



European Reference Network

for rare or low prevalence complex diseases

Network

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

NEWSLETTER

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LinkedIn

ERN CRANIO NETWORK MEETING NOVEMBER 2020: AN UPDATE!

Due to uncertainties regarding COVID-19, it has unfortunately been decided to cancel the ERN CRANIO network meeting in Barcelona on 13 and 14th November 2020. We are very disappointed not to be able to meet you all in Barcelona. However, we would still like to connect virtually.

Please continue to save the date on Friday 13th November for a series of ONLINE ERN CRANIO sessions. More information will follow on this! The face-to-face meeting in Barcelona will be re-arranged to a later time point. We will keep all invitees informed.

PROJECT FUNDING FROM THE CONNECTING EUROPE FACILITY OF THE EUROPEAN UNION

DEVELOPMENT OF ERN CRANIO E-LEARNING ANIMATION VIDEOS

ERN CRANIO has some additional funding from the *Connecting Europe Facility of the European Union* to develop informative animation videos for the network. The target audience for these videos is patients and families and their purpose is to provide information on aspects related to diagnosis and/or care. Ideas for development were generated at the 2019 annual meeting in Rome and we are following up on these.

We also remain interested in hearing about any existing informative, animation videos in relation to ERN CRANIO diseases, for possible dissemination and/or adoption/translation. Please let the ERN CRANIO project managers know if you are aware of any!

ERN CRANIO is now on YouTube! Subscribe to our dedicated channel here!

<https://www.youtube.com/channel/UCqJ3R7w9Jg5I7GaHm3nMi0A>

Watch this space for new content (including the animations)

CUSTOMISATION OF THE CPMS DATA SET

Under this action, we also have the opportunity to customise the existing CPMS data set to our specific ERN and disease groups. This will facilitate an optimised workflow for clinicians using the system.

This piece of work is running in parallel to the development of the ERN CRANIO registry data sets. Alignment as far as possible is valuable to promote potential future compatibility.

If any of our network members or affiliated partners require support with registering on and using the CPMS, please get in touch with the ERN CRANIO project managers.



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PATIENT VERSION OF ERN CRANIO GUIDELINE ON CRANIOFACIAL MICROSOMIA

The ERN CRANIO European guideline on Craniofacial Microsomia is awaiting publication and a patient version is now currently in development too. Thomas Luck, ERN CRANIO patient representative for Craniofacial Microsomia, has been involved in reviewing this patient version.

Here is a description of the guideline and its value from Thomas' perspective:

The patient version aims to inform patients and their families on the broad spectrum of abnormalities connected to the various CFM-syndromes giving orientation and some guidance on actions to be taken. The European level secures that state-of-the art information of medical and care standards is presented. The guideline supplements the recently disclosed patients' journeys also developed by ERN-CRANIO which describe personal experiences of CFM patients from the perspective of patients.

The intended audience – patients and their families - have to take into account that due to the multiple variation and combinations of anomalies no checklist is applicable. But they get valuable medical information on difficulties which can occur from birth to being young adults. The overview of treatment alternatives is written in a way that the reader does not need to be a medical expert.

The guideline also emphasizes the experience of CFM-patients that psychological support to patients and their families should be offered in addition to surgical treatments and networking with patient groups sharing experience are another important piece of mastering the challenges of being affected by CFM.

The guideline cannot answer every question of CFM patients and their families. But it gives advice and support to discuss with treating physicians the best way of a specific treatment of the unique patient.

ERN CRANIO GUIDELINE ON PIERRE ROBIN SEQUENCE

At the 2019 annual meeting in Rome, Pierre Robin Sequence was one of the diagnoses selected for ERN guideline development. We are now following up on this and the first step is to form the working group. The workstream lead for Cleft lip / palate (Aebele Mink van der Molen) will be contacting relevant ERN CRANIO centres to form part of this expert group.

Patients and families will also be involved in the development process. We aim to have patients (and families) involved from all participating countries to get their input on any gaps in care provision and any difficulties and challenges experienced.

NEW CROSS-ERN WORKING GROUP ON PREGNANCY AND FAMILY PLANNING

An ERN colleague from ERN ReCONNET has taken the initiative to set up a cross-ERN working group on pregnancy and family planning. This is an excellent area of collaboration for ERN CRANIO! ERN CRANIO coordinator Irene Mathijssen will take part in this group and may appoint a clinical representative and a patient representative to join.

Are you an ERN CRANIO clinician or patient representative with an interest in this area who would like to get involved?

Please let Project Manager Olivia Spivack know within 1 week (By 27 July)

