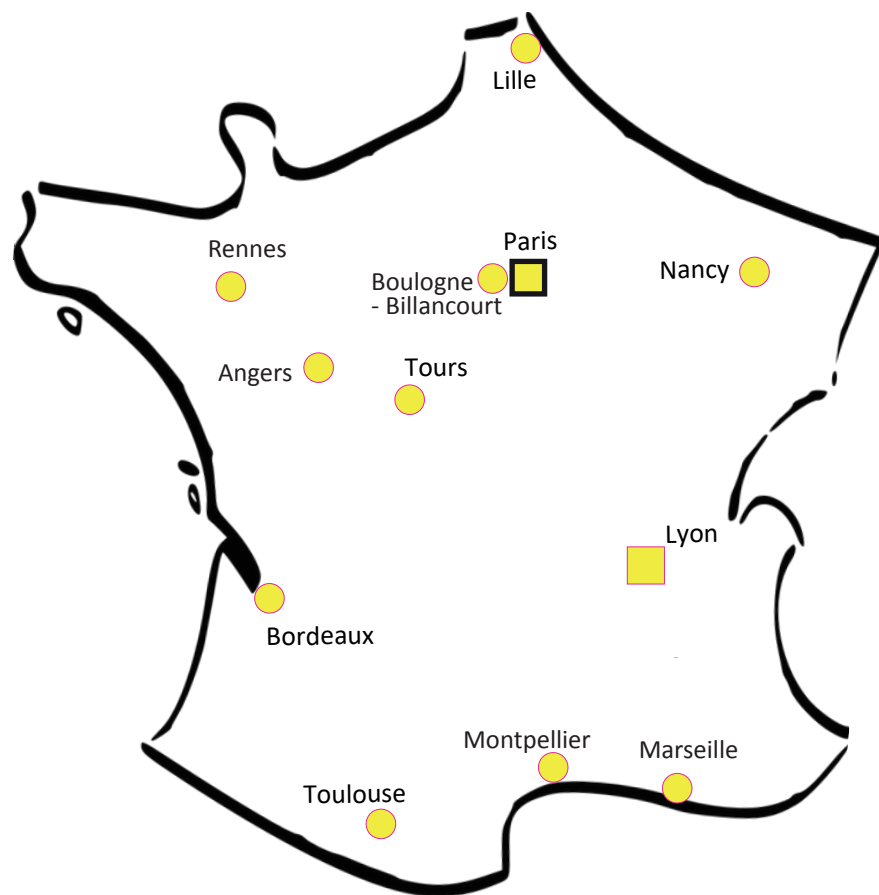


The CRANIOST network is composed of a coordinating site (Paris - Hôpital Necker-Enfants malades), a constitutive site (Lyon) and 10 competence centers distributed across the French territory.



- Coordinating Reference Center
- Constitutive Reference Center
- Competence Center

**Paris-Necker** Dr. Giovanna Paternoster / **Lyon** Prof. Federico Di Rocco / **Angers** Dr. Matthieu Delion / **Bordeaux** Dr. Édouard Gimbert / **Boulogne-Billancourt** Dr. Éric Arnaud / **Lille** Prof. Pierre Guerreschi / **Marseille** Dr. Grégoire Pech-Gourg / **Montpellier** Prof. Christian Herlin / **Nancy** Dr. Irene Stella / **Rennes** Prof. Laurent Riffaud / **Toulouse** Dr. Pierre Anthérieu / **Tours** Prof. Boris Laure

Leaflet edited in March 2025



centre de référence  
maladies rares

# CRANIOST

## Reference Center for Craniosynostosis and Craniofacial Malformations

A national network of expertise

Find the following at [www.tete-cou.fr](http://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!



### National coordination

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[www.tete-cou.fr](http://www.tete-cou.fr)

# The Reference Center for Craniosynostosis and Craniofacial Malformations (CRANIOST)

## Who we are



The Rare Disease Reference Center (CRMR) for craniosynostosis and Craniofacial Malformations (CRANIOST) has been accredited by the French Ministries of Health and Research since 2007, 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.

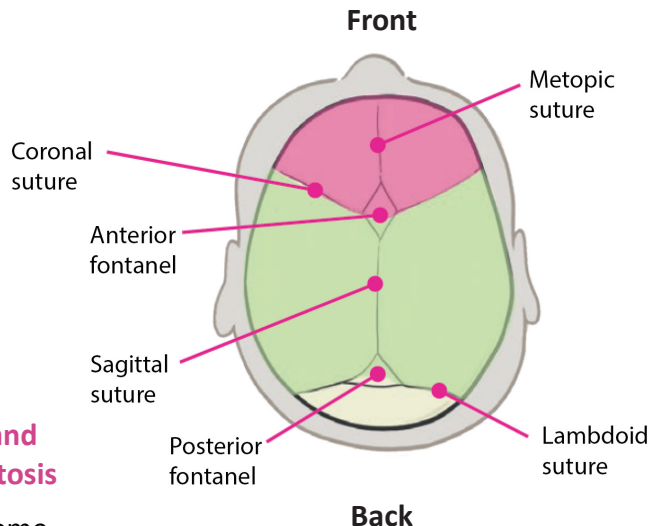
## Conditions covered by the CRANIOST network

### Craniosynostosis

- Plagiocephaly
- Brachycephaly
- Scaphocephaly
- Trigonocephaly
- Oxycephaly

### Craniofaciosynostosis and syndromic craniosynostosis

- Saethre-Chotzen syndrome
- Crouzon syndrome
- Pfeiffer syndrome
- Apert syndrome,...



### Other conditions managed by CRANIOST

- Craniofacial clefts with hypertelorism
- Craniofacial dysplasia and dysostosis
- Nasal, frontal and basal encephalocele
- Holoprosencephaly,...

## Our patient organizations



## Our missions

The CRMR carries out missions related to care, training and research for craniosynostosis and craniofacial malformations.

### Care

- ◆ Facilitate patient access to expert care and prevent complications
- ◆ Establish an accurate diagnosis thanks to a specialized team
- ◆ Offer personalized treatment based on multidisciplinary management and care
- ◆ Ensure the continuity of care into adulthood
- ◆ Develop clinical practice guidelines
- ◆ Provide expert opinion and advice to other healthcare professionals
- ◆ Develop a care network in collaboration with patient organizations

### Training and information

- ◆ Educate parents of patients and their family members
- ◆ Share medical knowledge and best practices
- ◆ Develop Therapeutic Patient Education (TPE) programs
- ◆ Provide information to the general public
- ◆ Train all healthcare professionals on the screening and management of craniofacial malformations

### Research

- ◆ Develop fundamental, translational and clinical research programs, as well as research in human and social sciences, at the national and international levels
- ◆ Study the pathophysiological and etiological mechanisms underlying these malformations
- ◆ Develop new surgical techniques and tools

Discover all of this information in detail at: [www.tete-cou.fr](http://www.tete-cou.fr)