

**Summary Report
of the
National Hemophilia
Foundation's
Accomplishments**

2011



NATIONAL HEMOPHILIA FOUNDATION
www.hemophilia.org

The National Hemophilia Foundation is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. The programmatic activities and accomplishments in support of this mission conducted in FY 2011 are detailed here.

2011 Board of Directors

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Research and Medical Information

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 2011, HANDI answered 4,200 requests for information in a range of subject areas that included hemophilia, von Willebrand disease, carrier testing, school issues, sports and exercise, co-infection, research, psychosocial issues, blood safety and insurance. HANDI also distributed over 12,000 NHF educational publications to individuals, local chapters and HTCs.

Research and Medical Information Department

Awarded NHF/Baxter Clinical Fellowship to:

Ayesha Zia, MD

Dr. Zia earned a MBBS degree from King Edward Medical College, Pakistan. Following an internship in pediatrics at the Children's Hospital, University of Oklahoma Health Sciences Center, she completed her second and third years of pediatric residency at the Children's Hospital of Michigan, Wayne State University in Detroit. Since becoming a hematology/oncology fellow in 2009, Dr. Zia presented at the American Society of Hematology and has had five abstracts accepted for presentation at other major hematology meetings. Dr. Zia will continue her specialized training in pediatric hemostasis-thrombosis under the directorship of Dr. Jeanne Lusher. The NHF-Baxter Clinical Fellowship award will foster Dr. Zia's development as a clinical scientist, allowing her to study clinical research design, statistical analysis as well as pursue research concerning the thrombogenicity of hormonal supplementation in adolescent girls under the mentorship of Drs. Madhvi Rajpurkar and Michael Callaghan, a previous NHF-Baxter clinical fellowship recipient.

Awarded the Janet and Jim Glass Judith Graham Pool Postdoctoral Research Fellowships to:

Brian Ingram, PhD

The University of North Carolina at Chapel Hill

"Biochemical Characterization of Vitamin K Epoxide Reductase."

Dr. Ingram's research project will study Vitamin K, and specifically the role of the Vitamin K Epoxide Reductase (VKOR) enzyme as it relates to coagulation. Deficiencies in VKOR, although rare, can lead to bleeding. Since the gene for VKOR was only recently identified in 2004, the goal of Dr. Ingram's research will be to gain a better understanding of the enzyme's biochemical properties and function. This information could lead to the design and development of more effective therapeutics for blood disorders.

Research and Medical Information

Dr. Ingram earned his PhD in Biochemistry from Duke University and already has two first-author publications resulting from his PhD research. He has been a postdoctoral research fellow since 2010. He will pursue his research under the mentorship of Dr. Darrel Stafford, Professor of Biology and Pathology at UNC-Chapel Hill.

The Bill Riley, Jr. Judith Graham Pool Postdoctoral Research Fellowship was awarded to:

Yingyu Chen, PhD

The Blood Research Institute, Milwaukee, Wisconsin

“In vivo Selection of Hematopoietic Stem Cells that are Genetically-Modified to Express Platelet-FVIII for Hemophilia A Gene Therapy.”

The goal of Dr. Chen’s research is to examine a method for selectively expanding hematopoietic stem cells expressing the factor VIII transgene. She will also examine the immune consequences of this approach, based on the idea that gene transfer in platelets evades immune recognition. This research has the potential to elicit important clues to developing an approach for gene therapy of hemophilia A and hemophilia A with inhibitors.

Dr. Chen earned a PhD in hematology from Fujian Medical University in China. She already has more than 27 papers published in the Chinese medical literature. Her research in hemophilia and gene therapy will be under the mentorship of Dr. Qizhen Shi, MD, PhD, Associate Investigator at the Blood Research Institute and Assistant Professor of Pediatric Hematology at the Medical College of Wisconsin

Awarded a NHF/Novo Nordisk Career Development Award to:

Jordan A. Shavit, MD, PhD

University of Michigan, Ann Arbor, MI

“Identification of Chemical and Genetic Modifiers of Bleeding Disorders Using a Zebrafish Model System”

Dr. Shavit’s research project focuses on better understanding the genetic and molecular pathways that modify or regulate hemostasis through the use of a zebrafish model. Specifically, he will utilize zebrafish genetics to potentially identify the modifier genes that result in reduced or absent bleeding. This innovative proposal may lead to improved therapeutic approaches, especially with regard to screening or potentially tailoring treatments to specific patients. As the recipient of our 2011 NHF/Novo Nordisk Career Development Award, Dr. Shavit will receive support for up to three years.

Dr. Shavit received his undergraduate degree in cell and molecular biology from the University of Michigan and both his MD and PhD from Northwestern University. Prior to his appointment as an Assistant Professor of Pediatrics and Communicable Diseases at the University of Michigan in 2009, he spent four years as a postdoctoral research fellow at the University of Michigan under the mentorship of Dr. David Ginsburg. Dr. Shavit is also a former NHF-Baxter Clinical Fellow, having received the award in 2006-2008.

Awarded a Nursing Excellence Fellowship to:

Carolyn Solomon, RN and Linda Carlson, RN

Michigan State University, East Lansing, MI

“A Web-Based, Real Time Menstrual Tracking Tool”

Menstrual cycles for females with bleeding disorders can present special challenges not experienced by other girls and women, resulting in physical, social, and emotional exhaustion. A new Web-based application will be available for download to personal mobile devices or desktop computers. This application will enable the user to track how long their period lasts, how much she is bleeding, any interventions utilized and how it affects her daily life. The application will be free and will be available to all girls and women through their federally funded hemophilia treatment center (HTC).

Awarded a Physical Therapy Excellence Fellowship to:

Nancy Durben, PT, MSPT

Oregon Health & Science University, Portland, OR

“Gait Parameters of People with Hemophilia Compared to Normal Control Subjects”

Gait analysis provides valuable information on the effects of joint or muscle impairments and provides the basics for targeting intervention. Small changes that can be identified early following joint or muscle damage can be addressed more promptly to improve short and long term outcomes in people with bleeding disorders. This project aims to collect a large database of typical walking patterns of people with hemophilia and people without physical impairments across the life course.

People with hemophilia have walking patterns that affect the integrity of their joints. By comparing gait patterns of people with hemophilia to age matched subjects who do not have physical impairments we will see when changes occur in both groups and relate them to any bleeding history in the bleeding disorders group.

We will be collecting gait data using the GaitRite® evaluation system which is an electronic, sensor embedded walkway developed as a gait evaluation tool. It records detailed information about foot position, weight bearing forces and other gait parameters that are typically affected by loss of strength, loss of joint range of motion or joint disease. Subject will be recruited for the cording and storage of data into a gait repository. Subjects without physical impairment will be compared to subjects with hemophilia and data will be analyzed for differences in order to understand the challenges faced by people with bleeding disorders.

Research and Medical Information

Awarded a Social Work Excellence Fellowship to:

Ellen Kachalsky, MSW, LMSW and Karen Allen, PhD, LMSW

Henry Ford Health System, Detroit, MI and Oakland University, Rochester, MI

“Resilience and Quality of Life in Individuals Aging with Hemophilia”

Individuals with hemophilia are living longer than previously expected because of advances in treatment, including the development of clotting factor replacement. However, we do not understand the psychological and emotional impact of aging with hemophilia, how this affects quality of life, and how resilience and healthy coping skills are developed and maintained. For example, we do not know if individuals with hemophilia: (a) retire early because of having a disability, although this may be a reasonable assumption; (b) if they are financially secure; and (c) how much joint damage impacts the ability to move, walk and perform everyday activities. We also do not know what special challenges arise from aging with hemophilia, and if this leads to more divorces, an increase in living alone, and a greater need for help to remain independent. There is little research showing which traits help persons with hemophilia continue to mature, and keep an emotional balance while dealing with a lifelong, chronic condition and how all these traits improve or reduce quality of life.

To answer some of these questions, we are planning a study to gather information from individuals with hemophilia about their experiences of aging with hemophilia. Our study will have three parts, including two standardized questionnaires which measure quality of life and one we have developed. The survey will be available online, to collect answers anonymously from people with hemophilia who are seen in the hemophilia treatment centers. There will be a paper version with pre-paid return envelopes provided to ensure anonymity. We will ask about work or disability, source of income, marital status, severity of hemophilia and ability to perform everyday activities. We will also ask about pain levels and pain management. We will then analyze the collected data and information and present a description of our findings.

Our theory is that age, the severity of the bleeding disorder and pain affect quality of life, but that other factors, such as social support, financial security, and faith or spirituality can help improve quality of life. As a result of this study, we hope to identify some of these positive and protective factors so that social workers may promote these strategies with patients to help improve their quality of life.

MASAC

NHF's Medical and Scientific Advisory Council (MASAC) held two meetings, May 1, 2011, and November 12, 2011, 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 2011:

MASAC Document #203

MASAC Recommendations for Treatment of Chronic HCV Infection in Individuals with Hemophilia and other Rare Bleeding Disorders

MASAC Document #204

MASAC Recommendations Regarding Physical Therapy Guidelines in Patients with Bleeding Disorders

MASAC Document #206

MASAC Recommendations Regarding Rare Coagulation Factor Disorders

MASAC Document #207

MASAC Recommendations Regarding Non-sterile Alcohol Prep Pads

Chapter Services

Chapter Development

NHF continued the implementation of its Chapter Development plan in 2011, with the expansion of the Chapter Services Department that now includes three field staff to guide and assist chapters. Collaboration between NHF and its 49 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 inclusion of the Education and Public Policy components. NHF's ACT initiative—*Access to Care Today, Achieving Cures for Tomorrow*—was rolled out initially to those chapters receiving Capacity-Building Grants, now numbering nine chapters across the country. Additional support was provided through three Regional Leadership Seminars that brought new training opportunities to staff and volunteer chapter leaders.

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 was finalized as of July 1, 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 2011 was the launch of the *Steps for Living* life stage education program developed in collaboration with Pfizer Hemophilia and the Centers for Disease Control and Prevention (CDC). 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. *Steps for Living* is composed of three sections: First Step (birth to 8 years), Next Step (9-15 years old), and Step Up (15-25 years old). First Step focuses on the basics of bleeding disorders, negotiating parent/provider relationship and childcare issues. Next Step provides information about working with schools; gaining independent at home; and healthy decision making. Step Up covers such topics as disclosure, dating, career choices and independence. The site utilizes interactive components such as videos, quizzes, and social media.

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:

- Twenty four NYLI members attended Annual Meeting in 2011, 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 groups and tasked with creating "health education flashmobs" to increase awareness about bleeding disorders. The videos were placed on YouTube and members shared the link with meeting attendees and through social media. There were over 1,000 views of the videos. 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: facilitating sessions on physical activity and nutrition at chapter events, providing peer-to-peer health education at summer camps, fundraising for local chapters, starting clubs for people with bleeding disorders at their university, and initiating a training in state advocacy for 8-12 year olds.
- NYLI members attended NHF's Washington Days in February 2011, 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.
- NYLI members traveled to two 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 in knowledge of participants.

Chapter Services

Women with Bleeding Disorders

The National Hemophilia Foundation has been committed to assisting women with bleeding disorders for more than 15 years. Victory for Women (V4W), NHF's current health initiative for girls and women with bleeding disorders, was built on the excellent foundation laid by Project Red Flag, the first NHF program to focus attention and raise awareness about females with von Willebrand disease. 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 – December 2011 include:

- Supporting the work of chapters by facilitating workshops at ten chapter events on topics relevant to women with bleeding disorders
- As part of a 5-year cooperative agreement with the Centers for Disease Control and Prevention (CDC), piloting a wellness program developed by a researcher at Stanford University, the Chronic Disease Self-Management Program, through an online version and in-person group sessions. Over 30 women went through the six-week program and reported positive outcomes, including increased physical activity, using stress reduction strategies and reporting more confidence with interactions with healthcare providers.
- Awarded two academic scholarships to women with bleeding disorders to support their continued effort to finish their degrees at institutes of higher education.
- Awarded 10 grants to NHF-affiliated chapters to support activities and programs for girls and women with bleeding disorders. Four of the grants provide resources to develop educational modules collaboratively with women in the community that can be replicated by other chapters around the country. Other grants propose activities such as community outreach to women who are symptomatic but not yet diagnosed, and on-time events such as a mother-daughter retreat.
- Attended three chapter regional trainings to provide an update on the current V4W projects, and receive feedback on the development of programmatic standards for chapters' efforts working with women and girls with bleeding disorders.
- Organized and facilitated four sessions at NHF's Annual Meeting in Chicago, Illinois on topics relevant to women and girls with bleeding disorders: hemophilia carrier status, sexuality and intimacy, updates on state of the art treatment for women with bleeding disorders, and aging and preventative care.
- Staffed tables at three professional health conferences to educate others about women and bleeding disorders. Conferences were for school health nurses, college health professionals and healthcare professionals in the field of reproductive care.

Minority Populations

In October 2011, the NHF Cultural Diversity Working Group worked with NHF to develop an English/Spanish coloring book titled *My HTC and Me/Mi CTH y Yo* for children with bleeding disorders. The bilingual coloring book introduces children to the various staff they will meet at their annual HTC comprehensive clinic visit. Initially 20 coloring books were distributed to each of the NHF chapter organizations (49) and HTCs (144). Over 200 coloring books were distributed at Annual Meeting and through requests.

The NHF Cultural Diversity Working Group attended the NHF Annual Meeting in 2011 to help with the development of NHF's *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.

At the 63rd Annual meeting, there were two sessions in Spanish, "Preguntando a los Expertos" and "¿Me Oyes Ahora? Como Comunicarse con Su Centro de Emergencia, al Equipo del Centro de Tratamiento y los Proveedores de sus Seguros Médicos Acerca de su Cuidado de Cuidado." There was a new session "Religious and Cultural Impacts on Treating a Chronic Illness" that explored the culture and different spiritual belief systems can impact healthcare decisions.

The 9th 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. Seventy four individuals from 25 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 the importance of exercise and fitness for long term health and mobility. To try to find fun ways to get fit as a family.
- I learned that as a mom who is guilty of being over protective it was helpful to think of him achieving new skills at camp. Hearing how the brain ties into "NomaDear" protecting was interesting.

Chapter Services

Physical Activity/Nutrition

NHF conducted wellness education sessions at the 2011 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.

NHF has worked toward our objective of increasing awareness and knowledge of physical activity/nutrition at NHF national meetings. At the 2011 Annual Meeting, a session entitled “I Only Get 30 Minutes of Screen Time? The Pros and Cons of Exergaming” discussed the pros and cons of exergaming for cardiovascular and physical health, the risks and benefits of exergaming for people with bleeding and clotting disorders, and other potential outcomes of exergaming including socio-emotional and cognitive effects. Another session, “Building a Better Body”, was led by a registered dietician, physical therapist, and a consumer and discussed the benefits of healthy eating and exercise for eliminating extra weight and strengthening your body. 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 were covered in depth on the new *Steps for Living* Web site: www.stepsforliving.hemophilia.org. One of the most popular pages on the site was a section called “Maintaining a Healthy Body” which provides information on nutrition and engaging in safe physical activity.

Emergency Preparedness

In 2011, 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

The goal of the Reimbursement Workshop is to empower patients and families to secure and retain appropriate healthcare insurance coverage throughout the life span.

NHF has conducted a successful Reimbursement Workshop over the past several years, specifically for social workers, given that they are often the very first information source for many new families and, therefore, the first line of defense on health insurance coverage, prescription benefits, disability insurance, Medicare and Medicaid for these two communities of patients. In 2011, NHF expanded this conference to include key chapter advocates experienced in insurance reimbursement and advocacy. Together the social worker and the chapter educate new parents and young adults transitioning to self-management and about the importance of identifying and obtaining sustainable health insurance coverage. And, serve as a critical source of essential counseling during life crises that may result in the loss or reduction of health coverage, such as divorce, death of a spouse, loss of employment or aging out of a parent's plan. The Patient Protection and Affordable Care Act was passed in 2010 in an effort to try to address the healthcare crisis in the United States. Changes in both the private and public payer arenas brought about by PPACA made the need for continued reimbursement training critical for those providing assistance to our particularly vulnerable population.

The 2011 Workshop was held April 8-9 in Chicago, Illinois and was attended by 48 social workers and seven chapter advocates. Topics included emerging trends in the private and public payer arenas, the impact of health reform on those with bleeding disorders, and the relationship between local chapters and hemophilia treatment centers. Presentations were delivered by experts in the field of health reform, reimbursement and private insurance.

Chapter Services

Healthcare Reform

Since the passage of the Affordable Care Act (ACA) on March 23, 2010, NHF has worked to ensure that our chapters and members of the bleeding disorders community are educated about the law and its potential impact on their care and their families. Examples of our education initiatives included 1) the delivery of presentations to community members at more than 15 chapter education programs; 2) participation in various federal and state town hall meetings and listening sessions, 3) the submission of comment letters relative to federal regulations; 4) preparation of regular updates to our chapters and the community at large through NHF's eNotes and Chapter Update.

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

2011 saw an increase in state “legislative day” events hosted by NHF chapters and associations in their capitols designed to educate legislators on bleeding disorders and the health care needs of those affected. State legislative day programs also include a training component geared towards educating consumers on the role of the community in advocacy and providing tips on how to become an effective advocate. Many continue to cite NHF’s Washington Days and other NHF programs as important models for these programs. The NHF state advocacy team is often asked to participate in these events and to assist with the training portion of the program as well as the drafting of key talking points. 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

NHF continues to make significant strides in elevating the needs of the community on the national health agenda through strategic partnerships and alliances with industry stakeholders and other health care advocates. One again, public policy staff attended the Families USA Health Action conference to ensure other advocates were aware of issues impacting those with bleeding disorders. We continue to be a recognized leader within the American Plasma Users Coalition (A-PLUS). We hosted a second webinar series in collaboration with the P&T Society and MedSpan Research designed to educate managed care executives about the management of hemophilia. As a result of the webinars, dialogue has been developed between state team members and the various insurance providers.

Assistance to NHF Chapters and Other Organizations

NHF’s state advocacy team increased their efforts to provide more structured support to help chapters deal with Medicaid and other state advocacy issues, such as the movement from traditional fee for service to managed care within many state Medicaid programs. Team members regularly monitored changes in both the private and public health arenas to ensure that the needs of those with bleeding disorders were preserved. In addition the state monitored and participated in conversations relative to key ACA initiatives at the state level, including the choice of state benchmark plans and the development of health insurance exchanges.

Due to an increase in the requests for assistance in the area of state advocacy, NHF increased the size of their staff to include an intern whose responsibility was to assist with research and the development of tools intended to help chapters and community advocates with their local advocacy efforts. In addition to tools designed to assist chapter leaders, the state advocacy team developed the Personal Health Insurance Toolkit a tool to assist consumers in better understanding of insurance in general as well as how to evaluate their health plan options. Hands on workshops were offered at chapter education programs and the NHF Annual Meeting.

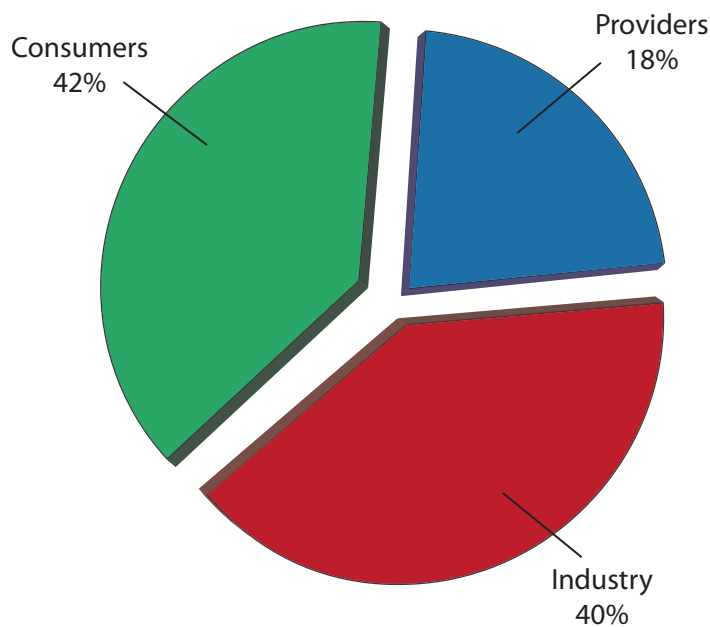
Annual Meeting

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 42%); healthcare providers (\pm 18%) 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:
2011 Annual Meeting held in Chicago, IL**

2011 Annual Meeting Attendees
N=2,685



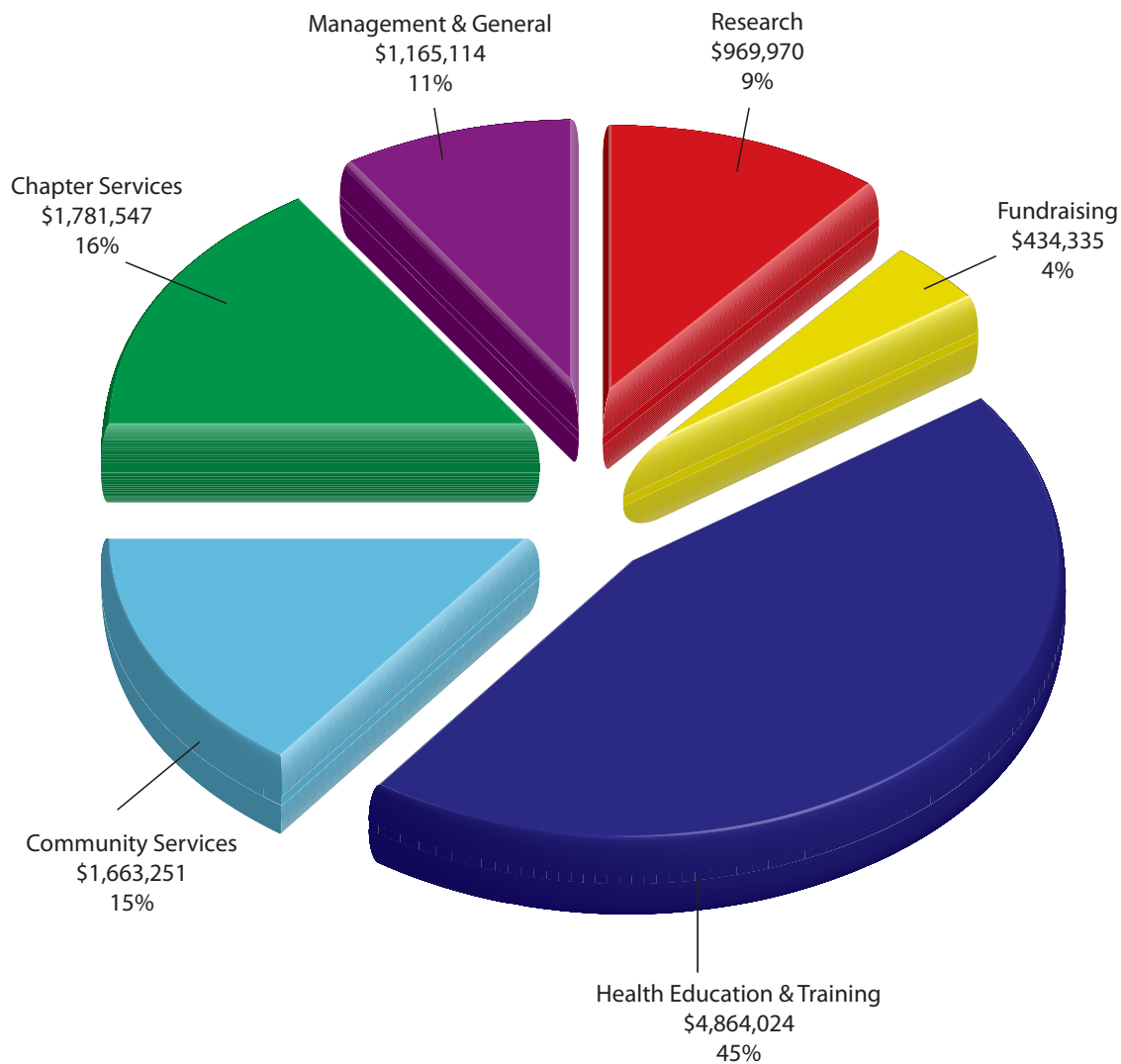
Session Evaluations

Track	Number of Sessions	Average Out of 4	Average Out of 100
Overall	68	3.68	92%
Chapter	10	3.57	89.3%
Consumer	33	3.70	92.5%
RN	11	3.69	92.2%
PT	9	3.74	93.5%
SW	9	3.63	90.7%

Audited 2011 Income and Expenses

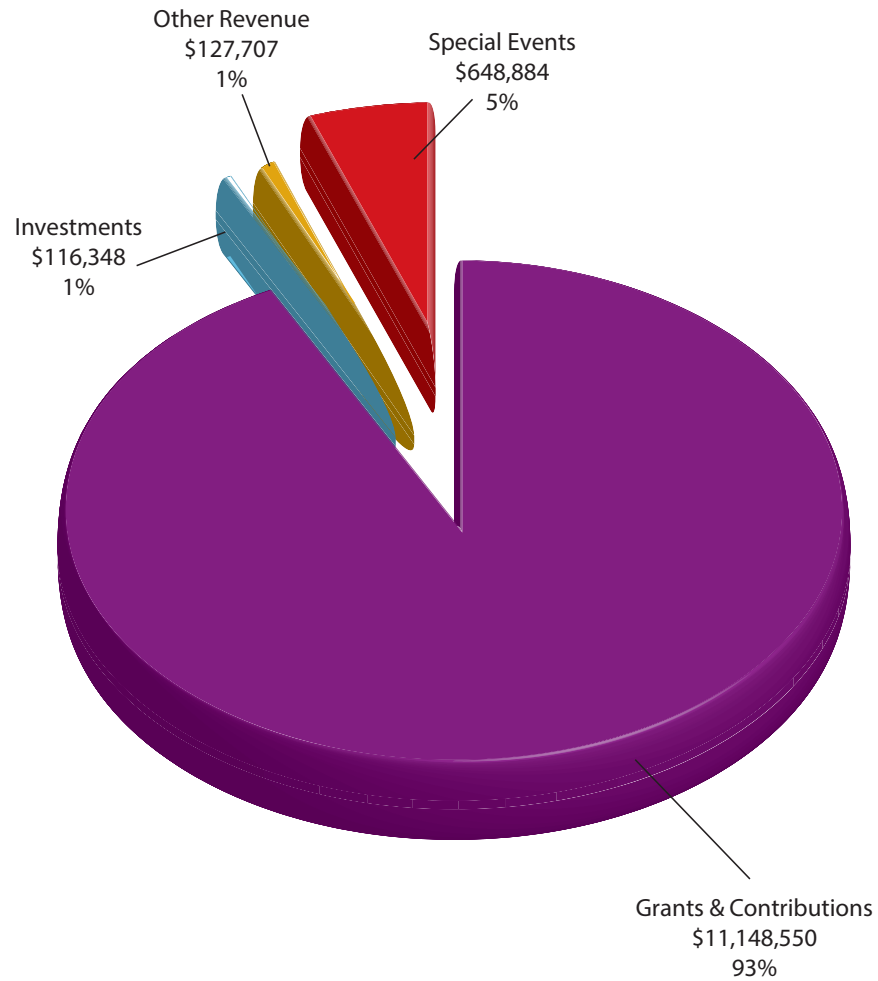
The complete financial statements, from which this financial summary is derived, have been determined to present fairly, in all material respects, the financial position of the National Hemophilia Foundation as of December 31, 2011, in conformity with generally accepted accounting principles. A complete set of audited financial statements for the year ended December 31, 2011 and the 990 are available online at www.hemophilia.org.

Expenses



The ending net assets for 2011 was \$7,206,535.

Revenue



2011 Major Contributors

\$2,000,001 to \$3,000,000

Novo Nordisk

\$1,000,000 to \$2,000,000

Pfizer
Baxter Healthcare Corp

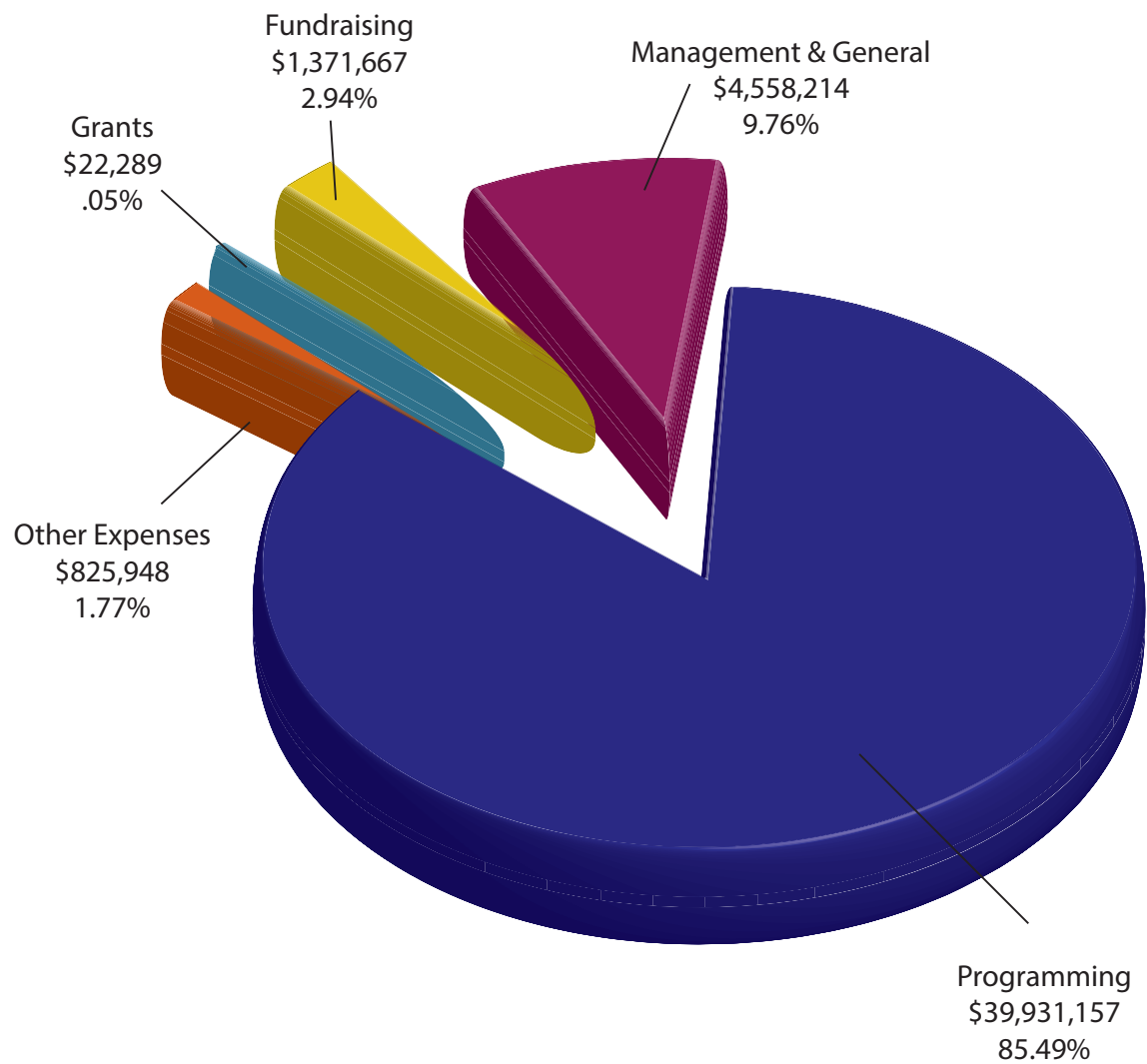
\$300,000 to \$999,000

Grifols
Biogen Idec
Bayer Corporation
CSL Behring, LLC

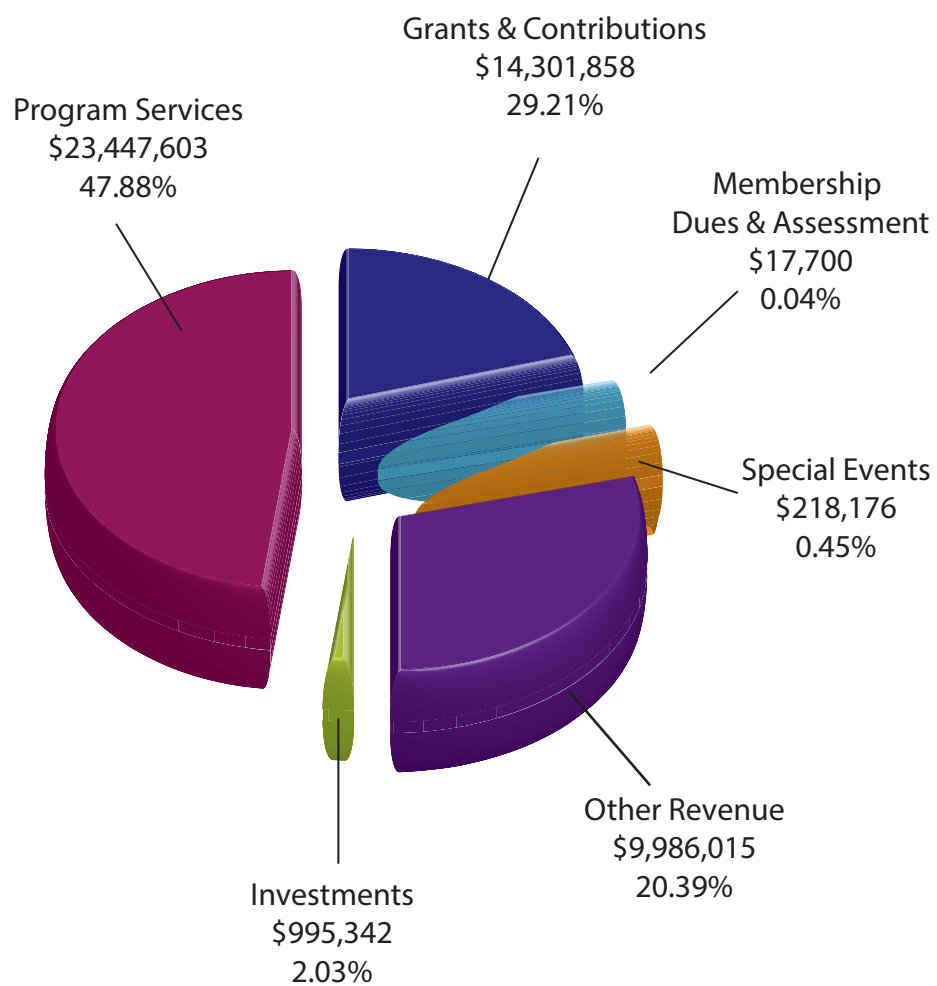
Centers for Disease Control and Prevention (CDC)

NHF & National Network of Chapters

Expenses



Revenue



NHF used 990 forms to produce this information.

14 chapters used the 990 short form. (1 was recorded in 2008, 3 in 2010 and 10 in 2011.)

31 chapters use the regular 990 form. (5 were recorded in 2010 and 26 were recorded in 2011.)

There are 4 chapters that did not fill a 990.

NHF & National Network of Chapters

Period ending December 31, 2011

Hemophilia & Bleeding Disorders of Alabama- Montgomery, AL

Arizona Hemophilia Association- Phoenix, AZ

Hemophilia Foundation of Southern California- Hollywood, CA

Hemophilia Foundation of Northern California- Emeryville, CA

Central California Hemophilia Foundation- Sacramento, CA

Hemophilia Association of San Diego County- San Diego, CA

Colorado Chapter, National Hemophilia Foundation- Edgewater, CO

Hemophilia Foundation of Greater Florida- Winter Park, FL

Florida Hemophilia Association- Palmetto Bay, FL

Hemophilia of Georgia- Atlanta, GA

Hawaii Hemophilia Foundation- Kaneohe, HI

Idaho Chapter, National Hemophilia Foundation- Boise, ID

Bleeding Disorders Alliance Illinois- Chicago, IL

Hemophilia of Indiana- Indianapolis, IN

Hemophilia of Iowa- Cedar Rapids, IA

Kentucky Hemophilia Foundation- Louisville, KY

Louisiana Hemophilia Foundation- Baton Rouge, LA

Hemophilia Foundation of Maryland- Parkville, Maryland

New England Hemophilia Association- Dedham, MA

Hemophilia Foundation of Michigan- Ypsilanti, MI

Hemophilia Foundation of Minnesota and the Dakotas- Mendota Heights, MN

Midwest Hemophilia Association- Leawood, KS

Rocky Mountain Hemophilia and Bleeding Disorders Association- Bozeman, MT

Nebraska Chapter, National Hemophilia Foundation- Lincoln, NE

Nevada Chapter, National Hemophilia Foundation- Las Vegas, NV
Sangre de Oro, Hemophilia Foundation of New Mexico- Albuquerque, NM
Mary M. Gooley Hemophilia Center- Rochester, NY
Hemophilia Center of Western New York- Buffalo, NY
Bleeding Disorders Association of Northeastern New York- Rensselaer, NY
New York City Hemophilia Chapter- New York, NY
Hemophilia of North Carolina- Morrisville, NC
Southwestern Ohio Hemophilia Foundation- Moraine, OH
Northern Ohio Hemophilia Foundation- Cleveland, OH
Tri-State Bleeding Disorder Foundation- Cleveland, OH
Central Ohio Chapter, National Hemophilia Foundation- Columbus, OH
Northwest Ohio Hemophilia Foundation- Toledo, OH
Oklahoma Hemophilia Foundation- Oklahoma City, OK
Hemophilia Foundation of Oregon- Portland, OR
Delaware Valley Chapter of NHF- Lansdale, PA
Western Pennsylvania Chapter of NHF- Cranberry Twp., PA
Hemophilia of South Carolina- Sumter, SC
Tennessee Hemophilia and Bleeding Disorders Foundation- Murfreesboro, TN
Texas Central Hemophilia Association- Dallas, TX
Lone Star Chapter of NHF- Houston, TX
Utah Hemophilia Foundation- Salt Lake City, UT
Virginia Hemophilia Foundation- Midlothian, VA
Hemophilia Association of the Capital Area- Fairfax, VA
Bleeding Disorders Foundation of Washington- Edmonds, WA
Great Lakes Hemophilia Foundation- Milwaukee, WI



NATIONAL HEMOPHILIA FOUNDATION

www.hemophilia.org

116 West 32nd Street • 11th floor • New York, NY • 10001
www.hemophilia.org • info@hemophilia.org

The National Hemophilia Foundation is dedicated to finding better treatments and cures for inheritable bleeding 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).