



2021

ANNUAL REPORT



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

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LETTER FROM LEN

Dear Friend,

Your generosity and support in 2021 laid the framework for ambitious and meaningful foundation activity. In the coming pages, you'll read how NHF fulfilled unmet patient needs and provided resources when families needed them most. Even in continually challenging times, your support and involvement helped NHF and the entire inheritable blood disorders (IBD) community respond to challenges, reduce inequities, build connections, and more.

NHF's staff could not do the important work of driving research, bettering treatments, and finding cures without you. That's why I hope you'll see yourself or your friends reflected in the quotes and photos throughout this report. You are an important part of this journey, and we are proud to move forward alongside you.

As you know, a critical part of NHF's role in the community is to provide and account for ALL life stages of ALL blood and bleeding disorders. Much of this work starts by diving into health equity, diversity, and inclusion (HEDI). I'm excited for you to read about how the foundational work of HEDI has built trust within NHF and with community and partners, thus establishing a framework to reduce health inequities within the IBD community. It is our hope that this work can set the tone in eliminating health disparities across all of medicine.

Over the past several years, this community has experienced disruptions to their lives and work. Families in the bleeding disorders community have faced tremendous changes in the delivery of treatment and how they access medical care. That is why NHF is committed to partnerships, research, and the growth of our nationwide chapter network to seek innovative solutions that ensure that the IBD community is continually served with efficiency and meaning. It is our shared belief that incorporating the whole community in our work will create community, eliminate duplication of efforts and redundancies, promote cost savings, and enhance the overall positive impact of programs.

There is much change on the horizon. This past year showed us that NHF and the community must evolve to address new and diverse needs, as well as challenges and opportunities. Whatever is ahead, I am glad you are a part of it. It is an honor to serve you and the many individuals and families affected by IBDs.

Thank you for being a special part of this community,



Dr. Leonard A. Valentino
NHF President and CEO

P.S. Are you on Twitter?
Follow me @LenValentino1 for the latest news and updates from NHF.

DEVELOPMENT: FUNDING THE FUTURE

NHF's development team is responsible for stewarding individual donors from first gift to legacy donation. Through a variety of virtual fundraising events, programs, and other initiatives, the development team raised funds for NHF community members. Take a look at some of the development highlights from 2021:

- Hosted the annual Red Tie Soiree virtually for the second year in a row with **350** community members attending nationwide, raising nearly **\$205,000** to support IBD patients and families;
- Welcomed **40** new members to the Young Hope Society (a young professionals networking group) and launched a National Advisory Board aimed at increasing engagement of young adults in the IBD community;
- Kicked off several point-of-sale campaigns and **corporate partnerships nationwide**, with retailers including Marble Slab Creamery, Great American Cookies, YAFO Kitchen, and SAS Cupcakes;
- Increased participation in endurance fundraising program NHF GO by **35%**;
- Partnered with Ameritas to receive a **\$20,000** grant;
- Awarded a **\$10,000** grant from the National Institutes of Health to support the NHF's first-ever State of the Science Summit; and
- Increased non-industry giving by **25%**.

ADVANCEMENT CREATING CLARITY AND COMMUNICATING HOPE

THE NATIONAL HEMOPHILIA FOUNDATION'S (NHF) ADVANCEMENT TEAM IS FOCUSED ON DEVELOPMENT, COMMUNICATIONS, AND EXTERNAL AFFAIRS. TOGETHER, MEMBERS FROM THESE THREE AREAS RAISE FUNDS AND AWARENESS FOR THE INHERITABLE BLOOD AND BLEEDING DISORDERS (IBD) COMMUNITY. READ ON TO LEARN MORE ABOUT THEIR EFFORTS IN 2021.



\$205,000

raised during the virtual
Red Tie Soiree to support IBD
patients and families

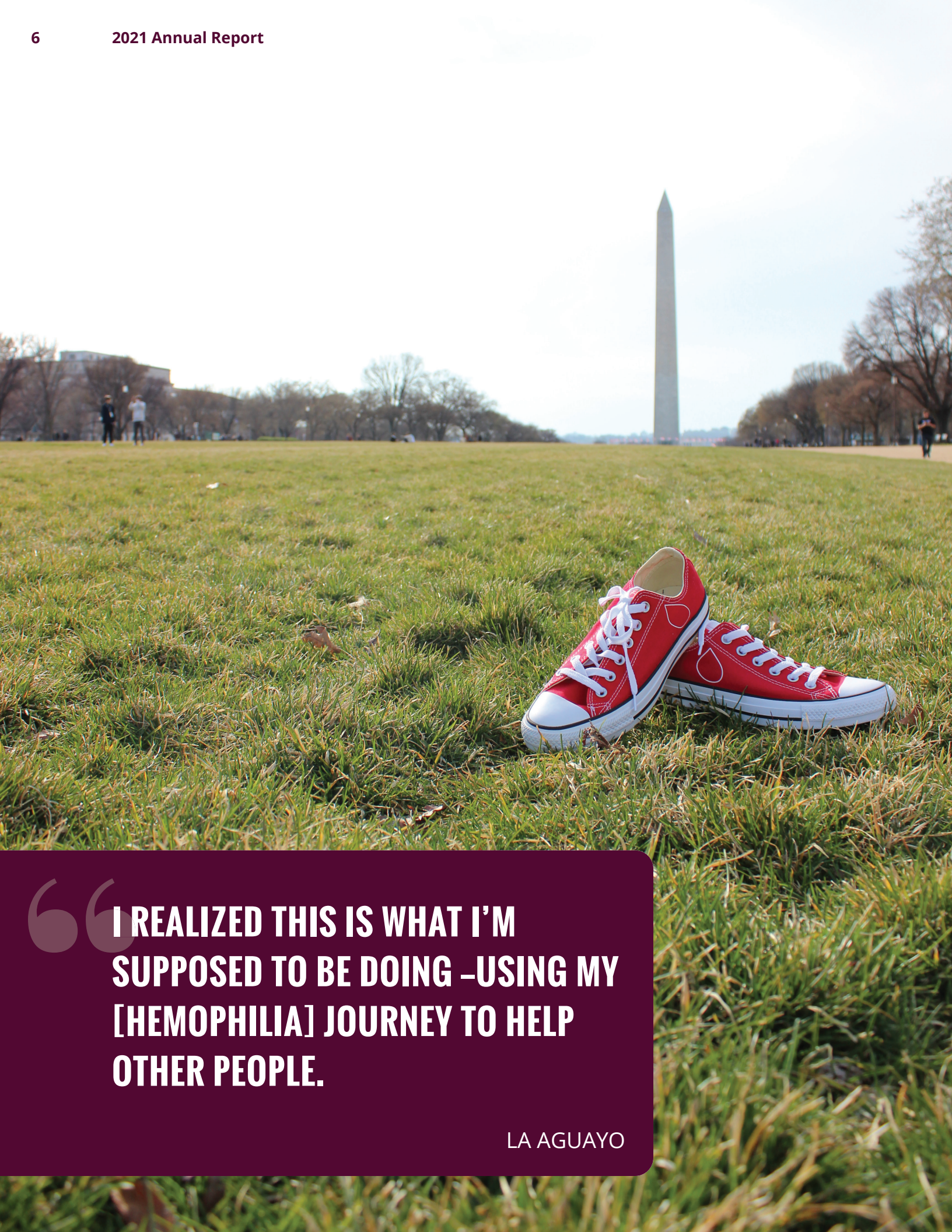


Increased participation
by **35%**



\$10,000

In grants to support
NHF's first State of the
Science Summit



“ I REALIZED THIS IS WHAT I’M SUPPOSED TO BE DOING –USING MY [HEMOPHILIA] JOURNEY TO HELP OTHER PEOPLE.

LA AGUAYO

COMMUNICATIONS: SHARING PROGRESS

NHF’s communications team tells the story of the foundation and how it intersects with the community. Through a variety of communication mediums—including email, internet, social media, print, and broadcast—NHF shares its programs with constituents to emphasize the support and strength of the IBD community. In 2021, communications staff employed new tactics to impressive results, including:

- Improved social media metrics and engagements thanks to **a variety of new multimedia tactics** including audiograms and increased video content, as well as created relevant community content around applicable awareness months;
- Used **YouTube** as a social channel and engagement tool rather than just a video archive platform;
- Delivered **221** emails to nearly **1.75** million recipients with an average open rate of **20%**, on par with the nonprofit industry average;
- Hosted **45** Wednesday Webinars to provide the IBD community with free education on a regular basis;
- Featured **two** community members on Instagram takeovers to share their IBD story and help others feel less alone; and
- Launched the HemAware.org column “Ask a Social Worker” in fall 2021 with **four** articles for community members that provided answers to intimate questions.

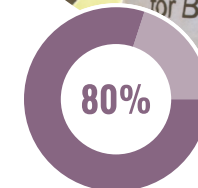
62% growth in impressions
 15% increase in engagements
 55% leap in clicks
 25% gained more subscribers
 10% views increased by

CHAPTER SERVICES ESTABLISHING COMMUNITY NATIONWIDE

NHF'S COAST-TO-COAST CHAPTER NETWORK IS INTEGRAL TO NHF'S MISSION OF FINDING CURES FOR INHERITABLE BLOOD DISORDERS AND TO ADDRESSING AND PREVENTING THE COMPLICATIONS OF THESE DISORDERS THROUGH RESEARCH, EDUCATION, AND ADVOCACY ENABLING PEOPLE AND FAMILIES TO THRIVE. NHF'S 52 CHAPTERS MAKE THE ENTIRE COMMUNITY STRONGER THROUGH DAILY GRASSROOTS ACTIVITIES.

THE NHF CHAPTER SERVICES TEAM MADE A DIFFERENCE IN THEIR COMMUNITIES IN 2021:

UNITE FOR BLEEDING DISORDERS WALK PARTICIPATION



In Person



Over 700
teams

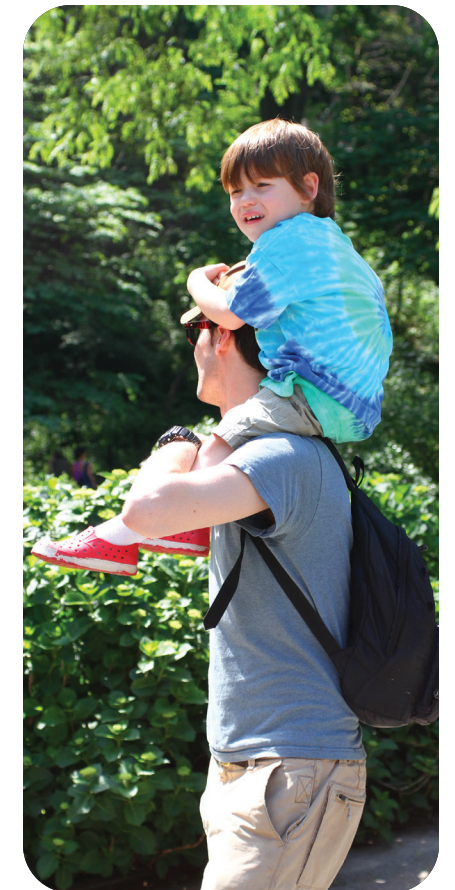


Virtual



Walks in
39 cities

- Hosted more than **5,500** participants in **39** cities through the Unite for Bleeding Disorders Walk series;
- Chapters received over **11,000 donations** through the United for Bleeding Disorders Walk program, and used those funds to support their local communities;
- This led to the series surpassing the **\$25 million** fundraising mark since its inception;
- Developed and executed a **new NHF chapter charter agreement** for 2022 – 2024;
- Conducted the largest-ever chapter leadership seminar, with over **180** in-person and virtual attendees;
- Awarded **10** capacity-building grants to **nine** chapters, totaling nearly \$120,000;
- Facilitated **56** board development training sessions with **13** participating chapters;
- Designed a Bleeding Disorders Conference chapter track with an average session score of **4.28 out of 5**;
- Led **27** educational/informational webinars and **11** office-hour sessions for chapter staff; and
- Established **Puerto Rico's first NHF chapter**.



NATIONAL CHAPTERS UPDATE

NHF's national chapters are chapters that have adopted the name, logo, and brand of the foundation and support its mission of providing services to local communities. Here are some of the merged chapters' accomplishments from 2021:

NHF COLORADO

- Provided **113** families with nearly **\$27,500** in financial assistance;
- Raised more than **\$67,000** during the 2021 Unite for Bleeding Disorders Walk; and
- Hosted **11** education series events across virtual and live settings, including an overnight women's group retreat, the forming of a men's group, and expanded translation services.

NHF IDAHO

- Received financial support from the Hemophilia Treatment Center at St. Luke's Hospital to **establish and strengthen** programs for the Idaho community;
- Surpassed** the 2021 Unite for Bleeding Disorders Walk fundraising goal for the first time in a decade; and
- Held a successful in-person annual **family educational weekend** event.



“MY LOCAL CHAPTER [EASTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION*] CREATES A SENSE OF COMMUNITY, CONNECTIONS, AND SUPPORT IN MY LIFE. NOT MANY PEOPLE HAVE HEMOPHILIA, SO MY CHAPTER MAKES ME FEEL LESS ESTRANGED FROM THE BIGGER PICTURE. IT'S NICE TO HAVE PEOPLE AROUND WITH HEMOPHILIA – IT MAKES IT EASIER TO COMMUNICATE AND FEEL LESS ALONE.

Hajar Abusief

*Eastern Pennsylvania Bleeding Disorders Foundation is an affiliated chapter of NHF, though not merged as of 2021.

NHF WEST VIRGINIA

- Added** administrative assistant and executive director positions to the chapter staffing structure;
- Expanded the chapter's dental program** to include financial assistance and an accredited continuing education course for dental care providers; and
- Strengthened partnerships** with West Virginia Hemophilia Treatment Centers through a summer camp program and the first-ever Unite for Bleeding Disorders Walk.

NHF NEVADA

- Hosted **three** in-person Unite for Bleeding Disorders Walks that raised over **\$75,000**, surpassing the last in-person Walk totals;
- Added** a new administrative assistant position to the chapter staffing structure and filled the executive director, program manager, and development manager positions with new team members; and
- Conducted virtual education programs for more than **60** families in 2021.

NHF NEBRASKA

- Hosted **21** in-person and virtual education programs in 2021, ensuring accessible programming for the entire community regardless of location or ability to attend on-site;
- Developed programming specific to **teen and adult males**, creating a space for dialogue and connection; and
- Completed the **strategic plan for 2022 – 2024**, which will foster growth and support for the Nebraska bleeding disorders community.

NHF HAWAII

- Welcomed a **new executive director**;
- Mobilized the annual **December Voices** program to provide a much-welcomed opportunity for community members to gather together in person;
- Identified the top **five** topics community members would like to learn more about through the chapter's 2021 needs assessment: von Willebrand disease, awareness/advocacy, caregiving, college life, and concussions; and
- Raised **over \$250,000** through the Unite for Bleeding Disorders Walk since becoming a merged chapter.



CONFERENCE & TRAVEL SERVICES CONNECTING VIRTUALLY AND IN-PERSON

THE NHF CONFERENCE AND TRAVEL SERVICES TEAM CREATES EVENTS THAT SERVE IBD COMMUNITY MEMBERS AND PHYSICIANS. IN 2021, THE TEAM CONDUCTED HYBRID EVENTS (IN-PERSON AND VIRTUAL) TO MEET PATIENT NEEDS AND TO CONNECT HEALTH CARE PROVIDERS.

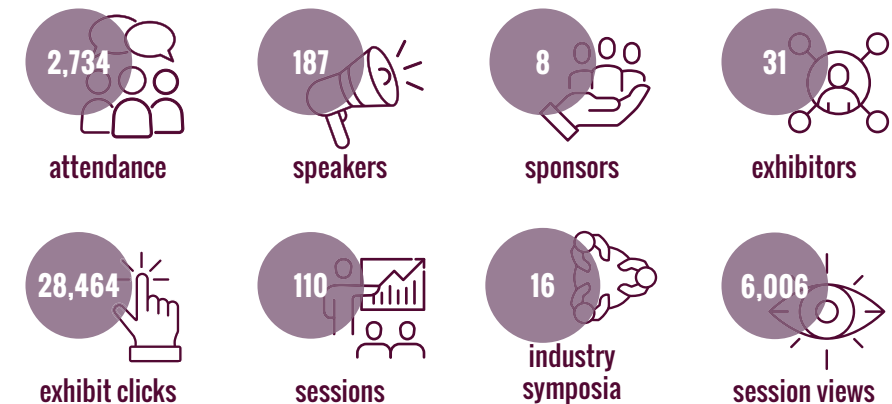
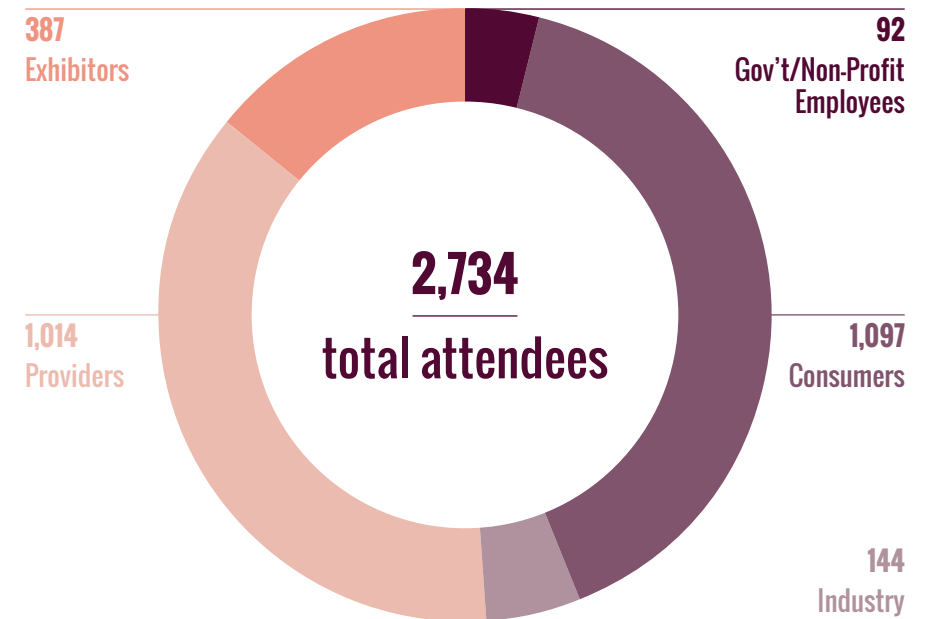
MAJOR EVENTS IN 2021 INCLUDED THE ANNUAL BLEEDING DISORDERS CONFERENCE (BDC; HELD VIRTUALLY FOR THE SECOND YEAR IN A ROW), THE FULLY VIRTUAL AND FIRST-EVER STATE OF THE SCIENCE RESEARCH SUMMIT, AND HYBRID EVENTS INCLUDING THE NOVEL TECHNOLOGIES ON GENE THERAPY AND THE CHAPTER LEADERSHIP SEMINAR.

HIGHLIGHTS FROM THE BDC AND STATE OF THE SCIENCE RESEARCH SUMMIT INCLUDE:

BDC HIGHLIGHTS

- Secured nearly **\$2 million** in revenue;
- Received **28,464** clicks for virtual exhibits;
- Welcomed **2,734** attendees and **187** speakers;
- Conducted **110** educational sessions and **16** industry symposia/roundtables; and
- Hosted **eight** sponsors and **31** exhibitors;
- Received **6,006** views for educational sessions.

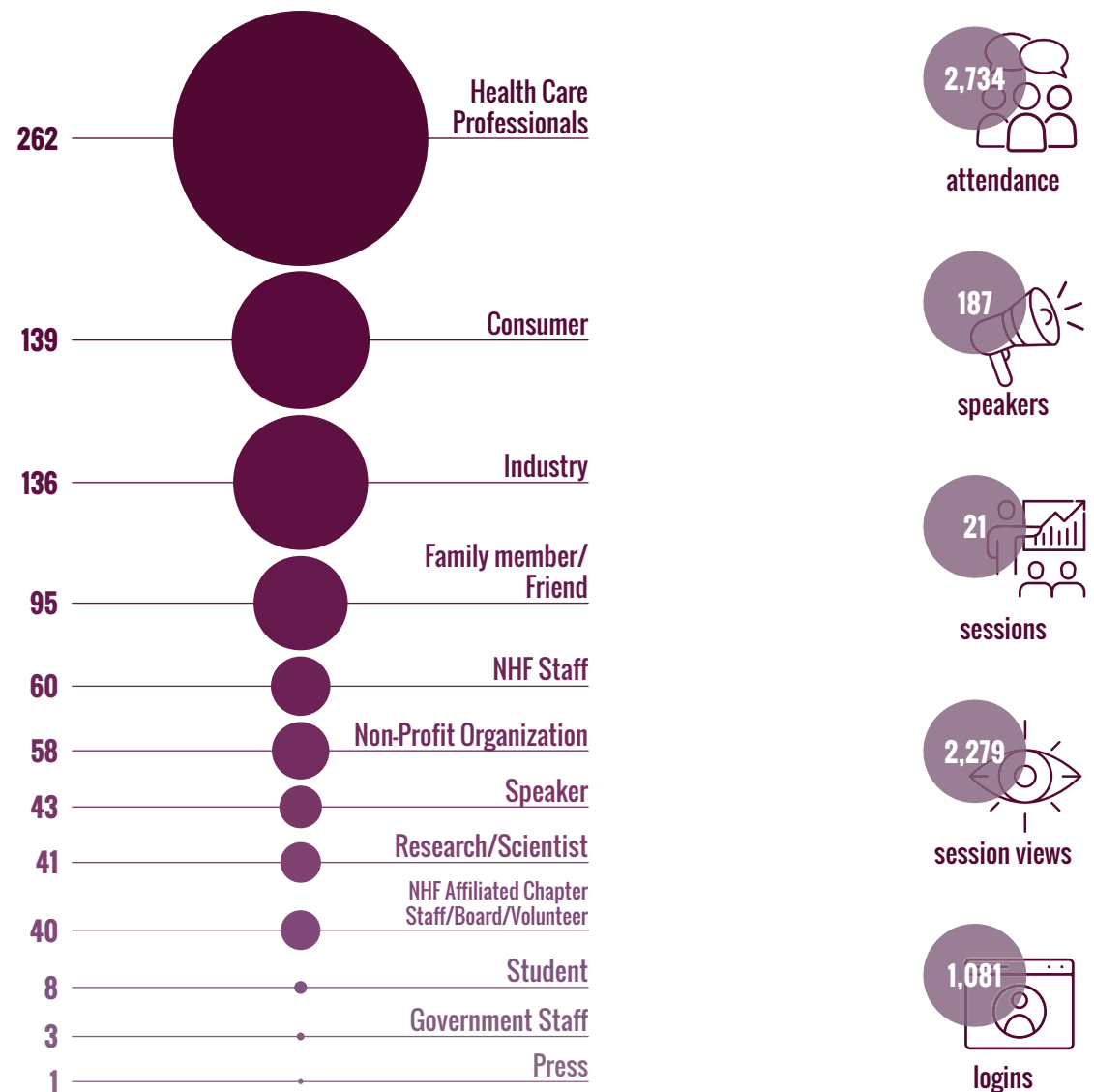
2021 CONFERENCE ATTENDEES



STATE OF THE SCIENCE RESEARCH SUMMIT HIGHLIGHTS

- Hosted **887** attendees (mostly health care providers and consumers) and **43** speakers;
- Conducted **21** informational sessions; and
- Received **2,279** views and **1,081** logins.

2021 CONFERENCE ATTENDEES

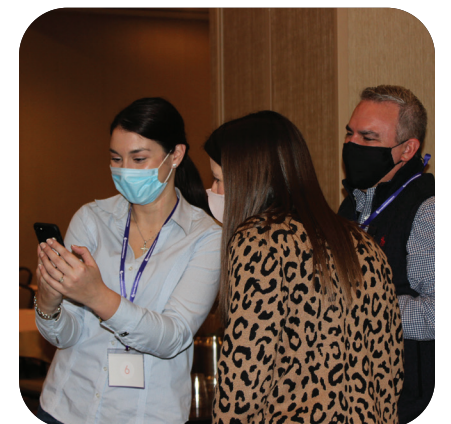


IT WAS A HUGE SIGH OF RELIEF THAT WE WERE ABLE TO DELIVER SAFE MEETING EXPERIENCES FOR ALL THOSE WHO WERE COMFORTABLE ENOUGH TO TRAVEL AND TO MEET IN-PERSON ONCE AGAIN. EVEN IF THE WORLD IS ON HOLD OR IN LOCKDOWN, NHF STILL HAS A COMMUNITY TO SERVE, AND WE WILL NEVER STOP SUPPORTING OUR COMMUNITY. I'M PROUD TO BE PART OF A TEAM THAT WORKS TOGETHER TO ADAPT TO MEET THE NEEDS OF OUR COMMUNITY AND PARTNERS.

Johanna Ong, Manager of Conference and Travel Services

IN DECEMBER 2021, I ATTENDED NHF'S IOWA CHAPTER ADVOCACY STAKEHOLDER MEETING. THIS WAS MY FIRST IN-PERSON EVENT SINCE THE PANDEMIC BEGAN. THE AUDIENCE'S INTEREST IN ADVOCACY WAS INFECTIOUS! THE MEETING IN IOWA REAFFIRMED MY BELIEF THAT THE PERSONAL TOUCH IN ADVOCACY WILL NEVER BE REPLACED BY ONLINE MEETINGS.

Bill Robie, Director, State Government Relations



EDUCATION

EMPOWERING AND ENGAGING COMMUNITY MEMBERS

NHF'S EDUCATION TEAM SUPPORTS AND EMPOWERS PATIENTS, FAMILIES, AND THEIR NETWORKS. IN 2021, THE TEAM FOCUSED ON SEVERAL DISTINCT PRIORITIES, INCLUDING IMPROVING AWARENESS OF SYMPTOMS OF BLEEDING DISORDERS IN WOMEN TO INCREASE DIAGNOSES LONG TERM; INCREASING AWARENESS OF AND SKILLS TO NAVIGATE TREATMENT OPTIONS AND CARE BEST PRACTICES; ELEVATING THE IMPORTANCE OF MENTAL HEALTH FOR THOSE LIVING WITH AN IBD; AND IMPROVING EQUITABLE HEALTH OUTCOMES BY IDENTIFYING ISSUES AND POTENTIAL SOLUTIONS. NHF CONTINUED TO INNOVATE IN 2021 TO MEET THE NEEDS OF THE COMMUNITY IN A VIRTUAL CAPACITY DUE TO THE COVID-19 PANDEMIC.

NHF developed an incredible virtual library for educational content during the COVID-19 pandemic in 2021 and will incorporate virtual attendance options in future offerings to make the foundation's educational programming accessible to as many people as possible. NHF's education team highlights from 2021 include:

BETTER YOU KNOW (BYK)

- Hosted over **17,000** user sessions on betteryouknow.org, leading to nearly **2,500** risk assessment tool takers, **80%** of whom showed signs of a bleeding disorder; and
- Introduced **BYK to new audiences** through partnerships with Healthy Women and the National Alliance for Hispanic Health.

healthywomen
PRESENTS

A Facebook Live Event Series
**Bleeding Disorders and Women:
Could You Be at Risk?**

Living With a Bleeding Disorder
November 17 | 12:00-1:00 p.m. ET

Created with support from the National Hemophilia Foundation

ACCEPTING THAT WE'RE DEALING WITH UNCERTAINTY IS KEY TO COPING DURING THIS CHALLENGING TIME.

Mary Karapetian Alvord, PhD

EDUCATIONAL MATERIALS AND AWARENESS BUILDING

- Hosted nearly **190,000** sessions on consumer education websites including stepsforliving.hemophilia.org, victoryforwomen.org, and betteryouknow.org;
- Developed **new IBD educational materials** and tools including videos on future therapies, FAQs, joint health webinars, and booklets for Glanzmann's thrombasthenia, factor X, factor VII, and factor XIII;
- Mailed almost **4,000** printed educational materials;
- Spearheaded education and outreach for the VWD guidelines;
- Hosted **quarterly** webinars in English and Spanish for ultra-rare bleeding disorders and inhibitors;
- Showcased **mental health as a community priority** during webinars and sessions at the BDC and on social media;
- Demonstrated **commitment to health equity** by translating all new materials into Spanish and hosted focus groups for patients of color and their health care providers to improve cultural competency;
- Welcomed over **400** attendees to education for empowerment workshops and chapter webinars;
- Provided education to **1,700** consumers via educational event series including the BDC, Rare Bleeding Disorders Series, Inhibitor Summit Series, and Viviendo con Inhibidores Series; and
- Trained **16** members of the National Youth Leadership Institute.



I'M A COMPLETELY DIFFERENT PERSON FROM WHEN I APPLIED TO NYLI TO RIGHT NOW.

NYLI 2021 graduate

ALTHOUGH YOU CAN'T CONTROL ALL OF YOUR CIRCUMSTANCES, YOU CAN CONTROL YOUR ROUTINES, BEHAVIOR, THOUGHTS AND ATTITUDES.

Mary Karapetian Alvord, PhD

MENTAL HEALTH CHALLENGES ARE NORMAL. IT'S NOT ALWAYS EASY TO MANAGE BUT THERE ARE TOOLS AND RESOURCES AVAILABLE.

Community Member





**HEALTH EQUITY, DIVERSITY,
AND INCLUSION**

WORKING TOWARD AN EQUITABLE FUTURE

NHF HAS A LONGSTANDING COMMITMENT TO HEALTH EQUITY, DIVERSITY, AND INCLUSION (HEDI). IN 2021, NHF MADE THIS COMMITMENT OFFICIAL BY ESTABLISHING A HEDI TEAM FOCUSED ON HEALTH EQUITY AND HEALTH DISPARITIES IN THE IBD COMMUNITY.



“AFTER THE NORD CONFERENCE, NEARLY 100% OF ALL SURVEY RESPONDENTS SAID THEIR UNDERSTANDING OF HEALTH DISPARITIES AND DIVERSITY, EQUITY, AND INCLUSION AS INDIVIDUAL CONCEPTS IMPROVED AFTER LISTENING TO YOUR PRESENTATIONS. THIS IS EXACTLY WHAT WE WERE HOPING FOR, AND KUDOS TO NHF FOR BEING ABLE TO COVER THESE COMPLEX CONCEPTS IN SUCH AN ENGAGING AND EASY TO UNDERSTAND MANNER.”

Ashanthi De Silva

With more energy dedicated to HEDI, NHF and the entire IBD community can climb to new heights regarding health equity. Here are some of the HEDI team's achievements:

- ◆ Established **13** new employee resource groups with **85%** NHF staff participation;
- ◆ Named **12** HEDI champions within the organization;
- ◆ Provided guidance for **four** chapters that received HEDI capacity building grants;
- ◆ **Updated** NHF protocols, policies, and procedures to incorporate diversity, equity, and inclusion best practices;
- ◆ **Collaborated across internal teams** so that all of NHF's activities continue to prioritize HEDI;
- ◆ Delivered evidence-based presentations and trainings at over **10 events**, including the Bleeding Disorders Conference, State of the Science Summit's, CEO Strategic Council, National Organization for Rare Disorders (NORD), and the American Thrombosis and Hemostasis Network; and
- ◆ **Trained U.S. board members** of the World Federation of Hemophilia on HEDI integration and the importance combatting health inequities.



MEDICAL PROGRAMS & INFORMATION ADVANCING PATIENTS, PROVIDERS, AND PROGRESS

THE MEDICAL PROGRAMS AND INFORMATION (MPI) TEAM AT NHF PLAYS A MAJOR ROLE IN DEVELOPING CONTINUING EDUCATION FOR HEALTH CARE PROVIDERS, INCLUDING PHYSICIANS, PHYSICIAN ASSISTANTS, NURSE PRACTITIONERS, PHARMACISTS, NURSES, SOCIAL WORKERS, AND PHYSICAL THERAPISTS. THE TEAM ALSO WORKS DILIGENTLY TO PROVIDE RELEVANT RESOURCES, SUPPORT, AND NEWS TO PATIENTS AND FAMILIES AFFECTED BY IBDS.

CARING FOR CONSUMERS

Through HANDI—NHF’s information resource center—NHF determines how it can better support unmet patient needs within the IBD community. HANDI provides resources and referrals to the community and the general public on a daily basis.

Additionally, the MPI team regularly publishes NHF news articles on hemophilia.org/news that provide the latest information to the IBD community on product advancements and clinical trial updates.

In 2021, the MPI team hit several milestones, including:

- ◆ Published **38 online news stories** that provide consumers with the latest relevant information for their needs;
- ◆ Translated **eight peer-reviewed journal articles** into plain-language summaries on hemophilia.org; and
- ◆ Answered over **1,200 requests** for information through HANDI.



**38 online
news stories**



**Translated eight
peer-reviewed
articles**

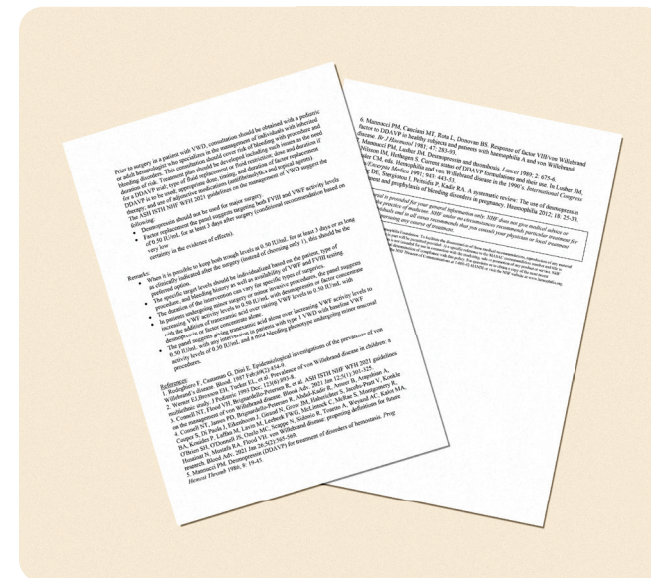
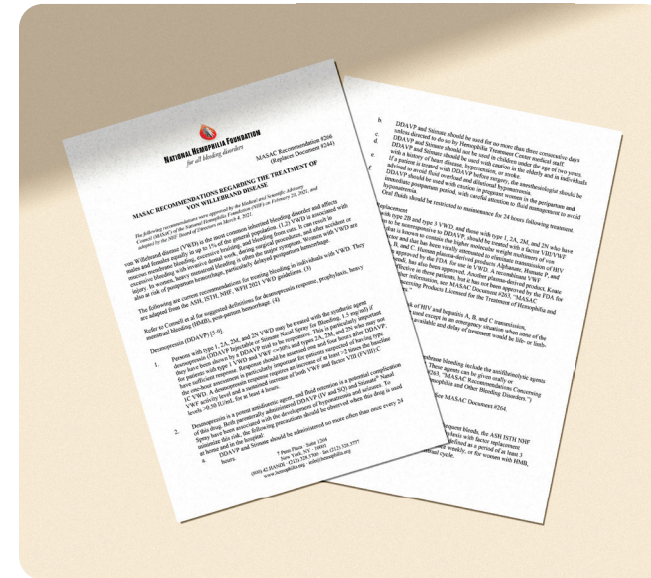


**Answered over
1,200 requests**

MAXIMIZING THE POTENTIAL OF MEDICAL PROFESSIONALS

The MPI team offered opportunities for professional engagement and continuing education for medical professionals throughout 2021, including:

- Organized and presented **four** educational tracks to over **1,000** health care providers at the 2021 BDC;
- Each track contained **10-12** hours of educational content and continuing education credits;
- Partnered with Medscape Education on **two** opportunities for health care providers to gain knowledge about gene therapy;
- Of these offerings, “From Principles to Practice: Preparing for the Advent of Gene Therapy” was made available as an online module through Medscape and provided continuing education for **1 year**;
- The second program entitled, “Gene Therapy and Hemophilia Care Updates: Bringing Your Treatment Center up to Speed” was a preconference symposium offered to **200** total attendees (in-person and virtual) at the American Society of Hematology Annual Meeting in December 2021;
- Hosted the **16th** Workshop on Novel Technologies and Gene Transfer for Hemophilia, bringing **120** researchers from around the world together to present the latest findings and collaborate with their colleagues;
- Held **two** virtual Medical and Scientific Advisory Council (MASAC) meetings and approved **three** new documents for the IBD community;
- MASAC Document #264 MASAC Recommendations Regarding Diagnosis and Management of Inherited Bleeding Disorders in Girls and Women with Personal and Family History of Bleeding
- MASAC Document #265 MASAC Guidelines for Pregnancy and Perinatal Management of Women with Inherited Bleeding Disorders and Carriers of Hemophilia A or B
- MASAC Document #266 MASAC Recommendations Regarding the Treatment of von Willebrand Disease;
- Produced **two new guidelines** through the NHF Nursing Working Group (NWG); and
- The NWG Infusion Therapy Guidelines
- The NWG Emicizumab Subcutaneous Injection Guidelines
- Developed educational materials, shared presentations, and created exceptional accredited content with more than **60 volunteer health care providers** through MASAC and NHF working groups.



I THINK THAT NHF REALLY KIND OF BINDS PEOPLE TOGETHER - BOTH PROVIDERS AND FAMILIES. I LOVE GOING TO THE ANNUAL CONFERENCE AND SEEING FAMILIES THAT I'VE TAKEN CARE OF OVER THE YEARS. I THINK IT'S A REALLY SPECIAL COMMUNITY WHERE WE GROW AND LEARN TOGETHER, OUTSIDE OF THE CLINIC.

Dr. Amy Dunn

PUBLIC POLICY ADVOCATING FOR A BETTER FUTURE

IN 2021, NHF'S PUBLIC POLICY TEAM CONTINUED TO SET A HIGH BAR FOR ADVOCACY ACHIEVEMENTS, DESPITE THE POLICYMAKING PROCESS STILL BEING MOSTLY REMOTE OR VIRTUAL. WHILE THIS CAN BE CHALLENGING AT TIMES, IT HAS ULTIMATELY SHOWN THE CONFIDENCE AND ADAPTABILITY OF THE INHERITABLE BLOOD AND BLEEDING DISORDERS COMMUNITY. IN SOME WAYS, IT HAS ALSO MADE ADVOCACY EFFORTS MORE INCLUSIVE, ALLOWING PEOPLE WHO ARE NOT LIKELY TO TRAVEL TO PARTICIPATE IN ADVOCACY FROM THE COMFORT OF THEIR OWN HOMES.

THE YEAR BEGAN SHORTLY AFTER THE PASSAGE OF THE SKILLED NURSING FACILITIES (SNF) BILL IN DECEMBER 2020, KICKING OFF THE NEW YEAR WITH A HEAVY FOCUS ON ITS IMPLEMENTATION IN THE RULEMAKING PROCESS AND EDUCATING THE SNF INDUSTRY AND COMMUNITY MEMBERS.

Here's a look at some the team's work in 2021:

- ◆ The virtual Washington Days program welcomed almost **400** participants from **46** states participating in more than **250** meetings with Congress;
- ◆ State chapters were engaged in at least **34** different bills in 2021, including the passage of step therapy bills in Arizona, Nebraska, and Oregon;
- ◆ More than **1,500** people participated in some form of advocacy training in 2021 provided by grantees in the State-Based Advocacy Coalition (SBAC) program;
 - ◆ **15** grants were also awarded to chapters in the SBAC program;
- ◆ NHF supported or participated in **15** virtual state chapter advocacy days;
- ◆ Thanks to NHF's virtual advocacy platform, **515** elected officials were contacted about issues important to community members;
- ◆ Incorporated public policy programming into Unite Walks with **8** chapters across the country ;
- ◆ Secured the signatures of **50** members of Congress on a letter to the administration asking for a Notice of Benefit and Payment Parameters fix;
- ◆ Helped **2** states (West Virginia and South Carolina) create Rare Disease Advisory Councils with the support of NHF chapters.



State chapters engaged in **34** different bills



1,500 advocacy training participants



250 meetings with Congress

ADVOCACY ACHIEVEMENTS

A remarkable amount of advocacy achievements progressed or finalized throughout 2021, including NHF being named as a Healthy People 2030 Champion by the U.S. Department of Health and Human Services.

This, alongside the passage of the SNF bill, and copay accumulator adjustment program (CAAP) legislation became NHF's top federal priorities. NHF commented with the Hemophilia Federation of America – and separately with a national coalition on the annual Notice of Benefit and Payment Parameters rule – requesting an administrative solution from the Biden administration.

NHF also was active during the Reconciliation process advocating for making Affordable Care Act (ACA) subsidies permanent, and signed an amicus brief in defense of the ACA in California v. Texas.

Additionally, NHF advocated for expanding eligibility for Medicare and Medicaid. As a member of the national Partnership to Protect Coverage coalition, NHF signed numerous letters to the Biden Administration on state waiver applications under the ACA (Sec. 1332) and Medicaid (Sec. 1115).

Finally, NHF partnered with the Hemophilia Alliance, the Hemophilia Federation of America, and the World Federation of Hemophilia to lobby the FDA to place Stimate on the National Drug Shortage List.

Lastly, the supporters of the State Based Advocacy Coalition grant program made 2021 an impressive year. Their support has taken NHF's state-level advocacy to new heights. In the program's 8th year, it was clear how much chapters have grown in advocacy capacity, sophistication, and confidence. It truly is rewarding to see how they have evolved and embraced their ability to be instruments of change in the policymaking process.

AS A COMMUNITY MEMBER, I GENUINELY APPRECIATE ALL THAT NHF DOES AT THE FEDERAL LEVEL, AND THE ASSISTANCE PROVIDED CHAPTERS FOR STATE ADVOCACY ISSUES.

Anonymous feedback received during an advocacy session at BDC 2021



MAKING #ALLCOPAYSCOUNT

Since early 2018, NHF has been a founding member of the All Copays Count Coalition (ACCC). As of 2021, the coalition proudly includes more than 80 non-partisan patient advocacy and provider organizations. In just a few years, the ACCC has grown to represent tens of millions of people in the U.S. living with serious, complex, and chronic illnesses.

The ACCC represents individuals and families who rely on health insurance to access appropriate needed medical care and treatment interventions. As insurers shift more and more cost burdens onto patients, cost shifting has exceeded what millions of Americans are able to afford without some sort of assistance. With annual deductibles and out-of-pocket costs up to \$8,700 for an individual – and up to \$17,400 for a family – millions of people living with chronic health conditions rely on financial assistance to be able to access their medications.

In 2017, health insurers and pharmacy benefit managers (PBM) began to implement policies that would no longer allow assistance to count towards out-of-pocket cost burden, even though the Affordable Care Act defines patient cost sharing as any amount paid by or on behalf of a beneficiary. When insurers and PBMs don't permit financial assistance to count toward a patient's deductible, copay, or coinsurance, it can leave patients who are

unable to pay thousands of dollars with no way to access their life saving treatments.

That is where NHF stepped in, and the All Copays Count Coalition was formed. Since its founding, NHF has – alongside other steering committee member organizations – worked tirelessly to educate legislators at state and federal levels about these harmful policies. With the introduction of H.R. 5801 at the federal level, and anti-accumulator legislation having passed in 14 states and Puerto Rico, with more pending, the ACCC's impact has already made a difference in the lives of chronic disease patients nationwide.

To learn more about the ACCC and NHF's role within the coalition, visit www.allcopayscount.org.



HEALTH PLANS HAVE CHANGED THE RULES ON HOW THEY COUNT COPAY ASSISTANCE PROGRAMS AND HAVE FOUND WAYS TO LIMIT PROTECTIONS FOR COVERAGE OF MEDICINES. THE ALL COPAYS COUNT COALITION IS A NECESSARY FORCE, AND ONE THAT NHF IS PROUD TO HAVE HELPED FOUND. THIS IMPORTANT WORK WILL HELP ALREADY VULNERABLE PATIENTS AFFORD MEDICALLY NECESSARY PRESCRIPTION DRUGS.

Kollet Koulianos, Vice President of Payer Relations

RESEARCH

ADDRESSING UNMET PATIENT NEEDS

THE NHF RESEARCH TEAM AIMS TO FIND BETTER TREATMENTS AND IMPROVE PATIENT CARE FOR ALL IBDs. NHF HELD ITS FIRST-EVER STATE OF THE SCIENCE RESEARCH SUMMIT AND LAUNCHED THE ADVANCED THERAPY MEDICINAL PRODUCTS COUNCIL (ATMPC) TO DEVELOP SCIENTIFIC PARTNERSHIPS WITH INDUSTRY RESEARCH AND DEVELOPMENT PARTNERS IN 2021.

In addition to the State of the Science Research Summit and the ATMPC, NHF's research team had a banner year, with achievements including:

- Disseminated information through posters and abstracts to major conferences and events, including **three** posters accepted by the American Society of Hematology annual meeting and **four** by the Hemostasis and Thrombosis Research Society annual meeting;
- Launched the research journal club, hosting **two** online events with **115** total attendees;
- Enrolled **1,332** individuals through the Community Voices in Research partnership, with nearly **50%** having completed a baseline survey;
- Held **five** virtual advisory panels with **35** participants;
- Published **three** manuscripts in **three** different journals; and
- Awarded **eight** fellowships to **11** individuals, investing **\$939,000** in the future of research.

“**MY ENROLLMENT SURVEY HAD QUESTIONS REGARDING SEXUAL ORIENTATION AND GENDER IDENTITY. I WAS THRILLED TO SEE THIS, AND I THANK YOU SO MUCH FOR INCLUDING THIS.**”

Community Voices in
Research Participant



Community Voices in Research
NATIONAL HEMOPHILIA FOUNDATION



115 participants at
Research Journal
Club



Enrolled **1,332**
individuals in CVR



Fellowships awarded
to **11** individuals

SECURING THE STATE OF SCIENCE

The online Securing the State of Science summit in September 2021 was a huge success, receiving positive feedback from nearly **450** virtual attendees. The event uniquely positioned patients to become subject-matter experts, providing input throughout the entire summit, for example, during in-person and virtual listening sessions with health care providers, nonprofit partners, and industry representatives to determine research priorities and knowledge gaps. This input helped create six different working groups with over **160** individuals.

FINDINGS FROM THE SUMMIT

Findings from the summit are now helping to define NHF's National Research Blueprint, which will feature **11** manuscripts — one for each of the six working groups, three dedicated to global regions (Latin America, Asia, and Africa), a previously published paper on methods, and an explanatory paper in the World Federation of Hemophilia supplementary.

NHF State of the Science Research Summit

September
12-15, 2021



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



IN 2021, I WAS ABLE TO CHALLENGE MYSELF TO STEP OUTSIDE OF MY COMFORT ZONE BY TAKING ON NEW PROJECTS THAT FURTHERED THE ORGANIZATION'S MISSION. IN OVERSEEING ALL LOGISTICS FOR NHF'S FIRST-EVER FIRST STATE OF THE SCIENCE RESEARCH SUMMIT, I FINE HONED MY SKILLS WHILE SUPPORTING NHF'S PRIORITIES AROUND RESEARCH.

Karina Lopez, Project Management Specialist

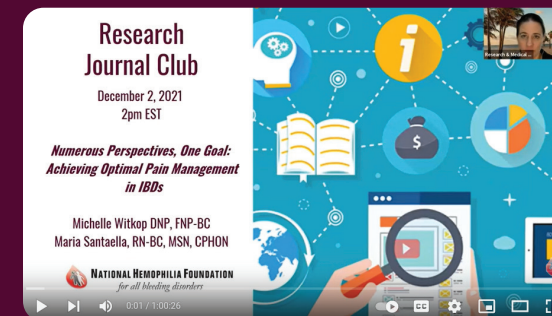
LAUNCHING THE ADVANCED THERAPY MEDICINAL PRODUCTS COUNCIL

The ATMPC aims to provide a collaborative forum for NHF partners to discuss emerging research and development trends related to advanced and experimental therapeutics, digital health, devices and diagnostics, regulatory policy, infrastructure challenges and opportunities, and cutting-edge concepts that could be applied for the benefit of patients.



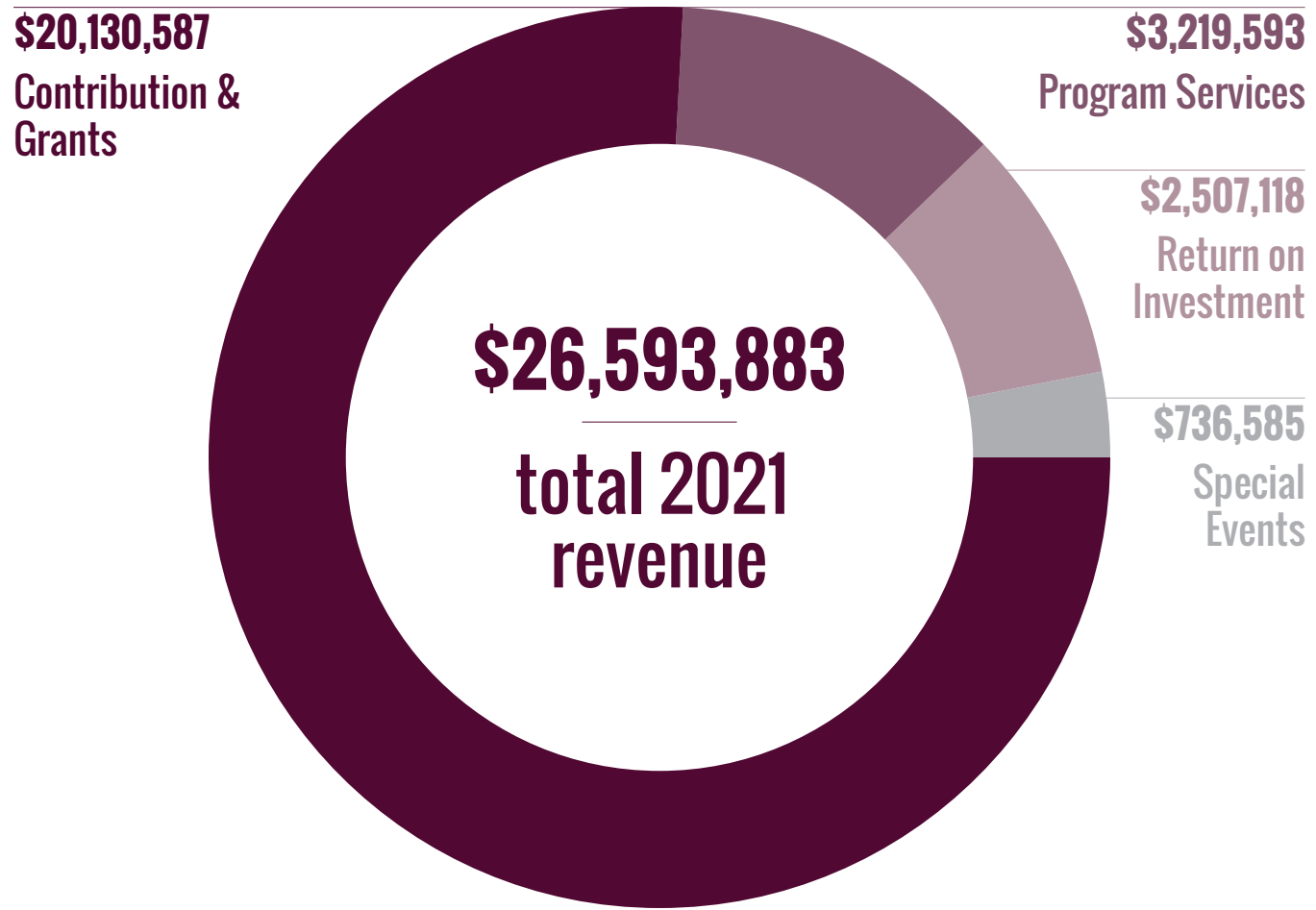
THE GENEROUS SUPPORT OF THE NHF HAS BEEN INSTRUMENTAL IN HELPING ME TO ESTABLISH A VIABLE CAREER PATH AS A PHYSICIAN-SCIENTIST FOCUSED ON THE BIOLOGY AND TREATMENT OF DISORDERS OF HEMOSTASIS. NHF HAS HELPED ME TO GAIN RECOGNITION AND COMMITMENT FROM MY HOME INSTITUTION AND I EXPECT WILL EVENTUALLY ENABLE ME TO LAUNCH AN INDEPENDENT CAREER WITH A FOCUS ON BLEEDING DISORDERS.

Dr. Sol Schulman
Judith Graham Pool Fellowship Recipient

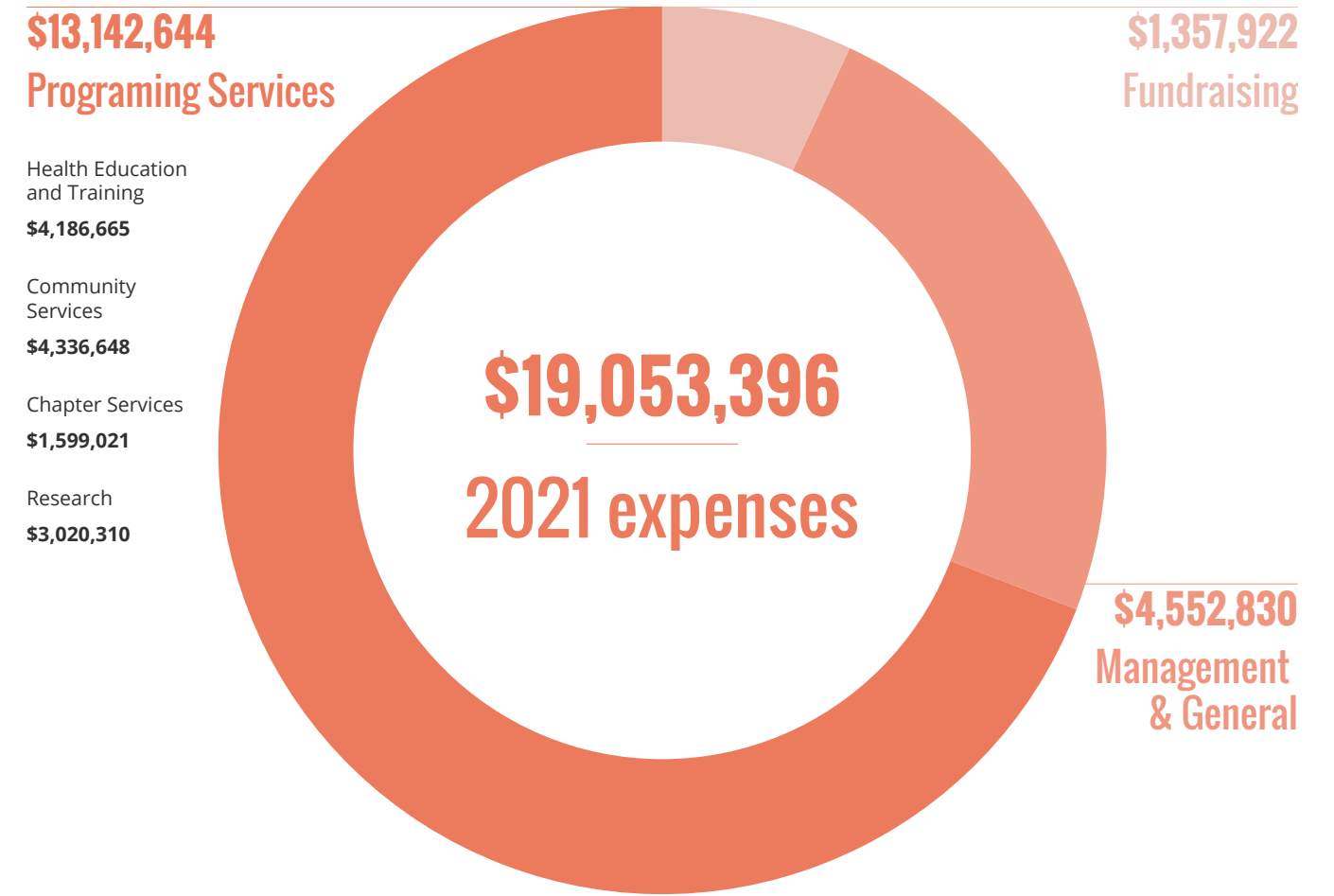


SEE RECORDINGS OF THE 2021 RESEARCH JOURNAL CLUB AT [YOUTUBE.COM/NHFVIDEO](https://www.youtube.com/nhfvideo)

REVENUE 2021



EXPENSES 2021



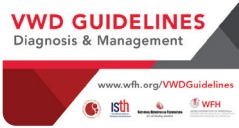
73% of revenue comes from pharmaceutical companies.
The ending net assets for 2021 was \$40,860,964


*Numbers based on 2021 audited financial statements


2021 AT-A-GLANCE


HERE ARE MONTHLY HIGHLIGHTS FROM NHF'S 2021 PROGRAMMING AND EVENTS:

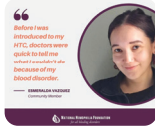
TO SEE MORE PROGRAMMING AND EVENT HIGHLIGHTS, FOLLOW NHF ON SOCIAL MEDIA!


01 January
NHF and partners published the first-ever guidelines for von Willebrand's disease diagnosis and management.



02 February
Debuted "Super Seven," a story for children with rare blood/bleeding disorders.



03 March
Community members like Melissa raised their voice during Bleeding Disorders Awareness Month.



04 April
NHF hosted a session as part of its Inhibitor Education Series.



05 May
Community member Esmeralda shared her experiences living with Glanzmann thrombasthenia.



06 June
NHF CEO Dr. Len Valentino scooped ice cream and served smiles at a fundraiser in North Carolina.



07 July
The weekly Wednesday Webinar series hosted an informative session on COVID-19 vaccination.


08 August
The annual Bleeding Disorders Conference went virtual and paid special tribute to a late member of our community, Ziggy Douglas, during the awards of excellence ceremony.


09 September
At the first-ever State of the Science Research Summit, community members like Amar were able to draw attention to rare conditions.


10 October
The Red Tie Soiree went virtual for the second year in a row.


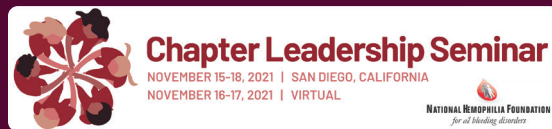
11 November
On Giving Tuesday, community members shared their stories.


12 December
Sadly, in December 2021, the blood and bleeding disorders community lost a champion. Val Bias was NHF's longtime CEO and a crusader in the fight for affordable health care and health equity. He is mourned by all.


NHF STAFF REFLECTIONS

I ATTENDED THE CHAPTER LEADERSHIP SEMINAR IN SAN DIEGO, WHICH WAS MY FIRST IN-PERSON EVENT IN A YEAR AND A HALF! IT WAS GREAT TO CONNECT WITH SO MANY INDIVIDUALS THAT I HAD MET VIRTUALLY IN-PERSON FOR THE FIRST TIME.

Nick Kallinicou
Chapter Development Specialist



IT'S HARD TO BELIEVE THERE ARE PEOPLE I'VE WORKED REMOTELY WITH FOR TWO YEARS THAT I'VE NEVER SEEN IN PERSON, YET I FEEL LIKE WE'RE FRIENDS. NHF HAS REALLY TAKEN VIRTUAL LIFE IN STRIDE, AND I'VE PERSONALLY ENJOYED OUR VIRTUAL BOOK CLUB DISCUSSIONS, ZOOM TRIVIA CONTESTS, ONLINE WORKOUTS, AND MORE.

Bill Robie, Director, State Government Relations



I JOINED THE NHF TEAM IN 2021, AND THE NYC MARATHON WAS MY FIRST OPPORTUNITY TO MEET MEMBERS OF THE COMMUNITY IN PERSON. GETTING TO CHEER THEM ON FROM THE SIDELINES DURING THE MARATHON WAS SO INSPIRING! THAT EXPERIENCE REALLY EXEMPLIFIED FOR ME HOW IMPORTANT IT IS TO HELP RAISE AWARENESS FOR THE COMMUNITY. MOST PEOPLE KNOW VERY LITTLE ABOUT BLEEDING DISORDERS, AND I'M HONORED TO HELP RAISE AWARENESS ON BEHALF OF THE AMAZING COMMUNITY MEMBERS I'VE MET.

Riley Breen
Development Specialist



IT'S IMPORTANT THAT ANY ORGANIZATION THAT IS TRULY COMMITTED TO ADDRESSING THE INEQUITIES THAT EXIST, DIVERSITY AND INCLUSION MUST BE INTEGRATED INTO ITS MISSION, VISION, AND STRATEGIC PLAN. THIS CAN ENSURE THAT ALL WORK ACROSS ALL DEPARTMENTS ALIGN WITH THE DIVERSITY AND INCLUSION GOALS.

Dr. Keri Norris
Vice President of Health Equity, Diversity, and Inclusion



NHF HAS RENEWED ITS FOCUS ON RESEARCH TO ACHIEVE A VISION OF A WORLD WITHOUT INHERITABLE BLOOD DISORDERS.

Dr. Len Valentino
NHF President and CEO



I'VE SEEN MEDICINE AS THE CLEAR GOAL THAT I WANT TO ACHIEVE, TO HELP OTHERS TO BE A LIFELONG STUDENT AND ALWAYS CONTINUE LEARNING AND GIVE BACK TO SOCIETY IN A WAY THAT I CAN BE REALLY EXCITED ABOUT.

Garrett Hayes, NYLI Member

2021 NHF OFFICERS

Leonard A. Valentino, MD

President and Chief Executive Officer

Dawn Rotellini

Chief Operating Officer

Michelle Rice

Chief External Affairs Officer

Peter Harvey, MBA

Chief Business Officer

Kevin Mills, PhD

Chief Scientific Officer

2021 MANAGEMENT STAFF

Michael Craciunoiu, EdM, PCC

Vice President of Chapter Services

Kate Nammacher, MPH

Vice President of Education

Neil Frick, MS

Senior Vice President of Medical
Programs and Information

Brett Spitale

Vice President of Advancement

Nathan Schaefer, MSW

Vice President of Public Policy

Michelle Witkop, DNP, FNP-BC

Head of Research

Keri Norris, PhD, JM, MPH, MCHES

Vice President of Health Equity,
Diversity & Inclusion

NHF'S 2021 CORPORATE PARTNERS

NHF WANTS TO THANK OUR 2021 CORPORATE PARTNERS FOR THEIR SUPPORT AND RECOGNIZE THEM FOR THEIR ONGOING COMMITMENT TO THE INHERITABLE BLOOD AND BLEEDING DISORDERS COMMUNITY.

AbbVie	CVS Health	Novo Nordisk	Spark Therapeutics
Accredo	Cascade Hemophilia Consortium	Optum Infusion Pharmacy	Takeda Pharmaceuticals America, Inc.
AscellaHealth, LLC	Catalyst Biosciences	Pfizer, Inc.	The Gulf States Hemophilia and Thrombophilia Center
Bayer	Freeline Therapeutics	Regeneron	uniQure
Bio Products Laboratory	Genentech	Sangamo Therapeutics	World Federation Hemophilia
BioMarin Pharmaceutical	Grifols	Sanofi	
BioMatrix Specialty Pharmacy	HEMA Biologics	Sigilon Therapeutics	
Biotechnology Innovation Organization	Hemophilia Alliance		
Bleeding and Clotting Institute of Illinois	Indiana Hemophilia Treatment Center		
Bluebird Bio	International Society of Thrombosis & Hemostasis		
CSL Behring	Louisiana Center for Bleeding and Clotting Disorders (Tulane University)		

NHF'S 2021 AFFILIATED CHAPTERS

Alaska Hemophilia Association	Kentucky Hemophilia Foundation
Hemophilia & Bleeding Disorders of Alabama	Louisiana Hemophilia Foundation
Arizona Bleeding Disorders	New England Hemophilia Association
Hemophilia Foundation of Northern California	Hemophilia Alliance of Maine, Inc.
Central California Hemophilia Foundation	Hemophilia Foundation of Michigan
Hemophilia Foundation of Southern California	Hemophilia Foundation of Minnesota and the Dakotas
Hemophilia Association of San Diego County	Midwest Hemophilia Association
Colorado Chapter, National Hemophilia Foundation	Gateway Hemophilia Association
Connecticut Hemophilia Society, Inc.	Rocky Mountain Hemophilia and Bleeding Disorders Association
Hemophilia Foundation of Greater Florida	Hemophilia of North Carolina
Florida Hemophilia Association	Bleeding Disorder Alliance of North Dakota
Hemophilia of Georgia, Inc.	Nebraska Chapter, National Hemophilia Foundation
Hawaii Chapter, National Hemophilia Foundation	Sangre de Oro, Bleeding Disorders Foundation of New Mexico
Hemophilia of Iowa, Inc.	Nevada Chapter, National Hemophilia Foundation
Idaho Chapter, National Hemophilia Foundation	New York City Hemophilia Chapter Inc.
Bleeding Disorders Alliance Illinois	Mary M. Gooley Hemophilia Center
Hemophilia of Indiana	

Western New York BloodCare	Western Pennsylvania Bleeding Disorders Foundation
Bleeding Disorders Association of Northeastern New York	Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado
Central Ohio Chapter, National Hemophilia Foundation	Bleeding Disorders Association of South Carolina
Southwestern Ohio Hemophilia Foundation	Lone Star Bleeding Disorders Foundation
Tri-State Bleeding Disorder Foundation	Texas Central Bleeding Disorders
Northern Ohio Hemophilia Foundation	Hemophilia Association of the Capital Area
Northwest Ohio Hemophilia Foundation	Virginia Hemophilia Foundation
Oklahoma Hemophilia Foundation	Bleeding Disorders Foundation of Washington
Pacific Northwest Bleeding Disorders	Great Lakes Hemophilia Foundation
Eastern Pennsylvania Bleeding Disorders Foundation	West Virginia Chapter, National Hemophilia Foundation



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders

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