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

OneVoice

A Lifeline in the Philippines

BY LAURIE KELLEY

Half way around the world, in a tropical country comprised of 7,100 islands, children with hemophilia cry at night from searing, throbbing pain in their joints, waiting for the dawn to come. Their mothers are exhausted, emotions raw. Daylight comes and goes, night returns, and pain rules for about ten days until the joint has swollen so much it shuts off the bleeding vessel. Eventually the blood gets reabsorbed and the pain goes away. But when a child feels tingling and heat again in his joint, he knows another ten days of agony are descending. This is life with hemophilia in the Philippines.

There are about 1,000 people registered with hemophilia, but in a country of 96 million, there should be thousands more identified. It's hard to find patients with such a puzzle-piece geography—transportation is

by car, boat, ferry and plane, all in one trip. But hemophilia patients are lucky: one man is on a mission to find them, to create a lifeline to those who could die without his help, and his mission brought Save One Life to the Philippines.

Converted to the Cause

Save One Life was irresistibly drawn to the Philippines as a partner country not only because there are so many in need, but also because of our unique partnership with Father Don Kill, a Columban priest who has lived for over 30 years in the Philippines. He runs a home for homeless or destitute teens, sheltering, educating and equipping them, and eventually graduating them to care for themselves.

Father Don was “converted” to the hemophilia cause about six years ago, when he came upon Dodong, a crippled teen living on the streets, begging for food. No one knew what caused his paralysis, and Father Don’s quest to know eventually brought him to the Philippine hemophilia treatment center in Manila. He learned about factor, treatment, joint bleeds, and hemophilia. He discovered Project SHARE, a factor donation program of LA Kelley Communications, and then learned about Save One Life. We enrolled the Philippines as a partner country in Save One Life, thanks to this meticulously organized advocate. Father Don eventually found more and more patients with hemophilia, and enrolled them, too, in Save One Life.

But with health issues of his own, and thinking ahead to a time when he would no longer be able to do this work, Father Don invited me to come to the Philippines, to see the problems, meet the patients, and transfer administration of Save One Life to a different nonprofit there. From October 11 to 23, 2008, I received every possible confirmation that Save One Life is vital, needed and is changing lives.



Above: The Philippines is made up of 7,100 islands.



Man on a mission: Father Don visiting a hemophilia patient.

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Welcome

BY JEANNINE CARDOZA

We welcome 2009 with the hope naturally associated with a new year. Looking back, 2008 was another great year for Save One Life. Our sponsorships increased and we partnered with Zimbabwe, a new country for our program. Our ability to thrive in this shaky economy is due to you, our dedicated supporters—our inspiration.

In this issue, “A Lifeline in the Philippines” takes you with Laurie as she travels throughout the Philippine islands, where she laid the groundwork for Save One Life to reach more individuals in need. Laurie’s detailed account of her visit evokes raw emotion and will move you to take action. Since Laurie’s return we have added over 50 individuals from the Philippines to our waiting list and will continue to add more as the year progresses. You can meet all of those awaiting sponsorship at our new and improved website: www.saveonelife.net, which is featured on page 4.

Our country update features the Zimbabwe Haemophilia Association’s recent annual general meeting, funded by Save One Life. Read how this struggling community is rising above the extreme challenges they face daily to provide care and hope. Sponsor Dorington Little, of Massachusetts, reports on his annual visit to two of his three beneficiaries in India.

You will meet little Pete Aparacio, of the Philippines, in Meet a Beneficiary, who is waiting for a sponsor. And meet Patrick M. Schmidt, on page 6, who is a sponsor, donor, and board member. His generosity abounds not only to Save One Life, but also to many organizations and individuals in need.

As always, we express our sincere gratitude to you—our sponsors and donors—who help us with our work, in all ways great and small. Although 2009 promises to be a challenge, we vow to meet it with optimism and hard work. Please help us by continuing to share *OneVoice* with co-workers, friends, and family. This small action can enable us to continue saving lives—one at a time! 🇺🇸



Save One Life's OneVoice
FEBRUARY 2009

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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.

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Save One Life is a registered 501(c)(3) organization.

Fascinating FACTS



wikipedia.org

Zimbabwe coat
of arms

At 80%, Zimbabwe’s unemployment rate is among the world’s highest. It has a negative population growth rate. Life expectancy is only 44 years. 90% of the population is literate.

Source: ciafactbook.gov

The Philippines has a life expectancy rate of 70 years, with a 2% population growth rate. 92% of the population is literate.

Source: ciafactbook.gov

There are 81 provinces and 136 cities in the 7,100 islands that comprise the Republic of the Philippines.

Source: encarta.msn.com



wikipedia.org

Philippine coat
of arms

Country Update

Zimbabwe: Hope in a Time of Cholera

BY SIMBARASHE MAZIVEYI
President, ZHA

On January 17, 2009, the Zimbabwe Haemophilia Association (ZHA) held an Annual General Meeting (AGM) for its members. The initial date for the meeting was December 13, 2008, but a cholera epidemic and the introduction of new currency denominations made it very difficult for the average person to attend, so the meeting was delayed a month.

In the meantime, efforts were made to encourage as many ZHA members as possible to attend. We had to notify them of the new meeting date so that they could change their plans. We decided to encourage at least one person from each of the major towns and cities to attend, by paying their transportation expenses to and from the meeting. We intended to have a truly national representation in attendance. Since the postal system is not very dependable and letters are often delayed or simply do not arrive at all, many telephone calls had to be made. While I was working on that, Mrs. Doreen Machona, a committee member and mother of a child with hemophilia, was making arrangements for the catering. She suggested that since we had people coming from out of town, it would be nice if they could get a meal before they depart. It was also cost effective to prepare the food ourselves. Besides the benefit of reduced cost, that meal could well be the first decent meal some of the people would have had in a long time. We came up with an organizing committee comprising of Doreen, five volunteers and me. Doreen came up with what kind of food to get, in what quantities, the cutlery, dishes, and the decor of the meeting room.

Two days before the date set for the meeting, the Governor of the Reserve Bank announced the introduction of 10, 20, and 50 trillion dollar notes in addition to 10, 20 and 50 billion dollar notes introduced only a month earlier.

One US dollar had been equal to 18,683 Zimbabwe dollars prior to the introduction. When the new currency took effect, one US dollar became equal to 10 billion Zimbabwe dollars. The introduction of the new currency immediately caused a rise in the cost of goods and services. A loaf of bread that was 300 billion (\$160 USD) went up to 1.5 trillion overnight. The sudden shift in prices stopped some people from attending the meeting, as transportation costs tripled overnight.

The meeting itself was held in a relaxed atmosphere. The main focus of the meeting was to plan how the ZHA and people with hemophilia can survive in the face of ever-increasing challenges being faced in the country. We decided to set up sub-committees with people heading them to look into fundraising, factor provision, and education and awareness. Zimbabweans are seeing so many problems in their daily lives that some have lost the belief that their efforts for ZHA can make a difference. Involving them in seemingly small events and activities will, we hope, raise the self-belief and confidence to such a level that hemophilia is not perceived as yet another burden on people who already have a lot to deal with. A young man with hemophilia, Kellie-Porter Mabhena, from Bulawayo, was co-opted into the committee as well as Mrs. Rhoda Holland, a mother of a factor IX deficient son, Ryan, from Harare, together with Limao Chiundo, also from Harare, who has a cousin and four nephews with hemophilia.

Save One Life was also formally introduced to the members and plans were made to enroll more individuals. After the meeting, people went to the canteen where lunch was available. It was after lunch and a lot of small talk that people dispersed.

This meeting allowed people to brainstorm and interact. It is surprising how



[L to R] Save One Life beneficiary, Fynn Machona, and ZHA President, Simba Maziveyi, enjoying lunch at the recent ZHA meeting.

people in different cities can face the same problems while thinking they are the only ones in such situations. I believe this meeting brought those who managed to attend closer to each other and the association itself, regardless of the prevailing environment where it may be easier to just quit or lose ourselves in the daily fight for survival.

Save One Life supported all costs for the AGM through a web-based fundraiser in December. Save One Life congratulates the ZHA for persevering in such difficult times.

A Sponsor's Annual Visit



Dori Little and Brijesh Bhatia

Dorington Little, a sponsor from Massachusetts, recently returned from his annual visit to his beneficiaries in India. It was his sixth visit to see Brijesh Bhatia, and his third trip to see Munna Rai.

He reports: "Over the years Brijesh's life has definitely seen improvements in both living conditions and in his overall health. His mother, Dimple, is very proactive regarding his care and has a supportive family with lots of love.

"Munna's plight is significantly more desperate. He lives a fair distance from the clinic, and while his

continued on next page

Dori Little



[L to R] Yashwant, holding Shantanu, Munna and Chanchal Rai, of Delhi, India.

family is very loving and increasingly attuned to his needs (as well as now to his baby brother's needs) their living conditions are harsher and economically they are often in tough shape. Therefore they are most grateful for the help they receive from Save One Life. It truly makes a huge difference in their quality of life, not to mention their sense of confidence and well being. Munna's mother, Chanchal, is very sweet and determined to assist her children to the best of her ability. All in all, it is a joy to visit these families, to deepen our ongoing rapport through the years. It is an honor and blessing, in fact, to see them with such regularity and to bring them a little encouragement."

Editor's note: Munna's baby brother, Shantanu, has recently been enrolled in Save One Life.

Donation to a Save One Life Family

Sandeep Pandey



[L to R] Mr. O.P. Pandey, Secretary, Mr. Shantil Lal Jain-Patron, chapter member, Mr. Ram Maheshwari-Patron, Vinkoo Singh, Ravindra Singh and Vikash Singh.

The Varanasi Chapter of the Hemophilia Federation (India) organized a winter hemophilia camp on November 6-9, 2008. The five Singh brothers, who are registered with Save One Life, attended. The chapter provided the Singh family with a refrigerator so that they will be able to have ice available to treat acute bleeding. 🇮🇳

Reported by Sandeep Kr. Pandey, Hemophilia Society Varanasi Chapter

Events

Save One Life Launches New Website



Save One Life launched a beautiful new website in December. It's now easier to locate children to sponsor, learn about what's new, and help us fund raise. Ujjwal Bhattarai, founding board member and talented web developer, and his team at MountPort.com invested weeks of donated time implementing the new design, which was based on a design generously donated by Brett Mentuck at MyCoff Advertising and Design in 2007.

Ujjwal explains, "Besides the beautiful and user-friendly front-end design, and very light-weight coding, the website also comes with an extensive custom-built CMS system that allows the administrators to update contents, publish newsletters, manage beneficiaries, and track stats on visitors." An early contribution of this new website was raising more than \$2,700 within two days for expenses for a beneficiary's upcoming surgery. Ujjwal adds, "While the new site for Save One Life is modern with a user-friendly look and feel, at the same time it also loads easily in browsers, is search engine friendly and meets the requirements of the management to be able to manage site contents, news, pictures, and beneficiaries through its custom built CMS system. It is a web application that will help our core mission by making our operation more efficient."

Visitors to the site can read about our origins, vision and mission, and archived newsletters and annual reports. They can also read about the countries we work in, meet our board of directors, watch short videos or view our photo gallery. Most importantly, they can meet the children, young adults and disabled adults on our waiting list, in need of sponsorship. 🇮🇳

Please visit the new site and then write to us. All comments and suggestions are welcome and encouraged. Write: contact@saveonelifeinc.org.

Inspiring Those with von Willebrand Disease

BY PRIYANKA RAWAT

I was age 17 when a hematologist diagnosed me with von Willebrand Disease (VWD), a chronic disorder in which the blood doesn't clot properly. There are different types of proteins, or "factors," in our blood that help in clotting whenever there is an injury to the blood vessel. Von Willebrand factor (VWF) is a blood protein that acts like glue to make platelets stick to the areas of blood vessel that are damaged. A lack of it, or a nonfunctioning form of it, causes VWD.

I was shocked and astonished to know that I was suffering from a chronic bleeding disorder. I was told that it cannot be cured but fortunately could be managed effectively. It all started when I had my first period. I used to bleed for days, longer than normal. My menstrual cycles were irregular and bleeding was profuse. I consulted a gynecologist, who recommended several medicines that did nothing. I was extremely frustrated and used to cry at night. I thought that nothing good had been stored in my fortune by God. My life became miserable. For years I suffered in silence without knowing that I had a chronic blood disorder.

Then one day the gynecologist advised me to get a blood test. The test indicated that the bleeding time (the normal time limit within which the blood should clot) was higher than normal and at last I was referred to the All India Institute of Medical Science, in Delhi. There I met Dr. Pravas Mishra, Assistant Professor, Department of Hematology, and he recommended further blood tests that would determine the problem. The blood report came after a long time and I was praying that everything would be fine. But it was opposite of what I expected. I was diagnosed with VWD. I was taken aback, and remained disturbed for many days and then became depressed. I thought that my life has come to an end.

I started considering myself incapable of doing anything. I was aware that the disorder is incurable, but how could it be

managed effectively? Dr. Mishra decided to start infusions of factor VIII concentrate that contains VWF whenever I had any bleeding episode. Currently I receive infusions monthly, and live a normal life. My condition has become better just because of the infusion of factor.

Unfortunately, it becomes very difficult for patients like me to get factor because it is not easily and widely available in India. There are various nonprofit hemophilia societies, which are functioning very well in different cities like Delhi, Calcutta, and Chennai. Patients who are suffering with a chronic bleeding disease can easily get in touch with the officials of the hemophilia society regarding the availability of factor. Patients can also become members of the society and receive benefits. These societies help the patients get factor when they are in need of it at the lowest possible cost. Still, factor is extremely costly and it becomes very difficult for the patients to purchase it. There are many unfortunate patients who live below the poverty line and cannot purchase factor for themselves. They suffer a lot.

My disorder doesn't hinder my growth; rather, it inspires me to work for the betterment of those individuals who are sharing the same pain as me. I used to think that I couldn't do anything great in my life but with time I transmuted my perspective and learned to manage my disorder and conquer my fear. I agree that it is not easy to live with a chronic disorder, but each and every individual who is suffering from any chronic disorder can make sincere efforts to manage the condition. The disorder should not be an obstacle to self-development. Take the disorder as a challenge, and try to live to the fullest, no matter what.

I am sharing my personal experience with you to inspire you—even if you are suffering from a chronic disorder you can also chase the dreams of your heart. My grandmother died because of a cardiac attack when I was in primary school. Since then I nurtured in my

heart the dream of becoming a doctor. This became a passion as well as an obsession. The television program "Grey's Anatomy," which is based on the medical profession, also inspired me. I worked hard for two years to secure good marks in my high school exams. After that I took the medical entrance exams and got selected. I was extremely happy and elated and felt as if I was in seventh heaven.

I was diagnosed with VWD in 2005 and knew that it would definitely interfere with my dream, but then also I took the risk and moved ahead like a brave warrior in the warfront to transmute my dream into a reality. I pursued the medical program for 183 days, packed my bags and returned back to my home. Why? I lived in a hostel and whenever I got a bleed there was no one I could call to get infused with factor. I was all alone. When I returned my father was taken aback, because he had high expectations for me. He wanted me to achieve what I always dreamed of achieving. My father, an emotional person, was not able to accept the reality. He felt defeated and I felt guilty for letting my father down. I felt that my disorder devastated my dream of becoming a doctor.

But I did not let my dreams die. I am now pursuing my masters in clinical psychology and satisfied to a great extent. I don't regret that I have a chronic disorder, but when I look back, my eyes get filled with tears. At the same time I thank the Creator, whose grace allows me to lead a wonderful and beautiful life. I didn't compromise my disorder in any way, but learned the art of managing it and not letting it control my life. You can, too. Harriet Beecher Stowe once wrote, "When you get into a tight place and everything goes against you, till it seems as though you could not hold on a minute longer, never give up then, for that is just the place and time that the tide will turn." ❧

Meet Our Board

Patrick Schmidt



Board member, sponsor, and donor Mr. Patrick M. Schmidt


Patrick M. Schmidt is the founder and chief executive officer of FFF Enterprises, the nation's largest distributor of flu vaccines, plasma products and critical-care biopharmaceuticals. Now in its 21st year, FFF continues to set the industry standard for patient safety, access and availability to the critical-care products that improve the quality of life for the patients it serves.

Patrick is a recognized leader in the healthcare community, and introduced many solutions to challenges faced by both healthcare providers and their patients. These include: FFF's MyFluVaccine program, which revolutionized the flu vaccine marketplace by bringing certainty in supply and delivery; FFF's new vaccine program, VaxAmerica, a network of convenient care sites that provide preventive vaccinations; Verified Electronic Pedigree™ (VEP) system, which electronically displays the chain of custody for every product; and the LotTrack™ service, which tracks products by lot number and provides recall notification to those affected. FFF's best practices to ensure supply chain integrity are called The 8 Critical Steps to Guaranteed Channel Integrity™.

FFF's specialty pharmacy subsidiary, NuFACTOR, was formed to provide IVIG, coagulation factors and vaccines directly to patients and healthcare consumers.

Patrick is motivated by the ability to have a direct impact on the quality of life of a patient. He is a nationally recognized expert on supply chain integrity. He is a regular commentator on the biopharmaceutical industry and a frequent speaker at government, industry and community conferences. In addition to supporting Save One Life, Patrick's company supports the Eric Dostie Memorial Scholarship, I Give For Kids, the Jeffrey Modell Foundation, the National Hemophilia Foundation and its local chapters, the Neuropathy Action Foundation, The Alliance for Plasma Therapies, The Myositis Association and The Neuropathy Association.

Patrick puts his faith and trust in God first in his life. He has a 19-year-old daughter who attends the University of California, Irvine. Patrick has been inspired by the work of Laurie Kelley for over a decade and is proud to serve on the board with so many distinguished colleagues to help extend hemophilia care throughout the world.

Patrick joined the Save One Life board of directors in 2006 and can be reached at patrick@SaveOneLifeinc.org. 


Thank You

The following contributed to program support:

FFF Enterprises, Inc, California:	\$ 10,000
LA Kelley Communications,	
Massachusetts (<i>last Q 08</i>):	5,000
Recoly NV, Netherlands Antilles (<i>last Q 08</i>):	2,500
Vladimir Ostapowicz, California:	500
Orjan Bjermert, Sweden:	250
Barbara Melanson, Massachusetts:	100
Brian Spahn, Massachusetts:	65
Nicole Nichols, Massachusetts:	50
Patricia Berman, New York:	25
Christina Hummel, Illinois:	25
Regina Ofiara, Illinois:	25
Christian Gierszewski, Austria:	20
Dorothea Zanetti, Massachusetts:	20

The following people contributed to our fundraiser for beneficiary Elton Sare of Zimbabwe, who will be coming to Chicago for knee surgery:

Beverley Zabriskie, New York:	\$500
Kevin Kelley, Massachusetts:	300
Patrick Schmidt, California:	270
Mark Howard, Shetland Islands, Scotland:	260
Greg Williams, Massachusetts:	200
Dave Landry, Massachusetts:	200
Brian Tinger, Massachusetts:	150
Mark Baker, Massachusetts:	100
Ellen Guthrie, Massachusetts:	100
Jim Ellard, Massachusetts:	100
Ann Baker, Massachusetts:	100
Gloria Healy/Michael Morse, Massachusetts:	100
Richard Grandoli, Massachusetts:	100
Ann Flynn, Massachusetts:	50
Joann Matheson, New Hampshire:	50
Jean Bastable, Massachusetts:	50
Nicki Cinelli, Massachusetts:	25
Rebecca Robbins, Arkansas:	25
Elizabeth Karyn Gabrielli, Massachusetts:	25
Kshitiz Chaudhary, Massachusetts:	25
Bill Goss, Massachusetts:	20

Thank you 



Pete Aparicio
of the Philippines

Meet... Pete

Pete is an eight-year-old from the Philippines, who has severe factor VIII deficiency. He suffers with frequent bleeding episodes and visited the clinic four times in the last year for treatment. Pete hit his head on an iron gate when he was one. The injury resulted in a hematoma that caused brain damage and left him developmentally delayed. He also has problems with one of his ankles.

Pete attends a special class for developmentally delayed children, where his favorite subject is art. He has a limited ability to speak the local language, Cebuano Visayan. His mother is able to read and write English.

Pete has a four-year-old brother, Antoninus, who does not have a bleeding disorder. Pete's father left the family and is not financially responsible for them. His mother, Nadine, is a tutor, earning about \$105 US a month. Nadine and her children live with her father in his simple urban home.

Pete likes to watch cartoons on television in his spare time. His favorite cartoon is the Power Rangers. He says he would like to be Superman when he grows up! 🇵🇭

Letters

We received a beautiful note from our beneficiary from the Philippines and wanted to share it in *OneVoice*. We are happy to be able to help this child and appreciate receiving this beautiful card.
Joe Cardoza and Renée Dupuis, Massachusetts

Congratulations to Save One Life and Laurie Kelley for the Breakthrough Spirit Award [from the Children's Cancer and Blood Foundation, October 28, 2008]. Her pledge [to continue to work for impoverished children] is a big motivation for all of us. *OneVoice* is always eagerly awaited. Wishing you all the best.
Vijay Kaul, India

Thank you for the latest issue of *OneVoice* that covered news from different hemophilia societies. The Nepal Hemophilia Society (NHS) highly appreciates your hard work to provide support to people with hemophilia. NHS is also a beneficiary organization of Save One Life and is trying its best to reach new patients and is committed to extend hemophilia care service to different parts of the country. I would like to thank you and editorial team for covering news and photos of NHS as well. We are looking forward to your cooperation in the days to come.
Dilli Adbikari, Nepal Hemophilia Society

I must express on behalf of our hemophilia society in Vijayawada thanks. We are grateful for your blessings. Kristine's volunteer work with our chapter (see *OneVoice*, November 2008) was possible with the help of Ms. Usha Parthasaratha. Congratulations and best wishes for Save One Life and especially to Laurie for her dedication to poor hemophilic children all over the world.
Dr. Maganti Prasad, India

The November issue was beautiful. I savored each word over the holidays.
Cheryl Nineff Dambrosio, Washington

Thank you for sending us *OneVoice*. I thoroughly enjoy reading it and look forward to receiving it. I have been encouraging my eight-year-old son Robert to read it also, so he understands that we live in a very insulated country here in the US. I pray that he will grow up knowing that he has been extremely blessed to be born in this country. I also want Robert to learn to give cheerfully and sacrificially and to make a mighty impact in someone's life. Thank you for all you do.
Vicky Lan, California





Untreated bleeds can lead to skin ulcerations.

Our “Missionary” Team

On October 13, less than eight hours after arriving in Manila, the capital, and following 30 hours in transit, I met our team for the trip: Father Don; Rose Noyes, an American Save One Life volunteer; and Andrea Trinidad-Echavez, a Filipino woman with von Willebrand Disease. Rose is a Renaissance woman—engineer, pilot, talented artist, and mother of three adult children. Her father was born in the Philippines, and this was her first trip here. Andrea is also a mother of three, as well as a journalist and media expert. Andrea arranged for us to meet newspaper reporters throughout our trip, leading to four articles covering hemophilia and our trip published in national newspapers. It was a dream team.

Meeting the Patients

On this first day, Monday, a small gathering of patients and families

spoke with us at the Columban House conference room. Some of them were enrolled with Save One Life, and our goal was to listen to their stories, complete applications for new enrollments, and learn how we could partner. We met Elmer, who had a leg amputated, and Angelo Cuevas, who had a large psuedotumor removed from his hip last year with factor provided by Project SHARE. A father and mother told us about their twelve-year-old son Paolo, who had a bleed on his spinal column the month before, which left him paralyzed from the neck down; he is now starting to move his feet again. Never complaining about their lot in life, these people seemed grateful that we were there, that we cared enough to help, and that there may be hope.

Rose took particular interest in Manny, a rail thin young man who traveled three hours to meet us and who had an elbow bleed. Both knees and elbows have contractures. When Rose heard he was an artist, like her, she confided, “I want to sponsor him.” That was just the kind of connection we had hoped for in inviting volunteers to come with us on a trip. Manny was hers! I gave Manny a vial of factor for his elbow. So much suffering, so much deformity in just this small group. We got the sense that we would not see many good things on this trip, if the patients in Manila, a major metropolitan city, were so badly affected.

In the afternoon we traveled to a nearby church, to meet the

Hemophilia Association of the Philippines for Love and Service (HAPLOS), the national hemophilia nonprofit. In a country that is predominantly Roman Catholic, churches abound and Scripture is written on billboards and even on the “jeepneys,” the often brightly colored Hummer-type cars that serve as hired buses. Meetings often open with prayers, and blessings from God are profuse when people say good-bye.

Ideally, we would like HAPLOS to be our partner for Save One Life, and this was a topic on our agenda. HAPLOS presented their board members one by one, and then a slide show of their history, while families trickled in and got seated.

A lot of families had come, and eventually we turned our attention to them, listened to their many stories, and could see for ourselves the physical deformities and bleeding. One foot was black and split with ulcers from the swelling; the patient had to travel for four hours by bus to go home, and I had no factor to give him. He shrugged and smiled. He is used to this way of life. Constant pain. One handsome boy was missing an eye, and an older man needed dental surgery to remove teeth—could we help? A child was in ICU, unconscious from a head bleed, and his mother cried in my arms.

As the sun set we concluded the meeting, promising to reimburse all the expenses to families for coming to



New beneficiary: Yancy Dorato, with Father Don, Laurie Kelley, and Rose Noyes.



With “Jun Jun,” who wants to be a photographer someday.

our meeting, and then set off to visit one last patient for the day. Manila is a bustling metropolis of 12 million, crowded with cars and motorbikes, taxis and jeepneys. We shouldered our way through the traffic to find Yancy, a young man with hemophilia now in college. We crossed a busy street, and then descended into a crowded, dirt alley. Yancy and his family live in a two room, concrete dwelling. They have a kitchen and a living room, which fits only a small TV, a bench and a plastic chair. The living room converts to a bedroom in the evening, as they sleep on the hard bench used for sitting. This is upscale for them; they used to be squatters, living in tents under power lines. Yancy will be one of our first formal enrollees on the trip.

That evening, we journeyed to the lovely home of "Tito" (Uncle) Rey Sarmiento, who is chair of HAPLOS, for a wonderful reception. The board of HAPLOS and some hematologists were present. We sampled Philippine food while the karaoke machine was brought out. Karaoke is available seemingly everywhere, and I soon learned that Filipinos love to sing along. Marietta, a mother of a son with hemophilia, volunteered the HAPLOS theme song, "If We Hold On Together," and one stanza seemed appropriate for our meeting and trip: "When we are out there in the dark; We'll dream about the sun; In the dark we'll feel the light; Warm our hearts, everyone..."

No Privacy or Luxuries

On our last day in Manila we criss-crossed the city, visiting patients who will be enrolled as beneficiaries. First on our list was 16-year-old Cid Juner, or "Jun Jun." Filipinos are fond of nicknames, and we met people named Duk Duk, Baby, and Jojo. Jun Jun lives on the second floor of a commercial building. His mother Mel owns a photography studio, which is really only two small rooms. The living room, about 12x12, serves as studio by day, bedroom by night. There is no privacy, no luxuries, and no space. The apartment complex smelled like fish, from the fish market downstairs. The family brought out delicate sweets in

honor of our visit, as we heard how Jun Jun attends school and wants to be a photographer some day, like his mother. As I struggled to take a decent picture, Mel smiled, took control of my camera, and snapped a nice photo of her family with us.

Next stop was Randolph Apanay, who has hemophilia and an active elbow bleed. At first glance, we thought Randolph lived in a lovely house, but then we realized he and his wife Melody only get to call the attached shed, or storage room, home. It is essentially one small room, with a loft. Their two tall sons sleep up in the loft, and the couple sleeps on a cracked vinyl bench seat, which doubles as a sofa. In the small kitchen area, a propane tank sits under the sink, like a dud bomb. Randolph and Melody were high school sweethearts, and are proud of their sons. Randolph is anxious to join Save One Life, which will help pay for expenses. We leafed through the family photo album, enjoying photos of them as teens, and photos of the boys as babies.

By 6 pm, we returned to the Columban House for dinner and to meet Jeff Rodriguez, a slightly built, quiet 24 year old with hemophilia. Jeff told a tragic story, with his eyes empty of hope: all four of his brothers with hemophilia died. His mother accompanied him, and with tears in her eyes, asked us to help save her remaining son. Jeff needs money for college, where he is studying psychology. He wants to be a counselor for all the young men with hemophilia, who he feels have been traumatized from bleeds, from being stigmatized by society, and from suffering so much pain. The school won't release his grades until the tuition is paid, and he cannot sign up for next semester with out his grades. He has no more money for tuition. How much? \$300, he said. I told him we would get the money the next day.

Later that night in the privacy of my room, I tried to journal, feeling bone

tired and jet lagged, and wondered what it would be like to bury four sons.

Best Foot Forward

The Philippines was discovered in 1521 by Ferdinand Magellan, on his quest to find the Spice Islands, during his circumnavigation of the earth. He landed in Cebu, now the Philippines'



Randolf's kitchen, inside his small home.



The team with Randolph, who has suffered psuedotumors.

second largest city, on the island of Cebu, where we landed Wednesday. Following a quick morning flight, Father Don, Rose, Andrea and I traveled in the humid sunshine to the Perpetual Succor Hospital, to meet the Hemophilia Association of the Philippines in Cebu (HAP-C), the independent organization, not yet affiliated with HAPLOS. The first thing we saw was a baby, Christian, whose head was wrapped with blood soaked bandages. His mother was breast-feeding the naked baby in the crowded hallway. Christian's head had been bleeding for a week, despite



Traditional greeting given to Save One Life founder Laurie Kelley, at Dumaguete.

receiving cryoprecipitate. The mother was visibly weary. I pulled out the one vial of factor I had and the nurses grabbed it and immediately infused. I spoke with the mother, and learned of her financial and social struggles. We decided to enroll Christian, and for the first time in days, the mother smiled. We learned the next day that Christian was discharged, his bleeding stopped.

Twice the number of patients greeted us at this meeting, eagerly awaiting our visit. Father Don addressed the group, stressing what parents can do to treat when their child has a bleed: RICE—rest, ice, compression and elevation of the joint. Two teens with hemophilia gave rousing speeches about being empowered and accomplishing goals. Wonderful to hear from young people! Several parents spoke as well, sharing their personal stories of hardship.

There is a desire, not just in the Philippines, but also in many countries,

to put one's best foot forward, to show visitors an assembly, speeches, banners, and singing. But what we really want most is to know the problems, and get to work to fix them. Unfortunately, with so many speeches, we had no time to speak individually with patients and families. Enrollment into Save One Life, so needed here, will have to wait till after we return home for these families.

“Give thanks with a grateful heart”

On Saturday Rose flew back to the States, and we would really miss her as a traveling companion. The Filipinos were delighted to meet her too, as they share a heritage. After a two and a half hour ride down coastal roads, where we caught glimpses of the sea and beach, Father Don, Andrea, our driver Honorato and I boarded a ferry for the 30-minute ride to the island of Negros.

The further south we went, the more beautiful the Philippines became. Created from ancient volcanic activity, the country is lush and fertile. Palm trees explode upward into a display of huge, leafy fireworks. The weather is sultry and heavy, and the sun scorching.

We arrived at a fishing town bustling with activity under startling blue skies, and then drove straight away for another 30-minute ride to the city of Dumaguete, where we would meet

staff from Little Children of the Philippines (LCP), the organization that will become our new partner for Save One Life. LCP is a nonprofit specializing in educating children in all aspects: scholastic, hygiene, livelihood and faith. Many of the staff are themselves graduates, and they are remarkably organized and efficient, yet compassionate.

When we arrived, we walked to a small pavilion, where the families and children with hemophilia waited. Unlike Manila and Cebu, these children were already enrolled in Save One Life. It was a thrill and privilege to meet them and monitor how they are doing. It's one thing to see a child's face and profile on paper. But to meet them in person? Priceless beyond words. Here before me were Allan, Ryan, Joseph, his brother Joshua, Carymar and Reymark. They greeted me with the traditional hello: each child took my hand and touched it to his forehead. The children honored us by singing, and even Father Don knocked off an Elvis song. The parents also sang a gorgeous song together called "Give Thanks," with spiritual themes. Three mothers then each took the mic, and in tears, thanked Save One Life and their individual sponsors for helping their children. Their cries were gut wrenching, and gave only an inkling into the level of the pain they see in their children. I suggested to the kids that they make thank you notes to their sponsors, which they readily did.



The Dumaguete beneficiaries, at the Little Children of the Philippines.



Baby Christian gets a needed infusion in Cebu.



Reymar suffers a shoulder bleed.

In the midst of this, one 15-year-old boy, Reymar, was not well. He kept his head down by his feet, his shoulder dropped. He was having a severe bleed in his right shoulder. He needed factor. We had none. So here was a Third World crisis right in front of us: what to do? He had a major bleed, needed factor, but had to settle for cryo or FFP. Then we find that there is no cryo. FFP costs \$30 a bag, and he might need ten bags. His mother sat in despair sobbing while her son writhed and moaned. It's not just a matter of going to the hospital to get treatment. She didn't have the \$300. We made a decision then and there to use his roughly \$300 in Save One Life sponsorship money to pay for whatever treatment he would get. Andrea knelt down with the family, held their hands and with powerful calm, said a prayer with them for his recovery and for strength for the family to endure.

When they left, we all felt a bit disconcerted. This was the future of these other kids staring them in the face. When they get hurt, what will happen to them? They can see how they cause their mothers so much pain, too. Finally we headed out, and LCP agreed to take on all the sponsorship responsibilities in the Dumaguete area as our new partner. In that regard the trip accomplished its goal.

We returned to our comfortable hotel a bit amazed at the day. Sobering. It must have worn us out more than we thought: I slept ten straight hours, the first time I was actually able to sleep since coming

here a week ago. I felt guilty when I awoke: my first thought was how many Filipino mothers that night had no sleep because their children cried in pain from untreated bleeds?

From Homes to Cemeteries

Our hotel, the Coco Grande, was lovely. Only \$20 a night, with a clean room, air conditioning, clean bath, and great food. One of the teens from Dumaguete, Joseph, stayed with us, to help Father Don get around. He's a beneficiary, and I enjoyed getting to know him. His funding is used to keep him in school, where he excels.

We visited patients in the humid air. The ride was brief, as the patients live close by. First, the home of Reynold Bilandal, a two year old with factor VIII deficiency. A chubby, well cared for child, he lives in poverty materially, but in love richly. The house sits back a bit from a main road, and it's open and airy, with no screens to filter out mosquitoes. They own little: simple beds, a table, a cassette player for the treasured music Filipinos love, a pet parakeet. This is a family with many members who have hemophilia, including brothers, uncles, and many children who have already died. We took photos for Reynold's sponsor, updated personal information about the family and child, and the family expressed much gratitude.

Our next home was in Tanjay City, a small village, to see three patients who are enrolled in Save One Life: Carymar, Reymar and Jhon. We walked through the village, garnering stares from the villagers, and soon left



Rice paddies of Negros.



Carymar's cellar.



Andrea interviewing Jhon and grandmother.

a wake of whispering children behind us. We saw a man getting a shave in the open air, chickens and roosters scuttling about, laundry being hung to dry and water being pumped from a well. The ground was thick with mud so we stayed close to the stones that formed a walkway. I noticed deeply embedded coral in the ground, and wondered, was this once an ocean floor?



Too many gone:
the cemetery search.

First we came to Jhon's house, with its bamboo walls, thatched roof, and mud floor entrance. Jhon is doing fairly well, and is being raised by his grandmother, a spry elder woman. As we spoke with Jhon, the crowd swelled; some were family members, and others were neighbors. Jhon attends school, and uses Save One Life funds to get medical treatment.

Down the dirt walkway is his cousin Carymar. Several family members live in his house. They have the basics—beds, kitchen, a TV—but they are so poor. Today was Carymar's 19th birthday. We sang happy birthday to him as we interviewed his family. They are all



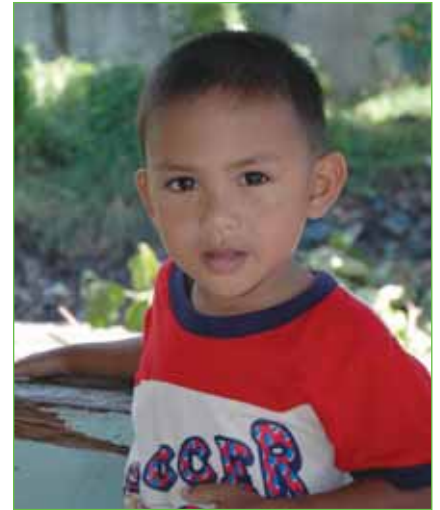
Laurie with Reymark.

deeply appreciative of the help from Save One Life and as we viewed their poverty, we knew how much the money meant to them. After the visits, we decided to go to the local cemetery, to locate the graves of Jeffrey's four brothers. Jeff's ambition to be a psychologist comes from the pain he experienced losing four of his brothers to hemophilia. He himself rarely is able to afford to travel all the way to Dumaguete to see the graves. We promised him we'd find them and then email the photos.

Easier said than done. We entered the cemetery gates and hacked our way through the dense undergrowth which covered the untended graves. The sky was a vivid blue in the pulsing heat. The graves are above ground mostly, a la New Orleans, and stacked, creating a labyrinth of graves and tombs that are not registered in any fashion. We had to walk for over an hour in the heat to find them. We read names on the stones: *Torres, Ramirez, Hernández*. Three young boys followed us, and soon we paid them to start clearing away the undergrowth to read the graves. Finally, we located one. We called Jeffrey via cell, who was really touched at our persistence. We paused a moment in prayer, to acknowledge the suffering these graves represent: hemophilia boys and men who will never complete their lives, who died only from lack of affordable treatment. As we left, we had one humorous moment when we spied three goats, tied up in the broiling sun to three graves, left for the day to nibble away the grass. Third World lawnmowers!

A Day of Travel, Back in Time

By the time Monday rolled around it was just Father Don and I. Andrea had to return to work and her family, and Joseph had to return to school. Now we were headed to the island of Mindanao, to where Father Don lives. We headed out by Ocean Jet, a two and a half hour ride, and then by car, a three and a half hour ride, to Ozamiz City. We were deep into Philippine countryside now, and I was constantly



Karl Tan.

stared at. Not many westerners make it here. The scenery was gorgeous, with rice fields carpeting the landscape, fringed by towering mountains. Clouds roiled up like white cotton dolphins leaping out of the liquid blue. Water buffaloes plodded in rich mud, their hoofs sucking with each step as they ploughed.

Ozamiz City is humble, as is Father Don's home for teens. The home spilled over with eager children who missed their "Lolo," or "grandfather." I saw in front of me another charity equally worthy, making remarkable changes in children's lives, and am pleased we are partners with such an organization, and such a man.



The Tan family.

Kent: My Little Boy

I awoke on Tuesday, day ten of my trip, with my eyes half closed. I looked into the mirror in disbelief—27 bug bites on my face. Apparently I had accidentally left the screen door open all night in the bathroom, and the mosquitoes had a midnight buffet. Malaria and dengue fever are widespread here, but there were no lasting effects, except to my ego.

We journeyed off to Molave first, to see the Quinalayo family, who are already beneficiaries. They have a nice, clean home, flowering garden, pet dogs, and steady jobs. I wondered why they were in Save One Life. As I listened to their story, I realized that \$240 a year, while seemingly a fortune to many poorer families, still can't cover the cost of factor. A single vial of factor, 500 IUs, can cost up to \$100.

Then we drove to Pagadian, a rural community, some two and a half hours from Ozamiz City. This was the highlight of the trip for me as I got to see my beneficiary. Kent Tan is a darling boy, as cute as his photo. His young parents welcomed us into their modest home. I met his younger brother Karl, sponsored by my friend Kyle, who also has hemophilia. Karl was just getting over a leg bleed, with factor we had donated from Project SHARE. Both boys looked in great shape. The mother, Hydeeh, stays home with both boys, where she allows them some freedom, but also watches carefully over them. The father, Juderick, only earns \$100 a month, not enough to pay for medical treatment for two boys with hemophilia. The use their Save One Life money as a savings account, in case of medical emergency. Kyle and I give them \$40 a month combined, which is an additional 40% of their monthly income. You can see how well Save One Life helps. The parents are savvy about saving their funds. When I asked them what more I could do for them, they very humbly declined to ask for anything more, counting their blessings.

It was our final day of the trip; tomorrow I would leave. I felt it was truly Mission Accomplished. Father Don and I were both deeply pleased to see Save One Life make such a difference. Imagine, from a sponsor's home in America, half way across the world to the rural outposts in a far away island in the Pacific, a family is enriched and has hope by a small donation. Father Don made the sign of the cross over me and said, "I now pronounce you a lay missionary." From one convert to another!

Lifeline to Many

We spent our final evening relaxing in the tropical heat. One of the young visiting missionaries broke out the beer and Sprite. We made popcorn and the ever-present geckos on the ceiling suddenly slithered down the walls, sprinted up to us and gobbled the popcorn. Lofty fan palms swayed and mist moistened the air.

I was up at 5:45 the next morning, and rocked in the chair on the veranda for a while before my flight home, enjoying the cool breeze, listening to exotic bird calls, surprised by how attached I had become to the Philippines. My final thoughts crystallized: Poverty is everywhere, but so is faith. Factor is crucial, but so is faith.

Families join voices to "Give Thanks" when they have buried their children, and are always at risk of losing another, in a place when suffering comes as sudden as the rain showers.

Hemophilia bleeds stalk each patient like a predator, waiting to pick off the unlucky. This is my 23rd developing country visited, and never have I seen such wide-scale devastation of untreated hemophilia: joint crippling, pseudotumors, intracranial bleeds, loss of life and amputations. The government doesn't buy factor, and the families cannot afford what little is commercially imported. The Philippines is in dire need of help—now. Save One Life is providing it, directly, immediately and perpetually, and while it's not enough, at least it's something, and it's a promise of continued help, annually, forever. It's a lifeline in a sea of suffering. 🙏🙏

To see a gallery of photos from the trip, visit www.kelleycom.com/gallery

Note: Jeff Rodriguez, Yancy Doroteo, Randolph Apanatby, and Cil Juner have been selected for sponsorship, along with five other individuals recently enrolled from the Philippines.



Faith trumps poverty in the Philippines.



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*.



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