

**Annual Report
of the
National
Hemophilia
Foundation**

2015



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 2015 are as follows:

2015 Board of Directors

Jorge de la Riva, Chair
Brian Andrew, Vice Chair
Mark A. Borreliz, Secretary
James A. Heer, Treasurer
Jeffrey D. Alexis, MD
Jordan Crows
David Cohenour
Scott Martin
Scott Miller
Kristie Kay Ostash, MD
Matt Rhodes
Dutta Satadip
Carol Simonetti
Gilbert White, MD

2015 Management Staff

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 2015, HANDI answered 2,284 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 4,002 NHF educational publications to individuals, local chapters and HTC's.

NHF-Baxter Clinical Fellowship

With guidance from NHF's Research Review Committee, NHF awarded two NHF/Baxter Clinical Fellowships in 2015:

Pavan K. Bendapudi, MD

Harvard University/Dana Farber Cancer Institute-Boston Hemophilia Center

Angela Weyand, MD

University of Michigan/C.S. Mott Children's Hospital

After finishing his graduate medical education at Stanford University, Dr. Pavan Bendapudi did residency training in internal medicine at Massachusetts General Hospital, where he developed a strong interest in bleeding and clotting disorders. This fascination led him to complete a fellowship in blood banking and transfusion medicine through the Harvard Combined Transfusion Medicine Program, where he was the first graduate of his residency program to have pursued additional training in this area. As an adult hematology/oncology fellow, Dr. Bendapudi provided care to patients at the hemostasis clinic at Beth Israel Deaconess Medical Center, but also pursued additional learning opportunities in the research labs of Drs. Robert Flaumenhaft and Bruce Furie. Dr. Bendapudi received a Mentored Research Award from the Hemostasis and Thrombosis Research Society (HTRS) and will join the faculty at Massachusetts General Hospital as an instructor with an appointment in the Division of Hematology.

As an NHF-Baxter Clinical Fellow, Dr. Bendapudi will receive training under the mentorship of Dr. Ellis Neufeld in pediatric hemophilia, continue expanded training in adult hemophilia, and focus on the transition of pediatric to adult hemophilia care.

Dr. Angela Weyand is finishing her second year of pediatric hematology/oncology fellowship at the University of Michigan Mott Children's Hospital. She is a native of Kansas City, Kansas and a graduate of Northwestern University in Evanston, Illinois. Dr. Weyand attended medical school at the University of Michigan and completed her pediatrics residency at the University of Washington/Seattle Children's Hospital.

Research and Medical Information

As an NHF-Baxalta Clinical Fellow, Dr. Weyand will train under the mentorship of Dr. Steven Pipe and Dr. Jordan Shavit, a former NHF-Baxalta Clinical Fellow. In addition to receiving dedicated clinical training in the care of patients with disorders of hemostasis, Dr. Weyand will also be exposed to research projects investigating genetic modifiers of coagulation in a zebrafish model.

Dr. Weyand's long term goals are to further the field of coagulation through translational research and to provide the highest level of comprehensive clinical care to patients with hemophilia and coagulation disorders.

Judith Graham Pool Postdoctoral Research Fellowship

With guidance from NHF's Research Grants Committee, NHF awarded two Judith Graham Pool Postdoctoral Research Fellowships in 2015:

Christopher Ng, MD

The University of Colorado Denver

Laura Sommerville, PhD

Duke University

One entire JGP award was made possible thanks to a generous grant from the Cirelli Family Foundation:

The 2015 NHF/Nicholas Cirelli Family Research Fund JGP Research Fellowship was awarded to Laura Sommerville of Duke University Medical Center for her project on "Understanding the loss of perivascular tissue factor during angiogenesis in hemophilia."

Dr. Sommerville's preliminary studies have suggested a role for tissue factor (TF) in dysregulated angiogenesis through down regulation of TF in the healing process in hemophilia. Dr. Sommerville's JGP project is concentrated on studying the mechanism and role of TF in the wounded tissues of hemophilia B mice. The broader implications of her work would be to improve our understanding of the onset of hemophilic joint disease. This resulting information might be useful to better tailoring prophylactic regimens, developing a surrogate marker or in exploring the role of anti-angiogenic agents in the prevention of joint disease.

Dr. Laura Sommerville graduated cum laude from Messiah College and then obtained her M.S. and Ph.D. degrees in cellular and molecular biology from Temple University. Her graduate work and doctoral dissertation produced several awards and publications in peer reviewed publications. She has been a postdoctoral fellow in the laboratory of Dr. Maureane Hoffman at Duke University since July 2014, and will continue her project under Dr. Hoffman's mentorship. Her long term career goal is to become an independently funded investigator studying the pathophysiology of vascular injury and disease.

Dr. Christopher Ng of UC Denver was awarded a 2015 JGP research fellowship award for his project on a "Multi-system Evaluation of von Willebrand Factor Function in Type 1 von Willebrand Disease Mutations." This research centers on the role of von Willebrand Factor – under flow conditions and its effect on platelet rolling velocity and adhesion using microfluidic-based technology. Dr. Ng's work will shed

light on the biological mechanisms of VWD Type 1 in hopes of identifying novel parameters to improve diagnosis and predict clinical bleeding in VWD.

Dr. Christopher Ng is a pediatric hematology/oncology fellow at the University of Colorado Denver - Anschutz Medical Campus. Dr. Ng attended medical school at the Keck School of Medicine at the University of Southern California and completed his pediatrics residency at the University of Washington - Seattle Children's Hospital. Dr. Ng received the NHF-Baxalta Clinical Fellowship in 2013 and has been training under the mentorship of Drs. Marilyn Manco Johnson and Jorge DiPaola.

Awarded a Nursing Excellence Fellowship to:

Mary B. Lesh, RN, MS, CPNP and Darcy Phelan, RN, MS, ANP-BC

UCSF Medical Center, San Francisco, California

"The Use of High Resolution Power Doppler Musculoskeletal Ultrasound (MSKUS) in Bleeding Disorders"

The advances in Doppler ultrasound/MSKUS imaging allow for high resolution and real-time imaging of soft tissue and articular structures. It is an emerging technology that has been useful in other fields in the imaging of joint disease. Advantages of this technology are many, including being non-radioactive, inexpensive, repeatable, and acceptable to patients. In patients with hemophilia, musculoskeletal ultrasound has been shown to be useful in detecting joint bleeds, synovial hyperplasia, and joint erosions comparable to MRI. It has also been demonstrated that pain perception within the hemophilia population is not clearly associated with bleeding episodes, nor is clinician physical assessment accurate in deciphering bleeding episodes from other non-bleeding pain etiologies in comparison to evaluation with MSKUS. Therefore, the role of this technology has clear implications for use within the hemophilia population for accurately managing bleeding symptoms as well as other etiologies causing pain. Ultrasound is a highly operator-dependent modality requiring advanced skill to implement. At the UCSF HTC, we have partnered with our radiology colleagues for utilization of MSKUS. This fellowship grant will allow for nursing time to perform the comprehensive analysis of our retrospective data with the use of MSKUS over an approximate two-year period in both adults and pediatrics. The project will allow for a presentation of a clinical pathway for use of MSKUS within the HTC. To promote awareness of the rationale for MSKUS use in the detection of bleeding or other painful etiologies, the project will create a pamphlet for both persons with bleeding conditions and providers involved in their care.

The project's ultimate goal is to expand nursing knowledge of hemarthrosis/soft-tissue bleeding detection by presenting our HTC's experience with how MSKUS improves accurate diagnosis and guides treatment of bleeding and other pain etiologies. By completing the retrospective data review, we hope that the experience of a large center HTC spanning both adults and pediatrics, will be made available. We believe that the current restraints of MSKUS implementation include cost of equipment, operator certification, and quality of interpretation to guide interventions. Therefore, partnering with radiology experts may be helpful for other HTCs around the country when using this modality in the future. Our center's experience will show that collaboration with radiologists for real-time imaging is successful with nursing evaluation and coordination.

Research and Medical Information

Awarded a Physical Therapy Excellence Fellowship to:

David Oleson, PT, PCS

Oregon Health & Science University, Portland, OR

“Effect of Exercise on Bone Mineral Density and Strength in Factor VIII Deficient Mice”

Decreased bone mineral density (BMD) resulting in osteopenia and osteoporosis are recognized problems in people with hemophilia. This loss of bone integrity has been thought to be due to decreased ability to exercise resulting from hemarthrosis and hemophilic arthritis as well as the influence of infection with HIV and/or hepatitis C. However, a recent study utilizing factor VIII deficient mice has demonstrated that decreased skeletal health in mice is related to fVIII deficiency.

Factor VIII knock-out (KO) mice have been developed and characterized. These mice have complete absence of factor VIII. Due to their size these mice do not spontaneously bleed and are otherwise identical to mice without hemophilia. A study from our institution using this mouse model comparing KO BMD to wild type (WT) mouse BMD demonstrated significant differences in BMD, thickness, stiffness, and resistance to fracture and stress of fVIII deficient mouse femurs compared to WT mouse femurs. Activity levels of both groups of mice were similar but there was no intervention to increase exercise level of either group in this study.

In order to study the effect of exercise on BMD in hemophilia, equivalent study groups are needed for comparison. Hemophilia is a very singular condition and it is difficult to find subjects with hemophilia who have similar bleeding histories, physical characteristics, diet, and activity levels to allow for comparative study.

We propose to use hemophilia KO mice to study the effect of exercise. Since KO mice do not bleed unless provoked, there will be no influence of hemarthrosis and decreased activity from hemophilic arthritis. The mice will be raised under identical conditions, except for exercise, so any influence of diet and environment would similarly be eliminated from the study.

For this study, we will have 30 KO mice divided into two groups of 15. They will be placed in separate cages after weaning, and exercise wheels will be placed in 15 of the cages. All mice will be grown to 20-22 weeks of age, the age of skeletal maturity of mice. At that time, the femurs will be studied. Bone density scanning and biomechanical structure of the femurs will be done using techniques previously described. We will measure BMD, cortical thickness, stiffness, resistance to fracture, and resistance to stress of exercise KO mice femurs versus non-exercise KO mice femurs. These results will also be compared to results from mice without hemophilia that were obtained in a prior study.

Awarded a Social Work Excellence Fellowship to:

Ellen Kachalsky, LMSW, ACSW

Henry Ford Health Systems, Detroit, MI

“The Role of the Hemophilia Treatment Center Social Worker: A National Survey”

Social workers have been active members of the multidisciplinary teams of hemophilia treatment centers for many years, but the roles of these social workers may differ greatly from center to center. Social workers are often the advocate for patients and a primary source of assistance, information, and

referral. In many HTC, they also provide counseling and therapy services to patients and consultation to staff. Indeed, these social workers appear to provide a wide variety of psychosocial and case management services to patients with bleeding disorder and their families.

This research project will attempt to describe the various role tasks of the HTC social worker, describe these tasks, and identify the influences of the role in each HTC. An online survey will be developed and emailed to the approximately 135 HTC social workers across the nation. Data will be analyzed and shared with the social work community through sessions and posters at the NHF annual meeting. It is hoped these findings will allow HTC social workers to develop and evaluate their roles in relation to their colleagues. These data may also be used to establish standards of practice that will attempt to meet the needs of social work professionals and their patients.

MASAC

NHF's Medical and Scientific Advisory Council (MASAC) held two meetings, April 18-19, 2015, and August 15, 2015, 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 2015:

MASAC Recommendation #232

MASAC Recommendations on the Care and Treatment of Individuals with von Willebrand Disease

MASAC Recommendation #233

MASAC Recommendation on Administration of Inhibitor Bypassing Agents in the Home for Patients with Hemophilia and Inhibitors

MASAC Recommendation #234

MASAC Recommendations on Treatment of Hepatitis C in Individuals with Hemophilia and Other Bleeding Disorders

MASAC Recommendation #235

MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders (Revised April 2015)

MASAC Recommendation #236

MASAC Recommendations on Standardized Testing and Surveillance for Inhibitors in Patients with Hemophilia A and B

MASAC Recommendation #237

MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders (Revised August 2015)

MASAC Recommendation #238

MASAC Recommendations Regarding Physical Therapy Guidelines in Patients with Bleeding Disorders

Chapter Services

Chapter Development

NHF's ACT initiative—Access to Care Today, Achieving Cures for Tomorrow—remains the guiding light for chapter development. Nine chapters received Capacity Building Grants to assist with staffing. Capacity-building grants have been of great use to chapters in strengthening their infrastructure. Eighteen chapters were provided Board Development Summit grants to assist in strategic planning and board development for local boards of directors. In 2015, 23 chapters received a NHF Chapter Review. This entailed looking at a wide variety of best practice standards to measure where chapters stood with meeting at least the minimum requirements in 5 categories, including governance/board leadership, programs/services, public policy/advocacy, fundraising/development, and marketing/communications. These chapter reviews assisted NHF and its affiliate and national chapters in identifying strengths and opportunities in policies, processes, and service delivery. In 2016, chapters scoring above 85% in these categories will be awarded the NHF Chapter of Excellence Award. Additional support was provided through two Regional Leadership Seminars and a full three-day chapter track at NHF's Annual Meeting that brought new training opportunities to staff and volunteer chapter leaders.

Education

Steps for Living

In 2015, the National Hemophilia Foundation expanded its content in *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. NHF launched three new videos on the website this year: "Making Your Clotting Factor Work For You," to help consumers better understand half-life; "Bleeding Disorders in the Workplace: What Employees Should Know About Rights and Accommodations;" and "Bleeding Disorders in the Workplace: What Employers Should Know." Both the workplace video for employees and the half-life video won silver awards as from the National Health Information Awards Program. In addition, new content was created for those aging with a bleeding disorder.

NHF also continues to train chapter and hemophilia treatment center (HTC) staff and volunteers in our Steps for Living Training where participants learn how to run some of our on the ground programming themselves for their local events. NHF trained 30 participants and added 3 new curriculum topics to our training manual.

Chapter Services

Education for Empowerment

New in 2015, NHF made a commitment to bring our high quality in person programming to local chapter or HTC events. NHF staff, speakers, and youth leaders facilitated 24 workshops across the country in 2015 on topics such as art workshops for youth, work-life balance, and communicating with your providers. These workshops were tailored for youth, adults, and women and were also facilitated in Spanish where requested.

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. The NYLI program in 2015 had 22 members ages 18-24. This three-year program was re-structured in 2015 to include general leadership development in year one, and opportunities for NYLI members to select a track to focus on for years two and three to truly apply their leadership skills in a more in depth way. The tracks include nonprofit development, outreach, and advocacy. NYLI members continue to participate in Washington Days and leading sessions at NHF's Annual Meeting.

Women with Bleeding Disorders

Victory for Women (V4W), NHF's current health initiative for girls and women with bleeding disorders has two main goals: 1) to increase awareness of women's bleeding disorders so that girls and women receive early, accurate diagnosis, 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.

Due to the great demand in 2014, NHF offered a second 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.

As part of a five-year cooperative agreement with the Centers for Disease Control and Prevention (CDC), to increase awareness of bleeding disorders so women can receive timely and accurate diagnosis and lead healthy full lives, NHF conducted a needs assessment survey in 2015 of over 200 women with bleeding disorders. The results have helped NHF better understand the often long and difficult path to diagnosis and what kind of support women need. NHF is using this to create a campaign for undiagnosed women with symptoms of a bleeding disorder to get the information and care they need.

Chapter Services

Von Willebrand Disease (VWD)

In response to the 2014 VWD Summit and report, NHF made a commitment to better understand the needs of the VWD community and offer more educational programming. In 2015, NHF held the first ever VWD Pre-conference at annual meeting for over 60 attendees, and followed that with a robust VWD track included nine additional sessions specifically on VWD. In addition, NHF created a VWD Welcome kit, including a booklet called “Piecing Together the VWD Puzzle” and a related VWD kid’s activity book. Over 1,000 kits were distributed in 2015. NHF also launched new on the ground workshops for chapters specifically about VWD.

Minority Populations

NHF continued to distribute and develop materials for Spanish speaking families, including translation of the new videos for consumers. NHF also conducted five focus groups across the country in Spanish to better understand the needs of this community and any barriers to accessing care or engagement in the community. These results informed additional tailored programming in 2016.

The NHF Cultural Diversity Working Group advised on content in both English and Spanish for the 67th Annual Meeting, and reviewed applications for NHF’s Connections for Learning Program, that provides assistance to individuals and/or families affected by bleeding disorders who would have been unable to attend due to financial constraints or had never attended an NHF Annual Meeting. Individuals from 35 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.

Healthy Lifestyles

As part of a Cooperative Agreement with the CDC, NHF conducted a needs assessment survey in 2015 of consumers with hemophilia to better understand motivations and barriers for physical activity and treatment adherence to inform future educational programming. The new Making Your Clotting Factor Work For You video also emphasizes the importance of treatment adherence to be able to stay active and maintain healthy joints. NHF will continue to offer Healthy Steps programming at Annual Meeting and in 2015 fitness sessions that included yoga, tai chi and dance.

Chapter Services

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, D.C consultants, other national patient advocacy groups and our various stakeholders.

Our Washington, D.C consultants work closely with various federal agencies and Congressional members to ensure that the needs of those with bleeding disorders are not lost in the process of reform.

For the past eight years, more than 300 individuals annually 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. Our 2016 Washington Days will be held February 24-26.

State Advocacy

Assistance to Chapters

The NHF State Policy Team monitors legislative activity at the state and national levels that impacts the bleeding disorders community's access to care. In support of our local chapters, we developed State Based Advocacy Coalitions (SBACs) in 10 states enabling chapters to build year round advocacy programs. The team delivered educational programming on multiple topics including advocacy training, insurance and reimbursement, healthcare climate and legislative activity across the country. Additionally, NHF provided technical assistance to chapters through strategic planning, grass roots capacity building and legislative expertise to increase and strengthen volunteer advocate engagement. More than 30 chapters received one-on-one support in the area of advocacy in 2015.

Insurance Education

In addition to providing support to local chapter leaders, the NAEP & State Advocacy programs are designed to help educate consumers, payers, healthcare providers, 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, D.C 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).

Access to care continues to be a primary focus for NHF. In order to ensure that the needs of the bleeding disorder community are considered as changes are made to the healthcare system, NHF

Chapter Services

has developed a multi-platform education series aimed at payer executives. These programs are intended to educate participants about hemophilia, its treatment, its impact on those affected, the importance of comprehensive care, and the current standards of care.

Not only is it imperative for payers to understand the community, it is important that the community, including patients, clinicians, and consumer advocates need to understand the healthcare system and the payers. Throughout the year, NHF hosts a series of in-person educational sessions for consumers. These workshops are designed to highlight the proper way to choose a health plan and how to talk to your insurance provider about your coverage.

Hemophilia treatment center (HTC) and chapter staff are often the first line of defense for community members trying to navigate their coverage. To ensure that these advocates are able to meet the community's needs, NHF also hosts an annual "Insurance & Reimbursement conference." Conference attendees hear from health coverage experts regarding the latest insurance trends.

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 expand opportunity for influence at the federal level by developing relationships with key decision makers and national patient advocacy coalitions.

NHF continues to be a recognized leader within the APLUS coalition and the Coalition for Accessible Treatments, and it is active in the development and drafting of coalition position and/or response letters. The APLUS Coalition is drafting comments in response to FDA guidance seeking questions and recommendations regarding blood donation policies. Last year, the Department of Health and Human Services amended their policy for blood donations from men who have sex with men (MSM) to allow donations from MSM who had been abstinent for the prior 12 months. Now, the FDA is seeking information about additional research that may be required to inform any further policy change.

NHF is also a leader within the Marketplace Access Project (MAP). Recently, MAP submitted comments regarding the Request for Information (RFI) entitled "Inappropriate Steering of Individuals Eligible for or Receiving Medicare and Medicaid Benefits to Individual Market Plans." MAP is a coalition of patient advocacy groups who strongly opposed the original interim final rule, Patient Protection and Affordable Care Act; Third Party Payment of Qualified Health Plan Premiums are seeking modifications. The IFR implied permission to insurance carriers in the state and federal exchanges to prohibit third party premium assistance by bona fide charitable assistance programs. The consequence of this policy is to undermine a pillar of the Affordable Care Act—the removal of the pre-existing condition exclusion. Although perhaps not intentional, this marked the first time that commercial plans have rejected third party assistance, and this event has set off a chain reaction where insurance carriers outside of the Exchange market are similarly prohibiting charitable assistance.

NHF staff worked with the Center for Pharmacy Practice Accreditation (CPPA) in the development of the Accreditation program for specialty pharmacy.

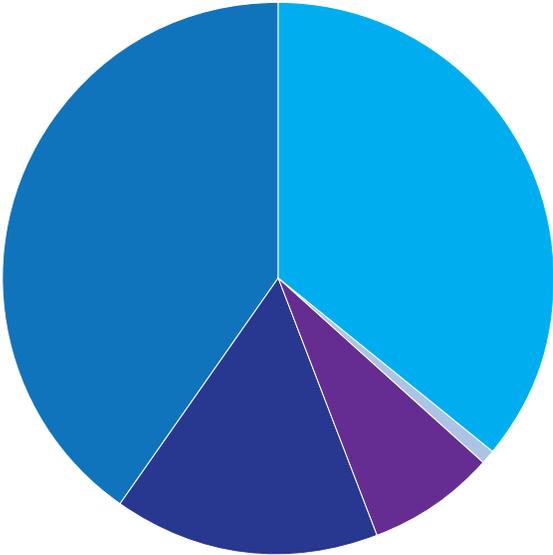
Annual Meeting

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: 2015 Annual Meeting held in Dallas, TX

2015 Annual Meeting Attendees
N= 2,834

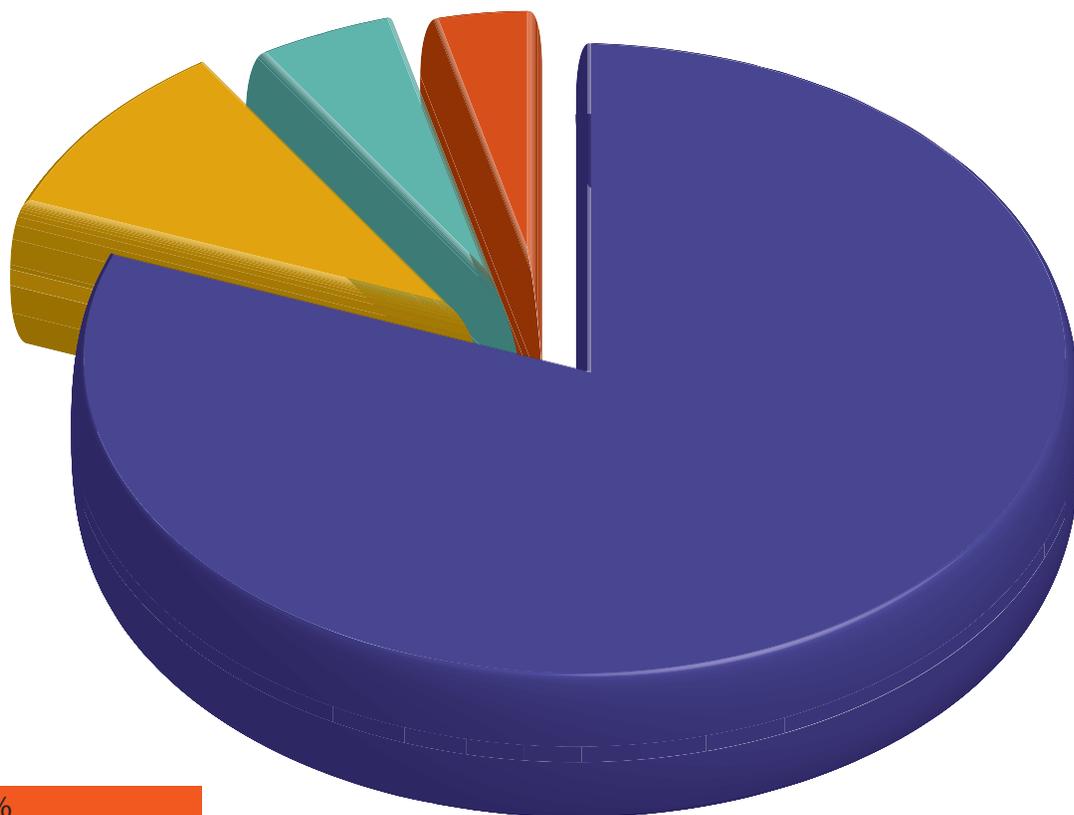


Exhibitor: 40%	1,137
Consumer/Chapter: 36%	1,020
Provider: 16%	444
Industry (non-exhibitor): 7%	212
Gov't/Nonprofit: 1%	21

Audited 2015 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, 2015, in conformity with generally accepted accounting principles. A complete set of audited financial statements for the year ended December 31, 2015 and the 990 are available at www.hemophilia.org.

Revenue for NHF



Investments: 4%	864,518
Special Events: 5%	1,075,624
Program Services: 10%	2,091,766
Grants & Contributions: 81%	16,947,878

2015 Major Contributors

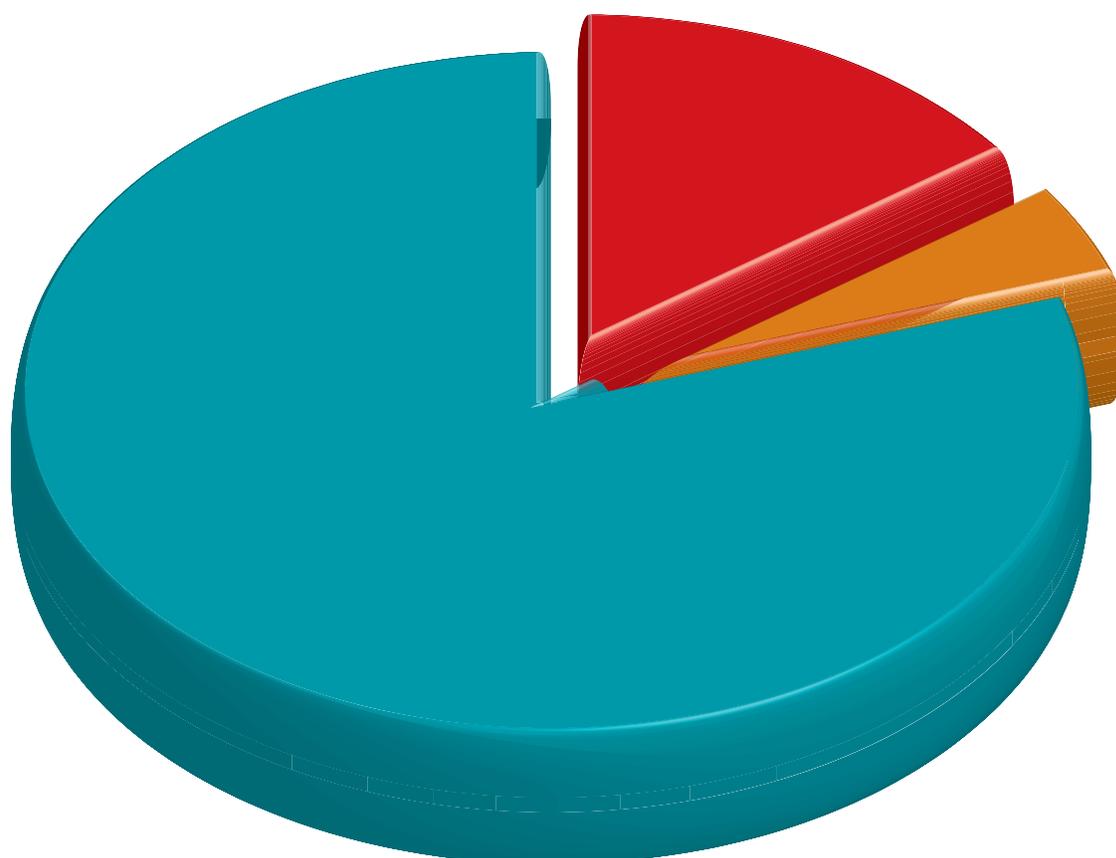
\$5.5M-\$6M	Baxter/Baxalta
\$4.5-\$5M	Novo Nordisk
\$1.5M-\$2M	Pfizer, Biogen
\$0.5M-\$1M	Bayer Corporation, CSL Behring, Grifols
<\$500,000	Centers for Disease Control and Prevention (CDC)

The ending net assets for 2015 was \$14,258,598.

*Numbers based on 2015 audited financial statements.

Audited 2015 Expenses — NHF

Expenses for NHF



Programming Services: 80%
14,636,719

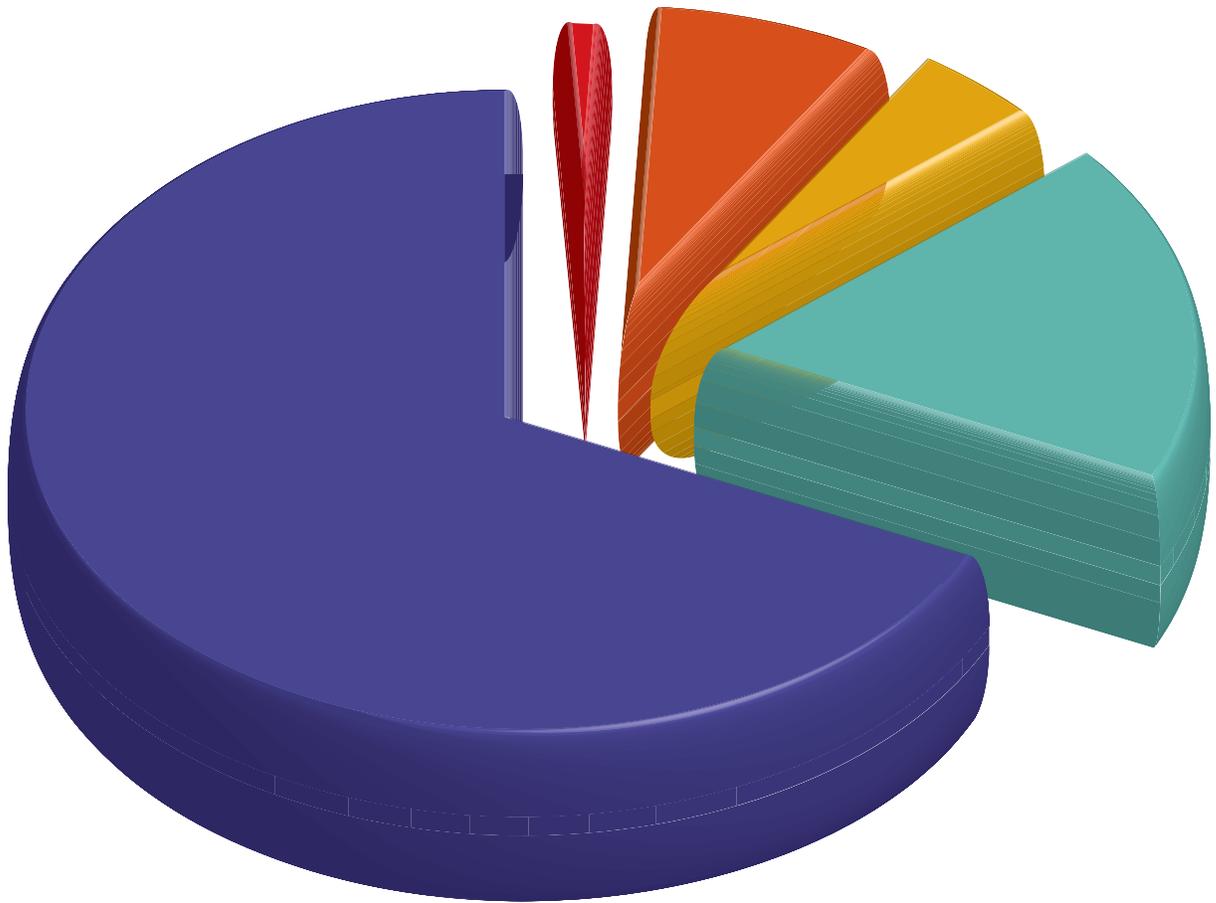
Management & General: 14%
2,574,989

Fundraising: 6%
1,070,830

*Numbers based on 2015 audited financial statements.

NHF & National Network of Chapters — Revenue

Revenue



Investment Income: 2%
992,980

Other Revenue: 5%
1,917,179

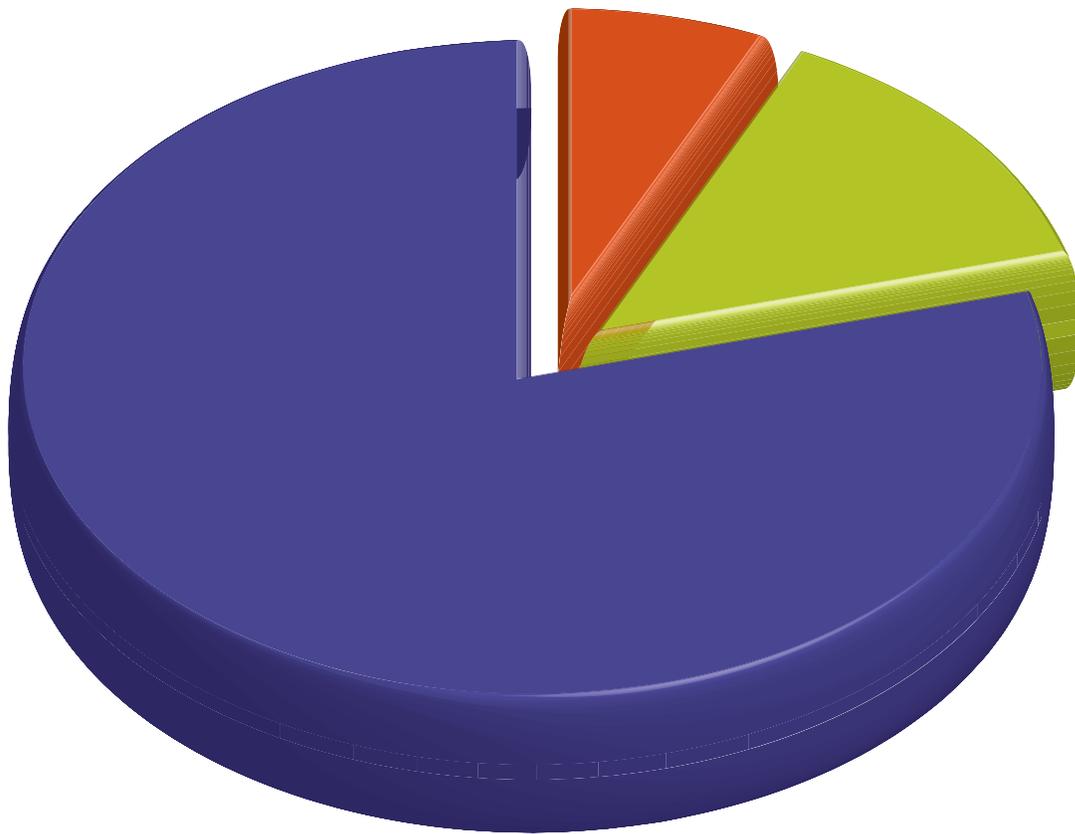
Program Services: 9%
3,625,575

Special Events: 15%
6,252,139

Grants & Contributions: 69%
28,077,667

NHF & National Network of Chapters — Expenses

Expenses



Fundraising: 7%
2,285,738

Management & General: 14%
4,268,090

Programming: 79%
24,269,060

990s were used to produce this information.

6 Chapters used the 990 short form. (2 were recorded in 2015; 3 in 2014; 1 was recorded in 2013)

34 Chapters used the regular 990 form. (9 were recorded in 2014; 25 were recorded in 2015)

10 Chapters' 990 revenue and expenses were applied across the total percentage of all 990'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, Mary M. Gooley Hemophilia Center, and Great Lakes Hemophilia Foundation.

NHF & National Network of Chapters

Period ending December 31, 2015

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

7 Penn Plaza • Suite 1204 • 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).