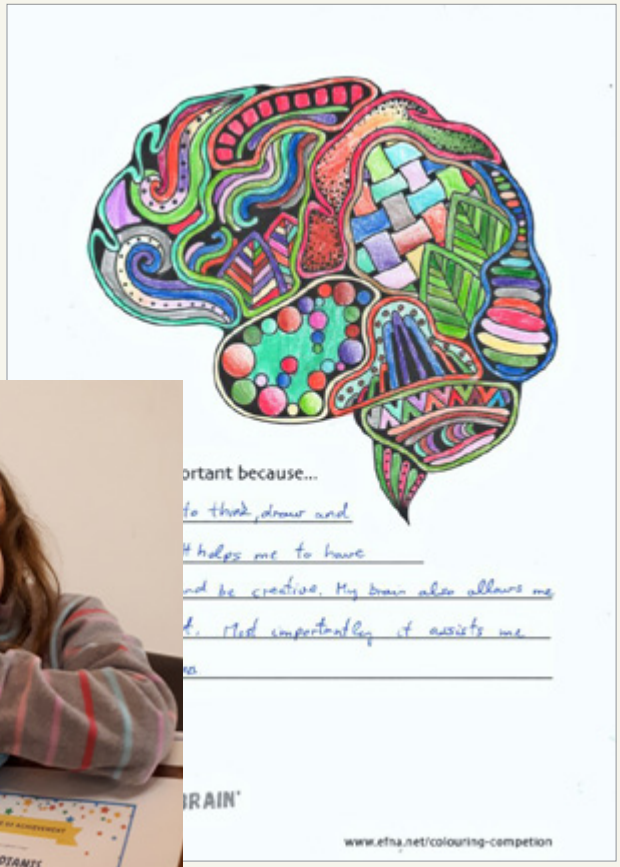
Patient advocates were encouraged to participate by sharing their own health and healthcare goals on social media alongside the #BrainLifeGoals hashtag. A toolkit was prepared to encourage people to get involved – including sample social media posts, graphics and a poster.

We arranged for video testimonies to be produced and shared with many of our member groups.

ART COMPETITION

During Autumn 2020, EFNA ran a competition on the theme 'Me and My Brain'. The public were invited to create a drawing, painting, collage or digital illustration representing their relationship with their brain, through artwork that explores their hopes, frustrations, or the day to day impact a neurological disorder has on their life.

83 artworks were received from across Europe. Our judges were extremely impressed by the artistic skill demonstrated and also moved by the meaningful nature of the works and their accompanying stories. A selection of entries have been used throughout this report and the full gallery of entries can be found on the EFNA website.



Alongside this EFNA ran a colouring competition for younger children. As well as colouring in an illustration of the brain, our young participants were asked why their brain is so important. On the right you can see the winning entry by Szofia Dianis (6), from Hungary, alongside a photo of Sofia with her prizes!

50,000+

TWITTER IMPRESSIONS MONTHLY

SPREADING THE MESSAGE

Social media continues to be a great way to share news and raise awareness of EFNA, our partners and members. Both Twitter and Facebook posts typically reach over 50,000 views in a month. Engagement with content is high, with a rate of 5.3% for LinkedIn content.

A GROWING FOLLOWING

EFNA's social following continued to increase in 2020. Twitter remains our most popular platform with almost 3,800 followers. Facebook has almost 2,000, while our newer accounts of Instagram and LinkedIn have about 600 followers each.

3,700+

TWITTER FOLLOWERS

3,000+

WEBSITE USERS MONTHLY

HOMEPAGE IS WHERE THE HEART IS

EFNA's website traffic has increased in the past year, with an average of 3,284 users monthly. 31.6% were returning users. Visitors to the website spent an average of over 2 minutes on the website each visit.

YOU'VE GOT MAIL

Of our 921 newsletter subscibers, an impressive 29% are classified as 'highly engaged', meaning they regularly open our emails and follow links.
EFNA sent 24 newsletters in 2020 - a mix of the EFNA Ezine, Policy Bites and special notices.

900+

NEWSLETTER SUBSCRIBERS

85+

ELEARNING PLATFORM USERS

LEARN SOMETHING NEW EVERYDAY

Since its launch at the end of 2020, upwards of 85 individuals have registered for EFNA's eLearning platform. Module 1 has 67 users, Module 2 has 18 and Module 3 has 59.

Follow us!

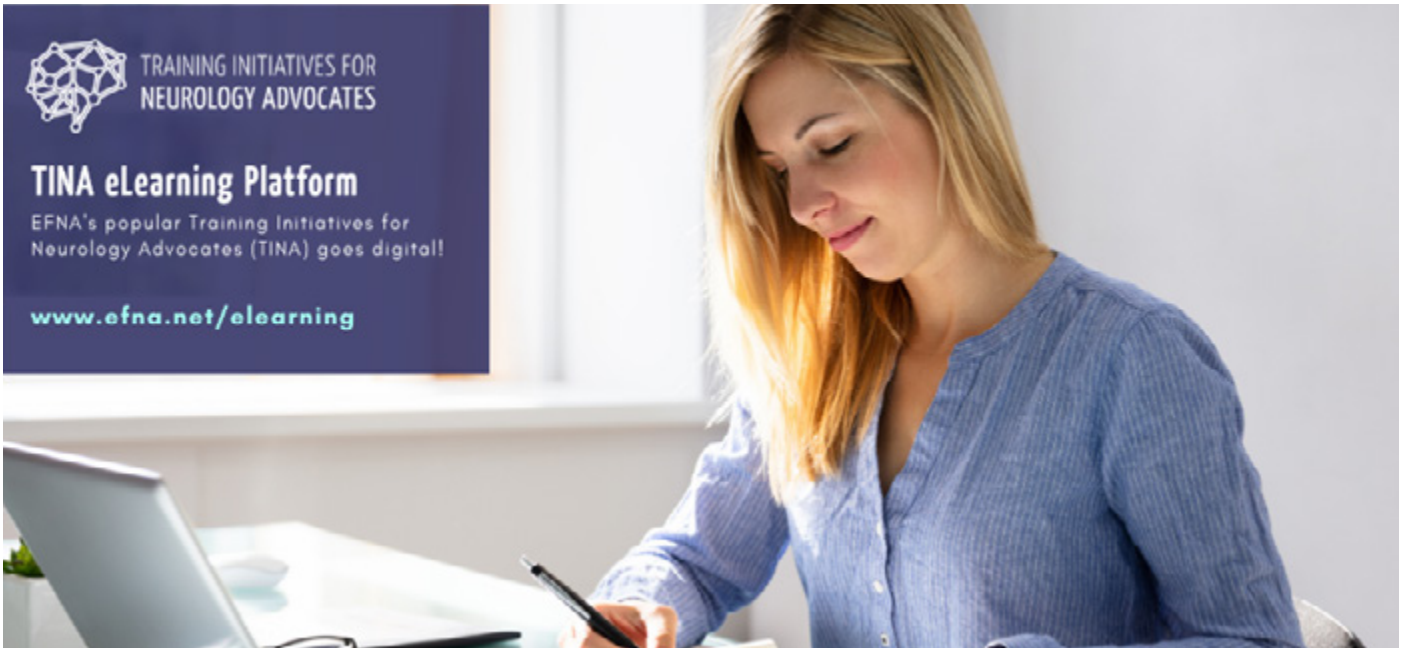
Twitter: @EUneurology
Facebook: /efna.net
Instagram: @EUneurology
LinkedIn: /company/efna

EMPOWERMENT

"Invisible me
brain, unreliably trying
loving you anyway
showing life's beauty
giving me hope
learning to enjoy life.
focusing on what I can."

Nancy Van Hoylandt, Belgium

TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES [TINA]



E-LEARNING PLATFORM

In 2016, EFNA launched its Training Initiatives for Neurology Advocates [TINA]. As part of the initiative, training and capacity building meetings have been held annually at both pan-European and National level.

Travel and meeting restrictions due to the Covid-19 pandemic make EFNA's training and capacity building meetings difficult to organise face to face in the short term. However, the pandemic has shown us that virtual solutions can be not only effective but also more inclusive – allowing the participation of patient advocates who can not easily travel to events. The pandemic has also accelerated the need to add capacity to patient organisations in terms of their skills in the online space.

For these reasons, in 2020, EFNA developed a pilot series of e-learning modules linked to our advocacy activities. These courses aim to upskill participants on how they can effectively advocate in a virtual world by identifying and engaging key stakeholders and developing partnerships, hosting successful online events and developing and disseminating key advocacy messages.

The courses are video-based and divided into sections that can be watched independently at times that suit the viewer. Each module includes supporting notes and worksheets, as well as the option to take a quiz on the content and receive a personalised certificate of completion.

To date, over 80 participants have registered for the e-learning modules.

You can check them out for yourself via the EFNA website at www.efna.net/elearning.

TINA POSITION PAPERS

EFNA published two position papers arising from our 2019 TINA workshops.

These papers captured the discussion which took place at the workshop, as well as outlining the recommendations for action. These are important outcomes from TINA as they highlight the interactive and mutual learning elements of these events. The position papers can be downloaded now from the EFNA website's Publications section.

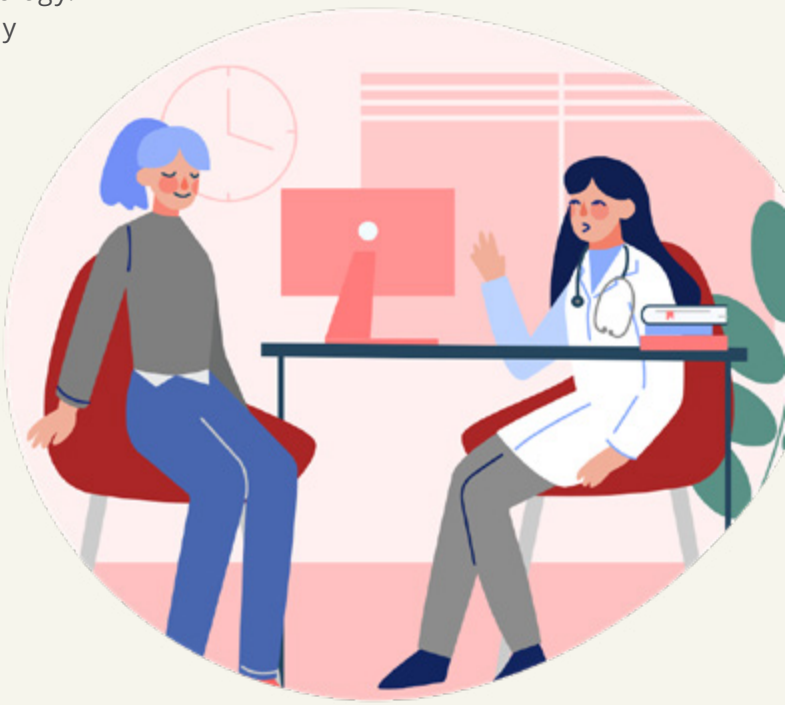
Above: EFNA Position Papers published in 2020

POWER OF THE PATIENT-PHYSICIAN PARTNERSHIP

Unfortunately, EFNA cancelled its planned workshop on the power of patient-physician partnership, which was scheduled to take place at the annual congress of the European Academy of Neurology.

Instead, a virtual workshop was organised as part of our online General Assembly programme. This sought to discuss, more specifically, patient involvement in the scientific panels at the European Academy of Neurology. The workshop was moderated – pro bono by Kathy Redmond of Redmond Consulting.

The recommendations made have now been taken up by EFNA and will be used to create a set of terms of reference in which this ongoing engagement is framed.



ENGAGEMENT

"This project was born out of my love of technology, art and music. 'Scattered' is about when you piece yourself together after a ms attack.."

Ioana Dobriou, Romania

EFNA maintains an ongoing programme of active external engagement to ensure that the voice of the neurology patient community is heard in the relevant forums. Below are some of the events and initiatives in which we have been active in 2020. Get in touch if you'd like to know more!

Note: Most of our advocacy and policy activities in this regard are covered in the section on 'Advocacy'.

- **Partnership Agreement signed with the European Academy of Neurology.** EFNA members sit on scientific panels. EFNA representatives sit on Education Committee, Gender and Diversity Taskforce, and Guideline Production Group. EFNA is also affiliated to the European Affairs Sub-Committee. EFNA actively participated in the virtual congress via slots at the scientific theatre, booth in the exhibition centre, involvement in special sessions and the selection of 'patient choice' sessions.
- **President is part of the Executive Committee at the European Brain Council, and Executive Director is a Board Member.** Active involvement in projects such as Value of Treatment, Brain Innovation Days, Brain Innovation Roadmap, European Brain Research Area, etc.
- **Participant to the EFPIA Patient Think Tank and Member of the Steering Committee**
- **Member of the European Patients' Forum**
- **Member of the European Cancer Patient Coalition's working group on cancer co-morbidities and complications**
- **Member of the European Health Coalition**
- **Member of EMA's Patient and Consumer Working Party**
- **Involvement in the Societal Impact of Pain Initiative**
- **Involvement in the Women's Brain Project**
- **Involved in Chrodis+ and speaker at final conference**
- **Interaction with the Patient Access Partnership and the Global/European Alliance for Patient Access**
- **Interaction with the European Paediatric Neurology Society and the European Association for Hospital Pharmacy**
- **Participated in panel discussion at Patients as Partners, London**
- **Participated in panel discussion at DtX London (digital therapeutics)**
- **Presenter to ERA-Net Neuron Meeting and collaboration on developing training for lay reviewers**
- **Presenter at Pfizer's HTA Patient Advocacy Summit**
- **Part of Roche's Personalised Healthcare Council**
- **Moderated the opening session of Roche's International Experience Exchange for Patient Organisations [IEEPO] 2020**
- **Part of the Lundbeck Institute Neuroscience Faculty**
- **Involvement in Lundbeck's 1Voice Summit**
- **Co-organised and moderated a roundtable on Huntington's Disease with the EHA.**
- **Speaker/moderator at other EFNA member events and initiative e.g. EMSP, RI, DE…**
- **Participated in WFN's Global Webinar on Brain Health (Neurology)**
- **Participated in UN GA Summit**
- **Involvement in starting European Narcolepsy Alliance**

"After my Stroke I have put myself more in my bell jar, I withdraw myself much more, it is often too busy.

People who do activities together, I don't participate, I have become a spectator.."

Marianne Beernink, Netherlands

FINANCE & GOVERNANCE

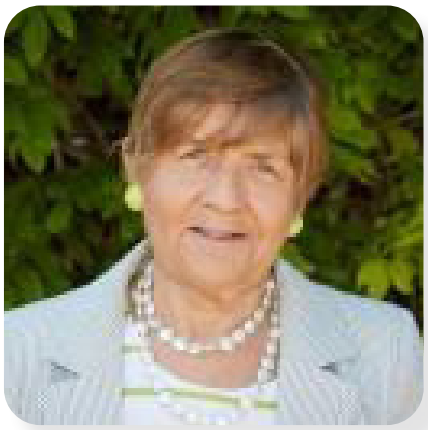
A WORD FROM OUR TREASURER

BEA DE SCHEPPER

In 2020, EFNA was pleased to raise sufficient income to support our workplan in full. Despite many events going virtual, thanks to the flexibility of our sponsors, we repurposed these funds to bring in external expertise to work with us on analysing and revising our strategic direction in various projects to ensure that we were ready to build on this new landscape – shaped by Covid-19 – in 2021. This meant we finished the year with a small surplus which will be allocated to our strategic implementation and sustainability fund – building up EFNA's reserve as we face into a potentially unpredictable few years when we encounter the aftermath of the pandemic. Also, as EFNA steps up its activities on a more global level it is more important than ever that we have the human and financial resources to advance our work effectively. So, thank you to our sponsors for their ongoing support to EFNA. These are listed below. And thank you also to our accountants and advisors at SBB for their work to ensure EFNA meets its financial and legal obligations. Good governance is important to EFNA and we rely of the expertise of our colleagues at SBB to ensure that we comply with all relevant Belgian legislation and requirements. This will continue and we look forward to working with you all again in the coming years.

A WORD FROM OUR SECRETARY-GENERAL

JENNY BAKER



In 2020, EFNA updated its Statutes to reflect the changes in Belgian Law for non-profit organisations. This was approved by our General Assembly – which became a virtual event this year. The new Statutes and associated by-laws can now be found on the EFNA website.

This year we launched our new strategic plan, which will run from 2020-2025. Please do take a look to see how EFNA will advance its activities in the years to come!

We also devised and approved a new set of EFNA membership principles, as well as terms of reference for EFNA Board Members. Again, this can be accessed online.

A first board meeting was held face-to-face in February 2020 but all later meetings were held via video conferencing.

We welcomed Richard Simpson to our Board on behalf of the EMEA, co-opted to replace his colleague Nancy van Hoylandt, who stepped down for health reasons. We thank Nancy for her years of dedicated service to EFNA. She was hugely committed and actively represented EFNA externally, in the Brussels arena and beyond!

Thank you Nancy!

Thanks to the following companies who have supported us in 2020:

NOVARTIS

MERCK

Roche

TEVA PHARMACEUTICAL INDUSTRIES LTD.

Lundbeck

Pfizer

ucb

SANOFI

IPSEN
Innovation for patient care

Biogen

MSD

GRÜNENTHAL

janssen

Thanks to Kathy Redmond of Redmond Consulting for providing pro bono moderation services at our General Assembly interactive session in 2020.

ANNUAL ACCOUNTS 2020

INCOME		EXPENDITURE	EURO
ADVOCATE FOR NEUROLOGY			
Merck	20,000.00	Depreciation on research papers/advocacy assests	- 9,591.48
Grunenthal	10,000.00	NCD Alliance Membership Fee	- 3,311.00
MSD	15,000.00	EBC and EPF Membership Fees	- 1,915.00
Novartis	45,000.00	Double Entry Ipsen	- 15,000.00
UCB	30,000.00	Advocacy Staff Costs	- 74,591.00
Lundbeck	30,000.00	Event Planning/Strategic Development/Analysis/Document Update - Weber Shandwick	- 53,077.86
Roche	20,000.00	TINA Position Papers (x2) - Incisive Health	- 16,940.00
Ipsen	25,000.00	EU Summit and other policy related meetings/external representation	- 15,938.87
TEVA	20,000.00	Communications Consultant - OneNeurology	- 8,999.38
Pfizer	30,000.00	Global Public Health Expert - OneNeurology	- 19,360.00
Novartis deferred	25,000.00	EFNA 20% project management fee	- 57,800.00
Pfizer deferred	19,000.00	Lunbeck deferral to 2021	- 20,000.00
Project Sub-Total	***289,000.00***		***- 296,524.59***
Project Surplus			**- 7,524.59**
BRAINLIFEGOALS			
Merck	30,000.00	Project Grants	- 30,000.00
Novartis	30,000.00	Communications Staff Costs	- 65,346.05
Sanofi	30,000.00	Stigma Survey Costs	- 3,285.81
Roche	30,000.00	E-Learning Platform Set Up Costs	- 4,837.15
Biogen	18,597.50	Presenter Fees (excluding Weber Shandwick - incl. above)	- 8,091.89
TEVA	15,000.00	Video and Online Content	- 1,662.83
		Non-refundable TINA venue costs	- 2,822.42
		EFNA 20% project management fee	- 30,719.50
Project Sub-Total	***153,597.50***		***- 146,765.65***
Project Surplus			**6,831.85**
GENERAL			
Project management fees	88,519.50	Other Staff Costs	- 103,636.50
EAN	20,000.00	Insurance and Legal Costs	- 1,814.86
Janssen	10,000.00	Accountant Fees	- 12,048.39
Membership Fees	3,600.00	Phone, Website, Internet and Other Office Costs	- 306.10
Honoraria	5,026.51	Payment Differences/Bank Costs	- 337.62
Project Sub-Total	127,146.01		- 118,143.47
Project Surplus			**9,002.54**
OVERALL SURPLUS			**8,309.80**
Result brought forward			*29,958.78*
Result to be allocated			*38,268.58*
50% to sustainability fund			*(19.134.29)*
25% to strategic implementation fund			*(9.567.14)*
RESULT TO BE CARRIED FORWARD			**9.567.14**

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LinkedIn: /company/efna

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Elizabeth Cunningham, Communications Manager: communications@efna.net