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

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Hemostasis, thrombosis, collaborative research, education

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Correspondence: Leonard A Valentino, MD, Rush Hemophilia and Thrombophilia Center, Rush University Medical Center, 1653 West Congress Parkway, Room 1591, Jelke Building, Chicago, IL 60612-3833. E: whybloodclots@gmail.com

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.
Current Issues

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.

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 Study1), 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 strength 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.