

PEN



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The Starfish Strategy: Saving Hemophilia Lives in Developing Countries

Laurie Kelley

You may know the parable. It's told in many ways, and it's often used in leadership training, in vision and mission development, and in motivational courses.

One day a man was walking along the beach when he noticed a young girl picking something up and gently throwing it into the ocean. When the man asked what the girl was doing, she replied, "Throwing starfish back into the ocean. The surf's up and the tide is going out. If I don't throw them back, they'll die." The man pointed out the thousands of stranded starfish and the miles of beach, and said, "You can't possibly make a difference." After listening politely, the girl bent down, picked up another starfish, and threw it back into the ocean. Then, smiling at the man, she said, "I made a difference for that one."

The starfish thrower¹ is a metaphor for making a difference in the world, the impact anyone can make for one starfish—or child, or puppy, or community, or recycled bottle—at a time. It teaches us not to lose hope, even when rational thinking or statistics tell us a situation seems hopeless. It's a metaphor about focus. Rather than feel powerless after hearing devastating news of an earthquake or famine, we can choose to take an action that helps just one person or cause. And by helping one, we contribute to a larger solution, especially when everyone decides to help just one.

How do we feel when we learn that over 300,000 patients with hemophilia worldwide have little or no access to factor or medical care, that many subsist on only \$1 a day, and that children die each week from untreated bleeds? The information shocks us, crushing hope. But we can make a choice: turn away from the thousands of hemophilia patients crying for help, or help just one person with hemophilia, knowing our actions will make a difference to that one.

The story of one person is the story of all humanity.

—Paulo Coelho

In this issue of PEN, I share the stories of four people, of the hundreds I have met in the past 15 years of traveling to developing countries. As you read, consider the starfish strategy. Don't focus on numbers. Focus on



A child whose father has hemophilia waves to American visitors. His family survives on \$1 a day in rural Kenya.

one child, one person, and do what you can today to change a life forever. Here's how.

Haiti: The Land That Time Forgot

FRIDAY, JUNE 11, 2010

My ultimate goal in visiting Haiti for the second time is to meet Mitch, a 10-year-old boy with factor VIII deficiency, currently the only known patient with hemophilia in Haiti. Mitch lives about 90 minutes outside Haiti's second largest city, Cap-Haitien. Haiti's January 2010 earthquake rattled the world, and monetary aid poured in. But no money for hemophilia. Why? There's no program; no national society; no one doctor, parent, or patient to be the leader and make a national program possible.

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¹ The starfish thrower story is attributed to Loren Eiseley.

welcome

Laurie Kelley

I did something in August I never dreamed I would do: I summited Mt. Kilimanjaro, Africa's highest peak at 19,340 feet. Why? Because "it was there"? Well, yes, partly as a challenge to myself. It's a six-day, strenuous hike with few amenities, and then a brutal seven-hour assault on the mountain in freezing temperatures (below 0°F at the top!) in the middle of the night. I had my doubts, which intensified when I overheard my mother tell a friend what I was doing, adding, "And she's not young, you know!" Ouch.

I accepted this challenge primarily as a fundraiser for Save One Life, the nonprofit I founded that offers sponsorships to patients with hemophilia in poverty. Our team of climbers were all from the hemophilia community, including my own daughter Mary. Our climb was successful: we summited, and in the process we raised more than \$66,000—twice the amount we expected. The funds will help support Save One Life's Africa programs.

We also succeeded in raising public awareness of the plight of Africans with hemophilia. Despite advances in hemophilia treatment, most of Africa has been left behind. It might as well be the 1800s in some African countries, considering the level of hemophilia care. Developed countries have resources and factor—we just need a way to deliver help and to make sure it's used properly. At Save One Life and Project SHARE, we're doing it, one person at a time.

The name Save One Life reflects my own belief: "He who saves one life, saves the world." I first heard this powerful proverb in 1993 in the movie *Schindler's List*. Then, when I watched the carnage in Rwanda on the news in 1994, I knew I had to *do something*. Initially, I wanted to adopt a Rwandan orphan, but that was not to be. Instead, Save One Life was born, focusing on patients with hemophilia in the poorest countries, who are forgotten by the world, by *our* world.

You don't need to do anything as dramatic—and crazy—as summiting a mountain or as life-changing as adopting a child. But you can help at least one child have a happier life and better healthcare. Read about my Starfish Strategy. I hope it inspires you to believe that you can save one life. You can make a difference.

Read about my journeys to other lands, to visit the homes of the poor with hemophilia. Climbing a mountain was great, but being so far aloft was surreal, making me feel farther away from where I should be. Being in the valley—in the homes of the poor—is much harder. But it reminds me of another quotation, this one from *The Valley of Vision*, a collection of Puritan prayers by Arthur Bennett: "The valley is the place of vision." For me, that's where the stars shine the brightest, where I can look up and clearly see the task ahead, whether it's a mountain to scale or a child with hemophilia to help. ☺



Laurie with Mt. Kilimanjaro in background

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as i see it

Adriana Henderson

Why Am I Here?



“Why are we here?” is a philosophical question concerning the purpose of life.

I have asked myself many times why I am *here*, but with the emphasis on here, in the US.

In 1970, I seemed destined for a different life, in Romania. My father was sentenced to spend his life in a communist prison for criticizing the government’s decision to deny the family the right to emigrate; and we, his children, were supposed to be sent to reeducation school. But we didn’t know that our situation had been receiving international attention. Following pressure from the United Nations and various churches, the Romanian government asked us to leave Romania immediately. It was a magnificent, magical, miraculous exit. We were the first family in Romania to leave legally, not only with a passport for emigrants, but also carrying an American green card.

As a young girl I never once looked back, or even thought about what I had left behind. I thought I would forget Romania, and hoped I would forgive. I pursued everything the US offered: freedom and opportunity. I had a wonderful family, a big house in the suburb, cars, trips around the world, a closet full of designer clothes. Most important, my family was healthy. Yet it felt like something was missing.

When the Iron Curtain fell in 1989 and images of the harsh realities in Romania besieged the world, I could not ignore my country and people anymore. The question “why am I *here*” started to nag me.

As a child, all I could think of was survival. Now, with my newfound freedom came a desire to succeed. When success wasn’t enough, I started to look for significance. I wanted to give back, to make a difference, to acknowledge the blessings that were bestowed on me and possibly see if there was a reason for my being *here*.

I was at a loss about what I could do, and for years I looked for some cause I could identify with. Then I met a woman who was looking for medicine to help a boy with hemophilia in Romania; he needed corrective foot surgery to walk. I barely knew anything about hemophilia, and the little I knew was mostly inaccurate. After a quick and shocking lesson on hemophilia, I began a quest to find the miracle medicine. It wasn’t easy, and the more I searched, the more I lost hope. I made hundreds of phone calls, all over the world, trying to source any kind of donation. It was a test of endurance and tenacity. I had one phone call left to make, the call to Project SHARE. They immediately shipped the factor, and the rest is history. That was more than 10 years ago.

Since then, I know why I am *here*. The boy had surgery and his wish was granted: he is now walking. That’s when S.T.A.R. (Start Thinking About Romanian) Children Relief was born. S.T.A.R. is a multipurpose organization with an emphasis on healthcare and a focus on blood disorders. Through S.T.A.R.’s efforts and donated factor concentrate, many Romanian boys and adults with hemophilia have had their lives improved or spared. On World Hemophilia Day, April 17, 2004, S.T.A.R. organized the first-ever hemophilia symposium in Romania. And S.T.A.R. organizes and hosts Camp Ray of Hope, in its sixth consecutive year this past summer, the only camp for children with hemophilia in Romania.

S.T.A.R. is also Save One Life’s partner for Romania. We have 59 children and adults with hemophilia sponsored through Save One Life. I know most of the beneficiaries personally, and have visited them at home or seen them at camp where they play with carefree enjoyment. I get to see them smile and hear them laugh. It feels awesome to be so intimately and personally involved.

I never thought I would be involved in charity or volunteer work. I don’t have the personality. I am shy, withdrawn, introverted, not the type that would organize international conferences and fundraise for summer camps. It’s said that we, in the non-profit world, change other people’s lives. That’s true, but in the process, our lives change too. We have a purpose, our life has meaning, we do things we thought we could never do. That’s a terrific feeling! We give a little, but we get a lot back.

I know—Romania is close to my heart, and I have a vested interest in helping my people. But to anyone who, like me, is searching and wondering if there is something more than just the fleeting pleasures in life: if you want to make a difference or improve a life, while you improve your own, consider sponsoring a child. Look at the Save One Life website, where many with hemophilia are waiting to be sponsored. Pick a country, pick a child. Put a sparkle in those eyes that look so hauntingly and sadly at the lens. Bring a smile and a chance for a better life. It’s a small gesture that will bring priceless rewards.

I know why I am here. Do you? ☺

Adriana Henderson is founder and president of S.T.A.R. Children Relief, a nonprofit dedicated to helping Romanian children in need. She was born in Romania and immigrated to the US, where she has lived for the past 40 years. She is a graduate of UCLA, and lives in North Carolina with her husband Tom, who often helps with her charitable work. They have two daughters.

Inhibitor Patients in Developing Countries: Not without Hope

As the holidays approach, inhibitor patients and families have their hands full: preventing potential bleeds, managing ports, trying immune tolerance therapy (ITT), infusing multiple times to treat bleeds, making frequent hospital visits, and managing mountains of insurance paperwork. Not to mention preparing for guests, traveling, and shopping!

We're lucky to have FEIBA VH and NovoSeven®RT to treat bleeding episodes, as well as factor VIII concentrates for ITT—and, usually, a way to pay for them. As the holidays approach, our thoughts turn to the less fortunate. How do patients with hemophilia in developing countries live? Do they have inhibitors too?

Invisible Inhibitor Patients

Some people think that patients with hemophilia in developing countries don't get inhibitors. It's a logical line of thinking: inhibitors develop when a patient is infused with clotting factor and the body doesn't recognize the factor as part of the natural blood-clotting process. The immune system launches an attack on the factor and destroys it by creating antibodies specific to the factor—inhibitors. If no factor concentrate is infused, no inhibitors develop.

Of the worldwide hemophilia population, 75% receive little or no healthcare, including factor products. So very few inhibitor patients exist in developing countries. Right?

Wrong. Inhibitors do exist worldwide. Statistics are incomplete, but it's possible to walk into a public hospital in almost any major city in the world and find inhibitor patients, sometimes two or three to a bed, sometimes with amputations, and always fearful.

Levels of Development

Hemophilia patients in developing countries are exposed to factor products—via government purchases, or as donations through humanitarian programs. Some get inhibitors when they are exposed to factor in cryoprecipitate, a common but less effective treatment for hemophilia in developing countries. At times, families sell everything they own just to purchase one or two treatments for their loved ones.

And those are the lucky ones—not all countries budget for



Cuevas family

Angelo (center) surrounded by his family. His life was saved by a donation of inhibitor product from Project SHARE.

or are legally prepared to import the costly drug. Countries develop at different levels and speeds. The governments of Egypt, Brazil, India, and Romania, for example, pay for factor purchases for at least some of their patients. Some countries, such as the Dominican Republic and Honduras, buy minimal amounts of factor, but are connected to the global hemophilia community and can sometimes get funding and factor donations. Still others, like Rwanda, have no known hemophilia care.

No matter the level of development, hemophilia families and healthcare workers on the ground in these countries paint a bleak picture. Inhibitor patients do exist, suffer terribly, and usually don't live long. Donations of regular factor products are hard to get from manufacturers, but inhibitor products are the rarest gems. Of the 5.9 million IU of product donated in 2011 to Project SHARE, only 258,000 U were FEIBA (only 4%) and only 48 mg was NovoSeven—enough for only two days of treating one bleed in one person with inhibitors. Although requests pour in weekly from patients worldwide, there simply aren't enough donations of FEIBA or NovoSeven.

Portraits of Pain

It doesn't take much imagination to feel a parent's terror at learning her child has hemophilia in an impoverished country—and then discovering an inhibitor.

Lillawattie Dass lives in Guyana, South America. Guyana has no hemophilia organization. Lillawattie's son Adrian, age 12, has severe factor VIII deficiency. Lillawattie has managed

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Kevin Correa



sponsored by Baxter BioScience

WORLDVIEW

A Powerful Trip to Africa

Just after midnight on June 3, 26-year-old Chris Bombardier stepped out of his tent and into the cold, starlit night on the slopes of Mt. Kilimanjaro, Africa's highest peak. The final leg of his bid to reach the summit was underway. If he succeeded, he'd be the first American with hemophilia to accomplish the climb.

As Chris took his first steps out of camp, he was driven by his personal desire to reach the summit and also his understanding of what the accomplishment would mean to others with hemophilia. The summit lay just a few hours away, the culmination of a journey to be measured more in changes of self-perception than in miles.

From Rockies to Rift Valley

Chris, who has severe hemophilia B, works as a research assistant at the University of Colorado's Hemophilia and Thrombosis Center in Denver. Linda Jacobson, senior medical technician at the center's lab, informed Chris that Indiana University was establishing a hemophilia lab in the town of Eldoret in western Kenya. She asked Chris if he'd like to travel to Kenya to help get the lab up and running.

"I said 'yes' before she had even finished the question," Chris recalls. When he broke out a map, he saw how close he'd be to Mt. Kilimanjaro, in Tanzania. Soon after, he decided to climb it.

Living in the mountains of Colorado, the outdoors have always been Chris's playground. Mountain biking, rock climbing and skiing are just a few of the rigorous pursuits he enjoys. He knows he's been fortunate in having few bleeds.

Chris's adventures serve a role beyond personal satisfaction. Each summer, Chris volunteers at hemophilia camp. Along with teaching skills like self-infusion, he shares his experiences with younger campers. "I want to show them that in spite of some limitations, they can still lead exciting, normal lives."

A Shift in Perspective

Coincidentally, as Chris planned his African trip, he learned that Save One Life had organized a fundraiser based on climbing Kilimanjaro. Save One Life is a nonprofit that provides sponsorships for people living with bleeding disorders in developing countries. Chris jumped at the chance to participate; but his climb would coincide with his work in Eldoret, so his trek up Kilimanjaro would occur two months before the rest of the Save One Life climbers made their attempt in July.

On May 16, Chris and the team from Indiana University arrived in Eldoret. En route to the Indiana University house, Chris got his first glimpse of African life.

"Huts lined the road," he recalls. "I can still clearly picture one boy sitting along the side of road, covered in dirt, no shoes, no adult in sight."

Chris experienced the culture shock typical of a first visit to a developing country. That afternoon, the team toured a hospital in Eldoret. "I had anticipated that the hospital would be different from what we have in the United States," says

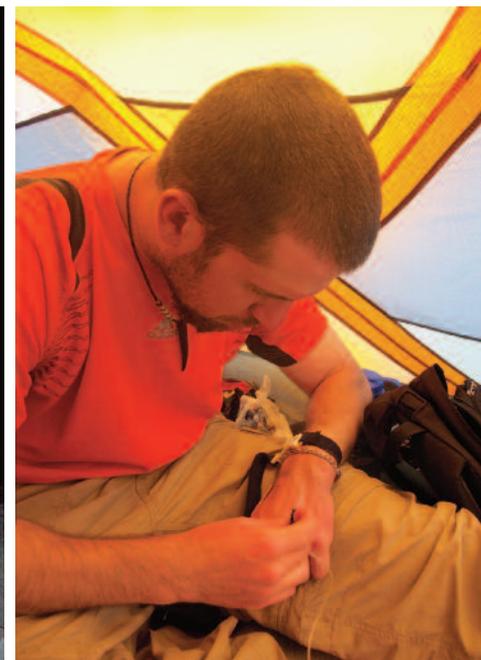
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Chris at the summit of Mt. Kilimanjaro

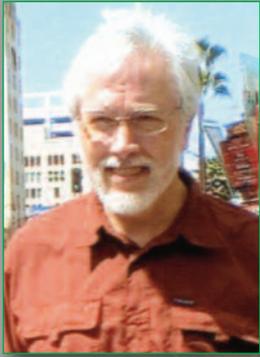


photos: Dave Bombardier

Chris infusing at 14,000 ft.



Richard J. Atwood



Solving Crime with Hemophilia

When the police can't solve a crime, who gonna call?

Perhaps a private detective. Fiction offers us some notable role models of private detectives who also happen to have hemophilia. Though this line of work may be considered too dangerous for someone with hemophilia, proper medical precautions can alleviate most concerns.

Read these fictional murder mysteries for the fun of it, or for the satisfaction of deciphering puzzles. Much like living with hemophilia, solving crime involves finding hidden answers to difficult problems, an important skill to master.



Mystery Man (2009)

The Day of the Jack Russell (2009)

Dr. Yes (2010)

Colin Bateman

Headline Publishing

The unnamed owner of the bookshop “No Alibis” in Belfast, Northern Ireland, had spent 20 years specializing in crime fiction. When he and his girlfriend Alison, along with his shop assistant Jeff, become part-time private detectives, it's more by chance than by choice.

Rather than venture out into Belfast to gather information, the crime book purveyor remains in his bookshop—using his telephone, Internet, and email to solve cases. He's beset by a host of phobias and illnesses, including hemophilia. But instead of the usual medical identification tag, this detective wears a plastic wristband because he's allergic to silver. Although his hemophilia causes occasional problems, it does not deter him from solving cases.

Each book in this trio of comical murder mysteries can be read separately or enjoyed in sequence. But to appreciate all of Bateman's ever-present, insightful humor, please read the complete series. The book-selling business and murder mystery fiction are astutely portrayed. And Bateman repeatedly

mentions the value of reading and purchasing books. His detective is able to solve crimes by using knowledge gained from reading all of the murder mysteries in his bookshop.

Writing under his last name only for this series, former journalist Colin Bateman is an award-winning mystery writer and children's book author.

Dead Man-Killer

Funerals—C.O.D.

They Die on Schedule

Edith and Ejler Jacobson

Popular Publications, 1939

In mystery novelettes published monthly in *Dime Mystery Magazine*, the married writing team of Edith and Ejler Jacobson introduced a character with hemophilia. Nat Perry is known as “The Bleeder.” His physical handicap bars him from the police force, but he works as a private investigator, gaining a reputation as one of the shrewdest detectives in New York. Though Nat carries a gun for safety, and “a bruised knuckle might have been fatal for him,” he has learned Japanese self-defense, enabling him, “if he wished, to kill a man by means of a scientific blow to the head with the side of his hand.” Yet this pulp-fictional character still knows he's vulnerable.

Three 1939 novelettes feature Nat Perry, but the Jacobsons wrote other pulp fiction. Ejler Jacobson subsequently was editor of the magazines *Galaxy* and *If*. The “defective detective” stories, a subset of the pulps, were most popular in the late 1930s, shortly before the demise of all genres of pulps by the late 1940s—to be replaced by television, which has continued to feed our fascination for detective stories.

It isn't easy to find the Jacobson novellas, but I located them in these two sources published by Bowling Green State University Popular Press:

The Defective Detective in the Pulps (1983)

Gary Hoppenstand & Ray B. Browne, ed.

More Tales of the Defective Detective in the Pulps (1985)

Gary Hoppenstand, Gary G. Roberts,

Ray B. Browne, ed.

Happy reading!



alex lieber memorial scholarship award

CONGRATULATIONS to the WINNERS!

Christian Mund



Ethan Jansen



Nicholas Popp



Rex Climer III

The Alex Lieber Scholarship Award was established in memory of Alexander Scott Lieber, of Florida, who had severe hemophilia A. Alex passed away on December 21, 2003, at age 16, from bacterial meningitis. Through this scholarship, his inquisitive and caring spirit lives on.

The scholarship provides financial assistance for people living with hemophilia or von Willebrand disease. Each student will receive \$500 to use for expenses related to higher education.

This year's winners include Rex Climer III, of Tennessee, a sophomore at the University of Tennessee at Martin studying engineering with a minor in agriculture; Ethan Jansen, of Florida, a sophomore at the University of Central Florida studying mechanical engineering; Christian Mund, of Massachusetts, a first-year student at Syracuse University studying film production and cinematography at the College of Visual and Performing Arts; and Nicholas Popp, of Illinois, a junior studying biochemistry and biology at the University of Chicago.

All four winners have demonstrated a strong commitment to education, volunteerism, and community service, and have been positive role models within the hemophilia community. Alex's parents, Tammy and Jim Lieber, note, "We were honored to take part in the selection process of these wonderful scholarships that have been awarded in Alex's memory. Best of luck to each of the applicants in this school year."



To apply for the 2012 Alex Lieber Memorial Scholarship Award visit www.kelleycom.com after January 1 for details

a project share story

Kathryn Ondek



It's time to give back

A Drop in the Ocean: Mission *Almost* Impossible



Jabir Abdul Malik

Slightly smaller than Texas, Somalia is located on Africa's east coast and bordered by Kenya, Ethiopia, and Djibouti. Somalia's population is 9.9 million, with a life expectancy of only 48.5 years for males, and that's *without* hemophilia. Somalia's capital is Mogadishu, home of six-year-old Jabir, who has hemophilia A.

Halfway across the world, in San Diego, lives Jabir's uncle Abdirisack. A refugee from Somalia, Abdirisack was receiving help from the International Rescue Committee (IRC), which contracts with the US State Department to assist refugees in their transition here.

"Abdirisack came to our immigration department to petition his nephew Jabir to come to the United States for medical help," says Jamie Robertson of AmeriCorps VISTA at the IRC. Jabir's doctor, Mohamud Zahid, knew that Jabir had a

bleeding disorder, but felt he needed more extensive tests performed outside of Somalia. "Unfortunately," explains Robertson, "we had to tell Abdirisack that there was no way to petition his nephew through the US immigration processes."

Abdirisack had been in the US for only a year; he was unemployed and unable to pursue other options for Jabir. So the IRC decided to focus on getting aid to Somalia for Jabir. "I contacted hemophilia associations in California and larger global organizations that focus on hemophilia patients and treatment," says Robertson, "as well as hematologists in Eastern Africa and the World Health Organization. It was at that point that I found Project SHARE."

In March 2011, Robertson contacted Project SHARE. She explained that Jabir's bleeding disorder was discovered

after he was circumcised at age four, but his family has been unable to obtain factor for the past two years.

Project SHARE worked closely with Jabir's uncle Abdirisack, to determine how best to get factor to Jabir. Because it's impossible to send factor to Somalia directly, there were many challenges: the language barrier, gaining access to Jabir's medical records, and finding a way to ship the factor.

Then we learned that Abdirisack has a sister living in Kenya. Luckily, Project SHARE donates regularly to Kenya through the Jose Memorial Haemophilia Society (JMHS). With help from Paul Kamau and Maureen Miruka, JMHS president, we were able to donate factor for Jabir. The next week, Jabir's aunt, Sucaad Adan Abdirahman, registered with JMHS so she could transport factor to her nephew.

"I was so excited when I finally found Project SHARE," recalls Robertson. "The work they do is incredible, and it was such a relief to know that this group truly cared about this one little boy from Somalia and had the resources to help him."

Today, Jabir is doing well. Without the help of a small group of caring people from San Diego, Boston, Kenya, and Somalia, working together with one common goal, helping Jabir would not have been possible. ☺



Jabir's aunt Sucaad Adan Abdirahman with Paul Kamau of JMHS, Kenya



Jabir's uncle Abdirisack

Project SHARE

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I think it's time for Haiti to join the rest of the world in receiving the hemophilia care it deserves. But first I must find the patients.

I'm staying at the guest house at the Saint Francois de Sales church compound. It's rustic, with good food, but noisy. All night long, trucks rumble past my window on the rough, unpaved street. Dogs bark incessantly. Music blares. I awaken at 5:30 AM to birds squabbling furiously in the tree outside my open window. I grab a cold shower and have a breakfast of eggs and cassava. I feel the heat rising, like an oven being stoked.

My partner in adventure is Randy, a nurse who is volunteering here at St. Francois. An Atlanta native, Randy arrived six months ago to help with earthquake relief for a few weeks—and never left. Haiti stole his heart.

Part of our plan is to meet people who might help us set up a hemophilia patient referral system for Randy. One is Dr. Maklin Eugene, a general physician with a heart of gold and a dazzling smile. For today's trip to see Mitch, we're traveling in our ambulance with Dr. Eugene, along with our translator Jorgen, a handsome 28-year-old who happens to be a big Lakers fan.

Mitch was discovered by a visiting US nurse, Mary Lou Larkin, medical director of Haiti Marycare of Connecticut. While doing outreach clinic work, she found an orphan with bruises and deformed joints, who could not walk. Haitian doctors performed surgery on his knee, not knowing he had hemophilia, and he almost bled to death. Mary Lou's colleagues at Yale University tested his blood, discovered hemophilia, and referred her to Project SHARE. We shipped medicine to stop the bleeding knee. Dr. Eugene has been caring for Mitch ever since. Mitch—a needle in the haystack of Haiti. For me, now, he's the only known patient with hemophilia in all of Haiti.

Roads are a major obstacle to healthcare in developing countries: decayed, pocked, crumbling, billowing dust, almost obscuring pedestrians. There are no rules of the road in Haiti, Randy says. No median strips, no painted dividers. Garbage borders the streets like strange edging on the fabric of poverty.

We're jostled back and forth, up and down, dodging potholes and motorbikes, popping over speed bumps. I start feeling nauseated.

An hour later we arrive in Jacquesyl, a quiet hamlet, one of hundreds in Haiti. It's flat, scorching hot, home to an estimated 12,000 people. But who really knows? No census is taken in Haiti, and all demographics are estimates only.

There are few trees, and dirt and dust are everywhere. Homes are made of branches fastened together then overlaid with mud. Some have concrete. The

roofs, always, are corrugated tin, baking the inhabitants.

We arrive at the small clinic where Dr. Eugene works every Friday, making this 90-minute trip by motorbike. Going by car today is a treat for him—but not for me. We walk into the rural clinic: just a few rooms, a short hallway where families are waiting, and no air-conditioning. Jorgen says, "This is a nice place." I look at him, incredulous, but he's sincere. "It's a nice town," he adds.

Mitch's grandmother enters the clinic's consultation room. She is rail-thin, about 65, and elegantly dressed as if going to church. She says something in Haitian Kreyol (Creole), and everyone points at me. She smiles and embraces me. Jorgen explains that she asked who donated the medicine for Mitch's operation.

We visit Mitch, who is in school only 300 feet away. Mitch cannot walk. He uses a wheelchair or is carried everywhere. We find him sitting in the antiquated schoolhouse, surrounded by curious classmates watching us.

Thin, good-looking in his blue school uniform, he glances at us, not terribly impressed. Dr. Eugene explains why we are here, and Mitch nods. Then we examine Mitch's knee and see the ghastly scar running from top to bottom like train tracks. We carry Mitch outside and place him in the ambulance. When I climb in, I'm surprised to see him sitting in Randy's lap in the driver's seat. Mitch has a cool, confident smile on his face, and we take off, with Mitch steering and Randy's foot on the brake and gas pedals, cheered by schoolmates who run alongside.

We arrive in minutes at Mitch's home. He is placed in a chair in the yard and his wheelchair is brought out. It's broken, and Randy pledges to get a new one. The house is nice: a little porch, concrete walls, several rooms, a yard. I imagine the inside is not as nice. We take some photos so I can document how Mitch lives, to help find him a sponsor.

We return to the clinic so Dr. Eugene can finish seeing patients. I become one of them. I'm not feeling well, and I need to rest out of the sun. There are no gurneys, no couches, no privacy. I'm escorted to the town's parish; inside is a nice living room. As I ease myself down on the hard sofa, I startle: next to me is a box with a huge, hairy spider on top. My escort, a young Haitian woman, smiles at me sweetly, then swats it with vengeance.

By 2:00 PM Dr. Eugene is finished with the patients, and we climb back into the ambulance. Two young boys watch us from the shade of a tree. I have only one stick of gum and one mint left, but I motion for them to come. They race toward us and grab the goodies.

Randy is compassionate: he drives very slowly over the rough roads, joking that we should reach Cap-Haitien by



Mitch and his grandmother in the schoolhouse



Mitch's horribly scarred knee after surgery



Laurie and Mitch

tomorrow. We are all happy, listening to Lady Gaga, chatting about Mitch, and discussing how we can structure hemophilia care.

Back at St. Francois, I take a cold shower to wash off the sweat, dirt, and insect repellent. I feel blessed to have fresh water and a bar of soap. Haiti surely makes me

treasure simple joys. Randy says grace before a dinner of rice, beans, and fried plantains. Never has dinner tasted so good. Bottled water, a glass of wine. I feel like the richest person on earth.



“Blanc!” [white!] a little boy cried out to me, smiling, as we rode to the airport the next day. Then, after an energy-draining, sweaty wait in the airless passenger room, I was airborne on what seemed like a time machine returning to the present.

I didn’t visit Haiti; I survived it. I was at once fascinated and uncomprehending. How did this country, smaller than Maryland, the first independent black nation in history, ever wind up so chronically underdeveloped while the countries around it are developing quickly?

On the plane, I felt oddly guilty: many Americans have more than enough, more than we need. Yet returning from Haiti, I’d never felt so alive. Never felt so sad to leave fellow humans behind. And now, I can’t wait to return.

Kenya: No Country for Old Men

THURSDAY, AUGUST 4, 2011

I am thrilled to hear that Eric Hill and his 14-year-old son Alex are finally arriving in Nairobi, Kenya, this morning at 6:30 AM. Eric is president of BioRx, a provider of specialty pharmaceuticals, and sponsor of children through Save One Life. Their connecting flight delayed, Eric and Alex spent two days in Europe, waiting. Now their luggage is missing, and they must be exhausted. We have a full day of family visits ahead in Murang’a, a two-hour drive from Nairobi. Surprisingly, when they touch down, father and son want to meet us immediately at the hotel and accompany us.



A busy Kenyan street

I usually travel with just a few locals, but now we are quite a group: Maureen Miruka, president of Jose Memorial Haemophilia Society–Kenya (JMHS) and mother of a child with hemophilia; Paul Kamau, who has hemophilia and works for JMHS; volunteers Isaac and Adam, young men with hemophilia; and Jagadish, JMHS board member, whose son has hemophilia. Also with us are some newbie visitors to Africa: Julie Winton, RN, of BioRx; Kara Ryan, medical student; Jeff Salantai, person with hemophilia, of BioRx; and Mary Kelley, my 17-year-old daughter.

We all pile into the van and head out. After battling Nairobi traffic, we finally reach our first stop: a meeting at Murang’a District Hospital, which cares for 70% of JMHS patients, all poor. We want to tour conditions at this typical rural county hospital. Our visitors are astonished at the dirt driveways, the outdoor, open-air waiting rooms, and the lack of facilities. And this is one of the nicer hospitals!

Next, we drive to meet several families. One visit stands out for me especially.

I first met Stanley in April 2010. We didn’t really warm to each other—Stanley is quite reserved—and I wondered how this meeting would go. Stanley is 40, thin and quiet, with factor VIII deficiency. It’s strange to find a patient Stanley’s age—most people with hemophilia don’t live beyond age 45 in developing countries.

To reach Stanley’s shack, we veer off the main road from the hospital, onto a dirt road and then a dirt path. As we squeeze out of the van, a small crowd of curious children gathers from neighboring shacks. When Alex stops to distribute candy, a near-riot ensues. We walk toward Stanley’s shack, passing an emaciated kitten, flea-bitten and sickly. We’re all wearing close-toed shoes, following Maureen’s warning about chiggers, tiny relatives of ticks that leave behind a bright red bump and cause severe itching. I notice that none of the residents is wearing shoes.

Stanley has a small farm: one cow, and a garden with some vegetables. No electricity or plumbing. No floor, either, in this one-room dwelling, just red dirt. No screens to keep out malaria-carrying mosquitoes. Stanley, his wife, and their two young children use candles at night.

Stanley remembers my visit from last year. He tells us how hard it is to farm with his joint contractures; and his wife is pregnant. The couple’s eyes reveal their fear. Stanley wants to start a business as a street vendor selling shoes, but it would cost \$400 to purchase the initial inventory.



The Save One Life team at Murang’a District Hospital



The neighborhood kids are curious about the visitors



Stanley's farm



Stanley shows his knee



Save One Life and JMHS team up to help Stanley

Did You Know...

Judaism, Islam, and Christianity all require service to the poor.

We ask questions about Stanley's treatment, bleeding episodes, and daily life. This is an eye-opener for our visitors. How can Stanley, the breadwinner, reach the hospital with no car, no bike, no telephone?

And if he's fighting a bleed, he can't work, and his family goes hungry.

This is Julie's first trip to a developing country, but she's a quick, strategic thinker. Immediately, she says that home infusion is the only way Stanley can break the cycle of bleeding so he can work. Home infusion is almost unknown in most developing countries. Our goal will be to break this mindset and to get as many patients as possible on home infusion.



Home visits mean a rough ride and seeing extreme poverty, sometimes starvation. But we must do it. In Africa, you can't wait for patients to come and see you; you must go to see them, or they will die.² So said Dr. Michael Wood, founder of African Medical and Research Foundation (AMREF), which includes the Flying Doctors of Kenya. And this is the foundation of Save One Life activities: we must see the individual patient, note his needs, and empower him. And—as Julie did—find a solution unique to him. In Stanley's case, home infusion and a loan to get his business started.

The Philippines: One-Shot Deal

FRIDAY, OCTOBER 17, 2008

I'm in the port city of Cebu, oldest and second largest city in the Philippines. I am traveling with Father Don Kill, our liaison here, and with Andrea Trinidad-Echavez, a woman with von Willebrand disease whose daughter also has VWD. We're meeting with the hematology team at Perpetual Succor Hospital to discuss factor donations.

While we're here, a hemophilia patient is admitted to the ward. This is always a learning experience: noting the patient's needs, observing the medical team in action. We snake our way through the mobbed, humid

² Paraphrase from *The Africans* by David Lamb (Vintage, 1987), p. 258.



Baby Christian gets an unexpected infusion

corridors, and there in middle of the hallway in the overcrowded pediatric department is a small, thin mother, breastfeeding a barely covered baby. The baby's head is swathed in a blood-soaked bandage; his foot is tethered to an IV pole. His mother is trying to soothe him amid the din.

The nurses tell us that baby Christian fell the previous week and hit his head. He has received fresh-frozen plasma (FFP), and he's been in the hospital since then. His mother stays with him, but she has other children at home. His bleeding is not being controlled.

What can I do? I feel helpless. I suddenly recall that I stuck a vial of factor VIII in my purse to show reporters at a press conference later. I whip it out dramatically, and everyone's eyes light up—as if I've taken out a bar of gold!

A nurse grabs the vial, then reconstitutes and administers factor to the baby in the middle of the hallway. The mother is a little wary of me. But when she learns that I also have a son with hemophilia, her face relaxes into an expression of understanding and gratitude. The baby, of course, is screaming more when his skin is pricked, but to us, these are happy screams.



Countries such as the Philippines have practically no factor: only the very wealthy can afford to buy it out-of-pocket. And most patients have no medical insurance and must purchase any medical items used in their treatment. Indigent patients like Christian's mom go to the public hospitals, where they receive free medical services but not medical items. Patients must pay for gauze, needles, syringes, bandages, and blood products such as the less-desirable FFP or cryoprecipitate. And even the less-expensive treatments are still too expensive. A bag of FFP costs about \$30 US. This is one-half to one month's salary for a family. It's completely unaffordable.

We traveled nonstop in the Philippines, by boat, car, and plane, for hundreds of miles, meeting with dozens of hemophilia patients. The stories are heartbreakingly similar: no factor, no money, much pain, and many patients have died.

Zimbabwe: A Lesson in Civility

TUESDAY, NOVEMBER 27, 2007

Zimbabwe is seven hours ahead of Boston, my home, but decades behind in development. Once a thriving country, Zimbabwe has been dominated by a dictator for 30 years, following its independence from Britain in 1980. The country now teeters on chaos, the economy failing. Today I sample a day in the life of an average Zimbabwean: long lines at the bank; no gas for the car; telephone lines down; frequent brownouts; few restaurants open, and no bread in the stores. People are starving here. Some crafty Zimbabweans dash across the border to Botswana, buy gasoline, hide it in milk crates or barrels, and then drive back, praying that government troops do not stop them and confiscate it.

The currency is near worthless. Ironically, I have brought Peter Dhlamini, my main contact here, a wallet as a gift. Yet buying a sandwich and Coke at lunch requires a *shopping bag* filled with Zimbabwe dollars. My wallet is pretty useless to Peter, and all we can do is laugh at the insanity of it all.

Worst of all for those with hemophilia, there is virtually no factor VIII, except for the stash I brought with me to donate.

I am privileged to work with the Zimbabwe Haemophilia Association (ZHA). Today, we brainstorm next steps for the organization. Along with Peter, its members include Simbarashe Maziveyi, Doreen Machona, and Caryn Thomas. Doreen and Caryn have sons with hemophilia, and the other members are young men with hemophilia. All are volunteers.

After meetings with the blood bank staff and its patients, we take a bumpy ride to the outskirts of Harare to visit more patients at home. This is the best part of my overseas trips: entering patients' homes, meeting families, learning firsthand what life is like. How can I possibly understand them if I don't visit them where they live?

At dusk we arrive at a small brick house on a dirt road. There's a brownout and sunlight is disappearing, so we meet inside in the near dark. In Zimbabwe, the traditional greeting is to clap hands while saying *Makadee*, Shona for "How are you?" I am greeted with much clapping. The family gathers in the small living room, and out of a bedroom wobbles Elton, age 17, and his brother Emmanuel, age 14.

A talented student, Elton had to drop out of school because he can't walk. He is in constant pain, but he bears it regally. The first thing I notice is his grotesquely swollen knee: he has the worst case of synovitis I have ever seen, and has been like this for a year. He can't wear long pants because of the swelling, and his calf muscles have atrophied. Most alarmingly, his lower leg is numb because the hideous swelling is compressing his nerves and blood vessels. Without intervention, gangrene will set in and his leg will need amputation.

Action springs not from thought, but from a readiness for responsibility.

—Dietrich Bonhoeffer

I am shocked by Elton's condition. He needs immediate medical care. But how? To bring him to a hospital, Simba explains, would accomplish nothing. Medical staff can't perform synovectomies here. Elton would need to travel to South Africa. We vow to do something, we tell the appreciative family.

Emotions high, the family wants me to meet Elton's older brother, Sylvester. We walk down the hall to the chilly kitchen where, lying on the grimy floor surrounded by grease-stained walls, Sylvester sleeps on a pillow of folded laundry. I want to let him sleep, but Elton wakes him, and Sylvester rises slowly, painfully. It's clear that he is ill: the whites of his eyes are yellow, and he's coughing. I learn later that he has tuberculosis. Sylvester smiles weakly, extends his hand, and says hoarsely, "Welcome to Zimbabwe. How was your trip?"

I have never experienced such warm hospitality and civility as in Zimbabwe. Sadly, Sylvester will die of tuberculosis in just a few months.



After many hugs and much clapping, we left that evening, promising to see each other again. Even in the cool weather, hordes of mosquitoes swarmed down the dusty, dark roads. The brownouts created suspense—we were never quite sure where we were driving! Back in Harare, in my comfortable hotel, I thought sadly about how differently the families I met had ended their day.

The Starfish Strategy

In his book *The Life You Can Save*, Peter Singer claims that most people, if passing a child drowning in a pool, would not hesitate to stop and help, even if it meant an inconvenience, such as ruining clothes, missing a plane, or being late to a meeting. Why? First, we consider ourselves personally *responsible*—there's no one else around to save that child. Second, we consider ourselves *capable*—we know we can do something to help.

Why then, asks Singer, do we do nothing to help the 27,000 children who die *daily* from diarrhea and other preventable diseases? Perhaps it's because they seem nameless, faceless, far away. We are not responsible—they are someone else's concern. We may have rational justifications for not acting to help children who are sick or in danger overseas—why aren't the local governments doing something? We may not trust international nonprofits—how do we know our money really gets to the child? We are taxed—don't our taxes go for international aid?

These are all valid arguments, but what if an organization offered *guaranteed* delivery of your money to a child in need with hemophilia? What if the organization worked with local hemophilia groups to lobby the government for long-term help, even while short-term aid was being given? And what if you started thinking of "poor people" as part of your hemophilia family? Wouldn't you help your brother or sister, just as you'd help that child in the pool?



Laurie with Elton, who has extreme synovitis

Hemophilia is rare, and many governments give it little or no attention. But we know that children in developing countries have the same bleeding disorder our loved ones have. Have you ever wondered why your child was lucky enough to be born in the US? Did *you* do something to deserve this? Did *they* do anything to deserve being born in poverty? Do any of us deserve hemophilia?

We live in the richest country on earth, with more luxuries and conveniences than at any time in history. Yet half the world's population lives in poverty, with over 1 billion in extreme poverty, on about \$1 a day. Add in hemophilia, and odds are that these children live in pain, stress, hardship, and hunger, with no future.

If you think of these children as part of our global hemophilia family, then we are all responsible for their survival. If you are capable of helping, then you can act. Almost all of us can do *something*. Just giving up the price of one bottle of water a day can help change a life with hemophilia. Check out the little "starfishes" on the Save One Life website and ask, *Can I make a difference to one?*

If you think you are too small to make a difference, try spending the night in a closed room with a mosquito.

—African saying

The Ones We Threw Back

Mitch is a lucky boy. Thanks to Mary Lou Larkin and Dr. Eugene, someone will always watch over him. Project SHARE will ship factor when needed—that's the easy part. Mitch's story was so compelling on my blog³ that he now has a sponsor to pay his school fees and a monthly stipend so he and his grandmother don't go hungry. I'm slowly building a hemophilia sup-

³ Read Laurie's blog at blog.kelleycom.com

port group, working with the Cap-Haitien Health Network. Best of all, I will return to Haiti soon to visit Mitch—and I'll bring his sponsor with me.

Starfish saved!

Stanley is not a typical poster child, but he deserves our help, too. He doesn't want charity. He only wants a loan of \$400, to start a shoe-selling business by the roadside. When I shared Stanley's story on my blog, I got an immediate reply from a young man with hemophilia who I helped once! Years ago, as a college graduate, he had asked me, "I need to stop working in restaurants because it's too hard on my joints. Can you help me find a professional job?" He now has an excellent job, easier on the joints, and he wants to give back. He's offering the \$400 loan to Stanley.

Starfish saved!

Baby Christian was lucky: I happened to be in the hospital ward that day, so I found out about him. The day after his impromptu infusion with the factor from my purse, Christian went home. He now has a personal sponsor, through Save One Life, who will help the impoverished family buy basic supplies.

Starfish saved!

Elton would lose his leg if he didn't have surgery. The hospitals in South Africa couldn't take him—who would pay for it? I turned to the US hemophilia treatment centers, and pleaded. An angel, Dr. Len Valentino of Rush Hospital, Chicago, accepted Elton as a patient. Pfizer, through Project SHARE, provided the factor IX for a synovectomy. A wonderful hemophilia family, the Castaldos, hosted Elton's visit. A generous donor, Neil Herson, provided free airline tickets. Juliet Hanlon, a UN goodwill ambassador I met at a charity event, kept me motivated and worked with Zimbabwe's ambassador to the UN to expedite a passport and visa. In March 2009 Elton arrived in Chicago, had a synovectomy, and returned home

six weeks later with a working knee, a laptop, an iPod, a wheelchair, and a suitcase full of clothing!

Elton is now taking a leadership role in ZHA, and he recently represented the organization at a county fair, greeting interested visitors and sharing his experience. He has matured immeasurably after his exposure to our fantastic hemophilia community. Elton and I text frequently, and I will visit him when I return to Zimbabwe soon. He is the future of Zimbabwe, even though he is just "one."

Starfish saved. ☺

Laurie Kelley is president of LA Kelley Communications, Inc., parent of a son with hemophilia, and author of numerous books on bleeding disorders. She founded Project SHARE (Supplying Hemophilia Aid and Relief), which donates about \$6 million of factor annually to dozens of developing countries. She is founder and president of Save One Life, Inc., a child sponsorship organization for children with bleeding disorders in developing countries. Currently, 140 children and adults are listed on the Save One Life website, waiting for sponsors, and more than 830 are sponsored annually.

Read about Elton's journey:

http://blog.kelleycom.com/2009_03_01_archive.html

Read more about Stanley:

http://blog.kelleycom.com/2011_08_01_archive.html

Read about Laurie's visit to the Philippines:

http://blog.kelleycom.com/2008_10_01_archive.html

View photos of Laurie's trips to developing countries:

<http://www.kelleycom.com/gallery.html>

What You Can Do Now to Save a Life

• **Donate unwanted and unused factor concentrate.**

Project SHARE: www.kelleycom.com

• **Sponsor a child.**

Save One Life: www.saveonelife.net

• **Make a one-time donation.**

Save One Life: www.saveonelife.net

World Federation of Hemophilia: www.wfh.org

• **Learn more.**

Watch *Hotel Rwanda*, *Romero*, *Invictus*, *Slumdog Millionaire*, or *City of Joy*. Read *The End of Poverty* by Jeffrey D. Sachs, *Mountains Beyond Mountains* by Tracy Kidder, *The Man Who Tried to Save the World* by Scott Anderson, and *Always the Children* by Anne Watts.

Travel. Call. Volunteer. Sponsor. Adopt. Pray.
You're limited only by your imagination.

Save One Life is 10 years old!

CAMPAIGN 1000

Help us reach our 10th anniversary goal of 1000 sponsored children with bleeding disorders.

140 children still wait for your compassion. Please sponsor a child — just \$20 a month!



To sponsor a child:
contact@saveonelife.com or 978-352-7652
www.saveonelife.net

headlines

manufacturer

Bayer Provides Nearly \$2.5 Million for Hemophilia Research

Through the Bayer Hemophilia Awards Program (BHAP), Bayer HealthCare has awarded nearly \$2.5 million to 18 recipients from 12 countries, to support research that helps improve the understanding and treatment of hemophilia and related bleeding disorders. Since 2002, BHAP has awarded nearly 200 grants—more than \$22.5 million—to researchers and caregivers from 29 countries.

Why this matters: BHAP supports research that examines inhibitor development and treatment methods, gene therapy, joint care, pediatric care models in underserved markets, and hemophilia counseling.

For info: bayer-hemophilia-awards.com

Whatever Happened to Pig Factor?

In the past, the hemophilia inhibitor community had porcine (pig) factor as an emergency treatment option for people with inhibitors or acquired hemophilia, an autoimmune disease. Plasma-derived porcine factor was pulled from the market several years ago because people using the product experienced frequent allergic reactions and a temporary drop in blood platelets. Currently, plasma-derived porcine factor is not commercially available. But now in clinical studies is OBI-1, a recombinant porcine factor VIII (rpFVIII) product developed by Inspiration Biopharmaceuticals. In initial studies it stopped bleeding in three patients with acquired hemophilia who had experienced severe bleeds not controlled with bypassing agents normally used to treat bleeds in patients with inhibitors. In a separate phase II study of patients with congenital hemophilia A and inhibitors, OBI-1 stopped bleeding even with high inhibitor levels. OBI-1 was well tolerated by all participants, with no drug-related adverse events. **Why this matters:** Porcine factor can offer new treatment options for inhibitor patients and people with acquired hemophilia.

For info: www.inspirationbio.com

To Market, To Market

The 2010 factor VIII market, without including von Willebrand factor complex, was estimated at slightly over 2 billion IU sold, a 3% increase from previous years. Recombinant factor VIII accounted for close to 90% of US factor VIII sales. **Why this matters:** It's always good to know statistics, and to have facts at your fingertips when advocating within your state or federal government.

Source: *The Plasma Proteins Market in the United States*, www.marketingresearchbureau.com

Vein, Vein, Go Away

Baxter International announced new data from a series of studies on BAX 499, an investigational compound for potential subcutaneous (under the skin) hemophilia therapy. BAX 499 is in phase I clinical trials for hemophilia A and B. BAX 499 may reduce activity of the tissue factor pathway inhibitor, which plays a critical role in the clotting cascade. **Why this matters:** By blocking this inhibitor activity, the treatment may promote blood clotting in people with hemophilia.

For info: Doreen Eaton, 805-372-3417

Free Trial Program

The Octapharma wilate[®] Bridge Program allows VWD patients a way to try up to 5,000 IU of wilate, a plasma-derived von Willebrand factor product, at no cost. Patients currently using another therapy, or not using any VWD therapy, are eligible. Patients must work with their physicians to enroll in the program. **Why this matters:** Free trials are an easy way to try a new drug without committing to a long-term switch.

For info: Ask your HTC physician or visit www.wilateusa.com



Going Solo!

Pfizer and Wyeth have introduced a new delivery device that provides both factor concentrate and diluent in a prefilled dual-chamber syringe for easy, needleless reconstitution. Xyntha[®] Solofuse[™] Prefilled Dual-Chamber Syringe is now available for using Xyntha to treat patients with hemophilia A. Available in 1,000, 2,000 and 3,000 IU doses. **Why this matters:** Eliminating the transfer step during reconstitution may make it easier to infuse and easier to follow your prescribed treatment regimen.

For info: www.xyntha.com

Long-Acting Factor Shows Promise

Biogen Idec announced phase 1/2a trial data showing that the company's long-lasting recombinant factor VIII Fc fusion protein (rFVIII Fc) was well tolerated. The protein also consistently showed a 1.7-fold increase in half-life compared with a commercially available factor VIII product, in 16 patients with severe hemophilia A. **Why this matters:** rFVIII Fc has an extended half-life, so may provide extended protection from bleeding and reduce the number of infusions needed for prophylactic treatment of severe hemophilia A.

For info: Tracy Vineis, senior manager, public affairs, Biogen Idec, 781-464-3260 or www.biogenidechemophilia.com or www.clinicaltrials.gov

Recombinant VWD Product in Trials

A phase I, 32-patient study conducted by Baxter International evaluated the safety, tolerability, and pharmacokinetics of recombinant von Willebrand factor (rVWF) versus plasma-derived von Willebrand factor (pdVWF), the current standard of treatment for patients with the disease. Results showed no serious and 12 non-serious adverse reactions in patients with type 3 and severe type 1 VWD. The half-lives of the two products were found to be similar. A larger phase III trial study is needed to further assess safety and efficacy. **Why this matters:** A recombinant VWF product provides greater therapeutic options for patients.

For info: Marie Kennedy, 805-372-354

nonprofit

Allies in Care

The Hemophilia Alliance recently awarded grants for 2011 to hemophilia organizations and HTC's, including a first-time grant to Save One Life, which assists patients in developing countries. The Alliance has given more than \$1,000,000 to the hemophilia community since its inception. **Why this matters:** With dwindling government funding, HTC's and chapters need financial assistance from all sources.

For info: www.hemoalliance.org

Aloha Hawaii!

The Hawaii Hemophilia Foundation (HHF), established in November 2010, has joined NHF as an affiliated chapter, bringing the number of NHF-affiliated chapters to 49. Led by president Jennifer Chun, HHF has already established a family camp and a holiday event. **Why this matters:** Affiliation is especially important for small hemophilia foundations, to increase resources and offer opportunities to provide services for community members.

For info: hawaiihemophiliafoundation@hotmail.com

Wanted: You! at NHF's Washington Days

March 7–9, 2012

Join your local and national community for a briefing and reception on Wednesday, March 7. Travel with your state team to Capitol Hill on Thursday, March 8. Attend a state advocacy workshop on Friday, March 9. The continued controversy over healthcare reform makes it critically important for the bleeding disorder community to advocate for policies. **Why this matters:** By telling your story in person, you put a human face to the medical and insurance issues affecting patients and families.

For info: www.hemophilia.org or contact your local hemophilia organization

international

CSL Donates Factor VIII to WFH

CSL Behring announced a donation of factor VIII worth approximately \$500,000 to the World Federation of Hemophilia. The donation supports WFH's Global Alliance for Progress (GAP) program, and will go toward treatment in South America, Thailand, the Philippines, Eastern Europe, parts of the Middle East, and Tunisia.

Why this matters: GAP encourages developing countries to eventually buy factor products, following the three-year donation program.

Source: CSL Behring press release, February 16, 2011

Indian Children Get HIV from Blood Transfusions

At least 23 children with thalassemia (a blood disease that may cause anemia) tested positive for HIV after receiving tainted blood transfusions in western India. The children all received free blood transfusions at a government-run hospital in the Junagadh district of Gujarat state in western India between January and August 2011. This is not the first time—more than 50 children with thalassemia contracted HIV from blood transfusions in India last year.

Why this matters: Although people with hemophilia do not use blood transfusions as a treatment, impoverished families with hemophilia in developing countries may use cryoprecipitate derived from blood plasma for treatment, potentially placing them at risk of contracting HIV.

Source: Associated Press, September 12, 2011



Octapharma

Save One Life Honors Octapharma Chairman

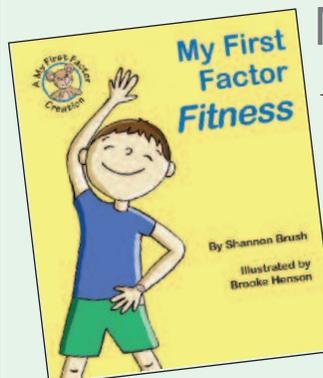
Save One Life, an international nonprofit that provides direct support to children and adults with bleeding disorders in developing countries, awarded Octapharma chairman Wolfgang Marguerre its prestigious

2011 Sponsor of the Year award. Mr. Marguerre personally provides sponsorships to 70 people with hemophilia in several countries yearly. His funds supply impoverished patients with money for food, vitamins, school fees, and transportation to clinics. The award was presented at the Decade of Dedication Gala in May. **Why this matters:** Corporate leaders set a valuable moral example by contributing personally to help impoverished people with bleeding disorders.

For info: www.saveonelife.net

featured by LA Kelley Communications

My First Factor series is designed to help young children ages 18 months to 4 years understand their bleeding disorder.



My First Factor: *Fitness*

My First Factor: Fitness stresses the importance of overall physical fitness and a healthy diet starting in childhood. By Shannon Brush, mother of a son with hemophilia. Illustrated by Brooke Henson. Published October 2010 by LA Kelley Communications, Inc. Sponsored by Bayer HealthCare.

To order: www.kelleycom.com

COTT & HFA Check New Test Equipment for Blood-Borne Diseases

Dave Cavanaugh, director of government relations for the Committee of Ten Thousand, and Paul Brayshaw, president of Hemophilia Federation of America, traveled to Virginia to visit the TessArae LLC Corporation in July. TessArae has developed advanced genetic testing equipment that can simultaneously test a blood sample for over 100 diseases, including all strains of hepatitis, HIV-1 and HIV-2, and simian immunodeficiency virus (SIV). Cavanaugh and Brayshaw met to learn about the practicality of establishing this testing capability at all blood donor stations in the US. **Why this matters:** Emerging pathogens in blood are a major concern for users of blood and blood products; COTT and HFA continue to monitor blood safety.

For info: www.cott1.org

PBM Powerhouse?

Leading consumer advocacy groups penned a letter to Chairman Jon Leibowitz of the Federal Trade Commission on September 20, opposing the proposed merger of Express Scripts, Inc., and Medco Health Solutions, two of the nation's three largest pharmacy benefit managers (PBM). The groups objected to the merger, stating that competitive markets help maintain lower prices, promote innovation, and develop drug distribution efficiencies. **Why this matters:** Specialty pharmacies handle the acquisition and distribution of expensive drugs, including many biologic drugs and most injectables, such as factor concentrates. A merger would give the new PBM more than a 50% market share in specialty pharmacy, already one of the most expensive segments of healthcare costs; the company would yield incredible power over prices and product access—including a large proportion of US factor.

For info: www.express-scripts.com

Inhibitor Insights... from p. 4

all these years to keep him alive with infusions of cryo, fresh-frozen plasma, and then, with donations of factor concentrate from Project SHARE. A stubborn knee bleed forced Adrian and Lillawattie to travel to the US this summer for consultation. They learned that Adrian has an inhibitor. Lillawattie is frightened and unsure what to do.

Zambia, in southern Africa, is home to Maurice, who contacted Project SHARE recently for inhibitor product to treat a complicated bleed in his 19-year-old son David. Maurice was so galvanized after learning about the help available internationally that he pledged to set up the first national hemophilia society in Zambia. We had product and shipped it right away. But by the time it arrived, David had died.

In the Philippines, Angelo, a young man with an inhibitor, suffers constantly, a large pseudotumor on his hip. The tumor is a mass of blood vessels and clotted blood that can erode bone and damage internal organs, and doctors are afraid to operate without product. Angelo can't work, can't walk, and is in excruciating pain. He cries silently every night, careful not to let his mother hear him.

The situation is complex, and it's impossible to blame just one person, organization, company, or country. Life with hemophilia in developing countries is a deadly combination of economic hardship, bankrupt governments, low incomes, natural disasters, political upheavals, infectious diseases that trump rare disorders like hemophilia, and lack of products. David didn't die just because there was no bypassing agent. He died because countries like Zambia are plagued by decades of poverty, poor infrastructure, inadequate hemophilia treatment, and lack of a national patient organization.

Not On Our Watch

Most patients with hemophilia in developing countries live unnoticed. India, for example, has an estimated 100,000 with

hemophilia, but fewer than 20,000 are identified. As efforts continue to identify hemophilia patients, more inhibitor patients will be found. Such countries are poorly equipped to handle these patients, and most can't afford high-priced bypassing agents.

But all is not lost. Maurice accepts his son's fate, but vows not to give up the dream of a hemophilia society in Zambia. Angelo received a donation of factor from Project SHARE, and doctors removed his pseudotumor. He has become an activist, and now serves as president of Blood Brothers Aid, a national organization in the Philippines whose members have united to lobby the government for treatment dollars. In Guyana, Lillawattie has been toiling quietly to find hemophilia patients. With a population of less than 1 million, Guyana will probably yield only 100 patients. She has already identified five.

Donations of product from outside a developing country are necessary in crises, but long-term advocacy from within the country is the true solution. Families, patients, and the medical community must unite to approach their own government to get the healthcare dollars needed to purchase product.

What can Americans do to help these families in times of crisis? During the holidays, direct your charitable giving to support programs that help inhibitor families overseas. Volunteer to get the word out through Facebook and hemophilia meetings. Or sponsor a child directly through Save One Life. It's time to share what we can with those who have little or nothing—and we can start by acknowledging that inhibitor patients *do* exist, in every corner of the world, waiting for our help and guidance. @

To directly sponsor a child in need: www.saveonelife.net

To learn more about worldwide efforts to aid people with hemophilia: www.wfh.org

Chris, “but it took my breath away. It was incredibly overcrowded, and there were people lying on floors suffering. And the smell—I can’t begin to describe the smell.”

Chris wrestled with sadness and guilt, as he pondered issues such as access to treatment and quality of care. “It was a huge wakeup call. I felt so hopeless as I looked at people who were clearly suffering, knowing there was little I could do.”

Chris also struggled with philosophical questions. “What if I wasn’t born where I was?” he wondered. “I felt guilty because instead of chasing dreams of climbing a mountain, I could have been dying in one of those hospital beds. I know I won’t complain anymore about something as trivial as having to wait a little longer to see my doctors.”

Making a Difference

After participating in a three-day bleeding disorder symposium, Chris helped organize the hemophilia lab and train local technicians to use instruments such as a coagulometer. “We gave them the ability to test for blood disorders and trained them to interpret the results,” explains Chris. “Now they know what to look for.” And he adds, “For me, that was the best part.”

Chris’s experience in Eldoret opened his eyes to the cruel

reality of hemophilia in the developing world. He also witnessed firsthand the positive impact that programs like Save One Life can have on people’s lives.

When the team wrapped up its work in Eldoret, Chris and his uncle (one of the Indiana University team) headed south to Tanzania to tackle Kilimanjaro.

Kilimanjaro: 19,340 Feet

Though most people fear altitude sickness, Chris’s biggest fear was having a bleed on the mountain. He infused the morning they set out. The first three days of the trek went as planned. “Looking back,” he says, “I should have infused on the third day, but I kept thinking, ‘This isn’t too tough.’”

On day four, during a side excursion to the Lava Tower, Chris felt a pull in the quadriceps muscle in his leg. “I knew what I’d done right away, and I was concerned. I infused when I got back to camp, but I was worried that I couldn’t continue.”

Then Chris remembered the kids from hemophilia camp. “I thought, ‘You can’t turn around. You have to show them that you can do anything—even with a bleed—as long as you treat it.’”

The next day Chris felt he could continue to climb. So at 14,000 feet above sea level, he infused before making the final six-hour push to the summit.

The guides leading Chris and his uncle wanted the pair to slow down at times, because they were going to reach the summit long before the target time of sunrise. Even with breaks, they were well ahead of the intended pace, and at 6:00 AM on June 3, Chris became the first American with hemophilia to reach the summit of Kilimanjaro.

The Impact

Chris arrived at a realization while in Africa: “I didn’t fully appreciate just how good we have it in the United States.” The disparity in hemophilia care between home and Kenya gave Chris the desire to make a difference.

It’s easy for young hemophilic men, trying to determine their place in the world, to feel insignificant. And it’s understandable that many wonder if one person can have an effect.

Chris shows that the answer is yes. His hard work helping to establish the hemophilia lab in Eldoret will benefit scores of people with blood disorders. His Kilimanjaro climb raised over \$1,300 for Save One Life. In the US healthcare system, that money wouldn’t go far, but in a developing country, it can mean the difference between life and death. Chris’s African journey serves as inspiration to countless others with hemophilia.

Whether at hemophilia camp or farther afield, Chris encourages other young men with hemophilia to get involved. Giving back and helping others doesn’t have to mean a trip around the world or a climb up a mountain, but it does require desire, motivation, and the belief that you can make a difference. As Chris says, “I just want to show the younger kids that they can do whatever they want if they put their minds to it.” ☺

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inbox

WE JUST WANT TO LET YOU KNOW THAT we use your educational materials in our clinic. Keep up the great work!

*Staff of Hemostasis and Thrombosis Center
Children's Hospital Los Angeles
California*



Project SHARE

THANK YOU FOR THE PRODUCT support given to our patients with hemophilia, especially those with hemophilia B, as we have no available factor IX concentrates on the market. Patients need to travel to Singapore to purchase the products. Some are just content with a local cryoprecipitate infusion.

I still treat hemophilia patients who come to my clinic for help. It's frustrating that I know what to do but can't. Keep up the good work.

*Mary Chua, MD
The Philippines*

MY FAMILY AND I EXPRESS OUR DEEPEST gratitude to Project SHARE for sending the medications for Shane. Words often fail us in lifesaving situations like this, and we know our thanks can never be enough, but nevertheless, thank you very much!

*Pearl Joy and Shane Tizon
The Philippines*

OUR SON SEAN BORDA, AGE FOUR, SUFFERED

a severe seizure and intracranial bleeding. He survived because of the factor VIII that Project SHARE donated to the Hemophilia Association of Davao.

*Nicol Borda
The Philippines*



I DON'T HAVE ADEQUATE WORDS TO EXPRESS my gratitude for what you've done to help my relative Kazi. I contacted other organizations, but no one else responded. You touched my heart. I called Kazi a few days ago, and he is improving. He is able to get up from his bed and go to the doctor. Kazi is more than happy and emotionally overwhelmed. He told me that he is grateful to Project SHARE.

*Mehdi Satter
representing Bangladesh*

THANK YOU, PROJECT SHARE. ON BEHALF of children with hemophilia, we highly appreciate Project SHARE's support in Cambodia.

*Dr. Chean Sophâl
Medical Advisor
Cambodia Hemophilia Association*

I AM TEN YEARS OLD. THANK YOU FOR supporting my life. I am grateful. May God bless you. Pray for me so that I grow up to be a doctor and save lives too. I wish I could see you face-to-face and thank you.



*Jovan Sseweugu
Uganda*

Test Your Knowledge about Health Insurance!

I READ YOUR HEALTH INSURANCE QUIZ [PEN, August 2011]. I have factor IX deficiency. I've always wondered if others with hemophilia had trouble getting affordable life insurance as I did. I believe insurers don't understand the progress the medical community has made through technology and in educating patients and families about controlling bleeding, allowing us to live relatively normal lives.

As a licensed agent in property and casualty/life and health insurance, I joined an agency that specializes in difficult-to-place life insurance cases for individuals and groups. Our agency has found a life insurance product that helps us provide life insurance for people with hemophilia. Some insurance products do this, but they can be costly, the application process can be time-consuming, and they require medical exams and sitting with an agent. With this product, the application process is simple and can be done by the applicant, either by phone or with an agent present. For information, call us at 609-770-7754.

*Mike Donnelly
Donnelly/Fuhrmeister Group
Pennsylvania*

Ed. note: PEN recommends that you discuss life insurance options with your HTC social worker and human resource department, to compare programs and make the best decisions for your own situation.



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*Every gun that is made, every warship launched,
every rocket fired signifies, in the final sense,
a theft from those who hunger and are not fed,
those who are cold and are not clothed.*

*—GENERAL DWIGHT D. EISENHOWER,
“THE CHANCE FOR PEACE,” APRIL 16, 1953 SPEECH*

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