From: ern-cranio@erasmusmc.nl
Sent: Thursday, June 25, 2026 5:34 PM
To: ern-cranio@erasmusmc.nl
Subject: FW: ERN CRANIO newsletter - June 2026

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European Reference Network
for rare or low prevalence complex diseases

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

ERN CRANIO newsletter

Issue 24 - June 2026

NEWS

ERN CRANIO updates

Welcome to the latest edition of the ERN CRANIO newsletter!

In this summer edition, we are pleased to share highlights from across our network, including recent achievements, ongoing initiatives, and upcoming events. These updates reflect the dedication, collaboration, and expertise of our healthcare professionals, researchers, patient representatives, and partners working together to improve care for patients with rare craniofacial and ENT conditions throughout Europe.

We hope you enjoy reading this edition and find it both informative and inspiring.
Do you have news, achievements, events, publications, or other updates that you would like to share with the network? We would be delighted to hear from you. Please contact us at ern-cranio@erasmusmc.nl to contribute to a future edition.

As many of us prepare for the summer holidays, we would like to thank you for your continued commitment to ERN CRANIO and wish you a relaxing and enjoyable summer break.

Warm regards,
The ERN CRANIO Coordination Team

New Patient Representatives in ERN CRANIO

We are pleased to introduce two new patient representatives, who have recently joined the ERN CRANIO network. Their valuable perspectives and lived experiences play an essential role in shaping our work and ensuring that patient voices are at the heart of everything we do.

Below, you will find short introductions of the two patient representatives and their associations.

APERTCRAS

“Together, we do more than endure: we move forward, advocate for our rights, and build the future.”

APERTCRAS is the Spanish National Association for Apert Syndrome and other Syndromic Craniosynostoses. Founded by families affected by these rare conditions, the organisation provides support, advocacy, awareness activities, and promotes research to improve the quality of life of affected individuals and their families. Today, APERTCRAS supports 65 affected member families and 27 partner members across Spain. The association plays an important role in connecting families, professionals, and researchers, strengthening the voice of the cranio community at national level.

The representative of the APERTCRAS network within ERN CRANIO is Dr. Katiuska Carolina Rosas Soto, Pediatric Neurosurgeon and mother of a child with Crouzon syndrome. She brings a unique combination of professional expertise and lived experience to the network.

We are also pleased to highlight APERTCRAS' online presence, where they continue to share updates, stories, and awareness activities:

Website:
https://share.google/ozpGkjmCM3EUreIaQ

Facebook:
https://www.facebook.com/share/1E4tUixSNA/

Instagram:
https://www.instagram.com/apertcras?igsh=ZXdvOWhjeWE4c2lw

We would also like to mention that the APERTCRAS Annual Conference will be held on June 27th.

ALPC

We are also pleased to welcome Vincent Bouldoires as the new representative for ALPC. Below, Vincent introduces himself and shares his perspective on joining:

"My name is Vincent Bouldoires, and I am honoured to join ERN CRANIO as the new representative of ALPC (Association nationale pour la promotion et le développement de la Langue française Parlée Complétée), the French association promoting Cued Speech (LfPC) and access to spoken French for deaf children and adults.

I am taking over this role from Michel François, who represented ALPC for many years within the French Centre of Reference for Genetic Hearing Loss, the SENSGENE network and ERN CRANIO. On behalf of ALPC, I would like to thank him for his long-standing commitment and for the strong relationships he helped build between our association and these important scientific and medical networks.

As member of ALPC, I am deeply committed to improving access to language, education and social inclusion for deaf children and adults. I strongly believe that

patient organisations have an important role to play alongside healthcare professionals, researchers and reference centres in shaping better care pathways and supporting innovation.

Through my involvement in ERN CRANIO, I hope to contribute the perspective of families and deaf individuals, while strengthening collaboration between patient communities and healthcare experts across Europe. I look forward to working with all members of the network to advance knowledge, share experiences and improve the lives of people living with hearing loss and rare hearing disorders."

Publication Alert

We are pleased to have contributed to this new publication in Frontiers in Public Health, which highlights the role of ERNs in supporting genomic newborn screening and ensuring rapid access to specialised care for children with rare diseases.

Within this work, developed as part of the Screen4Care project, ERN CRANIO was represented by our coordinator Irene Mathijssen and project manager Ikram L'khssim. The publication proposes an innovative framework connecting genomic newborn screening programmes with ERN expertise across Europe, with the aim of improving early diagnosis, referral pathways, and access to treatment.

👏 Congratulations to all authors and partners involved in this important collaborative effort.

Link:
Frontiers | European Reference Networks as core health structures where referring genetic newborn screening positive infants: an innovative operational research framework

Insights into psychological support needs presented at Scaplas Conference by ERN CRANIO Psychologist Working Group

The Scandinavian Conference of Plastic and Aesthetic Surgery (Scaplas) was held in Oslo, Norway in the first week of June. During the conference, Dr. Kristin Billaud Feragen, psychologist and co-lead of the ERN CRANIO Psychologist Working Group, presented preliminary results from the patient and caregiver survey on access to psychological support.

Her presentation highlighted important early insights into how patients and caregivers experience access to psychological care across different settings, contributing to a broader understanding of psychosocial support needs within craniofacial conditions. More information about the conference can be found here: https://www.scaplascongress.org/

Clinical Exchange Programme: OR Nurse to ASST Azienda Ospedaliera Papa Giovanni XXIII

From April 13 to 19, Silja Wiese, one of our OR nurses, completed a clinical exchange in the pediatric department of Papa Giovanni Hospital in Bergamo. She was warmly welcomed by Ramona Capelli (ERN ERNICA), who made this inspiring week possible. 👏

The exchange offered valuable insights into healthcare practices across countries and highlighted the diversity and expertise of nursing roles. Overall, it was an enriching experience that strengthened professional connections and fostered cross-border learning.

To read the whole story please click the link here

New Call: Become an ERN Affiliated Partner!

The European Commission has launched a call for new affiliated partners, aimed at countries that do not yet have full coverage across all European Reference Networks (ERNs). The objective is to strengthen the geographical reach of ERN expertise across all EU Member States and Norway, ensuring that highly specialised care becomes more accessible in countries and disease areas where full ERN membership is not yet established.

The initiative also supports further integration of ERNs into national healthcare systems and promotes cross-border knowledge exchange and clinical collaboration, ultimately contributing to more equitable access to expertise for patients across Europe.

The following countries are eligible to apply: Bulgaria, Cyprus, Croatia, Czechia, Estonia, Greece, Latvia, Romania, Slovenia and Slovakia.

If you know colleagues, centres, or networks in these countries that could be interested in becoming affiliated partners of an ERN, or that should be made aware of

this opportunity, please feel free to point them towards this call and encourage them to explore it further.

More information about the call can be found here: **https://lnkd.in/d7rsc_9Y**

WORKSHOP: Craniofacial basic and advanced Techniques

👏 Highlights of the 3rd CF Necker Workshop (26-28 March) 2026 👏

The 3rd CF Necker Workshop, held on March 26–28, 2026, brought together over 40 participants from 21 countries for an intensive and hands-on learning experience. We're proud to share that 97% of participants reported being satisfied or very satisfied, with their learning expectations fully met. 🌎🧬

The workshop welcomed more than 20 international faculty members from leading craniofacial centers worldwide. Through high-quality lectures and hands-on tutoring on resin models, participants benefited from an exceptional teaching experience focused on unicoronal synostosis and hypertelorism.

In addition, the informal atmosphere between faculty and delegates, as well as the considerable time allotted for open discussion, have favourized the scientific exchanges for the benefit of everyone. Many 2026 participants had previously attended the Monobloc workshop, while others are already planning to join the next Monobloc edition in April 2027 (exact dates will be announced by the end of September 2026).

A strong focus on continuous improvement ensures ongoing upgrades to models and instrumentation, creating the best possible environment for hands-on practice and learning.

We are looking forward to welcoming old and first-time participants in spring 2027!

👉 Read the full reflections of our members about this workshop on our website: here

New: ERN CRANIO Research Catalogue

Exiting news: the ERN CRANIO Research Catalogue is now live on the website.

The catalogue has been developed to provide a comprehensive overview of both ongoing research projects and previously published work within the network. Its primary aim is to strengthen connections between researchers working on similar topics, stimulate new collaborations, and offer visibility into potential opportunities for early-career researchers to become involved in existing projects.

By bringing together key research activities across the network, the catalogue highlights the breadth and depth of expertise within ERN CRANIO
If you would like a project, study proposal, or published article to be included, we kindly ask you to complete this survey: click here

The Research Catalogue is structured into six main thematic areas:

1. Translational research
2. Basic science
3. Quality of life
4. Registries
5. Clinical research
6. Other research areas
7.

Within each theme, a range of projects is presented. For more detailed information about a specific project or to explore collaboration opportunities, we encourage you to contact the designated contact person listed in the catalogue.

We hope this new resource will serve as a valuable tool to enhance collaboration, increase visibility of research efforts, and ultimately contribute to advancing knowledge and care within the ERN CRANIO community.

Yearly Monitoring Update

We are happy to share that all ERN CRANIO full member centers have received a performance update covering the period 2023–2025 by email. If you have any questions regarding your center's performance, please do not hesitate to reach out to us. Later this year, the European Commission will also publish the new ERN Monitoring Report, which will provide further insight into the performance of all European Reference Networks.

Why is this important?
This monitoring data helps us better understand how our member centers are performing within the network, highlighting strengths as well as areas where improvement or additional support may be needed. In this way, it contributes to the continuous development and strengthening of our network.

ERN CRANIO REGISTRY

Did you know the ERN CRANIO Registry page is live and ready for use? Different materials such as a template for bulk uploads, video's on how the registry works and other educational Materials can be found in the documents on the registry website: Registry.

We're happy to share that a new subregistry has been launched: the **Facial Nerve Palsy Subregistry**. This important step will help us further improve data collection, collaboration, and ultimately care for patients across our network.

If your centre also wants to upload data and needs support, you can request an onboarding meeting. So far, 15 centers have already started uploading their data, totaling over 1,500 patients – great work!

Good news! Centers that actively upload their data can benefit from our compensation plan. Centers that qualify will hear from us personally.

If your centre also wants to upload data but has not yet signed a data sharing agreement, or if you have any questions, please contact us at ern-cranioregistry@erasmusmc.nl.

DG SANTE vist to ERN CRANIO & ERNICA at the Erasmus MC

On 28 April a successful visit took place at Erasmus MC by a delegation from the European Commission's DG SANTE, together with representatives from both the ERN CRANIO and ERNICA networks. The visit provided an opportunity to present how both European Reference Networks are coordinated in practice and to showcase the work being carried out on a daily basis to improve care for patients across Europe. Throughout the day, several presentations highlighted key developments, including progress in registry implementation, the integration of Patient-Reported Outcome Measures (PROMs), initiatives to strengthen patient engagement, and the activities of the nurse specialist working group. The visit offered valuable insight into ongoing efforts within both networks to further enhance collaboration and improve patient care at a European level.

Register for CPMS 2.0 and upload your cases!

Have you registered for CPMS 2.0 yet? If not, now is the time!

CPMS 2.0 allows secure collaboration across ERNs, supports multidisciplinary case discussions, and helps share expertise to improve care for patients with rare and complex conditions.

Once you're registered, you can start uploading cases and participating in discussions, on both desktop and mobile. Every case you share strengthens our network, fosters collaboration, and helps improve patient care across Europe. Don't miss out! Learn more about CPMS and how to register here: CPMS | ERN CRANIO website

For questions regarding CPMS you can also always contact the ERN CRANIO CPMS helpdesk: ern-cranio@erasmusmc.nl

Survey on Psychological Support in Craniofacial Care

Many of you contributed to the recent European survey on access to mental health care within ERN CRANIO, and we are truly grateful for your support. A team of researchers from the psychologists' working group is now introducing a new survey that explores the perspectives of patients and parents. Based on the findings, the Psychologist Working Group aims to develop European recommendations for mental health care in craniofacial teams (cleft lip and/or palate and other rare craniofacial conditions).

To ensure that the recommendations reflect real needs, **we are inviting people with lived experiences to take part in a short survey**. If you have a craniofacial condition or are a parent of a child (young or adult) with such a condition, we would greatly appreciate your input. We kindly encourage you to share this survey with others who may want to contribute.

The survey is available in **17 languages**, is **anonymous** and does not include any personal information that could identify you. Completing it should take no more than 20 minutes.

If you would like more information, or material for dissemination, please contact the project manager, Kristin Billaud Feragen at email: krifer@ous-hf.no.

Thank you for taking the time to support and share this survey: click here

ERN CRANIO Online Presence Survey

To improve how we communicate with our community, we're gathering feedback on our online presence. How do you experience our Website? What do you think of our social media content? And how can we make our communication more engaging, accessible and useful for you?

To help us grow and reach more people, we kindly ask you to fill in this short survey (approximately 5 min). Your input will guide us in creating content that truly speaks to our readers.

If you have any additional ideas or suggestions, please feel free to reach out to us at ern-cranio@erasmusmc.nl!
find the link here

European Reference Networks (ERNs) factsheets now available in all 24 EU languagesRN CRANIO Online Presence Survey

The European Commission's Directorate-General for Health and Food Safety has published two new factsheets on the European Reference Networks (ERNs), providing a clear and accessible overview of their role and governance.
As these resources may not have reached all stakeholders yet, we are pleased to highlight them within our network.

- **Factsheet 1 – How ERNs work in practice**

This factsheet explains how ERNs function in daily practice, including:
* How patients can access the networks
* How healthcare providers collaborate through virtual case discussions
* How healthcare professionals benefit from ERN expertise and shared resources

🔹 **Factsheet 2 – Governance and EU support of ERNs**

This factsheet provides insight into:

* The approval and evaluation process of ERNs

* How the European Union supports and funds their development over time

Together, these factsheets are valuable resources for patients, healthcare professionals, policymakers, and all stakeholders involved in rare and complex diseases, helping to further strengthen understanding of the ERN system.

📚 Both publications are available in all 24 official EU languages:

🔗 Factsheet 1 – How ERNs work for patients and professionals

🔗 Factsheet 2 – ERN approval, evaluation, and EU funding

General News

Health without Postcodes: Accelerating Access to Rare and Complex Disease Therapies in Europe

Geographical boundaries should never dictate a patient's access to life-saving healthcare.

We are pleased to highlight the upcoming HLM4Rare high-level policy event, co-hosted by MEP Vytenis Andriukaitis, MEP Stine Bosse, the European Reference Networks (ERNs), and the **BRAINS FOR BRAIN FOUNDATION**.

Bringing together policymakers, institutional leaders, clinicians, and patient representatives, the event will address

🔹 Joint Clinical Assessments

🔹 Early access models

🔹 The broader coordination needed to accelerate equitable and timely access to therapies for people living with rare and complex diseases.

🗓️ When: 1 July 2026 | 14:00 – 16:00 CET

📍 Where: European Parliament, Brussels

🔗 Register now & explore the agenda: **https://lnkd.in/dBkYwQya**

24th ERN Coordinators meeting

On 20–21 May 2026, the 24th ERN Coordinators Group Meeting and the 32nd Board of Member States meeting took place.

The meeting brought together ERN coordinators, national representatives, hospital managers, and representatives of the European Commission in Luxembourg. Discussions focused on the sustainability of the ERN ecosystem, monitoring, evaluation methodology, registries, CPMS, disease coverage, and JARDIN deliverables.

On behalf of ERN CRANIO, the network was represented either in person or online by the coordinator, Irene Mathijssen, and project managers Roos Wensveen and Ikram L'khssim. During the meeting, they also had a dedicated agenda item to highlight ERN CRANIO, providing the opportunity to present the network's achievements and progress over recent years, including key milestones, ongoing initiatives, and the impact of our work across the network.

Strong collaboration between ERNs, policymakers, healthcare institutions, and Member States remains essential to strengthen cross-border healthcare and improve outcomes for patients across Europe.

Funding opportunities

The ERDERA Clinical Trial Call 2026 is live!

Hier specifiek info delen over deze call

- [European Rare Diseases Research Alliance (ERDERA) Calls]
- [HaDEA Calls for Proposals on Health]
- [HaDEA Calls for Tenders on Health]
- [Horizon Europe calls for Funding on Health]

Upcoming events

ISCFS 2027 | 7-10 September | Rotterdam The Netherlands

CLEFT 2029 | 3-7 September | Brisbane, Australia

Something to share?

Have you recently published an article with ERN members, or participated in an ERN CRANIO training?

If you have any ideas or updates you would like to share with the network, we would love to hear from you!

Please feel free to contact us by email: ern-cranio@erasmusmc.nl, we'd be happy to include your contribution in the next edition of the ERN CRANIO newsletter.

Funded by the European Union