

## 37. Pilot Thrombophilia Centers in the U.S.

*Last Updated: 2/15/2004*

**Q: "How come there are well structured Hemophilia Centers all over the U.S., but no Thrombophilia Centers? I thought clotting disorders are much more common than hemophilia. Why do we not have anybody looking after us?"**

A: Thrombophilia is indeed much more common than hemophilia. There are more than 100 Comprehensive Hemophilia Centers in the U.S., but until October 2001 there were no federally funded Thrombophilia Centers. The consequence is suboptimal care for patients with thrombophilia and a lack of thrombophilia research. The Center for Disease Control in Atlanta started funding 8 Thrombophilia Center pilot sites in November 2001. Goal is to collect data about the activities of these centers and the beneficial effect they have on patient care, to then go to Congress and make a case for funding of a large number of Thrombophilia Centers all over the U.S., so that everybody has access to medical care by a Thrombosis Specialist and that everybody gets the best possible care. There is a probably a need for more than 200 such centers. The important role of patient advocacy groups in making a case for such Centers to Congress is discussed in [Q/A 36](#).

**Some numbers** (for U.S. population; approximation)

- a. Hemophilia
  - o 28,000 have hemophilia A
  - o 5,000 have hemophilia B
- b. Thrombophilia
  - o 13 million are heterozygous for factor V Leiden
  - o 170,000 are homozygous for factor V Leiden
  - o 5,6 million are heterozygous for prothrombin 20210 mutation
  - o 28,000 are homozygous for prothrombin 20210 mutation
  - o 70,000 are heterozygous for factor V Leiden plus heterozygous for prothrombin 20210 mutation
  - o more than 200,000 people develop a DVT or PE every year
  - o more than 60,000 people die every year from pulmonary embolism

### **CDC (Center for Disease Control) activities**

The CDC has realized that Thrombophilia Centers are needed to improve the care of patients with thrombosis and individuals with thrombophilia. Finances from Congress are needed to create a large number of comprehensive Thrombophilia Centers spread all over the U.S. As an initial step the CDC designated 8 sites in the U.S. October 2001 as Thrombophilia Pilot sites, providing them with some funding (for thrombophilia nurses, data coordinators, and/or genetic counselors). Goal is to create structures that identify the needs of patients with thrombophilia and improve their care, to then demonstrate to the U.S. Congress that care of individuals with thrombophilia and patients with thrombosis at present is inadequate, and that it can be improved by creation of specialized Thrombophilia Centers. The 8 pilot sites are (alphabetically):

- Duke University Medical Center  
Durham, N.C.  
Dr. Thomas L Ortel (adults)  
For clinic appointments: 919-684-5350
- Mayo Clinic  
Rochester, MN  
Dr. John Heit  
At present does not accept external referrals
- Michigan State University  
East Lansing, MI  
Dr. John Penner (adults)  
Dr. Roshni Kulkarni (pediatrics)  
For clinic appointments: 517-353-3043
- Mountain States Regional Hemophilia and Thrombosis Center  
Aurora, CO

Dr. Marilyn Manco-Johnson (pediatrics)

For clinic appointments: 303-724-0362

Dr. Kathryn Hassell (adults)

For clinic appointments: 303-315-8474

- Robert Wood Johnson University Hospital  
New Brunswick, NJ

Dr. Claire Phillips (adults)

Dr. Lisa Michaels (pediatrics)

For all clinic appointments: 732-235-7223

- University of Michigan Medical Center  
Ann Arbor, MI

Dr. Steven Pipe (pediatrics)

For clinic appointments: 734-936-9814

Dr. Paula Bockenstedt (adults)

For clinic appointments: 734-647-8901

- University of North Carolina  
Chapel Hill, N.C.

Dr. Stephan Moll (adults)

Dr. Gilbert White (adults)

Dr. Geoffrey Allen (pediatrics)

For all clinic appointments: 919-966-3311

- Wayne State University, Detroit  
Medical Center

Detroit, MI

Dr. Judith Andersen

No telephone contact for clinic appointments available at present.