

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

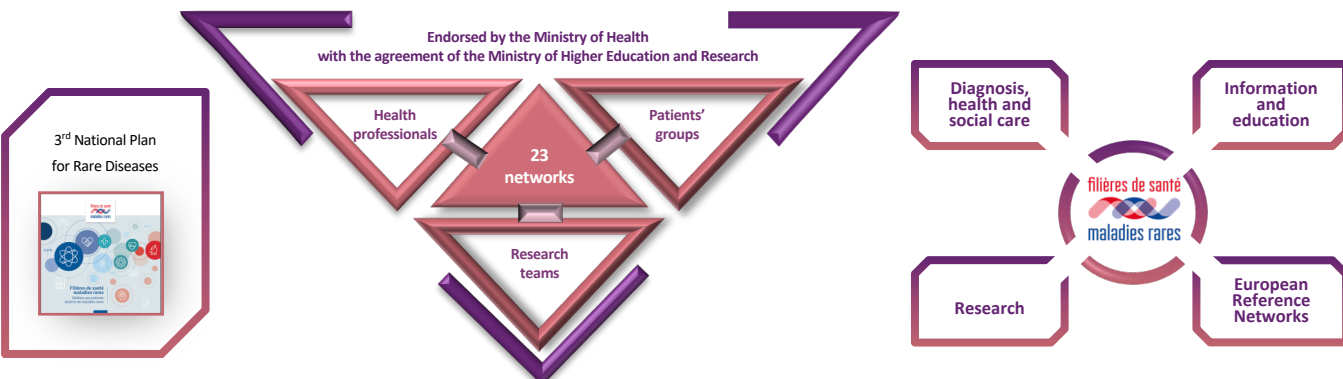


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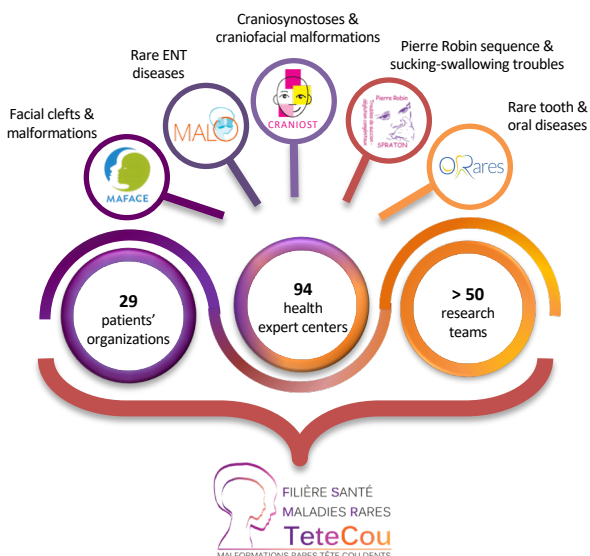
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The 2nd and 3rd french rare disease plan: creation of 23 national networks



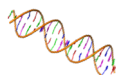
The TETECOU Network and some of its realizations

The TETECOU Network



Health and social care

★ National indications for whole genome sequencing



★ Clinical guidelines



★ Emergency cards



★ Multidisciplinary consultation meetings



★ Rare disease classifications and nomenclature in collaboration with orphancet

★ National data bank for rare diseases



with a registry of undiagnosed patients and ensuring the interoperability with each tool

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

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



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

