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## INTRODUCTION

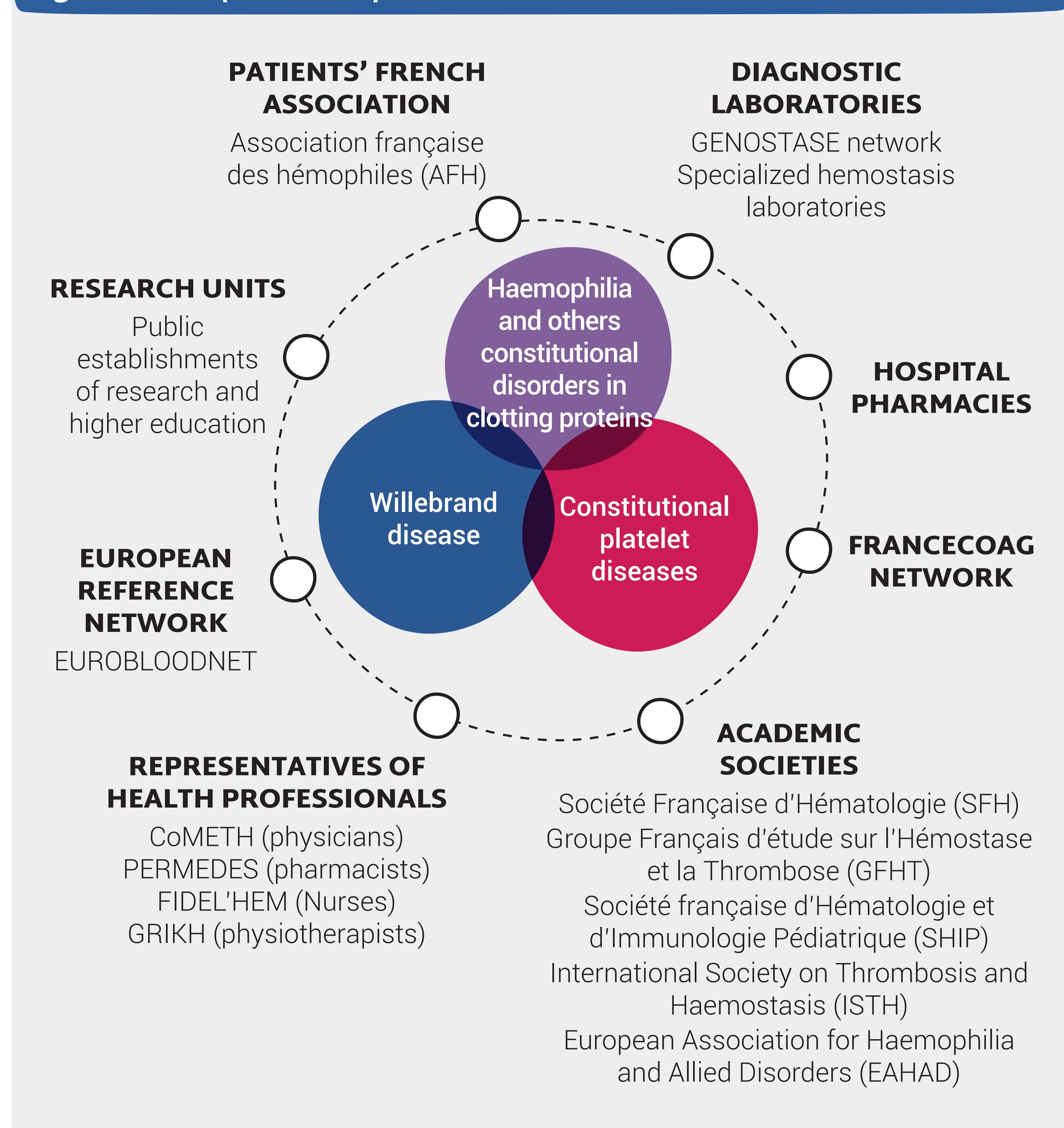
The 1st national rare disease plan (PNMR1) 2005-2008 allowed the creation in France of reference centers for rare diseases. In the field of hemostasis disorders, 3 reference centers were set up: the reference center for haemophilia and others constitutional disorders in clotting proteins (**CRH**), the reference center for Willebrand disease (**CRMW**) and the reference center for constitutional platelet diseases (**CRPP**). A second plan (PNMR2) 2011-2016 led to the creation of 23 rare diseases health's networks including the rare diseases health's network for inherited bleeding diseases (MHEMO). The 3rd plan (PNMR3) involving 2 Ministries (Health and Research and Higher Education) will be released shortly.

## WHY CREATE THE HEALTH'S NETWORK MHEMO ?

The gathering of the 3 reference centers (CRH, CRMW and CRPP) and the resource and expertise centers (Fig. 3) is justified by :

- Community of healthcare patients' pathway
- Proximity of medical and paramedical teams
- Common genetic platforms for diagnosis
- Community of research projects and epidemiological studies (a single common national register: FranceCoag Network)
- Existence of a single patient association for all constitutional hemorrhagic diseases

Fig. 1 - Participants and partners of MHEMO network



## THE PROJECT started early 2016 and responds to 3 mandatory focuses :

### Focus 1 : Improvements of patients global care

- Updating the nomenclature of constitutional haemorrhagic diseases and strengthening information for health professionals by updating and producing national diagnostic and care protocols,
- Harmonizing databases and facilitating data collection for epidemiological studies,
- Coordinating projects in the human and social sciences (child-adult transition, socio-school integration of children and socio-professional of adults),
- Promoting therapeutic patient education,
- Optimizing patient diagnosis and genetic counseling in families.

### Focus 2 : Research

- Mapping diagnostic and research laboratories,
- Promoting and developing research : clinical, fundamental, observational, translational and in human and social sciences.

### Focus 3 : Training and information

- Improving information sharing between partners of the network, health professionals, patients and their relatives,
- Improving access to training and e-learning to medical and paramedical professionals and scientists.

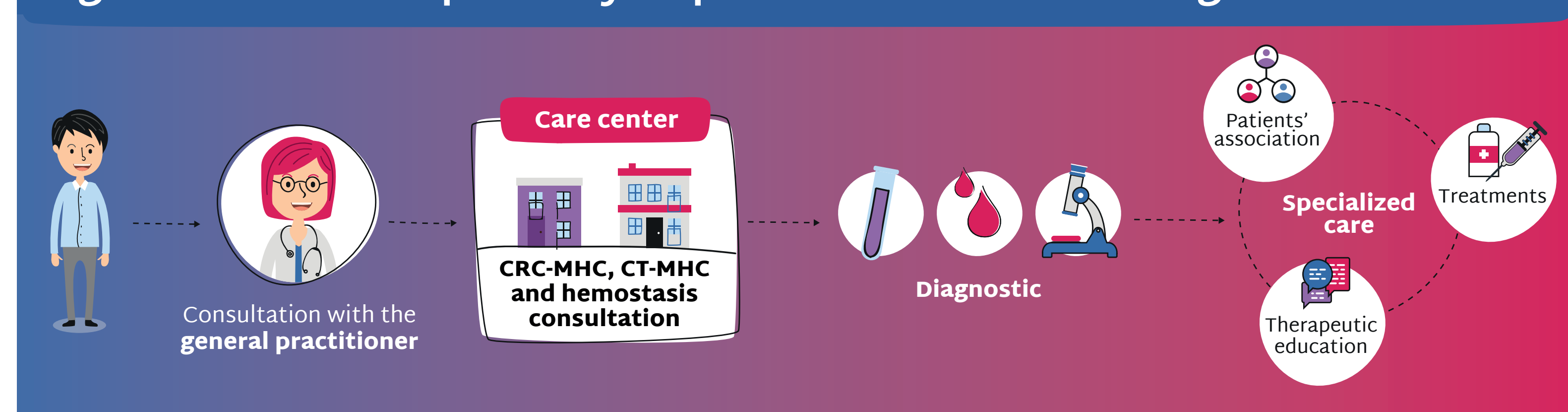
## OBJECTIVES AND MISSIONS OF THE HEALTH'S NETWORK MHEMO

**Objectives :** to group together all the cares of the constitutional hemorrhagic pathologies (Fig. 1).

### Missions :

- **Coordinating** actions between care centers and partners,
- **Informing** patients, relatives, general public and healthcare professionals,
- **Bringing together** all the actors around a common project,
- **Facilitating** meetings and exchanges within the network,
- **Developing** existing network (Fig. 2) doctors, nurses, physiotherapists, psychologists, pharmacists, biologists, social workers and the French association of the patients with haemophilia and other rare bleeding disorders.

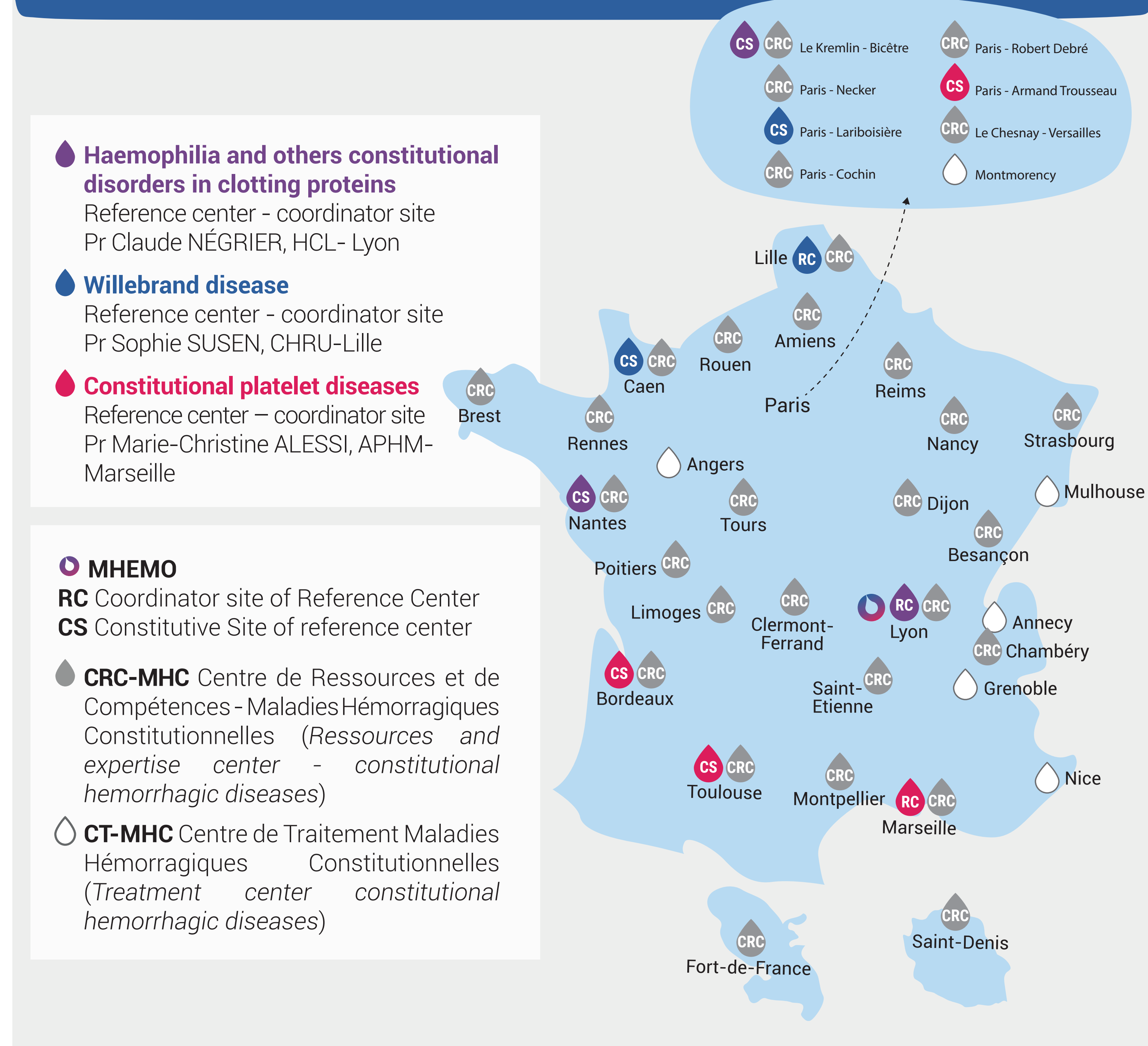
Fig. 2 - Health care pathway of patients with hemorrhagic disease



**THE GOVERNANCE** is provided by three committees with clearly defined missions :

- **The Coordination's Committee** : ensures compliance with commitments and functioning of the network, is responsible for exchanges with the French Directorate of Health Care Supply (DGOS) and ensures the management of finances and activity reports.
- **The Medical and Scientific Council** : sets strategies for epidemiological monitoring and health surveillance, promotion of research and participates in European labelling of health structures.
- **The College of Practitioners and Users Association** : is in charge of promoting therapeutic education programs, clinical research, ethical reflection and improved visibility of the network at conventions.

Fig. 3 - Reference centers, resources and expertise centers and treatment centers



The project team, led by Pr Négrier, ensures the proper functioning of the network and the realization of the guidelines validated by the governance.