

ERN EpiCARE

**A European Reference Network
for Rare and Complex Epilepsies**

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**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Epilepsies (ERN EpiCARE)



Disclosure

I have no actual or potential conflict of interest in relation to this program/presentation



The Epilepsies

A group of conditions characterised by tendency to recurrent epileptic seizures

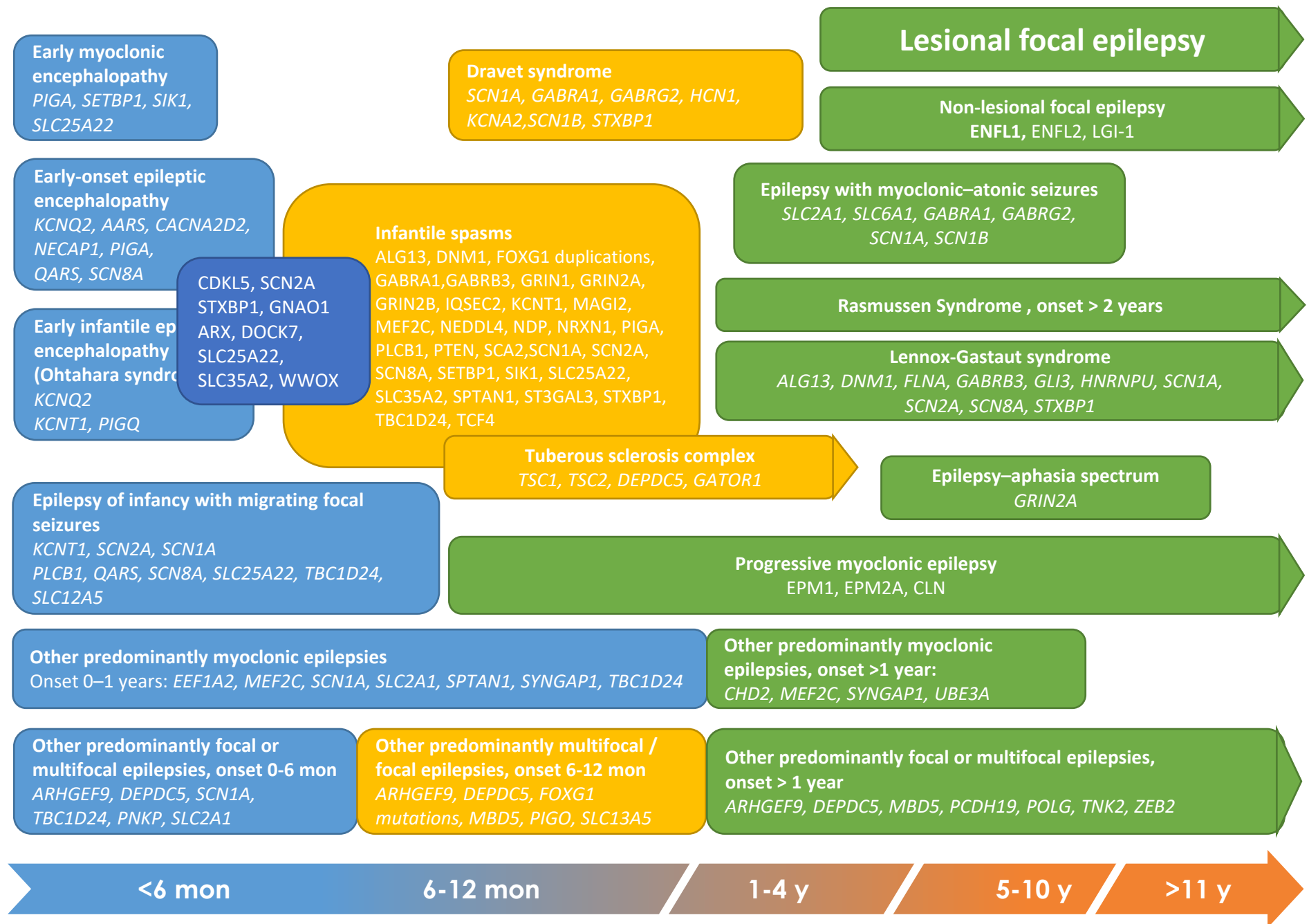
Treatments

- Antiepileptic drugs
- Dietary treatment
- Stimulation

Epilepsy surgery (curative) in carefully selected individuals

Changing concepts: a group of **rare diseases** for which **targeted treatment** are possible





Definitions



Rare epilepsies: an epilepsy with incidence < 5 in 10,000 population, either defined as epilepsy syndrome or aetiologically driven epilepsy

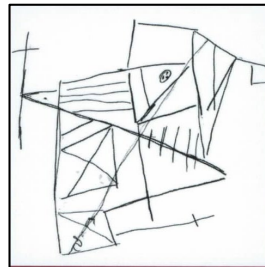
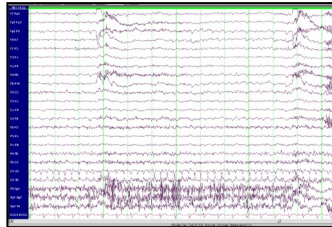
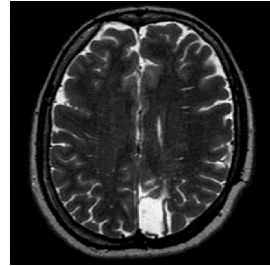
Complex epilepsies: an epilepsy requiring multidisciplinary management through care pathway or comorbidity, with or without known aetiology
eg surgically treatable epilepsies needing a high level of multidisciplinary expertise (including video-EEG analysis, functional and/or structural neuroimaging etc.)

Epilepsy surgery



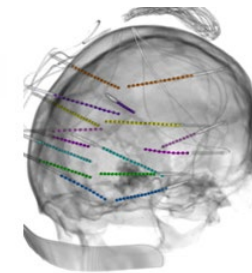
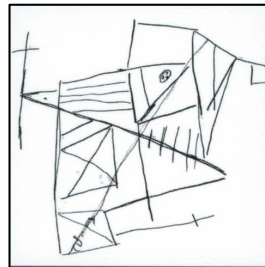
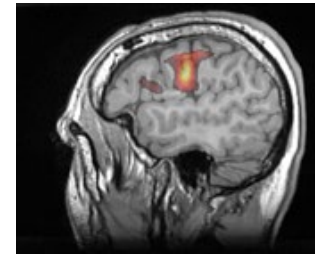
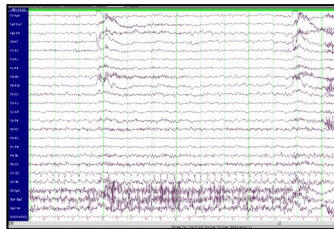
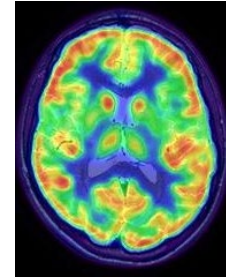
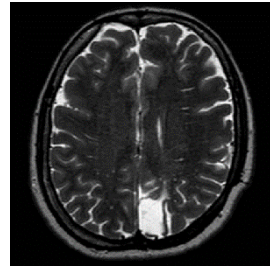
multidisciplinary expertise

Epilepsy surgery



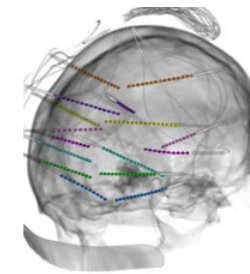
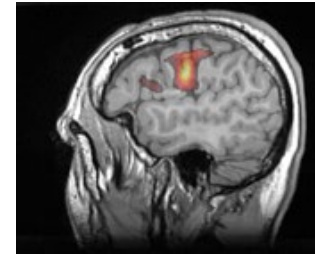
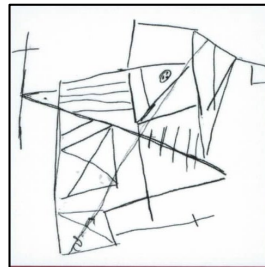
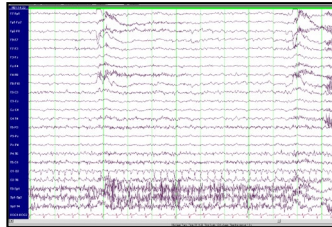
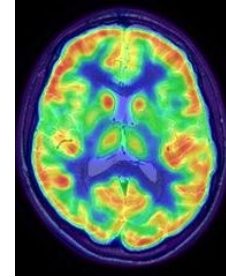
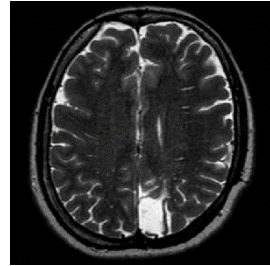
multidisciplinary expertise

Epilepsy surgery



multidisciplinary expertise

Epilepsy surgery



multidisciplinary expertise

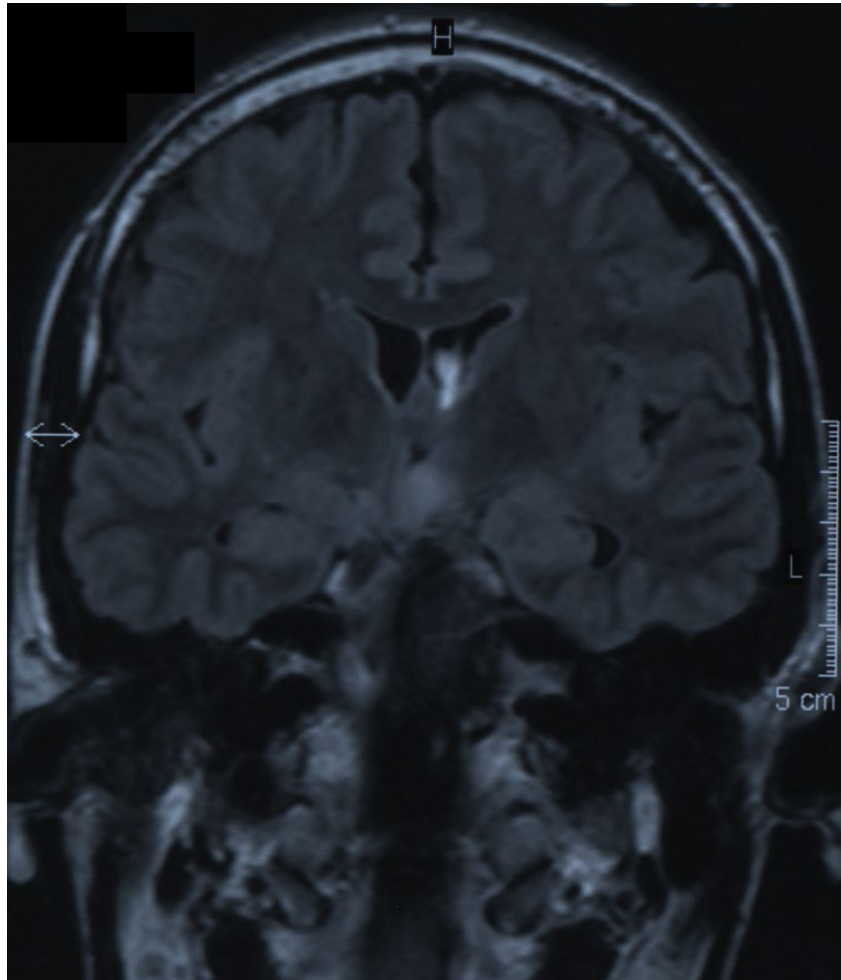
Hypothalamic hamartomas

With gelastic seizures – ORPHA:86906

- non-neoplastic developmental malformation
- other seizure types including focal and generalized seizures
- concomitant cognitive decline and behavioral disorders
- some patients also present a precocious puberty

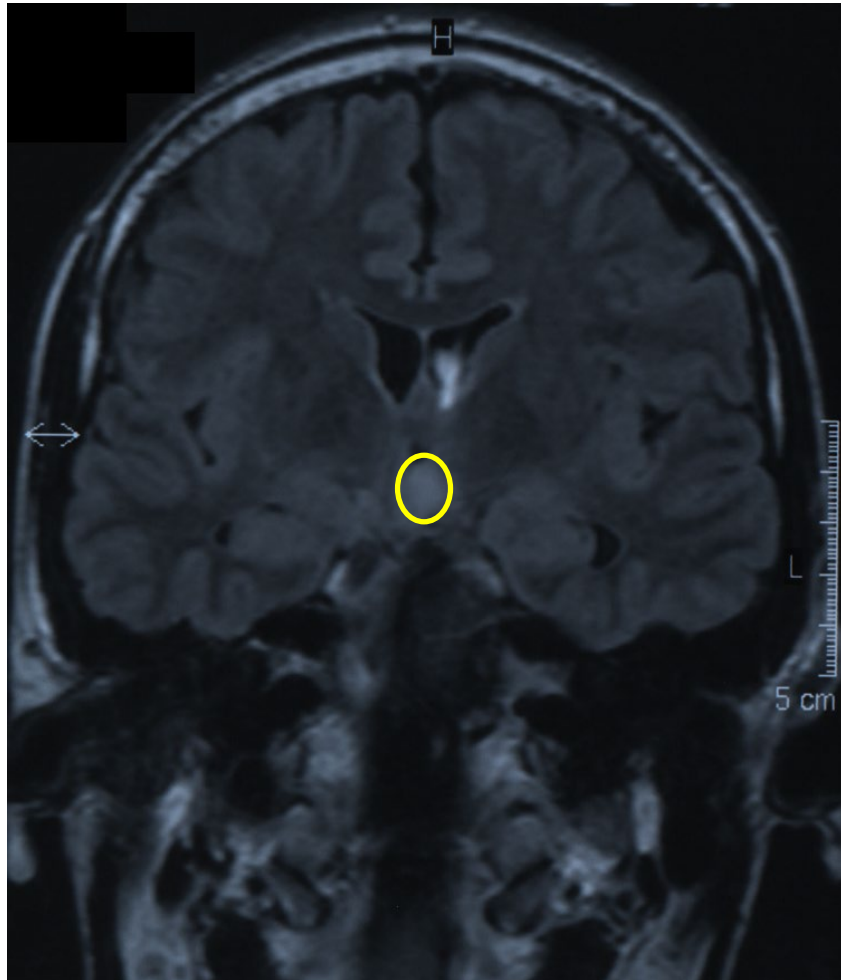


Hypothalamic hamartomas



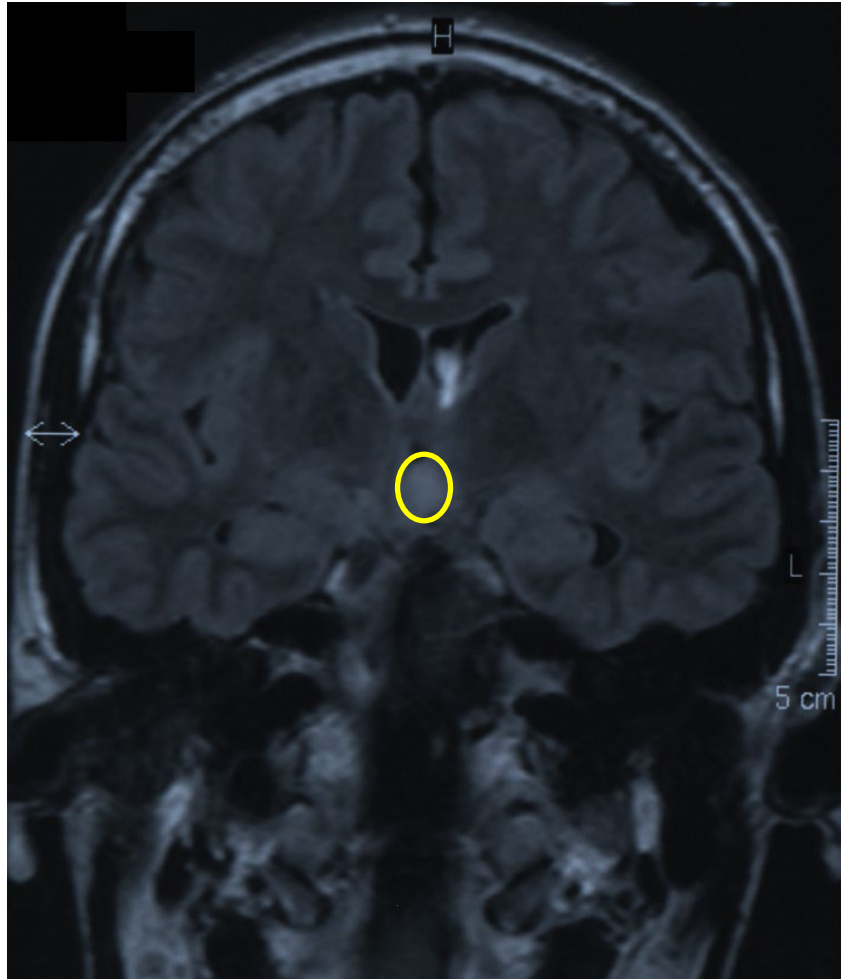
MRI – FLAIR, coronal section

Hypothalamic hamartomas



MRI – FLAIR, coronal section

Hypothalamic hamartomas



MRI – FLAIR, coronal section

Surgical resection

- transcallosal
- pterional
- endoscopic

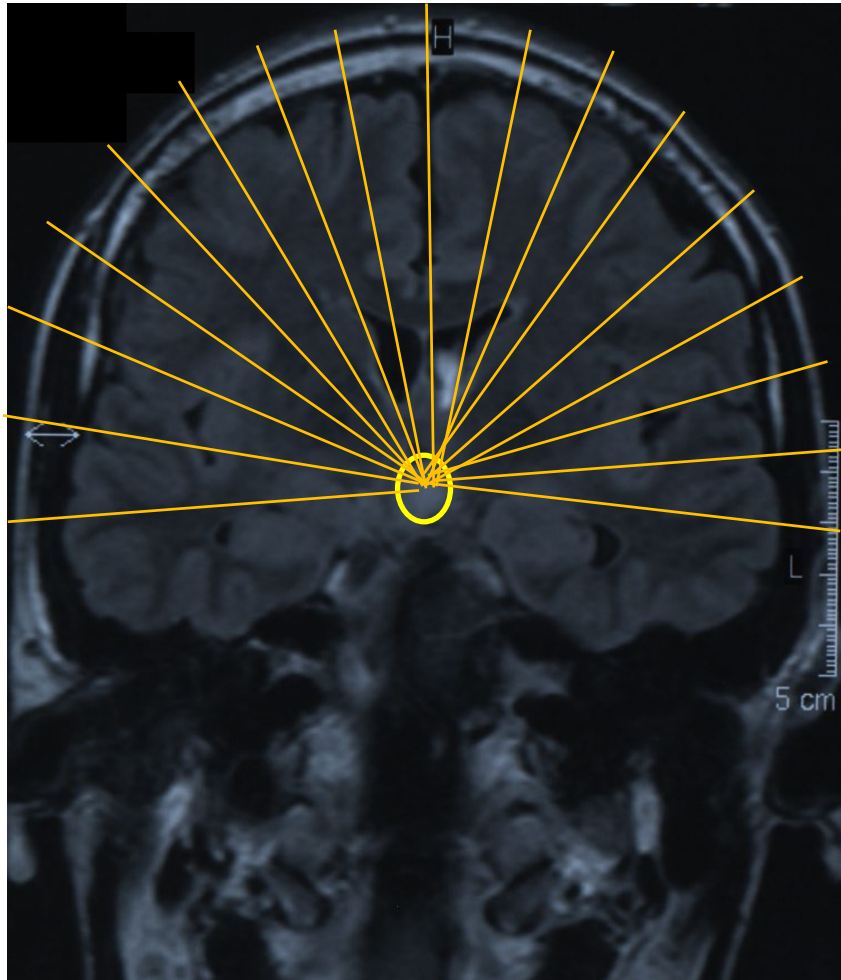
Stereotactic

- thermoablation
- thermocoagulation

Gama Knife[®] radiosurgery



Hypothalamic hamartomas



MRI – FLAIR, coronal section

Gamma Knife[®] radiosurgery

- many beams of radiation that converge on a single point
- individual beam is not powerful enough to destroy healthy tissue

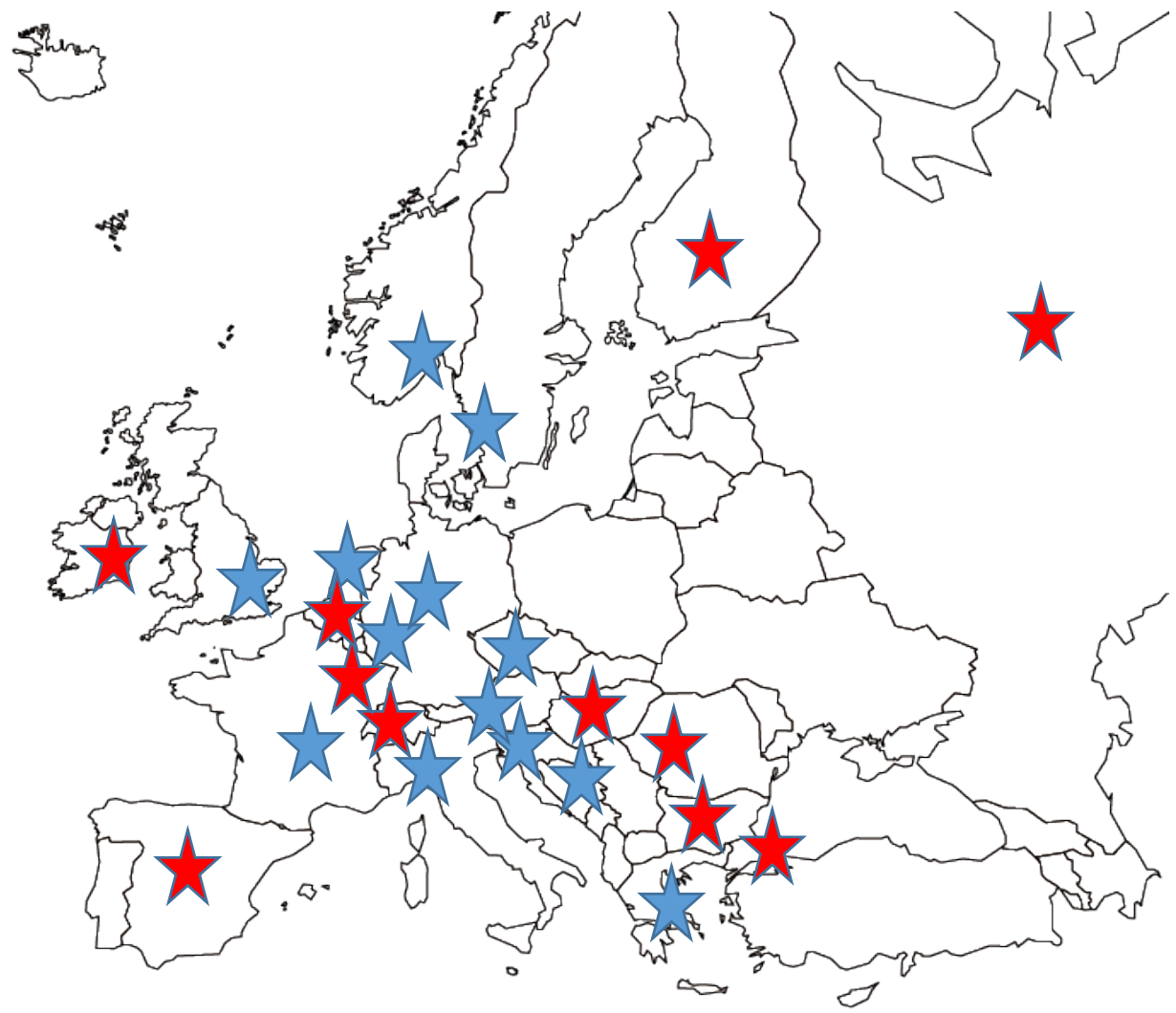




A pilot ERN: to raise awareness & accessibility of epilepsy surgery

13 members
11 associate partners

2013-2017



- 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
- Final conference



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[Network](#)
Epilepsies (ERN EpiCARE)



Summary EpiCARE showcase

The epilepsies: a group of rare diseases for which targeted treatment are possible

Vision: deliver highly-specialized care to improve diagnosis and outcome in individuals with rare and complex epilepsies

Multidisciplinary epilepsy surgery case discussions: European collaboration has already improved care for individual patients and their families



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A European Reference Network for Rare and Complex Epilepsies

J Helen Cross

**Coordinator, Great Ormond Street Hospital,
London**



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