



European Reference Network

for rare or low prevalence complex diseases

Network
Craniofacial anomalies and ear, nose and throat disorders (ERN CRANIO)

NEWSLETTER

AUGUST 2022

ISSUE 12



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

ERN CRANIO PROJECT MANAGEMENT TEAM CHANGES

As of 1st September 2022 Hannes Boeckhout will no longer be working for ERN CRANIO 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 ERN CRANIO 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, 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.

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

I have really enjoyed my time working within ERN CRANIO on a variety of different projects and I have learnt a lot from you all. Your commitment to supporting patients with rare and complex diseases is inspiring. I look forward to hearing about all the future ERN CRANIO activities and I wish you all the very best.



We look forward to welcoming two new project managers to the ERN CRANIO team: Carlos Vrins and Jana Steerneman.

Both Jana and Carlos start 1st of September and will be based at the ERN CRANIO coordination office in Rotterdam. They will work closely with the current ERN CRANIO team members, Irene Mathijssen (coordinator), Renée de Ruyter (senior project manager), and Ikram L'khssim (project manager).

We look forward to introducing you to Jana and Carlos in due course!



Funded by the European Union

The content of this newsletter represents the views of the author only and it is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the European Health and Digital Executive Agency (HaDEA) or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains. TWITTER, TWEET, RETWEET and the Twitter logo are trademarks of Twitter, Inc. or its affiliates

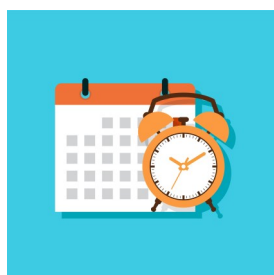
5-YEAR EVALUATION OF THE ERNS AND THEIR MEMBERS

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 ERN CRANIO project management team will provide more information on the evaluation in due course.

CONFIRM PARTICIPATION! ERN CRANIO ANNUAL MEETING, 17-18 NOVEMBER!



The 7th ERN CRANIO annual meeting will take place in Berlin on 17-18 November 2022.

There will be an ERN CRANIO board meeting and a welcome dinner on Thursday 17 November, followed by sessions, such as the Radiology educational session, on Friday 18 November. Please confirm your participation!

ERN CRANIO BOOTH AT EUROPEAN SOCIETY OF CRANIOFACIAL SURGERY CONGRESS, 23-24 SEPTEMBER 2022, OXFORD

The ERN CRANIO coordination team will have an exhibition booth at the European Society of Craniofacial Surgery congress in Oxford on 23-24 September 2022.

Come and see us at the booth on 23-24 September and find out more about ERN CRANIO and our activities! Click [here](#) to register for the event.

