We are exclusively focused on the bleeding disorders patient and caregiver community.

Our mission is to assist, educate and advocate for the bleeding disorders community.

The staff and volunteers of HFA have worked tirelessly each day since our founding in 1994 to advance patients’ rights and access to care, be a resource to patients and their families at every stage in their life, and to provide educational opportunities to give patients the tools they need to advocate for themselves.

By employing a boots-on-the-ground, federation model in partnership with 50 state-based Member Organization affiliates, our reach is national but our programs and services are tailored to the unique and complex needs of smaller, local communities within the national bleeding disorders community.

THE STORY OF HOW WE CONNECT IN NUMBERS

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>10%</td>
<td>The percentage by how much our Facebook following grew</td>
</tr>
<tr>
<td>14,477</td>
<td>Number of page “likes” up from 13,220</td>
</tr>
<tr>
<td>720</td>
<td>Facebook posts in 2018</td>
</tr>
<tr>
<td>10,500</td>
<td>Total shares of our content</td>
</tr>
<tr>
<td>72,000</td>
<td>Number of “likes” on the total shares of our content</td>
</tr>
<tr>
<td>357,505</td>
<td>Total website page views in 2018</td>
</tr>
<tr>
<td>88%</td>
<td>Percentage of new visitors</td>
</tr>
</tbody>
</table>
### FINANCIAL POSITION

#### Assets
- Cash & Cash Equivalents: $2,299,167
- Investments: $2,154,040
- Receivables: $1,842,886
- Other: $33,833
  - **Total**: $6,329,926

#### Liabilities
- Accounts Payable: $213,090
- Deferred Revenue: $2,102,510
- Other Liabilities: $198,052
  - **Total**: $2,513,652

#### Net Assets
- Net Assets: $3,571,664
- Temporarily Restricted: $244,610
  - **Total**: $3,816,274

### FINANCIAL HIGHLIGHTS

#### Income
- Grants & Donations: $3,384,147 (62%)
- Membership: $65,685 (1%)
- Informative Communications Symposium: $514,601 (9%)
- Interest & Dividends: $1,592,470 (29%)
- Change in Investment Values: -$111,741 (-2%)
  - **Total**: $5,472,110

#### Expenses
- Program Services: $5,176,458 (95%)
- Administrative: $156,837 (3%)
- Fundraising: $113,323 (2%)
  - **Total**: $5,446,618
Assisting Our Community

Our Helping Hands program aids our community’s most vulnerable families who are suffering from financial hardship because of their bleeding disorder. Helping Hands is one of our longest-running programs and is a cornerstone of the work we do to help the neediest families in the community in an efficient, private, and individualized manner.

**We disbursed $237,520 to 407 applicants**

- Emergency Assistance: 183
- Items Reimbursement: 157
- Inhibitor Support: 67

Our community has a long history of rallying around our families in need. In 2017, our country faced an unprecedented number of natural disasters that continued to challenge families with bleeding disorders throughout 2018. Raging wildfires in California displaced or left families homeless. Families in Puerto Rico are struggling to gain access to clean drinking water, food, electricity and transportation. In Texas and Florida, our families were still rebuilding from hurricanes.

Our Helping Hands Disaster Relief Program disbursed $31,488 to funded applicants.
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. With thousands of enrolled members and a network of 50 Member Organizations to deliver in-person sessions throughout the country, our team is the definitive resource for educational programming in the community. With four distinct program areas, we’re able to serve all family members impacted by a bleeding disorder:

- **BLOOD BROTHERHOOD** — Empowering adult men living with a bleeding disorder throughout their journey. Participants connect in our private and secure online forum and by attending in-person sessions throughout the country.
- **BLOOD SISTERHOOD** — Providing education and support, promoting healthy practices, and establishing a unique sense of community for women with a bleeding disorder throughout all stages of their lives.
- **FAMILIES** — Serving the whole family through our Moms in Action, Dads in Action and Kids in Action programs, by providing resources, tools and sessions intended for the entire family.
- **SANGRE LATINA** — Supporting Spanish-speaking families by providing culturally-relevant education, resources, tools and social support.

In 2018, our Programs team reached 10,632 people by hosting 258 local sessions across the country.
Advocating For Our Community

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. Throughout 2018, our team worked hard to ensure patients had the tools and education they needed to advocate for themselves, but also remained active on a national level to ensure the bleeding disorders community’s interests were at the forefront of policy discussions. Some 2018 highlights:

**MARCH**
We participated in the Institute for Clinical and Economic Review’s review of emicizumab by offering written comments and a statement during the public roundtable. Our input was utilized in the final report.

**JUNE**
We hosted our annual patient fly-in, Congressional Reception and Virtual Hill Day.

**AUGUST**
In conjunction with coalition partners from other patient advocacy organizations, we participated in #DefendPreEx campaign, showing our support to defend pre-existing conditions. We developed educational materials and advocacy infographics that discussed short-term and association health plans that were shared far and wide.

**SEPTEMBER**
We presented a statement at a public meeting of the federal Advisory Committee on Blood and Tissue Safety and Availability, providing a patient-perspective on the issue of tolerable infectious disease risk in blood safety.
Advocating For Our Community

OCTOBER
We joined in an amicus brief in federal litigation challenging the administration’s expansion of short-term, limited-duration insurance.

DECEMBER
We published layman-accessible explainers of the court decision in Texas v. US, litigation challenging the constitutionality of the Affordable Care Act.

THROUGHOUT THE YEAR

52,646 Impressions of our monthly email, The Washington Wire, a wrap-up of policy and advocacy items
5,800 Community members reached through face-to-face and online programming
42 Federal comment letters participated in or submitted to legislative or regulatory bodies
26 State-based legislative days we’ve assisted with, hosted by our Member Organizations
12 State-based policy and / or regulatory comment or sign-on letters participated in or submitted
Thank You For Your Support
Our Board & Member Organizations

EXECTUIVE COMMUNITTEE
Independent, Tracy Cleghorn, Chair
Independent, Josh Hemann, Vice Chair
Independent, Michael Birmingham, Vice Chair
New England Hemophilia Association, Diane Lima, Secretary
Hemophilia Foundation of MN / Dakotas, Aaron Reeves, Treasurer
Northern Ohio Hemophilia Foundation, Raymond Volney, Member at Large
Sangre de Oro, Inc., Bleeding Disorders Foundation of New Mexico, Sophia Minhas, Member at Large
Independent, Matthew Compton, Past Chair

MEMBER ORGANIZATIONS & BOARD MEMBERS
Alaska Hemophilia Association, John Palmatier
Arizona Hemophilia Association, Open Seat
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Bleeding Disorders Association of Northeastern New York, Michael Deeb
Bleeding Disorders Association of the Southern Tier, Lesa Kaercher
Bleeding Disorders Foundation of Washington, Allison Ritcey
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Eastern Pennsylvania Chapter, Open Seat
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Hemophilia Alliance of Maine, Lianne Lapierre
Hemophilia Association of New Jersey, Joseph Markowitz
Hemophilia Association of New York, Inc., Linda Mugford
Hemophilia Association of the Capital Area, Stephen Long
Hemophilia Foundation of Arkansas, Austin Hollandt
Hemophilia Foundation of Maryland, Natasha Burroughs
Hemophilia Foundation of Michigan, Patrice Thomas (Flax)
Hemophilia Foundation of Northern California, Ashley Gregory
Hemophilia Foundation of Oregon, Cody Holman
Hemophilia Foundation of Southern California, Mickey Price
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Hemophilia of Indiana, **Kasey Shade**
Hemophilia of Iowa, **Open Seat**
Hemophilia of North Carolina, **Gillian Schultz**
Hemophilia of South Carolina, **Bonnie Phifer**
Hemophilia Outreach of El Paso, **Yolanda Ortiz**
Lone Star Hemophilia Chapter, **James Setliff**
Louisiana Hemophilia Foundation, **Erica Simpson**
Mary M. Gooley Hemophilia Center, **Lindsay Hooper**
Mississippi Bleeding Disorder Foundation, **Janya Roland**
New York City Hemophilia Chapter, **Matthew Porges**
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Snake River Hemophilia and Bleeding Disorders, **Open Seat**
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Texas Central Hemophilia Association, **Tracy Mayer**
United Hemophilia Foundation, **Carletha Gates**
Utah Hemophilia Foundation, **Scott Muir**
Virginia Hemophilia Foundation, **Daniel Warren**
Wisconsin Bleeding Disorders Network, **Darcy Zwier**
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The Hemophilia Alliance
Octapharma USA, Inc.
Spark Therapeutics, Inc.
Shire
Pfizer, Inc.

DEMONSTRATION PROJECT
Bioverativ

GIFT IN KIND
CVS Specialty
Prophet

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The Hemophilia Alliance
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Shire
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Genentech
Shire

POLICY & GOVERNMENT RELATIONS INTERNSHIP
CSL Behring
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PROGRAMS: BLOOD BROTHERHOOD
Accredo
BioMarin
Centers for Disease Control and Prevention
CVS Specialty
Diplomat Specialty Infusion Group
Shire

PROGRAMS: BLOOD SISTERHOOD
Accredo
Centers for Disease Control and Prevention
CSL Behring
Novo Nordisk
Shire

Hemophilia Federation of America™
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Our Corporate Partners

PROGRAMS: FAMILIES
- Accredo
- Centers for Disease Control and Prevention
- CVS Specialty
- Diplomat Specialty Infusion Group
- Genentech
- Novo Nordisk

PROJECT CALLS
- Diplomat Specialty Infusion Group
- Genentech
- Grifols, Inc.
- Pfizer, Inc.
- Shire

RESEARCH
- Spark Therapeutics, Inc.
- Genentech
- HEMA Biologics
- Patient-Centered Outcomes Research Institute

SPECIAL EVENT FUNDRAISING
- Aptevio Therapeutics
- CSL Behring
- CVS Specialty
- Diplomat Specialty Infusion Group
- Grifols, Inc.
- Spark Therapeutics, Inc.

SYMPOSIUM
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- ARJ Infusion Services
- Bayer
- BioMarin Pharmaceuticals, Inc.
- BioMatrix
- BioScip Infusion Services
- Bioverativ
- Bio Product Laboratories
- BriovaRX Infusion Services
- Brothers Specialty Rx
- Cardinal Health
- CHES
- Cottrill’s Pharmacy, Inc.
- Colburn Keenan
- CSL Behring
- CVS Health
- Diplomat Specialty Infusion Group
- Drugco
- Genentech
- Grifols, Inc.
- HEMA Biologics
- Hemophilia Alliance
- Hemophilia Adoption Program
- Hope for Hemophilia
- Kedrion Biopharma
- Music for the Cause
- NCHS
- Noble Health Services
- Novo Nordisk
- Octapharma USA, Inc.
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Sigilon
Shire
Soleo
Spark Therapeutics
Superior Biologics
The Alliance Pharmacy
The Coalition for Hemophilia B
The Women’s BD Coalition
uniQure
World Federation of Hemophilia

YOUNG ADULT SUMMIT
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