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EpiCARE – a European Reference Network for rare and complex epilepsies

JA2015 - GPSD [705038]

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<th><strong>START DATE:</strong></th>
<th>01/03/2018</th>
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<td><strong>END DATE:</strong></td>
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<td><strong>DURATION:</strong></td>
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<td>EUROPEAN REFERENCE NETWORKS SPECIFIC GRANT AGREEMENTS COVERING YEAR 2018</td>
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<td>ERN Specific Grant Agreements Year 2</td>
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<td><strong>KEYWORDS:</strong></td>
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Project abstract

ERN EpiCARE is a network of 28 centres with expertise in the rare and complex epilepsies across 13 countries, developed to enhance diagnosis and ultimate management of these diseases. Since the launch of the European Reference Networks in March 2017 we have built on the existing pilot ERN e-pilepsy in developing an expanded network with regard to the range of diseases included. We have achieved all objectives set out in our initial SGA for the first 12 months.

The activities over the second year will be targeted at consolidating and further developing the network. The proposed care pathway for referral will be established to ensure accessibility and coordination with national networks. Online tools to aid evaluation of patients will continue in development, with a move to utilising the Clinical Patient Management System to enable discussion of complex patients.

A registry will be established and collaboration with Orphanet will enable revision of clinical phenotype genotype information available for all on specific diseases. Pilot treatment protocols will be developed to be utilised across all centres, along with guidelines in collaboration with specialist societies. There will be a further focus on training and education.

Through collaborative working, sharing of expertise and access to advanced diagnostics we will build on the number of individuals with refractory epilepsy having an underlying diagnosis and further options for treatment.
Work package

Work Package 1: WP1: Network Coordination
Start month: 1
End month: 12
Work Package Leader: GOSH

WP1: Network Coordination - coordination of the overall work of the EpiCARE network

Work Package 2: WP3: Neuroimaging
Start month: 1
End month: 12
Work Package Leader: GOSH

WP3: Neuroimaging

Work Package 3: WP7: Targeted medical therapies
Start month: 1
End month: 10
Work Package Leader: GOSH

Survey through network to determine existing protocols for treatment of rare epilepsies
Establish standardized protocols with outcome parameters for 5 key diseases to be utilized across network

Work Package 4: WP9: Neonatal seizures
Start month: 1
End month: 12
Work Package Leader: GOSH

Establish pathway for expert review of clinical and EEG data (view via Babylink)
Establish regular meetings, either as virtual meetings or as face to face meetings alongside international conferences or meetings to discuss work package tasks and clinical cases.
Become member of ENPR-EMA network (European Network of Paediatric Research at the European Medicines Agency)
Finalise European guidelines for EEG monitoring in high risk neonates which will be available on the EpiCARE website

**Work Package 5: WP 10: Dietary treatment**
Start month: 1  
End month: 8  
Work Package Leader: GOSH

- Current list of guidelines to be provided to expert group; prioritization of guidelines to be developed  
- Meeting of expert group during ‘ketocollege’ June 2018  
- Development of online tutorials in collaboration with Matthews Friends; needs assessment for e-learning

**Work Package 6: WP III: Education & Training**
Start month: 1  
End month: 12  
Work Package Leader: GOSH

- Inventory of existing courses organized by EPI CARE centres with content relevant available on website  
- Identify needs of EPI CARE centres to assume required educational role,  
- Identify needs of European chapters of the International League Against Epilepsy in collaboration with CEA-ILAE for further development of national and/or European based activities

**Work Package 7: WPIV: Research**
Start month: 1  
End month: 12  
Work Package Leader: GOSH

- Implementation of clinical database for research  
- Pilot through steering committee to assess suitability, first 50 cases  
- Inventory of all applications presented by EpiCARE members to national or international calls in which EPiCARE assets made available  
- Charter regulating data sharing
Work Package 8: WP4: Clinical Neurophysiology
Start month: 1
End month: 12
Work Package Leader: GOSH

Start-up of the EpiCARE EEG-cloud
Uploading EDF files and testing data transfer and storage on the cloud
Beta version of the EpiCARE EEG-cloud
Selected centres will participate in testing the beta version of the cloud
Webinar on the use of EpiCARE EEG-cloud
A webinar for teaching the participating centres how to use the SCORE in the EpiCARE EEG-cloud
Data upload and scoring
Uploading and scoring real (de-identified) EEG data

Work Package 9: WP6: Neuropathology
Start month: 1
End month: 12
Work Package Leader: GOSH

A neuropathology teaching course will be organized in July 26-29, 2018 at the University Hospital in Erlangen.
Establish a web-based reading and teaching platform for neuropathology and epilepsy surgery.

Work Package 10: WP7: Targeted medical therapies
Start month: 1
End month: 12
Work Package Leader: GOSH

Survey through network to determine existing protocols for treatment of rare epilepsies
Establish standardized protocols with outcome parameters for 5 key diseases to be utilized across network

Work Package 11: WP8: Surgery (E-pilepsy)
Start month: 1
End month: 12  
Work Package Leader: GOSH

Continue to expand the number and participants to the E-care visioconfences on epilepsy surgery, moving to use of the CPMS  
Further develop the IT platform devoted to presurgical post processing and visoconferences, and make available for use by other workpackages in EpiCARE by  
Installing centre specific readers of EEG data  
Installing Brainstorm software for analysis of individual brain recordings (MEG, EEG, fNIRS, ECoG and depth electrodes)  
Upgrading the currently available Curry8 software (3 licenses) with MAP for use in post processing  
Creation of tutorials and how-to’s for the use of the software installed on the platform. (monthly - one tutorial per software)

Work Package 12: WP I: E-database
Start month: 1  
End month: 12  
Work Package Leader: GOSH

Development of the EpiCARE registry  
Establishment of relevant clinical parameters for utilization in REDCap format  
Pilot use of EpiCARE registry

Start month: 1  
End month: 12  
Work Package Leader: GOSH

Establish the Task force for review of existing guidelines  
Establish inventory of existing guidelines, with links through website  
Link to established guidelines in English and various other languages through the website  
Identification of the unmet needs and selection of the topics for future activities on guidelines

Work Package 14: WP 14: Education & Training
Start month: 1
End month: 12
Work Package Leader: GOSH

Inventory of existing courses organized by EPiCARE centres with content relevant available on website
Identify needs of EPiCARE centres to assume required educational role,
Identify needs of European chapters of the International League Against Epilepsy in collaboration with CEA-ILAE for further development of national and/or European based activities
Work on recommendations as to how EpiCARE centres can host neurologists/child neurologists
Collect information on all available educational material on rare and complex epilepsies for patients and families in collaboration with ePAG group and Orphanet and widen availability

Work Package 15: WP15: Research
Start month: 1
End month: 12
Work Package Leader: GOSH

Implementation of clinical database for research
Pilot through steering committee to assess suitability, first 50 cases
Inventory of all applications presented by EpiCARE members to national or international calls in which EPiCARE assets made available
Charter regulating data sharing

Work Package 16: WP 16: Clinical trials
Start month: 1
End month: 12
Work Package Leader: GOSH

Develop an EpiCARE-based panel of experts to validate syndromic diagnosis and seizure classification for individual patients to be enrolled in clinical trials
Develop a database of clinical trials conducted to date in rare and complex epilepsy syndromes
Survey across network to determine prioritization of treatments to be tested in specific syndromes
## COORDINATOR

**Great Ormond Street Hospital for Children NHS Trust (GOSH)**

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United Kingdom

<table>
<thead>
<tr>
<th>Project leader contact</th>
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<tbody>
<tr>
<td>Name: CROSS Helen</td>
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<td>Email: <a href="mailto:h.cross@ucl.ac.uk">h.cross@ucl.ac.uk</a></td>
</tr>
<tr>
<td>Phone:</td>
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## PARTNERS

No partners related to the current project
Annual report with evaluation to be publicly available
GOSH
EpiCARE – a European Reference Network for rare and complex epilepsies (ERN EpiCARE)
Expected on: 01/03/2019
Annual report to include evaluation to be publically available by month 12. Planning and implementation of the annual work plan, to include metrics evaluating progress and added value.

Publication of imaging standards and guidelines for rare and complex epilepsies
GOSH
EpiCARE – a European Reference Network for rare and complex epilepsies (ERN EpiCARE)
Expected on: 01/03/2019
D 3.2 Publication of imaging standards and guidelines for rare and complex epilepsies at month 12

Report on treatment protocols for selected rare and complex epilepsies
GOSH
EpiCARE – a European Reference Network for rare and complex epilepsies (ERN EpiCARE)
Expected on: 01/01/2019
D7.2 Report on treatment protocols for selected rare and complex epilepsies

E-guidelines available on website on EEG monitoring high risk neonates at month 12
GOSH
EpiCARE – a European Reference Network for rare and complex epilepsies (ERN EpiCARE)
Expected on: 01/03/2019
D9.3: e-guidelines available on website on EEG monitoring high risk neonates
Guidelines for when/how ketogenic diet utilized month 8
GOSH
EpiCARE – a European Reference Network for rare and complex epilepsies (ERN EpiCARE)
Expected on: 01/11/2018
D10.2: Guidelines for when/how ketogenic diet utilized month 8

Needs assessment in collaboration with all other workpackages at month 12
GOSH
EpiCARE – a European Reference Network for rare and complex epilepsies (ERN EpiCARE)
Expected on: 01/03/2019
D14.3 Needs assessment in collaboration with all other workpackages at month 12

Common dataset for utilisation REDCap database month 6
GOSH
EpiCARE – a European Reference Network for rare and complex epilepsies (ERN EpiCARE)
Expected on: 01/09/2018
D15.3 Common dataset for utilisation REDCap database month 6