SERVIZIO SANITARIO REGIONALE
EMILIA-ROMAGNA

RegioneEmilia-Romagna

HUB & SPOKE NETWORK FOR RARE PEDIATRIC DISEASES IN EMILIA-ROMAGNA REGION

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OBJECTIVES

The Hub & Spoke model is used in Emilia-Romagna region to organize health care networks for rare diseases (RD) with the main purpose **to share experiences among centers** (due to the rarity and lack of knowledge of these diseases) **and to ensure uniform treatments throughout the region.**

METHODS

The 2011 regional act n. 1897 **set up the Hub & Spoke network for rare paediatric diseases** in Emilia-Romagna region. This network aims **to take global care of all patients with syndromal conditions developed during childhood** (0-14 years).

RESULTS

The network has achieved the objectives that had been defined, and in particular:

• **a team of specialists was identified in the centers** of the network to **share** and optimize a system of linked and multidisciplinary actions: 11 centers are involved (as shown in Figure 1;

• **diagnosis and care of patients in their childhood with RD are shared to ensure uniformity of the treatments and a better understanding** of the complications of these poorly known diseases, as described in Box 1.

• data deriving from patients with diagnosed rare diseases are **collected in the regional registry for rare diseases** to acquire epidemiological data and prevalence of RD: among the rare paediatric syndromal diseases the most certified diseases are congenital chondrodystrophies (283), neurofibromatosis type 1 (266) and duplication/deletion chromosomal defects (230)
Since the beginning of epidemiological survey of rare diseases 25,543 cases have been recorded; of these, 7,636 certificate the onset of disease under the age of 14 years (29.8%) and 4,245 cases of rare syndromal paediatric diseases

• **promoting the exchange of information** through the organization and participation in training of health professionals and the information of citizens and voluntary associations for RD

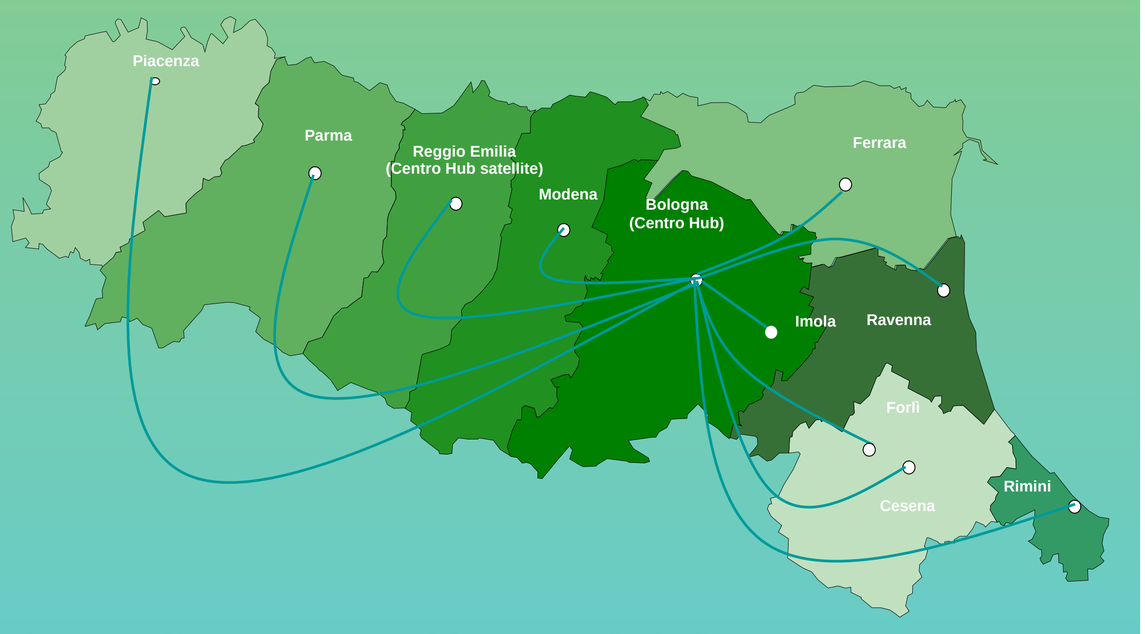

Figure 1. Emilia-Romagna network for rare paediatric diseases

Diagnostic and therapeutic care protocols defined by the network

RASopathies
- Noonan syndrome
- Noonan-like syndrome with loose anagen hair (Mazzanti syndrome)
- LEOPARD syndrome
- Cardiofaciocutaneous syndrome
- Costello syndrome

Turner syndrome (under approval);
Klinefelter syndrome (under approval);

Box 1. Protocols defined by the network

CONCLUSIONS

The RD followed by the centers taking part of Hub & Spoke network for rare paediatric diseases account for 30% of all patients registered in Rare Diseases Regional Registry.
Taking care of these young patients through an organized network guarantees access to centers of excellence in which the clinicians are highly connected and share the same diagnostic-therapeutic protocol, also ensuring psychological support (with expertise in these conditions) for the patient and his family.
The clinical teams meet regularly to discuss the most complex clinical cases and solve the organizational problems that may occur at regional level.
This organizational model allows **greater precocity in the diagnosis**, appropriate and timely administration of the different treatments and therapies and consequently the best possible prognosis for the patient.

For further information please visit the site
http://salute.regione.emilia-romagna.it/assistenza-ospedaliera/malattie-rare
or contact us at malattierare@regione.emilia-romagna.it