




# European Reference Network

for rare or low prevalence complex diseases

 **Network**  
Inherited and Congenital Anomalies (ERNICA)

# NEWSLETTER

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We hope you had an enjoyable holiday period. We look forward to involving you in many exciting ERNICA projects over the coming months but first, some important announcements!

## ERNICA PROJECT MANAGEMENT TEAM CHANGES

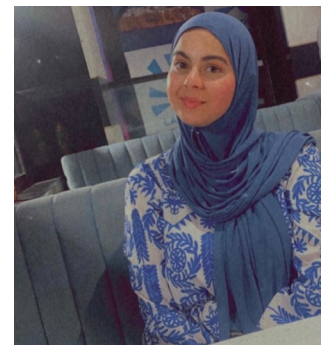
As of 1st September 2022 Hannes Boeckhout will no longer be working for ERNICA as a project manager. Thank you Hannes for your commitment to the role and we wish you lots of luck on your adventures!



It has really been a pleasure to work for ERNICA over the last year. I am sad to leave the network, but have taken the opportunity to travel the world for the coming 12 months. During my time as project manager, I have had the opportunity to meet a lot of surgeons, paediatricians, other health care professionals and patient representatives from different centres all over Europe. While everybody has different backgrounds and experiences all have the same goal: treating the patient with the best care as possible and improving standards of care. I think ERNs are the perfect way to do that. Starting in 2017, the ERNs have grown and were/are still growing when I joined early 2021. The networks have the opportunity to improve care for rare disease patients even further and make this available throughout Europe.

Ikram L'Khssim will also no longer be working for ERNICA as a project manager. Ikram will continue to be based at the Erasmus MC in Rotterdam but will work full-time for another ERN, ERN CRANIO.

I have really enjoyed working for ERNICA over the past year and I am so glad that I got the opportunity to get to know the ERNICA family. I have learned a lot from you all and your commitment to supporting patients with rare diseases is inspiring. I look forward to hearing about all the future ERNICA activities and I wish you all the very best.



**We look forward to welcoming two new project managers to the ERNICA team: Carlos Vrins and Iris den Uijl. Both Carlos and Iris start 1<sup>st</sup> of September and will be based at the ERNICA coordination office in Rotterdam.**

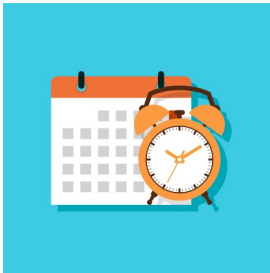
**They will work closely with the current ERNICA team members, René Wijnen (coordinator), Renée de Ruiter (senior project manager), and Olivia Spivack (project manager). We look forward to introducing you to Iris and Carlos in due course!**

# 5-YEAR EVALUATION OF THE ERNS AND THEIR MEMBERS AMEQUIS: AN ASSESSMENT, MONITORING, EVALUATION AND QUALITY IMPROVEMENT SYSTEM FOR THE ERNS



In September 2022, a 5-year evaluation of the ERNs and their members will be launched by the European Commission. This evaluation is part of the AMEQUIS (Assessment, Monitoring, Evaluation and Quality Improvement System) framework developed for ERNs, which was developed to ensure that ERNs remain responsive to patient needs, deliver their objectives and improve performance over time. The evaluation will be performed by an Independent Evaluation Body both at network and at hospital level. The ERNICA project management team will provide more information on the evaluation in due course.

## SAVE THE DATE! ERNICA ANNUAL MEETING 2023 - MADRID!



The 7th ERNICA annual meeting will take place in Madrid on 22nd-24th March 2023.

There will be an ERNICA board meeting on Wednesday 22nd March, followed by sessions on Thursday 23rd and Friday 24th for the whole network.

More information will be provided as soon as possible.

## ERNICA DISSEMINATION AT INTERNATIONAL CONGRESSES

### EUPSA CONGRESS JUNE/JULY 2022



This year, ERNICA had a booth at the European Pediatric Surgeons' Association congress in Tel Aviv. This was a fantastic opportunity to disseminate information about ERNICA to an international audience and promote our collaborative activities such as the [ERNICA-EUPSA clinical exchange programme](#).

It was also a great opportunity to connect with ERNICA colleagues and provide information to those interested in joining the network in the future.

### ESPGHAN ANNUAL MEETING JUNE 2022

ERNICA also had the opportunity to have a stand at the European Society for Pediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN)'s annual meeting. This provided another fantastic opportunity to disseminate information about ERNICA and its activities.

We also connected with our fellow ERN colleagues at ERN TransplantChild and ERN RARE-LIVER!

