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 23 - March 2026

NEWS

ERN CRANIO updates

Dear ERN CRANIO network members and all interested,

Welcome to the latest ERN CRANIO newsletter! In this edition, we are excited to share updates from across the network, highlight recent activities, and give you a glimpse of upcoming events.

If there is something you would like to see featured in the next edition of our newsletter, please **email us at ern-cranio@erasmusmc.nl**.

Kind regards,
The ERN CRANIO Coordination Team

Rare Disease Day 2026: 28th of February

On the 28th of February, Rare Disease Day 2026 took place. During this day and the weeks before we stand still by the 300 million people worldwide living with a rare disease. This day allowed us to honour their strength, to recognise the challenges they face, and to highlight the important initiatives working to improve rare disease care across Europe and beyond.

RARE DISEASE DAY®

Rare disease day Campaign Jardin

We are very proud of Ivana, as part of the JARDIN Rare Disease Day campaign she shared her story. The story she shared had some really positive feedback and was also highlighted by the European Commission on their LinkedIn profile. 👏

Ivana is part of ERN CRANIO as a patient representative. Her story portrays the dual role she embraces every day, as someone living with Treacher–Collins syndrome and as a practicing physician. Ivana: “Being both a patient and a physician means listening to medicine with the heart, not just the mind.“

To read the whole story please click the link here

How JARDIN is shaping the future of rare disease care in Europe by supporting the work of the ERNs

On Rare Disease Day, representatives of the JARDIN Joint Action spoke with HaDEA about how the initiative is helping EU countries better integrate the ERNs into their national healthcare systems. As many of you know, JARDIN’s mission is to support countries in embedding these expert networks more effectively, ensuring that people living with rare and complex conditions benefit from the knowledge and collaboration ERNs provide.

authorities, affiliated organizations, and rare-disease experts from all EU countries, JARDIN fosters knowledge-sharing, policy alignment, and long-term cross-border collaboration.

A major focus is improving patient pathways to help shorten the “diagnostic odyssey.” JARDIN promotes well-organized diagnostic routes, strengthens international cooperation, and pilots new structures for undiagnosed patients, all while preparing recommendations for future specialized services. Although progress is being made, further steps are needed to ensure that every patient in Europe has equal access to rare-disease expertise, regardless of where they live.

👉 **Read the full story here:**

New Call: Become an ERN Affiliated Partner!

For all non-ERN CRANIO members who would like to join as an Affiliated Partner, a new call is opening. The **Call for Applications opens on 13 April at 09:00 CET** and closes on **1 September at 23:59 CET**.

For any questions, please contact **ern-cranio@erasmusmc.nl**.

All information, including the call documents and templates, will be available on the DG SANTE ERNs website from 13 April – 09:00 CET.

Webinars will take place on **30 March** and **9 April** from 14:00–16:00 CET (a third webinar on 20 April may be scheduled if needed).

Transition of Care: Cross ERN Workshop

On 27–28 February, the first ERN overarching workshop on Transition of Care in Rare Diseases took place in Ghent, Belgium. Several members from **ERN CRANIO** joined the workshop, thank you to Dr. Frederic Acke, Dr. Youri Anastassov, dr. Petra Kavadzieva, Rossen Kolev, Elin Weissbach, Noelle O'Mahony and Aoife Dillon for representing ERN CRANIO.

The workshop was organised by **@ERN Rare Liver**, bringing together experts in rare disease care and a dedicated youth panel. This panel consisted of rare disease patients aged 18–25 who openly shared their experiences with the transition from paediatric to adult care. Our members emphasized how impactful these contributions were and expressed great appreciation for their insights.

Youri shared: *"The most impressive part was the participation of 4 young adults with different rare diseases, showing an extraordinarily high level of culture and intelligence, resilience, and the capacity to express their experiences in care during the pediatric period and in the transition to adulthood. The lectures were related to the topic and had practical and philosophical aspects."*

The programme included presentations from the youth panel, healthcare practitioners, and an EU policy maker, complemented by interactive sessions where participants explored key challenges within transition of care and worked together on potential solutions.

👉 **Read the full reflections of our members about this workshop on our website: [here]()**

We are happy to share that the annual ERN CRANIO monitoring exercise has been completed. Almost all centres managed to upload their data on time, thank you to everyone involved for your effort and collaboration.

In April/May, each centre will receive a personal performance update by email. Later this year, the European Commission will also publish the new ERN Monitoring Report, providing insight into how all ERNs are performing.

Why is this important?
The monitoring data helps us understand how our member centers are doing within the network, identifying strengths and spot any areas for improvement or where support is needed. Together, this helps us to keep improving 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.

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**.

Register for CPMS 2.0 and upload your cases!

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

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

Please find an overview of the training sessions on CPMS 2.0 organized by SANTE below:

- 🗓️ April 7 at 10:00 CET: Click Here
- 🗓️ May 7 at 15:00 CET : Click Here
- 🗓️ June 9 at 10:00 CET : Click Here

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.

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

General News

Declaration on a European Innovation and Care Ecosystem for Rare and Complex Diseases

Launched at the High-Level Meeting for Rare and Complex Diseases in December 2025, this Declaration is a

Europe.

Created together with patients, clinicians, ERNs, researchers and industry partners, it highlights 8 key actions, including:

- Faster and better diagnostics
- Improved access to treatments across Europe
- Stronger research and data infrastructures (like CoRDICs)
- Better use of real-world evidence
- And securing dedicated EU funding for the ERNs in the next budget

The ERNs already make a big difference by connecting experts across borders, sharing knowledge, and strengthening research through the ERN Registries.

💙 By signing, you help:
• Build political momentum for an EU Action Plan on Rare Diseases
• Support sustainability of the ERNs
• Strengthen the united voice of the rare disease community

👉 Sign the Declaration: **https://lnkd.in/e-yxpSrz**
Declaration toolkit

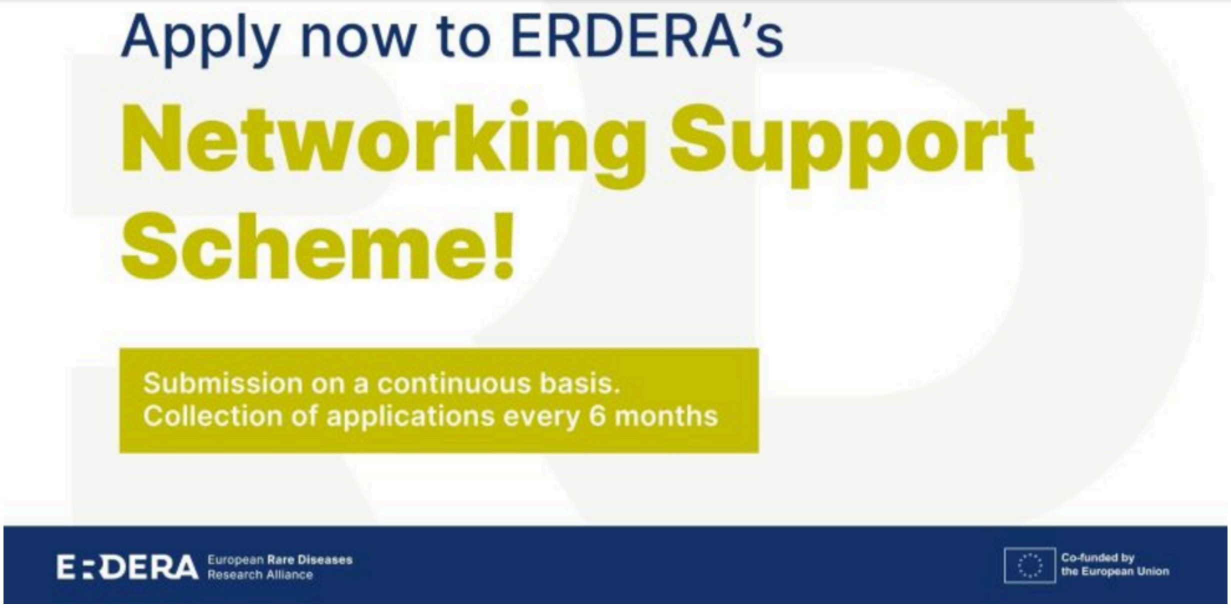
ERN Coordinators meeting

Austria (10-11 February 206). This meeting brought together coordinators and project managers from across Europe to strengthen collaboration within the European Reference Networks.
The ERN CRANIO Project Managers and ERN CRANIO Coordinator, Prof. Irene Mathijssen, participated in this meeting, contributing to key discussions on follow-up actions from the December High-Level Meeting on Rare Diseases, the creation of new cross-ERN working groups, governance updates, and the expansion of ERN disease areas.

Funding opportunities

- [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]

ERDERA Networking



Round 2 of ERDERA's Networking Support Scheme is open!

ERDERA's Networking Support Scheme is a competitive funding instrument supporting transnational networking events in the field of rare diseases and rare cancers. Applications are reviewed every six months, and proposal round 2 is now open until **7 April 2026 at 14:00 (CET)**.

The NSS provides funding of up to €30,000 per event to support transnational networking activities that promote knowledge sharing, research uptake, and collaboration among clinicians, researchers, and patient organisations. Eligible events must have a clear focus on rare disease or rare cancer research and meet both aims of the call: fostering knowledge exchange and increasing the inclusion of underrepresented countries.

Call for Applications: 2026 EURORDIS Open Academy Schools

Applications are now open for the2026 EURORDIS Open Academy Schools, a **face-to-face programme** offeringhigh-quality training for **rare disease patient advocates** and **early-careerresearchers** (PhD candidates and up to two years post-PhD).
Two programmes are available:

- *Open Academy School on Medicines Research & Development*
- *Open Academy School on Scientific Innovation & Translational Research*

research and advocacy.

Find out more and apply: https://openacademy.eurordis.org/open-academy-schools

Upcoming events

Craniofacial basic and advanced techniques 2 – Unicoronal and hypertelorism workshop will take place on the 26th- 28th of March 2026!

The Necker Workshop 2026 is organized by the French Reference Center for Craniosynostoses and Craniofacial Malformations (CRANIOST), in collaboration with an international expert committee and supported by ERN CRANIO. After two successful events in 2024 and 2025, this year edition will allow craniofacial surgeons to learn unicoronal craniosynostosis correction procedures, and how to manage hypertelorism. Hosted in the Necker–Enfants Malades Hospital in Paris, the workshop brings together renowned surgeons, researchers, and multidisciplinary experts from around the world to share their experience, discuss innovations, and review challenging clinical cases.

Through a combination of expert lectures, case discussions, and interactive sessions, the workshop aims to provide participants with a comprehensive overview of current surgical approaches, perioperative management, and emerging technologies in craniofacial surgery.

ERNs

You are now able to register for the next High-Level Meeting (HLM) on the 26th of March. This HLM meeting will focus on cross-border healthcare and the European Reference Networks.

🕰️ 26 March 2026
📍 Hybrid: Brussels, Belgium/ Online
👉 Register now: **click here**

High Level Meeting

on cross-border healthcare and the European Reference network

March 26, 2026

Hybrid meeting: Online/ Brussels, Belgium

Register now!

EPOS 2026 | 8–10 April | Seville, Spain

ESPO 2027 | 17-20 April | Prague, Czech Republic

ISCFS 2027 | 7–10 September | Rotterdam The Netherlands

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.

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