Education, Mentoring, and Collaborative Research—The Mission of the Hemophilia & Thrombosis Research Society

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Abstract

The Hemophilia & Thrombosis Research Society is a member-based organization to advance the care of persons wih hemophilia and other bleeding and clotting disorders through education, professional mentoring, and collaborative research.

Keywords

Hemostasis, thrombosis, collaborative research, education

Disclosure: Leonard A Valentino, MD, is immediate Past President of the Hemophilia & Thrombosis Research Society.
Received: January 20, 2009 **Accepted:** July 31, 2009 *DOI: 10.17925/OHR.2009.02.0.7*
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What should physicians and researchers expect from a professional membership? At the very least, we hope for a venue for peer interaction, opportunities for career development, and a way to maintain quality standards and currency within our chosen fields. Several organizations exist for those of us in hemostasis and thrombosis, including the International Society on Thrombosis and Haemostasis (ISTH), the American Society of Hematology (ASH), the National Hemophilia Foundation (NHF), the American Society of Pediatric Hematology-Oncology (ASPHO), and the Hemophilia & Thrombosis Research Society (HTRS), which quietly marked over 16 years of service to its members and the medical community in 2008.

What Is the Hemophilia & Thrombosis Research Society?

HTRS began as the Hemophilia Research Society of North America. After months of effort by several main founders—including Dr Robert R Montgomery, the Society's first President, and Dr Joan Cox Gill, who remains our Treasurer—the Society was formally established in 1992 as a tax-exempt, non-profit research society in the State of Wisconsin. In our first newsletter, published in September 1994, then President Keith Hoots called for "inspiration, participation, and collaboration," which remain the root tenets of the society. In the early 1990s, our mission was two-fold: to foster collaboration among North American clinicians and researchers, and to promote the mentoring of junior faculty in hemostasis. By 2003, it was clear that we needed to include thrombotic as well as bleeding disorders in our scope of work. The charter was duly amended, and 'thrombosis' became integral to both our name and our mission.

Today, HTRS is a member-based organization serving over 300 physicians, allied health professionals, and industry members in the US and Canada. As we consider opportunities for synergy with sister organizations in hemostasis and thrombosis, we remain grounded in our organizational mission: to advance the care of persons with hemophilia and other bleeding and clotting disorders through education, professional mentoring, and collaborative research. These three areas guide the development of our ongoing programs, including our annual symposia, grant-making efforts, and research agenda.

Focus on Continuing Medical Education

In less than five years, HTRS has turned its annual scientific conference into one of the premier symposia of its kind in the country. The first conference, in 2005, welcomed 130 participants, which was a fantastic turnout, we thought, for a first attempt. By 2008, we had 350 participants and hosted the meeting under joint partnership with the North American Specialized Coagulation Laboratory Association (NASCOLA). I am happy to report that due to overwhelmingly positive feedback from both organizations, we will again team up with NASCOLA for the 2010 Symposium.

This year's symposium was held on April 16–18 at Northwestern University in Chicago, Illinois. The conference offered state-of-the-art content related to basic, clinical, and laboratory-related matters in hemostasis and thrombosis. The program was divided into five major sessions, each chaired by a prominent clinical researcher charged with reviewing outstanding topics in that area. The first three sessions focused on important concerns in hemophilia, thrombosis and thrombophilia, and thrombocytopenia. The fourth session provided presentations and discussion on important matters relevant to hemostasis and thrombosis 'between the guidelines,' in the area where best evidence frequently consists of little more than limited case series and individual reports.

The final session provided 'point–counterpoint' discussions in two areas of therapeutic management, one involving the use of the pentasaccharide fondaparinux in patients with heparin-induced thrombocytopenia, and the other involving the use of plasma-based versus recombinant factor products. The meeting began with a lecture on thrombophilia by Trevor Baglin, MD, of the Cambridge Haemophilia Center, and ended with hemophilia care by Christopher Ludlam, MD, of the University of Edinburgh.

Co-operation among researchers dealing with diseases such as hemophilia and thrombophilia is mandatory in order to accumulate a sufficient substrate for investigation.

Hemophilia & Thrombosis Research Society Grant-making—Mentoring and Investigator-initiated Research

In addition to the symposium, the main focus of HTRS fundraising since 2006 has been to support our Mentored Research Award (MRA) Program, a competitive application and review process that funds two to three research awards per year for senior trainees (fellows) and junior faculty pursuing academic careers. Successful MRA applicants are awarded $75,000 per year for two years, administered through the applicant's institution. Eligible projects include basic or clinical research in hemostasis or thrombosis. An example of a recently funded MRA project is the study of non-overlapping epitopes in the C2 domain of factor VIII (FVIII). In 2008, HTRS also offered, for the first time, a single competitive investigator-initiated research award ($100,000 per year for two years) for the study of a mouse model of hemophilia B expressing humanized anti-factor IX (FIX) and human leukocyte antigen (HLA) class II genes.

Future plans include strengthening the MRA program by offering statistical support for applicants (particularly for clinical researchers during the 'request for proposal' stage) and continued expansion of investigator-initiated single- and multi-institution studies.

Collaborative Research

HTRS clinical research studies have been either HTRS-member-initiated, with or without industry financial sponsorship (registries have tended to dominate, but there have been occasional randomized control trials such as the Joint Outcome Study[1]), or industry-initiated but HTRS-sponsored, for example, the CSL Behring-sponsored von Willebrand's disease (vWD) prophylaxis study. To date, focus areas have included the fields of inhibitors, vWD, rare bleeding disorders, and the epidemiology of thrombosis.

A particularly productive area for HTRS research has been a registry of 2,205 congenital hemophilia inhibitor patients enrolled at 80 sites, operational since 2000 and supported until late 2008 by Novo Nordisk Inc; several analyses have been completed and published. Current attempts are focused on expanding the HTRS database for acquired hemophilia, an effort that continues to be supported by Novo Nordisk Inc.

The Future of the Hemophilia & Thrombosis Research Society

The needs of our patients and the research community are vast, diverse, and multidimensional. How do we as a discipline (hematology) and as an organization (HTRS) tackle the daunting task of approaching this challenge? As Dr Keith Hoots stated so well at the start: with inspiration, team participation, and collaboration. Collaboration leverages the strengths of diverse scientific approaches and resources. Co-ordination maximizes synergy and minimizes unnecessary duplication of effort. Team science is different from but complementary to traditional solo science, and emphasizes cohesion and effective management. Academic research enterprises have historically been organized along the traditional academic organizational structure of disciplinary silos, whose mutually reinforcing boundaries limit adaptation to changing research needs, co-ordinated clinical services, sharing resources, and competitive pressures. The future will challenge this paradigm. A multidisciplinary team strategy will be required to comprehend these complex processes and overcome the resultant diseases.

Co-operation among researchers dealing with diseases such as hemophilia and thrombophilia is mandatory in order to accumulate a sufficient substrate for investigation. Collaboration and the exchange of intellectual assets will increase the pace of discovery. Teamwork is vital to our success, and HTRS is one way we can make that happen. I hope that you will join me as a member: simply visit our website at www.htrs.org and click on the link for membership. Together, we can achieve much for the benefit of many. ■

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