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

OneVoice

The Remarkable Work of HFI Vijayawada

BY KRISTINE VANIJCHAROENKARN

When we think of global health, diseases like AIDS, malaria, diabetes and tuberculosis come to mind. But what about hemophilia? Affecting only 400,000 people worldwide, it hardly seems on scale with diseases such as AIDS, which affects 33.2 million. Because of its rarity, hemophilia has struggled to obtain from medical and public health organizations the level of awareness, support, and funding available to other disorders. The complications of the disorder, like any other health problem, are exacerbated in countries with fewer resources and a developing infrastructure. Even in the US, coverage for hemophilia is extremely costly and unaffordable for some families. Yet somehow, in a clinic in rural Mangalagiri, a town of 100,000 nestled on the coast of Southern India, Dr. Maganti Prasad offers medical service for those with hemophilia 24 hours a day, seven days a week. And factor concentrate, the medicine that stops bleeding, is free.

Dr. Prasad opened his private orthopedic practice in Mangalagiri 30 years ago, using the first floor of his house. Each day he heads downstairs at 10 a.m., and patients are waiting in line to see him. Today, the first patient is an elderly woman with excessive scarring resulting from a skin graft; the second

is a woman suffering from flat foot. The third is a 60-year-old man complaining of pain in the right hip.

The fourth patient is Praneeth, age 11, who has hemophilia. He is bleeding in both the left knee joint and calf muscle. After checking him over, Dr. Prasad prescribes 319 international units (IUs) of “factor,” the injectable medicine used to treat hemophilia bleeds. He hands the factor over to his staff, who infuse Praneeth and send him on his way. Dr. Prasad sees his patients on a first-come, first-served basis, and makes no distinction between his hemophilia patients and orthopedic patients, with one exception. The “sufferers,” another name for those with hemophilia, do not pay for his services. For the majority of the clinic’s hemophilia patients, who cannot come close to affording the \$250 per dose price tag, this is the only way they can obtain medicine. Such provision of factor and service are made possible largely through a non-profit organization, the Hemophilia Federation (India) based in New Delhi, India.

A Mission is Born

In 1982, Ashok Verma, a man with hemophilia, journeyed from Delhi to Italy, for a leg amputation because affordable and proper healthcare was not available in India. Upon his return home, he began reaching out to unite hemophilia patients via local newspaper columns. Within a year, in 1983, HFI was founded. Today, HFI has 65 chapters spread across India, helping hemophilia patients afford the expensive medicine needed to help their blood to clot.

Dr. Prasad is a father whose child with hemophilia was born in late 1970s when there was limited knowledge and medicine available, especially in developing countries like India. Due to hemophilia’s rarity, most doctors studied common maladies, such as diabetes, hypertension, and infections in medical school. Most doctors did not have the

Dr. Maganti Prasad



Kristine (center), with several beneficiaries from Vijayawada.

Welcome

BY JEANNINE CARDOZA

I was honored to be among 275 guests who gathered together on October 11 to celebrate the nuptials of Mark Zatyryka, a Save One Life board member, and Sasha Fless. We were blessed with warm sunshine bathing the changing leaves. Mark and Sasha are long time supporters of Save One Life, one of many charities they support. These two young people are dedicating their lives to changing the world, and there is no doubt in my mind they will do it! Save One Life also changes lives with the support of hundreds of sponsors like Mark and Sasha.

In this fall issue of *OneVoice*, be ready to be inspired to help the poor in many ways. Our feature showcases the difference one doctor is making in the lives of those with hemophilia in India. Kristine Vanijcharoenkarn, a graduate student at Yale University, shares her experiences with our country partner in Vijayawada, and how the ravages of hemophilia can be treated with our help. In our Events column, meet sponsor Laura Baay of Texas, and learn her reason to run. Laura, like Save One Life founder Laurie Kelley, is the mother of a child with hemophilia. Motivated by their children's courage and experiences, there is no stopping either of them.

We also celebrate the first year anniversary of the Islamabad and Rawalpindi chapters (Pakistan) as country partners in Save One Life, and a breakthrough in Zimbabwe. And we celebrate our own award—Save One Life was honored at a gala fundraiser in New York City at the Plaza Hotel on October 28.

OneVoice does more than inform—it inspires. Take action. Share *OneVoice* with your friends, family, and co-workers. This action helps spread the news of our humanitarian work and can inspire others to help. As always we want to extend our thanks to you, our sponsors and donors who make our work possible. Please remember together, we are changing lives!

Source: ciafactbook.gov



Save One Life's OneVoice
NOVEMBER 2008

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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

The Philippines is a collection of islands located between southeastern Asia, the Philippine Sea, and the South China Sea, east of



Vietnam. It gained independence on July 4, 1946 after being occupied by the Japanese during World War II.

Source: ciafactbook.gov

Major industries in the Philippines include agriculture and services. It has a population of 96 million, with a GDP per capita of \$3,400.

Source: ciafactbook.gov

Filipino and English are the official languages in the Philippines, however eight other dialects are also spoken.

Source: ciafactbook.gov

Country Update:

Islamabad and Rawalpindi Celebrate Year One as a Partner Country

BY SAIF-UL-ISLAM

August 16, 2008 was a happy day for people with blood disorders, especially hemophilia and VWD, in Islamabad and Rawalpindi, Pakistan. About 150 patients and their relatives gathered at the Pakistan Institute of Medical Sciences Islamabad (PIMS), one of the biggest and well-equipped hospitals in the country, to celebrate their first year with Save One Life.

The program began with the recitation of some verses from the holy book of Quran by Mr. Mushtaq Ahmed, the vice president of the Rawalpindi Chapter of the Pakistan Hemophilia Patients Welfare Society (PHPWS). Next, Dr. Tahira Zafar, chairperson of PHPWS addressed the audience with a comprehensive detailed talk about hemophilia and von Willebrand disease. The chief guest was PIMS executive director Mr. Abdul Majeed Rajpoot. His address emphasized a need for help

and he extended his hospital's help to all bleeding disorder patients. He also thanked the PHPWS and Save One Life for their joint venture, which will go a long way in helping people with bleeding disorders. Next, Dr. Samina Taufail, president of the Rawalpindi Chapter, gave a report of the efforts and activities of both the Rawalpindi and Islamabad in minimizing the pain and sufferings of their patients. One Save One Life recipient, Miss Fauzia Perveen, told the audience that with the help of her Save One Life sponsorship, she would complete her education and earn her masters degree in education. She was very excited and thankful to the society, Save One Life, and her sponsor, for the great help she is receiving. In conclusion, Mr. Saif-ul-Islam, president of PHPWS (Federal chapter), Islamabad, read a message from Save One Life founder and president Laurie Kelley in Pakistan's national language Urdu, in which she expressed her deep love, and pledged to come visit, with more help for patients. She said that she has a special place in her heart for Pakistan and its people with bleeding disorders. At this point everybody stood and clapped for Laurie and Save One Life. Mr. Saif-ul-Islam informed all recipients, the terms, and conditions of their sponsorships and promised to meet with them monthly to watch their progress. At the end every one was entertained with refreshments.

Zimbabwe: Obstacle Overcome with Help from Save One Life

Laurie Kelley noticed a substantial hindrance to hemophilia care during her visit last December to Zimbabwe—the refrigerator used to



Saif-ul-Islam

Mr. Abdul Majeed Rajpoot, executive director, PIMS



Saif-ul-Islam

Saif-ul-Islam, President, Federal HPWS



ZHA

The Zimbabwe Haemophilia Association's new refrigerator, compliments of Jan Bult!

store donated factor at the office of the Zimbabwe Haemophilia Association, now a partner country, was broken. She immediately pledged to find funding to buy a new one. That pledge was fulfilled in September, when a new refrigerator arrived at the ZHA office. Funding for the refrigerator was generously donated by Mr. Jan Bult, president of the Plasma Protein and Therapeutic Association. Moved by a video about Zimbabwe shown by Laurie during the North American conference last June, Mr. Bult personally pledged on the spot. The ZHA and Save One Life thank Mr.

continued on next page

Saif-ul-Islam



Guests enjoying tea and samosas (stuffed pastry common to the Middle East)

Saif-ul-Islam



Samina Taufail, President, Rawalpindi chapter PHPWS

Bult for his generosity, and even more for his obvious compassion.

Palestine Site Visit



One million live in poverty in Palestine

Board member Chris Lamb visited Palestine on August 17, 2008 and met with brothers Jad and Amjad Jadallah of the Palestinian Society for Bleeding Disorders. The meeting was held in Ramallah. Both brothers have hemophilia A and moved to Palestine a few years ago from Michigan, USA. They are extremely dedicated to improving hemophilia care in the West Bank. Key issues facing the Society include: lack of qualified physicians with specialized training in bleeding disorders which leads to poor diagnosis; inadequate factor concentrate supplies (only 40% of what is needed is available); and no treatment facilities. A visit to a local hospital where people with bleeding disorders are treated on an emergency basis showed the clear need for a modern hemophilia treatment center. Amjad and Jad have plans to build such a center and a space in a medical building has already been donated. However \$75,000 is needed to fully equip the facility and efforts are being made to raise the funds. The Society is currently preparing to enroll in Save One Life. According to the United Nations Relief and Works Agency, approximately 46% of Palestinians do not have enough food to meet their needs. The number of people in deep poverty, defined as those living on less than 50 cents a day, nearly doubled in 2006 to over 1 million. 🇵🇸

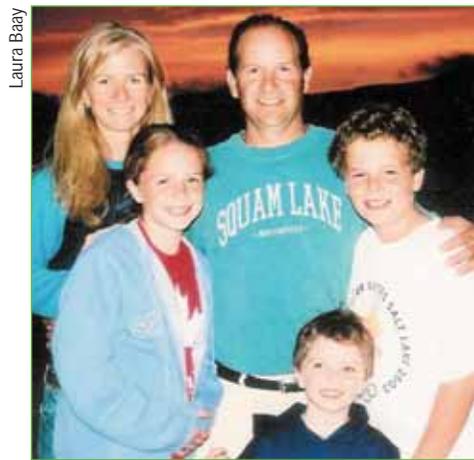
Running With Purpose: **Raising Funds for Zimbabwe**

BY LAURA BAAY

In July 2008, I contacted Save One Life after reading “This Is Africa” by Laureen Kelley [*OneVoice*, February 2008]. I was inspired by something my seven-year-old son Brooks said to me while we were reading the article. Brooks has hemophilia and understands very well the pain associated with knee bleeds. He saw a photo of a young man from Zimbabwe with a badly swollen knee and another photo of the same boy with a big smile on his face. Brooks then looked at me and asked, “How can he smile like that when his knee hurts so much like mine does sometimes? We should help him with his knee, Mommy.” It seemed so obvious to me at this moment that it is very true that everything that you ever need to know in life, you learn when you are in kindergarten....

I visited the Save One Life website, completed the forms and offered to have my family sponsor Elton, the young man in the photo. But, we were not alone. Elton had already been chosen for sponsorship. I asked Jeannine, executive director, if there were any other children about my son’s age in Africa who needed sponsorship: Brian Mugwenhi from Zimbabwe was enrolled. His story reminded me how similar we all really are in this great big world. Brian tells how his father Richard brings him to school each day on a bicycle, to keep his son from bleeding in his legs. My husband Peter, an avid cyclist, gently and lovingly cares for our Brooks this same way and has spent many a day with Brooks on the back of his bicycle, too.

It became clear to me what needed to happen next. I am a runner and was in the midst of training for the upcoming 2008 Chicago Marathon on October 12 under the instruction of my running coach and African genocide survivor, Gilbert Tuhabonye. I now realized that I could possibly use my marathon as a way to help those in Africa who are suffering with bleeding



(left to right) Laura, Peter, Maggie, Andy, and Brooks

disorders. My connection with running and hemophilia now appeared purposeful in my life.

I contacted Jeannine again, was granted permission to use Save One Life’s logo, and created a website (threetwenty.net) to facilitate a pledge drive for Brian and the Zimbabwe Haemophilia Association. I then showed up at the Chicago Marathon wearing a Save One Life charity shirt that I created that stated on my back, “A 3:20:00 finishing time doubles the \$3,850 of pledged donations already received for Brian/ZHA.”

However, even though many Chicago runners and fans encouraged me along my marathon journey that day, the unseasonably warm temperature left me a bit short of 3:20:00 and I hit the finishing mat in 3:23:15, a personal best for me. So, as I look back on the events leading up to October 12, the greatness of the day itself does not escape me even though my finishing time didn’t “double” the pledged donations for Brian. What I learned is the powerful affect that just one small idea can really have. This I believe is the premise under which Save One Life was built upon. Laureen Kelley had one idea a number of years ago and now Save One Life creates daily miracles all

over the world through generous and wonderful people everywhere.

Thank you to everyone at Save One Life, especially Jeannine, for encouraging and guiding me every step of the way on this journey. I will never again underestimate the power of one idea, one person, one community, one world... or one child's face in *OneVoice*.

Laura and her husband Peter live in Texas. They have three children: 15-year-old Maggie, 13-year-old Andy, and seven-year-old Brooks.

Save One Life congratulates Laura on her terrific finish time and thanks her for her work on our behalf!

It's Not All About Them: Board member Mark Zatyрка marries

Jeannine Cardoza



Introducing Mr. & Mrs. Mark Zatyрка!

On October 11, 2008, board member, Mark Zatyрка, and fiancée Sasha Fless were married. They celebrated their nuptials in a beautiful outdoor ceremony amidst the fall foliage. To promote Save One Life, Mark and Sasha placed the profile of their sponsored child, Mahesh Babu, from India, in honor of their wedding guests on each table. We wish Mark and Sasha lifelong happiness!

Save One Life Awarded

Laureen A. Kelley, president of LA Kelley Communications, Inc., of Georgetown, Massachusetts and founder of Save One Life, was recognized for her achievements in helping the world's poor with hemophilia by the Children's Cancer and Blood Foundation (CCBF) of New York at its ninth annual "Breakthrough Ball" gala

on October 28. Also honored with Laurie were rapper/music producer Swizz Beatz, actor Steve Guttenberg, and former MLB pitcher Al Leiter. The Breakthrough Ball was held at the newly renovated Plaza Hotel, and was attended by over 500 wealthy New Yorkers and patrons, who enjoyed dinner, the awards, and a surprise appearance by 1960s music icon Lou Christie, who sang his signature "Lightnin' Strikes." Actor Charles Grodin acted as master of ceremony for the evening, which included live entertainment by Sharon Jones & The Dap-Kings, a silent auction, and a live auction. Last year's honoree, NFL great Tiki Barber, helped present the Breakthrough Spirit Awards.

Laurie, the mother of a child with hemophilia, came to the attention of the CCBF when board member Tara Reddi learned that her cousin's son, who lives in India and who has hemophilia, was enrolled in Save One Life.

Grateful for the help, Tara and the CCBF board nominated Laurie for its prestigious Breakthrough Spirit award. Tara has now become a board member of Save One Life.

In her acceptance speech, Laurie said, "I accept this award, not for what I have done...but as a pledge for what I will do. I promise you on this evening... I will enter the second half of my life completely dedicated to Save One Life, which will become the voice of impoverished patients with hemophilia."

Laurie thanked attending gala patrons Bayer Corporation, Baxter BioScience, CSL Behring and Grifols, all manufacturers of blood clotting medicine. The CCBF gala raised over \$1.5 million for the foundation, which provides funding for research and treatment for children suffering from blood diseases. 🇺🇸



Laurie accepting award from CCBF president Ron Lervolino

Laurie Kelley



Left to right: Al Leiter, Laurie Kelley, Swizz Beatz, and Steve Guttenberg

Laurie Kelley



New Save One Life board member Dr. Donna DiMichele and awardee Laurie Kelley



Janis Cecil and Tara Reddi, with Laurie and Tara Kelley



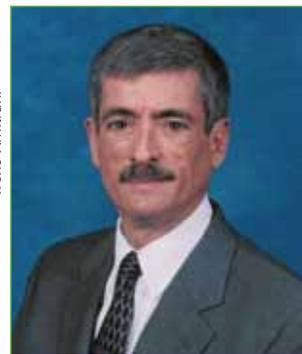
Laurie giving acceptance speech

We regret to announce that long time sponsor and person with hemophilia Paul Amitrani of New Jersey passed away on August 14, 2008. In response, Paul's beneficiary wrote the following eulogy for his sponsor and friend.

A Tribute to Paul Amitrani

BY TAMER HANNA

Irene Amitrani



Mr. Paul Amitrani

We are all mortal and death is unavoidable. Like sand spilling out of an hourglass, our life will end the day our Lord calls us to come home. Although most of us are certain of this, the death of someone we love leaves us sad and in pain. Our sadness increases when we discover how life without this beloved person turns empty. We realize that no one appreciates our full impact on life until we are gone. And that's probably the case with us all.

I felt this emptiness after hearing the shocking news of the death of Paul Amitrani. Paul was my friend and sponsor. I first knew him through Save One Life. I was suffering and isolated because of my difficult physical condition. I needed someone to share my thoughts and feelings with. Paul needed someone, too, to build a friendship with him, as he mentioned in his first e-mail. We were searching for each other till Save One Life brought us together more than a year ago. We were a perfect match.

After news of Paul's death, I collected all of his e-mails and read them again. I was lucky to have him as a friend. One of Paul's amazing characteristics was his optimism. He was always supporting and encouraging while I was complaining and nagging all the time about my difficult life with hemophilia. We shared the same chronic disorder but we did not share the same optimistic nature. He was always happy and upbeat during his fight with cancer. Many times I

thought he would win his battle and conquer this pernicious disease.

We shared the same suffering of not having enough treatment for our bleeds. He wrote to me many times about the early period in his life when there was no treatment for hemophilia. When he was young, up until he was age seven, he used some primitive methods to stop bleeding. He said he was thankful for this period in his life. He said, "Sometimes I feel it is a gift from God that he has permitted me to suffer many things to a slight degree so that I can understand and help those who have much greater sufferings." I assume this is why he understood every word I was saying to him about my suffering. He knew what I was talking about.

He was so caring and thoughtful. I discovered these characteristics of him after that journey in his last pieces of e-mail. He was not concentrating on his disease or his own pain, but he was concentrating on supporting me and quenching my anger. I believe not talking about his fight is the attribute of every fighter. He was not talking about his cancer because he might be sure of his winning.

He used to end his e-mails with talk about fishing. Fishing was his favorite hobby. I believe he liked the success of fishing bass. He was yearning for every new fishing season. Catching the biggest bass was his aim on every fishing trip. He kept describing how he was so happy and every one went crazy in his boat

when he caught a 4 lb large-mouth bass.

When I asked him to send me a photo of himself, he sent it: him, with his buddies, next to his boat while he was holding his 4 lb large-mouth bass. He wanted me to see his triumph with his success.

Paul believed in the power of prayer. He used to ask for the prayers of others and felt any progress in his fight with cancer was due to the prayers of all those who loved him. He told me once that faith was the strongest support for him in his life.

Paul Amitrani taught me a grand way to live. I had sad days after his death and then kind and happy thoughts about Paul and the patience and optimism with which he lived his life. Paul—you were a great person and a good friend. I will miss you and I will always miss reading your e-mails. You meant so much to me. 🇺🇸

Tamer Hanna lives in Egypt and has been a Save One Life beneficiary for three years. Paul's family will continue Paul's sponsorship of Tamer.

Tamer Hanna



Tamer Hanna

Fr. Donald Kil



Yancy Doroteo with his mother, Ronela

Meet... Yancy

Yancy Doroteo is an 18 year old with severe factor VIII deficiency who lives in Manila, the Philippines. He has approximately three bleeding episodes a month. He visited the clinic two times in the last year, requiring 20 infusions, when he suffered a serious stomach bleed.

Yancy is in his second year of college, where his favorite subjects are math and computer science. He tends to miss many classes due to his disorder. He speaks the local language, Tagalog, and can read English. His ability to write English is limited.

Yancy has a 20-year-old sister, Lou Raine, and

a 15-year-old sister, Sharleen. Lou Raine does not have a bleeding disorder, but Sharleen is experiencing bleeding symptoms and needs to be tested.

Unfortunately, the family cannot afford the expensive testing. Their father, Edelberto, is a driver, and their mother, Ronela, works in a laundry. Combined, they earn very little money. The family rents a simple two room urban apartment on a dark alley.

Yancy likes to play chess in his spare time. He would like to work as a medical technician and help others with hemophilia. 🇺🇸

Thank You

LA Kelley Communications, Massachusetts:	\$5,000 to operations
Texas Central Hemophilia Association:	\$1,000 to operations
Shellie Schmidt, Washington:	\$ 250 to operations
Marc Salit, Illinois:	\$ 100 to operations
Barbara Melanson, Massachusetts:	\$ 100 to operations
Dorothea A. Zanetti, Massachusetts:	\$ 20 to operations



Laurie Kelley accepts a donation from the Texas Central Hemophilia Association

Thank you

Mothers Making a Difference

Laurie Kelley was honored at the Texas Central Hemophilia Association on September 27 in Dallas, for her work with Save One Life, at a black-tie "Mothers Making a Difference" fundraiser and gala. Laurie presented a before and after slide show, to highlight the devastation of untreated bleeding, and the mobility, freedom and joy when a child receives treatment and education.

The Association presented Laurie with a \$1,000 check for Save One Life, and several new sponsors pledged to fund children. Save One Life thanks the Texas Central Hemophilia Association, especially president Shanna Garcia, for its recognition and support!

Letters

The Hemophilia of Iowa Chapter's First Steps Group recently sponsored Koshis Magar, a child with hemophilia from Nepal. The First Steps Group began three years ago as a support

group for families with children ages 0-8 years affected by a bleeding disorder. The group comes together several times each year for activities and education. They also host fundraisers

annually, which has enabled the group to sponsor Koshis and be able to send him care packages.

Koshis is a four-year-old boy with severe factor VIII deficiency, who

Karl Atkinson



Hemophilia of Iowa First Steps: Jill is in the third row in a pink shirt. Kari is in the fourth row, second from right.



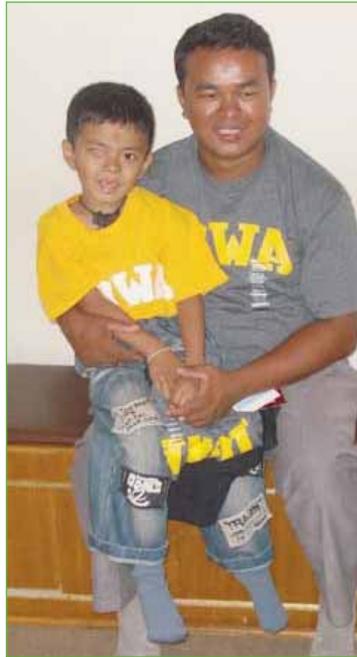
Koshis' father receives gift from Dilli Adhikari of the Nepal Hemophilia Society

lives in Nepal. First Steps learned of sponsorship opportunities through Save One Life, this past April, and immediately began a sponsorship. Beyond our annual support, First Steps' goal is to have frequent contact with Koshis and his family, through email and by sending small packages. First Steps has already sent crayons, a coloring book, and other fun stuff like Iowa t-shirts for each member of the family.

Koshis lives with his mother, father, and seven-year-old brother, Pranish. First Steps feels it is important to include his sibling when we send a package so there is always something for his brother. Hemophilia affects the whole family, not just the child with the bleeding disorder.

First Steps was thrilled to receive correspondence in return from Koshis, who recently began nursery school. His father included a copy of his report card and some drawings he made with the gift he received from the group. Especially enjoyed was the letter from his father thanking the group for sponsoring Koshis.

There are an estimated 2,300 with hemophilia in Nepal, but only 139 have been identified and registered. The Nepal Hemophilia Society makes every effort to help patients, however factor concentrates are expensive and beyond the reach of most patients. First Steps feels fortunate to have been connected with this family and to be able to make a difference in Koshis' life. It began the sponsorship to show the children of First Steps that life with hemophilia in developing countries is not as easy as it is for children in the United States.



Little Koshis and his dad wearing their Iowa T-shirts!

Everyone feels blessed to have Koshis and his family as part of our Iowa First Steps Family.

*Kari Atkinson and Jill Dirxx
Hemophilia of Iowa*

The August issue was fabulous! You did a wonderful job of editing the story and I can't believe you used all the photos we sent you. It is 1,000% incredible! A trillion thanks from the Club! Hopefully we'll inspire some other teens out there to start their very own Red Nose Club and help Save One Life!

Susan Phillips, Arizona

This looks awesome! Thank you so much; I cannot wait till Lucian [of Romania] sees it too. It really came together well and I hope it inspires people.

Andy Matthews, Texas

The newsletter looks fantastic. From just looking at the headlines and the pictures I can tell that you have captured some very compelling stories.

Debbie de la Riva, Texas

Thank you for the August issue. Very good to see the great job done by Red Nose Interact Club. And I really appreciate Andy Matthews. Well done!

Usba Parthasarathy, Chennai, India

It is so good to see the latest issue of *OneVoice*. I am happy to see the amount of effort you have put in. It comes out well.

Wilma Wilson, India

What a great issue. I really enjoy the personal stories. Thank you!

Angie Klersy, Minnesota

While the winter is approaching rapidly in Sweden and the days are short while the nights are long, cold and dark, a very nice ray of light was shed though, during the Arosenius Day meeting on October 10 in a city called Norrköping (not very far from Stockholm), when [Laurie Kelley's] name was mentioned with appreciation and admiration. The Swedish Haemophilia Association (FBIS) had invited Nepal representatives Aasif Khan and Manil Shrestha to talk about the situation there for persons with haemophilia. Save One Life was described, eliciting lots of good vibrations from the audience.

Christer Dybeck, Sweden

Christer Dybeck



Aasif Khan and Manil Shrestha visit Sweden and discuss Save One Life

More power to you and God bless you for all that you are doing for us, especially those with hemophilia in the Philippines.

*Gloria Cuevas, mother of Angelo,
a beneficiary, the Philippines*

knowledge to treat hemophilia, and many avoided treating it: they did not want to give a factor infusion because they feared the bleeding would not stop at the site of the infusion, though factor actually stops bleeding. Human plasma-derived factor was the only factor available until 1992, when recombinant, or genetically produced, factor concentrates became available to the developed countries. All factor in India must be imported.

With such difficulties, why does Dr. Prasad do so much to help? “Back then, there was no medicine, no knowledge. I saw how my son suffered,” he says, “I don’t want other kids to suffer the same way.” In response to this belief, Dr. Prasad founded in 1994 the hemophilia chapter in Mangalagiri, otherwise known as the Vijayawada Chapter. It is now one of the 65 chapters belonging to HFI.

Hemophilia Complications

Hemophilia occurs when one of the 13 proteins in the blood needed in the clotting cascade is missing. Without one of the proteins, called factors, the cascade cannot be completed and bleeding continues unchecked; injuries can become crippling and a gastrointestinal or head bleed deadly. According to the Hemophilia Federation (India), 80% of bleeds in hemophilia occur in the joints. Without factor and with repeated bleeds, the joints become permanently damaged. “Joint disabilities are a major problem,” says Roshan Jameer, office manager of the Vijayawada chapter and a factor VIII deficient patient. “Hemophilia is a rare problem, doctors don’t know what to do, and there is no proper treatment. Often patients come

to us too late [to treat] and later struggle with their disability.” He goes on to state that 30% - 40% of the chapter’s patients suffer from joint disabilities due to repeated bleeds. The disabilities make movement and further strengthening exercises even more difficult, predisposing the patient to even more bleeds.

With the bleeds comes excruciating pain. When Mr. Ramana, a factor IX deficient patient and a member of the central HFI’s executive committee was asked what the greatest challenge was for hemophilia, especially children, without hesitation he replied, “The pain.” And it’s true; you can see it etched on their faces. The only way to live pain-free is by preventing the bleeds before they start—a treatment regimen called prophylaxis. However, due to the scarcity of resources in India, the only solution is to stem the bleeds after they have already begun. With factor at least, the bleed and the pain last for a couple of days, instead of a couple of weeks.

Pain Compounded by Poverty and Price

Mangalagiri is a rural area, with 90% of the chapter’s patients well below the poverty line of a \$2,000 annual income. About 70% of the chapter’s patients earn an annual salary of a little over \$800. According to the clinic, the market price of factor in India costs around 18 rupees per unit, or about 42 cents. Praneeth has severe hemophilia, with less than 1% of factor VIII active in his blood. And 70% of the hemophilic patients at the Vijayawada chapter have severe hemophilia. With severe hemophilia, internal spontaneous bleeds can occur several times a month. To control a bleed, the patient’s factor level must be brought to a minimum of 30%. For a 40 kg. (88 lb.) person with factor VIII deficiency, a minimum of 600 units of factor must be used, translating into a market price of \$250 per dose. The more a person weighs, the more factor he/she must use. However, even 600 units is more than most at the Vijayawada chapter can afford for one

Dr. Maganti Prasad



The children enjoy a swim!

bleed, not to mention for the 20-30 bleeds that occur per year, such as in Praneeth’s case.

To make factors affordable, HFI does not buy factor from vendors at the market price. For the past 20 years, Baxter Healthcare, a factor manufacturer, has contracted to sell factor to HFI at the lowest prices in the world, about one third the market price, as part of its mission to help developing countries. Eliminating the middleman, Baxter sells HFI factor directly at 6.25 rupees (13 cents) per unit, and HFI sells this factor to its patients at 6.5 rs/unit. The 0.25 rs (0.005 cents) IU income, coupled with small donations from abroad, and interest from the chapter’s account in the bank, is used to fund the day-to-day workings of the chapter, including the \$70/month salary of the HFI office manager, an annual weekend camp for hemophilic children, and the chapter’s annual general meeting (AGM).¹

However, even the reduced factor price is impossible for most patients in Mangalagiri to pay. Only 10% of the patients at the Vijayawada chapter purchase their factor, with the other 90% receiving the factor mostly for free. Most of the free factor comes from donors abroad, usually parents of children with hemophilia themselves. This 90% of patients at the Vijayawada chapter pay however much they can, usually 300-400 rupees (about \$8) to help cover the transportation costs of the factor from the donors. “The integrity is there,” says Dr. Prasad of his patients. “This boy,” he says gesturing to a young man in for a check-up,

Dr. Maganti Prasad



Dr. Prasad addresses the AGM

¹ Vijayawada hosted its Annual General Meeting and Awareness program on November 11, 2008. About 250 persons with hemophilia and their families attended. The meeting stressed the need for everyone to lobby the government to provide anti-hemophilic factors.

Hemophilia results from a genetic mutation on the X-chromosome, and is passed down genetically, although one third of all hemophilia cases are the result of spontaneous mutation with no family history. Hemophilia affects mainly males due to the particular nature of its inheritance, and occurs in one in 5,000 male births. Hemophilia patients have little or no functioning factor VIII (Hemophilia A), or factor IX (Hemophilia B). About 80% – 85% of patients are afflicted with Hemophilia A, and about 15% - 20% with hemophilia B.

“When he first joined [the chapter] in 2001, he had cut his hands and could not stop the bleeding. We did not have a laboratory then, so I funded him 1,000 rupees to have his blood test [to make sure it was hemophilia]. His mom makes 40 rupees per day (\$1), [but] within a couple of months, she had paid it back.” The patient now works as a lab technician in a medical college, making \$50 - \$60 a month. “I don’t give him free factor anymore,” Dr. Prasad says grinning. “I tell him he has a responsibility to contribute to the chapter now that he can.”

Partnering with Save One Life

Another dimension of Vijayawada chapter’s success and commitment to helping its hemophilia patients is its partnerships. Vijayawada is a partner of Save One Life, a child sponsorship program that provides a child with a bleeding disorder \$240 per year. This money is given to the child’s

parents in four installments throughout the year. There are currently 16 chapters of HFI enrolled in the program, reaching 200 impoverished children.

In Vijayawada, sponsorship funds are used strictly for education, including school clothes, transportation costs, and books. The chapter keeps a close eye on the money use, requesting the parents deposit the money into a bank account, and asking the parents to bring in receipts of their purchases made with the money, as well as a bank slip noting the deposit. “Education is the only way for children with hemophilia to succeed,” notes Mr. Vasudeva Rao, office manager of HFI’s Hyderabad chapter. “We encourage them to become professionals, such as engineers, so that they can afford treatment.” Dr. Prasad agrees, citing the case of a young man, who is now finishing his MBA due to the chapter’s help. “Now I give him one to two vials to self-infuse at home before an exam,” he says, “and look what he can do in spite of his difficulties. Soon he will become an earning member of the community.” In the workplace, employees with hemophilia are usually terminated because they must incur lengthy and numerous absences during bleeding episodes when they have no factor. A knee bleed, for example, will last anywhere from ten days to a month without factor. During this time, the patient will suffer from intense pain and not be able to walk. With factor treatment and proper home care, the bleed will last for two to three days.

Overcoming Obstacles

Hemophilia in any part of the world is a challenge, but controlling hemophilia in rural India is even more so. Many patients travel over 60 miles one way to come to Mangalagiri for a check-up or a factor infusion. Srikanth, a young boy, regularly travels 300 kilometers round trip by himself to receive infusions, despite the pain of his joint bleeds. The roundtrip trip by public bus takes eight hours. The public transport infrastructure proves to be a

Dr. Maganti Prasad



Over 250 gather at the Annual General Meeting

further obstacle. Mr. Jameer travels one hour one way by bus every day to come to the chapter. Coming in late one rainy day he said, “Every bus was full. I had to wait for seven buses for a place to sit.”

Every year, the Vijayawada chapter registers about 30 new hemophilia patients, performing the diagnosis in their own lab started in 2003 with basic materials and methods. Late one evening a new patient came in due to continued bleeding, despite three blood transfusions, following a tonsil removal ten days before. He had never had a history of bleeding, or a family history of hemophilia. After the lab test, the boy was found to be factor VIII deficient. In addition, due to the rudimentary blood-screening techniques at many hospitals, there is a window period of six months before he will know whether or not he was infected with either hepatitis B or C from the transfusions. Many times, due to the emergency nature of bleeding, transfusions are given before the screening process is completed. The percentage of hepatitis-infected patients at the Vijayawada chapter is lower than the national average because when possible, vaccinations are given for free to hemophilia patients. Payment for these usually comes from Dr. Prasad’s own pocket. Of the Vijayawada chapter’s 477 current members, an astounding 300 have been vaccinated.

In addition to help from the HFI, there is some aid from the Indian government, but not much. Of the 75 million people in Andhra Pradesh, only an estimated 7,000 are affected

with hemophilia, according to Dr. Prasad. Therefore, there is little incentive for vote-seeking politicians to champion for the patients. Most hemophilia chapters feel that the only way the factor crisis will be solved is through more help from the government. Other countries, such as Switzerland, Sweden, and the Netherlands, buy or produce factor in bulk and supply it to their citizens. Following intense lobbying from HFI chapters ("The government doesn't listen," Mr. Jameer says, "but we lobby them every year.") the government is slowly beginning to pay attention. As of July 18, 2008, the state government of Andhra Pradesh, the location of five HFI chapters, has included hemophilia treatment under the Aarogyasri plan. This health care scheme aims to help

alleviate health care costs for those below the poverty line. The Aarogyasri scheme, however, only gives \$1,600 to hemophilia families to use for the entire family's medical expenses, so usually only a small amount of the fund can be put aside for hemophilia treatment. Nevertheless, some help is better than none. The effectiveness of the recent Aarogyasri plan still remains to be seen.

In the meantime, HFI chapters, such as the Vijayawada chapter continue to provide invaluable services to its patients, both to those who can afford treatment, and to those who cannot. Praneeth came back two days later with a gum bleed due to a loose tooth. Immediately, he was given two infusions, sent to Dr. Prasad's friend, a now-volunteer dentist for the clinic, and when he came back again in the

middle of that same night because he would not stop bleeding, there was somebody there to give him another dose of factor. None of the clinic staff or Dr. Prasad receive compensation from hemophilia families. Mr. Jameer sums the chapter up, saying, "Without Dr. Prasad and HFI, all 400 of us at this chapter would be gone." It is such dedication to service and true humanitarian spirit that make the HFI Vijayawada chapter a life-saving success story. 🇮🇳

Kristine Vanijcharoenkarn is a graduate student at Yale University in Connecticut. She worked in India this past August for a public health project and was able to observe Dr. Prasad and his staff for a week. She is interested in continuing to work with hemophilia patients when she completes her degree.

Meet Our Board



Sudha Chandrasekeran

Founding board member,
Sudha Chandrasekeran

Sudha is a founding member of Save One Life. She currently works with Skyscape.com Inc., in the purchasing and finance department. She holds a Bachelor of Science, a diploma in computer applications, and a cost accounting certificate from India.

Originally from India, Sudha worked with Hemophilia Federation (India) for ten years. She was a close friend with HFI founder, Ashok Verma, who had hemophilia. Motivated by Ashok, she worked with HFI and helped the organization grow from ten local chapters to 60, with 8,000 registered patients. As part of the HFI delegation, Sudha attended World Federation of Hemophilia congresses, where she met Laurie Kelley. She also has traveled all over India, to all of the chapters, visiting many individuals with hemophilia in their homes. She has seen first hand the problems and sufferings of those with hemophilia in India.

Sudha moved to Boston when she got married in 1999, and continued to volunteer with HFI. Fellow Massachusetts resident Laurie Kelley invited her to help with Save One Life. Sudha was immediately interested and became the first

executive director. Sudha eventually left the position of executive director but continued her work on the board of directors.

Sudha notes, "Living in developing countries is a challenge by itself. One can only imagine how it would be to live with a bleeding disorder, like hemophilia. Treatment is not available and families have limited resources. I had seen so many people suffer with hemophilia during my tenure with HFI. But I didn't realize how difficult it is to live with hemophilia, especially without medication to treat it or handicap access at home, until I saw my friend face a major bleed. When I was given the opportunity to be a part of Save One Life, I was really thrilled that in some small way I could make a difference in the lives of people with hemophilia who really need the support." 🇮🇳

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.
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