



TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES

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TINA is coming to Poland!

How to become your own advocate?

Workshop for Polish patient organisations representing those affected by brain disorders

Warsaw, 1 December 2017, 9.00 – 16.30

Training Center Adgar Ochota, Al. Jerozolimskie 181B, 02-222 Warsaw, Poland

Healthcare design and delivery should be organized, first and foremost, around the needs of patients. In this context, it is important that patients are equipped with the right tools so that they can understand how best to communicate their needs and influence healthcare policy and decision-making as effectively as possible – for example: defining research priorities, participating in R&D, understanding and influencing regulatory and payor models, engaging in shared decision-making and advocating for post-treatment support.

The European Federation of Neurological Associations (EFNA) responded to this need by launching, in 2016, its Training Initiatives for Neurology Advocates. Through a series of events conducted at both pan-European and national levels – and tailored to the actual needs of patients and their carers – it offers to invaluable support to patient advocates in improving and refining their advocacy efforts. The overarching theme of the initiative is putting neurology patients at the heart of research and beyond.

One of the upcoming TINA workshops will take place in Warsaw, Poland on 1st December 2017, with the participation of a Member of the European Parliament Bogdan Wenta and Polish Ombudsman Adam Bodnar. It will focus on the three areas that have been identified by Polish patients as priorities: i) what is Health Technology Assessment and why is it important for patients, ii) how to create an effective awareness campaign and iii) how to build partnerships for progress. The three “hands-on” workshops will offer concrete tools providing both theoretical insights and tips for practical application.

AGENDA AND REGISTRATION DETAILS BELOW



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AGENDA

9.00am Welcome

Izabela Czarnecka – Walicka, President, Neuropozytywni Foundation

9.15am Opening Statements

- ***We are all Patients***
Bodgan Wenta, Polish Member of the European Parliament
- ***Rights of Patients = Rights of Citizens***
Adam Bodnar, Polish Ombudsman
- ***Understand, protect, preserve, develop and nurture your most vital asset: The Brain***
Prof. Maria Barcikowska, Polish Brain Council
- ***Getting to know the brain with Brain Atlases***
Prof. Wiesław Nowiński, Creator of Human Brain Atlases

Followed by Q&A

10.30am Coffee break

11.00pm – 12.30pm 1st round of workshops

Note: Participants should register for two of the three workshops –one in the morning and the second in the afternoon.

Group A - What is Health Technology Assessment [HTA] and why is it important for patients

Moderated by Paulina Kieszkowska-Knapik

- Introduction to HTA
- Overview of process in Poland
- Exploration of current mechanism for patient involvement
- Discussion on how to optimize patient involvement

Group B - How to create an effective awareness campaign

Moderated by Foundation of Social Communication

- Developing a campaign message
- Creating a campaign strategy
- Disseminating the message, for example - to and through:
 - Media channels (new and traditional)
 - Policy platforms
 - Offline events and initiatives
 - Measuring success



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Group C - How to build partnerships for progress

Moderated by Anna Kupiecka OnkoCafe

- Identifying potential partners and key opinion leaders
- Developing guidelines for partnerships with other stakeholders incl. industry
- Optimizing partnerships to reach decision-makers
- Generating/presenting evidence to influence policy/decision-making

12.30pm – 1.30pm: Lunch

1.30pm – 3.00pm: 2nd round of workshops

3.00pm: Coffee break

3.20pm: Reports from groups and discussion

4.20pm: Concluding remarks and launch of joint statement/declaration – arising from the discussion

(proposed declaration reiterating a need for a Polish Brain Plan, having patients' needs at its centre)

THE TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES [TINA] HAVE BEEN MADE POSSIBLE IN 2017 THANKS TO OUR SPONSORS AND SUPPORTERS:

