A European pilot network of reference centres in refractory epilepsy and epilepsy surgery

On behalf of E-PILEPSY consortium

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6,000,000 people in Europe have epilepsy

30% are drug resistant (1,800,000)

At least 10% of them can be cured by epilepsy surgery (≥ 180,000 EU citizens)

Precise number of surgical procedures in EU unknown but < 3000 / year

Life-time cost-saving per surgery: 0.4 M€

Cost of epilepsy: 0.2% GDP (26,000 M€)

Main limitation: Access to optimal care
Impact of timely epilepsy surgery

Developmental age (years)

Age (years)

0 1 2 3 4 5 6 7 8

0 1 2 3 4 5 6 7 8

Epilepsy surgery
Patients, families, GP, treating neurologists, and policy makers are not well informed about benefits & risks of epilepsy surgery

Patients are not appropriately referred

Presurgical workup is not appropriately reimbursed

Lack of a national epilepsy surgery plan and organization in most EU countries

Large heterogeneity of practice and performance among epilepsy centers

Safety issues largely ignored

Most active epilepsy surgery centers have a 1 to 3 years waiting list ....

140 epilepsy monitoring units in 21 EU countries
13 associated partners

- Austria
- Bulgaria
- Croatia
- Czech Republik
- France
- Germany (#2)
- Greece
- Italy
- Netherlands
- Norway
- Sweden
- United Kingdom

15 collaborative partners

- 12 centers
- ILAE, WHO, EEMA
E-PILEPSY History

Incidence and mechanisms of cardiorespiratory arrests in epilepsy monitoring units (MORTEMUS): a retrospective study


First Conference on European Reference Networks, Brussels 23rd June 2014
E-PILEPSY aims at

- achieving significant and sustained progress in the quality and harmonization of healthcare provision delivered to children and adults with refractory epilepsy across Europe
- reducing current inequalities between EU countries in all aspects related to refractory epilepsy (expertise, quality of care, policies)
- triggering accelerated development of epilepsy surgery, by promoting cooperation between centres in all EU regions
- facilitating access to epilepsy surgery by working with all stakeholders (patients, professionals, policymakers)
- optimizing presurgical diagnostic procedures to offer a greater chance of postoperative seizure freedom at reduced risk of surgery related complication and morbidity
2nd health program: « the current economic and financial crisis underscores the need to invest effectively in health, in order to deliver better services with sustainable health budgets »

- highly cost-effective epilepsy surgery care where cost-saving can yield relevant economies of scale
- web-based eHealth / mHealth solutions which have the greatest leverage potential at the EU level
Resilient and Innovative Health Systems for Europe

Building Resilient Healthcare Systems

Free-Trade Zone Europe-US. Implications for Health Systems

Investing in Health

Mental Health. The Motor for a Healthy Economy

mHealth for Innovation. Health at your Fingertips

Non-Communicable Diseases
Resilient and Innovative Health Systems for Europe

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Investing in Health

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mHealth for Innovation. Health at your Fingertips

Non-Communicable Diseases
Primarily web-based deliverables

- Systematic reviews, guidelines and recommendations
- **E-PILEPSY website**
- E-Database
- **E-Care platform** *(web-based epilepsy conference)*
- E-Neuropsych
- E-Processing
- E-Eligibility
- Model of sustained development
- *Exchange program*
Primarily web-based deliverables

- Systematic reviews, guidelines and recommendations
- **E-PILEPSY website** → patients, families, all care-givers
- **E-Database** → ERN centers, policy makers
- **E-Care platform** → ERN centers
- **E-Neuropsych** → ERN centers, other epilepsy centers
- **E-Processing** → ERN centers, other epilepsy centers
- **E-Eligibility** → patients, all care-givers
- Model of sustained development
- *Exchange program*
Specific Objectives

- Exchange best practice and promote harmonization of care in the management of refractory epilepsy and epilepsy surgery

- Improve skills of EU professionals involved in the management of refractory epilepsy and epilepsy surgery

- Increase patient safety, accuracy of patient selection for epilepsy surgery, and favorable surgical outcome

- Increase access to epilepsy surgery programs
Specific Objectives

- Increase knowledge of European patients with refractory epilepsy, their families and primary care givers, regarding optimal management of their disease, treatment options, and epilepsy surgery.

- Enhance awareness of policy makers/health authorities and develop a model of sustained growth of epilepsy surgery in Europe.
Other expected impact of ERN

ERN label for epilepsy surgery centers
(provided fulfilled criteria including systematic data collection and audit)

Negotiation of appropriate reimbursement at the national level

Optimal organization of care + systematic data collection

Improved standard of care
mHealth / eHealth research in ERN

Opportunities

Threats
ERN represent a unique opportunity to improve and harmonize standard of care of complex and chronic conditions such as epilepsy, and to boost m.Health/e.Health in EU countries.

E-PILEPSY offers the potential to address the needs of 1.8 millions EU citizens with refractory epilepsy according to the 2011 written declaration of the EU parliament.

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E-PILEPSY indicators

- Number of patients presented at e.Care conferences (e.Care)
- Number of patients investigated for epilepsy surgery (e.database)
- Proportion of "state-of-the-art" pre-surgical evaluation (e.database)
- Proportion of centers using e.processing (e.processing, e.database)
- Proportion of centers using e.neuropsych (e.neuropsych)
- Proportion of patients with 'well localized epileptic focus' (e.database)
- Proportion of patients with "adverse events" (e.database)