



AGENDA

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

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

Thursday, October 13th – Friday, October 14th 2016
Trinity Biomedical Sciences Institute, Trinity College
Dublin, Ireland



Day 1: THURSDAY, OCTOBER 13TH

13'20h **Welcome and Outline of Workshop**
Donna Walsh, EFNA Executive Director

Chairperson: *Ann Little, EFNA President*

13'30h **Neuroscience – What Patients Need to Know**
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 **Questions and Answers, followed by discussion**

15'00h **Coffee Break**

15'30h **Generating Evidence to measure Patient Report Outcomes: The Role of e/m-Heath**
Dr. John Dinsmore, Health Innovation Lead & Deputy Director, Centre for Practice and Healthcare Innovation, Trinity College Dublin

16'00h **Questions and Answers, followed by discussion – close of Day 1**

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

Day 2: FRIDAY, OCTOBER 14TH

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

09'30h **Welcome and Outline of Day 2**

Chairperson: *Ann Little, EFNA President*

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 Professor of Health Policy & Management at Trinity College Dublin and Senior Investigator, All Ireland Institute of Hospice and Palliative Care

10'15h **Questions and Answers, followed by discussion**

MULTI-STAKEHOLDER INTERACTIVE WORKSHOPS

From Theory to Practice

Note: Participants will participate in one workshop only – as indicated.

- 10'30h** **Introducing the Workshops incl. Context-Setting Exemplar**
- Donna Walsh, EFNA Executive Director
- Jane Whelan, Migraineur and General Manager, European Headache Alliance
- 10'50h** **Coffee Break**
- 11'30h** **Interactive Workshops**
- Topic 1: Exploring Patient-Generated Evidence**
Facilitator: Dr Derick Mitchell, CEO, Irish Platform for Patient Organisations, Science and Industry
- Topic 2: Optimising Social Media to Communicate a Patient Perspective**
Facilitator: Marie Ennis-O'Connor, Social Media Strategist and Digital Engagement Professional
- Topic 3: Guiding Principles for Patient Partnerships with Relevant Stakeholders**
Facilitator: Audrey Craven, Past President, European Federation of Neurological Associations
- 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, EFNA Past President, with contributions from all facilitators and/or designated rapporteurs
- 15'10h** **Conclusions and Closing Address: Moving Forward as Empowered Patients**
Camille Bullot, Membership & Stakeholder Relations' Manager, European Patients' Forum (EPF)
- 15'30h** **Presentation of Attendance Certificates by Prof. Orla Hardiman of Trinity College Dublin and Ann Little, EFNA President**
- 15'45h** **Evaluation**
- 16'00h** **Close, Coffee and Departures**



**Special thanks to Trinity College Dublin
for their support in organising this event.**



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

This workshop has been made possible through unrestricted educational grants from the below sponsors, who have had no direct influence over the final agenda – including the selection of topics, speakers, case-studies, etc. The objective of this meeting is to upskill neurology patient advocates to participate in the R&D process and beyond – and the outcomes will be disseminated in an appropriate manner to allow for this objective to be met.

