A Message from the 2014 Board President and Executive Director

Dear Community Friends and Supporters,

How do you celebrate 20 years of service?

You could take a moment to reflect on your past; you could celebrate the achievements of today; or you could look to the future and all its possibilities. Or you could do all three!

At our annual Educational Symposium in Tampa, FL this year we honored our community’s past 60 years with an illustrated timeline, created by a talented committee of volunteers and staff. Visitors immersed themselves in this moving and comprehensive look at the milestones, adversities, and triumphs of our resilient community.

We were tremendously gratified by the overwhelmingly positive response to the timeline and so pleased by how many of our member organizations have since requested this exhibit at their own annual meetings. This confirmed for us that our role in empowering community members to become strong self-advocates is as important today as it was at our inception two decades ago. Individually and collectively, our futures are intertwined, and our efforts complement and support each other.

We are few, yet we are mighty...and we are moving forward!

The future of HFA depends on you: your gifts of time, heart and money. This annual report highlights the accomplishments of 2014 and we invite you to learn more about HFA by visiting our website at www.hemophiliafed.org or calling 202.675.6984.

Thank you,

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Financial Position

ASSETS
Cash and Equivalents $688,254.51
Receivables $220,336.74
Other $55,150.98
Furniture & Fixtures $14,754.34
TOTAL ASSETS $978,496.57

LIABILITIES
Accounts Payable $80,470.47
Other Liabilities $272,167.85
TOTAL LIABILITIES $352,638.32

NET ASSETS
Net Assets $726,415.94
Net Income ($100,557.69)
TOTAL NET ASSETS $625,858.25

TOTAL LIABILITIES & NET ASSETS $978,496.57

2014 Financial Highlights

REVENUE
Donations & Memorials 3% $70,272.78
General Funding 1% $12,931.62
Membership 2% $52,409.50
Special Events 2% $13,517.77
Grants 29% $644,414.43
Government Grants 22% $474,182.80
Publications 9% $201,125.00
Symposium 32% $695,568.85
Interest Income 0% ($234.02)
TOTAL REVENUE 100.0% $2,205,190.72

EXPENSES (By Class)
Symposium 27% $633,972.42
Blood Brotherhood 15% $348,290.20
Blood Sisterhood 2% $38,819.52
Outreach 8% $192,140.26
CHOICE 8% $189,633.66
HPP 2% $34,739.93
Helping Hands 9% $218,343.95
FitFactor 5% $119,591.75
Families 8% $173,461.75
Administrative 5% $112,979.37
Publications 8% $179,227.00
Fundraising 3% $64,548.60
TOTAL EXPENSES 100.0% $2,305,748.41

*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 by sending a request to 820 First Street NE, Suite 720 Washington DC 20002 or by calling 202.675.6984.

92.3% OF OUR BUDGET WENT TO OUR PROGRAMS AND SERVICES IN 2014.
According to the CDC, it is estimated that approximately 20,000 people are living with hemophilia in the United States.

Hemophilia is a complex disorder in which the blood does not clot properly. A person with a bleeding disorder does not necessarily bleed more intensely than anyone else, but can bleed for a much longer time. For people with severe hemophilia, even a minor injury can result in blood loss continuing for days or weeks, or never healing completely. Bleeds like these in areas such as the brain or inside joints can be permanently debilitating or even fatal. Hemophilia affects 1 in 5,000 male births in the US, or approximately 400 babies, each year.

Bleeding disorders are treated differently depending on which protein is missing in the blood and causing problems in the normal clotting process. These proteins work with platelets to help the blood clot. Typical clotting factor levels range from 50 to 150%. People with hemophilia tend to have clotting factors from 0 - 30%. Hemophilia is one of the most common bleeding disorders and is organized as follows:

Hemophilia A – Also called “classic hemophilia,” is four times more common than hemophilia B and occurs when factor VIII levels are deficient.

Hemophilia B – Also called “Christmas disease,” occurs when factor IX levels are lacking. This type of hemophilia has nothing to do with the winter holiday; it was named after Stephen Christmas, the first person diagnosed with the condition.

Hemophilia C – This occurs when factor XI levels are deficient.

Acquired hemophilia - A person can develop hemophilia as a result of illness, medications, or pregnancy. Acquired hemophilia is extremely rare and can usually be resolved with proper diagnosis and treatment.

Inhibitors – Approximately 30% of people with hemophilia A and 5-30% of people with hemophilia B develop inhibitors over time. Inhibitors are antibodies the body develops because it sees the infused factor as a foreign substance that needs to be eliminated. Antibodies are proteins that destroy the activated factor before it has time to stop the bleeding.

The most common complication of hemophilia is joint disease. This occurs when repeated bleeding into the joints leads to chronic swelling and pain, deformity and disability. Predictably, many people with hemophilia suffer from arthritis and, in severe instances, joint replacement or joint fusion surgeries may provide the only relief.

HFA is committed to providing women with the information and support they need to reach a diagnosis and throughout the stages of their life with a bleeding disorder. To receive information and support for women affected by hemophilia, visit www.hemophilia.org.

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Hemophilia A and B are X-linked recessive disorders. In these disorders, both parents must carry a gene for hemophilia for the child to develop the condition. The genetic characteristic is inherited from the mother. If she has one copy of the gene, she will be a carrier. If both parents are carriers, there is a 25% chance of having an affected child, a 50% chance of having a carrier, and a 25% chance of having a normal offspring. If one of the parents has hemophilia, all sons will have the disorder; all daughters will be carriers with a 50% chance of having the disorder.

Hemophilia C is an autosomal recessive disorder. This type occurs when factor XI levels are deficient.

Hemophilia D – Hemophilia D is not an issue in hemophilia, blood type does play a role in the levels of vWF factor found in the blood. Type O blood often has inherently lower levels of vWF.

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FA was born to advocate! In the 1980s and 90s, the bleeding disorder community in the US faced a true crisis with a blood supply that was becoming increasingly contaminated with human immunodeficiency virus (HIV) and hepatitis C (HCV), and with public policy that lagged behind in recognizing the dangers of this contamination. The unified voice of our community was instrumental in ensuring the safety of our nation’s blood supply for everyone and today the blood clotting factor products in use are significantly safer. The need for strong community advocates did not end with the onset of safer products, however. Our advocacy work now focuses on protecting those policies that positively impact our community, as well as protecting community members from policies that pose potential harm.

Factor replacement concentrates are enormously expensive. While the amount of product each person consumes to help their blood to clot is unique to the individual, the average cost runs about $300,000 per year. Of course this can increase exponentially if a hospitalization is required or if a person develops an inhibitor so the clotting factor doesn’t work as well. Our community needs safe and reliable access to blood clotting factor products, specialized physicians and infusion nursing care, and these essentials are only made possible through private insurance or public assistance programs.

In 2014, HFA continued to provide a vital voice for our community to policymakers, in addition to offering advocacy support and resources to our community members.

In honor of our 20 year anniversary, members of our staff and a small, dedicated group of community volunteers took a retrospective look at the last 60 years of our community’s evolution. This imaginative group created a storyboard poster exhibit, documenting by decade, the milestones, hardships, and achievements of our resilient community. It comprised five impressive 7’x5’ panels with stories and news items spanning six decades and illustrated with loads of community photos and videos, even the Ryan White AIDS quilt. The resulting exhibit was showcased at our annual meeting in Tampa and was viewed by more than 800 community members. Not surprisingly, it brought home to everyone who participated in its creation, as well as all those hundreds who visited it, that yes, we MAY be few, but we ARE mighty! In addition, HFA distributed more than 14,000 printed copies of the timeline in the summer and fall of 2014, as well as provided seven presentations (and counting!) of the exhibit to state-based organizations. Effective communication is the foundation for everything we do. It is vital that we listen to the bleeding disorders community’s needs, produce engaging educational tools, and connect in a meaningful way through our programs and services. This is precisely why we digitized all of this historical information into an interactive timeline and hosted it on our website. To date, the timeline has been viewed more than 5,000 times! We invite you to visit our website at www.hemophiliafed/history to view the timeline in its entirety.

WE ARE MIGHTY

"We owe it to the previous generations, to ourselves, and to our children not to forget the past.” – Anonymous, hemophilia mom

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HONORING OUR PAST

"It’s vital to remember our advancements and adversities in order to build a brighter future for the bleeding disorders community.” – Jim, severe hemophilia
Navigating an ever-changing health insurance environment is a daunting task for most people these days but it comes with extra challenges for our community. Because bleeding disorders trigger persistent and recurring health consequences, we rely heavily on health insurance plans to help us pay for our products and care. The HFA advocacy team pays special attention to understanding and evaluating all forms of insurance coverage, both public and private. We have, for example, supported continuing Medicaid expansion while keeping a watchful eye on the potential outcomes of moving Medicaid patients in our community to managed care.

We were pleased when HFA was invited to the Food and Drug Administration (FDA) Patient-Focused Drug Development meeting in Washington, DC in September 2014 to present the patient perspective on drug development. Our Executive Director Kimberly Haugstad presented testimony on the critical need for the bleeding disorders community to have access to the widest possible variety of treatment solutions. She also stressed the vital importance of enforcing a rigorous testing process to ensure product safety and efficacy prior to having treatments reach patients.

In an effort to respond efficiently to numerous advocacy questions raised by our community, HFA created an on-line “Dear Addy” column. In all, HFA responded to 21 widely-applicable issues reaching more than 20,000 community members. “Dear Addy” also incorporates links to valuable resources on our website, helping our community become better educated on these topics and, in turn, becoming stronger advocates.

Speaking of our on-line efforts, this past year HFA hosted four national advocacy webinars and provided 19 state-based presentations.

In June 2014, HFA advocacy took to The Hill! We hosted 14 community advocates from 10 states to participate in a “Hill Visit” to Congress in Washington, DC in support of federal bill HR600 - The Patients’ Access to Treatment Act. Simultaneously, we hosted our first “virtual Hill Visit” in which 239 community members participated by visiting our website and generating letters to their members of Congress in support of HR600. In conjunction with the Hill Visits, both actual and virtual, we also hosted a reception in one of the US Senate’s historic committee rooms, awarding four “Champion Awards” to congressional leaders who have worked tirelessly to ensure that Americans have access to affordable health care. This year’s winners: US Senator Bill Cassidy of Louisiana, Congresswoman Diana DeGette of Colorado, Congressmen Cedric Richmond of Louisiana and Congressman Fred Upton from Michigan. Thank you, one and all!

At year-end, HFA received survey responses from nearly 400 community members who participated in our CHOICE (Community Having Opportunity to Influence Care) Project, a cooperative endeavor supported by the Centers for Disease Control and Prevention (CDC). The project included a survey with questions about diagnosis, bleeding history, complications, treatment, insurance coverage, and quality of life and care. Together with the CDC, we will use the CHOICE survey data to examine the health status of individuals in the community who do not receive care from federally-funded Hemophilia Treatment Centers (HTCs). Independently, we will use the CHOICE survey data to identify issues in care and care access reported by the survey respondents to improve our advocacy efforts, program offerings, and to develop new offerings to serve our community more effectively.

**THE PAST AND PRESENT**

**Dear Addy,**

I have a question about...

Some of YOUR issues tackled by Dear Addy this year:

- Health care choices
- Maximum out-of-pocket expenses
- Open enrollment
- Major medical vs pharmacy coverage
- Self-insured plans
- Employee disclosure
- Lifetime vs annual caps
- Privacy protections

**ADVOCATING THROUGH**
Many adult men living with hemophilia who used factor products prior to 1988 were infected with HCV and HIV. The Blood Brotherhood Program supports adult men with bleeding disorders who survived the blood crisis by providing a safe forum for them to connect with others struggling with similar extraordinary health challenges. Blood Brothers help each other in managing their bleeding disorders and coping with life stress. Through regular in-person and on-line social interaction, these men experience a decreased sense of isolation. In fact, a July 2014 survey of Blood Brotherhood program participants involved in the program one year or longer indicated that “isolation with low support” or “social isolation” decreased by a full 10% from a baseline survey distributed in 2009. In 2014, the Blood Brotherhood program hosted more than 75 events connecting nearly 800 adult men in face-to-face meetings. Blood Brotherhood also brought together approximately 400 men through our on-line forums, including webinars and various chat forums. The number of men enrolled in our program grew by nearly 10% in 2014 alone!

I was infected with HIV and HCV through plasma-derived factor concentrates in the early 1980s. I thought I was taking something to protect my life, when in reality it was giving me viruses that could take my life away. Our community lost way too many.” – Carl, adult with hemophilia

Women with bleeding disorders face the challenges of unexpected bleeding episodes and limited access to necessary treatment. Add to those difficulties the fact that women can go undiagnosed, and therefore untreated, for years, and it becomes evident that this segment of our community has specific needs. Did you know that it is estimated that one percent of women in the US may have a bleeding disorder? Blood Sisterhood serves women at all stages of life. This program utilizes a multi-faceted approach to address issues such as reducing stress, increasing physical fitness, and building a strong and well-informed constituency.

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.” – Elizabeth, Type 1 vWD

Last year HFA enhanced its local presence by providing educational sessions via three face-to-face peer support meetings at our member organizations, reaching more than 100 women. In addition we offered an education track at our annual symposium in Tampa, where more than 50 women with bleeding disorders participated in sessions on self-care and self-advocacy. Focusing on enhanced technologies to improve our service to women was at the top of our priorities this year. We engaged a community focus group and medical advisors in the design and testing of a new mobile app that tracks monthly menstrual cycles, as well as logs symptoms and notes for healthcare providers. We also invested heavily in a complete redesign of our program webpages receiving more than 2,000 views. The updated site provides women with access to educational materials, resources and tools to assist them in their journey to understanding their condition and becoming strong advocates for themselves and their families.
Part of our Families Program, Dads in Action delivered 34 local, state-based meetings and connected more than 500 dads and 250 kids across the country last year. HFA developed and deployed four education learning modules. In honor of Father’s Day, HFA released a beautiful hard-cover book dedicated to all dads in the bleeding disorders community. The book is a collection of essays from 14 dads of children with bleeding disorders, telling their stories with humor and love. Each dad who registers in the Dads in Action program receives one of these heartfelt books.

"If I could give advice to other families, it would be not to treat your child any different from other kids. They are ‘normal.’ We are ‘normal.’ We can do the same things as everyone else – we just have a slightly different approach.” – Mickey Price, member of Dads in Action

Moms of children with bleeding disorders have traditionally taken the lead in the care of their children. In recent years they have turned to on-line resources to connect with others and share their experiences and insights, drawing inspiration from other moms in the same situation.

"I decided I had to know as much as possible. It was my responsibility to learn as much as my HTC team knew about hemophilia. I had to earn my own ‘degree’ to be an expert about my child. I read books, asked questions, and attended meetings. I jumped into volunteering in the hemophilia community and absorbed as much information as possible. It was a crash-course in all things hemophilia.”

– excerpt from Infusing Love: A Mom’s View blog, 2014

In 2013, HFA launched a weekly blog, Infusing Love: A Mom’s View. This blog had nearly 1,200 shares and a total reach of 154,700 people in its first year! Infusing Love was the catalyst for the Moms in Action focus of our Families Program that offered on-line education via four national webcasts and delivered joint presentations to moms and dads at six local meetings with more than 120 people in attendance.
At any point, our families can experience a financial hardship because of their medical situation. Helping Hands program provides some relief to this extraordinary burden and helps our members focus on what’s important: their health. The program provides emergency assistance for basic living expenses such as housing, utilities, and transportation but the support doesn’t end there. Our staff works closely with applicants to help connect them with their 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 bracelets. Filling the gap of financial need for the most vulnerable in our community is an ongoing challenge of our organization.

### 2013 by the numbers

(February 1 – December 31, 2013)

- **95** households assisted with durable medical items (e.g., walking supports, protective gear, braces, etc.)
- **120** households received assistance with housing expenses
- **33** households received assistance with utility expenses
- **20** households received assistance with transportation expenses
- **7** households received assistance with “other” expenses (e.g., funeral or other emergencies)

OVER $124,867 DISTRIBUTED IN DIRECT AID TO 275 HOUSEHOLDS

In 2014 we hosted our first eight-week summer policy advocacy internship. Our interns were encouraged to develop their core abilities and utilize those strengths to empower themselves and their community.

HFA also awarded 10 educational scholarships to promising students in the bleeding disorders community. Young adults who learn to advocate for themselves and band together with others in the community can help raise public awareness and can absolutely begin to impact government policies that affect them. Involvement in community advocacy efforts provides a sense of empowerment and control over a disorder that often seems to have a mind of its own. HFA proudly invests in building strong community advocates.

**WE ARE INVESTING IN OUR FUTURE**

**"My favorite part of being an intern at HFA was being a member of a small but highly effective policy and advocacy team."** – Lewis, HFA policy intern, 2014

**"I have become more informed about the intricate issues pertaining to hemophilia health policy and have become much more confident as an advocate."**

– Maria, policy intern, 2014

**SCHOLARSHIP RECIPIENT**

**Emily**

University of Nebraska Medical Center

“This support from the bleeding disorders community will help me tremendously during my education to become a physician assistant, where I can treat my own patients with the same amount of respect and empathy that I have received from my own hematologists.”

**SUMMER INTERNSHIP**

Apply for our summer policy and advocacy internship!

Apply today at [www.hemophiliafed.org](http://www.hemophiliafed.org)
“Healthy bodies bleed less” is the message embedded in all that we do at HFA. One of the ways of maintaining a healthy lifestyle is by using FitFactor on the HFA website. FitFactor provides tools and resources to encourage and motivate our community to improve their physical and emotional health through regular physical exercise, proper nutrition and stress management. Accompanied by inspirational stories from other community members who practice healthy living, FitFactor offers on-line fitness videos, many captioned for the hearing-impaired and several translated into Spanish, on everything from martial arts and bicycle safety to yoga breathing and meditation. A healthy lifestyle is for everyone, regardless of age, mobility issues, or financial constraints. Then there are the pages and pages of healthy, delicious downloadable recipes, tips on food safety, and even holiday menu ideas. With FitFactor, everyone has the information and inspiration they need at their fingertips!

Speaking of fitness, the Get in Gear mobile app has become hugely popular. This app is designed to encourage people with bleeding disorders to become more active and can be used to track any fitness activity, from walking to yoga to swimming. Since its launch in 2012, the app has been downloaded more than 23,000 times with nearly 48,000 hours completed by its users. An update to the app in October 2014 allows users to enter their bleeding disorder and joint or muscle bleed information for the purposes of tracking their progress.

“Being at a healthy weight can reduce the number of bleeding episodes you experience, and eating healthy foods can help you build strong muscles, keep your bones healthy, and help you recover faster from a bleed.” – Joe, had hemophilia B until a liver transplant in 1996

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HFA SYMPOSIUM

As a first-time attendee, I’m beyond impressed with HFA staff and their programs.” – 2014 Symposium Attendee

HFA Symposium was a three-day national event, packed with educational sessions, industry updates and special forums. We hosted more than 800 community members at this meeting, assisting more than 100 first-time attendees with financial scholarships for either transportation or lodging. The core meeting included nearly 40 education and advocacy sessions. Special highlights of the 2014 meeting included the Ryan White and Ricky Ray AIDS Quilt, the History Room housing our remarkable 60-year timeline, an educational session specifically for people affected by an inhibitor, a teen program focusing on self-advocacy, a FitFactor wellness lounge, and even art therapy sessions. We also took a moment to honor our indefatigable volunteers who continue to stretch above and beyond with their contributions of time, creativity and spirit.

Charles Stanley Hamilton Legacy Award
Donald Akers, Jr.

TEA (Teach, Empower, and Advocate) Award
Vicki Jacobs Pratt

The Terry Lamb Health and Wellness Award
Barry Haarde

Ron Niederman Humanitarian Award
Glenn Mones

Volunteers of the Year
Lee Hall & Ray Dattoli

Michael Davon Community Service Award
Nathan Wilkes
THANK YOU FOR YOUR SUPPORT
Thank you to our corporate donors and our federal partners for your charitable contributions!

Visionaries $500,000+
- Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Blood Disorders Division

Champions $300,000+
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- Novo Nordisk, Inc.

Guardians $150,000+
- Bayer HealthCare

Benefactors $75,000+
- CSL Behring
- Grifols USA
- Pfizer

Believers $25,000+
- AHF, Inc
- Ediekin
- National Cornerstone Healthcare Services

Fans $10,000+
- Accredo’s Hemophilia Health Services
- AR1 Infusion Services
- Biomed Pharmaceuticals
- Emergent Resolutions
- Hemophilia Alliance
- Octapharma

HFA Board of Directors and Governance

HFA is a collaborative federation of state-based member organizations across the US that unite and strengthen our community network. The Board of Directors is comprised of 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 closely with our members to offer programs and services that directly impact our community needs. HFA grew by two new state-based member organizations in 2014 for a total of 41! Join us in a huge welcome to our new members: Alaska Hemophilia Association and Eastern Pennsylvania Chapter of NHF!

Board of Directors
John Palmatter: Alaska Hemophilia Association, AK
Robin Parker: Hemophilia Foundation of Arkansas, AR
Tari Morrison: Arizona Hemophilia Association, AZ
Sean Hubbard: Central California Hemophilia Foundation, CA
Mickey Price: Hemophilia Foundation of Southern California, CA
Mandy McCullough: Connecticut Hemophilia Society, CT
Debi Adamski: Florida Hemophilia Association, FL
Josh Henman: Hemophilia of Iowa, IA
Open Seat: Idaho River Hemophilia & Bleeding Disorders, ID
Open Seat: Bleeding Disorders Alliance Illinois, IL
Scott Elmes: Hemophilia of Indiana, IN
Edgar Gueycoy: Louisiana Hemophilia Foundation, LA
Diane Lins: New England Hemophilia Association, MA
Carlelia Gates: Hemophilia Foundation of Maryland, MD
Jill Packard: Hemophilia Alliance of Maine, ME
Drew Evans: Hemophilia Foundation of Michigan, MI
Aaron Barnes: Hemophilia Foundation of Minnesota / Dakota, MN
Sumana Srisri-Carney: Gateway Hemophilia Association, MO
Sean Jeffrey: Rocky Mountain Hemophilia and Bleeding Disorders Association, MT
Zack Strange: Hemophilia of North Carolina, NC
Peter Marcano: Hemophilia Association of New Jersey, NJ
David Huczek: Bleeding Disorders Association of Northeastern New York, NY
Lea Kaseker: Bleeding Disorders Association of the Southern Tier, NY
Stephen Graziano: Mary M. Gooley Hemophilia Center of New Mexico, NM
Matthew Compton: Past President, CA

Officers
Tracy Cleghorn: President, VA
Mark Antell: Past President, VA
Douglas Hartsough: Treasurer, Hemophilia Foundation of Northern California, CA
Rea Watson: Secretary, Sangre de Oro Hemophilia Foundation of New Mexico, NM
Matthew Compton: Past President, CA

Professional and Medical Advisors

Donald Aberg, Jr., General Counsel
Christopher Walsh, MD, PhD, Medical Advisor
Linda Wyman-Callen, RN, Medical Advisor
Dottie Burry, RN, PhD, Medical Advisor
John Reed, Pharm D, RH, Medical Advisor
Cynthia McElroy, LSW, Medical Advisor

Stewart Worthington: Hemophilia Foundation of Oregon, OR
Open Seat: Eastern Pennsylvania Chapter of HSF, PA
Open Seat: Tennessee Hemophilia and Bleeding Disorder Foundation, TN
Hector Ortiz: Hemophilia Outreach of El Paso, TX
Jonas Sedarli: Laos Hemophilia Chapter, TX
Chad Fredericksen: Texas Central Hemophilia Association, TX
Stephen Long: Hemophilia Association of the Capital Area, VA
Zack Borden: Virginia Hemophilia Foundation, VA
Michael Birmingham: Bleeding Disorders Foundation of Washington, WA
Darci Zierer: Wisconsin Bleeding Disorders Network, WI
Linda Wyman-Callen: Independent Board Member, TX
Thomas Russomano: Independent Board Member, NJ

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