

# 2020

## ANNUAL REPORT



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

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**THE NATIONAL HEMOPHILIA FOUNDATION IS  
DEDICATED TO FINDING BETTER TREATMENTS AND  
CURES FOR INHERITABLE BLEEDING DISORDERS  
AND TO PREVENTING THE COMPLICATIONS OF  
THESE DISORDERS THROUGH EDUCATION,  
ADVOCACY, AND RESEARCH.**

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The programmatic activities and accomplishments in support of this mission conducted in FY 2020 are as follows:

## A Letter from Dr. Len Valentino

Dear friend,

Community is at the heart of everything NHF does. It was our community that centered us as we together experienced the dramatic and heartbreaking impact of the many tragic events of 2020, including the COVID-19 pandemic, racial injustices, and economic uncertainty.

While you or I cannot fully predict what the future holds, we can stand steadfast together in NHF's mission of finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy, and research.

Through all the unprecedented days of 2020, this community still rose to the challenge and worked together to advance our priorities and make progress toward a future with cures for inheritable blood disorders. It was impressive to witness the maintained focus, commitment, and dedication despite all. As 2020 was my first year at the helm of NHF, it was of course a challenging time to be a new CEO – but I was routinely put at ease by the spirit and positivity of our community. Every day, YOU reminded me of the intense spirit, positivity, and hope that resides within the inheritable blood disorders community. Thank YOU for being a beacon of light and a fortitude of strength.

This community proves unstoppable, again and again – even in a virtual setting! From the annual Bleeding Disorders Conferences to Run/Walks and more – this amazing community showed up and raised their voices for the cause. And NHF delivered new resources to amplify and respond to the community's needs, from a new Wednesday Webinar education series to a specialized COVID-19 resource bank for HANDI, NHF's resource and information library. This year's annual report highlights how we worked towards achieving increased research funding, awareness, and education for inheritable blood disorders around the country.

I invite you to read on to learn more about NHF's work, our partners, our national chapters, and more. Thank you for making an impact with us in 2020, and for your continued generous contributions to this cause. Here's to a future full of precedented times.

Sincerely,

*Len Valentino*

Leonard A. Valentino, MD  
NHF CEO and President



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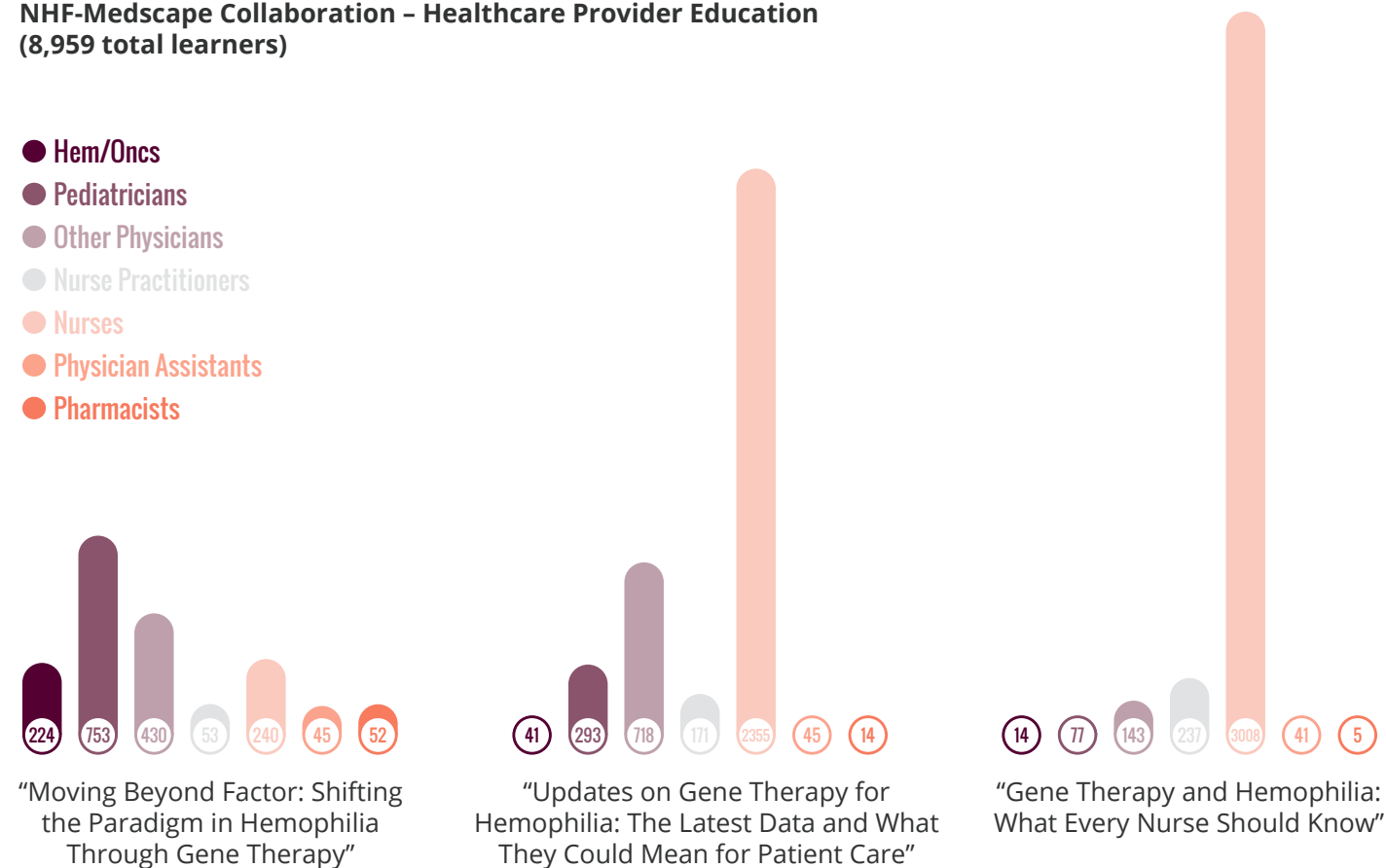
**Michelle Witkop, DNP, FNP-BC**  
HEAD OF RESEARCH

# Medical Programs and Information

NHF's Medical Programs and Information departments provides consumers with necessary information for living and thriving with an inheritable blood disorder, and also offers accredited continuing education programs for providers. Read on to see some of 2020's achievements.

NHF-Medscape Collaboration – Healthcare Provider Education (8,959 total learners)

- Hem/Oncs
- Pediatricians
- Other Physicians
- Nurse Practitioners
- Nurses
- Physician Assistants
- Pharmacists



# Provider Education - Women with Bleeding Disorders

NHF successfully extended the accreditation period until October 31, 2020 for 3 educational webinars focused on women with bleeding disorders. Jointly provided by NHF, Impact Education and Postgraduate Institute for Medicine, this webinar series was targeted to primary care physicians, obstetricians/gynecologists, registered nurses/nurse practitioners, dentists, other specialists and allied health professionals working outside the HTC network or outside the specialty of hematology.

**"An Introduction to the Recognition, Appropriate Diagnosis, and Timely Management of VWD and other Bleeding Disorders among Women in Non-Hematology Health Care Settings"**, (supported by an independent grant from Shire, as well as a cooperative grant funded by CDC).

**"Advanced Considerations for the Recognition, Appropriate Diagnosis, and Timely Management of VWD and Other Bleeding Disorders among Women in Non-Hematology Health Care Settings"**, (supported by an independent grant from Shire, as well as a cooperative grant funded by CDC).

**"Improving Outcomes for Females with Bleeding Disorders in Non-Hematology Healthcare Settings"**, (supported by an independent grant from Novo Nordisk, Inc., as well as a cooperative grant funded by CDC)

Designed to increase the knowledge of healthcare providers on the symptoms and treatment options for women with bleeding disorders, a total of 199 individuals completed the 3 webinars in the re-accredited period, bringing the grand total since launch, to 9,122 participants overall – with 467 webinar completers, and 95% representing providers practicing outside the field of hematology.

84%

84% of completers reported plans to implement changes to their practice or that the information shared reinforced their current practice. Among those completers, an estimated 19,760 patients would benefit from their increased knowledge and competence because of this activity.

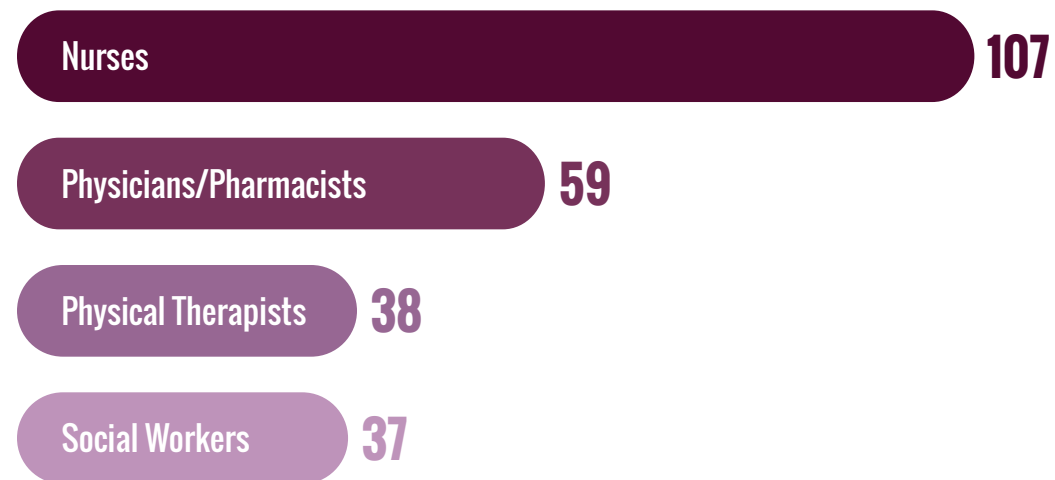
# NHF's 72nd Virtual Bleeding Disorders Conference Provider Education Tracks

Held August 1-7, 2020 – were attended by a total of 1,146 health care providers in the US and from several other countries around the world. Jointly provided by Postgraduate Institute for Medicine (PIM) and NHF, the accredited education sessions provided by this conference included:

- a maximum of 6.0 AMA PRA Category 1 Credits™ for Physicians
- a maximum of 6.0 contact hours (0.60 CEUs) of the Accreditation Council for Pharmacy Education
- a maximum of 10.25 continuing nursing education contact hours, and up to an additional 2.0 contact hours of pharmacotherapy credit for Advanced Practice Registered Nurses (APRN).
- Up to 1.5 Ethics and 5.0 Clinical continuing education credits for social workers

NHF additionally secured a maximum of 10.0 contact hours through California Education Connection for physical therapists.

PIM and NHF issued continuing education credits to a total of 241 health providers. [The breakdown of this number was as follows: 107 nurses, 59 physicians/pharmacists, 37 social workers and 38 physical therapists.]



# Provider Education

## Physician/Pharmacist/Physician Assistant Sessions:

- “Forging a New Path – Gene Therapy Readiness and HTC Implementation” – 309
- “The Next Wave: Clinical Updates on New Emerging Treatment Options in Hemophilia Part 1” - 248
- “The Next Wave: Clinical Updates on New Emerging Treatment Options in Hemophilia Part 2” - 217

## Nursing Sessions:

- Cannabis Applications – 143
- Care Coord for the Aging Pop – 106
- Challenging Cases – 111
- Disorders of Fibrinogen – 99
- Gynecologic Management – 114
- Management of Patients on Novel Therapies – 234
- Mild Phenotypes – 198
- Today's Technology and Ethics – 144
- Walking a New Pathway: Coagulation Measures – 109

## Physical Therapy Sessions:

- Demystifying the Iliopsoas – 69
- Hemo 201: What to Do When You Have No Clue – 63
- How to Survive 3-5: Developmentally Appropriate Care for PWBD Ages 3-5 – 55
- Just Do It or Not – 66
- Men? I Feel Like a WOMAN . . . With a Bleeding Disorder – 54
- Nipping Pain in the Bud – 135
- Pain Management: Tool Box Not a Pill Box – 124
- Total Joint Replacement – 97

## Social Work Sessions:

- COVID19 Provider Mental Health – 93
- Ethics and Boundaries – 74
- Marijuana Breaking It Down – 84
- Our Resilient Minds – 54
- Poverty and Barriers in HC – 105
- Prevalence of Depression – 97

## Five New or Updated MASAC Documents

- #263 - MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders
- #262 - MASAC Resolution on Off-Site Hemostasis Testing
- #261 - Recommendations for Bleeding Prophylaxis in Bleeding Disorder Patients Undergoing GI Endoscopy
- #260 - Management of Chronic Pain in Persons with Bleeding Disorders: Guidance for Practical Application of The Centers for Disease Control's Opioid Prescribing Guidelines
- #258 - Recommendation on the Use and Management of Emicizumab-kxwh (Hemlibra®) for Hemophilia A with and without Inhibitors

# 2020 Fellows

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## 2020 Nursing Excellence Fellow

Amanda Greene  
Emory University School of Medicine

*Retrospective Chart Review of Joint Outcomes and Hospital Utilization for Persons with Hemophilia A (with and without inhibitors) Who Were Switched to Emicizumab for Treatment Prophylaxis*

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## 2020 Physical Therapy Excellence Fellow

Nancy Durben  
Oregon Health & Science University

*Mindful Yoga for People with Bleeding Disorders and Chronic Pain*

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## 2020 Social Work Excellence Fellow

Kathaleen Schnur  
Hemophilia Center of Western Pennsylvania

*Defining the Micro and Macro Roles of the Hemophilia Treatment Center Social Worker in the United States from an Interdisciplinary Team Perspective*

# NHF-Takeda Clinical Fellows

## NHF selected 3 new NHF-Takeda Clinical Fellows to receive 2 years of mentored training through the NHF-Takeda Clinical Fellowship program.

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**Megan Brown, MD** is a third-year fellow in the Pediatric Hematology and Oncology program at Emory University. As an NHF-Takeda Fellow, she will be mentored by Dr. Robert Sidonio Jr., and Dr. Shannon Meeks at Emory/CHOA. Dr. Brown graduated AOA from Michigan State University College of Human Medicine. She did her residency at Denver Children's Hospital where she was exposed to the Hemophilia and Thrombosis Center there. This led her to choose Emory University given its strength in hematology. She was selected as Chief Fellow and has already had presentations at several national professional MD meetings. She was set to complete a Masters' degree in Clinical Research in May 2020 which was funded through an NIH TL1 award. Dr. Brown has an interest in medical education and will continue her work on a quality improvement project for adolescent women with heavy menstrual bleeding. Her long-term career goal is to be an externally funded, independent, physician-scientist at a pediatric academic institution where she will focus on pediatric hemostasis and thrombosis.

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**Mary McGrath, MD** is a pediatric coagulation disorders fellow at The University of Michigan, Mott Children's Hospital. A native of Buffalo, NY, she attended medical school at the University at Buffalo Jacobs School of Medicine and Biomedical Sciences and completed her pediatric residency at the Women and Children's Hospital of Buffalo. Dr. McGrath completed her pediatric hematology/oncology fellowship at Penn State Children's Hospital. As an NHF-Takeda Clinical Fellow, she will receive clinical training at the University of Michigan under the mentorship of Drs. Steven Pipe, Jordan Shavit and Angela Weyand in the comprehensive Hemophilia and Coagulation Disorders Clinic as well as in the special coagulation laboratory. Dr. McGrath will also continue her current research evaluating the impact of heavy menstrual bleeding on the mental health of adolescents and young adults with bleeding disorders. Dr. McGrath's long-term goals are to provide excellent care to patients with hemophilia and coagulation disorders, and to further the field of hemostasis and thrombosis through clinical research.



# NHF-Takeda Clinical Fellows

**Patrick Ellsworth, MD** is in a fourth year combined pediatric/adult hematology fellowship at the University of North Carolina at Chapel Hill (UNC). As an NHF-Takeda Fellow, he will receive mentored training from Dr. Nigel Key. Dr. Ellsworth received his MD from Ohio State University College of Medicine and went on to do his residency at the University of Rochester Medical Center, in both Internal Medicine and Pediatrics. He presented two posters at ASH 2018, both of which were focused on the utility of porcine factor VIII in patients with inhibitors and with acquired hemophilia A. One manuscript was submitted for publication, and the other is in preparation. In the lab, he has been involved in many projects relevant to hemostasis and thrombosis, with a primary focus on the development of a microfluidic system to model the role of endothelial cells in coagulation. In the past year, Dr. Ellsworth has taken care of pediatric and adult in- and outpatients with bleeding disorders and volunteered to assist with visits for patients enrolled in hemophilia gene therapy clinical trials. He is also initiating a collaboration with scientists at the FDA, investigating the mechanism of immune tolerance with FVIII-Fc fusion protein in patients with high-titer inhibitors.

# HANDI

HANDI is NHF's information resource center providing information, resources and referrals to individuals and families with bleeding disorders, healthcare providers and the public. Information specialists are available five days a week by phone, and inquiries can always be sent by email or vmail.



In 2020, HANDI answered 701 requests for information in a wide range of subject areas that included hemophilia, von Willebrand disease, gene therapy, rare bleeding disorders, questions related to Covid-19, psychosocial issues, and international requests.



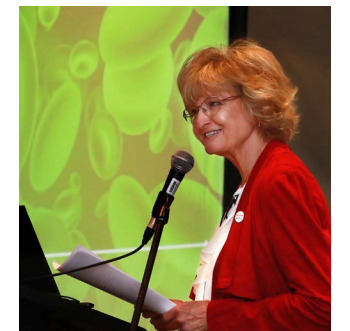
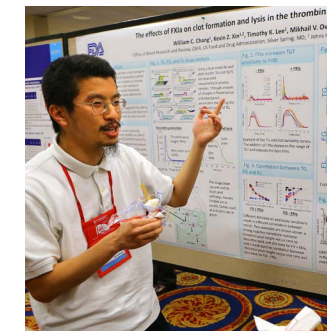
HANDI also distributed over 4,155 NHF educational publications to individuals, local chapters, and HTC's. Wrote 60 medical news stories that were posted on NH's web site.

# Research

**NHF's Research team aims to fund community research, conduct research, and provide community data analysis to inspire future research. Read this update to learn more about recent efforts.**

Fellowships and Awards: NHF continues with two annual cycles of award applications with a coordinated media campaign to notify all hemophilia treatment center (HTC) providers of upcoming awards in the hopes of increasing awareness within and outside of our community. Notifications are also sent out through multiple channels including Hemostasis and Thrombosis Research Society (HTRS), American Society of Hematology (ASH), and NHF media channels.

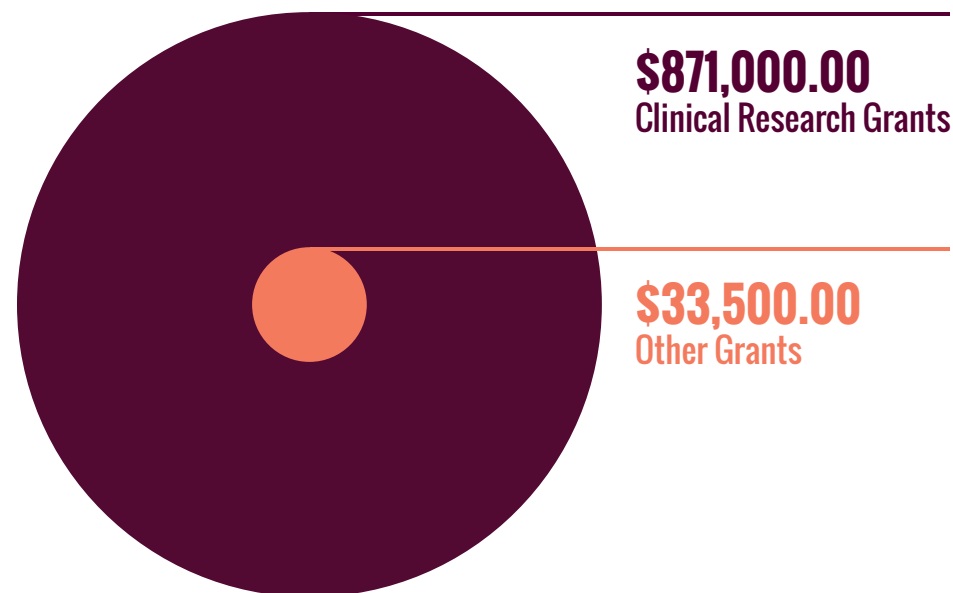
NHF's newest research fellowship program, the Jeanne Marie Lusher Diversity Fellowship offers \$52,000/year for three years to support new clinicians and researchers as well as those who may be in a fellowship program demonstrating interest in basic science and pre-clinical research in bleeding disorders. As NHF's newest fellowship, the scope is expanded beyond NHF's other awards. It will be broad and include a range of topics from pre-clinical or basic science research on the biochemical, genetic, or hematologic aspects of inherited blood disorders, including but not limited to hemophilia, von Willebrand disease, sickle cell disease, thalassemia, or hereditary hemorrhagic telangiectasia to health inequities faced by the inherited blood disorders community, joint disease/orthopedics, women's health, pain management, or other therapeutics modalities about blood disorders.



# Other NHF Fellowship/Awards

<b>Judith Graham Pool Fellowship</b>	Offers \$52,000/year for 2 years to a post-doctoral candidate for basic science and pre-clinical research.
<b>Career Development Award</b>	Provides \$70,000/year for 3 years to a mid-level investigator at a federally funded Hemophilia Treatment Center.
<b>Innovative Investigator Research Award</b>	\$60,000 is awarded for 12-18 months for an innovative project. It is intended for any member of the multi-disciplinary team within the federally funded Hemophilia Treatment Center.
<b>Bridge Grant</b>	Provides \$125,000 over 12-18 months to an experienced physician investigator who has applied for a National Institute of Health (NIH) grant and was scored, but not funded and needs additional data to resubmit.

## 2020 Total Grants Available



# NHF Initiated Research

## Camp Survey

A manuscript of this first-ever national survey of bleeding disorders camps has been submitted for peer-review and is scheduled for publication in early 2021.

## Pain Study

The MASAC Pain Initiative Taskforce completed analysis of the first-ever multi-disciplinary HTC survey evaluating pain management practices. Recommendations based upon the results were submitted to the general MASAC group, approved by the NHF Board, and published in February of 2020. A subsequent manuscript based upon the survey results has been submitted to a peer-reviewed journal for consideration of publication. A manuscript based upon the MASAC recommendations is being written and will be submitted for peer-review and consideration of publication.

## Community Voices in Research (CVR)

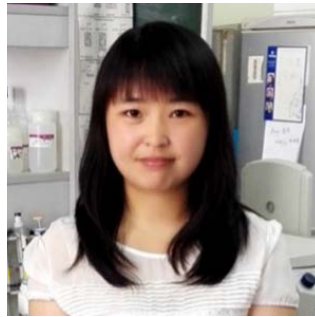
The NHF community powered registry changed its name from MyBDC to Community Voices in Research (CVR) in May 2020, recruitment from general to strategic and project-based with a modification in overall focus from general data collection to specific research projects done in collaboration with external researchers. Enrollment began in March 2019; the baseline survey was released to affected persons in August 2019 and the personalized dashboard was released in October 2019. By the end of 2020, there were over 1,300 persons enrolled with over 1,100 affected with an inherited bleeding disorder. NHF's CVR team began to collaborate with external researchers to promote the patient's voice in research opportunities.





# Specific Awardees

## Judith Graham Pool Postdoctoral Research Fellows



2020 to 2022  
Xuejie Chen, PhD  
The University of North Carolina at Chapel Hill

*Increasing the efficacy of prophylactic infused FIX in hemophilia B patients by manipulating its binding to collagen IV*

Dr. Xuejie Chen is a postdoctoral fellow in the laboratory of Dr. Darrel Stafford at the University of North Carolina at Chapel Hill. Before joining Dr. Stafford's lab, she received her Ph.D. degree in Cell Biology from Beijing Normal University, P. R. China. In her JGP Fellowship project, Dr. Chen aims to study the contributions of extravascular factor IX (FIX) to blood coagulation and to search for FIX variants that could efficiently displace the endogenous dysfunctional FIX in hemophilia B patients. To achieve this goal, Dr. Chen will study the binding between FIX and the subendothelial basement membranes, mainly type IV collagen, and use the site-directed random mutagenesis library to screen for tighter binding FIX molecules. In doing so, she hopes to identify a FIX variant that can be used in hemophilia B patients for better coagulation therapies.



2020 to 2022  
Kaushik Das, PhD  
University of Texas Health Science Center at Tyler

*The role of FVIIa-released endothelial extracellular vesicles in hemophilia therapy*

Dr. Das is currently working as a Postdoctoral Research Associate at the University of Texas Health Science Center at Tyler, under the mentorship of Professor L. Vijaya Mohan Rao. His research focuses on elucidating novel mechanisms by which FVIIa provides hemostatic and anti-inflammatory effects and the relevance of these mechanisms in treating bleeding disorders and hemophilic arthropathy.



2020 to 2022  
Jhansi Magisetty, PhD  
University of Texas Health Science Center at Tyler

*The role of EPCR-FVIIa in the pathogenesis and treatment of hemophilic arthropathy*

Dr. Magisetty completed Ph.D. doctoral training on the evaluation of FVIIa-EPCR interactions in the management of hemophilic arthropathy and is enthusiastic looking forward to the postdoctoral training on the "Role of EPCR-FVIIa anti-inflammatory signaling in the pathogenesis and treatment of hemophilic arthropathy".

## Career Development Awardee



2020 to 2023  
Ze Zheng, PhD  
Medical College of Wisconsin

*Reducing Severe Bleeding Symptoms in Hemophilia by Lowering Fibrinolysis*

As the 2020 recipient of the NHF Career Development Award, Dr. Zheng will be studying the mechanism of increased fibrinolysis in severe hemophilia patients in collaboration with the Comprehensive Center for Bleeding Disorders at Versiti Blood Center of Wisconsin. This work will explore novel therapeutic strategies to reduce basal fibrinolysis and bleeding symptoms in severe hemophilia patients.

# Specific Awardees

## Innovative Investigator Research Awardee



2020 to 2021  
Courtney Thornburg, PhD  
Rady Children’s Hemophilia and Thrombosis Treatment Center

*Gene Therapy for Hemophilia: Patient Preferences and Shared-Decision Making*

Dr. Thornburg is a Professor of Pediatrics at UC San Diego and Director of the Rady Children’s Hemophilia and Thrombosis Treatment Center. Dr. Thornburg completed her pediatric hematology/oncology fellowship at the University of Michigan during which time she was awarded a NHF-Shire Clinical Fellowship, participated in the 2004 ASH Clinical Research Training Institute and completed a Master in Clinical Research Design and Statistical Analysis at the University of Michigan School of Public Health. Overall, Dr. Thornburg has more than 15 years of experience in clinical and health services research. For the above study, Dr. Thornburg will be utilizing NHF’s CVR registry.



**“Life will always bring bleeds and challenges, but if you take care of yourself and stay proactive about your health, anything is possible.”**

**MIKEY BERKMAN**

# Chapter Services

**In a year like 2020, NHF’s chapters proved critical to our community. Despite all the challenges, chapters still helped patients and their families connect virtually, participate in programs, and find the resources and support they needed. Read on to learn more about the resources and support provided by NHF chapters in 2020.**

**Highlights:**

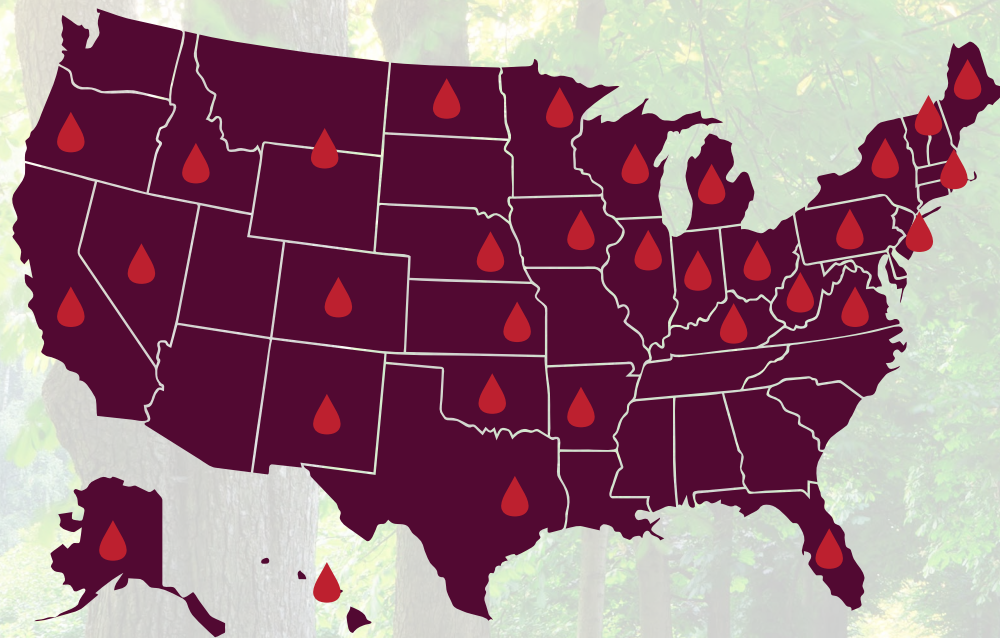
- 59 NHF chapters and HFA member organizations each received a \$7,500 grant.
- The Hemophilia Alliance provided a matching contribution of \$7,500.
- More than 150 individuals and families supported by funding local chapter patient/emergency financial assistance programs.
- Administrative and operational expenses support for the chapters to ensure the educational and health care support service needs of their local bleeding disorders community continue uninterrupted.

NHF responded swiftly to the impact the global COVID-19 pandemic continues to have on individuals, communities, and businesses around the world. The bleeding disorder community knows the value and power that comes with remaining resolute in facing crisis together. From the onset of the pandemic, we have seen an increase in collaboration and communication between all stakeholders in our community including the national organizations, chapters and member organizations, and our industry partners. Listed below are several pillars of NHF responsiveness:

- Communication – The NHF Chapter Services in collaboration the Hemophilia Alliance Foundation held frequent web meetings with chapters covering a wide range of topics including, but not limited to the following: CARES ACT & PPP; Navigating Patient Assistance Resources; Virtual Programming and Virtual Technology; and Fundraising in crisis.
- Resources – In addition to assisting 10 chapter virtual meetings, Chapter Services also provided access to several virtual technology tools at no cost to chapters. Additionally, to help address these financial challenges of the pandemic, NHF launched the “COVID-19 Relief Fund Bridge Grant Program”. The combined financial investments of NHF and our generous industry partners Pfizer, Sanofi Genzyme, and Genentech made the program possible.

# Unite

for Bleeding Disorders



**3,500+**  
walkers in  
**42**  
cities across the country



Teams

**706**



Participants

**3434**



Donations

**9556**



Total Revenue

**\$1,813,787,82**

## Affiliated Chapters

**Alaska Hemophilia Association**  
Anchorage, AK

**Hemophilia & Bleeding Disorders of Alabama**  
Wetumpka, AL

**Arizona Bleeding Disorders**  
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\*

**Connecticut Hemophilia Society, Inc.**  
Windsor, CT

**Florida Hemophilia Association**  
Fort Lauderdale, FL

**Hemophilia Foundation of Greater Florida**  
Winter Park, FL

**Hemophilia of Georgia**  
Sandy Springs, GA

**Hawaii Chapter, National Hemophilia Foundation**  
Ewa Beach, HI\*

**Hemophilia of Iowa**  
Iowa City, IA

**Idaho Chapter, National Hemophilia Foundation**  
Boise, ID\*

**Bleeding Disorders Alliance Illinois**  
Chicago, IL

**Hemophilia of Indiana**  
Indianapolis, IN

**Kentucky Hemophilia Foundation**  
Louisville, KY

**Louisiana Hemophilia Foundation**  
Baton Rouge, LA

**New England Hemophilia Association**  
Dedham, MA

**Hemophilia Alliance of Maine, Inc.**  
Brewer, ME

**Hemophilia Foundation of Michigan**  
Ypsilanti, MI

**Hemophilia Foundation of Minnesota  
and the Dakotas**  
Mendota Heights, MN

**Gateway Hemophilia Association**  
Saint Louis, MO

**Midwest Hemophilia Association**  
Ozark, 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**  
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 Inc.**  
New York, NY

**Western New York BloodCare**  
Buffalo, 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**  
Tulsa, OK

**Pacific Northwest Bleeding Disorders**  
Corvallis, OR

**Hemophilia Foundation of Oregon**  
Corvallis, OR

**Eastern Pennsylvania Hemophilia Foundation**  
Springfield, PA

**Western Pennsylvania Chapter of NHF**  
Cranberry Township, PA

**Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado**  
San Juan, PR

**Hemophilia of South Carolina**  
Greenville, SC

**Lone Star Chapter of NHF**  
Houston, TX

**Texas Central Hemophilia Association**  
Dallas, TX

**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\*

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**Affiliated Chapters for Period ending December 31, 2020**

**\*: Chapters owned by The National Hemophilia Foundation**

# Education

**NHF's education team provides informative and meaningful education opportunities for consumers, caregivers, and other community members. In 2020, education programming switched to virtual formats to continue serving the community. Read on for more insights.**

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## Steps for Living

In 2019, the National Hemophilia Foundation continued to grow Steps for Living, a life stage education program that combines online, life stages education content with in-person workshop curricula 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/their development. The Steps website hosted over 234,000 sessions in 2020, a 25% increase from 2019, and increasing international reach.

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## 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 workshops. NHF staff, speakers, and youth leaders facilitated 24 workshops across the country in 2015 and grew this to 152 workshops in 2019 reaching over 2900 participants. Due to COVID-19, 2020 faced new challenges for the community with many educational programs being cancelled. Despite that, the community pivoted to a virtual setting, still delivering critical educational programs to families locally, such as NHF's 3 new mental health focused webinars. One participant of one of the mental health webinars shared "It was good reminder to stop and think about me. I can't care for others if I don't care for myself. Talk about mental health. Don't let it be taboo." NHF delivered 61 workshops and webinars to over 800 participants in 2020. These workshops were tailored for youth, adults, and women and were also facilitated in Spanish where requested.





### Insights: Innovations in Treatment - Gene and Innovative Therapies

NHF continued to expand program offerings and reach for its Insight: Innovations in Treatment programming in 2020. NHF debuted its workshop/webinar on the basics of gene therapy at 6 chapter virtual events in 2020 and finalized its basics of innovative therapies workshop for chapters to request in early 2021. NHF hosted 4 sessions at its Bleeding Disorders Conference on these topics, with the highest attendance of any session with over 533 at its Advancements in Treatment session. NHF also continued to promote its online resources, with over 4,700 page views on its Future Therapies page, 644 views of its Gene Therapy Getting Up to Speed Webinar, and over 1,600 views of its explainer video on What is Gene Therapy. NHF continues to work on its strategic plan to roll out more educational information and tools, such as its Questions for Your Providers card, to help consumers make informed decisions for their best treatment and care.

### 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 2020 had 25 members ages 18-24 with continued diversity with 10 bleeding disorders represented. 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 apply their leadership skills in a more in-depth way. The tracks include nonprofit development, outreach, and advocacy. "The public speaking training from the first NYLI meeting this year really helped me level up when speaking to crowds. My number one takeaway has been that confidence and follow-through are essential. If I believe in what I'm saying, and I say it succinctly and assuredly, then speaking to crowds is a piece of cake."

NYLI members continue to participate in Washington Days and lead sessions at NHF's Bleeding Disorders Conference. Through these activities the NYLI program builds five core competencies for the participants: communication, self-management, career skills, emotional intelligence and meeting & group facilitation skills. "By attending Chapter Leadership Seminar, I communicated with people I normally would not have who are older than I am and at different points in their life which helped me grow my intergenerational communication skills."

### Women with Bleeding Disorders

NHF's programming 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 diagnoses, leading to better health outcomes, and 2) to provide women affected by bleeding disorders with the education, support, skills and resources they need to advocate for their healthcare, financial and social support needs.



Victory for Women (V4W), NHF's initiative for women affected by bleeding disorders, focused on growing its online community for women on [victoryforwomen.org](http://victoryforwomen.org) with close to 6,000 sessions in 2020. NHF also launched Let's Talk Puberty: A Guide for Girls with Bleeding Disorders book and adult companion guide to address a gap in educational information for girls and teens with a bleeding disorder.

As part of a cooperative agreement with the Centers for Disease Control and Prevention (CDC) to increase awareness of bleeding disorders so women can receive timely and accurate diagnoses and lead healthy full lives, NHF continues to spread the word for undiagnosed women with symptoms of a bleeding disorder to get the information and care they need. NHF launched its Better You Know Advocates (BYKA) program, training 7 community volunteers to do their own local outreach to women. One BYKA shared "A stranger contacted me to say my Facebook post led her to realize her daughter's symptoms might be a bleeding disorder, I was able to help her connect with an HTC," demonstrating the impact these volunteers can have.

Women can go to [betteryouknow.org](http://betteryouknow.org) to take a risk assessment tool and 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 do not feel alone and get the care they need, as well as created resources for chapters to use in local outreach for undiagnosed women. NHF's outreach efforts have continued to increase with a 419% increase in website sessions from 2019 to 2020 and more than doubling the number of risk assessment tool takers to over 3,700 in 2020, of those who took the assessment, 80% scored at risk for a bleeding disorder.



### Von Willebrand Disease (VWD)

NHF continues to offer dynamic educational programming for those living with VWD, from in person workshops/webinars delivered at chapters to the VWD track and pre-conference at NHF's Bleeding Disorders Conference and has partnered with WFH, ASH and ISTH to collaborate on an international VWD guidelines project with strong patient input that launched in early 2021.

### Reaching Our Diverse Community

The NHF has continued to strive for a more inclusive and representative spaces at its Bleeding Disorders Conference (BDC). In 2020, with a pivot to a virtual meeting, NHF was thrilled to have the highest participation in its history with over 3,500 attendees, with some who shared they had never been able to attend in person due to travel and conference costs. NHF also continued to prioritize diverse speakers and sessions at BDC and other conferences it runs to create spaces for the community to discuss the impact of religion, race/ethnicity, gender identity, sexual orientation, culture, and language on navigating life with a bleeding disorder.



NHF continued to promote its Guías Culturales program. The Guías are bilingual trained volunteers who are the path to service to the bleeding disorders community, acting as "guides" to diverse members of the bleeding disorders community.

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## Camp Unite

In response to COVID-19 NHF needed to rethink its kids and teen programming for its Bleeding Disorders Conference and heard from many chapters who were not able to hold their own camp programs due to COVID. NHF hosted Camp Unite in August 2020 at NHF's Virtual Bleeding Disorders Conference and at its Virtual Rare Bleeding Disorders Conference with great success in connecting kids and teens with bleeding disorders all over the country and partnering with national & global experts including Gut Monkey, Believe Ltd, WFH & Save One Life to have international awareness, and lots of fun!

Across both Camp Unite dates, NHF engaged 59 kids and teens and 39 families at the family campfires that wrapped up the week of activities. The impact on participants was great with 96% reporting that after attending Camp Unite, they feel more connected to the bleeding disorders community, 87% sharing that they made a new friend at camp, and 100% having a better understanding of people living with bleeding disorders around the world. NHF also hosted a Young Adult Campfire for 34 young adults 18-30 to connect during this global pandemic.

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## Inhibitor Education

NHF quickly adapted to new restrictions of COVID-19 in 2020 and shifted from two in person National Inhibitor Summits to one virtual summit, offering 25 virtual sessions for those with an active or tolerized inhibitor and their support network. The virtual educational conference reached 250 participants in 2020 with attendees from 16 countries around the world. In addition, NHF hosted one virtual Spanish Inhibitor Summit, *Viviendo con Inhibidores*, in 2020, offering educational workshops all in Spanish. Thirty-six participants from 7 countries attended the Spanish summit. One attendee shared about their experience at the summit "Excellent information to take into account during these difficult times for me and my family."

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## Rare Factor Deficiency and Platelet Disorder Programs

NHF offers unique educational programs for families affected by rare bleeding disorders such as factor VII, X, or XIII deficiencies, or Glanzmann's thrombasthenia. Due to COVID-19 in 2020, NHF invited the rarest of the rare to join at both NHF's BDC as well as its own separate virtual conference in late August 2020 to reach a now global audience with 218 users who logged onto the conference website and 23 average attendees per session. In addition, NHF held Camp Unite for kids and teens during the rare conference for the week of the virtual conference with a family campfire to wrap up the week of learning, connection and fun!

# Public Policy

Throughout 2020, our State Based Advocacy Coalition (SBAC) Grant program continued to thrive. Grant recipients (chapters) were mostly able to transition from live in-person advocacy events to virtual a few months into the pandemic. As the year went on most chapters successfully adapted to a virtual advocacy environment and hosted webinars, state Advocacy Days, and meetings with state legislators that probably would not have happened otherwise. Several chapters successfully hosted state Advocacy Days prior to the Covid quarantine. Given the challenges and uncertainty surrounding all chapter activities last year most chapters did an admirable job of adapting. By the end of the year all of the grantees hosted advocacy Stakeholder Meetings virtually, which was a sign of how far they had come.

We do not have a number for actual attendance, but we know anecdotally that overall attendance/participation in Advocacy activity was down considerably from 2019 because of fewer events and almost no in-person State Advocacy Days. We are confident the participation numbers were well below the 80% estimated figure based on planned events prior to the pandemic.

The seventeen SBAC Grant recipients represent 22 states and serve well over half of the bleeding disorders population in the country. The state advocacy programs reached approximately 10,000 – 12,000 patients.

The SBAC program is continually evaluated and revised as necessary to take advantage of the lessons learned each year working with the grantees. For example, three years ago as interest in the program was increasing, we split the program into two: a Capacity Building program to assist in the initiation and development of a chapter advocacy program for chapters that had little or no experience with advocacy, and an Advanced Advocacy program for more sophisticated chapters. That structure has proved to be successful in attracting new grantees into the program. Overall, the best practices we've identified for starting and sustaining a chapter advocacy program include 1) requiring a chapter to have an Advocacy Committee that meets regularly, 2) developing an advocacy strategic plan, 3) hosting a state Advocacy Day, 4) hosting an annual meeting of stakeholders to review accomplishments and plan for the future.

In 2020, chapter advocacy programs were challenged by Covid-19. NHF set to work learning about virtual advocacy and sharing those lessons with chapters. NHF compiled notes from webinars and the experience of other organizations into a document that we shared with grantees to help them understand how to engage in virtual advocacy. While most grantees struggled to accomplish the goals, they identified in 2019 planning sessions and had little to no opportunity to host an Advocacy Day, many were able to conduct effective virtual advocacy events including a virtual Advocacy Day in California. As always, one of the most effective elements of the SBAC program is the opportunities for grantees to learn from each other. Despite the pandemic NHF continued to host SBAC events, all virtual, that allowed grantees to interact and share their advocacy experiences in the virtual environment.

In 2020 NHF also used SBAC grant funds to start a new mini-grant program from July-December to attract even the most reluctant or hesitant chapters to engage in advocacy. Three grants were awarded to chapters that had not participated previously. Two others went to chapters that have extensive advocacy experience. Two of the three new grantees subsequently were awarded Capacity Building grants in the 2021 SBAC cycle. We plan to do the same thing this year. It was an effective way to lower barriers to participation and more chapters “in the door”.

Ten chapters were able to host a state Advocacy Day, either virtually or in-person, and secure Bleeding Disorders Awareness month resolutions/proclamations through a state or local government entity. Chapters also successfully hosted virtual events with state legislators and members of the bleeding disorders community.

NHF continued to be involved in national patient advocacy coalitions on key issues at the national and state levels. For example, NHF is a member of the State Access to Innovative Medicines Coalition, which advocates for step therapy and patient out-of-pocket expense legislation, and has a leadership position with All Copays Count, which advocates for legislation restricting the use of payer accumulator adjustment programs. In addition, state chapters in the SBAC program were participants in state coalitions tackling the same issues.

Each year NHF focuses on bringing new chapters into the SBAC program through the Capacity Building grant program to initiate and support their nascent advocacy efforts. In 2020 four new chapters participated in the SBAC program. Additionally, through the Advanced Advocacy part of the program we continued to support the efforts of more advanced chapters. To replicate the success of the program we use what we have learned from our experience with the program. For example, each SBAC grantee is required to have and update annually an advocacy strategic plan. NHF facilitates the development of the plan and uses the same template that other chapters have used to promote consistency within the program and ensure that chapters can collaborate more easily using the same “platform” or “language”. A foundational principle of the SBAC program is collaboration and leadership among chapters. We are developing advocacy leaders who can help their peers.

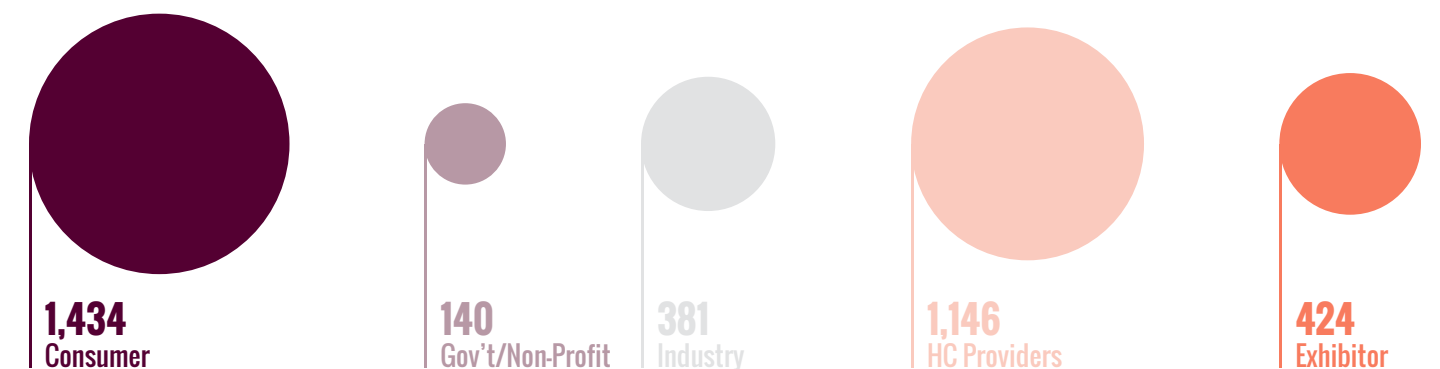


“Everyone has their own story to share. The more voices we have, the more power we have in making a difference for others.”  
MATTHEW DELANEY

# Conference & Travel Services

The Conference & Travel Services department (C&TS) of NHF is an internal Professional Conference Organizing (PCO) team in charge of the management of all NHF multi-day Conferences. The Department ensures NHF’s financial growth and positive, accessible, and safe experience for our entire community through our meetings and events. The Conference and Travel Services team handles a wide range number of events every year, from two-day meetings to the complete management of a 3 daylong conference for as many as 3,500 participants. In 2020, C&TS helped ensure that events had a successful and impactful transition to a virtual format.

2020 Attendees  
(3,525 total virtual participants)



## Bleeding Disorders Conference

NHF Bleeding Disorders Conference (BDC) 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 conferences of national voluntary health agencies.

There were several obstacles that we faced in 2020, including:

- Transitioning from in-person to virtual (finding a virtual platform host, re-building the event from start, re-design: format/dates/number of sessions, creating a new Industry Package, designing a new Exhibit Manual, integrating our registration platform to the virtual event host, learning, and adapting to a new system)
- Renegotiating hotels and venue contracts in Atlanta to avoid cancellation fees of over \$900,000
- Renegotiating vendors contracts to avoid cancellation fees of over \$250,000

Fortunately, despite the short time to pivot the event and the endless challenges that we encountered during production time; in the end the Conference was a success.

[Conference at a Glance >](#)

## 2020 Attendees by Country (top 10)



# Community Voices in 2020



“For me, having a bleeding disorder has never been a barrier. Instead, it’s been an inspiration.”

TAYLOR D. FLAKE-LAWSON

“While this is a time of uncertainty, it is also a time to be thankful for those around us.”

ROBERT LOUDEN, MSW, LCSW



“Accepting that we’re dealing with uncertainty is key to coping during this challenging time”

DR. MARY KARAPETIAN ALVORD

“It makes me feel good that I can empower other people with hemophilia. I’m able to share my story and not feel embarrassed about it.”

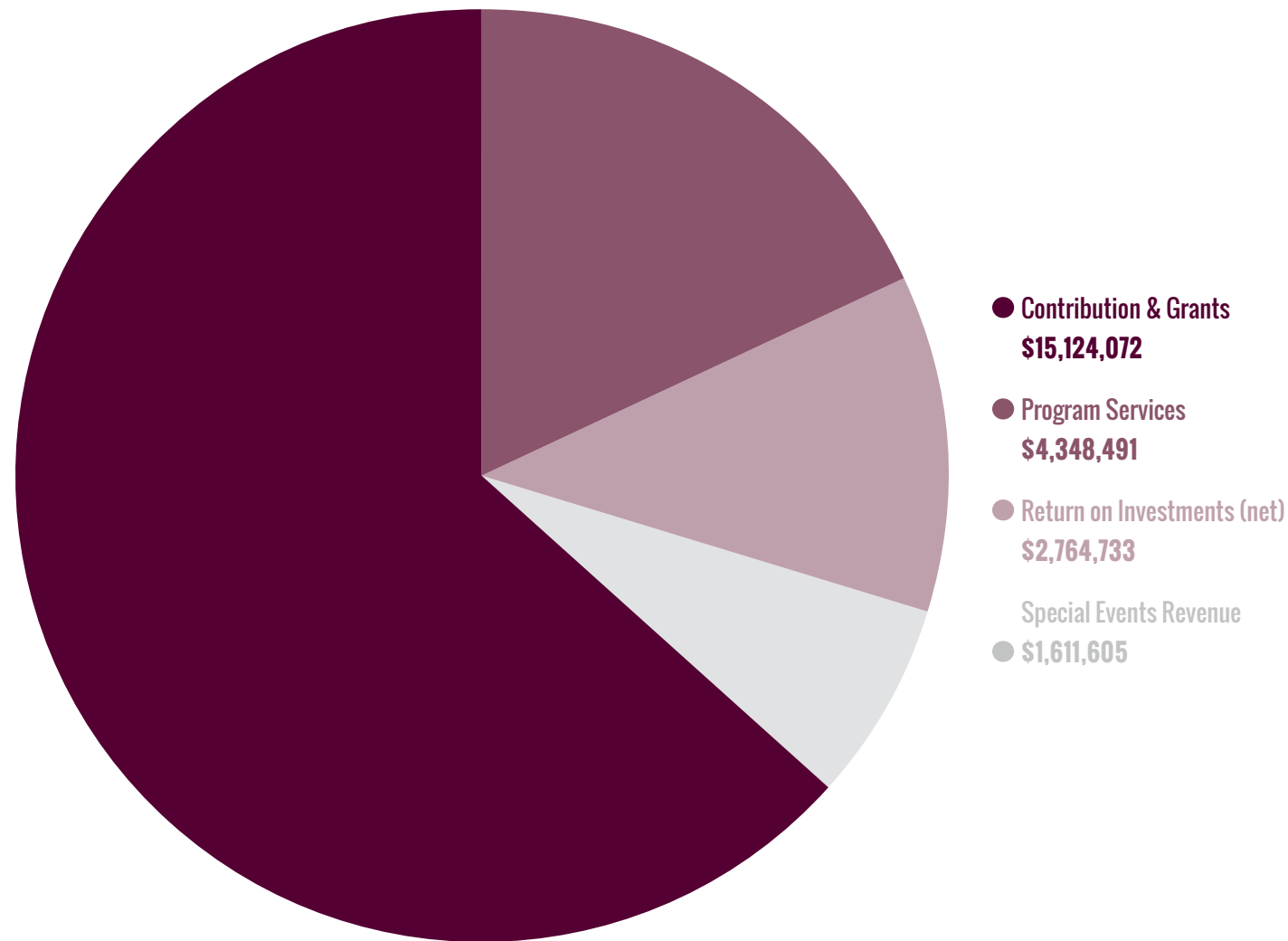
CHINEDU FELIX OSUCHUKWU



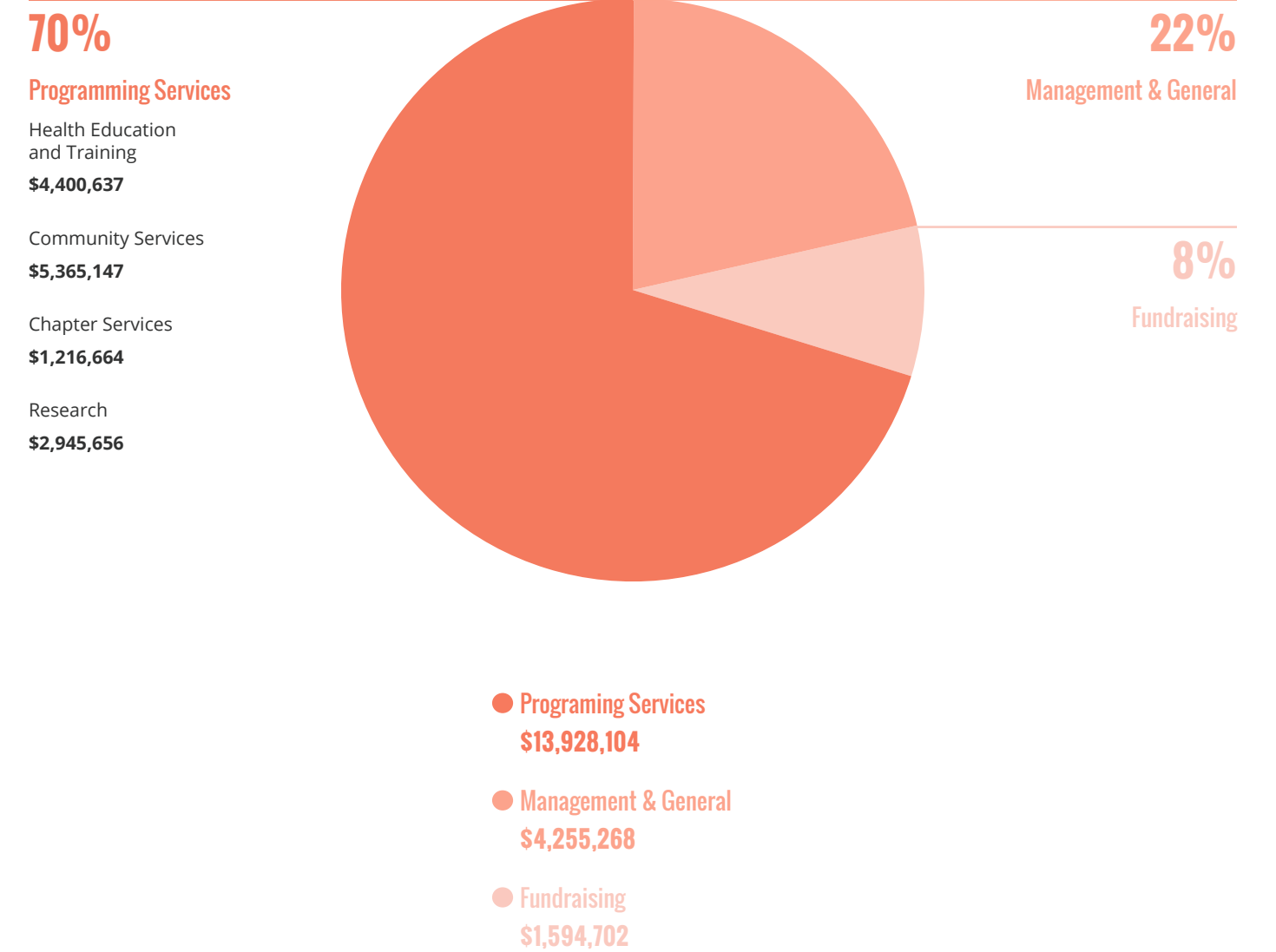


# Revenue 2020

Total 2020 Revenue  
\$23,848,901



# Expenses 2020





**NATIONAL HEMOPHILIA FOUNDATION**

*for all bleeding disorders*

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