

# The Need for a Guideline to Impact Patients Outcome in Craniofacial Microsomia

*Ruben W. Renkema, MD\*†, the ERN  
CRANIO Working Group on Craniofacial Macrosumia*

*“Normality is a paved road. It’s comfortable to  
walk on, but no flowers grow on it”.*

**D**iagnosis, treatment, and outcome assessment in craniofacial microsomia (CFM) is challenging due to its wide phenotypic spectrum. Treatment options vary within and among different hospitals and as the literature on CFM treatment options is scarce, treatment decisions are often based on expert opinion. These factors necessitate the development of a clinical guideline, a set of recommendations for clinical practice based on a systematic review of the available literature. This guideline aims to provide healthcare professionals and patients (and their parents/caregivers) with an evidence-based overview of the optimal multidisciplinary care for CFM. It also seeks to provide recommendations for the improvement of health outcomes and the organisation of care.

The development of this guideline is an initiative from the European Reference Network ERN CRANIO. European Reference Networks (ERNs) are networks of healthcare providers from across Europe with expertise in rare and/or complex diseases. Rooted in EU legislation, the networks seek to pool together disease-specific expertise, knowledge, and resources available across Europe. ERN CRANIO is the European Reference Network for rare and/or complex craniofacial anomalies and ear nose and throat disorders. An international, multidisciplinary working group was formed within ERN CRANIO to develop this guideline. The working group was made up of healthcare professionals involved in the care of patients with CFM.

Hospital facilities in Europe vary between nations. As this is a European guideline, the recommendations have been made so that all hospitals are able to adhere to them. It is expected that applying the recommendations in practice will result in a higher standard of care for patients with CFM, especially those in relation to the timely referral of patients to specialised craniofacial centres and the acknowledgement of the functional, aesthetic, and psychological aspects of CFM.

To further improve care for patients with CFM, future research could study indications and outcomes of treatment using patient reported outcome measures. Multicenter studies would be valuable. This could help fill the gaps in knowledge identified throughout the guideline.

This guideline is primarily written for all healthcare professionals involved in the care of patients with CFM, including pediatricians, plastic surgeons, maxillofacial surgeons, orthodontists, otorhinolaryngologists, neurosurgeons, orthopedic surgeons, ophthalmologists, anesthesiologists, geneticists, psychologists, and speech and language therapists. The guideline will also provide patients and parents/caregivers with information on the recommended care for patients with CFM across multiple disciplines.

Additional information regarding the European Reference Network CRANIO can be found on [www.ern-cranio.eu](http://www.ern-cranio.eu).

From the \*Department of Maxillofacial Surgery; and †Department of Plastic and Reconstructive Surgery, Erasmus Medical Center, Rotterdam, The Netherlands.

Received April 7, 2020.

Accepted for publication April 15, 2020.

Address correspondence and reprint requests to Irene Mathijssen, MD, PhD, Erasmus MC Dept. of Plastic Surgery, room SK-1202 Wyteweg 80, 3015CN Rotterdam, The Netherlands;

E-mail: [i.mathijssen@erasmusmc.nl](mailto:i.mathijssen@erasmusmc.nl)

The authors report no conflicts of interest.

Copyright © 2020 by Mutaz B. Habal, MD

ISSN: 1049-2275

DOI: 10.1097/SCS.00000000000006676