



## PARTICIPANT PACK

**Workshop on:**  
**ADVOCATING FOR ACCESS**  
*TO NEUROLOGY TREATMENT, SERVICES AND SUPPORTS*

**Monday 28<sup>th</sup> and Tuesday 29<sup>th</sup> October 2019**  
**Warsaw**

Hotel Witkowski, Aleja Krakowska 131, 02-180 Warsaw, Poland

**Participant Pack – Contents:**

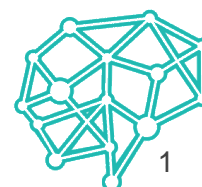
Page 2: Introduction

Page 3: Participant Profile and Eligibility Criteria

Page 4: Expenses Policy

Pages 5-7: Draft Agenda

Page 8: Registration details, sponsors and miscellaneous information



## INTRODUCTION

As part of our Training Initiatives for Neurology Advocates [TINA], in 2019 we will coordinate a meeting to explore the topic of 'access' with a focus on HTA. We will begin with a broad exploration of the challenges faced by patients in access to treatment, followed by a look at the obstacles in the neurology domain – based on the Value of Treatment White Paper of the European Brain Council.

A workshop will then take place to give participants an opportunity to discuss specific access challenges in their countries/disease areas – but also successes. They will be tasked with reaching a consensus on the main barriers to access, and to think about where the European neurology patient advocacy community could mobilise and act, with an opportunity to see tangible outcomes. These suggestions will then be discussed by a panel of expert stakeholders to give the group insights into how this advocacy/policy work could be moved forward effectively.

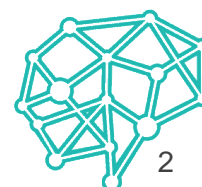
On Day 2, the focus will move more to HTA when participants will be asked to consider whether current work on pushing for more patient engagement and/or reform of HTA systems is a worthwhile use of resources in relation to improving access to treatment. A presentation of EFNA's research in this field will be provided, followed by a series of perspectives to contextualise the discussion.

To end, participants will be tasked with drawing up an interactive roadmap for neurology patient engagement which would lead to improved access for all. This should be based on the issues identified and suggested solutions discussed over the two days, and should align with other initiatives already ongoing in the field – such as the Patient Access Partnership, which will be presented as an example of good practice.

All learnings from this workshop will be encapsulated in a report and subsequent advocacy tool, created by colleagues at the European Alliance for Patient Access with whom we will collaborate on this event.

This will link with EFNA's advocacy work via its MEP Interest Group on Brain, Mind and Pain in which 'ensuring equitable access to treatment, services and supports' is one of the three thematic areas for the political mandate of 2019-2024.

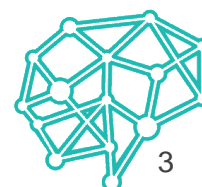
*Note: EFNA will cover the travel costs of participants up to 250euros per person, plus offer two nights accommodation in the designated hotel. Meals will be provided throughout. And there is no registration fee to participate.*



## PARTICIPANT PROFILE AND ELIGIBILITY CRITERIA

All participants should fulfil the below criteria:

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. Other relevant stakeholders with an interest, who are working this field, e.g. health professionals, researchers, etc. – may also be considered.
2. **Have a keen interest and knowledge of the topic:** This is an interactive workshop and participants will be expected to share their personal and/or organisational experiences in the area of access to treatment. They should also be prepared and able to discuss, with others, potential solutions and recommendations for action to address these challenges.
3. **Be willing to commit to applying the knowledge and skills learnt:** EFNA plans to use this workshop to build a set of recommendations and proposed actions which it can take forward as part of its policy work. Those attending should also be prepared to get involved in supporting this work, and aligning it to their activities in this field at the national or disease-specific level.
4. **Have a good working knowledge of English:** The workshop will take place in English. No translation will be provided.
5. **Be available** to travel on the relevant week-days and to participate actively throughout the two days and in all sessions. They should also be prepared to cover additional costs that are not covered by the travel bursary and accommodation provided by EFNA. See expenses policy on next page.



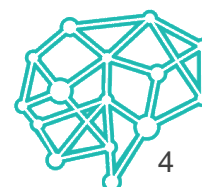
## EXPENSES POLICY

The below information is for participants attending this upcoming EFNA organised meeting. Here we set out the general criteria for reimbursement. Each participant 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 250euros towards the travel costs of each overseas delegate. 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.
- 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 participant for two nights – Sunday, October 27<sup>th</sup> and Monday, October 28<sup>th</sup>. 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 not cover any incidental hotel costs e.g. minibar, printing, etc.
- EFNA will only reimburse economy standard travel. First class travel will only be reimbursed at the equivalent economy cost.
- EFNA will cover a taxi to and from Warsaw Chopin airport for each participant. Outside of this, only related public transport costs will be reimbursed.
- EFNA will not reimburse airport parking.
- Participants 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.
- Participants 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.*

Contact: Donna Walsh, EFNA Executive Director E: [executivedirector@efna.net](mailto:executivedirector@efna.net) T: 00-353-879830816



# AGENDA

## **ADVOCATING FOR ACCESS** **TO NEUROLOGY TREATMENT, SERVICES AND SUPPORTS**

### **Monday, October 28<sup>th</sup> and Tuesday, 29<sup>th</sup> - Warsaw**

**Hotel Witkowski, Aleja Krakowska 131, 02-180 Warsaw, Poland**

**Note: Participants are asked to arrive on Sunday, October 27<sup>th</sup>.  
There will be a buffet dinner at the hotel for those who arrive in time on Sunday evening.**

#### **DAY 1**

##### **09.00 – 09.05: Welcome**

Joke Jaarsma, President, European Federation of Neurological Associations [EFNA]

##### **09.05 – 09.20: Introduction**

Donna Walsh, Executive Director, European Federation of Neurological Associations [EFNA]  
Brian Kennedy, Executive Director, Global Alliance for Patient Access [GAFPA]

##### **09.20 – 09.50: Access to Treatment: A challenge for patients**

Dr. David Charles, Founder, Global Alliance for Patient Access [GAFPA]  
Chief Medical Officer, Vanderbilt University Clinical Neurosciences Institute, Nashville

##### **09.50 – 10.50: Access to Treatment: A BIGGER challenge for NEUROLOGY patients**

Frederic Destrebecq, Executive Director, European Brain Council [EBC]

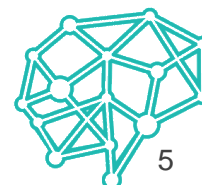
##### **10.50 – 11.15: Q&A**

#### **COFFEE BREAK: 11.15 – 11.45**

##### **11.45 – 13.30: WORKSHOP**

The workshop, moderated by Brian Kennedy, Executive Director, Global Alliance for Patient Access will:

- Give participants an opportunity to discuss specific access challenges in their countries/disease areas – but also successes
- To reach consensus on the main barriers to equitable access to neurology treatment in Europe – now and in the future
- To prioritize in which areas the neurology patient advocacy community should mobilise and act



## LUNCH BREAK: 13.30 – 14.20

14.20 – 16.20: Workshop Feedback, followed by: **Panel Discussion** with key stakeholders:

- Prof. David Vodusek, Chairperson, European Affairs Sub-Committee, European Academy of Neurology
- David Elvira, Europe Public Affairs Head, Sanofi-Genzyme
- Katarzyna Ptak, Policy Officer, DG SANTE, European Commission
- Mary Lynne van Poelgeest-Pomfret, Vice-Chair, European Forum of Good Clinical Practice
- TBC, Multiple Sclerosis International Federation

Panel discussion moderated by Dr. David Charles, GAFPA.

## COFFEE BREAK: 16.20 – 16.40

16.40 – 17.10: **Conclusion from Day 1 and Preview of Day 2**

Brian Kennedy, GAFPA

Donna Walsh, EFNA

17.10: Final Questions, Last Remarks and Close of Day 1 by 17.15hrs

19.00: Dinner

## DAY 2

09.00 – 09.10: **Welcome Back**

Joke Jaarsma, President, European Federation of Neurological Associations [EFNA]

09.10 – 10.45: **INTERACTIVE SESSION**

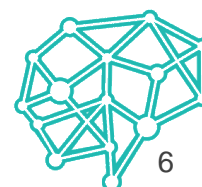
### Focus on Health Technology Assessment [HTA]

Introduction: Krystallia Pantiri, Pharmerit International

Moderator: Brian Kennedy, Executive Director, GAFPA

Question: Should neurology patient advocates/organisations:

1. Engage more in HTAs?
2. Push for reform of HTAs/HTA agencies?
3. Forget about HTA?



**Discussion and Debate, led by:**

Valentina Strammiello, Senior Programme Manager, European Patients' Forum

Matteo Scarabelli, Patient Engagement Manager in HTA, EURORDIS

**COFFEE BREAK: 10.45-11.15**

**11.15 – 13.30: INTERACTIVE EXERCISE**

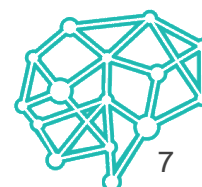
Introduction: Stanimir Hasurdjiev, Secretary-General, Patient Access Partnership [PACT]

Creating a Map for Neurology Patient Engagement in the Medicines Lifecycle, along the road to Access!

– *Development of Advocacy Tool*

13.30: Conclusions and Close

**LUNCH and DEPARTURES**



## REGISTRATION

If you are interesting in joining us, fulfil the participant eligibility criteria and agree with our expenses policy, then please register today!

To ensure that participants come from a diverse range of patient organisations, disease areas and nationalities, your place may not be confirmed until after registration closes.

So please **register before Friday, September 20<sup>th</sup> at 12pm CET.**

And your place will be confirmed before close of business on Monday, September 23<sup>rd</sup>.

You should register online at the following link:

<https://forms.gle/YHmwUe2fpt1hQf5A>

**Note: Please do not make your travel arrangements until your place is confirmed!**

And do get in touch if you have any questions in the meantime:

Donna Walsh, EFNA Executive Director

E: [executivedirector@efna.net](mailto:executivedirector@efna.net) T: 00-353-879830816

THE TRAINING INITIATIVES FOR NEUROLOGY ADVOCATES [TINA] HAVE BEEN MADE POSSIBLE THANKS TO OUR SPONSORS AND SUPPORTERS IN 2019:



MERCK

