European Reference Network
for rare or low prevalence complex diseases

Network
Inherited and Congenital Anomalies (ERNICA)

NEWSLETTER

JULY 2020
ISSUE 6

Linked in

ERNICA ONLINE MEETINGS APRIL 2020 & SAVE THE DATE!

The ERNICA annual meeting scheduled to take place in Lille in April was unfortunately cancelled due to the COVID -19 outbreak. However, a series of online meetings took its place. We would like to thank all attendees for their time and input. Many future plans for collaboration were made.

We would also like to take this opportunity to inform you that we plan to re-schedule this meeting to take place on 8 and 9th April 2021 *(with an additional meeting for the scientific committee during the evening of 7th).* **Save the date!**

PROJECT FUNDING FROM THE CONNECTING EUROPE FACILITY OF THE EUROPEAN UNION

DEVELOPMENT OF ERNICA E-LEARNING VIDEOS

ERNICA has some additional funding from the *Connecting Europe Facility of the European Union* to develop two types of video for the network: *Informative animation videos for patients and families (on aspects related to their disease/care) & (Live-recorded) surgical videos for clinicians including trainees.* We have already collected ideas through ERNICA's hospital representatives, patient representatives and working group leads and we are following up on these. We also asked to be informed of any existing relevant videos (for possible dissemination and/or adoption/translation). If you are aware of any, please let us know.

ERNICA is now on YouTube! Subscribe to our dedicated channel here:

https://www.youtube.com/channel/UCh9TWUGK-OxG29sOBr3oEtg

Watch this space for new content (including these videos)

CUSTOMISATION OF THE CPMS DATA SET

Under this action, we also have the opportunity to customise the existing CPMS data set to our specific ERN and disease groups. This will facilitate an optimised workflow for clinicians working with the system. This piece of work is running in parallel to the development of the ERNICA registry data sets. Alignment as far as possible is valuable to promote potential future compatibility.

Merel van Pieterson, research nurse and research coordinator for the pediatric gastroenterology department at Erasmus MC has been appointed to primarily support this CPMS customisation process.

Welcome to the team Merel!

Co-financed by the Connecting Europe Facility of the European Union

Co-funded by the European Union

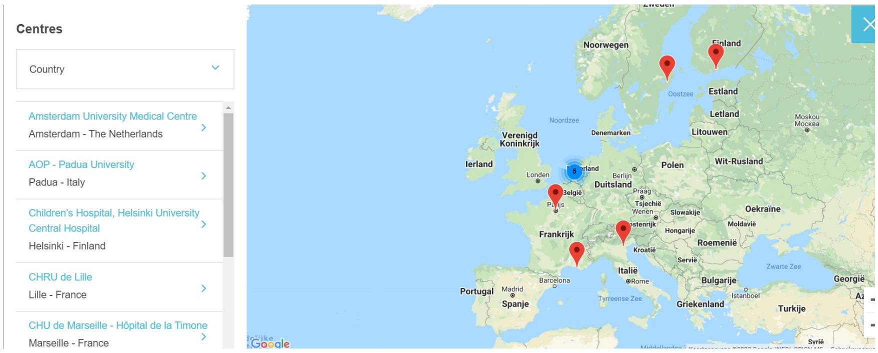
ERNICA MAP TOOL TO SUPPORT TRAVELLING ABROAD WITH INTESTINAL FAILURE

We are delighted to announce that ERNICA has developed an online map tool on our website so that pediatric patients with intestinal failure (whom are reliant on total parenteral nutrition [TPN]) and their families can easily identify specialist centres across Europe (that meet a defined criteria).

You can find the map tool here on our website. On this page, you will also find templates which patients/families can use to record the patient's medical history/any clinical precautions. These can accompany the patient on their trip abroad in case emergency care is required. A TPN holiday checklist is also available.

These will be valuable tools moving forward for patients and families.

More centres can be added to the map as and when appropriate, including our new affiliated partners.



Centres

Country

Amsterdam University Medical Centre
Amsterdam - The Netherlands

AOP - Padua University
Padua - Italy

Children's Hospital, Helsinki University Central Hospital
Helsinki - Finland

CHRU de Lille
Lille - France

CHU de Marseille - Hôpital de la Timone
Marseille - France

Our thanks go to Roel Bakx (Pediatric surgeon from Amsterdam University Medical Centre) and Nadine van Gent and Sylvia Griffioen (parents of children with intestinal failure on TPN) for this fantastic initiative.

WELCOMING NADINE! NEW ERNICA TEAM MEMBER FOR ERNICA REGISTRY PROJECT

Following a successful proposal for funding from the European Commission for development of ERN registries, development of the ERNICA registry officially started on 1st April 2020. The ERNICA registry will build upon an already existing registry infrastructure in The Netherlands, the European Paediatric Surgery Audit (EPSA), and work will be done in close collaboration with The Dutch Institute for Clinical Auditing (DICA). ERNICA has appointed a project manager to coordinate this 3-year project, welcome Nadine Teunissen!

This June I started as the Project Manager of the Registry within ERNICA. Amongst other things, I will be responsible for supporting clinicians in deciding what is to be measured, connecting ERNICA centres to the registry and for communicating the results back to them. With a master's degree in Medicine, as well as a bachelor's degree in Health Care Policy and Management, this project embodies the perfect combination of both areas of expertise. During the coming three years I will be focused on building a structurally sound and lasting registry. Next to that I am aiming to complete a doctoral degree on developing this registry as well as on the specific measured diseases and the resulting data. I am very excited to be part of such a grand undertaking and am looking forward to working with you all.

PUBLICATION OF ERNICA GUIDELINES FOR THE MANAGEMENT OF RECTOSIGMOID HISCHSPRUNG DISEASE

We are delighted to announce that ERNICA consensus-based guidelines for the management of rectosigmoid Hirschsprung's disease have now been published open access in the Orphanet Journal of Rare Diseases. You can access the publication here: https://lnkd.in/dxW5MSV

Congratulations to all those clinicians and patient representatives who were involved in this valuable piece of work to support healthcare professionals and their patients.

Co-funded by the
European Union