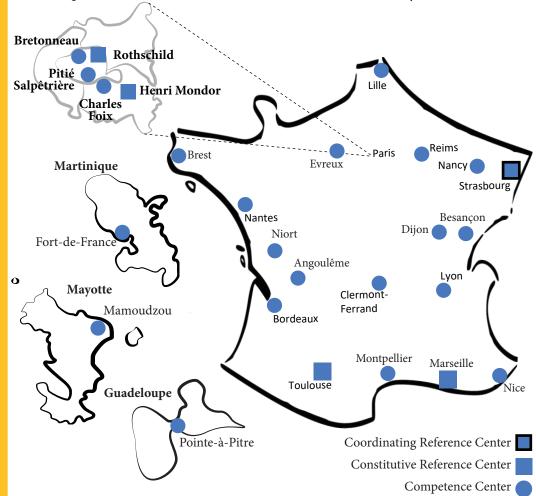
The O-Rares network is composed of a coordinating site (Strasbourg), 4 constitutive sites (Paris-Rothschild, Marseille, Paris-Mondor, Toulouse) and 21 competence centers distributed across the French territory.



Strasbourg Prof. Agnès Bloch-Zupan / Paris - Rothschild Prof. Muriel de La Dure-Molla / Marseille Prof. Corinne Tardieu / Paris - Mondor (Créteil) Prof. Bruno Gogly / Toulouse Prof. Frédéric Vaysse / Angoulême Dr. Frédérique Dhalluin-Olive / Besançon Prof. Edouard Euvrard / Bordeaux Dr. Elsa Garot / Brest Dr. Frédérique D'Arbonneau / Clermont-Ferrand Dr. Valérie Collado / Dijon Prof. Victorin Ahossi / Evreux Dr. Isabelle Fontanille / Fort-de-France Dr. Marie-Adeline Degouve / Lille Dr. Ludovic Lauwers / Lyon Prof. Béatrice Thivichon-Prince / Mamoudzou Dr. Nolwenn Lepouriel / Montpellier Prof. Estelle Trzaskawka-Moulis / Nancy Dr. Magali Hernandez / Nantes Prof. Serena Lopez / Nice Dr. Christine Voha / Niort Dr. Tony Rétat / Paris - Pitié-Salpêtrière Dr. Ali Nassif / Paris - Charles Foix (Ivry) Dr. Anne-Laure Bonnet / Paris - Bretonneau Prof. Elvire Le Norcy / Pointe-à-Pitre Dr. Cédric Lavoye / Reims Prof. Marie-Paule Gellé





# **O-Rares**

# Reference Center for Rare Oral and Dental Diseases

# A national network of expertise

# Find us at www.o-rares.com and www.tete-cou.fr:



Contact information for centers of care,

Information about the conditions and their management, Clinical practice guidelines,

Therapeutic patient education,

Patient organizations,

Training and education, research, news... and more!



www.tete-cou.fr

#### National coordination

Prof. Agnès BLOCH-ZUPAN
Department of Oral Medicine and Surgery
Hôpitaux Universitaires de Strasbourg
1 Place de l'Hôpital 67091 STRASBOURG
France

Tel: +33-3 88 11 69 10

Email: secretariat.o-rares@chru-strasbourg.fr

# The Reference Center for Rare Oral and Dental Diseases (O-Rares)

# Who we are



The Rare Disease Reference Center (CRMR) for Oral and Dental Diseases (O-Rares) has been accredited by the French Ministries of Health and Research since 2006, as part of the French National Rare Disease Plans.



It is part of the French Rare Disease Network for Malformations of the Head, Neck and Teeth (TETECOU).



It is a full member of the European Reference Network (ERN) CRANIO.

# The conditions covered by the O-Rares network

O-Rares cares for patients with rare diseases with oral and dental manifestations.

They can be isolated or syndromic.

These anomalies can involve:

- The number of teeth (agenesis, supernumerary teeth)
- The size and form of teeth (microdontia, taurodontism...)
- The **structure** of teeth (amelogenesis/dentinogenesis imperfecta, hypoplasia, hypomineralization, dentin dysplasia...)
- Tooth **eruption** (delay, failure, premature loss, premature eruption)
- The **periodontium** (gingival overgrowth/enlargement, periodontal disease...)

These anomalies can affect the **primary** and/or **permanent teeth** and require specialized multidisciplinary management and care.

The CRMR also addresses the **special oral care** of **rare disease** patients without a specific oral phenotype.



# Our missions

### **Expertise**

The accredited centers provide care for patients, from childhood to adulthood, within experienced multidisciplinary teams.

## French National Diagnostic and Care Protocols (PNDS)

The CRMR O-Rares develops clinical practice guidelines for the anomalies and malformation syndromes it covers.

## Care pathways

The experts of the CRMR improve the diagnostic and care pathways for patients by implementing Therapeutic Patient Education programs and multidisciplinary team meetings. They have also developed specific genetic tests (GenoDENT panel) and are the designated leads for a PFMG 2025 "pre-indication" for genome sequencing, aimed at providing a comprehensive diagnosis to patients.

## Teaching, training and information

The members of the O-Rares network share their expertise during the initial training of medical and paramedical professionals, through continuing education programs, and by developing information and resources for all stakeholders.

#### Research

The fundamental, translational, clinical, as well as social and human sciences, research developed by the professionals of the network is a source of many innovations that benefit patients.

Find all of this information in detail at: www.o-rares.com and www.tete-cou.fr