



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

*On behalf of E-PILEPSY consortium
Philippe Ryvlin (Lyon, France)*



Written Declaration on Epilepsy



EUROPEAN PARLIAMENT

2009 - 2014

0022/2011

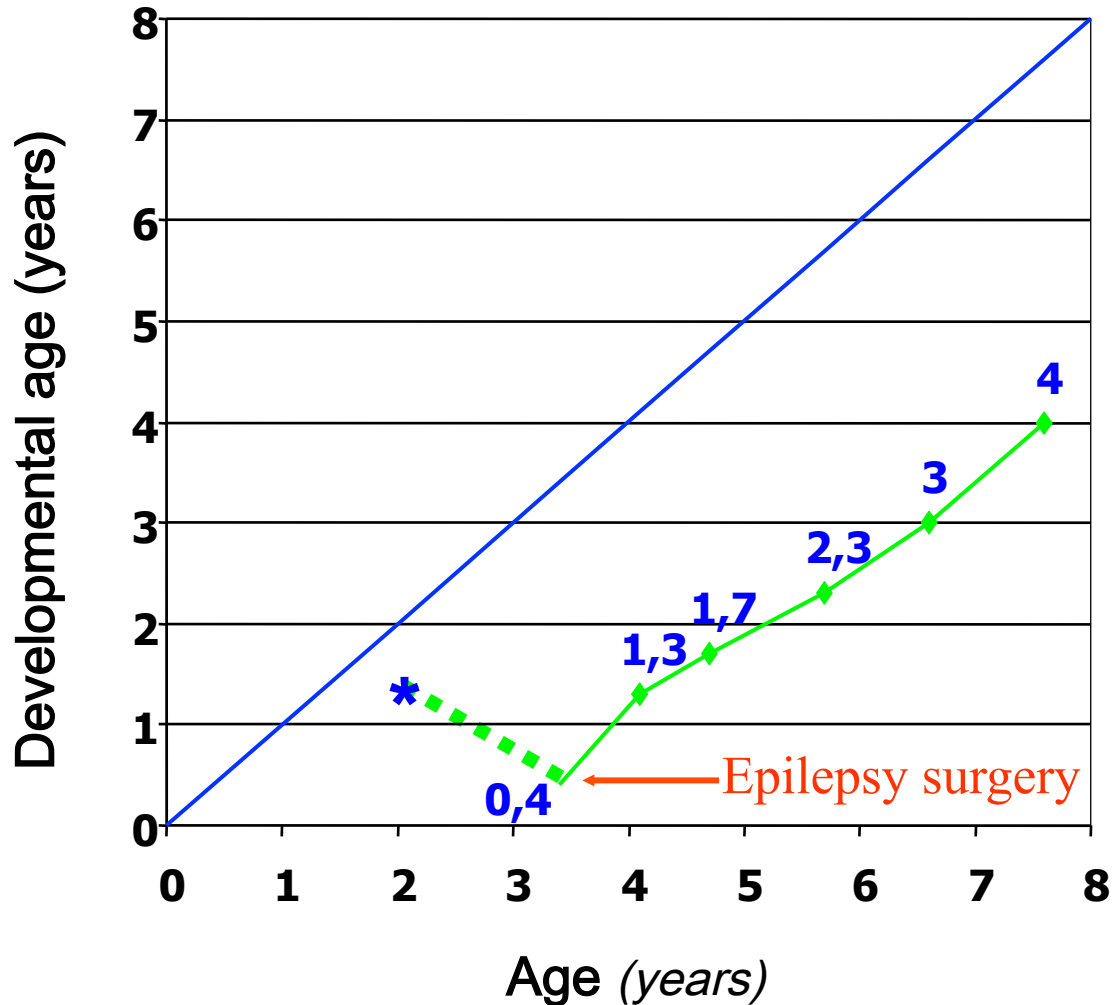
Written declaration on epilepsy

- **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**

The European Parliament,

- having regard to Rule 123 of its Rules of Procedure,
- A. whereas epilepsy is the most common serious disorder of the brain,
- B. whereas 6 000 000 people in Europe have epilepsy, with 300 000 new cases diagnosed each year,
- C. whereas up to 70% of people with epilepsy could be seizure-free with appropriate treatment, while 40% of people with epilepsy in Europe do not receive such treatment,
- D. whereas 40% of children with epilepsy have difficulties at school,
- E. whereas people with epilepsy in Europe experience high levels of unemployment,
- F. whereas people with epilepsy are exposed to stigma and prejudice,
- G. whereas epilepsy damages health but also disrupts every aspect of life, and can impose physical, psychological and social burdens on individuals and families,
- 1. Calls on the Commission and Council to:
 - encourage research and innovation in the area of prevention and early diagnosis and treatment of epilepsy;
 - prioritise epilepsy as a major disease that imposes a significant burden across Europe;
 - take initiatives to encourage Member States to ensure equal quality of life, including in education, employment, transport and public healthcare, for people with epilepsy, e.g. by stimulating the exchange of best practice;
 - encourage effective health impact assessments on all major EU and national policies;
- 2. Calls on the Member States to introduce appropriate legislation to protect the rights of all people with epilepsy;
- 3. Instructs its President to forward this declaration, together with the names of the signatories, to the Commission and the Parliaments of the Member States.

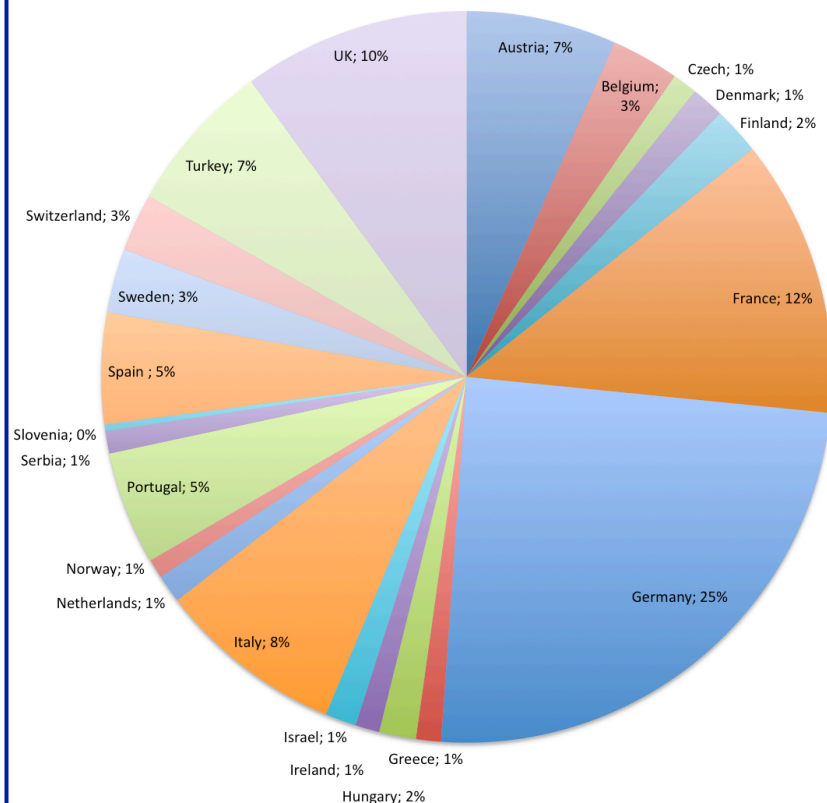
Impact of timely epilepsy surgery





- 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





Epilepsy Surgery in France





E-PILEPSY consortium

13 associated partners

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

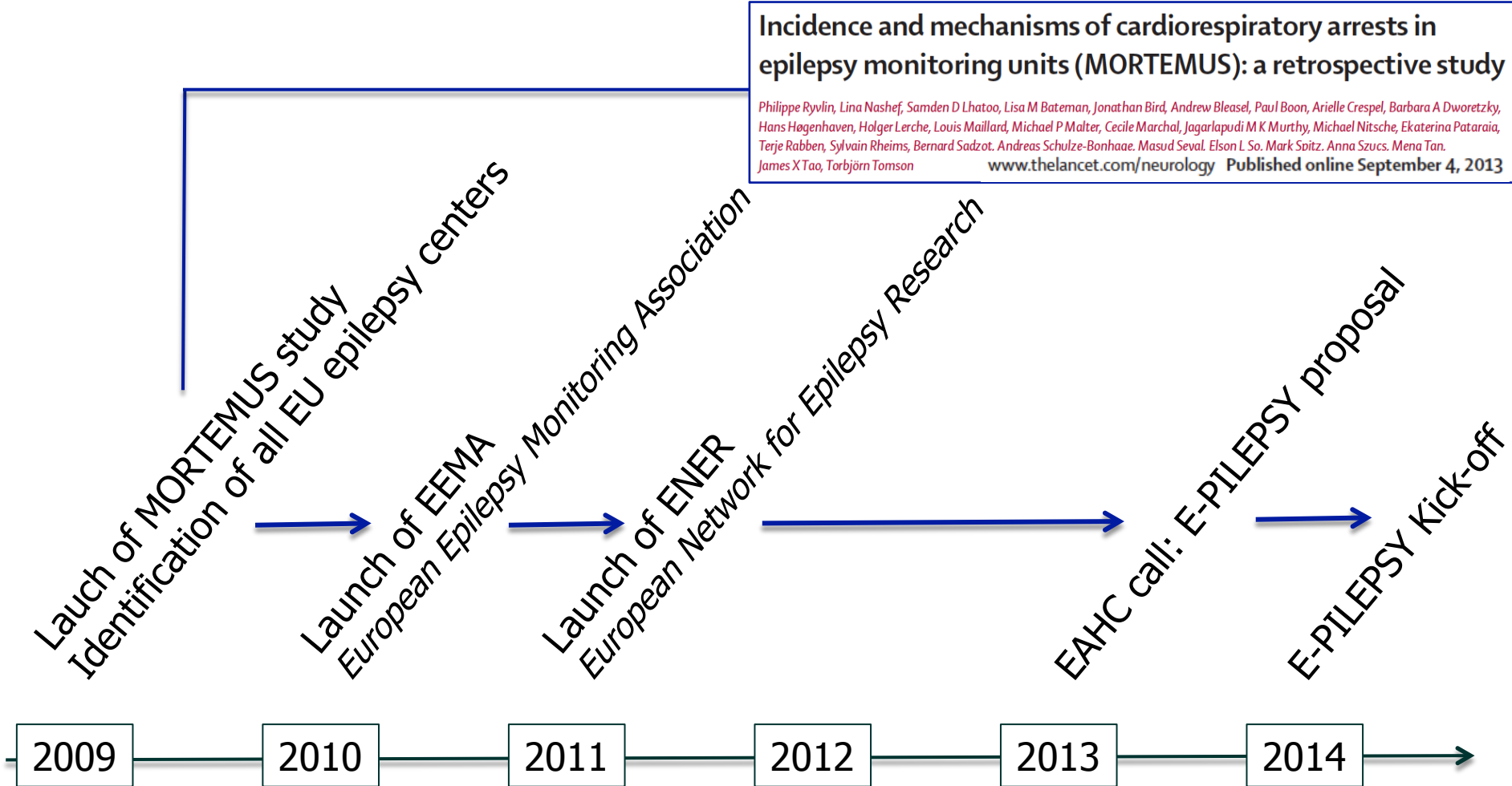
15 collaborative partners

- 12 centers
- ILAE, WHO, EEMA





E-PILEPSY History





E-PILEPSY: General Objectives

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

E-PILEPSY: General Objectives

- **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



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Non-Communicable Diseases



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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

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- 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



Opportunities



Threats

Conclusion

- 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
- Questions - Contact: philippe.ryvlin@chu-lyon.fr



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)