

**WE ARE ALL
IN THIS
TOGETHER!**



DON'T MISS

Be Prepared for ACA	2
Healthier Bodies Bleed Less	8
Inhibitors Will Not Inhibit Our Family ..	12
2013 Scholarship Winners	24

Dear HFA Family and Friends,

Transition is constant in today's world. As we swim through the ever-changing waters of the healthcare system, please know that HFA is working hard with you to prepare and meet the challenges that will arise. We will also work tirelessly to build our services to further meet the needs of our community families.

Already this year, many changes are taking place. Have you checked out HFA's column, Dear Addy, on our website or Facebook page? We recognize how confusing the current healthcare landscape is and so many new changes are occurring and will continue to do so in the upcoming year. Our intent is to continue to build easy-to-digest tools and resources like Dear Addy to make the policy changes and advocacy work of our community more personal and real for people with bleeding disorders.

You also surely know of our long-standing and popular Dads in Action Program, which was started years ago by several amazing community fathers. Now you are likely starting to see additional family activities, such as our Mom's blog, "Infusing Love: A Mom's View," which has become very popular since its introduction in February. Just a few weeks ago, we launched a fantastic Back-to-School Resource Toolkit on our website for families with school-age children. This toolkit was a dream that was in the planning since 2008, and it finally came true. Additions such as these have come at the request of the community. We've listened, we hear you, and we're transitioning to support you.

This summer, we welcomed our 37th HFA Member Organization, Mid-South Hemophilia and Bleeding Disorders in Memphis, into our mix, so our community reach is growing. These are just a few of our ongoing changes. Please stay active and tuned in to learn more! We take our responsibility to fulfill our mission very seriously. We are here to assist and advocate for people with bleeding disorders. Regardless of constant transitions, we're here!

Warm Regards,



Matthew T. Compton

Matthew T. Compton
Board President



Kimberly K. Haugstad

Kimberly Haugstad, MBA
Executive Director

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of all of revenue raised
in 2012 went to directly
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and outreach services for
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Be Prepared: Healthcare Insurance Marketplace

Open enrollment begins October 1, 2013

By Wendy Owens

The countdown to the launch of the new online Health Insurance Marketplace is on. Are you ready? If you, like many Americans, have questions about what the Marketplace is and what it does, there are excellent resources available to help answer these questions. Here are some of the most frequently asked questions:

“The Marketplace”

The Health Insurance Marketplace is a service where individuals and small businesses can compare, and, ultimately, purchase health insurance. The Marketplace will offer health insurance plans to individuals under the American Health Benefits Exchange, and to small employers (fewer than 50 or 100 employees, depending on the state) under the Small Business Health Options (SHOP) Exchange. No matter where you live in the U.S., with the Marketplace, you will be able to compare health insurance options based on price, benefits, quality, and other key plan features. Each state can choose whether to operate its own Marketplace, partner with the Department of Health and Human Services (HHS) to run some of the functions of their portion of the Marketplace, or have their portion of the Marketplace fully supported by HHS. A final list of state-run and HHS-supported Marketplaces will be available in October. To learn the status of your state’s Marketplace, visit: www.healthcare.gov/marketplace.

To Use the Marketplace or Not to Use the Marketplace? That is the Question.

Not everyone needs to enroll in a Marketplace plan. According to the U.S. Census Bureau, 55% of Americans had employment-based insurance in 2011. The Marketplace is intended for people who are self-employed, employed by small businesses that do not offer health insurance, or otherwise under-insured 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 (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. However, if an employer offers an employee an insurance plan that is affordable (one that costs the employee less than 9.5% of annual salary), then that employee still could choose a Marketplace plan, but they would not be eligible for premium assistance in the Marketplace. 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.

Choosing a Marketplace Plan

Whether you have employer-provided insurance or not, you will need to look at your current plan, its benefits, and the out-of-pocket costs (premiums, deductible, copays, etc.), and compare it to plans

available on the Marketplace. Compare plans based on what is important to you. Choose the combination of price and coverage that fits your needs and budget. 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
- The cost of your monthly premium verses deductible cost when you have a major procedure

When you apply on the Marketplace, you can see all plan options available to you and enroll in the plan that works best for you. You also will find out if you can qualify for lower costs on your monthly premiums and lower out-of-pocket costs for private insurance plans. As part of the application process, you will learn if you qualify for free or low-cost coverage available through Medicaid or the Children's Health Insurance Program (CHIP). Information about plan prices and benefits will be written in simple language, so you will know how much you will pay for which benefits and protections before you enroll.

For a helpful list of what to consider when comparing plans, see NHF's Personal Health Insurance Toolkit.

Benefits Covered by Marketplace Plans

Insurance plans in the Marketplace are offered by private insurance companies. These plans cover the same core set of benefits, called essential health benefits. All insurance

plans must cover essential health benefits under the new health care laws. No plan can turn you away or charge you more because you have an illness or medical condition. They must cover treatments for all conditions. Plans can't charge women more than men for the same plan. All health insurance plans available on the Marketplace must offer comprehensive coverage, including doctor visits, hospital stays, wellness and prevention services, and medication. Each plan is considered a Qualified Health Plan (QHP). A QHP is a plan that meets certain minimum standards, including offering all essential health benefits requirements and not discouraging enrollment in the plan by people with significant health needs. A QHP plan must present benefits and plan options in a standardized format, provide a quality-improvement strategy, use a uniform enrollment form, and meet other quality and reporting requirements.

A graphic advertisement for Baxter. It features a large blue headline, a paragraph of text, the Baxter logo, and several circular images of people. A network diagram of colored circles is on the right side.

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Applying for Insurance on the Marketplace

You can apply for Marketplace coverage three ways: online, by mail, or in-person with the help of a Navigator or other qualified helper. Telephone help and online chat will be available 24/7 to help you complete your application. You can go online to learn more about Marketplace plans now. Open enrollment starts October 1, 2013 and ends March 31, 2014. Plan prices will be available on October 1, too. Coverage by Marketplace plans starts as soon as January 1, 2014.

Categories of Coverage & Financial Assistance

The Marketplace will offer four categories of health insurance coverage: Bronze, Silver, Gold, and Platinum. Assistance, in the form of Premium Assistance Credits or Cost-Sharing Subsidies, will be available to people who qualify to pay for these plans. The type and amount of assistance will be based on the amount of money you make and the size of your family. Cost-Sharing Subsidies will be available for people who have incomes from 100% up to 400% of the federal poverty level – or about \$24,000 to \$94,000 a year for a family of four.

The amount of Premium Assistance Credits is determined based on the price of the Silver level plans available in the area in which you live. The premium credits will be delivered as tax credits and will be available to all people who are eligible for them, whether they file taxes or not. The credits will be paid directly to the insurer that the individual chooses,



with individuals responsible for the remaining premiums. The credits will be delivered in advance, so that people do not have to pay all of their premiums up front and wait for reimbursement. Only Silver level plans and above will qualify for premium assistance credits.

People with lower incomes will receive more Premium Assistance Credits and Cost-Sharing Subsidies to help them pay for coverage. When you fill out your Marketplace application, you will find out how much you can save based on your income and family size. According to www.healthcare.gov, most people who apply will qualify for lower costs of some kind.

Price Tags for Marketplace Plans

It is not clear yet whether plans offered via the Marketplace will be less expensive than current private health insurance plans. In the past several months, states running their portion of the Marketplace have announced, and continue to announce, lower-than-expected rates for health insurance. Experts say both state and regional issues play a part in how much a consumer will pay for insurance beginning in January 2014. For example, in Nevada, plans for young adults to cover catastrophic health situations will sell for less than \$100 a month. In Maryland, the insurance commissioner recently said that the expected new rates for residents who will need to buy insurance are around 33% lower than expected. A Connecticut insurer (HealthCT) announced that the cost of its plans would drop an average of 36% from its original proposal in the individual market. HHS announced in August 2013 that the Silver level Marketplace plans are an average 18% lower than anticipated in the 11 states the department studied. ■■

If you have questions about the Marketplace, its plans, or how to get started, you can chat online at healthcare.gov or call 1-800-318-2596, 24 hours a day, 7 days a week. (TTY: 1-855-889-4325).

We Are All In This Together!



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.

HFA understands and recognizes the ongoing medical, physical, emotional and financial challenges that a chronic condition poses on individuals and families living with a bleeding disorder. Since 1997, the Helping Hands program has been able to assist people experiencing a temporary financial crisis due to their bleeding disorder. This program is funded by donations, membership dues, and contributions made in honor of community members.

On September 27th, 28 riders from across the country will Pedal with a Purpose as they start a 156-mile bike ride from West Virginia to Washington, DC to raise funds for this crucial program.

From January 2011 through December 2012, we distributed a total of \$257, 811 to 610 households via Helping Hands. Applicants are parents of children with hemophilia, adult males with complications and co-infections, as well as females struggling with their bleeding condition. The financial struggles associated with a bleeding disorder have been further deepened in recent years by our nation's overall economic crisis.

By large, the majority of applications received requested assistance with rent, mortgage, utility bills and transportation. From January 1, 2011 through December 31, 2012, 55% of households received assistance with housing payments, such as rent and mortgage. Our analysis has shown that most of the applicants are parents of a child or children with a bleeding disorder who have lost all or some of their wages due to their children's condition.

Are we really helping?

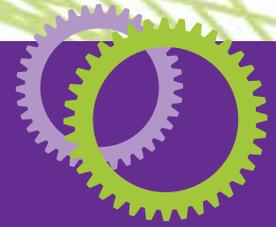
A recent analysis showed 98.7% of Helping Hands recipients think so! These parents and individuals living with a bleeding disorder felt the assistance they received along with the guidance provided was useful and valuable in helping them get back on their feet after a temporary crisis.

All in all, 100% of the participants expressed gratitude and appreciation to the program, to HFA and to the kind and generous people whose contributions make the program possible. Please join our team of kind and generous donors — **WE ARE ALL IN THIS TOGETHER!**

100% of funds raised will be distributed to applicants who are eligible for assistance.

Please help your family and donate today! Every bit counts and no donation is too small! www.razoo.com/story/Hemophiliafed

Why we are participating in the Gears for Good Bike Ride...



“I RIDE in support of people like Barry, Vaughn, Nick and others who treat hemophilia like a bump in the road and do things people without hemophilia aren’t capable of doing. I ride in support of parents like Kim/Jeff, Dianne, Candy, Allie/Jim and others who are raising kids who happen to have hemophilia, with the attitude that their kids can be anything they want to be.” *Dan McKinley, CSL Behring*



“AS ALBERT EINSTEIN SAID, ‘Life is like riding a bicycle; in order to keep your balance, you have to keep moving.’” *Barry Haarde*



“THE GEARS FOR GOOD BIKE RIDE allows me to fulfill two great passions of mine—giving back to the hemophilia community and biking. The fact I get to spend a weekend with such a special group of people is just a bonus. I can’t wait.” *James Boutin*



“HEMOPHILIA is not only physically and emotionally painful, it can be financially challenging. I ride to help moms and dads who have lost their jobs or paychecks because they stayed in the hospital with their children. I ride for adult males who aren’t able to work because of their debilitating and chronic pain. I understand how this can happen—we are lucky and I want to help.” *Allie Boutin*



“I WAS INSPIRED to participate watching riders in our community whom I know and admire complete their rides. I’ve become a cyclist this past year thanks to Barry Haarde, one of the riders, and I enjoy the camaraderie and great physical challenge. We become role models for others in the community! HFA is a wonderful organization that deserves our efforts and funding.”

Laurie Kelley

DONATIONS CAN STILL BE MADE AFTER THE BIKE RIDE IS OVER.

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Healthier Bodies Bleed Less

By Janet Chupka



Barry Haarde



Dawn Evans



Trevor Dunn

It is important for individuals with bleeding disorders to participate in some form of physical activity. Being physically active helps to strengthen one's muscles, bones and joints. One of the many benefits of having a strong healthy body can be a reduction in the number of bleeding episodes an individual might experience. Many in the bleeding disorders community are championing the effort to stay healthy and be physically active.

In this article, we introduce you to three such people: Trevor, a young adult male with von Willebrand Disease, Dawn, an adult woman who is a symptomatic carrier of Hemophilia A, and Barry, a forty-seven year old male with severe Hemophilia A. All of them have discovered a form of physical activity that

is enjoyable and adaptable to their specific needs. They have all overcome obstacles along the way and are now using their voices to raise awareness about the benefits of physical activity and to motivate others to find their own activities to champion. Their stories are exciting and inspiring and are proof positive that you are never too young or too old to start your own story to a healthier you!

When and how did you become physically active?

■ **BARRY:** I was never a particularly active person until I had a total knee replacement surgery in 1999 at the age of 34. My orthopedic surgeon had encouraged me to do a moderate amount of exercise both pre and post surgery to make the operation and rehabilitation more successful. Once the damaged joint had been replaced, I was able to do a lot more, which led to me taking up the sport of cycling in a much more serious way.

■ **DAWN:** In 2004, I turned 40. I knew I needed to get off the couch and do something, so I set my sights high and put my name into the lottery for the New York City Marathon. I ended up getting in but didn't train properly and injured myself (I DID finish though). It took me four years after that to get the nerve up to enter again. In 2008 I entered again, and this time around trained properly, and finished without any injuries! I've never looked back.

■ **TREVOR:** I became physically active around the age of 17. I was always stressed out from missing a lot of schoolwork from my constant nosebleeds and from the stress of my dad being diagnosed with cancer. For some reason, my solution to my stress problem was to start working out in the gym.

Do you have some type of support system that encourages you to stay active? What, who, and how?

■ **BARRY:** I've found that I accomplish a lot more when working out with others, so I make a point to ride competitively with local bike clubs, and I participate in quite a few organized charity rides which can be found in most parts of the country. I invariably work a lot harder when in the company of others and find a lot more motivation that way than when riding on my own.

■ **DAWN:** My family and friends have always supported my activities. They were all there at the finish line of my first 70.3 Ironman! By the time I finished the swim and bike portion, I was exhausted and really struggling. I considered quitting at the start of the run. My husband, Brad, knew I was having a hard time. He started walking with me and telling me to "trust my training." By mile three, I was running and he never left my side. He came to take pictures and ended up running the half marathon with me. Now that's support!

■ **TREVOR:** For a while, my parents didn't support my decisions simply because I chose health and fitness over my school work. Once I learned to balance both, my parents became my number one fans. To this day, I can always count on them to help me in any way they can, whether it's encouraging me to infuse if I'm injured, or simply complimenting me on my dedication.

What does your regular fitness routine consist of? How do you manage your bleeding disorder while staying active?

■ **BARRY:** At the moment, I'm averaging a little over 250 miles a week on the bike. One of the principal motivations for pushing this hard is to illustrate that neither HIV or hemophilia should limit what we think we can do, as long as we're being wise about the choices we make.

■ **DAWN:** I try and run or get to the gym at least 5-6 days a week. Even if I walk around the track, I try my best to do something. Being a symptomatic carrier, I have heavy periods, and that can be a challenge during any long training run or marathon, but I've never let it slow me down.

■ **TREVOR:** My fitness routines are always changing and I normally change my plans every 4 weeks. I always make sure I work my full body in one week, and that I'm doing some form of cardio every day. I try to have at least one day of rest to help my joints and muscles recover after a week of hard work. Listening to your body is key.

What are some of the benefits of being physically active?

■ **BARRY:** In addition to the physical benefits, I think that being active really helps in terms of staying on top of the mental and spiritual stress that inevitably arises from managing all of the financial, psycho-social, and physical effects of living with multiple chronic medical conditions.

■ **DAWN:** I have more energy, feel better, and know there isn't anything I can't do! I've met some great people along the way who share the love of being active. It's contagious.

■ **TREVOR:** When I'm able to exercise regularly, my body is extremely energized. I never feel tired, and my sleep cycles are always consistent. Being physically active has actually helped me in every aspect of bleeding prevention.

What other things do you do to take care of yourself and stay healthy?

■ **BARRY:** I like to think that maintaining a reasonable diet, working full-time, and keeping a good spiritual outlook, all contribute to keep everything going in the right direction.

■ **DAWN:** I drink lots of water throughout the day, have been a vegetarian for almost 7 years, and have always tried to eat healthy. However, after I finish a race, I treat myself to things like an entire box of Kraft macaroni and cheese! It's all about balance.

■ **TREVOR:** I focus on stretching and nutrition. Stretching every morning when I wake up, as well as after every workout has kept my joints loose and strong. Nutrition is the most important aspect of overall health.

Do you face any additional challenges because you are physically active?

■ **BARRY:** The best results are invariably achieved through consistent effort, so I always try to get on the bike as often as possible.

■ **DAWN:** I try and listen to my body, knowing when to take a break.

■ **TREVOR:** When I first started exercising, I didn't know much about proper nutrition and eventually trained myself to the point of being underweight, and I developed an eating disorder. I had to learn that being physically active also means being smart when it comes to food.

...continued on page 10

Would you encourage others with a bleeding disorder to become physically active? What words of wisdom/advice would you offer them?

■ **BARRY:** Absolutely!! There is simply no reason, in the age of effective meds and access to prophylaxis, to think that people with a bleeding disorder cannot live active lives. Developing a sound exercise routine takes effort and should be done carefully and gradually, with the supervision of a physician. Comparing notes with other community members who've successfully integrated physical activity into their lives (and there are many) is another good way to stay motivated.

■ **DAWN:** YES! First, talk to your doctor and determine if you have any limitations. Once you know what you CAN do, get out there and just do it! It's easy to convince yourself the weather is too cold or hot for a run, bike ride, or walk, but once you make the decision to get moving, you'll feel amazing. Being outside is good for the soul as well! Physical activity keeps your muscles and joints strong. There's nothing better than a healthy body and mind.

■ **TREVOR:** In my opinion, being physically active every day is the best decision anybody with a blood disorder could make. My joints have become so much stronger and I don't get nosebleeds unless I stop exercising. Most of the time, I feel like I don't even have a blood disorder because I feel just as strong as any healthy individual my age. Health and fitness has become my natural cure to my VWD, and I don't ever plan on quitting. ■■



Barry Haarde

Barry Haarde

Barry Haarde is 47 years old, has severe hemophilia A, and lives and works in Houston, Texas. He serves on the boards of the Committee of Ten Thousand and the Lone Star Chapter. Barry has logged over 70,000 miles on a bicycle and frequently participates in charity fundraising rides for hemophilia and other organizations, including two coast-to-coast rides across America for Save One Life and HFA's "Gears for Good" ride.



Dawn Evans

Dawn Evans

Dawn Evans is originally from Ohio, and currently lives in Michigan. She works for the Hemophilia Foundation of Michigan as the Special Events Coordinator. Her father had severe hemophilia A, she is a symptomatic carrier, and her 20 year old son, Dylan, is a college junior and is also affected with severe hemophilia A.



Trevor Dunn

Trevor Dunn

Trevor Dunn was diagnosed with von Willebrand disease type 1 & 2N at the age of 7. He is a counselor for the New England Hemophilia Association's (NEHA) family camp and is passionate about health and fitness. He lives in Maine.

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Inhibitors Will Not Inhibit Our Family

By Rachel Katzman

I'm sitting and watching my son Blake play catch in the park with a friend. He runs for the ball and trips on a rock and lands in the dirt. I stay seated... and it's really hard. I remind myself that we are in a different place now, but it's still very hard. A year ago, I would have been up and running. I would have taken him home and infused him right away. A year ago, Blake had a high inhibitor. Now, after eight long years of immune tolerance, we are in "wait and see" mode. What a different world, and what a different way of living life.

It's been nine and a half years since my son Blake was diagnosed with hemophilia. The ups and downs have made my family feel like we are living on top of a huge yo-yo. Hemophilia was a scary diagnosis. It was not something that we knew anything about. It took his first bleed for us to begin to understand what we were now facing. It took a few more bleeds for us to start living life like we should again. Then, at 18 months, we were sitting in our hemophilia treatment center the day before Blake was scheduled to have his port surgery when the other shoe dropped. Who knew five words could send us reeling again? Our doctor had just told us, "Your son has an inhibitor."

It felt like we were diagnosed all over again. The port surgery went on as planned. Our doctor wanted us to begin Immune Tolerance Therapy (ITT) right away, using the same brand of factor we had already been on. His inhibitor was only at 1-1.5 Bethesda Units (BU) when it was discovered, which is pretty low, and this gave us hope that the ITT could work. The next four years were pretty uneventful. Blake started nursery school and had a few bleeds. When he was about 4-1/2 years old, his inhibitor began to rear



its ugly head. A right calf bleed sent us to the hospital. We found out Blake's inhibitor had gone past 10 BUs, which means that he was now considered a "high responder." Another bleed occurred and his inhibitor continued to climb. We connected with other families who had inhibitors, met other doctors, and

“The biggest worry I have is that the inhibitor will come back.”

learned about different strategies to eradicate the inhibitor. I remember pleading with our doctor to please change the factor that we were using for ITT, but she refused. It took another bleed for me to finally go get a second opinion. We left our HTC and found a new one, just in time for another hospital stay.

At this point, Blake could not use either of his calf muscles or his elbows. It was way past the time for a change. Our new doctor took Blake off the recombinant factor that he had been on for two and a half years and switched him to a plasma-derived product that contained factor VIII and von Willebrand factor. This was scary. We knew that plasma-derived products were much safer than they used to be, but there is always a small chance of something tainting the plasma supply. We felt we no longer had the choice. Blake's inhibitor had made this choice for us. It took some time, but we began to get Blake's hemophilia under control again.

Around this time, our doctor left our HTC to pursue research. She asked us to stay and give the new doctor a chance, and, unfortunately, we did. This doctor made a medical decision that we strongly dis-



Approximately 30% of people with Hemophilia A and 2-3% of people with Hemophilia B DEVELOP INHIBITORS.

agreed with—he put Blake back on recombinant factor VIII, and it brought back his inhibitor. He was back to having three or more bleeds a week. He was living in an arm sling and using his wheelchair. He was also mad—something he had never been before. The difference was that now Blake knew what it was like to live without an inhibitor. He knew what it was like to live without pain. I felt helpless and angry.

I decided I was no longer waiting for the doctor to make decisions for us. I took control. I insisted that our doctor put Blake back on the factor VIII and von Willebrand product—the one that worked. I emailed our previous doctor for advice, as well as other doctors across the country. I took Blake for second and third opinions. I gathered my information and confronted our doctor. Instead of acknowledging that I was right about the fact that putting Blake back on the product with factor VIII and von Willebrand factor had brought his inhibitor back down to an undetectable level, our doctor's biggest problem was that I had gone over his head. It was time for another change. It was hard to leave our nurse and the comfort of knowing and understanding our hospital, but it had to be done.

For a over a year now, Blake's inhibitor has been undetectable. He has not had a bleed in a very long time. We went from at least three bleeds a week to Blake getting to be a child again. He has done things that I never thought he would do, including going to a sleep away camp that is not

structured to help kids medically. Blake went for four weeks this summer and in his words “had the time of his life.” There is no way that my husband and I would have let him go if he still had the high inhibitor. Blake was able to make up some of the time that he had lost living on the couch at home and in the hospital.

This is an important time in our lives and in the world of inhibitors. Right now it appears that we may actually have beaten the inhibitor. It scares me to say this out loud. After living in “operation alert” for so many years, we finally have some breathing room. I wish I could say that I don't worry as much anymore, but I still do. The biggest worry I have is that the inhibitor will come back. I have trained myself to stuff this worry down deep inside. It's my worry, not Blake's. Blake just needs to be Blake, and he is finally getting that chance. ■ ■

Rachel Katzman lives in Connecticut with her husband, Dan and her three boys, Blake, Matthew, and Kyle. Blake is the only one of her children with hemophilia, but it's important to remember that his two brothers are just as special. Rachel and Dan had no idea what hemophilia was when Blake was diagnosed. They have since educated themselves not only about hemophilia, but inhibitors as well. The Katzman family sponsors an annual Alpine Snowshoe Walk that raises money for hemophilia, and it has become one of New England's premier community-building events.

Back to School – Are You Ready?

By Scott Boling



I'm just like any other father when it's time for my children to go back to school—so excited! All kidding aside, transitioning back to school can be difficult for everyone if you're not prepared. When it comes to the extra challenges our kids with bleeding disorders face, the added stress can become an even larger obstacle. Let's face it—the daily routine (or lack thereof) that goes with summer has ended, and it's time to refocus on the classroom.

Each year, my wife and I tend to revert back to those routines that have helped smooth out this transition in the past. For instance, we start talking about school early, so all our kids start thinking about it. With six sons that fall within a broad age range, it means something different

to each of them, so this creates an opportunity to discuss any of their individual concerns one-on-one. In our household, we've found that the sooner we start, the better it is for everyone. Our kids are used to running around outside until dark each night, which brings up one of the biggest obstacles for most parents—establishing bedtimes. During the summer, we become more relaxed, but it's time to transition the kids from the couch and trampolines back to their own beds. My wife and I like to ease into it by starting their bedtime routine about 10 minutes earlier each night and waking them up 10 minutes earlier each morning. If you can get their body to adjust, it's easier to adjust emotionally as well.

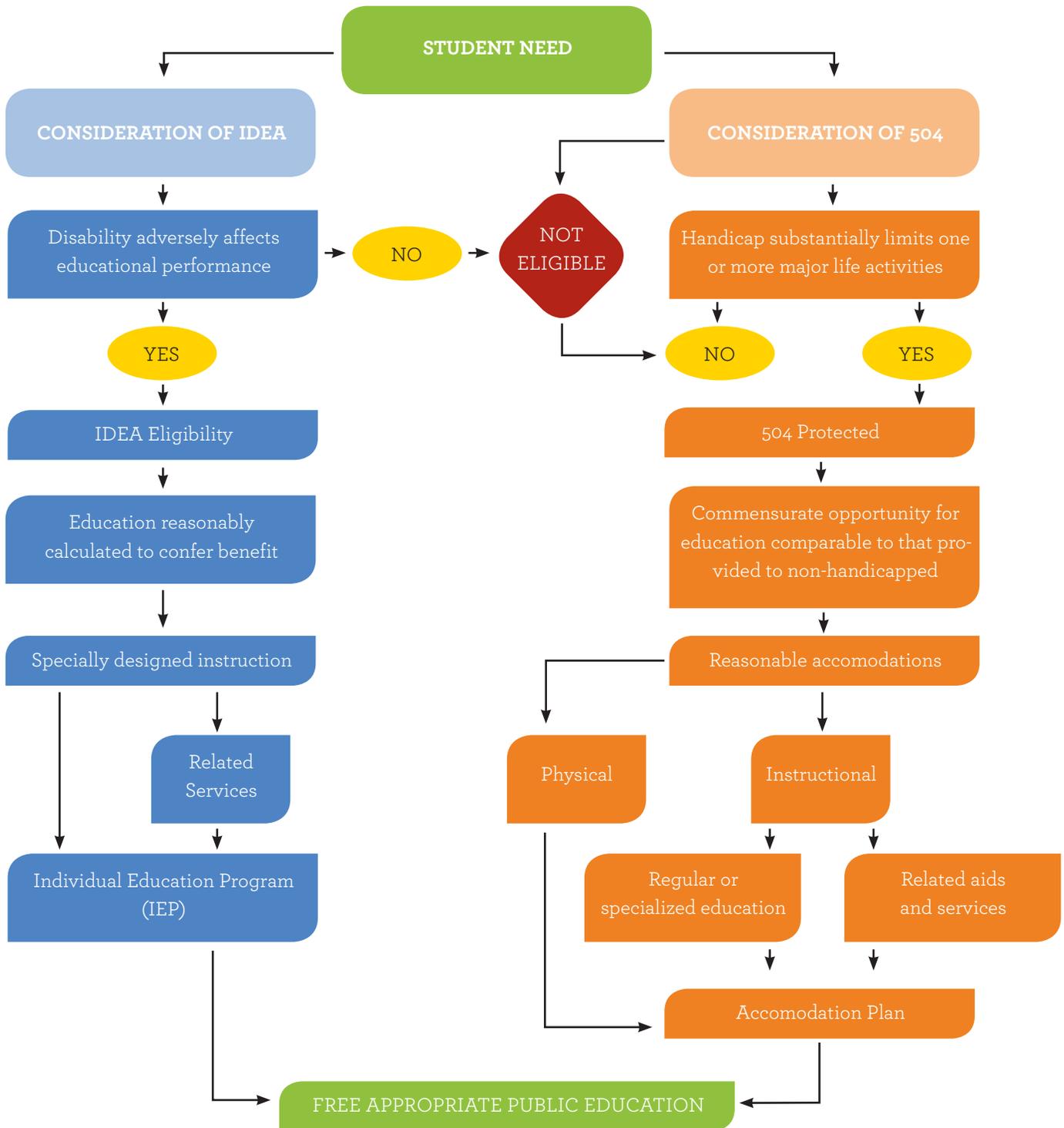
If your family is anything like ours, your pantry is filled with potato chips, cookies, and other junk food. Transitioning back to school is the perfect time to reload and focus on healthy foods. It's really not too difficult, especially when our kids already know our expectations for healthy school lunches. Don't get me wrong, if we forget the treat—we'll hear about it for days. We also make sure we have an assortment of healthy options available for when they come home from school and instantly hit the fridge for the all-important after school snack.

If all this doesn't sound any different than preparing other kids without hemophilia for school, you're right, because hemophilia doesn't require us to isolate our kids or make

...continued on page 16

IDEA/504 FLOW CHART

There are two laws for K-12 students in public school that may offer supports and services for children with a bleeding disorder: the Individuals With Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973. This chart will help determine which plan may be appropriate for your child.



Council of Administrators of Special Education, Inc. (CASE) - *Student Access, A Resource Guide for Educators, Section 504 of the Rehabilitation Act of 1973*

See Special Education Handbook 2003, Appendix I, Classroom Accommodations, IDEA/504 Flow Chart
<http://www.eedstate.ak.us/tls/sped/Handbook03/word/appisec1.doc> (July 19, 2005).

...continued from page 14

them feel different. Two of our six boys have hemophilia—yet you wouldn't know it without careful interaction with them. This doesn't mean it's not important to make absolutely sure that teachers and other school officials become acquainted with hemophilia and what to look for. That's why we make several trips to the school before the first day, to ensure that everyone is knowledgeable and all questions have been answered. It's important to make time to meet and greet the key people in your child's school for the upcoming year. Let them know who your son or daughter is and tell them about his/her bleeding disorder. We let our kids help educate teachers and staff on how to oversee and respond to any bleeds that they may encounter. It's a positive way to help teach them the importance of advocating for themselves.

We're finding that the majority of our younger son's teachers are more comfortable now because most have already met or taught our oldest son (he has since moved on to high school). However, despite having shared his story with many teachers and staff over the years, we still visit the high school and prepare in the same manner. He may be old enough to take care of himself and self-infuse, but everyone needs to become acquainted with hemophilia and what to do in case of an emergency.

By the end of the first week, it's time to celebrate. We all go out to dinner as a family and talk about surviving the new school year. Did someone say "homework?" ■ ■

Scott and his wife, Angie, live in Idaho and have been married for 17 years. They have 6 sons, including two little boys they just adopted after having been foster parents since 2011. Preston is 15 years old, Parker is 12, Payton is 9, and Paxton is 5. Their newest family members are Crew, 6 years old, and Jaxson, 2 years old. Two of Scott's sons, Preston and Payton, have moderate hemophilia. Scott enjoys spending time with his family and being outdoors – particularly cycling and flying. Scott serves on HFA's Board of Directors as the Idaho representative and also serves as Vice President for the Snake River Hemophilia and Bleeding Disorder Association.





CHOICE: Improving HFA Services for the Community

By Wendy Owens

To all of you who have taken the time to participate in the CHOICE (Community Having Opportunity to Influence Care Equity) Project by taking the survey, thank you. For those who have yet to take the survey, please do (call 800-230-9797 or go to choice.hemophiliafed.org). CHOICE is about the bleeding disorders community and working with the community to raise the bar on care, services, and advocacy. The CHOICE survey asks questions about diagnosis, bleeding history, treatment, insurance coverage, quality of life, and quality of care. The more information we have about the community, the more we can work to improve the health of people with bleeding disorders.

Already we are learning so much from your responses to the CHOICE survey questions. There is power in this knowledge—power to change lives, improve medical care, and help ensure access to the services people with bleeding disorders need. We are taking what we are learning and applying it to improve and expand HFA programs and advocacy efforts now. Here are a few things we are doing:

CHOICE
(Community
Having Opportunity
to Influence Care
Equity)

1.

Dear Addy

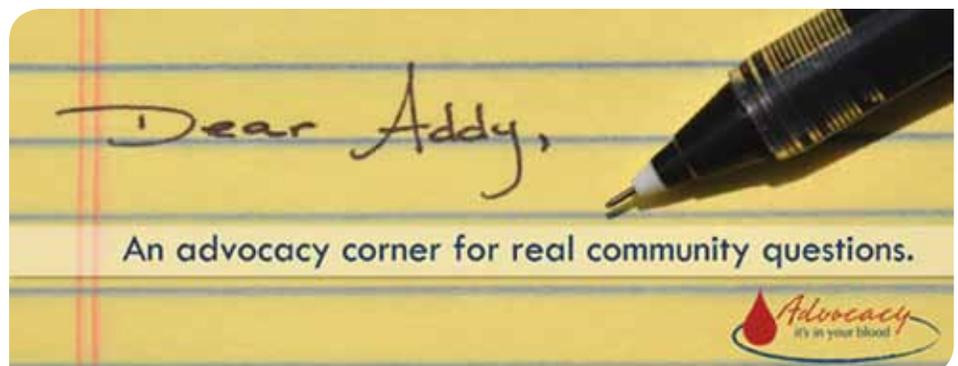
HFA frequently receives questions from the bleeding disorders community related to advocacy issues. In response to the insurance and personal advocacy questions raised by participants in the CHOICE survey as well as from community members' participation in other HFA programs, HFA launched its Dear Addy column this summer. The issues raised by survey-takers and program participants often impact the entire community. Questions submitted to this column are edited in order to protect privacy and should be considered educational only, not individual guidance. HFA posts a new Dear Addy question and response twice monthly in conjunction with a new advocacy-related vocabulary word. Look for Dear Addy announcements on HFA's Facebook page, as well as part of HFA's Community Voices section of our website.

2.

Rural Working Group

The mission of the HFA's Rural Working Group is to identify solutions to lack of access to care and connection to community experienced by under-served members of the bleeding disorders community. The Group is working to accomplish its mission through (1) research of the impact living in rural areas has on members of the bleeding disorders community, (2) development of solutions to access to care, education, and other community-based mechanisms that increase empowerment, efficacy, and community, and (3) creating a national network of support for those that are living in rural communities. Knowledge gained through the CHOICE Project is a critical part of supporting the Group's mission. If you are interested in participating in the group, please contact HFA for more information.

...continued on page 22



Developing Autonomy vs. Relying on Others

By Joshua Lunior

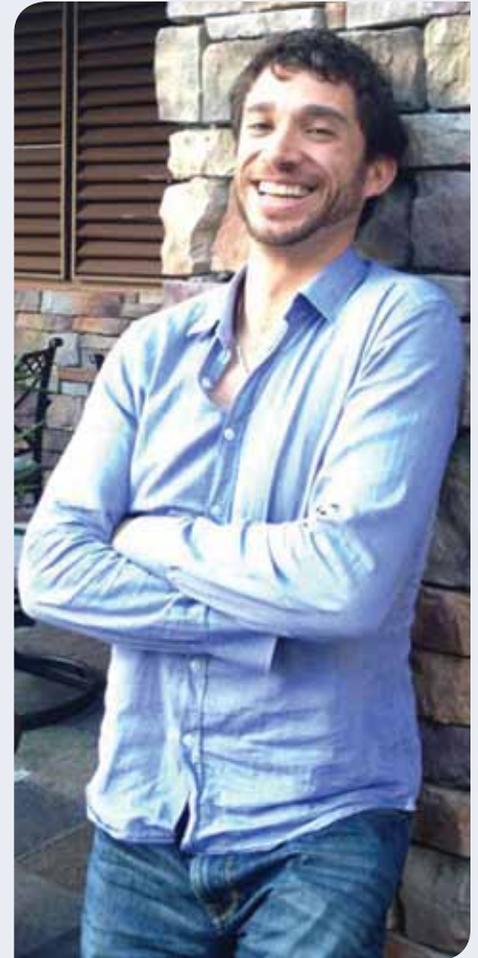
The transition from childhood to adulthood can be full of exciting opportunities to have new experiences and shape one's own unique individuality. However, adulthood can also come with its own set of challenges, including decreased reliance on parents and taking important steps to reach personal life goals. For young adults living with bleeding disorders, additional challenges include self-advocacy for health issues and navigating the complexities of medical expenses and health insurance, while also balancing school, work, relationships, and seeking out new experiences. Joshua Lunior shares his experiences from transitioning to adulthood.

Having hemophilia, I had to depend on my parents to help me more than the average child. Like most children growing up, I still yearned for a feeling of autonomy to prove to my parents I could juggle school, work, and most importantly, my health. My parents helped me learn that I needed to teach people about my hemophilia. I learned at a young age how to advocate for my needs in school, such as requesting to take longer time on tests, communicating with teachers about missing school for doctor's appointments, and making sure the health staff knew who I was and what I needed from them.

I was so excited to go to college. In many ways, it was the best experience because it meant having the independence and freedom that I yearned to have growing up. I wanted to choose when I was going to infuse or whether I padded up my elbows, knees, head, and wrists before going roller-skating with friends. These were not always the easiest or safest decisions, but they were mine.

I loved my autonomy from my parents and felt proud that I knew how to manage my health and take care of important tasks such as ordering my medication. However, navigating my insurance, making sure my premiums were covered, and ensuring medical bills were all paid for, took me longer to master. Because of this, I had feelings of shame when I had to rely on them.

While there were so many positives of being away at college and gaining independence, I also experienced some challenges. Some college professors weren't always as lenient with their syllabus rules, such as allowing extra time on exams. It was yet another obstacle to negotiate as I made sense of college and growing up. During my fourth year of college, I had a particularly discouraging experience when I had a teacher tell me that I wouldn't be successful with my goal of becoming a math teacher. This teacher told me that my HIV status would inhibit me in my profession, and since I was very public about my health status, it would only take one parent to cause waves within the school system. She said they could not do anything legally, so would



it truly be worth the headache? I decided to take a different path and graduated with a degree in inner city development and programming, followed by a master in School Counseling because I was worried about finding a career that could pay for my health insurance costs. It was the first time someone convinced me from pursuing a passion because of the way the community might react to me.

“I loved my autonomy from my parents and felt proud that I knew how to manage my health and take care of important tasks such as ordering my medication.”

“I push myself hard to be independent and tell myself I am resilient and my hemophilia does not define me.”

I have learned that obstacles are still presenting themselves, particularly as my arthritis gets worse. I consistently remind myself I am resilient and my hemophilia does not define me. That also means I rarely ask for help from my friends when I need it. What I realize is I need to let my community of friends in the Big Apple be a support, because as my arthritis gets worse and when the pain level is so intolerable, what I want more than anything is for a someone to pick me up, take me home, help nurse me back to health, and be there to distract me from the pain. While I have learned to develop autonomy and live my life very much independently, I realize that it is okay at times to reach out for support from my community.

■ ■

Joshua Lunior lives in New York City where he participates in HFA's Blood Brotherhood program at the Hemophilia Association of New York and has lead presentations on empowerment. Joshua has participated on a planning committee for the North American Camping Conference for Hemophilia Organizations (NACCHO), 2007-2010, Adult Fellowship for Integrating Responsible Mentors (AFFIRM), 2008-2010, National Youth Leadership Institute (NYLI) Task Force of the National Hemophilia Foundation, 2003-2007, and has received the Ryan White Award for commitment to HIV community education in May 1995.

College Care List

A student going away to college is an exciting time, but can also be scary and unsettling if he/she has a bleeding disorder. Whether living in a college dorm room or on an off campus apartment, a student will need some basic items to stay healthy. This short list of essentials will help a college student maintain a healthy lifestyle while away from home and on their own:

Bleeding Disorder Related Information

- individualized health plan –should include hemophilia type/severity, medical/treatment plan, medical history and bleeding pattern, and self care steps
- medical alert
- address of local hospital
- address of the nearest Hemophilia Treatment Center (HTC)
- insurance documentation
- first-aid kit
- sharps container
- ICE (In Case of Emergency) number in your cell phone and posted somewhere visible
- establish a relationship with the disability office and health service center
- other medication (including vitamins)
- small refrigerator or storage bin for medication

Fall/Winter Fruit

- apples
- grapes
- oranges or tangerines
- pears

Essentials (purchase in bulk)

- oatmeal packs
- instant soups
- cold cereals
- whole grain bread or bagels
- sandwich spreads (nut butters or condiments)

Snacks

- whole-grain crackers
- granola/energy bars (low in sugar)
- dried fruit/nuts/trail mix
- dark chocolate (great antioxidants)
- popcorn or pretzels

Hydration

- water filter container
- nutrient-enhanced water
- probiotic drinks
- protein shakes
- 100% fruit or vegetable juice
- coconut water
- soy, rice or almond milk

Personal Basics

- shower gel
- toothpaste and toothbrush
- shampoo and conditioner
- vitamins and supplements
- other must haves

Exercise Gear

- workout t-shirts and bottoms
- running/cross-training shoes & socks
- exercise mat
- other equipment if they participate in a specific sport

I was a Runner; Now I'm a Warrior

By Courtney Squellati



Most of September 24th, 2012 is still a blur in my mind, but what clearly stands out is that it was the day my body stopped moving forward. My name is Courtney, and I have von Willebrand Disease (vWD) Type 1. People with von Willebrand Disease have decreased or malfunctioning von Willebrand factor and cannot form a proper platelet plug. If you look at my clotting level numbers, I am considered to be a mild bleeder. In my case, numbers didn't really matter.

Before my injury, I was a runner. I used to walk and run without ever thinking it was a privilege. Running challenged me both physically and mentally. It reduced stress and anxiety from work and school. I craved what is called a "runner's high,"—running to the point that endorphins are released into my system. Running taught me to not give up and to push through. I always competed only against myself. It was my own challenge and accomplishment. It was freedom.

It's only now that I realize what I took for granted. One day while running, I suffered an injury to my gastrocnemius soleus muscle that resulted in a bleed. I rehabilitated quickly and was soon able to run again. However, I re-injured the same area during a "hill workout" the first week of cross-country. My leg swelled. I used factor and did rest, ice, compression, and elevation (RICE) but I was told that I had "chronic compartment syndrome,"—a condition caused by exercise that results in pain, swelling, and even permanent damage of the muscle. Due to the risk of bleeding, it was thought that massaging the fascia would help with the release, but for me, it only made things worse. Within a matter of days, I felt tingling in my leg, I had lost full range of motion in my ankle, the belly of my calf was swelling, and my leg was feeling cold. On September 24th, I underwent a number of tests, including a compartment test. My leg had locked into an odd angle and my pain kept getting worse. It seemed like I was on every IV narcotic imaginable, yet I was still in so much pain that I was constantly wide awake. The amount of pain medication made my blood pressure drop, and I was soon transferred to Children's Hospital. By day three, I had developed a drop foot and by day nine, I had seen so many physicians that my head was spinning. What was happening to my leg was affecting the peroneal nerve, and my leg eventually turned black. I lost complete function of the limb. The pain was so great that even air moving by my leg sent me over the edge with mind-numbing pain. Not one narcotic medication alleviated the fire. At the time, all I knew was my leg didn't work and it did not look normal. Thoughts raced through my mind, but I could not put words to feelings because I was so afraid.

I thought I knew what fear was. This, however, was a different type of fear that I didn't know existed. I was afraid to even say the words I was thinking because

“Approximately 1/3 of women carrying the hemophilia gene experience bleeding symptoms.”



“Be strong.
Fight back the tears.
Overcome your fears.
Make yourself better as a result.

And once again,
the feeling of accomplishment you get
in spite of the pain you felt
IS WORTH IT
versus the horrible feeling of knowing
YOU GAVE UP BECAUSE YOU THOUGHT
it was just too hard.”

I thought that if I did, it would make all of my fears come true. My life flashed before my eyes. The normal life I had with my leg. I could not imagine living the rest of my life with the pain I was feeling. Every time my leg turned black, I thought for sure I would lose it. Running did not matter anymore. Walking was now what did matter. I was diagnosed with Complex Regional Pain Syndrome (CRPS), a disease characterized by neurological pain from receptors mis-firing constantly. Ten days after I was admitted to the hospital, I moved to a rehabilitation center to learn how to walk again.

At this point, all narcotics were stopped because they could not help with nerve pain. One of my physical therapists told me that I had to learn how to breathe to manage the pain. Later, I learned that this was called biofeedback—a technique that allows you to control your body’s physiological responses, such as pain. I had nothing left but my mind to fight what was happening, so I latched onto the hope that the physical therapist knew what he was talking about. My pain scale went from a 1-10 to a 1-100, because for me, I had to see (in my mind) that a 98 on the pain scale was better than a 99.

I started therapy in a warm pool and experienced the type of pass-out pain many people never do. My leg was still black and mottled—it floated because I still couldn’t control it. I breathed as I was taught to do. I also cried a lot. No one was allowed to touch me, as the simplest of vibrations shot my pain to a 100 or more.

It was aqua therapy that helped rehabilitate me and aided in pain control, in addition to the breathing exercises I was being taught to master. My running coach taught me to never give up, and I used that to focus my mind when pain would become too much for me. My mom was by my side day and night and ended up becoming my new coach. The one thing I knew was that if I did not fight, von Willebrand disease and CRPS would overcome me. I fought hard even when pain took me away from everyone that loved me. Thankfully, no one ever gave up on me. When I took my first steps, it was like hundreds of pins, needles, and knives stabbing my foot and leg, but I did it. And I did not stop there. I used biofeedback to bring me back when I hit the “pass-out” type of pain. As I was figuring out how to breathe correctly, I started to learn that biofeed-

back wasn’t going to heal me or take my pain away completely. What it did do was bring me back to my baseline pain level. At this level, I could make the choice to live with it or let it take me and end up bed-ridden. I had to fight. I spent a total of 30 days in the hospital. When I was released, I was only taking small steps outside of the pool and was still wheelchair-bound. My long-term goal was to walk freely across the stage at my high school graduation. The following May, I did just that. There have been setbacks along the way and new challenges, and I am sure there will be more in the future. But this will not define who I am or will become. I will breathe with every step. I still refuse narcotics now, even with staggering muscular and mechanic pain. Pain will not win.

I was a runner, but now like my family reminds me, I am a warrior. ■ ■

Courtney is a freshman at the Moberly Area Community College and lives in Missouri with her mom Nancy, her brother Connor (both are also affected with von Willebrand disease) and her father, Greg.

HFA Welcomes New Staff!

Katie Verb, Policy, Advocacy, and Blood Sisterhood Manager

Prior to joining HFA, Katie was a member of the government affairs team at the Toy Industry Association. Before turning her interest to policy and advocacy work and moving to Washington, D.C., Katie worked in Chicago for a nonprofit that educated and prepared women to run for office. She also helped found a nonprofit that provided educational and mentoring opportunities for women in the business world. Katie earned her law degree from Michigan State University in 2008, and has a B.A. in Political Science from Loyola University Chicago. Having a family history of hemophilia, Katie is excited to work with HFA and be an advocate for the bleeding disorder community! ■■



...CHOICE continued from page 17

3.

Women's Issues

A special thanks to all of the women with bleeding disorders who have taken the CHOICE survey and made us aware of the issues you face. The information you shared, as well as your forthright and insightful feedback, is helping us identify issues women with bleeding disorders face locally and nationally. Hearing from women via the CHOICE survey is critical to advancing our legislative and personal advocacy efforts on behalf of women. HFA is sharing what it learns with local chapters to aid them in their support of women with bleeding disorders. CHOICE responses also are being applied to HFA's Blood Sisterhood program. Blood Sisterhood is a peer network of women who support women with bleeding disorders on their life's journey

through diagnosis, treatment and day-to-day living. Ultimately, through furthering the conversation among women, we seek better health outcomes and a better quality of life for women with bleeding disorders.

CHOICE continues to be a community project. Over 150 community members helped develop the CHOICE survey and community member feedback continues to help us improve it. HFA will continue to put what we learn from the CHOICE survey to work for the community. If you know a friend or family member with a

doctor-diagnosed bleeding disorder and/or carrier who has not taken the survey, please encourage them to do so.

*Through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), HFA is running the CHOICE Project. The focus of the CHOICE Project is to collect information regarding health experiences of people in the bleeding disorders community. HFA is asking everyone in the bleeding disorders community to participate in this project by taking the CHOICE survey. ■■

300 MEMBERS
OF THE BLEEDING DISORDERS COMMUNITY
HAVE TAKEN THE CHOICE SURVEY!

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CONGRATULATIONS

to the 2013 Educational Scholarship Winners!



Hunter Montgomery

Artistic Scholarship
Brigham Young University: Provo, UT

"This scholarship will help support me through my first year of college as I study music performance and pre medicine. This scholarship will help me to pursue both of my passions as I work towards my goal of becoming a hematologist."



April Baird

Parent Scholarship
Piedmont Technical College: Greenwood, SC

"I decided to pursue a degree in nursing, because the nurses that take care of my two boys with hemophilia have played a huge part in my family's life. This scholarship will help me pursue a career that could benefit a wide range of people."



Crystal Climer

Sibling Scholarship
University of Tennessee at Martin: Martin, TN

"I am on my way to achieving my dream of becoming a veterinarian and I would not have been able to get this far without my family and friends. Receiving this scholarship has been a blessing!"



Austin Hanse

Educational Scholarship
Bradley University: Peoria, IL

"Engineering is a field that has always interested me and with the help of this scholarship, I can pursue and accomplish my goal to graduate from college with a degree in mechanical engineering."



Joeleen Heman

Educational Scholarship
University of Missouri Kansas City: Kansas City, MO

"I am so excited to begin my degree in education and am beyond thankful to have the support of the bleeding disorders community behind me."

Shawn Whelan

Educational Scholarship
Western University: Pomona, CA

“The bleeding disorder community has not only helped me manage living with hemophilia, but has propelled me forward to excel and even given me an added sense of purpose and direction in life. This scholarship will aid me in my journey to becoming a physician.”



Perseus Patel

Educational Scholarship
University of California: San Francisco, CA

“Living with hemophilia has presented the opportunity to meet some extraordinary individuals who have overcome significant hardships to give back to the community. They serve as my inspiration to complete medical school and reciprocate to the community in a meaningful manner.”



Johnna Cesta

Educational Scholarship
Boston University: Boston, MA

“Through volunteering within the bleeding disorder community, I’ve discovered a passion for people and desire to help others. With the help of this scholarship, I will be studying psychology at Boston University, in effort to nurture this passion and contribute positively to the world.”



Joshua Kim

Educational Scholarship
Pomona College: Claremont, CA

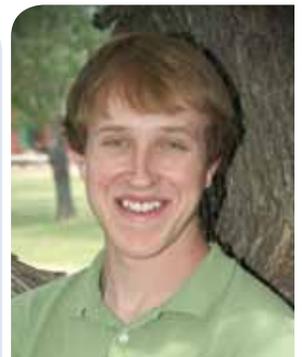
“I am incredibly thankful for this scholarship as without the help of the bleeding disorder community it would have been very difficult to attend Pomona College. I plan on attending medical school afterwards and I hope to become a hematologist and give back to the blood disorder community.”



William Eshleman

Educational Scholarship
University of Washington: Seattle, WA

“Hemophilia is a huge part of my life, and the lessons I’ve learned from it and the bleeding disorders community have helped me get where I am today. With this scholarship, I will be able to continue my studies in physics and astronomy, while still staying active in the bleeding disorders community.”



Learn more about educational scholarships for the bleeding disorders community: www.hemophiliafed.org

Don't Get Caught in the Weeds of Hemophilia

By Sonji Wilkes

One day, in a stellar mothering moment shortly after my son, Thomas, turned nine years old, I said to him, "I'm halfway done with you. I've invested nine years in raising you. I've only got nine more that I'm responsible for you. After that, it's all on you."

Yeah, it wasn't one of my finer mommy moments.

Or maybe it was.

Afterwards, I realized that I really AM halfway done with him. I've now given him ten years of infusions, doctor appointments, sibling fights, teacher-parent conferences and fights over unfinished chores. Have I taught him well? Will he be able to take care of himself? Have I found the right balance of being protective without hovering? As he matures, will he be capable of transitioning from his parent's constant supervision and decision-making to making informed, intelligent choices for himself?

We've tried to give ownership of hemophilia to Thomas in a developmentally appropriate way since he was a toddler. He helped pick out Band-Aids or what color Coban he would use when he was two years old. The pediatric pain chart was a helpful tool in toddlerhood and we worked on giving him the words to tell us when he had a bleed. He started helping push the factor out of the

"We've tried to give Thomas ownership of hemophilia in a developmentally appropriate way since he was a toddler."

syringe by the time he was three or four years old. We set a goal for him of knowing how to mix by the time he entered kindergarten. And summer camp set him on a path of self-infusion by the time he was seven years old. We include him in conversations about treatment decisions



and try to offer explanations of what his hemophilia means, both on a medical level and on a day-to-day level, so that he can begin advocating for himself and teaching others. Just recently, he began calling into the pharmacy each month to place his factor and supply order. I see Thomas beginning to plan ahead for his future - for his independence - when recently he wondered aloud, "I guess I'll need to have a car without a clutch... because if I have a left ankle bleed, I wouldn't be able to drive." I

was both terrified and proud. He's starting to think about those issues - which are ultimately his issues - now. He is proactively problem solving and transitioning from having me doing all the problem solving for him.

I feel like we've done a pretty decent job of teaching him the mechanics of hemophilia, but what about all that other stuff that

comes with growing up - you know, the normal stuff that everyone, bleeding disorder or not, has to learn? Has he learned how to make solid choices about safety? Does he know right from wrong? Can he balance a checkbook? In a lot of cases, no, I have a lot more to teach him. Learning is a continual process. In our family's case, I think we've been hyper-aware about teaching him about his bleeding disorder and need to remember that there's more to life than hemophilia. It's about half past time to teach him other pertinent life skills.

As moms of children who bleed, we spend our kids' entire childhoods (and I'm betting their adulthoods too) worried about their well-being. Every bump and bruise is cause for concern. We wonder if it ever gets any easier and if we'll ever be able to let go.

I'm not sure that moms can ever really let go completely. And maybe we shouldn't. But I don't want to be a helicopter mom, hovering over my kids, not giving them room to grow. I certainly don't want to be the even more extreme "Velcro parent"—attached to a child throughout their college years and into adulthood. These kiddos have to grow up to be independent, strong self-advocates capable of taking care of themselves, so I suppose it's best if I start pushing them out of the nest now, giving them wings to soar on their own. ■■

Sonji Wilkes lives in Colorado with her husband, Nathan, and three children, Nora (11), Thomas (10) and Natalie (7). Sonji is a program consultant with the Hemophilia Federation of America working on HFA's family programming and writes for HFA's weekly Mom's Blog, "Infusing Love: A Mom's View."



35 "Infusing Love" entries since February 2013 

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