PEN

inside

Overseas Adoption:
A Child with Hemophilia is Waiting

Sara P. Evangelos

When his birth parents in China realized Michael had a chronic medical condition, they probably felt helpless and desperate. Perhaps they thought his disorder was untreatable, or they couldn't obtain treatment. They may have assumed he wouldn't live long, and hoped he could receive end-of-life care in a hospital or institution. So they abandoned him at age 2.

Michael's medical condition? He has hemophilia.

Now age 4, Michael is living at Yangzhou Orphanage in Jiangsu Province, on the eastern coast. The orphanage has an exclusive partnership with the California-based agency Across the World Adoptions, finding families for eligible children.

Michael playing a game with Lianna, daughter of Pam Thomas. Lianna was born in Nanjing and adopted in 1995, and now travels to China with Pam to help gather information about children waiting for adoption.

Pam Thomas, China Program Director for the agency, first met Michael in May 2014. There in the orphanage, among a group of toddlers and preschoolers, Pam says Michael stood out as "one of the healthiest, most robust, most playful, active, adorable little boys I have ever seen."

Then a caregiver told Pam about Michael's hemophilia. And Pam immediately responded, "I think I can find a family for him."

The surprised caregiver turned to her colleagues, translating Pam's words.

"They looked stunned," recalls Pam. In the hemophilia adoption cases she has handled, "the orphanage staff were reluctant to put the children's required adoption paperwork together, thinking that there would be no interest from anyone to adopt these children."

Why Adopt?

People adopt for different reasons. Most just want to be parents. But why adopt a child with a serious medical need like hemophilia?

For Jasmin Davidson, the reason is humanitarian. "I see it as an act of service."

Jasmin is an electrical engineer, social worker, and single mother of Kiran, 8, adopted domestically; Adi, 7, adopted from China with severe hemophilia A; and Nanda, 5, adopted domestically. Jasmin also has a new foster daughter. "Through the adoption of Adi," says Jasmin, "I realize that I have saved my son's life. You can say it in a spiritual way, I serve

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welcome

I've always been interested in helping children in developing countries, and from age 10, I wanted to join the Peace Corps to make a difference. Life took me in other directions, but working overseas was always on my mind. After a stint in child psychology, I got a master's in international development, hoping to become a Middle East expert and work at the UN in a humanitarian capacity. I ended up in economics (long story of survival as a starving student), which was not a bad thing. But I still yearned to make a humanitarian difference.

When I had a child with hemophilia in 1987, life took more turns. I left economics and launched my own business, writing books on hemophilia. In 1994, with my one-month-old third child in my lap, I watched the Rwandan Genocide unfold daily. I begged my husband to adopt a Rwandan orphan–so many were left homeless and abandoned. But we had our hands full with two young children and a new baby. In lieu of adoption, I decided to someday help children in need overseas. Eventually, Save One Life was born.* Though I never did adopt a child, we now have over 1,000 children with bleeding disorders enrolled from 11 countries. All these children receive financial aid, scholarships, and microenterprise grants.

But adoption remains compelling to me. I consider families who adopt children from developing countries especially as my heroes. I missed my chance to adopt, but I have been blessed to help in several overseas adoptions of children with hemophilia, and hope to do more. I am pleased in this issue of PEN to be able to share the stories of several families in our community who adopted children with special medical needs. These parents can help you decide whether this is the right path for you.

You may know the stats: 400,000 people with hemophilia in the world, of which only one-fourth receive treatment. Imagine your child with hemophilia with no factor–and worse, no parents to love him, tuck him in at night, comfort him. Adoption can truly change a child's life.

Laurie in Rwanda, March 2014

This past March I visited Rwanda on the 20th anniversary of the genocide, toured the Genocide Museum, and saw the actual bones of some of the victims, both adults and children, left in the locations where they were slaughtered. I wondered about the thousands left orphaned. And I remembered the words of the character Billy Kwan from my favorite movie, *The Year of Living Dangerously*. Kwan leads Guy Hamilton, the newly arrived Australian journalist covering the communist uprising, into the Jakarta slums to shock awake his compassion. And Kwan quotes Tolstoy: "'What then must we do?' We must give with love to whoever God has placed in our path."

Find your own path–perhaps it will be to adopt a child with hemophilia from overseas.

* Visit www.SaveOneLife.net to learn how to sponsor a child.

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Aung at World Federation of Hemophilia Congress in Melbourne, Australia

Eyes Wide Open:
A Brave Traveler for Hemophilia

I attended the World Federation of Hemophilia (WFH) Congress in Australia May 8–15, where I had the pleasure of meeting Aung, a young man with hemophilia from Myanmar, formerly known as Burma. Aung had written me months earlier requesting sponsorship to the event. Myanmar is not a WFH member organization and therefore not eligible for funding to the congresses. One of my specialties is trying to get organizations formed in countries where none exist, hoping that one day they will be accredited by WFH. Aung impressed me so much that my company provided his airfare to Australia. Please read his thoughtful essay. We live in two worlds—the haves and have-nots. The have-nots are asking only for the know-how to learn to stand on their own, literally and figuratively. —Laurie Kelley

Aung Kaung Myat writes,

At the Yangon Airport

My mother's worries perhaps foresaw the difficulties ahead. It's not an easy task for me to deal with the airline staff who told me I am not allowed to travel on the flight because I have no companion to look after me–because I am disabled. However, I had a hard time with anger management in my teenage years, especially on discriminations against hemophilia and disability. But I showed great demeanor in engaging with the staff of the airline. They finally said they would call the captain, just minutes before the flight. I managed to stay cool and wait for the response, which was positive.

This is my first trip outside of my country, and everything I perceived in Melbourne is the total opposite of my country. There are disabled-friendly sidewalks here. There's proper treatment for people with hemophilia. The attitudes of the people here, especially the attitudes on the disabled, are really civilized. Wherever I went in Melbourne, I was never given quizzical looks that said, "Why is this guy in a wheelchair here?" In Myanmar, it will be many decades before I will be seen as a person, not as a person in a wheelchair.

First Day at the Congress

I planned to go to the WFH Congress for the opening ceremony. With Aboriginal music and dance, the congress was wonderful. I met some people who have hemophilia, including an elderly person who has a pseudotumor from hemophilia, a teenager whose legs became paralyzed after being injected with painkillers in his spine, a severe hemophiliac from Tasmania who has inhibitors and joints with bleeds. Back in my country, I always had this feeling of being alone.

Appointment with a Hemophilia Specialist

Although I see hematologists often in my country, they don't seem to be able to give me a solution to treat the bleeding episodes of my knees, which turned me into a wheelchair user when I was 14. I intended to see the doctor at the treatment room of the WFH Congress to consult with him about my knees. The doctor told me it would take approximately $100,000 to have a knee replacement operation [this includes the cost of factor]. It might be a ray of hope, although I do not have any finances for such an expensive operation.

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Aung with trip sponsors Stephen Russell and Fred Wensing, Australians with hemophilia, and Laurie Kelley

Richard J. Atwood

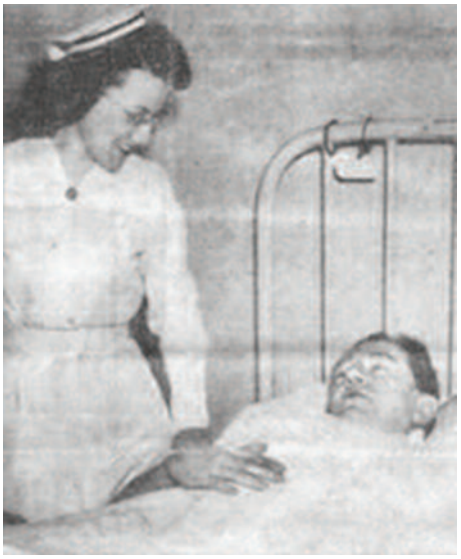
William Purcell:
First Reported Case of an Inhibitor in Hemophilia

If you have von Willebrand disease (VWD), you may have heard of the young girl in Finland who became the first diagnosed patent with VWD. The disorder was named after her physician, Erik von Willebrand. If you're a hemophilia B patient, you've probably heard about Stephen Christmas, the first patient diagnosed as factor IX deficient, who lent his name to the disorder also known as Christmas disease. But who was the first patient known to have inhibitors?

By 1940, leading hematologists thought the presence of an inhibitor in circulating blood was theoretically possible, though it was considered impossible in hemophilia. At that time, there were no known cases of hemophilia with an inhibitor, or a "circulating anticoagulant," as it was commonly called.

Then, in a 1942 medical journal article, John Lawrence and John Johnson at the University of Rochester School of Medicine and Dentistry in Rochester, New York, reported on a case of hemophilia with a circulating anticoagulant in the blood. The patient, William Purcell, was a 44-year-old unmarried man with hemophilia. There was also a history of hemophilia in the extended Purcell family: William's maternal uncle had died from bleeding following an incision, and William's brother Garrett showed classic symptoms of hemophilia.

William Purcell was described as a cheerful, red-haired Irishman, popular with hospital staff.[1] He had an extensive clinical history since his birth in 1897. When he was age 3, he had a bleeding episode lasting 22 days from a cut of the lip. Later, at age 6, he passed blood in his urine, and up to age 15, he sometimes oozed blood from his gums. William also suffered from sporadic pain and swelling in the elbows and knees, with stiffening of the joints. He had several tooth extractions with subsequent bleeding, and had many large spontaneous hematomas (bruises).



Dick's Genealogy and History Corner, rochistory.com

Rare photo of William Purcell receiving treatment

William's first hospital admission was on September 19, 1929, for bleeding following tooth extraction. He had 18 hospital admissions after that, for bleeding from his teeth (2), blood in his urine (9), gastrointestinal bleeding (4), coughing up of blood (1), and bleeding into his joints (7). He received many blood transfusions as treatment.

There were repeated clinical investigations of William. Though his red blood cell, hemoglobin, white blood cell, and blood platelet values were within normal limits, his coagulation time varied from 12 hours to 70 minutes. Repeated coagulation times taken from 1939 to 1941 were not markedly reduced after transfusions with normal blood or fresh plasma, and were reduced less than would be expected in patients with typical hemophilia. When 350 mL of William's blood was transfused into another patient with hemophilia, that other patient began bleeding 3 hours after transfusion and did not stop bleeding until 48 hours later.

The circulating anticoagulant in William's blood could not be identified, though heparin was ruled out. Physicians advised checking coagulation time shortly after administration of fresh normal blood to every patient with hemophilia to rule out the presence of a circulating anticoagulant.

Follow-up on William was provided later, in a 1947 medical journal article by Charles Craddock and John Lawrence from the University of Rochester School of Medicine and Dentistry. Over the five-year span since the previous report, the now 50-year-old William Purcell had recurrent episodes of bleeding in his joints, kidneys, and gastrointestinal tract. He also developed high blood pressure and hypertensive heart disease. Treatment of bleeding episodes with transfusion of fresh blood

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1. Eileen Welsome, *The Plutonium Files: America's Secret Medical Experiments in the Cold War,* New York: Random House, 1999.

Richard J. Atwood

Following the Hemophilic Dogs

Occasionally I'm asked how I first became involved in the bleeding disorder community nearly 30 years ago, because I don't have a relative with hemophilia. I tend to briefly pause before replying that I followed the dogs.

Hemophilic dogs.

Who are these dogs? Now that every breed of dog has been thoroughly investigated, every bleeding disorder found in humans has also been found to occur naturally in dogs. But years ago, hemophilia in any species other than humans was not thought possible. The earliest references to hemophilic dogs were in veterinary journals. A report from France in 1935 found hemophilia in a fox terrier. And there were more reports: in 1936, Aberdeen terriers in England; in 1938, greyhounds in Indonesia; and in 1943, Scottish terriers in Denmark.

Critics dismissed these veterinary reports of canine hemophilia because there were no confirmatory lab tests, although personal and family history evidence of bleeding episodes suggested hemophilia. An even earlier report of hemophilia in a dog was published in a French veterinary journal in 1904, but that recently located citation hasn't yet been subjected to thorough medical scrutiny.

And unexpectedly, in 1944 American writer Zelda Popkin included the possibility of a hemophilic dog in her mystery *So Much Blood*. A terrier in the novel bled to death after eating rotten clover. One of the characters, a psychoanalyst, then wondered whether the dog had hemophilia. So by the 1940s, veterinarians–and even a mystery writer–knew about canine hemophilia, but few people realized its significance.

Irish setter with hemophilia A, Chapel Hill, North Carolina

In 1946, a breeder brought several purebred Irish setter puppies, who were suffering from severe joint bleeds, to the Veterinary College at Cornell University in Ithaca, New York. Several other puppies, from earlier litters, had already died from hemorrhages. The vets performed the confirmatory lab and genetic tests needed for a diagnosis of severe hemophilia. In 1946 and 1948, they published their results for 17 affected male dogs. The surviving dogs were successfully treated with whole blood and plasma.

When Dr. Kenneth Brinkhous, a pathologist at the University of North Carolina–Chapel Hill (UNC–CH), learned about these Irish setters, he quickly realized their significance. Early in 1947, Brinkhous obtained two adult proven carrier dogs: sisters Nora and Lynn, one of whom was pregnant. With these dogs, Brinkhous started the first breeding colony of hemophilic dogs, with the help of NIH (National Institutes of Health) funding. This breeding colony of hemophilic dogs at UNC–CH, now called the Francis Owen Blood Research Laboratory, still operates, although the breed of dog used has varied over time.

How do I fit into this story? I was born in Ithaca, New York, several years after the Irish setter carriers had already left for North Carolina. To get me to behave when I was young, my mother would bribe me with a visit to the barns at Cornell's vet school. Her strategy worked, and looking back, I now feel that I followed those hemophilic dogs.

Fast-forward to 1976, when I entered a graduate program in public health at UNC–CH. It was easy to spend long hours studying in the library during the winter, but come springtime, I had to get outside. I often visited University Lake, where I heard dogs barking in a nearby kennel. At that time, I knew only that blood research was being conducted there, and I loved the idyllic location. But I was still following the hemophilic dogs.

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a project share story

Laurie Kelley

The Ones Who Dream

While the US argues the merits or drawbacks of the Affordable Care Act–the 2010 legislation that reformed the national healthcare system–hemophilia patients in developing countries may see our reform angst as a luxury problem. For 300,000 hemophilia patients around the world, access to factor is just a dream.

Without factor, people with hemophilia suffer relentlessly: Children sob at night with unimaginable pain. Young men are slowly twisted into hobbling stick figures. And old men are not to be found.

Yet dreams precede action. "Nothing happens unless first a dream," wrote American poet Carl Sandburg. Securing factor from a government takes tremendous time, energy, strategic planning, persistent lobbying, and above all, the vision of what could be. But when you live in a developing country, your day is spent trying to survive and earn a few dollars. Finding the time and energy to lobby is a Herculean effort. It's the dream of what could be–access to affordable factor–that can compel patients to action.

India recently celebrated major wins in securing free factor for hemophilia patients in several states. India has one of the largest known populations with hemophilia. Because Odisha ranks as the 6th poorest state of India's 29 states, it seems an unlikely candidate for purchasing factor.

In Bhubaneswar, the capital of Odisha, a promising leader has emerged: 20-year-old Chittaranjan Das, a tall, soft-spoken man with hemophilia who is also a nursing student. Chitta has helped spearhead an effort to request that his government cover the cost of factor. He is currently secretary of Hemophilia Federation (India), Bhubaneswar Chapter, a recipient of Project SHARE donations.

This spring, Chitta wrote to Project SHARE, "After a long journey to get free factor from the government of Odisha, that day finally came." On March 22, 2014, Sriram Chandra Bhanj Medical College and Hospital in the city of Cuttack began distributing free factor to impoverished hemophilic patients. Patient Alekh ku Patra was the first with hemophilia to benefit from this new policy.

Chitta acknowledged his team: "We specially thank Dr. A. K. Chand, Mr. Vikash Goel, Dr. R. K. Jena and all the Hemophilia Federation (India) members, and the officers and ministers of the government of Odisha, who helps us to get free factor."

Hemophilia Society, Bhubaneswar Chapter

Patient Alekh ku Patra was the first person with hemophilia to benefit from new policy in India

This accomplishment was remarkable. But Chitta surprised us further by writing that on June 3, 2014, a second hospital, Capital Hospital, Bhubaneswar, began distributing free factor to the indigent. Humbly, Chitta explained that it took him and his chapter team a lot of time to accomplish this because Capital is not a medical college and doesn't even have a hematology department.

> THE POOR MAN IS NOT HE WHO IS WITHOUT A CENT, BUT HE WHO IS WITHOUT A DREAM.
> —HARRY KEMP

I've journeyed twice to Bhubaneswar, and it's one of my favorite places to visit in India. But the poverty is startling and pervasive. In the midst of such poverty, the fact that government funding can be found for an expensive drug like factor should give courage and hope to individuals and organizations worldwide who lobby for factor against great odds.

And Project SHARE will continue to ship donated factor overseas to countries with no factor, and for patients in remote areas of countries that do buy some factor. In the meantime, these patients will continue to dream–and work toward the day when factor is free.

Captured Memories

Luke, Isabella, Anya, Shari, Jay, and Dave Luckey (from front to back)

God. You can say that I serve humanity. I know that my life has not been in vain. I have made a difference."

For the Luckey family, the reason was a unique child. Shari, a speech pathologist, and Dave, an IT consultant, have three biological children: Jay, 20, Anya, 14, and Isabella, 14. Jay has severe hemophilia B with inhibitors, and Anya is a symptomatic carrier of hemophilia B, just like her mom Shari.

When they first learned about Luke, a child in China with severe hemophilia A, Shari says, "We were not considering adoption. We thought our family was complete with our three biological children." But then, "We were so touched by the story of this little boy, that we felt led to make him a part of our family."

So in 2010, the Luckey family adopted Luke at age 9 from Nanjing, China.

Not just a child with a special medical need, but an older child?

Jasmin says that unfortunately, "Children over age 5 are not sought after." So for her, "It was set in my heart to adopt an older boy. And a boy with a more significant medical condition–a child that was considered unadoptable."

Why Adopt a Child Overseas?

For Jasmin, it's about social justice, about the haves and have-nots. "In the US, we have access to many resources. I can give to a child. I can provide medical care. I think that if one can, one *must*."

She believes that ideally, "children should stay in their home countries, and be connected to their birth cultures."

> "Adi was abandoned when he was 16 months old. What really made me decide to adopt Adi was when I read in his description that the birth parents had left a letter, begging for someone to adopt him. And they wrote, 'We hope that a kind-hearted person will save him.' Every time I say this, I'm in tears. The kind-hearted person. It was singular language, not plural. It was *one* person; one kind-hearted person who could adopt their son. And I thought, I can do that. It just takes one person, one American middle-class person."
>
> —*Jasmin Davidson*

But if the child has a disorder that is untreatable, or inadequately treated in the home country, adoption can be a lifesaving solution.

As an international adoptive parent, Jasmin adds, "People will sometimes ask, why do you not adopt the children right in our backyard, the foster children? I will say that's a good argument, but international adoption of a child with hemophilia, for example, is a humanitarian act. My son would have died. No foster child [in the US] dies because of lack of medical care."

> "When we adopt children who have lost everyone and everything, and who have medical needs we can meet, the bond is profound."
> —*Pam Thomas*

Bleeding disorder treatment is inadequate or nonexistent in many countries. Why? Factor is a prohibitively expensive drug. It's near the bottom of the list of available treatments in developing nations, which also face infectious disease outbreaks such as tuberculosis, malaria, and cholera. Add to that natural disasters, political unrest, and sluggish economies. When governments decide on budgets and drug formularies, scarce healthcare dollars are spent to benefit the most people. Because hemophilia is rare, patients are left behind.

"What is possible here in the United States for children with hemophilia," explains Pam, "is only a concept for children born in developing nations." She notes that domestic adoption in the US "is rarely a life-or-death issue, but it is certainly that for so many children born abroad."

And that's one reason parents choose overseas adoptions. Pam says, "When we adopt children who have lost everyone and everything, and who have medical needs we can meet, the bond is profound."

Lane, Paisley, Josh (bottom left to right), Sarah, and Christian Henderson

Family: A Shared Experience

Bonding with a child whose medical need you understand. That was a goal for Sarah and Josh Henderson of Nebraska. Josh is a rancher and farmer, and Sarah, until recently a stay-at-home mom, telecommutes for a specialty pharmacy. The Hendersons have three children: Paisley is age 5. Lane, age 7, has severe hemophilia A with inhibitors. Christian, age 16, was adopted in 2006, and has special medical needs including autism, epilepsy, and cerebral palsy.

After Lane was born and then diagnosed with hemophilia, Sarah had genetic testing. "We chose not to have any more biological children because of my symptomatic hemophilia carrier status," she explains, "but we weren't done having kids. We knew that we would adopt someday, and that they would be special needs."

Sarah had received a newsletter about children waiting for adoption in Nebraska, and she began looking at international websites. On RainbowKids.com, parents can check boxes for special needs. When Sarah checked 'hemophilia,' she found 13-year-old Gabriel, in Eastern Europe. "Once we found that there were kids with hemophilia waiting to be adopted, we had our 'Duh!' moment," laughs Sarah. The Hendersons decided to adopt Gabriel.

From the medical records Sarah and Josh have seen so far, they know that Gabriel has severe hemophilia, and that he probably doesn't have inhibitors. They've been told that he is living in an orphanage, and that he is receiving factor.

As PEN goes to print, the Hendersons are anxiously awaiting the rest of Gabriel's records, and hoping to make their first trip to Eastern Europe to meet him later this year. After the adoption process is complete, they'll make a second trip to pick him up.

Overseas Medical Records: What to Believe?

How certain can you be about the validity of medical reports from overseas orphanages and hospitals?

"The medical reports we receive from the CCCWA [China Center for Children's Welfare and Adoption] vary in their reliability, as do reports from other countries," explains Pam. "We need to depend on the local medical resources to correctly diagnose and document medical conditions for the children, and they may not employ the sophisticated techniques that US citizens are accustomed to." Pam adds that parents can consult international adoption doctors in the US who specialize in reviewing reports, photos, and videos, and helping to identify concerns in a child's health report.

"There is always risk in becoming a parent," Pam stresses, "so adoptive parents are wise to put together a team that includes a good placing adoption agency, a good home study social worker, and one of the international adoption doctors to help them understand the medical aspects of a referral. Agencies can often use questions formulated by the international adoption doctors to request updates through their placing agency."

"When they tell you about the medical condition," advises Jasmin, "be prepared that it could be more severe, or that there could be medical conditions you didn't know about." Jasmin was told that Adi had mild to moderate hemophilia, but when she arrived in China, "I took one look at him and I knew that he had severe hemophilia." And this turned out to be true. "I found out later that Adi had been undertreated for hemophilia and received factor concentrate on only a few occasions."

Jasmin Davidson with her children Kiran, Nanda, and Adi (left to right)

She explains, "The medical records I had gotten before I went to China were partial, indicating that Adi had a bleed about once a year. The full medical records, which I received while in China, indicated that there was a bleeding incident about once a month."

By contrast, the medical reports that Shari and Dave Luckey received for their son, Luke, were accurate.

Luke was living in an orphanage located next to a hospital in Nanjing. When he had a bleed, he was hospitalized and given cryoprecipitate. Shari says, "Our hematologist here was amazed that Luke had severe hemophilia and was in such great shape. He said they must have taken really good care of him and protected him."

Pam sums it up: "In the end, there is always a leap of faith required in becoming a parent."

Insurance: The Good News

Insuring your child–biological or adopted–is crucial. Do your homework with your insurance company before beginning the adoption process.

Pam reassures parents: "Families adopting abroad should have no problem getting their children covered by their insurance. There is no more denial of coverage for pre-existing conditions, and children adopted by US citizens are covered from the date of their adoption."

Shari confirms this. "Luke was immediately added to our private insurance plan, and we also signed up for Michigan Children's Special Health Care Services insurance. We had to provide information that proved we had adopted him, but it was very simple."

As Sarah continues to navigate Gabriel's adoption process, she wants to be absolutely sure. "We have verified–again, and again, and again–that as soon as the adoption is finalized, he will be good to go on our insurance just as he if he were born to us."

Jasmin and Adi had a smooth transition. "The minute the child is placed with you, whether it be a foster or an adoptive placement, insurance kicks in and the child is covered." But, she stresses, "You definitely need good insurance." Jasmin also got assistance through Patient Services Inc. (PSI). And her specialty pharmacy and local hemophilia association were great resources. "I had so much support, I was amazed. I would tell adoptive parents: Don't be afraid of it. There is such a network in place, and a political lobby, and one can figure things out. Go for it!"

And most important, the pre-existing condition clause, which Jasmin calls "a horrific thing," is gone. Its elimination, she believes, "will make all the difference for future hemophilia adoptions."

Eligibility, Paperwork, Paperwork: The Adoption Process

"It seemed like the whole process was hurry-up-and-wait," recalls Shari. "We would rush to get paperwork turned in, and jump through all the hoops, then would have to wait for everything to be processed and to begin the next step." But she adds, "We worked with an amazing adoption agency that had so much experience with special needs China adoptions, that they walked us through the process and told us how long we should have to wait for each step. Our experience was very fast, with very few hurdles."

Pam gives the typical run-down for China adoptions: "Families must have a home study done in their home state by a Hague-accredited[1] agency. They must undergo hours of online pre-adoption education classes, have meetings with a social worker, and gather documents that the Chinese government needs to review before approving the parents to adopt."

What about eligibility requirements? Pam reports, "Those are more flexible than they have ever been. The CCCWA will accept couples who are at least 30 years old, up to age 55. They will accept single women up to 50. It's possible to obtain waivers for age issues, financial requirements, and a variety of other issues, on a case-by-case basis."

However, before Jasmin found Adi, she was rejected based on age when trying to adopt from India. "I applied to adopt a special needs child with a serious blood disorder, and I was turned down. At the time I applied, I was 50, and their age limit was 50. So I did meet their requirement, but the Indian adoption authorities still rejected my application on the grounds that I'm 'too old.'"

When an older child has a serious medical need, it may seem crazy to set age limits for adoptive parents, but age restrictions are country specific. Some countries, such as China, may negotiate age waivers. Others, such as India and Korea, may be more rigid about age requirements and won't negotiate. Pam advises any parent who requests an age waiver to "have a formal guardianship plan in place and good resources to ensure that a child would be cared for until maturity."

1. "The Hague Convention on the Protection of Children and Co-operation in Respect of Intercountry Adoption (Convention) is an international agreement to safeguard intercountry adoptions. Concluded on May 29, 1993 in The Hague, the Netherlands, the Convention establishes international standards of practices for intercountry adoptions. The United States signed the Convention in 1994, and the Convention entered into force for the United States on April 1, 2008." Source: Bureau of Consular Affairs, US Dept. of State, http://adoption.state.gov/hague_convention/overview.php (accessed June 28, 2014).

Inside an Overseas Adoption

Pam Thomas, China Program Director for Across the World Adoptions, describes working on her first overseas adoption of a child with hemophilia, in 2009:

"I was in an orphanage where we had previously funded renovations. I visited the sleeping areas to see how the beds were holding up. When I entered what I thought was an empty room, I was startled to see something moving under the covers. Then, out popped a little head with a shock of straight black hair, two sparkly eyes, and the widest grin. A hand crept up and flashed me a peace sign. Here was an adorable little boy of 5 or 6, but he looked very pale and ill. I asked my translator what was wrong with him, and the answer was hemophilia. The child had suffered a bad bleed, and was in tremendous pain. No medication was available.

I came back to the States, but could not get that little face out of my mind. I called an adoptive parent I knew whose birth son had hemophilia, and through her kind advocacy was introduced to Laurie Kelley.

Between these two women, the word spread, and a family appeared that was eager to adopt this little guy. In the interim, Laurie arranged for a doctor in-country to visit the child and administer the correct medication, to keep him stable while the family worked through the paperwork, including the home study, the USCIS clearance process, and the dossier of documents required in Beijing.

Finally, the day came, and this little sweetheart walked out of the orphanage for the last time, holding the hands of his new mom and dad. It felt like a miracle!

That was several years ago. Recently, his mom sent me a photo of him…rock climbing!"

Sarah outlines the relatively smooth steps so far in adopting Gabriel: "We started exploring in November, and in January sent in all of our waiting child paperwork. We received our unofficial referral for Gabriel in February, and then had our dossier [of required documents] translated and submitted by July."

Sarah notes, "The biggest surprise has been the number of times we have to be fingerprinted! It's amazing that we have done it three times already and we have another set to go when we return from Eastern Europe."

But, she adds, "When we get frustrated with paperwork and technicalities, we just think of his sweet dimpled face waiting to meet his family! Just like pregnancy or childbirth, it's all worth it in the end."

What Will It Cost?

That's one of the first questions parents should ask when considering an adoption, either domestic or overseas.

For China adoptions today, notes Pam, "The average cost is about $35,000. This includes an agency fee in the US, home study costs, document preparation cost, USCIS [US Citizenship and Immigration Services] fees, in-country adoption fees, orphanage donation required by the Chinese government, and travel and living costs in China for about two weeks."

Sarah recalls that when she and Josh began researching overseas adoption, "the cost was shocking." But now they know what to expect, and so far, no more financial surprises have popped up.

Pam explains that parents are now protected by the Hague Convention.[1] "Agencies placing from Hague countries are mandated to provide prospective parents with a written list of costs and fees that they can expect to spend, both in the US and in the Hague signatory country. Families report these costs to the USCIS during their child's visa process, and the USCIS evaluates the fees to be sure they are appropriate."

The Hague Convention protects families from illegal adoption practices. Pam adds that in non-Hague countries, and in independent adoptions, "there may be additional risk, but families should not hesitate to ask for full fee disclosure, no matter which service provider they choose."

How to raise funds for an overseas adoption?

"One of our families sold all their collectables on eBay to raise money," Pam reports. "Some go to their church or social group for support. Others apply to organizations that offer grants. There are low-cost or no-cost adoption loans. There is also a $13,000 federal tax credit for adoptive families."

Pam recommends consulting an accountant about the adoption tax credit.

"I was never so-called financially ready when I adopted any of my kids," admits Jasmin. "With my oldest son, who was adopted domestically, I had savings, and then I put him on a credit card."

Would she advise other adoptive parents to do the same?

"For one year? Absolutely! Apply for interest-free credit cards for six months or one year."

When adopting her daughter Nanda, Jasmin got an interest-free loan from the local Jewish community. "As a Jewish single female," she explains, "I had practically no options. If you're a Christian married couple, there are many grant organizations available to assist. But if you're of the 'wrong' religion and the 'wrong' marital status, then things are a lot harder, but still doable."

For Adi's adoption, Jasmin worked through her adoption agency to negotiate with the overseas orphanage director. China required an orphanage donation, so Jasmin negotiated a waiver based on the fact that Adi was hard to place because of his hemophilia. She did her research first: "I found out that in the past, another single mom was interested in adopting Adi. She didn't go through with it, but in her case a waiver was given. So I said, if we were able to do it then, we can do it now."

Jasmin also got a grant through A Child Waits Foundation, an organization that offers grants for adopting children in orphanages abroad, and children with special needs. "So together with the adoption tax credit that I received later," explains Jasmin, "Adi's adoption was paid for. It was a huge blessing for me."

When the Luckeys were adopting Luke, Laurie Kelley emailed all her contacts, and within 48 hours had raised $17,000. "The hemophilia community often will rally to help a family in need," says Laurie.

Setbacks, Stress, Travel, Stress, Hurdles, Stress

There are as many adoption stories as there are families. Some are full of stress and setbacks, some are smooth. Always be prepared for delays and surprises.

Shari relates, "We began the process in March 2009. We had not had a home study, so we had to go through the whole process. Our agency said we completed our home study faster

than anyone else ever had! We left to pick up Luke in January 2010, so just about ten months from start to finish. Had we already had a home study completed, it probably would have been even quicker."

Sarah describes "a mess of hurdles" in her adoption process: "Because we had a current foster daughter, we had almost a two-month delay waiting for the initial approval to release her information into our home study." From there, the delays continued. "The most frustrating has been unnecessary delays from the state because of our foster care placement. Waiting for emails and letters to arrive has been nearly unbearable; we are definitely learning about patience." But, she adds, "As hard as it is for us waiting on each step, it's harder for us to know he is sitting in an orphanage, oblivious to the fact that there is a family who wants him and can't wait to bring him home!"

Overseas adoption usually means traveling to meet your child, sometimes to a developing country where standards and services vary from those in the US. For some parents, traveling is smooth; for others, it's stressful.

If you're adopting an older child, Jasmin emphasizes, "Learn the basics of the language of your child because it helps in the initial bonding process." Before she left for China to pick up Adi, Jasmin learned some Chinese. "I spoke like a one-year-old!" But even a little Chinese helped, because "it took three months before Adi was able to communicate pretty well."

When Shari and Dave traveled to China, "It was recommended that we go to Hong Kong initially and spend a day or two getting acclimated to the time change, because when we arrived in Nanjing, we received Luke the very next morning. This was excellent advice. Hong Kong is easy to navigate and a fun place to visit."

By contrast, while in China, Jasmin had to take Adi to a local children's hospital for a tetanus shot after a fall. "I thought, a children's hospital, it's going to be nice and rosy, like in the US. But it looked just like a prison, overcrowded and understaffed." She couldn't wait to get Adi home.

Parenting Moment

Children are the living messages we send to a time we will not see. — John W. Whitehead

In spite of the six thousand manuals on child raising in the bookstores, child raising is still a dark continent and no one really knows anything. You just need a lot of love and luck — and, of course, courage. — Bill Cosby

Jasmin had doubts when she arrived overseas. "Can I really do it? Is it the right thing? Will I go bankrupt? Will he die? You go through the worst, and just want your old life back."

The unknown can be scary, especially when you're traveling thousands of miles to meet your new child. But as Sarah advises other adoptive parents, "Keep your eye on the goal."

Eyes on the Goal

Adoption is about so much more than shared experience, humanitarianism, or meeting a medical need. It's about the wonder–and challenges–of creating a family.

"It has been so rewarding to see Luke blossom," says Shari, "from a child who was tentative and afraid to be physically active–because he had little access to medication–to a child just like every other boy his age, playing and being active, because he is on prophylaxis and hasn't had a bleed in over three years."

Jasmin believes, "Hemophilia adoption is probably one of the most rewarding things you can ever do." She recalls, "Adi was so happy when I came to take him. When we boarded the airplane, he was beaming, and when we landed and went to American immigration at the airport, he just soaked it all up." Adi has adapted well to his life in America, fitting in with his school mates, learning English quickly, and also learning Hebrew, the Davidsons' language at home.

Sarah is ready for the challenges of adopting an older child overseas. "Gabriel doesn't know us, and as a normally functioning teenager, it will be a transition from orphanage to family life, and especially to another country and culture." But she's excited about the future. "The biggest reward will be adding to our family and having another child to love. Our children will have another sibling to grow up with and learn from."

Ready to Explore Adoption?

If you want to adopt a child with a bleeding disorder, first learn all about the process. An electrical engineer, Jasmin even returned to school to become a licensed social worker, "because I thought that by being a social worker, I'd understand the child welfare world, and by understanding adoption, including policies and regulations, I would be able to serve my children better." Of course you don't have to go that far, but you do need to be well prepared.

Next, start searching for your child. Currently, there is no specific adoption agency you can contact to find a child with hemophilia, but you can contact a qualified adoption provider. Check online resources including those mentioned in this article. And keep reading publications in the bleeding disorder community.

» *page 15*

AISI... from page 3

The doctor also recommended I see a physiotherapist in the congress treatment room. I had never before thought physiotherapy played a role in treating people with hemophilia. The physiotherapist advised me to do some basic exercises in the water. The very important thing, she said, is to do the exercise slowly and to the limit that will not cause my joints to bleed. It will be a little difficult for me since I have to practice on my own. But I will have to try some of the easy exercises. My muscles have suffered atrophy over the period of seven years I haven't been able to walk. I hope that regular exercise and diet will make the muscles and joints of my legs fit for some movement.

Wheelchair Talk

I saw the man from Tasmania again, and we headed to a restaurant for our lunch together. He is 33, and he is in a wheelchair because of his damaged joints. On the way to the restaurant and at lunch, we were engaged in conversation ranging from relationship and romance to our favorite music. He said he has been going out with a female friend recently but doesn't want it to evolve into a deeper relationship. "I don't want her to babysit me, you know." I could give him nothing but an emphatic nod. I know what it feels like to be in a wheelchair and to have a romance at the same time. Anyone who has been in a wheelchair for seven years will know it too.

We continued to talk about our lives, and at one point he asked if my government gives me a disability pension. It is a new word to me because our country does not offer any social welfare service to its citizens. Luckily, I have earned money for my personal expenses from freelance translation and writing this year. I will have to thank my parents for keeping me at the university until I graduated.

Experience Sharing

At one interesting congress session, there were many speakers sharing their experiences: a doctor, a community leader, and a person with hemophilia, all under the topic "Eliminating the Gap in Care Between Developed and Developing Worlds." As someone who comes from a country with only 2% of the government budget spent on healthcare, I have concerns for the people with hemophilia in Myanmar. We have to pay for all the expenses of the treatment, and it is extremely difficult even for middle-class people like my parents. There will be many more people in rural areas who are not diagnosed with hemophilia and who pass away because of it.

I caught curious looks from the audience when I took the mic and talked about Myanmar. For the rest of that day, people asked me about the conditions in Myanmar. Alone, I cannot bring better treatment, better living conditions, and better lives to the people with hemophilia in Myanmar. But I can spread information to the global community. And in this way, I might be able to find somebody who is willing to work with us to find a solution for the thousands of people with hemophilia in Myanmar.

Aung Kaung Myat

Aung meets with WFH president Alain Weill

Learning Things with Open Eyes, Meeting People with Open Heart

My country, Myanmar, has been off the map of the global hemophilia community until now. I am probably the first person with hemophilia from Myanmar who has been to a WFH Congress. It is very important for all the people with hemophilia in my country to have a representative in the congress.

I also found people from neighboring countries of Myanmar during the congress: Malaysia, Indonesia, and Cambodia. We share an interest in forming a hemophilia society for ASEAN [Association of Southeast Asian Nations]. We would be able to lobby the ASEAN governments to improve the care and treatment of hemophilia as one voice. I will keep in touch and work with these people to form an ASEAN Hemophilia Association in a few years.

Having hemophilia and living in an isolated country, I always have the feeling of "only me." This is the first time in my life I have seen so many people with hemophilia at one single place. Their happiness and motivation spread to me. Along with gifts from some attendees, Melbourne gave me another gift—courage. Courage to live with hemophilia and be a community leader for the people with hemophilia in Myanmar is probably the most important gift I received from the WFH Congress.

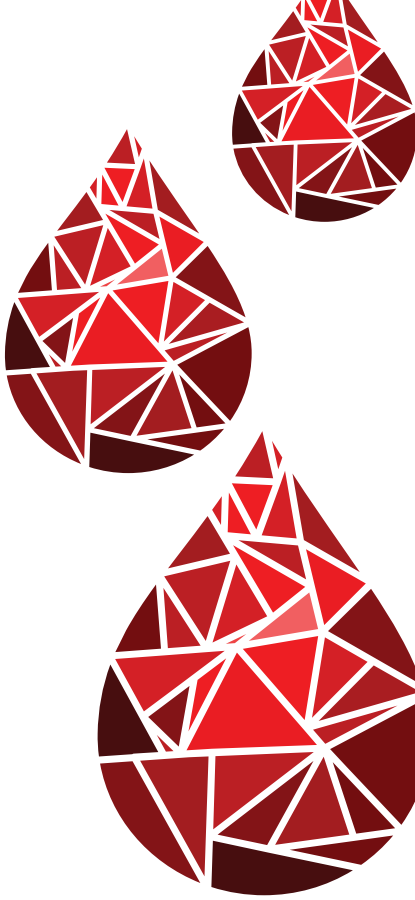
Insights... from page 4

or plasma had little effect. A test taken in 1945 for the presence of a circulating anticoagulant was negative.

William was hospitalized from December 1945 until March 1946 because of severe continuous hemorrhage in the rectum. During these three months, he received 30 transfusions, 500 mL each, of whole fresh blood. William did not improve, and his coagulation time consistently varied from 60 to 120 minutes. No tests for a circulating anticoagulant were performed. The last transfusion in this three-month period was given on February 9, 1946, and William slowly improved once the bleeding stopped. He was then seen repeatedly in clinic for chest pain associated with heart disease. A test on September 9, 1946, for the presence of a circulating anticoagulant was negative.

William was readmitted on April 15, 1947, for rectal bleeding lasting three to four hours. He was pale, had trouble breathing, and suffered repeated attacks of chest pain. He received six transfusions, 500 mL each, of fresh whole blood with no improvement by either clinical or laboratory findings. No test for a circulating anticoagulant was done.

Eventually, the transfusions of whole blood were stopped. William then received 500 mL of washed red cells, and showed some signs of improvement. Another transfusion of whole blood given inadvertently caused an immediate recurrence of symptoms. William then received another 500 mL of washed red cells, and showed steady symptomatic improvement. But as he continued to bleed, his clotting time remained prolonged, and the circulating anticoagulant persisted. William gradually improved, and the attacks of chest pain disappeared.



William's physicians believed he was deficient in antihemophilic globulin (factor VIII) in his blood. With laboratory testing, his circulating anticoagulant was shown to be associated with plasma proteins known as gamma globulins (we now know most antibodies, an important part of the immune system, are gamma globulins). The physicians hypothesized that the action of the anticoagulant against the factor was essentially that of an antibody-antigen reaction as a result of repeated transfusions or injections of factor. They concluded that certain people with hemophilia who are deficient in a clotting factor may be capable of developing antibodies (inhibitors) against the factor when it is given repeatedly.

William entered medical history books, but not just because of his inhibitor. Without his knowledge, William eventually became one of a group of guinea pigs in medical experiments using plutonium at Rochester University in the late 1940s. Several patients were injected with an average of 5 mcg of plutonium–*five times* the amount of plutonium the Manhattan Project scientists had just declared could be retained without harm in the human body.

William died on August 4, 1948, less than three years after receiving the plutonium injections, from what doctors described as "brain disease."[2] William Purcell, first known person with hemophilia and an inhibitor, is buried in the Purcell family plot in Section One South of Holy Sepulchre Cemetery in Rochester.

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Lawrence, J. S., and J. B. Johnson, 1942. "The Presence of a Circulating Anti-coagulant in a Male Member of a Hemophiliac Family." *Transactions of the American Clinical and Climatological Association* 57: 223–31.

2. Ben Dobbins, "News of Plutonium Injections Pains Tests Victims' Families," *Daily Gazette,* Mar 8, 1994. http://news.google.com/newspapers?nid=1957&dat=19940307&id=whYxAAAAIBAJ&sjid=IeEFAAAAIBAJ&pg=1856,1677198 (accessed July 8, 2014).

Overseas Adoption... from page 12

"I joined a Yahoo group for waiting children," says Jasmin. "I scoured the Internet. I knew about hemophilia, and then I came across Adi on a website that advocated for waiting children."

Shari and Dave learned about Luke "through an email blast sent out by Laurie Kelley." Shari notes, "Since our adoption, I have been involved in hearing about children with hemophilia, and trying to spread the word throughout the community, via email, word of mouth, and social networking." She adds, "Anyone interested in adopting a child with hemophilia can contact me, and I'll help try to help connect them with the appropriate people."

When you need advice and support, tap into the resource network: your adoption agency, home study agency, local bleeding disorder association, grant organizations, accountant and lawyer. Shari says, "I found both our adoption agencies such a pleasure to work with; they were truly excited for us and wanted to assist us throughout the whole process."

Remember: Always follow acceptable legal channels for overseas adoption. Use a reliable agency and social worker. Consult an international adoption doctor for help understanding your child's medical records.

One Child's Future

And what will happen to Michael, currently waiting for adoption in China?

"He is a gem," says Pam, "and someone is going to have the most stellar little son ever!" She stresses, "This precious little boy needs a very special family to help him with his medical needs and to reach his full potential."

Luckily, the director of the orphanage where Michael is living has arranged for him to have medication that will maintain him for now. And as PEN goes to print, Pam reports that an American family wants to move forward with Michael's adoption: "They are waiting for more information about his specific medical condition from the orphanage." But if Michael is not adopted, warns Pam, "he will age out of the social welfare system at age 14, and could be on his own, with no medical support."

Jasmin notes, "In China and other countries, too, it's an effort to prepare a child for adoption–the bureaucracy, paperwork, social work, medical exams. They don't bother if they think that parents aren't open to it. But we can change that."

"There are way too many orphans," adds Sarah, "and if word can get out that adopting a child with a bleeding disorder truly is possible and not as bad as people think, maybe more people will try."

Sara P. Evangelos is a writer and editor who has worked with LA Kelley Communications for more than 15 years. She is co-founder of JAS Group Writing and Editorial Services: www.jasgrouponline.com.

Resources

- Information on Hague and non-Hague country adoptions http://adoption.state.gov/index.php
- A Child Waits Foundation • www.achildwaits.org
- Across the World Adoptions Pam Thomas: atwachina@gmail.com
- Rainbow Kids • www.rainbowkids.com

Contact LA Kelley Communications at laurie@kelleycom.com and ask us to forward your message to Shari Luckey.

Richard's Review... from page 5

What is life like for these research dogs? Federal and university regulations closely govern living conditions and research procedures for all research animals to ensure their well-being. The dogs at UNC–CH are treated better than federal regulations specify. In fact, the hemophilic dogs in the breeding colony were treated episodically at first, and then prophylactically, with transfusions of normal blood or plasma supplied by a small group of normal donor dogs, before those procedures were even made available for patients with hemophilia at the UNC–CH hemophilia treatment center (HTC) on campus. Though the dogs are research subjects, they are not subjected to unnecessary pain.

How do humans benefit from this research on hemophilic dogs? In many ways: for example, the blood from these dogs is crucial for the development of laboratory bioassay methods; for determining half-life and disappearance curves of transfused antihemophilic factor (AHF); for the biochemical characterization of AHF; for developing methods of separating AHF from plasma; and for determining the location of the hemophilia genes. The hemophilic dogs have also contributed to the curing of hemophilia with a liver transplant, and have been instrumental to investigating gene therapy.

Many aspects of hemophilia care and treatment have been improved because of the research conducted on hemophilic dogs. These dogs are currently helping with other research investigations, notably new gene therapies.

My involvement with the bleeding disorder community truly began when I was employed (in a variety of psychosocial and administrative capacities, for 17 years) by the HTC at Wake Forest University, Winston-Salem, North Carolina. When I retired, I continued volunteering for Hemophilia Foundation of North Carolina. But to be honest, I really got involved in bleeding disorders because I needed a job, and then stayed because of the commitment. Even so, if you ask me, I'll just say that I was following the hemophilic dogs.

headlines

NONPROFIT

NHF's 66th Annual Meeting!

Nothing About Us Without Us

Washington DC

September 18–20

National Hemophilia Foundation's annual meeting will be scheduled a month earlier each year, until the date coincides with the World Federation of Hemophilia (WFH) Congress in Orlando in 2016.

Why this matters: This is the largest and oldest gathering of the US hemophilia community, where patients, healthcare providers, and advocates all meet to learn and share.

For info: www.hemophilia.org or handi@hemophilia.org

Wheels for the World: Big Wheels Keep On Turnin'

Barry Haarde completed his incredible third ride across America on May 17. The 2,904-mile tour started on April 19 in Costa Mesa, California, traversed nine states, and ended in Savannah, Georgia. Barry raised $47,550 for Save One Life. The funds will help the international organization support needy children and families with bleeding disorders around the world. Barry is the first person with hemophilia and HIV to cycle across the US. Congratulations, Barry, from everyone at LA Kelley Communications!

To sponsor a child with hemophilia in a developing country, visit www.saveonelife.com

NEWS FROM LA KELLEY COMMUNICATIONS

Pulse on the Road, our unique symposium devoted to educating patients about insurance and healthcare reform, visited families in San Diego on June 28 at the San Diego Zoo. Families learned about the Affordable Care Act and how it impacts bleeding disorder insurance coverage. Highlight: participants explored the CoveredCA.org website using laptops we provided, to try to choose an insurance policy. POTR was followed by an afternoon at the largest zoo in the world!

Next stop: Austin, Texas, Aug. 10

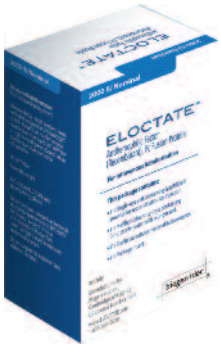
A family thanks Laurie Kelley for providing her book in Spanish

Below: Elizabeth Stoltz, Nicole Quinn-Gato, and Laurie Kelley (left to right), speakers for POTR in San Diego

Nicole Quinn-Gato helps a family navigate the Marketplace

MANUFACTURER

First Prolonged Half-Life Factor VIII Product Approved



Eloctate™ antihemophilic factor Fc fusion was approved by the US Food and Drug Administration for people with hemophilia A. It's designed to control and prevent bleeding episodes, for surgery, and for routine prophylaxis in adults and children with hemophilia A. Providing a longer half-life, it keeps infused clotting factor circulating in the body longer. Why this matters: Eloctate reduces the frequency of prophylactic infusions to every three to five days, in contrast to the typical three-times-weekly infusion regimen for people with severe hemophilia A.

For info: www.eloctate.com

Insurance Questions? Factor Solutions

Bayer HealthCare's *Factor Solutions* offers access to a team of trained case specialists to assist with insurance questions. The program provides: 1) expert advice; 2) factor assistance to qualified patients through Bayer's Patient Assistance Program (PAP), a short-term assistance program for patients who are uninsured or lack third-party coverage, and GAP, a short-term assistance program for patients who are privately insured who have a lapse in coverage; 3) copay assistance program for qualified patients. Why this matters: Insurance reform has left many people confused and needing guidance about factor coverage and out-of-pocket costs.

For info: 800-288-8374, 8:30 am – 5:30 pm ET, Mon–Fri

Breakthrough! First Recombinant Factor VIII from Human Cell Line

Octapharma has created a recombinant factor VIII (rFVIII) product derived from a human cell line; current rFVIII products are derived from Chinese hamster ovary (CHO) or baby hamster kidney (BHK) cell lines. Brand named Nuwiq®, this is the first human cell line rFVIII protein to be granted marketing authorization in Europe by the European Medicines Agency (EMA). Why this matters: Nuwiq contains no nonhuman materials, which cause allergic reactions in some patients; and human cells are capable of properly "finishing" the factor VIII protein, which may reduce the risk of the generation of neutralizing inhibitor antibodies to factor VIII.

For info: www.octapharma.com

Recombinant von Willebrand Factor Trials Going Well

Baxter International reported excellent results from a phase III clinical trial evaluating the safety, efficacy, and pharmacokinetics of BAX 111, an investigational recombinant von Willebrand factor (rVWF) intended to treat bleeding episodes in patients with VWD. On-demand treatment in all 22 patients who experienced bleeds achieved bleeding control as pre-specified in the protocol. Inhibitor development or thrombotic events were not reported in any study participants. BAX 111 is prepared using a plasma- and albumin-free manufacturing method. Why this matters: There is currently no recombinant VWD product available; Baxter intends to file for marketing approval in the US before the end of 2014.

For info: baxter.com

Getting to the CoRe

CoRe Conversations are bimonthly hour-long webinars and regular live presentations exploring topics of interest to the hemophilia community.

Braving Change

Resources and possible approaches to informed decision making during times of change.

Oct. 21, 8 pm ET / 7 pm CT / 5 pm PT

The Art of Transition

The importance of facilitating transitions in our lives, and some tools to do it proactively.

Dec. 9, 7 pm ET / 6 pm CT / 4 pm PT

Why this matters: Live discussions are often inconvenient to attend, but webinars make live presentations accessible to all.

For info: www.biogenidechemophilia.com

SCIENCE

Gene Therapy News

Bayer HealthCare and Dimension Therapeutics, a company focused on developing novel adeno-associated virus (AAV) gene therapy treatments for rare diseases, have contracted to develop and commercialize a novel gene therapy for hemophilia A. Bayer will conduct the confirmatory phase III trial, make all regulatory submissions, and have worldwide rights to commercialize the potential future product. Why this matters: Dimension Therapeutics's AAV vector technology allows for systemic IV administration of the clotting factor gene in vivo; this has been shown in preclinical studies to target the liver, resulting in long-lasting expression of factor VIII protein.

For info: www.dimensiontx.com or rosemarie.yancosek@bayer.com

WORLD

Largest Factor Donation Pledge Ever!

Biogen Idec and Swedish Orphan Biovitrum pledged at the WFH Congress (Australia, May) to donate up to 1 billion IU of recombinant clotting factor products over ten years in support of WFH's humanitarian aid efforts to raise the standard of care for patients with hemophilia in countries where factor concentrates are not easily available. Why this matters: This commitment is expected to allow physicians to treat more than 75,000 joint bleeding episodes and 2,000 life-threatening bleeding episodes, and conduct thousands of elective surgical procedures that would be impossible without clotting factor.

Source: *IBPN*, May 2014

SOUNDBITES

- The FDA approved a new reconstitution system, called Baxject III, for Baxter International's Advate recombinant factor VIII product.
- The FDA approved a new indication for Bayer HealthCare's Kogenate FS recombinant antihemophilic factor, for routine prophylaxis to prevent or reduce then frequency of bleeding episodes in adults with hemophilia A.
- Check out NHF's new user-friendly website: www.hemophilia.org
- HemAware now provides articles in Spanish at HemAware en español: www.hemophilia.org/Newsroom

Making History in Hemophilia

Chris's Seven Summits Quest

On July 6, Chris Bombardier made hemophilia history! Chris, who has hemophilia B, summited Mt. McKinley, also known as Denali. This is Chris's fourth summit in his quest to become the first person with hemophilia to conquer all seven summits–the highest peaks on each continent. He has already summited Kilimanjaro (Kenya), Aconcagua (Argentina), and Elbrus (Russia).

Chris, 28, is a native of Colorado and also a Save One Life board member. Chris recognizes that life with hemophilia isn't easy, but he knows how fortunate he is to live in a country where treatment is readily available. Thankful for his health, Chris climbs mountains to help raise awareness about hemophilia. He also raises money for Save One Life, an international nonprofit based in Boston that offers financial aid to children and families with bleeding disorders in developing countries.

Chris says he first became interested in Save One Life after attending a talk by its founder, Laurie Kelley, which "opened my eyes to how others live with this disorder, and mainly how lucky I am." Now, after visiting and working with people with bleeding disorders in developing countries, Chris has witnessed the great difficulties they face. "My time with the hemophilia community in Kenya made me realize how important Save One Life sponsorships and scholarships are. I want to help Save One Life continue its amazing programs and, I hope, expand to other parts of the world."

Chris adds, "I look forward to standing on the summits of these incredible mountains and feeling that sense of accomplishment and pride in doing it with hemophilia. More important, I look forward to spreading the word about hemophilia, opening people's eyes to the massive disparity in care that exists in the world, and introducing them to Save One Life. I'm also excited to show young people with hemophilia what's possible. Our world is an amazing place, and I don't want people with hemophilia thinking they have to live in a bubble. I want them to get out and experience life to the fullest!"

Chris's climb was funded by sponsorships from Reliance Factor of America, ASD Healthcare (Gold-level sponsor), and BDI Pharma (Friend-level sponsor).

Congratulations, Chris!

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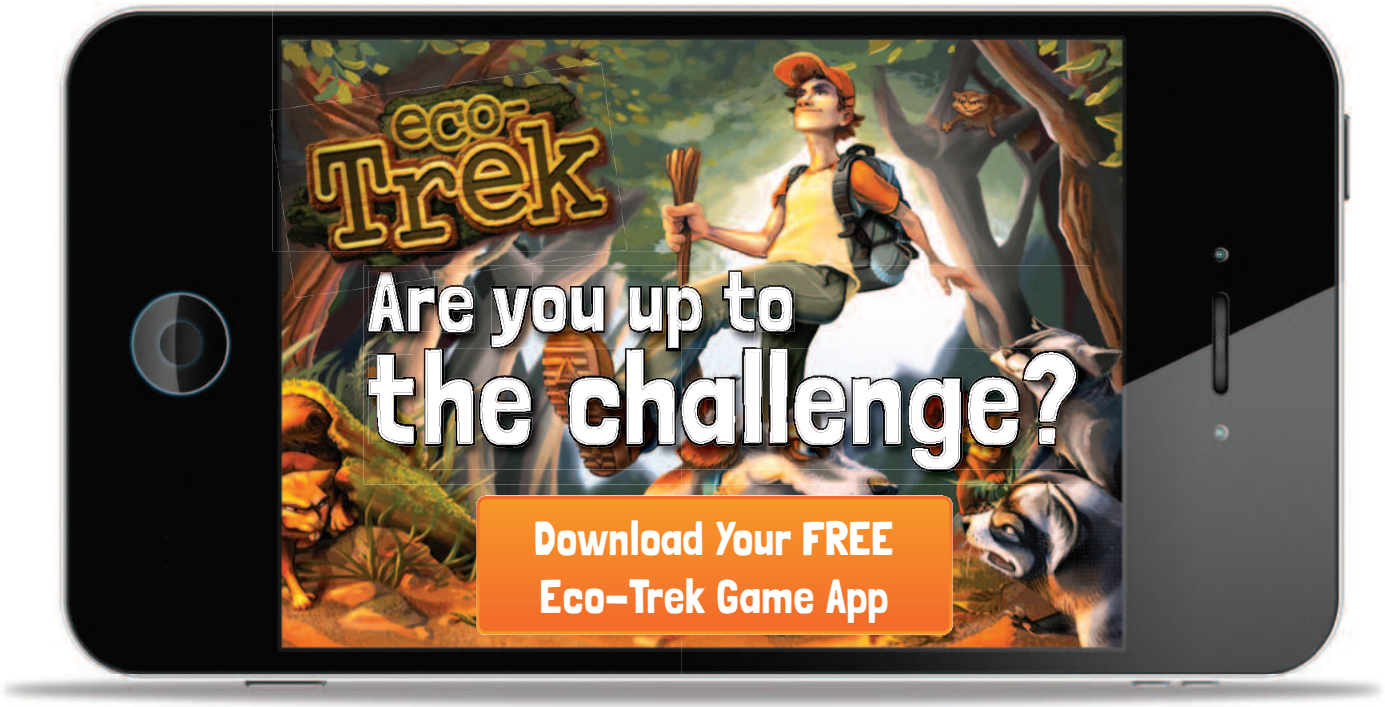

ADVATE
[Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method]

- 3 outdoor adventure games in 1
- An online leaderboard for nationwide competition
- Answer educational questions about ADVATE for bonus scoring

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GET IT ON Google play

Baxter