

**Annual Report  
of the  
National  
Hemophilia  
Foundation**

**2014**



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

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 2014 are as follows:

### **2014 Board of Directors**

Jorge de la Riva - Chair  
Kenneth Trader - Vice Chair  
Carol Simonetti - Secretary  
Keith Moore - Treasurer  
Jeffrey D. Alexis, MD  
Jordan Black  
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David Cohenour  
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Val D. Bias - Chief Executive Officer  
Jordana Zeger - Chief Operating Officer  
Joseph J. Kleiber - Senior VP for Chapter Services  
Neil Frick - VP for Research & Medical Information  
John Indence - VP for Marketing & Communications  
Mary Ann Ludwig - VP for Development  
Michelle Rice - VP for Public Policy & Stakeholder Relations  
Dawn Rotellini - VP for Chapter Development & Education

# 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 2014, HANDI answered 2,577 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 more than 5,700 NHF educational publications to individuals, local chapters and HTCs.

## **NHF-Baxter Clinical Fellowship**

With guidance from NHF's Research Review Committee, NHF awarded three NHF/Baxter Clinical Fellowships in 2014:

### **Lindsey Greene, MD**

*UPenn/The Children's Hospital of Philadelphia*

### **Maissaa Janbain, MD**

*Tulane University/Louisiana Bleeding and Clotting Disorders Center*

### **Stacy Croteau, MD, MMS**

*Harvard University/Dana Farber-Boston Children's Blood and Cancer Disorders Center*

Dr. Lindsey Greene is completing her third year of fellowship training in Hematology/Oncology at the Children's Hospital of Philadelphia. She did her pediatric residency training and chief residency training at Weill Cornell Medical College, where she had the fortunate opportunity to interact with Dr. Donna DiMichele. Dr. Greene already has four peer-reviewed publications and she is the first author on three. She has presented abstracts at national and international meetings, receiving several abstract travel and achievement awards (most notably an ASH Training award in 2013). Dr. Greene will continue to develop her clinical skills in hemostasis and thrombosis under the mentorship of Dr. Leslie Raffini. She will also be pursuing her basic science training in translational science in coagulation molecular biology and gene transfer. She has recently completed a two week course on mammalian genetics at the Jackson Laboratories (run by the Johns Hopkins Genetics Dept.) as a way to begin analyzing inherited disease from a molecular genetic perspective.

Maissaa Janbain was born in Lebanon and received her MD degree from the Lebanese University in 1999. After completing her internship and residency in Internal Medicine in Lebanon, she came to the U.S., where she completed a second internship and residency in internal medicine at Case Western Reserve University in Ohio. She then entered the Hematology/Oncology Fellowship program at Tulane University, which she is scheduled to complete in 2015. Dr. Janbain has developed a strong interest in coagulation medicine and has spent much time with her mentor Dr. Cindy Leissing, working with her on clinical research projects for porcine rFVIII and FXIII. She has had abstracts accepted and has presented at several meetings. Dr. Janbain is also interested in global assays and spent a 2-week elective in Michigan with Dr.

# Research and Medical Information

Meera Chitlur to learn thromboelastometry. She has been applying this technique to predict thromboses in sickle cell patients and in pregnant women. Dr. Janbain will use the first year of the NHF-Baxter Clinical Fellowship to complete her hematology/oncology fellowship.

Dr. Stacy Croteau received her BS and MS in neuroscience, and MD at Brown University, where she was awarded AOA. She was resident and chief resident in pediatrics at Boston's Children's Hospital and received the Sydney Farber Award. She is now completing her fellowship in Pediatric Hematology-Oncology at Boston Children's Hospital and has been accepted on faculty at Harvard as an instructor in pediatrics. Her research during fellowship was a clinical review of Kaposi form Angioendotheliomas and this resulted in two publications in the Journal of Pediatrics (2013, and 2014) as well as an ASH Trainee Research Award. She was the first fellow to complete the BCH-Novartis Clinical Fellowship in Early Oncology Drug Discovery. Dr. Croteau, who is being mentored by Dr. Ellis Neufeld, stated in her application that she would eventually like to lead a comprehensive hemophilia treatment center one day. She plans to pursue clinical research in "rationally designed personalized prophylaxis regimens" during her sponsored fellowship years. She has also performed advocacy work for the hematology-oncology community, and formed a relationship with the local NHF chapter.

## **Judith Graham Pool Postdoctoral Research Fellowship**

With guidance from NHF's Research Grants Committee, NHF awarded three Judith Graham Pool Postdoctoral Research Fellowships in 2014:

### **Ji-yoon Noh, PhD**

*The Children's Hospital of Philadelphia*

### **Hongxia Fu, PhD**

*Harvard University/Boston Children's Hospital*

### **Sudharsan Parthasarathy, PhD**

*The Children's Hospital of Philadelphia*

A 2014-2016 JGP Research Fellowship was awarded to Ji-yoon Noh, PhD for her project on "Induced Pluripotent Stem Cell-Derived Platelet Therapy for Hemophilia A." Dr. Noh's research will utilize induced pluripotent stem cells (iPSC) and manipulate them in vitro to expand production of megakaryocytes and platelets that express therapeutic proteins, including FVIII. The project will further determine whether this system of autologous platelets which overexpress FVIII can be delivered directly to the site of injury and hemorrhage, thereby circumventing and evading neutralization by alloantibody inhibitors in hemophilia A. Dr. Noh received her PhD in preventive pharmacology from Seoul National University in South Korea. She has been a postdoctoral fellow in Dr. Mitchell Weiss' lab at The Children's Hospital of Philadelphia since 2012. Dr. Noh is currently being mentored in this JGP project by Dr. Mortimer-Poncz at CHOP.

Two JGP Research Fellowship awards were awarded thanks to a generous grant from the Hemophilia of Georgia:

The 2014 NHF/Rueleen Kapsch JGP Postdoctoral Research Fellowship was awarded to Hongxia Fu, PhD, of Boston Children's Hospital and Harvard University for her project on the "Mechanoregulation of von Willebrand Factor Inhibition and Activation."

Dr. Fu's research project centers on the role of von Willebrand Factor --in particular, why it travels in plasma in a globular form and then stretches when needed for hemostasis. She is investigating how the electrostatic interactions and forces in various flow conditions regulate VWF conformation and its ability stop bleeding using novel fluorescence-force-sensor and charge mutants. Dr. Fu's project is significant because it will shed light on how the body responds to injury and potentially pave the way for more directed diagnosis and therapeutics in von Willebrand disease. Dr. Fu obtained a Master's degree in Structural Engineering from Dalian University of Technology in China and received her Ph.D. in Bioengineering from the National University of Singapore in 2007. She has been a research fellow at Boston Children's Hospital/Harvard University since 2011, and has been conducting her research under the mentorship of Dr. Timothy Springer.

The 2014 NHF/Bob and Margaret Carton JGP Postdoctoral Research Fellowship was awarded to Sudharsan Parthasarathy, PhD, of the Children's Hospital of Philadelphia for his project on the "Molecular Basis of Procofactor to Cofactor Activation in FVIII."

Dr. Parthasarathy's research tackles two important biological issues in coagulation: more specifically, how procofactor FVIII converts to the active cofactor form (FVIIIa) and binds to IX and X, and the location of FVIII in generating the active Xase complex. The implications of this study are that it will provide molecular and biochemical insights into the role of FVIIIa in regulating hemostasis and further elucidate the interactions between coagulation complexes.

Dr. Parthasarathy obtained his Masters in biotechnology from Jawaharlal Nehru University in New Delhi, India and received his PhD in biochemistry from the University of Kansas in 2011. He has been a postdoctoral researcher in the lab of Dr. Rodney Camire at The Children's Hospital of Philadelphia and the University of Pennsylvania since July 2011, and will continue pursuing his project under Dr. Camire's mentorship.

Awarded a Nursing Excellence Fellowship to:

**Michelle Witkop, DNP, FNP-BC**

*Northern Regional Bleeding Disorders Center, Traverse City, MI*

"Bleeding Disorders Pediatric Pain Initiative"

Pediatric pain, especially in the hemophilia population, is under-recognized and under-treated. Barriers to adequate treatment include lack of knowledge, variability of practice, and outmoded beliefs. All of these factors lead to a culture of slow to no change in practice patterns. Health care providers need

# Research and Medical Information

current, state-of-the-art education and tools to assist them in developing the skills required to assess and manage pain in children.

Children are often given minimal or no analgesia for procedures that would be treated aggressively in adults. Although more is now known about pain management in children, this knowledge has not been widely or effectively translated into routine pediatric clinical practice, including the practice of most HTC's.

In the bleeding disorders community, especially for those with hemophilia, children begin to experience frequent pokes secondary to frequent factor infusions and blood draws at an early age. Depending on the severity of their disorder, they may experience a poke daily or more frequently. This gives rise to anxiety for the child as well as their parents and other family members. Anticipatory anxiety is not uncommon in this setting. The child and their family often feel as though they have no control over the situation.

A distraction box is filled with tools for providers to implement during any procedure involving children. The simple act of distraction (in whatever form) can significantly decrease pain and anxiety for both the child as well as their parent. This box offers multiple methods of distraction and informational videos on techniques.

The focus of the Poke Plan is to give control over a painful or anxiety provoking situation back to the parent/child. The simple wallet card quickly educates any provider on how the child best handles the discomfort and anxiety associated with a poke/needlestick. Filling out the card educates the parents on distraction techniques that may be helpful for their child in painful and anxiety provoking situations.

To date there have not been any studies done in this population. However centers in Michigan using similar Poke Plans in the general pediatric population include but not necessarily limited too are: Sparrow Hospital in Lansing Michigan, Munson Medical Center in Traverse City, Michigan as well as the University of Michigan Children and Women's Hospital in Ann Arbor, Michigan.

Awarded a Physical Therapy Excellence Fellowship to:

**Grace Hernandez, PT**

*Center for Inherited Bleeding Disorders, Orange, CA*

“Prevalence of Gross Motor Delays in Children with Hemophilia”

The purpose of this project is to determine if children with hemophilia have gross motor delays. Gross motor skills include, but are not limited to walking, running, jumping, climbing, crawling, balancing, kicking, catching and throwing activities. The large muscles of the body are responsible for performing these types of activities. Strength, balance and coordination are needed to demonstrate and improve these skills. Children with hemophilia may experience internal bleeding in their joints or muscles, which limits their activity. Some children with hemophilia may be restricted from active play or sports for fear of getting an injury that could cause internal bleeding. When activity is restricted, there can be decrease in strength, balance and endurance. If a child has gross motor delays, it puts him at risk for injury when playing with his peers.

Physical therapy evaluations in the hemophilia treatment center help determine changes caused by bleeding episodes. There are specific motor skills children master as they grow, which represent strength, balance and coordination. The comprehensive clinic visits do not allow time to complete an intensive gross motor assessment. Physical therapists use Manual Muscle Testing (MMT) to grade the strength of each muscle group. MMT strength testing is not appropriate for young children and does not represent strength during functional activities. To accurately determine children's muscle strengths, a standardized gross motor test should be used.

The PT at the Comprehensive Care Center for Inherited Blood Disorders will conduct gross motor evaluations in conjunction with the annual visit. The scores will be evaluated to determine which patients have gross motor delays, so they can be referred for therapy services. The BOT 2 is the standardized gross motor test that will be used to determine gross motor levels. The gross motor skills that will be evaluated include bilateral coordination, balance, running speed and agility, upper limb coordination and strength. All patients with hemophilia between the ages of 4 and 12 years will be eligible to be evaluated in the upcoming year with additional PT testing with their annual visit. Patients may be referred to therapy or given a home exercise program depending on the deficits noted during the assessments. The goal is to improve our standard of care at the HTC, by adding gross motor screening for our patients to ensure appropriate referrals are made for therapy services.

Awarded a Social Work Excellence Fellowship to:

**Shannon Brown, LMSW**

Center for Inherited Bleeding Disorders, Orange, CA

“A Standardized Approach to Empowering Families with Hemophilia”

Parents bear a significant responsibility for delivery of medical care because the treatment for hemophilia begins early in life for children within the home setting. As a result, parents frequently exhibit a heightened level of stress, anxiety, and subsequent trauma around the acceptance of the illness and the administration of medication management (Furmedge et al., 2013). To address the multifaceted nature of chronic illness for patients and their families, the ideal treatment utilizes a multidisciplinary team. Our proposed 3P Patient Parent Power Program aims to standardize care for families with patients of hemophilia using a tiered approach of psychosocial support. The necessary level of support will be provided to parents in order for them to successfully provide in-home prophylactic factor treatment. The goal of the program is to reduce parental stress and anxiety related to this chronic illness and increase feelings of empowerment for the parent and child.

# Research and Medical Information

## MASAC

NHF's Medical and Scientific Advisory Council (MASAC) held two meetings, April 12-13, 2014, and September 20, 2014, 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 2014:

MASAC Recommendation #224

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

MASAC Recommendation #225

MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders (Revised April 2014)

MASAC Recommendation #226

MASAC Recommendation Regarding the Use of Recombinant Clotting Factor Products with Respect to Pathogen Transmission

MASAC Recommendation #227

MASAC Recommendation Regarding Home Factor Supply for Emergency Preparedness for Patients with Hemophilia and Other Bleeding Disorders

MASAC Recommendation #228

MASAC Statement Regarding Use of Various Clotting Factor Assays to Monitor Factor Replacement Therapy

MASAC Recommendation #229

MASAC Resolution Regarding Consumer Participation in the National Patient Notification System

MASAC Recommendation #230

MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders (Revised September 2014)

MASAC Recommendation #231

MASAC Recommendation Regarding the Need for Updated Guidelines for Diagnosis and Management of von Willebrand Disease



# Chapter Services

## Chapter Development

NHF developed a new 3-year Chapter Services Action Plan, to cover 2014-2017. This plan encompasses a comprehensive set of guiding principles and standards designed to strengthen chapter effectiveness in fulfilling their respective missions. Collaboration between NHF and its 51 chapters continues to result in a chapter network more viable and sustainable in order to better serve NHF's owners (individuals and their families affected by bleeding 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*—remains the guiding light for Chapter Development. Capacity-Building Grants have been of great use to chapters in strengthening their infrastructure. Fifteen chapters were provided grants to hold Board Development Summits to assist in strategic planning for local boards. Additional support was provided through two 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

### *Steps for Living*

In 2014, 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 has continues to promote the *Steps for Living* website in Spanish, as well, with steadily increasing web visits in Spanish throughout the year. In 2014, NHF launched two new videos on the website, "What Schools Should Know," and "What is von Willebrand Disease?"

The *Steps for Living* Training for NHF's chapters and hemophilia treatment centers was met with great success in 2014 with 32 people trained to engage young people in educational programming at the local level. The program was rated very highly with 93.3% of participants rating the training as excellent or great.

# Chapter Services

## 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:

The NYLI program in 2014 had 25 members and was the most diverse class of NYLI to date, including African American, Asian American, and Spanish speaking members.

In addition to ongoing leadership training NYLI members receive from NHF, 12 have also assumed leadership positions in a variety of NHF programs, including serving as a non-voting member of the NHF Board; NHF Annual Meeting Planning Committee; CDC Content Advisory Groups for Joint Health and Women with Bleeding Disorders; First-Year NYLI Leadership Training; Washington Days; NHF Annual Meeting NYLI Training Committee; Annual Meeting Teen Track; *HemAware* magazine editorial group; and Social Media Representative.

At NHF's 66th Annual Meeting, NYLI members were speakers at six different sessions and helped lead the two-day Teen Track for 13-17 year olds. NYLI members also participated in NHF's Washington Days, learning advocacy skills and holding meetings with Congressional members and staff from their home states.

## Women with Bleeding Disorders

NHF 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 2014 include:

- Successful launch of V4W Ventures Program, an eight-week webinar series to develop leadership skills in women with bleeding disorders, and chapter and HTC staff who will run women's programming. In addition, participants who complete the program could receive funding to implement their women's programming.
- Continued support of the work of chapters by facilitating workshops at chapter events on topics relevant to women with bleeding disorders
- As part of a five-year cooperative agreement with the Centers for Disease Control and Prevention (CDC), NHF aimed to increase awareness of bleeding disorders so women can receive timely and accurate diagnosis and lead healthy full lives. Through a college health center pilot project in 2014, NHF worked with pilot sites to implement NHF's clinical guidelines and audit criteria related to bleeding disorders in their chart reviews.

## 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. NHF translated the Guidelines for Growing brochure series into Spanish, as well as the *Steps for Living* website

The NHF Cultural Diversity Working Group attended the NHF Annual Meeting in 2014 to help with the development of NHF's Steps for Living program and to welcome the recipients of the Educational Participant Grant program for first-time attendees. 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 30 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.

At the 66th Annual meeting, there were two sessions in Spanish, "Preguntando a los Expertos" and "Rap Session: en Español." There was also a roundtable, "Free to Be Me: Respect My Diversity," a rap session for LGBTQ and a session called "We Are Family! African American Voices" to continue to address the diverse set of experiences and needs within the bleeding disorder community.

## Physical Activity/Nutrition

NHF conducted wellness education sessions at the 2014 Annual Meeting. The topics included "Fit Living: Exercise and Wellness for Adult Men" which provided information on how to create a healthy and supportive environment, set realistic goals, eat a healthy nutrition-rich diet, create a cardiovascular base and improve strength, flexibility and balance. Another topic was "Healthy Cooking: It's Easier Than You Think" which demonstrated quick and easy ways to eat in a more healthful manner. Attendees walked away with ideas on menu planning, and where to find healthy recipes. 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.

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.

# Chapter Services

## Insurance & Reimbursement Conference

The ongoing roll out of health reform across the country continues to present challenges, not only to consumers trying to evaluate their options, but to health plans themselves, providers and those whose job it is to assist these individuals and organizations. Therefore, NHF chose to once again offer two conferences in 2014.

The initial conference held January 15 – 17th, 2014, was a repeat of the December 2013 conference titled *Introducing the Health Care Marketplace*. Many missteps had occurred with the launch of the new marketplaces and the January conference provided attendees some insight as to “lessons learned” to date in order to ensure that any remaining applicants could avoid the pitfalls of the initial registrants.

The second conference held September 21st – 22nd, 2014 focused on access challenges both in the private and public payer arenas and for immigrants. Also discussed were issues related to skilled nursing facilities and patient assistance programs. Collectively 160 individuals attended the 2014 Insurance and Reimbursement Conferences.

## Healthcare Reform

### *National Advocacy Empowerment Program (NAEP)*

Healthcare reform continues to move forward and various provisions of the Affordable Care Act (ACA) continue to be challenged. It is difficult to fully understand how implementation is impacting those with bleeding disorders. It is imperative that the NHF policy team remain diligent in their monitoring of the implementation process and its proposed timeline to ensure that our community is kept up to date on any trends that may impact their access to care. This is accomplished through working closely with our Washington DC consultants, other national patient advocacy groups and our various stakeholders.

Our Washington DC consultants work closely with various federal agencies and congressional members to ensure the needs of those with bleeding disorders are not lost in the process of reform.

For the past six years, more than 300 individuals from across the country have gathered to learn about federal and state advocacy and to take part in NHF’s Washington Days program. This is their opportunity to share their stories and educate their federal representatives about bleeding disorders and to request continued support for the hemophilia treatment center network.

## **State Advocacy**

### *Assistance to Chapters*

NHF has worked with our chapter and community leaders to increase their ability to build and maintain a year-round advocacy program in their respective states. NHF's state advocacy team has provided technical assistance in the areas of strategic planning, state legislative day development and training, messaging and stakeholder engagement. These trainings were delivered, locally, regionally and nationally and participants were able to leave each training with various tools and templates they could utilize to become more efficient at identifying and responding to challenges as they arise. More than 25 chapters received one-on-one support in the area of advocacy in 2014.

### *Education*

In addition to providing support to local chapter leaders, the NAEP & State Advocacy programs are designed to help educate consumers, payers, healthcare providers and state and federal policymakers and legislators. Oversight of the program is the responsibility of the state advocacy team in collaboration with the CEO and NHF's Washington DC consultants. Education and training is provided in various formats (webinars, conference calls, primers, online materials, etc.) and venues (local and national meetings, including educational and lobby day trainings) .

In 2014 NHF expanded their payer education initiatives to include a program entitled the "Comprehensive Care Sustainability Collaborative" (CCSC). The CCSC brought together payer and provider thought leaders to identify collaborative opportunities to improve care for those with bleeding disorders while also reducing costs.

## **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

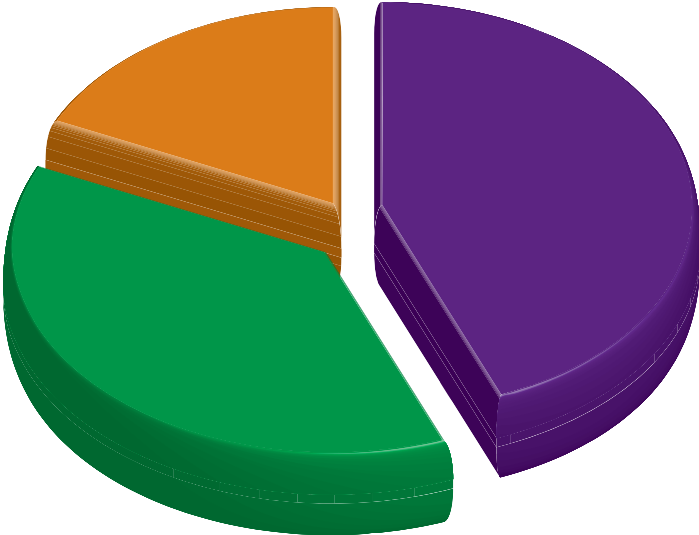
# Annual Meeting

## 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:  
2014 Annual Meeting held in Washington, DC**

2014 Annual Meeting Attendees  
N=2,931



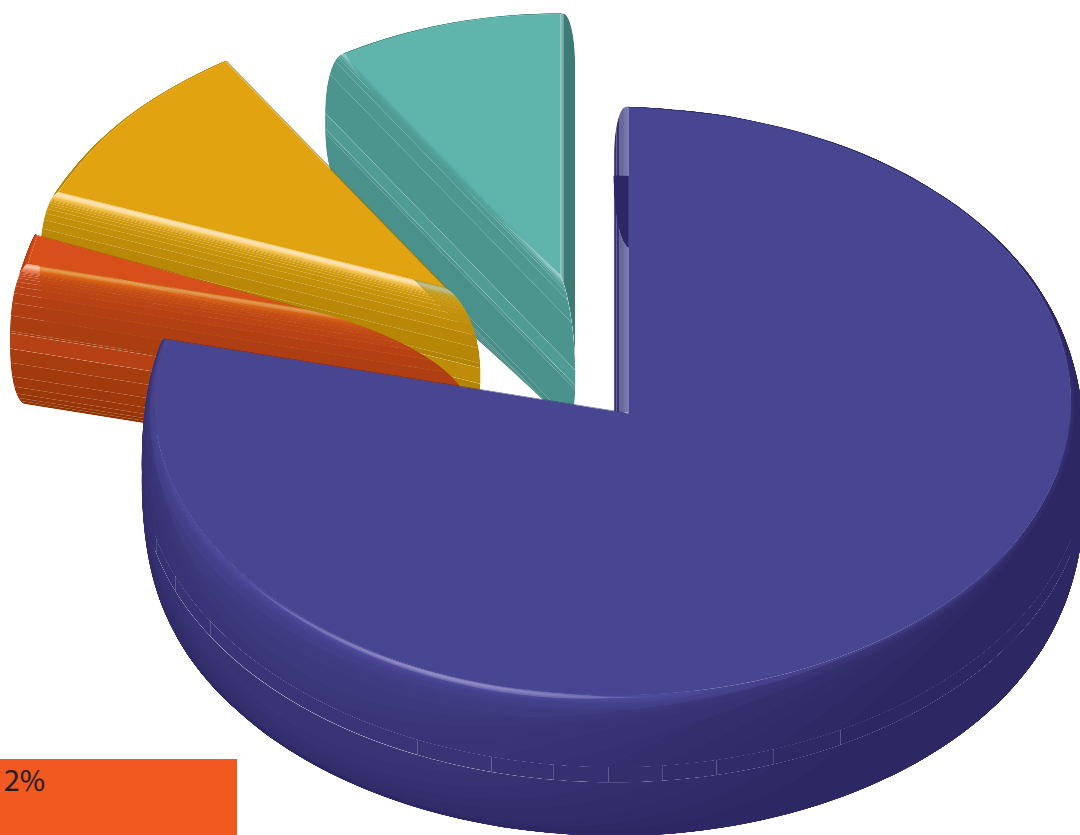
Exhibitor/Industry: 44%	1,266
Consumer/Chapter: 38%	1,102
Provider: 18%	521



# Audited 2014 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, 2014, in conformity with generally accepted accounting principles. A complete set of audited financial statements for the year ended December 31, 2014 and the 990 are available at [www.hemophilia.org](http://www.hemophilia.org).

## Revenue for NHF



Investments: 2%	484,700
Special Events: 9%	1,835,323
Program Services: 10%	2,052,483
Grants & Contributions: 78%	15,252,599
Other Income: -940,068	Not shown on pie chart

### 2014 Major Contributors

\$2,000,001 to \$3,000,000	Baxter Biogen Novo Nordisk
\$1,000,000 to \$2,000,000	Pfizer
\$500,000 to \$999,000	Bayer Corporation CSL Behring, LLC Grifols

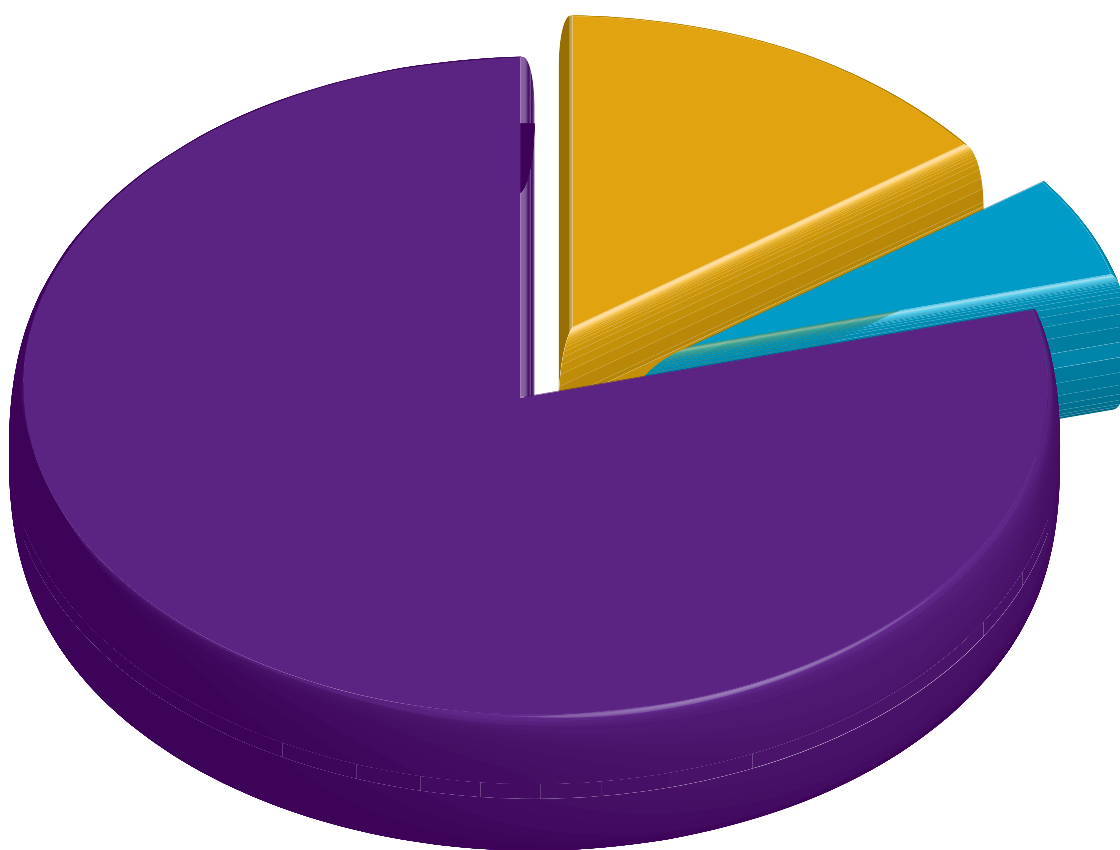
The ending net assets for 2014 was \$12,603,670.

Centers for Disease Control  
and Prevention (CDC)



# Audited 2014 Expenses — NHF

## Expenses for NHF



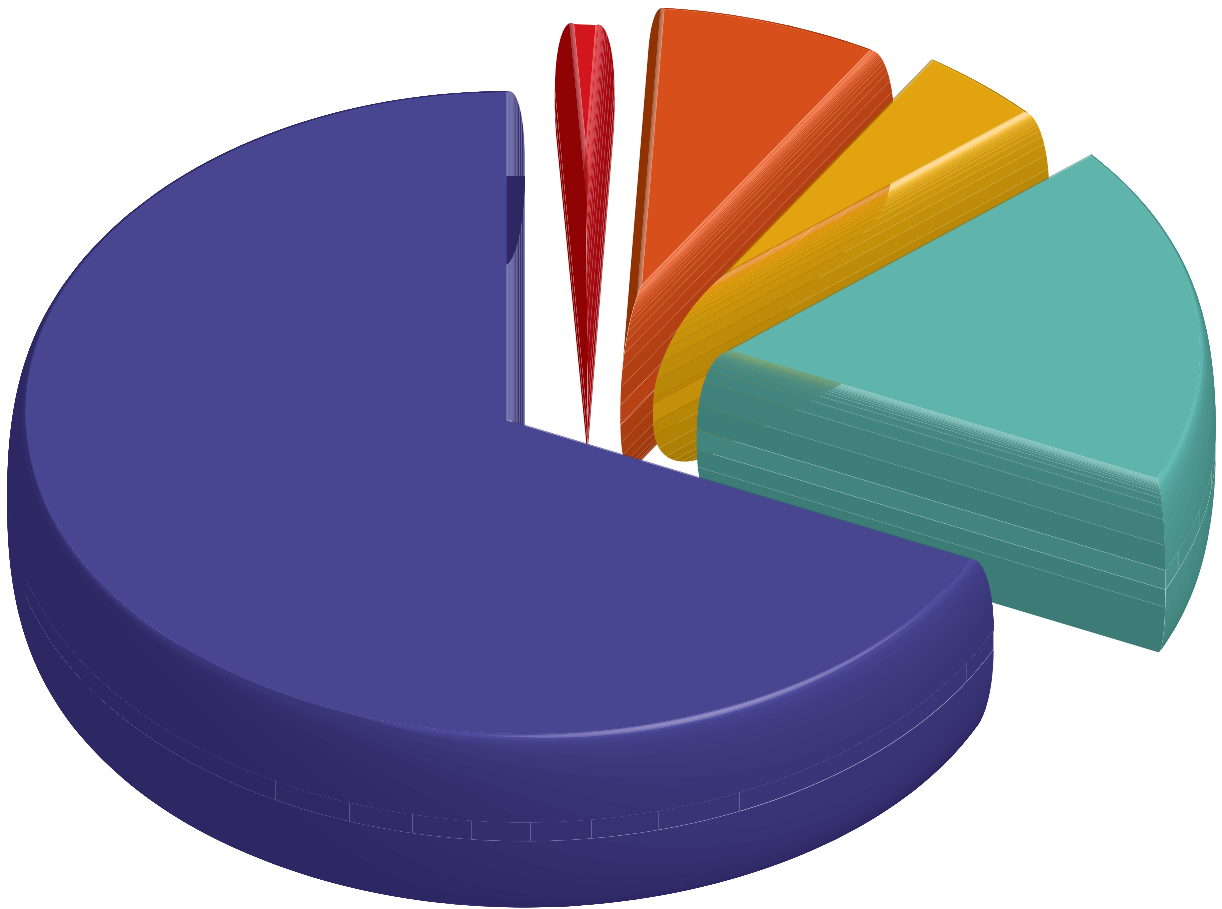
Fundraising: 6%  
836,383

Management & General: 15%  
2,052,319

Programming Services: 79%  
11,011,870

# NHF & National Network of Chapters — Revenue

## Revenue



Investment Income: 1%  
400,507

Other Revenue: 5%  
1,734,375

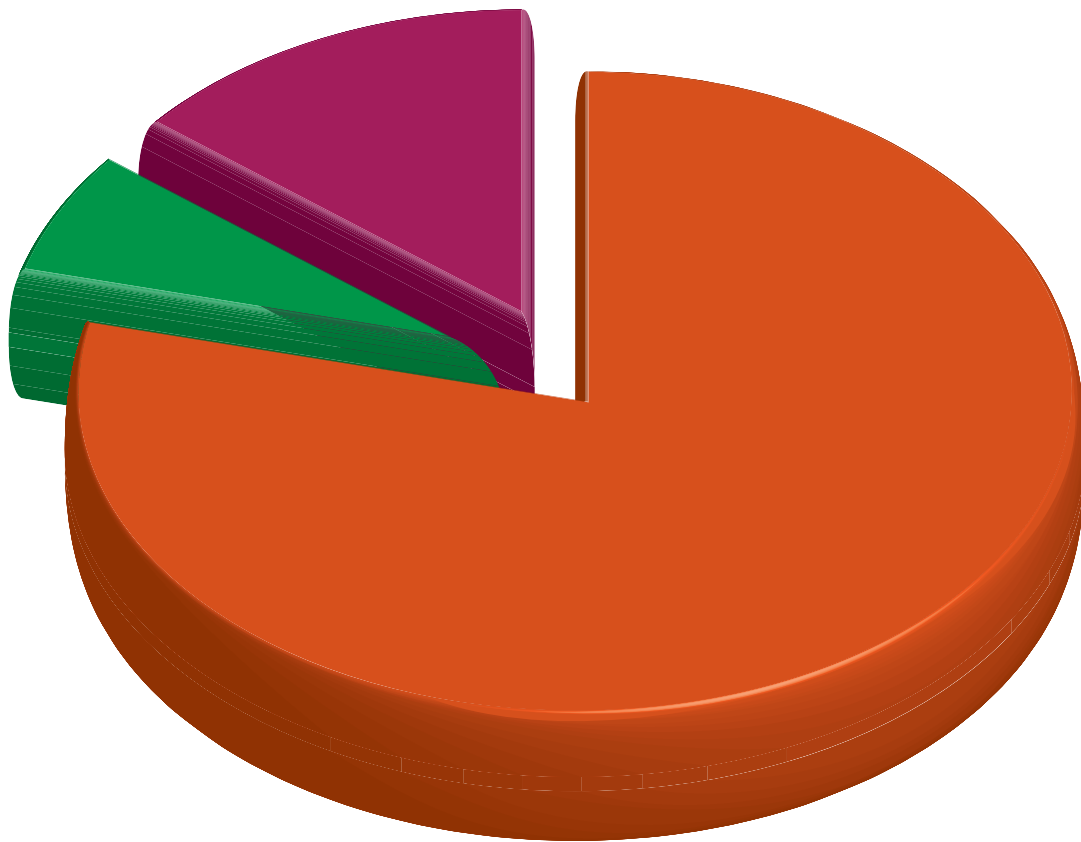
Program Services: 8%  
3,028,723

Special Events: 18%  
6,866,080

Grants & Contributions: 68%  
25,569,614

# NHF & National Network of Chapters — Expenses

## Expenses



Fundraising: 7%  
2,124,559

Management & General: 14%  
3,765,485

Programming: 79%  
26,648,136

990s were used to produce this information.

10 Chapters used the 990 short form. (6 were recorded in 2013; 4 in 2014)

30 Chapters use the regular 990 form. (11 were recorded in 2013 and 19 were recorded in 2014)

10 Chapters' 990 revenue and expenses were applied across the total percentage of all 900's. (One chapter did not file.)

The following Chapter's numbers are included in NHF's financials: Colorado Chapter, Idaho Chapter, Nebraska Chapter, Nevada Chapter, Central Ohio Chapter, and West Virginia 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, 2014

Alaska Hemophilia Association- Anchorage, AL  
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 Alliance of Maine-Hampden, ME  
New England Hemophilia Association- Dedham, MA  
Hemophilia Foundation of Michigan- Ypsilanti, MI  
Gateway Hemophilia Association-Manchester, MO  
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  
Eastern Pennsylvania 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  
West Virginia Chapter, National Hemophilia Foundation- Morgantown, NY  
Great Lakes Hemophilia Foundation- Milwaukee, WI



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

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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).