

INTRODUCTION

The European Federation of Neurological Associations [EFNA] is an umbrella group representing 20 pan-European neurology patient groups. Our slogan 'Empowering Patient Neurology Groups' encapsulates our goals as an Association. We strive to add capacity to our members - allowing them to be the most effective advocates in their own disease areas. EFNA's aims are to improve the quality of life of people with neurological disorders, their families and carers by working in four strategic areas: **Advocacy, Empowerment, Awareness and Engagement**.

One of EFNA's central activities as part of its 'empowerment work' is its Training Initiatives for Neurology Advocates [TINA]. The upcoming pan-European Autumn Academy "**The future of healthcare in the EU: Towards more sustainable patient organisations**" is the latest workshop as part of this programme, which has been designed to educate and empower patient groups in the field of neurology, to equip them with the right skills and knowledge to become efficient health advocates both at national and EU level.

With a focus on the upcoming EU elections that will take place in May 2019, alongside the need for improved sustainability of patient groups, the Academy will address both the current health scenarios and future priorities at EU level, while looking at how patient advocates could become more empowered to address the pressing challenges they face at national level.

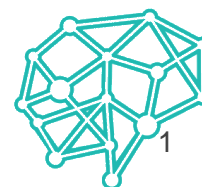
PARTICIPANT PROFILE

Participating patient advocates should have the motivation and skill-set to acquire and apply expert-level knowledge across the whole spectrum of awareness raising and advocacy at national level, as well as coordinating and implementing projects in the access to healthcare field. Accordingly, places are open to individuals who meet all the following requirements:

1. **Be a Neurology Patient Advocate.** 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.

Priority will be given to patient organisations from the following countries: Austria, Bulgaria, Croatia, Czech Republic, Hungary, Poland, Slovenia, Slovakia and Romania.

2. **Have a keen interest in the topic.** The objective of the training is the help patient groups in Central and Eastern European countries learn more about the future of EU healthcare, while providing them with the knowledge to improve the sustainability of the organisations they represent. Health funding opportunities will be addressed, as well the means to access them and the skills that are needed to partnership in such projects.
3. **Be willing to commit to applying the knowledge and skills learned.** This also extends to working with EFNA to develop future trainings, as well as collaborating with other patient groups present at the Academy, in health-related projects.
4. **Possess good working knowledge of the English language.** All presentations and course documents will be made in English.
5. **Be available** to travel on the relevant days and be prepared to do so within the framework of EFNA's Expenses Policy (EUR 250 travel allowance + one night of accommodation) – or be willing to cover additional costs (see policy below).

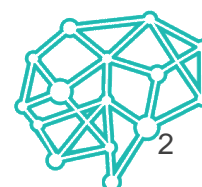


AGENDA

Day One – Monday, October 15th 2018

Focus on: Advocacy in Europe

- 13.30 – 15.00hrs** *Meet and Greet! – with lunch and registration*
- 15.00 – 15.15hrs Welcome and Introductions
Donna Walsh, EFNA Executive Director
- 15.15 – 16.15hrs Health priorities and objectives of the Presidencies of the Council of the EU
- Austrian Presidency (July – December 2018)
 - Romanian Presidency (January – July 2019)
- Rodica Nassar**, Secretary of State, Ministry of Health, Romania
(TBC)
- 16.15 – 16.30hrs** **Energising break**
- Positioning the voice of patients in the context of the 2019 EU Elections
- 16.30 – 16.45hrs The Future of Health in the EU
TBC, European Public Health Alliance
- 16.45 – 17.30hrs Discussion:
Optimising EU policies to become a more effective patient advocate through:
- ✓ Identifying EU policy areas of relevance
 - ✓ Linking EU initiatives to national advocacy efforts
 - ✓ Building partnerships for progress
- Moderator: **Donna Walsh**, EFNA
- 19.30hrs** **Informal dinner**



Day Two – Tuesday, October 16th 2018
Focus on: Funding and Fundraising in Europe

- 09.00 – 09.10hrs Welcome and plans for the day
- 09.10 – 10.30hrs [Opening Presentations](#)
The importance of research funding for patients and patient groups

***Anna Graca**, Policy and Programmes Officer, DG Research,
European Commission*

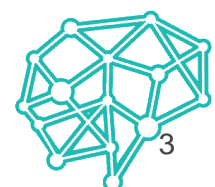
***Frédéric Destrebecq**, Executive Director, European Brain Council*

Followed by Q&A
- 10.30 – 11.00hrs **Energising break**
- 11.00 – 13.00hrs [Workshop](#)
Health funding opportunities for patient groups

*The workshop will focus on funding opportunities available for NGOs in the
neurology field. Where to look for funding, what are the criteria and what
can be done to improve your chances for a successful application.*
- 13.00 – 14.00hrs **Lunch**
- 14.00 – 16.00hrs [Interactive Group Work](#)
Paving the path to securing funding for your organization

*In groups, participants will be tasked with developing a fundraising action
plan – based on the earlier presentations, workshops and discussions. In
advance, selected participants will be invited to share examples of
fundraising actions they have undertaken in the past; presenting the lessons
learned.*

*Following this interactive exercise, there will be a short coffee break, before
each group will report back. Feedback will be provided by the
speakers/experts in attendance – before a final discussion to close the
event.*
- 16.00 hrs **Closing of the day - followed by departures**



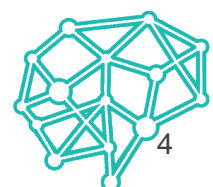
DELEGATE EXPENSES POLICY

The below information is for delegates attending this upcoming EFNA organised meeting. Here we set out the general criteria for reimbursement. Each delegate will be asked to confirm that they have read and agree to the terms of this policy when registering online.

- EFNA will pay up to EUR 250 towards the travel costs of each overseas delegate. This is to include flight, parking, bus/train tickets, etc. If this is exceeded, the delegate (or their organisation) will be asked to cover the balance of costs.
- EFNA encourages participants to make the most economical choices when making travel arrangements to events.
- EFNA will only reimburse participants AFTER the event – and not before.
- EFNA will only reimburse participants who complete the official Expenses Claim Form and attach proofs of expenditure e.g. flight tickets.
- EFNA will only reimburse expenses that are accompanied by original receipts. Photocopied proofs will not be accepted.
- EFNA asks that claims are returned within one month of the event. Expenses submitted more than three months after the event may be rejected.
- EFNA will provide accommodation for each delegate for one nights – October 15th. Additional nights can be booked via EFNA (subject to availability) but the cost must be covered by the participant/their organisation.**
- Meals will be provided throughout the two-day event. Therefore, no additional food/beverages will be covered.
- EFNA will only reimburse economy standard travel. First class travel will only be reimbursed at the equivalent economy cost.
- EFNA will only reimburse ground travel by public transport and will not reimburse private or taxi costs – unless no other options are available or private costs are less than or equivalent to public.
- EFNA will only reimburse long-term parking rates at the airport, short-term/business/premium parking will not be covered.
- Delegates driving long-distance to events will only have mileage covered if this is cheaper than available flights/public transport, and this must be approved in advance.
- Delegates with accessibility requirements should get in touch with EFNA to discuss travel/transfers and accommodation needs.
- EFNA asks that delegates give at least one week's notice of cancellation if they cannot attend. Otherwise, the delegate will be held liable for the cancellation costs incurred.

Note: The above guidelines may be waived in exceptional circumstances but agreement must be reached with EFNA in advance. EFNA retains the right to reject expenses claims that do not comply with the above rules. Please contact EFNA if you wish to discuss.

*** If travel times or other issues mean delegates must stay an additional night, please contact us to discuss.*



The Future of Healthcare in the EU
Towards more sustainable healthcare organisations.
Novotel Hotel, Bucharest, October 2018

For more information contact:

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

SANOFI GENZYME 

MERCK

 MSD

TEVA

 Biogen

