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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



NEWS

Issue 22 - December 2025

Happy Holidays

Dear ERN CRANIO members,

As the year comes to an end, we would like to wish you and your loved ones a wonderful holiday season and a very happy New Year ✨

Thank you for your enthusiasm, commitment, and support throughout the past year.

We truly value working together with you and look forward to continuing our collaborations in the year ahead!



ERN CRANIO 10th annual meeting, 12-14 November

The 10th Annual Meeting last November was a great success!

It was wonderful to see so many of you in person—around 150 ERN CRANIO members attended the meeting in Lisbon, Portugal. We are truly grateful to everyone who joined us. A special thank you goes to the Lisbon team for their warm hospitality and organisation.

The meeting featured a programme with several disease-specific working group sessions, inspiring presentations on team-based care, and an interactive workshop. Speakers shared diverse approaches to multidisciplinary collaboration, highlighted the role of care coordinators, showcased family-centred initiatives, and presented innovative strategies to further strengthen collaboration within craniofacial teams.

The interactive workshop focused on recognising subtle language and communication blind spots and how these can shape patient and family experiences in craniofacial care. You can read more about the meeting [here](#).



We are happy to announce the date and location of the **11th ERN CRANIO Annual Meeting!** Next year, we look forward to welcoming you all in **Budapest**.

The general theme of the meeting will be **transition of care** — more details will follow. For now, please make sure to **save the date** in your calendar!

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📍 Budapest, Hungary

ERN CRANIO ePAG lead honoured at International Cleft Congress

At the 15th International Congress on Cleft Lip/Palate and Related Craniofacial Anomalies in Kyoto, Japan in October, Gareth Davies, ERN CRANIO ePAG Lead, was honoured with an award for the *most significant lifetime contribution to cleft care*. We are incredibly proud of this achievement and warmly congratulate Gareth on this well-deserved recognition.



ERN CRANIO coordinator: First Female President of ISCFs

During the ISCFs 2025 conference (27–30 October, Shanghai, China), several highlights were shared. A particular highlight was the announcement that Prof. Dr. Irene Mathijssen has been appointed as the new President of the International Society of Craniofacial Surgery. We are extremely proud of our ERN CRANIO coordinator, as she will be the first female president in the Society's history.



Clinical Exchanges: Learning Across Borders

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October. This visit, arranged through ERN CRANIO connections, provided a wonderful opportunity to share ideas and best practices on perioperative care, teamwork, and safety, fostering an inspiring and informative week for all involved.

Ramona shared her experience:

"My visit was amazing. It was truly an enriching experience, and it helped me clarify the focus of my research."

Currently enrolled in a master's program in Surgical Instrumentation for perioperative nurses, Ramona will focus her thesis on preoperative briefings as an additional safety measure, exploring how structured pre-op briefings can improve communication and reduce risks in the operating theatre.

We are delighted that ERN CRANIO connections made this exchange possible and proud to see such fruitful collaborations in action.

Heads-up: Yearly Monitoring Data – 2025

The annual ERN CRANIO monitoring data exercise is **just around the corner**. The **same template as last year** will be used.

Data collection for **2025** will start in **Q1 2026**. Centre representatives will soon receive exact dates and instructions by email.

ERN CRANIO REGISTRY

Did you know the ERN CRANIO Registry page is live and ready for use?

At our annual meeting in Lisbon, we presented a short preview on how to upload data, along with a handy flyer showing step-by-step how to upload data. All information can also be found in the documents on the registry website.

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!

As presented in Lisbon, there is a compensation plan for centers that actively upload their data. Centers that qualify will be contacted directly.

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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!

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](#)

Change in the ERN CRANIO Coordination Team

As of 1 December, Roos Wensveen has joined us as the new Project Manager for the ERN. Some of you may have already met her at our annual meeting in Lisbon, where she had the chance to get a sneak peek at the network's work before officially starting. We warmly welcome Roos to the team and look forward to working together.



General News

Continuous Monitoring Report for the ERNs

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The European Commission has published the first-ever Continuous Monitoring Report for the ERNs, confirming a 160% increase in new patients referred to ERN centers between 2018 and 2024, clear evidence of how this EU infrastructure strengthens Europe's health capacity and resilience.



The report presents detailed indicators across seven core areas, including clinical activity, guidelines, registries, training and cross-border collaboration, reflecting the 2023 & 2024 monitoring cycles.

ERNs connect 1,600+ specialized units in 375 hospitals, creating a single pool of rare disease expertise no country could build alone. An estimated 30 million EU citizens are living with a rare disease. That's a huge challenge, and ERNs are working together to make sure everyone gets the specialised care they need.

The report documents over 2,100 virtual CPMS consultations, delivering expert, multidisciplinary advice across borders so patients can access specialist input without the need to travel.

ERNs demonstrate the power of European cooperation, strengthening health resilience, supporting clinical excellence, and improving access to expertise for rare disease patients across all Member States.

Read the report and learn more about how ERNs, and the clinicians and multidisciplinary teams who power them, support patients across Europe.

[ERN Monitoring Report](#)

In-depth analysis of the public consultation of the European Parliament on rare diseases

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wide range of participants, including patients and families, patient support groups, healthcare professionals, stakeholder interest groups and international organisations, government and other public bodies, aim to guide future policy actions in the field of rare diseases. This document was provided by the Policy Department for Transformation, Innovation and Health at the request of the Committee on Public Health.

[REPORT](#)

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](#)

JARDIN is halfway through its life cycle!

JARDIN has now reached the midpoint of its journey, marking significant progress in its mission. Several key achievements and insights from the project have been shared in **JARDIN's third newsletter**, giving a view of the work done so far. You can explore these highlights [here](#) to see how JARDIN is advancing.

ERDERA Networking

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Apply now to ERDERA's **Networking Support Scheme!**

Submission on a continuous basis.
Collection of applications every 6 months

ERDERA European Rare Diseases
Research Alliance

 Co-funded by
the European Union

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.

ERDERA 2026 Joint Transnational Call: Launching

On 10 December 2025, ERDERA launched its 2026 Joint Transnational Call, **“Resolving unsolved cases in rare genetic and non-genetic diseases through variant validation and new technological approaches”**. The call welcomes proposals focused on providing diagnostic clarity in unsolved rare genetic and non-genetic diseases. For more information on this call please visit the ERDERA website [here](#).

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Applications are now open for the 2026 EURORDIS Open Academy Schools, a **face-to-face programme** offering high-quality training for **rare disease patient advocates** and **early-career researchers** (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*

Dates: 25–28 May 2026

These schools provide invaluable knowledge and skills to drive forward rare disease research and advocacy.

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

HLM RARE 2025

High-Level Meeting on a European Research and Innovation Ecosystem for Rare Diseases



**High-Level meeting
on a European Innovation
and Care Ecosystem
for Rare and Complex Diseases**

9-11 December, Brussels

European Reference Networks | S&D | Horizon Europe | Co-funded by the European Union

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The High-Level Meeting (HLM) on a European research and innovation ecosystem for rare diseases took place from 9 to 11 December 2025 in Brussels, Belgium.

ERN CRANIO joined this meeting online. If you were interested but could not attend, you can watch the recording here:

Upcoming events

EPOS 2026 | 8-10 April | Seville, Spain



ESPN 2026 | 22-24 January | Rome, Italy

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ISCFS 2027 | 7-10 September | Rotterdam The Netherlands



CLEFT 2029 | 3-7 September | Brisbane, Australia

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