



February 2010
Volume 6 • Issue 1

OneVoice

*Caring for families with hemophilia
around the world — one at a time*

Fostering Independence in India

BY MARTHA HOPEWELL

An old Chinese proverb says “Give a man a fish and you feed him for a day. Teach a man to fish and you feed him for a lifetime.” While Save One Life primarily offers financial aid to individual families, we believe in much more than direct charity. We are also committed to teaching people with bleeding disorders in developing countries to “fish.” One long-term goal of Save One Life is to encourage and equip hemophilia organizations — many of which are lead by people with bleeding disorders — to manage their own hemophilia sponsorship programs. One step toward this goal is happening in India now.

Of the 560 beneficiaries currently sponsored through Save One Life, almost 50% are from India. We work with 20 program partners, ranging from Kolkata and Delhi in the north to Angamaly and Trichy in the south. Given the huge need in India, we plan to double the number of sponsored beneficiaries by the end of 2010.

To accomplish this goal, Save One Life established an India Outreach program last year with a grant from Talecris Biotherapeutics, Center for Science and Education.

Partners in Development: Usha and Krish

To accomplish our outreach goals, we recruited a qualified national to head our operations in India. Mrs. Usha Parthasarathy is a trusted colleague of Save One Life and mother of a son with severe hemophilia A. Based in Chennai and a former board member of the Hemophilia Federation (India), Usha launched the outreach program in October 2009 by traveling to eleven partners over two months. These trips were the first of a series toward her goal to personally meet as many of our India beneficiaries as possible, and to assess the effective implementation by each of our partners by the summer of 2010. Currently all our partners are chapters of the Hemophilia Federation (India). During her visits, Usha trains each partner to ensure that truly needy individuals with bleeding disorders are enrolled in the program, monitors the distribution and accounting of sponsorship funds to beneficiaries, and reviews adherence to key program policies.

Usha’s visits have helped to forge a closer alliance between beneficiaries, program partners, and our US headquarters in Georgetown. Save One Life has a point person in each organization who, in most cases, is a volunteer. Our volunteers generally have full time employment elsewhere, and have other personal and professional obligations. In most instances our point person has a bleeding disorder, and is personally committed to developing the chapter to meet the many pressing needs of the bleeding disorders community. When we don’t hear from our point person in a while, it’s usually because he or she has a bleed and couldn’t come to work.

This is also true of our sponsorship program assistant, Krishnan, who has severe factor VIII deficiency. Krish joined the team just as Usha began her travels. He supports the program by preparing all the Indian annual beneficiary update reports that we’ll begin to send to spon-



Usha delivers sponsorship funds to a beneficiary in Durgapur, India

continued on page 8



This year should be a watershed year for Save One Life. With new staff, new office and upgraded database and reporting system, we are ready to roll! Our feature article takes you on a journey through India with our new program coordinator, Usha Parthasarathy. This outreach, funded by Talecris Biotherapeutics, Center for Science and Education, has already improved our connection and performance compared

to previous years. Almost all our partners have submitted the annual information on each beneficiary that we prepare and send to sponsors. Krish, our sponsorship assistant in Chennai, is busy placing the information in a new PowerPoint format that we will introduce in March. We sincerely hope that sponsors will like this new look, and we'll welcome your feedback.

In 2010 we plan to reach 1,000 sponsorships of people with hemophilia in developing countries. New program partners are joining Save One Life and opening sponsorships to their members. You'll read about six new partners in the Program Partner Update. You'll also read about our 10th new country, Kenya, which we officially welcome in the Country Profile. In our column "Meet a Life to Save," you'll get to know our first Kenyan enrollee, Moline Odwar.

All of this is possible due to the enthusiastic support of our bleeding disorders community around the world. We look forward to working with you to meet, and even exceed, our goal of 1,000 sponsorships. Thank you for sharing the word, and being our best ambassadors!

Laurie A. Kelley
President



**Save One Life's OneVoice
FEBRUARY 2010**

president ■ Laurie A. Kelley

chair ■ Chris Lamb

executive director ■ Martha Hopewell

editor-in-chief ■ Laurie A. Kelley

sponsorship manager ■ Zoraida Rosado

webmaster ■ Ujjwal Bhattarai

layout design ■ Tracy Brody

Save One Life's mission is to encourage individuals and organizations to focus their compassion and resources on improving the quality of life of people with bleeding disorders and their families in developing countries, through direct sponsorship programs.

To better meet the medical, educational and social needs of the community, Save One Life also directs sponsorship resources to strengthen and support national bleeding disorder organizations in developing countries.

We've Moved!

Save One Life, Inc.

65 Central Street, Suite 204

Georgetown, MA 01833 USA

1.978.352.7652 Fax: 1.978.352.8184

contact@saveonelife.net

www.saveonelife.net


Save One Life is a registered

501(c)(3) organization.

Country Facts: Kenya

The geography of Kenya, located in East Africa, varies from tropical low coastal plains along the Indian Ocean, to central high plains marked by the Great Rift Valley, to mountains that include the second highest peak in Africa, Mt. Kilimanjaro.

Kenya has diverse ethnic groups, including Kikuyu 22%, Luhya 14%, Luo 13%, Kalenjin 12%, Kamba 11%, Kisii 6%, Meru 6%, and other groups. More than 75% of the population is Christian. About 85% of the population is literate, with English and Kiswahili as official languages.

The country continues to be ravaged by HIV/AIDS. It has had the fourth largest number of AIDS related deaths in any one year (behind South Africa, India, and Nigeria). It is estimated that 700 Kenyans die from AIDS-related diseases every day. More than one million AIDS orphans live in Kenya. This has a major impact on the productivity of the country. The per capita GDP is estimated at \$1,600. It is considered that half the population lives below the poverty line, with more than 40% of the population under the age of 14 years. The median age in Kenya is just over 18 years. 



Country Profile Jambo Kenya!

BY MARTHA HOPEWELL

In the August issue of *OneVoice*, Laurie Kelley shared her adventures in East Africa as she traveled into impoverished slums and countryside villages to see people with bleeding disorders and their families. Laurie was in Kenya at that time to meet Maureen Miruka, the founder of the recently established Jose Memorial Haemophilia Society (JMHS), and her colleagues to assess the readiness of the organization to implement our sponsorship program.

Maureen established JMHS in 2007 after the death of her oldest son, Joseph, age six. Maureen and her colleagues created the organization to be proactive; they feel there is not sufficient factor, fresh frozen plasma or cryoprecipitate for patients. They realize that most parents cannot afford factor, and there is lack of understanding about comprehensive care for patients. They also desire to create practical information for patients on how to manage hemophilia.

Kenya, a country comparable in size to Texas, has a population of about 37 million, with nearly three quarters under age 30. In Nairobi alone there are more than three million people — with more than half of them living in Kibera, considered to be the third largest slum in the world.

There are approximately 3,000 people with bleeding disorders in the sprawling city slums, towns, and isolated countryside. Only two hospitals, both based in Nairobi, are

equipped to a certain degree to treat hemophilia. The government of Kenya does not purchase factor; patients must either purchase it privately, or depend on donated factor from the World Federation for Hemophilia or programs such as Project SHARE.

Based in Nairobi, the JMHS faces the great challenge of registering, educating, and serving this population, including enrolling impoverished people with bleeding disorders in Save One Life's sponsorship program.

Two high agenda items for the JMHS is establishing a treatment center, and lobbying the government. Maureen writes, "Hemophilia is rare and the government faces other urgent medical needs. Our case can get lost in the many voices crying for government attention. It will be the JMHS's responsibility to campaign for government attention, support and assistance. In the long run the society aims to have factor included in the Ministry of Health (MOH) list of essential medications and hemophilia included in the country's chronic disease programs."

In past years Save One Life president Laurie Kelley has worked closely with potential partners to help them gain the administrative and financial rigor to qualify for our program. This year Save One Life added an additional component: review of the enrollment application by the

Save One Life board of directors before final approval. The JMHS was the first to be vetted by the board, and we are happy to announce that, at the end of December, the JMHS became our 30th partner, and Kenya our tenth program country to join Save One Life.

We look forward to furthering the work of this East African partner, and to growing the number of Kenyan beneficiaries that Save One Life sponsors. Our first two candidates have just been posted on our Save One Life website, and you can read about one, Moline Odwar, in this issue. 🇰🇪

Maureen Miruka, president of the JMHS



Save One Life founder and president Laurie Kelley with children registered with the JMHS

Celebrating the launch of the JMHS, April 2009



In My Words

The Hidden Disability: Hemophilia

BY JAD K. JADALLAH TAWIL

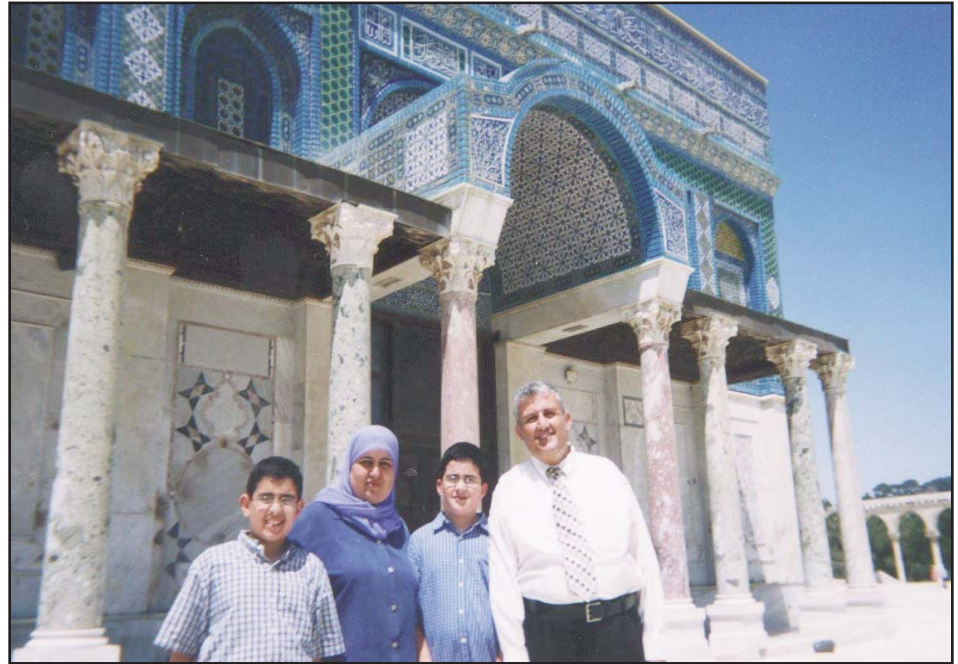
After 45 years my life has changed. I am cured of hemophilia. I've entered history as one of the few people in the world who have been cured. But I am still living with a hidden disability; hemophilia is still in my genes, like thousands of people with hemophilia worldwide. Hemophilia is a hereditary condition in which one of the proteins needed to form blood clots is missing or reduced. I received a liver transplant due to liver failure, which resulted from using unsafe hemophilia products. My new liver is able to produce its own protein. Hemophilia and its complications are considered a disability throughout the world.

I was born in Palestine, and later became a naturalized US citizen.

Though I travel around the globe, I have never abandoned Palestine.

After years of complications and suffering, I am trying to adjust to a new life free of hemophilia. Now I don't need to inject clotting factor into my bloodstream to stop minor or major bleeds. I don't take pain medication as often as before to relieve muscle and joint bleeds. I don't even worry about minor bleeds that could become fatal. Although I still live with arthritis and other disabilities, they have not prevented me from moving forward. And, of course, I must take medication for my liver regularly.

Nothing has prevented me from being active. I have been working since graduating from college, and I volunteer with many local and international organizations. Even during the few periods of "rest" (hospitalization and recovery related to the liver transplant), I worked as an advocate for hemophilia sufferers via phone and e-mail.



Jad Jadallah of Palestine and family: Cured, but still fighting for those with hemophilia

I still sense the pain and suffering of those with hemophilia and their families around the world and in Palestine, in particular, where hemophilia is not a priority and where people with hemophilia are not recognized as people with disability.

Does the world understand hemophilia, and its treatment and complications? From personal experience, I can confidently say no, which is why it is crucial for health professionals and organizations to advocate for treating hemophilia as a priority. People with hemophilia and their families face tremendous challenges every day as they try to live normal lives.

In a developed country such as the United States, where I lived for two decades, people with hemophilia and their families have access to comprehensive medical and health care, including clotting factors. It is obviously impossible to compare the conditions there to any developing country, such as Palestine,

where specialized health care is not available. In the West, people with hemophilia live almost-normal lives, and their disorder is a private matter.

In Palestine, hemophilia is low on the list of health priorities, even though there are a number of voices that have tried to advocate for the rights of those with hemophilia. If people are more aware of this hidden disability, it will become easier to improve the lives of those who suffer with hemophilia.

To those with hemophilia, I say: Be proud of yourselves, advocate for your rights and the rights of others. Don't let disability stop your life. 🇵🇸

Jad K. Jadallah Tawil is a Palestinian-American with hemophilia who lives in Al-Bireh and works for an international humanitarian agency. He is also a volunteer for the Palestinian Society for Bleeding Disorders. He can be reached at jadtawil@yahoo.com.



Meet Our Board Jessica Swann

Jessica (Jess) Swann just joined the Save One Life board of directors in 2010. Recently relocated to Massachusetts from California, Jess has more than 15 years experience in the health care sector, with a special emphasis on hemophilia.

Jess is Associate Director of Product and Market Development at Biogen Idec Hemophilia in Waltham, Massachusetts. Previously she worked as Area Business Manager for hemophilia in Northern California at Bayer HealthCare Pharmaceuticals.


Jess has an MBA from the University of California Berkeley, with a focus on international marketing, brand management and designing global organizations.

Before working at Bayer, Jess served six years as the executive director for the Hemophilia Association of San Diego County.

Jess is an accomplished and passionate fundraiser. While volunteering for the Hemophilia Foundation of Northern California (HFNC), she co-developed a successful fundraiser, called "Speeders for Bleeders," which raised over \$100,000 in two years. As co-chair of HFNC's Sonoma Mission Inn Wine Event, she helped increase the profitability and attendance of the event significantly over several years. HFNC honored her as their

National Hemophilia Foundation (NHF) Dual Volunteer of the Year (for NHF and HFNC) in 2006. Jess is also a recipient of several NHF Award of Distinction for Outreach and Communications programs.

"As someone who has dedicated my entire career to hemophilia," Jess said, "it is an honor to serve alongside other dedicated board members who are making a difference in the lives of those who most need help."

Jess enjoys international travel, and is especially fond of exploring the worlds' wine regions. Her fluency in Spanish and aspiring French language skills have enriched many such travels, and helped forge many international friendships. At home in Charlestown, Massachusetts, Jess and her husband Brian Curry enjoy cycling/spinning, home improvement and entertaining. 


Meet a Life to Save Moline Odwar, Kenya

Moline is a 24-year-old woman with type 1 von Willebrand disease. She lives in Nairobi, Kenya, with her mother, father, and four siblings in a one-room house that has electricity, but no running water, toilet, or refrigerator. Her father, David, is an electrician, and her mother, Florence, is a dressmaker. Together they earn about \$150 a month.

Moline averages one or two bleeding episodes per month. She attends a clinic monthly that is about six miles away, and went to the hospital once last year. She uses factor concentrate to control her bleeds. Moline's father and younger brother Javan also have von

Willebrand disease.

Moline speaks English and completed a certificate in pharmacy; however she has been unable to find a steady job. She would like to be a physician. Save One Life president Laurie Kelley met Moline in April

2009 at her home in Naoribi. She found Moline to be intelligent and engaging. She is well educated, despite her extreme poverty. Moline loves to sing, read and enjoy her friends, and looks forward to having a sponsor. 



Save One Life's first enrollee in Kenya: Moline



Street scene in front of Moline's home

Partner Update

Establishing New Partnerships

BY MARTHA HOPEWELL

With the establishment of our new office and additional staff at Save One Life, we are poised to extend our program to more partners and countries.

In addition to Usha Parthasarathy's travels to current program partners in India as described in our feature article, she has also been working to enroll new partners. Since our last issue of *OneVoice*, four local chapters of the Hemophilia Federation (India) have joined our team.

The Hemophilia Society Kunnankulam Chapter is located along one of the major commercial routes in the southwestern state of Kerala, just inland from the Arabian Sea. Originally a small farming village, it was settled by the Dutch in 1683, and is known for its printing and bookbinding industry. The chapter was founded in 1996 and its office is not far from the Unity Hospital treatment center. Our contact is the general secretary, Mr. Raghunandan, whose son, Kannan, has factor VIII deficiency. In less than a month Mr. Raghunandan has submitted 16 beneficiaries to enroll with Save One Life. Eleven-year-old Arya Vandanappily — a girl with von Willebrand disease — has already been selected by a new sponsor.

Karnataka is the eighth largest state in India, with a population of more than 52 million, and is located primarily on the Deccan plateau of south central India. There are two new program partners in this state. The Hemophilia Society Bangalore Chapter was founded in 2000 and is located in the Bhagawan Mahaveer Jain Hospital. Known as the "Silicon Valley of India,"

Bangalore is the third largest city in India. More than 550 patients are registered with the chapter. Our contact, Mrs. Ranjana Ramachander, an artist whose late husband was a founding member of the chapter, serves as the secretary of the board of directors.

The Karnataka Hemophilia Society is about 300 kilometers north of Bangalore in the city of Davanagere. It was founded in 1990 by the current president of the Hemophilia Federation (India), Dr. Suresh Hanagavadi. Dr. Suresh, a person with severe factor IX deficiency, decided to train as a pathologist after witnessing the challenges and eventual death from hemophilia of his maternal uncle. He is now Professor of Pathology at JJM Medical College. Our contact, Mr. H. M. Sreedhar Rao, is the father of a son with hemophilia who just completed his medical degree and is planning to pursue a master's. Mr. Rao serves as the secretary of the board of directors for the chapter, which has more than 300 registered patients.

Our most recent Indian partner, the Hemophilia Society of Hyderabad, is located to the east of Karnataka in the state of Andhra Pradesh. Hyderabad is a fast-growing city located in the heart of south India. It is the sixth largest city in India with more than four million inhabitants. The chapter has more than 400 registered patients. Our contact, Mr. Vasudeva Rao, has a son with hemophilia and is a member of the chapter's board of directors. He has already submitted nearly 30 beneficiaries to Save One Life.

We have a pending partner in another new state — Orissa. Located along the eastern seacoast of India, Orissa is an underdeveloped state with a popula-

tion of 36.7 million and a poverty rate almost twice the average for India. The Hemophilia Society Bhubaneswar is in the state's capital and largest city. Known as a "Temple City of India," with more than 600 temples, Bhubaneswar has a 3,000-year history. The chapter has more than 300 registered patients. Dr. Lalatendu Mishra, a member of the Board of Directors, has responded enthusiastically to Save One Life's offer, and we look forward to accepting beneficiaries from Orissa soon.

Save One Life is also growing in the Philippines. In addition to working with the national organization HAPLOS in Manila, the Little Children of the Philippines in Dumaguete, and HAPI-C in Cebu, we are now partnering with Blood Brothers Aid, a new organization founded by young adults with bleeding disorders who are excited to help meet the needs of their community. Our colleague Reverend Donald Kill is currently enrolling beneficiaries in the cities of Davao and Cayagan de Oro, both located on the southernmost island of Mindanao. The eighth most populous island in the world, Mindanao is primarily Muslim; its first mosque was built in the mid-fourteenth century. Father Kill looks forward to establishing patient organizations in both cities that will become Save One Life partners in a few years.

In addition to new program partners in countries where we already operate, Save One Life is working to establish partnerships in new countries as well. Look forward to hearing more about our outreach in Tanzania and Honduras in the coming months. 🇹🇿 🇮🇸

Events Sponsor of the Year!

BY MARTHA HOPEWELL



President Laurie Kelley presents Neil Herson, president of ASD Healthcare, with a Sponsor of the Year 2009 award

Save One Life was honored on February 1 to present the 2009 “Sponsor of the Year” award to Mr. Neil Herson. Neil, the president of ASD Healthcare in Frisco, Texas, sponsors 51 beneficiaries in India, the Dominican Republic, Romania, and Zimbabwe. In addition to his generous sponsorship, Neil also went above and beyond: he sponsored the airfare for one of his beneficiaries, Elton Sare, to come to Chicago one year ago for emergency surgery at RUSH University Hospital. And, Neil flew in from Texas to greet Elton at a farewell dinner, held in his honor! Neil provided a laptop, soccer ball and many athletic clothes for Elton, and had the chance to chat with him all night.

Neil knows more than most sponsors about the realities of living in a developing country. He grew up in South Africa, and witnessed poverty and apartheid first-hand.

Laurie Kelley presented Neil with his award at a presentation about Save One Life to his employees. Neil was unaware he was to be awarded.

“I’m certainly honored to receive this award from Save One Life, but it was even more humbling and moving for me to get to know Elton Sare last year,” said Neil. “The people that Save One Life helps have such an urgent need for the compassion and support that the organization provides. I’m proud to be even a small part in carrying out Save One Life’s mission to the bleeding disorder community.”

In Memoriam

On November 26, 2009, Thanksgiving Day in the United States, we were sad to learn of the death of Khumbs Ndlovu, a 19-year-old beneficiary from Zimbabwe whom Laurie Kelley had met during her first trip there in 2000. At that time Khumbs was a nine-year-old boy who had recently lost his mother, and who had also lost a leg due to an unresolved bleed. Laurie saw Khumbs again during her second trip to Zimbabwe in 2007. Since that time our Save One Life family has lost three more beneficiaries: 22-year-old Mahesh Suryavanshi from India; three-year-old Sebastian Rodríguez from the Dominican Republic; and 12-year-old John Wilfred Ybasco from the Philippines.

Mahesh died from complications due to an illness. Sebastian died in a coma from an undetected head bleed that was treated too late on January 11. John, whose twin brother James is also a person with hemophilia, hit his head after falling off a motorcab, and passed away four days later, on January 31.

These events poignantly illustrate why our organization is named Save One Life. For us, each of these lives represented an individual. It reminds us why our mission of sponsorship and supporting partners in their advocacy is critical, because each life matters.

This month we will be introducing a new page on our website to remember the young people and adults who touched our lives, and who have passed on. We hope that you will visit it often.

In Appreciation

We'd like to thank the new sponsors and current sponsors who took on additional sponsorships during the second half of 2009. Welcome, and thank you so much!

Jan Barnett	Leah Jones	Dawn Rotellini
Wendy Barringer	Benjamin Koslow	Jeff Salanti
Lisa Broadhurst	Chrisopher Lamb	Patrick Schmidt
Joseph Caronna	Robert & Barbara	Ujjwal Shakya
Gustavo Castellanos	Maunus	Edward P. Sotherden
Susan Cowell	Craig Mears	John Strell
Julie DuRoss (in honor of David DuRoss)	Yammah Morgan	Holly and John Stump
Nelson Escoto	Andreas Mueller-Beckhaus	Erin Streiff
Anneth Edberg	Brenda Neubauer	Michael Sweeney
Hassling	Reyne Palfreyman	James Valentine
Carole Flynn	Jennifer Peterkins	Kari Smith Woolf
Neil Herson	Leonard Poe	Mary P. Echeverria
		Zanella

Save One Life forwards 100% of sponsorship funds to its program partners and beneficiaries. As a result, we must raise all our additional program and operating funds independent from the sponsorship program. For the first time, Save One Life sent an annual appeal — a cheerful red postcard — in December. We were encouraged by the generous donations we received. We thank the following corporations and individuals listed, who responded to our appeal and contributed to our operations since July of 2009.

American Homecare Federation	For camp in the Dominican Republic	Ilana Levin
Charles Auger	Anne M. Donovan	Novo Nordisk
In honor of Eric Hill and Jeff Salanti's Mt. Rainier Climb	Pamela Pantos	Haemophilia Foundation
Matt Barnes	Nelson Escoto	Vladimir Ostapowicz
J.C. Olszowka	Health Logix	Ziva Mann Robison
Bayer Pharmaceuticals	Jeremy Foster	Rotary Club of Waltham
Ujjwal Bhattarai	Bill Haley	Glenn Sieverson
Andrew Blackledge	Eric & Alyce Hill	Betty Styles
Tracy Brody	LA Kelley Communications, Inc.	Arthur Whitcomb
Paul and Linda Clement	Lorie Kerstetter	
	Robert Kilkenny	
	William Kilkenny	

Thank you

We apologize for any errors or omissions in these lists.

Fostering Independence ... continued from cover

sors this March. Krish sometimes has to suspend his work with us for a few days to treat bleeds.

A Passage Through India

Usha began her visits by going to the Save One Life program partners operating in her own state of Tamil Nadu: Chennai and Coimbatore. In Chennai Usha reported the transformation she observed in some of our beneficiaries — including educational progress and improved living standards — due to the support from their sponsor. When Usha visited Coimbatore, not only the 34 beneficiaries but also their families attended her meeting: a gesture of respect and appreciation families have for Save One Life. In honor of Usha's visit, the beneficiaries decided to draw greeting cards for their sponsors. A packet of 34 cards arrived in our office in time to send to sponsors for the holidays!

Usha's visit to Trivandrum in the verdant state of Kerala revealed that our contact, Mr. Vishnu, a young man with hemophilia, was gallantly trying to run the chapter on his own. He was hard pressed for time, with work pressure and family commitments, and had a limited understanding of the Save One Life program. This explained why he only had one beneficiary — a girl with von Willebrand disease. Usha immediately identified ten additional beneficiaries to enroll.

Usha discovered a similar situation in Angamaly, where only three beneficiaries were enrolled. With her support, Angamaly sent nine more patients who are now posted on our website, ready to receive sponsorship. While in Kerala Usha invited a third chapter located in the city of Kunnankulam to join our program. Usha writes, "I realized that many patients' families are under the poverty line and that Save One Life would be a great support here." She added that our contact, Mr. Raghunandan, is an active and compassionate leader. Within a couple of weeks of becoming a partner, he had 16 beneficiary enrollment forms already submitted to us.

Carrier Status – Deadly Stigma

Usha's next trip was to the national capital Delhi, where she met 27 out of 29 Save One Life beneficiaries. Even though a

number of our Delhi beneficiaries are older and self sufficient, they continue to receive sponsorship due to the high cost of living, and difficulties in making ends meet. Usha discovered that the average beneficiary family income is between 3,000 to 3,500 Indian rupees a month, about \$35 dollars. You can see the significant impact that a \$20 sponsorship can have on the life of a person with a bleeding disorder and his/her family.

Usha learned that our school-age Delhi beneficiaries have a wide spectrum of career aspirations – from becoming a doctor, to being a police officer, pilot, teacher, engineer—even a fashion designer!

From Delhi Usha traveled to Lucknow, the capital city of Uttar Pradesh, a northern India state that shares a border with Nepal. Lucknow is a city rich in history that reveals, through its architecture, the influence of the Mogul Empire. Save One Life has seven beneficiaries there, who had the rare fortune of being treated in 2009 with free factor, available in the major government hospitals. Even though some of the beneficiaries live far from these facilities, it is worth the trip. “The beneficiary families personally thanked Save One Life for the support they receive. One boy came forward to transfer his support to another needy beneficiary since he will be finishing his education this year, and he’s confident about getting a good job,” Usha reported.

Usha learned that the state government of Uttar Pradesh is conducting a genetic study to assist with carrier reduction. Being a carrier is a challenge in any society, but it’s a stigma in India. A carrier means possibly giving birth to a child with hemophilia, and this may cause husbands to send wives back to their families, despite an arranged marriage. Given the very low literacy level of poor women in Uttar Pradesh, carriers generally earn little money.

The impact of carrier status is sadly demonstrated by the Singh family in Varanasi, located on the Ganges River and considered to be one of the oldest continuously inhabited cities in the



Usha interviewing the Khan twins in Mumbai



Usha standing with beneficiaries in front of the new center in Durgapur

world. Of the eleven beneficiaries sponsored here, five are brothers who live in severe poverty. When their only sister became pregnant and discovered that she was a carrier, she committed suicide. She didn’t want her unborn child to face a life of suffering like her brothers.

Usha writes, “In Varanasi I met a beneficiary with an amputated leg, who runs a shop with a phone booth, photocopying machine, and mobile phone recharge facility. He is a motivating influence for the five Singh brothers and other patients. He shows everyone how to



Usha visiting our partner in Varanasi



Usha visiting the home of Kavitha in Trivandrum



Usha with Avik Chakraborty who will soon be receiving his medical degree

actually fish, and has inspired the brothers to open a shop to sell tea and cookies.” For impoverished families with multiple siblings with hemophilia or carrier status, the generosity of Save One Life sponsors can be transformative.

Loss in Mumbai

Usha’s third trip was to our western partners in Mumbai, Pune and Nashik, where 60 beneficiaries live.

In Mumbai, Usha made two home visits, one of them to see Mahesh, a 22-year-old beneficiary with severe factor VIII deficiency and HIV; he had received a contaminated transfusion in 2004. In 2009 he suffered a head bleed. Despite the Mumbai chapter’s and his family’s best efforts to get Mahesh proper treatment, he passed away in December. His younger brother Nilesh continues to be sponsored by Save One Life.

A Real Graduation Gift

Usha’s fourth trip was to Kolkata and Durgapur in the east. Kolkata has 21 beneficiaries; one of them is Avik Chakraborty, the son of a tea vendor who earns only \$30 a month. With Save One Life’s financial support over the past five years, Avik will realize his dream of becoming a doctor in 2010. Since he is looking forward to getting a good job, Avik told Usha that he will offer his sponsorship to another beneficiary once he graduates. Avik is not unique by offering this generous gift; throughout her travels, Usha met older beneficiaries who, due to improved circumstances with the help of sponsorship, have offered to pass their sponsorship on to other, more needy members of their hemophilia community. They always express gratitude to Save One Life and their sponsors for their indispensable role in improving life. This is the ultimate goal of Save One Life — not only to provide ongoing support to people with a bleeding disorder, but to contribute to their eventual ability to support themselves.

After Kolkata, Usha visited a relatively new partner, Durgapur, in its new care center. Usha arrived in Durgapur just in time to witness the third quarter distribution of sponsorship funds. Usha writes, “They were very happy to have me visit their new center, which is a dream come true for this chapter. All the members were present, and they arranged a small ceremony for the distribution of funds, which they invited chapter dignitaries to personally hand to each beneficiary. All the families expressed gratitude to their individual donors. The kids were visibly happy to receive their funds personally, treating it like a reward.” Throughout her travels to all partners, Usha observed that the largest percentage of sponsorship funds are spent on education, with treatments and the cost of transportation to clinics next in priority.

Usha’s visits and daily presence in overseeing the administration of our program in India has helped our partners feel more connected, and understand their responsibilities more fully. Usha adds, “This initiative of traveling to the partners was very well received and appreciated.” Usha’s visits have helped to continue to foster independence in the partners, who in turn help to empower and support each person with hemophilia— one at a time. 🇮🇳

name	
company or organization	
address	
city/state/zip/country	
daytime phone	email address
Do you have a child with hemophilia? <input type="radio"/> yes <input type="radio"/> no	
ages, factor deficiency, severity	

- I would like to sponsor a child with hemophilia.
- I would like to make a one-time contribution.
- I would like a subscription to *OneVoice*.

www.SaveOneLife.net



Credit for the photos in this issue, unless otherwise noted:
 Copyright © 2010 Save One Life, Inc. and its licensors.
 All rights reserved.



OneVoice

Save One Life, Inc.
 65 Central Street, Suite 204
 Georgetown, MA 01833 USA

RETURN SERVICE REQUESTED