



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

Summary Report
of the
National Hemophilia
Foundation's
Accomplishments

2010

Introduction

The programmatic activities conducted in FY 2010 focused on the implementation of a comprehensive plan to address *ACT: Access to Care Today, Achieving Cures for Tomorrow*. Given the changing healthcare environment NHF's focus was to ensure access to specialists skilled in the care of individuals with bleeding and clotting disorders. Our objective was to: 1) educate both Congress and the administration of the critical needs of our chronic illness patient group including the most helpful changes in healthcare that would ensure access to care. 2) To ensure a comprehensive approach to our goals we focused on strengthening and supporting our chapter network in formalizing its relationships with our hemophilia treatment center (HTC) network. 3) We invested in the infrastructure and training of the professionals in our chapter network to further their professional abilities to provide support and educational programs for patients locally.

We have continued to work collaboratively with CDC to develop educational programs for all life stages as part of their Health Protection goals. 4) Our objective was to create an easily accessible online education resource to address patient education and information needs. We have been successful in creating *Steps for Living*, a dynamic and effective online educational tool. 5) We further worked collaboratively with our HTCs in developing educational opportunities on the value of the comprehensive care model and how access to HTCs enhances patient outcomes. 6) NHF further invested in research by adding the professional expertise of a medical advisor to our staff and securing funds to support infrastructure and escalation of our research agenda.

Research and Medical Information Department

HANDI

HANDI is NHF's information resource center providing information, resources and referrals to individuals and families with bleeding disorders and their healthcare providers. Information specialists are available 5 days a week via an 800 phone line, through e-mail and fax. In 2010, HANDI answered 4,500 requests for information in a range of subject areas that include hemophilia, von Willebrand disease, carrier testing, school issues, sports and exercise, co-infection, research, psychosocial issues, blood safety and insurance. HANDI also distributed 10,000 NHF educational publications to individuals, local chapters and HTCs.

Research and Medical Information Department

Awarded NHF/Baxter Clinical Fellowships to:

Rachael Grace, MD

Dr. Grace joined Children's Hospital Boston / Dana Farber Cancer Institute as a Pediatric Resident after receiving both her undergraduate and doctoral degrees from Brown University. She has since gone on to become a fellow in the institution's Hematology/Oncology program and was chief fellow in her final year of fellowship. As Dr. Grace begins her NHF-Baxter Fellowship, she will be on staff as a Hematologist at Children's Hospital Boston / Dana Farber Cancer Institute.

Brian Branchford, MD

Since 2009, Dr. Branchford has been a hematology/oncology/bone marrow transplant fellow at the Children's Hospital of Denver. Prior to this post, he served as Chief Resident at the Children's Hospital of Wisconsin-Milwaukee. Dr. Branchford received his doctoral degree from the University of Wisconsin School of Medicine and Public Health, and his BA in Biology from Lawrence University. He is also a member of the American Academy of Pediatrics and Colorado Medical Society as well as the American Societies of Hematology, Clinical Oncology and Pediatric Hematology/Oncology. As an NHF-Baxter Clinical Fellow, Dr. Branchford will be continuing both his clinical and research training under the mentorship of Dr. Marilyn Manco-Johnson. In addition, he will be working in the lab of Dr. Jorge DiPaola on a project researching the microfluidic properties of von Willebrand disease as well as the role of the TAM pathway in platelet activation and thrombus formation.

Awarded a Judith Graham Pool Postdoctoral Research Fellowship to:

Lacramioara Ivanciu, PhD

The Children's Hospital of Philadelphia
Philadelphia, PA

"FXa Variants for Treatment of Hemophilia"

Awarded a Nursing Excellence Fellowship to:

Research and Medical Information Department

Linda Grooms, RN, CPON

Nationwide Children's Hospital

Columbus, OH

"A New Approach for a New Generation"

Awarded a Social Work Excellence Fellowship to:

Marie Mitchell, MSW, LICSW

Boston Hemophilia Center, Brigham and Women's Hospital

Boston, MA

"Socialization of Adult Men with Hereditary Bleeding Disorders and the Role of Spouse and Significant Other"

MASAC

NHF's Medical and Scientific Advisory Council (MASAC) held two meetings, April 18, 2010, and November 14, 2010, to update and develop new recommendations regarding the treatment of individuals with bleeding disorders. The following are the recommendations that were approved by the council in 2010:

MASAC Recommendation #194

MASAC Recommendations Regarding Radionuclide Synovectomy

MASAC Recommendation #196

MASAC Recommendations Regarding the Treatment of von Willebrand Disease

MASAC Recommendation #197

MASAC Recommendations Regarding Girls and Women with Inherited Bleeding Disorders

MASAC Recommendation #199

MASAC Resolution on Blood Donor Deferral Policy

MASAC Recommendation #201

MASAC Recommendation on Use of Emergency Medical Identification Devices for Children

Chapter Services Department

Chapter Development

NHF continued the implementation of its Chapter Development plan in 2010, with the full formation of the Chapter Services Department that now includes three Regional Directors to guide and assist chapters. Collaboration between NHF and its 46 chapters is resulting in a chapter network more viable and sustainable in order to better serve NHF's owners (individuals and their families affected by bleeding and clotting disorders) throughout the country. Most services now provided to chapters have been consolidated into the Chapter Services Department, with the recent addition of the Education and Public Policy components.

NHF's new ACT initiative—*Access to Care Today, Achieving Cures for Tomorrow*—was rolled out initially to those chapters receiving Staffing Assistance Grants: Hemophilia of North Carolina, Hemophilia Foundation of Northern California, Southwestern Ohio Hemophilia Foundation, and the Rocky Mountain Hemophilia and Bleeding Disorders Foundation.

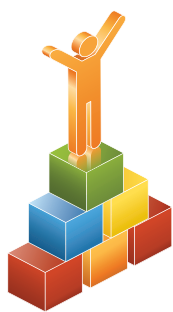
In reorganizing how chapters interface with NHF, options were provided to all chapters as to how they would affiliate with NHF. Five chapters chose to merge with NHF. The legal process is continuing and the mergers are expected to be completed in early 2011. The merging chapters are: Central Ohio Chapter of NHF, Nebraska Chapter of NHF, Hemophilia Society of Colorado, Hemophilia Foundation of Idaho and Hemophilia Foundation of Nevada.

Education

The National Hemophilia Foundation's primary education initiative in 2010 was the creation of the *Steps for Living* life stage education program in collaboration with the Centers for Disease Control and Prevention

(CDC), chapters, HTC's and consumers. The *Steps for Living* curricula is an online, life stages education curriculum to assist those affected by bleeding disorders and continue supporting families not only in the first years of a child's life, but throughout the various stages of his/her development. *Steps*

for Living builds on the success of NHF's *First Step* program and will provide an outlet for families through which they can continue their education and involvement with their local chapter as their child grows and his/her needs change. Further, *Steps for Living* is in keeping with one of the 5 Priority Areas under NHF's 5-year ACT initiative, "Education for All Life Stages," through which NHF is committed to responding to the evolving needs of people with bleeding disorders throughout various stages of their lives.



Steps
for Living

Education for all Life Stages

Chapter Services Department

First Step is NHF's successful collaborative model of new parent/family education. For parents and families with newly diagnosed children, *First Step* provides an opportunity for them to become more educated about bleeding disorders, and to meet other new parents and families experiencing similar "firsts" for children with bleeding disorders. *First Step* is a replicable program based on a detailed curriculum that "teams" or volunteers can follow and implement locally.

The *Steps for Living* curriculum contains three different modules targeted at three separate age groups:

- *First Step* for ages 0-8
- *Next Step* for ages 9-15
- *Stepping Out* for ages 16-25

Steps for Living is primarily an online program, with information and resources for all three modules, targeted directly to three main audiences: consumers, chapters and HTC staff. It is further divided into topics of importance to each audience. *First Step* focuses on the basics of bleeding disorders and treatment; negotiating parent/provider relationships; childcare issues; insurance; and maintaining a healthy body. *Next Step* provides information about working with schools (legal rights, educating school staff, PE class, field trips); gaining independence at home (transitioning to home infusions and on to self-infusions, limit setting, discipline, when to leave your child home alone); and healthy decision making (vacation/travel, organized sports, and nutrition). *Stepping Out* covers topics such as disclosure, dating, career choices, moving away to college and adherence.

For consumers, the information will be available in various user-friendly formats, including podcasts, interactive features, and pop-up surveys to help further the opportunities for learning in each module.

Young Adults

NHF's National Youth Leadership Institute (NYLI) fosters the development of youth leaders to help NHF chapters and associations across the country build strong youth programs. Accomplishments for this program period include:

- 21 NYLI members attended Annual Meeting in 2010, where they received leadership training in group facilitation, peer-education and the process communication model of personality leadership. As part of their leadership training, NYLI members were broken into three groups and tasked with discovering and learning about a particular issue in New Orleans: the BP oil spill, hurricanes Katrina and Rita, and crime rates. NYLI was asked to view these events as a metaphor to some of the challenges the bleeding disorders community has been through and to discover how New Orleans has coped and managed these challenges. Members prepared presentations on the lessons learned that they can bring back to the bleeding disorders community to help manage the adversity this community faces. They also attended general education sessions on bleeding disorders to further their understanding of prevention behaviors.
- NYLI members are required to implement local projects in their home areas. Examples of local projects include: translating resources into Spanish for a local chapter, facilitating sessions on physical activity and nutrition at chapter events, providing peer-to-peer health education at summer camps, fundraising for local

- foundation, starting a summer arts camp for children with chronic conditions, creating a theater workshop for youth, initiating a training in state advocacy for younger teens, developing a session for siblings of youth with bleeding disorders at a chapter annual meeting, and creating an art project for youth with bleeding disorders at a summer camp.
- NYLI members attended NHF's Washington Days in February 2010, where they learned about the legislative process, state vs. federal advocacy, and how to effectively share their stories with legislators. NYLI members stayed after Washington Days to receive more training in peer-education techniques for their summer project, Youth Fit.
 - NYLI members traveled to three bleeding disorders summer camps and facilitated Youth Fit, a program to educate younger teens at camp in healthy decision making, physical activity and healthy nutrition. Evaluations from that program show an increase of more than 30% in knowledge of participants between pre-tests and post-tests.

Women with Bleeding Disorders

The National Hemophilia Foundation has been committed to assisting women with bleeding disorders for more than 15 years. Project Red Flag laid the groundwork by instituting a national awareness campaign regarding von Willebrand disease and other bleeding disorders. The program successfully instituted a chapter grants program, which provided funds to local chapters to initiate or expand existing educational and support efforts for women, as well as developed print materials and a Web site. In 2010, phase two of NHF's women's initiative, Victory for Women (V4W), was launched. V4W has two main goals: 1) to increase awareness of women's bleeding disorders so that girls and women receive early, accurate diagnoses, leading to better health outcomes, and 2) to provide women affected by bleeding disorders with the education, support, skills and resources they need to advocate for their healthcare, financial and social support needs.

Program accomplishments during the period of January 2010 – December 2011 include:

- Development and distribution of a print piece in English and Spanish on the signs and symptoms of a bleeding disorder. More than 5,000 cards have been distributed to chapters, HTC's and relevant health professionals, including those working with young women in college health centers.
- In partnership with the Centers for Disease Control and Prevention (CDC), a national survey was conducted through Harris Interactive involving more than 1,200 young women between the ages of 18 and 25. Information was collected about their knowledge of bleeding disorders, where they seek health information, their menstruation challenges and concerns. This information is being used to pilot test new marketing strategies to provide information about bleeding disorders to those women who are symptomatic but not yet diagnosed.
- Victory for Women launch, which included a new logo, a calendar for 2011 with health information and photos of women from the bleeding disorders community. A scarf, song and video were also created and produced in order to raise awareness of the new program efforts.
- V4W staff attended six relevant professional health conferences providing information about women and bleeding disorders, and building bridges with other health organizations.

Chapter Services Department

- V4W awarded 14 grants to fund projects at NHF chapters, totaling \$90,000. Projects range from developing educational modules on important topics for women that can be disseminated nationally to hosting informational dinners for local OB-GYNs to learn about women and bleeding disorders.
- Evaluation of past women's programming efforts at NHF, and revisions of curriculum for the Women to Women program and Anyone Can Have a Bleeding Disorder lesson plan for middle school.
- Awarded four academic scholarships to women with bleeding disorders to assist with their post-secondary education.
- Reorganization of the women's task force to provide closer alignment to the current program goals and allow participants more hands-on involvement.

Minority Populations

- The NHF Multicultural Task Force attended the NHF Annual Meeting in 2010 to review and comment on the new *Steps for Living* English/Spanish coloring book and helped with its Spanish translation. The Multicultural Task Force members helped in the development of NHF's new *Steps for Living* Program. NHF will be updating the translated Fast Facts, to include our new programs along with a summary of general information on bleeding disorders, von Willebrand disease, clotting disorders and NHF programs. These will also be translated into two dialects of Chinese and Vietnamese.
- For NHF's 62nd Annual Meeting, the 8th Annual Educational Participant Grant Program for first-time attendees was implemented. NHF provided assistance to individuals and/or families affected by bleeding disorders who would have been unable to attend due to financial constraints and had never attended an NHF Annual Meeting.
- Sixty-five individuals from 18 families were awarded educational participant scholarships to attend. The families were very appreciative of the opportunity to attend and meet other families with bleeding disorders. Evaluations from these families showed how vital the information gathered at Annual Meeting was to their ability to manage bleeding disorders. The information we received from the families showed what they learned:
 - ◇ I learned that infusions and other medical procedures do not have to be adversarial between the parent and the child.
 - ◇ I learned that not all patients with bleeding disorders still need human blood/plasma. Also learned that NHF has a strong working relationship through its blood safety working group in case recalls are made or so that alerts can get out within 24 hours.
 - ◇ I did learn that vaccinations are not to be given during or before factor. I knew what the inhibitor was but further learned how its developed and that knowing the genetic mutation can help with risk of inhibitors.

Physical Activity/Nutrition

NHF conducted wellness education sessions at the 2010 Annual Meeting and planned wellness education sessions during the Youth Fit summer program to further encourage the importance of physical activity/nutrition for people with bleeding disorders. Youth Fit was a mobile youth program led and facilitated by young adults for younger campers at bleeding disorders summer camps. Evaluation data show an overall increase in knowledge of more than 30% between the pre- and post-tests.

NHF has worked toward our objective of increasing awareness and knowledge of physical activity/nutrition at NHF national meetings. At the 2010 Annual Meeting, the session “Fit Kids: Addressing Pediatric Obesity in the Bleeding Disorders Community” received an overall rating of 97.36 out of 100 and “Promoting Movement Across the Ages with Cajun Dance” received a 79.15 out of 100. As a more active way of engaging the population, NHF’s Education staff teamed with the Physical Therapy Working Group to host a “Fit ‘n’ Fun Walk/Run” for all conference attendees.

Further, nutrition and physical activity are covered in-depth on the new *Steps for Living* Web site: www.stepsforliving.hemophilia.org.

Emergency Preparedness

In 2010, NHF focused on disseminating information on emergency preparedness through HANDI. Additionally, an extensive section of the *Steps for Living* Web site is dedicated to this topic. NHF also marketed its HANDI resource line as the primary information center during an emergency in the community. It is implementing its 24/7 emergency phone line with veteran and newly trained staff.

Social Workers and Reimbursement Information

In the US, healthcare providers, insurers, employers, and the government are all unofficial partners in a complicated and loosely defined healthcare “system.” In contrast to most other nations where the government finances healthcare for the majority of its residents, most Americans have some form of private health insurance sponsored by employers. A sizable number have government-sponsored insurance, with those over 65 years of age covered by a federal program (Medicare) and some poor children and their families eligible for a state-federal program (Medicaid). This public-private model is unique among nations and affords those who are most affluent and who have insurance with access to among the best quality of care in the world. At the same time, 45 million individuals in the US have no insurance and experience considerable barriers to care. In many instances, they experience poorer health outcomes than their insured counterparts.

In an effort to better understand the differences between the public and private coverage options and how each affects those with bleeding disorders, identified experts in the above fields were brought in to guide program attendees through the maze of their respective fields. They also participated in small group break-outs where real-life scenarios, provided by the program participants, were addressed and discussed.

The meeting was held in Dallas, Texas, April 23-24. Thirty eight social workers participated; 18 were new to the training conference. Since 2006, 117 social workers have received training through the Insurance & Reimbursement conference.

Chapter Services Department

Healthcare Reform

Healthcare reform continued to be a main focus of NHF's policy efforts, with our public policy team active, both singularly and in collaboration, with various coalition partners. In order to achieve our goal of ensuring the priorities of those affected by bleeding disorders was heard by both state and federal policymakers, NHF worked diligently to keep our chapter leaders and the community at large abreast of the issues and engaged in the debate. Examples of some of the health reform activities undertaken were: 1) an analysis of healthcare reform proposals by the major Congressional committees in charge of coming up with a plan; 2) clarification of our position on issues, such as follow-on biologics and comparative effectiveness; 3) regular updates to chapters and the community at large through NHF's eNotes and Chapter Updates; and 4) the development of Web campaigns aimed at letting lawmakers know where the community stands on the crucial issues.

Medicaid and Other State Issues

We again increased efforts to provide more structured support to help chapters deal with Medicaid and other state advocacy issues. We monitored emerging trends within the private and public payer markets, and alerted chapter leaders to potential coverage issues in their state and assisted in preparing a response to the appropriate agency. For example, an emerging trend in the private market was the use of specialty tiers (or Tier IV) to reduce prescription costs to plan providers. This practice drastically increased the patient's cost share and had the potential to affect access to care. NHF worked with local chapters and other community advocate groups on legislative efforts to prevent and/or limit the use of specialty tiers.

Another example of an emerging trend was the narrowing of provider networks, in some instances to a sole provider situation. NHF responded by writing letters, and in some cases, providing testimony, to state legislatures, Medicaid directors and insurance providers expressing our concerns related to patient access and continuity of care.

Bleeding Disorders Advisory Boards and Standards of Care

NHF continues to assist chapters and associations in their efforts to establish Bleeding Disorders Advisory Boards and Standards of Care at the state level. The advisory board is an initiative that was spearheaded by NHF in collaboration with several industry partners. In addition to providing feedback on draft legislation, NHF prepared letters of support for the advisory board bills in Illinois, Alabama, California and Connecticut. Likewise, we continue to support efforts underway in Pennsylvania and Missouri to pass standards of care. In both cases, we sent support letters to members of the legislature.

"Awareness-Raising" Days

More NHF chapters and associations are developing legislative days in their capitols and legislative advocacy "awareness-raising" days and training for their members. Many continue to cite NHF's Washington Days and other NHF programs as an important model for these programs, as well as an important learning and training opportunity for their active members. Moreover, the NHF public policy team continues to be sought out to help chapters develop the issues for these events. For example, we assisted the NYS Hemophilia Advocacy Coalition organize its second hemophilia day in the state capitol. We also helped to prepare the background materials. This effort continues to create new opportunities for us (and the NY advocates) to forge a working relationship with key state policymakers.

Building Strategic Alliances and Partnerships

- We continued to make significant strides in elevating the needs of the community on the national health agenda through strategic partnerships and alliances with other healthcare advocates. In January, public policy staff attended the Families USA Health Action 2010 Conference, an event that brings together patient advocates from across the country to learn about the major healthcare policy issues and to build alliances and networks. The continued cultivation of the relationships forged at last year's Health Action conferences resulted in many requests for stories that come through our "Tell Your Story" feature on the NHF Web site, hemophilia.org, and our participation in other stakeholder meetings.
- In an effort to assist our chapter leaders in developing relationships with key decision makers at the state level, the NHF state advocacy team developed an Advocacy Boot Camp program. Participants received training on the "who, what, how and whys" of developing and implementing a year-round, multi-pronged advocacy program in their state. Representatives from 38 chapters attended training.
- NHF continues to partner with other consumer groups serving rare, chronic conditions to address issues affecting access to care on both the state and federal levels. For example, as part of the Plasma User's Coalition, NHF has shared its concerns and goals for the establishment of the national high-risk pool and submitted comments to the Institute of Medicine with respect to the development of the "Essential Health Benefits" for insurance plans participating in the state exchange programs in 2014.
- In addition, we were a leading partner of the Raise the Caps Coalition to ensure that hemophilia patients were not subjected to lifetime caps on insurance coverage amounts. While the health-care reform law abolished caps and made other insurance reforms, there is considerable leeway for their implementation. The coalition continues to monitor the regulations as they are issued and responding accordingly with concerns and/or comments.

Assistance to NHF Chapters and Other Organizations

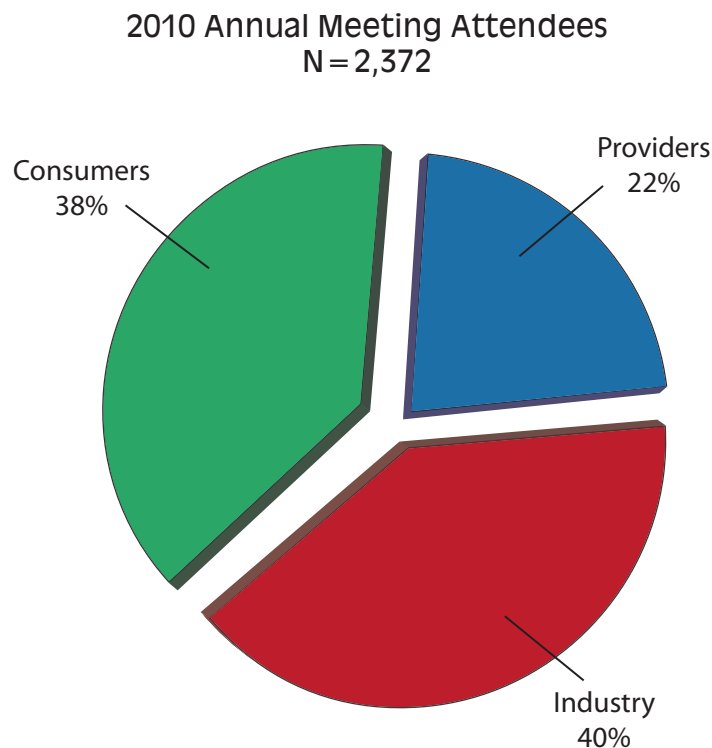
Requests for our assistance continued to increase as chapter leaders and community members try to monitor the implementation of the market reforms included in the Affordable Care Act. We support our member chapters by participating in advocacy events and annual meetings, helping prepare background materials, and serving as a resource to organizers of state legislative days. For example, in addition to working with the NYS Hemophilia Coalition, NHF staff participated in lobby days in South Carolina and Wisconsin. We also conducted advocacy trainings and provided updates on a range of advocacy issues including healthcare reform in several states, including annual meetings of our chapters in Indiana, Idaho, California and Ohio and HTC regional meetings in Florida and Maryland. We also had a unique opportunity to use our advocacy campaign portal to run a state-specific Web campaign for the Tennessee chapter. We continue to refine that tool so that more chapters will be able to use our portal to run state-specific campaigns.

Annual Meeting

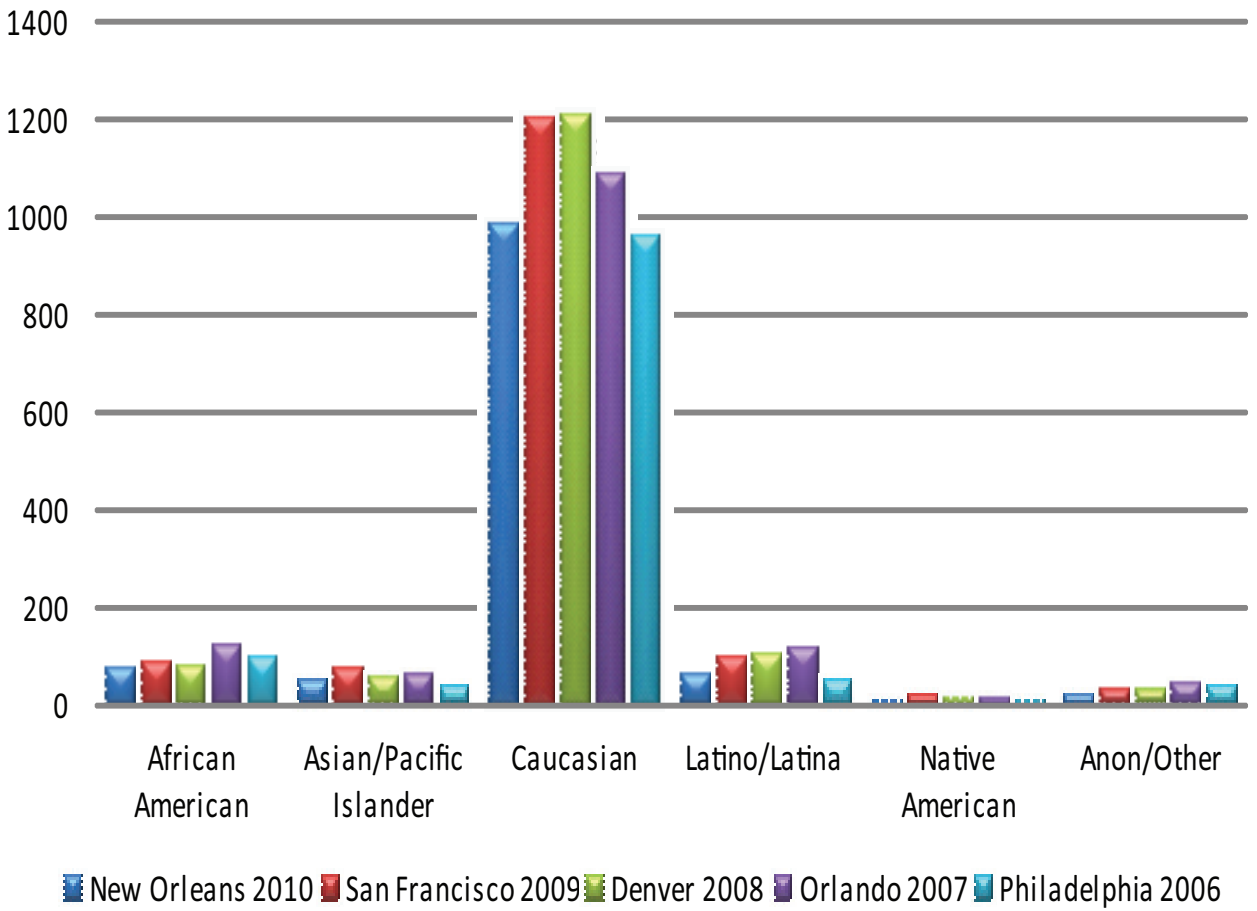
Annual Meeting

The NHF Annual Meeting is the national education event of the year for the combined audiences of people with bleeding disorders and their families ($\pm 40\%$); healthcare providers ($\pm 20\%$) and industry representatives (approximately 40%). Unique among annual meetings of national voluntary health agencies, NHF brings together at one conference these varied, but connected, constituencies. The Annual Meeting is one of the methods NHF uses to deliver prevention education messages to the bleeding disorders community.

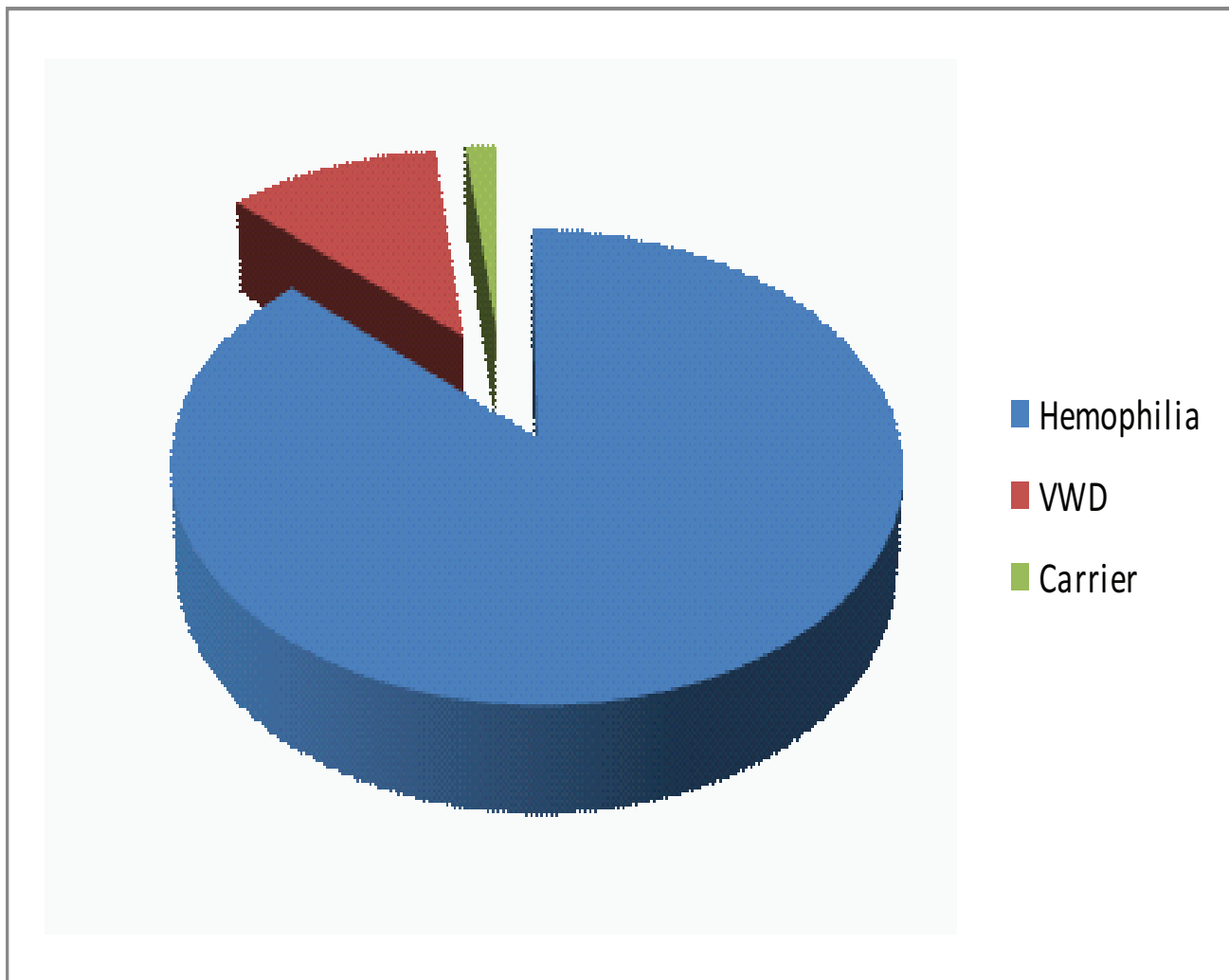
Reaching and Educating Individuals and Families with Bleeding Disorders: Highlights for this reporting period: 2010 Annual Meeting held in New Orleans, Louisiana



Ethnic Distribution



Bleeding Disorder Breakdown N = 573



Hemophilia	483
FV Deficiency	1
FVII Deficiency	5
Carrier	9
VWD	62
Antiphospholipid Antibody Syndrome	1
Glanzmann's Thrombasthenia	1
Platelet Dysfunction Thrombocytopenia	4
Inhibitor	1
Other	5

Session Evaluations

Track	Number of Sessions	Average Out of 4	Average Out of 100
Overall	60	3.65	91%
Chapter	7	3.53	88%
Consumer	26	3.64	91%
RN	8	3.79	95%
PT	9	3.69	92%
SW	9	3.58	90%



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The National Hemophilia Foundation is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing the complications of these disorders through education, advocacy and research. Its programs and initiatives are made possible through the generosity of individuals, corporations and foundations as well as through a cooperative agreement with the Centers for Disease Control and Prevention (CDC).