EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

YOUNG PEOPLE AND HEALTH ADVOCACY

2018 PROJECT PROPOSAL

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YOUNG PEOPLE AND HEALTH ADVOCACY

In 2018 the European Federation of Neurological Associations [EFNA] plans to focus attention on young neurology patients. Our goal is to create a programme that assists young people in becoming advocates for their own disease areas. This pan-European programme would engage young people from across the continent, with the potential to be recreated at National level through our member organisations.

EFNA represents 20 European and International associations across a wide variety of neurological disease areas such as multiple sclerosis, epilepsy, migraine and ADHD. Consensus among our members is that young people are currently under-represented in their associations. It is also felt that the issues facing young people affected by brain and brain-related disorders are not getting the public or political attention they should.

Those living with chronic illness face a number of additional burdens as young people. Often they are unable to complete their education, unable to take a place in the workforce, fear they will not find a romantic partner or have to watch their peers participate in activities they cannot access. Comorbidity between neurological diseases and mental health disorders such as depression and anxiety is common. These comorbidities increase disease burden and stigma – issues acknowledged across our membership.

PROJECT PLAN

A steering committee will be convened in early 2018 to assist in the development of the project. It is envisaged that the steering committee will be drawn from younger members of our Partners, Associates and Member Organisations.

EFNA plans to conduct a pan-European survey of 18 - 35 year olds living with neurological disorders. The survey will explore problems faced by this age group, as well as their feelings around levels of understanding of their disorder and their engagement in advocacy work or patient groups. Based on our research, a survey of this type has not been conducted in Europe.

The survey will be completed online, and promoted with the assistance of our Members and Associates via social media and newsletters. It will be launched during Brain Awareness Week 2018 (March 12th - 18th). Preliminary findings of the survey will be announced at the 4th Congress of the European Academy of Neurology (EAN), taking place in Lisbon, Portugal from June 16th - 19th.

EFNA's exhibition stand at the congress will raise awareness of issues arising from the survey and will highlight the contrast between the lives of young people with and without brain disorders. Findings of the survey will be published on World Brain Day 2018 (July 22nd).

In November 2018 EFNA will host a workshop in Brussels specifically for young neurology patients entitled *'Patient Advocacy in the Digital World'*. Up to 40 Europeans aged 18-35, living with a wide variety of neurological disorders, will be invited to participate in this two-day event, the first of its kind in the EU. A series of workshops will explore how participants can raise awareness of the

issues identified and advance their proposed solutions. Sessions will include:

- **How to influence change and lead in your community**
- **Social media for advocacy**
- **Advocacy at EU level (eHealth)**
- **Building an online community**
- **Debate - Patient organisations in the modern world**

Participants will have the opportunity to attend the Brain, Mind and Pain MEP Interest Group at the European Parliament, where young people's issues will be the focus of the day. The EFNA Advocacy Awards will also take place during the event. This year's awards will be for young people, with categories for Young Advocate, Young Policy-Maker and Young Health Professional.

Following the workshop, participants will be tasked with completing a digital advocacy project (such as a blog post or campaign proposal). Support will be provided by EFNA and national patient organisations. Engagement with these projects, along with participant feedback, will be measured to assess the programme's success.

Our work with young people throughout 2018 will provide a platform from which we plan to launch a political campaign in 2019, to coincide with the European Parliament elections. Here we will bring the issues of young people living with neurological disorders to the attention of the newly elected MEPs, whom we will work alongside to create change during their 5-year terms and beyond.

SUMMARY

Our goal is to create a programme that empowers young people affected by brain disorders to become advocates for their own disease areas. This goal addresses an unmet need as recognised by EFNA's membership - a need that spans the areas of health and society. Development of this programme will see a group of young adults exposed to new ideas and new technologies and empowered to engage with patient groups and the wider community to advocate for the issues of most importance to them.

FUNDING/LEVELS OF SPONSORSHIP

EFNA is seeking funding from a consortium of industry partners to support the roll-out of this project. Support will have:

- **Company's name and logo on associated materials.**
- **Invitation to attend and participate in meetings as an observer**
- **Invitation to any planning meetings or associated roundtables.**

Should you require further information or more detailed agendas for any of the above events, please let us know.