

# Educating pain patients on HTA



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President, European Headache Alliance

# **1. Patient Organisations**

- As advocates for all patients**

# **2. Patients**

- As empowered individuals**

# 1. Patient Organisations

- **Identify and Acquaint with National HTA Body**
  - **Personnel**
  - **Process (criteria, patient involvement, etc.)**
- **Ensure patient voice is represented/heard**
  - **Lobbying**
- **Compile (and present) Data**
  - **Journal Articles**
  - **Study results and statistics**
  - **Patient Questionnaires and feedback forms**
  - **Helpline calls, emails, queries, etc.**
- **Empower (and identify) Patients**
  - **Training Days**
  - **Workshops**
  - **Briefings**
  - **Toolkits**
  - **Support**
- **Identify a suitable spokesperson**

# **2. Patients**

**Personal Testimony**

**BUT**

**‘Distress is not enough’**

**- Mary Baker**

**European Federation of Neurological Associations**

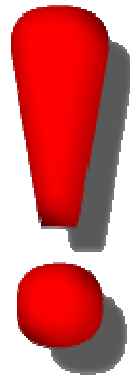
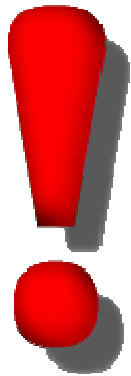
# 2. Patients

**Patients – as spokespeople – must:**

- **Be P**repared
- **Be A**rticulate
- **Be C**oncise (and confident)
- **Be E**ngaging

# Why are patients important?

**Only patients and their caregivers know precisely how a disease impacts on daily life and how specific treatments or management strategies can influence its quality**



**Jean Mossman, Policy Advisor**  
*European Federation of Neurological Associations*

# Why are patients important?

- **Personal testimony brings to life the reality behind facts and figures**
- **Patients may already be using the technology – experience**
- **Patients will ultimately benefit or not benefit from the technology**
- **Patient empowerment is increasing – patients want a say in their own health**
- **Policy makers are not patients**

**Caregivers should also be consulted on impact of disease and new technologies**

# Further Education

## HTA Summer School for Patient Groups

- **Collaboration between EFNA and London School of Economics**
- **Sponsored by 16 companies**



[www.efna.org](http://www.efna.org)

