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>
<th></th>
</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: $514,601 (9%)
- Symposium: $1,592,470 (29%)
- Interest & Dividends: $26,948 (0%)
- 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

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Hemophilia Federation of America™
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

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency Assistance</td>
<td>183</td>
</tr>
<tr>
<td>Items Reimbursement</td>
<td>157</td>
</tr>
<tr>
<td>Inhibitor Support</td>
<td>67</td>
</tr>
</tbody>
</table>

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

HFA
Hemophilia Federation of America™
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Our Board & Member Organizations

EXECUTIVE COMMITTEE
Independent, Tracy Cleghorn, Chair
Independent, Josh Hemann, Vice Chair
Independent, Michael Birmingham, Vice Chair
New England Hemophilia Association, Diane Lima, Secretary
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Sangre de Oro, Inc., Bleeding Disorders Foundation of New Mexico, Sophia Minhas, Member at Large
Independent, Matthew Compton, Past Chair

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Arizona Hemophilia Association, Open Seat
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Hemophilia Foundation of Southern California, Mickey Price
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Wisconsin Bleeding Disorders Network, Darcy Zwier
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- Genentech
- 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
- Novo Nordisk

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- Genentech
- Novo Nordisk
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- Grifols, Inc.
- Bioverativ
- Genentech
- Shire

POLICY & GOVERNMENT RELATIONS

INTERNSHIP
- CSL Behring
- Shire

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
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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

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Diplomat Specialty Infusion Group
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Grifols, Inc.
Pfizer, Inc.
Shire

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

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Hope for Hemophilia
Kedrion Biopharma
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