

EPILEPSY ALLIANCE EUROPE

Working to make epilepsy a healthcare priority in Europe



Athanasios Covanis



Philippe Ryvlin

News from the Chairs

July 2016



EpiCARE



A European Reference Network for Epilepsy

Dear Friends

Over the past few months, the EpiCARE group, with coordinator Prof J Helen Cross, Great Ormond Street Hospital for Children (GOSH), has been working long hours to complete a submission for a European Reference Network (ERN) on rare and complex epilepsies. This was in response to a call from the EU issued in March and which closed on 21 June.

Dissemination of activities will be core to the network, and will be the responsibility of the coordinator and Epilepsy Alliance Europe.

Over the coming months, all of the network applications submitted to the EU before the deadline will be reviewed but, in the meantime, there is the opportunity to promote to EU national members the tremendous benefits to patients, care providers and health departments that would be provided of an ERN dedicated to rare and complex epilepsies.

WHY AN EPILEPSY ERN?

Traditional antiepileptic therapies will achieve seizure freedom in 60-70% of patients. In the remainder, who continue to have seizures, the clinical outlook is poor.

The EpiCARE network would develop and deliver highly-specialized diagnostics and care to improve interventions and outcome in individuals with rare and complex epilepsies, defined as those with incidence <5 in 10,000 population, either defined as an epilepsy syndrome or aetiologically driven epilepsy.

Traditionally treatments have been targeted at the seizures with little understanding of the underlying cause; advances in structural brain imaging, as well as molecular and metabolic diagnostics, have determined an increasing number of causes resulting in the description of in excess of 130 rare diseases. With an understanding of underlying cause, treatments can be more targeted.

The relative prevalence of each disease means a coordinated

Members of the Network (Stage One)

1. Great Ormond Street Hospital for Children, London, UK
2. University College London Hospitals, UK
3. Queen Elizabeth University Hospitals Campus, Glasgow, UK
4. Oxford University Hospitals, UK
5. University Hospital Gasthuisberg KU, Leuven, Belgium
6. Motol University Hospital, Czech Republic
7. St Anne's University Hospital, Czech Republic
8. Kuopio University Hospital KUH, Finland
9. CHRU Lille Epilepsy Unit, France
10. GHE-HCL (Hospices Civils de Lyon), France
11. Hôpital Enfant Malade, Necker, Paris, France
12. Dept of Epileptology, University Hospital Bonn, Germany
13. Epilepsy Center, University Hospital Freiburg, Germany
14. RCCS Inst of Neurological Sciences of Bologna (INSB), Italy
15. Azienda Ospedaliero- Universitaria A. Meyer, Florence, Italy
16. Fondazione IRCCS Istituto Neurologico, C Besta, Milan, Italy
17. Fondazione Istituto Neurologico Nazionale Casimiro Mondino, Pavia, Italy
18. Ospedale Pediatrico Bambino Gesù, Rome, Italy
19. The Children's Memorial Health Institute, Warsaw, Poland
20. Centro Hospitalar e Universitario de Coimbra, Portugal
21. Centro de Referencia de Epilepsias Refractarias, Hosp de Santa Maria, Lisbon, Portugal
22. Centro Hospitalar do Porto, Portugal
23. Alexandru Obregia Clinical Hospital, Bucharest, Romania
24. Hospital Sant Joan de Deu Hospital Clinic, Barcelona, Spain
25. Hospital de Mar-Pare de Salut Mar, Spain
26. Hospital Universitario y Politecnico La Fe, Valencia, Spain
27. Sahlgrenska University Hospital, Gothenburg, Sweden
28. University Medical Center Utrecht (Brain Center Rudolf Magnus), The Netherlands

approach is required across key centres of expertise, with the development of e-tools to enable complex diagnostic and therapeutic interventions in a wider number of patients across Europe. Only then can we increase the possibility for new treatments that can be integrated into the clinical care pathways.

E-PILEPSY PILOT NETWORK

One such example has been the advances in clinical assessment, neuroimaging and neurophysiology increasing the number of individuals proceeding to resective surgery, with resultant cure from otherwise drug resistant epilepsy. The pilot ERN E-epilepsy (EU EAHC 534055, 2014, Ryvlin & Cross, 3 years) has increased the awareness and availability of epilepsy surgery across Europe through the utilisation of e-health, and further demonstrated the absolute need for a clinical network devoted to the rare and complex epilepsies. Through EpiCARE it would plan to expand on this work to increase availability of specialist diagnostics and health care to the wider group of rare and complex epilepsies, incorporating E-epilepsy as one of several therapeutic networks.

NETWORK GOALS

The main goals would be:

- Full access and utilisation of presurgical evaluation and epilepsy surgery;
- An increase in diagnosis of rare causes of the epilepsies;
- Enhancement of identification of patients with treatable rare causes of the epilepsies
- Increase access to specialized care for rare causes:
- To foster research on innovative causal treatments in rare and complex epilepsies.

ATTAINING NETWORK GOALS

With a strategy of collaborative working, sharing of expertise and access to advanced diagnostics EpiCARE anticipates an increased number of individuals with refractory epilepsy to have an underlying diagnosis as a cause for the epilepsy.

By collecting information about where such patients exist, the ERN would be able to collate information on clinical presentation and evolution across the life span, constitute cohorts of these rare conditions and advance the development of clinical trials, utilising innovative trial design for small select numbers of patients.

EpiCARE would also continue to increase awareness and accessibility of epilepsy surgery for carefully selected individuals through a continuation of the core network, the successful pilot ERN E-epilepsy. E-epilepsy has proven the ability to build a sustainable pilot network using e-tools and multidisciplinary team discussions. This would continue through the future EpiCARE network, increasing the number of resultant seizure free patients in the next five years.

By networking centres with expertise in diagnosis of rare and potentially treatable causes of epilepsies, and the use of highly technological investigative tools and diagnostic investigation, a collaborative effort will be made at collecting and developing guidelines for diagnosis and treatment of rare and complex epilepsies within the first three years of the EpiCARE network. Collecting common outcomes through registries of specific diseases will enhance both experience and knowledge base as to optimal management in these rare conditions.

The participation of network members in virtual discussion utilising an existing IT platform, and the integration of expertise in teaching programmes, will also enhance the likely diagnosis of individuals in EU member and non-member states. This is specifically relevant to reducing the gap of knowledge on rare epilepsies in adult patients.

REDUCING THE NEED FOR CROSS BORDER TRAVEL

Ultimately, such exchange of data will enhance local delivery of care and minimise the need for patients to travel to other centres, or indeed utilise the cross border directives, facilitating optimised care for all. This will enable a wider number of individuals to access better and safer healthcare care within the next five years, thus impacting positively on the quality of life of the patients and their families and also having a direct economic impact at family and societal levels.

CAN YOU HELP?

While we believe that an ERN focussed specifically on rare and complex epilepsies could lead to enormous benefits for patients, care providers and national health departments, we are aware that there will be a significant number of other applicants who also believe their proposed network to be vital. For this reason, we need to persuade EU national members to look favourably on the EpiCARE submission. If you think you can help, by contacting your national health department, we would be happy to provide you with some information to accompany your message. Please email ibeexecdir@eircom.net for further information.

With best wishes

Athanasios Covanis and Philippe Ryvlin
Co-chairs, Epilepsy Alliance Europe Task Force

Patient path to care

