Supporting people with a bleeding disorder and their families.

Assisting, educating and advocating.
MEMBER ORGANIZATIONS
Working in partnership with 50 Member Organizations across the country

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
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 Center
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 Chapter
Northern Ohio Hemophilia Foundation
Oklahoma Hemophilia Foundation
Pacific Northwest Bleeding Disorders
(formerly Hemophilia of Oregon)
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
HOW WE CONNECTED

- **313,350** website views
- **13,369** email subscribers

SOCIAL MEDIA FOLLOWERS

- **15,954** on Facebook
- **5,260** on Twitter
- **3,182** on Instagram

- **40,000** copies of **Dateline** mailed to almost **13,000** households
## Financial Position

### Current Assets
- Cash & Cash Equivalents: $2,184,237
- Investments: $4,465,950
- Receivables: $1,455,900
- Other: $26,093
- **Total**: $8,132,180

### Current Liabilities
- Accounts Payable: $165,655
- Accrued Liabilities: $47,458
- Deferred Revenue: $3,313,295
- Deferred Rent Payable: $239,970
- **Total**: $3,766,378

### Net Assets
- Without Donor Restrictions: $4,295,331
- With Donor Restrictions: $70,471
- **Total**: $4,365,802

### Total Liabilities & Net Assets
- **Total**: $8,132,180

## Income & Expense

### Revenue
- Grants & Donations: $3,478,491
- Symposium: $2,081,847
- Advertising: $543,746
- Gain on Investments: $229,427
- Member Dues: $100,805
- Interest & Dividends: $182,483
- **Total**: $6,516,799

### Expenses
- Program Services: $5,588,067
- Fundraising & Development: $254,249
- Management & General: $124,955
- **Total**: $5,967,271

### Change in Net Assets
- Beginning of Year: $3,816,247
- End of Year: $4,295,331
ASSISTING

Helping Hands Fund
Providing financial relief to our community’s most vulnerable

- **$242,908**
  Amount disbursed in direct payments for housing, utilities and medically necessary items like braces or wheelchairs

- **426**
  Number of applications funded

Disaster Relief Fund

- **$6,496**
  Amount distributed to five applicants who experienced a natural disaster in 2019 or were still rebuilding from 2018’s natural disasters

Educational Scholarships

- **$22,000**
  Amount disbursed to 13 students

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“I am majoring in biology with a minor in chemistry. After graduation I plan to attend medical school in hopes to become a pediatric hematologist. Living with a bleeding disorder and seeing the positive impact my own hematologist has made on my journey, has sparked my long-term career choice. I am very appreciative of accepting this scholarship!”

—Olivia Hoff, Saint Mary’s College
Team Resilience
Our endurance fundraising team, participating in various athletic and competitive events across the country to raise awareness about bleeding disorders and funds for our programs and services.

RAGBRAI
The Register’s Annual Great Bicycle Ride Across Iowa, an annual seven-day bicycle ride across the state and the oldest, largest and longest recreational bicycle touring event in the world.

11 Riders  500 Miles  $11,000 Raised

Gears for Good National Ride
Our annual bike ride from West Virginia to D.C., Gears for Good is not a race, it’s a ride and so much more. It is camaraderie, friendship, a passion to help others, inspiration, determination and pure enjoyment.

38 Riders  156 Miles  $54,000 Raised
Our team is consistently developing and distributing innovative, engaging and topical educational materials and programs to meet the unique needs of our community.

We partnered with 41 Member Organizations to host 199 sessions for 7,423 attendees.

Our Programs have 3,440 enrolled participants:

- Blood Brotherhood • 751
- Blood Sisterhood • 584
- Families • 1,263
- Sangre Latina • 842
EDUCATING

Summer Educational Seminars
July 26-28

Reach Your PEAK (Plan, Education, Advocacy, Knowledge) Workshop
Twenty teens from across the country gathered for information and tools to assist with the process of transitioning to independent, functional adults who are able to manage their disorder, advocate for and support themselves.

Blood Sisterhood Glamp Out
Our first-ever national event for women where 16 women gathered for a two-day weekend of education, empowerment and connection.

TEACH Immersion in Spanish
Provided the opportunity for 16 men, women, mothers and fathers from the bleeding disorders community to come together for three days of educational training to develop their leadership and self-defense.
ADVOCATING

Through the education and empowerment of patients and families, we mobilize 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.

- **18** Legislative days participated in
  - **500+** Community members in attendance

- **76** Advocacy trainings offered at Member Organizations
  - **3,300+** Community members in attendance

- **14** State comment letters
- **24** Federal comment letters
- **43** Sign-on letters

**Topics included:**
- Healthy People 2020 Objectives
- Medicaid Managed Care Rule
- Notice of benefit and payment parameters for 2020
- Reinsurance waivers
- Step therapy rule in Medicaid Part B and management of protected drug class for Medicaid Part D
We were official members the following patient-advocacy coalitions:

- Accumulator Adjuster Working Group
- Alliance for a Stronger FDA
- American Plasma Users Coalition (APLUS)
- Burrito Coalition
- Keeping Patients Stable on Their Medications
- National Center for Birth Defects and Developmental Disorders (NCBDDD)
- State Access to Innovative Medicines (SAIM)
- Partners for Better Care (PBC)
- Patient-Driven Health Reforms Coalition

We partnered with the following associations:

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

Advocacy Leadership Council
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.

- 12 Ambassadors
- 48 Online Discussions
- 3 In-Person Trainings
Internships
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 issues.

“I am glad I had the opportunity to work for an organization like HFA, it made me excited about the possibility of pursuing work at a non-profit. This experience helped me understand how important and selfless nonprofit work is.”
—Jasmin

“The most important thing I learned is that our voices are more powerful than we realize. Politicians and their aides really listen and react to our stories, signing onto bills and pushing policies that benefit us. We have a duty to each other to speak out for the policies that can give us a better live, as well as other Americans. This internship helped me realize the power of my own story, something I have always discounted.”
—Dylan
Patient Fly-In, Congressional Reception and Virtual Hill Day

June 10

Community members from across the United States traveled to Washington, D.C., for meetings with their elected officials and staff. In our meetings with House and Senate members and staff we stressed the critical need for patient protections to gain and maintain meaningful healthcare coverage.

- **24**
  Community members representing 14 states visited 25 congressional offices

- **188**
  Connections with congressional delegations via our online action center

- **17,700**
  Reach via Facebook posts

- **100+**
  In attendance at congressional reception
Young Adult Advocacy Summit
Oct. 19-22
We hosted young adults with bleeding disorders, ages 18 to 30, from across the country for a four-day event at our office in D.C. Participants received training on state and federal policy issues, advocacy, communications and health insurance, attended meetings on Capitol Hill, and discussed issues facing young adults with bleeding disorders.

- 17 Attendees
- 14 Congressional offices visited
- 6,700+ Reach via social media takeover
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- CSL Behring
- Diplomat Specialty Infusion Group
- Spark Therapeutics Inc.