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### ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease

**JA2015 - GPSD [705038]**

<table>
<thead>
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<th>START DATE:</th>
<th>01/03/2018</th>
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<td>28/02/2019</td>
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<tr>
<td>DURATION:</td>
<td>12 month(s)</td>
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<td>CURRENT STATUS:</td>
<td>Finalised</td>
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<td>PROGRAMME TITLE:</td>
<td>3rd Health Programme (2014-2020)</td>
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<td>CALL:</td>
<td>EUROPEAN REFERENCE NETWORKS SPECIFIC GRANT AGREEMENTS COVERING YEAR 2018</td>
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<td>TOPIC:</td>
<td>ERN Specific Grant Agreements Year 2</td>
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<td>KEYWORDS:</td>
<td>Autoimmune Disease, Genetic Disease, Liver, Paediatric, Transitional Care</td>
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Project abstract

This proposal is to support the delivery of ERN-RARE-LIVER, the European Reference Network (ERN) in rare hepatological diseases. Liver disease is a major and growing problem in the European population. The expansion in clinical need because of increasing disease impact has not been matched by expansion in the clinical workforce leading to a relative lack of expertise. The challenge is particularly acute in rare liver disease; a setting in which Europe leads the world in terms of academic innovation. The ERN model is particularly attractive in the setting of rare liver disease as it will foster the development of ‘virtual critical mass’ across European centres with benefits in terms of clinical care deliver, teaching and training and research capacity. We are also supported by the relevant professional societies, the European Association for the Study of the Liver (EASL) and the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN), who are the communities of our field. Covering all ranges, from paediatric to adult through transitional care, ERN-RARE-LIVER has 3 themes reflecting important disease groupings (Autoimmune Liver Disease; Metabolic, Biliary Atresia and Related Disease; Structural Liver Disease) with a coherent plant to increase both our disease scope and geographical coverage. We will improve patient care directly through our work on guideline optimisation, care pathway development and the implementation of a model of “TELE-BOARDS” with multi-centre discussion of complex and challenging cases. We will also facilitate improvement in diagnostics capacity through development of quality assurance programmes in serology and histopathology, and case referral pathways to support centres lacking diagnostic technology. Our training and research programmes will enhance care delivery through increase in the trained workforce and knowledge respectively.
Work package

Work Package 1: Management and Coordination
Start month: 1
End month: 12
Work Package Leader: NUTH

Task 1.1 Financial Management – the project administration team will provide monthly updates of spend against project budget. They will also administer the project travel budget against the procedures developed in year 1
Task 1.2 Project management – The governance of ERN Rare Liver will be reviewed and updated as necessary, to ensure that it is fit for purpose. Progress against the tasks, deliverables and milestones will be monitored. Project risks will be reviewed and updated.
Task 1.3 Coordination – maintenance of Grant and consortium agreement. Assistance in the process of adding new members.
Task 1.4 Brexit contingency planning – a plan for the continuation of the ERN should Brexit mean that the UK can no longer take part in ERN’s will be drawn up

Work Package 2: IT and Logistics
Start month: 1
End month: 12
Work Package Leader: NUTH

Task 2.1 Registry. Extend the RARE LIVER registry to all centres for quality control purposes covering all the disease areas.
Task 2.2 CPMS. Work to ensure all centres have access to and use the CPMS system. Monitor the usage to ensure use.

Work Package 3: Training Activities
Start month: 1
End month: 12
Work Package Leader: NUTH

Task 3.1 Identify key training resources within the network for translation and organize translation as relevant. Translated materials will be available on website.
Task 3.2 Work with EASL and ESPGHAN to commission, develop and deliver a 2-yearly School of Hepatology in rare liver disease.
Task 3.3 Develop, facilitate and monitor the progress of a clinical exchange
Work Package 4: Standardisation and uniformity of care
Start month: 1
End month: 12
Work Package Leader: NUTH

Task 4.1 The registry will be used to monitor and track outcome data this will be used to assess treatment and diagnosis methods.
Task 4.2 Develop and implement with EASL and ESPGHAN a program of guideline development
Task 4.3 Develop a panel of reference informative sera with linked clinical data for use in an evaluation programme. Assess the reliability of serological testing by sending selected sera for reassessment in reference laboratories. Define the need for standardised reference sera, make available to all network laboratories.
Task 4.4 In order to improve standards for histopathological diagnosis of rare liver disease, the ERN will hold a workshop of expert liver histopathologists and develop a strategy, which shall encompass aspects of improved training, reference pathology services and panel discussions of selected cases. Then we will work with interested centres (3-5) to develop a clinical referral network for serological, histopathological genetics and other diagnostic technologies.

Work Package 5: Research
Start month: 1
End month: 12
Work Package Leader: NUTH

Task 5.1 – Grant development. Continue to develop and deliver a strategy for network grant development both nationally and internationally funded and ensure full coordination between network members in developing and supporting relevant grant applications.
Task 5.2 – Clinical cohorts. Develop and deliver a strategy for clinical cohort development building on existing resources and supported by a clinical research database and deliver a strategy for network support for clinical trials.

Work Package 6: Dissemination and Additional Activities
Start month: 1
End month: 12
Work Package Leader: NUTH

Task 6.1 Patient information resources. Undertake an audit of existing patient-
information resources across the disease areas of the network and identify best practice. Develop a resource of patient-information leaflets to be disseminated through web and social media. Develop patient information content appropriate for clinician and research training.

Task 6.2 Publications. Develop a strategy for publication to ensure that all stakeholders are addressed

Task 6.3 Sustainability. Develop a strategy for placing RARE-LIVER on a stable long-term footing, and for it to become self-sustaining after the 5 year grant ends.

Task 6.4 Communications. Maintain and grow the project website and resources as well as communication means and methods to stakeholders.
COORDINATOR

THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST (NUTH)

FREEMAN ROAD
NEWCASTLE UPON TYNE

United Kingdom

PARTNERS

No partners related to the current project
Interim finance report
NUTH
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 17/05/2019
Report on the use of budget

Patient Information resources dissemination
NUTH
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 17/05/2019
Report on the development of a resource of patient-information leaflets to be disseminated through web and social media

Risk Monitoring
NUTH
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 17/04/2019
Updated risk register and actions taken to mitigate risks

Brexit contingency plans
NUTH
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 17/04/2019
A plan for the continuation of the ERN should Brexit mean that the UK can no longer take part in ERN’s will be drawn up

Report on governance
NUTH
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 17/04/2019
Report the governance review and any changes made to the governance structure of the ERN

Check-list evidencing that all centres are using registry
NUTH
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 17/04/2019
Report showing evidence that the registry is being used by the network

CPMS Implementation
NUTH
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 17/04/2019
Report on the usage of the CPMS system

Work with EASL and ESPGHAN to commission, develop and deliver a 2- yearly School of Hepatology in rare liver disease
NUTH
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 17/04/2019
Report on the development and delivery of a 2- yearly School of Hepatology in rare liver disease

Embed the framework for outcome data assessment
NUTH
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 17/04/2019
Report on the outcome data from the registry
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<th>Title</th>
<th>NUTH</th>
<th>ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)</th>
<th>Published on: 17/04/2019</th>
<th>Report on guideline development</th>
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<td>Plan for grant development</td>
<td>NUTH</td>
<td>ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)</td>
<td>Published on: 17/04/2019</td>
<td>Report on the strategy and implementation of a plan for additional grant funding</td>
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<td>Patient information resources</td>
<td>NUTH</td>
<td>ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)</td>
<td>Published on: 17/04/2019</td>
<td>Audit of existing patient-information resources across the disease areas of the network and identify best practice.</td>
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<td>ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)</td>
<td>Published on: 17/04/2019</td>
<td>Report on a strategy for publication to address all stakeholders</td>
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Sustainability
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 17/04/2019
Report on a strategy for placing RARE-LIVER on a stable long-term footing, and for it to become self-sustaining after the 5 year grant ends

Key training data content translated
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 15/04/2019
Report on the Identification of key training resources within the network for translation and organisation of translation as relevant

Develop, facilitate and monitor the progress of a clinical exchange programme across the network
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 15/04/2019
Report on the development, facilitation and monitoring of a clinical exchange program

Workshop of expert liver histopathologists
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 15/04/2019
Report on the workshop for histopathologists

Clinical cohort development
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 15/04/2019
Report on clinical cohort development building on existing resources and supported by a clinical research database and deliver a strategy for network support for clinical trials.

Patient Information resources training
NUTH
ERN-RARE-LIVER: The European Reference Network in Rare Liver Disease (ERN-RARE-LIVER)
Published on: 15/04/2019
Report on the development of patient information content appropriate for clinician and research training.