



Empowering Patient Neurology Groups

Operational Plan 2017

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Who are we?

The European Federation of Neurological Associations [EFNA] is an umbrella group representing pan-European neurology patient groups.

Our slogan 'Empowering Patient Neurology Groups' encapsulates our goals as an Association. We strive to add capacity to our members – allowing them to be the most effective advocates possible in their own disease specific areas.

EFNA embraces the concept of Partnership for Progress – working at a high level with relevant stakeholders from the fields of policy, medical, scientific/research, industry, patient partners and other key opinion leaders. See: www.efna.net

Our Vision

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

Our Mission

- To influence policy makers and legislators in Europe (and particularly in the European Union) to prioritise resource allocation to reduce the burden for people living with a neurological disorder.
- To communicate with our members to achieve positive change and to ensure that our actions both represent and provide added value to their own concerns and activities, and ensure that patients are empowered and encouraged to participate in relevant decision-making processes.
- To establish strong partnerships and alliances with relevant stakeholders in the scientific, clinical, political and corporate arenas to help us to reach our goals – partnership for progress.

Our Values

- Trustworthiness and transparency – we will be open, honest and ethical in all we do.
- Respect and democracy – we respect one another's differences and contributions.
- Sustainability – we will make best use of our resources to bring about changes that produce permanent benefits for our members and will plan our activities to ensure EFNA's future.

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

Advocacy – Empowerment – Awareness – Engagement

STRATEGIC GOALS

GOAL 1: **ADVOCACY**

To raise awareness and generate patient based evidence of the burden and impact of neurological disorders; increasing priority given to neurology by policy and decision makers and by health care providers.

GOAL 2: **EMPOWERMENT**

To ensure that our member organisations are empowered and supported to be active in advocating for neurology, and provided with the opportunities and channels to do so effectively.

GOAL 3: **AWARENESS**

To promote public awareness and understanding of neurological conditions; eliminating the associated prejudice/stigma.

GOAL 4: **ENGAGEMENT**

To work closely with our partners and relevant stakeholders in the field to ensure that the neurology patient perspectives and preferences are represented and considered in policy and decision-making – ensuring a multi-stakeholder approach, with patients taking the lead.

ACTION AREAS

Bearing in mind EFNA's aims and objectives, as well as the current landscape in which we operate, the below describes (in general terms) the areas of action in which EFNA will focus most of its work in order to meet the strategic goals identified above. These action areas will frequently encompass more than one strategic goal in the areas of: Advocacy, Awareness, Empowerment and Engagement. The more specific initiatives to be rolled-out in these areas will be detailed in the Operational Plan 2017, which follows from Page 5.

Action Area 1: **ADVOCACY AND AWARENESS ACTIVITIES**

- Ensuring a high level presence and constructive input at relevant external health events, on behalf of our membership and all those affected by neurological disorders.
- Adding patient-led research and opinion to the pool of data which highlights the impact and burden of neurological disorders, whilst campaigning for ongoing patient-relevant research, and the creation of disease-specific data registries in the field of neurology.
- Using this data to advocate for neurological disorders to become a political priority via annual activities and meetings at the EU Institutions.
- Building on existing relationships with and within the EU Institutions, following EFNA's successful involvement in the steering committee for the EC-designated European Month of the Brain.
- Rewarding those who showcase best practice in partnering with patients to advocate for our shared agenda.
- Developing internal and external communication tools and strategies, whilst continuing to produce the EFNA e-news, to update the website and to participate on social media platforms.

- Striving to run an annual awareness campaign on issues of concern to our membership e.g. stigma.

Action Area 2: **PATIENT TRAINING AND CAPACITY-BUILDING INITIATIVES**

- Continuing to provide training workshops to patient representatives from the neurology arena; whilst ongoingly reviewing and assessing unmet training needs and other new training tools becoming available in Europe e.g. EUPATI.
- Providing platforms for our Members to interact, share best practice and avail of peer support, and providing channels and opportunities for patients to influence the scientific and political agendas.
- Disseminating accurate, reliable information gained from EFNA engagement with key opinion leaders and relevant stakeholders – increasing the health literacy of the EFNA membership.
- Equipping and empowering our Members and other patient representatives to be ambassadors for EFNA and within their own disease areas by organising the annual Advocate for Neurology Workshop or similar.

Action Area 3: **PARTNERSHIPS AND ALLIANCE BUILDING**

EFNA will continue its programme of external outreach and representation with:

- Other umbrella health and social NGOs and networks (including the European Patients Forum, European Brain Council, etc.) – ensuring that the issues of those affected by neurological disorders are represented in these fora; whilst sharing best practice, encouraging cooperation and reducing duplication of effort.
- EU-level Health Professional Organisations active in the area of neurological disorders (including the European Academy of Neurology, European Society of Radiology, etc.) – allowing the patient perspective to be central to the scientific research and education agenda.
- National Neurological Alliances and National Contact Points – building a channel of consultation from the national to European platform, and vice-versa. This will ensure we can accurately advocate for those affected by neurological disorders. This channel will also allow us to assess the implementation of relevant Union legislation – alerting us to challenges or gaps as they arise.
- Other health-related partners (industry, clinical practice, patient safety, health economics, etc.).
- EFNA will also reach out to prospective new Members to ensure as wide a representation as possible in this sector.

Introduction

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

This means, that for 2017, we already have the majority of our workplan defined and have simply undergone a process of adding and refining – which will continue as we move forward within the four overarching goals of our strategic plan: advocacy, empowerment, awareness and engagement.

The plan below is divided up amongst these strategic goals, where – for each – we outline our plans for this year and our measures of success, by which we will internally assess our progress and invite you to do likewise.

To successfully meet these measures and implement another ambitious workplan requires the input and support of all our partners and we would like to take this opportunity to request that you please consider getting involved.

Members, partners, sponsors (current and prospective) and allied organisations – please read through the below and let us know if there are areas where you can see possibilities for us to align and work together. This annual workplan is a fluid document that can be adapted and amended as required. Therefore, we value your suggestions for further inclusions or adaptations.

We have endeavoured to keep this document concise, covering top-line plans but allowing scope for change and flexibility in approach.

This will facilitate expansion or contraction of plans, allowing us to be proactive and reactive, but also ensuring that we can adapt based on available resources – both human and financial.

EFNA currently contracts an Executive Director, Senior EU Policy Officer and Communications Coordinator, who work a combined total of approx. 30 days per month – due to budget constraints. Therefore, we see partnership as the most important resource to enable us to roll-out our plans, which were shaped following our General Assembly, Annual Partners Meeting 2017 and subsequent feedback.

Should you have any comments or questions on the contents of this document, you can email our Executive Director, Donna Walsh at: executivedirector@efna.net

We look forward to hearing your thoughts on our plans and working with you in 2017.

Goal 1: Advocacy

Member of the European Parliament Interest Group on Brain, Mind and Pain

2016 was EFNA's most successful year yet, in terms of structured advocacy at the European Institutions. This was made possible through the continuation of the Member of the European Parliament Interest Group on Brain, Mind and Pain.

2017 will mark the half-way point of the parliamentary term and so will see the Interest Group return to familiar topics that were explored in the earlier meetings. The aim will be to recap, assess progress and set out workplans to 2019 (the next date for EU elections), to ensure that the issues identified in our Book of Evidence have been addressed before the current term comes to an end. The Book of Evidence can be accessed here: <https://goo.gl/zv0CDG>

Meeting 1: Access to Employment

The first meeting of 2017 will return – once again – to the topic of employment, which has become the focus of much of our advocacy work at the European Institutions.

This meeting will present an opportunity to raise further awareness of the challenges faced by so many in accessing work, and increase the pressure on European policy-makers to partner with us in devising solutions – with a focus on optimising the European Social Pillar and the upcoming EU Presidencies.

This meeting will be held in partnership with our colleagues at GAMIAN-Europe, and their MEP Interest Group on Mental Health, Wellbeing and Brain Disorders. It will be hosted by our joint co-chair, Marian Harkin MEP.

Meeting 2: Early Intervention

The second meeting of 2017 will take place in July and explore the topic of prevention – from the angle of early intervention. It will be hosted by our co-chair MEP Daciana Sarbu.

The aim will be to show that, indeed, while many neurological disorders cannot be prevented – we can engage in early interventional approaches to delay onset/progression, and to allow an acceptable quality of life to be maintained.

However, to do so effectively, we will be calling on the European Institutions to support this work in terms of sharing best practice, resourcing promising research and raising awareness – which is, ultimately, cost-effective.

This topic will also align with the European Brain Council's Value of Treatment study which is likely to show the socio-economic benefits of early intervention in many brain disorders.

Meeting 3: Featuring - European Academy of Neurology and European Pain Federation

The final meeting of 2017 will be held in partnership with our health professional partners at the European Academy of Neurology and the European Pain Federation – the theme will be set following a meeting with these organisation in mid-2017.

EFNA not only works with our colleagues at Pain Alliance Europe to plan these meetings, but we will also continue to be responsible for engaging MEPs, producing the promotional materials, updating the website/social media, hosting the annual Stakeholders Planning Meeting, etc. Additionally, as we approach the halfway mark of the 5-year Parliamentary term, we will also explore the possibility of commissioning a piece of research to assess the current status/progress of a particular topic of interest, based on one of our calls to action in the Book of Evidence.

Advocacy Awards

In 2016, EFNA held its second Neurology Advocacy Awards. These annual awards recognise the contribution of an individual or group to the development and promotion of advocacy for people with neurological disorders in Europe.

There was an increase in nominations for the 2016 edition of these Awards, which were presented at a well-attended gala dinner. Therefore, we plan to run the awards again in 2017 with categories to be determined by the General Assembly.

Each winner will be presented with a small trophy and certificate, and awarded the title of 'EFNA Honorary Ambassador/Member'. The prizes will be presented at an evening dinner event, which we hope to organise – in 2017 – in partnership with our colleagues at the European Brain Council – who will be celebrating their 15th birthday in 2017.

Success in 2017 looks like:

- EFNA organises three meetings of the MEP Interest Group with each resulting in at least one concrete outcome based around recommendations in the Book of Evidence.
- EFNA to host advocacy awards 2017

Objective 2: Empowerment

Training Initiatives for Neurology Advocates

In 2016, EFNA launched its Training Initiatives for Neurology Advocates [TINA] with a pan-European workshop in Dublin, supported by Trinity College. This event explored patient reported outcome measures and patient-based evidence, with a focus on why patient involvement is particularly important in neurology. This was open to high-level patient advocates from across the continent, representing a wide range of neurological disorders.

Supplementing the pan-European workshop were two national workshops in Bucharest, Romania and Utrecht, the Netherlands – which took a narrower look, from the national viewpoint, at these topics.

Initial feedback has suggested that all events were worthwhile and well received. However, there was clear demand for further attention to be paid to the topic of communication.

Pan-European Communications Workshop

With this in mind, EFNA – working with experts in the field – now plans to host a workshop in April 2017 which will explore how patient advocates can tell their story in the most impactful way. These patient testimonies will be recorded (on video) and developed into a resource for use by EFNA and the individual, relevant patient organisations when advocating to policy/decision-makers and/or raising awareness more broadly. This event will be held in partnership with the European Brain Council, who will also use the recorded testimonies to add a patient perspective to their ongoing Value of Treatment study – which is due for publication in mid-2017.

As a second part of the this workshop, we will also work with representatives of patient organisations on how they communicate the ‘value’ of their work. In this era of scepticism towards the role of non-governmental organisations and the threats to our sustainability, it is essential that we can adequately communicate the importance of our work.

Therefore, EFNA will invite two representatives of each of our member organisations to this event – one patient advocate and one organisational representative. The working title for the event is: Effective External Ambassadorship

Members’ Only Workshops

Another stream of our training initiatives for neurology advocates will be open to members only and will take place at our General Assembly 2017 – organised to coincide with the annual congress of the European Academy of Neurology [EAN]. Again, we will explore the topic of communication but, this time, in relation to working with health professionals. Using the input of representatives from EAN, we will explore how patient advocates can engage effectively in their work e.g. via scientific panels, presentations at training workshops, etc.

A second members-only training initiative will be held on the topic of transparency and governance (see page 12).

National-Level Workshops

At the national level, we are keen to replicate and extend our work. The first step will be a follow-up meeting to our Romanian workshop, at which participants expressed a desire for more ongoing support. However, we would also like to continue to expand our network of national events and – currently – we are planning workshops in Poland and in Spain, in conjunction with our associate partners at Neuropozytywni and Neuroalianza, respectively. We will remain open to approaches from partners to organise events – jointly – in other parts of Europe, in response to need. The programmes for these national workshops will be tweaked to cover the most pertinent issues nationally – decided in consultation with our partners in each country.

Multi-Stakeholder Roundtable

A learning from the workshops in 2016 was that those in attendance were most interested in the practical application of knowledge which is of direct relevance to their day-to-day work – either organisationally or as a patient partner in policy and decision-making, including playing an active part in their own care. Therefore, the theoretical discussions held as part of TINA workshops in 2016 on how we can advocate for changes to the regulatory and HTA systems to facilitate equitable decision-making and access in the field of neurology, were not of such relevance to the attending audience – yet these topics form an integral part of our work. So, in 2017, alongside the training

workshops for patient advocates, we also plan to host a multi-stakeholder roundtable on such high-level topics, which would create a framework to supplement and support the work of our expert patient advocates.

Beyond 2017

Initial discussions have already been conducted with Trinity College Dublin re. the possibility of a certificate-level course being developed for patient advocates, incorporating annual face-to-face training and supplemented by online modules via a system such as MOOC (massive online open courses). These discussions will continue, with a view to producing a syllabus for implementation from 2018.

Success in 2017 looks like:

- EFNA will host one pan-European workshop, attended by at least 40 patient advocates.
- EFNA will host two national workshops, attended by at least 30-40 patient advocates each.
- Feedback from participants at each workshop will indicate that they attained new information and are committed to applying the learnings.
- Participating companies and regulator/payor institutions will more actively involve neurology patients and see the necessity for incorporating patient based evidence to support patient reported outcome measures.
- A three-year training syllabus from 2018 to 2020 will be defined and supported by an academic institution, with an internal faculty convened to support its implementation.

Objective 3: Awareness

Together Under the Umbrella awareness campaign and beyond

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

The aims of this campaign were:

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

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

The campaign was scheduled to actively run for one-year, to March 2017. However, we do not plan to have an official closing of the initiative. The branding, logos, taglines, etc. will be used ongoingly in our work – especially as an integral part of our internal and external communications strategy e.g. through engagement with the membership and co-promotion of activities.

We will also look at how we can optimise specific days/weeks dedicated to raising awareness of brain disorders e.g. Brain Awareness Week and World Brain Day.

During Brain Awareness Week 2017 (March 13th to 19th) we plan to organise a viral photo/video campaign where one organisation/individual ‘passes’ the umbrella to another by tagging them (mentioning them in their social media post). We’ll encourage our members to pass the umbrella to an organisation from a different brain disease area. In this way, we will be highlighting the connections between the various disease areas that come under the umbrella of neurology.

For World Brain Day, July 22nd 2017 we will be active in sharing patient stories from across the wide range of disease areas covered by EFNA. These are currently being compiled and will be further developed through our planned communication workshops and other initiatives this year.

We will look to link with the EBC’s ‘I love my brain’ series of events – possibly using this tagline on our umbrellas at the annual congress of the European Academy of Neurology, where we will host a joint booth in the exhibition centre.

Success in 2017 looks like:

- EFNA will continue to roll-out the Under the Umbrella campaign – with a focus on Brain Awareness Week and World Brain Day.
- EFNA will build and disseminate a library of patient stories.
- EFNA will use the Under the Umbrella concept as the thread through which our internal and external communications activities are shaped; particularly in relation to the development of a framework for improved engagement with our members.

Objective 4: Engagement

EFNA, as a pan-European umbrella organisation, must strive to continually engage with and understand the needs of our current members, reach out to prospective new members and represent their interests accurately to relevant external stakeholders. The overhaul of our Communications Strategy will include individual discussions with our members to better ascertain how they would like to see communication channels to and from EFNA developed.

EFNA must also extend our reach beyond our members and make connections with relevant, multi-stakeholder partners with whom we can work to advance our mutual interests. With this in mind, EFNA will also again hold our interactive Annual Partners Meeting in mid-2017.

Our 2017 General Assembly will be held to coincide with the Congress of the European Academy of Neurology [EAN] from June 24th to 27th in Amsterdam. This is more than just a business meeting. Our annual Ideas Exchange Forum will continue, which gives our Membership the opportunity to share experiences, challenges and concerns with the EFNA Board and their fellow members. There will be presentations from some of our key external stakeholders, allowing our members direct access in shaping the agendas of these organisations and learning more about EFNA’s work on behalf of the wider membership there.

One such stakeholder is the EAN itself. In 2016, EFNA signed a Memorandum of Understanding with the European Academy of Neurology [EAN] to formalise and acknowledge our special working relationship. EFNA has enjoyed meaningful patient involvement within EAN since its conception. In 2016, this included participation on their Training and Education Committee and Liaison Committee, participation of EFNA members on the EAN's sub-specialty, scientific panels, a joint awareness session as part of their annual Congress programme and a booth in the exhibition centre, etc.

In 2017, EFNA will work to see the above participation replicated at the annual congress, where we will also host a joint special session on: *Advanced Treatment and Management – Eliciting Patient Preferences* and a public day exploring *Palliative Care for Neurological Disorders*.

As mentioned above, EFNA will also run a session at the Congress where patient involvement in EAN activities is discussed and the EFNA members are provided with information and training to allow them to do so effectively. This will include an introduction to the internal framework/mechanism of EAN, a glossary of scientific terminology, a workshop on doctor-patient communication and an open dialogue to outline mutual expectations.

Outside of the Congress, EFNA has also agreed with the EAN to have a patient organisation profile – from one of our members – in each monthly edition of their newsletter throughout 2017.

EFNA works closely, too, with the European Society of Radiology (ESR) via its Patient Advisory Group (ESR-PAG). In 2017, EFNA will speak at the ESR Congress on the topic of: *Patient-centered care in clinical radiology: do we really put our patients first?*

EFNA has also been continually involved in the Societal Impact of Pain symposium. In 2016 this included moderating a working group and also participating on the steering committee. This involvement will continue in 2017.

EFNA also represents its members at other organisations such as:

- European Brain Council [EBC]
- European Patients Forum [EPF]
- Patients and Consumer Working Party at the European Medicines Agency [PCWP]
- Think-Tank at the European Federation for Pharmaceutical Industry Associations [EFPIA]
- European Alliance for Access to Safe Medicines [EAASM]
- Europa-Bio Patients Bio-Forum
- BioPontis Alliance

Our involvement in the above groups, ensure that we can bring a neurology perspective to wider discussions on healthcare, including R&D.

Throughout the year, EFNA will also attend, participate and present at other relevant events to which we are invited – including those of our members.

Success in 2017 looks like:

- EFNA will consolidate its relationship with EAN and see a similar level of involvement in its work as compared to that of 2015.

- EFNA to provide training and information to its members to facilitate their involvement in EAN, as outlined.
- EFNA will participate actively at the various other fora outlined above; accurately representing our members' views which will be sought ongoingly in a more structured manner, including at the GA.

Other Objectives: Internal Communications and Governance

Communications

EFNA's Communication Coordinator has devoted her time to the implementation of the awareness campaign in 2016. As the campaign winds-down in early 2017, we will have additional resources available to begin to look more at our internal communications.

This will include an overhaul of www.efna.net and the updating of our Communications Strategy.

A new logo, promotional materials and publications will also be developed to reflect EFNA's current areas of work and to include our growing list of members and partners.

EFNA will also continue to circulate our bi-monthly e-zine and to update our various websites, including: www.brainmindpain.eu and www.undertheumbrella.eu – we shall also continue our active presence on social media, and to develop new platforms for this means of engagement.

There also plans to build a contact database and calendar of events for our members, to allow for cross-promotion of activities and easier correspondence.

Governance

In September 2016, EFNA attended a workshop – coordinated by the European Patients' Forum – which explored governance, transparency and ethics.

Following this workshop, EFNA has been reviewing its governance and assessing its current policies and procedures. It is now likely that an updating and renewal of our Statutes will be required. To complete this process, EFNA will convene an EGM in February 2017.

Alongside the EGM, EFNA will host a Leadership Meeting. To this we will invite the President/CEOs/equivalents from our member organisations (who are not always directly involved in our work, as representatives of their organisations). This will provide us with an opportunity to present our activities and receive feedback on same, from those ordering priorities in our member organisations.

This will also be an opportunity to review our strategic plan 2015-2020 with the wider membership, as we reach the stipulated time for a mid-term review.

A workshop on governance and transparency will also be organised to coincide – with external experts contracted to coordinate.

Fundraising

As mentioned above, sufficient financial resources are necessary for EFNA to implement our annual

workplans. This means that raising funds must remain part of our workplan. In 2017, EFNA will aim to diversify our sources of income and will look at possible fundraising events (e.g. gala dinner awards ceremony), build relationship with new supporters and look to new possibilities e.g. Foundations.

Success in 2017 looks like:

- EFNA will have an approved Communications Strategy, as well as a stock of new promotional materials, leaflets and publications by year-end.
- Official website www.efna.net to be updated.
- EFNA to build a contact database and calendar for our members.
- EFNA to review, update and create policies and procedures, as well as reviewing strategic plan.
- EFNA to remain sustainable at year-end, having implemented all aspects of the annual workplan.

Summary of Keynote Activities 2017

- MEP Interest Group on Brain, Mind and Pain
 - 3 meetings
 - Focuses on Employment, Early Intervention and a joint EAN/EFIC led event
- EFNA Advocacy Awards
 - Awards to be presented at a gala dinner event (possibly in conjunction with EBC)
- Training Initiatives for Neurology Advocates
 - At least one Pan-European, focus on Communication
 - A number of National Workshops – including a follow-up in Romania
 - A selection of events for the membership – including a workshop on governance (alongside the EGM) and a second on patient participation in the activities of the European Academy of Neurology (alongside the AGM)
 - Multi-stakeholder roundtable on a specific policy objective, arising from TINA
- Together Under the Umbrella campaign
 - Online activity to mark Brain Awareness Week and World Brain Day
 - Creation of patient stories
 - Development of Under the Umbrella framework for member engagement
- Development of Communications Strategy and associated publications/tools
- Active participation at the EAN Congress 2017 including:
 - General Assembly,
 - Special session
 - Public day on Palliative Care in Neurology
 - Large booth in the exhibition centre
- Annual Partners Meeting
- External Representation Activities

CALENDAR OF EVENTS

To end-July 2017

The below events are those organised directly by EFNA. It does not include the meetings/events of our members/partners in which we participate throughout the year. A separate calendar shall be created to highlight all such events.

January

Ongoing promotional events for the Written Declaration in Brussels and Strasbourg

February

Board Meeting 1*	Brussels	February 10 th
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March

MEP Interest Group Meeting 1	Brussels	March 8 th
Extraordinary General Meeting* <i>incl. Governance Workshop for Delegates</i>	Dublin	March 22 nd and 23 rd

April

Communications Workshop*	Brussels	May 3 rd to 5 th
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June

National TINA Workshop	Bucharest	June 9 th
EAN Congress, including: *		
- General Assembly		
- Board Meeting 2		
- Special Session		
- Public Day		
- Exhibition		
- Patient Participation Workshop	Amsterdam	June 25 th to 27 th

July

Networking Dinner	Brussels	July 11 th
MEP Interest Group Meeting 2	Brussels	July 12 th
Annual Partner Meeting <i>incl. Leadership Forum</i>	Brussels	July 12 th

* = Costs reimbursed for participants