

2019 ANNUAL REPORT



www.hemophiliafed.org



Supporting people with a bleeding disorder and their families.

.....
Assisting, educating and advocating.



HOW WE CONNECTED

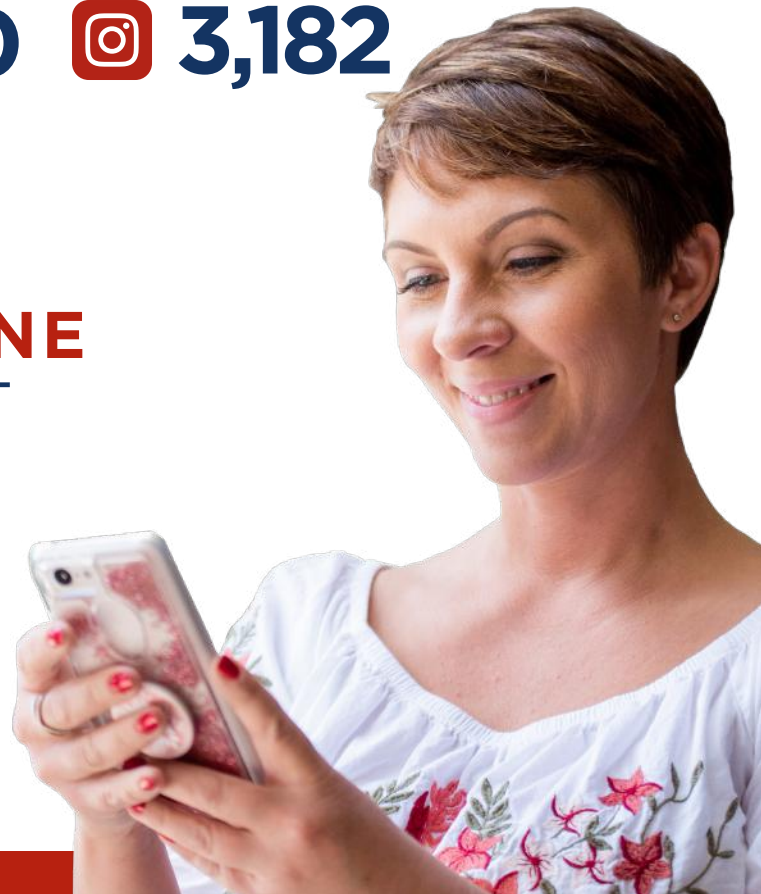
🔴 **313,350** WEBSITE VIEWS

🔴 **13,369** EMAIL SUBSCRIBERS

SOCIAL MEDIA FOLLOWERS

f 15,954 **🐦 5,260** **📷 3,182**

🔴 **40,000**
COPIES OF **DATELINE**
MAILED TO ALMOST
13,000
HOUSEHOLDS





FINANCIAL POSITION

As of Dec. 31, 2019

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 Restrctions	\$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

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





ASSISTING

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**





EDUCATING

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



ADVOCATING

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





ADVOCATING

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 life, as well as other Americans. This internship helped me realize the power of my own story, something I have always discounted.”

—Dylan



ADVOCATING

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



ADVOCATING

Young Adult Advocacy Summit

Oct. 19-22

We hosted young adults with bleeding disorders, ages 18 to 30, from across the country for an 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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Kasey Shade

Kristine Manns

Laura Portales

Lesa Kaercher

Lianne Lapierre

Lily Schwartz

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THANK YOU TO OUR CORPORATE SPONSORS

Helping Hands

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Genentech
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