

European Reference Network (ERN) for Rare Craniofacial Anomalies and ENT Disorders

CranioFacDent

PARTICIPANTS

Rotterdam, The Netherlands

Nijmegen, The Netherlands

Utrecht, The Netherlands

Paris, France

Strasbourg, France

Lille, France

London, UK

Oxford, UK

Birmingham, UK

Liverpool, UK

Manchester, UK

London Royal Free, UK

Dundee, UK

Berlin, Germany

Madrid, Spain

Barcelona, Spain

Lisbon, Portugal

Göteborg, Sweden

Uppsala, Sweden

Karolinska, Sweden

Helsinki, Finland

San Paolo Milan, Italy

Padova, Italy

Monza, Italy

Carlo Besta Milan, Italy

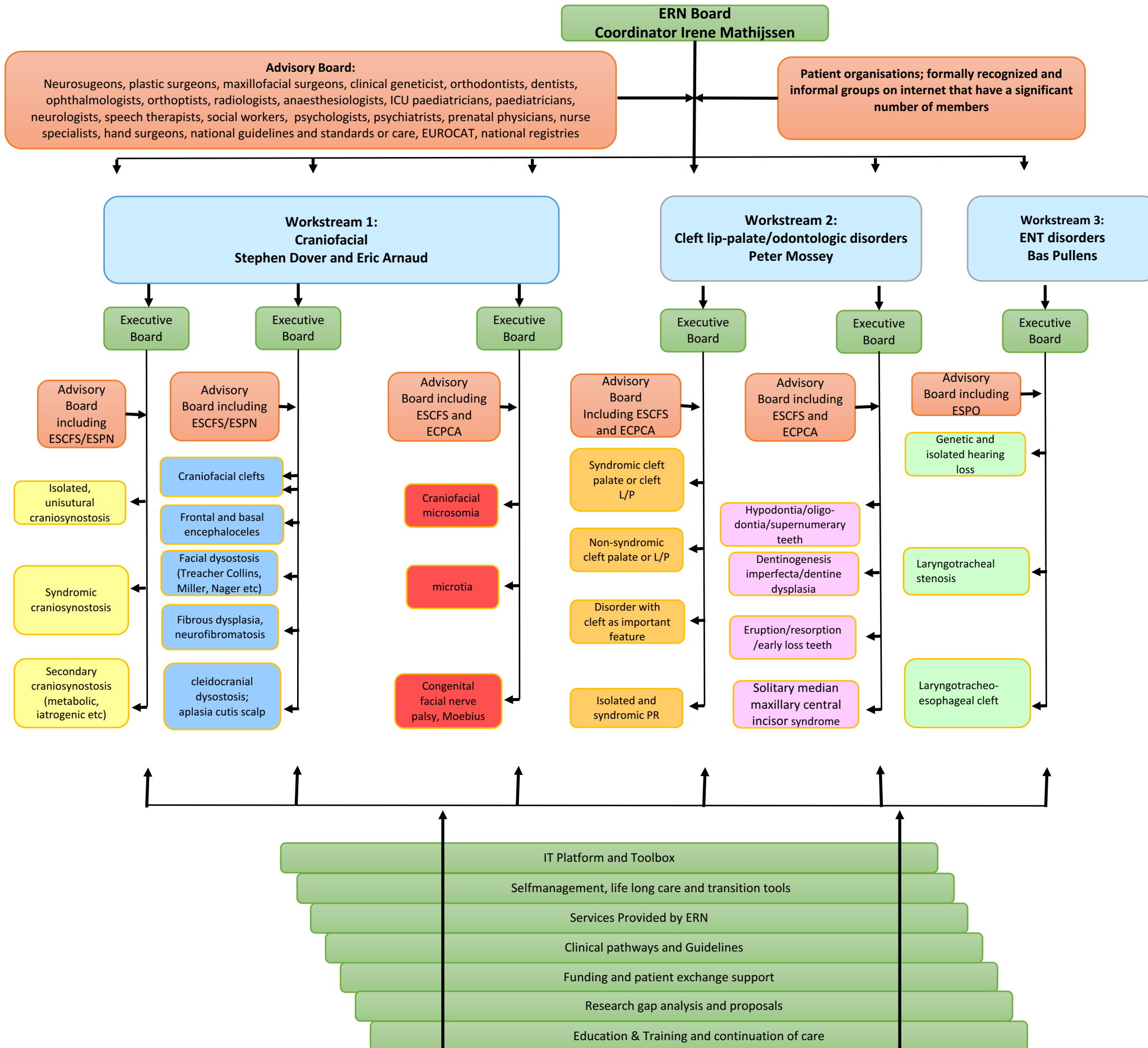
Rome, Italy

Vicenza, Italy

PECS, Hungary

Praha, Czech Republic

ERN for Rare Craniofacial Anomalies and ENT Disorders



CranioFacDent

	Nr of centers	Nr of centers baseline	Baseline: procedures/yr
Craniosynostosis	21	18	20
Encephaloceles/facial clefts/dysostosis	21	14	5
Neurofibromatosis/fibrous dysplasia	16	7	10
Craniofacial microsomia	14	6 8	10 5
Microtia	12	9	10
Facial palsy	10	2 5	10 5
Cleft/dental (Robin)	19	11	120
ENT	11	5	30



EUROPEAN COMMISSION
DIRECTORATE-GENERAL FOR HEALTH AND FOOD SAFETY

Health systems, medical products and innovation

Brussels,

Dear Prof. Mathijssen,

Subject: Rare craniofacial anomalies and ENT disorders Eligibility check result

With reference to the Rare craniofacial anomalies and ENT disorders application which you have submitted in your capacity of applicant ERN Coordinator in the framework of the first call for interest for European Reference Network, please find here the result of the first eligibility check carried out by the European Commission as established in Commission Implementing Decision 2014/287/EU.

ERN application: eligible

ERN Members: all eligible

We remind you that the next phase of the assessment will be carried out by the Independent Assessment Body (IAB) contracted by DG SANTE. You should be contacted by the IAB end of August- beginning of September.

We kindly ask you to communicate the result to the Rare craniofacial anomalies and ENT disorders Members.

Sincerely yours,

[Signed electronically]

Andrzej RYS

Prof. Irene Mathijssen
Erasmus MC
Wytemaweg 80, Room SK-1202
2015 CN Rotterdam
The Netherlands
i.mathijssen@erasmusmc.nl

Technical assessment

- Coordinating center Erasmus MC on-site visite
November (3 days)
- 5 teams paper assessment:
 - GOSH, London
 - Manchester
 - Karolinska, Stockholm
 - Helsinki
 - Lisbon, Portugal



ePAG Leadership Programme – *“learning together, from each other”*

version 1.2

European Patient Advocacy Groups (ePAG)

What's next?

- Formal approval or not January 2017
- Decide on committees within workstreams
- Make by-laws and set the standards
- Allow affiliated and new members to join who match the standards

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8. Madrid, Spain
9. Gothenborg, Sweden
10. Uppsala, Sweden
11. Lille, France
12. Helsinki, Finland
13. Barcelona, Spain
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15. Lisbon, Portugal
16. Padova, Italy
17. Monza, Italy
18. Berlin, Germany
19. Carlo Besta Milan, Italy
20. Praha, Czech Republic
21. Rome, Italy
22. Vicenza, Italy
23. London Royal Free, UK
24. Karolinska, Sweden
25. Utrecht, The Netherlands
26. Dundee, UK
27. PECS, Hungary
28. Strasbourg, France
29. Manchester, UK

ERN for Rare Craniofacial Anomalies and ENT Disorders

ERN Board
Coordinator Irene Mathijssen

Advisory Board:

Neurosugeons, plastic surgeons, maxillofacial surgeons, clinical geneticist, orthodontists, dentists, ophthalmologists, orthoptists, radiologists, anaesthesiologists, ICU paediatricians, paediatricians, neurologists, speech therapists, social workers, psychologists, psychiatrists, prenatal physicians, nurse specialists, hand surgeons, national guidelines and standards of care, EUROCAT, national registries

Patient organisations; formally recognized and informal groups on internet that have a significant number of members

**Workstream 1:
Craniofacial**
CHAIR: Stephen Dover and Eric Arnaud

Executive Board

Advisory Board including
ESCFS / ESPN

Isolated craniosynostosis
Marie-Lise van Veelen (1)
Centers 1,2,3,4,8,9,18

Syndromic
craniosynostosis
David Johnson (4)
Centers 1,2,3,4,12,21

Secondary
craniosynostosis
Mattieu Vinchon (11)
Centers 5,7,11

Advisory Board including
ESCFS / ESPN

Craniofacial clefts
Lars Kolby (9)
Centers 1,2,4,9,24

Frontal and basal
encephaloceles
Chris Parks (6)
Centers 6,7,11,24

Facial dysostosis
Sarah Versnel (1)
Centers 1,2,14,16

Fibrous dysplasia,
neurofibromatosis
..... (2)
Centers 1,2,3,16,18,24

cleidocranial dysostosis;
aplasia cutis scalp
Martini (16)
Centers 4,16,22,24

Executive Board

Advisory Board including
ESCFS/ECPCA (...)

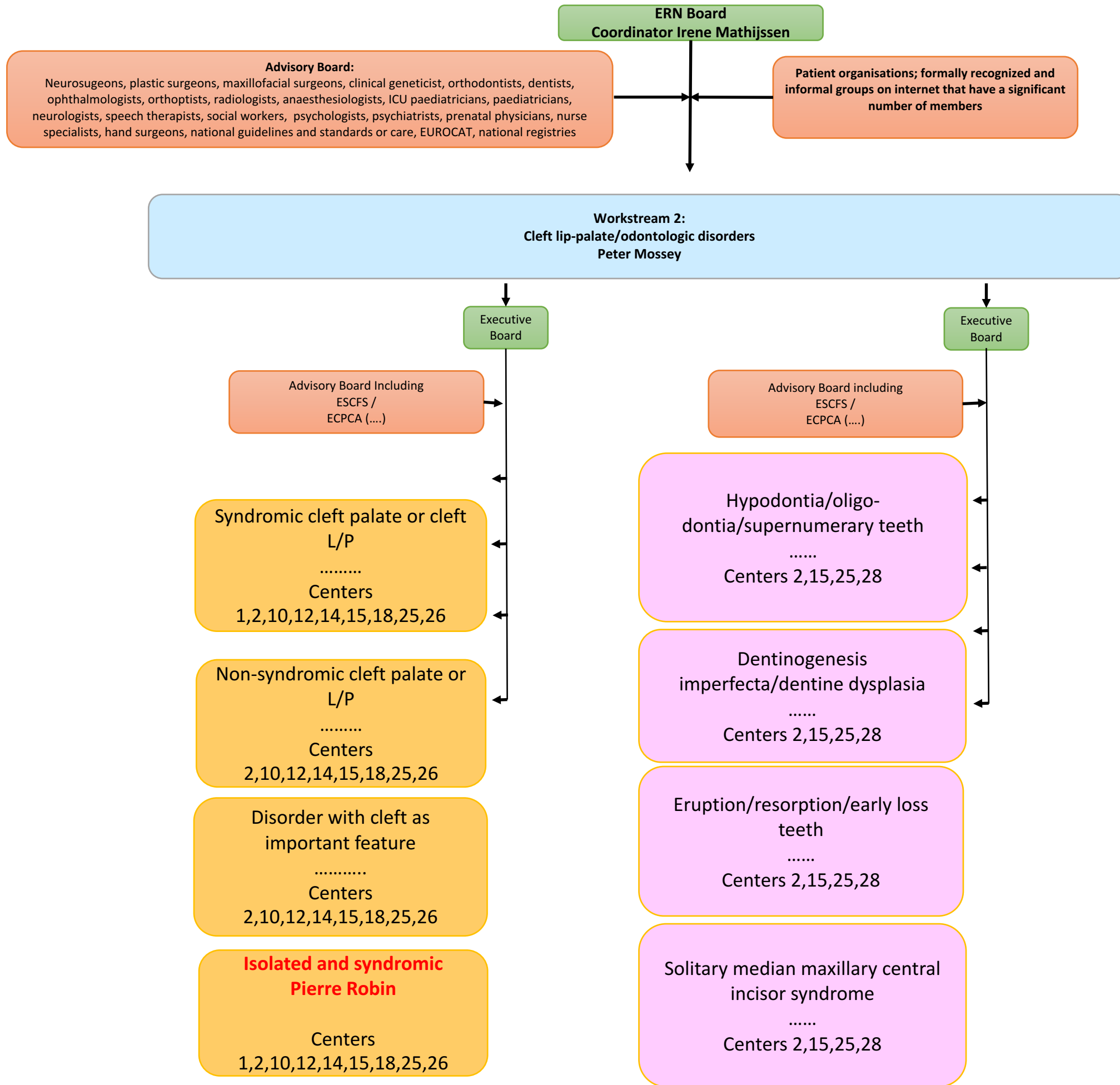
Craniofacial microsomia
Maarten Koudstaal (1)
Centers 1,2,3,8,12

Microtia
Neil Bulstrode (3)
Centers 2,3,13,25

Congenital facial nerve palsy
Addy Grobbelaar (23)
Centers 12,15,23

Executive Board

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