

**Annual Report  
of the  
National  
Hemophilia  
Foundation**

**2012**



**NATIONAL HEMOPHILIA FOUNDATION**  
[www.hemophilia.org](http://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 as follows:

### **2013 Board of Directors**

Kenneth Trader-Chair of Board  
Shannon Penberthy- Vice Chair of Board  
Steve Helm- Secretary of Board  
Jorge de la Riva- Treasurer  
Stephen Bender  
Jill R. Birdwhistell, PhD  
Eileen Bostwick, PhD  
Barbara Gordon  
Keith Moore  
Danielle Nance, MD  
Dutta Satadip  
Carol Simonetti  
Dave Sternberg  
Gilbert C. White, II, MD  
Adam Wilmers

# 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 five days a week via an 800 phone line, through email and fax. In 2012, HANDI answered 4,350 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 11,000 NHF educational publications to individuals, local chapters and HTCs.

## Research and Medical Information Department

Awarded NHF/Baxter Clinical Fellowship to:

### **Jonathan Roberts, MD**

*Medical College of Wisconsin and the Children's Hospital of Wisconsin*

Dr. Jonathan Roberts is currently a pediatric hematology and oncology fellow with the Medical College of Wisconsin and the Children's Hospital of Wisconsin. His fellowship mentor will be Joan Gill, MD, Professor of Pediatrics at the Medical College of Wisconsin and Director of the Comprehensive Center for Bleeding Disorders (CCBD) at the BloodCenter of Wisconsin. Roberts graduated with honors from Greenville College, Illinois, and received his MD from Southern Illinois University School of Medicine. He did his residency in Pediatrics at the University of Illinois at Peoria and Children's Hospital of Illinois, where he also distinguished himself, receiving awards of excellence for critical care and research. During his pediatric residency, Roberts worked with Dr. Michael Tarantino to initiate a clinical research trial to assess the role of FXIII on intraventricular hemorrhage in premature, low birth weight infants. As a NHF-Baxter Clinical Fellow, Roberts will receive focused training and gain clinical experience through the hemostasis clinics at CCBD and further develop his research skills in a project to develop a new ELISA-based assay for assigning VWF phenotype. Roberts has plans to pursue a Master's Degree in Clinical and Translational Science. His goal is to become an expert physician/scientist with a long-term career focus on hemophilia, and other bleeding and clotting disorders.

### **TammueLLa Chrisentery-Singleton, MD**

*Tulane University School of Medicine*

Dr. TammueLLa Chrisentery-Singleton is an Assistant Professor of Clinical Pediatrics at Tulane University and is board certified in pediatric hematology/oncology. She will receive training under the mentorship of Cindy Leissing, MD, Chief, Section of Hematology & Medical Oncology at Tulane University School of Medicine and Director of the Louisiana Center for Bleeding and Clotting Disorders. Chrisentery-Singleton graduated with honors from Xavier University, received her MD from Louisiana State University and then completed her pediatric residency at the University of Miami. Following residency, she completed pediatric hematology/oncology fellowship training at Johns Hopkins University, where she worked with Dr. Jim Cassella and developed a serious interest in disorders of coagulation, particularly hemophilia. After her fellowship training, she was recruited to join the pediatric hematology/oncology faculty at LSU and Children's Hospital of New Orleans. In 2010, Chrisentery-Singleton accepted a position at Tulane University because of her desire to receive more training and spend more time in the specialized coagulation medicine program. As an NHF-Baxter Clinical Fellow, she will receive dedicated training in bleeding and clotting disorders for both children and adult patients, along with mentoring in clinical research related to bleeding disorders. She will also continue her work on several ongoing clinical trials, and pursue her project in developing models to better determine pharmacokinetic parameters with a minimal number of needle sticks in pediatric patients with hemophilia. Her goals are to steadily improve her knowledge and skills in caring for patients with coagulation disorders, and continue building her academic career in coagulation medicine.

# Research and Medical Information

Awarded a Physical Therapy Excellence Fellowship to:

## **Lorraine Flaherty, PT**

*Puget Sound Blood Center, Seattle, WA*

“Identifying fall risk in patients with hemophilia”

This project will examine risk of falling in people with hemophilia. People with hemophilia may be at increased risk for falls due to chronic joint pain and stiffness. As people with hemophilia age they will share the increased risk of falling that comes with aging in the general population. Some studies suggest that people with hemophilia may have an increased risk of falling before they come elderly due to joint damage. In this study we plan to identify a screening tool that can be used during the comprehensive annual assessment. This will allow us to target further evaluation and intervention for people with hemophilia who are at an increased risk of falling. This will improve quality of life for our patients, allowing them to avoid pain and injury and stay independent and active in their communities as they age.

## **MASAC**

NHF’s Medical and Scientific Advisory Council (MASAC) held two meetings, May 6, 2012, and November 10, 2012, 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 2012:

MASAC Recommendation #208

MASAC Recommendation on Orphan Drugs

MASAC Recommendation #209

MASAC Statement on Biosimilars

MASAC Recommendation #211

MASAC Recommendations Regarding Inhibitor Risk and Recombinant Factor VIII Concentrates

MASAC Recommendation #212

MASAC Document Regarding Risks of Gene Therapy Trials for Hemophilia

MASAC Recommendation #213

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

MASAC Recommendation #214

MASAC Recommendations on the NHF Genotyping Project for Persons with Hemophilia



# Chapter Services

## Chapter Development

NHF continued the implementation of its Chapter Development plan in 2012, with the expansion of the Chapter Services Department that now includes three field staff to guide and assist chapters. Collaboration between NHF and its 51 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 sixteen chapters across the country. Additional support was provided through three Regional Leadership Seminars and a full Chapter Track at NHF's Annual Meeting that brought new training opportunities to staff and volunteer chapter leaders.

## Education

In 2012, the National Hemophilia Foundation continued to build *Steps for Living*, a 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), *Step Up* (15-25 years old), and *Step Out* (26 and older). *First Step* focuses on the basics of bleeding disorders, negotiating parent/provider relationships 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. *Step Out* was launched in 2012 and provides information for adults living with a bleeding disorder including financial health, end of life planning, reproductive health, workplace issues, and living arrangements. NHF created four videos for parents and a game for children called "Are you Up on the facts" to increase knowledge about self infusion.

NHF also created two new programs for chapters. The Steps for Living Training for NHF's chapters and hemophilia treatment centers is an extension of the First Step Train the Trainer developed in 2005. The training manual includes newly developed curriculum based on the Steps for Living website including Next Step (9-15) and Step Up (16-25). Topics include, but are not limited to, sibling issues, anti bullying, career development for teens, college planning, puberty, and disclosure. There are lessons for parents and children, the goal is to train families on the same content so when they return home they can continue the conversation. The activities will help health professionals in the bleeding disorders to better

discuss and address these important issues.

Another new print material is *Guidelines for Growing*, a series of age-specific brochures (targeting ages 0-4, 5-8, 9-12, 13-15, and 16-18) adapted from the NHF's Medical and Scientific Advisory Council (MASAC). Each brochure focuses on social and developmental milestones specific to the general age range of a child or young person with a bleeding disorder. This resource is designed to be used in conjunction with the HTC provider team to guide the parent or young person through transitional periods. These brochures were distributed at Annual Meeting and there were 2255 English brochures requested by consumers, chapters and HTCs.

### *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 2021, where they received leadership training in group facilitation, advocacy, personal accountability, and public speaking. They also attended general education sessions on bleeding disorders to further their understanding of prevention behaviors.
- NYLI led peer education programs for 40 children ages 10-13 at the Annual Meeting. The experiential education activity focused on goal setting, adherence, and making health decisions. They also presented two sessions for families. "Been There, Done That: Raising a Parent When You Have a Bleeding Disorder" featured a panel of NYLI members who shared their childhood experiences of their adjustment to diagnosis, discussed the challenges that having a bleeding disorder can present with a goal of reassuring new families that life with a bleeding disorder is not as frightening as the initial diagnosis.
- NYLI members attended NHF's Washington Days in February 2012, 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.

# 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

NHF continued to distribute and develop materials for Spanish speaking families. *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. More than 200 coloring books were distributed at Annual Meeting and through requests. NHF translated the Guidelines for Growing brochure series into Spanish. Initially one set of Spanish brochures were sent to each Chapter, during 2012 nearly 500 Spanish brochures were requested by chapters, consumers, and HTCs.

The NHF Cultural Diversity Working Group attended the NHF Annual Meeting in 2012 to help with the development of NHF's *Steps for Living* program. NHF will be updating the an Outreach Guide to help chapters reach unserved and underserved consumers.

At the 64th Annual meeting, there were two sessions in Spanish, "Preguntando a los Expertos" and "Es un Ssunto de Familia: Trabajando Juntos Rara Crear un Ambiente Positive de Familia". There was a new session "How Spirituality Affects Your Healthcare Decisions" that explored the culture and different spiritual belief systems can impact healthcare decisions.

The 10th 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. 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.

# Chapter Services

## *Physical Activity/Nutrition*

NHF conducted wellness education sessions at the 2012 Annual Meeting. The topics included “Head, Shoulders, Knees and Toes! Exploring the Pros and Cons of Protective Devices” which provided information on how to take safety precautions when engaging in physical activity. NHF’s Education staff teamed with the Physical Therapy Working Group to host a “Fit ‘n’ Fun Walk/Run” for all conference attendees.

Nutrition and physical activity were covered in depth on the new *Steps for Living* website: [www.stepsforliving.hemophilia.org](http://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 exercise. In 2012, NHF launched the *Step Out* section for adults with a “Wellness and Prevention” featuring articles including “Exercise and Activity Options”, “Nutrition and Weight Management”, and “Joint Prevention”.

The *Steps for Living* Training for NHF’s chapters and hemophilia treatment centers is an extension of the First Step the Train-the-Trainer developed at NHF in 2005. The training includes “Playing it Safe,” which is a lesson plan on how children and young adults can make healthy choices when engaging in physical activity and sports.

## *Emergency Preparedness*

In 2012, NHF focused on disseminating information on emergency preparedness through HANDI. Additionally, an extensive section of the *Steps for Living* website 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*

NHF has hosted an annual Insurance & Reimbursement Conference for several years. The targeted audience is comprised of hemophilia treatment center social workers and chapter leaders. These individuals often serve as an initial resource for new families with respect to health care coverage options, often providing hands on assistance to consumers as they navigate the red tape associated with access to care. Together the social worker and the chapter staff provide educate those affected by bleeding disorders and their families about the importance of identifying and obtaining sustainable health insurance coverage.

The Affordable Care Act was passed in 2010 and contained many market reform initiatives, many were implemented in 2010, while others are scheduled to occur in 2014. The bleeding disorder community has already benefited from many of the implemented market reforms, however, a lack of clarity still surrounding many of the impending changes has left many consumers confused and anxious about the impact the ACA will have on their care. It is critical that we continue to provide chapters and social workers with the most up to date information on reform implementation and its impact in both the public and private payer arenas to ensure that they are equipped to assist our particularly vulnerable population.

The 2012 conference was held in Denver, Colorado on April 25-27th and had more than 70 attendees. The theme of the meeting was “*Increasing Motivation to Accept the Insurance Challenge*”. Topics included an update on the reform implementation process, the importance of communication and the concept of motivational interviewing.

# Chapter Services

## Healthcare Reform

NHF continues to work to ensure that chapters and members of the bleeding disorder community remain aware and informed about the health reform implementation process and its potential impact on their care and their families. Our education initiatives included 1) the delivery of presentations to community members at more than 25 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 continue to increase 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. Again in 2012, we saw an increase in the use of specialty tiers in the private insurance market. 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.

In addition, we continued to see the shrinking 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*

2012 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. Once 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 third 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 again increased the size of their staff to include four staff members focused on 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 continued to refine and revise 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.

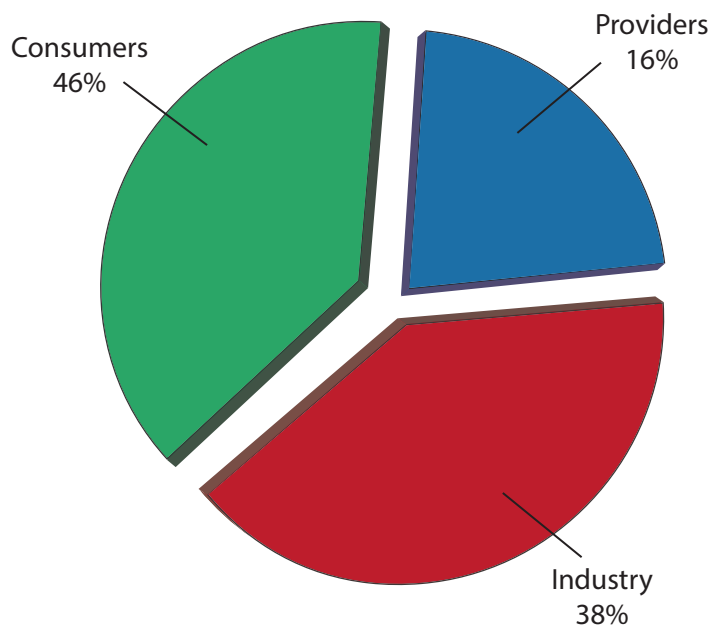
# Annual Meeting

## 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 (+ 46%); healthcare providers (+16%) and industry representatives (approximately 38%). 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: 2012 Annual Meeting held in Orlando, FL

2012 Annual Meeting Attendees  
N=2,930



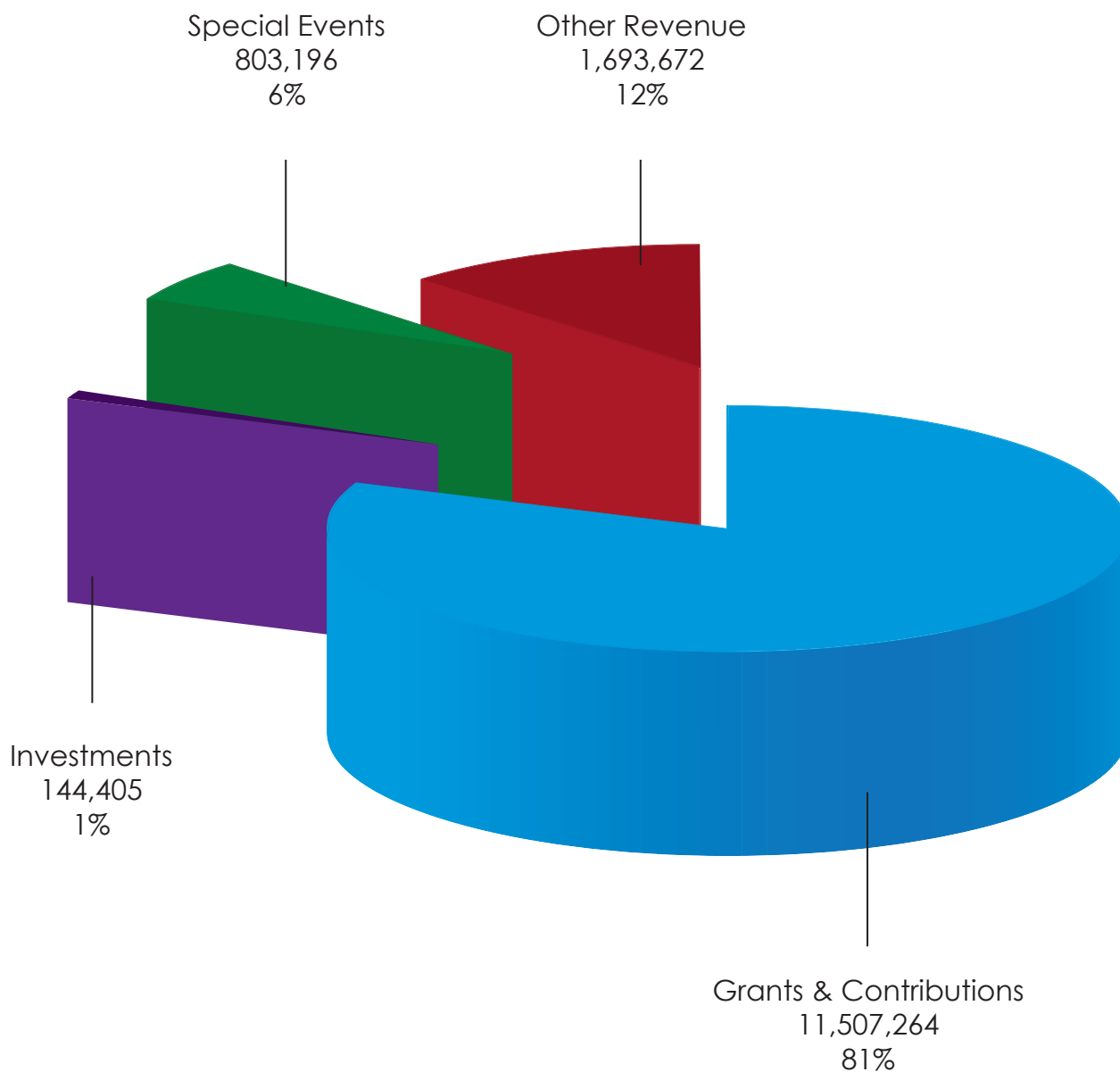
# Session Evaluations

| Track    | Number of Sessions | Average Out of 4 | Average Out of 100 |
|----------|--------------------|------------------|--------------------|
| Overall  | 43                 | 3.71             | 92.8%              |
| Chapter  | 10                 | 3.52             | 88.1%              |
| Consumer | 37                 | 3.73             | 93.4%              |
| RN       | 10                 | 3.78             | 94.5%              |
| PT       | 8                  | 3.77             | 94.4%              |
| SW       | 8                  | 3.68             | 92.2%              |

# Audited 2012 Revenue — NHF

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, 2012, in conformity with generally accepted accounting principles. A complete set of audited financial statements for the year ended December 31, 2012 and the 990 are available online at [www.hemophilia.org](http://www.hemophilia.org).

## Revenue for NHF

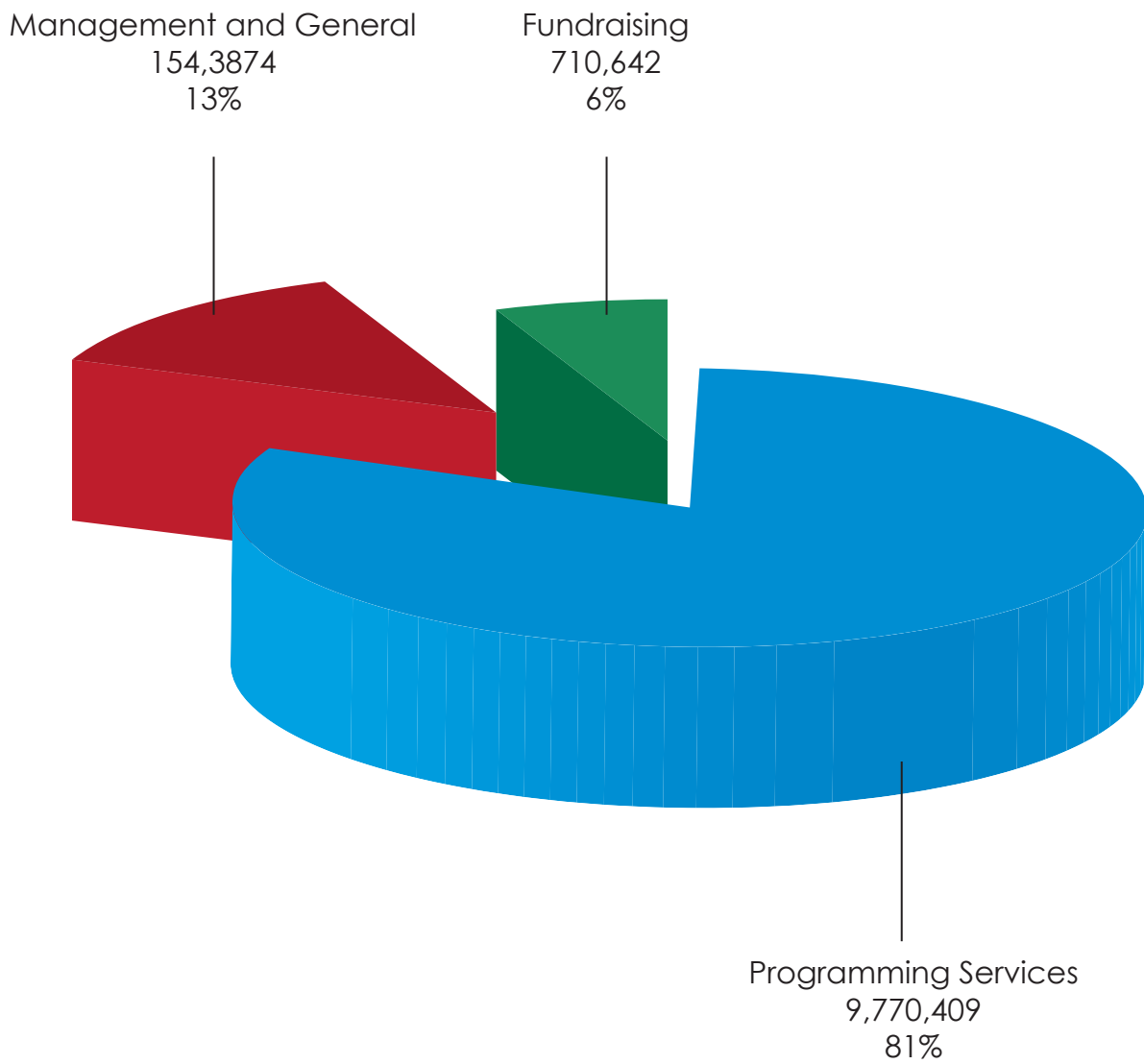


The ending net assets for 2012 was \$9,500,371.



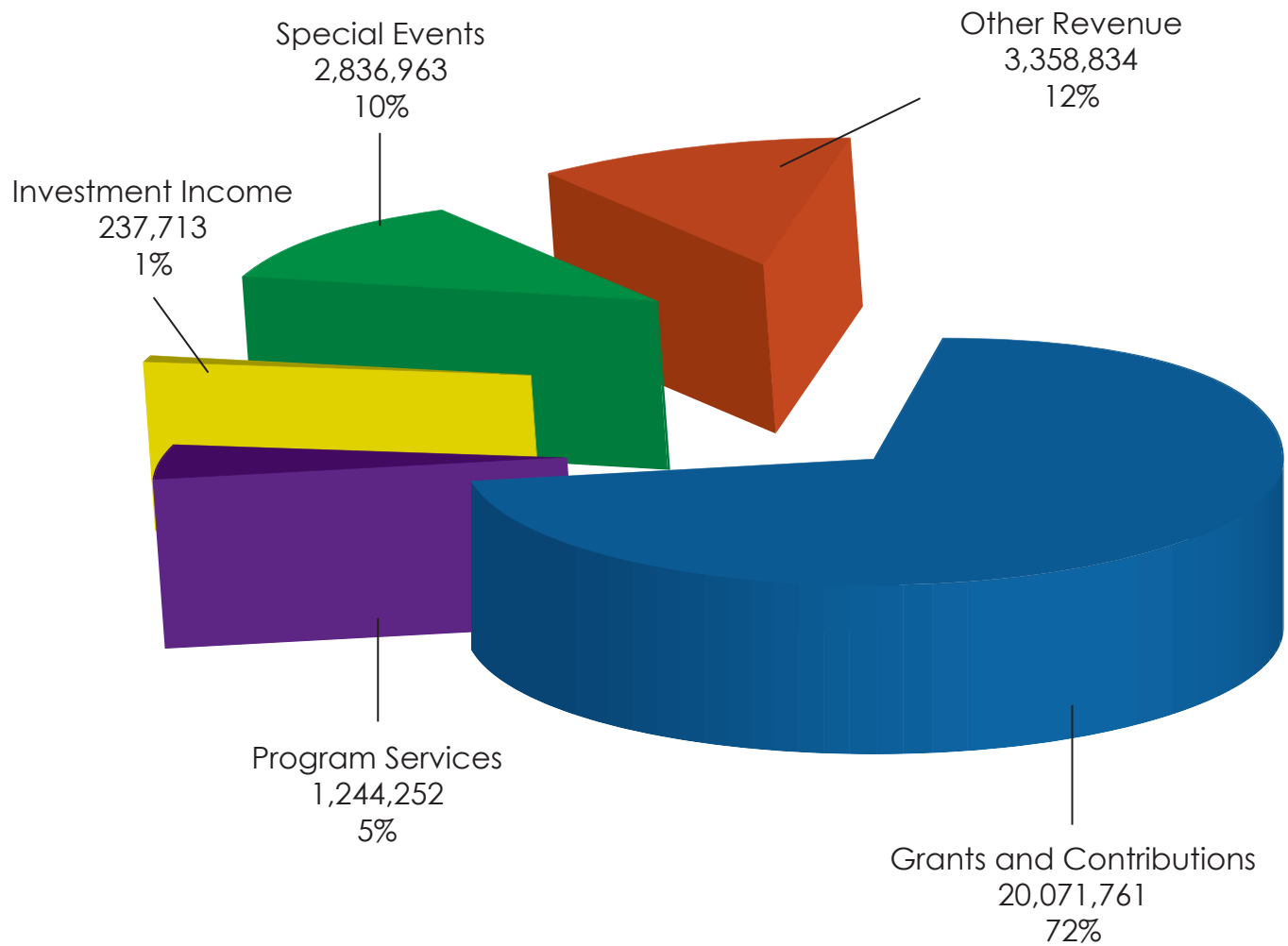
# Audited 2012 Expenses — NHF

## Expenses for NHF



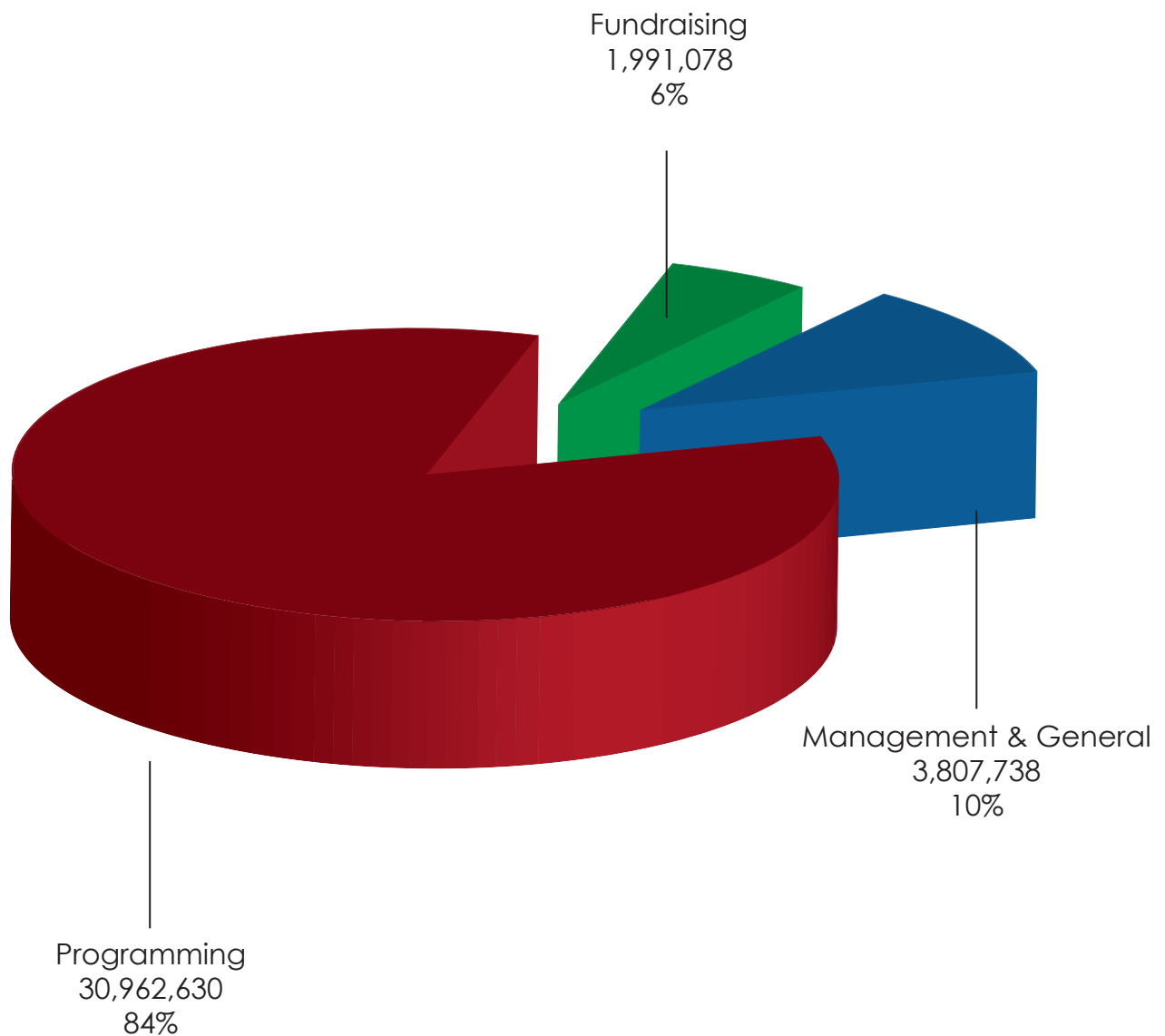
# NHF & National Network of Chapters — Revenue

## Revenue



# NHF & National Network of Chapters — Expenses

## Expenses



990s were used to produce this information.

13 Chapters used the 990 short form. (5 were recorded in 2011, 8 in 2012.)

31 Chapters use the regular 990 form. (10 were recorded in 2011 and 21 were recorded in 2012.) 2 chapters did not file a 990.

The following Chapter's numbers are included in NHF's financials: Colorado Chapter, Idaho Chapter, Nebraska Chapter, Nevada Chapter and Central Ohio Chapter.

The following four chapters have not been included in these numbers, due to their combined financials with large institutes: Hemophilia of Georgia, the Hemophilia Foundation of Michigan, Hemophilia Center of Western New York and the Mary M. Gooley Hemophilia Center.

# NHF & National Network of Chapters

## Period ending December 31, 2012

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- Rennselaer, 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](http://www.hemophilia.org)

116 West 32nd Street • 11th floor • New York, NY • 10001  
[www.hemophilia.org](http://www.hemophilia.org) • [info@hemophilia.org](mailto: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).