European Reference Network
for rare or low prevalence complex diseases

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

NEWSLETTER

APRIL 2021
ISSUE 8

ERN CRANIO ANNUAL MEETING

Due to COVID-19 and the ongoing uncertainty about travel possibilities, we have decided to cancel and postpone the ERN CRANIO annual meeting which was re-scheduled to take place on 11 and 12 June at Vall d'Hebron hospital in Barcelona. We intend to host a face to face meeting with a smaller group of participants in November 2021. More information will follow!

THE ERICA PROJECT

JOINING FORCES TO INTEGRATE RESEARCH AND INNOVATION CAPACITY ACROSS ALL 24 ERNS

The European Rare disease research Coordination and support Action (ERICA) Project received a positive evaluation for a H2020 grant to establish a structural framework in support of the research activities of the ERNs.

ERICA will strengthen research and innovation capacity by integration of ERN research activities, outreach to European research infrastructures to synergistically increase impact and innovation. This will result in safe, accessible and efficient access of therapies for the benefit of patients suffering from rare diseases and conditions.

The ERICA Project builds on the strength of the individual ERNs by promoting inter-ERN research activities and by establishing firm collaborative ties with existing European and international infrastructures and consortia involved in rare disease research and innovation.

The ERICA Consortium consists of 29 partners, amongst which all 24 ERNs, EURORDIS, the EJP RD, Orphanet, Mapi Trust Research, and EATRIS. The ERICA Project is coordinated by Alberto Pereira (ENDO-ERN coordinator, Leiden University Medical Center, The Netherlands).

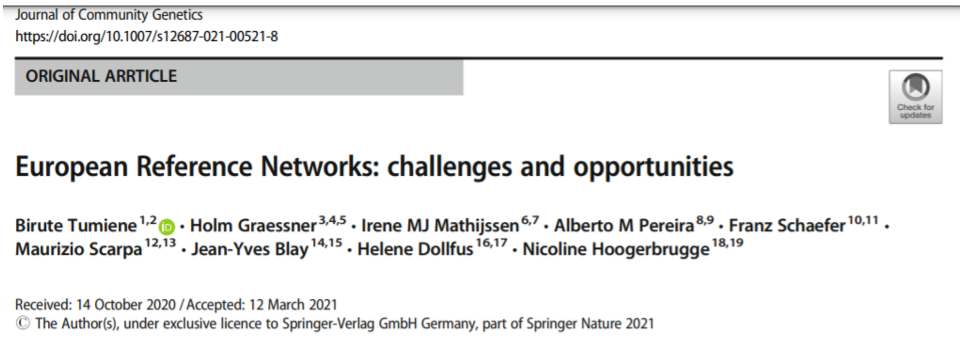
ERICA
European Rare Disease Research
Coordination and Support Action

EUROPEAN REFERENCE NETWORKS: CHALLENGES AND OPPORTUNITIES

This new paper was published on 17 March 2021 in the *Journal of Community Genetics*. It presents a number of challenges faced by the ERNs and possible solutions and opportunities.

This paper is co-authored by ERN CRANIO coordinator Prof. dr. Irene Mathijssen.

You can access the article here.



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ORIGINAL ARRTICLE

European Reference Networks: challenges and opportunities

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NEW ERN CRANIO VIDEOS FOR PATIENTS AND FAMILIES!

Series of educational videos on psychological topics

ERN CRANIO created a series of videos to provide patients and their families with practical techniques to support their psychological wellbeing. The videos were developed in consultation with ERN CRANIO patient representatives and experienced ERN CRANIO psychologists throughout Europe. **Video topics include, amongst others, techniques for dealing with unwanted comments and techniques for managing worries and challenging thoughts.**

The videos are presented by Marije van Dalen, a PhD student and research psychologist at Erasmus MC Sophia Children's Hospital with experience in researching the psychological effects of living with a visible difference.

All videos are published for free on the **ERN CRANIO YouTube channel**, in English and in a range of other subtitled languages. **Find out more on our website.**

Animation videos

ERN CRANIO is progressing with development of animation videos for patients and families. These animation videos are designed to inform patients and families about a particular treatment or medical procedure. Topics are based on identified learning needs. Two new ERN CRANIO animation videos are now available on the ERN CRANIO Youtube channel:

- ⇒ **Pediatric Tracheostomy**
- ⇒ **Ear reconstruction**

Feel free to share the links to these videos with your colleagues, patients and patient organisations.

Would you like to have a video translated in your native language? Please get in touch with Project Manager Olivia Spivack before 7th May!

RESEARCH DEVELOPMENT IN CRANIOSYNOSTOSIS

'A bibliometric overview of craniosynostosis research development'

This article recently published in the European Journal of Medical Genetics "reviews the development of research in the field of craniosynostosis from a bibliometric standpoint". Research developments, publication trends and characteristics and topic shifts are described. We expect this to be of interest to the ERN CRANIO community and beyond.

WELCOME KAREN AND ANNE-SOPHIE! NEW PATIENT REPRESENTATIVES

We would like to warmly welcome Karen Wilkinson-Bell and Anne-Sophie Mercey-Jarosz as new ERN CRANIO patient representatives for craniosynostosis [syndromic & non].

Karen represents the patient organisation *Headlines* in the United Kingdom. Anne-Sophie represents *Association mille et une têtes* in France. Welcome! We are happy to have you both on board.