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Parent Empowerment Newsletter

Journeys of Hope

by Laureen A. Kelley

The recent devastation of New Orleans by Hurricanes Katrina and Rita has shaken and saddened all Americans. We cannot imagine what it's like to experience such terror, and to lose all possessions—even lose loved ones. In particular, we in the hemophilia community can't imagine what it's like to be without the blood-clotting medicines that protect and preserve us. In response to the catastrophe in the New Orleans area, we've seen a tremendous outpouring of aid: money, medicine and volunteer help. We can't allow our fellow Americans to suffer alone. Admirably, the National Hemophilia Foundation (NHF), Hemophilia Federation of America (HFA), all pharmaceutical companies and many homecare companies have organized relief efforts to assist families with hemophilia affected by the hurricanes.

The hurricanes have opened our eyes, sadly, to terrible suffering. Yet the poverty and loss they have created is something that of the rest of the world experiences routinely. Most of the world's population lives in poverty. Half the world's population—nearly three billion people—survives on less than two dollars a day. The output of the poorest 48 nations (a quarter of the world's countries) is less than the wealth of the world's three richest people combined. According to UNICEF, approximately 30,000 children die each day because of poverty. And *Time* magazine reports that each day, six million children die unnecessarily from disease (see *News Notes*, page 19).

ome of the children living in poverty suffer from hemophilia. I have met them.

In this issue of *PEN*, I share excerpts from my journeys around the world to visit and help children with hemophilia. This has been a year of catastrophic natural disasters: the Asian tsunami, torrential rains in Bombay, horrific mudslides in Guatemala and, incredibly, as I write, a devastating earthquake in northern Pakistan that has left more than 70,000 dead. In this season of charity and holiday giving, we are grateful for our many riches and blessings. And as we offer aid to our fellow Americans in need, we should remember that children with hemophilia in many countries outside the US have nothing. They suffer continually, and they need our help.

Read about life with hemophilia in five different countries. Then, if your compassion stirs you to action, learn how you can help.

Dominican Republic

January 1999

The Dominican Republic (DR) occupies half of the island of Hispaniola, Christopher Columbus's first stop when he first visited the New World in 1492. A magnificent white mausoleum near the beach allegedly houses his body. (A tomb in the Seville Cathedral, Spain, makes the same claim.) The mausoleum reportedly cost $5 million, in a country where the average person earns about $2,130 a year; lasers erupt from the roof nightly in a fantastic display for the burgeoning tourist industry, even as brownouts promptly darken half the capital. Only the fortunate few with generators have consistently working lights, TVs or computers.

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inside PEN

welcome

Sherrell Portrait Design

When I attend hemophilia meetings in various parts of the country, parents and patients often ask me, "Where have you traveled recently? Tell me about your trips!" They know that I've been traveling to the developing world for the past ten years, and are curious to hear about the adventures I've had and the people I've met. As patients and parents who live with bleeding disorders, they're curious about hemophilia in the developing world, and want to know how the "other half" lives.

But how can I condense a twelve-day journey through the heart of India into sound bites? How can I put into words a life-changing experience in Africa? How can I describe the breathtaking beauty of Brazil, the warmth of the Dominicans, the exotic panorama of Pakistan? How can I express the courage, fortitude and suffering carried by people with hemophilia in these places?

I've decided that the only way I can do this is to share my journals from the past ten years. Our feature "Journeys of Hope" will take you on a brief excursion around the globe. I'll describe what I have witnessed while attempting to offer help to people in need. Something you read here in *PEN* may touch your sense of compassion for our extended family with bleeding disorders in developing countries: people who must cope not only with political upheaval, natural disasters, epidemics and economic hardship, but endless days and nights of untreated bleeds.

During this season of charity and Thanksgiving, it's appropriate to remind ourselves how fortunate we all are to be families with bleeding disorders living in America, the wealthiest country on earth. And it's important to learn some simple ways to offer help. Your help can ease the endless journey of tired families, desperate young men and tender children with hemophilia and von Willebrand disease who are suffering right now.

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letters

Readers respond to PEN's three-part series on insurance

Two years ago, we had to switch insurance companies because Ryan, age seven, was quickly approaching his lifetime maximum. Ryan has mild/moderate hemophilia A and VWD type II. He is on prophylaxis therapy three times a week. Fortunately, my husband works for a large corporation and we could choose another insurance provider. Prior to the switch, I contacted the new provider to verify that we could continue to use our HTC to obtain Ryan's factor. We had used this HTC for all of his factor needs, and wanted to continue our relationship.

I was informed that this would not be possible, and that I would need to switch to the new insurer's preferred provider, a homecare company. I worried that the homecare might be more expensive than my HTC; but when I asked how much the homecare company was charging the insurance company, I was told that this was negotiated between the two companies, and I was not privy to this information. The insurer informed me that I didn't need to worry because I no longer had a lifetime maximum.

I pointed out that while it was great not to worry about a lifetime maximum, I was concerned about how Ryan's factor would impact my husband's company's premiums and benefits. The insurer still refused to give me information, and told me that if I didn't switch to the homecare company, it would not pay for any factor.

I fought this situation for several months but to no avail. I switched, begrudgingly, to the homecare company. Although the service was equal to that of my HTC, I was very upset a year later when our premiums went up and our benefits went down–and I still don't know what I'm being charged for factor.

Janet Harty
Massachusetts

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Treat Yourself—and Change a Life

by Leah Jones

I've found the perfect spot to type: a cozy café on a busy street. Today's my favorite kind of writing day, grey and wet, inspiring the young baristas to play CDs of acoustic Spanish guitar. I warm myself with a medium café Americano, extra hot, cream, no sugar. $2.95. I might treat myself to a cookie–another $1.75. Not as pricy as the double latte, which is $3.60 here, or the large mocha slide, which tops the charts at a whopping $4.50.

At age 31, I'm still on a post-graduate school, nonprofit educator's budget. These little goodies add up quickly! I exceeded my allocation of cell phone minutes last month and was slapped with an extra $15. I found a cute purse the other day and spent another $11. I skipped the subway after a festive night of bowling, and took a $12 cab ride that saved me a chilly half hour in the rain. I've seen more than a few so-so movies recently, but don't begrudge the $10 admission later. Some months I'm more careful than others, but I like treating myself now and again.

Save One Life, Inc.

Happy beneficiaries of Save One Life in India, with Director Leah Jones.

Despite my modest budget, last spring I made a decision that I haven't regretted once. Through Save One Life, the nonprofit I manage, I chose to allocate $20 per month to Sudha, an 18-year-old with hemophilia in Durgapur, India. Sudha's legs are wasted so severely that they are now no thicker than his arms. He can no longer walk. I have a photo of him being held in his brother's arms. But I know from Sudha's local hemophilia society that he has acquired a wheelchair since that photo was taken about three years ago. Because I'm in the unique position of being both a Save One Life director *and* a sponsor, I'm not shy: I'm vocal and enthusiastic about soliciting support from family, friends and strangers on behalf of these deserving young people who live in poverty. Even if Sudha didn't have a disorder that wreaks havoc on his body, his family's finances, his education and possibly his self-esteem, this young man's health and education needs would not be met without support.

Before joining Save One Life, I was a US Peace Corps volunteer in Malawi. When I returned to America after two years of bucket baths, coal-stove cooking and candlelit evenings, a friend asked me whether I felt "guilty" now that I was home and had access to daily luxuries. Actually, I was thrilled to reunite with my CD collection and clear running water, but I appreciated these things more than ever before. I also missed many things about Malawi: neighbors who would cook their last chicken because a stranger was coming to dinner, teachers who worked some months without pay, and friends who never hesitated when anyone–even a "well-off" American–asked for help.

Last February, my visit to India for Save One Life was the same. Doctors, hemophilia volunteers and families gave joyfully and repeatedly of their time and resources, delivering hope to the young people who are the future of their country, and of our world. Leaders like these in Nepal, the Dominican Republic, the Philippines, and the many countries Save One Life has not yet reached are determined that all kids with hemophilia will someday be free of disability and pain.

Supporting young people's education and health costs is not a sacrifice. It's a treat. The letters written by our Save One Life beneficiaries bring me far more satisfaction than my now lukewarm coffee. My entire monthly $20 goes overseas–mostly to Sudha, with a little kept aside for his hemophilia clinic. I feel happy knowing that Sudha's family can purchase nutritious food, transport him to clinic, and perhaps watch his self-sufficiency and confidence grow. If sponsoring Sudha means one less latte, movie, or cab ride each month, it's well worth it.

Leah Caroline Jones is executive director of Save One Life, Inc., a sponsorship program founded by Laureen Kelley that assists children and young adults with bleeding disorders in the developing world. Currently, Save One Life has approximately 15 beneficiaries waiting for sponsorship in India, Nepal, the Philippines and the Dominican Republic. To sponsor a young person or make a donation, please visit www.saveonelifeinc.org or call 617-497-0626. All donations are tax deductible.

by Julia Q. Long

Helping the Patient, Knowing the Person

Project SHARE℠ donates millions of units of factor each year to patients in poor countries. Factor requests must be made on our official request form, which gives us basic information about a patient, including name, address, factor deficiency and amount of factor requested. This information provides a good overview of the patient's medical situation, but tells me little about the person behind the request. I learn more when I email or call the person making the request to find out more details. I learn about the patient's personal situation, and about the important people in his life. I have the honor to learn how patients are loved and cared for. I also learn about the people who, in turn, depend on them. And I find out what makes them happy.

Nanak Singh Nishter of Hyderabad, India is one of these patients. The 68-year-old grandfather of seven and his wife have two sons and two daughters. Nanak's granddaughter was the first to call us, seeking factor for her grandfather's upcoming surgery. Over time, through subsequent communication with her, and later with Nanak's daughter and Nanak himself, I learned not only about Nanak the patient, but about Nanak the person.

Nister family

The person behind the request: Nanak Singh Nister of India.

Of Nanak's three brothers, two were also born with hemophilia. But because so little was known about hemophilia in India before the 1980s, one brother lost his life in 1976 to an untreated bleed. Another brother's life was spared only by amputating a gangrenous leg.

In 1980 Nanak was diagnosed with factor IX deficiency in Bombay, where he was hospitalized with excessive bleeding from his gums. His daughter C.J. Kindra recalls her fear when she learned that he had hemophilia. "I was scared as I found out how life-threatening it could be, and I told him how I felt." But she thinks often of his words of consolation: Don't be afraid of hemophilia, but instead gain knowledge of it.

In the mid-1970s, Nanak began suffering from a hernia. For thirty years he lived in pain, in need of an operation. But it was impossible: The family lacked the 30,000 units of factor IX required for surgery.

Early in September 2005, Nanak's pain began to intensify. The Nishter family searched everywhere for factor donations so Nanak could have the surgery he had needed for so long. But at that time, factor IX was scarce internationally and the family had little luck. Project SHARE, however, had a few vials of factor IX. On September 16 we donated as much as we could–just over 20,000 units–hoping it would be enough for Nanak's operation.

Fortunately, Nanak's doctors determined that there was enough factor to proceed with the long-awaited surgery. On September 30, the head of the Medicine Department at Nizam's Institute of Medical Sciences in Hyderabad carefully supervised the dosages and administration of the factor throughout the operation. According to Nanak, the surgery was "successful, with no more loss of blood than a normal patient [experiences]."

Nanak is a theologian, social activist and writer. C.J. describes her father as "one of those real positive people who looks at a glass as always half full." Nanak stands by his belief that knowledge is better than fear, asking other people with hemophilia to live "carefully" and prepare themselves with knowledge of their disorder.

This gentleman who learned about hemophilia uncommonly late in life–at age 43–has brought the international face of hemophilia much closer to me. As Project SHARE requests continue to arrive daily, I increasingly appreciate my chance to learn about the people behind them: people with real hopes, real fears, loving families and unique lives who need our help. We assist more than 250 patients in more than 40 countries. My friendship with Nanak compels me to continue learning about the people behind the requests. And I will always remember the humble invocation in his latest email to me: "May God bless all mankind."

PROJECT SHARE
It's time to give back

To make a donation of factor concentrate or money, or to obtain advice on donating factor internationally, please contact Julia Long at julia@kelleycom.com

or visit

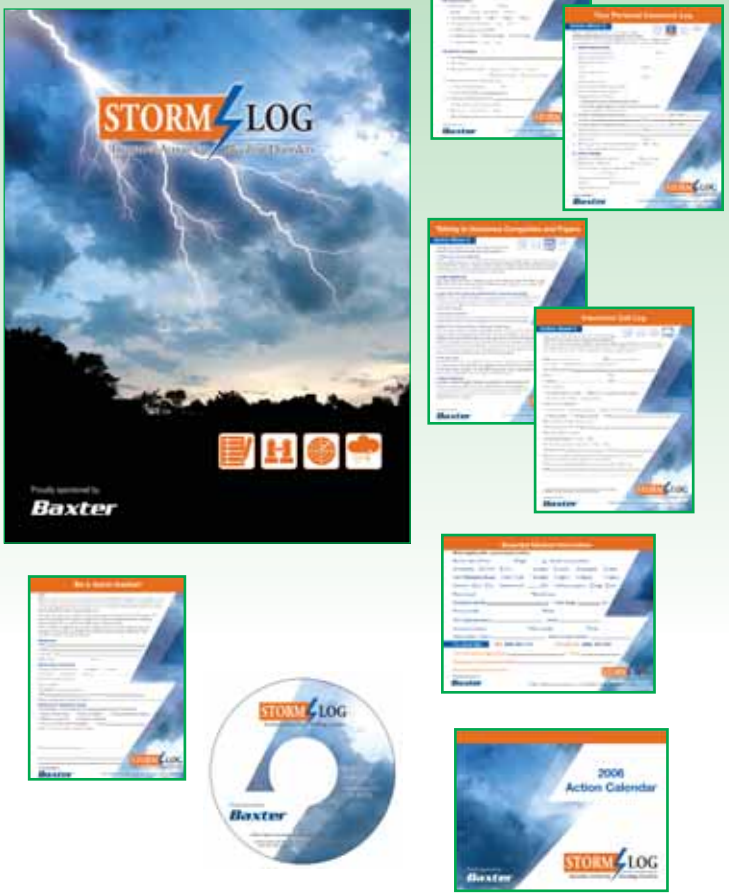
www.kelleycom.com

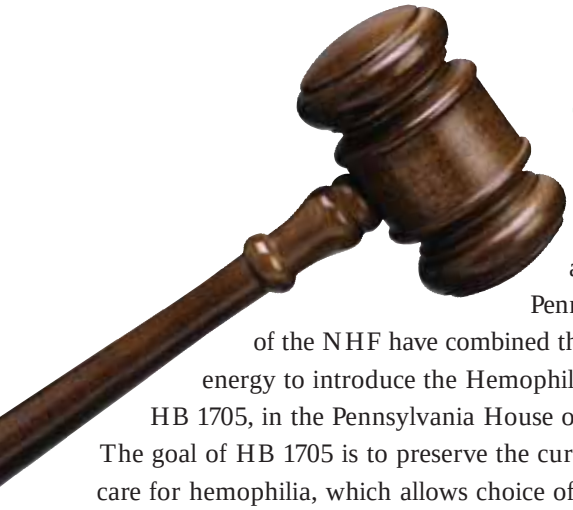
Introducing Storm Log™

You can't protect your hemophilia healthcare until you understand your own personal medical and insurance situation. **Storm Log** is a new action toolkit that helps you understand both the changing climate of insurance reimbursement and your own insurance situation.

Created by LA Kelley Communications, Inc. with The Bruckner Group, Inc. and funded by Baxter BioScience, **Storm Log** contains everything you need to gather information, track changes, and speak to insurance payers and factor providers with confidence and authority. The **free** toolkit includes a guidebook, calendar, action sheets, magnet and software. Contact LA Kelley Communications, Inc. or your local Baxter representative.

STORM LOG
Insurance Action for Bleeding Disorders





Pennsylvania Introduces Legislation to Protect Choice: Who Will Benefit?

The Delaware Valley Chapter and Western Pennsylvania Chapter of the NHF have combined their resources and energy to introduce the Hemophilia Health Care Act, HB 1705, in the Pennsylvania House of Representatives. The goal of HB 1705 is to preserve the current standard of care for hemophilia, which allows choice of product and factor provider. The NHF supports this initiative, as do the medical directors of Pennsylvania's eight HTCs. Pennsylvania is using as its model the state of New Jersey, which already has standards of care approved by its legislature and followed by all insurers and HTCs.

The initiative is in direct response to state insurers' attempts to implement measures to control skyrocketing hemophilia costs. According to Mesfin Tegenu, vice president of Keystone Mercy, the state Medicaid insurer, "This legislation seeks preferential consideration for patients with hemophilia versus patients with other chronic diseases. It may encourage inappropriate utilization of medication and medical and financial resources for the benefit of special interest groups who stand to profit the most–pharmaceutical manufacturers, specialty pharmacies, certain advocate groups and home infusion companies. Medicaid payers must base their benefit decisions on evidence-based medicine. HB 1705 sidesteps this requirement and mandates that healthcare coverage be dictated as desired by special interest groups. The goal of this legislation doesn't seem patient-centric but rather special interest focused."

Pennsylvania's situation is being watched carefully in the hemophilia community, as the outcome may influence the impact of the "coming storm" on cost-cutting outcomes in other states. *PEN* will report on developments in Pennsylvania and other states in future Storm Watch columns, and explain how they may affect your access to choice of product, provider and therapy.

Journeys of Hope... continued from cover

No problem with lights today. It's 90 degrees and 100% humidity, despite the gentle Caribbean breeze that blows into the port capital of Santo Domingo. The sun is relentless. I sweat like I am melting, but my heat-acclimated Dominican friends are not the least bit damp. We pack into Haydée de Garcia's SUV to visit hemophilia patients. Haydée is a striking 43-year-old who commands the spotlight when she enters a room. She is six feet tall, well dressed and fair-skinned. But it's her direct style that makes her so commanding: She knows how to get to the heart of matters. I couldn't have asked for a better partner for my first journey to the developing world as a humanitarian.

Haydée is president of the Fundacion Apoyo al Hemofílico (FAHEM), the country's hemophilia organization. This shared journey, which began with a simple fax from Haydée requesting help, has made us not only partners in development, but friends for life. We have boys of similar age with hemophilia. We both are in a position to help others, and we desperately want to help. A language barrier doesn't stop us from understanding and communicating.

Our first stop is the Robert Reid Cabral Hospital, the place to go if you need treatment for hemophilia in the DR. The only problem: There is no treatment. There is only a kind and intelligent hematologist, Dr. Rosa Nieves. The hospital is publicly funded, so anyone can obtain free care. But patients and families still pay a price–it's hot, a bit dirty, and crowded. The waits are long. Babies wail incessantly. There is no air conditioning. Mothers gather in the sun-drenched parking lot since no waiting rooms are available. Some are asleep in the grass; no beds are allotted to accommodate parents staying overnight with their children. Dr. Rosa summarizes briefly: There is no factor, no cryo. There are no machines to store cryo. She cares for more than one hundred patients with hemophilia as well as her oncology and other hematology patients.

In come the patients. Elisabeth and her hobbling four-year-old enter. He has a painful ankle bleed. I scold myself silently for not bringing some of my son's stock of factor. Ice, Dr. Rosa tells Elisabeth. And get better shoes–sandals are no good. A father enters next, awkwardly carrying his teenage son on his back like a sack. Christian, age 11, is severely crippled because of repeated bleeds in his ankle. His foot hangs uselessly from nerve damage. Why not use a wheelchair? Rosa smiles: Not only do the families lack wheelchairs; the hospital doesn't have them. They get stolen, or there is no budget for them. I take photos, but Christian is reluctant to show me his deformed foot.

Elisabeth watches, her eyes wide with terror. It's clear what's going through her mind: This will be my son when he's older. Aloud, I vow to Elisabeth that I will not let her son become crippled. But she is still scared as she wipes away her tears.

We exit to the hallway, where more parents and children sit quietly in the heat, waiting their turns to be told that they have bleeds and nothing can be done. We take a lunch break far from the hospital, and Haydée tells me her story. Her husband Damaso was a professional ballplayer for the Toronto Bluejays in the 1980s. She has American insurance, and her son gets all the factor he needs. For a time, she had no worries about him and was ignorant of the suffering of the Dominican hemophilia community. One day Haydée was invited to attend a hemophilia workshop sponsored by a local pharmaceutical company. She was shocked to hear the concerns of the other families. They didn't know that ice could help with pain, swelling and bleeding. They didn't know that hemophilia is hereditary. What was factor? Haydée decided on the spot to form a foundation, if only to educate Dominican parents and patients. Desperate for assistance, she contacted me.

All photos in this article: LA Kelley Communications, Inc.

Christian can't walk because of joint damage in his knee and foot.

Parents at the Robert Reid Cabral must sleep outside.

The next day Haydée and I travel to the slums to meet Santa and her family. Accompanying us is Luis, a pharmaceutical representative who serves as translator. This is the first home I have visited in the developing world. I want to see firsthand how people live in economic hardship, what they need, how it feels. It's the first of many trips to foreign urban slums, and the first thing I learn here is that absolutely no privacy of body or mind can exist. Merengue, the percussion-driven music of the DR, blares at all hours, day and night. Cars, kids, clatter, noise: I think, *I would go mad here, not from the poverty but from the lack of peace*.

Santa is petite and pretty, direct and honest. She invites me into her simple three-room concrete dwelling. The DR has just celebrated Three Kings Day, and Santa moves aside a few plain, sad Christmas decorations so we can sit. There is a tiny family room with hard plastic furniture. No TV, no video games. The electricity flickers off and on as we talk.

Santa and her three boys with hemophilia.

A wall of sheet rock separates the family room from the bedroom. There is a single mattress on the bedroom floor, for five people. As I lean against the wall it begins to totter, and I see that nothing is really holding it up. At the back is the kitchen, a small, standing-room-only place. I look out through the holes in the concrete blocks that form the wall, and see the endless tin rooftops of Santa's neighbors. Tin traps heat, so anything inside bakes. I scout around quickly. Every pot is rusty and dented. The refrigerator doesn't work. A huge propane tank sits on the floor: the source of their cooking fuel, Haydée explains. Every winter, explosions burn and kill people in these slums.

I meet the family, and they are thrilled with our visit. The children are beautiful: ten-year-old twins Joedy and Parletto, who are the same size as their seven-year-old brother Julio. The children are dressed to perfection. The Dominicans take great pride in their children, and clothe them cleanly and neatly. One of the twins is starting to show signs of hemarthrosis, or joint disease. Santa tells me that although the twins are ten, they are only in first grade because they have missed so much school. Aside from factor, I ask Santa, "What can I get for you?" A wheelchair, she replies without hesitation, so her boys don't miss school when they have bleeds.

As we step outside to take photos, Santa's next-door neighbor is washing clothes in a bucket on the sidewalk. A small crowd

Burning wire to resell "just to survive."

gathers. Their faces are a beautiful blend of Spanish, African, North American and Indian heritage. There really is no "Dominican look." Even the pretty Dominican dolls, stocked in every souvenir ship, are created without faces to emphasize the multidimensional racial and ethnic mix. The neighbors exchange grins. Having foreign visitors must make Santa feel special. In the middle of the street, a gang of kids gathers around a roaring bonfire, whooping and laughing. "They are burning wire," Luis explains. "They find industrial wire, burn off the insulation, and resell it." Luis is quiet a moment, then adds, as if to himself, "just to survive."

Coming home from my first humanitarian trip, I feel odd. I sit on the plane, straddling two worlds while sunburned Americans board, homeward bound after vacations. They jostle each other noisily, complaining about the late departure, the heat, the service–everything. Our fast-paced culture of instant gratification contrasts starkly with the infinite patience required to live in the developing world. The Boston accent I hear is jarring, like a foreign language. I am anxious to get home and secure a wheelchair for Christian, and one for Santa's boys.

Romania — April 2004

I sleep until 7:30 AM–much too late. When I'm on a mission overseas, I want to spend every second helping others. The Moldavita monastery where I'm staying is peaceful and quiet. A nun knocks quietly at my door and offers hot tea on a tray, apologizing for the lack of warm water. My shower is icy cold, the morning damp and raw. We step out of the guest quarters and finally see the historic monastery in the dawn. Spectacular and solid, the monastery was created in the fifteenth century as a fortress for King Stefan I of Romania. Its walls are adorned with colorful frescoes, never retouched, painted with local pigment and still glorious. Looking carefully, I can see carved graffiti left behind by the Prussian army. The monastery sits like a stone guardian in the early morning mist, preserving memories of a lost Romanian era.

I am with Adriana Henderson, a native Romanian who emigrated to California 30 years ago during the Cecescue

Laurie Kelley in Romania with Alexandru Cobarlie and his siblings.

The Cobarlie home, only ten feet by ten feet, houses six people.

regime. At age 51, Adriana is soft-spoken and elegant. Once, on a trip to Romania to visit her relatives, she met a Romanian child with hemophilia. The child's crippled joints shocked her. When Adriana learned that factor would help prevent further crippling, she searched the internet, found our company and discovered Project SHARE (see *A Project SHARE Story*, page 4). Adriana now devotes all of her time to helping children with medical problems in Romania, although hemophilia patients have the biggest hold on her heart. When I gave her a big shipment of factor for her patients, she vowed to bring me to Romania. And here we are, freezing at an ancient monastery on the Moldavian border.

During my week-long trip to Romania, we travel by car from Bucharest in the east to Tmisoara in the west on the Hungarian border, then back again–about 3,000 miles. Adriana begged me to travel by car because she is afraid of flying in small aircraft. So we are traveling the hard way, visiting patients in their homes, seeing doctors, and making promises to provide factor, medical equipment and money.

We set off today in our rented car to pick up Aurora, a local nurse who cares for the children with hemophilia. She is a plain, middle-aged woman with a heart of pure gold. She's fixed an amazing breakfast of homemade strawberry jam, butter, sour cream, breads, and eggs with sausages. We eat a lot, and it will be our only meal until 10:00 that night.

Our journey takes us to many patients' homes. We visit Marius, who has abscessed teeth, which he needs to have pulled. Adriana says that everyone in Romania has bad teeth. There is no fluoride in the public water, and dental care is poor. This is especially dangerous when you have hemophilia. We give Marius 8,000 units of factor VIII, worth a small fortune–an amount some Romanians would never see in a lifetime. Yet it's a two-week supply for a typical American teen on prophylaxis.

Next we visit Alexandru Cobarlie's house, only 20 minutes away. The town is picturesque, nestled in a green valley dominated by a tall Orthodox church. Not far away are the Carpathian Mountains. I expect a small cottage like the others we've seen, but I'm not prepared for this home. Alexandru's village is clean and respectable, yet he lives in a one-room shack, ten feet by ten feet, with his four siblings and grandmother. They all sleep on one bed, retrieve water from one well, and use one outhouse right next to the pig pen. As we enter the yard, Alexandru's grandmother grabs me, hugging and kissing me as if I'm their long-awaited rescuer. Alexandru emerges on homemade crutches that are too short, causing him to bend over. He's only 14 but looks tough, roughened. He is thin, with a permanent knee joint contracture. He doesn't smile, eyeing us guardedly. Alexandru has an older sister who is working, a 13-year-old sister, and twin eight-year-old brother and sister Claudio and Claudia. The children are wide-eyed, silent and cautious. Adriana gives them presents and, slowly, they warm up to us. The children recite some poems and songs, which we video record. Alexandru lets us film him walking and having his joints examined.

His story is sad: an alcoholic mother, a father who deserted them. The grandmother cares for the five children, who all look clean, with hair combed and clean clothes. This seems almost impossible given where they live. They have no running water or place to bathe. The mother refuses to let Alexandru attend school, although a beautiful school stands next to his home, within walking distance and accessible even with his

Alexandru stops glaring and starts smiling when he learns that he is getting an exercise bicycle and factor.

The gypsy villagers are suspicious of the newcomers.

Romania is a beautiful pastoral country that struggles to help its people with hemophilia. Below, a shepherd with his flock.

disability. The mother has a million excuses, the grandmother tells us, and is ruining the boy's life. The father used to beat the children. When the grandmother was in the hospital, the twins would not leave her side, preferring to sleep on the cold hospital floor, afraid to go home where they would be unprotected.

Adriana is deeply concerned about Alexandru. She offers to send him to a boarding school, hoping for a better future, but Alexandru vigorously shakes his head. He will not leave his brother and sisters. He wants to stay to protect them. The grandmother and Adriana have tears in their eyes.

When he grows up, Alexandru wants to be what he can never be: a policeman. Aurora suggests that Alexandru might work a desk job in the police department; he'd get to lock up bad guys. His face brightens a bit. The children then show us their dog Rex, a mangy animal locked in a pen filled with feces, flies and a raw piece of chicken. Next on the tour is a hutch filled with Dutch bunnies, and the children cuddle them. "How cute!" I exclaim, and Adriana whispers, "That's tonight's dinner."

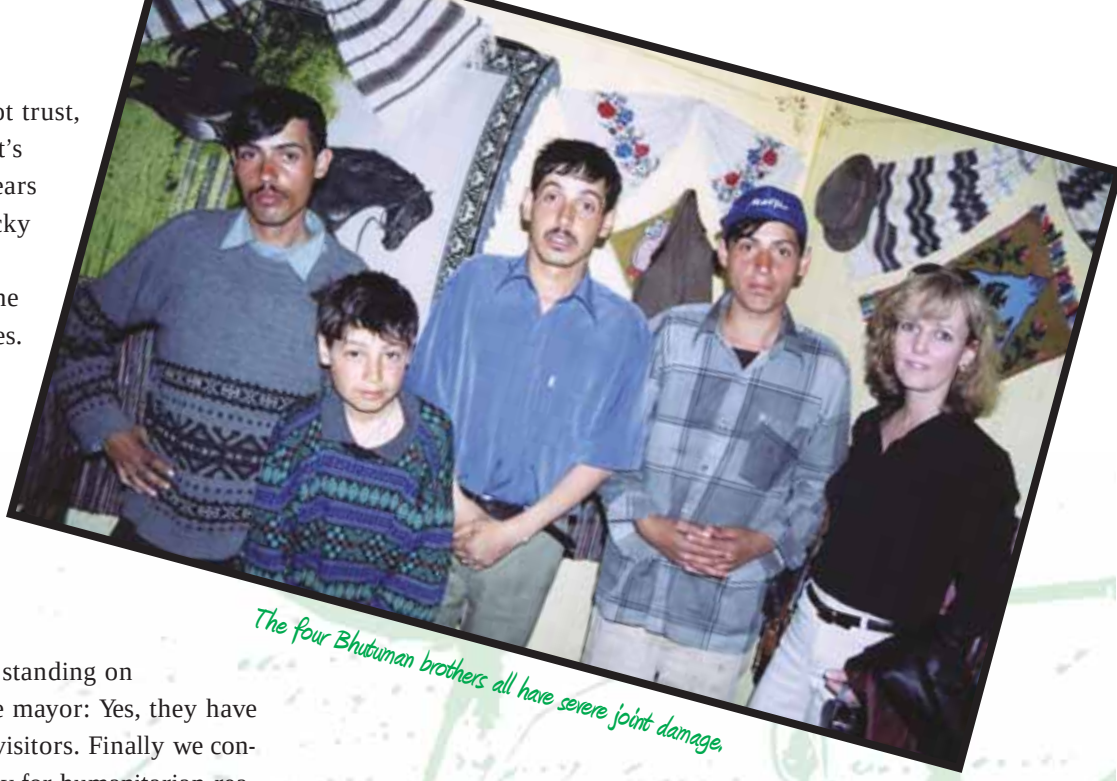
We ask Alexandru what he would like. A stationary bike, he says, in order to exercise. That would be easy to get locally. Alexandru's eyes light up, and he smiles spontaneously for the first time. He also asks for elastic bands to use for exercise. I happen to have some in my luggage, and promise to drop them off. Now he radiates joy.

The visit takes an ugly turn when the mother shows up, stumbling down the street. She is drunk, and her lover is with her. He is undernourished, dirty and also drunk. Adriana and I shrink back, but not Aurora. She suddenly leaps into action, confronting the mother: *Why don't you let this child attend school? Why won't you let him attend camp?* The mother looks tough, but little by little she loses her grip and begins to cry as Aurora interrogates her. The children are all watching. While it isn't a pleasant scene, I hope they notice that some people will fight for them. We're standing out on the road, and neighbors begin to gather. We learn that the children's mother earns $10 a month in social security for each child, but $150 a month for Alexandru, who has a disability. This is a fortune. Yet they live in poverty because the mother drinks away her money. We leave, disgusted and angry, vowing to change Alexandru's life.

Next we visit the "Village of Death," a gypsy (formally known as "Roma") settlement next to the town of Malini. The village was nicknamed by a local reporter, who wrote a story alleging more than 100 cases of hemophilia caused by inter-marriage; people were said to be dying in droves. The village is remote. We drive up a mountain road, and along dirt roads where villagers are chopping down trees for firewood to sell. We pass many horse-drawn carts. The drive takes about two hours, mainly because the roads are filled with gravel, dust and potholes. The mayor of Malini has driven to greet us. He is well dressed and asks us to follow him in our car.

As we approach the gypsy village, the quality of life deteriorates dramatically. When we get out of our cars, a crowd encircles us. Everyone wants to know who we are

and what we're doing. Gypsies do not trust, Adriana explains, and are clannish. It's how they've survived hundreds of years as nomadic people. Walking up a rocky street, we pass lopsided picket fences and small cottages before we reach the house where a hemophilia family lives. A big crowd has gathered. Mothers with babies, children and adults materialize out of every bush, yard and alley. Adriana tells me that the gypsies feel they have a right to know everything about their neighbors. Their clothes are soiled, fingernails black, faces smudged with soot. Two young men standing on the porch of the house argue with the mayor: Yes, they have hemophilia but no, they don't want visitors. Finally we convince the two men that we are here only for humanitarian reasons. When they learn that I have a son with hemophilia, their faces soften and their shoulders relax. When they invite us in, the crowd wants to follow but the mayor holds them back.



The four Bhutuman brothers all have severe joint damage.

We gather in a small room at the back of the house. The Bhutuman family is headed by four brothers with hemophilia: Stelica, 32, father of one boy and two girls; Calistrat, 27, father of two girls; Ilie, 24 and unmarried; and Petrica, 14. Their home has two rooms, but one room is completely uninhabitable, with a dirt floor, crumbling plaster and dust. In the back room, we inhale pungent charcoal fumes from a stove between the two beds. The mattresses are made of straw. A big painting of Jesus hangs on the wall, and a homemade cradle stands on the floor.

Stelica is sharp. He knows exactly what hemophilia is and how to treat it. He knows that his daughters are carriers. I am impressed by his accurate description of the genetic inheritance of hemophilia. Young Petrica is terribly disabled and hobbles like an old man. We want to examine his joints, and try to remove his sweater but it causes him too much pain. Every joint on every brother is contracted, most notably the elbows, which are contracted at 90 degrees. These young men have suffered tremendously.

The mayor joins us, and occasionally another argument breaks out. But the gypsies have made a connection with Adriana and me; we have soft voices and a calm demeanor, and we don't push. When we tell the brothers that we don't want Petrica to suffer as they have, they calm down, sit on the bed and listen. Then they answer our questions. They live far from the hospital where Aurora works, and must travel two hours to receive only plasma. Petrica has stopped attending school because he can't walk. They would use ice but there is no place to make or store ice, so this is a luxury. We see that they have a TV and electricity, so I ask if they would like a refrigerator. Most definitely! We promise to buy them one for ice. We return to the car after many good-byes and the repeated promise of a refrigerator. A crowd follows, and as we drive off, the villagers turn to the mayor, besieging him with questions and concerns.

We drive through Transylvania and on to Tmisoara, on the Hungarian border. Many days and many patients later, we circle back on the long trip to Bucharest. I am not prepared for the stunning beauty of Romania. We pass peaceful, pastoral scenes of farmers plowing, old women tilling the fields, children running. Mighty draft horses pull plows in the early morning, steam pouring off their backs, looking almost on fire. Bleating sheep dot the soft green hills. We film some farmers, who stop plowing to pose for us. A horse-drawn logging cart squeezes by and the men in the cart point and laugh at the farmers, lightly teasing.

We have met so many Romanians, who seem to me a dignified, gentle people. They have suffered terribly, not so much physically from hemophilia, but psychologically after living under dictatorship for many years. They are at times fearful, suspicious and pessimistic. But they radiate faith, and have welcomed me with grace and hope. At the end of my trip, I tell Adriana how enthralled I am by Romania's beauty, and how grateful to have visited so many homes, helping so many. She smiles. "I'm not really afraid to fly in small planes," she confesses. "I knew you would fall in love with Romania if you saw the whole country by car."

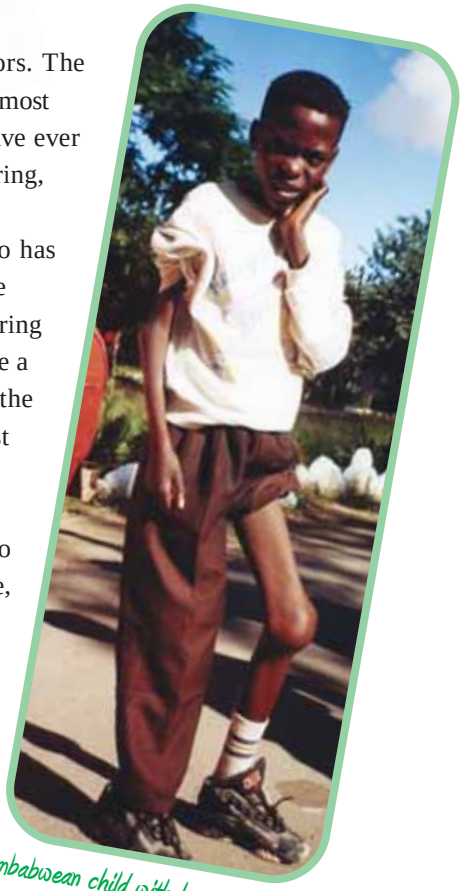
Zimbabwe August 2001

Harare has deteriorated since I was here last year. Once the bustling, vibrant capital of Zimbabwe, it's like a ghost town now. In its 21 years of independence, the country once known as Rhodesia has slowly slid into economic ruin and political corruption. I note the long lines of more than 100 cars waiting for gas; some people sleep in their cars to keep their places in line. The exchange rate has skyrocketed, and there is a thriving black market for foreign currency, especially US dollars. But foreign currency is hard to find. Everyone is fleeing, and taking their money with them. A country that once imported factor cannot afford it now. US factor must be bought in US dollars, which are as scarce as honest politicians here.

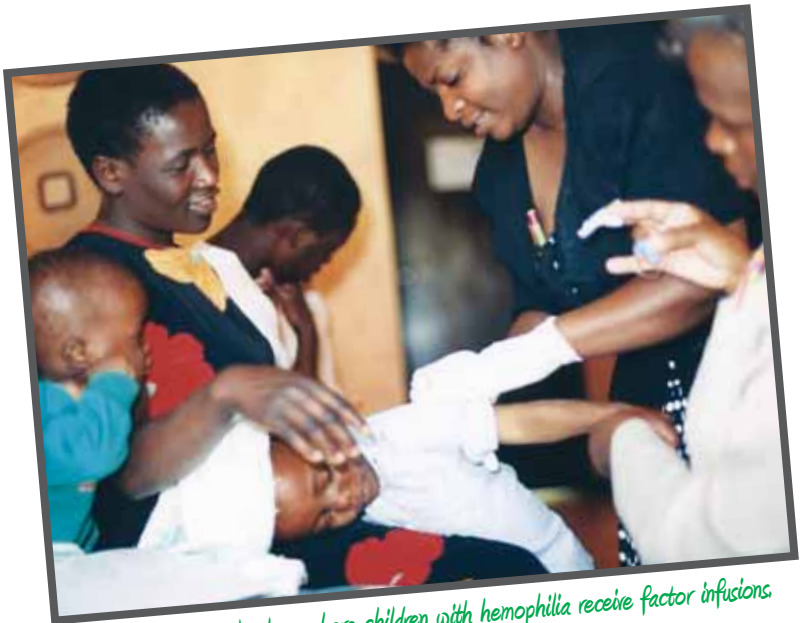
My trip from Boston took 30 hours. This time I am here to inaugurate the first hemophilia camp in Zimbabwe's history. I have a lot of factor in my suitcases and, mercifully, customs treats this American woman and her suitcases respectfully. I travel by car to Victoria Falls, the world's largest, and catch a cab to the town of Hwange, another two-hour ride.

Africa is a beautiful continent: foreign but friendly, not poor but not wealthy, intriguing and amazing. It's clear and dry today as we were now in the dry season when everything is brown, brittle and dusty. I first visited during the wet season when everything was lush and green. But the dry season is better for game viewing, since the animals swarm the water holes. We hope that our hemophilia campers will see game.

I arrive at the Hwange Safari Lodge, the scene of our hemophilia camp. I am greeted by the staff of the Zimbabwe Haemophilia Association (ZHA), who have organized camp. About 60 people are present, including families, medical staff and financial contributors. The Zimbabweans are among the most civil and gracious people I have ever met. They are used to suffering, and do it with stoicism and patience. It's hard to tell who has active bleeds because no one complains. That evening during the opening ceremonies, I give a motivational talk to remind the Zimbabweans that they must persevere in their efforts, no matter what economic hardships they face. I ask them to remember Norman Mubaiwe, former president of the ZHA, and dear friend, who died the previous year from an untreated bleed. Norman would be so proud to see today's attendance. He was poor, with only a basic education, and suffered from a speech problem, hemophilia and hepatitis C. Who suspected that such a man would capture the attention of the world hemophilia community? Perhaps he was told, *Forget it, don't bother*. But he tried anyway, and succeeded. I am here in Zimbabwe, I tell the audience, because of Norman's undying dream, persistence and passion. We name the camp Norman Mubaiwe Memorial Camp.



A Zimbabwean child with hemophilia shows the devastating effects of untreated bleeds.



Camp is often the only place where children with hemophilia receive factor infusions.

The next morning I open my sliding glass doors to see the Hwange savanna. I'm greeted by a troop of baboons that swarms into camp each morning, foraging for leftovers and handouts. Baboons are dangerous and bold, and will walk right into the rooms. I toss out some oranges, and eventually they disperse.

We start the day with clinic. I have four huge suitcases full of toys for the kids and lots of factor. The campers range in age from two to 30, and Dr. Andrew Cakana, Zimbabwe's chief hematologist, evaluates each one. Medical records are updated, joints evaluated, factor infused. This is the beauty of camp: People who can't often travel to clinic have the opportunity to travel, bond socially, be educated, and obtain medical treatment.

The boys board several safari jeeps to spy Zimbabwe's colorful and diverse animals: elephants, giraffes, gazelle, crown cranes, baboons, warthogs and meerkats. Most of the campers have

Laurie Kelley in Zimbabwe with Koombs (right) who lost his leg to a simple, untreated toe bleed.

never ventured outside their cities or villages, never seen these animals live. I watch the safari vehicles lumber away while standing at the camp's perimeter fence with ten-year-old Koombs and his brother. I know Koombs's story because I visited his home on my previous trip. At age eight, Koombs had a toe bleed, which festered without factor until the foot became gangrenous. I received an urgent fax begging for factor. My company wanted to rush some to Africa, but Project SHARE didn't exist then, and we weren't prepared to handle such requests. Koombs' leg was amputated–because of an untreated toe bleed. Not long after that, Project SHARE was born and we've been able to prevent other children from losing legs. Today, Koombs follows me and smiles the dazzling smile of the Zimbabwean. We can't speak each other's language, but we understand.

There's a pool at the lodge and it takes convincing to get Koombs and his brother into the water. Finally, sure that they won't get into trouble, the boys strip off their outer clothes and dive in. So happy to be in a pool–a luxury for a poor boy–Koombs is not self-conscious about his stump.

The next day we visit Victoria Falls. The children are so excited! Most live in poor surroundings or slums, and some have never seen the natural beauty of their own country. Norman Mubaiwe's cousin Daisy sits next to me, but she is feeling ill. We suspect that she has malaria. Parasites and disease go hand in hand in the developing world, and malaria is common. I lift her son onto my lap, and he promptly pees on me.

Victoria Falls form a roaring, thunderous curtain of water creating a natural boundary with Zambia, visible from where we stand. The first European to see the falls was missionary Dr. David Livingstone, in 1855. Named after the most famous carrier of hemophilia, Victoria Falls is one of the great wonders of the natural world. Livingstone wrote, "Scenes so lovely must have been gazed upon by angels in their flight." The campers have a great time and, luckily for us, no bleeds. Rainbows abound here, thanks to the mist pouring up from the deep gorge formed by the Zambezi River, which creates a perpetual rain forest around the falls. Deer lie quiet under the thick growth, and the campers gape at them. A warthog scuttles across the path. There are no handicap facilities. Developing countries don't acknowledge that handicapped people have needs; or they simply lack the funds to build ramps or rails. So the slippery walkway makes us nervous.

When we board the bus back to camp, the boys are thirsty. I offer to buy Cokes, and some members of the ZHA take my US dollars with a wink, then negotiate an exchange of funds on the street. This is known as the black market, of course. I buy 65 bottles of Coke for $6.

Later that day, the good-byes are difficult as we all return to our own worlds. My trip continues to Kenya, while the campers return to impoverished homes, political tension, lack of food, and no factor. I can only promise them continued factor shipments. Months later, I will learn that the all the hemophilia doctors have fled the country. Only the ZHA remains, trying its best to keep hope–and patients–alive.

Victoria Falls, one of the natural wonders of Africa.

Kenya August 2001

This is a grueling trip, and I'm used to foreign travel. We've toured for three hours in the broiling sun through the slums not far from my hotel. We trudge up and down dirt alleys, between tin shacks, over rickety planks crossing muddy rivulets of sludge. We're in the outskirts of Nairobi, in a slum of one million people that has simply swallowed us whole. Even the taxi driver stopped short of actually delivering us to our destination. "Get out here," he said. "I'm not going near there." But here we are: Christina, mother of four (two with hemophilia); Jane, mother of one with hemophilia; Margaret, a friend; and me. Christina wants to locate a family she knows with hemophilia. It's like finding a needle in a haystack–this is an illegal settlement with no postal addresses or even roads.

A Kenyan family with hemophilia is finally located.

The poverty here is staggering. No electricity, no running water, no outhouses. The smells are overpowering. But I'm getting comfortable in this work. I understand it, and I'm no longer depressed or repulsed by it. One million people, more than half of them children, are crammed into the flimsiest, dirtiest slum imaginable. So many bare-footed, runny-eyed, partially-dressed children. So much sewage, mud and garbage. And the ubiquitous little blue plastic bags: The Third World is plagued by these bags that bring home items from market, then are discarded for the goats and pigs to eat. A polluted stream runs by the slum, but people wash and drink from it. Goats urinate in it. I taste acrid black smoke from the charcoal cooking fires, and feel its grit on my hair.

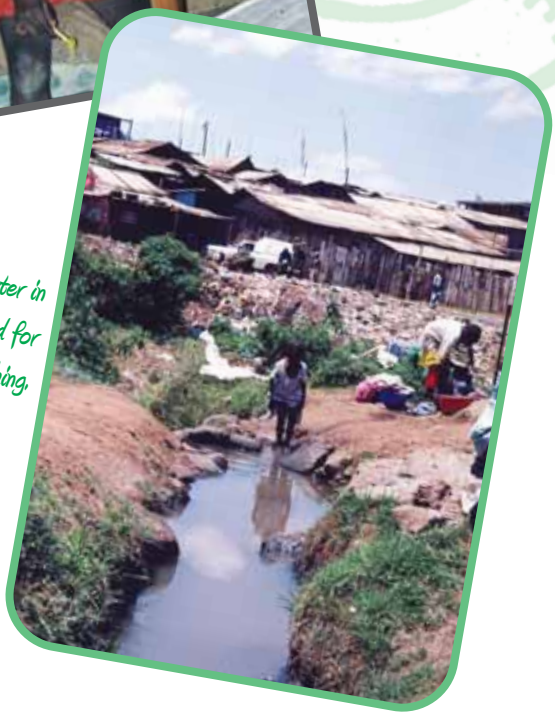
We walk on, carefully sidestepping rotted food and dead rats, and a small group of children shadows us. Christine assures me that I am the first white person these kids have met. They cry, "Al-lo! Tik a peecture!" I snap some great photos. The children want to touch my skin, and I let them. When we stop, the air teems with flies possibly carrying diseases like malaria and yellow fever.

After more than three hours, we find the hemophilia family living in a two-room dwelling with a tin roof. The building is surrounded by dozens more just like it. Ruth Akinyi is pregnant with her eighth child. She and her husband have two girls and five boys. Seven-year-old Stephen has hemophilia; another brother with hemophilia has died. Ruth earns about $1 a day selling charcoal. The family sleeps four to a bed, head to foot. Inside the home it's dark and stuffy, and the cooking fire steals any fresh air. The mother is cooking vegetables for lunch. It's customary for families to offer us food when we visit, but this time I can't accept, because they have so little. The mother tells us that they don't often go to clinic because they lack transportation money.

We sit on the front step to pose for photos. I have a child in each arm, hugging one and cursing his fate, hugging the other

Laurie Kelley searches for hemophilia families in a Nairobi slum of one million people.

Stephen Akinyi's mother earns only $1 a day.



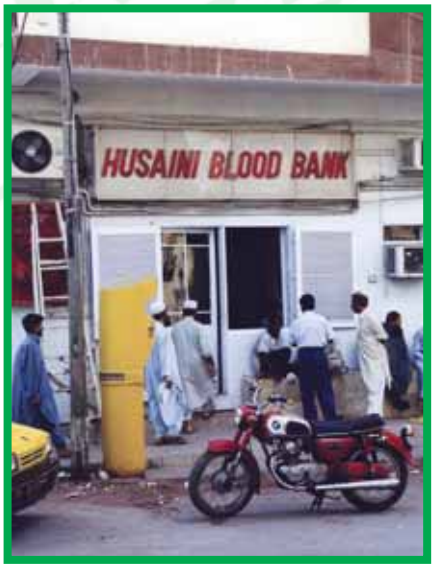
Polluted water in the slum is used for drinking and washing.

and feeling blessed to be here. I hope we can offer direct aid–it took so long to find this family, and impoverished families sometimes relocate suddenly so the national hemophilia organizations lose track of them. We give the family some money and a gift of flour, sugar and lollipops. The kids are ecstatic about the lollipops.

When we return to the hotel, I throw away my running shoes before I enter the lobby. This slum isn't indicative of Kenya. All countries have slums. Kenya is gorgeous, lush and expansive. Nairobi is a huge city, bustling and active. With its tall buildings and wide avenues, it was once the New York City of Kenya. Now the city is in decline. There is no cryo anywhere in Kenya, I am told. This is perplexing. How can such a country not even have cryo? There is money here. But the patients are not well organized. They don't know how to address their needs or stand up for their rights. This is the legacy of poverty: People feel they can't make a difference, can't empower themselves. Once that attitude changes, almost anything is possible.

Pakistan April 1999

I awaken in the dead of the night to screams. No, shouts. I forget for a moment where I am, and lie paralyzed in bed. Then I remember: prayers. It's the muezzin on the minaret, calling the faithful to worship. But it's not a muezzin anymore, just a recording. I get out of bed at the Sheraton Karachi, look across the street and see a Catholic church. Two Americans were killed not far from here last year. They stayed at this hotel. It's only 5:00 AM and still dark. After 31 hours in transit, I still can't sleep well due to jet lag. I'll lose ten pounds before the week is over, from the heat, traveling and general stress.



The Husaini Blood Bank in Karachi treats hemophilia patients.

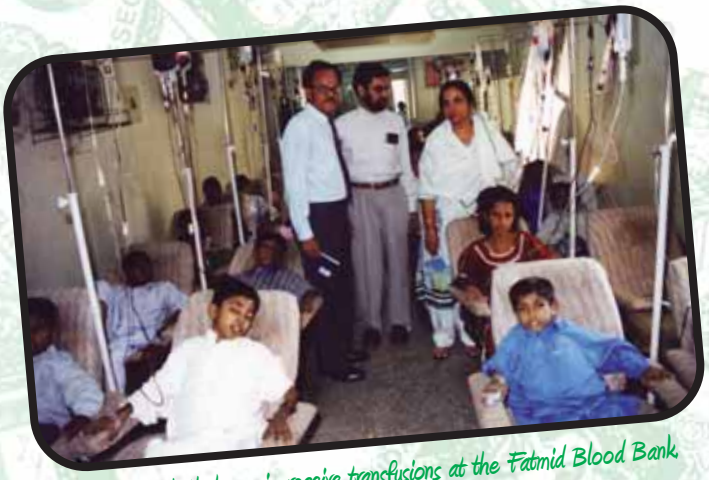
Pakistan is the most exotic place I've ever visited. Perhaps it seems exotic because it's so insulated, and lacks a tourist industry. Many people asked me why I would go to Pakistan. They think, as I once thought, that Pakistan is too cut off, too different. But I learn quickly that Pakistanis are just like anyone else. I find them extremely warm, gracious, generous and curious. So curious! Many times this week I am questioned about my life, my religion, my children and country. The Pakistanis I meet can't seem to get enough information about life in America.

Pakistan is predominantly a Muslim country, once part of India until its birth as an independent nation in a bloody 1947 war. Karachi, once the capital of Pakistan, is a city of 13 million. It seems that they are all out shopping or working today, as the city is simply mobbed. It's a very hot 90 degrees. I am greeted by my friend Dr. Tahir Shamsi, a young hematologist I met at a hemophilia world conference who has invited me to visit. Tahir has a special passion for people with hemophilia, and seeks ways to help improve their treatment in Pakistan.

As the only blonde, blue-eyed Westerner around, I am stared at intensely and constantly all week–more Pakistani curiosity. When our car is stuck in traffic, a boy presses his face against the window long and hard to get a good look at me. At mosques and monuments the guards treat me deferentially, offering me the best viewing places. I feel more like a foreign dignitary or CNN correspondent than just the mother of a boy with hemophilia trying to do some humanitarian work. People beg to take my photo and I begin to feel like a celebrity.

The week-long trip takes me to three cities: Karachi in the south, Lahore in the country's center, and Islamabad, the capital, in the north. Each city has a different flavor and past, but the needs of hemophilia families are always the same. With approximately 8,000 people with hemophilia, Pakistan is a country with overwhelming medical needs.

In Karachi, I meet with the Pakistan Hemophilia Patients Welfare Society (PHPWS). The office is across the street from a cinema, now showing *Broken Arrow*, a John Travolta movie. I learn that most of the movies preferred here are American action movies; this seems odd, especially when I learn that religious censors eliminate the violent and explicit scenes. This must make for a short movie night.



Children with thalessemia receive transfusions at the Fatmid Blood Bank.

I tour the PHPWS office and meet the staff, all people with hemophilia. It's very nice here: air conditioning, a refrigerator with some donated factor, and a bed for tired patients. What they need most is a computer, and I pledge to get them one, along with more factor.

I then tour the clinics and hospitals, and meet with doctors. I must be careful of my etiquette, since the Muslim culture has many expectations. I visit the Aga Khan, a private hospital of gleaming marble, and the public Hussaini Blood Bank, with computerized blood donor information. I visit the Fatmid Blood Bank, where blood donations are recorded by hand in a notebook that looks as old as the Dead Sea Scrolls. Rows and rows of thalessemic children are being infused, and the outlook for them is not optimistic. A few hemophilia patients are present, and we talk. The doctors are all fantastic: knowledgeable, kind, devoted. But they often lack resources. The hospitals are places

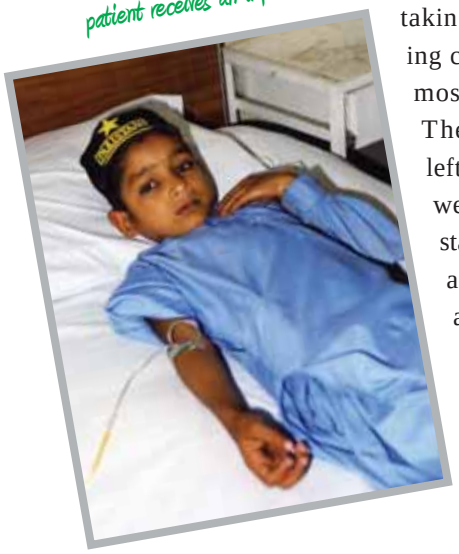
to be treated only. There are no TVs, no games, no books–nothing to do but lie in one place for hours or days. The children seem endlessly patient, asking for nothing. We visit an OB/GYN clinic where the waiting room is filled with women in burkas, the traditional black robes that cover face, hair and clothes. I clear the room in about 30 seconds when I try to take a photo. Islam disapproves of graven images, and most women don't want their photos taken. But one brave lady smiles broadly and tosses off her scarf for a photo.

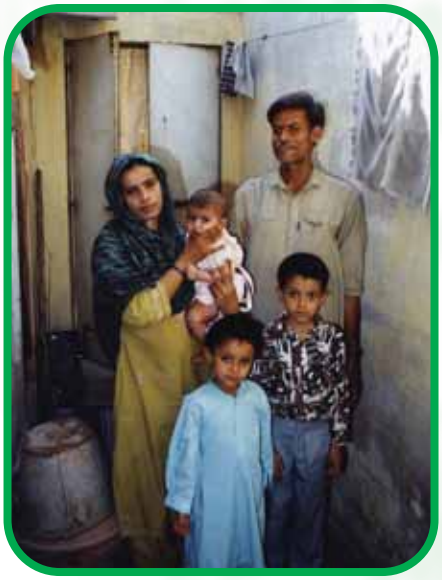
I visit a hemophilia family in Karachi, in a small concrete abode on a dusty street. There is one bed for five people, and one small pot over a tiny grill to cook food. The walls of the home are stained and there are no windows. Little Mohammad Ali, an angelic eight-year-old, is learning English. He shows me his schoolwork. School costs $20 a month, and his father makes only about $20 a month as a postal employee. School is their only hope, the father explains through an interpreter. Pakistan, like many developing countries, has no social security system. When you are old, he says, your family must care for you. This responsibility normally falls on the eldest son, in this case Mohammad. So it's essential that the eldest be educated and get a good job. But when you have hemophilia, you're crippled. You can't do manual labor, and can't finish school because you miss so much. It all becomes a hopeless cycle. I can see this father's fear in his eyes. Bouncing Mohammad's baby brother on my lap, I suddenly form the idea of a child sponsorship program. So many Americans can easily afford $20 a month for a charitable cause (see *As I See It*, page 3).

If we gave $20 a month, I ask, would that help? Yes, says the father, with tears in his eyes. *Yes.*

The next day we plan to fly to Lahore, but all civil aircraft is grounded. This morning Pakistan has decided to fire a missile in response to India's missile firing. We wait six hours at the airport before taking off. Lahore is a charming city with magnificent mosques and many parks. The British Empire certainly left its mark here, with well-paved roads, parks and stately architecture. I meet another hemophilia family: a sad-faced man with his little son. He explains softly that his other little boy, eight-year-old Shere Khan, died just four months ago from a head bleed. I put my hand on the father's arm in sympathy, even though this may be taboo. He gives me a photo of Shere Khan, which I still have on my office desk. It's heartbreaking to read this man's face: Please don't let my last child die.

A young Pakistani hemophilia patient receives an infusion.





Mohammad Ali (child at right) has hemophilia. His family lives on $20 a month.

Afterwards, we walk in 100-degree heat to find another family. It's scorching in the car because the air conditioner doesn't work. We drive over bumpy roads and dust-filled streets and arrive at the home of Sophie, who has six children, three with hemophilia. Her dwelling is in a slum alley. Millions of flies are everywhere; I'm afraid that if I open my mouth they'll get inside. They swarm our faces, our hair and eyes. I swish them away, pretending that I am fixing my hair so as not to draw attention.

Shere Khan of Lahore, Pakistan died at age eight from an untreated bleed.

Sophie's 85-year-old mother lives with her. Her face is captivating, exquisitely lined with creases that seem to tell the story of her life. Although elderly, she squats easily on the ground while I speak with Sophie. Squatting is a way of life here. When people are tired, they squat to rest. To use the toilet, one must squat over porcelain-lined holes in the ground. A child with joint deformities and crippling has a terrible time using squat toilets.

Sophie's mother keeps touching my face tenderly, amazed that an American would visit her home. The children are gorgeous, and so poor. They crowd around, happy and curious. The three boys are green-eyed and red-haired, making me think of Tom Sawyer. We enter the family's home, which consists of two beds for six children, two parents and an old woman.

Sophie tells me that her neighbors believe she is cursed: Not only did she have a child with hemophilia, she had *three*. A Shaman once told her to cut off a goat's head and hang it in her bedroom overnight to absorb the evil spirit that afflicts her family. In the morning, she could throw out the goat's head and, with it, the evil spirit. I tell her that in hope of curing my son Tommy, my mother once traveled to Yugoslavia to pray to the apparition of the Virgin Mary. We eye each other suspiciously for a moment. "So, did it work?" Sophie asks. "No," I reply. "Did the goat's head work?" She laughs hard. "Do you think I'm going to put a *goat's head* in there?" she asks, pointing to the dark and windowless bedroom. Everyone laughs. We are friends.

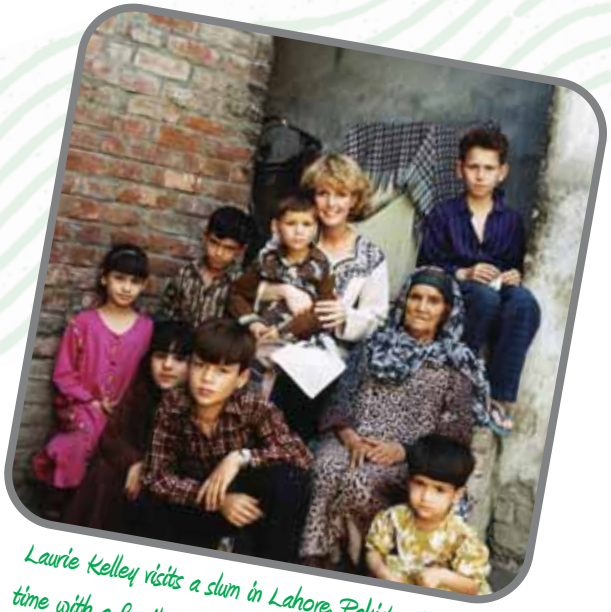
While I also give lectures and meet with medical staff during my trips, I most enjoy meeting families in their homes. I record their stories, take photos and try to stay in touch with them. Each person has a story to tell, and all stories are worth sharing. Some of the greatest heroes I know are people who quietly live their lives, suffering terrible hardships with dignity, strength, grace and faith.

The Pakistanis have so much faith. I was privileged to visit a mosque during prayers, and while I am here we begin all my speeches and presentations with prayers. Flying home on Pakistan International Airlines, I watch with great respect as the male flight attendants interrupt dinner service to take out prayer rugs, face Mecca and bow, stand and kneel repeatedly to recite prayers for 20 minutes. They do this five times each day.

Three cities in one week, and by the end of the trip I am badly dehydrated and ready to go home. I will return twice more to Pakistan, to this enchanting land filled with passionate and hardworking people who welcome me back.

When I finally arrive at my home in America, it's dark, late at night. I quiet the dog and bring in my luggage. My traveling is becoming routine for our family. I slip into the bedroom and then the bathroom. As I flip on the light switch, I stop in awe. Electricity. It seems like such a miracle, such a luxury, yet so simple. I flip the switch on and off, marveling. And the bathroom seems surreal: clean, sparkling, color coordinated, gleaming. I feel a bit guilty and more deeply appreciative than ever before. Then I walk across the hall and tiptoe into the room where Tommy is sleeping. I gaze at him and wonder at the gifts we have been given in America–abundant factor, medical care, money. I think of the privilege I have of meeting people who suffer. I couldn't walk a day in their shoes, although I have tried.

I am not asked to live their lives. But I am called to ease their suffering. Can I harness the power, resources and compassion of the US, the richest nation on earth, to help people with hemophilia in poverty and in need? I believe that the outpouring of generosity we've witnessed following recent natural disasters is always present in Americans. I believe that when Americans see someone in pain, we act swiftly and generously. We're aware of our global economic and military power, but most of us are unaware of our global hemophilia status. Americans represent less than 4% of the world's hemophilia population, yet consume more than 33% of the world's factor. In this season of Thanksgiving and faith, we can help the people who suffer in silence around us, waiting for scraps from our bountiful American table. We can make a difference in many lives. On the tomb of David Livingstone, the English missionary who devoted his life to helping the poor in Africa, are inscribed his words: "May Heaven's rich blessing come down on every one, American, English or Turk, who will help to heal this open sore of the world." We already have immeasurable blessings; now it's time for us to heal the wounds of hemophilia.



Laurie Kelley visits a slum in Lahore, Pakistan to spend time with a family of six children and their grandmother; three brothers have hemophilia.

Laureen A. Kelley is president of LA Kelley Communications, and author of ten books on bleeding disorders. She has traveled to countries in Central and South America, Africa, Asia, Eastern Europe and the Caribbean to help families with hemophilia living in poverty. She is founder of Project SHARE℠, which donates about $5 million in factor to poor countries each year, free of charge; and founder of Save One Life, a child sponsorship program for children with hemophilia. Ms. Kelley is the mother of 18-year-old Tommy, who has hemophilia, 15-year-old Tara and 11-year-old Mary. Contact her at laurie@kelleycom.com if you'd like to join her efforts to help the world's poor with hemophilia.

Letters... continued from page 2

As a mother of a son with hemophilia, I've been re-reading *PEN* on the impact of insurance pressures, and I can tell you that what you warn about is already here for mental healthcare. It's something that I deal with constantly as a psychotherapist. Certain insurance companies approve only certain antidepressants–or have prohibitive copays for the more expensive, and superior, medications. After a certain number of psychotherapy sessions, there may be payments only if the therapy is for a life-or-death crisis. Some companies will not pay, regardless.

The good news is that I ran across information about a bill that four democrats have introduced in the House of Representatives for universal healthcare in the US, including decisions about choice of medications being entirely up to the doctor and patient. This would mean that people would be able to work anywhere without worrying about insurance coverage. I'm sure the program wouldn't be perfect, but it certainly looks like a huge improvement over our current nightmare.

Sibyl Freud
North Carolina

We have had problems with factor brands that require a large amount of diluent, and having to use large syringes–often we lose the vein during the infusion. So our doctor suggested a low volume concentrate. This has made infusions bearable again. We had dreaded infusions so much that although Garrett was supposed to be on prophylaxis, we treated only when absolutely necessary. He has had trouble with an ankle, and this just complicated things. If we had to use the brand our insurance company insisted we use, I'm sure it would eventually affect Garrett's view of hemophilia and his health. We would be devastated.

Thanks for all you do for the hemophilia community. Your books and newsletters have always been my best resources.

Susan Shawley
Pennsylvania

We have been forced to use a homecare company that we didn't choose. I've had Aetna HMO for several years, and was told this spring that we would be converted automatically to the Aetna Specialty Pharmacy and couldn't continue using our current hemophilia homecare company. When I inquired about other options in the network, Aetna told me that there are none.

It was a rough transition, because Aetna Specialty Pharmacy made mistakes with our first two factor orders. The first month, it didn't fully process the order because the person who initiated the order was on vacation. The second month, the order was "lost by FedEx" and had to be re-shipped. I called and informed Aetna Specialty Pharmacy that on first impression, it didn't have my trust and confidence. The third order came with no problems, so I'm crossing my fingers that they have their act together now.

Susan Gaede
Florida

Once again, Project SHARE's donation came at a very critical moment. Two people with hemophilia were in serious need of factor VIII. Thank you very much for the medication.

What pains me most is that when there is nothing in stock, people phone me but there is little I can do. Our situation with the government is tough. I don't see our health ministry buying factor any time soon, because at this time they can't even import enough fuel.

Tachiona Svunurai
National Blood Transfusion Service, General Secretary, Zimbabwe Haemophilia Association, Zimbabwe

Two of my boys have hemophilia. My eldest is Dennis James, age 18, and the other is Kevin Andrew, age 15. They get three shots per week at home. They are both severe factor VIII deficient, and have had the best treatment available in Rochester, New York.

When I read the note from the Marcy Jones in North Carolina (*PEN*, February 2005) I started to cry. When my sons were born, the fear of AIDS was all I could think about morning, noon and night. I thank God for the excellent products available now. Dennis is going to college this fall to study to be a pharmacist and has never spent a night in a hospital. Our biggest concern now is finding scholarship money.

I quickly learned that with a good support system, nobody could treat my boys better than I. You must be strong and do what's needed to become an expert at hitting veins. Your children learn to trust you, and the shots hurt you more than them! Children also need to learn as early as possible to give themselves shots. I remember letting Dennis practice drawing my blood with a bigger needle before trying on himself. He was so careful to hit the vein, and we thought we'd gone over everything. He got the vein, but went in so slowly that I had to fight off tears. That time it may have hurt him more–but it sure did hurt me, too! We still laugh about it, and when it was Kevin's turn, we made sure that he understood to get in quickly and not worry if he missed. I've missed sometimes, and so do doctors and nurses.

Always let your son be a boy, but be careful at the same time. My boys do almost everything that anyone else does: skateboard, swim, ride dirt bikes, and play football, volleyball and paintball. We infuse before we do the wilder activities. When he was 14, I let Dennis pilot a Cessna 182. The boys go every year to Camp High Hopes in the Adirondack Mountains–for free, thanks to the pharmaceutical companies. I advise parents to send their children to hemophilia to camp by age seven. Kids from around the world attend. They understand each other. Most of the counselors have hemophilia, and the nurses are terrific.

I remember seeing older people with hemophilia who could barely walk after years of joint bleeds. They got hepatitis, or died of AIDS–because we didn't know better. The new fear now is cost and insurance. I've been a single parent for 16 years, and the financial burden of insurance helped drive me to bankruptcy. But I learned how unimportant money is, how important good insurance is, and how important a good HTC is. Always remember that many kids and adults have much bigger problems.

Tom Conolly
New York

Loss of Hemophilia's Bright Star


Comedy Lifeline International

Brian Craft of Costa Mesa, California died at age 47 on July 12, 2005. Brian sought to inspire people with hemophilia and HIV/AIDS through comedy. He traveled around the country, speaking and entertaining the community at annual meetings and summer camps. Brian, who had hemophilia and HIV, emphasized the value of humor and optimism. He also stressed the importance of good doctor-patient communication. With his wife Kelly, Brian co-founded Comedy Lifeline International, a nonprofit organization that continues to deliver messages of hope and humor to the hemophilia community in Brian's honor.

To contact Comedy Lifeline International: kellycomedylifelineinternational@yahoo.com

Wyeth Enters Fifth Year of Support for WFH Twinning Program

Wyeth Pharmaceuticals continues as the sole supporter of the World Federation of Hemophilia Twinning Program for 2005. Through this program, treatment centers and hemophilia patient organizations in developed countries are paired with corresponding centers and organizations in developing countries to share knowledge and best practices. Worldwide, there are 28 active hemophilia treatment center twins and 14 active patient organization twins.

Source: Wyeth news release

Bayer Funds International Nursing Fellowship Program for WFH

Bayer Biological Products is funding the WFH International Hemophilia Nursing Fellowship Program, which provides state-of-the-art hemophilia education and training to nurses in developing countries. Funding will support three to four nurses annually to travel to one of the 31 WFH-designated International Hemophilia Training Centers (IHTC), where they will each be paired with a hemophilia nurse to receive clinical and laboratory training. Since 2002, the Bayer Hemophilia Awards program has provided approximately $6 million in grants to fund nearly 50 cutting-edge basic and clinical research projects and caregiver education programs. HTCs and hemophilia chapters and organizations: Look for an award application invitation in the mail soon.

Source: Bayer BP news release

On the Horizon: Another Albumin-Free Recombinant for Hemophilia A

Wyeth Pharmaceuticals has announced the initiation of a new clinical trial of an investigational recombinant factor VIII drug, produced from a completely albumin-free cell culture manufacturing process. The production of this investigational drug includes a purification process free of any biologically-derived materials, with the addition of a viral filtration step for added viral safety.

For more information: www.hemophiliavillage.com

Kogenate® FS and Helixate® FS OK at Room Temperature

The US Food and Drug Administration has approved a labeling change for Kogenate FS and Helixate FS. The products may now be stored at room temperature (77° F or 25° C) for up to three months. Starting in November, each package of Kogenate FS and Helixate FS will include a special notification with details on the new labeling. Both Bayer and ZLB Behring recommend refrigerating at 36° – 46° F or 2° – 8° C whenever possible.

Contact Bayer Clinical Communications at 800-288-8371 (option 3) or ZLB Behring Medical Information at 800-504-5434.

Source: Companies' news releases

Baxter Set to Collaborate on Longer-Lasting Factor

Baxter International will collaborate with Nektar Therapeutics, based in California, and Lipoxen Technologies, based in London, England, with the aim of developing longer-acting factor concentrate. If successful, the collaboration could lead to treatments that reduce the frequency of injections required to treat blood-clotting disorders such as hemophilia A.

Source: Datamonitor Newswire

Inhibitor Patient Education Summit

Novo Nordisk sponsored a first-of-its-kind Inhibitor Patient Education Summit in Philadelphia, Pennsylvania on November 5–6, 2005. The agenda, tailored specifically for people with hemophilia and inhibitors, was developed by a national steering committee consisting of national and local hemophilia leaders. Topics included joint health, immune tolerance, pain management, reimbursement and psychosocial issues. Look for more inhibitor-specific educational offerings from Novo Nordisk in 2006.

For more information: www.novonordisk.com

CORRECTION

In "The 2005 PEN Bleeding Disorders Resource Guide" (August 2005) we provided an incorrect telephone number for Wyeth Pharmaceuticals. We apologize for any inconvenience this has caused. To receive free materials from Wyeth, the correct number to call is **888-999-2349, option 2**.

Read about the heroes who combat infectious disease in the Third World in the November 7 issue of *Time* magazine.

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