

# 2020 ANNUAL REPORT



[www.hemophiliafed.org](http://www.hemophiliafed.org)



**Supporting people with bleeding  
disorders and their families.**



Hemophilia Federation of America™

**Assisting. Educating. Advocating.**

# The COVID Pandemic: Meeting the Challenges of 2020

There is strength in numbers – especially when an entire community comes together for the greater good. The year 2020 was undoubtedly marked by challenges, loss and uncertainty. However, HFA reaffirmed its resilient spirit by responding with urgency, generosity and courage.

## Unprecedented Crisis, Unprecedented Collaboration

### HFA COVID-19 Relief Fund

Helping Hands has provided a safety net for bleeding disorders families facing financial need for more than 20 years, and in 2020 the need was greater than ever. The first family to express a need for financial assistance because of COVID-19 did so on March 18, 2020. HFA staff worked together to quickly determine the best way to respond to families facing financial instability during the pandemic while keeping staff and financial resources available to continue our cornerstone Helping Hands programs throughout the year. Thanks to generous donations and efforts across the organization, we created the **COVID-19 Relief Fund** to provide efficient, effective and rapid financial relief for bleeding disorders families facing urgent need due to COVID-19. Within four weeks, we secured funding, created guidelines, streamlined the processing of requests, created a COVID-19 information and resource hub on our website, which included ways to find financial assistance, publicized the program to stakeholder groups, and onboarded colleagues to temporarily help staff the program.

Our Helping Hands  
COVID-19 Relief Fund  
disbursed \$387,172 to  
funded applicants.



HFA changes lives by providing meaningful programs and services.  
Now you can make a difference with your gift of support.  
Donate today at [www.hemophiliafed.org/donate](http://www.hemophiliafed.org/donate).

# HFA COVID-19 Relief Fund

- We paid **637 bills for 523 families** whose incomes were impacted by the COVID-19 pandemic.
- **253 families** served by the COVID-19 Relief Fund were totally **new** to HFA and were introduced to our programs and services.
- **More than 500 unique organizations submitted referrals** to the program, including HTC's, homecare/specialty pharmacies, bleeding disorder organizations, and other health care providers.
- The program served applicants from **44 states and territories**.
- **82% of households were at or below the Federal Poverty Line** for a family of four at the time of application.
- **\$607.92** was the average amount of bill paid per application.



**“They cared.  
We asked for  
help. They just  
reached out and  
cared about  
us. Helping  
Hands stopped  
eviction.”**

*- COVID-19 Relief Fund Recipient*

# Advocating For Our Community

Through the education and empowerment of patients and families, we mobilized a grassroots network of engaged advocates to raise awareness, ensure strong legislative and regulatory protections, and improve health outcomes and quality of life for people living with bleeding disorders. We track legislation on policy priority areas and provide assistance addressing them to Member Organization staff.

While in-person events were limited to the first few months of the year, policy and advocacy for the bleeding disorders community did not slowdown in 2020. HFA worked in tandem with our Member Organizations and coalition partners to protect access to the treatments patients need. With access to care, coverage and affordability as core tenets of our work, we advocated on a plethora of issues, including COVID related topics.

## Topics included:

- Medicaid 115 waivers
- Notice of benefit and payment parameters for 2021
- COVID related measures including relief for nonprofits and individuals, PPE, plasma collection, surprise billing, telehealth and more
- Step therapy, accumulator adjuster protections, Affordable Care Act protections and surprise billing
- State Rare Disease Advisory Councils

## THE NUMBERS

**11** Legislative days participated in

**189** Community members attended legislative days

**78** Advocacy trainings offered at Member Organizations

**813+** Community members attending advocacy trainings

**7** State comment letters

**25** Federal comment letters

**977** Sign-on letters



# Advocating For Our Community

**SAFETY SUMMIT:** In our ongoing commitment to blood and product safety, we partnered with the National Hemophilia Foundation to co-host a Safety Summit over three days in late January in Washington, D.C. The summit was convened in recognition and response to community concerns arising from a series of drug safety reports in 2019. Eighty-five stakeholders participated in the summit, including patients, patient organizations (national, international, and state-level), clinicians, manufacturers, specialty pharmacy, federal health agencies and more. The summit addressed safety notification standards and processes and the rights, roles and responsibilities of different stakeholder groups with respect to product safety and safety reporting.

**COALITIONS AND PARTNERSHIPS:** We engage with a robust and dynamic network of other non-profit partners and coalition groups. Some of our ongoing partnerships include:

- All CoPays Count
- Alliance for a Stronger FDA
- American Plasma Users Coalition (APLUS)
- Partnership to Protect Coverage
- Friends of National Center for Birth Defects and Developmental Disorders (NCBDDD)
- State Access to Innovative Medicines (SAIM)

We partnered with the following associations:

- Biotechnology Industry Organization (BIO)
- National Organization for Rare Disorders (NORD)
- Plasma Protein Therapeutics Association (PPTA)



# Advocating For Our Community

**ADVOCACY LEADERSHIP COUNCIL (ALC):** The program built a strong, engaged army of champions to fight for meaningful healthcare and thus help to improve care and quality of life for all people living with bleeding disorders.

*11 Ambassadors      4 Online Educational Webinars*

**IMPACT OF PARTICIPATION IN ALC:** Participants in the ALC have continued their involvement in the greater bleeding disorders community by pursuing graduate degrees in public health, assuming leadership (paid and volunteer) roles with local HFA member organizations and writing for HFA's Dateline Federation magazine.

**YOUNG ADULT ADVOCACY SUMMIT:** Participants received online training on state and federal policy issues, advocacy, communications and health insurance, attended virtual meetings on Capitol Hill, and discussed issues facing young adults with bleeding disorders.

*20 Attendees      25 Congressional Office Visitors*



# Advocating for Our Community

**INTERNSHIP:** We mentored two college-aged members of the community by offering a policy-focused internship program where they learned about the policies that affect access to care and insurance needs.

As part of the interns' capstone project, the BloodFlow podcast was launched. This periodic podcast was hosted by our 2 interns, Will and Tamleelah, and focused on advocacy issues of importance to a broader young adult audience.

Interns were provided detailed weekly assignments with recorded and live webinars, podcasts and readings. The interns met at least once a week with a member of the HFA policy & advocacy staff and joined all other policy & advocacy meetings and HFA staff meetings during their tenure. Interns completed a weekly report detailing the number of hours worked and providing synopsis from their assignments. This gave the interns clear expectations for the week, but also allowed them to set their own work schedule and to engage in critical thinking and analysis of complex policy issues.



# Advocating for Our Community

**FLY-IN AND CONGRESSIONAL RECEPTION:** Due to ongoing concerns regarding public gatherings and the impact COVID-19 had on in-person legislative visits, HFA pivoted the Fly-In and Congressional Reception curriculum and experience to an online campaign that took place November 16-20. Although we had to shift our legislative outreach visits to either a phone call or Zoom video call, we found the experience and effort to be as equally effective as meeting in person. Switching to a virtual experience afforded HFA the opportunity to provide more educational outreach via webinar than we have in the past. Typically, our Fly-In education only reaches the patients we bring to Washington DC, but this year we were able to provide education throughout the week to a broader audience, in addition to our advocate training prior to legislative visits. We continued our tradition of honoring two congressional champions through our annual congressional reception.

## THE NUMBERS

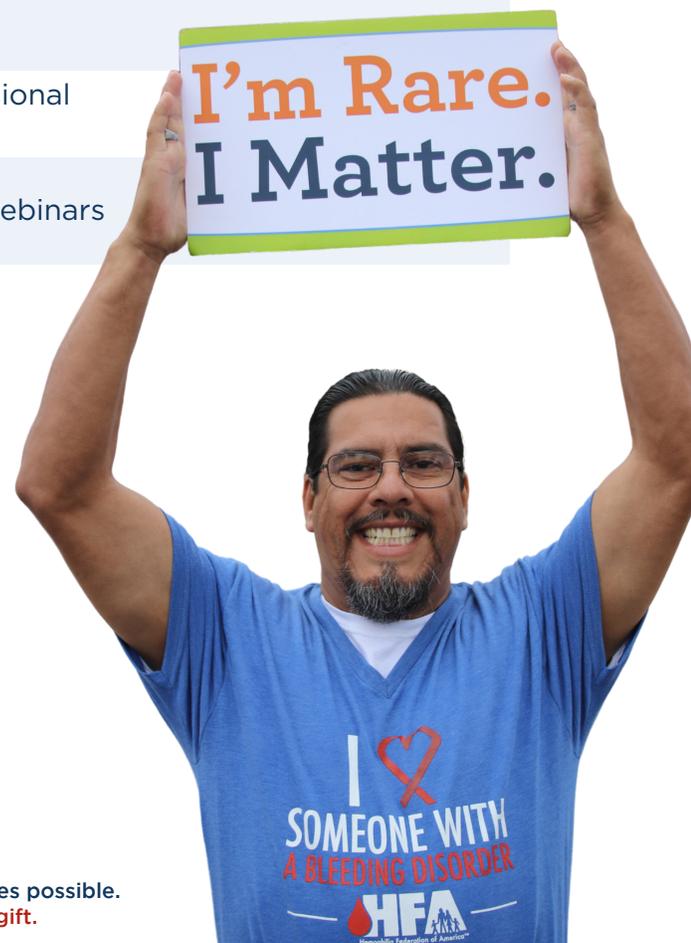
**16** Community members representing 11 states visited 26 congressional offices

**145** Connections with congressional delegations via our online action center

**13,639** Reach via Facebook posts

**58** In attendance at virtual congressional reception

**71** Webinar attendees across two webinars



Thank you to our donors for making our programs and services possible.  
Go to [hemophiliafed.org/donate](https://hemophiliafed.org/donate) to make your secure online gift.

# Assisting Our Community

Helping Hands had a 113% increase in applications funded (412 to 787) and a 150.36% increase in dollars distributed (\$478,818 to \$524,286) in 2020 compared to 2019.

## We disbursed \$524,286 to 874 applicants

456	bills for housing
233	bills for utilities
96	bills for transportation
67	bills for medically recommended items
14	bills for medical travel or tutoring for people with inhibitors
8	bills for people recovering from natural disaster

## DISASTER RELIEF FUND

\$6,556 – Amount distributed to eight applicants who experienced a natural disaster in 2020 including earthquakes and storms in Puerto Rico, wildfires in California and Oregon and a hurricane in Louisiana.

**HELPING FORWARD:** The Services team maintained the new COVID-19 program while also building the Helping Forward program to address the root causes of financial insecurity and empower community members with career planning, employment rights, and financial planning information. New resource guides about mental health were created as was a video series with mental health tips. The new program also provides community members in need with tailored recommendations for financial, community, and educational supports. A new website featuring resource guides and digital learning about career planning, employment rights and financial planning was also developed.

**HOLIDAY GIVING:** We distributed gift cards to 58 families and individuals to help them through the holidays.

“I don’t cry at night worrying about if I’ll have a home for my son.”

*– Emergency Assistance Recipient*



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# Educating Our Community

Our team is consistently developing and distributing innovative, engaging and topical educational materials and programs to meet the unique needs of our community.

## Our Programs have 3,108 enrolled participants:

Blood Brotherhood	765
Blood Sisterhood	598
Families	1,292
Sangre Latina	453

HFA Programs was poised to react and adapt to the ever-changing needs of the community in light of the COVID-19 pandemic. As in-person events were canceled, HFA Programs quickly pivoted to offer a virtual program model for Member Organizations to continue to provide vital education and peer connections to the bleeding disorders community. HFA Programs adopted the motto, “You are Not an Island” and wove that theme into every session and resource that was produced.

HFA Programs continued to educate nationally through multiple timely and relevant webinars to provide much needed support. Topics included: Mental Health in a Time of Crisis, Camp and Parenting in a Pandemic. Over 400 community members took part in these educational sessions.

The Sangre Latina and Blood Brotherhood programs began hosting monthly chat sessions for the community to connect virtually and continue to build their peer support networks.

HFA Programs also began hosting “Meeting of the Minds” sessions to continue the “you are not an island” theme to our member organization support. This group meets monthly to share best practices and identify educational gaps.



**We partnered  
with 43 Member  
Organizations  
to host 155  
sessions for  
4,429 attendees.**

# Raising Awareness & Dollars

**TEAM RESILIENCE:** Our endurance fundraising team participated in various virtual events which helped bring the community together when we could not physically be together. We were able to raise awareness about bleeding disorders and funds for our programs and services.

## Star Wars Rival Run Weekend

While this runDisney event was cancelled there were many runners that rolled over their participation into the 2021 event to continue to support those living with bleeding disorders.

*183 runners 0 miles \$3,180 raised*

## Gears for Good National Ride

Our signature cycling event pivoted and brought together new teammates in a virtual experience, creating friendships, inspiration, determination and new training partners across the United States.

*31 riders 4,836 miles \$24,963 raised*

## Wine & Dine Half Marathon Weekend

Our first virtual runDisney event provided participants with a unique Disney villain twist as Disney villains took over more than just the Magic Kingdom!

*26 runners 102.3 miles \$7,220 raised*



# Researching for Our Community

Community driven, community centered, community focused research.

**SPANISH-LANGUAGE GENE THERAPY:** Funded by BioMarin and Spark Therapeutics, we designed and delivered a survey in Spanish to assess the current knowledge and understanding of gene therapy in our Spanish speaking community. Data was captured from 64 participants and the results were shared with the sponsoring partners and back to the community during a webinar.

**FEMALES IN RESEARCH SHARING AND TRANSLATION (FIRST) PROJECT:** Funded through a Patient Centered Outcomes Research Institute (PCORI) Eugene Washington engagement award, we collected qualitative data through a series of five focus groups across the country with 34 women in the community. The focus groups centered around barriers and facilitators for women engaging in research. In 2021, a Community Based Research Network (CBRN) of patients and other community stakeholders will be assembled to further the discussion and to outline a research agenda for women.

**PROVIDER PERSPECTIVE PROJECT:** In partnership with Novo Nordisk, we have conducted key informant interviews and developed a survey to help assess and identify barriers and facilitators to care for women with bleeding disorders from a provider's perspective. The project will conclude, and results disseminated in 2021.

**CDC HEALTH PREVENTION AND PROMOTION COOPERATIVE AGREEMENT 1405:** Work has been completed on a 6-year cooperative agreement with the CDC focused on joint health, inhibitors, and women with bleeding disorders. Gap assessments were conducted, and programs developed to help address the gaps within the focus areas of the community.

**CDC HEALTH PREVENTION AND PROMOTION COOPERATIVE AGREEMENT 2002:** Work has commenced on a new 5-year cooperative agreement with CDC. This work will focus on treatment for males with hemophilia, and on women with bleeding disorders. Initial work is aimed at assessing gaps and gathering information about programs that have been successful in other disease states that may be adapted to address the needs in the bleeding disorders community as well as assessing community needs.

**PRESENTING OUR FINDINGS:** A poster abstract about the findings from our FIRST focus group sessions with women was presented at the Patient Centered Outcomes Research Institute (PCORI) at their annual meeting on September 16-17th, 2020.

A presentation was delivered about the findings from our FIRST project at the National Hemophilia Foundation's annual meeting in August 2020.

Findings of interest to the community were shared through eleven posters that were on display and discussed during HFA's second annual poster session at Symposium. Poster authors were able to discuss their work in plain language to community members over chat or Zoom.

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# Growth in Digital Marketing



## HOW WE CONNECT IN NUMBERS

**135,614** Number of people who saw any content from our Facebook

**16,520** Number of Facebook page “likes” up from 15,960

**32,703** Total engagement with our content

**3,300** Number of Instagram Followers

**227,787** Total website page views in 2020

**174,557** Total website users in 2020

**21,951** Total email subscribers



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## FINANCIAL POSITION

As of Dec. 31, 2020

### Assets

Cash & Cash Equivalents	\$1,420,281
Receivables	\$640,091
Prepaid Expenses	\$21,556
Investments	\$6,068,123
Total	\$8,150,051

### Liabilities

PPP Loan	\$453,638
Accounts Payable	\$135,547
Accrued Liabilities	\$60,762
Deferred Revenue	\$1,507,400
Deferred Rent Payable	\$239,970
Total	\$2,397,317

### Net Assets

Without Restriction	\$131,006
With Restriction	\$5,621,728
Total	\$5,752,734

### Total Liabilities and Net Assets

Total \$8,150,051

## INCOME & EXPENSE

As of Dec. 31, 2020

### Public Support and Revenue

Grants & Donations	\$3,936,647
Membership	\$64,215
Directory and Advertising	\$601,793
Symposium	\$1,711,953
Investment Income	\$302,172
Total	\$6,616,780

### Expenses

Program Services	\$4,871,516
Management & General	\$201,408
Fundraising & Development	\$156,924
Total	\$5,229,848

### Changes in Net Assets

Net Assets January 1	\$4,365,802
Net Assets December 31	\$5,752,734



# Thank You For Your Support

## Our Board of Directors

The HFA Board of Directors is made up of individuals from our 50 Member Organizations representing families and individuals from all over the country. HFA appreciates the hard work and dedication of these volunteers.

### EXECUTIVE COMMITTEE

**Allison Ritcey**, *Chair*  
**Stephen Long**, *Vice Chair*  
**Gillian Schultz**, *Secretary*  
**Clyde Brawner**, *Treasurer*  
**Natasha Burroughs**, *Member at Large*  
**Ashley Gregory**, *Member at Large*  
**Maria Chavez**, *Member at Large*  
**Carletha Gates**, *Member at Large*  
**Joseph Markowitz**, *Member at Large*  
**Donnie Akers**, *Legal Counsel*  
**Josh Hemann**, *Past Chair*

### BOARD MEMBERS

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Jesus Escobedo-Soto  
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Lindsay Hooper  
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Britnee Vieira  
Alice Arapshian  
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Dena Shepard  
Anne-Louise Wirthlin  
Taha Amir  
Scott Muir  
Scott Domowicz  
Stephanie Mancusi



# Thank You For Your Support

## Our Member Organizations

Our 50 Member Organizations across the country provide programs, services and support to thousands of families and individuals every year. These organizations are vital to the work being done by HFA.

Alaska Hemophilia Association  
Arizona Bleeding Disorders  
Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado  
Bleeding Disorder Foundation of Washington  
Bleeding Disorders Alliance Illinois  
Bleeding Disorders Alliance of North Dakota  
Bleeding Disorders Association of Northeastern New York  
Bleeding Disorders Association of the Southern Tier  
Blood Bond Bleeding Disorder Network  
Central California Hemophilia Foundation  
Connecticut Hemophilia Society  
Eastern Pennsylvania Hemophilia Foundation  
Florida Hemophilia Association  
Gateway Hemophilia Association  
Hemophilia Alliance of Maine  
Hemophilia Association of New Jersey  
Hemophilia Association of New York Inc.  
Hemophilia Association of the Capital Area  
Hemophilia Foundation of Arkansas  
Hemophilia Foundation of Maryland  
Hemophilia Foundation of Michigan  
Hemophilia Foundation of Minnesota / Dakotas



# Thank You For Your Support

## Our Member Organizations

Hemophilia Foundation of Northern California  
Hemophilia Foundation of Southern California  
Hemophilia of Indiana  
Hemophilia of Iowa  
Hemophilia of North Carolina  
Hemophilia of South Carolina  
Hemophilia Outreach of El Paso  
Lone Star Bleeding Disorders Foundation  
Louisiana Hemophilia Foundation  
Mary M. Gooley Hemophilia Center  
Midwest Hemophilia Association  
New England Hemophilia Association  
New York City Hemophilia Foundation  
Northern Ohio Hemophilia Foundation  
Oklahoma Hemophilia Foundation  
Pacific Northwest Bleeding Disorders  
Rocky Mountain Hemophilia and Bleeding Disorders Association  
Sangre de Oro, Inc., Bleeding Disorders Foundation of New Mexico  
Snake River Hemophilia & Bleeding Disorders  
Southwestern Ohio Hemophilia Foundation  
Tennessee Hemophilia and Bleeding Disorder Foundation  
Texas Central Bleeding Disorders  
United Hemophilia Foundation  
Utah Hemophilia Foundation  
Virginia Hemophilia Foundation  
Western Pennsylvania Chapter of NHF  
Wisconsin Bleeding Disorders Network



# Thank You For Your Support

## Our Corporate Partners

Accredo  
ARJ Infusion Services  
Bayer  
BioMarin Pharmaceutical  
BioTek ReMEDys  
Bleeding Disorders Resource Network  
Bloomberg Philanthropies  
Brothers Speciality Rx  
Catalyst Biosciences  
Colburn Keenan Foundation  
Cottrill's Pharmacy  
CSL Behring  
CVS Health  
Diplomat Specialty Infusion Group  
Drugco Health  
Fidelis Specialty Pharmacy  
Genentech  
Grifols  
HEMA Biologics  
Kedrion Biopharma  
Matrix Health Group  
National Association of Orthopedic Nurses  
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Northrop Grunman Foundation  
Novo Nordisk  
Octapharma USA  
Option Care Health  
Optum Specialty Pharmacy  
Paragon Healthcare Speciality  
Patient-Centered Outcomes Research Institute  
Pfizer  
Pfizer Foundation  
PlatformQ Health  
Sanofi Genzyme  
Save One Life  
Sigilon Therapeutics  
Soleo Health  
Spark Therapeutics  
Takeda  
The Alliance Pharmacy  
The Coalition for Hemophilia B  
The Hemophilia Alliance  
Tremeau Pharmaceuticals  
U&I Inc.  
uniQure  
World Federation of Hemophilia





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