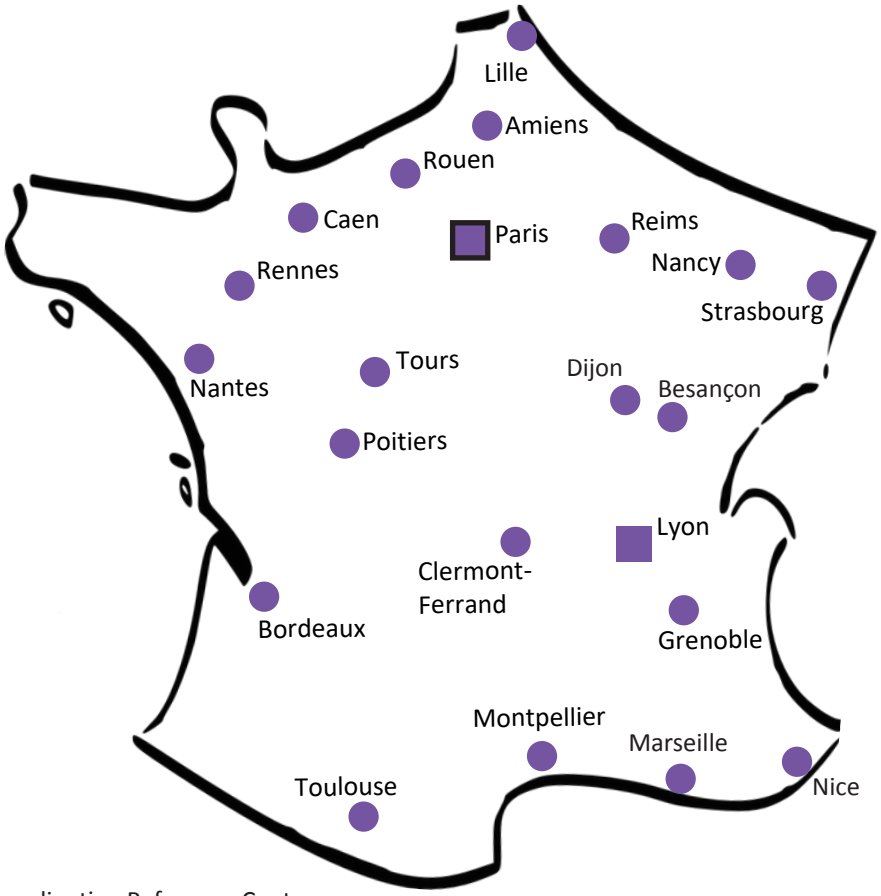
The SPRATON network is composed of a coordinating site (Paris-Hôpital Necker-Enfants malades), a constitutive site (Lyon) and 20 competence centers distributed across the French territory.




Coordinating Reference Center

Constitutive Reference Center

Competence Center

**Paris - Necker** Dr. Pauline Adnot / **Lyon** Dr. Laurianne Coutier / **Amiens** Dr. Cica Gbaguidi / **Besançon** Dr. Clémence Mougey / **Bordeaux** Dr. Olivier Tandonnet / **Caen** Dr. Anne-Sophie Trentesaux / **Clermont-Ferrand** Prof. Isabelle Barthélémy / **Dijon** Dr. Julie Levasseur / **Grenoble** Dr. Valérie Belin / **Lille** Pr. Pierre Fayoux / **Marseille** Dr. Nathalie Dégardin / **Montpellier** Dr. Maliha Badr / **Nancy** Prof. Cyril Schweitzer / **Nantes** Dr. Justine Loin / **Nice** Dr. Sonanda Bailleux / **Poitiers** Prof. Jiad Mcheik / **Reims** Prof. Caroline François / **Rennes** Dr. Armelle Thomas De La Pintière / **Rouen** Dr. Caroline Lardennois / **Strasbourg** Dr. Isabelle Chevalier / **Toulouse** Dr. Julie Abbal / **Tours** Dr. Amélie Favreau

Leaflet edited in October 2026

Pierre Robin
Troubles de succion - déglution congénitaux
SPRATON

centre de référence
maladies rares

# SPRATON

## Reference Center for Robin Sequence and Congenital Sucking-Swallowing Disorders

## A national network of expertise

Find the following at
**www.tete-cou.fr/spraton/accueil:**

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!

FILIÈRE SANTÉ MALADIES RARES
TeteCou
MALFORMATIONS RARES TÊTE COU DENTS
www.tete-cou.fr

**National coordination**
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# The CRMR for Robin Sequence and Congenital Sucking-Swallowing Disorders (SPRATON)

## Wo we are

The **SPRATON Rare Disease Reference Center (CRMR)** is accredited by the French Ministries of Health and Research, as part of the French National Rare Disease Plans. It carries out missions related to care, training, and research for Robin sequence and rare diseases associated with a congenital sucking and swallowing disorder.

It is a member of the French Rare Disease Network for Malformations of the Head, Neck and Teeth (TETECOU) and the European Reference Network (ERN) CRANIO.

It is composed of a coordinating site located in Paris, a constitutive site in Lyon and 20 Competence Centers distributed across the French territory. It is coordinated by Dr. Pauline Adnot, who is a pediatrician at Hôpital Universitaire Necker – Enfants malades.

## Conditions covered by the SPRATON network

The SPRATON network cares for children with Robin sequence and congenital sucking and swallowing disorders.
These conditions are characterized by orofacial malformations and functional feeding and respiratory disorders of varying severity.

### Robin sequence:

A triad of rare and complex facial malformations, affecting approximately 1 in 10,000 births. It associates the following:

- retrognathia (receding chin)
- glossoptosis (posterior placement of the tongue)
- +/- a posterior cleft of the hard and soft palate
- +/- neonatal airway obstruction

It may occur in isolation or be associated with other malformations.

### Sucking-swallowing disorders associated with another syndrome

- CHARGE syndrome
- 22q11.2 deletion
- Kabuki syndrome
- RASopathies
- Cornelia de Lange syndrome
- Treacher-Collins syndrome,…

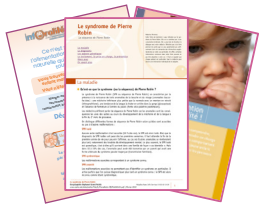
### Early-onset eating disorders

## Our patient organizations

## Our missions

### Care

- Facilitate patient access to expert care
- Diagnosis: identify the phenotypes and genotypes of patients
- Offer multidisciplinary management and care for affected children
- Ensure the national standardization of care strategies
- Provide expert opinions and advice for other healthcare professionals
- Develop clinical practice guidelines



### Training and information

- Initial and continuing education for professionals
- Therapeutic Patient Education (TPE)
- Providing information to patients, their families, and the general public (for exemple via the website www.inforalite.fr)

### Research

- Fundamental and clinical research programs
- Human and social sciences

**Find all this information and more at:**

**www.tete-cou.fr/spraton/accueil**