



European Reference Network

for rare or low prevalence complex diseases

Network

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

NEWSLETTER

NOVEMBER 2020

ISSUE 7



5TH ERN CRANIO ANNUAL MEETING

This year, the ERN CRANIO annual meeting took place virtually, with over 80 people attending! On Friday 13th November, all 9 ERN CRANIO [Affiliated Partner hospitals](#) were formally introduced and key network updates were provided by the ERN CRANIO coordination team. Updates were provided on a range of topics such as *guideline development*, *ERN data monitoring and patient journeys*.

The afternoon also featured a more in-depth presentation about the development of the ERN CRANIO patient registry; *'Towards a CRANIO meta-registry'*. This was presented by Morris Swertz representing *Molgenis*, which is the chosen data platform for the ERN CRANIO registry.

The general meeting concluded with a presentation focusing on linking existing registries to help answer clinically relevant research questions. This presentation titled *'Enabling Large-Scale Analysis of Electronic Health Records in Europe'* was presented by Peter Rijnbeek representing the European Health Data and Evidence Network.

You can find copies of the Powerpoint presentations presented on the [European Collaborative Platform](#).

The following working group meetings also took place and meeting notes will be circulated in due course; *ENT*, *Craniosynostosis*, *Craniofacial Microsomia*, *Cleft Lip/Palate and Orofacial*.

We hope to meet in Barcelona for the next ERN CRANIO annual meeting in 2021.

NEW ERN CRANIO INITIATIVES

ERN CRANIO radiology group

The value of establishing an ERN CRANIO working group dedicated to radiology has been identified. ERN CRANIO clinician Davide Broto from AOP Padua (ENT working group) will coordinate the involvement of three clinicians from 3 ERN CRANIO centres (Erasmus MC, AOP Padua, Necker-Enfants Malades Paris), with specific expertise in pediatric radiology and neuroradiology. These individuals will kick-start initial discussions on the needs, scope and valued activities related to this topic within ERN CRANIO. Please get in contact with the ERN CRANIO project managers if you have any ideas or suggestions for development of this group.

ERN CRANIO nurse specialists group

Discussions have started on setting up an ERN CRANIO nurse specialists working group. Relevant updates will follow on this.

Cross-ERN Pregnancy and Family Planning Group

A transversal cross-ERN Pregnancy and Family Planning working group now exists. This is an area of relevance to ERN CRANIO. In this group, ERN CRANIO is represented by Irene Mathijssen as ERN coordinator, Lars Kolby as clinical representative (from Sahlgrenska University Hospital, Gothenburg) and Elisa Nurmenniemi as patient representative (from SUHUPO—Society for Cleft patients in Finland).

EJP-RD JOINT TRANSNATIONAL CALL 2021 ON SOCIAL SCIENCES AND HUMANITIES RESEARCH: PRELIMINARY ANNOUNCEMENT



Open to ERN members and affiliated partners

Topic: Social sciences and humanities research to improve health care implementation and everyday life of people living with a rare disease.

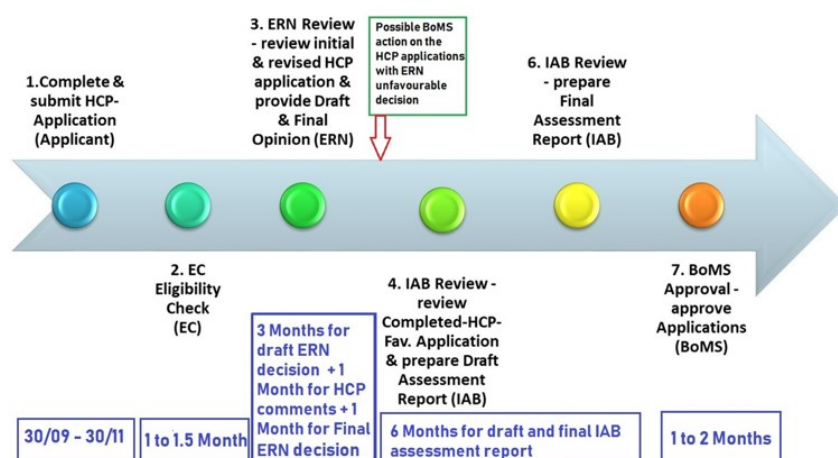
Research proposals should cover at least one of the following areas (other research topics are possible providing they focus on social science and humanities research and are not in the list of excluded topics):

- Health & social care services research to improve patient and familial/household health outcomes
- Economic Impact of Rare diseases
- Psychological and Social Impact of Rare diseases
- Studies addressing the impact/burden of the delay in diagnosis and of the lack of therapeutic intervention.
- e-Health in rare diseases: Use of innovative technology systems for care practices in health and social services
- Development and enhancement of health outcomes research methods in rare diseases
- Effects of pandemic crisis and the global outbreak alert and response on the rare disease field, and the emergence of innovative care pathways in this regard

Dates & Deadlines: 2-stage submission process: pre-proposals (deadline : 16th February 2021) and full proposals (deadline : 15th June 2021). The call is scheduled to open in early December 2020. The maximum duration of the project is three years.

More information? Click [here](#). Please let the ERN CRANIO coordinator and project managers know if you do have an idea and plan to submit a proposal

ASSESSMENT PROCESS FOR NEW ERN MEMBERS; WHERE ARE WE?



**Due to the COVID-19 pandemic, the ERN review period was suspended by the European Commission from April – September 2020

Step 3 of the assessment process (the ERN review process) is now complete. The Independent Assessment Body (IAB) review will now take place, followed by approval from the ERN Board of Member States representatives. We expect new members to join ERN CRANIO in 2021.

‘PATIENT JOURNEYS’: PERSONAL EXPERIENCES SHAPING CLINICAL PRIORITIES



A poster on the ERN CRANIO patient journeys was presented at the 10th European Conference on Rare Diseases and Orphan Products (ECDRO 2020) in May 2020 and won a 2nd place award! An abstract on this topic has subsequently been published in the Orphanet Journal of Rare Diseases; <https://ojrd.biomedcentral.com/articles/10.1186/s13023-020-01550-1>