

**Thank
you!**

**This is
YOUR
community!**

**Your
voice,
be heard!**

**We're
here
for
you!**

**This is
YOUR
organization!**

DON'T MISS

Advocacy It's In Your Blood 4
Navigating Patient Assistance Programs . 6
Gears for Good Bike Ride..... 10
Girls Have Hemophilia, Too 20

Season's Greetings HFA Family and Friends,

Welcome to our last edition of *Dateline* in 2013. Please enjoy this issue and know that we will be back in 2014 to provide you with more great information and community stories!

Your Voice, Be Heard is a mantra HFA has held since our founding and we continue to emphatically champion that each voice matters. We use our voices to support each other, to challenge the status quo, and to insist on change when needed. In the celebratory spirit of the season, we express our heartfelt thanks to our avid writers and readers who utilize *Dateline* to learn and share the voices and experiences of our fellow community members. Whether your role has been one of the voices heard this year or one of the community members listening, we are glad to have you part of our family.

We are so thankful to our physicians, pharmacies, and manufactures that support our community. You provide us with the critical care, services, and therapies we need.

To our donors, we truly cannot do this without you! Through your giving, you have personally helped people keep the lights on in their homes this year. You have helped dads connect more fully with their children. You have ensured our community adult men are able to meet and support each other as they survive the pain of joint damage obtained in their youth before factor and prophylaxis were readily available, as well as the HIV and HCV co-infections from the dark days in our not-so-distant past.

Finally, to our volunteers and members, know that you are incredible. Volunteers give when they can, and we gratefully value each and every contribution.

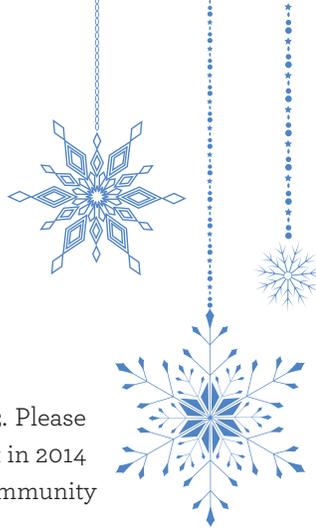
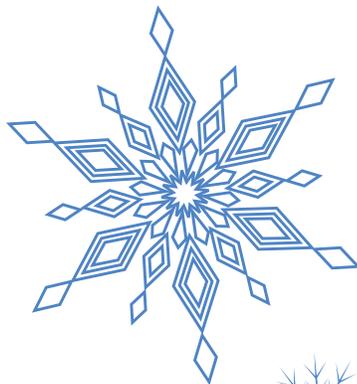
In Appreciation,



Matthew T. Compton
Board President



Kimberly Haugstad, MBA
Executive Director



OFFICERS

Matthew T. Compton, President
Tracy Clegghorn, Vice President
Rocky Williams, Secretary
Douglas Hartsough, Treasurer
Paul Brayshaw, Past President

PUBLICATIONS COMMITTEE

Margie Yancey, Vice Chair
Jill Williams
Barbara Chang
Lori Long

MISSION

The Hemophilia Federation of America is a national non-profit organization that assists and advocates for the bleeding disorders community.

Dateline Federation is published four times a year by the HFA, 820 First St., NE, Suite 720, Washington, DC 20002. Toll Free Number: 800.230.9797; Local Number: 202.675.6984; Fax: 202.675.6983. Requests for permission to translate and/or reprint contents of *Dateline Federation* should be directed to the Editor at info@hemophiliafed.org. *Dateline Federation* is available as a PDF file from the HFA website at www.hemophiliafed.org.

DISCLAIMER

The material provided in *Dateline Federation* is provided for general purposes only. HFA does not give medical advice or engage in the practice of medicine and recommends that you consult with your physician or local treatment center before beginning any form of treatment.

© 2013 Hemophilia Federation of America.
All rights reserved.

CONTRIBUTORS

Special thanks to HFA community members, staff and speakers who contributed to this issue.

Rich Pezzillo, Communications Director
Shelly Mattson, Editor
Kristin Mitchell Design, Graphic Design
Michael DeGrandpre, Graphic Design
Gina Sierra, Photographer
Melissa Lathlean, Photographer
Amanda McCallum
Jane Forbes, RN
Odgen M. Forbes, Ed, D
Derek Nelson
Philip Hardt
Sharon Ingram
Christine Bond
Glenn Mones

This is Your Community!

Become a HFA Member!

How many organizations exist to support the bleeding disorders community?

There are many regional organizations that support families and individuals living with a bleeding disorder at a local level. The two biggest nationwide, non-profit organizations supporting the bleeding disorders community in the United States are the National Hemophilia Foundation (NHF) and the Hemophilia Federation of America (HFA).

How are NHF and HFA different

NHF and HFA complement each other to effectively support the bleeding disorders community. NHF is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy, and research. HFA's mission is to advocate, assist, and support the bleeding disorders community to ensure the best quality of life for all people living with a bleeding disorder.

What is the cost of becoming a member?

The membership dues are very low - \$25 for an annual individual membership and \$50 for an annual family membership.

How do I become a member?

Check your home mailbox and your inbox for membership information or register online at <http://member.hemophiliafed.org>

What is the benefit of becoming a member of HFA?

Since 1994, HFA has proudly supported the bleeding disorders community by providing educational programming, support for the entire family, interactive national conferences, and critical assistance programs. Your friendship and loyalty are very important to us. We develop our programs and services with *you* in mind. We listen to your comments, posts, calls, emails, and develop our materials, webinars, social media, and meetings based on your feedback. In 2014, we are celebrating our 20th anniversary! We feel great about what we have accomplished and we are anxious to do more! In the year ahead you will see:

- New local sites added for our popular **Dads In Action** program
- New materials, webinars, and local sites for our re-energized **Blood Sisterhood** program
- Educational articles and support information as we grow our new **MomsConnect** program
- A tremendous amount of information on **Advocacy and Policy** via our online "Dear Addy" articles, our website, and new printed materials
- A new *inhibitor track* at Symposium, a first of its kind day session geared towards uniting individuals and families living with a high responding inhibitor
- **The biggest and most exciting Symposium yet!** As always, many scholarships will be available to new attendees, but in celebration of our 20th anniversary, **we will be raffling scholarships among individuals and families who become members of HFA in 2014 (even if they have attended Symposium in the past)**
- **And much, much, more!**

How will HFA use the funds raised from membership?

100% of the funds raised via membership dues in 2013 will go to support the Helping Hands program. This one-of-a-kind critical program assists individuals and families living with a bleeding disorder who are going through a temporary financial crisis.

Dear Addy: A Resource for the Bleeding Disorders Community

To help you and your family understand complicated advocacy issues like the Affordable Care Act (ACA), “Dear Addy” was created as a resource for the bleeding community. Each question submitted are real concerns and scenarios from community members across the country. Questions submitted to this column are edited in order to protect privacy and should be considered educational only, not individual guidance.

Send us an email at:
dearaddy@hemophiliafed.org.

Your name will be changed in the response.

EMPLOYER-SPONSORED INSURANCE

Dear Addy,

I am confused about whether the Healthcare Marketplace is right for me and my family. We have insurance through my work, but it is not clear if I have to use the Marketplace to get coverage starting next year. Who is supposed to use the Marketplace?

Signed,
Confused by Options

Dear Confused by Options,

The Marketplace is intended for people who are self-employed, employed by small businesses that do not offer health insurance, and who are otherwise underinsured or uninsured. This is not to say that people who have health insurance through their employer can't use the Marketplace. It all depends on which option, a Marketplace plan or employer provided plan, is the best and most cost-effective choice for you and your family. Most people who choose to sign up with a Marketplace plan will get some help with costs. Other people may qualify for lower costs on their monthly premiums and out-of-pocket costs, or get free or low-cost coverage from Medicaid or CHIP.

You will need to look at your current plan, its benefits, and its out-of-pocket costs (premiums, deductible, co-pays, etc.), and compare it to plans available on the Marketplace. When making the comparison, some things to consider are whether you can keep your doctor on a Marketplace plan, if and how your medications are covered, and monthly premiums versus deductible costs. For a list of what to consider when comparing plans, see NHF's Personal Health Insurance Toolkit. You can go online to learn more about Marketplace plans now and view plans starting October 1.

Sincerely,
Addy

LIFETIME CAPS VS. ANNUAL CAPS

Dear Addy,

I know “Obamacare” will eliminate lifetime caps beginning January 1, 2014, but will there still be annual caps on healthcare costs?

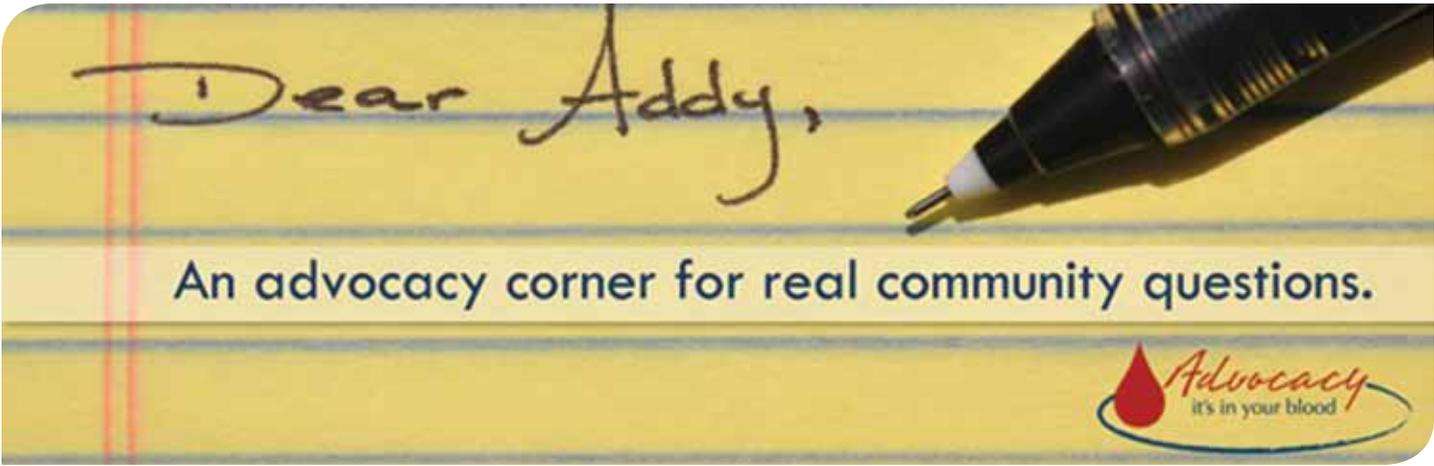
Signed,
Capped Out

Dear Capped Out,

Luckily, the answer is no, as of January 1, 2014. Actually, it was on September 23, 2010 that the Affordable Care Act (aka, “Obamacare”) eliminated lifetime limits (a cap on the total amount of lifetime benefits your insurance company will pay) on most benefits in any health plan or insurance policy issued or renewed on or after September 23, 2010.

On January 1, 2014, ACA also will prohibit new plans and existing group plans from imposing annual dollar limits (a cap on the total benefits your insurance company will pay in a year) on the amount of coverage an individual may receive.

Sincerely,
Addy



Dear Addy,

An advocacy corner for real community questions.



PRIVACY PROTECTION

Dear Addy,

I rarely attend bleeding disorder-related events because I want to protect my privacy. When I do attend, it seems like every time I turn around, someone is trying to get me to complete a survey. Why is that? How can I protect my privacy?

Signed,
Under the Radar

Dear Under the Radar,

Some companies, organizations, and medical providers collect information from the bleeding disorders community for legitimate reasons. There are surveys out there that offer community members an opportunity to have their voices heard, like HFA's CHOICE Project. However, there are others that collect your information to market a product to you or perhaps use your responses for purposes that they don't disclose.

No matter what the reason for the survey is or who is giving it, it is important to protect your personal information at all times. The group giving the survey should inform you in advance of who will control the survey data, what it will be used for, and with whom it will be shared in its raw and aggregated forms. If you choose to take a survey, be careful about (1) giving out personally identifiable information like your name, address, social security number, etc.; (2) making any statements in your responses that you wouldn't want to appear on the front page of a newspaper, and (3) answering any questions that make you feel uncomfortable in any way.

Ultimately, it is your responsibility to protect your privacy. So if you don't want to participate in surveys, then don't. The choice is yours.

Sincerely,
Addy

PRIVATE EXCHANGE

Dear Addy,

I have health insurance through my employer. Next year my employer is giving me a lump sum each month to pay for health insurance on a "private exchange." What does that mean?

Signed,
Month-to-Month

Dear Month-to-Month,

Private exchanges are online marketplaces that allow employers to offer their employees a range of choices for health insurance coverage. These exchanges are different from the Marketplace through, in which each state will offer health insurance plans to individuals and small businesses in accordance with the Affordable Care Act (ACA). On private exchanges, employees can shop for different types of health plans from a variety of insurers as well as other types of benefits like dental or vision plans. Since your employer is offering you a lump sum, or "defined contribution," each month to pay for health insurance, if you choose a plan that costs more than that monthly sum, it is likely you will have to cover the difference.

You are not alone in having your employer choose to use a private exchange. Accenture PLC projects that around a million Americans will get employer health insurance coverage through private exchanges next year. That number will increase to 40 million by 2018. Get ready to go shopping.

Sincerely,
Addy

Navigating Patient Assistance Programs

With the uncertainty of healthcare, many in the bleeding disorders community are concerned about the future of cost and access to factor products. Co-payments and out-of-pocket expenses can result in a large chunk of a family’s monthly budget. Many manufacturers of factor products have co-pay assistance programs that can provide a source of relief.

| Manufacturer | Co-pay/Co-insurance Program Name and Contact Information | Limit Total | Notes |
|--------------------------|---|---|--|
| Bayer | Kogenate FS Co-pay/Co-insurance Assistance Pilot Program Bayer Factor Solutions 1-800-288-8374 | \$6,000 (Assistance available for up to 12 months, or until pilot program ends) | <ul style="list-style-type: none"> • Must have Hemophilia A • Must have private health insurance • <400% FPL; eligible to receive up to \$6,000 in financial assistance • >400% FPL; eligible to receive up to \$500 in financial assistance • Must first contact Bayer’s Factor Solutions to apply |
| Baxter | Hemophilia Co-pay/Co-insurance Assistance Pilot Program (facilitated by Patient Services, Inc.) 1-800-366-7741 | \$10,000 (Assistance available for up to 12 months while program is in effect) | <ul style="list-style-type: none"> • Must meet financial criteria for enrollment—FPL is set at 400% • Must have private health insurance • Funds can only be used towards patient’s out of pocket expenses for Baxter hemophilia products • Apply online via PSI’s website |
| CSL Behring | MyAccess Cost-Share Program 1-800-676-4266 Corifact Co-Pay Program (Factor XIII deficiency only) 1-888-267-1440 | \$12,000 | <ul style="list-style-type: none"> • Must take a CSL Behring product for the treatment of von Willebrand disease or hemophilia A • Must currently have a private insurance plan (federal or state insurance programs are not eligible) • Annual enrollment |
| Pfizer | Pfizer RSVP Co-Pay Program 1-888-327-7787 | \$10,000 | <ul style="list-style-type: none"> • Must meet income eligibility requirements • Must not have public insurance, may have private insurance |
| Novo Nordisk* | SevenSECURE 1-877-668-6777 | \$1,500 | <ul style="list-style-type: none"> • Must have hemophilia with inhibitors, factor VII deficiency, or acquired hemophilia |
| Octapharma | No co-pay program currently available | N/A | N/A |
| Grifols* | AlphaNine SD Savings Card Program 1-855-355-2574 | \$6,000 (\$500 each month maximum) | <ul style="list-style-type: none"> • Must have a valid prescription for AlphaNine SD • Must not have a state or federally funded healthcare plan • Card is available for one year from date of enrollment. Eligible patients may re-enroll. |
| Biogen Idec* | No co-pay program currently available | N/A | N/A |
| Kedrion Biopharma | No co-pay program currently available | N/A | N/A |

*Hemophilia Federation of America (HF A) makes every attempt to provide accurate information regarding patient assistance programs and resources. However, since program policies often change, please contact the manufacturer directly for the most updated information. **This chart has been updated on January 10, 2014.

For those in the bleeding disorder community who are uninsured, underinsured, or experiencing lapses in insurance coverage, there are also assistance programs to help families facing financial strain get access to factor products:

| Manufacturer | Product Assistance Program Name & Contact Information |
|--------------------------|--|
| Bayer | Bayer Factor Solutions www.livingwithhemophilia.com www.kogenatefs.com 1-800-288-8374 |
| Baxter | CARE Program https://nava.baxter.com/nava/redirectThereForYou.jsp 1-888-229-8379 |
| CSL Behring | Patient Assistance Program To be eligible, patients must be uninsured 1-800-676-4266 Assurance Program Must currently have private health insurance coverage; a certificate program that helps with potential future lapses in private health insurance plans 1-866-415-2164 Cslbehringassurance.com |
| Pfizer | RSVP 1-888-327-7787 Factor Savings Card 1-888-240-9040 www.hemophiliavillage.com |
| Novo Nordisk* | SevenASSIST 1-877-668-6777 Changingpossibilities-us.com |
| Octapharma | No program currently available |
| Grifols* | Grifols PatientCare Program 1-888-325-8579 www.grifolspatientcare.com |
| Biogen Idec* | No program currently available |
| Kedrion Biopharma | No program currently available |

HFA's Helping Hands Program is an urgent financial assistance program that provides aid to individuals and families to assist in crisis situations with expenses such as housing, transportation, and utility bills.

*2013 supporters of Helping Hands



RIXUBIS
[COAGULATION FACTOR IX
(RECOMBINANT)]

To learn more, visit www.RIXUBIS.com.

Baxter and Rixubis are trademarks of Baxter International Inc (US85MG45130043). © Baxter Healthcare Corporation, 2013

Baxter

A Therapeutic Revolution is Underway

By Ogden M. Forbes, Ed.D. and Jane Forbes, R.N.

Swimming is fun! No doubt about it. Did you know that water is a great place for people who have hemophilia to build stronger bodies? It's true and for many families swimming has become just the thing to provide not only fun, but a great form of exercise to keep a bleeders body healthy and strong. The Forbes family from Pasadena, California is living this example. Learn more about them and how finding a swimming facility in their area has positively impacted their lives.

Each year as the holiday season begins, the Forbes family gives thanks for the many gifts and blessings we have received. Perhaps no gift has been greater for our family than the discovery of an oasis in our neighborhood—an oasis that brings strength to our four sons with severe Hemophilia A. It is the oasis known today as the Rose Bowl Aquatics Center—a non-profit organization in Pasadena, California. Now that our children are becoming fully independent adults, moving on to college, and self-infusing, we wanted to share a few insights we have learned along the way.

To minimize bleeding episodes, it is commonly known that individuals must infuse prophylactically. It is also known that selective exercising can help reduce bleeding episodes by strengthening those muscles around the target joints that support the bones that frequently cause the bleeding to occur. For many years, hematologists have been producing top lists of exercises and sports most helpful to those with bleeding disorders. For years, swimming has been at the very top of these lists. No other form of exercise or sport comes close to providing for the unique medical needs of those with bleeding disorders. Why is this true?



First, swimming provides buoyancy, an all-surrounding, anti-gravity environment. For approximately ten years, our sons have been swimming from two to three hours a day, six days a week, in this environment. In other words, our sons have been strengthening their muscles in the pool where their bones and the weight of their bodies, cannot in any way cause bleeding. No other sport can provide this buoyant, anti-gravity environment. Is it any wonder why many professional athletes almost universally participate in a variety of anti-gravity rehabilitation exercises?

Second, swimming brings viscosity, an all-surrounding natural resistance applicable to all movement directions, to the athletic environment. Exercise intensity can be varied easily by increasing surface area or movement speed. Thus, the swimming exercise becomes a highly efficient workout for nearly all individuals, no matter the age, the conditioning, the weight, or the experience.

Third, swimming provides a substantial reduction in momentum. Speed is reduced caused by the resistance of the all-surrounding water—a reduction that nearly eliminates any form of impact or trauma. Though our sons are outstanding competitors, their swimming speeds will never match the speed of athletes running or bicycling precisely, because those athletes experience much less overall environmental resistance.



Finally, swimming is a sport that can be enjoyed for nearly the entire length of an individual's life. Long after swimmers return from college, they can be found competing in Masters Competitions all over the country. It is not uncommon to see such swimmers at the ages of 60s, 70s, and 80s. Those with bleeding disorders can live almost their entire lives without further bleeding episodes by following this path open to them.

This is not to say that swimming cannot lead to bleeding episodes. It is important to be careful with slippery decks. It is also important to master proper stroke and turn techniques to minimize injury. Fortunately, our sons have gone another year without joint bleeds and have no joint damage. In their annual checkups with their doctor, their range of motion is absolutely unimpeded. They suffer no arthritic problems. Thus, the Forbes family is thankful. Ultimately, their success has everything to do with the oasis in our neighborhood.

Doctors cannot prescribe buoyancy, environmental viscosity, or reduction in momentum sports. But doctors can prescribe aquatics therapy. Younger parents may be able to embrace the recommendations of hematologists, find the swimming pools, and manage the time of their children in this process. Knowledge and commitment are essential for parents considering competitive swimming.

Families nationwide have been encouraging their children affected with a bleeding disorder to swim in clubs and on high school teams, with incredible levels of competitive success. Our hope is that this appreciation for swimming for individuals with bleeding disorders will continue to increase, and that there will be many more families in the years ahead that will turn to swimming as a perfect complement to the regular prophylactic factor therapy that they now embrace. ■ ■



Michael and Jane Forbes have six children, the four sons all having severe Hemophilia A. Michael earned a Doctorate in Education from the University of San Francisco. For several years, he ran in marathons and is currently a sports enthusiast. Jane earned her Registered Nursing degree from Seneca College in Toronto, Canada. For several years, she trained in Judo and was a Junior Olympian in this sport.

Healthier Bodies, Bleed Less



3 DAYS
4 STATES
 (WV, MD, VA, DC)
28 RIDERS
156 MILES

\$51,569
RAISED



A SPECIAL THANK YOU TO ALL WHO DONATED, ESPECIALLY: CSL Behring, Grifols, Get Out and Go Tours, CVS Caremark, AHF, BioRx Employees, Alliance Data Systems



2013 RIDERS: Allie Boutin, James Boutin, Barry Haarde, Vaughn Ripley, Dan McKinley, Kathryn Temple, Jodi Delnickas, Susi von Ottingen, Diane Lima, Andy Matthews, Tracy Cleghorn, Candida Ross, Kimberly Philo, Craig Voorhees, Jeff Widberg, Matthew Stinger, Rich Pezzillo, Ryder Haske

Virtual Riders: Sonji Wilkes, Nathan Wilkes, Kimberly Haugstad, Eilaine Alred

Day Riders: Mark Antell

Sag Support: Get and Go Tours (Tom Knoerzer), Kyle Raymond, Lucy Slevin



“Gathering so many like-minded folks for this ride is a fantastic opportunity to share emotions and stories. **OUR LIVES ARE FOREVER CHANGED,** and we’ve all created new bonds and friendships. I am eternally grateful to HFA for giving me and my blood brothers and sisters this unique experience and opportunity.”

~ Vaughn Ripley, patient with hemophilia



“Simultaneously, it has been the most difficult and most rewarding experience of my life. I took on the challenge to raise funds for Helping Hands, and in return was rewarded **WITH A PRICELESS, LIFE-CHANGING EXPERIENCE.** I will never forget the weekend or the group of people that I shared it with.”

~ Tracy Cleghorn, mom of a child with hemophilia and HFA board member

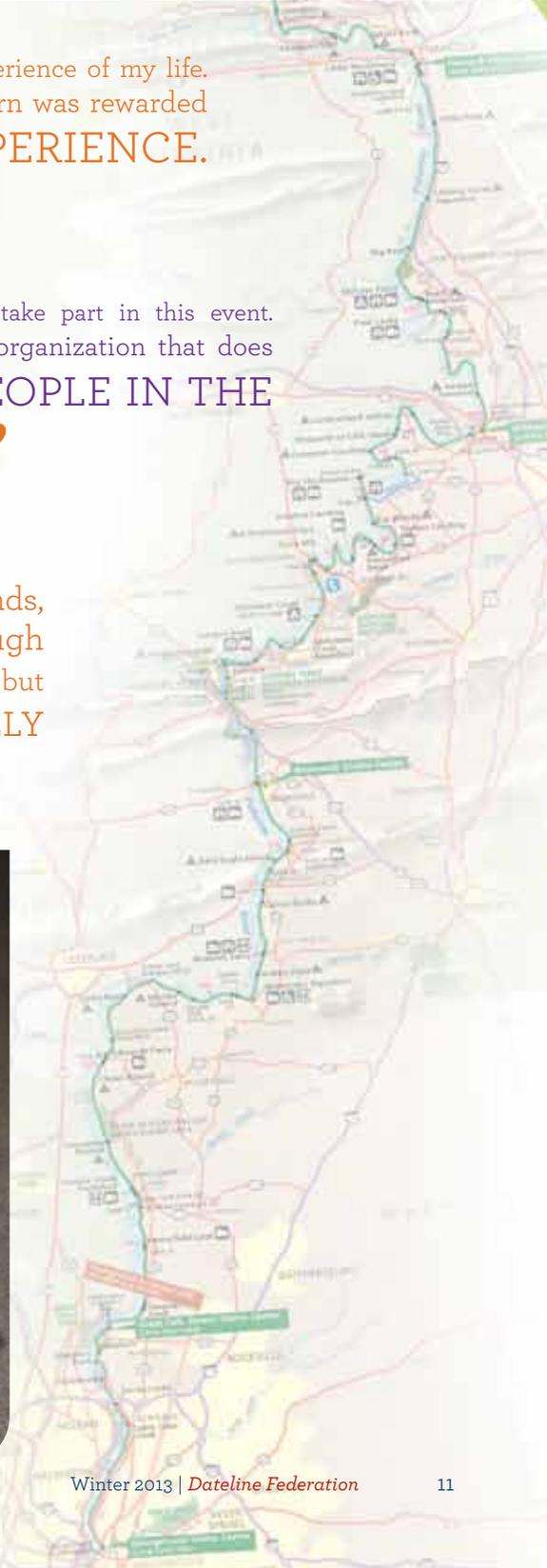


“I am very grateful that I decided to take part in this event. Most importantly, I got to help out an organization that does **SO MUCH GOOD FOR PEOPLE IN THE HEMOPHILIA COMMUNITY.**”

~ Jeff Widberg, friend of hemophilia family

“Riding for Gears for Good not only helped to raise funds, but it also enabled us to tell our story as we peddled through communities and met other bikers. I rode to support families in need, but **I TRULY BELIEVE THAT I WAS THE ONE WHO REALLY BENEFITTED FROM THE EVENT.**”

~ Susi von Oettigen, mother of daughter with vWD



Inhibitor Family Camp: Our Own Kind of Oz

By Derek Nelson

Grateful to be nearing the end of a long day of travel, my family finally reached the welcoming gates of Victory Junction—the site of inhibitor family camp in Randleman, North Carolina. The shuttle driver maintained his happy grin as the vehicle slowly rolled over speed bumps, passing a small, serene lake. In the distance, a brightly colored tower in the shape of a hot air balloon seemed to stand guardian over the wooded grounds. It reminded me of the hot air balloon from the opening of the Wizard of Oz. What adventures would we have over the next few days?

Life is an adventure for those of us who live with inhibitors. Because of extremely unpredictable bleeding patterns for children with inhibitors, local hemophilia camps are often not an option. But at inhibitor family camp, which we attended on October 17th-20th, the world opened up to us. With attentive counselors and medical staff, a safe environment was provided for these amazing children and their families to experience life. Whether riding horses, bowling, making art projects, shooting bows and arrows, acting, or catching (and kissing!) fish, families were able to experience a whole lot of fun.

While the children were having fun, parents were able to connect, learn new life skills, and share life stories. There were two formal education programs: “How Inhibitors Affect the Family Unit,” presented by Dr. Gary McClain, and a 504/IEP workshop run by Janet Brewer, MEd. We were lucky to also have three parent rap sessions where everyone could discuss a long list of other issues in which we have shared concerns. Few are the moments where I feel that others truly understand what life is like with an inhibitor. At in-



hibitor family camp, everyone seems instantly connected. It didn't take long before we were all acting like life-long friends, sharing laughs and tears that maybe only those affected understand.

The holiday season is always a great time to reflect on what we are most grateful for. For me, being connected to other families with inhibitors is a tremendous blessing, and I am so appreciative to Comprehensive Health Education Services (CHES)—the driving force behind camp, to Victory Junction for providing the facility and wonderful staff, and to Novo Nordisk for the educational grant that funds this amazing experience.



I am always amazed by how much I learn from my inhibitor friends—ways to survive the tough times and ways to thrive in the good times. More than anything, I am thankful not to be dealing with inhibitors alone—there’s an entire family willing to help me, just as I am willing to help them. Indeed, if I was in the Wizard of Oz movie clicking my heels together, chances are that I might just wake up at inhibitor family camp. ■■

Derek and his wife Krisdee live in Kaysville, Utah with their 3 children. Their two sons, Hayden (20) and Braxton (9) both have severe hemophilia A, and Braxton has a long-standing inhibitor. Derek has been highly involved in the hemophilia community as a board member, a camp nurse, a camp director, an industry representative, and a Save One Life sponsor. He enjoys being outdoors and is currently training for his first Ironman triathlon.



Inhibitor Family Camp was founded in 2010 by Comprehensive Health Education Services (CHES), and is made possible through an educational grant provided by Novo Nordisk. There are currently two programs held annually, both take place at camps that are part of the Serious Fun Network (formerly known as The Hole in the Wall Camps): Spring camp is at Painted Turtle in Lake Hughes, CA; Fall camp is at Victory Junction in Randleman, NC. Because they often cannot attend other camps due to their challenging medical needs, priority is given to children who have a current measurable inhibitor titer. Inhibitor Family Camp serves up to 25 families per session; registration is currently open for the April 11-14, 2014 program. **More information can be found at www.comphealthed.com**

The Unexpected Blessings

By Phillip Hardt



Way back in 1950, my brother Gary was born. He was the first child my mom had who was affected with Hemophilia B. We lived in a tiny mining town called Bisbee, in southeastern Arizona. When Gary was 5 years old, he fell off a teeter-totter, hit his head, and died that night from uncontrollable bleeding. My mom and dad were devastated because he had previously only bruised easily while playing. Later that year, my dad decided to leave my mom, not knowing she was already pregnant with me.

When my mom found out she was going to have another baby, she hoped and prayed it wouldn't be another son who was a "bleeder," as they called it back then. She even picked out only girl's names, but on March 3, 1956 I was born.

Her favorite girl's name was Phyllis Joanne, so when I popped out as a baby boy, she had a big dilemma. Phyllis had to be changed to Phillip and Joanne to Joel.

My mother was so afraid of losing me too when I had bleeds; she made me sleep with her, so that she could easily monitor my bleeding during the night. I remember being called into the principal's office in 3rd grade. The office was full of important-looking people. The principal, Mr. Rose, told me that my teacher and others had noticed continual bruising on my head and arms, and they wanted to know if my mother was abusing me. I told them that she was not, and tried to explain that I was a "bleeder."

I made regular trips to our family doctor growing up. He said he "didn't know beans" about my bleeding disorder, but noticed that my most serious bleeds were in my joints, so he recommended that I partake in non-contact sports such as weight lifting, tennis, and swimming (to build the muscles around my target joints). This was inspiring advice and has helped me minimize joint bleeds ever since. He also forbade me to play football, baseball, and basketball—the sports that I really wanted to play. As I moped around mourning my losses, my mom and older sister decided I needed other activities in my life. They began to take me to choir concerts, band concerts, and just happened to show me how popular the pianist was. Their propaganda worked, as I took up playing the E flat alto saxophone, singing in my church choir, and piano

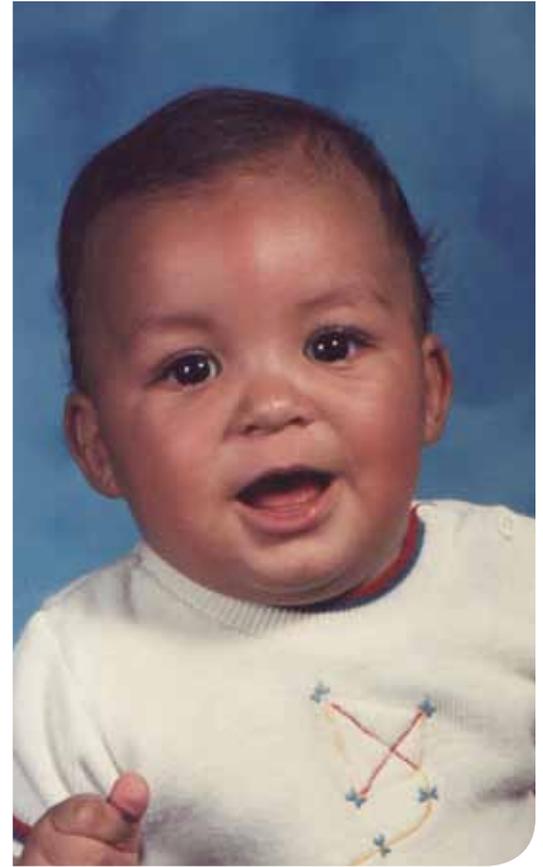
lessons. The blessings these musical pursuits have brought to my life continue today. I feel very fortunate that I am still able to enjoy each of these talents, especially as I watch other guys of my generation who were totally involved in sports in their younger years and are now relegated to sitting on the sidelines or watching them on TV.

In addition, my family doctor and my mom also recommended that I pursue as much education as possible so that I wouldn't have to worry about getting hurt doing a manual job, losing time off work, and not taking home enough money to make ends meet. I obtained my Master's Degree in English and secured a great job with full medical benefits.

My former wife and I have been blessed with three wonderful children. We felt so blessed that we wanted to share our abundance with others and decided to adopt. During our first adoption, we were almost disqualified because of my hemophilia. It took a lot of educating the social worker on our case that my hemophilia was not an imminent threat to my life. As luck—or fate—would have it, the same social worker remembered my diagnosis when a child named Ammon came up on the hard-to-adopt network in Texas. Ammon had Hemophilia A. She immediately called us and asked if we would consider adopting him. Of course, we said yes!

We came to find out that Ammon's hemophilia was much more severe than mine. Just six months after we welcomed him to our home and began the adop-

...continued on page 16



IT IS IMPORTANT to take time and think of all of your blessings during this holiday season.

...continued from page 15

tion process, he had a spinal cord bleed and had to be resuscitated. My moderately severe Hemophilia B and infrequent bleeds paled in comparison to his severe Hemophilia A and continuous bleeds. It seemed that he was constantly having spontaneous bleeds caused by circumcision, learning to walk, and bumping into things. Unfortunately, the spinal cord bleed left him with some residual problems that still affect him today, such as walking problems, incontinence, and mental challenges. Sometimes his mental challenges caused him to refuse infusions because he said the needles were “poisoned.” To overcome this obstacle, we decided that Ammon should get a port-a-cath, which helped the infusion process considerably.

Ammon is now in an assisted-living home, having developed psychiatric and behavioral problems that require that he be heavily medicated to prevent him from running away or hurting himself. He has no safety awareness for himself or for others. He continues to be a very important part of our family and one of the highlights of my week is spending time with him and taking him to the movies.

Of course, we never regretted Ammon’s adoption and we were blessed to adopt three more children, two of whom also have severe special needs. Bringing Ammon into our family taught me a lot – about myself, about hemophilia (who knew it could be so different from one person to another?), and about the power of love. Ammon is my movie

buddy, my blood brother, and my son. He is also one of my greatest blessings. ■■

Phillip Hardt has moderate Hemophilia B and is from Glendale, Arizona, where he’s involved with HFA’s local Blood Brotherhood group. He has a Master’s Degree in English and is retired from Honeywell, Aerospace. He is the proud father of 8 children (3 biological and 5 adopted, including Ammon, age 23, who has severe Hemophilia A.) Phil also has two grandsons who have Hemophilia B. Phil is a musician, loves to play the piano and sing, and is a great supporter of the bleeding disorders community.

Most Common Types of Hemophilia:

| | HEMOPHILIA A | HEMOPHILIA B |
|--|-------------------------------|--------------------------------|
| Protein that is deficient or missing: | factor VIII | factor IX |
| Incidence: | 1 in 5,000 male births | 1 in 25,000 male births |
| Typical prophylaxis schedule: | 3-4 times per week | 2 times per week |
| Inhibitor development: | approximately 30% of patients | approximately 2-3% of patients |
| Also known as: | Classic Hemophilia | Christmas Disease |
| Number of factor concentrate brands: | (5) recombinant products | (2) recombinant products |
| Currently being manufactured: | (3) plasma-derived products | (2) plasma-derived products |

Thank You!

*Your support makes
it possible to serve our
community nationwide!*

2013 HFA FUNDERS AND SPONSORS

\$500,000+ VISIONARIES

CDC Collaborative Partners

**Supports:*

Blood Brotherhood

Fit Factor

CHOICE Project

\$300,000+ CHAMPIONS

Baxter

Novo Nordisk, Inc.

\$75,000+ BENEFACTORS

Bayer Healthcare
Pharmaceuticals

Biogen Idec Hemophilia

CSL Behring

Grifols USA

Pfizer Pharmaceuticals

\$50,000 + Grifols USA

\$10,000+ FANS

AHF, Inc.

ARJ Infusion Services

National Cornerstone
Healthcare Services

Hemophilia Alliance

The Homecare That Cares!

AHF's® homecare pharmacy works exclusively
with bleeding disorders.

We operate on **two principles...**

Superior Service
100% Client Satisfaction

**Community
Involvement**

*Donating a Large
Percentage of Proceeds
Back to the Community
with Countless Volunteer
Hours*

**Independently Owned
Family Operated**

800-243-4621

AHF@AHFinfo.com

www.AHFinfo.com



American Homecare Federation, Inc.
The Bleeding Disorders Homecare Company

One of HFA's Largest Homecare Donors!

CYRIL HOME CARE PHARMACY

We only have one
motto and mission.

We would like for you to be
able to look back and say:

*"My life with
hemophilia is better
today than it was
before we ever met."*

John and Carol Reed



John Reed DPh

214 Missouri • PO Box 676 • Cyril, OK 73029
Toll Free: 888.258.2453 • Fax: 877.464.3108
chcp@tds.net • www.cyrilhomecare.com

My Life as I Know It

By Sharon Ingram

My husband has a bleeding disorder called hemophilia. Prior to beginning a relationship with him, I did not have an understanding of hemophilia and the intrusive nature it can have on someone's life and marriage. My miniscule understanding of hemophilia only consisted of someone "bleeding a lot" if they had an open wound. It was explained to me that a hemophiliac may bleed a little longer than normal and may need to take medicine to stop it.



I was curious about the limp Warren had (or, as he calls it, his "swagger") when he walked. He shared information with me about the unseen debilitation and physical damage that someone with hemophilia could experience, depending on the severity of his or her disorder. The effects of hemophilia could include disability in the joints—ankles, elbows, shoulders, knees, and hips. Warren was extremely open and very comfortable in sharing that in 1986, he had undergone a bar lateral hip replacement due to bleeding. Because of that surgery, his hips are not quite level, hence, he has a swagger.

Later that night, during a phone conversation we were having, Warren shared more information about the complications of hemophilia because of tainted blood products. While he was very specific and detailed in the account of his story, I noticed for the first time a heaviness and sadness in the tone of his voice. As I carefully listened, not asking one single question or interrupting him, I knew that what he was sharing the trajectory of his life. This pain was not only physical, but also extremely mental and emotional. There was silence on the phone, and I realized that he was waiting for my response. I said cheerfully, "Well we're friends—let's see where this friendship takes us." Those were my words, but my heart thought that it was hopeless to continue.

To fast-forward, Warren began taking me to doctor visits with him and the doctors were very kind to discuss various situations and discoveries with me. I became less anxious and more interested to learn more. Soon, I would take trips to Washington D.C. and meet the spouses of his friends who would tell their stories and share what was working for them. Warren and I eventually got married, and every day we pray for continued better health.

After lengthy conversations with and visits with my husband to his hematologist, I had knowledge about what hemophilia was. But, it was not until my life began as a wife, caregiver, and cheerleader fifteen years ago, that I really did grow to understand it. Although at times I desired just a "normal" day, I discovered early on that I had to adjust to a new normal. For example, several of the traditional husband and wife duties were divided up differently in our household. Chores such as yard work, car maintenance, and caring for our girls, were shared and became a different situation for us compared to most. As a child, my husband's father would take him for all of his doctor appointments. So scheduling checkups and dental appointments for our girls was not only comfortable for Warren, but also enjoyable.

“At the end of the day, we're just like any other couple making the adjustments to assist each other on this journey called life.”

Since being married to Warren, my life has taken on a richness that I cannot really put into words, but that I have been able to show through my actions; in particular, with my involvement in the bleeding disorders community. Educating and sharing with those who may have an undiagnosed bleeding disorder, along with sharing with other spouses at rap sessions about the importance of self-care and open communication with one's spouse is powerful and inspires me every time I do it. ■■

Sharon has been involved with advocacy and outreach in the hemophilia community for over 14 years along with her husband, Warren, who has severe Hemophilia A. Sharon's love for the hemophilia community is evident by her ongoing volunteerism and the support she constantly provides. Sharon and Warren live in Charlotte, North Carolina with their two daughters, Emma and Jasmine.

November was National Caregiver Month

A good reminder to take Time for YOU!

The bleeding disorders community is made up of dedicated caregivers. Moms, dads, grandparents, and partners/spouses play a crucial, supportive role in their loved one's well-being. However, caregivers can often feel stressed, overwhelmed, and burnt out. Therefore, it is important for caregivers to remember to take time just for them. Caregivers often feel guilty or selfish for paying attention to their own needs. But, despite these common feelings, making a little time for yourself each day can go a long way in managing stress—which will better equip you to take care of yourself and others.

Here are some quick tips to practicing self-care:

MOVE YOUR BODY.

Take a walk, stretch, run, dance, practice yoga, play a sport. Do whatever you enjoy doing to get your body moving.

LEARN TO SAY 'NO.'

If adding something else to your already busy plate is going to induce more stress, learn that it is okay to say "no." You're only one person, you can't do everything.

EAT WELL.

Caregivers are often so focused on making sure everyone else is fed and eating nutritiously that they often forget about themselves. Eat a balanced meal and take time to enjoy eating rather than gobbling it down between tasks.

PRIORITIZE 'ME TIME.'

Take a little time for yourself each day. Read a book, meditate, or engage in a prayer or spiritual practice (if that comforts you), write in a journal, or listen to music. Even if you only have 5 minutes per day to spare, do something just for you.

FORGIVE YOURSELF.

When things don't go as expected, we often place blame on ourselves. Take a moment to acknowledge these feelings, but then release them. Nobody is perfect.

REMIND YOURSELF OF THE POSITIVE.

Take some time each day to remember the positives in your life, such as family, friends, or whatever else makes you feel happy.

ASK FOR HELP.

Talk to trusted family members and friends when you need help or just need someone to listen to you. Do not feel shameful if you think you might need to talk with a professional, like a psychologist or a social worker. Taking care of your mental health is just as important as going to the doctor for your physical health.



Girls Have Hemophilia, Too!

By Christine Bond

My childhood was relatively normal. I grew up the oldest of three children, had two caring and attentive parents, and did well in school. As a family, we went on regular vacations. I faced many challenges growing up and did not know at the time that they were related to an undiagnosed bleeding disorder. There were many instances that ran like a ribbon throughout my childhood, which, if they had been tied together, would have led to my bleeding disorder diagnosis much sooner. As the saying goes, “Hindsight is 20/20.” I have used these challenges to grow, move on, and to make life better for others and myself.

Being a woman with hemophilia can be very similar to being a man with hemophilia. As an infant, I suffered a fall which resulted in a large hematoma over my right eye. After going to the local emergency room, hospital officials suspected I had been physically abused. The incident was quickly resolved when my pediatrician informed the hospital that my mother would never have abused me. During the first grade, I would get random nosebleeds that resulted in several emergency room visits over the years. The last time I was seen in the emergency room due to a nosebleed, hospital officials again suspected that I was being abused. These suspicions were quickly dismissed after I was questioned by a hospital worker. At this time, my nose was cauterized and my nosebleeds, for the most part, had stopped.

At the age of 19, I was in a serious car accident. I suffered severe head trauma and massive injuries to other parts of my body. The hematoma on my head was so large that it fit into the palm of my hand. I had short term memory loss, dizziness, loss of appetite, and other issues related to this head injury. Also, I had serious damage to both of my knees. One year later, I had knee surgery to repair some damage from the accident. Part of that surgery was to clear out old blood that had accumulated under my kneecaps. Throughout my life, I have had seven surgeries, but only one of these surgeries occurred after I knew I had hemophilia.

Being a woman with hemophilia does have unique issues. As a very young teenager, I experienced heavy menstrual bleeding, which caused me to have anxiety. When I ovulate, I experience slight cramping and occasionally have issues with spotting

around this time. Also, after the birth of my first child, I bled continuously for seven weeks. I have heard that other women with bleeding disorders experience similar issues. Even though I have a low factor level, doctors tend to minimize my concern by not identifying my condition as hemophilia, but as a symptomatic carrier.

For the most part, I had never even heard of hemophilia until my second child was born. Tony was born on a cold winter’s day in January of 2006. He was a handsome little Italian boy with jet black hair and tan skin. It was not until he continued to bleed from his circumcision surgery that my gynecologist realized that Tony might have a bleeding disorder. Tony was diagnosed with severe Hemophilia B.



Shortly after Tony was released from the hospital, I started to examine my own life and my past issues with bleeding. I realized that I had exhibited some of the symptoms of a person affected with a bleeding disorder. The only thing that was different about me was that I was a woman. After speaking with the nurse practitioner that was functioning as my primary care doctor at the time, I was tested to identify my factor IV activity level. When that test finally came back, it was a shock to learn that my factor level



was only eighteen percent. I could remember times where I most likely needed factor but had gotten past my injuries and surgeries without it.

I never saw hemophilia as a burden on my life. Hemophilia has brought me a sense of purpose. Since the diagnosis of my son and myself, I have found great joy in advocating for people with bleeding disorders. For years, I have strived to increase access to adequate healthcare for patients within the bleeding disorder community. I have made it my life's mission to improve the lives of everyone affected by a bleeding disorder. I have turned what some might see as a negative experience into a chance to grow and make my life worth living.

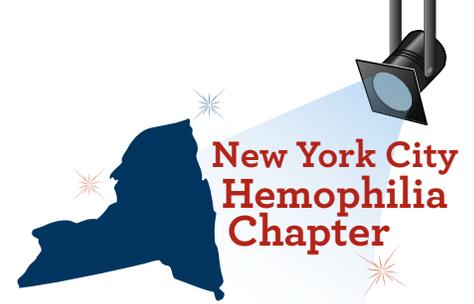
It is during this time of the year that I realize how thankful and blessed I am to have hemophilia in my life. Because of this condition, I have found my passion and purpose in life. I believe that the pain I feel today is my strength tomorrow. For every challenge I encounter, there is an opportunity for growth. ■■

Christine Bond lives outside of Baltimore with her two children Alexandra (12) and Anthony (7). Both Christine and her son Anthony have Hemophilia B. Christine has formerly served as a board member and as an advocacy chair for the Hemophilia Foundation of Maryland. Christine also serves on the Maryland Health Benefit Exchange Plan Management Advisory Committee, HFA's Advocacy Advisory and Blood Sisterhood Committees.

**APPROXIMATELY 1/3 OF WOMEN
carrying the hemophilia gene
EXPERIENCE BLEEDING SYMPTOMS.**

“Chipping” Our Way Towards Victory

By Glenn Mones



Until recently, outpatient clotting factor was covered by the Child Health Plus (CHP) program in every state except one: New York. The bleeding disorders community was aware of the issue for many years, but could not get any traction on efforts to change it. However, that was before bleeding disorders chapters and associations across the state united into a cohesive coalition, determined to take on hard issues and find real solutions.

The coalition got an early win in an effort to eliminate Tier IV drug pricing in the state. Tier IV is a method some insurance companies use to base co-payments for biologic drugs on a percentage of cost rather than a flat fee. With Assembly Member Micah Kellner leading the charge, New York became the first state in the country to ban this practice.

Using the momentum of this victory, the coalition decided to take on the CHP issue, and once again, Assembly Member Kellner took the lead. Legislation was drafted, position papers were created, co-sponsors were signed on, supporters in the community were enlisted, and progress was made. However, the bill never made it out of committee or on to the floor.

The following year, the coalition returned, strengthened with additional member—including colleagues from the hemophilia treatment centers, lobbyists “on loan” from friends, and many others. We went back to Albany, and, lo and behold, the bill passed in the Assembly. Unfortunately, the Senate version, sponsored by Senator Joe Robach, died again. There were many theories as to why the bill didn’t get through that year. Some speculated that it was the legislature’s late-session preoccupation that year with the same-sex marriage debate. Rent stabilization laws in New York City were also a hot issue. Others felt that nothing could be accomplished while Federal healthcare reform was still being crafted. And still others felt the enemy was the economy. No one can say for sure...but, we didn’t give up.

Undeterred and more committed than ever, the coalition continued to gain strength through unity, collegiality, and tireless efforts. Members sought answers to the difficult questions about how the program came to be this way in the first place, and what would be the cost of making this change. Passionate advocates visited Albany again and again, explaining to anyone who would listen why it was unfair to deny this cov-

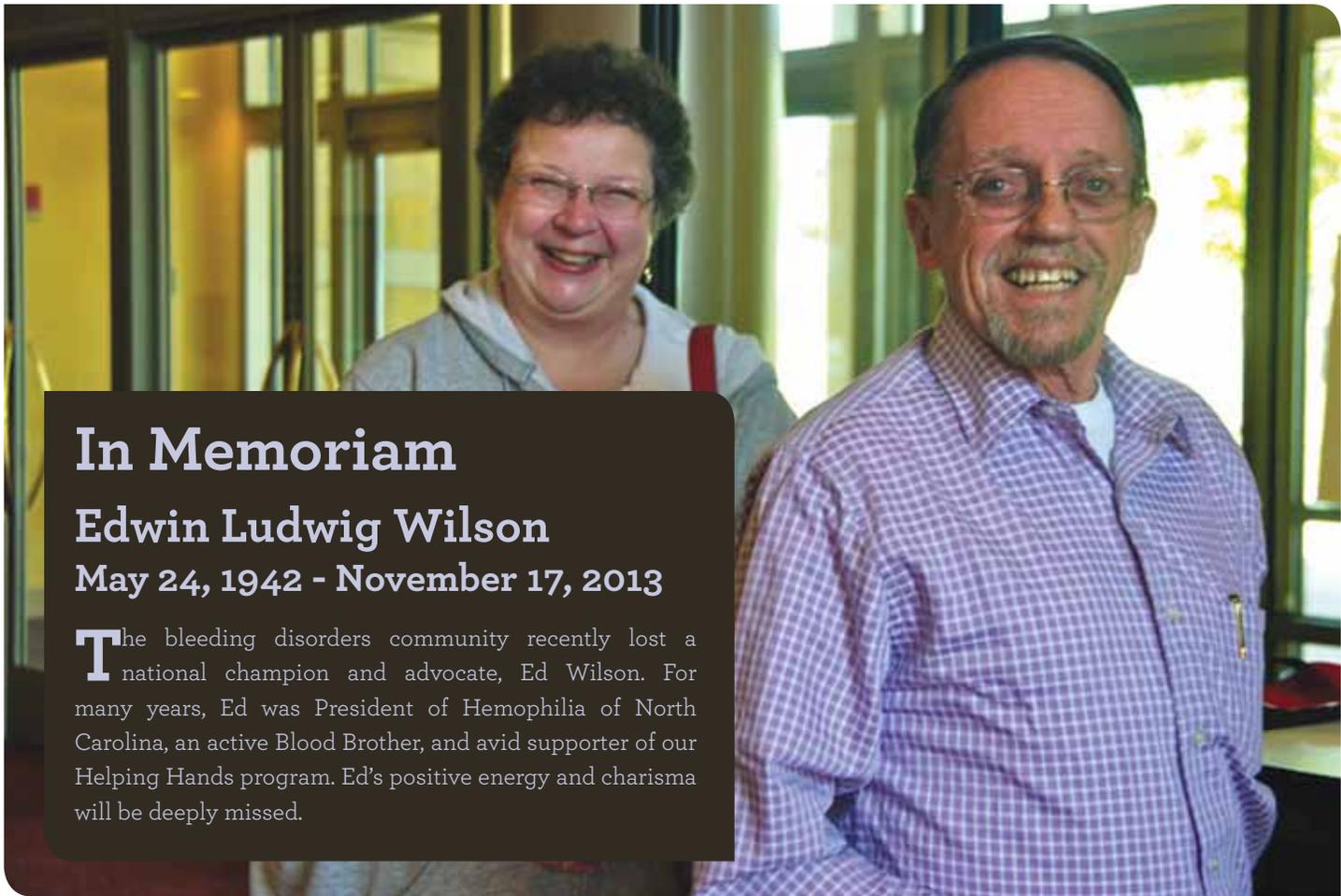
erage of medically necessary care to one group of children – children with bleeding disorders.

Our efforts really started to pay off. Richard Gottfried, chair of the Assembly Health Committee, took notice and started to work with us. We honed our arguments, using the onset of health-care reform and the role of CHP as another reason why the problem had to be fixed. Senators listened too, but there were some monkey wrenches that were thrown into the process as well. An insurance industry trade group filed a memo objecting to the legislation, saying that it would cost too much, and that in any case it wasn’t needed since children with bleeding disorders could still be taken to the hospital if need be. Their claims were outrageous, and could not go unchallenged. The coalition filed its own memo explaining how outpatient clotting factor was the standard of care, would lead to better outcomes, and ultimately, would save the state money. We also explained that this wasn’t just dollars and cents; it was a matter of simple justice. We explained and explained...and finally, they listened. As the session headed towards its final days, coalition members returned to Albany many times. Finally, the bill passed a floor vote in both chambers, and after several more nail-biting months, Governor Andrew Cuomo signed the bill in October of this year.

Advocacy works. The members of the New York State Bleeding Disorders Coalition are truly thankful for the ability to come together as a community, identify and work towards a common goal, stay the course, and achieve victory.

Glenn Mones is the Executive Director of the New York City Hemophilia Chapter.





In Memoriam

Edwin Ludwig Wilson

May 24, 1942 - November 17, 2013

The bleeding disorders community recently lost a national champion and advocate, Ed Wilson. For many years, Ed was President of Hemophilia of North Carolina, an active Blood Brother, and avid supporter of our Helping Hands program. Ed's positive energy and charisma will be deeply missed.



Here's to your defining moments.

Living with hemophilia isn't just about hemophilia, it's about life ... and the incredible moments that define it. This understanding is the driving force in everything we do, whether developing new therapies or creating meaningful programs.

So here's to you and to the defining moments that inspire all of us.

Discover BiogenIdecHemophilia.com

 facebook.com/BiogenIdecHemophiliaCoRes

© 2013 Biogen Idec. All rights reserved. Printed in U.S.A. 10/13 HEM-1001424

A Phone Call That Changed Our Lives

By Amanda McCallum



I have been married to Matt, an amazing and supportive husband, for eight years. We have been blessed with two beautiful children: Dominick, eight and Delaney, five. Our family was made aware of Delaney's condition almost three years ago. She was diagnosed during Christmas week in 2010 with von Willebrand's Disease (vWD). At that very moment, we knew that one phone call had changed our lives forever. Matt and I were completely unaware what a bleeding disorder would bring to our family. We questioned, "How did this all happen?"

At first, Delaney's diagnosis was extremely difficult to absorb. Delaney was only two and half at the time. As parents, we did not want to see suffering at such a young age, especially our precious little girl. Yet I knew I had to be resilient: I am the mom!

Everyone was crumbling around me and I was trying to keep my head above water for all of the family. I would say to my husband, "There has to be a reason to be so

overwhelmed, correct?" What we thought was a nightmare ended up being a blessing in disguise. We have experienced life in ways we never thought possible. I knew as the mother, wife, and a role model in our house, I could not stand by and be fragile. I had no choice but to somehow change our new turn in life into a positive. I was not quite sure exactly how I was going to overcome the challenges, but I was on a mission to do whatever it took to protect my family.

Matt and I attended our very first hemophilia event, a dinner with the Northern Ohio Hemophilia Foundation. As I sat there and listened to other parents share their stories, I realized, "Wow! We really are not alone in our ordeal." At that moment, I felt overwhelmed with gratitude to have been invited to the dinner. That evening was a tremendous turning point for me. I was not going to let this disease take over my family or my life. I have always believed that things happen to people for a reason. Matt and I knew in our hearts that God would only give us what we could handle. We felt thankful.

As I left the dinner, my position took a new outlook towards the positive. I had a thirst and desire to learn, read, and attend everything I could to help my daughter's condition. I was determined to meet people in the hemophilia community. I knew I had to hear other stories pertaining to having a child with Delaney's disorder, and I felt a passion to share mine. This made me feel so blessed to know that we were not the only ones. The more I heard, the more I grew to educate myself.

It seems simple to learn and become educated on a life threatening disease, right? Things are not always effortless! Seeing your child in pain because of a blood disorder is grueling, especially realizing that you cannot take the pain away from him or her. The questions from other children taunt you. I can recall children asking, "Why is Delaney not allowed to do this with us?" My precious child would always have to explain her condition. It tore my heart for her to endure something most adults could not handle themselves.

SEEING YOUR CHILD IN PAIN because of a blood disorder is grueling, especially realizing that you CANNOT TAKE THE PAIN AWAY.



Hearing someone else's story and what they have been through can bring you to tears. It is never easy to see your child suffer but knowing that we have the support of the hemophilia community, and especially our local chapter's support, has made a difference for my family. There is always someone to talk to and you are never alone. We have met so many wonderful families in the hemophilia community from all over the world. The relationships we have made have changed our lives in an extremely healthy way. There are not too many communities as united as the bleeding disorders community. There is an understanding and respect for one another, which allows support to be nurtured in a dynamic way.

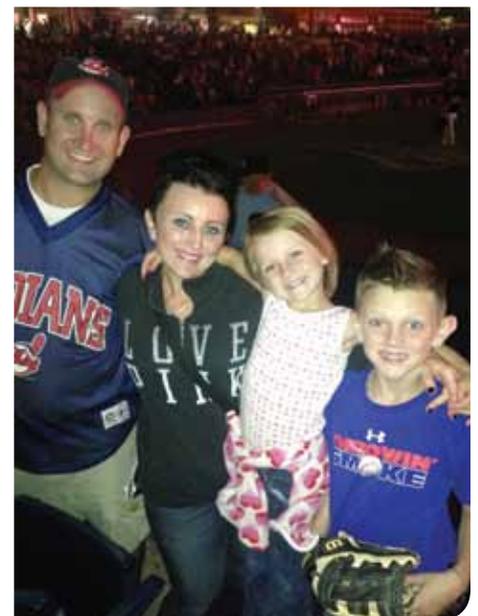
Since Delaney was diagnosed, I have chosen to take one new lesson from each meeting, dinner, or conference and grow into a stronger person. I try to utilize what I have learned in my everyday life. I have seen the benefits growing in my entire family. My son, Dominick, has grown into a beautiful support and absolutely loves the hemophilia community. We do not treat our children any different from each other and I want Dominick to feel equally as important as Delaney is in our family. It's an open book at our house; We are very honest. We talk and I answer their questions. At moments I feel guilty as a mother and try to make sure nobody is left behind. Dominick understands Delaney may need more attention from time to time, and he completely has grasped why she needs additional support. I believe the support groups we have attended have helped my son develop maturity about the situation his sister lives with everyday.

I found that I needed to give back to the community, and I was focused to give back in anyway possible. I decided to become involved and active with our chapter. I chose to sign onto the board and chair the Women's Task Force. Matt and I also have a yearly fundraiser for the chapter, which allows us to raise awareness within our own communities. We feel it is our duty as parents of a child with a bleeding disorder to raise awareness.

Let's face it: Some days are really good. As mothers, we like to think that we have this in control, but then we wake up the next day and it's all falling apart. It's never going to be easy. You have to take the good with the bad. Just remember that you have a dynamic and extensive community to support you! I am very grateful for every person I have met. I look forward to what the future holds, and in the McCallum household we always say, "It might be a crazy life, but it's our life!" We chose to embrace every ounce of this life that is tossed to us! ■■

Knowing that we have the support of the **HEMOPHILIA COMMUNITY** has made all the **DIFFERENCE** for my family.

Amanda McCallum lives in Massillon, Ohio and is the owner of Studio 5. She is married to Matt McCallum and have 2 children, Dominick & Delaney. Amanda had been an avid volunteer, and is the co-chair of the NHF's Women's Task Force. Amanda is a supporter of their local chapters Hemophilia Walk, Red Derby Run, and Black & Blue Ball.



Alphanate®

Antihemophilic Factor/von Willebrand
Factor Complex (Human)

With Alphanate® you have a choice!

Available in the following potencies and packaged
with Mix2Vial® Filter Transfer Set:

| Potency | Diluent Size |
|---------------------|--------------|
| 250 IU FVIII Range | 5 mL |
| 500 IU FVIII Range | 5 mL |
| 1000 IU FVIII Range | 10 mL |
| 1500 IU FVIII Range | 10 mL |

WVF:RCo and FVIII potency on vial labels
and folding cartons



You are encouraged to report negative side effects of prescription drugs to the FDA.
Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.



For more information: Grifols Inc.
Customer Service: 888-325-8579 Fax: 323-441-7968

Mix2Vial® is a registered trademark of Meding Medical Projects, Ltd., a subsidiary of West Pharmaceutical Service, Inc. © 2012 Grifols Biologics Inc. All rights reserved. Printed in USA. January 2012 A803-012

GRIFOLS a new era begins

www.grifolsusa.com



Having issues with co-pays or gaps in coverage for your **hemophilia A** treatment ???

We may be able to help.

Bayer offers a range of programs that can help you navigate insurance questions about your **hemophilia A** treatment. If you're having issues with co-pays or gaps in coverage, we may be able to offer assistance. Speak with one of our case specialists to find out more.

Call **1-800-288-8374** and press 1 to speak to a trained **insurance specialist!**

Bayer and the Bayer Cross are registered trademarks of Bayer.

© 2013 Bayer HealthCare Pharmaceuticals Inc. All rights reserved. 04/13 KN10000213B

REGISTER NOW!



This year we are excited to celebrate our 20th year anniversary!

Honoring Our Past, Building Our Future.

Symposium is an annual community-centered educational event that draws over 400+ patients and their families, 100+ exhibitors, 20+ speakers, and over 50 community volunteers from across the country! We award over 100 travel scholarships to first time attendees each year for families who need financial assistance. This national meeting is a place where community members come together to share information, learn new advancements, and build a network of support.

Join us for this special celebration to reconnect and meet new community members!



Tampa Marriott Waterside Hotel & Marina

700 South Florida Avenue | Tampa, Florida

March 27-29, 2014

To register visit our website: www.hemophiliafed.org



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

NON PROFIT ORG
US POSTAGE PAID
LAFAYETTE, LA
Permit No. 735

A red hand truck with a black wheel and handle is shown from a low angle, carrying a large, brown cardboard box. The background is a dark blue, textured surface with several small, white, star-like sparkles scattered across it. The text 'OUR WASHINGTON, DC Office Has Moved!' is written in a large, white, sans-serif font, slanted upwards from left to right, and is positioned above the cardboard box.

OUR
WASHINGTON, DC
Office Has Moved!

PLEASE NOTE THE
ADDRESS CHANGE TO:

820 First Street, NE
Suite 720
Washington, DC 20002