ERN on craniofacial anomalies and ENT disorders (ERN CRANIO)

Congenital craniofacial anomalies include children born with underdeveloped or maldeveloped parts of their brain, skull and/or face that result in significant functional problems and psychosocial challenges. Patients require follow-up and treatment from birth into adulthood. Clinical and public knowledge of many of these presentations is low, and diagnosis can be extremely challenging.

The network is developing instructional courses on numerous conditions to be made available through an open access website.

This ERN addresses several gaps in care by significantly improving familiarity of primary caregivers with craniofacial anomalies. The network is developing instructional courses on numerous conditions to be made available through an open access website.

Members are working together to improve education, training and research in close collaboration with patient organisations. Where no patient organisation exists, focus groups of patients are consulted. ERN CRANIO is evaluating the type and timing of surgical treatment at participating centres to shed light on their impact and benchmark best practices in Europe.

By collecting data on long-term outcomes of the various conditions, the network will aid in counselling patients and parents and can direct the focus of treatment to areas that have received too little attention. The network will support the detection of new causative genes by increasing the numbers of participants in research studies.

NETWORK COORDINATOR

Professor Irene Mathijssen
Erasmus MC: University Medical Center Rotterdam, The Netherlands