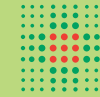




SERVIZIO SANITARIO REGIONALE
EMILIA-ROMAGNA



SERVIZIO SANITARIO REGIONALE
EMILIA-ROMAGNA

Healthcare model is organized in integrated networks – involving hospitals, local authorities, health and social services – that aims to assure follow up to patients.

According to 2006 data, in Emilia-Romagna Region there are 627 patients affected by inherited bleeding disorders.

Diagnosis and healthcare regional network of these rare diseases is organized according to Hub & Spoke model (applied to other health fields, such as cardiac surgery, neurosciences, transplants, genetics and other rare diseases, as Thalassemia and Marfan Syndrome). This model connects high specialization hospitals (Hub Centre) to hospital on the regional area whose main task is to guarantee basic healthcare (Spoke Centres).

The Regional Blood System works in the same way. Blood and plasma collection, ensures the availability of haemocomponents and plasma to produce plasmaderivates, useful to treat Haemophilia.

The structure of the Regional
Healthcare Service
for the diagnosis
and care of inherited
bleeding diseases
in Emilia-Romagna

Emilia-Romagna
Healthcare service
toll free number

NumeroVerde
800 033033

*working days 8,30 - 17,30
saturday 8,30 - 13,30*

Emilia-Romagna
Healthcare service
web portal

www.saluter.it

 Regione Emilia-Romagna

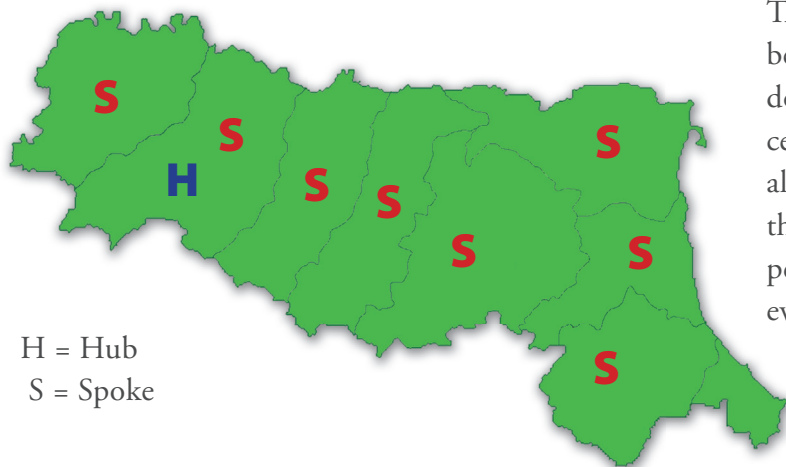
 Regione Emilia-Romagna

The Emilia Romagna Region network for diagnosis and treatment of inherited bleeding disorders

The Emilia-Romagna network for diagnosis and treatment of inherited bleeding disorders aims at guaranteeing people with haemophilia with equitable access to services and high quality standards of care across the region.

This has been established by the “Haemophilia” Regional Multidisciplinary Working Group, including Physician, Regional Authorities and Regional Federation of Haemophilia Patients Associations (Fed-Red) in the Haemophilia Network Planning 2006-2008 - approved by Emilia-Romagna Region (Deliberation n.46/06 established by the Legislative Assembly).

The network for diagnosis and treatment of inherited bleeding disorders has been structured since 2003 according to the Hub&Spoke model (deliberation n.1267/2002 established by the Regional Committee). The “Hub” – as high specialization regional centre -- is located in the Azienda Ospedaliero-Universitaria of Par-



H = Hub
S = Spoke

ma (Parma Hospital Trust) and play the role of reference point and coordination for 8 Spoke centers (Piacenza, Parma, Reggio Emilia, Modena, Bologna, Ferrara, Cesena, Ravenna, Faenza). The network is based on a dynamic system of relationship between different centers which treat patients with inherited bleeding diseases at different steps of their diagnostic-therapeutic path. Spoke centers provide patients with first level haemophilia care. Hub Center other than taking care of more complex cases and providing second level haemophilia care, coordinate the network and run the Emilia-Romagna Register of inherited bleeding disorders. The Register ensures epidemiological surveillance and provide measurement of haemophila Centre performance and treatment provided to people with haemophilia. Patients' data treated for inherited bleeding diseases are gathered in a computerized case history which is the same in every center. The case history enables the network connection between all the subjects involved: doctors working in inherited bleeding diseases centers, family doctors, patients. Patients will be allowed to enter their personal data everywhere they are and they will also be able to input their personal data in their case history, like bleeding events or treatment done at their place.

Blood system network

Blood System in Emilia-Romagna Region is the result of deep synergy among Blood donor Associations, Region, local institutions and Health public organisations.

Regional Health Authority elaborates program lines on blood system.

The CRAT (Comitato Regionale per le Attività Trasfusionali) defines multi-year Blood Plan to ensure the blood collection and to monitor correct blood use.

The CRCC (Centro Regionale Coordinamento e Compensazione) in Maggiore Hospital – Bologna, coordinates Regional Special Blood Program created since 2002 to manage in a better way collection activities and production of haemocomponents and plasmaderivates.

In Emilia-Romagna there are 13 transfusion services located in hospitals, organized in 7 Local Special Blood Programs: Piacenza, Parma, Reggio Emilia, Modena, Bologna, Ferrara, Ravenna, and one for Forlì, Cesena, Rimini.

AVIS and FIDAS-ADVS are the most important Associations of voluntary blood donors and give the system more than 130.000 donors. These donors give about 280.000 donations per year.

Blood donors Associations manage directly about 60% of blood collection according to national law.