



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding and clotting disorders

Summary Report
of the
National Hemophilia
Foundation's
Accomplishments

2009

The National Hemophilia Foundation (NHF), founded in 1948, has a history of service through education, research and advocacy for individuals and families living with and affected by hemophilia and, later, other bleeding disorders. Now as a well-established organization in its 61st year, responsiveness is the hallmark of the successful evolution of NHF services. The organization has evolved to meet new, emerging and evidence-based needs as they have arisen. NHF has grown to encompass a network of 46 community-based chapters nationwide— independent organizations of varying capacity. In collaboration with 24 independent associations*, and collaboration with 140 hemophilia treatment centers (HTCs),* the chapters are instrumental in implementing NHF's health promotion programs. These programs are developed and run in conjunction with partners at the Centers for Disease Control and Prevention (CDC) and its Division of Blood Disorders.

The programmatic activities conducted in FY 2009 aimed to prevent secondary conditions in people with bleeding disorders by improving their access to public health programs and implementing effective health promotion and wellness programs. NHF's overall objective is to increase the percentage of people with bleeding disorders who: 1) know about and have access to HTC-based comprehensive care services and local chapter/NHF services; 2) recognize and know strategies to prevent typical and emerging secondary conditions; 3) are aware of and understand emergency preparedness initiatives; and 4) are aware, have knowledge of and participate in safe physical activities and health eating.

The variation in disease impact and needs in different subgroups of the bleeding disorders population demands a life stages approach to NHF's work plan objectives and activities. The CDC recognize the validity of this approach, as mentioned in one of its Health Protection Goals, "Healthy people in every stage of life," and in Healthy People 2010's focus on the "unique health issues and risk behaviors that affect the quality of health in every stage of life." The NHF strategies are tailored and targeted for all life stages, from early childhood—by reaching new parents/families—through teens and young adults to adults. Gender and race/ethnicity are also important subgroup focus areas.

HANDI

HANDI is the 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 2009, HANDI answered 3,358 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 12,708 NHF educational publications to individuals, local chapters and HTCs. At an educational summit for inhibitor patients in October 2008 in Birmingham, AL, and at the Region VII, IX and X meeting in Arizona, HANDI exhibited educational materials and answered questions. HANDI also produced a new consumer publication, "What is Mild Hemophilia."

*Hemophilia treatment centers (HTCs) are federally funded and provide state-of-the-art medical and psychosocial services, and research through a team of bleeding and clotting disorder specialists.

Awarded NHF/Baxter Clinical Fellowships to:

- Romina Sabella-River, MD, a second-year fellow in Pediatric Hematology-Oncology at the University of Texas Medical School--M.D. Anderson Cancer Center of the University of Texas Health Science Center at Houston.
- Mona D. Shah, MD, an Instructor in the Texas Children's Cancer Center Pediatric Hematology-Oncology Service at Baylor College of Medicine. She earned her Medical Doctorate from the University of Maryland School of Medicine in 2001.

Awarded a Career Development Award to:

- Veronica H. Flood, MD, Medical College of Wisconsin, for her project, "Studies of VWF Function in VWF-Platelet and VWF-FVIII Interactions."

Awarded a Judith Graham Pool Postdoctoral Research Fellowship to:

- Mettine H.A. Bos, PhD, Children's Hospital of Philadelphia, for her project, "Regulatory Mechanisms in the Activation of Blood Coagulation Factors V and VIII."

Awarded a Nursing Excellence Fellowship to:

- Robin Chapman, FNP-BC, MSN, Emory University, Atlanta, GA, for her project, "Development of an Institution-Wide, Customizable, Computer-Based, Training Module Designed to Teach the Administration of Products Routinely Prescribed in the Treatment of Bleeding Disorders and Bleeding Disorder Diagnoses."

Awarded a Social Work Excellence Fellowship to:

- Laurel Pennick, LCSW, and Maria Iannone, MA, Arizona Hemophilia and Thrombosis Treatment Center, Tucson, AZ, for their joint project, "The Prevalence and Risk Factors for Depression in Adults with Hemophilia."

Awarded a Physical Therapy Excellence Fellowship to:

- Heidi Lane, PT, PCS, Primary Children's Medical Center, Salt Lake City, UT, for her project, "Outcomes Following Ankle Arthrodesis for People with FVIII/FIX Deficiency: A Look at the Universal Data Collection Project."



NHF's Medical and Scientific Advisory Council (MASAC) held two meetings, November 15, 2008, and March 21, 2009, to update and develop new recommendations regarding the treatment of individuals with bleeding disorders. The following are the recommendations that were approved by the committee in 2009:

MASAC Recommendation #183

MASAC Statement Regarding Use of Herbal or Homeopathic Products to Treat von Willebrand Disease

MASAC Recommendation #184

MASAC Consensus Statement Regarding the Use of Fresh Frozen Plasma for the Immediate Reversal of the Anticoagulant Effects and/or Bleeding Complications Associated with Oral Vitamin K Antagonists

MASAC Recommendation #185

MASAC Recommendations Regarding Women with Inherited Bleeding Disorders

MASAC Recommendation #186

MASAC Recommendations Regarding the Treatment of von Willebrand Disease

MASAC Recommendation #188

MASAC Recommendations Regarding Standards of Service for Pharmacy Providers of Clotting Factor Concentrates for Home Use to Patients with Bleeding Disorders

MASAC Recommendation #189

MASAC Consensus Statement on Plasma Safety

MASAC Recommendation #190

MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders

MASAC Recommendation #191

MASAC Recommendation for Ongoing CDC Surveillance for CJD

Chapter Development

NHF continued the implementation of its Chapter Development plan in 2009, 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. Also in 2009, most services provided to chapters were consolidated into the Chapter Services Department, with the addition of the Education and Public Policy components.

NHF's new ACT initiative—*Access to Care Today, Achieving a Cure Tomorrow*—was rolled out to chapters, 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 2008, options were provided to all chapters as to how they would affiliate with NHF, and five chapters chose to merge with NHF. The legal process is continuing and the mergers are expected to be completed in early 2010. 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 2009 was the creation of the *Steps for Living* life stage education program in collaboration with the Centers for Disease Control and Prevention (CDC), chapters, HTCs and consumers. The *Steps for Living* curricula will be an on-line, 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 a person's development. *Steps for Living* will build upon 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.

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. The *First Step* program is a replicable program based on a detailed curriculum that "teams" or volunteers can follow and implement locally.

Chapter Services Department

The *Steps for Living* curriculum will contain 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 will be an online program, with information and resources for all three modules, targeted directly to three main audiences: consumers, chapters and HTC staff, which will be further divided into topics of importance to each audience. *First Step* will focus on the basics of bleeding disorders, negotiating parent/provider relationships, and childcare issues. *Next Step* will provide 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* will cover 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, e-learning courses and pop-up surveys to help further the opportunities for learning in each module.

Chapters and HTCs will be given sample activities that they can implement with consumers that will provide direct education pieces as well as help consumers connect with others like themselves in an environment where they can not only learn, but also share their feelings, tell their stories and ask questions about their children and family life.

Annual Meeting

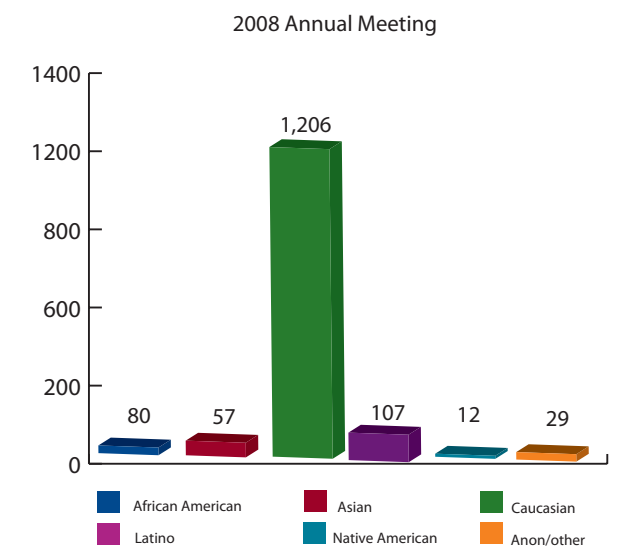
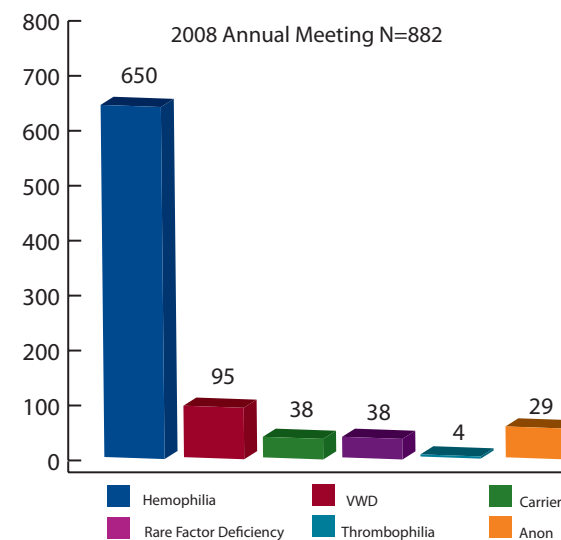
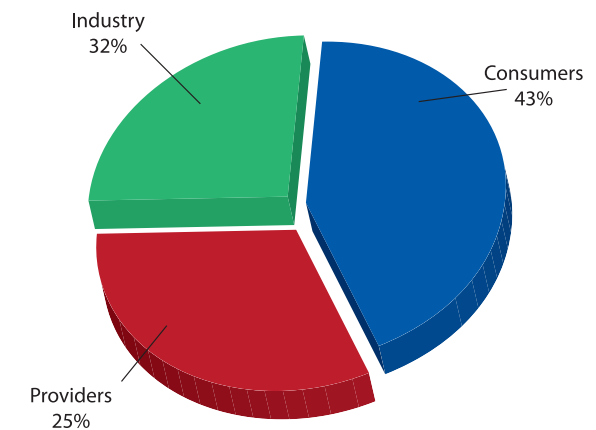
The NHF Annual Meeting is the national education event of the year for the combined audiences of people with bleeding disorders and their families (+ 60%); healthcare providers (+20%) and industry representatives (approximately 20%). Unique among annual meetings of national voluntary health agencies, 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.

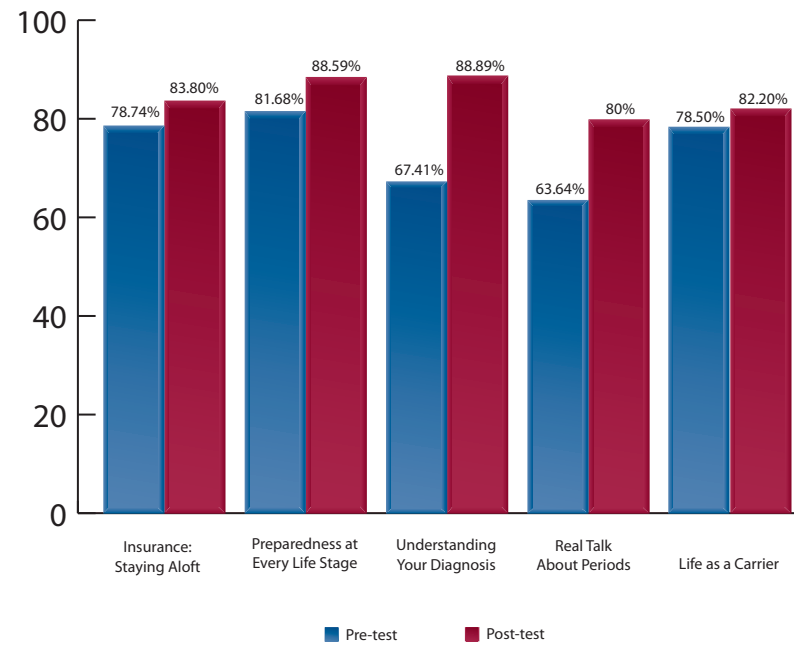
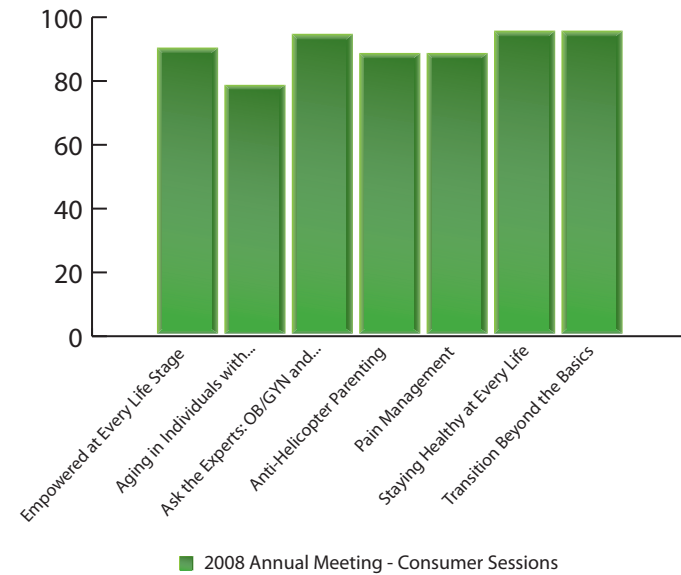
Reaching and Educating Individuals and Families with Bleeding Disorders

Highlights for this reporting period:

2008 Annual Meeting held in Denver, Colorado

2008 Annual Meeting Attendees
N = 2,285





- Awards of Distinction were also given in Health Education, Outreach and Communications, with each awardee receiving \$1,000
- 8 Awards of Excellence were given in the areas of nursing, social work, advocacy, volunteerism, physical therapy, meritorious service and others

Education in Thrombosis and Thrombophilia

In conjunction with the National Alliance for Thrombosis and Thrombophilia (NATT), NHF hosted a session for physicians on Updates in the Clinical Management of Thrombosis and Thrombophilia. NHF's information and resource center, HANDI, provided and distributed state-of-the-art treatment articles, and refers patients to both NATT and HTC's in a patient's local area.

Objectives and Activities

Newly Diagnosed Families

NHF provides education, mentoring and social networking for parents/guardians and families with newly diagnosed children through its *First Step* Program. Accomplishments for this program period include:

- The *First Step* Task Force continued to expand the curriculum, transitioning the materials into *Next Step* to address the needs of parents of school age children. Three major modules were constructed: Chalk it Up: Independence at School, Independence at Home, and Making Positive Choices. Resources were identified and case studies were developed. We also distributed an additional 85 *First Step* welcome kits to local programs.
- The *First Step* Discussion Board has continued to flourish. As of July 2009, there were 257 members and 641 posts. A new component to the Web site was developed, "Share your Story," to provide an outlet for parents to post and tell their stories about their child's diagnosis, first trip to the ER, etc.
- In 2008-2009, *First Step* grants were awarded to seven local chapters. Of those, 5 were successful in completing their proposed strategies, which included maintaining monthly support/networking groups, hosting educational/social gatherings, and building infrastructure and leadership among local *First Step* coordinators.

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:

- 23 NYLI members attended Annual Meeting in 2008 where they received leadership training in group facilitation and group dynamics, and board governance training. They also attended general education sessions on bleeding disorders to further their understanding of prevention behaviors. Additionally, NYLI members spoke to public audiences about the program at the Chapter Leadership Reception, the Consumer Reception, the NYLI Reception and to the Youth and Adolescent program participants. Additionally, NYLI members are required to implement local projects in their home areas. Examples of local projects include: facilitating sessions on physical activity and nutrition at chapter events, providing peer-to-peer health education at summer camps, continuation of a summer camp for campers with bleeding disorders in Mexico, participating in bike rides to raise funds for local chapter, and working on chapter website.

- NYLI members also planned and facilitated the second NHF Winter Youth Retreat. 45 younger teens attended the retreat in Burton, TX, in February 2009 and participated in activities that encouraged critical thinking, leadership, physical activity, healthy decision making and communication. Along with NYLI and NHF staff, collaboration from medical staff of Gulf States Hemophilia and Thrombophilia Center, Youth Development Expert Pat Torrey and the staff at Camp-for-All ensured the success of the retreat. NHF conducted a pre- and post-test using the Perceived Competence of Functioning Inventory (PCFI). This is a statistically valid and reliable outcomes tool for measuring changes in self-efficacy, and our results recorded a significant increase in each measure of self-efficacy: motivational, relational, cognitive, affective and overall general level of functioning. NYLI members also attended NHF's Washington Days in February 2009 where they learned about the legislative process, state v. federal advocacy and how to effectively share their stories with legislators. NHF's Leadership Weekend also occurred in February 2009 and NYLI members attended this as well, learning peer-education techniques for physical activity and nutrition, and they participated in several of the joint sessions.
- NYLI members traveled to five bleeding disorders summer camps and facilitated Team Hemophilia, 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.
- Early in the fall of 2009 young women from NYLI facilitated the "Anyone Can Have A Bleeding Disorder" curriculum in local junior and high schools. Evaluations with knowledge gain are pending.



Women with Bleeding Disorders

For the past decade, the National Hemophilia Foundation has provided education and support to women with bleeding disorders. Through this initiative NHF, chapters, Hemophilia Treatment Centers and volunteers have worked tirelessly developing the Project Red Flag public awareness campaign to women affected by von Willebrand disease and other bleeding disorders. In 2009, the Project Red Flag program continued offering grants to chapters through funding by the Centers for Disease Control, CSL Behring and Grifols. Accomplishments for this program period include:

- PRF grants were awarded to 14 chapters, totaling \$110,000
- Site visits to chapters in Arizona, Indiana and Northern Ohio
- The Hemophilia Foundation of North Carolina collected data on the increase in women attending an HTC during the 2008/09 grant period. UN-HC reported 63 women in 2007 and 67 in 2008, indicating a 6.35% increase. East Carolina University reported 17 women in 2007 and 27 in 2008, a 58.82% increase.
- Several overall achievements were indicated by the 14 chapters involved in women with bleeding disorders programs. They include:
 - ♦ Providing materials and information to more than 1,000 attendees at nursing conferences in the 14 chapter areas
 - ♦ Brochures/newsletters disseminated to more than 10,000 individuals/families
 - ♦ Training 45 peer educators in 10 chapters who presented to 1,500 attendees
 - ♦ In 2009, 12 women with bleeding disorders attended Washington Days
 - ♦ Presentations to 500 youth on "Anyone Can Have a Bleeding Disorder"
 - ♦ Women's Health and Bleeding Disorders Initiative created in October 2009 consisting of three subcommittees: MASAC, Project Red Flag and Public Awareness
- Five articles in *HemAware* magazine in 2009
- NHF Web site includes link to Project Red Flag information and resources, with approximately 25,000 hits to the web page
- Project Red Flag materials were distributed at the 2009 Annual Meeting and Region XIII, IX and X meeting in Arizona

Do you have heavy periods?

If so, you might have a bleeding disorder.

What is a bleeding disorder?
It is a condition that keeps your blood from clotting properly after a cut or injury.

How can I tell if I have a bleeding disorder?
Only a doctor can tell for sure. However, if several of the statements below are true, you might have a bleeding disorder.

- My periods last 7 days or longer.
- During my periods, pads or tampons are soaked in 1 or 2 hours.
- I bruise easily.
- My gums bleed often.
- Bleeding takes a long time to stop after I give birth.
- Bleeding takes a long time to stop after I have dental work, surgery, or an injury.
- I have a family member with one or more of these symptoms.
- I have a family member with a bleeding disorder such as hemophilia or von Willebrand disease

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CDC

project red flag

lockphoto

In 2009, NHF made the commitment to expand the awareness program and incorporate it with a broader National Public Awareness Campaign. Now known as the Women's Health and Bleeding Disorders Initiative, the focus remains on expanding the program to more chapters and creating a public awareness campaign that reaches women not yet diagnosed with a bleeding disorder. To the existing task force of experts, NHF has added not only volunteers with expertise in women's health issues outside of bleeding disorders but also experts in marketing. In collaboration with the CDC, CSL Behring and Grifols, the institute will create a broad spectrum of education programs and key messages.

Chapter Services Department

Minority Populations

The NHF Multicultural Task Force attended the NHF Annual Meeting in 2008 to review and comment on new brochures for translation. In this program time period, NHF has translated Fast Facts, a summary of general information on bleeding disorders, von Willebrand disease, clotting disorders and NHF programs into two dialects of Chinese and Vietnamese. The task force also translated a nosebleeds brochure into Spanish. Currently, several other brochures are in the process of being translated into Spanish, including one on inhibitors, and several targeted to women: "Women with Bleeding Disorders: Facts You Should Know about Bleeding Disorders"; "Tips for Living with Bleeding Disorders"; Talking To Your Doctor about Bleeding Disorders"; and "Do You Have Heavy Periods?"

For NHF's 60th Annual Meeting, the 6th Annual Travel 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.

- Fifty-two individuals from 16 families were awarded travel grant 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. NHF will provide a six-month follow-up report from the awardees about their retention of information learned and their use of the information.

Physical Activity/Nutrition

The core activity for this objective is the Physical Activity and Nutrition Initiative partnered with the YMCA and CDC. We have developed program guidelines for chapters and local YMCAs to participate in a pilot physical activity/nutrition initiative and have identified 6 local chapters (collaborating with an HTC) to participate in the initiative. To date:

- 6 pilot chapters have begun programs
- 116 people 16 years old and older completed the pre-assessment
- 62 families have joined the program, totaling more than 226 people (including children under 16 years of age)

NHF will not have full evaluation data until the end of the program to be able to quantify the changes in sustained behavior or changes in overall health status. NHF has received much anecdotal information of weight loss, changes in amounts of factor needed due to weight changes, and improved overall health and joint stability.

In addition to this initiative, NHF conducted wellness education sessions at the 2008 Annual Meeting and planned wellness education sessions during the Team Hemophilia summer program to further encourage the importance of physical activity/nutrition for people with bleeding disorders. Team Hemophilia 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 2008 Annual Meeting, the session "Fighting Monk: Kung Fu for People with Bleeding Disorders" received an overall 97.22% rating out of 100. To take an active approach, NHF's Education staff teamed up with the Physical Therapy Working Group to host a "Fit n'

Run/Walk" for all conference attendees. The Annual Meeting Working Group met in January 2009 in San Francisco, to help plan wellness sessions for the Annual Meeting taking place in October 2009. Additionally, HANDI continues to disseminate brochures to promote awareness and increase knowledge of participating in physical activity.

Emergency Preparedness

This year we have worked with both our chapters and the NHF Disaster Preparedness Task Force (DPTF) to meet this objective. DPTF produced a Family Emergency Check List in English and Spanish that has been distributed widely, along with our NHF Readiness Cards and Go Bags. The checklist is a template for building a family emergency plan. NHF also conducted targeted sessions at the Spring Summit in Atlanta, GA. Separate sessions were conducted for chapter leadership, providers and consumers focused on pandemic flu.

Two pilot programs were started in local chapters. The Michigan chapter created emergency plans for all its off-site meetings, including its SpringFest and Summer Camp. Hemophilia of Michigan staff prepared evacuation plans for the meetings and coordinated off-site backup for their data and emergency contact numbers of all participants. Finally, they work closely with Gregory Thomas, an expert in Emergency Preparedness formerly from Columbia University's National Center for Disaster Preparedness, and a member of NHF's DPTF, to educate their camp staff and chapter staff on proper procedures. The Nebraska Chapter is also working with an expert in preparedness from our task force on conducting consumer education events throughout the state.

Finally, NHF has created and 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

Planning and content for the fourth year symposium came from concerns voiced at the 2008 conference: "We, as social workers, are armed with the information and resources, but how can we communicate this to our patients, taking into consideration diverse backgrounds and generational/cultural communication barriers?"

To address this and the various barriers the social workers face, we built our agenda and curriculum around effective communication strategies. Diane Zosky, PhD, ACSW, LCSW, our primary speaker, focused on the use of the Myers-Briggs Type Indicator as a tool for understanding the impact of personality type on communication. A panel representing generational and diverse backgrounds gave first-hand experience and stories from the Amish, Native American, Asian, and Latino communities and the young-adult transitional years. Finally, the group of social workers engaged in interactive break-outs of scenario problem-solving.

Other aspects of the meeting included an overview of current issues, with presentations by Glenn Mones, former VP of public policy at NHF; Beth Sufian, JD, Director of the Bleeding Disorders Legal Information Hotline; and Cheryl Fish-Parcham, Families, USA. A representative from NHF's resource library, HANDI, was available onsite to help participants customize their resource binders with state and content-specific material.

The meeting was held in Washington, DC, May 1-2, 2009. Forty individuals were trained on the Insurance/Reimbursement curriculum; 17 individuals were new to the Social Work training, i.e., had not attended year one, two or three.

Healthcare Reform

With a new administration come changes in policy focus. This year, reforming our broken health-care system is a top national priority issue of the new administration. To ensure that our chapters and members of the bleeding disorders community understand the issues being debated on Capitol Hill, NHF is working diligently to keep the community abreast of the issues and engaged in the debate. Examples of some of the health reform activities we have undertaken are: 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 eNews 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 increased efforts to provide more structured support to help chapters deal with Medicaid and other state advocacy issues. Two crucial issues facing the community are sole source contracts and preferred drug lists (PDL). As an example, earlier this year we collaborated with the Washington chapter and various stakeholder groups to defeat a measure that would have allowed the Washington Medicaid program to enter into a sole-source contract with a 340B provider for blood clotting factor therapies. Public policy staff facilitated a stakeholder grassroots call, explained the potential impact of the proposal on the community to chapter representatives and partnered with the chapter on a joint letter to lawmakers. We also assisted the chapter with preparing comments for meetings with lawmakers. Our collective efforts resulted in the proposal eventually being dropped and a new working relationship with key staff in the Medicaid Division. In a more recent example, we worked on letters to prevent the Medicaid Divisions in Nebraska and Georgia from adopting a PDL or, at the very least, ensure that the full range of products is included on any such list. We are continuing to monitor any developments in both of these instances.

We also worked on several other projects, including assisting the Hemophilia Association of the Capital Area (HACA) with comments aimed at opposing a DC bill that would have granted unlimited discretion to pharmacists by increasing their ability to substitute drugs, including factor products, for whichever product is cheapest in the therapeutic class. We continue to monitor this proposal which, if adopted, could likely serve as a model for other cities and states trying to curb rising prescription drug costs.

Bleeding Disorders Advisory Boards and Standards of Care

NHF continues to assist chapters and associations in their efforts to establish Bleeding Disorders Advisory Boards (BDAB) and Standards of Care (SOC) at the state level. The advisory board is an initiative that was spearheaded by NHF in collaboration with several industry partners. This year, chapters in Georgia, Ohio and Massachusetts each used our BDAB model legislation to develop similar bills in their state. In addition to providing feedback on draft legislation, NHF prepared letters of support for the advisory board bills in Ohio and Massachusetts. 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. We are working with the Alabama chapter to draft a standards of care bill that, when complete, will serve as model language that could be easily shared with other groups interested in pursuing standards of care.

"Awareness-Raising" Days

More NHF chapters and associations are planning 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 helped the NYS Hemophilia Advocacy Coalition organize its first advocacy training and hemophilia day in the state capitol. We also prepared the background materials and scheduled appointments for the NYC and Long Island participants. The event was a huge success, with roughly 60 participants and more than 40 appointments scheduled with members of the legislature or their staff. In addition, NHF organized separate meetings for key chapter and association representatives to meet and educate staff in the Department of Health and Division of Insurance on the needs of the community as it relates to Medicaid, Child Health Plus and Healthy New York. This effort created new opportunities for us (and the NY advocates) to forge a working relationship with key state policymakers.

Building Strategic Alliances and Partnerships

We made 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 2009 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 relationships we developed at this meeting have 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 May, we joined 22 other advocacy organizations in Albany, NY, for the Health Care for All New York Spring meeting and lobby day. In the weeks that followed we continued to encourage our NY members to contact their representatives, which resulted in the passage of several issues we supported. Two important proposals were adopted: 1) a bill to extend COBRA coverage from 18 to 36 months for workers who were laid off or had reduced hours and 2) a bill allowing young adults (ages 19-29) to obtain COBRA-like coverage through their parent's insurance.

Assistance to NHF Chapters and Other Organizations

Requests for our assistance have been on the rise for the last year, as more chapters and others continue to need help. This year, we supported those groups by participating in advocacy events and annual meetings, helping prepare background materials, and serving as a resource to organizers. For example, in addition to working with the NYS Hemophilia Coalition, NHF staff participated in lobby days in Virginia and Wisconsin. We also conducted advocacy trainings and provided updates on a range of advocacy issues in several states, including annual meetings of our New England and Louisiana chapters and HTC regional meetings in Arizona. We also had a unique opportunity to use our advocacy campaign portal to run a state-specific Web campaign for the Illinois chapter. We are working on refining that tool so that more chapters will be able to use our portal to run state-specific campaigns.



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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).