

**Annual Report  
of the  
National  
Hemophilia  
Foundation**

**2016**



**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 2016 are as follows:

### **2016 Board of Directors**

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# Research and Medical Information

## **HANDI**

HANDI is NHF's information resource center providing information, resources and referrals to individuals and families with bleeding disorders and their healthcare providers. Information specialists are available five days a week via an 800 phone line, through email and fax. In 2016, HANDI answered 2,885 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 4,231 NHF educational publications to individuals, local chapters, global meetings, and HTCs.

## **NHF-Shire Clinical Fellowship**

Jessica Garcia, MD

2016-Present

### **Medical College of Wisconsin**

Dr. Jessica Garcia is currently a pediatric hematology/oncology fellow at the Medical College of Wisconsin/Children's Hospital of Wisconsin. Her clinical mentor is Dr. Joan Gill, Director of the Comprehensive Center for Bleeding Disorders (CCBD) in Milwaukee, Wisconsin. Dr. Garcia's primary research mentor will be Dr. Veronica Flood, with Dr. Bob Montgomery as her secondary research mentor. Dr. Garcia attended medical school and completed her pediatric residency at the University of Illinois College of Medicine at Peoria/Children's Hospital of Illinois. During her pediatric residency, Dr. Garcia worked with Dr. de Alarcon studying the mechanisms underlying the thrombocytosis seen with iron deficiency anemia in an animal model. As a NHF-Baxalta Clinical Fellow, Dr. Garcia will receive specialized training in hemostasis and thrombosis, available through the Comprehensive Center for Bleeding Disorders (CCBD) and Blood Research Institute (BRI). Her research will focus on the biology of von Willebrand factor.

Yasmina Abajas, MD

2016-Present

### **The University of North Carolina at Chapel Hill**

Dr. Yasmina Abajas is a clinical assistant professor in pediatric hematology/oncology at the University of North Carolina at Chapel Hill, where she also completed her subspecialty training in 2016. A native of Miami, FL, she attended medical school at the University of Miami and completed her pediatrics residency at the University of Miami/Jackson Memorial Hospital. During her fellowship training, she focused on studying hemophilia B inhibitors in a humanized mouse model under the mentorship of Dr. Paul Monahan. As a NHF-Baxalta Clinical Fellow, Dr. Abajas will work on transitioning her efforts from bench research to a translational/clinical research focus under the mentorship of Nigel Key, MB ChB, FRCP, section chief of hematology and director of the Hemophilia Treatment Center at UNC Chapel Hill. Dr. Abajas will continue to focus on FIX inhibitors and evaluate whether or not a combined B and T cell immunosuppressive regimen helps with inhibitor eradication in affected hemophilia B patients.

# Research and Medical Information

## Judith Graham Pool Postdoctoral Research Fellowship

### **Klaus Bonazza, PhD**

2016–present

**Boston Children's Hospital/Harvard University**

**Boston, MA**

*JGP project: Mechanisms of Flow regulated VWF-platelet Adhesion at Different Length Scales*

*Mentor: Timothy Springer, PhD*

Klaus Bonazza received his Ph.D in chemistry from Vienna University of Technology. He is currently a postdoctoral researcher at Boston Children's Hospital and appointed at Harvard Medical School, mentored by Dr. Timothy Springer. His field of interest is the ultra-large concatemeric protein von Willebrand factor (VWF), which accounts for the adaptability of hemostasis to different flow conditions in the blood vessels.

At moderate, physiological flow VWF has a packed, “bird nest's” shape whereas strong elongational flow conditions, occurring downstream of vascular restrictions or injuries, induce a transition to a threat-like, elongated state. On top of this overall unpacking, tensile forces, which are exerted on the chain and transmitted by its A1 domain, cause local conformational changes which activate binding of thrombocyte receptor Glycoprotein Ib ( $\text{GPI}\alpha$ ) to initiate coagulation. With his JGP fellowship award, Dr. Bonazza will pioneer a new method to obtain structural insights into force dependent VWF unpacking, A1 deformation and  $\text{GPI}\alpha$  binding based on hydrogen deuterium exchange under elongational flow conditions.

### **Shekhar Kumar, PhD**

2016–present

**The Children's Hospital of Philadelphia**

**Philadelphia, PA**

*JGP Project: Structural Biology of Blood Coagulation Proteins and Their Complexes*

*Mentor: Sriram Krishnaswamy, PhD*

Dr. Shekhar Kumar is currently a postdoctoral research associate in Dr. Sriram Krishnaswamy's laboratory in the Hematology Division of The Children's Hospital of Philadelphia. Before joining Dr. Krishnaswamy's lab, he received his PhD in biochemistry from the Institute of Microbial Technology, Chandigarh, India.

In his JGP postdoctoral research, Dr. Kumar will be seeking a better understanding of the prothrombinase assembly and the vital role of membranes in the acceleration of clotting reactions. Dr. Kumar's project will generate some new structural insights about the membrane dependent assembly of the prothrombinase complex and the molecular and structural determinants of high affinity membrane binding in coagulation factor V. The information gleaned from these studies will provide molecular and biochemical insights into the role of FVa in regulating hemostasis and further elucidate the interactions between coagulation complexes.

**Megan S. Rost, PhD**

2016–present

**University of Michigan**

**Ann Arbor, MI**

*JGP project: Analysis of Blood Clot Structure and Function in the Presence and Absence of von Willebrand Factor*

*Mentor: Jordan Shavit, MD, PhD*

Dr. Megan Rost is a postdoctoral fellow at the University of Michigan. She received a BS in biochemistry and biotechnology from Michigan State University, and her PhD in molecular and developmental biology at the University of Cincinnati - Cincinnati Children's Hospital Medical Center. Her graduate work focused on understanding vascular endothelial development using zebrafish as a model organism. In July 2015, she joined the lab of Dr. Jordan Shavit in the Department of Pediatrics – Hematology/Oncology at University of Michigan. For her 2016 JGP research fellowship project, she will be using the zebrafish model to analyze blood clot structure and function in the presence and absence of von Willebrand Factor. In studying this, Dr. Rost will be elucidating how arterial thrombus formation occurs in the absence of VWF, aiding in uncovering possible new therapeutic targets for VWD treatment.

**Sol Schulman, MS, MS PhD**

2016–present

**Beth Israel Deaconess Medical Center/Harvard Medical School**

**Boston, MA**

*JGP project: Role of Protein Disulfide Isomerase in Prothrombin Activation*

*Mentor: Bruce Furie, MD*

Dr. Sol Schulman is a hematology/oncology fellow at the Beth Israel Deaconess Medical Center and Harvard Medical School. After receiving BS and MS degrees in biochemistry from Brandeis University, he earned his MD and PhD degrees through the joint Harvard/MIT Medical Scientist Training Program. Dr. Schulman performed his PhD thesis research in the laboratory of professor Tom Rapoport on human vitamin K metabolism and the mechanisms of warfarin resistance. He subsequently completed an internal medicine residency training at the Brigham and Women's Hospital in Boston. Dr. Schulman is currently a research fellow under the mentorship of Dr. Bruce Furie. His JGP award project focuses on understanding the role of protein disulfide isomerase in prothrombin activation. Protein disulfide isomerase has been found to associate with prothrombin to stimulate clot formation. Therefore, it presents a novel strategy to acutely overcome bleeding in many assorted rare coagulation disorders that remain hard to treat.

# Research and Medical Information

## **Tine L. Wyseure, PhD**

2016–present

**The Scripps Research Institute  
San Diego, CA**

*JGP project: Mechanisms and Therapeutic Strategies Targeting TAFI-mediated Vascular Remodeling in Hemophilic Arthropathy*

*Mentor: Laurent O. Mosnier, PhD*

Dr. Tine Wyseure obtained her master's degree in drug discovery and development, and earned her PhD in pharmaceutical sciences at the University of Leuven, Belgium. Since 2015, she has been a research associate in the lab of Dr. Laurent Mosnier at The Scripps Research Institute in San Diego. Dr. Wyseure's 2016 JGP research fellowship award project is focused on investigating the effects of impaired TAFI activation in hemophilia on the progression of hemophilic joint disease. The lack of active TAFI worsens joint bleeding and chronic inflammation and drives the striking development of fragile blood vessels in diseased joints. In search of the missing link, Dr. Wyseure has discovered a novel paradigm on how the formation of new blood vessels is controlled by TAFI and suggests that patients with hemophilia may lack this control switch, causing the formation of unstable and leaky blood vessels.

## **NHF/Novo Nordisk Career Development Award**

## **Janice M. Staber, MD**

2016-present

**University of Iowa Children's Hospital  
Iowa City, IA**

*Project title: PiggyBac-mediated Gene Transfer for Coagulation Disorders*

Janice Staber, MD, is currently an assistant professor and pediatric hematologist at the University of Iowa Children's Hospital. She is also a physician of the Iowa Hemophilia and Thrombosis Center in Iowa City. She received her undergraduate degree in biochemistry from the University of Iowa and her M.D. from the Carver College of Medicine at UI as well. Dr. Staber received strong mentorship under the guidance of Drs. Paul McCray and Steven Lentz during her post-doctoral research studies in gene therapy and hemophilia. She was subsequently appointed a faculty position at the University of Iowa Children's Hospital in 2010 and became an assistant professor of pediatrics in the Division of Hematology/Oncology in 2013. Dr. Staber has been the recipient of an ASH award, a Bayer award, in addition to having been a principal investigator on several external and internal grants.

As the 2016 recipient of the NHF/Novo Nordisk Career Development Award, Dr. Staber will be studying the feasibility of a novel gene therapy strategy to cure hemophilia A. This work focuses on the application of nonviral vector developed from an insect-derived DNA transposon termed "piggyBac" to transduce hepatocytes in a murine model of hemophilia A. Dr. Staber will test the 'piggyBac' system with factor VIII and von Willebrand factor to determine if the system will correct the bleeding problem and provide tolerance to inhibitors.

## **Nursing Excellence Fellowship**

Charmaine Biega, RN  
2016

**Nationwide Children's Hospital  
Columbus, Ohio**

*"A Feasibility and Usability Study of a Nursing-Orchestrated, Customized Immersive 3-Dimensional Virtual Reality Environment in Children with Hemophilia Undergoing Routine Intravenous Procedures"*

Children with hemophilia experience many needle sticks that can cause fear and pain. Virtual reality is like being inside a video game. This project is to determine if the use of a three dimensional virtual reality game that has been specifically designed for children with hemophilia can be used in the clinic setting during needle sticks. This game will be orchestrated by a hemophilia nurse who can increase or decrease what is going on in the game if the child is getting anxious or scared. We also want to know if children, their caregivers and nurses like this tool and find that it is helpful.

## **Physical Therapy Excellence Fellowship**

Anne Gonzales, PT, DPT  
2016

**Nationwide Children's Hospital  
Columbus, Ohio**

*"Exercise versus DDAVP in patients with mild hemophilia A – Which is better and do they work additively in improving hemostasis?"*

Preliminary work done by Dr. Riten Kumar and colleagues has documented that moderate intensity exercise is associated with a significant improvement in multiple coagulation parameters in post-adolescent males with mild-moderate hemophilia A. As a continuation to our previous work, we now hope to compare the impact of moderate intensity exercise to DDAVP on laboratory coagulation parameters in post-adolescent males with mild hemophilia A. We also hope to investigate the impact of sequentially administering these interventions on hemostatic indices. Our over-arching hypothesis is that increase in coagulation parameters (particularly FVIII:C) with moderate intensity aerobic exercise would be non-inferior to DDAVP. We additionally hypothesize that we will appreciate an additive effect of sequentially administering these interventions. Should our hypothesis be correct, our study would have significant clinical implications for patients with MHA. It may negate the use of DDAVP pre-exercise and could potentially lead to clinicians advising patients to appropriately warm-up (e.g. running), to raise the FVIII/VWF levels prior to undertaking more rigorous sports. It will also lay the foundation for future studies investigating the interaction between aerobic exercise and hemostasis in subjects with bleeding disorders.

# Research and Medical Information

## Social Work Excellence Fellowship

**Erin Stang, LCSW**

2016

**Oregon Health & Science University**

**Portland, Oregon**

*“Mothers’ Perceived Vulnerability, Protective Behaviors and Stress in Relation to Their Sons with Hemophilia”*

Some mothers of sons with hemophilia had a known family history of hemophilia, others did not. This research explores the differences between these two groups of mothers. It is well known that life experience impacts mothers’ parenting attitudes and behaviors toward their own children. It is unknown if there are differences between mothers of sons with hemophilia with a known family history of hemophilia when compared to mothers without a known family history. Comparison will be made of the mothers’ perceptions of how vulnerable their sons are, mothers’ protection of their sons and the stress between mothers and their sons. The results of this project will help identify differences. These differences will influence social work assessment and intervention in the comprehensive care model of hemophilia treatment center care.

## MASAC

NHF’s Medical and Scientific Advisory Council (MASAC) held two meetings, February 27, 2016, and October 22-23, 2016, to update and develop new recommendations regarding the treatment of individuals with bleeding disorders. The following are the documents that were approved by the council in 2016:

MASAC Document #239

MASAC Recommendations on Screening for Development of Hepatocellular Cancer in Patients with Hepatitis C

MASAC Document #240

MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders (Revised February 2016)

MASAC Document #241

MASAC Recommendation Concerning Prophylaxis (Regular Administration of Clotting Factor Concentrate to Prevent Bleeding)

MASAC Document #242

MASAC Recommendations Regarding Doses of Clotting Factor Concentrate in the Home

MASAC Document #243

MASAC Recommendation on SIPPET (Survey of Inhibitors in Plasma-Product- Exposed Toddlers): Results and Recommendations for Treatment Products for Previously Untreated Patients with Hemophilia A

MASAC Document #244

MASAC Recommendations Regarding the Treatment of von Willebrand Disease

MASAC Document #245

MASAC Recommendations Regarding Girls and Women with Inherited Bleeding Disorders

MASAC Document #246

MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders (Revised October 2016)

MASAC Document #247

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

# Chapter Services

## Chapter Development

It is with great pleasure that NHF recognized the Inaugural Chapters of Excellence Awards at the 2016 NHF Annual Meeting. These awards were given to chapters who demonstrated excellence in the achievement of standards and best practices evaluated through the rigorous chapter review process, scoring 85% or greater in one or more of the five chapter review areas: Congratulations to the following chapter of excellence award winners:

### **NHF Chapter Partnership Award**

Hemophilia of Indiana  
Nevada Chapter, National Hemophilia Foundation  
Nebraska Chapter, National Hemophilia Foundation  
Colorado Chapter, National Hemophilia Foundation  
Virginia Hemophilia Foundation  
Hemophilia of South Carolina  
Hemophilia Foundation of Oregon  
Rocky Mountain Hemophilia & Bleeding Disorders Association  
Lone Star Chapter of the National Hemophilia Foundation

### **Programs & Services**

Nevada Chapter, National Hemophilia Foundation  
Virginia Hemophilia Foundation  
Hemophilia of South Carolina  
Hemophilia Foundation of Oregon

### **Advocacy & Public Policy**

Virginia Hemophilia Foundation  
Hemophilia of South Carolina  
Hemophilia Foundation of Oregon  
Lone Star Chapter of the National Hemophilia Foundation  
Bleeding Disorders Association of Northeastern New York  
Bleeding Disorders Alliance of Illinois  
Northern Ohio Hemophilia Foundation

### **Fundraising & Development**

Nevada Chapter, National Hemophilia Foundation  
Hemophilia Foundation of Oregon  
Bleeding Disorders Alliance of Illinois  
Great Lakes Hemophilia Foundation  
New York City Hemophilia Chapter



## **Governance & Board Leadership**

Virginia Hemophilia Foundation  
Bleeding Disorders Alliance of Illinois  
Northern Ohio Hemophilia Foundation

In 2016, the NHF Chapter network grew to 54 strong...and counting! Please join us in welcoming the newest members of the NHF chapter network – the Arkansas Hemophilia Foundation, the Bleeding Disorder Alliance of North Dakota and the Central California Hemophilia Foundation. The chapter network has experienced a 54% growth rate in chapters since chapter services department was created in 2009 (from 35 chapters to 54 chapters).

In addition to facilitating growth within the chapter network, the chapter development team carried out 83 chapter visits in 2016. These visits included, but were not limited to the following activities:

- Facilitating board development training summits to share best practices and foster the advancement and evolution of the chapter organization;
- Chapter reviews audits designed to assist chapters with their individual growth and development toward achieving a level excellence in operations;
- Education program facilitation to support increased knowledge and exposure for consumers and chapter leaders at local chapter events;
- Supporting staff and board leadership transitions through succession planning and bridging the gap in program and services implementation; and
- Focus group facilitation to help chapters assess the needs of their local communities.

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.

# Chapter Services

## Education

### *Steps for Living*

In 2016, the National Hemophilia Foundation continued to grow *Steps for Living*, a life stage education program developed in collaboration with Pfizer Hemophilia and the Centers for Disease Control and Prevention (CDC). *Steps for Living* combines online, life stages education content with in-person workshop 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 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 27 participants and added new curriculum topics to our training manual such as communicating with providers, relationships and disclosure, parent/patient rights and responsibilities, and more.

### On the Ground Programs

Beginning in 2015, NHF made a commitment to bring our high quality, in-person programming to local chapter or HTC events through our *Education for Empowerment* and *Collaborating in Care* workshops. NHF staff, speakers, and youth leaders facilitated 24 workshops across the country in 2015 and grew this to 85 workshops in 2016. 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 2016 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 non-profit development, outreach, and advocacy. NYLI members continue to participate in Washington Days and leading sessions at NHF's Annual Meeting. New in 2016, 3rd year NYLI were matched with 1st year NYLI as mentors.

### Women with Bleeding Disorders

Victory for Women (V4W), NHF's 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 previous years, NHF offered another 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. For the first time ever, NHF brought all V4W Ventures graduates together for an in-person conference to further share with each other, gain program insights and ideas, and strategize on the future focus for women with bleeding disorders.

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 launched a campaign for undiagnosed women with symptoms of a bleeding disorder to get the information and care they need in 2016. Women can go to [betteryouknow.org](http://betteryouknow.org) to take a risk assessment tool, find more information on next steps to finding a diagnosis and treatment. NHF produced a series of videos of women sharing their stories to ensure that women don't feel alone and get the care they need, as well as created resources for chapters to use in local outreach for undiagnosed women.

## **Von Willebrand Disease (VWD)**

NHF continues to expand its educational programming for those living with VWD. NHF launched two new workshops for those with VWD: "Advocating for Yourself in the ER" and "VWD: Your Voice Matters." NHF continued to offer a robust full track on VWD at Annual Meeting, including hosting its second annual VWD Pre-Conference. VWD is a disease that affects both men and women, so NHF also launched a survey of men with VWD to better understand their needs, and debuted the men's side of [betteryouknow.org](http://betteryouknow.org) where men with symptoms of VWD are directed to find out if they are at risk.

## **Reaching Our Diverse Community**

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, which provides assistance to individuals and 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 43 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. NHF continued to distribute and develop materials in Spanish via *Steps for Living*.

## **Healthy Lifestyles**

As part of a Cooperative Agreement with the CDC, NHF launched two new nurse-led workshops that were facilitated at local chapter events and annual meeting in both English and Spanish: Half-Life in Your Life, and "It's Not Too Late to Save Your Joints". NHF also debuted its new "Make Your Move: PT Webinar Series" in 2016 with its first of six webinars on healthy active living.

# Advocacy and Public Policy

## Healthcare Reform

### National Advocacy Empowerment Program (NAEP)

NHF's public policy team is focused on insuring access to care for those affected by inheritable bleeding disorders. Healthcare across the country continues to evolve and change since the passage of the Affordable Care Act in 2010. The release of new, longer lasting therapies within the hemophilia space has been both exciting and challenging to the population we serve. As payers struggle with to manage the rising cost of healthcare, the hemophilia class of therapies has become more managed.

In response to new access challenges, NHF's policy team expanded their team to both strengthen their state and federal policy impact, and bolster their impact on challenges in the payer arena by adding staff experienced in payer relations to assist in building lines of communications between payers and providers to minimize the impact of these challenges. It is imperative that the NHF policy team remain nimble in their ability to respond to legislative, administrative and regulatory changes in all arenas that may impact access to care. This is accomplished through working collaboratively with our Washington, DC consultants, other national patient advocacy groups, and various other stakeholders.

Our Washington, DC consultants closely monitor the work of key federal agencies and Congress to ensure that the needs of those with bleeding disorders are not lost in the process of reform.

In 2016, more than 350 individuals from across the country gathered to learn about federal and state advocacy and to take part in NHF's Washington Days program. Washington Days provides community members with the opportunity to share their stories and educate their federal representatives about bleeding disorders and the impact that access to the federal hemophilia treatment center network has on treatment outcomes and quality of life. This year, NHF successfully obtained recognition from the Health and Human Services department (HHS) of the month of March as Bleeding Disorders Awareness Month.

## State Advocacy

### Assistance to Chapters

NHF's policy team includes staff dedicated to state policy. In addition to monitoring legislative, regulatory, and administrative activity at the state level that may impact access to care, the state policy team provides advocacy and healthcare coverage training and education to community members and chapter leaders. In order to insure our chapters have the capacity to advocate on behalf of the bleeding disorder communities in their respective states, NHF has helped to develop and support state based advocacy coalitions (SBAC) in 10 states in 2016. SBACs receive technical and financial support to assist them in developing a strategic plan for year-round advocacy. These programs help to create and distribute best practices for state advocacy that can be shared with other chapters. The state team also provides hands-on support to chapters in the areas of grassroots capacity building and volunteer engagement. More than 30 chapters received one-on-one support in the area of advocacy in 2015, and 27 received assistance with their state hill day programs

## 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, and state and federal policymakers and legislators. Oversight of the program is the responsibility of the Sr. VP of Public Policy and Stakeholder Relations and the Senior Policy Director 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).

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 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. As of 2016, NHF's payer websites, managedcare-hemo.com and ccschemo.com, received more than 20,000 visits with 12,340 case study participants. Our live payer webcasts included 1,800 attendees.

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.

## 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 is active in the development and drafting of coalition position and/or response letters.
- Policy Team members have been asked to speak at conferences and advisory board meetings by various national organizations (for example, Bio, PQA, Kelley Communications, Inc.)
- In addition, policy team members are often asked to provide guidance or consultation to other national advocacy associations.

## 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, healthcare providers, industry representatives, and government. 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.

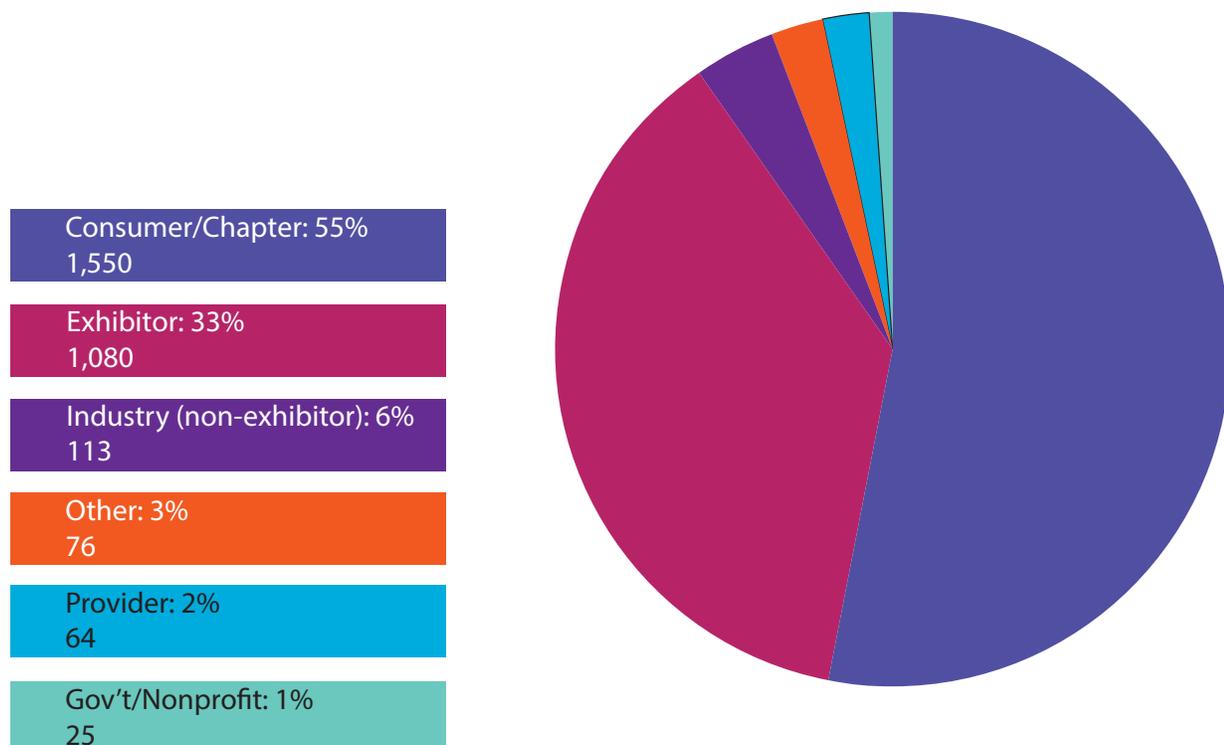
The final numbers for Orlando show that there were 2,791 participants in attendance, which does not represent an increase in attendance, but considering that we did not have a provider's track, this is a fantastic number.

There were a few obstacles that were faced from the beginning, including contracted meeting space, hotel communication and hotel overbooking of some of the meeting space contracted. In the end, the planning of the meeting ran smoothly.

NHF's Annual Meeting continues to grow and is becoming more complex to plan. With each new Annual Meeting under our belt, we are forced to review current policies and procedures and adapt, when necessary, so that we remain the single largest meeting in the bleeding disorders community in the US.

### Highlights for this reporting period: 2016 Annual Meeting held in Orlando, FL

2016 Annual Meeting Attendees  
N= 2791



## Annual Meeting 2016 Financial

Knowing that Annual Meeting registration would be at least 30% lower, all registration revenue projections were decreased over 2015 numbers to reflect this change.

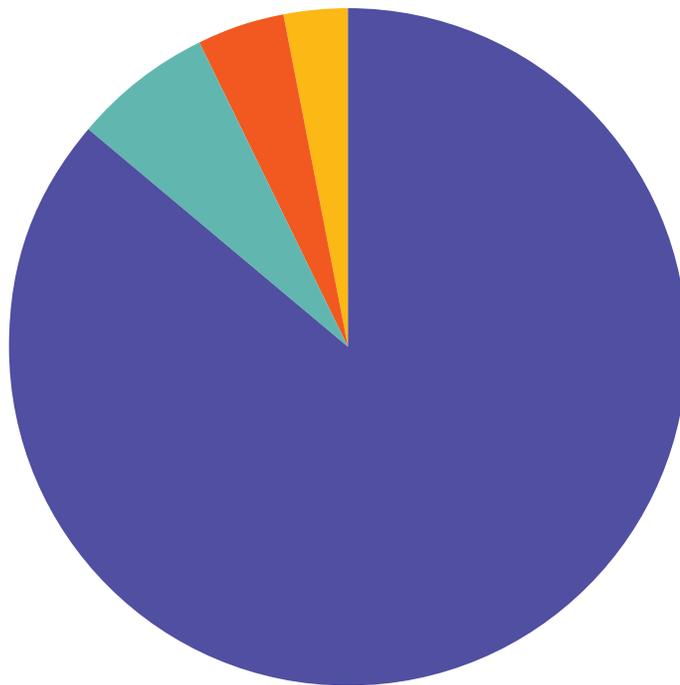
Total estimated revenues for Annual Meeting are \$4,547,106 with total estimated costs of \$1,193,613 and a total estimated gross surplus of \$3,353,493. This represents a 45% or \$1,035,198 increase over the initial budgeted gross surplus.

<b>Annual Meeting</b>	<b>2016</b>
Sponsorship	\$3,323,767.00
Exhibits	\$928,500.00
Registration	\$322,964.00
<i>HemAware</i>	(\$28,125.00)
<b>Total revenue</b>	<b>\$4,547,106.00</b>
Subtotal expense	\$1,428,399.00
Hotel credits	-\$234,786.00
	included above
<b>Total expense</b>	<b>\$1,193,613.00</b>
<b>SURPLUS</b>	<b>\$3,353,493.00*</b>

# NHF Audited 2016 Revenue

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, 2016, in conformity with generally accepted accounting principles. A complete set of audited financial statements for the year ended December 31, 2016 and the 990 are available at [www.hemophilia.org](http://www.hemophilia.org).

## Revenue for NHF



Investments: 3%  
735,745

Special Events: 4%  
1,109,328

Program Services: 6%  
1,647,784

Grants & Contributions: 87%  
22,105,480

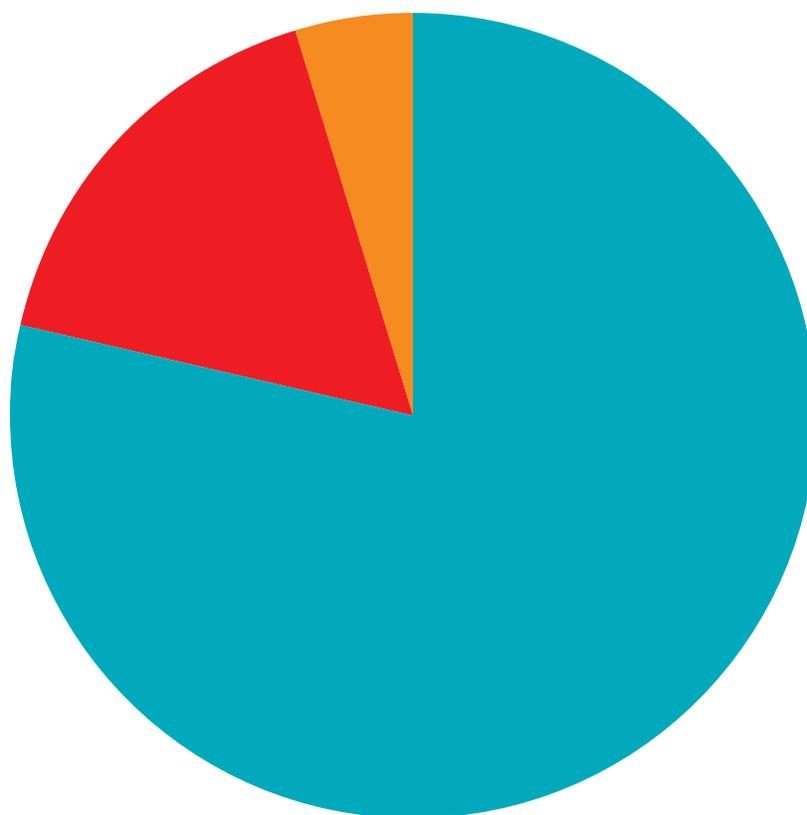
**76% of revenue comes from pharmaceutical companies.**

The ending net assets for 2016 was \$20,032,110

\*Numbers based on 2016 audited financial statements.

# NHF Audited 2016 Expenses

## Expenses for NHF



Programming Services: 79%  
15,632,191

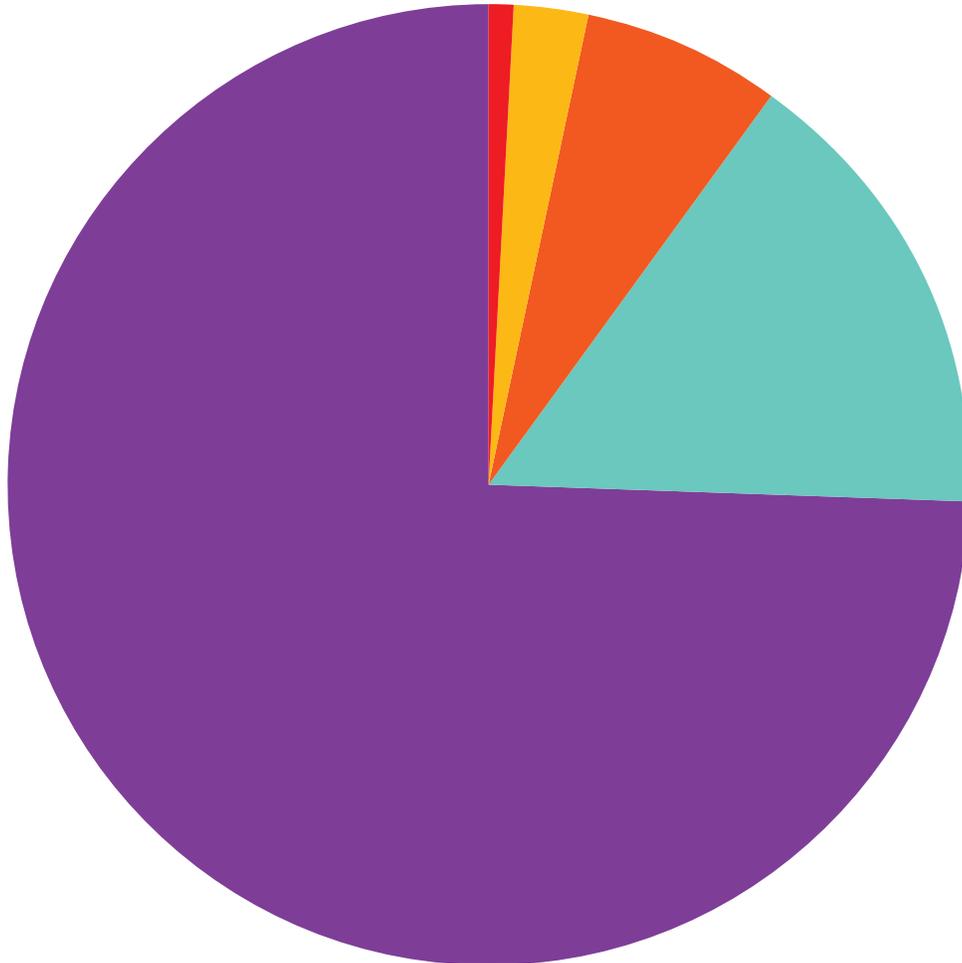
Management & General: 17%  
3,282,587

Fundraising: 4%  
910,047

\*Numbers based on 2016 audited financial statements.

# NHF & National Network of Chapters Revenue

## Revenue



Grants & Contributions: 74%  
36,602,916

Special Events: 16%  
7,691,169

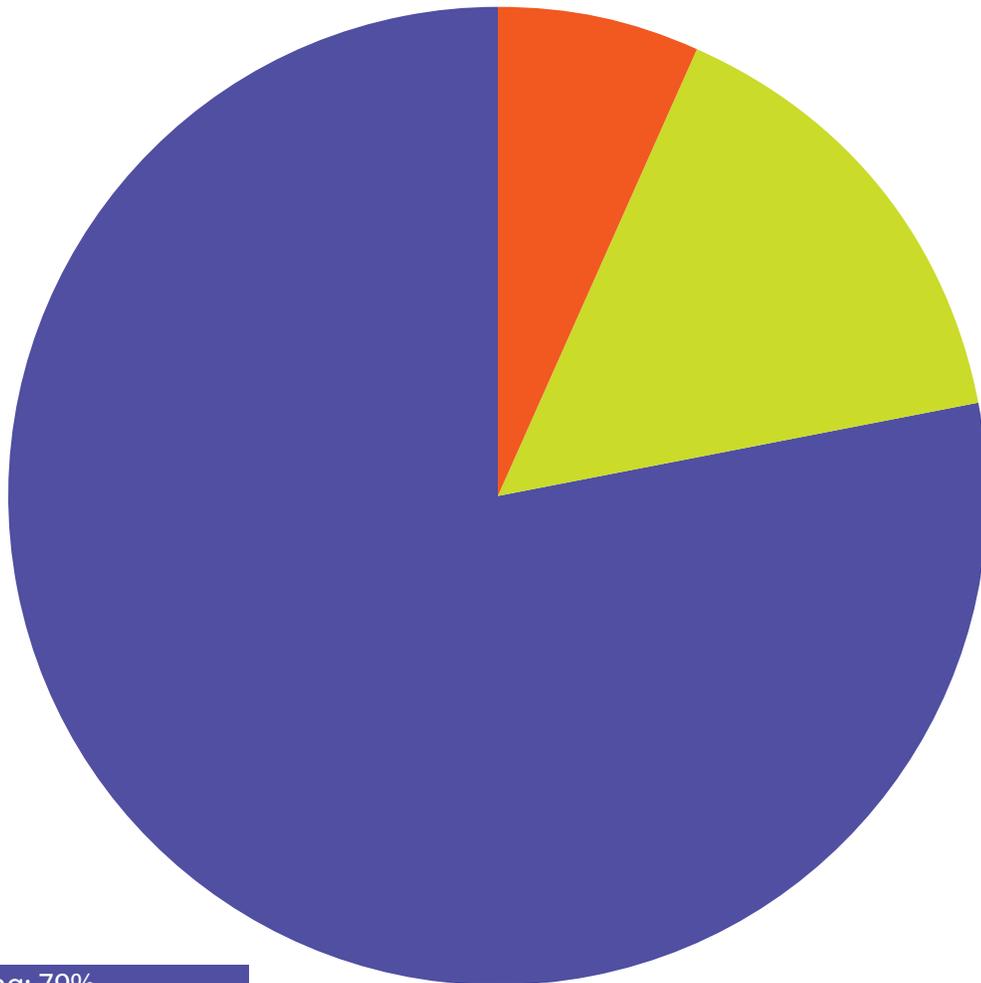
Program Services: 7%  
3,304,585

Other revenue: 2%  
1,172,931

Investment Income: 1%  
527,036

# NHF & National Network of Chapters Expenses

## Expenses



Programming: 79%  
15,632,191

Management & General: 17%  
3,282,587

Fundraising: 4%  
910,047

990s were used to produce this information.

6 chapters used the 990 short form. (4 were recorded in 2015; 2 in 2014)

35 chapters used the regular 990 form. (10 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. (Two chapters 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 Mary M. Gooley Hemophilia Center.

# NHF & National Network of Chapters

## Period ending December 31, 2016

Alaska Hemophilia Association, Anchorage, AL  
Hemophilia & Bleeding Disorders of Alabama, Wetumpka, AL  
Hemophilia Foundation of Arkansas, Inc., Little Rock, AR  
Arizona Hemophilia Association, Phoenix, AZ  
Central California Hemophilia Foundation, Sacramento, CA  
Hemophilia Association of San Diego County, San Diego, CA  
Hemophilia Foundation of Northern California, Emeryville, CA  
Hemophilia Foundation of Southern California, Pasadena, CA  
Colorado Chapter, National Hemophilia Foundation, Denver, CO  
Florida Hemophilia Association, Fort Lauderdale, FL  
Hemophilia Foundation of Greater Florida, Winter Park, FL  
Hemophilia of Georgia, Atlanta, GA  
Hawaii Hemophilia Foundation, Kaneohe, HI  
Hemophilia of Iowa, Cedar Rapids, IA  
Idaho Chapter, National Hemophilia Foundation, Boise, ID  
Bleeding Disorders Alliance Illinois- Chicago, IL  
Hemophilia of Indiana, Indianapolis, IN  
Midwest Hemophilia Association, Leawood, KS  
Kentucky Hemophilia Foundation, Louisville, KY  
Louisiana Hemophilia Foundation, Baton Rouge, LA  
New England Hemophilia Association, Dedham, MA  
Hemophilia Alliance of Maine, Inc., Augusta, ME  
Hemophilia Foundation of Michigan, Ypsilanti, MI  
Hemophilia Foundation of Minnesota and the Dakotas, Mendota Heights, MN  
Gateway Hemophilia Association, St. Louis, MO  
Rocky Mountain Hemophilia and Bleeding Disorders Association, Bozeman, MT  
Hemophilia of North Carolina, Morrisville, NC  
Bleeding Disorder Alliance of North Dakota, Fargo, ND

Nebraska Chapter, National Hemophilia Foundation, Lincoln, NE  
Sangre de Oro, Bleeding Disorders Foundation of New Mexico, Albuquerque, NM  
Nevada Chapter, National Hemophilia Foundation, Las Vegas, NV  
Bleeding Disorders Association of Northeastern New York, Troy, NY  
Hemophilia Center of Western New York, Buffalo, NY  
Mary M. Gooley Hemophilia Center, Rochester, NY  
New York City Hemophilia Chapter, New York, NY  
Central Ohio Chapter, National Hemophilia Foundation, Columbus, OH  
Northern Ohio Hemophilia Foundation, Independence, OH  
Northwest Ohio Hemophilia Foundation, Toledo, OH  
Southwestern Ohio Hemophilia Foundation, Moraine, OH  
Tri-State Bleeding Disorder Foundation, Cincinnati, OH  
Oklahoma Hemophilia Foundation, Oklahoma City, OK  
Hemophilia Foundation of Oregon, Corvallis, OR  
Eastern Pennsylvania Chapter of NHF, Springfield, PA  
Western Pennsylvania Chapter of NHF, Cranberry Township, PA  
Hemophilia of South Carolina, Greenville, SC  
Tennessee Hemophilia and Bleeding Disorders Foundation, Murfreesboro, TN  
Lone Star Chapter of NHF, Houston, TX  
Texas Central Hemophilia Association, Dallas, TX  
Utah Hemophilia Foundation, Salt Lake City, UT  
Hemophilia Association of the Capital Area, Springfield, VA  
Virginia Hemophilia Foundation, Richmond, VA  
Bleeding Disorders Foundation of Washington, Edmonds, WA  
Great Lakes Hemophilia Foundation, Milwaukee, WI  
West Virginia Chapter, National Hemophilia Foundation, Morgantown, WV



**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).