



European Reference Network

for rare or low prevalence complex diseases

Network

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

NEWSLETTER

MAY 2019
ISSUE 2



AFFILIATED PARTNERSHIP: AN INITIATIVE TO INCREASE GEOGRAPHIC COVERAGE

The next call for new healthcare centres to join the ERNs as full members is expected this year. In the meantime, member states can designate 'affiliated partners'. This call is now open!

What are affiliated partners?

Affiliated partners are not members of an ERN. Affiliated partners are expected to provide a link to the ERN for those European countries without a healthcare provider involved. Therefore, if a member state already has a healthcare provider involved in the network as a full member, they cannot designate an affiliated partner. This European Commission-led initiative thus addresses concerns related to the geographic coverage of the networks.

There are currently 29 European hospitals involved in ERN CRANIO, from 11 member states. Our aim is for all member states to be represented.

We seek to facilitate cooperation between multidisciplinary experts to support the provision of high quality care to patients from across the European Union, regardless of where they are located.

Find out more about affiliated partnership and the application process on our website:

<https://ern-cranio.eu/news-and-events/news/affiliated-partnership-with-ern-cranio/>



PATIENT JOURNEYS

Our ERN CRANIO patient representatives have been working hard on developing their own 'patient journeys'. These are visual documents and their development requires patient representatives to reflect on each stage of their personal journey and map out identified clinical needs against what would have been considered the 'ideal' standard of care. Thoughts can then be shared with and built upon by others with experience of the disease/family members.

Other ERNs have also been working on developing patient journeys. They can be used to help guide discussion and foster patient-clinician partnerships.

Patient journeys are currently being developed for: **Goldenhar Syndrome, Pierre Robin Sequence, Craniosynostosis, Cleft Lip/Palate and congenital or prelingual post-natal deafness...**



INTRODUCING RUBEN RENKEMA! OUR CPMS HELPDESK REPRESENTATIVE



We would like to take this opportunity to welcome **Ruben Renkema** as ERN CRANIO's CPMS helpdesk representative! Ruben is based at Erasmus MC, Rotterdam and he is available to help you with any CPMS-related queries.

Send him an email on r.renkema@erasmusmc.nl

The Clinical Patient Management System (CPMS) is a web-based clinical software application developed by the European Commission which allows healthcare providers from all over the EU to work together virtually to diagnose and treat patients with rare, low prevalence and complex diseases. Follow this link for a video on how to get started: <https://webgate.ec.europa.eu/ern/imgs/CPMS%20Getting%20Started.mp4>

NEED SOME PROJECT MATERIALS TRANSLATED?



The ERN coordinators and project managers now have access to the eTranslation tool set up by the European Commission. This can be used to support your translation needs. This tool can be used to exchange information across languages in the EU, Iceland and Norway.

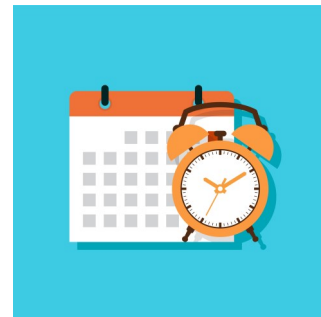
The tool can translate text in a large variety of formats (doc, pdf, jpg, excel, powerpoint...).

If you have any project-related materials that you would like translated please make contact with the ERN CRANIO project managers Olivia Spivack and Renée de Ruiter: o.spivack@erasmusmc.nl & r.deruiter.1@erasmusmc.nl

SAVE THE DATE! FOR THE 4TH ERN CRANIO ANNUAL MEETING - 29-30 NOVEMBER 2019, ROME

The 4th ERN CRANIO annual meeting will be hosted by Fondazione Policlinico Universitario A. Gemelli in Rome on Friday 29th – Saturday 30th November 2019. The educational session this year will be focused on difficult airway including feeding and breathing difficulties.

Save the date and keep your eyes peeled for more information!!



OTHER UPCOMING MEETINGS AND EVENTS YOU MAY BE INTERESTED IN

JUNE 2019

12th-15th: European Cleft Palate Craniofacial Association (ECPA) Congress (+ ERN CRANIO cleft workstream meeting), Utrecht

24th: 8th ERN Coordinators meeting, Brussels

26th: Focus group meeting, WP17 of the European Joint Programme on rare diseases – development of the ERN research programme, Leiden

SEPTEMBER 2019

16th-19th: XVIIIth meeting of the International Society of Craniofacial Surgery, Paris

17th-19th: European Joint Programme on rare diseases general assembly meeting, Gdansk

A CALL TO OUR MEMBERS- PATIENT REPRESENTATIVES AND HEALTHCARE PROVIDERS:

Please let the ERN CRANIO project managers know of any relevant meetings and events so that we can share these on our newsletter and on our other dissemination platforms!