

TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES [EFNA]

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Strategic Focus Areas

ADVOCACY

AWARENESS

EMPOWERMENT

ENGAGEMENT

Empowerment

To ensure that our member organisations are empowered and supported to be active in advocating for neurology, and provided with the opportunities and channels to do so effectively.

Background

- * 2009 – Early 2016: Workshops on Pharmaceutical Pricing, Access and Reimbursement (HTA) at London School of Economics
- * 2016: Alumni Survey
 - * Need to run more practical workshops for application of learnings at a national level – culturally and language appropriate
 - * Focus on specific challenges in neurology
 - * Multi-stakeholder approach
- * Late 2016: Launch of Training Initiatives for Neurology Advocates

Activities 2016/2017

2016

- * Two national workshops in Romania and the Netherlands
- * Pan-European Workshop at Trinity College Dublin on Patient Generated Evidence and Patient Report Outcomes

2017

- * Pan-European Workshop on Effective External Ambassadorship
 - Brussels, May 3rd and 4th.
- * Three national workshops planned in Romania (follow-up), Spain and Poland
- * Development of an associated policy arm – Focus on HTA

Logistics

- * Industry Funded (from European/International Pot)
- * National Coordinator
- * Partnership with local patient organisations
- * Desire to diversify partners and participants
- * Inexpensive and sustainable

NBC Involvement?

As a way to....

- * Build contacts with patient groups
- * Identify and create partnerships around areas of mutual interest nationally – alliances for awareness and advocacy
- * Upskill patients/patient advocates to better understand and be involved in your work
- * Learn what matters most to patients and how to optimise their participation in your activities

What have we covered before?

- * Introduction to Neuroscience
- * Focus on Health Technology Assessment (How do we value care?)
- * Integrating Patient Relevant Outcome Measures in R&D and beyond
- * Creating and optimising real-world Patient Generated Evidence
- * Effective External Ambassadorship
- * Shared Decision-Making
- * Developing Guiding Principles for multi-stakeholder cooperation

Discussion

What should we cover next and where?

Are you or someone you care about affected by a brain disorder?

GET TOGETHER **#UNDERTHEUMBRELLA**
ON WORLD BRAIN DAY

Join in
JULY 22ND



Take a photo of yourself under an umbrella and post it here to raise awareness!



Keep in touch!

- * Sign up to receive our bi-monthly EFNA e-zine
- * Visit: www.efna.net, www.undertheumbrella.eu and www.brainmindpain.eu
- * Follow us on Twitter and Facebook
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