

## AGENDA

### PATIENT ADVOCACY IN THE DIGITAL WORLD

Day One – Monday, November 19th 2018

**12.00 – 13.00hrs**

**Lunch & Registration**

**13.00 – 13.30hrs**

Welcome and Introductions -  
Donna Walsh, EFNA Executive Director

#### *Young Neurology Patients' Survey*

**13.30 – 14.00hrs**

Presentation of Survey Results -  
Elizabeth Cunningham, EFNA Communications Manager

**14.00 – 15.00hrs**

Discussion -

- Do feelings in the room reflect the results?
- Which outcomes are seen as most important?
- How can we use this information to address the issues raised?

**15.00 – 15.30hrs**

**Coffee Break**

#### *How to Influence Change and Lead in Your Community*

**15.30 – 15.50hrs**

The Power of Storytelling -  
Emma Lawton, Parkinson's campaigner & author  
Case-study and Q&A

**15.50 – 16.10hrs**

Building an Online Community -  
George Pepper, Founder of Shift.ms  
Case-study and Q&A

**16.10 – 16.30hrs**

Digital Media in an Awareness Campaign -  
Louis Gustin, S'adapter  
Case-study and Q&A

#### *Working with Patient Organisations*

**16.30 – 18.00hrs**

Discussion -

What are the advantages and limitations of working with patient organisations?  
*Facilitator:* Elisabeth Kasilingam, MD of European MS Platform

**19.30hrs**

**Dinner – NH Bloom Hotel restaurant**



## Day Two – Tuesday, November 20th 2018

### *eHealth and Technology-enabled Solutions*

**9.00 – 9.15hrs**

**Welcome and Introductions –**  
**Elizabeth Cunningham**, Communications Manager, EFNA  
**Frederic Destrebecq**, Executive Director, European Brain Council

**9.15 – 9.40hrs**

**Artificial Intelligence - What does it mean for health policy and patients in Europe?**  
**Goncalo Carrico**, Political Adviser, Innovation, Technology and Digital Policy Issues, European People's Party

**9.40 – 10.05hrs**

**Digital Transformation – Optimising the Patient Journey**  
Presentation on digital applications being developed for neurology patients  
**Kim Baden-Kristensen**, Co-founder & CEO at Brain+

**10.05 – 10.30hrs**

**Ethics and the Emerging Issues in eHealth -**  
**Marcello Ienca**, Postdoctoral Researcher, Health Ethics & Policy Lab, Department of Health Sciences and Technology, ETH Zurich will explore ethical & policy issues associated with new and emerging technologies for healthcare.

**10.30 – 11.00hrs**

**Panel discussion with our speakers -**  
*Moderator:* **Frederic Destrebecq**, Executive Director, European Brain Council

**11.00 – 11.30hrs**

**Coffee Break**

**11.30 – 12.30hrs**

**Workshop: Value Assessment of Digital Products -**  
In this session we will learn about a digital health app in the early stages of development and discuss the factors that will make it most successful.  
*Case Study:* MyBrainNET - **Monika Benson**, Executive Director at Dystonia Europe and **Eelco Uytterhoeven**, Special IT Advisor & Coordinator  
*Led by:* **Kim Baden-Kristensen**, Co-founder & CEO at Brain+

**12.30 – 13.30hrs**

**Lunch**

### *Advocacy in Action*

**13.30 – 14.45hrs**

**#LifeGoals vs #BrainLifeGoals**  
EFNA present our planned campaign for 2019. The campaign will bring the issues of young people living with brain disorders to the attention of the EU's newly elected MEPs.

**14.45 – 15.15hrs**

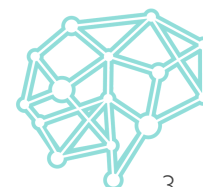
**Coffee Break**

**15.15 – 17.00hrs**

**Next Steps...**  
Each participant is required to complete a short digital advocacy project as part of this programme. Participants will have time to refine their idea and present to the group for feedback. (For more see Project Brief - Appendix C).

**19.00 – 22.00pm**

**EFNA Advocacy Awards Dinner** **\*\* ATTENDANCE OPTIONAL \*\***  
Location: Fondation Universitaire, 11 Rue d'Egmont, Brussels 1000



Day Three – Wednesday, November 21st 2018

- 7.00am** ***BUS DEPARTS FROM HOTEL FOR EUROPEAN PARLIAMENT***
- 8.00 – 10.00hrs** ***Brain, Mind and Pain MEP Interest Group*** **\*\* ATTENDANCE OPTIONAL \*\***
- 'Future of Healthcare in Europe - What next for brain, mind & pain?'*  
Location: European Parliament  
[Registration required](#). For agenda please see Appendix A.
- 10.15hrs** ***BUS DEPARTS EUROPEAN PARLIAMENT FOR GARE DU MIDI / EBC MEETING AT THE EGG BRUSSELS***
- 10.30 – 16.30hrs** ***EBC Value of Innovation Series meeting*** **\*\* ATTENDANCE OPTIONAL \*\***
- 'Enhanced engagement through public-private partnerships: Sustaining therapeutic innovation to address patient needs'*  
Location: The Egg Brussels  
[Registration required](#). For more please see Appendix B.

**NOTE:** As shown above, bus will be available on the morning of Wednesday, November 21<sup>st</sup> to bring participants who wish to attend the MEP Interest Group meeting to the European Parliament. Following that meeting the bus will make two stops - bringing the group to Gare du Midi station, or to the EBC Value of Innovation Series meeting, should they wish to attend. Anyone attending the EBC Value of Innovation Series meeting should make his or her own way to the airport/train station after that event. Those attending either meeting should bring their luggage with them that morning, as we will not return to the hotel.

