



TRAINING INITIATIVES FOR
NEUROLOGY ADVOCATES

Science for Advocates

(Neurology)

@ FENS Forum, Berlin, Germany: July 6th and 7th 2018

- In partnership with the Federation of European Neuroscience Societies [FENS]

**Venue: H10 Berlin, Ku'damm Hotel
Joachimsthaler Straße 31-32
D-10719-Kurfürstendamm
BERLIN, GERMANY**

READ ON THE FIND OUT MORE
AND [REGISTER HERE](#) BEFORE FRIDAY JUNE 8TH

This event is organised by:



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AGENDA

Friday, July 6th

Morning

Arrivals to Berlin

From 12.30

Registration & Lunch

14.00 – 14.15

Welcome

Chairperson: Joke Jaarsma, EFNA Board Member

14.15 – 14.45

An Introduction to Basic Neuroscience

What is it and why should patient advocates care?

Monica di Luca, President, European Brain Council

14.45 – 15.15

Making the Unknown Known

What next for neurology patients?

Gaia Novarino, FENS-Kavli Network of Excellence and Assistant Professor,
Institute of Science and Technology Austria

15.15 – 15.30

Q&A

15.30 – 16.00

Coffee Break

16.00 – 16.30

Ethics and the Emerging Issues in Neuroscience

Exploring ethical & policy issues associated with advances in neuroscience

Marcello Ienca, Postdoctoral Researcher, Health Ethics & Policy Lab,
Department of Health Sciences and Technology, ETH Zurich

16.30 – 16.45

Q&A

16.45 – 17.15

Case-Study: Animal Research

*How and why patient advocates can help improve public understanding of
animal research*

Kirk Leech, Executive Director, European Animal Research Association

17.15 – 17.45

Discussion - with all speakers and audience participation

Moderator: Donna Walsh, EFNA Executive Director

17.45 – 18.00

Concluding Remarks, Preview of Day 2 and Close of Day 1

Alexis Willett, Punch Consulting/Day 2 Facilitator



19.30

Dinner at the hotel

Saturday, July 7th

9.00 **Introduction to Day 2** with Punch Consulting: Alexis Willett, Liam Drew & Caroline Philpott

9.25 **HOW TO ...**

Facilitated by Punch Consulting: Alexis Willett, Liam Drew & Caroline Philpott

- **WORKSHOP 1:** *Breakout Room: London*
Find science. Find quality – Where to find scientific information and how to appraise it
There is a lot of science and data out there that have the potential to provide compelling supporting evidence in a campaign but it can often seem inaccessible or overwhelming. This workshop will provide insight into where to look for relevant science and how to make sure it offers good quality data.
- **WORKSHOP 2:** *Breakout Room: Barcelona*
Build a strong foundation – How to capture credible data and develop a strong evidence base
The data you require for a campaign may not always be available and you may need to generate it yourself. While you may not have the expertise and resources to run clinical trials, you may want to capture data through surveys or focus groups, for example, or build a broader picture by pulling together a range of data sources. This workshop will focus on how to design strategies to capture credible, high quality data, as well as how to develop a strong and compelling evidence base, for maximum impact.
- **WORKSHOP 3:** *Breakout Room: Rome*
Turn evidence into action – How to effectively communicate science to raise awareness and influence decision-making
You may already possess plenty of data to underpin your campaign but want to know how you can use it most effectively to get your message across. This workshop will consider different ways to communicate science, focusing on target audiences and desired outcomes.

10.50 ***Coffee Break***



11.15 **PLAN FOR ACTION**

Facilitated by Punch Consulting: Alexis Willett, Liam Drew & Caroline Philpott

Working in groups, you will design a political or public awareness campaign, based on a controversial issue in neuroscience that will be provided. The aim will be to devise a work plan, based on learning from the workshops, and create a campaign pitch to deliver to a judging panel in the next session.

12.50 ***Lunch***

13.50 **TIME TO PITCH**

Each group will deliver their campaign pitch and outline their proposed campaign strategy to a judging panel – who will provide feedback and choose a ‘winning’ campaign.

14.45 Keynote Closing Address: Topic to be confirmed

15.30 Open Feedback, Close and Departures before 16.00hrs



PARTICIPANT PROFILE AND ELIGIBILITY CRITERIA

This pan-European workshop, held as part of EFNA's Training Initiatives for Neurology Advocates [TINA], has been designed to equip and empower neurology patient advocates with the information and skills needed to understand, access and communicate basic neuroscience, to improve their advocacy efforts.

Taking place as a satellite session to the FENS* Forum – this 'Science for Advocates' event will draw on the expertise of Europe's leading neuroscientists and other relevant players in the field.

Day 1 will provide a theoretical introduction to the topic, with tangible examples of how basic neuroscience has led to real progress in the treatment and management of neurological disorders. We will also explore emerging trends and controversial scientific issues in neuroscience, from the patient perspective. And we will discuss how we can build relationships between the researcher and patient communities, working together for our mutual benefit.

Day 2 will be an interactive, workshop-based opportunity to apply this knowledge. Delegates will be divided into groups where they will learn: how to access credible science, build their own evidence base (e.g. via surveys) or effectively communicate science to achieve change. This will be followed by a peer learning activity which will allow the participants to design and pitch a fictional public awareness or political campaign around a controversial issue of their choice.

Places are open to individuals who meet the following requirements:

1. **Be a Neurology Patient Advocate:** Participants should be an employee or volunteer of a neurology patient organisation at either a national or European level. However, patients with a neurological disorder or a family member/carer who are active advocates or interested in getting more involved (but not yet formally associated with a patient organisation), will also be considered.
2. **Have a keen interest in the topic** of neuroscience and be willing to actively contribute to the discussions and interactive workshops, as well as a commitment to applying relevant learnings in the course of their own work/activities.
3. **Possess working knowledge of the English language.** All presentations and course documents will be made available in English. There will also be interactive workshops to which participants will be expected to contribute and comprehend. Those who cannot work efficiently in English should, therefore, not attend.
4. **Be available** to travel on the relevant days and be prepared to do so within the framework of EFNA's expenses policy (250euros travel allowance + one night's accommodation) – or be willing to cover additional costs (see policy below).

Note: EFNA strives to ensure fair opportunity for each member organisation to be represented. Therefore, each member/disease area is allocated two places. A waiting list will be used and places awarded if/when they become available.

* FENS = Federation of European Neuroscience Societies



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 one night – Friday, July 6th. 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: Donna Walsh, EFNA Executive Director E: executivedirector@efna.net T: 00-353-879830816