



2015 ANNUAL REPORT



A Message from the 2015 Board President and Executive Director

Dear Friends and Supporters,

Thank you for your ongoing commitment to Hemophilia Federation of America (HFA). 2015 was a year of positive outreach and support. HFA embraced a “Gateway to a Stronger Community” theme, engaging thousands of community members in outreach and advocacy efforts as well as the many programs and services we have to offer. In doing so, community members were challenged to ask questions, take action and become involved, so they were empowered to make the best decisions for themselves and their families.

We could not make the impact we do without our donors’ support and trust. Their faith in us means so very much. Every gift matters and we pledge to honor our commitment to utilize each dollar wisely. It has been a point of pride that HFA consistently uses more than 90% of all revenue raised for direct services and support of our community families. In 2015, we exceeded this pledge at 93%!

Moving forward, we see the landscape continuing to evolve with new therapies and the associated challenges to accessing treatment. Our ongoing work together is critical to ensure that families receive the care they need. We look forward to continuing to assist and advocate for those families living with bleeding disorders.

Warm regards,



Kimberly Haugstad
Kimberly Haugstad, MBA
Executive Director



Tracy L. Cleghorn
Tracy Cleghorn
Board President



MISSION:

Assist and advocate for the bleeding disorders community.

VISION:

Removing barriers to quality of life.

About HFA

Hemophilia Federation of America (HFA) formed in 1994 as a place of education and support for bleeding disorders families. HFA came to be in a time of confusion in the community as HIV and hepatitis had run rampant in the blood supply. During this period, many in the hemophilia community felt they were not getting the answers they needed to explain how this tragedy could have occurred. HFA began as a grassroots, community-led organization dedicated to serving patients and unifying their voices in advocacy.

Today, HFA is a premier national organization which continues to serve as a trusted voice of the bleeding disorders community. As such, we assist and advocate for patients and their families and remain dedicated to serving as the voice for the needs of the bleeding disorders community. Through our programs, services, and outreach, we provide support and information to patients and their families so they can become stronger, more resilient advocates continuously improving their quality of life and health outcomes.

As we look forward, we plan to carry on this mission, expanding our programs at the local level, increasing education through our digital and print media presence, and offering an innovative initiative through our new research unit, with programming that is community centered, community focused, and community driven.

“TO ME, HFA MEANS FAMILY. I’m beyond grateful to have such a strong network of support.”

“They say blood is thicker than water, and I believe that is what ties this community together. Knowing that others are going through the same issues helps bind me to the bleeding disorders community. I was off-balance after my vWD diagnosis. After meeting others in the community, I found my balance; I was grounded.”



400,000+

Reached via HFA’s social media campaign for Hemophilia Awareness Month

26,000+

Downloads of HFA’s Get in Gear Fitness mobile app

14,000+

Community members receive *Dateline Federation*, HFA’s quarterly publication

3,000+

Men, women and children attended HFA educational sessions at local member organizations

1,800+

Men and women enrolled across programs

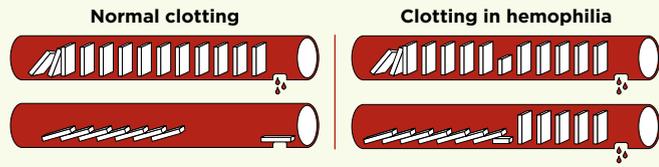
750+

Downloads of HFA’s Blood Sisterhood mobile app

200+

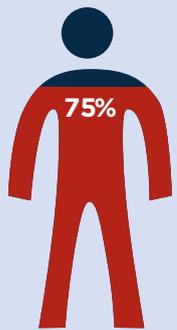
HFA program sessions at our member organization meetings

Bleeding Disorders: A Primer



A person with a bleeding disorder lacks a clotting protein that stops or prevents excessive bleeding. The most commonly recognized bleeding disorders are hemophilia and von Willebrand Disease.

20,000 people in the United States have hemophilia.



400,000 people in the world have a bleeding disorder. Sadly, 75% of those with a bleeding disorder have no access to treatment.

Hemophilia A is the most common type of hemophilia.

Hemophilia B (or Christmas Disease) is another type of hemophilia.



Treatment options vary depending on diagnosis; most patients have to take intravenous injections to replace the missing clotting protein their body lacks. It costs an average of

\$250,000

per year to treat hemophilia.

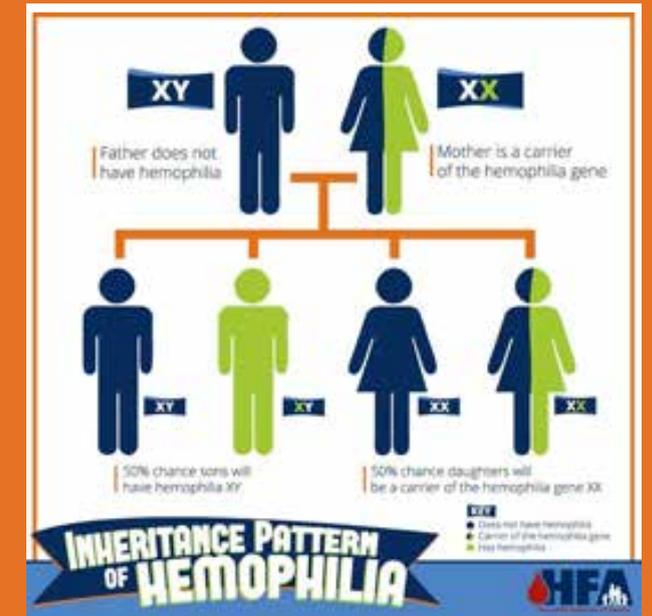
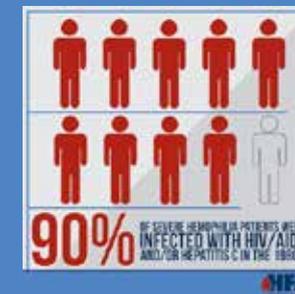
In 1973, the Hemophilia Act was passed to form a nationwide network of federally funded Hemophilia Treatment Centers to provide comprehensive care and medical experts for bleeding disorders patients.

30%

of Hemophilia A patients will develop an inhibitor, or antibodies, to treatment. 1-2% of Hemophilia B patients will develop inhibitors. A 2014 CDC study found that anyone with hemophilia can form an inhibitor and that all patients should be tested yearly.



In the 1980s many members of the bleeding disorders community contracted HIV/AIDS and/or Hepatitis C from tainted blood products. Tragically many of those infected have since died.



Bleeding disorders are inherited genetic conditions. However, 30% of new hemophilia diagnoses happen with no family history. Women who carry the hemophilia gene have a 50% chance of passing it along to all of their offspring. Women can and do have bleeding disorders, including hemophilia.

1-2% of the population is thought to have von Willebrand Disease and have not been properly diagnosed.

In 1990, the Patient Notification System (PNS) was created to provide a fast, free, and confidential program alerting patients with bleeding disorders of a withdrawal or recall of therapy products or ancillary supplies.

2015 Financial Position

ASSETS

Cash and Equivalents	\$1,479,869.00
Receivables	\$814,745.00
Investments	\$255,354.00
Other	\$19,022.00
Furniture & Fixtures	\$10,255.00

TOTAL ASSETS **\$2,579,245.00**

LIABILITIES

Accounts Payable	\$134,313.00
Deferred Revenue	\$1,269,910.00
Other Liabilities	\$31,609.00

TOTAL LIABILITIES **\$1,435,832.00**

NET ASSETS

Net Assets	\$1,129,486.00
Temporarily Restricted	\$13,927.00

TOTAL NET ASSETS **\$1,143,413.00**

**TOTAL LIABILITIES &
NET ASSETS** **\$2,579,245.00**

2015 Financial Highlights

REVENUE

Grants and Donations	53.6%	\$1,688,367.00
Membership	1.8%	\$55,477.00
Symposium	34.2%	\$1,077,538.00
Informative Communications	10.5%	\$330,500.00
Interest and Dividends	.3%	\$10,267.00
Change in Investment Values	-.4%	(\$13,736.00)
Other	0%	\$1,063.00

TOTAL REVENUE **100.0%** **\$3,149,476.00**

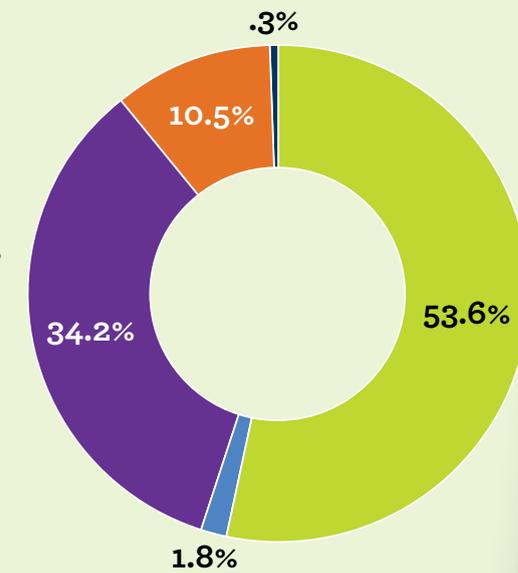
EXPENSES (By Class)

Program Services	92.87%	\$2,443,273.00
Administrative	4.59%	\$120,869.00
Fundraising	2.54%	\$66,717.00

TOTAL EXPENSES **100.0%** **\$2,630,859.00**

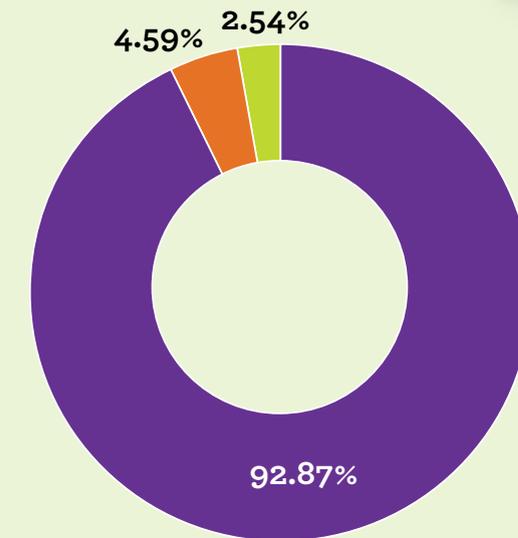
Revenue

- Grants and Donations 53.6%
- Membership 1.8%
- Symposium 34.2%
- Informative Communications 10.5%
- Interest and Dividends .3%
- Change in Investment Values -.4%
- Other 0%



Expenses

- Program Services 92.87%
- Administrative 4.59%
- Fundraising 2.54%



93% OF OUR BUDGET WENT TO OUR PROGRAMS AND SERVICES IN 2015.

*The financial statements of Hemophilia Federation are audited by the accounting firm Winter, Kloman, Moter & Repp, S.C. Complete audited financial statements for Hemophilia Federation of America can be obtained by request from: www.hemophiliafed.org or sending a request to 820 First Street NE, Suite 720 Washington DC 20002 or by calling 202.675.6984.

Year in Review | Outreach/Advocacy

Changing or Protecting Policies that Impact the Lives of People Living with Bleeding Disorders.

Advocacy is at the heart of all we do at HFA. Our unwavering community-centered commitment has contributed to building trust and true community engagement. Our practical, hands-on advocacy materials help community members navigate the healthcare system and our support efforts empower members to advocate, individually and collectively. Our key issues include access and **affordability to care and treatment, safety of therapies** and **integrity of data collection**. Some examples of specific advocacy outcomes and accomplishments in 2015 include:

- Assisted dozens of community members with individual support concerning payer issues, including, but not limited to, providing written support and testimony in appeals processes, and providing support and advice in obtaining individual exceptions to prohibitive decisions, denials or policies.
- Solicited and published personal accounts of advocacy stories of community families in our quarterly newsletter, *Dateline Federation*.
- Created toolkits for community members to use when advocating for issues in their state that includes issue briefs, policy updates, sample letters and talking points in areas such as specialty tiers, biosimilars, etc.
- Supported our 43 member organizations with testimony, written letters, and coalition-building as they sought to pass legislation about the use of specialty tiers, prior authorization, Medicaid managed care, and other coverage issues.

“I advocate for the bleeding disorders community to provide help for our families, education for people who do not know about bleeding disorders, and a better life for my son as we deal with his severe hemophilia type A.”



19 Advocacy educational programs delivered at local meetings

18 Letters submitted to executive agencies on issues like discriminatory tiering practices, biosimilars, and the 340B drug discount pricing program

16 Dear Addys (Q&A on healthcare & insurance issues) posted to HFA's website

10 Meetings of Advocacy Working Group

4 State-based legislative days

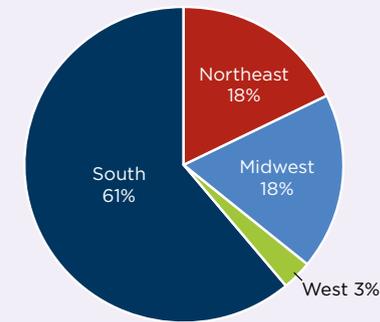
4 State-based coalition advocacy summits

Year in Review | Project CALLS

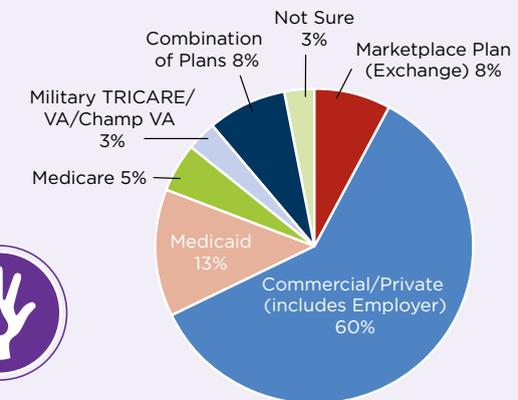
In August 2015, HFA launched an initiative designed to help the bleeding disorders community collect data and stories about how changes in insurance company policies are impacting the care of those with bleeding disorders. HFA started Project CALLS in order to create a more accurate picture of the types of insurance issues encountered by the bleeding disorders community. Through the community's participation in Project CALLS, HFA will continue to collect stories from the bleeding disorders community across the country, collate the data, identify trends, and use the information to build cases for change.



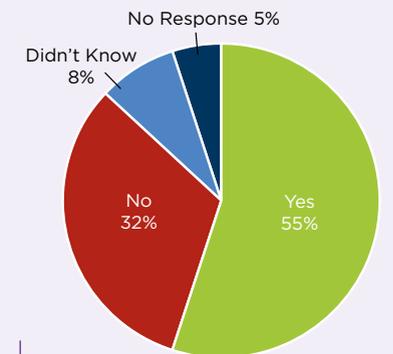
Where did participants live?



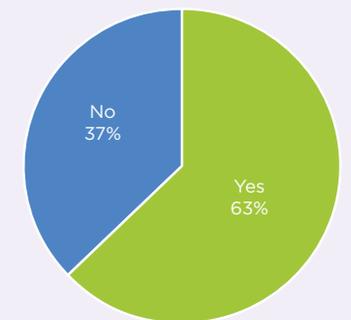
What types of plans did participants have?



Are participants being mandated to use a particular specialty pharmacy?



Did participants' insurance issue lead to delayed care?*



“My son orders his factor as instructed from our new Specialty Pharmacy, but the pharmacy ships later than requested and sometimes not at all. This has caused him to miss treatment, experience a bleed, and visit the doctor.”

“Insurance refuses to cover home infusion per information from the manufacturer.”

Year in Review | Summer Internship Program

Each summer, HFA hosts a 10-week internship for two college-aged community members. The objective is to improve and increase active community advocacy efforts by encouraging participants to develop their core abilities, understand their individual strengths, and utilize those strengths to empower themselves and others in the bleeding disorders community, ultimately building effective advocacy efforts. The Internship also encourages and provides the necessary tools for members of the bleeding disorders community to stretch their personal potential and champion their own needs through self-advocacy at the state and federal levels.

“The most important thing I learned was that it often takes a large, concerted effort to get legislation passed, but that with enough pressure and desire to make a change happen, policy progress can occur. Seeing how grassroots support can help legislation move through Congress helped me understand the importance of our community’s advocacy efforts.”



20 Visits to Capitol Hill

2 Summer interns

2 Issue briefs written

1 Intern continued as part-time Policy and Government Relations staff member

Year in Review | Advocate Fly-In and Congressional Reception

In 2015, HFA held its 2nd annual Advocate Fly-In and Congressional Reception, bringing in community members from all over the country for targeted meetings with their representatives. Representatives are sought out based on their involvement in particular legislation, their memberships on specific committees, and/or their willingness to support our community, making these meetings incredibly effective. Specific policy topics and messaging are developed in advance, preparation of constituents is conducted before the meetings via an advanced webinar as well as at a briefing the night before, and continued coaching is provided after the Fly-In as well. Following the Fly-In, community members are given the opportunity to mingle with Congressional staff and continue to share their stories at our Congressional Reception where we honor members of Congress who have championed patient issues that year.



“The hemophilia community should never doubt that it has the strength to make big things happen.”

“[The other participant’s stories] enlightened me, and surely the legislative staff as well, on how much lawmaking truly impacts the bleeding disorders community and holds the potential to make a big difference in many peoples’ lives.”



150 Attendees to Congressional Reception

80 Letters submitted electronically in support of Patients’ Access to Treatment Act (PATA) during corresponding Virtual Hill Day

18 Meetings with members of Congress

11 Community member attendees exposed to Capitol Hill Advocacy

4 Issues advocated for (3rd party payers, PATA, Medicare Part D Appeals Act, funding for Executive Agencies)



Year in Review | Blood Brotherhood

Supporting Adult Men with Bleeding Disorders

Since 2006, HFA has addressed the complex health issues of adult men (aged 18+) with bleeding disorders by supporting the Blood Brotherhood Program. This evidence-based program provides a safe environment where men can come together peer-to-peer, both in person and online, to share their experiences with their bleeding disorders and receive education on how to lead healthier lives—all nurtured within a framework of community-building and social support. Blood Brotherhood connects men of all ages with bleeding disorders, from the men who lived through the HIV/AIDS and HCV crisis to the younger generation of men learning to navigate adulthood and embarking on their lives as independent adults. HFA recognizes that tremendous opportunity exists for mentorship between these younger and older Blood Brothers. The Blood Brotherhood Program provides a variety of tools and resources to improve the quality of life of men living with bleeding disorders.



“Blood Brotherhood helped me get rid of a lot of stress and bond with others living with hemophilia. It’s a great support group!”

“I have enjoyed myself at Blood Brotherhood sessions. This program has become a huge positive influence in my life. As men with hemophilia, we need this.”

“My Blood Brothers are an extension of my family. The Blood Brotherhood Online Forum is a meeting place where I read, listen, learn and share my thoughts freely and without bias.”



912 Blood Brothers enrolled in program

827 Blood Brothers attended local sessions

73 Local Blood Brotherhood Sessions hosted in 23 partnering HFA Member Organizations

12 Live Online Chats hosted via HFA’s Blood Brotherhood Online Forum

8 Blood Brothers participated in Advocacy Intensive hosted in Washington, DC

6 New Educational Modules developed

6 Young Adult Hangouts hosted live for young adults ages 18-35 with archived recordings on HFA’s Resource Library

2 Educational Webinars hosted and archived recordings on HFA’s Resource Library

1 Educational Online Toolkit

Year in Review | Blood Sisterhood

Building Communities of Women with Bleeding Disorders

Women with bleeding disorders face healthcare challenges such as unexpected bleeding episodes, difficulty receiving a diagnosis, and limited access to necessary care and/or treatment. HFA supports women with these challenges through the Blood Sisterhood Program by providing education, resources, tools, and social support to improve their quality of life. The ultimate goal of Blood Sisterhood is to build a network of women to empower one another.



“As women, we need to be vigilant, educated, and vocal about hemophilia.”

“HFA gave me the strength and the security to have my daughters get tested.”

“When I found out that both [my daughters] had von Willebrand disease, it was not as scary as I thought it would be. I had a world of information and people to help us get through it.”

“At my first Blood Sisterhood session, the room was filled with women of all ages and personalities, coming together and bonding over one common goal—to share laughter, education, and support in the company of someone who had walked in their shoes.”



750 Downloads on HFA's Blood Sisterhood Mobile app (launched in March 2015)

388 Blood Sisters enrolled in program

234 Blood Sisters attended local sessions

53 Women from 26 states participated in the “Share Your Story” (launched in February 2015) to offer women with bleeding disorders or symptoms the opportunity to tell HFA about the care they have received

23 Local Blood Sisterhood Sessions hosted via 16 partnering HFA Member Organizations

6 Young Adult Hangouts hosted live for young adults ages 18-35 with archived recordings on HFA's Resource Library

6 New Educational Modules developed

1 Educational Online Toolkit developed

1 Educational Webinar hosted live with archived recording on HFA's Resource Library

Year in Review | Families

Connecting Dads and Moms in the Bleeding Disorders Community

When a child is diagnosed with a bleeding disorder, life can feel like it was turned upside down. Rarely are new parents fully equipped for the task of raising a child with a bleeding disorder. Addressing the disorder, managing the stress, and identifying a solid network of support are the essential building blocks for healthy parenting.

The HFA Families program includes the Dads in Action, Moms in Action, and Kids in Action programs. We support parents by providing peer networks and educational resources to help stock the “parenting toolbox.” Since 1997, these programs have helped serve a previously-unmet need in the community for providing national and local educational training and resources for families to build strong bonds with their children, tools to improve advocacy skills, and a place of belonging and support. HFA also offers a robust library of community stories that help build a parent’s confidence in knowing they are not alone in raising a child.



“Knowing we are not alone and being inspired to continue on our path of advocacy has been very beneficial for my family.”

“Love talking with other moms who can give positive advice and answer those hard questions.”

“The HFA Families Program has had a huge impact on my family. It has given us feelings of support and empowerment. We also feel good about helping other families deal with emotions of having a child with a bleeding disorder.”

“I have been able to connect with other dads through this program. Speaking and sharing my experiences has helped me deal with my child’s bleeding disorder and made me a better dad.”

“HFA has made us stronger advocates for our son.”



2,373 Moms, dads, kids who attended local sessions

287 Moms and 293 dads total enrolled as of 12/31/15

74 Local Families sessions hosted in 2015 via 27 partnering HFA Member Organizations

54 Blog entries in 2015 of *Infusing Love: A Mom’s View* with 10,162 Facebook likes, 1,546 Facebook shares producing a total reach on Facebook of 208,638

10 Dads participated in Advocacy Intensive hosted in Washington, DC

4 Educational Online Toolkits developed

4 Educational webinars hosted live with archived recordings on HFA’s Resource Library

4 New Educational Modules developed for adults and 3 developed for children

3 Educational modules translated to Spanish

Year in Review | CHOICE Project

As a result of a cooperative agreement with the Centers for Disease Control and Prevention (CDC), HFA ran the CHOICE (Community Having Opportunity to Influence Care Equity) Project from October 2011 to September 2015. Through the CHOICE survey, HFA collected data from non-HTC patients on demographics, insurance coverage, socio-economic status, health services utilization, education and employment status, diagnosis, number and location of bleeds, treatment type, treatment products used, vaccination status, infectious disease status, inhibitor status, joint function and disease, invasive orthopedic procedures, and conditions of aging.

Using the data from the CHOICE Project as a springboard, HFA will seek to engage in research projects in 2016. Each research project will be undertaken with the goal of using the end results to improve the lives of our community, including their health outcomes and personal advocacy capabilities, among other advancements. Internally, HFA's research endgame is the unceasing improvement of our programming and advocacy efforts. We will continue to use the Participatory Action Research Method as a cornerstone of our efforts to involve patients in the research process as their engagement proved invaluable to CHOICE and to making the Project a success. HFA's research activities will give community members a voice not only in the type of inquiries we perform but on the research process itself through their meaningful participation.



“We can’t effectively serve this community if we don’t know who is a part of it. CHOICE is a crucial step towards filling in the blanks in what we know about people affected by bleeding disorders.”

“In the age of information, no knowledge is more important than an awareness of our own health.”

“The CHOICE survey is our chance to tell our story.”

“With the CHOICE survey, we have an outlet to give our feedback and to be heard.”

“I fully support the CHOICE effort for a few reasons: 1) If the CDC is able to do more in the way of care for those who do not attend HTCs, people like my dad (who died of a head bleed after playing racquetball without factor on board) might have a chance at better care, and 2) the more people identified, the more can be served, so that women like me can be diagnosed and treated at an earlier age. That way others might be able to avoid some of the permanent damage that my body incurred from untreated bleeds over the years. When I support CHOICE, I’m looking for my dad. I’m looking for myself. I’m helping the CDC create a better future for people just like me.”

“I thought I knew everything. I knew a lot—but not as much as I’ve found out.”



665 Completed surveys

48 States represented in survey

22% Participants were non-HTC patients

4 Research projects to be initiated in 2016 based on CHOICE results



Year in Review: Helping Hands

Assisting Families in Temporary Financial Crisis Resulting from their Bleeding Disorder

At any point, bleeding disorder families can experience a financial hardship because of their medical situation. The Helping Hands program provides a measure of relief to this extraordinary burden and helps families focus on what's important: their health.

Helping Hands provides emergency assistance for basic living expenses such as housing, utilities, and transportation, but the support doesn't end there. Our staff of master's level social workers work closely with applicants to help connect them with other national, state, and local community resources as well. The program also offers reimbursement of the cost of durable medical equipment necessary in managing a bleeding disorder, such as braces, heating and cooling packs, and Medic Alert jewelry. Helping Hands provides a vital safety net for the bleeding disorders community.



“It is so nice when someone says ‘here’s some help’ when you’re struggling with your kid. It means so much.”

“I wanted to say thank you so much for helping our family. You really helped us in a desperate time of need. I am finally seeing some relief at my job with personal time off. My job is now permanent and stable. Things are looking much better. And, again, thank you for all of your help.”

“Thank you for helping us. My son being in the ER and having to make trips to the hospital caused me to miss many days of work. As a working parent, this has been a struggle. Thank you for the assistance to help my family get by this month. I truly appreciate all of this.”

“The girls are so happy they will have their own home again and that we will be together again. Thank you so much! Without your help, we would be homeless. With my new job it would have taken months to save because of trying to pay for food and shelter for all of us.”



Over \$124,851

Distributed in Direct Aid to **295** families

118 Households received assistance with durable medical items (e.g. walking supports, protective gear, braces, etc.)

90 Households received assistance with housing expenses

37 Households received assistance with transportation expenses

26 Households received assistance with utility expenses

24 Households received assistance with “other” expenses (e.g. funeral expenses and other emergency expenses)

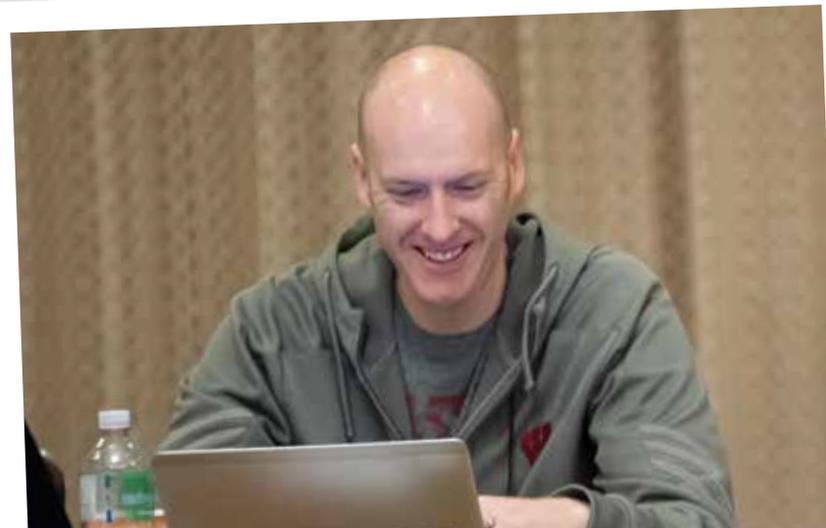


Year in Review | Communications

Effective communication serves as the foundation for everything we do at HFA. As an organization, we strive to empower the community through education and information. It is vital that we listen to the needs of the bleeding disorder community, produce interactive educational tools, and engage through quality content and social media. Through our large national membership and deep social media outreach, we got through to hundreds of thousands of people across the country, building awareness and knowledge of bleeding disorders in the US.

“HFA truly represents the patients of the bleeding disorders community. I am proud to be part of this community.”

“HFA is honestly the voice of all patients in the bleeding disorders community!”



14,500 *Dateline Federation*
Quarterly Newsletter distribution

10,551 Facebook fans

5,874 E-blast distribution

3,019 Twitter followers

1,150 Instagram followers

249 Pinterest followers

13 Member organizations hosted HFA History Presentations

7 Voices videos

Year in Review | Educational Scholarships

Each year, HFA awards scholarships to promising students in the bleeding disorders community. In order to serve the students in our community more effectively, in 2015 we awarded just four scholarships, instead of the usual 10, but with an increased amount of \$2,000-\$4,000 (instead of the previous \$1,000 each). These scholarships were awarded in three areas: Educational Scholarship, Parent/Sibling/Child Educational Scholarship, and Medical/Healthcare Services Educational Scholarship.

“I work at a summer camp for kids with bleeding disorders and I would love to be the arts and crafts director one day and be able to share my love of art with the kids there.”

“The hope and resilience of the bleeding disorders community inspired me to go into medicine.”

“Knowing that the hemophilia community is backing up my decision to pursue a course of study in music at college is very reassuring.”

“My goal of becoming a physician’s assistant began when I became involved with the hemophilia community because of my diagnosis of a bleeding disorder.”



\$10,000
In total scholarships

\$2,000-\$4,000
Per scholarship

474 Applicants

4 Scholarships awarded

4 States represented (Colorado, Louisiana, Indiana, Tennessee)

Year in Review | Gears for Good

Raising Awareness and Support for Helping Hands

For the past four years, cyclists from all over the country have been meeting in beautiful West Virginia for a 156-mile trek on the C&O Canal Trail to Washington, DC to raise money for Helping Hands. This three-day trip on a crushed-rock trail across three states and the District of Columbia is not for everyone, but it celebrates a dedication to health and wellness for those who work hard to achieve beyond their disorder. Also in 2015, HFA continued its regional Gears for Good bike ride in Connecticut. This regional ride spanned two days and 100 miles on the Farmington Heritage and River Trails in and around picturesque Farmington, CT. The trails were less daunting than the WV-to-DC trek, but the motivation was the same: to help our community.

One hundred percent of the contributions raised by individual donors went to providing families and patients in need with emergency financial assistance for expenses like housing, utilities, transportation, and medically-necessary goods. Together the rides raised more than \$100,000 which went directly to the Helping Hands program.



“The Gears For Good bike ride is my favorite hemophilia event to participate in. I ride in hopes of inspiring others to be active and take care of their bodies to reduce bleeds. I am also happy to raise funds to help those in our community in need of a little extra support.”

“Each ride has been a great experience in its own way, and we love the supportive, fun atmosphere in support of a tremendous cause...and we plan to continue to support it as best we can in the future!”

“Simultaneously the most difficult and most rewarding experience of my life! I started the weekend knowing four or five people and left with this amazing bond with all 20 members of the group. I took on the challenge to raise funds for Helping Hands and in return was rewarded myself with a priceless, life changing experience. I will never forget the weekend or the group of people with whom I shared it.”



\$100,000

Raised for Helping Hands

26 Riders from **10** states biked **100** miles in the Gears for Good New England ride

25 Riders from **12** states biked **156** miles in the Gears for Good WV-to-DC ride



Year in Review | Symposium

Uniting Community at Our National Annual Meeting

Our annual educational Symposium is a family-friendly meeting dedicated to improving the lives of those living with and affected by a bleeding disorder. Living with hemophilia, von Willebrand Disease, or any other type of bleeding disorder is a lifelong journey that requires diligence and flexibility in dealing with the challenges along the way. Symposium is designed to encourage mentoring, sharing, and learning from one another, all while providing the necessary tools to become stronger self-advocates! This year, Symposium was in beautiful St. Louis, MO. For the first time ever, we partnered with our member organization, Gateway Hemophilia Association, to help bring members of the bleeding disorders community from around the country to Symposium! This meeting was our biggest yet, and would not have been possible without support from our sponsors.

We were also proud to honor our tireless volunteers who continue to give above and beyond with their contributions of time, creativity and spirit.



2015 AWARDEES

President's Award: John Reed

Charles Stanley Hamilton Legacy Award:

David Huskie

TEA (Teach, Empower, and Advocate) Award:

Robert Sidonio Jr., MD

The Terry Lamb Health and Wellness Award:

Vaughn Ripley

Ron Niederman Humanitarian Award: Michelle Burg

Volunteer of the Year: Maryann May

Michael Davon Community Service Award:

Lori Long



“This is the one meeting I look forward to EVERY YEAR!”

“Symposium has more of a ‘family’ and intimate feeling than any other national meeting. It is like a three-day reunion that I look forward to every year.”

“As a first-time attendee, I’m beyond impressed with the HFA staff and their programs.”

“This was the best kids’ program anyone in the bleeding disorders community has done. My kids love it!”

“I had an awesome experience and would love to be able to attend next year’s Symposium. I learned new concepts and met other members in the community who shared common interests and stories. As the spouse of a Blood Brother, I really benefited from the spouses/partners rap session. I WOULD LOVE TO ATTEND ANOTHER SESSION.”



1,024 Symposium attendees

144 Children/teens participated in age specific programming

105 Participants in pre-conference Inhibitor Track

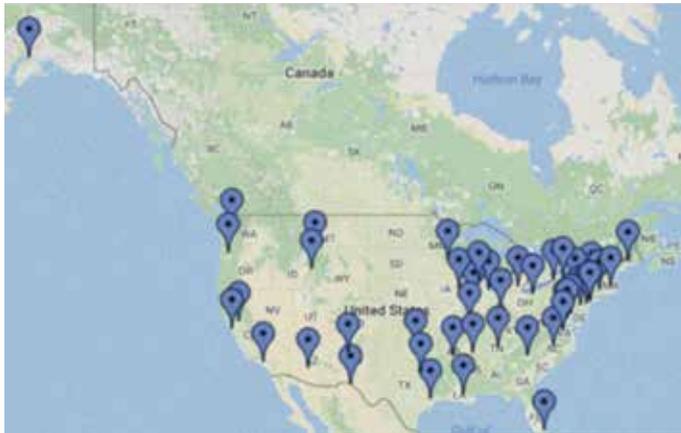
100+ First-time attendee scholarship recipients

50+ Educational sessions dedicated to providing families with vital information and resources

18 Wellness sessions delivered to **156** adults and **90** children

Board of Directors

HFA is a collaborative federation of state-based member organizations across the US that unite and strengthen our community network. The Board of Directors comprises a delegate from each member organization and independent members. Ensuring that our strategic direction aligns with our operational objectives is a key function of our board. We work collaboratively with our member organizations to offer programs and services that directly impact their community's needs. HFA grew by three new member organizations in 2015 to a total of 44. Join us in welcoming our new members: Comprehensive Bleeding Disorders Center (IL), Hemophilia of South Carolina, and Hemophilia Center of Western New York.



Officers

Tracy Cleghorn, President

Scott Boling, 1st Vice President

Mark Antell, 2nd Vice President

Aaron Reeves, Hemophilia Foundation of MN / Dakotas

Amanda McCullough, Connecticut Hemophilia Society

Josh Hemann, Hemophilia of Iowa

Michael Birmingham, Bleeding Disorders Foundation of WA

Matthew Compton, Past President

Member Organizations and Board Members

ALASKA | Alaska Hemophilia Association: John Palmatier

ARKANSAS | Hemophilia Foundation of Arkansas: Robin Parker

ARIZONA | Arizona Hemophilia Association: Open seat

CALIFORNIA

Central California Hemophilia Foundation: Sean Hubbert

Hemophilia Foundation of Northern California: Open seat

Hemophilia Foundation of Southern California: Mickey Price

CONNECTICUT | Connecticut Hemophilia Society:

Amanda McCullough

DISTRICT OF COLUMBIA | Hemophilia of the Capital Area:

Dana Brayshaw

FLORIDA | Florida Hemophilia Association: Maria Rubin

IDAHO | Snake River Hemophilia & Bleeding Disorders: Open seat

ILLINOIS

Bleeding Disorders Alliance Illinois: Bob Robinson

Comprehensive Bleeding Disorders Center: John Redington

INDIANA | Hemophilia of Indiana: Scott Ehnes

IOWA | Hemophilia of Iowa: Josh Hemann

LOUISIANA | Louisiana Hemophilia Foundation: Edgar Guedry

MAINE | Hemophilia Alliance of Maine: Vicki Jacobs-Pratt

MARYLAND | Hemophilia Foundation of Maryland: Carletha Gates

MASSACHUSETTS | New England Hemophilia Association:

Diane Lima

MICHIGAN | Hemophilia Foundation of Michigan: Dawn Evans

MINNESOTA | Hemophilia Foundation of Minnesota/Dakotas:

Aaron Reeves

MISSOURI | Gateway Hemophilia Association:

Suzanne Sirko-Carney

MONTANA | Rocky Mountain Hemophilia and Bleeding Disorders:

Brad Benne

NEW MEXICO | Sangre de Oro Hemophilia of New Mexico:

Rea Watson

NEW JERSEY | Hemophilia Association of New Jersey:

Thomas Russomano

NEW YORK

New York City Hemophilia Chapter: Wendy Chou

Mary M. Gooley Hemophilia Center: Stephen Graziano

Bleeding Disorders of Northeast New York: David Huskie

Hemophilia Association of New York: Linda Mugford

Hemophilia Center of Western New York: Open seat

Bleeding Disorders of the Southern Tier: Lesa Kaercher

NORTH CAROLINA | Hemophilia of North Carolina: Zack Strange

OHIO | Northern Ohio Hemophilia Foundation: Ray Volney

OKLAHOMA | Oklahoma Hemophilia Foundation: John Reed

OREGON | Hemophilia Foundation of Oregon:

Stewart Worthington

PENNSYLVANIA | Eastern Pennsylvania Chapter: Open seat

SOUTH CAROLINA | Hemophilia of South Carolina: Bonnie Phifer

TENNESSEE

Tennessee Hemophilia and Bleeding Disorders: Suzie Harlan

Mid-South Hemophilia & Bleeding Disorders: Derek Flake

TEXAS

Texas Central Hemophilia Association: Chad Fredericksen

Hemophilia Outreach of El Paso: Hector Ortiz

Lone Star Hemophilia Chapter: James Setliff

VIRGINIA | Virginia Hemophilia Foundation: Zack Bordone

WASHINGTON | Bleeding Disorders Foundation of Washington:

Michael Birmingham

WISCONSIN | Wisconsin Bleeding Disorders Network:

Darcy Zwier

Independent Members

Tracey Cleghorn

Scott Boling

Mark Antell

Matthew Compton

Professional Advisors

Donald Akers, Jr., JD, General Counsel

Christopher Walsh, MD, PhD, Medical Advisor

Robert Sidonio, MD, MSc, Medical Advisor

Linda Wyman-Collins, RN, Medical Advisor

Detrice Barry, RN, PhD, Medical Advisor

John Reed, Pharmacist, Medical Advisor

Greg McClure, LSW, Medical Advisor





Thank You for Your Generous Support!

Thank you to our corporate donors and our federal partners for your generous support. HFA appreciates every donor who has generously given funds and services in support of our mission to assist and advocate for the bleeding disorders community. Thanks to you, we have been able to educate, empower and support individuals and families as they navigate through the challenges of living with a rare chronic disorder.

Visionaries \$500,000+

Baxalta Incorporated
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Novo Nordisk, Inc.

Champions \$300,000+

Biogen

Guardians \$100,000+

Bayer HealthCare
CSL Behring

Benefactors \$50,000+

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Cotrill's Pharmacy, Inc.
CVS Health
Hemophilia Alliance Foundation
Matrix Health

Hemophilia Federation of America (HFA) is a national 501c3 non-profit organization that assists and advocates for the bleeding disorders community.



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820 First Street NE Suite 720 | Washington DC 20002 | www.hemophiliafed.org