Dear HFA Community,

Throughout the year, we hear a lot about giving: buying candy to send kids to camp, car washes for Little League, tickets to a seemingly-endless variety of fundraising events. And at this time of year, we’re almost overpowered by year-end annual appeals, Christmas gift lists, toy for tots, and canned food drives. While it can seem overwhelming at times, giving does feel great, and organizations do need financial support to fuel their efforts. Whether your contribution is $10 or $1,000, you are filling your heart by helping an organization fulfill its mission. I often hear from community members who don’t have large disposable incomes that they are discouraged by their inability to contribute $100 or more to HFA. I assure you that even a $10 or $15 donation to HFA goes a long way within our nonprofit organization, and has a direct and abiding impact on families in this community.

An equally powerful way you can give to HFA is the donation of your time, passion, and energy. I am currently serving my second one-year term as president of HFA. I take much pride in this volunteer role and devote several hours each week to assist our board of directors. Our organization is fueled by dedicated community members and supporters who contribute their time through serving on the board of directors, program committees, or in many other volunteer capacities. The value of this volunteer time is immense and incalculable.

I hope you received the letter from our Executive Director, Kimberly Haugstad, outlining our Helping Hands program’s efforts over the past year. In that missive, we were pleased to announce that HFA dispersed more than $124,000 to community members experiencing financial need in 2014. We expect that we’ll exceed that number for 2015, and 2016 will see an increase in the amount needed to cover requests from our community. If you are in a position to do so, I hope you’ll consider making a financial contribution to support this and all our vital programs. A gift of just $25 can provide a medical ID bracelet, or an elbow or knee brace, to a family who can’t afford one.

Thank you for supporting HFA! The gifts of your time, heart and money are vital to the work we do. I have been an honor and a privilege serving as your president during 2015. I am moved and inspired by the outpouring of love and affirmation from this community and am optimistic about HFA’s year ahead.

Warm regards,

Tracy Cleghorn
Board President

“The gifts of your time, heart, and money are vital to the work we do.”

DISCLAIMER

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Lending a Helping Hand

HFA Supports Community Members and Families by Providing Assistance With:

- Housing Expenses
- Durable Medical Items (e.g., walking supports, protective gear, braces, etc.)
- Utility Expenses
- Transportation Expenses
- “Other” Expenses (e.g., funeral expenses and other emergency expenses)

For more than 18 years, HFA has proudly offered Helping Hands to assist families and individuals experiencing a financial crisis. Helping Hands provides direct assistance to more than 200 families per year, and is generously funded by donors like you.

“IT IS WONDERFUL THAT THERE IS A PROGRAM LIKE HELPING HANDS BECAUSE SOMETIMES WE ARE JUST ONE BAD BLEED AWAY FROM NOT MAKING IT. THANK YOU, THANK YOU, THANK YOU.”
- 2015 Helping Hands recipient

“We were there when we needed you. We appreciate the help you gave us and other families. Sometimes things happen and it’s hard to find the light. HELPING HANDS WAS OUR LIGHT.”
- 2015 Helping Hands recipient

CONSIDER MAKING A GIFT TO HELPING HANDS TODAY:

- $25 provides a medical ID bracelet or elbow or knee braces.
- $50 provides protective gear or a gas card to get to medical visits.
- $100 helps repair a wheelchair or pays an electric bill.
- $500 or more pays rent or puts new tires on a car.

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OVER $124,000 DISTRIBUTED IN DIRECT AID TO 275 FAMILIES

ESTIMATED $145,000 DISTRIBUTED IN DIRECT AID TO OVER 275 FAMILIES

WE NEED YOUR SUPPORT FOR AN ANTICIPATED INCREASE IN COMMUNITY NEEDS

Winter 2015 | Dateline Federation 3
Thanks to our amazing riders, volunteers, and corporate sponsors, we have reached our goal of RAISING OVER $110,000* for our Helping Hands program in 2015!

100% OF THE CONTRIBUTIONS raised by all individual donors will go to providing families and patients in need with immediate financial assistance for expenses like housing, utilities, transportation, and other medically necessary items.

*unaudited number

In 1997, we began our Helping Hands program to provide financial assistance for basic living expenses (housing, utilities, and transportation related costs) to individuals and families experiencing hardships related to their bleeding disorders. We work with applicants to connect them to their local community resources and empower individuals and families to advocate for themselves.

To help sustain and support Helping Hands while raising awareness for bleeding conditions and promoting healthy living, we created our annual Gears for Good charity bike ride.

SECOND ANNUAL REGIONAL RIDE
Farmington Canal Heritage Trail
June 26-28
70 MILES
26 RIDERS

26 riders arrived in Farmington, Connecticut on a late Friday afternoon in June to get ready for an unforgettable weekend. Members of the bleeding disorders community in New England, as well as from Florida and Pennsylvania, were preparing to raise funds for the second regional Gears for Good bike ride. These amazing individuals pedaled with a purpose and completed the 70 mile challenge to raise funds for HFA’s Helping Hands program.
THANK YOU!

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Dates and locations for the 2016 Gears for Good rides will be announced in February 2016. For more information visit: www.hemophiliasfed.org

“We were so glad to be riding to support this community, and to now be part of this family.”
– Meredith and Bob, regional riders

“This ride helps an organization that does so much good for people with bleeding disorders.”
– Michael, regional and national rider
FIFTH ANNUAL NATIONAL RIDE
C&O Canal
September 25-27

156 MILES
27 RIDERS

For the fifth year, riders once again gathered to pedal 156 miles from Paw Paw, West Virginia to Washington, DC to help raise awareness and funds for our Helpings Hands program. Community members, industry friends, and supporters of the community spent 3 days pushing themselves while sharing experiences, laughter, and tears as they completed this physical challenge. In addition to raising critical funds, riders handed out educational cards at rest stops in an effort to help educate others riding about bleeding disorders.
“It's all about what you can do, not what you can't. We're riding as a family to support our community, and to show each other that anything is possible.”

– Ann, regional rider
COMMITTEE PERSPECTIVES:
PAIN MANAGEMENT & PRESCRIPTION DRUGS

Almost every family has been affected by addiction in some capacity. Be it from alcohol, drugs, or gambling, most can tell a story of how addiction has impacted their life. The bleeding disorders community is no exception, and in many situations being a member of this community puts individuals in high-risk situations to develop an addiction to narcotics. HFA asked community members to share their perspectives on pain management and prescription drugs. Names of contributors have been changed to protect their identities.

I became addicted to painkillers at the age of 13 or 14. After I broke my ankle and had screws surgically implanted to repair the fracture, I was prescribed painkillers and that’s when I started abusing pills.

At first it was pleasant, even enjoyable, but I gradually began feeling helpless. I started showing signs of dependency and addiction, so my doctors stopped the prescriptions. Then I started stealing medications from family and friends, combining other drugs with the painkillers. I ultimately put myself in debt to feed my addiction.

My mother found out that I had stolen pills out of her medicine cabinet and confronted me about it, a discussion that prompted the decision to go to rehab. After three days of treatment, I decided that I was “better” and no longer in need of help. I couldn’t have been more wrong: I relapsed within a month. It was then I started using needles to take drugs intravenously and continued down that road for about a year, feeling bad about myself but not being able to stop on my own. I was a failure and a disappointment to myself and my family.

I hid my track marks by wearing long sleeves all the time but eventually this ruse, and my other stratagems to avoid detection, began to take their toll. I finally decided it was time to make a change. I told my mom I had relapsed and needed to go back to rehab; she took me that same day. I was in rehab for 30 days and have now been sober for almost two years. It feels great! I recently turned 21 and am feeling good about life.

If you or someone you know is dependent on or addicted to painkillers, do not be ashamed to ask for help: we have an epidemic on our hands and there have already been too many casualties.

John, 21 years old, severe hemophilia A with an inhibitor

“DO NOT BE ASHAMED TO ASK FOR HELP.”
We never expected to be here. We never expected to be this emotionally drained. We miss Alex; he would just have celebrated his 22nd birthday. We had so many hopes, dreams, and expectations that will now never be realized and we never expected to be in so much pain. A part of us died as well.

As a society, we don’t like to talk about addiction. It’s uncomfortable and difficult to admit that we have issues with narcotics, heroin, and methamphetamine. The social stigma associated with addiction brings shame, guilt, and isolation. Yet, in the United States, death from drug overdose has increased over 400% since 1999. We have a public health epidemic on our hands that is not being addressed adequately. We need to talk about this and will not be silent.

People ask us when Alex’s addiction started. That’s a tough question to answer. He had used narcotics for pain control for as long as we can remember. He had several bad joint bleeds and surgeries for which pain medication was necessary. We’ve talked with many addicts over the last year who became addicted to opioids following sports injuries or orthopedic surgeries. They had no idea that the pain would be as intense as it was and compensated for it by taking more medication than was prescribed. And when their prescriptions ran out, they started “borrowing” from friends and neighbors who might have leftover medications in their medicine cabinets.

We realize now that there are many people with hemophilia fighting addiction. Since Alex’s death, many individuals have shared their own struggles, or their children’s struggles, with us. It is heartbreaking to see the pain in the eyes of so many blood brothers. It is heartbreaking to hear a mother tell us that she is waiting for the phone call that will inform her that her son has died. These conversations are happening all too often.

People seek us out, needing to tell their stories. Addiction within the bleeding disorder community is sadly all too prevalent. Hemophilia is a painful condition that often results in acute bleeding episodes which in turn cause acute pain. This acute pain then leads to anatomical changes that can cause chronic pain. Chronic pain has a ripple effect, often leading to lost time from work, a loss of self-confidence, depression, and social isolation. Individuals in our community are generally skilled and comfortable with the self-administration of IV medications. While the fear of venipuncture is a deterrent for most novice heroin users, this is not the case for our community—and that is a recipe for disaster.

Pain exists, so we treat it. Pain medications are easy to obtain: well-intentioned practitioners liberally prescribe opioid medications to provide relief. Scrips can come from multiple prescribers such as hematologists and primary care physicians, but rarely from pain specialists. We doubt most people understand the dangers of dependence and addiction arising from the use of these medications. Are our brothers being properly counseled about these risks? Are they provided advice on what to do if they feel they are becoming dependent or addicted? Do they even know what signs to look out for? It can be really difficult for someone with hemophilia to approach their HTC treatment team and admit to addiction for fear that the physicians will take their pain pills away.

Though public opinion is slowly changing, many people continue to view addiction as a character flaw; we know we used to think this ourselves, but it’s not. Addiction is a disease, as much as hemophilia is a disorder, and we have to treat it accordingly.

We were particularly frustrated to discover that many detoxification programs refused to treat Alex for addiction simply because he had hemophilia. We’d get approval to check in, but when we arrived there was always a complication. “We’re sorry, we can’t handle that here” was a common phrase. We’d be handed brochures for others programs accompanied by a comments like “you might want to try this one.”

We called them all and visited most. We were told IV administration of medications would be a “trigger” for others at the center and that it might cause them to relapse. It was only with the help of our HTC and extreme persistence that he was ever admitted. The centers were understandably concerned about their own liabilities. But that meant Alex had to hide in a small room at the recovery center to administer his factor and that took a toll on his self-esteem.

We knew Alex was struggling with addiction, having been through detox programs a couple of times, but never realized how close he was to dying. When he finally agreed to attend an inpatient treatment program that accepted him, and he completed 34 days at the center, we thought he was on the road to recovery. We always assumed that he would beat it: he was a fighter. But addiction can spiral out of control faster than anyone might anticipate. Five days after leaving the recovery center, he was dead.

David and Katie, parents of two sons with severe hemophilia A

Addiction can spiral out of control faster than anyone might anticipate.”
Children do not come with instruction manuals. Even if they did, of course, it wouldn’t have helped me—unless the manual included a section on children born with severe hemophilia A, who developed inhibitors, and who became addicted to prescription pain pills.

The past three years have been a struggle for our family. “When did this happen?” I asked myself, when I realized that my middle son, Calvin, was a full-blown addict. As a mother of three boys with severe hemophilia A, and being affected myself, I never imagined that two of my three boys would also become addicts. So while I may have suspected it a few years ago, I ignored the signs. Calvin would say he was having a bleed though there were no obvious reasons to be bleeding. He would say he had taken his factor but it wasn’t helping, and would ask if he could have something for the pain. I would offer Tylenol and he would reply “you know that doesn’t work for me.” I only wanted to take my child’s pain away and honestly didn’t think about the risks of addiction while doing so.

I was alarmed by the frequency with which he was amassing injuries, not realizing he was injuring himself on purpose so that he could obtain more pain pills. When those quantities didn’t satisfy him any longer, he began buying pills on the street. Who would have thought that the lunch money I was giving him weekly was going to buy narcotics from other kids at school?

I noticed that Calvin was dealing with nausea, diarrhea, moodiness, and a lack of appetite. After a month of observing these symptoms, I confronted him and told him he was going to rehab. I didn’t realize at the time that unless an addict is ready, rehab does not work. Since Calvin was now technically an adult, he was able to check himself out early, still in the clutches of his addiction. It was an entire year later when he finally ended up asking for help on his own and checked back into rehab.

I feel such guilt after watching my son become addicted to the narcotic pain pills that I gave him. I now believe that if we as parents ease our children’s pain with narcotics, it can become expected, even routine. My youngest has bravely said to me “pain is just weakness leaving the body.” I hope we can teach our children that learning to deal with pain shows us that we are stronger than pills.

Sarah, mom to three boys with severe hemophilia A and inhibitors

I agree it is important to consider the risks of opiate addiction. But let’s also keep in mind the danger of under-treatment of pain. In the mid-20th century, public focus on opiate addiction was so powerful that people with hemophilia were denied effective pain therapy and instead were given drugs that were worse than useless.

Darvon, enhanced with aspirin or acetaminophen, was the drug of choice for hemophilia patients with moderate-to-severe pain from 1957 to about 1970. It was initially advertised with claims that it was equivalent to codeine in pain relief but came with fewer side effects and posed less of a risk of developing an addiction. Darvon is now widely described as the worst drug ever prescribed because of its numerous side effects and low efficacy. And taking aspirin, a component of Darvon compound, can be disastrous for people with bleeding disorders, as it carries with it an increased risk of bleeding.

Mark, Blood Brother, severe hemophilia A

In conversations with my blood brothers about issues related to pain, I have found many who rely on medications. They take a couple hydrocodone pills in the morning and just a few hours later they take oxycodone for joint pain. This routine is followed regularly, sometimes totaling two or three different types of pain medications in a single day.

This is their “normal.” I often ask them how they can function during the day. I’m personally worried to use pain medication for fear of becoming addicted. Even in a hospital setting I refuse the pain medications when they are prescribed: I’ve become paranoid.

I wonder where we are headed. Hospitals now have pain management clinics and while I think that helps, we need to lean on each other more. This is a subject that definitely needs to be talked about.

Anthony, Blood Brother, severe hemophilia A

We need to talk about this and will not be SILENT.”
OPIOIDS & ADDICTION

By Erika Mora, PharmD

It is recognized in the hemophilia community that opioid medications can be a helpful addition to the treatment plan for patients experiencing refractory acute pain, as well as for those with long-standing chronic pain resulting from joint disease. Opioids as a class of drugs are used for many types of pain. According to the Centers for Disease Control and Prevention in 2012, healthcare providers wrote 259 million prescriptions for opioids, a number that had actually leveled off after decades of escalation. This leveling off is likely due to increasing awareness of opioid abuse, underscored by the fact that each day 46 people die from an overdose of prescription painkillers in the US (CDC). Clearly, despite being a highly effective medication class, awareness of the potential for harm needs to be discussed.

Opioids have a distinct place in the treatment of patients with hemophilia who are experiencing severe acute pain or chronic pain and are unresponsive to non-steroidal anti-inflammatory drugs (NSAIDs). Because of the biochemical processes that take place when opioids are administered, varying degrees of tolerance and physical dependence can be expected over time with chronic exposure. Physicians, particularly pain experts, are well versed in navigating these effects safely with patients who require opioid therapy, however this requires that the patient and the prescribing physician develop a plan for appropriate opioid use that is closely followed. Certain patients are at a much higher risk of developing addiction and physicians should be aware of these risk factors. Patients displaying addictive tendencies should undergo a multidisciplinary evaluation with their primary hemophilia physician, a mental health expert, and an addiction specialist.

Erika Mora is a Clinical Pharmacist Specialist practicing in inpatient hematology and oncology at the University of Michigan CS Mott Children’s Hospital in Ann Arbor, Michigan. Mora graduated with her PharmD degree from the University of Georgia and completed post-graduate residencies at Northeast Georgia Health System and Mayo Clinic. She has been in her current position for six years.

**Tolerance**
- A need for a greater amount of a drug to maintain the therapeutic effect with the loss of efficacy over time.

**Dependence (Physical)**
- Neurochemical changes in the body require continued use of the substance. Withdrawal syndrome occurs if the medication is discontinued, the dose is substantially decreased, or an antagonist is administered.

**Addiction (Psychological Dependence)**
- A psychiatric disorder characterized by continued compulsive use of a substance despite harm to the patient. Effects from the use of the medication are desired and reinforce continued use.
Finding and securing employment can be an exciting, if stressful, process. For those living with a bleeding disorder, the challenges are amplified. A job providing flexibility and adequate insurance benefits from an employer who upholds and respects the rights of a person living with a chronic disorder is not simply a ‘nice to have,’ but an absolute necessity. Given that young adults with bleeding disorders tend to have a strong connection with the bleeding disorders community, many find that employment within the community can provide a perfect fit for their skills and passions. Juggling these roles however can create ethical issues around developing boundaries, managing dual roles, clarifying conflicts of interest, maintaining confidentiality, and using social media and other communication technology in a thoughtful, responsible way.

In October, HFA hosted a Young Adult Hangout to explore this topic further, discussing the challenges associated with members of the bleeding disorders community working in that community. The featured panelists share their highlights.

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“It is a true honor to be able to work as a part of the community. My interest in a public policy career was driven by my passion for advocacy in the bleeding disorders community. My role in the Public Affairs Department includes government affairs, advocacy, and patient organization relations which allows me to maintain a high level of engagement with the issues that are important to people with bleeding disorders and to help support those initiatives. When it comes to maintaining boundaries as a member of the community and working for industry, I find that transparency and honesty are incredibly important. I am always upfront about my employment with industry and the fact that I am a hemophilia carrier. I feel that this helps to build a level of trust, as well as keep the lines of communication clear.”

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“It is an honor and a privilege to belong to, and work in, the bleeding disorder community. In order to maintain boundaries, first and foremost, it is important to make sure you are working for an organization whose value system aligns with your own. I understand that no matter where my career takes me, I will always be a man who has hemophilia, and because I greatly value that connection, I always act with the best interest of the community or individual at heart. Honoring that connection and using my core value system as a compass keeps me on the right path.”
THINKING ABOUT WORKING IN THE COMMUNITY?

Do your homework.
What are the values and policies of the company? Do they align with your own values? Talk to your potential employers to learn what your specific role would be and what you’re expected to bring to the table. Most importantly, listen to your gut to determine if it’s the best fit for you.

Be transparent.
When you are juggling the dual roles as a community member and employee, it is critical to communicate your purpose and role clearly and always disclose that you are employed by your company.

Confidentiality is king.
When working in our community, you will inevitably learn information about community members. It is up to you to respect the privacy and confidentiality of others and not to disclose this information, especially if it involves people you know on a personal level.

Conflicts of interest are inevitable.
You may have to step down from certain volunteer roles within the community because of your employment. While this may be temporarily disheartening, it is critical to keep community members’ interests in the forefront.

Think before you post.
While social media can be a great tool to connect and engage with our community, it can also be an easy way to blur the lines between the personal and professional. Post and share topics and pictures that you would be comfortable with anyone seeing: your employer, your best friend, your grandmother, your client/customer, et al.

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Growing up with hemophilia made waking up with bruises, joint pain, or the inability to bear weight on my ankles a normal occurrence. Time and time again, my mother had to drive me to the local hematology clinic to have factor infused. I did not feel like a normal child. I let hemophilia bring me down and hold me back from living the life I wanted to live.

During a clinic visit when I was 12, my hematologist encouraged me to become more physically active. He suggested aquatics and that ignited a glimmer of hope within me. He explained that aquatic activity would exercise my joints in an unstressed environment. It was time to stop letting hemophilia hold me back and start working towards feeling like the other children. I was full of determination, and began a routine of aquatic therapy, weight training, and healthy eating. Just a year later I was infusing only on a prophylaxis regimen; I’d lost weight; and I’d actually begun playing basketball: I had never felt better! There was no turning back!

“It was time to stop letting hemophilia hold me back.”

For the past 13 years I’ve worked hard to prevent complications and joint bleeds by eating healthy foods, infusing independently on a prophylactic basis, participating in activities including aquatic exercise, running, weight lifting, and basketball, and being aware of my surroundings. The changes I saw in the way I looked and felt, and my ability to overcome the challenges of hemophilia and manage my bleeding disorder, motivated me to pursue a career in physical therapy. In 2014, I graduated from Chatham University with a Doctorate in Physical Therapy and began working in an orthopedic clinic in Old Bridge, New Jersey.

I am an advocate for aquatic therapy in conjunction with land-based exercise. I seek to motivate others with bleeding disorders to feel better both physically and emotionally. Recently, I developed a relationship with HFA through their Blood Brotherhood program to inspire individuals of all ages to stay active and ensure that they are never timid about pursuing an activity simply because of their bleeding disorder. I have been fortunate to have given several presentations on exercising with a bleeding disorder to the Blood Brothers of New Jersey, Indiana, and Rhode Island. Topics in those presentations have ranged from sharing pain management strategies, to discussing safe sports for the dads who have kids with hemophilia, to an actual aquatics exercise session. In March 2016 I will be presenting an aquatic therapy session for individuals with bleeding disorders at HFA’s Symposium in Las Vegas, Nevada.

At 26 years old, I look back at the past half of my life and take pride in my hard work. I’ve pursued a healthy lifestyle, suffered no major joint bleeds, and have now run three marathons in one year. I’ll continue eating healthy foods, training with weights five or six days a week, and bringing my story to hemophiliacs across the country to persuade everyone: never settle for life as a couch potato!

I encourage everyone to participate in aquatics for all the health benefits it provides and I invite all who are interested in learning more to join me at this year’s Symposium, being held from March 31 to April 2, 2016 in Las Vegas, Nevada.
Aquatic Therapy

What the research says:

• The biggest benefit to working out in the pool is that the patient can offload about 65% of his or her body weight through the buoyancy of the water. That helps increase strength and function, free up range of motion, and reduce swelling and pain.1

• Implementing a training program comprising 30-minute sessions each of swimming, cycling, basketball, and yoga 3x/week will significantly reduce hemarthrosis (bleeding into the joint) and increase range of motion.2

• Aquatic exercise statistically and significantly improves knee and hip flexibility, strength and aerobic fitness. A recent study showed that an overwhelming majority (81.7%) of people were able to stick with the program and no exercise-related adverse effect was observed or reported.3

• Other positive effects of aquatic therapy include: a decrease in fatigue levels and an increase in aerobic capacity; weight loss at the waist (50%) and neck (85%); decreased heart rate and blood pressure while in the water; improvement of blood circulation to the muscles; relaxation of muscles for a better stretch; enhanced mobility; added pain relief; more controlled breathing; and the benefit of being able to exercise multiple joints at the same time.4

1“Physical Therapy and Aquatic Therapy: Land and Pool Based Therapy for Those with Bleeding Disorders,” Hemaware, 2012
2“The Effect of Aquatic Exercise Therapy on Muscle Strength and Joint’s Range of Motion in Hemophilia Patients.” 2013
3“Effects of aquatic exercise on flexibility, strength and aerobic fitness in adults with osteoarthritis of the hip or knee.” 2007
4“The effect of aquatic exercise therapy on muscle strength and joint’s range of motion in hemophilia patients.” 2013
SAFETY TIPS:

- Check with your health care provider, physical therapist, or HTC to make sure aquatic exercise is right for you.
- Wear water shoes to prevent cuts while in the water as well as ankle bleeds from contact with the hard surface.
- Seek out a physical therapist to supervise your first couple of sessions.
- Be monitored by someone if you’re not yet a confident swimmer.
- Take it easy! Don’t overwork! Your muscles will be sore later even if they do not feel like they are working in the water.

Aquatic Exercises to Try:

WALKING
Walking forward and backward in chest-high water works the leg muscles while exerting no impact of the knees or hips. This is particularly important for people who have arthritis in those joints.

SIDE LUNGE
Face the pool wall and take an oversized step to the side. Keep toes facing the wall of the pool. Repeat on the other side. Try three sets of 10 lunge steps. For variation, you can lunge-walk in a forward or sideways direction instead of standing in place.

PUSH-UPS
While standing in the water by the side of the pool, place your hands shoulder-width apart on pool edge. Press weight through your hands and raise your body up half-way out of the water, keeping elbows slightly bent. Hold for three seconds and slowly lower into pool.

Michael Zolotnitsky is an orthopedic physical therapist in Old Bridge, New Jersey, specializing in working with post-surgical patients, young athletes, older adults, people with post-concussion syndrome, and patients with neurological disorders such as multiple sclerosis and Parkinson’s disease. He was diagnosed with severe hemophilia A as a child and is committed to helping individuals in the bleeding disorder community. His long-term goal is to conduct research on developing exercise regimes that are safe for people with bleeding disorders, in order to encourage everyone to prevent bleeds and live a long, healthy life through physical activity.

*Before beginning any new activity, or if you are having joint or bleeding problems, make sure you check with your physician or physical therapist.
Thank You! Your support makes it possible to serve our community nationwide!

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Erik von Willebrand, a Finnish physician, noticed several young girls in one family shared symptoms of a bleeding disorder. The year was 1924, and von Willebrand recognized that the girls’ symptoms were different from those of someone with hemophilia, a disease mostly affecting males. He called this new disease pseudohemophilia, or false hemophilia, but others later attached his name in acknowledgment of his important discovery.

Von Willebrand disease, or VWD, is a genetic bleeding disorder affecting the blood’s ability to clot. It occurs in both men and women and can be passed on by either parent to their children. Often it happens in families in which many family members may have bleeding symptoms and may simply have been called “free bleeders.” It is also possible for VWD to appear in a person who has no family history of bleeding. Having VWD results in lifelong symptoms ranging in severity from minor and annoying to life-threatening.

Symptoms of VWD often appear first in childhood but the disorder is not always diagnosed until later in life. Bleeding in the nose and mouth, excessive bruising, and bleeding that is difficult to stop after an injury or surgery are all early signs that someone may have VWD. A person may reach his or her teen years or adulthood without doctors properly diagnosing the problem. Identifying VWD in women most often happens when it causes major bleeding after surgery or childbirth, however there are clues that can aid in early detection:

- Frequent nosebleeds that happen less often after puberty.
- Large bruises from unknown causes.
- Heavy menstrual periods from the start of puberty.
Most women and girls with VWD experience heavy periods that can include bleeding for more than seven days, flooding or gushing blood, passing clots larger than a quarter, or having the need to change a pad or tampon every few hours. Women with these menstrual symptoms should be tested for VWD and other bleeding disorders if they also have a family history of bleeding, additional bleeding symptoms themselves, or anemia. The Centers for Disease Control (CDC) website, www.cdc.gov, offers a questionnaire designed to help women with heavy periods decide whether they should be tested. HFA has developed an app that is available for download on mobile devices to help women keep track of their bleeding and accurately communicate about it with their doctors. Men may likewise be diagnosed with VWD after injury or surgery. They may also be misdiagnosed as having hemophilia, however, which can lead to ineffective treatment.

To make a diagnosis of VWD, a doctor will need to perform a number of standard blood clotting tests, possibly including prothrombin time (PT), partial thromboplastin time (PTT), fibrinogen, and platelet function analyzer (PFA) tests to rule out other disorders.

Tests for von Willebrand factor (VWF), the specific protein that is deficient or defective in people with VWD, must also be performed. These tests typically include:

- VWF antigen test, measuring the quantity of von Willebrand factor.
- VWF activity test, allowing doctors to evaluate the function of the von Willebrand factor.
- Factor VIII activity test, allowing doctors to evaluate the functioning of the factor VIII protein.
If any of these tests is abnormal, additional testing will be required to determine the type of VWD present in the patient, helping doctors decide the best course of treatment. On occasion, tests may need to be run more than once to be certain that VWD is present because test results may change over time. Tests specific to VWD are not available at all doctors’ offices and hospitals. To find out where testing can be done, a doctor or patient can contact a hemophilia treatment center or a local hemophilia organization.

Once VWD is diagnosed and the type is known, a treatment plan can be made. There are three major types of VWD. About 85% of people living with VWD, have Type 1 VWD, caused by having too little VWF. Type 2 VWD is caused by the body’s production of abnormal VWF. Type 3 VWD is caused when VWF is totally absent. Type 3 VWD is rare, affecting only about 3% of people with VWD, and causes more severe symptoms, sometimes including bleeding inside the joints.

At the moment, two treatments exist for VWD. Desmopressin, or DDAV, is a drug often used to treat VWD. It can be dispensed as a nasal spray, often done to ameliorate the effects of a heavy menstrual period, or intravenously for a longer lasting effect. It is typically used to control most bleeding that occurs in people with Type 1 VWD. For post-surgical bleeding that requires extended and stronger control, and for most bleeding in Type 2 and Type 3 VWD patients, concentrated VWF is administered intravenously to replace the defective or missing VWF.

With early diagnosis of VWD, treatment can be given to prevent bleeding and allow any surgical or dental procedure to be done with minimal adverse effects. It is important that every doctor and dentist know that a patient has VWD before any procedure is undertaken and that a doctor with experience with VWD prescribe the appropriate treatment. The weakening, fatigue and other disruptive effects of VWD can be stopped. Even childbirth can be made safe for a mother and baby. If you have unexplained bleeding symptoms, remember to ask your doctor, “Could I have von Willebrand disease?”

Connie H. Miller, PhD, has studied genetic and laboratory aspects of von Willebrand disease and hemophilia for 40 years. She has recently retired from the Atlanta Centers for Disease Control and Prevention’s National Center on Birth Defects and Developmental Disabilities’ Division of Blood Disorders and continues to work as a consultant to that group. She can be reached by email at cmiller2@cdc.gov.

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Do you have heavy periods?

**If so, you might have a bleeding disorder.**

A bleeding disorder is a condition that keeps your blood from clotting properly after a cut or injury. Women are more likely to notice the symptoms of a bleeding disorder because of heavy or abnormal bleeding during their menstrual periods and after childbirth.

**SIGNS AND SYMPTOMS OF A BLEEDING DISORDER:**

- I have heavy menstrual periods, such as:
  - Bleeding for more than 7 days from the time bleeding begins before it completely stops.
  - Flooding or gushing of blood that limits daily activities such as housework, exercise, or social activities.
  - Passing clots that are bigger than a quarter.
  - Changing a tampon or pad, possibly even both, every hour or more often on heaviest day(s).

- I have been told I am “low in iron” or I have received treatment for anemia.

- I have experienced heavy bleeding after dental surgery, other surgery, or childbirth.

- I have experienced prolonged bleeding episodes such as might occur as a result of:
  - Dental surgery, other surgery, or childbirth;
  - Frequent nose bleeds (longer than 10 minutes);
  - Bleeding from cuts or injury (longer than 5 minutes); or
  - Easy bruising (weekly, raised, and larger than a quarter in size).

- I have one or more of the bleeding symptoms above and someone in my family has a bleeding disorder such as von Willebrand disease or a clotting factor deficiency such as hemophilia.

If you have one or more of these signs and symptoms, please talk with your doctor or other health care professional.

Source: Centers for Disease Control and Prevention
Remembering A Gentle Giant: Joe Caronna

Joe Caronna passed away on Thursday, September 10, 2015. Joe dedicated his life to raising awareness about bleeding disorders through his educational workshops. Through these workshops, Joe gave thousands of people from our community the tools to become stronger advocates for themselves and their families. In HFA’s earlier years, Joe served on key committees to help create content for the programs we have today. Joe will be missed by everyone who knew him. Joe was the past president of the Hemophilia Association of New Jersey (HANJ). Rich Vogel, current president of HANJ, shares some reflections on Joe’s extraordinary life:

1. How would you describe Joe?
   Joe was a dedicated husband, father, and friend. Joe was larger than life. He lit up a room with warmth, compassion, and humor.

2. What made his contributions to the bleeding disorder community unique?
   Joe was devastated when his son Alex was diagnosed with hemophilia. He liked to be in control of all situations and this diagnosis was outside his authority. He started doing research to gather as much information as he could and found that the bleeding disorders community lacked a support system. There were new family ‘buddy systems,’ but this was not enough for Joe. He was determined to provide a support system where families, patients, and caregivers could connect. To accomplish this, Joe developed educational programs, workshops, and retreats. He invested much time into researching speakers, reading their books, and hearing them speak before committing to using them in workshops. In an effort to reach more people, Joe began producing a video series called A Bright Future.

3. How will HANJ remember Joe?
   Joe will be remembered as a warm-hearted man, willing to do anything for the community he loved with passion. He will be greatly missed.

4. What legacy does Joe leave behind?
   Joe’s legacy will live on through the continuation of Inalex Communications, the A Bright Future DVD series, his wife Cathy, and his children, Alex and Christina, who will continue to bring new and exciting programs to the hemophilia community.
My internship with HFA involved working on a variety of rewarding advocacy projects and provided me with the opportunity to explore our nation’s capital. As a member of the policy and government relations team, I learned about funding for federal agencies and the appropriations process, federal specialty tier legislation, and state pharmacy bills. A highlight of the experience was when I was able to speak directly with senators and representatives on Capitol Hill about the issues facing people with hemophilia as well as others in the patient community. Being on the Hill and advocating for important policy is an exhilarating experience. In my capacity as an HFA intern I was given the opportunity to tour a plasma collection facility, something I could appreciate as a hemophiliac who uses plasma products, witnessing first-hand the effort that goes into the donation and processing of these life-saving resources.

I did real work on real issues that I knew would help many people in our community, giving me a feeling of satisfaction that is hard to convey in mere words. I had the pleasure of meeting with community members from around the country, many of whom had been advocating for decades themselves and had amazing stories to tell. I find purpose in advocating and speaking up for those who cannot, and this internship helped me to develop that passion while providing me with the experience and skills to do so meaningfully. I plan to continue advocating for my community and am more prepared and more focused than ever before because of my internship with HFA.

During this time of personal and professional development I also had the valuable opportunity to live in the heart of our nation. Washington, DC is one of my favorite cities and I had many enjoyable experiences with my roommates, one of whom was an HFA coworker, and the other interns living in the building. Fridays were spent listening to live jazz music in the Smithsonian Sculpture Garden, often with up to two thousand people also in attendance. I was able to spend time touring the many museums, landmarks, and local sites that are off the beaten path for most tourists. I also made new friends with whom I keep in contact with and share fond memories. My two favorite things about the city, however, were the energy of the place and, funnily enough, the food! The palpable sense of vibrancy in DC stemmed from the impression that everyone always seemed to be going somewhere important. No matter what building you might see, chances were that something significant was happening inside. And then there was the food: amazing! I would often stop at one of the countless food trucks lining the streets to purchase a gyros or shawarma, eager to sample just some of the delicious and exotic foods from around the world. On one occasion, I even went to the fish market to buy live crab for dinner, something I’d never done at home!

My internship provided me many wonderful memories and it is an experience I will cherish for the rest of my life. The chance to spend a summer in the nation's capital doesn’t come around very often, if at all. I feel so fortunate to have had the opportunity to look out from my balcony each night with the Washington, DC skyline in sight, and ponder where the next day, and next opportunity, might take me.

Below: Adam meeting with Senator Elizabeth Warren’s aide during HFA’s Community Fly-In, June 2015.
Two summers ago, HFA launched an internship program based in its Washington, DC office for young adults interested in advocacy, policy, and government relations. Opportunities for young people to become involved abound within the bleeding disorders community. At HFA however, we are specifically seeking to develop a passion in individuals for health care policy and self-advocacy, so that they return home committed to continuing their advocacy leadership.

Advocacy is at the core of HFA’s mission and we strive to educate our future leaders about the issues that affect our community. We want our interns to follow along the path of the many advocates who came before them and accomplished amazing things, like securing the passage of the Ricky Ray Hemophilia Relief Fund Act or successfully working with the FDA to implement procedures that greatly improved the safety of the blood supply. Our intern program truly speaks to one of the main adages of HFA: “Honoring Our Past, Building Our Future!”

Last summer, two members of the bleeding disorders community spent 10 weeks at the HFA office in Washington, DC participating in, and contributing to, all of the efforts of our policy and government relations team. Specifically, the interns:

- Received legislative, policy, and advocacy training.
- Built communication and media skills.
- Attended congressional hearings and made visits to offices on Capitol Hill.
- Collaborated on activities with partners and coalitions including the National Organization for Rare Disorders (NORD), American Plasma Users Coalition (APLUS), Coalition for Accessible Treatment (CAT), and Plasma Protein Therapeutics Association (PPTA).
- Authored at least one policy work paper or issue brief.
- Supported staff on activities including HFA’s advocacy blog Dear Addy, Action Alerts, and social media outreach.
- Assisted a local member organization in planning their 2016 legislative day.
- Assisted a local member organization in reading and analyzing state legislation.
- Gained valuable exposure to the workings of state and federal government.
- Developed a comprehensive understanding of HFA’s programming and services, and how it serves the national bleeding disorders community.
- Improved skills, knowledge, and abilities in order to participate actively in the public policy process.

Over the past two years, we have been delighted to have had four remarkable interns and are currently looking for two young adults to participate in the 2016 program which runs from June 2016 to August 2016. If you know of any current or recently graduated college students who are community members and have an interest in health advocacy, please encourage them to apply!
Do you have a budding chef or nutrition expert in your home? Do they like to see themselves on camera? Do you want to win a trip to sunny Las Vegas for Symposium in March? Then this is your thing!

HFA would like to showcase what the youngest members of our community know about eating healthy and being physically active, in hopes of inspiring others to do the same!

Simply submit a video clip of your child/children sharing what healthy eating and healthy choices means to them and your family will be entered to win our grand prize — a trip for the child and one accompanying adult to HFA’s Symposium! What’s more, your child/children could be featured or included in an HFA-produced video about children’s nutrition that will be shown online and at live events around the country.

Here are a few questions that your child/children can answer about nutrition in the video submission:

- Why is it important to eat healthy foods?
- What foods are important to eat?
- How does eating healthy make you feel?
- Where did you learn to eat healthy?
- What is your favorite healthy food?
- What is a healthy diet?
- What is your favorite physical activity?

FREQUENTLY ASKED QUESTIONS:

What is the purpose of the video?
To raise awareness of the importance of a healthy diet and maintaining a healthy weight in children with bleeding disorders and their families.

Who can enter?
Any child in the bleeding disorder community, between the ages of 4-13 years old.

When can I submit my entry/entries?
Entries can be submitted through February 15, 2016. No late entries will be accepted.

How many videos can you submit?
There is no limit to the number of entries you submit. However all material must pertain to the questions/topic as stated above.

Can videos be submitted any way other than by uploading to the contest?
Unfortunately no. In order to submit a video, you will have to use the link located on HFA’s website.

How long should the videos be?
Video submissions should be no more than 1-2 minutes in length.

Are there prizes?
Yes! Everyone who submits a video will be entered, and one randomly drawn grand prize winner will receive a trip (airfare & hotel) to Symposium 2016 in Las Vegas, NV for the child entered and one accompanying adult. Other children featured in the video will receive a gift card to Whole Foods. (winner must reside in the United States)

How will you be notified?
Winners will be notified via email by February 20, 2016.

Who is sponsoring this contest?
This project is supported by a charitable donation from Novo Nordisk.

Do the sponsors have rights to use/maintain the footage I submit?
No, the sponsors will not be able use your video, name, or information.

Food photos courtesy: www.superkidsbook.com
Entries will be judged by HFA staff and a winner will be determined based on the following criteria:

1. **Meets guidelines.** Follows length and content requirements.

2. **Quality.** Clarity of communicating accurate messages for healthy eating and physical activity.

3. **Creativity & originality.** Contains creative, new ideas and ways to show a healthy lifestyle that can be replicated.

By submitting an entry, you give HFA the permission to use the video content for its intended purpose and for promotional purposes. The submission of your entry is your permission for HFA to use and distribute any/all of your submitted material.

Deadline to submit a video is February 15, 2016

Submit your entry online at www.hemophiliafed.org
HFA Receives Donation of VeinViewer Flex
By Sonji Wilkes

Christie Medical Holdings Inc., a global leader in portable vein imaging systems to aid in venipuncture procedures, has donated a VeinViewer Flex to HFA as part of the Christie CARES philanthropy program.

The primary treatment that bleeding disorder patients use to control or prevent bleeds consists of intravenous infusions of clotting factor replacement therapy. Many patients and their families learn to self-infuse these products at home, and those with severe hemophilia, may be infusing multiple times per week. HFA conducted a study in 2013 that found 48 percent of parents identified infusions and venous access as high concerns. As a result, HFA developed an educational curriculum and published resources online to offer tips and tricks for smoother infusions.

Since 2004, HFA’s Dads in Action and Moms in Action programs have provided education, support, and outreach to parents of children with bleeding disorders. These programs offer local and national educational sessions, online resources, webcasts, and printed materials. In November, HFA used the donated VeinViewer Flex at the Hemophilia of North Carolina’s annual family retreat and will use it at Symposium and local meetings throughout the country in 2016. With the assistance of trained medical personnel, community members will be able to see their veins and practice self-infusion techniques.

“Many in our community experience great difficulty accessing their own or their child’s veins. Giving families the confidence to continue working toward independently infusing at home is crucial to improving the quality of life for bleeding disorder patients. We are so fortunate and thankful that we are now able to incorporate VeinViewer into our educational programming.”
- Kimberly Haugstad, HFA Executive Director

“Recently experienced a lot of trouble with my son’s last infusion. I’m going to see if my HTC can get a VeinViewer so that we can have a better experience the next time. Thanks HFA for bringing this to us, it was so helpful to see his veins!”
- Attendee of Hemophilia of North Carolina’s annual family retreat.

Available via healthcare practitioners, the VeinViewer Flex vein finder has been shown to greatly increase first-stick success for intravenous (IV) access. VeinViewer Flex is the only device of its kind that is rated for use in all environments, including alternate care facilities and homes.

The Christie VeinViewer Flex system uses harmless near-infrared light to detect patient veins and then projects a real-time, high definition image of the vein pattern directly on the skin surface. Nurses can quickly find more options for accessing a patient’s veins. A more thorough assessment with VeinViewer Flex means patients may avoid multiple needle sticks and possible future complications sometimes associated with IV access.

Please contact your provider to discuss the VeinViewer Flex and/or other tools available to assist with infusions. Also visit HFA’s Resource Library to learn about: Tips & Tricks for Smoother Infusions. www.hemophiliaped.org

HFA conducted a study in 2013 that found 48 PERCENT of parents identified INFUSIONS AND VENOUS ACCESS AS HIGH CONCERNS.
Life is made of small moments that inspire, motivate, and make us feel that our work is worthwhile.

As a company, as a team, and simply as individuals, we strive to discover, enable, and celebrate more of them.

Today, possibility is in the air.
Project CALLS is designed for individuals or families who have been:

- Denied services or have received an exception,
- Forced by an insurance company to “fail” on a product before being allowed to use the product of their choice,
- Mandated to use a pharmacy that is not meeting their needs, and/or,
- Forced to go through a lengthy pre/prior-authorization process.

TO PARTICIPATE in Project CALLS, visit the HFA website: www.hemophiliafed.org/project-calls and share with others in the community.

SHARE YOUR STORY!