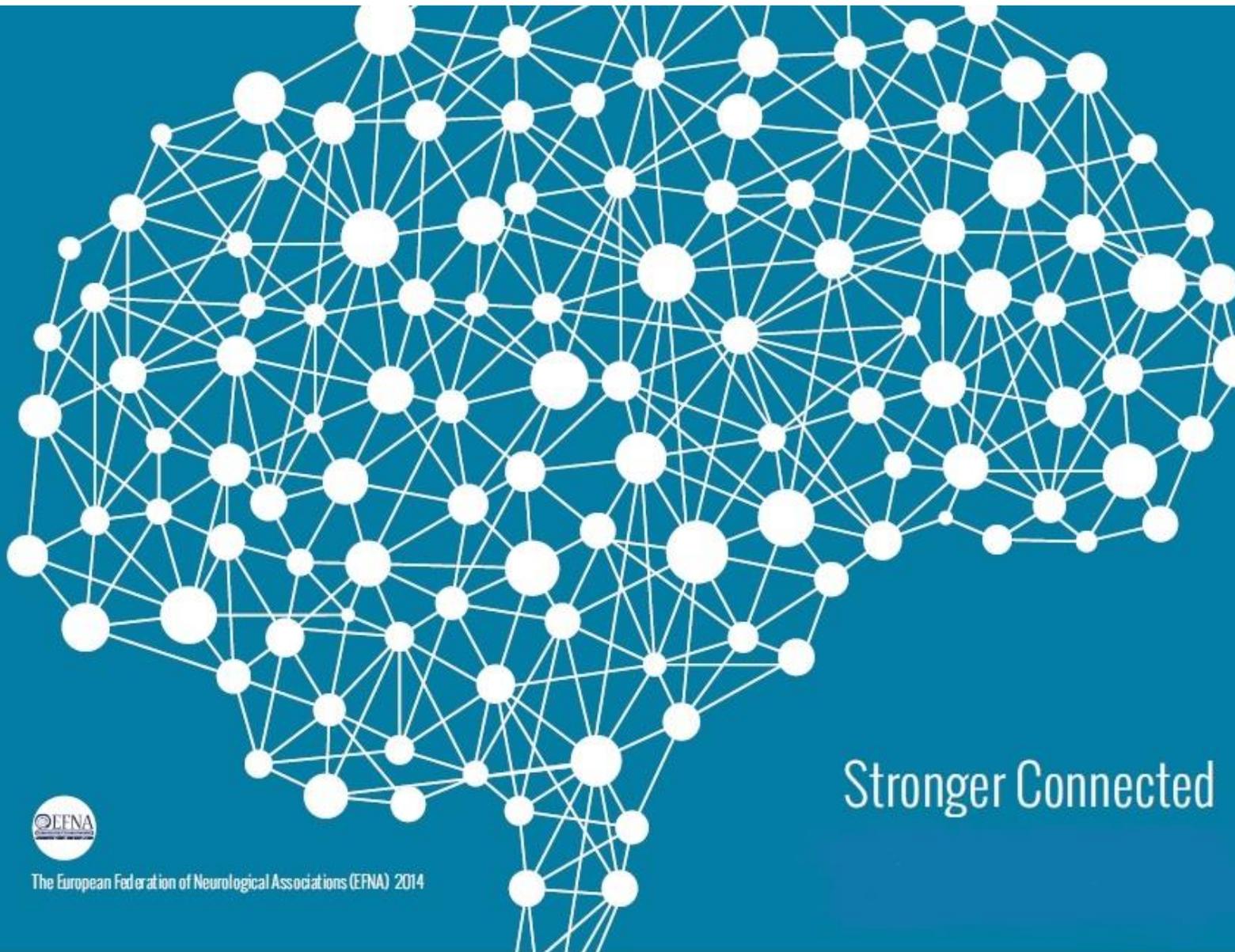


ADVOCATE FOR BRAIN, MIND AND PAIN

- A workshop organised by the European Federation of Neurological Associations



Stronger Connected



The European Federation of Neurological Associations (EFNA) 2014

Hotel Bloom, Brussels
September 24th and 25th 2014

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INTRODUCTION and SUMMARY

In 2015, the European Federation of Neurological Associations [EFNA], together with Pain Alliance Europe, will launch an MEP Interest Group on Brain, Mind and Pain in the European Parliament.

The purpose of this group will be to: *Raise political awareness of the impact of neurological and pain disorders from a biological, psychological, social and economic perspective – towards policy solutions aiming to prioritise these disorders, encourage research, increase access to innovative treatment, improve quality of life and decrease stigma.*

EFNA sees this Interest Group as a forum to highlight the issues and challenges that are affecting neurology and pain patients - and their carers - across the EU member states. It also wishes to showcase the good work that is happening across Europe that could be replicated elsewhere. However, to achieve this aim, EFNA recognises the need to develop a closer working relationship with national patient organisations.

So, on September 24th and 25th 2014 in Brussels, EFNA held its Advocate for Brain, Mind and Pain Workshop to allow for representatives of national neurology and pain patient organisations from across Europe to have their say on the issues that need to be on the European health agenda. This was also an opportunity to identify potential case-studies, speakers and content for the meetings and supporting briefing documents.

A second aim of the workshop was to develop more formal channels of communication between EFNA and the national patient organisations that are most aware of the situation 'on the ground'. Whilst Day 2 focussed on the issues needed to be tabled in Europe, Day 1 focussed on this second aim of creating structures for communication between the national and European platforms.

An introductory presentation from the European Patients' Forum highlighted the growing competence of the European institutions in healthcare. It also outlined examples of how national and European organisations can work successfully in tandem. EFNA would like to replicate the EPF membership structure; encompassing pan-European disease-specific groups and national patient coalitions, by opening its membership to National Neurological Alliances.

Neurological alliances bring together and represent organisations working on a wide range of neurological issues, such as multiple sclerosis, epilepsy, stroke and many more. Alliances allow organisations with similar interests to be heard as a collective voice for greater impact.

At the workshop, EFNA launched Stronger Connected – a guide to building national neurological alliances. This is a collection of experiences and advice from existing alliances. These groups have been successful in putting neurology policy issues on the agenda, sharing experiences and resources, and rolling-out/participating in various projects and initiatives.

The guide can be accessed here: <http://efna.net/national-neurological-alliances/>

This was followed by a Euro-Café (reports below), where participants discussed the benefits and challenges of Alliances, as well as the resources needed, issues that could be tackled and the future format of such groups.

EFNA wants to inspire and encourage organisations in other countries to follow the lead of existing Alliances, as outlined in the guide, and plans to:

- Invite new and existing alliances to become Associate Members, providing a forum for interaction, ideas exchange and peer support
- Develop a two-way channel of communication from the national to European stage, ensuring that EFNA can accurately advocate for those affected by neurological disorders
- Work with national groups to disseminate information, appeal to national MEPs/key stakeholders, organise regional events and inform us of challenges, barriers or examples of best practice which can feed into our activities in Europe

*If you are a representative of a national neurology patient organisation in your country and would be interested in working with EFNA to build an Alliance, contact: executivedirector@efna.net
Existing alliances are also invited to get in touch and get involved!*

On Day 2, attention turned to the issues that participants felt needed to be put on the agenda at the European institutions (report below) – with discussions focussing around four thematic areas: stigma, quality of life, research and patient involvement.

This was followed by presentations on how national patient groups can get involved and benefit from European research and awareness-raising programme, which an emphasis on Horizon 2020, IMI2 and Year of the Brain.

Following a successful two days, EFNA will now take the learnings forward and we finalise our advocacy plans for 2015. Read on for the full report...

Note: The first meeting of the MEP Interest Group is scheduled to take place in February 2015, keep checking www.efna.net for more details.

IS EUROPEAN HEALTH POLICY RELEVANT NATIONALLY?

To set the scene, Camille Bullo and Laurene Souchet of the European Patients' Forum illustrated the increasing relevance of European health policy at a member-state level. They said that although responsibility for the organisation of health systems and delivery of healthcare is the competence of the Member States – with the principles of subsidiarity & proportionality applying – the EU is playing a growing role in healthcare.

Donna Walsh, EFNA Executive Director, commented that the roll-out of the European Semester (a cycle of economic and fiscal policy coordination and surveillance within the EU), meant that the European Commission and financial institutions would be looking at how much member states spent on healthcare. In this climate, she said, it was important for patient organisations to advocate for this expenditure to be seen as an investment and not a cost. She also said that a recent move to place responsibility for pharmaceutical and medical devices from DG SANCO to DG ENTERPRISE was further confirmation of healthcare being approached from an economic perspective.

The speakers explained to participants how the EU legislative process works and how patient organisations can play a role in influencing this process, as well as monitoring the subsequent implementation of European Directives, for example – using the EPF's work on the Cross Border Healthcare Directive as a case-study.

They highlighted how European umbrella organisations and national patient groups can work successfully in tandem. Pan-European Patient Organisations are closer to European decision-makers, in a better place to monitor the legislation at EU level and are better able to compare situations and transfer best practices whenever possible. However, National Patient Organisations are closer to patient and national decision-makers (including Council of the EU), have a greater influence on MEPs from their country, and know more about national-specific situations/realities and national legislation.

One pertinent example of successful partnership was a collaboration between the European Patients Forum and the National Patient Organisation of Bulgaria in working on access to medicines.

Therefore, EFNA would like to replicate the structure of the European Patients' Forum by opening its membership to National Neurological Alliances – as well as to pan-European disease-specific groups. With this in mind, the second presentation entitled 'Stronger Connected' was given by Donna Walsh, EFNA Executive Director. The full EPF presentation can be accessed by following the link in Annex 4.



Pictured: EFNA President Audrey Craven with Laurene Souchet and Camille Bullo of the European Patients' Forum

NATIONAL NEUROLOGICAL ALLIANCES: STRONGER CONNECTED

... As we all know there is "strength in numbers" and therefore Alliances of patient organisations are much more likely to gain access to decision makers and to be persuasive in having a particular course of action pursued ...
- Mary Harney, Former Irish Minister for Health

In recent years, EFNA has stepped up its advocacy efforts on the European stage. From its newly established Brussels-base, EFNA wants to continue to be actively involved in shaping the European healthcare agenda. We need to ensure that neurological disorders are prioritised.

To be most successful, we must develop a channel from the European platform, on which we operate, to the national stage. So, EFNA would like to better engage with existing national neurological alliances, and work to support the development of these groups elsewhere.

Neurological alliances bring together and represent organisations working on a wide range of neurological issues, such multiple sclerosis, epilepsy, stroke and many more. Alliances allow organisations with similar interests to be heard as a collective voice for greater impact.

On Day 1, Donna Walsh, EFNA Executive Director launched Stronger Connected – the EFNA guide to building national neurological alliances, which is a collection of experiences and advice from existing alliances. These groups have been successful in putting neurology policy issues on the agenda, sharing experiences and resources, and rolling-out/participating in various projects and initiatives. So, we want to inspire and encourage organisations in other countries to follow their lead.

This guide can be accessed here: <http://efna.net/national-neurological-alliances/>

As outlined in the summary, EFNA plans to:

- Invite new and existing alliances to become Associate Members, providing a forum for interaction, ideas exchange and peer support
- Develop a two-way channel of communication from the national to European stage, ensuring that EFNA can accurately advocate for those affected by neurological disorders
- Work with national groups to disseminate information, appeal to national MEPs/key stakeholders, organise regional events and inform us of challenges, barriers or examples of best practice which can feed into our activities in Europe

"Having an alliance representing an issue to a policy maker can really save time and also presents as a much more powerful force, with all the individual organisations standing behind the same message. This is great for the broader issues and saves individual organisations repeating the same thing when they come to see me. - John Bowis, Former UK Minister for Health and MEP

Following this presentation, participations were invited to partake in a Euro-Café where they discussed the benefits, challenges and future format of neurological alliances – as well as the issues an alliance can represent and the resources need to do so. A synopsis from each facilitator is included below.

REPORTS FROM THE EURO-CAFÉ

Table 1: Potential Benefits of Alliances

Facilitator: Camille Bullot

Aim: Participants identify multiple benefits of neurological alliances and think about how an alliance might benefit them.

1. Visibility

- a. Neurological diseases are not 'glamorous' (in comparison to other diseases who touch the wider public more easily)
- b. Attracting media attention/media coverage
- c. Especially interesting for smaller groups

2. Fighting together for a common cause, increased impact, louder voice

- a. Ability to identify common priority issues and raise them at national level e.g. medicines access/reimbursement
- b. Choir effect Vs. talking solo: Unique voice for decision-makers so easier to get in touch with national authorities and to raise profile as an entry point/unique interlocutor
- c. Better for lobbying: Increased impact on decision-makers: more voters, more weight
- d. The name and the fact you are trying to cooperate shows good will, willingness to move forward and makes your movement credible: "we were suddenly taken seriously".

3. Sharing good practice and good experiences

- a. Focus on bigger issues (access, social protection, reimbursement)

4. Comprehensive way of tackling co-morbidities

5. Role of national alliances in organising the neurological movement, guiding and structuring it



Pictured: Facilitator, Heather Clarke, reports back following the Euro-Café on Issues that Alliances, rather than individual groups may represent. Read on to find out more...

- 6. Access to national-specific material in a language understandable by all and integration of country-specific information into European initiatives**
- 7. The industry's perspective:**
 - a. Broader platforms are good interlocutors
 - b. Safe way to avoid duplications
 - c. The industry is likely to fund horizontal causes
- 8. Governance and eliminating the risk of competition (between organisations)**
 - a. Common interest must prevail
 - b. Shutting down the egos (of bigger organisations): one organisation = one vote
 - c. "Put the smaller ones in the driving seat".

Table 2: Potential Challenges of Alliances and how they might be overcome

Facilitator: Audrey Craven

Aim: Participants identify and share concerns about potential challenges that alliances might face.

The group suggests ways in which each challenge might be overcome.

1. Funding

- a. Sustainability
- b. Competition in the sector
- c. Ensuring transparency and accountability

Solution: Industry participants stated that it is preferable to support Alliances due to the wider reach and benefit they can deliver.

2. Influence and Power

- a. Larger organisations may wish to dominate
- b. Organisations representing rarer/less disabling diseases may not feel like equal partners with their issues not tabled
- c. Trust can also be an issue between organisations
- d. Competition between the organisation and disease areas can also be problematic e.g. 'my disorder is worse than yours'.

Solution: The first step in establishing any Alliance will be to identify the common issues for all, with equal weighting given to all contributions, and to devise a workplan based on this – adding value to all.

3. Lack of Resources

- a. In addition to funding, there is limited time which individual organisations can commit to the Alliance
- b. Most Alliances also have limited staff, and a staff member is essential for a formal Alliance to be effective
- c. Despite this lack of resources there can be unrealistic expectations amongst the members in relation to what can be achieved by the Alliance

Solution: An 'early win' may lead to increased engagement from members. It is also important to remember that the individual organisations are a source of expertise in themselves.

4. Identity

An Alliance can struggle to find its own distinct identity. It must not duplicate and replicate the work of its members.

Table 3: Issues that alliances, rather than individual groups, might represent

Facilitator: Heather Clarke

Aim: Participants identify particular issues that alliances might be able to work on that individual organisations may struggle to drive forward alone or may not have the time or expertise to address.

The following issues were suggested as topics that Alliances, rather than individual organisations, can tackle:

- Prevention and health promotion
- Early and accurate diagnosis
- Education and Employment Issues for those with neurological disorders
- Challenging stigma and discrimination
- Promotion of the multi-disciplinary team, incl. increasing numbers of neurologist, specialist nurses and other specialities
- Pricing, Access and Reimbursement issues in relation of pharmaceutical, medical devices and services e.g. rehabilitation
- Quality of Life
- Monitoring implementation of national/EU laws
- General advocacy, lobbying and raising awareness
- Empowering and educating patients and adding value and capacity to patient organisations

Table 4: Resources that might be needed for building and managing an alliance

Facilitator: Cathalijne van Doorne

Aim: Participants consider what a neurological alliance in their own country might look like and identify what they would need, in practical terms, to start building an alliance.

The below resources were suggested as useful to National Neurological Alliances

- Access to EFNA network of contact and connections e.g. MEPs
- Evidence to aid advocacy activities, especially in relation to common issues – with specific national data as compared to other EU Member States. The planned *EFNA Patient Experience Survey* was cited as an example.
- Funding is required but identifying sources can be problematic as different patient organisations may have different policies e.g. acceptance of funding from industry (or not). A membership fee could also exclude some groups. Funding is also often restricted to certain projects and cannot be allocated to core costs e.g. staff.
- Despite the above, a staff person is required to drive forward the workplan.
- The individual patient organisations can also be an asset/resource in providing expertise, personnel, etc.

Table 5: The Future Format of Neurological Alliances

Facilitator: Ann Little

Aim: Participants are encouraged to think ‘outside the box’ in how neurological alliances of the future might look. Facilitators frame the discussion within the context of there potentially being fewer resources available in future for alliances but greater opportunities in developing technologies. Participants suggest ideas of how neurological alliances could be developed in alternative formats to maximise limited resources whilst engaging as many people as possible and maintaining impact in the influencing arena.

Most of the discussion in this group was focussed on the use of social media as a means of promotion and dissemination of the activities of alliances. However, it was thought that face-to face-meetings are vital, with Skype and teleconferences useful for interim meetings only. A Digital Platform was discussed with a number of advantages and disadvantages identified:

- It was a means of sharing resources across associations in an efficient manner.
- A closed members section – virtual private network - was likely to be the most useful.
- If the platform offered something extra – such as legal aid, consultancy issues, etc. – it might prove more attractive.
- Patients were more likely to visit the website of an association dealing specifically with their disease so any online forum would be used only by the Alliance members i.e. patient organisations.
- Language could also be an issue in some countries, and also for such a platform at European level.
- Fundraising could be carried out online e.g. auction sites, crowd-sourced funding, etc.
- Facebook and Twitter were mentioned repeatedly as free resources which could be exploited. Apps too were suggested as a tool.

Other ideas of how an Alliance could work outside of a traditional format were to develop informal networks where organisations could partner on specific projects of mutual relevance. One organisation may develop the concept, seek the funding, etc. and could then reach out to potential partners. This could be done using a digital platform as mentioned above. Project based work may also be a more sustainable option as it is generally easier to fundraise for a specific project and it also allows organisations to work remotely without the need for an office space, etc. In terms of office space and personnel, it was suggested that larger organisations may be able to provide a ‘home’ for the Alliance. Staff from the member organisations may also agree to take up a role within the Alliances based around their specific areas of expertise e.g. webmaster, fundraiser, etc.

Pictured: Nadia Radulescu (Romania) and Valentina Malafoglia (Italy) discuss over lunch



REPORTS FROM THE BREAK-OUT SESSION

On Day 2, Donna Walsh outlined the four areas in which the MEP Interest Group would focus its attention: Stigma, Quality of Life, Research and Patient Involvement. These thematic areas had been chosen following wide consultation and narrower scoping meetings. She asked that participants consider what issues are prevalent in their countries in relation to these areas and associated examples, recommendations for tackling these issues at the European level and examples of national good practice. She also asked that other burning issues be tabled for inclusion on the agenda. The below is a synopsis of the discussions.

Stigma

- As a first step we should define what we mean by 'stigma'. This definition should encompass both internal and external stigmas - recognising these two diverse forms, each of which has a different impact.
- In terms of internal stigma, some people will not reveal that they actually live with a condition, even to those close to them. This can impact on employment and quality of life. This can also extend to carers. Patients must also be empowered to speak out.
- Stigma can be created by both visible and invisible symptoms e.g. Chronic Fatigue or Chronic Pain have unseen symptoms and are often not recognised as neurological conditions/disorders, with patients being referred to a psychiatrist!. Conversely, Parkinson's UK are working with UK Breweries and Shopping Malls to train staff in how to recognise the visible symptoms of Parkinson's so they understand that a person appearing 'drunk' may in fact live with Parkinson's Disease.
- Education and awareness of all elements of society including general public, medical practitioners, policy-makers, etc. – and patients themselves – is needed. Sweden has started a campaign targeting these different societal groups via the national authorities (e.g. social insurance) to have these diseases recognised.
- There is also a need to 'brand the brain' in a similar way to cancer; uniting all neurological disorders under the 'brain umbrella'. This could be coordinated by EFNA as part of a pan-European awareness campaign on stigma.
- An early and accurate diagnosis is important to reduce stigma – both internal and external – as well as reducing the fear associated with the diagnosis of a brain disorder. Emotional support may be needed ongoingly.
- There is a need to tackle perceptions that patients are only concerned with accessing social benefits - 'A hand up, not a hand out'.

Quality of Life

- The WHO's 'Participation in the Community' is an important document in influencing ongoing work.

- Although there is European disability legislation, each individual country defines what constitutes a 'disability'. It was agreed that it could be very helpful if EFNA could help define disability and provide a common guidance in terms of neurological disorders.
- It was suggested that the European Commission could be approached to conduct benchmark studies, which would allow us to look at where we have come from, perhaps 20 years ago, where we are now and where we would like to be in the future. This could be in relation to the impact of EU social legislation.
- The impact of neurological disorders on quality of life can run from 'cradle to grave' i.e. (neurological) disadvantage early in life can impact on educational attainment, which in turn can impact on employment opportunities, which in turn can disadvantage a person for life, including their financial standing. Therefore, support early in life is essential.
- It was suggested that we link ongoingly with European organisations working in the field of occupational health e.g. Occupational Safety and Health Associations [OSHA]. A national example was the National Learning Network in Ireland, which retrains people affected by disability and helps them reintegrate into the workforce. It is important to recognise that in many neurological disorders, the intellectual capacity of the person affected remains intact. Therefore, we must promote and embrace new ways of working to enable these people to remain in the workforce longer e.g. working from home, flexible hours, etc.
- The importance of multi-disciplinary teams and self-management were emphasised. It was acknowledged that self-management needed to be considered but, more importantly supported self-management, which allows people to take ownership of their condition, taking responsibility for self, independent of a 'nanny state', but against a backdrop of structured support networks on which people can rely when necessary. There is a role for European institutions in sharing good practice and perhaps issuing guidelines here.
- For multiple sclerosis patients in Poland there exists 'Principles for Quality of Life' in relation to transportation, access to treatment, rehabilitation, etc. This could be replicated in other disease areas at a European level, with the setting of minimum standards based on existing national and disease specific policies.
- The focus for EFNA should be on working in the areas where problems/issues are common to all brain disorder patients e.g. mental wellbeing, unemployment, activity limitation, etc. Although, there is a Cost of Brain Disorders Document from 2010 which can be used to highlight the economic impact, EFNA should focus on the indirect costs e.g. loss of productivity, absence from the workforce, informal carers, etc. EFNA will be generating evidence in this regard via its *Patient Experience Survey*.

Research

- It was suggested that a benchmark study in terms of research into neurological and pain disorders, funded by the EC, be considered. This would provide a detailed track record of European research, to reflect on what had and had not worked and to focus on what we need to achieve in the future.

- Securing funding at European level is a laborious and time-consuming challenge, with no assurance of success. There is a lack of knowledge amongst patient groups as to the funding pots available. It was also acknowledged that some disorders (e.g. chronic pain) lack recognition as disabling disorders in the European Union and struggle to attract funds.
- The need for guidelines on information to patients engaging in a research project was discussed. The clinical trials and transparency directives provide an opportunity to strengthen this provision.
- Personalised medicine was discussed, which led to a conversation on the need for further research, and then back to supported self-management and patient involvement!
- Need to make the research environment more ‘user-friendly’ and to educate/empower patients about why they should get involved and how they can do so. Patients need to be more proactive in seeking opportunities, and also in assessing benefit vs. risk.
- Need for the European Institutions to insist on patients being involved at the early stages of all research activities. No funding should be awarded for EU projects in which active patient involvement could not be demonstrated.
- Research must meet the unmet needs of patients and not serve the commercial or academic objectives of industry/researchers/professional groups. The research programme supported by the European Commission must continue to reflect these unmet needs upon consultation with the patient community.

Patient Involvement

- Patients need to be involved in political decision-making processes – not just in research.
- Patient advocates who participate and decide should be reflective of the real patient community and not professional advocates, nor ‘my favourite advocate’.
- Patients need to be more proactive in securing their seat at the table and empowered to participate as an equal stakeholder.

Other

- ACCESS: Access to Medicines emerged as a key concern for patient representatives in attendance from Eastern Europe. On Day 1, the European Patients’ Forum explained that they are working on developing an EU Parliamentary Interest Group to focus specifically on this topic and information will be disseminated as it becomes available. Donna Walsh also suggested that access issues could be covered under Quality of Life as part of EFNA’s Interest Group.

The workshop finished with two presentations focussing on how national patient groups can get involved and benefit from participation in European research and awareness initiatives.

Patient Involvement in European Research Initiatives

The first presentation was from Dr. Ciarán Duffy, National Contact Point, Horizon 2020 and State Representative, Innovative Medicines Initiative [IMI]. He spoke about these two initiatives in terms of how national patient groups can get involved.

He explained that Horizon 2020 is the EU's 2014-20 programme for research & innovation, providing research for societal challenges, one of which is 'health, demographic change and wellbeing' – the area he felt most relevant to the audience. He explained that the topics had already been set for 2014-2015 but that patient groups needed to brief the Commission on what should be included in the coming years. He explained that a lot of the terminology used in the calls for proposals outlined the importance of patient involvement and patient relevance, and encouraged the patient groups in attendance to proactively seek ways to get involved with research consortia. In fact, in the Executive Summary of the advice from the Horizon 2020 Advisory Group for the 2016/7 work programme, it states: "Patients and citizens must be involved in the whole process, from the design of the research programmes to the dissemination and implementation of results in health and social care, public health and society." He said the IMI purported to be patient-centric and was tackling unmet needs. Currently, neurodegeneration is a priority area.

Cristian Leorin, from the audience, encouraged patient groups to register their interest in being a research partner on the online portal for this purpose (see link in the annex). His colleague, Eloisa Stella, also encouraged representatives of patient organisations to think about becoming project evaluators, which is a paid position for which training is provided and another way of ensuring funded projects are patient relevant.

Dr Duffy summarised his presentation by stating that national groups should be involved in Horizon 2020. However, it can be difficult for these groups to engage directly with the Commission and/or Advisory Group but they can do this effectively via umbrella organisations such as EFNA. They can also reach out to the National Contact Point in their country (see link in annex). Patient organisations must push for a leadership role, he said, by demonstrating their real value to research. It was suggested that a benchmarking exercise be undertaken to assess meaningful patient involvement in European research and to assess whether projects which actively involve patients in the development of the proposal and methodology setting are more successful in accessing funds.

Patient Involvement in European Awareness-Raising Activities

The second presentation was from Tadeusz Hawrot in relation to the Year of the Brain project of the European Brain Council [EBC]. He explained that the EBC initially campaigned for an EC-designated Year of the Brain [YotB]. However, despite garnering significant support, the financial crisis hit and political priorities changed. The EC did, however, designate and support a Month of the Brain in May 2013, and this project was mooted to build on that momentum.

He explained that although the project will not be as large-scale as first conceived, many organisations have been badging their events under the Year of the Brain banner, and using the developed branding. He encouraged groups in attendance to do likewise as the year will encompass 2014-2015.

He also spoke of how the EBC has been linking in with its network of National Brain Councils [NBCs] and equipping and empowering them to be actively nationally in helping with the roll-out of the campaign and beyond. He encouraged the national patient organisations to engage with these NBC's, and to investigate whether such a group exists in their country and to get involved. EBC encourages all NBCs to include patient organisations. Donna Walsh said that if neurology patient groups were operating as an Alliance, then getting a seat at such a table would be an easier task.

To find out more, visit the European Brain Council and Year of the Brain websites. The links can be found in annex 4.

NEXT STEPS

1. MEP INTEREST GROUP

EFNA will use the feedback gained from the Break-Out session to draft a 'Book of Evidence' which will outline why brain and pain disorders should be a political priority, and the areas/issues that need to be tackled immediately. This will also include good practice examples and proposed solutions.

EFNA will launch this document during the first meeting of the MEP Interest Group in February 2015, and subsequent meetings will be shaped around its contents. EFNA will also reach out to participants identified who could provide a personal testimony, case-study or exemplar – for either the Book of Evidence or for presentation at the Interest Group meetings.

The current aims and objectives for the group are as follows:

1. STIGMA: INVISIBLE AND VISIBLE

Many of those affected by neurological and pain disorders report high levels of stigma and social exclusion. Therefore, this Interest Group will:

Work towards the eradication of stigma for patients with neurological and pain disorders, by supporting and enabling patient-led campaigns to raise awareness at a European and Member State level.

We call on the European Institutions to recognise the need for adequate funding to be provided to the relevant patient organisations to enable such a campaign to be rolled-out across the EU Member States.

2. QUALITY OF LIFE: EMPLOYMENT AND EDUCATION

Many of those affected by neurological and pain disorders report lower level of job/educational satisfaction and attainment, with many forced to leave the workplace following diagnosis. Therefore, this Interest Group will:

Aim to ensure the implementation of relevant EU social legislation is effective in the Member States in enabling those affected by neurological and pain disorders to maintain their Quality of Life through remaining in education or the workplace for as long as possible. Recognizing that early access to appropriate treatment can slow down or cease the progression of many neurodegenerative diseases, the group will aim to nurture a policy & regulatory environment that will allow for safe and rapid access to new innovative treatments.

We call on the Commission to undertake/support an assessment of the national implementation of its relevant social legislation for those affected by neurological and pain disorders in its Member States. We call on the Commission to recognize the value of innovative medicines in keeping the European population at work longer.

3. RESEARCH: BASIC AND ADVANCED

The causes of many neurological and pain disorders still remain unknown. In spite of this, investment in CNS research is decreasing due to the high level of uncertainty, complexity and cost. Data registries, a key tool in building disease knowledge, also only exist in a small number of diseases in this area. Therefore, this Interest Group will:

Highlight the need for more investment in basic and clinical research into neurological and pain disorders, to better reflect the burden of disease, and the need for data registries/repositories to build knowledge of disease – whilst highlighting the challenges of research in this area.

We call on the Commission and Member States to continue to support and incentivise basic research in neurological and pain disorders. Today's medical challenges need a stable and predictable competitive environment in which innovation can flourish, as well as a political and regulatory framework that encourages research and development into new medicines and treatments. In particular, regulation should be introduced to encourage/facilitate the creation, maintenance and use of large data sets for research purposes, whilst existing regulations must be more flexible to incentivise and allow for more novel approaches to drug development.

4. PATIENT INVOLVEMENT

Ongoing studies suggest that involving patients meaningfully at the early stages of research, policy-setting and decision-making results is of benefit to all – resulting in more patient relevant outcomes, patient adherence and lower costs. Therefore this Interest Group will:

Showcase the benefits of active patient involvement in health policy setting, healthcare decision-making, research processes (incl. assessment of risk/benefit), etc. – in terms of facilitating innovative and smart approaches to healthcare.

We call on the European Institutions to call for and encourage patient involvement in all patient relevant processes and decision-making bodies, as well as continuing to support/provide tools for patient empowerment.

The first meeting of the MEP Interest Group is scheduled to take place in February 2015, keep checking www.efna.net for more details.

2. NATIONAL NEUROLOGICAL ALLIANCES

As outlined in the summary, EFNA plans to:

- Invite new and existing alliances to become Associate Members, providing a forum for interaction, ideas exchange and peer support
- Develop a two-way channel of communication from the national to European stage, ensuring that EFNA can accurately advocate for those affected by neurological disorders
- Work with national groups to disseminate information, appeal to national MEPs/key stakeholders, organise regional events and inform us of challenges, barriers or examples of best practice which can feed into our activities in Europe

If you are a representative of a national neurology patient organisation in your country and would be interested in working with EFNA to build an Alliance, contact: executivedirector@efna.net
Existing alliances are also invited to get in touch and get involved!

EFNA will also continue to develop a relevant section on our website dedicated to supporting these Alliances – existing and developing – so keep check www.efna.net for more details.

3. OTHER

EFNA will arrange a follow-up meeting with Dr. Duffy to discuss the issues he raised such as benchmarking studies, briefing the Commission/Advisory Group on topics for Horizon 2020, etc.

EFNA will also share these learnings with external stakeholders and identify areas of mutual concern e.g. industry, health professionals, etc.

Our Operational Plan 2015 will reflect feedback received.

ANNEX 1 – PROGRAMME

Advocate for Brain, Mind and Pain

- A capacity building workshop for patient groups

Day 1 – September 24 2014

Registration, Lunch and Networking from 12.00hrs

13.00hrs: Welcome

Audrey Craven, President, European Federation of Neurological Associations

From European Platform to National Stage ... and back!

13.15hrs: Is European health policy relevant nationally? – Focus on European Directives

Laurène Souchet, Policy Officer and Camille Bullot, Membership Officer, European Patients Forum

14.00hrs: Stronger Connected

Launch of EFNA Guide for the Development of National Neurological Alliances

incl. outline of aims and objectives of workshop

Donna Walsh, Executive Director, European Federation of Neurological Associations

Coffee Break: 14.25hrs to 14.45hrs

14.45hrs: Euro Café

Topic: National Neurological Alliances

An Introduction by Existing Neurological Alliances

- *Table 1: Potential benefits of alliances*
- *Table 2: Potential challenges of alliances and how they might be overcome*
- *Table 3: Issues that alliances, rather than individual organisations, might represent*
- *Table 4: Resources that might be needed for building and managing an alliance*
- *Table 5: The future format of neurological alliances*

Coffee Break: 16.25hrs to 16.45hrs

16.45hrs: Feedback from Facilitators of World Café

17.30hrs: Response and Discussion

Moderator: Audrey Craven

Day 1 CLOSE at 18.00hrs

Day 2 – September 25 2014

09.00hrs: Recap of Day 1 and Aims and Objectives of Day 2

Donna Walsh, Executive Director, European Federation of Neurological Associations

From National Stage to European Platform ... and back!

09.15hrs: Break-Out Session

Topic: EU Parliamentary Interest Group on Brain, Mind and Pain

What national issues should be on the European agenda?

10.45hrs – 11.05hrs: Coffee Break

11.05hrs: *Feedback from Facilitators of Break-Out Session and Response*

12.30hrs – 13.15hrs: Lunch

European Initiatives for National Groups

13.15hrs: How can patient groups benefit from European research and funding frameworks – Focus on Horizon 2020 and IMI 2?

Dr Ciaran Duffy, National Contact Point, Horizon 2020 – Health, Demographic Change and Wellbeing

INCL. Questions and Answers Session

14.15hrs: Year of the Brain in Europe – How can we get involved?

Tadeusz Hawrot, Senior Public Affairs Manager, European Brain Council

INCL. Questions and Answers Session

Day 2 CLOSE at 15.00hrs (incl. completion of feedback forms)

15.15-15.30hrs: Goodbye Coffees

ANNEX 2 – PARTICIPANTS LIST

Participants List				
Name	Disease Area	Email	Organisation	Country
Ulf Baumhackl	Multiple Sclerosis	ulf.baumhackl@oemsg.at	Austrian Multiple Sclerosis Society	Austria
Manuela Messmer Wullen	Stroke	messmer.wullen@drei.at	Austrian Stroke Organisation	Austria
Cristian Leorin	Dementia	cristian.leorin@novilunio.net	Novilunio	Italy
Eloisa Stella	Dementia	eloisa.stella@novilunio.net	Novilunio	Italy
Valentina Malafoglia	Chronic Pain	valentinamalafoglia@yahoo.it	ISAL Foundation	Italy
Sabina Gall	Dystonia	distonia.office@gmail.com	Association of Children's Joy	Romania
Crainic Catalina	Dystonia	lina_bumbi@yahoo.com	Association of Children's Joy	Romania
Nadia Radulescu	Myasthenia Gravis	asociatia.miastenia@gmail.com	Romanian Myastheia Gravis Association	Romania
Romeo Beghes	Myasthenia Gravis		Romanian Myastheia Gravis Association	Romania
Gelu Stanulescu	Epilepsy	anber.romania@gmail.com	Romanian Epilepsy Association	Romania
Viorica Cursaru	Chronic Pain	viorica@myeloma.net	Myeloma Euronet/Pain Alliance Europe	Romania
Adina Maria Roceanu	Migraine/Headache	amr2012mar@gmail.com	Headache Society - Romania	Romania
Claudiu Berbece	Multiple Sclerosis	claudiu.berbece@emsp.org	European Multiple Sclerosis Platform	Romania
Ingemar Farm	Migraine/Headache	ingemar.farm@telia.com	Swedish Migraine Association	Sweden
Iza Czarnecka	Neurology	i.czarnecka@neuropozytywni.pl	Neuropozytywni	Poland
Agata Byszewska	Neurology	a.byszewska@neuropozytywni.pl	Neuropozytywni	Poland
Ana Torredemer Mercat	Multiple Sclerosis	presidencia@esclerosismultiple.com	Neuroalianza	Spain
Cathalijne van Doorne	Ataxia	cathalijne.van.doorne@telenet.be	Dutch Brain Council	The Netherlands
Robert Scholten	Dystonia	r.scholten1@chello.nl	Dutch Brain Council	The Netherlands
Heather Clarke	Parkinson's Disease	heather.clarke23@outlook.com	European Parkinson's Disease Association	Belgium
Lia Le Roy	Brain Tumour	info@wg-hersentumoren.be	Study Group Brain Tumours	Belgium
Candice Dillon	Neurology	candice.dillen@scottishneurological.org.uk	Neurological Alliance of Scotland	Scotland
Daragh Bogan	Restless Legs	chair@rls-uk.org	Restless Legs UK	UK
Rachel Evans	Parkinson's	revans@parkinsons.org.uk	Parkinson's UK	UK
John Lindsay	Chronic Pain	john.lindsay66@gmail.com	Chronic Pain Ireland	Ireland
John Farrelly	Chronic Pain	jfarrelly@hiqa.ie	Chronic Pain Ireland	Ireland
Ann Little	Epilepsy	IBExecdir@eircom.net	International Bureau for Epilepsy	Ireland
Audrey Craven	Migraine/Headache	audreycraven@migraine.ie	European Headache Alliance	Ireland

ANNEX 3 – FEEDBACK

ADVOCATE FOR BRAIN, MIND AND PAIN WORKSHOP FEEDBACK ANALYSIS

1. Overall how would you rate this event?

Poor: 0% Fair: 0% Very Good: 28% Excellent: 72%

Comments:

- Thought provoking.
- Better than the last workshop, which was very good in itself!
- If we work together our voice is stronger.

2. How would you rate the presentations at this event? Please consider content, style, relevance, etc.

Poor: 0% Fair: 0% Very Good: 50% Excellent: 50%

Comments:

- **We found out many useful things.**

3. How would you rate the Euro-Café and break-out sessions at the event?

Not Useful: 6% Useful: 11% Very Useful: 83%

Comments:

- **Lots of great ideas, encouragement and good energy among participants.**
- **Could also have had break-out in the afternoon of Day 2 to keep brains alert.**
- **Insightful and dynamic.**

4. How would you rate the organisation of this event? Please consider registration process, delegates' packs, communications, etc.

Poor: 0% Fair: 0% Very Good: 0% Excellent: 100%

Comments:

- **You've been impeccable as usual!**
- **Everything I needed was taken care of – thank you.**
- **Very well organised.**

5. How would you rate the venue? Please consider facilities, location, catering, accommodation, etc.

Poor: 0% Fair: 0% Very Good: 50% Excellent: 50%

Comments:

- **It was a pity that we kept bumping into other groups meeting in the hotel.**
- **Lots of noise from the lift but otherwise excellent. Closer to town centre would have been a bonus.**
- **Fun and charming venue.**

6. How likely would you be to attend another EFNA organised workshop in future?

Not Likely: 0% Maybe: 0% Likely: 39% Definitely: 61%

7. Please list any other topics/issues that you think could be covered by future EFNA Workshops in relation to the training and capacity-building of patient organisations s e.g. communications, fundraising, advocacy, etc.?

Topics

- A. Fundraising Toolbox incl. how to apply for grants**
- B. Advocacy Resources and Strategies**
- C. Communication – focus on how to exploit social media**
- D. Doctor-Patient Communication**
- E. Creating connections and networks – formal and informal**
- F. Empowerment**

8. How likely are you to work towards building a neurological alliance in your country with contacts made at the workshop and support from EFNA? (If applicable)

Not Likely: 0% Maybe: 8% Likely: 62% Definitely: 30%

Note: Responses from those from countries where alliances already exist are excluded

If not, please state why:

- **A formal Neurological Alliance may not be a realistic prospect currently but a network or informal collaboration may be possible. We will continue to communicate and collaborate as a group.**

9. Would you be willing to be interviewed for EFNA publications, participate/speak at upcoming meetings, engage ongoingly with EFNA, etc?

Not Likely: 6% Maybe: 28% Likely: 33% Definitely: 33%

Any other comments:

- **Thank you for this great learning and engaging opportunity**
- **Really useful event – thank you for all your efforts**
- **Thanks for all your work**
- **The format was good for involving and engaging participants**

ANNEX 4– LINKS TO PRESENTATIONS AND FURTHER READING

TO ACCESS ALL PRESENTATIONS, please visit the DropBox here:

<http://bit.ly/1vFRofM>

TO DOWNLOAD STRONGER CONNECTED: <http://efna.net/national-neurological-alliances/>

The link for the national contact points across the EU:

http://ec.europa.eu/research/participants/portal/desktop/en/support/national_contact_points.htm
!

For those interested in registering as an expert:

<http://ec.europa.eu/research/participants/portal/desktop/en/experts/index.html>

Also available in the Dropbox are the below documents mentioned during the presentation of Dr Ciaran Duffy:

- Health Work Programme 2014-2016
- Health Advisory Group report
- IMI-2 Call 2 draft topics available here: <http://www.imi.europa.eu/content/future-topics>
- IMI-2 Strategic Research Agenda

Visit the following websites:

Year of the Brain: <http://www.yearofthebrain.org>

European Brain Council: <http://www.europeanbraincouncil.org/>

European Patients' Forum: <http://www.eu-patient.eu/>