Honoring Our Past, Building Our Future
Dear HFA Friends and Family,

Welcome to summer! Hopefully, wherever you are reading this, you are enjoying some beautiful weather and time off from work!

Recently, the hemophilia community gathered in Tampa, Florida for our annual Symposium, with the theme Honoring Our Past, Building Our Future — an appropriate theme, since we are celebrating our 20th anniversary. Symposium has quite often been called a family reunion, and this year was no different.

I was introduced to this very large, loving family at my first Symposium six years ago. At that time, it was less than two years since our son Nicholas was diagnosed with severe hemophilia. Nicholas received a bleeding disorder diagnosis we knew nothing about. During his young life, he has endured several bleeds, had a port implanted, and began prophylaxis. When we came to Symposium, we were still settling into the diagnosis and what our life would entail. Over these past six years, we’ve all grown and learned so much, and our bleeding disorders family has continued to grow.

This year, we had a wonderful addition to Symposium: a first-of-its-kind historical journey over the past seventy years of hemophilia. Two rooms were filled with easy-to-read and follow timeline boards dating back to the 1940s, binders of documents, hundreds of community resources, the Ryan White and Ricky Ray AIDS Quilt, and hundreds of community photos dating back to the 1950s. This room evoked powerful emotions from new and long-participating community members alike. I commend the committee that worked long and hard on bringing this room to us.

Reflecting on our community’s past and future as the mother of a young son with severe hemophilia, I often consider how to best educate my son. Honoring Our Past, Building Our Future is a thought provoking statement; both past and future are equally important. It’s my job as a mother and community member to find the balance between the two, and share that with him. Our past is so significant that I feel I would be doing an injustice to him and his blood brothers that sacrificed so deeply if I didn’t educate him on the history. At the same time, my son and his young blood brothers and sisters are the future of this community.

As the newly elected president of the Hemophilia Federation of America, I ask you to join me by encouraging our children to do the same — Honor Our Past, and Build Our Future! Our children will inherit our history, and with our help, they will become strong advocates for the bleeding disorders community.

Warm regards,

Tracy L. Cleghorn
Board President
Symposium is like a 3 day family reunion. I look forward to it every year!

Symposium is a family-friendly educational meeting dedicated to improving the lives of those living with and affected by a bleeding disorder. Having hemophilia or von Willebrand Disease is a lifelong journey that requires diligence and flexibility in dealing with the challenges along the way. Symposium is designed to help you with that by providing opportunities to learn and grow, all while giving you the necessary tools to become strong self-advocates.

This year, we celebrated our 20th anniversary in Tampa, Florida with the theme of Honoring Our Past, Building Our Future. In tandem with our 39 member organizations, we brought together over 800 moms, dads, caregivers, spouses, siblings, and stakeholders from across the country to make this our largest and best meeting yet!

**Highlights from Symposium 2014**

- Over 100 first time attendees received scholarships
- A History Room was launched to honor the milestones of our community that included: a historical timeline, binders full of information organized by decade, hundreds of pictures from community members dating back to the 1950s, Ryan White and Ricky Ray’s AIDS Quilt, a community resource table, and a viewing area for documentaries and old video clips
- An educational track for inhibitor patients
- A teen program where young adults learned the power of self-advocacy and starred in Season 3 of “Stop the Bleeding: A Comedy Web Series”
- A FitFactor Wellness Lounge that included: massages, Nia classes, and art therapy sessions
- Lots of educational sessions dedicated to providing a family with vital information and resources

We hope you will join us next year in St. Louis! Go to www.hemophiliafed.org for more information!
“HFA serves as the ‘voice of the bleeding disorders community.’”

“Symposium has more of a ‘family’ and intimate feeling than any other national meetings.”

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

“I’ve been to many Symposiums, this was the best yet!”
HFA Annual Awards

Each year, HFA recognizes the service of special volunteers who have stretched above and beyond with their contributions to make a difference in the bleeding disorders community. Nominations are collected across the country through HFA’s board and 36 member organizations. HFA’s board of directors has the responsibility of casting the vote for who will receive these awards of distinction.

Charles Stanley Hamilton Legacy Award:  
Donnie Akers  
Award for extraordinary lifetime service that encompasses volunteerism, professionalism, and leadership.

TEA (Teach, Empower, and Advocate) Award:  
Vicki Jacobs Pratt  
An award to an outstanding woman who supports women’s bleeding disorders issues.

The Terry Lamb Health and Wellness Award:  
Barry Haarde  
Award for exceptional commitment to supporting and encouraging health, nutrition, and wellness behaviors in the bleeding disorders community.

Ron Niederman Humanitarian Award:  
Glenn Mones  
Award for extraordinary service to the community via one’s professional service and work.

Volunteer of the Year Award:  
Lee Hall & Ray Dattoli

Michael Davon Community Service Award:  
Nathan Wilkes  
An award for extraordinary service to the community via one’s volunteerism and charitable giving.

Left to right: Vicki Jacobs Pratt, Barry Haarde, Lee Hall, Ray Dattoli, Donnie Akers, Nathan Wilkes, Glenn Mones.
As we honor our past, it’s important to look ahead to our future. This timeline will help you gain a better understanding and insight of our community to become a stronger advocate.

This is only a snapshot of our community's legacy — a volunteer advisory committee made a considerable effort to be historically accurate. This summer, we will launch a virtual interactive timeline to help you easily access this information.

We thank our volunteer advisory committee for their invaluable knowledge as they searched through thousands of resources.

Donnie Akers  Priscilla Oren
Detrice Berry  Sonji Wilkes
Lew Collins  Rich Pezzillo
Ray Datolli  Kimberly Haugstad
Barry Haarde  Susan Swindle
Jan Hamilton
This timeline was originally displayed at this year’s Symposium to recognize the milestones, adversities, and triumphs of our resilient community.

“This was an amazing exhibit!! Kudos to all involved!! Hope there is a way to make it a traveling exhibit!”

“We owe it to the previous generations, to ourselves, and to our children to not forget the past.”

“This was my favorite part of Symposium. I could have spent hours in this room.”

“So incredible, humbling, and wonderful. Love this exhibit.”
**1930s and 1940s**

People living with hemophilia struggle with health problems and only have a median life expectancy of 27 years. Treatment is limited to transfusions of whole blood and icing the joints. In 1949, the US Army concludes soldiers using pooled plasma have a higher incidence of jaundice. Later research proves that jaundice was a symptom of hepatitis. The National Hemophilia Foundation is founded in 1948 by Robert Lee and Betty Jane Henry.

**1950s and 1960s**

Improvements in blood transfusions in World War II led to hemophilia patients being able to get fresh frozen plasma. The World Federation of Hemophilia is established in 1963. After cryoprecipitate is developed in 1964 by Dr. Judith Graham Pool, life expectancy rises to 39.7 years.

1958
Life expectancy for those living with hemophilia is only 27 years old in the 1950s.

1959
This era marks a time of research into effective treatment for hemophilia as whole blood continues to be the only effective treatment.

1959
Mary M. Gooley assembles one of the first comprehensive care teams in Rochester, NY to help families affected by hemophilia.

1963
During the early 1960s, hemophilia is often referred to as the “Disease of Kings” and “Bleeders Disease.”

1963
The World Hemophilia Federation is formed.
1964
After cryoprecipitate is developed, life expectancy rises to 39.7 years.

1964
Dr. Judith Graham Pool discovers cryoprecipitate.

1966
Researchers Dr. Edward Shanbrom and Dr. Murray Thelin (who was also a hemophilia patient) work on developing a concentrate for hemophilia treatment.

1967
Clotting factor is administered to a hemophilia patient for the first time at Hyland Labs in Glendale, CA.

1968
Girls living with hemophilia are not forgotten in the media coverage. However, people of color are not well represented in the media.

1969
The National Hemophilia Foundation features young boys to help generate attention in the media.

1969
Camp Bold Eagle in Michigan becomes the first hemophilia summer camp in the US.
1970s

Clotting factor becomes available for home use. The network of comprehensive, federally funded Hemophilia Treatment Centers begins. Positive outcomes for hemophilia patients increase dramatically as life expectancy rises to 60 years old.

**1970**
Despite medical advancements, many patients with hemophilia have joint damage from years prior. The community rallies support to help these patients receive appropriate care.

**1971**
Factor concentrate usage continues to vary. Some doctors are still prescribing and instructing patients to use cryoprecipitate in the early 1970s. Treatment at home is becoming more prevalent and patients no longer feel tethered to the hospital.

**1972**
Blood drives remain common as cryoprecipitate and clotting factor become more widely available.

**1972**
Richard Burton, who has hemophilia and is famously married to Elizabeth Taylor, serves as an ambassador for hemophilia awareness.

**1972**
Celebrities join the cause to help promote blood drives.

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**Doctor Claims 95% Accuracy in New Test for Hemophilia**

**8 Hospitals to Be Hemophilia Units**

**University Students Give Blood to Hemophiliac for 12 Years**

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**Burton Heads Hemophilia Drive**

NEW YORK (UPI)—A fund drive in the name of Richard Burton to benefit hemophilia victims was launched yesterday with Burton’s wife, actress Elizabeth Taylor, as chairman. At a news conference announcing the drive, Burton acknowledged he has had “slight hemophilia all my life.”

Hemophilia is a disease characterized by slow blood clotting and excessive bleeding even from superficial injuries. A tooth extraction may necessitate as many as 100 blood transfusions and an operation may result in 1,000, the Hemophilia Foundation said.

In addition to helping victims of hemophilia, said to number 100,000 in the United States, the “Richard Burton Hemophilia Fund” also will help finance medical research aimed at eradicating the disease.

With Burton and Miss Taylor at the news conference were Charles Gerard Bugbee, a hemophiliac sufferer who was reported to have undergone 400 blood transfusions.
1973
The Hemophilia Act passes, launching the formation of a nationwide network of federally funded hemophilia treatment centers.

1975
Hemophilia affects many generations within one family. The media continues to draw attention to the plight of living with the condition.

1973
Researchers identify a new method for identifying carriers of the hemophilia gene.

1974
Hepatitis non-A, and non-B, later known as Hepatitis C is a growing concern.

1977
An article in The Journal of the American Medical Association notes it is possible to heat treat albumin, a blood product, to effectively kill some of the hepatitis viruses.

1978 and 1979
Those living with hemophilia now enjoy an improved quality of life.
In 1982, CDC reports the first cases of HIV/AIDS among people with hemophilia. By mid-1983, researchers are able to isolate the virus that causes HIV/AIDS. Manufacturers of plasma derived clotting factor concentrates, attempt to kill these viruses with dry heat, solvent detergent treatment, and pasteurization with varying degrees of success. Manufacturers license and begin developing heat-treated products, but these are not widely available due to high cost, perceived risk, and efficacy. Many in the hemophilia community become isolated due to discrimination and fear of being identified as HIV/AIDS positive. Children, most notably Ryan White and the Ray brothers, are denied entry to school. By the late 1980s, over 50% of the hemophilia community has been infected with HIV/AIDS and/or Hepatitis C. In those with severe hemophilia, the infection rate is over 90%. The decades-old concern over hepatitis is now far overshadowed by the HIV/AIDS epidemic.

January 4, 1983
CDC hosts a meeting to address the growing concern over the safety of the nation’s blood supply. No changes were made.

1982
CDC reports first AIDS cases among people with hemophilia.

1983
Manufacturers begin issuing factor recalls.

1983
The National Hemophilia Foundation sends notices to individuals and local chapters urging patients to continue use of clotting factor, despite warnings from the CDC that the blood supply is tainted with HIV/AIDS.

1984
The first diagnostic test for the retrovirus that causes HIV is developed. The number of people with hemophilia being diagnosed with HIV/AIDS is growing rapidly.

Several manufacturers begin the development of heat treated factor concentrate after testing shows the process kills both HIV and some hepatitis viruses.
During this period, many in the hemophilia community felt they were not getting the answers they sought. The Committee of Ten Thousand (COTT) and Hemophilia-HIV/PEER Association are formed to demand more information and transparency for those who have contracted HIV/AIDS from tainted blood products.

1989

The first World Hemophilia Day is observed on April 17 to increase awareness of hemophilia and other bleeding disorders.
1990s

The 1990s are a period of action in the hemophilia community. National grassroots associations like the Hemophilia-HIV Peer Association, Committee of Ten Thousand (COTT), and Hemophilia Federation of America (HFA) form to address the unheard needs of the community. Recognizing their role in the failure of the public health system to protect the hemophilia community, the National Hemophilia Foundation undergoes aggressive re-organizational efforts, with new leadership NHF unites with the grassroots community to push for legislative action and strident blood safety regulations. During this time, the gay community supports those with hemophilia and HIV/AIDS, and strong coalitions form.


1990
Ryan White dies at the age of 18.

1992
The hemophilia patient community begins to independently ask their own questions and galvanize. Local hemophilia organizations, COTT, and others seek answers to why they were given misinformation and to hold accountable those who failed to prevent the spread of HIV/AIDS to people with hemophilia.

1992
Ricky Ray, one of three brothers infected with HIV/AIDS, dies at age 15.

1994
Hemophilia Federation of America forms as a sub-group of COTT in 1993 and becomes independent in 1994.

HFA bridges the gap between the advocacy efforts that COTT is working on, and is a place of education, advocacy, and support for families living with a bleeding disorder. HFA continues today to serve as the voice of the community.

1994
Litigation against the drug manufacturers dominates most of the 1990s. Some patients file individual cases, while others are part of a large class action suit. Others choose not to pursue a settlement.
1995
Following a request from the Department of Health and Human Services, a Committee of the Institute of Medicine (IOM) reviews the scientific evidence available to decision makers during the early 1980s. The IOM releases a report called, HIV and the Blood Supply: An Analysis of Crisis Decision Making, which outlines ways to make the blood supply safer. The report is a turning point for the community.

1996
The financial burden of those who lost loved ones is felt by their families.

While other countries were finalizing settlements by 1996, negotiations in the US continue due to years of stalled litigation.

After the IOM report and many attempts at class-action suits, victims and their families gain traction in holding the pharmaceutical companies accountable for infected clotting factor products.

The negotiations of the settlement bring up painful questions for patients and their families.

1997
As a result of the community’s grassroots effort, Congress begins to show support against the tainted blood supply.

1997
Frequent updates and information to the community are being sent regarding the status of the Ricky Ray Hemophilia Relief Fund Act.

1998
After tireless efforts from HFA, NHF, COTT, and others, President Clinton signs the Ricky Ray Hemophilia Relief Fund Act of 1998 on November 12, 1998.
2000s

The divide in the hemophilia community between the HIV/AIDS-era families, post-heat treated, and recombinant factor using families slowly begins to heal. The financial burden of living with hemophilia is felt in lifetime caps and out-of-pocket expenses. In 2007, the Joint Outcome Study is released showing that prophylactic treatment is favorable to on-demand treatment in reducing joint and life threatening bleeding. Increased attention is being paid to women with bleeding disorders, and the development of inhibitors in hemophilia. The passage of the Affordable Care Act in 2010 assures those living with bleeding disorders cannot be denied for pre-existing conditions and that most plans eliminate lifetime cap issues. Future treatment includes the development of new clotting medications and gene therapy. Quality of life is dramatically improved for most living with hemophilia and life expectancy is nearly the same as most healthy people.

2000 to 2005
The hemophilia community sees a resurgence in families coming together through camps, local, and national meetings. The term “hemophilia” begins to be replaced by the term “bleeding disorders” to acknowledge all bleeding conditions. The financial burden of living with hemophilia is felt in lifetime caps and out-of-pocket expenses. In 2007, the Joint Outcome Study is released showing that prophylactic treatment is favorable to on-demand treatment in reducing joint and life threatening bleeding. Increased attention is being paid to women with bleeding disorders, and the development of inhibitors in hemophilia. The passage of the Affordable Care Act in 2010 assures those living with bleeding disorders cannot be denied for pre-existing conditions and that most plans eliminate lifetime cap issues. Future treatment includes the development of new clotting medications and gene therapy. Quality of life is dramatically improved for most living with hemophilia and life expectancy is nearly the same as most healthy people.

2006

Since clotting factor was discovered in the 1960s, inhibitors have been of concern. About 30% of Hemophilia A and 2-3% of Hemophilia B patients will form an inhibitor. Education and outreach increases for inhibitor families.

2007
Dr. Marilyn Manco-Johnson, et al., publish in the New England Journal of Medicine, a multi-year study showing a prophylactic regimen of treatment prevents joint damage in pediatric patients.
The Affordable Care Act (ACA) passes in 2010. The ACA addresses lifetime caps, pre-existing conditions, out-of-pocket expenses, young adult coverage, and other needs important to people with bleeding disorders.

2008
Lifetime caps are a growing concern in the hemophilia community, and especially for inhibitor patients.

On May 21, 2008 President George W. Bush signs into law the Genetic Information Nondiscrimination Act (GINA) to protect Americans against discrimination based on their genetic information when it comes to health insurance and employment.

2010
The Affordable Care Act (ACA) passes in 2010. The ACA addresses lifetime caps, pre-existing conditions, out-of-pocket expenses, young adult coverage, and other needs important to people with bleeding disorders.

2011
Hepatitis C continues to devastate the hemophilia community and is the leading cause of death in adults. Currently there is no cure and treatment is not always effective.

2013
Increased research and awareness is being conducted for women with hemophilia, carriers, and von Willebrand Disease.
Our Future

As we look to the future of the bleeding disorders community, there remains uncertainty regarding advancements in treatment for patients. However, we remain vigilant and guarded that our clotting factor and the blood supply remain attainable and safe. We remember the thousands of lives affected by the HIV/AIDS epidemic, the lives lost, and those still living today. Without these unsung heroes of the community, we would not be as strong, resilient, and unified as we are today. HFA supports the creation of a national memorial to remember and honor all the lives lost.

Despite much adversity, the bleeding disorders community has made much progress over the past 70 years. However, as we look ahead to the future, our advocacy work is far from finished:

- Many women are still left undiagnosed.
- Hepatitis C continues to be a life-threatening problem for many adults.
- People with inhibitors have seen very little advancement in prevention and treatment.
- An influx of new products entering the market is creating competitive pressures.
- Families are still burdened by access to care, high cost, and quality of treatment issues.
- The community still waits for a cure.

THE FUTURE LIES IN YOU!

Take Action
Be Involved
Ask Questions
We Are Excited to Welcome Elaine, Stephen and Sonji to Our Team!

Elaine Chan, MSW, MPH
Helping Hands and Dads in Action Coordinator

Elaine joined HFA after working eight years as a social worker providing therapeutic services for inner city youth in Philadelphia and Boston. Elaine has extensive experience within the cancer and homeless communities throughout her academic pursuits. Elaine holds a Bachelor’s Degree in psychology from University of Pittsburgh, Master’s Degree in social work from Temple University, and Master of Public Health from Boston University. She is excited to learn more about the bleeding disorders community while experiencing the diversity and vibrancy in DC.

Stephen Fitzmaurice
Communications and Policy Coordinator

Stephen joins HFA after serving People for the American Way Foundation’s Young Elected Officials Network, where he oversaw the telecommunications and broadband policy portfolio. Stephen has a Master’s Degree in Legislative Affairs from the George Washington University’s Graduate School of Political Management, as well as a Bachelor’s Degree in Political Science from the University of Florida. Stephen is excited to help HFA’s policy and communications shops as they further the message of the bleeding disorders community. Stephen resides in Washington, D.C.

Sonji Wilkes
Families Coordinator

After a year and a half of serving as a consultant with HFA, Sonji joined us as a full time staff member serving as a Program Coordinator with our Families Program. Sonji develops educational content and helps local member organizations deliver programs and services through Dads in Action and MomsConnect. She began HFA’s popular “Infusing Love” mom’s blog; over 225,000 people saw the blog on social media in 2013, the blog’s first year. Sonji graduated Magna Cum Laude with a BA in Behavioral Science from the Metropolitan State College of Denver. Sonji and her husband, Nathan have been married for nearly 19 years and have three children: Nora (12) Thomas (10), who has severe hemophilia A with an inhibitor, and Natalie (8).
Never Let the Things You Can’t Do Define You

By Michael Birmingham

Exercise has always been pretty important for hemophiliacs, especially severe hemophiliacs like my brother and I. My parents felt that living an active life would go a long way toward fulfilling that goal. However, exercise is a series of trade-offs.

Growing up I was told, “exercise those muscles, but do it in a low impactful way that hopefully won’t cause joint bleeds.” For my parents, it was all about steering us toward things we could do, rather than focusing on things we couldn’t do. Organized sports for kids growing up consisted of the “Big Three”: baseball, basketball and football (all high impact sports). Certainly in school, these would have caused more problems than they were worth, especially since when I was growing up, treatment was “on-demand” vs. prophylactic.

How do you keep kids focused on being active then? By providing them with plenty of options!

Where we lived was critical. With nearby parks and little traffic, we could always hike or ride bikes, and in the winter, we went sledding. We had nearby pools for swimming, and a driving range where we could hit a bucket of balls. Even the big sports were not really off limits to us, as long as they were not the full contact versions: driveway basketball with shooting games like “HORSE” could be fun; catch or keep away with a baseball was fine; and even football could be made safer with “two hand touch” or similar rules. But my brother and I spent most of our time in the pool.
From the time I was seven years old until just before I graduated high school, we always had a pool in our backyard, and swimming was a great, safe way to exercise. During the summer months, we would get up, walk to swimming lessons in the morning, and by midafternoon we were back in the pool, pretty much until the sun went down again. Unfortunately for us, familiarity bred more than a little contempt for it. When you have to swim back and forth one hundred times a day, even in a little 35 foot pool, you start to see it more as a chore than a fun toy. Still, being active made for a happy childhood, and prepared us for the challenges that lay ahead.

The biggest thing I regret not being able to do when I was younger is treat prophylactically. Kids today get to keep their clotting levels much higher all of the time, which not only allows them to participate in those higher contact sports, but if they keep it up, they will not have the joint deterioration that caused me to have both ankles and one knee replaced.

Today my joints are worn down and I am battling arthritis, but I haven’t given up on being active! As I have gotten older, I began to challenge myself, and have recently tried mountain climbing! Though I have had to cut that out, since it was too painful to descend the mountains, I won’t give up until I find something that fits for me. That’s the example I am trying to set for our younger generation: it’s not about focusing on what we can’t do, but finding what we can do. Now if you’ll excuse me, I have to start planning for a kayaking trip!

Michael Birmingham, has severe Hemophilia A, and resides in Washington with his wife Margaret of 25 years and his three children. Michael is a technology strategist with more than 25 years of experience in the field. Michael earned his BS degree in Computer Science from Gonzaga University and an Executive Leadership MBA from Seattle University. Recently, Michael joined the board of director for the Bleeding Disorder Foundation of Washington and the Hemophilia Federation of America.

*While extensive efforts are made to ensure accuracy of the content of each FitFactor article, these entries are not intended to be construed as medical advice or the official opinion/position of HFA, its staff, or its board of directors. Readers are strongly encouraged to discuss their own medical treatment, diet plan, and physical activities with their healthcare providers.

20,098
NUMBER OF DOWNLOADS SINCE JUNE 2012
Download this free fitness app on your smartphone to:
• Track duration and/or distance of fitness activities
• Keep an ongoing history log
• Share your fitness achievements with friends
• Access important health news
• Learn more about bleeding disorders

www.getingearapp.com

Version 3.0 COMING THIS SUMMER!

Get healthy. Give support. Get in Gear!
A NEW ONE-OF-A-KIND BOOK
DEDICATED TO ALL DADS IN THE BLEEDING DISORDERS COMMUNITY!

Since 2005, we have offered Dads in Action, a program for dads in the bleeding disorders community to educate, support, and challenge each other to be the best role models for their families. For Father’s Day, we released a collection of essays from 14 dads living with and/or having a child with a bleeding disorder. These dads shared their hopes, dreams, and fears and gave a glimpse into their lives. By reading the stories, you may see parallels of your own experiences. The following is an edited excerpt from *Dads in Action: Real Stories from the Bleeding Disorders Community*.

Register to become a Dad in Action and get a free copy of this book.
www.hemophiliafed.org

Hemophilia is Only a Handicap if You Let it Be

By Mickey Price

I am 38 years old. I live with severe Hemophilia A, but I don't suffer from it. I have a beautiful wife of 10 years and a gorgeous little girl who is 4. I was diagnosed in infancy due to a family history and good doctors.

Growing up had its challenges, however, my mom set some limitations and Children’s Hospital of Columbus was my home away from home. I never let having hemophilia slow me down though, and I did not live in a bubble. The house I grew up in wasn't covered with socket caps and rubber pads on the corners. I would run, jump, dive, roll, fight, and play sports. I tried hard to be just like any other kid. I had lots of friends during my childhood and I cannot remember ever being shunned or treated differently because of my health. To say that it never affected me emotionally, though, would be a lie — I can remember many times asking when my knee was the size of a small cantaloupe because of a joint bleed, “Why do I have hemophilia?”

While I enjoyed going to summer camp as a kid, I never knew about other chapter events or community activities. By the age of 7, I had learned to infuse thanks to my older brother (who also has hemophilia). Since my mom suffered from alcoholism,
I needed to learn to take care of myself. Self-infusing helped to cut down the number of times I went to hospital.

One day, when I was fourteen years old, I came home from school and my mom was sitting at the kitchen table drinking a beer and smoking a cigarette. She started talking all kinds of nonsense and I thought she was joking around. I then realized that something was seriously wrong and I called my stepdad, who told me to call an ambulance. Hours later, as I sat in the hospital waiting room with assorted family members, I heard a Code Blue called. Somehow, I knew it was her. My mom had died from cirrhosis of the liver — ultimately from alcohol.

My stepdad has been and remains a positive and regular presence in my life. I was given the choice about where to live after my mother died — either in Ohio with him or in California with my middle brother. My older sister was already out there and convinced my brother to come. Not wanting to abandon him, I told the court that I wanted to go to California, too.

Unfortunately, our sister was very unreliable, and it didn’t take long before we knew we couldn’t stay with her. Our oldest brother, who has hemophilia, was also out there, so we moved in with him. This ended up not being the solution we hoped for either. As our living situation continued to break down, I talked to my school counselors and was placed in foster care.

It was around this time that I found out I was a member of the 3-H Club (Hemophilia, HIV, and Hepatitis C). I had contracted HIV and Hepatitis C from contaminated blood products. This made foster care rough, being shuffled around to a couple different foster homes. I finally ended up in a group home for gay and lesbian youth. While not HIV positive themselves, my housemates were very accepting of me. Moving into the group home also opened the door for two other guys with hemophilia who needed a place to live. Unlike them, I refused to take my HIV meds, since the medications had so many side effects. I decided that I would rather feel good and die than feel lousy and live. At the time, HIV was a death sentence, so what difference would it make? Fortunately, unlike those guys, I am here today.

Many years later, my life today is fairly normal despite everything I have been through. I have an extraordinary wife and a little firecracker of a daughter — a beautiful gift that I never thought possible. She helps me infuse, and has been hitting veins since she was three years old!

God has truly blessed my life and continues to do so. I know how lucky I am to be here today, and I see that reflected in the men around me. Some of them may not have the best joints, but they are happier than guys I know without bleeding disorders!

I’ve also learned that hemophilia is only a handicap if you let it keep you down. I am grateful for the advancements in treatment, for all those who work in the hemophilia community, and for how close we all are. HFA’s Symposium in 2012 was my big introduction to our community — it really lit my fire.

When I look to the future as a dad with hemophilia who has a daughter that is a carrier, I am encouraged at the progress our community has made and continues to make. If I could give advice to other families, it would be to not treat your child any different from other kids. They are “normal.” We are “normal.” We can do the same things everyone else can — we just have a slightly different approach.

#BLEEDON

Mickey Price is 38 years old, has severe hemophilia, HIV, and in 2013 underwent treatment which cleared his HCV. Mickey was diagnosed very early in life due to his family history of hemophilia. Mickey is from Ohio, but currently lives in California with his wife, Tanya, of 10 years and their 4 year-old daughter, Kaelee.
A carrier of the hemophilia gene is a female who has a genetic mutation on one of her X chromosomes. About 1/3 of carriers experience bleeding problems and are often referred to as symptomatic carriers. By definition, if a woman has clotting factor levels less than 50%, she has mild hemophilia.

Ashley and Sarah are sisters from Michigan who were diagnosed at a young age as carriers of the hemophilia gene. Even though Ashley and Sarah have a close relationship, they have a different story when it comes to how hemophilia has affected their lives. Read their stories to learn more about these two remarkable women.

**Q. WHEN WERE YOU DIAGNOSED AS BEING A CARRIER OF HEMOPHILIA?**

SARAH: I was diagnosed at around 6 months.

ASHLEY: My understanding is that my factor levels were checked at birth. My mom is a carrier as well as my older sister, so it was natural for them to check me. My legs were always terribly bruised as a child, so I often had to explain to my friends and teachers why I was black and blue.

**Q. WHAT WAS YOUR FEAR GROWING UP WITH A BLEEDING DISORDER?**

SARAH: I did and still do fear passing it on to a child.

ASHLEY: I didn’t have any fears in terms of my carrier status. I was an active teenager and a competitive cheerleader. I knew someday I could have a child with hemophilia, but I never understood the gravity of that and all that goes along with that.

**Q. WHAT ARE YOUR FACTOR LEVELS?**

SARAH: They range from 18-29% with a preventative IUD. I am not sure what they are without hormone birth control.

ASHLEY: It’s awful to say, but I don’t know at the moment. Now that I am ready to start my own family, it’s time for me to start monitoring them much more closely.

**Q. DO YOU HAVE BLEEDING SYMPTOMS?**

SARAH: Oh yes! Bloody noses, bruising, bad ankle, severe periods, etc.

ASHLEY: I don’t have many serious symptoms other than a heavy period, bruising easily, and the occasional nosebleed. My sister has much lower factor levels than I do, and she experiences consistent mild joint bleeds. Isn’t it astounding how different it can be within one family?
I have always known that we had hemophilia in our family. I knew that she struggled with her mobility, but it didn’t directly impact my life in a major way until the AIDS crisis. It was my reality and part of what made me ‘me.’ I loved to explain it to other kids. I think I gained my tenacity from having to explain to my teachers that some women DO have hemophilia. I began attending camp at age nine, made some incredible friends, and always associated the disorder with fun and love. However, as I grew older, I saw firsthand the depth of pain my aunt dealt with. It was then that I realized the severity of the condition.

Absolutely, she has helped and encouraged my involvement in the community.

My aunt’s disorder has helped me understand hemophilia. I have always known I was a carrier so there was no need for “acceptance.”

No, I am always having to educate them on why I say I have hemophilia.

I don’t think people truly understand, even though I try to explain it as easily as possible. When it comes to dealing with medical personnel, I think they are beginning to understand.

My biggest challenge has been learning to advocate for myself and other women.

My physical issues are not severe, so the hardest part is the emotional impact. My husband and I are considering a family, and the thought of having a child with hemophilia can be frightening.

This questions is always so tricky! More days than not I would say no. There are rare days I would say yes. I wouldn’t be who I am or have the friendships I do without it, so today my answer is no!

This is a difficult question that I struggle with for many reasons. Without it, I wouldn’t have the weight of the fear for my future children. But I also wouldn’t have had many life experiences, like at Camp Bold Eagle and Eagle Outpost (in Michigan). The people that I met at those camps and the experiences we had together shaped me into who I am today. Who would I be without hemophilia? I don’t know the answer to that.
A Critical Safety Net from the Past to the Present

By Elaine Chan, MSW, MPH

Helping Hands is a unique financial assistance program that assists individuals and families within the bleeding disorders community with basic living expenses. It was designed to be a rapid, non-invasive, temporary resource for emergency situations and to provide a foundation for future financial stability.

In 1997, HFA started the Helping Hands program when it noticed there was an unmet need within the bleeding disorders community. Initially, the assistance provided was in a compassionate nature, rather than financial assistance. Assistance included a Nintendo for a co-infected young patient to find joy in his last days, a catered dinner for a man who wanted to do something nice for his wife who took care of him while single-handedly supporting the family, and movie tickets for a family to “get away” from the daily struggles of doctors’ appointments and infusions. Over the years, Helping Hands evolved into a program providing assistance with basic living expenses for individuals and families experiencing hardships related to their bleeding disorders.

Today, the program assists with housing, utilities and transportation-related expenses. Helping Hands also works with applicants to connect them with local community resources, empowering individuals and families to advocate for themselves. In 2012, Items Reimbursement was incorporated into Helping Hands to provide durable medical equipment and necessary items to better manage their bleeding disorder. Items Reimbursement has assisted individuals in purchasing protective gear, braces, heating and cooling packs, and Medic Alert jewelry, and has even assisted community members in obtaining refrigerators to store excess factor.

Helping Hands is completely funded by donations from program sponsors, annual membership dues, contributions made in memory and in honor of members of our community, and funds raised from HFA’s annual Gears for Good bike ride.

In 2014, HFA will host two Gears for Good bike rides to raise funds to support this critical community safety net. In June, riders rode along the Northern Rail Trail in New Hampshire for the inaugural regional Gears for Good bike ride. In the fall, the fourth annual Gears for Good bike ride from West Virginia to Washington, DC will take place September 26th to 28th. In both bike rides, riders will have the opportunity to connect while raising awareness and funds for community members in need.
2013 BY THE NUMBERS
(JANUARY 1 – DECEMBER 31, 2013)

OVER $95,000 DISTRIBUTED IN DIRECT AID TO 242 FAMILIES

114 households assisted with durable medical items (e.g. walking supports, protective gear, braces, etc.)

68 households received assistance with housing expenses

36 households received assistance with utility expenses

17 households received assistance with transportation expenses

7 households received assistance with “other” expenses (e.g. funeral expenses and other emergency expenses)

“We are so thankful for this program. We were approved to receive one month of rent, and that’s what we needed to get back on our feet. I found another job and we are back to our ‘regular’ life.”

“Helping Hands assisted my family with a utility bill to help me get back on track so I could focus on caring for my children and their serious health care needs.”

“I really appreciate your time, and am glad that I can get caught up on this bill. I feel like a huge weight has been lifted, and your assistance is a blessing to me and my family.”
Motherhood Doesn’t Have An Expiration Date
By Sonji Wilkes

Motherhood doesn’t have an expiration date. From a young age, a mother begins shaping their child into the person they grow up to be. A mother’s bond with her child will never spoil or expire.

Interestingly, moms also have a sisterhood amongst each other, because they need each other to learn and laugh from. Through our weekly blog, “Infusing Love,” moms of children with bleeding disorders are helping each other through social media and technology to learn and laugh by sharing stories of their trials and victories. Our dedication to mothers continues through our newest program called, “MomsConnect.” This program will provide education and support for mothers who live with and/or have a child with a bleeding disorder. Go to www.hemophiliafed.org and register to become part of MomsConnect.

In case you’ve missed some of the wisdom our bloggers have shared over the last year and a half, we’ve highlighted some of our favorite tidbits. Take some time to reflect and read through these powerful insights of wisdom. Join us each Wednesday on Facebook to see what other moms of a child with a bleeding disorder are thinking and feeling — you might just see yourself in their reflections!

“For a long time, I lived and breathed the persona of being a strong person. No matter what adversities we faced as a family, I was the strong one – I was the mom – I had to hold it together. The fact of the matter is no one is that strong.

We all have our breaking points.”
– Taking Off the Super Woman Cape

“Sometimes I see a disconnect between the younger generation with hemophilia and those who lived through the bleeding disorders community’s darkest days. How many of us moms of younger kids really know about that history and the challenges our fellow moms faced? What have we learned from moms of the older generation, and more importantly, how are we supporting and loving those moms today?”
– Honoring All Moms – Past & Present

“Hemophilia has taught me and my son a fantastic life lesson that instant fixes are hard to come by without a little ingenuity and adaptation, and that a little patience and a lot of hard work make you a stronger person physically and mentally.”
– Keep Calm and Use Frozen Hash Browns

“I’ve often said that my fellow hemo moms are the fiercest gladiators. They will move mountains to take care of their children. They will sacrifice everything at hand to take care of their children. Every hemo mom I know has thought (or said out loud to their child),

“If I could take this on for you instead, I would.”
– The Power of Unconditional Love
“I know that many of us are separated by far distances and it is difficult to connect with other families in the hemophilia community.

Be aware that there are moms and families out there that would love to connect with you, talk with you, cry with you, bring you coffee while you are sitting in the umpteenth hospital room, or be that quick email every once in awhile. We share so much in common. That is a tie that will bind us forever.” – Community: You Are Never Alone

“Will he have bleeds?
Yes, most likely. Will he need extra infusions?
Probably. But in the end, he will be living and experiencing activities he wants to try. I’m ready to gulp down the fears, knowing that I’m letting him be a kid who just happens to have hemophilia.” – The Gasp Factor

“I think we as Hemo Moms are often faced with a similar challenge, where we’re perceived as bossy, demanding, b*#%!y and even crazy. The simple fact is that we need to be in control and we need to be assertive in order to advocate for our child to get them what they need.

No apology necessary.”
“I’m Not Bossy. I’m a Hemo Mom”

“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 Earning My Mommy Medical Degree
Living With a Bleeding Disorder Across the Decades

Blood Brotherhood is a national program for adult men with a bleeding disorder and provides a sense of community through education and support. The below articles are written by Blood Brothers enrolled in the program and feature their stories of what growing up was like in different decades. These stories are excerpts of longer stories that can be found on www.hemophiliafed.org.

CARL | Severe Hemophilia B | 1960s thru 1970s

I was born in 1961 with severe Hemophilia B. When I was young, treatment for hemophilia was difficult; we either employed the RICE method (rest, ice, compression, elevation) or went to the hospital to receive whole-blood transfusions. The problem was it took about eight hours to drip into my veins and upwards of 20 hours before bleeding would stop! When I had a joint bleed, I was admitted to the hospital for a week and was kept on bed rest (which meant having to use the dreaded bedpan). I remember getting my first pair of crutches at the age of four and my mom crying the day she taught me how to use them. Even when we switched to fresh frozen plasma, which took less time to transfuse, we had similar experiences. Without access to factor at home, we wound up with vast joint damage and pain. When factor concentrates came on the market in the 1970s, we started home treatment. Infusing at home was a major relief and it meant pain would diminish sooner and cause less joint damage!

The darkest days, though, were in the 1980s when I was infected with HIV and HCV through plasma derived factor concentrates. I thought I was taking something to protect my life, when in reality, it was giving me viruses that could take my life. I am very thankful to be part of the few still alive today. Our community lost way too many.

Even though I had some extremely difficult times, God has used hemophilia as a blessing in my life. I have been given an extended family and a better appreciation for each day. The way I see it: “I woke up this morning and was NOT in hell or the hospital; it’s a good day!”

Carl lives in Kentucky with Gwyneth (his wife of 31 years), is a past President of HFA, and has severe Hemophilia B.
**MARK | Severe Hemophilia A 
1980s thru 1990s**

I was born in 1980 with severe Hemophilia A. At nine months old, I got my first bleed and went to the pediatrician for my first dose of factor. We would continue to only infuse when I had a bleed, as prophylaxis wasn’t really an option at the time.

At the age of two, I fell, hit my chin, and bit my tongue. We went to my pediatrician and I was administered factor. When the bleeding didn’t stop, they sent us to the hospital where I spent the next three days. They couldn’t hit my veins because there wasn’t any blood left in them! After multiple invasive cuts to find a usable vein, I was saved by an infusion through my ankle; they had to slice through my skin to try to infuse the vein while holding it! I cannot imagine how hard this was for my parents, who could do nothing while I almost bled to death. I still have the scars from those cuts — a great reminder of how precious life is.

It is impossible to talk about living in the 1980s without talking about HIV/AIDS and Hepatitis C. I was told I was HIV positive in the early 1990s. I spent many days traveling the country with other youth educating others and spreading awareness. Tragically, the majority of the kids I traveled with are only with me in spirit today.

What I find unique about having hemophilia in the 1980s, besides the tainted-blood tragedy, is our desire for independence. With the innovation of factor and home infusion, everyone wanted to take advantage and see how far these innovations could take us towards that “normal life” most hemophiliacs dreamt of in the preceding decades. It was very powerful.

Mark lives with his wife, Sasha, and 15-month old twin daughters in Connecticut. He is the Director of Marketing at American Homecare Federation (AHF), on the board of directors of the AIDS Foundation of W. Mass, and is a Founder of the Connecticut Hemophilia Society. Mark is also a previous recipient of HFA’s Ron Neiderman Humanitarian Award.

**JOZEF | FVII Deficiency 
1990s thru 2000s**

I was born in 1991 with FVII Deficiency. During this time, the dust was just beginning to clear from the epidemic of co-infections that wracked the community. While I was too young to understand the gravity of the past, one of the biggest issues that I grew up with was that my factor product hadn’t been approved by the FDA until I was almost 10 years old. For several years, I lived with sleep apnea and needed my adenoids to be removed before I would ever get a decent night’s sleep, which had a detrimental effect on my daily life. The thought of using a new factor product scared doctors, and it wasn’t until years after my product was approved that a surgeon finally agreed to work with me.

This era seemed to bring bleeding disorders into the mainstream. Suddenly, that weird disease your cousin’s-neighbor’s-sister’s-boyfriend had was something you heard about on the news and in the vocabulary of celebrities and politicians. It was real, and so was the residual stigma. Hemophilia was hard enough to explain, it was harder to explain that not all hemophiliacs died from paper cuts or had HIV/AIDS, and harder still to explain that what I had wasn’t hemophilia. This serious misunderstanding caused havoc for many, including myself, who were denied insurance and deemed “high risk.”

Another stigma that came with having a bleeding disorder was it was perceived as unmanageable. There are people who treat me like I didn’t, and still don’t, know what I’m doing simply because of how chaotic they perceive my bleeding disorder to be. Growing up during the 1990s and 2000s was a great time to grow up as a “bleeder.” However, this generation, like each before and after, had its unique trials and tribulations with a reward to be reaped and passed on to the following generation. We are coming up as the next leaders of the community and we aim to give something back to a community that has given us so much.

Jozef lives in Wisconsin. He is a patient advocate for ASAP Pharmacy.
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one person at a time

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