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## A New Community Resource

### Frequently Asked Questions about ATHN

The American Thrombosis and Hemostasis Network (ATHN) is a non-profit corporation founded in July 2006 with a vision to advance and improve the care of individuals affected by bleeding and thrombotic disorders.

#### 1. What are ATHN's mission and values?

ATHN's mission is to provide stewardship of a secure national database, adherent to all privacy guidelines, which will be used to support clinical outcomes analysis, research, advocacy and public health reporting in the hemostasis and thrombosis community.

ATHN will foster collaboration with patients, providers, suppliers, government agencies and non-profit organizations in the thrombosis and hemostasis community. The organization's core values are:

- Improving clinical outcomes and care
- Facilitating continuity of care
- Fostering collaboration
- Maintaining confidentiality
- Conserving resources through a common infrastructure

#### 2. Why was ATHN Formed?

ATHN was formed in response to nationally identified needs related to bleeding and clotting disorders:

- Need for research that links medical interventions with clinical outcomes;
- Need for evidence-based clinical standards;
- Need for standardization and an improved means of collaboration with one national database;
- Need to conserve and consolidate scarce resources.

The ultimate decision to form ATHN as an independent organization was based on the recommendation of two working groups – clinical and operational - that included participation and representation of a broad range of hemophilia organizations, institutions, clinical disciplines and fields of expertise.

#### 3. What is the relationship between ATHN, the CDC and the Hemophilia Treatment Centers?

In a joint effort with the Centers for Disease Control and Prevention (CDC), Division of Blood Disorders, ATHN will create a formal coalition with the 140 federally funded Hemophilia Treatment Centers (HTCs) across the U.S. with the goal to conserve resources through use of a common information infrastructure and to foster collaboration within the thrombosis and hemostasis community.

Hemophilia Treatment Centers (HTCs) provide comprehensive, multi-disciplinary care to the individuals in the U.S. with bleeding disorders. These disorders include hemophilia, von-Willebrand disease, and other coagulation factor deficiencies or disorders. These centers are well positioned to apply the same comprehensive multi-disciplinary approach to the blood clotting disorders that result in pediatric and adult thrombotic disorders which affect millions more Americans.

#### **4. How will the data be used to benefit the bleeding and blood clotting community?**

The work of ATHN will help ensure that health care decisions, at the individual as well as population level, are optimally based on complete, standardized information, as opposed to fragmented data that must be pieced together. The ATHN infrastructure will produce the breadth and scope of standardized data needed to better understand the epidemiology, genetics and natural history of these disorders, analyze clinical outcomes of persons with bleeding and blood clotting disorders, facilitate the development of standards of care, aid in the post-marketing surveillance of FDA approved therapies, as well as support advocacy and community education. We believe that assessing high cost, but effective, necessary and expected therapies and regimens (e.g., immune tolerance, prophylaxis, etc.) will help to preserve access to high quality care.

#### **6. Will ATHN have access to the patient's name and address?**

Absolutely not. ATHN will not have access to information such as name and address that identifies the patient. Patient privacy will be protected.

#### **7. Who comprises the leadership of ATHN?**

The ATHN board of directors is comprised of a prestigious group of healthcare thought leaders. Broad community-based leadership is one of ATHN's organizational strengths. The present ATHN Board of Directors reflects the broader hemostasis and thrombosis community with representation of consumers, providers and HTC regions. Seven of its 17 members are physicians providing care as pediatric or adult hematologists. Included are the immediate past president and a current board member of the Hemostasis and Thrombosis Research Society (HTRS), as well as a former chair of the National Hemophilia Foundation's

Medical and Scientific Advisory Council (MASAC), the professional body that recommends standards of care. Other ATHN board directors are drawn from different regions of the country to bring insight and expertise from clinical nursing, social services, law, and the management of treatment centers. A consumer member and the ATHN CEO complete the voting membership. In addition, to help ensure compatibility with the increasingly sophisticated public health network dedicated to bleeding and clotting disorders, a well respected hematologist represents the Centers for Disease Control and Prevention (CDC) Division of Blood Disorders as an ex officio member. The Co-chairs of the ATHN Board of Directors are:

Jeanne Lusher, M.D.  
Co-Chair, ATHN Board of Directors  
Director,  
Hemostasis and Thrombosis Center;  
Co-Director  
Hematology / Oncology  
Children's Hospital of Michigan  
Distinguished Professor of Pediatrics,  
Wayne State University  
Detroit, MI

Amy Shapiro, M.D.  
Co-Chair, ATHN Board of Directors  
Medical Director  
Indiana Hemophilia and Thrombosis Center  
Indianapolis, IN

#### **7. Are individuals affected by bleeding and blood clotting disorders involved?**

Yes! The ATHN board includes the mother of a college aged individual with severe hemophilia who has inhibitors. Consumer representatives have been appointed to key ATHN committees related to privacy and access to data, the structure and security of the technological infrastructure, as well as community relations.

Available soon: [www.athn.org](http://www.athn.org)