

## **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**

**Saturday, November 5<sup>th</sup> from 08'30h**  
**PGO Support, Daltonlaan 600, 3584 BK**  
**Utrecht, NETHERLANDS**

### **Prospective Participant Pack**

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## DRAFT AGENDA

**From 08'30h Arrivals, Registration and Coffee**

**09'00h Welcome and Opening Address**

*Chairperson: Joke Jaarsma, Secretary-General, European Federation of Neurological Associations*

**09'10h What is Neuroscience?**

An Introduction to How the Brain Works and Current Research Trends

*Prof. dr. Jeroen Pasterkamp, Professor of Translational Neuroscience, UMC Utrecht*

**09'40h Patient Involvement in Neuroscience Research**

*What? Why? When? How?*

*Cathelijne van Doorne, Secretary-General, European Federation of Neurological Associations*

**10'10h Discussion, Questions and Answers**

**10'30h Coffee Break**

### **From Research and Development to Pricing, Access and Reimbursement**

**11'10 Dutch Pharmaceutical Policy**

How do we value care? VS. How should we value care?

**PANEL DISCUSSION** – *facilitated by: Dr Nick Guldemond, Integrated Care Expert, Value of Treatment Programme, European Brain Council*

**Including:**

- A Patient Perspective
- An Industry Perspective
- A Regulatory/Payor Perspective

**12'30h Lunch**

### **From Theory to Practice**

**13'30h Communicating, Negotiating and Advocating a Patient Perspective to:**

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

*Bettina Hausmann, Executive Trainer and Coach*

**15'30h Conclusions, Coffee and Departures by 16'00h**

## PARTICIPANT PROFILE AND ELIGIBILITY CRITERIA

### Training Initiatives for Neurology Advocates

Dutch National Workshop, Utrecht, November 5th 2016

*This national workshop, 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, applications are open to individuals who meet all the following requirements:*

1. **Be a Neurology Patient Advocate in the Netherlands:** 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.
3. **Be willing to commit to applying the information and skills learnt** and to provide feedback to EFNA on how this knowledge was applied subsequently. This may also include joining an alumni network.
4. **Be available** to participate in this Saturday workshop and to cover their own travel costs. EFNA will be unable to cover travel costs so interested participants should cover their own costs or secure reimbursement from their own organisation.

*Note: All presentations will be given in Dutch – so no knowledge of English is required.*

## LOGISTICS/PARTICIPATION PLANNER

Interested in participating? The first step is to complete the online registration form, available at: <https://goo.gl/forms/3M8N5tWqUBzC3Jq13>

Once you receive confirmation of your registration, then you can proceed to make your travel arrangements using the below directions.

Please remember, we are unable to reimburse the travel costs of participants.

### Venue Address and Details

PGO Support  
Daltonlaan 600 3584 BK Utrecht

Email: [secretariaat@pgosupport.nl](mailto:secretariaat@pgosupport.nl)  
Telefoon: 030 2040 700  
Website: <http://www.pgosupport.nl/>

PGOsupport is een onafhankelijke netwerkorganisatie, die versterking en ondersteuning biedt aan alle patiënten- en gehandicaptenorganisaties die landelijk werken. Waar nodig leveren wij ondersteuning op maat.

### Directions

[Routebeschrijving PGOsupport voor de auto](#)

[Routebeschrijving PGOsupport voor fiets en OV](#)

**Special thanks to the Dutch Brain Council  
for their support in organising this event.**



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.

