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**European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021**

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| **START DATE:** | **01/03/2019** |
| **END DATE:** | **28/02/2022** |
| **DURATION:** | **36 month(s)** |
| **CURRENT STATUS:** | **Ongoing** |
| **PROGRAMME TITLE:** | **3rd Health Programme (2014-2020)** |
| **PROGRAMME PRIORITY:** | **-** |
| **CALL:** | **Multiannual Grant Agreements for European Reference Networks** |
| **TOPIC:** | **ERN Specific Grant Agreements 2019 - 2021** |
| **EC CONTRIBUTION:** | **600000 EUR** |
| **KEYWORDS:** | |

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Project abstract

CRANIO - This proposal outlines the activities of ERN CRANIO for the years 2019, 2020 and 2021, which are line with the FPA. ERN CRANIO aims to support specialised centres across Europe to provide care of the highest quality to patients with rare and/or complex craniofacial anomalies and Ear Nose and Throat (ENT) disorders. The network seeks to connect the most highly specialised centres in Europe so that professionals can share their knowledge and best practice. It also seeks to connect patient groups across the continent. It is hoped that the pooling of resources and expert information from both patients and professionals will facilitate access to high quality, multidisciplinary care for all European patients. The focus of the next 3 years will be; Expansion of the network across Europe (both healthcare providers and patient groups), development of disease-specific standards of care, initiation of a quality improvement cycle so that ERN-accepted standards of care can be monitored and refined, data collection and benchmarking via use of a registry, organisation of professional training, collaborative, multi-centre research and full implementation of the Clinical Patient Management System. Disseminating information on the network and its outputs to target groups will be crucial, in addition to evaluating progress.
COORDINATOR

ERASMUS UNIVERSITAIR MEDISCH CENTRUM ROTTERDAM (Erasmus MC)

's Gravendijkwal 230
3015 CE ROTTERDAM
2040

Netherlands
WEBSITE: http://www.erasusmc.nl

PARTNERS

No partners related to the current project
2019 Annual ERN meeting report
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders
2019-2021 (ERN CRANIO)
Expected on: 01/03/2020
Summary report annual ERN CRANIO meeting
http://azorina.cc.cec.eu.int:8082/publications//

2020 Annual ERN meeting report
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders
2019-2021 (ERN CRANIO)
Expected on: 01/03/2021
Summary report annual ERN CRANIO meeting
http://azorina.cc.cec.eu.int:8082/publications//

2021 Annual ERN meeting report
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders
2019-2021 (ERN CRANIO)
Expected on: 01/03/2022
Summary report annual ERN CRANIO meeting
http://azorina.cc.cec.eu.int:8082/publications//

Network governance document
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders
2019-2021 (ERN CRANIO)
Expected on: 01/03/2020
Adapted governance to Brexit http://azorina.cc.cec.eu.int:8082/publications//

Role description ERN CRANIO patient representatives
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2020
Document outlining the roles of patient representatives within the network
http://azorina.cc.cec.eu.int:8082/publications//

Midterm website report
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/09/2020

Final website report
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2022

Patient versions of guidelines
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2022
Patient versions of guidelines will be produced and made available in multiple languages. http://azorina.cc.cec.eu.int:8082/publications//

2019 Annual Network Evaluation Report
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2020
2020 Annual Network Evaluation Report
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2021

2021 Annual Network Evaluation Report
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2022

Disease-specific outcome indicator set
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2020

ERN CRANIO specifications for CPMS
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2021
CPMS platform tailored to ERN CRANIO needs; implemented in all diagnostic groups. http://azorina.cc.cec.eu.int:8082/publications//

Scientific paper(s) on ERN CRANIO registries
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2022
Publication of scientific paper(s) on data analysis in ERN CRANIO registries. http://azorina.cc.cec.eu.int:8082/publications//
ERN CRANIO data set for registries
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2021
Set of data elements to be included in ERN CRANIO registries (integrated in ERN IT platform). http://azorina.cc.cec.eu.int:8082/publications/

Training programme for one selected HCP
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2020
Two-year training programme for a candidate HCP to become full member. http://azorina.cc.cec.eu.int:8082/publications/

Educational webinars
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/09/2020

Clinical Guidelines
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2022

Patient-journeys
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2020
Development of patient-journeys to support patients engaging with local healthcare providers. [http://azorina.cc.cec.eu.int:8082/publications/]

Benchmark report on CRANIO outcome measures
ERASMUS MC
European Reference Network for Craniofacial Anomalies and ENT Disorders 2019-2021 (ERN CRANIO)
Expected on: 01/03/2022