



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**

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



ERN CRANIO Newsletter

December 2022, Issue 13



Dear ERN CRANIO members,

The ERN CRANIO coordination team wishes you and your families all the best for the festive season and the forthcoming New Year. We want to thank you for all the support, dedication and enthusiasm this year. We are looking forward to seeing you in 2023!

ERN CRANIO coordination team

ERN CRANIO news

7th ERN CRANIO annual meeting

We would like to thank everyone who attended the 7th ERN CRANIO annual meeting in Berlin. We hope you enjoyed the meeting this year. The summary report and meeting minutes have been sent out to all ERN CRANIO members. If you have an initiative or question regarding the 7th ERN CRANIO annual meeting, please feel free to contact the coordination team via: ern-cranio@erasmusmc.nl

The 8th ERN CRANIO annual meeting will be held in Dublin, Ireland on 16 & 17 November 2023. **Save The Date!**



In the Spotlight:

Mariët Faasse (ePAG from LAPOSA) has written a patient and family version of the guideline on treatment and management of craniosynostosis. This guideline will be published in the Journal of Craniofacial Surgery in January 2023. This will be an open access publication!

The coordination team would like to congratulate Mariët on this ERN CRANIO endorsed guideline!



EDUCATIONAL SUPPLEMENT

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

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European Reference Network Craniofacial Anomalies and Ear-Nose-Throat Disorders (ERN CRANIO), co-funded by the European Union.

The authors report no conflicts of interest.

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The Journal of Craniofacial Surgery: December 6, 2022 - Volume - Issue - 10.1097/SCS.00000000000009143
 doi: 10.1097/SCS.00000000000009143



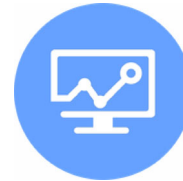
ERN CRANIO updates



ERN CRANIO is now live on Instagram!

As of this month, ERN CRANIO is live on Instagram! Follow us by searching for erncranio or click on the button below!

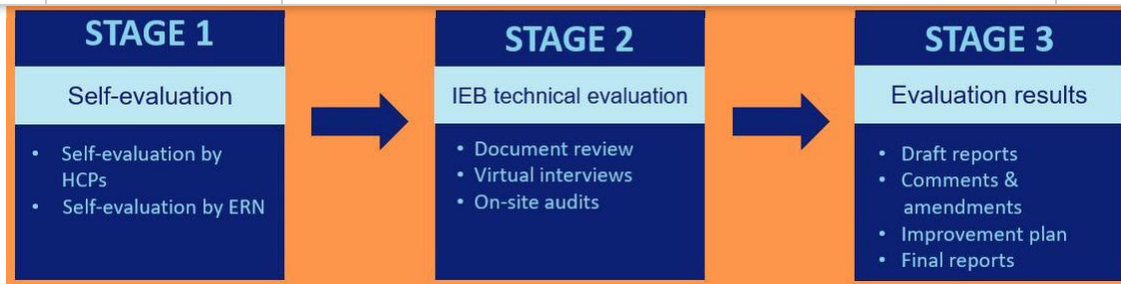
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Upcoming: ERN CRANIO annual data collection

As you all know, each year every ERN CRANIO HCP member has a responsibility to provide information on the number of patients with rare diseases that it is treating, as well as other activities undertaken to support the network. This information is then collected by the Coordination Team and submitted to the European Commission. The current data collection exercise is to collect data for 2022.

We are waiting to hear back from the European Commission on the updated ERN indicators, but as soon as we hear back from them we will send you the data collection form.



Stage 1 has just kicked-off. The European Commission has sent members that joined ERN CRANIO in 2017 their login credentials to visit the portal where the self-evaluation forms can be found. Click here to visit this online tool. The self-evaluation has to be filled in **before 19 February 2023**.

For more information in regards to the evaluation, please click on the button below. In case of any questions you can also contact project manager Ikram L'Khssim via this e-mail address: i.lkhssim@erasmusmc.nl

Click here for more information

Call for cross-workstream working groups!

We call upon our members to join cross-workstream working groups. In 2023, we are aiming to develop a cross-workstream workgroup for geneticists, radiologists, nurse specialists and psychologists!

Geneticists, radiologists, nurse specialists and psychologists in the field of craniosynostosis and other craniofacial anomalies, ENT disorders and cleft lip/palate and orodental anomalies can join one of these working groups. The main goal of these workgroups will be to join forces and knowledge in the expert field of these workstreams, start working together and have regular meetings together to improve knowledge exchange across Europe.



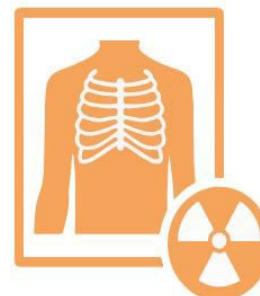
Geneticists



Nurse specialists



Psychologists



Radiologists

Do you want to join or do you know someone that would like to join one of these cross-workstream working groups? Contact the coordination team via: ern-cranio@erasmusmc.nl

Please note that these cross-workstream working groups are exclusively for ERN CRANIO members.

ERN-wide News



The European Joint Programme on Rare Diseases launched the **Joint Transnational Call 2023**, a funding opportunity for **research projects on the development of new analytic tools and pathways** to accelerate diagnosis and facilitate diagnostic monitoring of rare diseases.

This year's topic is: **“Natural History Studies addressing unmet needs in Rare Diseases”**

The aim of the funding opportunity is to **enable scientists in different countries to build an effective collaboration on a common interdisciplinary research project** based on complementarities and sharing of expertise, with expected impact to use the results in the future for benefit of patients.

[Learn More](#)

EJP RD ERN Workshop: RARE TOGETHER

Registration is open (deadline 1 February) for the **RARE TOGETHER Workshop** organised by Dr. Rosanne Smits (Radboudumc).

This in-person event is now open to all researchers within the ERNs and will take place on **8-9 May 2023** at the Van der Valk Hotel, Nijmegen-Lent (NL). The workshop aims to raise awareness for the psychosocial impact of having a rare disease and form a group of researchers in the mental well-being and social sciences domain of rare diseases.

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