EFNA

EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

ANNUAL REPORT 2021

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A MESSAGE FROM EFNA'S PRESIDENT

2021 has been an eventful year, for a number of reasons. In spite of Covid-19, our work continued, even increased, during the year.

In March we launched what has become one of our flagship projects, OneNeurology. Ever since that memorable event in the European Parliament in February of 2020, our plans for neurology had gathered pace. Meetings to discuss the plans followed in rapid succession and were held with many external stakeholders, as well as our partners– until the early months of 2021 and the launch of OneNeurology in March.

EAN had become our co-founder, partners and endorsers had joined and the project met with great enthusiasm by people worldwide. Contact with WHO intensified after it was decided to make their 10-year Intersectoral global action plan on epilepsy and other neurological disorders central to OneNeurology's work. And so it happened that this great global action plan, which will help make neurology the global health priority it deserves to be, quite clearly reflects the input of OneNeurology and its partners. The OneNeurology summit on December 17th was an absolute highlight, with more than 200 people attending online.

Other work continued as usual, and grew, in line with EFNA's reputation. Our partnerships with the European Academy of Neurology and the European Brain Council were both fruitful and rewarding and continue into 2022. Our industry partners showed a high level of loyalty to and appreciation of our work. The EFNA team, spread over three countries, worked very well together- full of enthusiasm, mutual trust and respect, which of course then bears fruit. So, awareness, advocacy, our training initiatives and e-learning modules, external representation – all business as usual.

Until one evening in October, when Donna Walsh, our tower of strength, called to say she would be leaving EFNA. Following 10 years of total dedication and success, this came as a great shock. I had known this was bound to happen someday, but still. In December we said goodbye to Donna, wished her all the best in her new endeavours, and soldiered on.

I am very happy to say that EFNA has found a most worthy successor to Donna, in Orla Galvin. Our new Executive Director brings new energy to the team and is a pleasure to work with.

And thus, EFNA is ready for even more adventures! I thank everyone who has been with us in the past year for the support we received – in whatever form – this was much valued. I look forward to continuing to work together.

Joke Jaarsma
EFNA President

EFNA MEMBERS

New member

Provisional member

BOARD MEMBERS 2021

Joke Jaarsma
President
European Alliance for RLS

Cathalijne van Doorne
Vice-**President**
Euro-ataxia

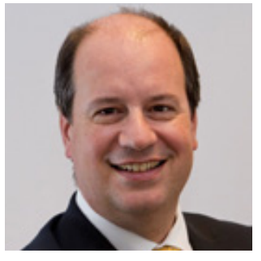
Astri Arnesen
Secretary-General
European Huntington Association

Klaus Knops
Treasurer
European MS Platform

Anne Goodchild
Board Member
European ME Alliance

Ivanka Jovanovic
Board Member
European Alliance of Neuromuscular Disorders Associations

Robin Pinkston
Board Member
International Bureau for Epilepsy

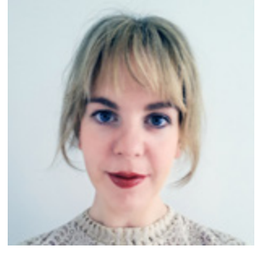


Russell Patten
Board Member
European Parkinson Disease Association

Viorica Cursaru
Board Member
Pain Aliance Europe

STAFF 2021

Donna Walsh
Outgoing Executive Director



Dr. Orla Galvin
Incoming Executive Director

Tadeusz Hawrot
Senior Policy Advisor

Elizabeth Cunningham
Senior Communications Manager

ADVOCACY

"Dystonia Europe is a small organisation and dystonia is a rare disease and by working together with other neurological organisations on topics such as stigma, disease awareness, access to treatment and better quality of life we can all benefit."

Monika Benson, Vice President, EFNA and Executive Director, Dystonia Europe

"We are so much stronger when we stand together under the umbrella of EFNA and advocate for the same objectives with one strong voice."

Astri Arnesen, Secretary General, EFNA and President, European Huntington Association

A NEW CHAPTER OPENS

In the policy domain, 2021 has been a truly remarkable year for EFNA. The highlights include:

ONENEUROLOGY

We spearheaded the creation of a new global advocacy partnership - OneNeurology - which has already firmly established its position among the global neurological community, as well as key stakeholders like WHO and the NCD community.

We provided the secretariat for the OneNeurology Partnership and led numerous activities spanning communication actions such as podcasts and articles as well as advocacy activities, including the organization of several policy meetings with both global and European focus.

We also represented the partnership at numerous global events such as the following WHO meetings: consultative meetings related to the development of the neurological global action plan, brain health consultations or Informal consultation with NGOs on the ongoing intersessional work on NCDs and mental health in preparation for the 150th session of the WHO Executive Board. More detail on these events can be found on pages 12 - 13.

INTERSECTORAL GLOBAL ACTION PLAN ON EPILEPSY AND OTHER NEUROLOGICAL DISORDERS

Coinciding with our earlier campaigns in 2019-2020 to have a global framework addressing neurological disorders as a distinctive field, in 2021 WHO published the draft global action plan on neurological disorders 2022 – 2031 (GAP). The plan offers a horizontal and integrated approach to neurological disorders and brain health. It also maps out priority areas and sets global targets.

It is the first time in the history of the WHO that neurological disorders and brain health have been captured as a distinct field, enveloped in a global framework of actions and measurements. It is a framework that the neurological community has been calling for for several decades.

EFNA coordinated gathering extensive feedback - both on behalf of its European members and global neurology groups - to the GAP discussion paper and then the 1st draft. Our comments were submitted as part of the GAP ongoing consultations and we were pleased to see that a lot of them were subsequently included in further iterations of the draft GAP.

Between various consultation periods, we kept on engaging with numerous governments, Geneva missions, WHO and EU officials, to make sure that all states across the globe support the development of a strong and ambitious GAP and start planning its implementation.

EUROPEAN UNION AND THE EU4HEALTH PROGRAMME

In Europe, we continued to demand from all 27 EU health ministers the addition of neurological disorders to the priority list of European NCDs. We also called for an alignment of the EU4Health Programme with the GAP implementation. We suggested that the Commission provides an exchange platform in the form of an EU Joint Action (or similar), to facilitate the creation of national neurological plans that are the primary target of the GAP. Along the way, we developed a neurological disorders memo for DG SANTE, including policy recommendations.

More broadly, 2021 was a year of significant changes when it comes to scaling up ambitions in the EU public health domain. DG SANTE's EU4Health Programme - officially adopted in March - received a 12-fold budget increase, compared to the previous one. A new concept of the European Health Union has also started taking shape. In parallel, COVID put in the spotlight NCDs or chronic diseases. Not only are NCDs responsible for some 80% of premature deaths in the EU, but now they are also the main risk factor for becoming severely ill or dying from the virus.

Of extreme importance to the neurological community was the moment when neurological disorders were recognised as one of the 6 priority NCDs in the EU4Health text. Neurology was the only new disease area compared with the previous EU NCD list, which comprised cancer, CVD, diabetes, respiratory diseases and mental health. This was a direct result of our targeted, extensive and tireless advocacy efforts happening over several years towards EU capitals, the European Commission and the Parliament.

NCD INITIATIVE – HEALTHIER TOGETHER

The importance of the inclusion of neurology in the major league of NCDs became apparent in December when DG SANTE launched a new initiative to support EU countries in reducing the burden of NCDs: NCD Initiative – Healthier Together. It will focus on 5 key areas, including neurological disorders. To roll it out, over €110 million will be earmarked each year and it will include grants for NGOs to assist member states in implementing relevant actions.

The Initiative announcement came at a perfect moment – just before our OneNeurology European Summit that took place in December and which was officially hosted by the Slovenian Presidency to the EU.

Moving forward, we are shifting our advocacy work to a new phase: from calling for the prioritisation of neurology we can finally move to develop solutions for people living with neurological disorders, and assist with their implementation. This allows us to look into the future with optimism and anticipation.

Other relevant meetings:

- Multiple meetings with the WHO Brain Health Unit
- DG SANTE Deputy Director General Pierre Delsaux
- 6 WHO NCD Hard talk meetings
- EU4Health SANTE webinars
- Alzheimer Disease roundtables organized by Biogen
- Various meetings to support the creation of the European Health Union
- GAP WHO public hearing
- EBC policy and advocacy committee
- Numerous calls with Geneva health missions and countries governments
- Liaison with POLITICO which resulted in two articles mentioning EFNA
- Liaison with IBE surrounding the GAP development
- OneNeurology meetings
- Meeting with WHO Europe – Dr. Dan Chisholm
- National Brain Councils Academy
- EBC Brain Innovation Days
- Portuguese EU Presidency conference: 3As Conference - Availability, Accessibility, Affordability - of Medicines & Medical Devices"
- Meeting with WHO Europe Director Dr. Hans Kluge
- Meetings of the NCD Alliance Peer Learning Advocacy Network (PLAN) on an Inclusive NCD Agenda
- OneNeurology roundtable
- Cannabinoid Education 360 focus group meeting
- Meeting with WHO – Dr Alarcos Cieza (rehabilitation unit)
- World Health Assembly and associated side-events
- Meeting with MEP Line Sogaard-Lidel
- Meeting with WHO Europe: Dr Ledia Lazeri
- OneNeurology workshop
- EBC Pharma Strategy workshop
- WHO GAP meeting with civil society
- WHO Informal consultation with NGOs on the ongoing intersessional work on NCDs and mental health in preparation for the 150th session of the EB
- EU4Health Programme consultations meetings
- WHO Mental Health Forum
- EBC Brain Innovation Days and European Brain Summit
- Meeting with DG SANTE Director John F. Ryan
- Meeting with WHO Europe: Dr Natasha Azzopardi-Muscat and Dr Ledia Lazëri

BRAIN, MIND AND PAIN MEP INTEREST GROUP

The MEP Interest Group on Brain, Mind and Pain is an initiative of the European Federation of Neurological Associations [EFNA] and Pain Alliance Europe [PAE].

The Group focuses on the below themes in an attempt to improve the quality of life of all those living with brain, mind and pain disorders across the EU, as well as their families and carers:

- **Eradicate stigma, isolation and discrimination**
- **Ensure equitable access to treatment, services and supports**
- **Promote patient empowerment for increased involvement and engagements**

Due to the ongoing travel and meeting restrictions in 2021, EFNA was unable to organise its face-to-face MEP Interest Group meetings. However, two successful online conferences were held.

ACHIEVING HEALTH EQUITY AFTER THE COVID-19 PANDEMIC

15 JUNE 2021

On 15 June 2021, the MEP Interest Group on Brain, Mind and Pain organised a virtual working session entitled "Achieving health equity after the Covid-19 pandemic". The event's main objective was to understand the long-term impact of the Covid-19 outbreak on different population groups affected by BMP disorders, and to define and frame the inequalities and challenges they experience. The working session was attended by EU policy-makers, healthcare professionals, patient organisations and industry representatives.

Ms Donna Walsh, Executive Director of EFNA and Ms Deirdre Ryan, Presidential Candidate of PAE presented the results of two recent surveys that looked at the impact of Covid-19 on those living with neurological and chronic pain in Europe. The two surveys had similar findings, with almost 45% neurological patients and 48% chronic pain patients experiencing difficulties in receiving appropriate care during the pandemic. Additional respondents' concerns and fears included long waiting times to see specialists, the impact on mental health/social isolation, medicine shortages or increased use of digital technology. Based on these results, EFNA and PAE presented their key conclusions and recommendations to policy-makers.

The audience was provided with the EU institutional perspective by Ms Katarzyna Ptak-Bufkens from the European Commission and the Interest Group's co-chair, MEP Tilly Metz (Greens / EFA, Luxembourg). Both representatives stressed their personal and professional interest in the topic. Ms Ptak-Bufkens referenced some of the Commission's ongoing complementary policy tools to address health inequalities, including the European Pillar of Social Rights and Action Plan, and the Health Systems Performance Assessment (HSPA), highlighting that a 'one size fits all' solution is impractical and that tools should serve the national and subnational context and help those most vulnerable. MEP Metz welcomed Ms Ptak-Bufkens' remarks while strongly emphasising the importance of putting non-communicable and chronic diseases, such as BMP disorders, at the forefront of future-proofing and building resiliency of European healthcare systems.

Following the opening plenary, three parallel workshops allowed for a more interactive discussion on the Interest Group's core themes: stigma, access and patient empowerment. Inspired by the design thinking methodology, these key themes were "matched" with different population groups prone to experiencing healthcare inequities: younger and older people, vulnerable groups impacted by geographical disparities, and women with BMP disorders. Based on desk research and interviews with patients from each population group, patient persons were developed and their experiences were discussed during the workshops.

Participants at the workshops were then asked to identify which of the challenges experienced by the personas were the most feasible to solve. Attendees also contributed to the discussions and co-decided the right level of engagement and the resources needed to address them.

Through this exercise of gathering insights from different players in the healthcare arena and promoting a co-decision approach, the challenges experienced by people with BMP disorders were better framed, and this will ultimately contribute to identifying more person-centred solutions.

Based on the identified challenges, the Interest Group will now look to assess how EU-level action can help to support the advancement of the priority issues identified. Best practice interventions in the wider healthcare space will be sought via desk research and a call for solutions. Shortlisted solutions will form the basis of the MEP Interest Group's direction/workplan in 2022.

The full meeting report from this event is available at www.brainmindpain.eu/june2021

TURNING PRINCIPLES INTO ACTIONS: BEST PRACTICE IN REDUCING HEALTH INEQUALITIES

19 NOVEMBER 2021

On 19 November 2021, the MEP Interest Group on Brain Mind and Pain (BMP) hosted a virtual event entitled *"Turning principles into action: best practice in reducing health inequities"*. The event's main objective was to discuss how the Interest Group can advance meaningful policies and interventions to address the drivers of health inequity, whilst taking a practical look at examples of best practices that can be scaled up and applied to these disease areas. The event was attended by EU policymakers, healthcare professionals, patient organisations and industry representatives.

Ms Sandra Gallina, Director General for Health and Food Safety (DG SANTE), addressed the audience and presented the European Commission's commitment to reduce health inequity and promote sustainable wellbeing across all EU Member States. Moreover, she thanked the MEP Interest Group for shining light on such an important topic that directly and indirectly affects society.

Sir Michael Marmot, Director of the University College London Institute of Health Equity. sent a supporting message, focusing on the impact of the Covid-19 pandemic on health equity and the further strain it placed on the existing fragile systems. Sir Marmot noted the importance of recognising the underlining social determinates of health and outlined the actions and mechanisms that should be taken to address them through "building back fairer".

A panel debate followed, which looked at advancing meaningful policies and interventions to address drivers of health inequity.

Ms Dorota Sienkiewicz stated that health inequality between and within Member States results from adopting downstream solutions instead of systemic changes that could offer the best value for what can be offered across Europe and that political mandates on health equity need to come from an executive level, with all actors working together to reach a common goal.

MEP Sirpa Pietikäinen (FI, EPP) highlighted that health inequalities still exist in Europe today, especially with regard to correct and timely diagnosis, further noting the importance of developing a roadmap for neurological and chronic pain at a European level.

PRESENTATION OF BEST PRACTICES IN THE AREAS OF STIGMA, ACCESS AND PATIENT EMPOWERMENT

In advance of the annual conference of the Interest Group, the Group launched a call for examples of best practices in the fields of neurological and chronic pain. The best practices focused on the three priority thematic areas of the Interest Group (stigma, access and patient empowerment) and had to address specific challenges of the patient community. The assessment of each proposal was made by a Selection Panel composed of a multi-stakeholder group with extensive expertise and professional experience in policy and advocacy.

The selected best practices under each thematic area are as follows:

STIGMA, DISCRIMINATION AND ISOLATION

- Federación Española de Párkinson (FEP) (Spanish Parkinson's Federation) developed and implemented an awareness campaign campaign called "#TagOnAPositaveLebal", which sought to raise awareness of the importance of a patient's emotional and psychological health.
- The ME/CFS Netherlands Foundation's best practice brought together young patients with ME suffering from extreme fatigue and healthy peers. Through a community service internship that both groups undertake, they address discrimination and stigma whilst showing that ME patients have a meaningful contribution to society.

ACCESS TO TREATMENT, SERVICE AND SUPPORT

- MS21 is an initiative supported by Merck, aiming to gain real-world, actionable insights into unmet needs in managing multiple sclerosis (MS), from the perspective of healthcare professionals (HCPs) and people living with MS.
- 'Plain Talking' is an awareness campaign initiated by European Pain Federation (EFIC), targeting both clinicians and people living with chronic pain. As part of the campaign, a Health Literacy Working Group is working to increase awareness about the concept and impact of limited health literacy.

PATIENT EMPOWERMENT

- The ADHD Women Project is the initiative of two patient organisations from Belgium and Germany, empowering women living with a neurological condition to engage more effectively in shared decision-making.

To find out more about the selected best practices please visit www.brainmindpain.eu/bestpractices2021/

The co-chair of the Interest Group, MEP Tilly Metz (LU, Greens/EFA), closed the event by calling for a more holistic approach in the fight against health inequalities and the need for independently collected data to create targeted policies and better understand health inequalities across the EU Member States. MEP Metz also noted how health inequalities range from stigma, isolation and discrimination to improving education and information as well as gender equality, highlighting the need for specific mandates to address social health inequalities during Covid and beyond.

A full meeting report is available at www.brainmindpain.eu/nov2021.

ONENEUROLOGY ACTIVITIES

ONE VOICE FOR NEUROLOGY - A PODCAST

The One Voice for Neurology podcast is a series of podcasts exploring why it's time to make neurology a global priority, how that can be achieved and what that could mean for those living with a neurological disorder. Episodes 1-9 were launched in 2021. All podcasts including those launched to date in 2022 can be found here: www.oneneurology.net/podcasts

GLOBAL ADVOCACY WORKSHOP

29 JUNE 2021

Policy momentum is building-up with the development by the WHO Brain Health Unit of the Global Action Plan on epilepsy and other neurological disorders [GAP], to be adopted by the World Health Assembly in May 2022. The GAP represents a unique opportunity worldwide to build, with all relevant stakeholders, an integrated response to neurology across the life course and within healthcare systems to improve lives of people living with neurological disorders. However, we need to mobilise the community to ensure that the plan serves the needs of all those living with neurological disorders across the globe!

Objectives of the Workshop:

- **To present the first draft of the GAP to advocates worldwide**
- **To present the views of the OneNeurology Partnership on the first draft of the GAP**
- **To bring together neurology advocates from across the world (regional and national), to gather their perspectives on the GAP – based on their region/disease area/stakeholder group.**
- **To empower global advocates with the information, tools and resources needed to ensure a coordinated response to the GAP consultation via submissions, regional hearings and outreach to national policy makers.**

Please follow this link to view the full recording of the OneNeurology Global Advocacy Workshop

The meeting report and resources can be found here

ONENEUROLOGY ROUNDTABLE

12 NOVEMBER 2021

The Global Action Plan on epilepsy and other neurological disorders is a unique opportunity to build a multi-stakeholder, integrated response to neurology across the life course and within healthcare systems.

What do we mean by 'an integrated response to neurology across the life course and within healthcare systems'? How can we collectively build this integrated response at country level?

Objectives of the Workshop:

- **To showcase to participants what an integrated response to neurology looks like, and how to build this integrated response at country level.**
- **To present OneNeurology Partnership's position on the latest draft of the GAP**
- **To further engage in a proactive dialogue with WHO and member state representatives on the GAP process to ensure a meaningful outcome for people living with neurological disorders**
- **To further understand and collect insights on the Member States' positions via-a-vis the latest draft of the GAP and consolidated comments in advance of the WHO Executive Board [EB] meeting (January 2022).**

The full report of the OneNeurology Roundtable November 12th 2021 can be found here.

THE ONENEUROLOGY EUROPEAN SUMMIT

18 DECEMBER 2021

The OneNeurology European Summit was organised under the auspices of the Slovenian Presidency of the Council of the European Union 2021, and the OneNeurology Partnership, advanced the ambition to build a European Health Union in which we address key common EU health challenges together, in a more coordinated and efficient way. In this regard, the EU needs to raise the priority of neurological disorders, which are the third leading cause of deaths in the EU and are identified as one of the NCD priority areas in the EU4Health Programme.

The event featured high-level speakers and panelists, including Dr. Janez Poklukar (Minister of Health, Slovenia), Dr. Natasha Azzopardi-Muscat (Director of the Division of Country Health Policies and Systems, WHO Europe), John F. Ryan (Director, Public Health, Country Knowledge, Crisis Management, DG SANTE), Dr. Tarun Dua (Head, Brain Health Unit, WHO), Prof. Claudio Bassetti (President, European Academy of Neurology) and Prof. Wolfgang Grisold (President Elect, World Federation of Neurology).

The global action plan on neurological disorders will be adopted by WHO in 2022. The EU countries overwhelmingly supported the development of the plan. The Summit discussed how the EU can best prepare for its implementation in Europe in a coordinated way, and in an alignment with the EU4Health Programme, to improve brain health and neurological care for one-third of the EU population that will be affected by neurological disorders. The programme and speakers can be found here.

A full recording of the summit can be found here.

INITIAL ONENEUROLOGY AMBASSADORS MEETING

7 DECEMBER 2021

To ensure the adoption and implementation of the 10-year intersectoral global action plan on epilepsy and other neurological disorders, the OneNeurology Partnership has sought the support of regional ambassadors to ensure the plan has the support of national governments and parliaments. For up to date information on the OneNeurology Ambassadors and how to become and Ambassador, click here.

EFNA ADVOCACY AWARDS 2021

The European Federation of Neurological Associations (EFNA) Advocacy Awards recognise the contribution of an individual or group to the development and promotion of advocacy for people with neurological disorders in Europe. In 2021 the awards focused on the topic of 'Action against stigma'.

As part of our Brain Awareness Week celebrations, EFNA were delighted to announce the winners of the 2021 awards, each of whom would receive a prize of €2,000 to assist with the continuation and development of their projects.

And the winners are…

ACTION AGAINST STIGMA – OUTSTANDING ACHIEVEMENT BY AN INDIVIDUAL

WINNER: NATALIE DAVIDSON

Natalie Davidson is British teacher who lives with Tourette Syndrome.

Natalie first engaged with advocacy work nine years ago, participating in a British regional TV programme called 'Inside Out' that showed the public how, although Tourette Syndrome brings real challenges, Natalie is leading a happy and successful life. The UK television channel Channel Five later developed a full documentary about Natalie and the work that she does. The programme 'Teacher With Tourette's: Cursing In the Classroom' provided a fantastic opportunity to help spread awareness, reduce discrimination and raise aspirations for those with Tourette Syndrome.

Natalie has worked with national and regional support associations to deliver live talks, workshops, presentations and webinars. She has connected with teachers, lecturers, parents and patients. Natalie's work has focussed on raising aspirations and giving hope to parents and individuals who have Tourette Syndrome and showing them that the pathway is going to be hard but it is a pathway that you can reach the end of. Natalie warmly encourages positivity and as well as acceptance and belief that people can achieve their goals as well as facing the challenges of having Tourette Syndrome. One of Natalie's goals has been to educate teachers and lecturers on different strategies to enable those within their classrooms and schools to reach their highest potential.

Natalie was nominated by Seonaid Anderson of neuro-diverse.org. The nomination was also supported by Sarah Sharp, CEO of Tictock Therapy. Sarah explained:

> "Natalie Davidson is an incredible role model for our Neurodiverse community. Natalie has bared all in a documentary following her life, living with Tourette's & OCD, yet still fulfilling her dream to become a teacher. I direct people daily to follow her journey via social media, as she shows resilience and how she copes with the stigma of living with these conditions. I love how she portrays the journey as 'real' and doesn't just show the highs."

You can follow Natalie on social media to learn more about her story and her advocacy work:

Facebook: https://www.facebook.com/nataliepearson1981

Twitter: @tourettesteach

ACTION AGAINST STIGMA – OUTSTANDING ACHIEVEMENT BY AN ORGANISATION

WINNER: EUROPEAN MIGRAINE AND HEADACHE ALLIANCE
PROJECT: THE TRUTH BEHIND MIGRAINE

For Migraine Awareness Day of Action on 12th of September 2020, the European Migraine Headache Alliance (EMHA), launched the 'The Truth Behind Migraine' – a video piece that portrayed real testimonies of how migraine affects the day to day of those who suffer from it.

The piece reveals a serious insight on the disease: that general practitioners have very little knowledge about the disease, resulting in delays to diagnosis of more than 4 years in many cases. 'The Truth Behind Migraine' sought to raise general awareness but also to put pressure on one of the main actors in the problem: the medical community.

This work was linked to a sub-action called 'The Missing Lesson' in which EMHA reported that migraine, as the second most disabling disease in the world, is only studied for 4 hours at university by prospective doctors. Together with the neurologist Dr. Dimos Mitsikostas, EMHA developed a syllabus for this 'missing lesson' and shared it via Instagram, providing the basic knowledge to understand and not underestimate migraine.

The campaign was presented at the European Parliament with the aim of raising awareness among policy-makers of the necessity to improve the training of the medical community on migraine.

Elena Ruiz de la Torre, Executive Director at EMHA explained:

> "The Truth Behind Migraine' does not settle for the 'typical' arguments of migraine, but goes further and investigates much more real 'insights' from those affected by the disease. With this, we are giving a real and updated image of migraine sufferers."

You can learn more about the work of the European Migraine and Headache Alliance, as well as about migraine itself, through their website and social media channels:

Website: https://www.emhalliance.org/

Facebook: https://www.facebook.com/EMHAlliance/

Twitter: https://twitter.com/EMHAlliance

Natalie Davidson

Elena Ruiz de la Torre, EMHA

COLLABORATION

"EFNA's employees and management have succeeded in establishing the organisation as a leading voice in the field of neurology. I am honoured to serve on the Board."

Kluas Knops, Treasurer, EFNA and Executive Committee member at European MS Platform

"EFNA shows clear goals for the global future of neurology, while supporting rarer and under-researched neurological diseases. In a year, the actions carried out by EFNA as well as the results obtained have made me very proud to be on the Board."

Anne Goodchild, Board Member, EFNA and European ME Alliance (EMEA) representative

COLLABORATION

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 2021. 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' - see page 7.*

- **Partnership Agreement 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 a 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**
- **Member of the European Patient Advocacy Leadership Council (EPALC)**
- **Involvement in the Societal Impact of Pain Initiative**
- **Involvement in the Women's Brain Project**
- **Involvement in Chrodis+**
- **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**
- **Collaboration with ERA-NET NEURON Meeting on developing training for lay reviewers**
- **Part of Roche's Personalised Healthcare CouncilPart of the Lundbeck Institute Neuroscience Faculty**
- **Partnered with the European Brain Council and Gamian Europe on the Brain Awareness Week event 'Patient Engagement in EU-Funded Brain Research Projects'**
- **Co-organised and moderated a roundtable on ME/CFS with the EMEA**
- **Presenters at Epicluster event 'Accelerating Patient Involvement in European Epilepsy Research'**
- **Participated in cyclical meetings of the NeuroCovid WHO Forum**
- **EU4Health Civil Society Alliance: Ongoing input, participate in meetings and support the campaign to restore operational grants in the EU4Health Programme**
- **Participated in NCD Alliance meetings and present on the GAP neurology targets**
- **Joined the European Alliance for Transformative Therapies - TRANSFORM**
- **Support the work of the EBC Advocacy and Policy Committee**
- **Participate in the NCD Alliance Peer Learning Advocacy Network (PLAN) on an Inclusive NCD Agenda**
- **Joined other health-focused civil society groups in supporting a manifesto, coordinated by European Health Forum Gastein, on shaping the future of the European Health Union.**
- **Assisted in organization of the Cannabinoid Education 360 focus group, with two extra EFNA members joining the focus group meeting.**
- **Speaker/moderator at other EFNA member events and initiatives**

EMPOWERMENT

"Being a member of EFNA has helped IBE have an even stronger voice in advocating for positive changes in Europe for people with epilepsy and other neurological disorders as we are truly "better together."

Robin Pinkston, Board Member, EFNA and International Bureau for Epilepsy (IBE) representative

"Membership of EFNA has meant better access to information about new medical treatments for neuromuscular disorders and cooperation with scientists, medical doctors, pharmaceutical companies and other hi-tech industries in order to achieve more efficient communication between them and NMD patients' associations."

Ivanka Jovanovic, Board Member, EFNA and European Alliance of Neuromuscular Disorders Associations (EAMDA) representative

TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES

E-LEARNING PLATFORM

In 2020, as part of EFNA's Training Initiatives for Neurology Advocates, a pilot series of e-learning modules was developed. 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.

Building on the success of the pilot modules, two further series of e-learning modules were developed in 2021.

PERSONALISED HEALTHCARE SERIES *Access the modules here!*

Personalised medicine is a medical model that aims to provide tailor-made prevention and treatment strategies for defined groups of individuals. This usually involves genomics, information technology and patient empowerment. However, at EFNA, we feel it's important to go beyond medicine only and look towards personalised health and social care – tailoring medical management and patient care to the needs of the individual. Participants will learn more about the challenges and opportunities posed by personalised healthcare, and what role patient representatives can play in making this approach a reality.

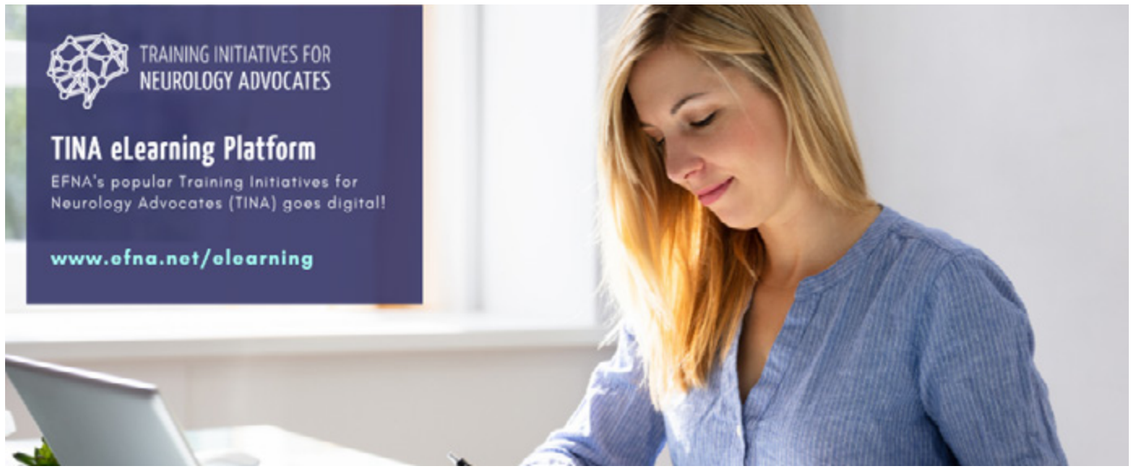
Across 5 modules, our expert presenters explain this concept, discuss the role of patient empowerment, the future of research, the regulatory and reimbursement models of tomorrow, and the ethical implications of treatment based on genomics and supported by information technology.

Three of the modules in this series were developed with the support of the Women's Brain Project [WBP].

EU FUNDING SERIES *Access the modules here!*

The EU provides funding for a broad range of projects and programmes covering almost all areas. Navigating all these programmes and applying for funding can be quite a daunting process! Therefore, in this series of modules, we take the audience step by step and provide them with all the information needed through modules covering: The Recovery Plan for Europe, Horizon Europe, EU4Health, Erasmus+ and The EU Cohesion Policy

This series was developed with the support of Weber Shandwick Brussels.



WEBINARS

PERSONALISED HEALTHCARE: THE FUTURE OF NEUROLOGICAL CARE?

3 NOVEMBER 2021

This event introduced the concept of personalised healthcare/precision medicine in neurology – with a focus on identifying key themes for those living with neurological disorders and their representatives in the years to come.

The introductory presentation was provided by Dr Maria Teresa Ferretti, Chief Scientific Officer at the Women's Brain Project.

Leading experts and key stakeholders then shared their views in a roundtable discussion, with time for audience contributions and questions.

A recording of the webinar is available from EFNA's YouTube channel here.

TOGETHER FOR BRAIN RESEARCH

APRIL 20TH AND 21ST

ERA-NET NEURON, a European funder of neurological research, would like to increase the involvement of people affected by neurological disorders in its activities. Specifically, in 2021, they sought lay reviewers to help assess funding applications for their latest call which covers neurodevelopmental disorders.

This two-day virtual workshop aimed to bring together people affected by neurological conditions, experienced funding panel lay reviewers and secretariat members from ERA-NET NEURON to discuss the role of patients, carers and family members in shaping and funding research, and to prepare anyone interested in becoming a lay reviewer to participate in this latest funding call.

'Together for Brain Research' Workshop

EFNA GRANTS 2021

In 2021, EFNA once again provided grants to support work on one of our chosen advocacy themes. This year's focus was on 'Personalised Health and Social Care'.

A fund of €30,000 was made available for this scheme, which could be divided among up to ten projects. 29 applications were received from across Europe, all featuring exciting and worthwhile projects.

We are delighted to announce that EFNA's chosen grant recipients in 2021 are:

+ WOMEN'S BRAIN PROJECT
'Supporting women to manage their ADHD'
Award: €10,000

+ EUROPEAN HUNTINGTON ASSOCIATION
'Let Us Talk: building up the communication skills of HD professionals to empower HD families'
Award: €7,500

+ MIGRA PORTUGAL
'Personalized Health Support on Call'
Award: €5,000

+ ASSOCIATION OF PERSONS WITH MULTIPLE SCLEROSIS (AOPWMS) – GREECE
'MS-health management program for PwMS due to Long-term side effects of COVID-19'
Award: €2,500

+ POLSKIE TOWARZYSTWA STWARDNIENIA ROZSIANEGO (POLISH MS SOCIETY)
'I have MS & it's O.K.'
Award: €2,500

+ SPANISH PARKINSON'S FEDERATION
'MAP-PD: Parkinson's disease associations map. Find your local health resource.'
Award: €2,500

Congratulations to all awardees!

EFNA would like to extend sincere thanks to our judging panel for giving their time to assessing all applications. They are:

- Isabelle Wilbois, Boston Scientific Foundation Europe
- Russell Patten, European Parkinson's Disease Association (EPDA)
- Orla Galvin, Retina International
- Klaus Knops, European MS Platform (EMSP)

PUBLICATIONS

Russell Patten, Board Member, EFNA and Director General of the European Parkinson Disease Association (EPDA)

"I look forward to being more involved in the work of advocacy which EFNA has successfully carried out for years and by matter of consequence was able to capture the interest of the EU MPs in addressing the problems of the patients with neurological disorders."

Viorica Cursaru, Board Member, EFNA and Pain Alliance Europe (PAE) representative

ADDRESSING THE IMPACT OF COVID-19 ON THE LIVES OF PEOPLE LIVING WITH NEUROLOGICAL DISORDERS

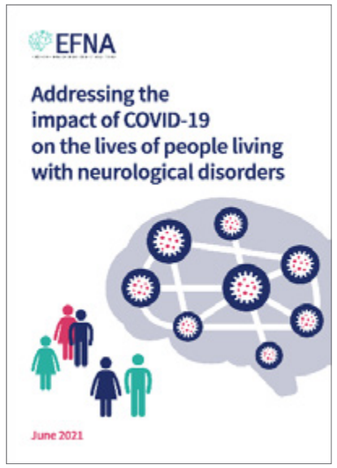
June 2021

As global, EU and national policy priorities turn towards post-COVID-19 recovery planning, to future pandemic preparedness and efforts to make healthcare systems more resilient, the impact that the pandemic has had, and continues to have, on those living with neurological disorders needs to be accounted for. Europe needs to apply the lessons learned and address the challenges people living with neurological disorders had to endure. The patients' perspective must not be forgotten.

This report summarises evidence gathered from organisations across the European neurology community about the impact of COVID-19 on people living with neurological disorders in Europe. It shows how care pathways for the neurology patient community were reconfigured during the early waves of the pandemic and makes key recommendations that policymakers and decision-makers should follow in order to ensure that any future changes to service delivery are made in the interests of patients and those affected by neurological disorders – rather than, solely, in the interests of the healthcare system.

This report was created by Incisive Health and supported and funded by EFNA's EU advocacy and policy sponsors for 2021: Ipsen, Merck, Novartis, Pfizer, Roche and Teva.

Read the report here.



LESSONS LEARNED FROM PEOPLE WITH NEUROLOGICAL DISEASES AT THE TIME OF COVID-19: THE EFNA-EAN SURVEY

August 2021

The European Federation of Neurological Associations (EFNA), in partnership with the NeuroCOVID-19 taskforce of the European Academy of Neurology (EAN), has investigated the impact of the first wave of the COVID-19 pandemic on individuals with neurological diseases, as well as the hopes and fears of these patients about the post-pandemic phase.

An EFNA-EAN survey was available online to any person living with a neurological disorder in Europe. It consisted of 18 items concerning the impact of the first wave of the COVID-19 pandemic on the medical care of people with neurological disorders, and the hopes and fears of these individuals regarding the post-pandemic phase.

For 44.4% of the 443 survey participants, the overall care of their neurological disease during the pandemic was inappropriate. This perception was mainly due to significant delays in accessing medical care (25.7%), insufficiently reliable information received about the potential impact of COVID-19 on their neurological disease (49.6%), and a substantial lack of involvement in their disease management decisions (54.3%). Participants indicated that their major concerns for the post-pandemic phase were experiencing longer waiting times to see a specialist (24.1%), suffering from social isolation and deteriorating mental well-being (23.1%), and facing delays in clinical trials with disinvestment in neuroscience research (13.1%).

Despite the great efforts of health services to cope with the first wave of the COVID-19 pandemic, individuals with neurological conditions feel they have been left behind. These findings provide invaluable insights for improving the care of patients with neurological disorders in the further course of the COVID-19 pandemic.

Access the publication here.

FINANCE & GOVERNANCE

Although I am looking forward to a new challenge, my departure from EFNA is bittersweet.

When I took over in 2012, I didn't realise just what a challenge I had before me. But I quickly went from thinking I might have just made the worst mistake of my life, to realising it was probably the best decision I ever took! It's absolutely never felt like 'just a job' to me. It's meant so much more.

For the past nine years, I've invested everything I could in building EFNA up to what it is today – as well as fighting for neurology to have the recognition it deserves.

Obviously, I didn't do this alone and I've been blessed with brilliant colleagues along the way (you know who you are!). I've learned from them, from so many of you and from everyone I've met along the way; as well as forming relationships and friendships I hope will last beyond my time at EFNA. Some of the most important people in life today are people I would never have met but for my work here.

I feel confident that I will leave EFNA in a good place from which my successor can build – availing of all the new opportunities that are coming our way. It's time for new energy and new ideas – and time for me to also challenge myself again elsewhere.

I will be moving to take up the position of CEO at the International Bureau for Epilepsy from January 2022 – so I will still be active in this field and hope our paths continue to cross!

But I will miss EFNA and the wider family who have been so inspirational.

I am always in awe of all those living with neurological disorders and their carers who are so determined to advocate for a better quality of life for themselves and their communities.

I'll always be a supporter of EFNA and a believer in the value of working together, from near or far!

Of course I'm not leaving just yet, and I look forward to working with you all over the coming months to enable a smooth transition to my successor Orla Galvin, who I know will do a wonderful job and who I hope will enjoy the role as much as I have.

I am sending her lots of luck and my sincere best wishes.

To finish, I'd like to thank the EFNA Board for their trust in me over these years and their openness in allowing me to learn on the job, implement new ideas and take the occasional risk together!

I feel it has paid off, I hope you all do too. I'll be forever grateful for this opportunity.

Donna Walsh,
Outgoing EFNA Executive Director

I would like to introduce myself as the incoming Executive Director of EFNA.

I am thrilled to be here, and energised by many of the items we'll be working on in the near future.

Over the past three years I've worked for an EFNA member: Retina International- a global umbrella organisation for patient organisations covering rare and common retinal degenerations.

Earlier this year I was appointed to the Board of EFNA, in particular to the role of Secretary General. I'm delighted to continue to represent the patient voice through multi-stakeholder engagement, patient and public involvement (PPI) and real world data (RWD) generation to support advocacy and policy actions.

It was fantastic to observe how EFNA has grown and developed to empower the neurology patient community over the past twenty years. Over the next twenty years, we will see the growth of increasingly personalised diagnostic interventions, where we use data to understand, diagnose and provide care pathways and treatment options that are targeted to people on an individual basis. For the EFNA membership, this holds incredible potential for improving quality of life and overall health status. With impactful collaborations and expansion of the EFNA network, we can accelerate these discoveries for people living with neurological diseases and make sure the EFNA membership are at the cutting edge in receiving equitable and affordable clinical and social care.

It is an exciting time to work in advocacy and policy in the field of neurology. In recent years there have been major successes in medical and scientific discovery. Now, artificial intelligence and bioinformatics are helping to improve our understanding of both rare and common conditions and could be utilised to the advantage of patients and care providers.

This is where we as health advocates play a critical role. When it comes to timely access to diagnoses, care pathways, treatments, and improvements in quality of life, it has never been more important to include research and RWD generation through PPI to guide decision makers to support and benefit the neurology community. In fact, it is our duty to do so.

I am eager to commence working with you on our shared strategic goals and look forward to meeting you as we emerge from COVID-19 restrictions!

Dr. Orla Galvin,
Incoming EFNA Executive Director

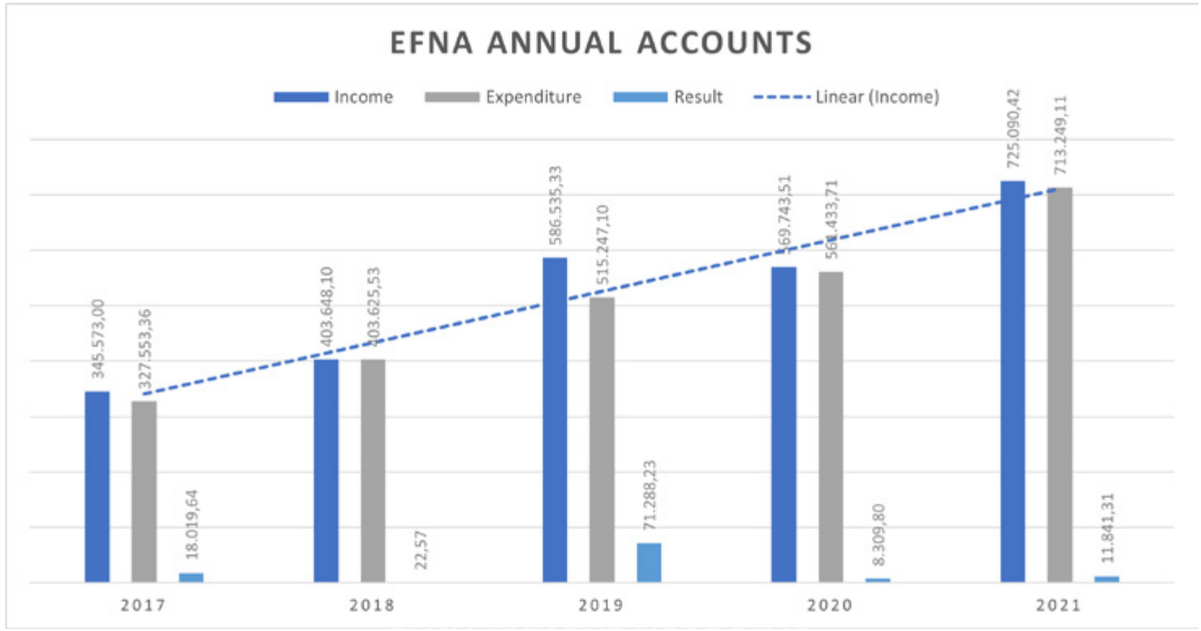
A WORD FROM OUR TREASURER

KLAUS KNOPS

In 2021, EFNA was pleased to raise sufficient income to support our workplan in full. 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.

From the graph below you will see that EFNA's income and expenditure has been rising over the past five years. This has been necessary to support our increased activities at both European and global level. It is now 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 on page 29.

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.



EFNA ANNUAL ACCOUNTS 2021

EFNA ANNUAL ACCOUNTS 2021

Income		Expenditure		Result
MEP INTEREST GROUP ON BRAIN, MIND AND PAIN				
Grünenthal GmbH	€ 5,000.00	Brussels-based Coordinator (PAE)	€ 6,210.00	
Novartis Pharma AG	€ 25,000.00	Incisive Health Limited	€ 19,360.000	
TEVA Pharmaceuticals Europe BV	€ 40,000.00	Cmgrp Belgium Scrl	€ 78,248.280	
F. Hoffmann - La Roche ltd	€ 30,000.00	Communication/Promotional Materials incl. website	€ 1,651.760	
Sas Ipsen Pharma	€ 30,000.00	Associated Meetings planning a representation	€ 7,431.710	
Merck Heatlhcare KGaA	€ 30,000.00	Senior Advocacy Coordinator	€ 10,061.150	
Alexion Pharma GmbH	€ 30,000.00	Other Advocacy Costs incl. TINA policy/HTA work	€ 26,391.610	
		Recalled	€ 5,804.030	
		20% EFNA Management Fee	€ 38,000.00	
Project Sub-Total	**€ 190,000.00**		**€ 193,158.54**	**€ -3,158.54**
TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES				
Biogen International GmbH	€ 25,000.00	TINA- Consultant/Speaker Fees	€ 19,407.69	
European ME Alliance	€ 2,500.00	Advocacy awards and TINA grants	€ 33,000.00	
Merck Sharp & Dohme (Europe) Inc. Vbr	€ 20,000.00	Fee of Communications Manager	€ 4,719.00	
Novartis Pharma AG	€ 20,000.00	TINA e-learning platform hardware/software	€ 845.67	
Sanofi Belgium nv	€ 20,000.00	Brain Life Goals	€ 24,144.94	
F. Hoffmann - La Roche ltd	€ 20,000.00	Young People In Advocacy	€ 12,450.90	
Boston Scientific Foundation Europe	€ 25,000.00	20% EFNA Management Fee	€ 28,928.07	
ERA-NET Neuron at DLR-PT	€ 9,140.35			
Federacion Espanola de Parkinson	€ 3,000.00			
Project Sub-Total	**€ 144,640.35**		**€ 123,496.27**	**€ 21,144.08**
OneNeurology Iniatitive				
European Academy of Neurology	€ 50,000.00	Meetings and Events incl. EU Summit	€ 16,170.34	
Novartis Pharma AG	€ 60,000.00	Fee of Senior Advocacy Coordinator	€ 69,774.65	
Ucb Biopharma Sprl	€ 40,000.00	Fee of Communications Consultant	€ 77,114.48	
Pfizer	€ 30,000.00	Fee of Policy and Strategy Specialist	€ 26,534.13	
H Lundbeck A/s	€ 25,000.00	Communication/Promotional Materials incl. Toolbox	€ 5,040.05	
H.Lundbeck A/s brought forward from 2020	€ 20,000.00	External Representation	€ 72.00	
F. Hoffmann - La Roche ltd	€ 40,000.00	Miscellaneous Project Costs	€ 5,414.11	
External representation	€ 3,076.50	20% EFNA Management Fee	€ 51,255.30	
Project Sub-Total	**€ 268,076.50**		**€ 251,375.06**	**€ 16,701.44**
GENERAL				
Membership	€ 3,400.00	Other Staff Costs	€ 122,087.20	
Other external representation	€ 790.20	Accommodation and Venue Costs for Board Meetings (loss)	€ 11,412.57	
EFNA Management Fees	€ 118,183.37	Governance and Overheads/Membership	€ 11,599.47	
		Miscellaneous	€ 120.00	
Project Sub-Total	**€ 122,373.57**		**€ 145,219.24**	**-€ 22,845.67**
Total				**€ 11,841.31**
50% to sustainability fund				€ 5,920.66
25% to strategic development fund				€ 2,960.33
Result Carried Forward				**€ 2,960.32**

Thanks to the following companies who have supported us in 2021:

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