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

JA2015 - GPSD [705038]

START DATE: 01/03/2019

END DATE: 28/02/2022

DURATION: 36 month(s)

CURRENT STATUS: Finalised

PROGRAMME TITLE: 3rd Health Programme (2014-2020)

PROGRAMME PRIORITY: -

CALL: Multiannual Grant Agreements for European Reference Networks

TOPIC: ERN Specific Grant Agreements 2019 - 2021

EC CONTRIBUTION: 599987 EUR

KEYWORDS: Autoimmune Disease, Genetic Disease, Liver, Paediatric, Transitional Care

Project abstract

This proposal supports the European Reference Network (ERN) in rare hepatological disease. 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 ERN model is attractive for rare liver disease as it fosters the development of "virtual critical mass" across European centers with benefits in terms of clinical care delivery, teaching, training and research capacity. The ERN covers both adult and paediatric patients in the disease groupings (Autoimmune Liver Disease; Metabolic Biliary Atresia and related diseases; Structural Liver Disease) with a coherent plan to increase both disease scope and geographical coverage. Patient care will be improved through work on guidelines, care pathway development and the use of the Clinical Patient Management System for multi-centre discussion of complex cases. We 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: Network Management

Start month: 1

End month: 36

Work Package Leader: UKE

Review of governance and operation

Review and change to governance structure as necessary.

Monitor the operational implementation against plan and budget

Review and update project risks

Work Package 2: ICT and Logistics

Start month: 1

End month: 36

Work Package Leader: UKE

Task 2.1 - Improve the use of CPMS by ensuring that all ERN Rare Liver partner institutions have personnel registered on the system and that all diseases covered by the network have case used it for case reviews.

Work Package 3: Training program development

Start month: 1

End month: 36

Work Package Leader: UKE

Task 3.1 - Develop training content and deliver training events: School of hepatology. Define a specialist nurse job description and implement a training program (1 per year). Implement a histopathology workshop.

Task 3.2 - Initiate a clinical exchange program (2 per year) that allows clinicians to travel to partner institutions to develop skill and knowledge.

Work Package 4: Standardisation and Uniformity of Care

Start month: 1

End month: 36

Work Package Leader: UKE

Task 4.1 Review and report on the patient outcomes to analysis the effectiveness of the CPMS.

Task 4.2 Review current disease guidelines for update requirements and identify where new guidelines are needed. Work with EASL and ESPGHAN to promote the adoption of these as healthcare providers often require such endorsement before uptake.

Task 4.3 Develop a job description for the specialist rare liver disease nurse post and a training curriculum.

Task 4.4 Assess the outcomes of the R-Liver registry and provide recommendations for improvement

Work Package 5: Research

Start month: 1

End month: 36

Work Package Leader: UKE

Task 5.1 - Setup of research working group

Network members will collaborate to create a sustainable collaborative research environment and working group.

The work will identify the key gaps in knowledge across the different disease groups within ERN RARE LIVER and between adult and paediatric requirements

Work Package 6: Dissemination and additional activities

Start month: 1

End month: 36

Work Package Leader: UKE

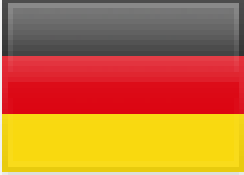
Task 6.1 - Develop a resource of expert definitive information on rare liver diseases for patient organisations.

Task 6.2 - Develop materials for a symposium on rare liver disease agreeing the content across the network.

Task 6.3 Collect and collate all material disseminated by ERN Rare Liver

Task 6.4 Work with CHAFAEA and healthcare providers across Europe to implement a sustainable future for the network

COORDINATOR



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PARTNERS

No partners related to the current project

Report on CPMS use

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 05/07/2022

Report on the use of CPMS across the network partners and by disease

Analysis of CPMS impact and patient outcomes

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 05/07/2022

Assessment of the effectiveness of the CPMS in improving patient outcomes and analysis of outcomes

Impact of R-Liver registry

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 05/07/2022

Assessment of the R-Liver registry including patient outcomes and recommendations for improvements

Report on identified areas requiring research support

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 05/07/2022

Report detailing the identified areas within scope of ERN RARE LIVER that require additional funding due to gaps in knowledge or infrastructure.

Report on Sustainability

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 05/07/2022

Report on the actions taken and methods employed to ensure ERN RARE-LIVER is sustainable at the end of EU funding

Rare Liver Publications V2

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 27/05/2022

Updated compendium of rare liver publications to include a list of scientific publication and copies of all other publications.

Curriculum for specialist nurse training

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 26/05/2022

Specification and curriculum definition for speciality nurse training

Job descriptions of rare liver specialist nurses

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 26/05/2022

Work with all the centres to develop local level posts of rare liver disease specialist nurses to support service development and delivery

Review of ERN governance and operation

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 27/08/2020

Review of the governance and operational structures to ensure they are effective in running the ERN

Guidance pack for patient information resources

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 27/08/2020

Provision of expert definitive information on disease to patient groups for inclusion into patient information leaflets. (minimum of 3 disease)

Program for clinical exchanges

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 25/08/2020

Definition of the clinical exchange program. Diseases, centres, proposed dates, personnel etc. with training objectives.

School of Hepatology

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 25/08/2020

Content and material for the school of hepatology

Programme of new guideline development

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 25/08/2020

Identification and development new and updated guidelines. Collaboration with EASL and ESPGHAN to promote adoption

Report on Rare Liver symposium

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 25/08/2020

Deliver a symposium on Rare Liver disease at the International Liver Congress

Rare Liver Publications V1

UKE

ERN RARE LIVER: The European Reference Network in Rare Liver Disease (ERN RARE LIVER)

Published on: 25/08/2020

Compendium of rare liver publications to include a list of scientific publication and copies of all other publications.