



*Empowering Patient Neurology Groups*

## **PUTTING THE NEUROLOGY PATIENT PERSPECTIVE AT THE HEART OF RESEARCH AND BEYOND**

**FOCUS ON: PATIENT REPORTED OUTCOMES AND PATIENT BASED EVIDENCE**  
**A training initiative from the European Federation of Neurological Associations**

**Thursday, October 13<sup>th</sup> – Friday, October 14<sup>th</sup> 2016**  
**Trinity Biomedical Sciences Institute, Trinity College**  
**Dublin, Ireland**

### **Prospective Participant Pack**

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**THE TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES [TINA] HAVE  
BEEN MADE POSSIBLE THANKS TO OUR SPONSORS AND SUPPORTERS:**



## DRAFT AGENDA

### Day 1: THURSDAY, OCTOBER 13<sup>TH</sup>

13'20h Welcome and Outline of Day 1

*Chairperson: Donna Walsh, Executive Director, European Federation of Neurological Associations*

13'30h What do patients need to know about Neuroscience?

*Prof. Orla Hardiman, Professor of Neurology, Trinity College Dublin  
Consultant Neurologist, Beaumont Hospital, Dublin*

14'00h Integrating Patient Reported Outcomes into Neuroscience Research and Beyond: The Role of the Patient Advocate

*Prof. Melanie Calvert, Professor of Outcomes Methodology, Institute of Applied Health Research, University of Birmingham*

14'30h Discussion, Questions and Answers

15'00h Coffee Break

15'30h Generating Patient-Based Evidence to measure Patient Report Outcomes: The Role of e/m-Health

*Dr. John Dinsmore, Health Innovation Lead & Deputy Director, Centre for Practice and Healthcare Innovation, Trinity College Dublin*

16'15h Discussion, Questions and Answers – close of Day 1 at 16'45h

16'30h *Bus for overseas delegates leaves for Clontarf Castle Hotel*

### Day 2: FRIDAY, OCTOBER 14<sup>TH</sup>

08'30h *Bus for overseas delegates leaves hotel for Trinity College Dublin*

09'30h Outline of Day 2

*Chairperson: Ann Little, President, European Federation of Neurological Associations*

09'40 **Beyond Research: How do we value care? vs. How should we value care?**

Are patient reported outcomes and patient based evidence really considered in health investment decision-making?

*Prof. Charles Normand, Edward Kennedy Chair in Health Policy and Management, Trinity College Dublin – to be confirmed*



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*Followed by Questions and Answers & Discussion. Coffee Break from 10'30 – 11'00h.*

## **MULTI-STAKEHOLDER INTERACTIVE WORKSHOPS**

### **From Theory to Practice – A CASE-STUDY**

Note: Participants will enrol for one workshop only.

**11'00h**            **Introducing the Case-Study:**  
*Donna Walsh, Executive Director, European Federation of Neurological Associations – with representative of the European Headache Federation (to be confirmed)*

**11'30h**            **Interactive Workshops**

#### **Topic 1: Generating Patient Based Evidence**

- Awareness Raising and Advocacy
- Patient Relevant Evidence of Impact and Burden
- Post (conditional) Reimbursement Real-World Data

#### **Topic 2: Communicating, Negotiating and Advocating a Patient Perspective to:**

- Health Professionals and Researchers
- Policy and Decision-Makers
- Industry

#### **Topic 3: Guiding Principles for Patient Partnerships with:**

- Industry
- Health technology assessment (HTA) bodies
- Regulatory bodies

**13'00h**            **LUNCH**

**14'00h**            **Reporting Back and Panel Discussion: Putting the Neurology Patient Perspective at the Heart of Research and Beyond**  
*Moderated by: Audrey Craven, Past President, European Federation of Neurological Associations*

**15'30h**            **Conclusions and Closing Address**  
*Moving Forward as Empowered Patients: European Patients Forum*

**15'50h**            **Presentation of Attendance Certificates by Trinity College Dublin**

**16'00h**            **Coffee and Departures**

## PARTICIPANT PROFILE AND ELIGIBILITY CRITERIA

The pan-European workshop, held annually 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 influence decision-making during the Research & Development [R&D] process, and beyond – in areas such as pricing, access and reimbursement.

With a focus on patient reported outcome measures and patient based evidence, the course will explore why the engagement and involvement of patient advocates from the neurology sector is particularly important, and how this can be achieved.

Participating patient advocates should have the motivation and skill-set to acquire and apply expert-level knowledge across the whole spectrum of the neurology R&D process, and beyond. Accordingly, places are open to individuals who meet all 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.  
*Note: Health professionals and researchers – working in the field of neurology – who also want to learn more about how to involve patients in their work and how to partner towards influencing pricing, access and reimbursement decisions are also invited to participate. Sponsors are also invited to attend as observers.*
2. **Have a keen interest in the topic** of getting involved in the development of patient reported outcomes and the generation of patient based evidence to influence the R&D processes and beyond. Participants should also have – at least – a basic knowledge of some of these concepts already.
3. **Be willing to commit to applying the knowledge and skills learnt.** This also extends to working with EFNA to develop workshops at the national level, which are language and culturally appropriate and open to a wider number of interested participants who may not meet the high-level criteria for the pan-European course.
4. **Possess 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. Those who cannot work efficiently in English should, therefore, not attend.

5. **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*).

## 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 – October 13<sup>th</sup> – at Clontarf Castle Hotel. 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.



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*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, Executive Director

E: [executivedirector@efna.net](mailto:executivedirector@efna.net) T: 00-353-879830816

## LOGISTICS/TRIP PLANNING

**Interested in participating? The first step is to register officially online.**

**You can access the registration form here: <https://goo.gl/yToBzN>**

**Once you receive confirmation of your attendance, then you can begin to make travel plans.**

- Overseas delegates are asked to make their own travel arrangements. As outlined in the expenses claim policy, EFNA will reimburse up to 250euros only.
- After arriving at Dublin Airport, delegates should come straight to the workshop venue by the Airlink Service – Number 757, which runs every 20 minutes. This costs 6euros one-way (or ten euros return) and will be reimbured by EFNA. EFNA will not reimburse taxi costs, should you chose to travel by car. To save time you can buy your ticket in advance (otherwise you will need to queue and have the exact amount in coins). For more information, see: <http://www.dublinbus.ie/en/Your-Journey1/Timetables/Airport-Services/>
- Delegates should disembark at Bus Stop No. 399 (Pearse Street, Westland Row) and walk just a few steps (less than 1 minute!) to the venue: Trinity Biomedical Sciences Institute, Trinity College Dublin, Ireland. Here is a map showing the location of the bus stop and the workshop venue: <https://goo.gl/maps/PPBQsEApBau>
- Registration will be open from 9'15h to 13'15h – you are free to leave your luggage and enjoy the city until the event starts. A tour of the Book of Kells Exhibition at Trinity's famous Long Room Library will be open to early arrivals/ interested delegates from 11'20h to 12'20h. Anyone interested in participating, should assemble at the workshop registration desk for departure at 11'00h sharp.
- A buffet lunch will then be served at the workshop venue from 12'30h to 13'15h.
- Following Workshop Day 1, a bus will take delegates to their accommodation at Clontarf Castle Hotel for group check-in: <http://www.clontarfcastle.ie/> One night's accommodation will be covered by EFNA, including breakfast.
- That evening, delegates staying at the hotel are invited to participate in a Gala Dinner where EFNA's Annual Advocacy Awards ceremony will take place. This is a formal occasion and will be followed by entertainment.
- On Day 2, a bus will leave Clontarf Castle Hotel at 08'30h for the workshop venue in Trinity College. Delegates are advised to check-out and take their luggage to the venue, where it will be stored. This will allow delegates to depart straight to the



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airport on Friday evening to take flights home. Again, delegates are asked to take the Airlink. Delegates should give themselves at least 1 hour to get to the airport during Friday evening traffic.

- For any other queries, please get in touch! We hope to see you soon in Dublin.