



# European Reference Network

for rare or low prevalence complex diseases

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

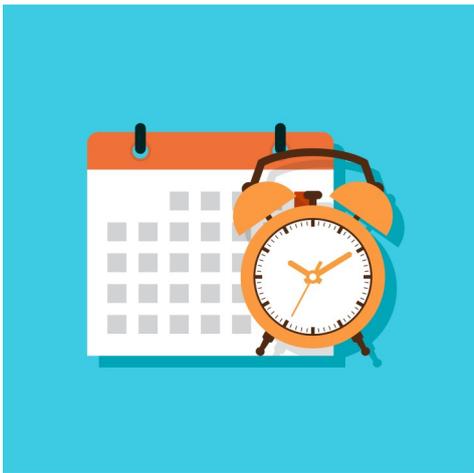
# NEWSLETTER

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## UPCOMING ERNICA ANNUAL MEETING, LILLE : 29 SEPTEMBER—1 OCTOBER



We are happy to announce that the 5<sup>th</sup> ERNICA annual meeting is rescheduled to take place in Lille, France from Wednesday 29<sup>th</sup> September-Friday 1<sup>st</sup> October 2021.

We are closely monitoring the news regarding COVID-19 and associated travel possibilities but plan at this moment to host this meeting in Lille. For part of the general sessions we also plan to organise a livestream, so many more ERNICA colleagues can join part of the meeting online.

**We are looking forward to providing key ERNICA updates and collaborating further on ERNICA activities.**

## NEW ERNICA PROJECT MANAGERS!

**Hannes Boeckhout**



*"As of May, I have started as Project Manager for ERN CRANIO and ERNICA. Together with project managers Renée and Olivia, and Ikram, who also joined ERN CRANIO and ERNICA as Project Manager. I have a masters degree in Human Movement Sciences and worked for over three years for a contract research organisation specialized in the organization of medical device and IVD clinical trials. I am excited to have the opportunity to work for both ERNs and facilitate further cooperation of our expert centres in treating rare diseases"*

**Ikram L'Khssim**



*"I recently joined the CRANIO and ERNICA networks as one of the project managers. I'm really excited to join both ERN's and I can't wait to start contributing in pooling together all expertise and knowledge available across all Europe to increase the access to care and diagnosis-specific information for patients and healthcare professionals. I hope to meet many of you as I settle in and learn more about the networks. Before becoming a project manager, I was a scientific teacher at the Erasmus University in Rotterdam for almost two years. There I taught students in health sciences, with the focus on health policy and management. Besides teaching I was also involved in organizing and coordinating educational activities."*



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# RE-LAUNCH OF ERNICA CLINICAL EXCHANGE PROGRAMMES!



## ERNICA/EUPSA clinical exchange programme

This programme has been on hold due to the COVID-19 pandemic and is expected to resume as of September 2021.

Pediatric Surgery fellows and consultants from centres in the EU (both within and outside of ERNICA) can apply for a travel grant to visit an ERNICA centre for clinical training purposes (1 day—2 weeks). The programme is accredited by EUPSA.

Applications are open. Please visit the [ERNICA website page](#) for more information on the programme, the centres involved and the application procedure.

Should you have any queries please contact Project Manager Hannes Boeckhout:  
[h.boeckhout@erasmusmc.nl](mailto:h.boeckhout@erasmusmc.nl)



## ERNICA/EU clinical exchange programme

The European Commission has granted ERNICA the possibility to use 34 clinical exchange packages until August 2022. This programme will be rolled-out in the coming months. Each package is up to 5 working days long and applications will be open to individuals from all full ERNICA member and affiliated partner hospitals. We would like to particularly invite non-surgical disciplines to apply (e.g. psychologists, nurses, physiotherapists, dieticians). More information will be circulated soon on the programme and application procedure.

## CALL FOR CPMS CASES!

Since the last ERNICA general meeting in April 2021, a pilot implementation plan for the CPMS has been rolled out. Four groups of experts have been defined and a planned rota for bi-monthly discussions has been created. All healthcare providers are invited to propose cases for discussion.

The case discussions we have had so far on the CPMS have been successful but the number of cases proposed for discussion have been less than anticipated. We are confident that ERNICA can facilitate more case discussions to support more patients and healthcare professionals across Europe.

Do you have a patient to discuss with experts in the field? Fill in the survey below with your details and we will contact you: <https://it.surveymonkey.com/r/NHY9PV5>

Looking forward to seeing you on the CPMS,

Francesco Fascetti Leon & Rebecca Pulvirenti (CPMS helpdesk)

[cpmshelpdesk@ernica.ern-net.eu](mailto:cpmshelpdesk@ernica.ern-net.eu)

## RECENT PUBLICATIONS: CDH TOTAL TRIAL



The Tracheal Occlusion to Accelerate Lung Growth (TOTAL) trial led by Professor Jan Deprest from UZ Leuven has recently been completed and results relevant to unborn babies with moderate and severe congenital diaphragmatic hernia (CDH) have been published in The New England Journal Of Medicine.

You can find more information and links to the publications on the TOTAL trial website: <https://totaltrial.eu/>