



Operational Plan 2016

Together Under the Umbrella

Introduction

In 2015, EFNA took time-out from certain projects to review and refocus, whilst introducing some new flagship initiatives to strengthen our advocacy work in Europe.

So, 2016, will be a busy year in which these flagship initiatives (e.g. MEP Interest Group on Brain, Mind and Pain) are continued to be rolled-out, and refined versions of previous EFNA standards are re-launched (e.g. Training and Capacity-Building Workshops).

2015 was also a time when EFNA built new relationships or strengthened ongoing partnerships and is now ready to play a larger part in the central workplan of these important organisations (e.g. European Academy of Neurology).

And... we have exciting plans ahead in driving forward our work on raising awareness with a planned pan-European campaign: *Together Under the Umbrella* – which is also the theme of this 2016 operational plan.

All this planned work could not have been possible without the growth of EFNA's team and with an EU Senior Policy Officer and Communications Coordinator joining our Executive Director, we have been enabled to produce one of our most ambitious plans to date. However, we need to ensure that these roles continue over the longer-term if we are to be able to accomplish the plans set out below.

Of course, the Board also play an important role and each member has taken on additional assigned responsibility for 2016 – acting in an oversight and advisory capacity on many of the projects/initiatives which you will read about over the coming pages (see appendix).

Much of our workplan also requires the engagement and support of our multi-stakeholder partners and so we would encourage you to get involved where there are clearly identified areas of mutual interest. With that in mind, for more information on any of the content contained here, please contact: executivedirector@efna.net and we shall be happy to provide/discuss.

As this plan is derived from the Strategic Plan 2015-2020, it is aimed at progressing the strategic objectives under the priority areas identified therein. Therefore, we preview the activities for 2016 below under the themes of:

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Objective 1: Advocacy

MEP Interest Group on Brain, Mind and Pain

BACKGROUND

In 2015, EFNA – along with our partners at Pain Alliance Europe – launched a Member of the European Parliament Interest Group on Brain, Mind and Pain.

This group will run over the course of the parliamentary term and the aim is to allow us to contribute to the innovative, efficient and sustainable health systems as desired by the European Institutions; by providing a forum to share and exchange best practice, encourage debate and discussion, and lead to tangible actions in the areas outlined in the Interest Group mission statement. This is: *To encourage research into and access to innovative treatments, promote prevention and self-management approaches, decrease stigma and work together to improve quality of life for people living with these disabling conditions.*

The group is co-chaired by MEPs Marian Harkin, Jeroen Lenaers and Daciana Sârbu, with almost 50 additional MEPs already signing a Register of Supporters. For more information you can access the Interest Group website at: www.brainmindpain.eu

Alongside the website, in 2015, EFNA worked to produce a ‘Book of Evidence’ which outlines why brain disorders must be a political priority. Data for this document was collated via literature reviews, focus groups with national and pan-European patient organisations, interviews with industry, health professional and other stakeholder groupings, etc.

The Book of Evidence (which can be downloaded from the website) is divided into 4 pillars:

1. Stigma – Visible and Invisible
2. Improving Investment in Research
3. Patient Involvement
4. Quality of Life – Education and Employment

After the official launch event in 2015, the subsequent meetings focussed on *Health Promotion/Prevention* (June 2015) and *Stigma* (October 2015). After each meeting a workplan is produced (also available on the website), which is pursued by the Interest Group – led by EFNA’s Senior EU Policy Officer. Some of the suggested next steps from Year 1 are reflected throughout this operational plan (see Objective 3: Awareness).

PLANS FOR 2016

The Interest Group will be convened three times in 2016 – provisionally scheduled for February, June and October.

Meeting 1:

The first meeting of 2016 will take place in the European Parliament on February 24th over breakfast at the Members’ Salon. The focus will be on ‘the workplace’ i.e. Pillar 4: Quality of Life – Education and Employment.

Millions of Europeans of all ages struggle with brain, mind and pain disorders. Brain disorders cost around €800 billion each year, 6% of GDP. Chronic pain may be an additional 3% of GDP. Much of the associated costs arise from restricted employment of those affected.

EU social and disability legislation is central to employment and educational opportunities for people with chronic conditions. Although there is no EU definition of the term 'disability' there are many examples of good practice which could be applied e.g. offering all employees with long-term illnesses the possibility to work part-time.

This meeting will look to:

- Share information on good workplace practices such as flexible working hours, basic workstation redesign and special resting areas which can be provided at little or no cost.
- Encourage Member States to use Social Funds which assist best-practice employers to create appropriate working environments.
- Ensure EU social legislation is applied across Member States, to support patients to live economically productive lives by ensuring the maximum level of employment and education possible for themselves and their caregivers.

These issues – or refined versions of same – will then be used to form the basis of a Written Declaration which the MEP Interest Group will strive to have passed in the first half of 2016. If passed, in the latter months of 2016, we will work on a toolkit for its implementation at a European and national level.

Meeting 2:

The second meeting of the MEP Interest Group will address Pillars 2 and 3 – by focussing on 'Patient Involvement in Research and Beyond'.

EFNA is encouraged by the increasing dialogue re. patient involvement but this is coupled with the realisation that the level of understanding and implementation varies enormously. Despite some progress having been made, there is much further to go.

It is right that patients should be involved in helping to shape priorities for research that is publicly funded and ultimately carried out for their benefit, and a growing body of evidence suggests that involving patients in research improves the relevance, quality and/or speed of that research – but we need to define what this means specifically to neurology patient groups. This would also extend to the processes 'beyond' the R&D cycle where patient reported outcomes/patient based evidence can be collated and used to influence subsequent decisions in pricing, access and reimbursement.

During a workshop at the 2015 EFNA General Assembly, it was suggested that an MEP Interest Group Meeting on this topic could be a useful vehicle to begin our work in this area – as it would lead to a workplan outlining the next steps to direct subsequent activities, whilst also generating political support for same. It would allow us, too, to align with ongoing work in this area at the EU level e.g. EU Reference Networks.

So, the event would take the form of a 'Hearing' and would include a respected researcher to outline the benefits of patient involvement, an MEP with a special interest in clinical research and responsibility for EU Regulatory Affairs and an 'expert patient' who can speak of their success is

challenging established practice in another disease area – as well as industry input on how new technology can be used to collate patient based evidence which can then be translated into data capable of influencing decision-making.

This approach then links in with EFNA’s plans in terms of Training and Capacity-Building (see Objective 2: Empowerment).

The final meeting of 2016 may look at the International Classification of Diseases (ICD-11) and how this provides both opportunities and challenges for neurology patient groups. The new edition is due for publication in 2017. However, the topic will not be set until much closer to the date to ensure flexibility should other pressing issues arise.

Objective 2: Empowerment

Training and Capacity-Building

BACKGROUND

EFNA has a long and successful track-record in rolling-out training and capacity building activities, especially via its Patient Academy at the London School of Economics on Health Technology Assessment and, more recently, Pharmaceutical Pricing, Access and Reimbursement.

However, in 2015 EFNA undertook a review of this activity with the goal of redefining and restructuring our approach to training and capacity-building activities to better reflect the current landscape and to ensure its sustainability.

An alumni survey – alongside a strategic planning workshop at the annual Corporate Partners Meeting – showed that the pan-European approach was still a valuable exercise, in spite of recent new initiatives such as EUPATI coming on stream. However, it was felt that the themes of this training should be changed to reflect the need for implementation of the theoretical knowledge gained via the aforementioned initiatives. It was suggested that future training focus on: *‘Patient-Based Evidence: Why? What? How?’*

This theme will allow participants to explore the ways in which evidence can be generated by patients/patient organisations (surveys, registries, etc.) and how it can then be used (to influence regulatory and reimbursement decisions, for example). This, of course, would still mean that a theoretical/conceptual understanding of these processes would be required – but with follow-on interactive sessions on the more practical side of participation.

All agreed that these courses would need to take place over 2 days – at least – and be supplemented by digital learning tools to enable dissemination beyond the 30-40 participants who would undertake the face-to-face training, which was deemed preferable.

Taking information from this pan-European level and making it applicable nationally – considering the principle of subsidiarity in healthcare decision-making – was also put forward as an important consideration. This means that national workshops on the same theme will be organised annually, following the central pan-European event. Those who participate in the pan-European training

could help EFNA in developing these activities in their own countries – in terms of making materials/agendas culturally/language appropriate, identifying speakers/participants, etc.

Other partners/stakeholders should also be engaged e.g. health professionals, researchers, payers and regulators – not just as speakers but as participants in a Mutual Learning Exercise. This would allow participants to explore WHY patient-based evidence is important.

The need to build a support network for the alumni of these courses was also recommended and should be further explored.

PLANS FOR 2016

EFNA will hold two national workshops on the topic of ‘Policy-Making for Patients’. This broad title will allow for national patient representatives – who will be engaged to work with EFNA on planning these courses – to be flexible in terms of setting an agenda that reflects the climate/culture in which they operate. These workshops will be held in Romania and the Netherlands in early 2016.

EFNA will then establish a multi-stakeholder steering committee/expert faculty to work together to plan a 2016 autumn course around the topic of ‘Patient-Based Evidence’ at a pan-European level. This will be one of the Calls to Action from the June 2016 MEP Interest Group Meeting on Patient Involvement in Research and Beyond (see Objective 1: Advocacy). The first meeting of this group will take place in Spring 2016.

The steering committee will be composed of patient representatives, industry partners, academia, health professionals/researchers and members of the decision-making community – drawn from across the EU member states. It will be tasked to plan an agenda for the pan-European workshop, discuss ongoing support strategies for participants, plan dissemination of learning and advise re. sustainable funding streams. The committee will also be encouraged to attend and participate in the workshops as speakers/facilitators/chairpersons.

The first pan-European workshop is scheduled to take place in Brussels during October 2016 – over three days – and will be open to 40 patient representatives from the field of neurology.

It has been decided that future EFNA workshops should focus on the specific challenges faced by neurology patient groups and the obstacles to be overcome. For example, for many of these disorders, symptoms and disease progress cannot be directly measured but must be assessed using questionnaires or interviews with patients. However, regulators now require evidence that a drug/device changes the patient’s real-world functioning as well as improving symptoms. In neurological disorders, where external progress of disease progress are often absent and preferred clinical scales are of limited use, this is a positive step which re-orientates drug development towards the most patient-relevant outcomes. However, if the neurology patient community is to capitalise on this shift, then they need to be empowered and equipped to do so by collating and presenting data that can influence the process.

A review of the October workshop will be carried out at year-end 2016 before plans are made for subsequent years.

Objective 3: Awareness

Pan-European Awareness Campaign: Together Under the Umbrella

BACKGROUND

During the first meeting of the MEP Interest Group on Brain, Mind and Pain – focussing on Health Promotion and Prevention – speakers and participants emphasised the need to raise general societal awareness of neurological disorders.

The EFNA General Assembly also focussed on this point and the need to ‘brand the brain’ by grouping these disorders under a common symbol to create a unified and identifiable ‘brand’ – as part of a year-long campaign. This could indirectly lead to an increase in public, political and scientific support for all such disorders, resulting – ultimately – in a reduction of stigma.

Such a campaign would also provide opportunities for neurology patient organisations to work together at a national and European level, whilst also allowing them to further promote their individual disease areas through awareness-raising, fundraising and advocacy activities. This would clearly align with EFNA’s aims in its strategic plan 2015-2020 re. working with national neurological alliances across the EU Member States.

However, it is clear that EFNA would need to enable, equip and inspire its member organisations to take part in the campaign by providing opportunities for hands-on training with the experts in new and traditional media and from the fundraising and advocacy sectors. To allow for this process, EFNA organised a campaign workshop in Brussels from October 12 to 14th – open to 80 patient advocates drawn from a mix of disease areas and European countries. Those who registered to participate were asked that they return to their own organisations/countries and work with EFNA to roll-out the campaign on the ground.

EFNA also appointed a Communications Coordinator to work on a draft campaign toolkit, to be further refined through the harnessing of feedback from its membership and the wider neurology patient community.

PLANS FOR 2016

In the early months of 2016, the draft toolkit – mentioned above – will be further refined, designed and made available by the EFNA Communications Coordinator, along with downloadable campaign branding materials. These will be based around the common symbol of the umbrella.

The online campaign hub/website – to be coordinated and monitored by EFNA: www.undertheumbrella.eu – will be created and populated. We will also work to develop the central social media channels to be used during the campaign: primarily Facebook and Twitter.

The Communications Coordinator will work with engaged and committed supporting organisations to ‘seed’ the campaign. The initial seeding phase will involve the preparation of content such as images, the development of campaign webpages, outreach to ambassadors/champions, planning of events/initiatives, etc. This will allow for the launch – scheduled to coincide with Brain Awareness Week in March 2016 – to make a large ‘splash’ and to create an initial momentum on which the campaign will build.

It was envisaged that the campaign would begin by asking the patient community (followed by general public, and hopefully including high profile figures) to take a picture of themselves ‘under an

umbrella' using #undertheumbrella and with the following text (or similar): *1 in 3 Europeans fit under the umbrella – do you?* This text will link to the campaign's online hub where key messages, interesting facts/statistics, campaign details, etc. will be displayed – alongside a list of supporting neurology patient organisations and further information on the disease areas they represent. Additional links to these individual organisations will also be provided here.

However, this initial online activity would need to be supplemented by offline events/initiatives: Viral, social media campaigns have a limited shelf-life and follow-up activities will be required to keep the campaign 'alive'. Some flagship events will be organised by EFNA but much will depend on the engagement of patient organisations at the national level.

The toolkit will be a key resources which – as well as containing instructions for dissemination on participation in the online activity – will also include an ideas list with suggestions on how the campaign could be adapted and expanded by the various organisations/individuals involved offline – through communication, advocacy and fundraising activities.

The implementation process of the items on the ideas list will be structured in phased steps – starting with some basic and 'free' activities requiring little resources and ranging to large-scale events for organisations with bigger budgets and staffs. This would facilitate the participation of groups/individuals of varying financial/human resources.

The October 2015 workshop was planned with the aim of providing Initial training on the implementation of the toolkit – but ongoing support will be available through EFNA's Communication Coordinator, so this is a position that will need to be sustained during the lifetime of the campaign for it to be optimally effective.

The campaign could be launched in March 2016 (with a kick-off PR event at the European Parliament) to coincide with Brain Awareness Week and run for 12 months. This would lead up to summer 2017 when EFNA is planning a mid-term review of the success of the MEP Interest Group and associated activities. This would then provide us with an opportunity to see how this general awareness raising/branding campaign could be taken forward to support the advocacy workplan at the European level.

Advocacy Awards

In 2015, EFNA launched its inaugural Advocacy Awards. These awards recognise the contribution of an individual or group to the development and promotion of advocacy for people with neurological disorders in Europe. EFNA recognises that many stakeholders are active in advocating on behalf of patients affected by neurological disorders. In 2015, nominations for these awards could be made in respect of patient advocacy in each of the following categories: Volunteer Patient Representative, Policy-Maker, Health Professional or Health Professional Organisation, and Journalist, Blogger or Media Outlet. There was a Lifetime Achievement Award which was presented to Ms Eveline Sipido (now of the European Academy of Neurology) for her ongoing contribution and commitment to the cause. In 2016, an award for Employer is also to be introduced – reflecting EFNA's planned advocacy in this sphere (see Objective 1: Advocacy).

Nominations will be reviewed – again – by an external judging panel. Each winner will be presented with a small trophy and certificate, and awarded the title of 'EFNA Honorary Ambassador'. The prizes

will be presented at an event during our planned October Training/Capacity-Building Workshop 2016 (see above).

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. In 2016, EFNA will continue to be presented at the below forums:

- European Brain Council [EBC]
- European Patients Forum [EPF]
- European Academy of Neurology [EAN]
- European Platform for Patient Organisations, Science and Industry [EPPOSI]
- Patients and Consumer Working Party at the European Medicines Agency [PCWP]
- Think-Tank at the European Federation for Pharmaceutical Industry Associations [EFPIA]
- European Society of Radiology Patient Advisory Group [ESR-PAG]
- Patient-MedTech Dialogue/EUCOMED
- European Alliance for Access to Safe Medicines [EAASM]
- Europa-Bio Patients Bio-Forum
- BioPontis Alliance

CASE-STUDIES

Health Professionals: In 2015, EFNA participated at the first Congress of the newly-established European Academy of Neurology [EAN].

Here, EFNA hosted a Patient Corner in the Exhibition Centre, held a Public Day (Meet the Experts) on Headache and Sleep Disorders, coordinated the involvement of a patient representative on many of the relevant sub-speciality scientific panel and participated in the EAN's Liaison and Training & Education Committees.

Arising from our participation on the aforementioned committees, EFNA has been invited to submit questions, from the patient perspective, for inclusion in the Teaching Courses at the next congress – scheduled to take place in Copenhagen 2016. (In fact, for Amsterdam 2017, we have been invited to contribute proposals for symposia, case-based facilitated workshops, interactive sessions and focused workshops).

To coincide with this next EAN Congress, EFNA will once again hold our General Assembly. This ensures that our wider membership are given the opportunity to participate in the various activities/initiatives we plan there. For 2016, this will include – again – the Patient Corner and, hopefully, increased numbers of our members participating in the scientific sub-speciality panels. EFNA will also organise a special session in partnership with the EAN – the working title of which is: *Sleep, Sex and Stress: What really matters to patients?* There will also be a public awareness day/'Brain Fair' which will be aimed at the general public and will take forward the messages of the

first MEP Interest Group Meeting on health promotion/prevention. And, there will be an information meeting for carers – with a focus on Huntington’s Disease.

EFNA has also begun to work more closely with the European Society of Radiology (ESR) via its Patient Advisory Group (ESR-PAG). In 2015, EFNA presented on ‘Brain Disorders: The Communication Challenge’ at the European Congress on Radiology during the session: ‘From High Tech to Human Touch Imaging’. In 2016, EFNA will once again be on the programme, this time covering the topic: *‘Patient-centred care in clinical radiology: do we really put our patients first?’*

Industry: EFNA will host its annual Corporate Partners Meeting in 2015 to coincide with our MEP Interest Group Meeting – June 2015. This will ensure that our Members and our Industry Partners can engage in a direct dialogue, enabling our Members to articulate the unmet needs in their specific disease areas.

As mentioned above, EFNA is already active within the EFPIA Think Tank, EuropaBio Patients Forum and Patient-MedTech Dialogue, and will continue to be in 2016.

Summary of Keynote Activities 2016

- MEP Interest Group on Brain, Mind and Pain: Meetings and Associated Activities
- National Patient Advocate Training Workshops: The Netherlands and Romania
- Pan-European Patient Advocate Training Workshop: Patient-Based Evidence
- Pan-European Awareness Campaign: *Together Under the Umbrella*
- EFNA Advocacy Awards
- Active Participation and Associated Events at the EAN Congress 2016
- General Assembly and Corporate Partners Meetings

APPENDIX: GOVERNANCE STRUCTURE

PRESIDENT: Ann Little

- With special responsibility for Communications

- Oversight for Planned Awareness Campaign
- Editorial Role on EFNA Publications
- External Communication with Key Partners
- Internal Communication with Members
- Liaison with Industry Partners/Fundraising

VICE-PRESIDENT: Cathalijne van Doorne

- With special responsibility for Research

Representing EFNA at below organisations

- BioPontis Alliance
- EATRIS - PAC
- Europa-Bio
- European Alliance for Access to Safe Medicines

PAST-PRESIDENT: Audrey Craven

- With special responsibility for Advocacy

- Involvement with MEP Interest Group on Brain, Mind and Pain
- Relationship building with MEPs and other policy-making contacts

(Role during handover period – to be transferred once complete [Period: June 2015 – June 2016])

TREASURER: Bea de Schepper

- With special responsibility for Financial/Legal Policy and Procedures

- Liaison with Accountants, Bank and Notary
- Payment of Invoices/Expenses
- Ongoing contact with Executive Director re. financial policy, planning and fundraising

SECRETARY-GENERAL: Joke Jaarsma

- With special responsibility for Training and Education

- Oversight and involvement in devising EFNA's internal training and capacity building programmes
- Participation in EAN Training and Education Committee
- Participation at the Patient and Consumer Working Group at EMA

BOARD MEMBER 1:

Maggie Alexander

- Liaison to EBC

BOARD MEMBER 2:

Manuela Messmer Wullen

- Liaison to ESR and EPPOSI

BOARD MEMBER 3

Nancy van Hoylandt

- New Board Member

EFNA staffing structure comprised of:

Executive Director – 4 days per week

Senior EU Policy Officer – 3 days per week

Communications Coordinator – 6 days per month