



TRAINING INITIATIVES FOR  
NEUROLOGY ADVOCATES

## PATIENT ADVOCACY IN THE DIGITAL WORLD

BRUSSELS: NOVEMBER 19th – 21st

## PROSPECTIVE PARTICIPANT PACK

[Register here before Friday, September 21st](#)

This event is organised by EFNA as part of the Training Initiatives for Neurology Advocates [TINA] programme:



And sponsored by:



## INTRODUCTION

The European Federation of Neurological Associations [EFNA] is an umbrella group representing 20 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. EFNA's aims are to improve the quality of life of people with neurological disorders, their families and carers by working in four strategic areas: **Advocacy, Empowerment, Awareness and Engagement.**

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.

For these reasons, EFNA is focusing attention on young neurology patients during 2018. Our goal is to create a programme that assists young people in becoming advocates for their own disease areas.

The 'Patient Advocacy in the Digital World' workshop, will take place in Brussels from Monday, November 19th - Wednesday, November 21st, as part of EFNA's Training Initiatives for Neurology Advocates [TINA] programme.

The workshop will cover topics such as: How to Influence Change and Lead in Your Community - Social Media for Advocacy and Building an Online Community, Working with Patient Organisations, eHealth and Technology-enabled Solutions - Artificial Intelligence for Europe, Ethics and the Emerging Issues in eHealth and a Value Assessment of Digital Products.

The EFNA Advocacy Awards will take place on the evening of Day 2. Participants will be welcome to attend.

On Day 3 participants will also have the option to attend a meeting of the MEP Interest Group on Brain, Mind and Pain, taking place at the European Parliament.

## PARTICIPANT PROFILE

Participating patient advocates should have the motivation to learn about these topics and to contribute to the discussions. Accordingly, places are open to individuals who meet all the following requirements:

1. **Be a Young Neurology Patient:** Participants should be aged between 18 and 35 years and living with a neurological condition. Participants should be resident in Europe.
2. **Have a keen interest in the topic** and want to learn more about how digital tools can be used to support, empower and influence the neurology community.
3. **Be willing to commit to applying the knowledge and skills learned.** Each workshop participant is required to complete a small digital advocacy project as part of this programme. You might choose to create a blog or blog post, make a video or write a campaign proposal. Projects may be personal or conducted in association with a patient association. There will be time during the workshop to discuss and refine your ideas but work should be undertaken following the workshop and we will liaise with you to see how it is progressing. All projects will be shared during Brain Awareness Week 2019 (March 11-19).
4. **Possess good working knowledge of the English language.** All presentations and course documents will be made in English. There will also be interactive workshops to which participants will be expected to contribute and comprehend.
5. **Be available** to travel on the relevant days and be prepared to do so within the framework of EFNA's Expenses Policy (€250 travel allowance + two nights accommodation) – or be willing to cover additional costs (see policy below).



## AGENDA

### PATIENT ADVOCACY IN THE DIGITAL WORLD

Day One – Monday, November 19th 2018

**12.00 – 13.00hrs**

**Lunch**

**13.00 – 13.30hrs**

**Welcome and Introductions -  
Donna Walsh, EFNA Executive Director**

#### *Young Neurology Patients' Survey*

**13.30 – 14.00hrs**

**Presentation of Survey Results -  
Elizabeth Cunningham, EFNA Communications Manager**

**14.00 – 15.00hrs**

**Discussion -**

- Round-table discussion of survey results
- Do feelings in the room reflect the results?
- Which outcomes are seen as most important?

**15.00 – 15.30hrs**

**Coffee Break**

#### *How to Influence Change and Lead in Your Community*

**15.30 – 16.00hrs**

**The Power of Storytelling -  
Emma Lawton, Parkinson's campaigner & author  
Case-study and Q&A**

**16.00 – 16.30hrs**

**Building an Online Community -  
George Pepper, Founder of Shift.ms  
Case-study and Q&A**

#### *Working with Patient Organisations*

**16.30 – 17.00hrs**

**Discussion -  
What are the advantages and limitations of working with patient organisations?**

**17.00 – 17.45hrs**

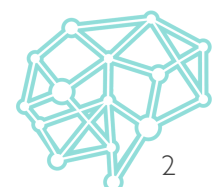
**Group feedback & recording of outcomes**

**17.45 – 18.00hrs**

**Conclusion and end of day**

**19.30hrs**

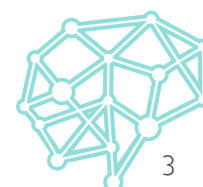
**Informal dinner**



Day Two – Tuesday, November 20th 2018

*eHealth and Technology-enabled Solutions*

- 9.30 – 10.00hrs**      **Artificial Intelligence for Europe -  
What does it mean for health policy and patients?**  
Cécile Huet (Deputy Head of Unit Robotics & AI, European Commission)
- 10.00 – 10.30hrs**      **Digital Transformation – Optimising the Patient Journey**  
Presentation on digital applications being developed for neurology patients  
Kim Baden-Kristensen, Co-founder & CEO at Brain+
- 10.30 – 11.00hrs**      **Ethics and the Emerging Issues in eHealth -  
Marcello Ienca**, Postdoctoral Researcher, Health Ethics & Policy Lab,  
Department of Health Sciences and Technology, ETH Zurich will explore ethical &  
policy issues associated with new and emerging technologies for healthcare.
- 10.30 – 11.00hrs**      **Panel discussion -**  
Our speakers will discuss the subjects covered and answer questions from  
workshop participants.  
Moderator: **Frederic Destrebecq**, Executive Director, European Brain Council
- 11.00 – 11.30hrs**      **Coffee Break**
- 11.30 – 12.30hrs**      **Workshop: Value Assessment of Digital Products -**  
Fewer digital health products than expected are being deployed in real-world  
clinical settings. This may be related to complaints that, in practice, these products  
have failed to deliver on the promise that they will lead to improved quality and  
outcomes and reduced costs in the management of chronic diseases.  
- What are our expectations of a product? What makes a successful product?  
Led by: **Monika Benson**, MyBrain.net
- 12.30 – 13.30hrs**      **Lunch**
- Advocacy in Action*
- 13.30 – 13.50hrs**      **#LifeGoals vs #BrainLifeGoals**  
EFNA present our planned campaign for 2019. The campaign will bring the issues  
of young people living with brain disorders to the attention of the EU's newly  
elected MEPs.
- 13.50 – 15.30hrs**      **Workshop: Let's Put our Brains Together!**  
In groups, participants will brainstorm ideas relating to EFNA's upcoming campaign  
and pitch their idea to the wider group.
- 15.30 – 17.00hrs**      **Next Steps...**  
Each participant is required to complete a short digital advocacy project as part of  
this programme. Participants will have time to refine their idea and present to the  
group for feedback.
- 18.30 – 22.00hrs**      **EFNA Advocacy Awards Dinner** **\*\* ATTENDANCE OPTIONAL \*\***



Day Three – Wednesday, November 21st 2018

**Brain, Mind and Pain MEP Interest Group** **\*\* ATTENDANCE OPTIONAL \*\***

**8.30 – 10.30hrs**

**Meeting of the Brain, Mind and Pain MEP Interest Group at the European Parliament**

Agenda will focus on the future of health care.

## DELEGATE EXPENSES POLICY

The below information is for delegates attending this upcoming EFNA organised meeting. Here we set out the general criteria for reimbursement. Each delegate will be asked to confirm that they have read and agree to the terms of this policy when registering online.

- EFNA will pay up to 250euros towards the travel costs of each overseas delegate. This is to include flight, parking, bus/train tickets, etc. If this is exceeded, the delegate (or their organisation) will be asked to cover the balance of costs.
- EFNA encourages participants to make the most economical choices when making travel arrangements to events.
- EFNA will only reimburse participants AFTER the event – and not before.
- EFNA will only reimburse participants who complete the official Expenses Claim Form and attach proofs of expenditure e.g. flight tickets.
- EFNA will only reimburse expenses that are accompanied by original receipts. Photocopied proofs will not be accepted.
- EFNA asks that claims are returned within one month of the event. Expenses submitted more than three months after the event may be rejected.
- EFNA will provide accommodation for each delegate for two nights – November 19th and 20th. Additional nights can be booked via EFNA (subject to availability) but the cost must be covered by the participant/their organisation.
- Meals will be provided throughout the two-day event. Therefore, no additional food/beverages will be covered.
- EFNA will only reimburse economy standard travel. First class travel will only be reimbursed at the equivalent economy cost.
- EFNA will only reimburse ground travel by public transport and will not reimburse private or taxi costs – unless no other options are available or private costs are less than or equivalent to public.
- EFNA will only reimburse long-term parking rates at the airport, short-term/business/premium parking will not be covered.
- Delegates driving long-distance to events will only have mileage covered if this is cheaper than available flights/public transport, and this must be approved in advance.
- Delegates with accessibility requirements should get in touch with EFNA to discuss travel/transfers and accommodation needs.
- EFNA asks that delegates give at least one week's notice of cancellation if they cannot attend. Otherwise, the delegate will be held liable for the cancellation costs incurred.

**Note:** *The above guidelines may be waived in exceptional circumstances but agreement must be reached with EFNA in advance. EFNA retains the right to reject expenses claims that do not comply with the above rules. Please contact EFNA if you wish to discuss.*

**Contact:** Elizabeth Cunningham, EFNA Communications Manager - **Email:** [communications@efna.net](mailto:communications@efna.net)

