European
Reference
Network
for rare or low prevalence
complex diseases

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

NEWS

ERN CRANIO Newsletter

May 2023, Issue 15

ERN CRANIO project management team

The ERN CRANIO project team has undergone some exciting changes in recent months. We're sad to see our colleagues, Renée de Ruiter and Carlos Vrins, leave the team, but we're incredibly grateful for their hard work and contributions to the network. We wish them all the best in their future endeavors!

On a brighter note, we're delighted to welcome Inga Bos as a new ERN CRANIO project manager!

have joined the ERN CRANIO team as a Project Manager, and I am excited to meet all of you in the near future and contribute to the success of our team. My background is in finance and management. With over two decades of experience in the field, I have worked in Project Control and coordination, in Consultancy, Supply Chain and Hotel Managment.

During my 7-year tenure at Erasmus Medical Center, I served as a Finance Advisor and Project Controller. In these roles, I successfully managed complex projects, improved financial processes, and prepared financial reports for international donor organizations.

In addition to my professional experience, I hold MBA and Master's degree in Economics and English Language.

We're thrilled to continue our work with our amazing team and look forward to making a positive impact in the rare disease community. If you have any questions, don't hesitate to contact the project management team, which now consists of Inga Bos, Jana Steerneman & Ikram I'khssim

ERN CRANIO 2023 - 2027

ERN CRANIO, along with all other ERNs, is seeking a grant that will provide support for coordinating centers and members across all 24 networks. This grant will facilitate the sharing of knowledge, resources, and expertise at the EU level, ultimately improving the diagnosis, treatment, and research of rare diseases for patients and healthcare professionals.

application to be submitted at the end of May.

Do you also have a good and innovative idea that aligns with the ERN CRANIO goals? Please let us know and contact project manager Jana Steerneman: j.steerneman@erasmusmc.nl

ERN CRANIO updates


THE JOURNAL OF CRANIOFACIAL SURGERY
An international journal dedicated to the art and science essential to the global practice of craniofacial surgery, maxillofacial surgery, skull base surgery, and pediatric plastic surgery
ESTABLISHED 1985

EDUCATIONAL SUPPLEMENT

Guideline on Treatment and Management of Craniosynostosis: Patient and Family Version

Faasse, Mariët MSc*; Mathijssen, Irene M.J. MD, PhD†; ERN CRANIO Working Group on Craniosynostosis

Author Information

The Journal of Craniofacial Surgery 34(1):p 418-433, January/February 2023. | *DOI:* 10.1097/SCS.0000000000009143

Translation of patient-friendly craniosynostosis guideline

Mariët Faasse (ePAG from LAPOSA) has written a patient and family version of the guideline on treatment and management of

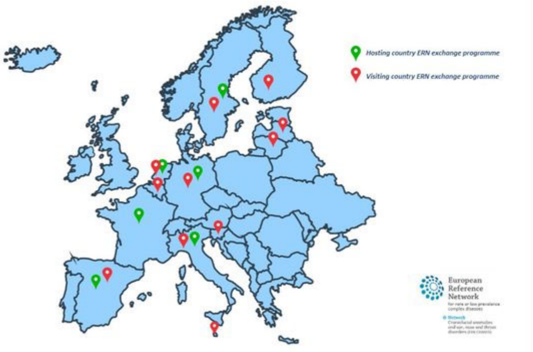
ERN CRANIO supporting partner!

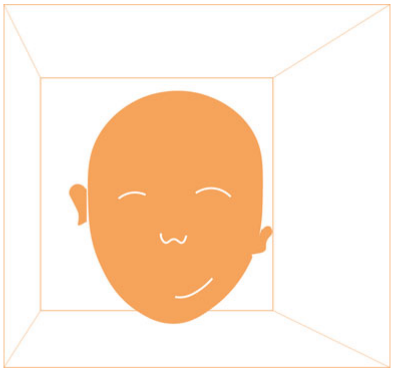
Surgery in January 2023 with open access.
We are currently working on professionally translating this patient-friendly guideline in 5 other languages: German, French, Spanish, Polish, and Slovenian! Keep an eye out on our social media channels for the release of these translations!
Want to provide your input on the translation of this guideline (not the content!)?
Please contact project manager Jana Steerneman: j.steerneman@erasmusmc.nl

Partners! These Supporting Partners are healthcare providers, medical societies, and other individuals or entities who contribute to the work of the network in various ways. It's important to note that Supporting Partners do not have a commercial relationship with ERNs or their Full Members, Affiliated Partners, or the European Commission.

We're thrilled to announce that in April 2023, we signed a supporting partnership agreement with the Craniofacial center of the University Hospital Zurich. We extend a warm welcome to them! Over the next few months, we'll introduce this partner to the network and involve them in ongoing ERN CRANIO projects.

Are you aware of a center that might be interested in becoming a supporting partner of ERN CRANIO? Or do you need more information about supporting partnerships? Please feel free to contact our ERN CRANIO Project Manager, Ikram L'khssim, at i.lkhssim@erasmusmc.nl.





ERN CRANIO Clinical exchange programme

The current ERN CRANIO exchange programme is available for all members and will run until August 2023. We strongly encourage those who have not yet participated in the programme to take this opportunity. You can even go on an exchange with your colleagues for a unique experience!To learn more about the current exchange programme, please click here.

Want to go on exchange? Contact the coordination team for more information via: ern-cranio@erasmusmc.nl

3D working group

The first kick-off meeting of the 3D working group of ERN CRANIO has taken place on the 25th of April 2023.

The goal of the workgroup is to develop and implement a standardized 3D photogrammetry protocol for image acquisition and pre-processing, create a user-friendly framework/tool, and perform uniform 3D analysis across multiple centers to assess outcome differences. During the Berlin annual meeting in November 2022, a call was send out to members with craniosynostosis expertise to join this specific working group. From this moment onwards, the group will work together on shared goals. The working group is co-lead technicians from Hôpital Universitaire Necker Enfants-Malades, Radboud UMC, and Erasmus MC. Further in the future, the goal is to expand the use of the 3D photogrammetry protocol to the other diseases covered within ERN CRANIO.

ERN-wide News

TIME TO ACT – IMPROVING RARE DISEASE DIAGNOSIS AND SOLVING THE UNSOLVED RARE DISEASE THROUGH COLLABORATION IN EUROPE

The Solve-RD consortium and associated European Solve-RD network, including among others six European Reference Networks, EURORDIS, Orphanet and leading EuropeanRare Disease Clinicians and Researchers in 20 countries, call upon all EuropeanRD stakeholders, including EU Member States, the European Commission, the Council of the European Union, the general public and private organizations active

Europe.
This unique opportunity is characterized by pan-European access to diagnostic technologies, in particular, Whole Exome Sequencing, the just reached maturity of the European Reference Networks ecosystem, the looming opportunity to share RDdata on a European-wide scale within the forthcoming European Health Data Space, the upcoming RD-Partnership as well as - with Solve-RD - the availability of a scalable transnational diagnostics research platform.
Solve-RD has summarized the critical action points in this statement.
We call upon all European RD stakeholders to partner to jointly improve Rare Disease diagnosis.

EU Academy Course: ERN Clinical Practice Guidelines and Clinical DecisionSupport Tools Academy

The ERN Guideline Programme, under the support of the Andalusian Health Technology Assessment Agency, has launched the **"Development of Clinical Practice Guidelines"** course, now available on the EU Academy of the European Commission. This training aims to enhance the capacity of ERN healthcare professionals, linical practice guideline (CPG) developers, and expert panel members to efficiently develop, appraise and implement ERN CPGs and clinical decision support tools (CDSTs). To access the course, interested participants need to create an EU login account and link a mobile phone to enable double-factor authentication.
In case you do not have one yet:

1. Go to the EU login landing page: EU Login
2. Click on Create Account.
3. On the page that opens up, fill in the required information: First Name, LastName, E-Mail and Verification Code.
4. Click on Create an account

1. Login to https://academy.europa.eu
2. Search for the course: Development of Clinical Practice Guidelines
3. Click Resume
4. Follow the course

For any inquiries or clarifications, please feel free to contact the agency via mail: cristobal.munoz@juntadeandalucia.es

Training Workshop

Paediatric Patients

The workshop, devoted to 15 paediatric patients in Europe, is organised by the TEDDY European Network of Excellence for Paediatric Research, in collaboration with EURORDIS and the Sant Joan de Déu Research Foundation in the framework of the European Joint Programme on Rare Diseases (EJP RD).
The EJP RD is an EU-funded project aimed at raising the level of knowledge and awareness on rare diseases (RD) research. It namely aims at empowering patients and creating expert patients by providing training materials, workshops and courses on scientific innovation and research.
This year, the paediatric training workshop will take place

NEW SESSION MOOC

The new session of the MOOC “From Lab to Clinic: Translational Research for Rare Diseases” has been launched. Learn the fascinating journey of translating research into treatments for Rare Diseases.
With expert guidance, explore drug discovery, clinical trials, regulatory approval, and challenges in this unique field. Gain insights from patients and experts, understand trial planning, design, and data sharing. By the end, you’ll have a comprehensive understanding of how evidence is built for safe and effective treatments.

Read more about the workshop here.

RARE DISEASES TRAINING COURSE

The International Summer School on Rare Disease Registries and FAIRification of Data is an upcoming virtual course that will be held from June 20th to June 24th, 2023. This course aims to provide participants with an understanding of rare disease registries and the importance of making data Findable, Accessible, Interoperable, and Reusable (FAIR) for rare disease research. The course is designed for researchers, clinicians, data managers, and other stakeholders in the field of rare diseases. The sessions will cover topics such as the use of registries for patient care and research, FAIR data principles, data sharing, ethical considerations, and more. The course will also provide opportunities for networking and collaboration. Click here for more information.

the European Union