

2017

ANNUAL REPORT

NATIONAL
HEMOPHILIA
FOUNDATION



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 2017 ARE AS FOLLOWS:



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HANDI

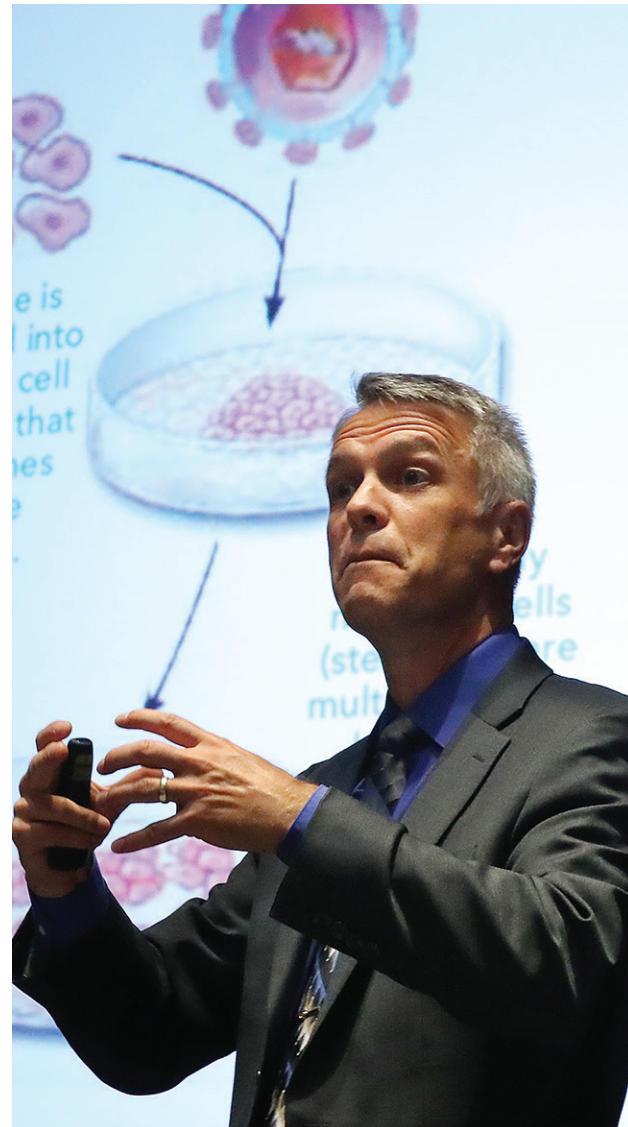
HANDI is NHF's information resource center providing information, resources and referrals to individuals and families with bleeding disorders and their healthcare providers. Information specialists are available five days a week via an 800-phone line, through email and fax. In 2017, HANDI answered 2,532 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, global meetings and HTCs.

“

I really think we are on the cusp of seeing true bioengineered variants that will substantially transform how we treat patients.

”

STEVEN W. PIPE, MD



NHF-SHIRE CLINICAL FELLOWSHIP

Patricia Zerra, MD

2017 to 2019

Emory University/Children's Healthcare of Atlanta (CHOA)

Dr. Patricia Zerra is currently completing her pediatric hematology/oncology fellowship at Emory University/Children's Healthcare of Atlanta (CHOA) and will begin an additional fellowship in Transfusion Medicine focusing on coagulation in July 2017. Dr. Zerra graduated from Connecticut College followed by two years of research at Boston Children's Hospital. She received her M.D. from Jefferson Medical College in Philadelphia and completed pediatrics residency at the University of Miami/Jackson Memorial Hospital where she served as chief resident with an additional year practicing general pediatrics. As an NHF-Shire Clinical Fellow, Dr. Zerra will work under the mentorship of Dr. Robert Sidonio, Pediatric Director of the Emory/CHOA Hemophilia Treatment Center to focus on the clinical management of children with bleeding disorders. She will also continue her current research under the mentorship of Drs. Shannon Meeks and Sean Stowell, focusing on the immune response to FVIII in an effort to identify initiating immune events that can serve as targets to prevent FVIII inhibitor formation. Her goal is to serve as a pediatric hematologist and clinical/translational researcher focusing on the care of pediatric patients at risk for developing inhibitors.

Karen Zimowski, MD

2017 to 2019

Emory University/Children's Healthcare of Atlanta (CHOA)

Dr. Karen Zimowski is a pediatric hematology/oncology fellow at Emory University/Children's Healthcare of Atlanta (CHOA). Dr. Zimowski received her BS in Biochemistry from Clemson University and her MD from the Medical College of Georgia. She completed pediatric residency at Johns Hopkins University. As a NHF-Shire Clinical Fellow, she will receive clinical training under the guidance of Drs. Robert Sidonio and Shannon Meeks in the Comprehensive Bleeding Disorders Clinic at CHOA and Special Coagulation Laboratory at Emory University. In addition, she will continue her current research projects, investigating the structure-function relationships of both coagulation factor V and factor VIII. Dr. Zimowski aims to become an expert physician-scientist in the field of pediatric hemostasis and thrombosis. She seeks to apply the knowledge gained through laboratory analysis to the clinical setting and provide the highest level of medical care to patients with bleeding and coagulation disorders.

JUDITH GRAHAM POOL POSTDOCTORAL RESEARCH FELLOWSHIP

NHF/Nicholas Cirelli Family Research Fund JGP Research Fellowship Award

Esther Cooke

2017 to 2019

University of California San Diego

Identification, Characterization and Therapeutic Targeting of Key Molecular Markers and Pathways Implicated in the Development of Hemophilic Arthropathy

Dr. Esther Cooke received her Ph.D. from the Leeds Institute of Cardiovascular and Metabolic Medicine at the University of Leeds, U.K., where she studied the role of fibrinogen phosphorylation in thrombosis. Dr. Cooke is currently a postdoctoral fellow in the laboratory of Dr. Annette von Drygalski, at the University of California San Diego, and in collaboration with the laboratory of Dr. Laurent Mosnier at the Scripps Research Institute. Dr. Cook's JGP Fellowship project will focus on pathological mechanisms associated with joint bleeding, re-bleeding, and the development of hemophilic arthropathy. Dr. Cooke will perform comprehensive gene expression analyses to explore key molecular markers and pathways that drive soft tissue inflammation and vascular changes in joints after bleeding. In this way, she hopes to identify new therapeutic targets and develop novel treatment strategies to down-regulate these processes, thereby reducing re-bleeding tendency and slowing the progression of hemophilic arthropathy.

NHF/Robert Long and Irwin Katzman JGP Fellowship Award

Satish Nandakumar

2017 to 2019

Boston Children's Hospital

Development of Hematopoietic CRISPR/Cas9 Gene Activation for Hemophilia Therapy

Dr. Satish Nandakumar is currently a postdoctoral fellow in the laboratory of Dr. Vijay Sankaran at the Boston Children's Hospital. Previously, he did his graduate work at the St. Jude's Children's Research Hospital in Memphis, Tennessee. In his JGP Fellowship project, Dr. Nandakumar aims to develop a novel gene therapy approach for hemophilia that involves activation of the endogenous factor VIII or IX genes within hematopoietic stem cells by taking advantage of the CRISPR/Cas9 gene activation system. This work has the potential to benefit patients with mild hemophilia mutations.

JGP Postdoctoral Research Fellowship

Kasturi Pal

2017 to 2019

The Scripps Research Institute

Dissecting the Roles of Non-muscle Myosin IIA in May-Hegglin Platelet Disorders

Dr. Pal is currently a postdoctoral fellow in the laboratory of Dr. Velia Fowler at the Scripps Research Institute. She received her doctoral degree working in the laboratory of Dr. Kathryn Defea at the University of California Riverside. Her current research focuses on the role of actomyosin cytoskeleton in megakaryocyte to platelet differentiation and hemostasis. Dr. Pal is specifically trying to decipher the molecular mechanisms and signaling pathways which contribute to bleeding disorders and macrothrombocytopenia associated with May-Hegglin anomaly. This research will reveal novel insights into the mechanisms of thrombopoiesis, which can be harnessed for ex-vivo platelet generation with high yields for therapeutic purposes. In the future, Dr. Pal would like to direct her research endeavors to solving platelet signaling defects contributing to hemostatic failures using multidisciplinary experimental approaches.



NHF/NOVO NORDISK CAREER DEVELOPMENT AWARD

Christopher Ng

2017 to 2019

University of Colorado Denver

The National Hemophilia Foundation (NHF) is pleased to announce Christopher J. Ng, MD, Assistant Professor of Pediatrics, University of Colorado Denver, as the recipient of the 2017 NHF/Novo Nordisk Career Development Award (CDA). The overall objectives of the CDA are to advance bleeding disorders research by promoting the development of innovative studies among established investigators. The award funds basic, pre-clinical or clinical research approaches to yielding scientific information or answers contributing to better treatments for inheritable bleeding disorders.

Dr. Ng's CDA project is on "von Willebrand Factor (VWF) regulation in blood outgrowth endothelial cells from individuals with altered VWF levels". By using blood outgrowth endothelial cells, Ng will identify the transcriptional and epigenetic modifiers that play a role in the regulation of VWF levels. He will also be utilizing novel assays for characterizing the effects. The proposed studies should shed light on our molecular understanding of VWD, advance other areas of investigation and potentially lead to better diagnostic and prediction algorithms for bleeding in VWD. Ng will be mentored on this award by Jorge DiPaola, MD, Director of Basic and Translational Research in Pediatric Hemostasis and Thrombosis at University of Colorado Denver.

Dr. Ng received his medical degree in 2008 from the Keck School of Medicine at the University of Southern California and completed his pediatric residency at the University of Washington–Seattle Children's Hospital. Dr. Ng has the distinction of having received a several previous awards from NHF and others during the early stages in his career. He is a former NHF-Shire Clinical Fellow, having received the award in 2013 while training under the mentorship of Dr. Marilyn Manco-Johnson, Director of the Hemophilia and Thrombosis Center at UCD and Dr. DiPaola (see below). Ng has been the recipient of NHF's Judith Graham Pool Postdoctoral Research Fellowship in 2015 for his project on a "Multi-system evaluation of von Willebrand factor function in Type 1 von Willebrand disease mutations" (see below). Ng also received a 2013 HTRS Mentored Research Award, the CSL Behring Professor Heimburger Award and the Hemophilia Association of New York Research Award.

Ng's immediate focus is to continue building his career as a physician-scientist, through basic and translational studies on VWF for enhancing knowledge of hemostatic and thrombotic disorders while continuing to treat patients and providing clinical leadership at the University of Colorado Denver's Hemophilia and Thrombosis Center. For the longer term, Ng hopes to one day have an independent, NIH-funded laboratory studying VWF and the biological factors that lead to varied clinical phenotypes in hemophilia and VWD.

Through the CDA, Ng will receive \$70,000 per year for up to three years. This award was selected through a process of peer review conducted by NHF's Research Review Committee. This volunteer committee is made up of highly experienced and respected physicians and researchers working in the field of hematology. NHF wishes to thank the reviewers as well as Novo Nordisk, Inc. for their very generous support of this research award.

SOCIAL WORK EXCELLENCE FELLOWSHIP

Anne Phillips, MSW

2017

Children's Hospital of Michigan, Detroit, Michigan

"Empowering the Future of Hemophilia through Swimming"

Swimming is an important life skill that benefits hemophilia patients medically and psychosocially. The goal of this project is to provide inner city children and teenagers the opportunity to learn how to swim. The swim program will be held at the Detroit Medical Center where a team of professionals will teach the basics of swimming with the goal of independent swimming by the end of the program. The team will measure the children's progress medically and psychosocially throughout the program. This program will provide children and teenagers at our HTC with an amazing opportunity and a very important life skill. We will also be utilizing adult hemophilia patients to teach the children how to swim, which will provide them with work experience and community involvement.

MASAC

NHF's Medical and Scientific Advisory Council (MASAC) held two meetings, April 8-9, 2017, and August 26, 2017, 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 2017:

MASAC Document #248

MASAC Recommendations on the NHF Genotyping Project for Persons with Hemophilia

MASAC Document #249

MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders (Revised April 2017)

MASAC Document #250

MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders (Revised August 2017)

MASAC Document # 251

MASAC Guidelines for Perinatal Management of Women with Bleeding Disorders and Carriers of Hemophilia A or B

MASAC Document #252

Guidelines for Emergency Department Management of Individuals with Hemophilia and Other Bleeding Disorders

Chapter Services

CHAPTER DEVELOPMENT

It is with great pleasure that NHF recognized a select group of chapters during the Chapters of Excellence Awards session at the 2017 NHF Bleeding Disorders Conference. 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:

National Hemophilia Foundation is proud to recognize the 2017 Chapters of Excellence Awards. (* Denotes new awardee for 2017) 41 total awards, 1 Five-star Chapter (BDAL).

NHF Chapter Partnership Award

- Bleeding Disorder Alliance of Illinois*
- Colorado Chapter, National Hemophilia Foundation
- Gateway Hemophilia Association*
- Great Lakes Hemophilia Foundation*
- Hemophilia Foundation of Oregon
- Hemophilia of Indiana
- Hemophilia of South Carolina
- Lone Star Chapter of the National Hemophilia Foundation
- Nebraska Chapter, National Hemophilia Foundation
- Nevada Chapter, National Hemophilia Foundation
- Rocky Mountain Hemophilia & Bleeding Disorders Association
- Texas Central Hemophilia Association*
- Virginia Hemophilia Foundation

Programs & Services

- Bleeding Disorder Alliance of Illinois*
- Hemophilia Foundation of Oregon
- Hemophilia of South Carolina
- Lone Star Chapter of the National Hemophilia Foundation*
- Nevada Chapter, National Hemophilia Foundation
- New England Hemophilia Association*
- Northern Ohio Hemophilia Foundation*
- Virginia Hemophilia Foundation

Advocacy & Public Policy

- Bleeding Disorder Alliance of Illinois*
- Bleeding Disorders Association of Northeastern New York
- Hemophilia Foundation of Oregon
- Hemophilia of South Carolina
- Hemophilia Foundation of Southern California*
- Lone Star Chapter of the National Hemophilia Foundation*
- New England Hemophilia Association*
- Northern Ohio Hemophilia Foundation
- Texas Central Hemophilia Association*
- Virginia Hemophilia Foundation

Fundraising & Development

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

Governance & Board Leadership

- Bleeding Disorder Alliance of Illinois
- Hemophilia Foundation of Southern California*
- Northern Ohio Hemophilia Foundation
- Virginia Hemophilia Foundation
- Western Pennsylvania Chapter of the National Hemophiia Foundation*

In 2017, NHF Chapter Services conducted a comprehensive needs assessment survey to guide the goals and activities of the department through the next chapter charter agreement (2018-2020). Seventy-Four percent (74%) of chapters participated in the survey, representing all regions of the country, as well as chapters both large and small. Listed below is a summary of chapter services focus areas through the year 2020, as identified through the needs assessment feedback results.

Expansion of fundraising and development training and support to assist chapters in creating systems and strategies to help them diversify revenue and maximize funding options.

Continuation of the successful capacity-building grant programs which have expedited growth and improvement efforts as well as best practice standards alignment when coupled with Chapter Services assistance.

Creation of comprehensive volunteer management system tools, resources, and on-going training to build true volunteer opportunities within the chapters.

Modification of chapter board development summit support to focus on fewer chapters, but with a more intensive assistance plan, to ensure chapter leadership infrastructure is advancing at the pace of chapter operations.

Contribute to the development of chapter marketing and communications campaigns to raise awareness and overall chapter relevancy both within the bleeding disorders community as well as within the general public.

EDUCATION

Steps for Living

In 2017, 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 36 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 134 workshops in 2017. 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 2017 had 23 members ages 18-24. This three-year program includes 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 2017, 4 NYLI participated in internships at local chapters or NHF.

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 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. This program started in 2017 but finished in 2018 with 11 participants. NHF also piloted 3 new workshops for Girls at Camp in 2017.

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. Women can go to 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. The total reach of these outreach efforts (social media impressions, partnership reach, publications distributed etc.) in 2017 was over 700,000.

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 3rd annual VWD Pre-Conference.

Reaching Our Diverse Community

The NHF Cultural Diversity Working Group advised on content in both English and Spanish for the 68th 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.

NHF also launched its new Guías Culturales program. The Guías are culturally intelligent volunteers who are the path to service to the bleeding disorders community, acting as “guides” to diverse members of the bleeding disorders community. NHF recruited and trained 9 Guías in 2017 who presented at 2 chapter events in 2017.

Healthy Lifestyles

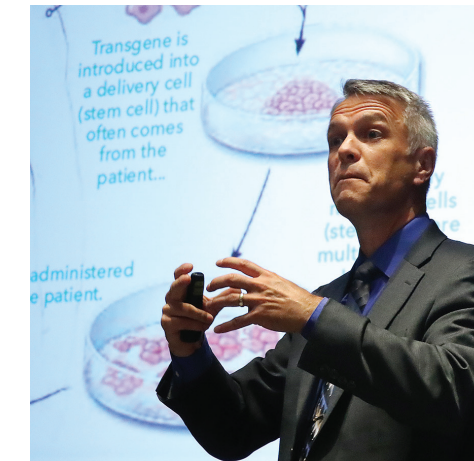
As part of a Cooperative Agreement with the CDC, NHF continues to offer two new nurse led workshops that were facilitated at local chapter events and annual meeting in both English and Spanish: Half-Life in Your Life, and “It’s Not Too Late to Save Your Joints”, as well as a PT led workshop on Playing It Safe: Bleeding Disorders, Sports & Exercise. NHF updated the Playing it Safe publication and distributed it to all HTC’s and Chapters.

Inhibitor Education

NHF hosted 3 National Inhibitor Summits in 2017, for those with an active or tolerized inhibitor and their support network. The 3-day educational conference reached 727 participants in 2017. In addition, NHF hosted one Spanish Inhibitor Summit in 2017, offering educational workshops all in Spanish. 87 participants attended the Spanish summit.

Rare Factor Deficiency Programs

NHF offers unique educational programs for families affected by rare bleeding disorders. For those with factor XIII deficiency, NHF hosted its 3rd annual Strength in Numbers: Factor 13 Family Conference. New in 2017, NHF launched The Power of Ten conference, for those with factor X deficiency. Both programs were held as pre-conferences to NHF’s Annual Meeting, allowing families to attend all the education content of the larger meeting as well. NHF was pleased to be able to bring 46 factor XIII participants and 43 factor X participants together for education and connections at these programs in 2017.



Advocacy and Public Policy

HEALTHCARE REFORM

National Advocacy Empowerment Program (NAEP)

Federal based advocacy for the bleeding disorders community is of utmost urgency at this time. The lifetime cost of treating someone with a bleeding disorder is widely acknowledged and documented. Provisions included in the 2010 Affordable Care Act (ACA) have particular resonance for this community, notably protections for people with a pre-existing condition (like hemophilia and VWD), the federal definition of essential health benefits (EHBs), and coverage under Medicaid for adults without children in the 32 states where Medicaid was expanded.

All of these critical provisions were at risk with various legislative proposals introduced in Congress throughout 2017. Due to the high stakes for the bleeding disorders community, NHF engaged in unprecedented ways to defend healthcare for the community. This was evidenced in the magnitude and frequency of our efforts in Washington. Approximately 500 consumers attended NHF's Washington Days program to learn more about legislative and administrative changes happening at both the federal and state levels and an additional 50 consumers returned to Washington 2 months later to visit the offices of their Senators in response to the passage of the AHCA by the House of Representatives.

In addition, we continued to expand our efforts to raise awareness of the condition and the need for affordable healthcare through enhanced advocacy efforts across social media in new and innovative ways. We continued to partner closely with other national health organizations, payers and employer groups consistently throughout the year to ensure the needs of this community were understood and considered.

STATE ADVOCACY

Assistance to Chapters

The NHF 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 helped to develop and support state-based advocacy coalitions (SBAC). The SBAC program has grown from 5 states at inception in 2013 to 15 states in 2017 and included a new advanced advocacy track for our more seasoned advocates. technical and financial

The intent of the program is to move our chapters beyond the capacity building phase to the "next level" of advocacy, which would include developing more sophisticated volunteer advocates, playing a more significant role in state patient coalitions, and establishing stronger relationships with key legislators and administration officials, such as the state Medicaid programs and insurance commissioner offices. NHF's state policy team provided ongoing financial and technical support to both the capacity building and advanced advocacy participants.

These programs continue to help create and distribute best practices for state advocacy that can be shared with other chapters and other health advocacy groups. NHF's policy team also continues to provide ALL NHF chapters hands on support 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 2017 and over 28 received assistance with their state hill day programs.

“ A lot of volunteer advocates come to Washington Days, feel empowered by their experience and then go home wanting to get involved with their chapters' advocacy program.

”

NATHAN SCHAEFER



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 External Affairs and the Senior Policy Director 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 the core 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 continues to expand its education programs for payer executives. These programs are intended to educate participants about hemophilia, the current treatment landscape, as well as emerging therapies, and their collective impact on those affected. Like NHF's other advocacy programs, the payer program is delivered across various platforms including online educational modules, webinars and live presentations. NHF also hosts two websites dedicated to payer education and collaborative opportunities.

Not only is it imperative for payers to understand the community, it is important that the community, including patients, clinicians & consumer advocates need to understand the health care system and the payers. Throughout the year, NHF hosts a series of in-person educational sessions for consumers focused on health insurance, now it works and how to choose the plan that is right for you.

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 is active in the development and drafting of coalition position and/or response letters.

Policy Team members are invited to present at national conferences and advisory board meetings by various professional organizations (for example, Bio, AMCP, and others).

In addition, NHF's team is often sought out by other national advocacy associations looking for guidance and/or consultation on key healthcare issues.

“

When you all come together and speak with one voice, you can accomplish great things.

”

VAL D. BIAS, CEO



Conference & Travel Services

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 Chicago show that there were 2,979 participants, which represents an increase in attendance, making the 69th edition of Annual Meeting the largest in NHF's history.

There were several obstacles that we faced from the beginning, including contracted meeting space, and Union negotiation and fees. In the end, the planning of the Conference ran smoothly.

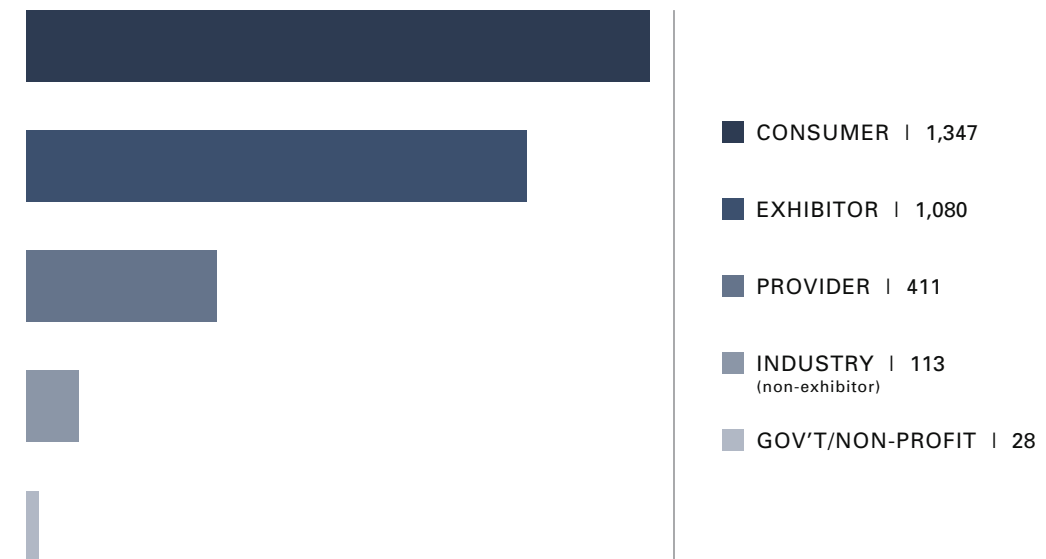
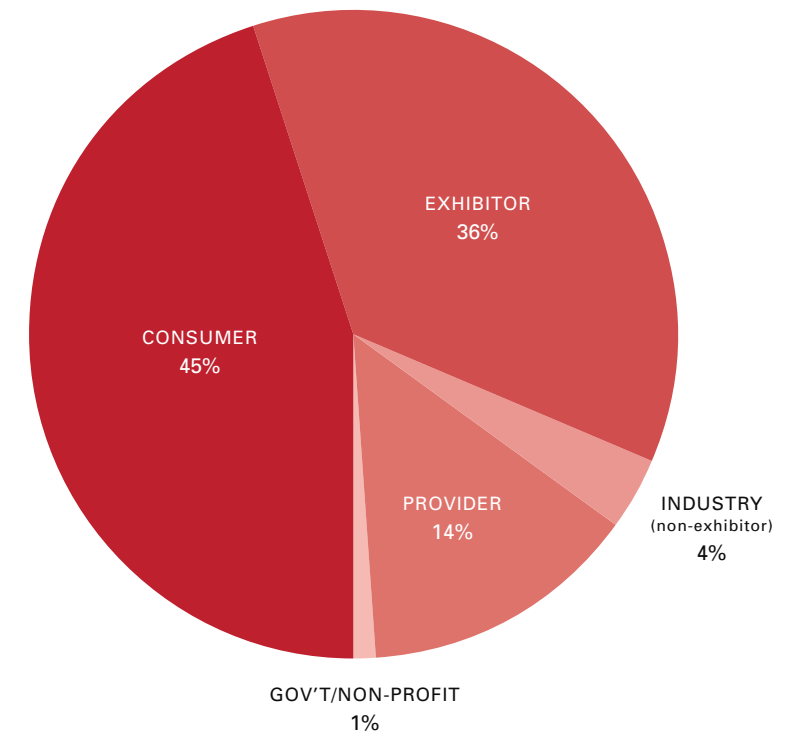
NHF's Annual Meeting continues to grow and is becoming more complex to plan. With each new Annual Meeting under our belt, it is essential to review current policies and procedures and adapt, when necessary, so that we remain the single largest meeting in the bleeding disorders community in the USA.

Registration

Attendance 2,979 participants. There were 50 Exhibitor groups (10 or more attendees) that registered for Annual Meeting, which represented approximately 1,080 Annual Meeting registrations. Once again, all group coordinators were asked to make an appointment just prior to the start of the conference so that they could verify the names of all their guests/attendees and ensure that all necessary documentation was included in their attendee kit. These appointments were held in a meeting room at the Hyatt Regency Chicago on August 22 and 23, 2017.

HIGHLIGHTS FOR THIS REPORTING PERIOD:

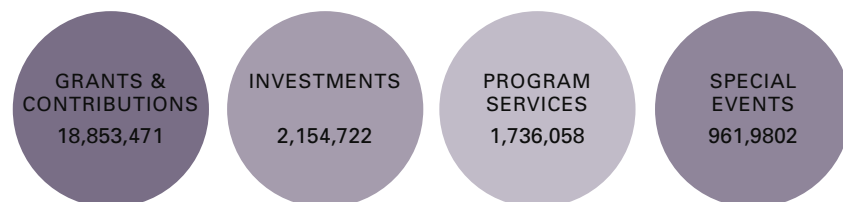
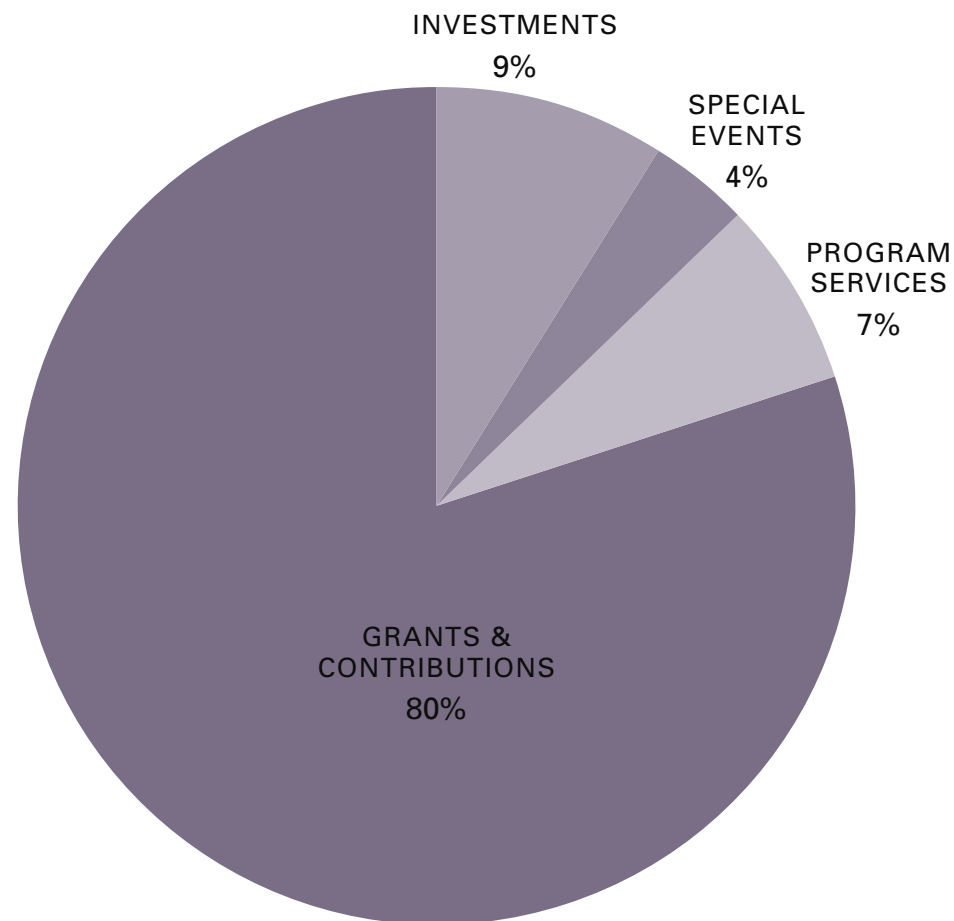
2017 Annual Meeting: Total Attendees 2,979



NHF Audited 2017 Revenue

REVENUE FOR 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, 2017, in conformity with generally accepted accounting principles. A complete set of audited financial statements for the year ended December 31, 2017 and the 990 are available at www.hemophilia.org.



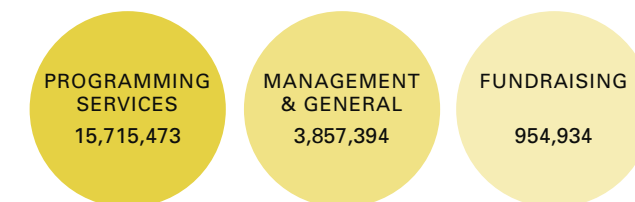
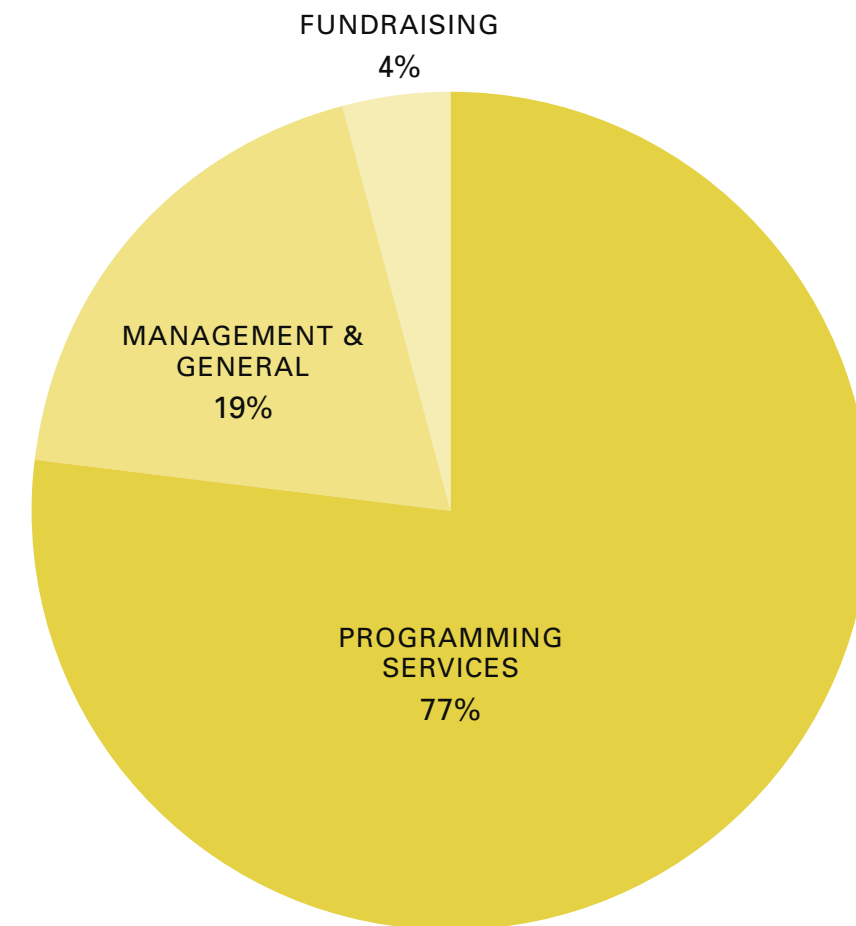
82% of revenue comes from pharmaceutical companies

The ending net assets for 2017 was \$23,210,540

*Numbers based on 2017 audited financial statements

NHF Audited 2017 Expenses

EXPENSES FOR NHF



Affiliated Chapters

period ending December 31, 2017

Alaska Hemophilia Association

Anchorage, AK

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

Omaha, NE*

Sangre de Oro, Bleeding Disorders Foundation of New Mexico

Los Ranchos, 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, NY*

*Chapters owned by The National Hemophilia Foundation

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