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.
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.

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

ADVANCEMENT TEAM

COMMUNICATING HOPE

DEVELOPMENT: FUNDING THE FUTURE

$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
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.

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

LA AGUAYO
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:

- 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.

UNITE FOR BLEEDING DISORDERS WALK PARTICIPATION

- Over 700 teams
- 39 cities

80% In Person
20% Virtual

8
9
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.

**NHF WEST VIRGINIA**
- 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 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 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.

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.
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:

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

### 2021 Conference Attendees

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumers</td>
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<tr>
<td>Providers</td>
<td>1,014</td>
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<tr>
<td>Exhibitors</td>
<td>387</td>
</tr>
<tr>
<td>Industry</td>
<td>144</td>
</tr>
</tbody>
</table>

**Total Attendees**: 2,734
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

- 262 Health Care Professionals
- 139 Consumer
- 136 Industry
- 95 Family member/Friend
- 60 NHF Staff
- 58 Non-Profit Organization
- 43 Speaker
- 41 Research/Scientist
- 40 NHF Affiliated Chapter Staff/Board/Volunteer
- 8 Student
- 3 Government Staff
- 1 Press

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
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.

Mary Karapetian Alvord, PhD

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.
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.

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.

"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
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.
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
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.
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 Stimlate 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.

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 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

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

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
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.
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.

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

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

SEE RECORDINGS OF THE 2021 RESEARCH JOURNAL CLUB AT YOUTUBE.COM/NHFVIDEO
**REVENUE 2021**

- **$20,130,587** Contribution & Grants
- **$3,219,593** Program Services
- **$2,507,118** Return on Investment
- **$736,585** Special Events

**Total 2021 Revenue**: **$26,593,883**

**EXPENSES 2021**

- **$13,142,644** Programming Services
  - Health Education and Training: $4,186,665
  - Community Services: $4,336,648
  - Chapter Services: $1,599,621
  - Research: $3,920,310
- **$1,357,922** Fundraising
- **$19,053,396** 2021 Expenses
- **$4,552,830** Management & General

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

*Numbers based on 2021 audited financial statements*
HERE ARE MONTHLY HIGHLIGHTS FROM NHF’S 2021 PROGRAMMING AND EVENTS:

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

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

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

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

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

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

**February**
Debuted “Super Seven,” a story for children with rare blood/bleeding disorders.

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

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

**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.

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

**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’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

“I’ve 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 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

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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.

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NHF’S 2021 AFFILIATED CHAPTERS

Alaska Hemophilia Association
Hemophilia & Bleeding Disorders of Alabama
Arizona Bleeding Disorders
Hemophilia Foundation of Northern California
Central California Hemophilia Foundation
Hemophilia Foundation of Southern California
Hemophilia Association of San Diego County
Colorado Chapter, National Hemophilia Foundation
Connecticut Hemophilia Society, Inc.
Hemophilia Foundation of Greater Florida
Florida Hemophilia Association
Hemophilia of Georgia, Inc.
Hawaii Chapter, National Hemophilia Foundation
Hemophilia of Iowa, Inc.
Idaho Chapter, National Hemophilia Foundation
Bleeding Disorders Alliance Illinois
Hemophilia of Indiana
Kentucky Hemophilia Foundation
Louisiana Hemophilia Foundation
New England Hemophilia Association
Hemophilia Alliance of Maine, Inc.
Hemophilia Foundation of Michigan
Hemophilia Foundation of Minnesota and the Dakotas
Midwest Hemophilia Association
Gateway Hemophilia Association
Rocky Mountain Hemophilia and Bleeding Disorders Association
Hemophilia of North Carolina
Bleeding Disorder Alliance of North Dakota
Nebraska Chapter, National Hemophilia Foundation
Sangre de Oro, Bleeding Disorders Foundation of New Mexico
Nevada Chapter, National Hemophilia Foundation
New York City Hemophilia Chapter Inc.
Mary M. Gooley Hemophilia Center
Western New York BloodCare
Bleeding Disorders Association of Northeastern New York
Central Ohio Chapter, National Hemophilia Foundation
Southwestern Ohio Hemophilia Foundation
Tri-State Bleeding Disorder Foundation
Northern Ohio Hemophilia Foundation
Northwest Ohio Hemophilia Foundation
Oklahoma Hemophilia Foundation
Pacific Northwest Bleeding Disorders
Eastern Pennsylvania Bleeding Disorders Foundation
Western Pennsylvania Bleeding Disorders Foundation
Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado
Bleeding Disorders Association of South Carolina
Lone Star Bleeding Disorders Foundation
Texas Central Bleeding Disorders
Hemophilia Association of the Capital Area
Virginia Hemophilia Foundation
Bleeding Disorders Foundation of Washington
Great Lakes Hemophilia Foundation
West Virginia Chapter, National Hemophilia Foundation