



**NATIONAL HEMOPHILIA FOUNDATION**  
*for all bleeding and clotting disorders*

## **Summary Report of the National Hemophilia Foundation's Accomplishments in 2008**

### **Introduction**

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 60<sup>th</sup> 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 48 community-based chapters nationwide; independent organizations of varying capacity. Along with about 15 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 2008 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 healthy 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.

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\* For purposes of this report, all chapters and independent associations are referred to as "chapters." Chapters pay membership dues to NHF, associations do not. Both work in collaboration with NHF. Membership in NHF is not required to receive NHF services and materials.

\* 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.

## **Education Department/HANDI**

Successful Information Forums—Mechanisms for disseminating bleeding disorders information and conducting education sessions: NHF has identified two successful information forums that help achieve the objectives delineated in this report: Annual Meeting and HANDI. Through outreach, education and networking at Annual Meeting and through the services offered by HANDI, NHF's information resource center, NHF reaches all subpopulations or life stages.

### **HANDI**

HANDI is NHF's information resource hotline and library for consumers (people with bleeding disorders), their families and healthcare providers who are seeking more information about bleeding and clotting disorders. Information specialists are available 40 hours a week, via an 800 phone line, and through e-mail. In 2008 they answered more than 2,220 requests in 33 subject areas, distributing approximately 12,000 publications that have addressed each of the subpopulations or life stages.

In collaboration with NHF's Education Department, HANDI exhibited bleeding disorders information at NHF's 10<sup>th</sup> Anniversary Women's Conference, the American College of Obstetricians and Gynecologists (ACOG) Clinical Meeting in May 2008 and the World Federation of Hemophilia's 28<sup>th</sup> World Congress in Turkey in June 2008.

HANDI also works with NHF's Education Department to update brochures for Project Red Flag (PRF), the women with bleeding disorders awareness campaign, and for the National Prevention Program. To accommodate a burgeoning Spanish audience, it created a Spanish translation of NHF's general fact sheet on bleeding disorders.

HANDI and NHF's Education Department have begun preparations to be available 24 hours a day, 7 days a week to ensure that information dissemination and referrals for vital resources are maintained for the bleeding disorders community in an emergency. Staff members in the Education and Communications Departments have been trained by HANDI staff on proper procedures and resources available in a disaster emergency. Certain requirements have been set up for these additional staff such as the length of a shift, the ability to have Internet and phone access, a USB drive containing essential referral information and laptop computers. Education and HANDI are currently working on developing protocols for gathering information, creating an emergency services e-mail and means for remotely accessing the NHF database.

### **NHF National Prevention Program (NPP)**

The National Prevention Program is NHF's primary education initiative collaborating with the Centers for Disease Control and Prevention (CDC), chapters, HTC's and consumers to help individuals make informed decisions to prevent or reduce the complications of bleeding disorders. NPP's theme is *Do the 5!*, five strategies for living a longer and healthier life. NHF conducts annual trainings, develops materials, and provides grants to chapters to get individuals to *Do the 5!* The campaign messages are featured prominently at the NHF Annual Meeting.

The *Do the 5!* messages are:

1. Get an annual comprehensive checkup at a hemophilia treatment center
2. Get vaccinated — Hepatitis A and B are preventable
3. Treat bleeds early and adequately
4. Exercise and maintain a healthy weight to protect your joints
5. Get tested regularly for blood-borne infections

### **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 ( $\pm$  60%); healthcare providers ( $\pm$ 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:***

In this report period, NHF conducted its Annual Meeting in November of 2007 in Orlando, Florida. Of the total 2762 attendees, 1,447 or 52% were consumers—with persons with bleeding disorders comprising 33% of consumer-attendees and family members/significant others 50%. Others in the consumer category describe themselves as “friends” or “supporters.”

Youth at the 59<sup>th</sup> Annual Meeting in Orlando, FL, totaled 413. This is typical for the location, which attracts the largest number of youth and children. Of these youth, 25 were the young adult members of the NHF National Youth Leadership Institute (NYLI), who receive training at the Annual Meeting.

Among consumers 75% report their race/ethnicity as Caucasian; 22% as a racial-ethnic minority: African-American (9%), Latino (8%), Asian (4%) and Native American (1%); 3% declare “other” or give no reply. Concerning specific bleeding disorders, the highest number of attendees is affected by hemophilia—613 reporting hemophilia as their personal/family disease; and 143 reporting von Willebrand disease (VWD).

The special character of the NHF meeting, bringing together the key, interacting constituencies in one location allows NHF to train and educate consumers (patients and families) simultaneously with their healthcare providers—delivering best practices and the same uniform, consistent messages across groups, and amplifying the efficacy and the learning impact.<sup>1</sup> HANDI staff disseminated more than 100 discrete resources and patient education materials throughout the Annual Meeting.

#### ***Education Sessions and the National Prevention Program (NPP) Messages:***

Education Sessions are the centerpiece of the NHF Annual Meeting. They extend and enhance the core prevention messages stressed in NHF’s National Prevention Program (NPP) and help reach underserved populations and women with bleeding disorders. Sessions at the Annual

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<sup>1</sup> Of almost 550 bleeding/clotting disorder healthcare providers: 35% were RNs, 19% MDs, 16% SWs and 8% PTs.

Meeting cover exercise and nutrition, proper treatment of bleeds; hepatitis and blood-borne infections; the value of HTC comprehensive care—all synchronizing with the *Do the 5!* prevention messages. And every annual meeting since 1998 has included sessions for women with bleeding disorders. Each of the education sessions is evaluated on a 4.0 scale, where 4 = excellent. Of the 43 Education Sessions offered to consumers (non-MD sessions) in 2007, 26 (60%) received scores equal or greater than 3.6. Examples of sessions with their ratings in 2007 include:

- ABCs of Bleeding Disorders (3.88)
- Building Resiliency (3.40)
- Hepatitis C: What You Need to Know (3.83)
- Evaluating Your Hepatitis C via Biopsy (3.46)
- Blood and Product Safety (3.41)
- Preparedness: A Refresher (3.87)
- NPP Chapter Grant Initiatives (3.79)
- Do the 5!—Fit Adults, Fit Kids (Lifestyles for a long and healthy life) (3.68)
- Workshop on VWD Basics: Women and Men (3.80)
- Managing and Living with VWD (3.50)
- Ask the Experts: Women (3.85)

NHF also recognized outstanding chapter programs with Awards of Distinction for health education, outreach and communications. Winning chapters received a \$1,000 incentive to enhance their program. NHF gave 16 Awards of Excellence to outstanding individuals in such areas as nursing, social work, research, physical therapy, genetic counseling, volunteering and advocacy. Physician and humanitarian of the year awards were also conferred.

### **Education in Thrombosis and Thrombophilia**

Education in thrombosis and thrombophilia has been developed by NHF specifically for the providers within the Hemophilia Treatment Center (HTC) network. For example, at the 59<sup>th</sup> Annual Meeting of NHF, sessions that were specialty-specific were conducted, i.e., for Nurses, Social Workers and Physicians.

In developing our provider sessions in the area of clotting, we work with the National Alliance for Thrombosis and Thrombophilia to acquire the top faculty and for the appropriate support materials.

Through HANDI, NHF's information resource center, an average of five requests are received per month, from both patients and providers in the area of clotting disorders. NHF disseminates state-of-the-art treatment articles and refers patients to both NATT and to HTCs in their local area.

### ***Annual Meeting Planning for 2008 – Denver, Colorado***

In January 2008, HTC, chapter and consumer representatives, CDC partners and NHF staff met in Denver, Colorado, to plan the education sessions for the 60<sup>th</sup> Annual Meeting November 13-15, 2008. Using recent literature as well as evaluations of prior meetings as guidelines, the Annual Meeting Working Group developed more than 40 education sessions for constituents and 15 medical education sessions.

### *Meeting the Needs of Patients and Families*

Parents of newly diagnosed children consistently report a high level of learning through Annual Meeting education sessions, both in evaluation grades and in their comments. "The sessions provide a good mix of technical information and everyday good advice," wrote one parent. The written feedback on evaluation forms also provides suggestions to improve education offerings. Concerning the Emergency Preparedness session in 2007, participants asked for a template to guide them in creating their own emergency plan and a more hands-on learning approach to the session. Our Annual Meeting planning team for 2008 incorporated these elements, including a table-top practice exercise, for the next Annual Meeting. The context of the NHF Annual Meeting as a teaching/learning environment offers the singular opportunity to tackle substantive, poignant topics and issues openly and thoroughly. For example, several comments on the "Managing and Living with VWD" session are captured in this participant's response: "I really appreciate the emphasis on problems and answers about life issues, (such as) intimacy and communication with your partner."

### **Objectives and Activities**

- *Newly diagnosed families, in 10 First Step-trained communities, will improve their knowledge, attitudes and behaviors concerning their bleeding disorder.*

NHF provides education, mentoring and social networking for parents/guardians and families with newly diagnosed children through its First Step Program. In this project period we have enhanced NHF's First Step program with new education modules and activities including sections on inhibitors, physical activity/nutrition and ethics in the bleeding disorders community; monitored the First Step discussion board and online web services; funded 7 chapters to conduct First Step programs;<sup>2</sup> conducted 2 mentor training sessions; convened the First Step Task Force for program and strategic planning; conducted education and networking sessions at our Annual Meeting in 2007; conducted focus groups to explore topics of interest to families of children up to age 12; and trained veteran parents to become mentor parents; and distributed more than 300 First Step brochures and welcome kits to families with newly diagnosed children.

As of May 2008, of the 7 funded chapters, 6 had completed their programs. These chapters conducted education sessions at local First Step meetings and parent dinners, hosted support and networking groups, trained veteran parents as mentors and coordinated social outings with educational components. Each chapter conducted at least 3 First Step meetings and, on average, approximately 20-25 parents attended an event<sup>2</sup> or meeting. According to pre- and post-tests distributed at the First Step meetings, knowledge, attitudes and behaviors related to the prevention messages increased by at least 10% among the families of newly diagnosed children.

In April 2008, 7 new First Step grants were awarded (including 3 chapters that had never had a previous First Step program). A workshop to guide chapters on implementing First Step (Refresher Course) will be conducted September 9, 2008.

- *Improve self-efficacy and leadership skills of youth and young adults who participate in NHF events*

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<sup>2</sup> Through a public-private partnership education grant

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. 25 NYLI members attended the Annual Meeting in November 2007, where they received leadership training in the following areas: presentation/public speaking skills, conflict of interest and marketing practices within the bleeding disorders community. NYLI also attended general education sessions on bleeding disorders to further their understanding of prevention behaviors. Several members presented their local project, which allow them to work with their local chapter. Some of the local projects included writing a children's book on bleeding disorders and siblings, preventive health education for youth attending summer camp, and creating a new camp for children with bleeding disorders in Mexico. Ninety-two percent (92%) of NYLI members in attendance found the sessions at Annual Meeting to be useful in helping them implement programs on the local level.

NYLI members also planned and implemented the first NHF Winter Youth Retreat., Forty-seven (47) teenagers from 26 states, Guam and Mexico attended the Youth Retreat at Camp-for-All in Burton, TX, in February 2008, and participated in activities that encouraged critical thinking, leadership and physical activity. Along with NYLI and NHF staff, collaboration from the medical staff of Gulf States Hemophilia and Thrombophilia Center, Youth Development Specialist Pat Torrey and the staff at Camp-for-All ensured the success of the retreat. The overall feedback from the retreat was positive. One camper said, "I learned new ways in which you can be a leader. I also learned that you don't have to be an expert at something to teach it to someone else."

Since the retreat, NHF has received many calls requesting further information about NYLI, how people can get involved and how younger youth, not yet old enough for NYLI, can get involved as well. Anne Henningfeld, Director, Camp Bold Eagle in Michigan, stated, "I have gotten calls now from kids out of state that attended the retreat and friends of those who attended the retreat asking to take part in our youth programs here. There has been a huge ripple effect from your retreat." One NYLI member chronicled his participation as a counselor at the Youth Retreat in the May/June 2008 issue of *HemAware*, NHF's bi-monthly magazine.

NYLI members attended NHF's Washington Days in March 2008, where they learned about the legislative process; how a bill becomes law, state vs. federal advocacy and how to share their stories with legislators. Additionally they sat in on a hearing on the Hill where Dr. Julie Gerberding, Director of the CDC, presented, "Health Issues and Opportunities."

In May, two women from NYLI and one alumnus facilitated "Things I wish my mother had told me..." a session at the NHF national women's conference., It provided young adults' perspective on living with a bleeding disorder for chapters, providers and consumers from across the country. The NYLI also takes advantage of opportunities that might arise where they can meet with and bring leadership training to youth in local chapters.<sup>3</sup>

- *Increase the knowledge of women's bleeding disorders and strategies for preventing*

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<sup>3</sup> NYLI took part in planning and implementing Team Hemophilia on Tour, a public awareness initiative with Andretti Green Racing and Bayer Healthcare. NYLI members boarded the tour bus and headed to different Indy Car Race sites during the summer, stopping at chapters and summer camps along the way to facilitate youth programs on leadership, self-efficacy and prevention education.

*secondary conditions, among national women's conference attendees*

At the NHF Annual Meeting in 2007 a pre-conference symposium for consumers, "Focus on von Willebrand disease (VWD)," was attended by 60 consumers and received an overall evaluation of 3.8 of a possible 4.0. Expert speakers included Roshni Kulkarni, MD; Andra James, MD; Thomas Abshire, MD, and Edward Kuebler, LMSW-ACP. The session, "Ask the Experts: Women," received an overall evaluation of 3.8 of a possible 4.0. Drs. Barbara Konkle and Andra James addressed hematologic as well as gynecologic concerns of women patients.

The Women with Bleeding Disorders Task Force and NHF staff planned a curriculum for a national women's conference<sup>4</sup>, May 16-17, 2008, in Durham, North Carolina, to address compelling issues for women in the bleeding disorders community and to mark the 10<sup>th</sup> anniversary of NHF's women's initiative – Project Red Flag (PRF). The conference focused on:

- reducing secondary complications for women with bleeding disorders and carriers
- reducing unnecessary medical procedures within the same population
- reducing obesity (within the same population)
- addressing areas of misinformation about bleeding disorders in women
- providing strategies to maximize the use of evidence-based medical guidelines published by the NHLBI on diagnosis and treatment of VWD
- addressing unmet needs identified by younger women with bleeding disorders

An expert faculty was recruited; approximately 150 people attended. Highlights of this 10<sup>th</sup> anniversary celebration along with an historical perspective on the success of Project Red Flag are presented in the May/June 2008 issue of *HemAware*.

In this project period, with CDC input, we have updated and redesigned all PRF brochures to reflect the NHLBI Guidelines on diagnosis and treatment of VWD. Two \$2500 Project Red Flag Scholarships have been awarded to women with bleeding disorders pursuing college degrees. Competitive applications were reviewed for best practice model programs at local organizations and 10 grants were awarded, totaling more than \$72,000. These grants provide much needed funds for local chapters to educate women and provide information on women's bleeding disorders. At ACOG in May 2008, Education and HANDI staff disseminated PRF materials and the NHLBI guidelines as well as hosted a symposium for 60 obstetricians and gynecologists, presented by Dr. Andra James (former chair of the Women with Bleeding Disorders Task Force), to raise awareness and improve the diagnosis and treatment of women with bleeding disorders.

- *Increase access to language-appropriate information and prevention strategies among minority populations*

The NHF Multicultural Task Force attended the NHF Annual Meeting in November 2007 to review and comment on the English version of NHF's "Fast Facts," summarizing general information on bleeding disorders, von Willebrand disease, clotting disorders and NHF programs. Three of the task force members translated the "Fast Facts" into Spanish for distribution to all federally funded HTC's and all chapters/associations. Translation of the Fast Facts sheets into Vietnamese began in September 2008.

For NHF's 59<sup>th</sup> Annual Meeting, the 5<sup>th</sup> Annual Travel Grant Program for first-time attendees

<sup>4</sup> Through public-private partnership education grant

was implemented. NHF provided assistance to individuals and/or families with bleeding disorders who would be unable to attend due to financial constraints and had never attended an NHF Annual Meeting. Forty-three individuals, from 12 families affected by bleeding disorders, were awarded travel grant scholarships to attend. The families represented predominantly Latinos, Asian/Pacific Islanders, African-Americans and a small number of Caucasians. Registration data show that this program increased by approximately 10% the number of minority families who have attended the Annual Meeting in 2007. The families were very appreciative of the opportunity to meet other families with bleeding disorders. NHF will provide a six-month follow-up report from the awardees about what they learned at Annual Meeting and their use of this information.

- ***Increase awareness and knowledge of the importance of physical activity/nutrition for preventing secondary conditions among attendees at NHF national meetings***

The core activity for this objective is the Physical Activity and Nutrition Initiative NHF partners with the YMCA and CDC. We have developed draft program guidelines for chapters and local YMCAs to participate in a pilot physical activity/nutrition initiative and identified 6 local chapters (collaborating with an HTC) to participate in the initiative. NHF has been organizing and planning for this initiative for the first 6 months of this agreement – solidifying YMCA relations, developing program materials and canvassing and identifying 6 pilot chapters and corresponding local YMCA branches. In addition to this initiative, NHF conducted wellness education sessions at the 2007 Annual Meeting and planned wellness education sessions at the May national women’s conference to further encourage the importance of physical activity/nutrition for people with bleeding disorders.

NHF has worked toward meeting its objective of increasing awareness and knowledge of physical activity/nutrition at NHF national meetings through educational and fitness sessions. At the 2007 Annual Meeting, “Doing the 5--Fit Adults, Fit Kids: Lifestyles for a Long and Healthy Life” was attended by more than 100 individuals and received a score of 92.3% 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 2008 in Denver, Colorado, to help plan wellness sessions for the 2008 Annual Meeting taking place in November 2008.

On May 17, 2008, at our national women’s conference we conducted a session on reducing obesity rates in women with bleeding disorders presented by our CDC partners. As the NHF/YMCA physical activity/nutrition initiative is in the planning phase, the creation and dissemination of educational materials has not yet taken place. In the meantime, HANDI continues to disseminate brochures to promote awareness and increase knowledge of participating in physical activity. Once the program officially begins, then we will be able to monitor the progress of individuals participating in it and measure intention to incorporate regular physical activity into their lifestyle in an ongoing manner, and adherence to regular physical activity for the project year as outcomes.

- ***Increase knowledge, attitude and behavior toward emergency preparedness among families with bleeding disorders in 5 local areas***

This year we have worked with both our chapters and the NHF Disaster Preparedness Task Force to meet this objective. As mentioned above, based on feedback we have received from



consumers at chapter preparedness meetings and at the NHF Annual Meeting, we have charged the Task Force with compiling a very detailed check list of preparedness activities for both consumers and chapters. This check list will act as a template for a preparedness plan ensuring that consumers and chapters have detailed instructions for how to prepare for possible emergencies in their areas. It was available at NHF's Annual Meeting in Denver, Colorado, rolled out in an interactive session run by the Task Force members and our CDC partner, so that those attending gained exposure to the type of questions that need to be answered to put their plans together.

At the NHF Annual Meeting in 2007 the session, *Preparedness: a Refresher*, was co-presented by Sally Owens of the CDC and Gregory Thomas, MS, then with Columbia University's National Center for Disaster Preparedness. The objective of this session was to lead families and individuals with bleeding disorders and chapter and HTC representatives through best practices in essential preparedness planning. (This session received an overall average rating of 3.87.) This education session complemented the information presented in the September/October 2007 issue of *HemAware* -- "Preparing for Disaster." This feature article included precautionary information for people with bleeding disorders and provided important links for additional emergency preparedness resources. And as stated, feedback from this session was integral to planning an interactive 2008 Annual Meeting preparedness training session.

We have also worked with chapters and are starting 3 pilot site programs in Preparedness. Specifically, the Nebraska Chapter of the NHF is working on patient education seminars throughout the state so that all their members have the important information they need in an emergency; Hemophilia Foundation of Michigan is developing preparedness plans for its off-site meetings and summer camping programs, and the Hemophilia Foundation of Hawaii chapter is working on an inter-island communication plan in case of a disaster. All pilot programs will receive a supply of NHF Emergency Go-Bags and emergency contact cards, or "NHF Readiness Cards," to distribute to their constituents.

As NHF and CDC have identified HANDI as the primary information center during an emergency in the community, NHF is currently implementing its 24/7 HANDI phone line and has trained the staff who will implement the plan.

- *Increase knowledge of HTC Social Workers on Insurance and Reimbursement Issues*  
Recognizing the central role of social workers in increasing the patients' and families' understanding of insurance coverage, NHF inaugurated a special training workshop for social workers on this important topic. In April 2008, NHF conducted its third Insurance/Reimbursement workshop, *Access to Insurance at Every Life Stage*, for 36 social workers from across the country. The one-and-a-half-day workshop received an overall rating of 3.9 on a 4.0 (4=Excellent) scale; continuing education units (CEUs) were provided for the participants. In the program's 3 years, NHF has trained a total of 111 social workers.

## **Research and Medical Information Department**

Awarded a Clinical Fellowship to:

- Mindy Grunzke, MD, University of Colorado at Denver and Health Science Center Mountain States Regional Hemophilia and Thrombosis Center

Awarded Career Development Awards to:

- Qizhen Shi, MD, PhD, Medical College of Wisconsin for her project, "Immune Response in Platelet-Derived FVIII Gene Therapy of Murine Hemophilia A."
- Alisa Wolberg, PhD, University of North Carolina at Chapel Hill, for her project, "Recombinant Factor VIIa and RL Platelets as a Hemophilia Therapy."

Awarded Judith Graham Pool Postdoctoral Research Fellowships to:

- Jyoti Mathur, PhD, Stanford University, for her project, "AAV Vectors for the Treatment of Hemophilia B."
- Ruijin Su, MD, PhD, Puget Sound Blood Center for her project, "Targeting Dendritic Cells to Induce Immune Tolerance to Factor VIII."
- Jun-Jiang Sun, MD, University of North Carolina at Chapel Hill, for his project, "Hemophilia Arthropathy: Gene Delivery Vectors for Determining Mechanisms and Therapy."

Awarded a Nursing Excellence Fellowship to:

- Judith Kauffman, RN, BSN, MS, CPNP, and Kacie Kaufman, RN, MSN, BC-APN, The Children's Mercy Hospital, Kansas City, MO, for their joint project, "The Effects of an Educational Intervention on Joint Health in Children with Hemophilia."

Awarded a Physical Therapy Excellence Fellowship to:

- Jenny Robison, PT, Vanderbilt University Medical Center, Nashville, TN, for her project, "The Effect of Inframalleolar Orthotics on Temporal Gait Characteristics and Foot Pressures in Children with Hemophilia."

Held in conjunction with Baxter BioScience the first meeting of all current and graduated NHF Clinical Fellows

Held NHF's 9<sup>th</sup> Novel Technologies and Gene Transfer for Hemophilia Workshop, February 22-23, 2008, at the Children's Hospital of Philadelphia

Exhibited NHF materials, answered questions and received requests for information at the American College of Obstetricians and Gynecologists Annual Meeting in New Orleans, LA, World Federation of Hemophilia Congress in Istanbul, Turkey, and the International Society on Thrombosis and Haemostasis Congress in Geneva, Switzerland.

Produced a new consumer publication, "Nosebleeds."

Through NHF's resource center, HANDI, specialists answered approximately 4,500 requests for information and distributed more than 30,000 publications.

In conjunction with volunteers, HANDI staff assisted in developing all educational tracks for the providers--physicians, nurses, social workers and physical therapists-- who attended NHF's Annual Meeting in Orlando, FL.

## **Public Policy Department**

In 2008, the highlight NHF's public policy work was the introduction of the Health Insurance Coverage Protection Act (S. 2706/H.R.6528), introduced by Senator Byron Dorgan (D-ND) and Representatives Anna Eshoo (CA), Betty Sutton (OH), Jason Altmire (PA) and James Langevin (RI) in the House. The legislation would ultimately set the minimum lifetime caps on private insurance plans at \$10 million with an annual inflationary index.

The Senate version of the legislation was introduced during NHF Washington Days 2008, an annual event where members of the bleeding and clotting disorders communities from across the country converge on the Hill to learn about key issues and meet with legislators and staff. This year's event attracted a record of more than 250 participants representing 40 states. Since its introduction, the bill has attracted the interest of many legislators as well as the media and a broad coalition of organizations representing healthcare consumers and industry. The original sponsors have agreed to reintroduce the legislation in the new Congress. NHF is now working with the rest of the coalition to commission a study from Price Waterhouse documenting the impact of lifetime caps and the potential impact of this legislation.

Also on the federal level, NHF is proud to have been part of the effort that led to the passage of the Genetic Information Nondiscrimination Act (GINA). In the bleeding disorders community, GINA is of particular importance to women who are interested in determining whether they are carriers of the gene for hemophilia but may have avoided testing in the past for fear of discrimination by insurers or employers.

Another important highlight was the establishment of pharmacy standards for hemophilia as outlined in NHF's Medical and Scientific Advisory Council's (MASAC) Recommendation #188, "MASAC Recommendations Regarding Standards of Service for Pharmacy Providers of Clotting Factor Concentrates for Home Use to Patients with Bleeding Disorders." This document recognizes the contribution of specialty pharmacy to the health and well-being of people with bleeding disorders. It furthermore establishes minimum standards that must be adhered to by pharmacies serving the bleeding disorders

population. Establishing such standards had become increasingly necessary as large specialty pharmacies lacking requisite experience on bleeding disorders began to enter the marketplace, in some cases as the recipient of sole or limited source contracts with large payers. NHF continues to work to promulgate these standards with pharmacies and payers. In addition, NHF is promoting these standards as a model initially for other groups dependent on specialty pharmacies for plasma-derived products and their recombinant analogues.

NHF has also worked closely with our chapters in a number of states around the country to respond to a variety of threats to access to high-quality care. These threats have included attempts by payers to reduce reimbursement rates for clotting factor, to limit access to products by means of restrictive formularies or preferred drug lists, or to establish sole source provider contracts. In almost every case, NHF has been successful in either completely preventing or at least mitigating the effects of these harmful actions. NHF is also working to minimize or prevent such actions through the establishment of legislative standards of care in the states or the establishment of bleeding disorders advisory boards to advise state governments on what is appropriate care for people with bleeding disorders.

## **Chapter Services Department**

Beginning in 2005, the NHF Board, Senior Management, and chapter leaders throughout the U.S. engaged in a collaborative process of exploring new structures and models for NHF, aimed at improving services to individuals with bleeding and clotting disorders nationwide.

The consensus was that NHF was not adequately structured to face present and future challenges. This effort culminated in a Chapter Development plan designed to create a more viable and sustainable chapter network in order to better serve NHF's owners (individuals and their families affected by bleeding and clotting disorders) throughout the country.

Options were provided to all chapters for how they will affiliate with NHF, and a set of Chapter Standards were developed to ensure a minimum level of program services, fundraising and operations throughout the chapter network. NHF established a new Chapter Services Department, with regional staff in place to help guide and assist chapters.

To fund the Chapter Development plan, the Campaign for Our Future was launched late in 2008. Proceeds from this effort will assist chapters with staffing and operational needs as they strive to meet Chapter Standards.