

2018 ANNUAL REPORT



www.hemophiliafed.org





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

10% The percentage by how much our Facebook following grew

14,477 Number of page "likes" up from 13,220

720 Facebook posts in 2018

10,500 Total shares of our content

72,000 Number of "likes" on the total shares of our content

357,505 Total website page views in 2018

88% Percentage of **new** visitors



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%)
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



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

EXECUTIVE COMMITTEE

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**
Bleeding Disorders Alliance Illinois, **Tessa McConnell**
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**
Blood Bond Bleeding Disorder Network, **Jeffery Watkins**
Central California Hemophilia Foundation, **Sean Hubbert**
Connecticut Hemophilia Society, **Katherine Rosevear**
Eastern Pennsylvania Chapter, **Open Seat**
Florida Hemophilia Association, **Maria Rubin**
Gateway Hemophilia Association, **Anne Parrott**
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**



Thank You For Your Support

Our Board & Member Organizations

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**
Oklahoma Hemophilia Foundation, **JR (Clyde) Brawner**
Rocky Mountain Hemophilia and Bleeding Disorders Association, **Brad Benne**
Snake River Hemophilia and Bleeding Disorders, **Open Seat**
Tennessee Hemophilia and Bleeding Disorder Foundation, **Robert Bond**
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**



Thank You For Your Support

Our Corporate Partners

CONGRESSIONAL FLY-IN AND RECEPTION

CSL Behring
Genentech
The Hemophilia Alliance
Octapharma USA, Inc.
Spark Therapeutics, Inc.
Shire
Pfizer, Inc.

DEMONSTRATION PROJECT

Bioverativ

GIFT IN KIND

CVS Specialty
Prophet

HELPING HANDS

Alnylam Pharmaceuticals, Inc.
Diplomat Specialty Infusion Group
Grifols, Inc.
The Hemophilia Alliance
Novo Nordisk

INFORMATIVE COMMUNICATIONS

Aptevo Therapeutics
Bayer
Bioverativ
Genentech
Grifols, Inc.
HEMA Biologics
Novo Nordisk
Octapharma USA, Inc.
Pfizer, Inc.
Shire
Spark Therapeutics, Inc.

LEARNING CENTRAL

Alnylam
Aptevo Therapeutics
Genentech
Novo Nordisk
Shire
Spark Therapeutics, Inc.

OUTREACH & ADVOCACY

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



Thank You For Your Support

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

Aptevo Therapeutics
CSL Behring
CVS Specialty
Diplomat Specialty Infusion Group
Grifols, Inc.
Spark Therapeutics, Inc.

SYMPOSIUM

Accredo
Alnylam Pharmaceuticals, Inc.
Aptevo Therapeutics
ARJ Infusion Services
Bayer
BioMarin Pharmaceuticals, Inc.
BioMatrix
BioScrip Infusion Services
Bioverativ
Bio Product Laboratories
BriovaRX Infusion Services
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CHES
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Colburn Keenan
CSL Behring
CVS Health
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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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Our Industry Contributors

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PPTA
Save One Life
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

Bioverativ
CSL Behring
Genentech
NCHS
Pfizer, Inc.
Spark Therapeutics, Inc.
Shire





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