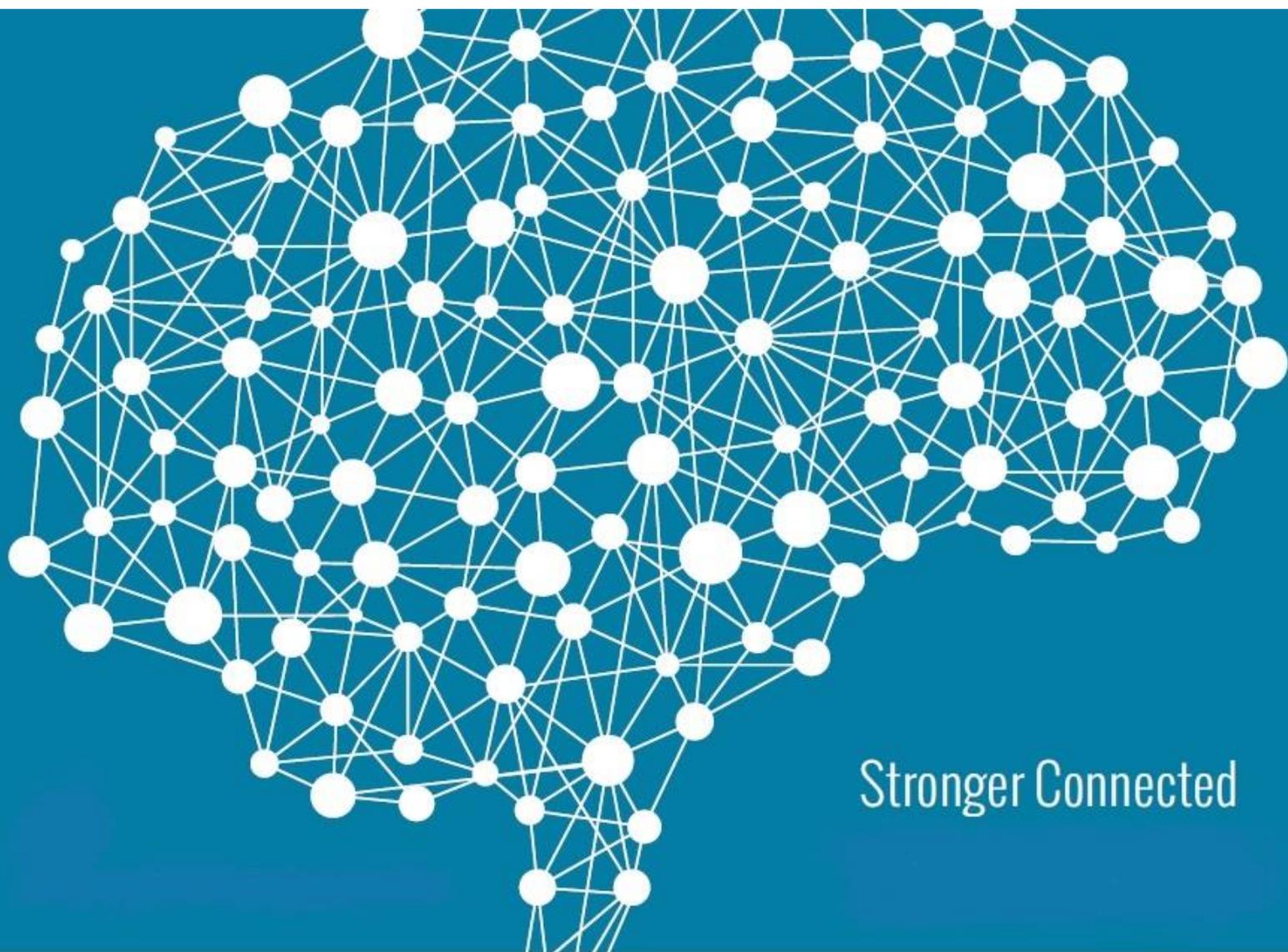




*Empowering Patient Neurology Groups*



Stronger Connected

**EFNA STRATEGIC PLAN 2015 – 2020**



## Foreword

**Audrey Craven, EFNA President**

We are our brains – you may not now be affected by a neurological disorder but your brain has a huge role to play in how you function and cope throughout life.

Brain related disorders, most of them chronic and many degenerative, affect 1 in 3 European. Treating these disorders costs almost €800 billion annually – equating to approximately €1.5 million per minute! These figures are comparable to the cost of cancer, cardiovascular disease and diabetes COMBINED!! However, the investment in neurological disorders does not reflect the social and economic burden.

In this climate, empowering patient neurology groups is not just the slogan of the European Federation of Neurological Associations [EFNA]; it underpins all our efforts in advocating and lobbying for neurology in Europe.

As President of EFNA, I had the privilege of serving on the Scientific Committee for the ‘Healthy Brain: Healthy Europe’ conference held under the Irish Presidency of the EU in May 2013 – billed as a new horizon for brain research and healthcare. We were encouraged to see that all speakers and chairs acknowledged the need for active patient involvement as we strive to reach this new horizon.

The recommendations and conclusions of this conference have been published but we need to ensure that they get from bookshelf to bedside – and the patient community will be a key player in ensuring that we see their implementation in a meaningful and innovative way.

EFNA has come a long way since its creation in 2006. I believe that our current projects and activities have a common thread and a real purpose in helping us to achieve our strategic aims and objectives as outlined throughout this plan.

My thanks to the EFNA staff for their work on this document, and to the Board and wider membership for their contributions in ensuring that the strategy outlined over the following pages will really bring added value to the work of pan-European and national neurology patient organisations, as well as those they serve who live with these disabling disorders.

It is important that all stakeholders come together in what I like to call ‘A Coalition of the Willing’. Everything I heard from the European Commission is about aligning our efforts when competing for scarce resources in times of austerity.

The title of this plan is *Stronger Connected* – reflective of the millions of connections our brains make every day, but also our belief in Partnership for Progress. We look forward to working with all of you as we move forward with our new strategic plan. Remember, there’s nothing that can’t be done if we raise our voice as one!

A handwritten signature in black ink that reads "Audrey Craven". The signature is written in a cursive style.

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Audrey Craven, EFNA President

## About this Plan

Donna Walsh, EFNA Executive Director



Thank you for taking an interest in reading our Strategic Plan 2015-2020: *Stronger Connected*. This plan arises from an internal consultation with the EFNA Staff and Board Members, and was further refined following input from our Member Organisations.

It is divided into a number of sections. The first introduces EFNA; our vision, mission and overarching strategic goals. This is then followed by a narrative of the SWOT analysis conducted by EFNA on the current landscape in which we operate. Combining both, we have then identified our Action Areas which will form the basis of our annual operational plans. Finally, we look at how we will evaluate and measure our progress over the five year time frame.

As you will see, the strategic plan is quite a high-level, general document. We have endeavoured to ensure that this is a concise text which encapsulates our strategic direction, without excessive detail.

Our ongoing work will be further detailed in the operational plans we produce annually. It is important to note that this is not a static document. It is a flexible tool which we will use as the directional basis of our work and it will be amended in view of any change in the internal and/or external landscape.

Should you have any queries, please feel free to get in touch with me at: [executivedirector@efna.net](mailto:executivedirector@efna.net)

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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](http://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:

**Awareness – Advocacy – Empowerment – Engagement**

## STRATEGIC GOALS

### GOAL 1: AWARENESS

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

### GOAL 2: 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 3: 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 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.

## The current landscape

### Increasing Prevalence

Despite the enormous strides that have been taken in the understanding of neurological disorders, healthcare systems in Europe face an unprecedented challenge in dealing with the unmet need associated with this disease area. It is estimated that 1 in 3 of us will develop a brain disorder<sup>1</sup>, and this will increase as Europe's population ages. People aged 65 and over are the fastest growing segment of the population, and this age group is projected to grow to more than 25% of the total population of the European region by 2050<sup>2</sup>. Many neurological disorders are most prevalent in this older age group e.g. dementia. Also, those who acquire a neurological disorder at a younger age are living longer, thanks to modern medical treatments. Therefore, these disorders will only increase in prevalence and, therefore, impact and burden in the coming years.

### Growing Cost

Healthcare costs, in general, are increasing faster than the economy can currently keep up<sup>3</sup>. This is especially problematic in the field of brain disorders where the total cost of brain disorders in Europe for 2010 has been estimated as €798 billion<sup>4</sup>. This is more costly than cancer, diabetes and cardiovascular disease combined! The breakdown of these costs is as follows: 37% direct healthcare costs; 23% direct non-medical costs; and 40% indirect social costs and productivity losses that are often overlooked. These indirect social costs are frequently the ones most difficult to quantify and

<sup>1</sup> Race T, Parkes R, Clark M. *Psychiatric disorders: The 21st century health challenge*. Deutsche Bank Markets Research. Deutsche Bank A/G London 2013

<sup>2</sup> *The European health report 2012*. WHO regional office for Europe, 2013. Available at <http://www.euro.who.int/en/what-we-do/data-and-evidence/european-health-report-2012>

<sup>3</sup> Josep Figueras and Martin McKee, *Health systems, health, wealth and societal well-being. Assessing the case for investing in health systems* (World Health Organisation, 2011), at [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0007/164383/e96159.pdf](http://www.euro.who.int/__data/assets/pdf_file/0007/164383/e96159.pdf)

<sup>4</sup> Gustavsson A, et al. *Cost of disorders of the brain in Europe 2010*. *Eur Neuropsychopharmacol*. 2011; 21: 718–79.

thus overlooked by payors. However, they are also the areas in which patients are the 'experts' and can reflect most accurately. Therefore, further dialogue and patient involvement is needed in these decision-making processes. For many years, EFNA has run training workshops at the London School of Economics for patient representatives on Health Technology Assessment and, more recently, Pharmaceutical Pricing, Access and Reimbursement. We will continue to have training and capacity-building as part of our strategic/operational plans as part of the 'empowerment' strand in our strategic direction.

As the impact of the financial crisis is likely to continue into the foreseeable future, economic considerations will feature prominently in the political discussions around health and healthcare reforms. In this environment, EFNA is eager to ensure that those affected by neurological disorders have an equal say in how these limited resources are allocated. Only by engaging with patients and caregivers, can we ensure that decisions taken will bring the greatest benefit to those affected. Investing in neurological disorders is a smart investment as it will reduce the impact and burden from a socio-economic perspective – benefitting everyone.

### Rising Political Will

Strides have already been taken to ensure that neurological disorders are seen as a political priority in the coming years; a platform which EFNA must now build upon.

In May 2013, the European Commission coordinated the European Month of the Brain, which resulted in ten conclusions and recommendations for advancing brain research and healthcare in Europe. Many stakeholders are now active in working towards the implementation of these recommendations. EFNA must work with these partners – such as the European Brain Council and the CINP – to ensure that tangible progress is made in the coming years.

The current EU Health Programme also lists chronic disease – including neurodegenerative – as a priority area. As many of EFNA members represent those affected by chronic neurological disorders, including the neurodegenerative, we are confident that this new programme will address the unmet needs currently in existence. We will continue to advocate for neurological disorders to be a focus of future programmes and funding frameworks.

### Lack of Understanding

The majority of people are unaware of the prevalence of brain disease and its burden on society – not least because of the stigma surrounding brain diseases.

Also, the field of neurological disorders is fragmented. The classification of neurological disorders provided by the World Federation of Neurology includes cerebrovascular/stroke, dementia/Alzheimer, epilepsy, headache, infectious diseases, movement disorders, demyelinating diseases/multiple sclerosis (MS), neuromuscular diseases and neuro-oncology. Many people know of these disorders individually but do not classify these as neurological/brain disorders.

### Decrease in Investment

EFNA is concerned that the pharmaceutical industry seems to have abandoned the CNS arena in recent years. At least three global pharmaceutical companies announced the closure of their neuroscience divisions worldwide in 2011, with four others significantly downsizing their CNS

operations<sup>5</sup>. This is despite the growing cost and prevalence of neurological disorders, as outlined above. Clearly, this is creating a huge unmet need.

Improved therapies for serious neurological disorders would positively impact Quality of Life and ability to function for those affected, leading to improved labour productivity and a reduction in healthcare costs and overall burden on society. However, this area is not seen as a good investment for industry as there is a higher failure rate in CNS; with those drugs that do succeed taking longer to get through both the development and regulatory processes<sup>6</sup>. With a shorter patent life for these drugs, the speed of generics coming to market reduces potential profits.

Unless something is done to address these regulatory hurdles and incentivise neurological research and development, then many Europeans – and Europe – will continue to be impacted by these disorders.

### Limited Resources

Although EFNA is a pan-European umbrella organisation, representing 21 – and growing – member groups, our staffing capacity is just 1FTE. Clearly this limits the levels of work in which we can actively engage.

Financial constraints too impact on the ability of EFNA to achieve all of its desired activities. Too often funding received is allocated to specific projects and essential core costs such as staffing, board meetings, etc. are more difficult to sustain.

However, with an active and engaged Board – working on a voluntary basis – and wider membership, EFNA can draw upon this energy, enthusiasm and expertise to advance our workplan.

## **ACTION AREAS**

Bearing in mind EFNA's aims and objectives, as well as the current landscape in which we operate, this section of the strategic plan describes in general terms the areas of action in which EFNA will focus most of its work in order to meet the strategic objectives identified above. These action areas will frequently encompass more than one strategic objective in the areas of: Advocacy, Awareness, Empowerment and Engagement. The more specific initiatives to be rolled-out in these areas will be detailed in our annual Operational Plans.

### **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.

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<sup>5</sup> Skripka-Serry J. The great neuro-pipeline 'brain drain' (and why Big Pharma hasn't given up on CNS disorders). *Drug Discovery World* Fall 2013; 9-16

<sup>6</sup> Riordan H and Cutler N. The Death of CNS Drug Development: Overstatement or Omen? *Journal for Clinical Studies* 2011; 3: 12-5

- 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 (and beyond); 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.

## **EVALUATION**

EFNA has set the below performance indicators in relation to the strategic goals identified. These will be reviewed during a mid-term assessment in 2017, and the plan adjusted based on the results if required.

EFNA will be satisfied with progress if we meet the below performance indicators in each strategic area by 2020:

### **1. AWARENESS**

- EFNA will have implemented an effective Communications Strategy, which will focus on both internal and external communication.
- EFNA is successful in leading a pan-European awareness campaign on raising awareness of neurological disorders, which will lead to greater societal understanding/acceptance and the eradication of stigma.

### **2. ADVOCACY**

- EFNA will have held at least three annual events within the European institutions, a part of which will include a platform for the sharing of best practice and cooperation, whilst also highlight inequalities between the EU Member States. The focus of these events will be in the area of stigma, quality of life, innovation and research. Guidelines/recommendations arising will be disseminated widely.

- EFNA will have generated evidence on the burden and impact of neurological disorders, which – combined with current biopsychosocial evidence – will have enabled us to position neurological disorders as a political priority.
- EFNA will have supported the creation of at least one National Neurological Alliance each year and will be successful in engaging with these groups where they exist.
- EFNA will have been successful in influencing decision-making, in line with patient perspectives and preferences, in areas of concern as identified by our membership and in encouraging the creation of data registries.

### 3. EMPOWERMENT

- EFNA will hold at least one training and capacity-building initiative annually, including workshops at a national level.
- EFNA will hold an annual ideas exchange forum for our Members at our General Assembly on topics of common concern which will influence the EFNA Operational Plan.
- EFNA will be successful in creating opportunities for our membership to be part of the relevant decision-making processes at a European and national level.

### 4. ENGAGEMENT

- EFNA will be a respected and equal partner of the European Academy of Neurology, in which our member groups will be active on the relevant scientific panels and other committees.
- EFNA will host an annual corporate partners meeting at which we will highlight our unmet needs to industry and outline our plans for ongoing, transparent collaboration on areas of common interest.
- EFNA will continue to table the interests of our membership and those they represent at the various fora convened by our partners and key stakeholders in the field.
- EFNA will attract, on average, one new member annually – totalling five by 2020.

## **CONTACT**

To contact EFNA, please email: [executivedirector@efna.net](mailto:executivedirector@efna.net)