Empowering the community through education and community support.
FROM THE CEO

Dear Patients & Families,

My name is Ron Cleutat, CEO of HPC Specialty Pharmacy. I wanted to take a moment to introduce myself and our great company. My early experience working as an RN with CRS (Children’s Rehabilitation Services) really developed my interest in caring for patients with special needs and chronic illnesses. I am a father of four; my youngest son Bradley has severe autism. I have devoted both my personal life and career to bettering the lives of those with these setbacks because I understand their needs.

Nearly 14 years ago, our team embarked on a journey to improve the quality of life for hemophiliacs. We have since broadened our scope of care to include many additional chronic illnesses. (HIV, Hepatitis, Crohn’s, Rheumatoid Arthritis, IVIG, etc.)

I personally thank each of you for your continued confidence in HPC. On behalf of the entire company, I can tell you that we are motivated and inspired by the opportunities that you give us to help you and your families flourish and live better lives. Delivering results that exceed your expectations is our top priority, as it has always been and will continue to be.

Over the years, we have remained dedicated to developing our employees, strengthening our capabilities and knowledge, and building trusting relationships with our patients and partners. We also pride ourselves on providing superior talent to deliver the highest quality of care to our patients, 24/7. We are excited for the future and the great progress the pharmaceutical industry continues to make.

If there is anything that we can do to improve our services to you, I will listen. Please do not hesitate to contact me.

Sincerely,

Ron Cleutat

"The definition of insanity it doing the same thing over and over again and expecting different results."

-Albert Einstein
WELCOME HOME MAXEN

By: Danelle Humphreys, HPC RN, IL

It's hard to know exactly where to start so we will just jump right in. We are the Humphreys Family! Jason and I have been blessed with two absolutely amazing children, Jaxon and Ella. Having kids of our own was a decision we struggled with given I am a carrier of a genetic disorder, hemophilia. Over a year ago now, we began the process of adopting a Chinese orphan with hemophilia, Maxen. With the help and support of our community and loved ones, we finally brought our son home to the USA. This is the continuation of our story.
We made it to China to pick up our son Maxen on December 21st, 2015. That morning we met our guide and van driver in our hotel lobby and were driven to the Civil Affairs office where we would finally meet Maxen. I was busy doing paperwork but my husband saw them walk Maxen in after we arrived. I use the term walk loosely, and will explain more in a bit. We are still not sure if Maxen realized he was coming to meet us or had any knowledge of us until the moment they walked him back out of the children’s play area. He had not received the picture books we had sent to the orphanage a few months earlier and to say he was overwhelmed at meeting us is an understatement. We won him back out of the children’s play area.

We won him over with Hot Wheels cars and suckers, and when he would finally sit with us he showed him a photo book. It had pictures of our family and included the four pictures we had of him from his life in the orphanage. You could see things finally make sense when he saw the pictures of himself mixed in with those of his new brother, sister, and parents. He instantly relaxed, and our whole chaotic meeting a few minutes earlier finally made sense to him. He raised his arms for me to carry him out to the van and from then on seems to know he was our son.

“Does he speak English?” was a question we were asked a lot. Maxen speaks Cantonese and we only speak English, so the conversations we have had up to this point are very limited. We made it through those first few days and weeks with hand gestures and motions. He is quickly learning English so our biggest worry of how we would communicate has come and gone. However, while in China, we immediately realized we had much bigger worries with Maxen. He was not able to walk and had severe contractures to both of his knees, meaning he cannot straighten them. He walked at most ten feet before becoming too exhausted and sitting down or asking to be held. The contractures have come about from much activity and would easily get him to have severe tremors. While in China and the first few weeks home we had to help him eat and drink. His hands would shake too much for him feed himself or hold a cup steady enough to take a drink. He was very weak and unable to tolerate much activity and would easily get out of breath. Our initial worries were that he had suffered a bleed in his brain or that the nutritional and iron deficiencies would cause irreversible damage. I do want to mention through all of this and our worry about Maxen’s health that he never stopped smiling. He is so very patient with his new family as we work hard to understand and meet his needs. He has bonded well despite being abandoned at an older age and being 8 years old when he was adopted.

He is loving and caring and always thinks of others.

How life has been since we arrived home...

The first day home from China Maxen managed to get a horrible black eye which we were not able to treat as he hadn’t had a full lab work up and there was no way to know what factor he needed. He also had a bleed in his elbow which left him unable to move his arm.

We had arrived home over the weekend and we didn’t have an appointment with our HTC until the following Thursday. We made arrangements prior to our leaving to see them as soon as we could upon our return and start his care. We ended up calling our on call hematologist (our HTC doctors always take their own call, a huge plus in my book) who told us to come in the next morning and they would work Maxen in. They drew labs, were able to get his diagnosis of severe hemophilia A, and give him an infusion of factor for his bleeds all before the end of the day. They gave us a referral to neurology and an orthopedic surgeon as well. We returned for a full comprehensive hemophilia visit and saw a physical therapist as well. We saw a specialty pediatric dentist, optometrist, and an international adoption specialty physician. Maxen has had x rays, tons of lab work, and an MRI. So far our only long term issue is his hemophilia.

The other things are being treated and hopefully will be corrected in a matter of time.

The lasting effects of the untreated bleeding in his joints is still unknown. To know that something as easy to treat as hemophilia can go untreated for eight years of a child’s life is heartbreaking. I cannot imagine the pain he has suffered with joint bleeds too numerous to count. The weakness and muscle deterioration he has had from nonuse we hope he is able to make up. He is working hard in physical and occupational therapy, and is on prophylactic treatments every other day for his hemophilia. We are so happy to finally have him home. He will look and me and smile and say “thank you Mommy” after his infusions and I get the biggest and best hugs. I think it is safe to say he is pretty happy to be home too!

We try and keep everyone as updated as possible and post lots of pictures of our adventures to our Facebook page: Bringing Home a Brother like and follow us!
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. 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.

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 how addiction can get a hold of an individual faster than anyone might anticipate. An addiction can spiral out of control and completely take over. We need to talk about this and will not be silent.

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I was alarmed by the frequency with which he was honestly didn’t think about the risks of addiction while for me. “I only wanted to take my child’s pain away and Tylenol and he would reply “you know that doesn’t work if he could have something for the pain. I would offer had taken his factor but it wasn’t helping, and would ask were no obvious reasons to be bleeding. He would say he were three boys would also become addicts. So while I may suspected it a few years ago, I ignored the signs. Calvin would say he was having a bleed though there have 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 & Katie, parents of two sons with severe hemophilia A

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 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.

Anthony, 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.

Mark, Blood Brother, severe hemophilia A

ADDICTION HELPLINES

If you suspect yourself or someone you know may be addicted to prescription medicine please seek help. Below are organizations associated with addiction recovery that can supply information to the road of recovery.

SAMHSA National Helpline: 1-800-662-4357 (Confidential, open 24/7)
Nasac National Helpline: 1-800-784-7776 (Confidential, open 24/7)
American Society of Addiction Medicine: 301-656-3920

PAIN MANAGEMENT & PRESCRIPTION DRUGS

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Hi, my name is Liz Crain and I am very excited about becoming a part of the HPC family. I was born in Iuka, MS, but have spent my entire life in the surrounding Memphis, TN area. My husband and I raised both our children, Stephanie and Bradley here. I am a graduate of Baptist College of Health Sciences where I obtained my Registered Nurse certification and my Bachelor of Science degree in Nursing.

Like most nurses right out of school, I worked at our major area hospital to get some much needed skills down-pat; eventually moving on to community health where I became a Case Manager for Children's Special Services at the Memphis and Shelby County Health Department. I had always had a huge interest in Public Health Nursing, so this seemed to fit me just perfect. My case load consisted of around 300 children, all with special health concerns. These children and their families became my family...giving me a pretty large family at this point.

After about 4 years at the Health Department, I was offered a job to be an infusion nurse. At first I turned it down. I could not fathom leaving my families, and basically the thought of something I knew nothing about was terrifying to me, making it way out of my comfort zone. A year later, the job was offered to me again and although it was a tough decision, I felt it was where God was leading me to go. I would be working with people who had been diagnosed with Multiple Sclerosis (MS) and infusing them with, at the time, the first medication for MS to be given Intravenously (IV). It was a huge learning curve for both the patients and myself, but we managed it together for the next 7 years. We spent a lot of time laughing together and crying and built many memories doing fun MS activities in the community like the MS Walk every year.

These patients changed my life forever and I will be forever grateful. Not only was it an honor to be able to care for, advocate, educate, administer their medication, and give them lots of TLC....these patients taught ME something new every day.....things you can’t learn from a textbook.

I look forward to this new chapter in my life. With every change comes new challenges and opportunities and most importantly the chance to make a difference in the life of someone else. I am beyond ready for this adventure with working with children with hemophilia and other chronic illnesses. My goal is not only to provide each patient and family with unprecedented care and amazing TLC, but for them to know that there is nothing we can’t accomplish together. I am grateful for HPC giving me this opportunity and sharing their very special patients and families with me.

**Nurse Spotlight**

**Liz Crain, RN, BSN, HPC Infusion Nurse**

By Everyday Health Editors

Medically Reviewed by Sanjai Sinha, MD

Scientists don’t completely understand what causes MS, an often-debilitating disease.

Multiple sclerosis, or MS, is a disease of the central nervous system, the network of nerves found throughout your brain, spinal cord, and the rest of your body. Your nervous system is made up of nerve fibers that transport electrical impulses. These nerve fibers are wrapped in a fatty tissue called myelin, which helps transmit the impulses.

In multiple sclerosis, the myelin sheath that covers nerve fibers becomes inflamed and gradually is destroyed, leaving areas of patchy scar tissue (sclerosis, also called plaque or lesions) that disrupt the electrical impulses between the brain and other parts of the body. In multiple sclerosis, the underlying nerve fibers can also be damaged or destroyed. This nerve damage leads to a variety of MS symptoms, such as numbness or tingling, balance problems, weakness, pain, muscle spasms, and blurred vision.

**WHAT IS MULTIPLE SCLEROSIS?**

**MS Prevalence and Statistics**

More than 2.3 million people are affected by multiple sclerosis worldwide, according to the National Multiple Sclerosis Society (NMSS), making it a relatively rare disease. More than 10 percent of them, between 250,000 and 350,000, live in the United States. MS is more common in women than men, although the sex difference is a lot smaller for some types of the disease.

**Who Develops MS?**

Anyone can develop MS, but many patients share the following characteristics:

- **Age:** The majority experience their first symptoms between the ages of 20 and 40.
- **Race:** Caucasians are more than twice as likely as other races to develop MS.
- **Gender:** MS is 2 to 3 times more common in women as in men, according to the NMSS.
- **Climate:** MS is five times more common in temperate climates — like the northern United States, Canada, and Europe — than in tropical climates.
- **Genes:** People whose close relatives have MS are more susceptible to developing the disease, but there is no evidence the disease is directly inherited.
What Causes MS?

Scientists don’t know exactly what causes multiple sclerosis. But there’s increasing evidence that the body’s immune system plays a prominent role in its development, and some scientists think MS is an autoimmune disease (like rheumatoid arthritis, psoriasis, and type 1 diabetes).

Your immune system, which usually protects the body by fighting foreign bodies such as bacteria, may instead attack the myelin in your central nervous system.

Some researchers suspect that those attacks are triggered by certain kinds of viral infections.

Researchers have also observed that some groups of people are more susceptible to MS than others, suggesting there’s a genetic component to the disease.

Types of Multiple Sclerosis

MS follows a few recognized patterns:

**RELAPSING-REMITTING MS (RRMS):** In this type of MS, the patient experiences a series of actively symptomatic periods, called attacks, flares, or relapses.

These attacks are followed by quiet periods called remissions, during which symptoms become much less severe. Remissions may last months or years before a relapse occurs.

**SECONDARY-PROGRESSIVE MS (SPMS):** This pattern begins after a relapsing remitting course. The disease advances progressively, punctuated by acute attacks.

More than half of patients who start out with RRMS will develop SPMS within 10 years, with the number rising to 90 percent within 25 years.

**PRIMARY-PROGRESSIVE MS (PPMS):** This pattern is marked by a gradual worsening of symptoms. Patients generally do not experience acute exacerbations.

While there are no distinct remissions, patients with PPMS may have temporary plateaus during which symptoms lessen somewhat. About 10 to 15 percent of people with MS are diagnosed with PPMS, according to Johns Hopkins Medicine.

**PROGRESSIVE-RELAPSING MS (PRMS):** In this pattern, patients experience gradual progression of disease that’s accompanied by acute exacerbations as well.

PRMS is a relatively rare form of the disease. Fewer than 10 percent of people with MS have PRMS.

In addition to these four types of MS, a small percentage of people with MS have a benign form of the disease, according to Johns Hopkins Medicine.

In the benign form of MS, after the initial attacks, symptoms progress very little over the course of a person’s lifetime.

There’s some controversy over how (or whether) to classify people with benign MS, since the progress of the disease can vary over a person’s lifetime, according to the NMSS.

And a small number of patients have malignant MS, which is marked by a rapid decline that leads to disability and possibly death.

**MS Complications**

Bladder problems are very common in people with MS, affecting at least 80 percent of them, according to the National MS Society.

Some people have trouble holding their urine (incontinence), while others can’t fully empty their bladder (retention).

This bladder dysfunction may also lead to kidney infections.

If microbes find their way into the bloodstream, the infection can cause sepsis, a whole-body inflammation that, in turn, may cause organ failure and death.

In fact, sepsis may be the biggest cause of MS-related deaths, according to a 2014 report in the journal PLoS One.

Sometimes, people with MS have trouble chewing and swallowing. This can allow foods and liquids to deposit in the lungs.

This may lead to a potentially fatal complication: aspiration pneumonia, which develops from inflammation and fluid accumulation in the lungs.

MS may also cause the respiratory muscles to become weakened, reducing airway clearance, which raises the risk of lung and other respiratory tract infections.

Lung infections were the second-biggest cause of MS-related deaths, PLoS One reported in 2014; other research gives it the top spot.

Many people with MS require canes or crutches, which increases the risk of physical trauma from falls and accidents.

**MS & Depression**

Depression is common among people who have MS, though scientists don’t fully understand the relationship between depression and MS. On the one hand, depression may be a direct result of the immune system’s attack on the protective myelin sheaths that envelop nerve fibers, causing behavioral changes, including depression.

Multiple sclerosis can also change what is known as the body’s neuroendocrine system, which oversees hormone release, including hormones implicated in depression, such as serotonin.

On the other hand, depression may develop as a result of the stresses and challenges associated with having MS. Additionally, the medications used to treat MS, such as interferon beta, can also cause depression.

**MS Prognosis**

Though MS can sometimes be a debilitating disease, the majority of people who have it don’t become severely disabled, according to the National MS Society.

About a third of people with MS completely lose their ability to walk, while many others can function using canes, crutches, or scooters or motorized wheelchairs for long distances.

**MS Prognosis**

People with MS who have the best prognosis are usually those who:

- Are female
- Were younger than 30 when the disease started
- Have infrequent attacks
- Have BRMS
- Have few signs of disease in diagnostic scans

**MS Life Expectancy**

MS is rarely fatal, and many people with MS have a life expectancy that’s about as long as that of the general population.

Additionally, with better treatments now available, the life expectancy for people with MS has increased over the years.

According to a 2014 study published in the journal Multiple Sclerosis and Related Disorders, people in the United States with MS have a life expectancy that’s six years shorter than people without the disease.

MS is associated with various life-threatening complications, hence the lower life expectancy. There’s no cure for MS, but there are numerous medications that may slow the progression of some forms of the disease and reduce the frequency and severity of relapses.

People with MS who take these medications have a better life expectancy than those who don’t, a 2017 research report in the journal Neurology showed.
to consider a camp that specializes or learning disabled, you may want he or she is physically, emotionally, or learning disabilities. If your child has a special need, if disease or disability, build a peer camps help a child to adjust to the these children as well, and these there are specialty camps for cancer, hearing and vision Impaired, Epilepsy, Muscular Dystrophy as well as many others. There are camps for almost every disability. Although many mainstream camps can accommodate children with disabilities, you may still decide that a specialized camp will benefit you and your child. If your child has a chronic or life-threatening disease, there is the security of knowing that your child is surrounded by professionals who understand their needs. One of the most important benefits is that it provides a child with a peer support group. A child is surrounded by other children his age who have the same disease or disability, and they can connect with those who have to cope with the same issues. Also, at camp, a child learns empathy; they find out that lots of children have the same problems that they have, and some might even be more serious.

When a child attends a special needs camp, the camp does the adapting for the camper. The camp diet, activities, equipment, and physical layout have all been developed to meet the specific needs of campers. The camper does not have to adjust to meet the demands of a mainstream camp. Special needs camps also help children develop coping skills to deal medically and emotionally with their disease. While some programs have formal educational programs, in others the educational component is more informal, but still effective.

Also, when the campers see counselors and staff members who are leading full complete lives with the same disease, they see that they too can pursue their dreams even with their illness. At a special needs camp the entire staff, has been trained to deal with the disease or disability, so your child will be surrounded by people who understand their needs.

Of course, the most important ingredient for your child is still fun. This type of program, in addition to other benefits, should provide summertime fun based on the concept that the special needs children are still kids.

Starting the Search
Ask your HPC Community Advocate for help locating camps near you! To find the right camp for your child, start with your doctor. Your child's specialist may be on an advisory board or be a medical consultant for this type of camp. Health care professionals understand the value of a summer experience. Another excellent resource is word of mouth from parents of children who share the same disability. Other good sources include: parent support groups, camp fairs for families with special needs, teachers and guidance counselors, camp advisers, online websites and news group, and the American Camp Association.

Check It Out
Once you have a list of possible camps, the steps you follow should be similar to any other summer camp. If you can, visit the camp while it is in session, interview the director, and check references with other parents whose children have attended the camp. Before you enroll your child, you need to know:

1.) How the camp program, facilities, and dietary plan are adapted to meet the special needs of the campers.
2.) How the educational component, if there is a formal one, is integrated into the camp day.
3.) The range of disabilities in the camp. Some camps are more targeted than others.

Lastly, many camps are sponsored by different organizations and may offer “camperships” to help with costs or allow children to attend for no cost at all. It never hurts to ask!
Why Should You Get Involved?

- Blood cannot be manufactured - it can only come from generous donors.
- Every two seconds someone in the U.S. needs blood.
- Approximately 36,000 units of red blood cells, 7,000 units of platelets, and 10,000 units of plasma are needed every day in the U.S.
- Donors can help save the lives of up to three people.

How to Organize a Blood Drive

What is your potential for a successful drive?

A great way to figure this out is to find out how many donors would be interested in participating in a blood drive. Ask others to put their name on a list of interested participants, this can be done via email, posters, or commitments sheets. Use the benefits of word-of-mouth advertising. Talk to people in your group and get their feedback to determine interest level.

Set a date
When choosing a day and time, consider the appropriate time of day for the group of donors participating. Think about time of year, peak vacation times (including you, as the sponsor), scheduled events, etc. Drives are typically scheduled for a 4 hour time frame, but can be adjusted to what is best considering your group of donors. These should be the 4 hours of the day when the majority of the potential donors are available.

Choose a location
Tour the potential site with the Blood Drive Coordinator. Choose a location that is convenient for your group of donors. Discuss traffic flow, space requirements, restroom access, temperature, and lighting.

Set a goal
Consider the number of people in your group and discuss a goal with the Blood Drive Coordinator. Get creative! Some ideas include organizing teams or offering rewards for certain achievements. Consider extras like pizza parties, themes, contests. Be as creative as you like and make it fun!

Before the Drive
The best strategy for a successful drive is direct contact! Ask group members to sign-up for the drive, one on one communication is proven to be the most effective way to promote the drive. Many blood centers will provide sign-up sheets (and access to online sign-up), posters, flyers, bulletin inserts, and table tents, and pledge cards.

Lead the Drive
Remind donors of their scheduled times. Stay in close contact with the Blood Drive Coordinator to fine tune details of the drive. Be sure to be available (or have a designee pre-assigned) the day of the drive for last minute questions and group support.

Acknowledgement Donors
Recognize the donors and thank them for their wonderful contribution! Remind each donor that their gift is helping our local community to meet its blood needs and they have helped make a difference in someone's life.

And finally...
Always feel free to ask questions during the process! Contact your local blood center to help you make your drive as successful as possible.

Blood Drive Planning Checklist

6 to 8 Weeks Before the Drive
- Meet with the Blood Drive Coordinator to create a plan and discuss procedures.
- Obtain internal approvals needed to host the blood drive.
- Set a date and time for the drive the sooner it is on the calendar, the better!
- Discuss possible locations and check availability.
- Tour the location with the Blood Drive Coordinator.
- Determine interest level.
- Set goal for number of donations.
- Discuss promotional materials with the Blood Drive Coordinator.
- Choose from types of materials offered and numbers of each. (Posters, flyers, table tents, bulletin inserts, pledge cards and other needed supplies are provided for you.)
- Discuss sign-up sheets, online sign-up, and sponsor’s contact information.
- Contact any fellow staff/volunteers to discuss goals for the drive and plan their involvement.

3 to 4 Weeks Before the Drive
- Receive promotional materials and distribute them. Spread the word of the drive date and time via bulletins, newsletters, emails, word of mouth.
- Begin active recruitment of donors. Person to person contact will always produce the most successful results. Personally ask individuals to sign up for an appointment time and thank them for their support!
- Call from a list of possible donors (whether from a previous year’s drive, an office list, organization membership directory, church directory, etc.).
- Set up a sign-up table. Be energetic and enthusiastic when asking individuals to participate.
- If using both the online sign-up and a hard copy sheet, coordinate the two often to avoid overlap.
- Assume a 20% cancellation rate and schedule more donors than the intended goal to ensure the success of meeting that goal. (Example: goal = 100 donors, recruit 125 donors)
- Communicate frequently with the Donor Recruitment Coordinator about sign-up progress and any questions you may have. Suggestions, help, and advice is always readily available!

One Week Before the Drive
- Touch base with the Blood Drive Coordinator about sign-up sheets. Fax or email the most recent copy.
- Remind donors of their appointment times.
- Remind fellow employees, supervisors, and members of the date and time of the drive.

1 to 3 Days Before the Drive
- Confirm that the number of donor appointments are sufficient for the set goal.

Day of the Drive
- Double check to be sure the room and the parking spaces are open.
- Greet helping staff (have them arrive approximately 1 hour beforehand) and lead the way to the location.
- Check with Charge Nurse about any temperature or lighting alterations.
- Continue recruiting donors via face to face, announcements, and emails.
- Thank donors personally for their donation and support.

After the Drive
- Post results of the drive.
- Thank donors!
- Confirm/book the date of the next blood drive.

The information in this article was published by:
University of Iowa Hospitals and Clinics
200 Hawkins Drive
Iowa City, IA 52242
https://www.uihealthcare.org/content.aspx?id=1663
Phone: 800-777-8442

One Week Prior:
- Fax or email the most recent copy of the sign-up to the Blood Drive Coordinator.
- Confirm room reservation and contact any necessary people to arrange furniture placement. Remind donors of pre-donation information (bring a photo ID, eat a good meal...)
- Confirm any volunteers needed the day of the drive.
- Check to be sure all elevators are working for equipment loading/unloading.
How did you and your wife meet?
“We met at work. My uncle owned the place.”

How many years have you been married?
“We have been married for 36 and a half wonderfully terrific years together.”

Tell me about your wedding day.
“We were married at St. Denis Catholic Church in Benton, Missouri on June 30th, 1979. It was one beautiful and great day for the two of us. When we left after part of the dance, we were foot loose and fancy free as Mr. and Mrs. Lappe. Feeling terrific and in each other’s arms forever together.”

Has your hemophilia diagnosis had an effect on your relationship?
“I would say it brought us a lot closer and we were longing for our love to last forever. Then we had three beautiful children whom are all grown now and we have four terrific grandchildren.”

What advice would you give to couples?
“Respect and love each other always. Do not take each other for granted at any time during life. Love, honor and respect each other every day. Tell each other how much you love them every day. Always kiss good night and good morning.”

This time of year is perfect to highlight some of the love stories in our hemophilia community. When I first asked our nurses to suggest a patient that has a perfect love story to highlight, Nancy Ellman, our HPC RN in MO, did not hesitate to suggest that I call the Lappes. I talked to Billy Lappe’s wife, Sherry, and she was happy to be able to share their story with us. When I first received her answers to the interview questions, it brought tears to my eyes. I hope that you all enjoy getting to know our community a little bit better and follow the amazing advice they provided in hopes that all couples experience a lasting love like theirs.

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China Ott, Dawson’s mom

Another family that was quickly recommended to have their love story highlighted was the Ott family. This story is a little different, because it is from the perspective of the parents of a hemophiliac rather than the hemophiliac themselves, but is just as moving. We are so lucky to have so many love stories in our community!

Get your tissues ready:
“Kevin and I have been married 3 years in June and actually have been dating for a little over 4 years. It was my own little love story. I guess you could say love at first sight too! We had been together a little over a year when we found out we were pregnant with a sweet little bundle of joy. So now we have Joshua Lee, who is Dawson Reed’s older brother. My pregnancy was completely normal just like it was with my oldest child. When Dawson was born he weighed 7lbs 3oz. He was so adorable and just so precious. So what could go wrong? He was circumcised and they could not control his bleeding. Something had to be wrong. After several hours the doctor finally got it under control. We spent two nights at a local hospital and went home and thought maybe everything was okay; it was not. Later that night we were contacted by our local hospital and told to go on to LeBonheur hospital and that they were waiting on us to arrive. When we got there, the news was confirmed. Our sweet 3 week old baby was a severe hemophiliac. How could this be true when big brother doesn’t have it? Goodness, where do we go from here? What do we do! We took it one day at a time. Our love for sweet Dawson only grew stronger.

Dawson being diagnosed with hemophilia allowed me and my husband to grow a lot closer. I had to depend on my husband to support me emotionally, as well as him needing me. It was definitely something that took days, even months to accept. My husband would remind me every day that God gave us Dawson because he knew we could pull together and give Dawson the love he needed! Kevin and I share a certain bond with Dawson that only other parents that have a child with hemophilia can share with their kids. It’s a love like no other!

He started to receive prophy infusions at the age of 6 months, 2 times a week. When he became mobile, we went up to 3 times a week. It was such a wreck at first. Everybody was nervous and scared. We thought: he’s such a tiny baby and should never have to experience this! Dawson became so strong though! He encouraged me and his daddy every day to do the same, just through his smiles! At the age of 2, he was sitting on his own receiving his medicine by himself with me beside him talking calmly. Now, he’s just another little boy who can take on the world like any other! He wrestles with big brother, plays outside in the dirt and keeps his mommy and daddy on their toes! My advice for any parent with a child that has hemophilia is to be patient and be strong. They are one of a kind! Our Dawson Reed is amazing, and this is our love story!”

China Ott, Dawson’s mom
Find the Differences!

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Memphis MS Walk  
(Memphis, TN)  
RSVP: Keitrus Clark at 901-850-6226.

HNC Walk  
(Charlotte, NC)  
RSVP: Marty Napper at 707-788-4048.

Baxalta Patient Education Dinner  
(Memphis, TN)  
RSVP: Keitrus Clark at 901-850-6226.

Chattanooga Women’s Event  
(Tennessee)  
RSVP: Jenni Denham at 423-243-8876.

OHF Walk  
(Oklahoma)  
RSVP: Val Simms at 918-606-2215.

Baxalta Patient Education Dinner  
(Tupelo, OK)  
RSVP: Val Simms at 918-606-2215.

WVH Men’s & Women’s Day  

Women’s Painting Event  
(Baltimore, MD)  
RSVP: Emma Miller at 410-661-2307.

Memphis Support Group  
(Memphis, TN)  
RSVP: Keitrus Clark at 901-850-6226.

AR Hemophilia Educational Day  
(Arkansas)  
RSVP: Johni Parsons at 504-289-7136.

*For more information about upcoming events please visit the HPC Specialty Pharmacy Facebook page.

What You Missed At These Past HPC Events

Follow us on social media to learn more about how HPC is serving the chronic illness community.