EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

PROPOSAL FOR TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES

2018

TRAINING INITIATIVES FOR
NEUROLOGY ADVOCATES

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OVERVIEW OF 2017

In 2017, EFNA ran the following Training Initiatives for Neurology Advocates [TINA]:

- **A pan-European two--day workshop in Brussels on Effective External Ambassadorship**
- **A follow-up one-day workshop in Romania on Science, Storytelling and Social Affairs**
- **National workshops in Spain and Poland, focussing on HTA and Communication**

More details can be found here: https://www.efna.net/projects/training-initiatives/
Based on the feedback from the above workshops, we have devised the below proposed structure for TINA 2018.

PLANS FOR 2018

1. TINA: SUMMER SCHOOLS

In summer 2018, EFNA will run two pan-European TINA activities.

PORTUGAL

The first event will be a workshop, in partnership with the European Brain Council, and taking place at the Champalimaud Foundation, Lisbon – to coincide with the National Brain Council Academy. This event will have a multi-stakeholder participant profile, in order to discuss how all parties can partner to overcome the hurdles to innovation in the field of neurological disorders. This will include a focus on how we can better integrate patient relevant outcomes measures in biomedical research and beyond in, for example, pricing and reimbursement decision-making.

GERMANY (PAN-EUROPEAN)

The second event will be a 'Science for Advocates' workshop in partnership with FENS – the Federation of European Neuroscience Societies. This will take place as a satellite session to the annual FENS Forum in Berlin on July 6th and 7th. This will allow for the participation of expert speakers, drawn from the FENS faculty, to address the patient advocates on a range of topics. Day 1 will focus on introducing neuroscience, explaining ethics and emerging issues, exploring current controversies (e.g. animal research), etc.

Day 2 will take a more practical approach and a series of workshops will present ways patient advocates can access science, generate their own scientifically validated evidence and communicate complex scientific concepts to external audiences.

2. TINA: AUTUMN ACADEMY

In autumn 2018, we will run three further national workshops.
These will take place in Romania (expansion), Spain (follow-up) and Austria (new).

ROMANIA

Following feedback from participants at the Romanian workshops in 2016 and 2017, personalised medicine has emerged as a concept around which the patient advocates feel further education is required. To date, the conversations around personalised medicine have so far been largely confined to the fields of oncology and rare diseases. But, both patients and medical professionals have recognised the need to go beyond that. To become patient-centred, personalised medicine requires a major change in the way medicines are tested and evaluated; bringing together all stakeholders. Changes will also be needed in the way healthcare is delivered and healthcare systems are structured. And the health literacy of patients will need to be improved to allow them to become active participants in the process. Additionally, personalised medicine implies the use of extensive patient and population data. This raises challenges in terms of integrating information and communication science technologies into clinical practice. Most of the conversations happening in this field have taken place at a pan-European level, but we want to bring the debate to the national platform – considering the challenges and opportunities listed above, and equipping patient advocates to be involved. This year, the training will take place in Romania but will be open to participants from other CEE counties as we expand our training offerings here.

AUSTRIA

In the second half of 2018, Austria will hold the Presidency of the EU. We believe that an event to be held in late June, will set the tone for the focus on this Presidency. This will be coordinated by the Austrian Ministry of Health and be entitled: 'Healthy Innovation for Austria: HTA, patent law, price setting'. We, therefore, would like to join this ongoing discussion and plan to host an autumn event in Austria, around which we can engage national stakeholders, to explore patient participation, engagement and involvement in pharmaceutical policy – such as HTA; asking: What is the value of innovation to patients?

SPAIN

Much of the feedback from the 2017 Spanish workshop focussed on the fact that the agenda was intense and time was limited to discuss all aspects. There was a clear appetite for a follow-up event in 2018. We believe that in the early part of 2018, the Spanish HTA agency will publish a guide to patient involvement in HTA. Given the introduction to HTA provided to participants in 2017, this will be a clear opportunity for follow-up in a more practical manner. The participants were also introduced to how they can optimise social media to raise awareness and generate evidence to support their advocacy efforts. However, there were clear calls for more information on how to develop communication and fundraising strategies, and build partnerships for progress.