

36. Thrombophilia Patient Interest Groups (NATT and TAP)

Last Updated: 2/15/2004

Q1: "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?"

A1: Thrombophilia is indeed much more common than hemophilia. Hemophilia patients and families have been very successful in creating a national patient advocacy group that has, over the last 30 years, led politicians to fund comprehensive Hemophilia Centers all over the U.S. Individuals with thrombophilia and patients with thrombosis do not have advocacy groups, and therefore do not have support with politicians in Washington. The consequence is that the U.S. have few thrombophilia centers, and a lack of thrombophilia experts, of thrombophilia awareness, of educational materials, and of financial support for thrombophilia research.

Q2: "One thing coming up a lot on the FVLeiden List is that many of us are buying home testing machines and are being denied reimbursement by insurance companies, even though we have tried to fight it."

A2: I wonder whether denial of reimbursement would also occur if patients with thrombosis or individuals with thrombophilia had a strong patient advocacy group with political lobbyists in Washington.

Q3: "My first hemo visit is FINALLY here. I've only had to wait 6 months... 2 months to get in, and 4 months to convince my primary MD I needed to go!"

A3: I wonder whether a strong patient interest group would be able to increase awareness of the needs of patients with thrombosis, such as the need for access to specialized Thrombophilia Centers.

Q4: "My doc couldn't answer any of my questions about factor V Leiden. Don't these guys keep up-to-date? He got kinda upset when I told him the few things I had learned on the internet. Shouldn't they all be up-to-date if this is such a common disorder?"

A4: I wonder whether education of health care providers would be better if a patient advocacy group with educational materials, regular meetings, and media representation existed, and specialized thrombophilia centers were in place.

In the United States, patients with diseases other than thrombosis (even with disease much less common than thrombosis, such as hemophilia, and cystic fibrosis) have been successful in forming patient interest groups that have gained political influence in Washington and have achieved change: improved health care delivery, raised disease awareness, better education of public, patients and health-care providers, and financing of research. Surprisingly, no prominent interest group of patients with thrombosis exists at present, even though venous thromboembolism is such a common problem.

NATT (National Alliance for Thrombosis and Thrombophilia)

In August 2003, patients attending a thrombosis and thrombophilia awareness meeting at the Centers for Disease Control and Prevention (CDC) established the National Alliance for Thrombosis and Thrombophilia (NATT). NATT is a community-based organization working with doctors, researchers, patients, families, care providers and other stakeholders who share a common goal: To ensure thrombosis is prevented and all persons suffering from thrombosis and/or thrombophilia receive early diagnosis, optimal treatment and quality support. NATT is made up of the following groups:

A. Steering Committee

1. Mark Jablonski, the current chairperson, is a business development executive with extensive project management experience, Illinois
2. Kathy Barone, librarian, Assistant Professor, University of Montevallo, Alabama
3. Gina Coleman, Event coordinator, Colorado
4. John Coleman, Marketing and fundraising, Colorado
5. Kathy Earley, Information Manager, North Carolina Air National Guard
6. Thomas Hogan, Connecticut
7. Georgianna Jablonski, Illinois
8. Pat Koppa, MPH, Public Health Consultant, Minnesota
9. Lori Preston, MBA, Marketing, writing, fundraising, Maryland

10. Mike Reynolds, founder, Airhealth.org website, New York
 11. Elizabeth Varga, genetic counselor, University of Kansas
- B. Medical Advisors
1. Edward Libby MD, Associate Professor Internal Medicine, Associate Director Anticoagulation Clinic and Hemophilia Treatment Center, University of New Mexico School of Medicine, Albuquerque, New Mexico
 2. Marilyn J. Manco-Johnson, M.D. Professor of Medicine, University of Colorado Health Sciences Center; Director, Mountain States Regional Hemophilia and Thrombosis Center, Aurora, Colorado
 3. Stephan Moll, MD, Assistant Professor of Medicine, Director of UNC Thrombophilia Program, Chapel Hill, North Carolina
- C. Support team
1. Val Bias, Consultant, legislative action; co-author of the Ricky Ray Hemophilia Relief Fund Act
 2. Sara Critchley, RN, MS, Division of Hereditary Blood Disorders, Centers for Disease Control and Prevention, Atlanta, GA
 3. Sally Crudder, Deputy Director, Division of Hereditary Blood Disorders, Centers for Disease Control and Prevention, Atlanta, GA
 4. Bruce Evatt, MD, Director, Division of Hereditary Blood Disorders, Centers for Disease Control and Prevention, Atlanta, GA
 5. Line Robillard, MBA, former Executive Director of the World Federation of Hemophilia (1994-2003)
- D. Stakeholder Support
1. Individuals: many individuals across the country are working to establish the organization.
 2. The CDC is providing technical assistance.
 3. The American Society of Hematology (ASH) has offered technical assistance.
 4. Several pharmaceutical companies have given preliminary indications of support.

NATT's long-term objectives are to address all major treatment issues in order to:

1. Prevent thrombosis and complications of thrombosis
2. Reduce morbidity and mortality related to thrombosis
3. Assist in the establishment of standards of care
4. Promote the establishment of health care structures and comprehensive thrombophilia programs that will allow every patient access to thrombosis specialists within a reasonable distance of the patient's place of residence
5. Encourage the creation and funding of thrombosis treatment centers and delivery of specialty care for people affected by thrombosis and thrombophilia
6. Promote and assist with research efforts relating to all aspects of thrombosis and thrombophilia
7. Encourage activities aimed at increasing the number of specialists in thrombosis and thrombophilia, such as endowing training fellowships
8. Initiate and promote educational activities for the medical and patient community, and for the public
9. Create a network of self-funded local chapters to improve the quality of life for all patients/families through appropriate support
10. Create a national policy agenda and a grassroots advocacy network

NATT is in the process of becoming a non-for profit organisation (501c3), creating a website, producing educational material on thrombosis and thrombophilia that can be made available to interested individuals, organizing regional patient/public education seminars on thrombosis and thrombophilia, and raising funds to become a nationally recognized, powerful patient advocacy group.

TAP (Thrombophilia Awareness Project)

TAP is a non-for-profit group of non-medical individuals dedicated to further public and patient education on thrombophilia and thrombosis and to work on specific projects dealing with health care needs of patients. TAP was created in 2002 under the leadership of Deb Smith, CA, has 501c3 status.