The French Rare Diseases Network TETECOU:
improving diagnosis and healthcare, promoting education and supporting research
for head, neck and tooth malformations

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The 2nd and 3rd french rare disease plan: creation of 23 national networks

Endorsed by the Ministry of Health with the agreement of the Ministry of Higher Education and Research

Diagnosis, health and social care

Information and education

Research

European Reference Networks

The TETECOU Network and some of its realizations

The TETECOU Network

Health and social care

★ National indications for whole genome sequencing
★ Multidisciplinary consultation meetings
★ Rare disease classifications and nomenclature in collaboration with orphanet
★ National data bank for rare diseases
★ Emergency cards with a registry of undiagnosed patients and ensuring the interoperability with each tool
★ Clinical guidelines

Research

★ Promotion of research labs and projects
★ Call for proposal watch
★ Supporting training of young researchers (congresses, courses, exchanges) through calls for proposals
★ Funding research projects and registries (through calls for proposals)
★ Exploit databases for epidemiological and research information
★ Bridges between patients, healthcare professionals and researchers
★ Promotion of research labs and projects
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Information and communication

★ www.tete-cou.fr
★ Informing health professionals
★ Information tools for patients, families, local professionals (through calls for proposals)
★ Informative factsheets, booklets and leaflets
★ Social networking

Education

★ Promotion of courses and congresses of interest
★ Supporting training of young professionals (congresses, courses, exchanges) through calls for proposals
★ Thematic training conferences
★ Innovative educational materials (through calls for proposals)
★ Patient education programs
★ Training courses for patients’ groups and parents
★ Promotion of courses and congresses of interest
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The 3rd National Plan for Rare Diseases

23 networks

Patients’ groups

Health professionals

Research teams

29 patients’ organizations

94 health expert centers

> 50 research teams

Facial clefts & malformations

Rare ENT diseases

Craniosynostoses & craniofacial malformations

Pierre Robin sequence & sucking-swallowing troubles

Rare tooth & oral diseases