



August 2008
Volume 4 • Issue 3

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

OneVoice

Why I am so passionate about giving back to hemophilia worldwide..... **And why you should be too!**

BY ANDY MATTHEWS

At age 42, with all the problems that come with hemophilia, I still think having hemophilia was the greatest gift I was ever given. It's taught me that I cannot change the lot I was dealt, but I can choose how I live my life. And when I recently realized how the other half of the world lives with hemophilia—without medication, in poverty—it hit me one day; I want to help people in general to improve their outlook on hemophilia. And I want to encourage everyone to give back to those around the world who are not as fortunate.

My epiphany

It all started about seven years ago while I was on the Internet, participating in an online support group. One day a young man emailed the news group to request help finding factor, the medication used to clot blood. His name was Lucian, age 21, from Romania. When I contacted him directly, I learned he had no access to clotting factor. He could not

even get cryoprecipitate—the treatment I used for my first 18 years. I started an email friendship with him and it has spun into one of the deepest friendships I have, without us ever having met face to face.

While I was able to live an active life in the US, Lucian's life was a struggle. On prophylaxis, I worked out with weights, and participated in mountain biking. Lucian, without reliable access to treatment, does not participate in any physical activities for fear of bleeding. He had to quit school at age ten due to his frequent bleeding episodes. While resting in bed often, he taught himself to read, write and speak English by watching American television. Can you imagine going for days or weeks with a bad bleed, with its throbbing pain, with joints swelling like a balloon and not being able to treat it?

Then Lucian wrote in 2006 about changes in treatment protocol in Romania. Those with hemophilia would no longer be treated at an ambulatory center. All treatment, even for minor bleeding episodes, would require a two-week stay in the hospital. The challenges Lucian faces daily are mind boggling to me and yet my Romanian friend lives this way every day, just hoping he does not get another bleed. Thousands of others like him living in developing countries face the same daily challenges. I feel guilty knowing how Lucian lives, but I reconcile that by giving, in some way, to someone in a developing country who has a bleeding disorder who needs help. You could, too.

How blessed we are

Reading about Save One Life founder Laurie Kelley's hemophilia adventures in the poorest villages from Africa to India has

Lucian Uritescu



Lucian Uritescu with his painting

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Welcome

BY JEANNINE CARDOZA

Last December, Laurie Kelley, president and founder of Save One Life, visited Zimbabwe. Since then, Zimbabwe has become our ninth country partner! We've added six beneficiaries from Zimbabwe and continue to work closely with the Zimbabwe Haemophilia Association to help improve patient care in a country with a devastated economy. We are proud to note we are the only ones in the international hemophilia community helping Zimbabwe in any way.

Our feature article, "Why I am so passionate about giving back to hemophilia world wide," was written by sponsor Andy Matthews. Andy shares the story of a friendship that blossomed through the common bond of hemophilia. And Susan Phillips, mother of a child with hemophilia, shares the details of a successful fund raising event held by the Red Nose Interact Club of Scottsdale, Arizona. This amazing group of high school students raised enough money in one night to sponsor two beneficiaries from India for the next four years.

Our country update features Romania, where Camp Ray of Hope, a camp for children with hemophilia, was recently held. Six Save One Life children participated. Adriana Henderson, president of S.T.A.R. Children Relief, shares the details of camp, that includes how Bob Graham's Camp High Hopes of New York helped to provide joy to the Romanian campers.

Meet the Board features Mark Zatyarka, a dynamic board member who has dedicated his life to helping children with hemophilia. Finally, we would like to welcome two new members to our board of directors: Tara Reddi of New York, and Christopher Lamb, of Massachusetts.

As always, thank you for supporting our program. Please remember to share *OneVoice* with friends, co-workers, and family. Together we are helping to improve the lives of over 280 deserving individuals from nine developing countries! 🇷🇴



Source: ciafactbook.gov

Save One Life's OneVoice
AUGUST 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

wikipedia.org



Romania is located in south-east central Europe and has been part of the European Union since January 1, 2007.

Source: wikipedia.org

Major industries in Romania include services and agriculture. The population is 22 million and the GDP per capita is \$12,285.

Source: wikipedia.org

Soccer is the most popular sport in Romania with an average of over 5,400 fans in attendance for each professional match.

Source: wikipedia.org



Country Update:

Hemophilia Fun in the Mountains of Romania: Camp "Ray of Hope"

BY ADRIANA HENDERSON

For the past three years, S.T.A.R. Children Relief has organized a one-week camp for children with bleeding disorders in Romania. This year, from June 28 to July 4, we held the camp at a rented facility in central Romania at the foot of the Apuseni Mountains.

Attending were 40 children with a bleeding disorder: 39 boys with hemophilia and one girl with von Willebrand Disease, ages eight to 18, from all corners of Romania. Among the forty children were six Save One Life beneficiaries. S.T.A.R. Children Relief helps administer Save One Life in Romania. Save One Life funds have provided much needed financial support to these children's families. They have helped buy clothing, school supplies and vitamins.

The camp facility was modern, with spacious rooms and private bathrooms. The dining area overlooked a peaceful pond and the food was great! The clinic was in a separate room under the

direct control of the camp nurse and doctor. The factor was plentiful thanks to several generous donors. The medical staff conducted infusion classes outside the clinic on a patio overlooking the pool; the children learned to infuse using a latex arm. An English physiotherapist who specializes in hemophilia examined all the children to assess joint damage, and taught water exercises. A psychologist helped the children face certain fears and anxieties, such as nervousness about leaving home for the first time.

Each year we identify a camp theme: in 2006, we celebrated beach and water sports; in 2007, we adopted a Dracula theme; and this year, karate. My husband, Tom, a second degree black belt in Tae Kwon Do, did not want to focus on karate as a series of fighting methods and techniques or of combat sports and self defense. He wanted to showcase karate for its philosophy: self development, perseverance, fearlessness, virtue, personal conviction, and

leadership skills. Gichin Funakoshi, the father of modern karate, once said, "The ultimate aim of karate lies not in victory or defeat, but in the perfection of the character of its participants."

Once we established a camp theme, we created activities specifically designed for children with hemophilia that would incorporate karate activities and philosophy.

We did karate every day—easy arm and leg movements without body contact, followed by talks on the philosophy and meaning of the sport. Instead of karate belts, the children received colored stripes on their caps, so that by the end of the week, every child received a yellow, green, red and finally the much sought after black stripe.

Other activities included arts and crafts, swimming, soccer, table tennis, billiard, basketball, tennis, boating and water fights. One day we held a birthday party for everyone born in the months of June and July. Ten children and adults, including myself, had to feed

S.T.A.R. Children Relief



Adriana Henderson [far left] with Ray of Hope campers.





Camper Vlad Pufu with his new friend, Bright Eyes!

each other ice cream while blindfolded. Most of the ice cream went on our face and clothes, a fun activity for those watching.

Another day we had a weird dress up day. It was so much fun to see everyone's imagination in using the few things they found in their suitcase and their room to create something funny and weird to wear. We paraded our garb through the village and drew the attention and laughter of many onlookers.

On another day we participated in Outward Bound, a program that uses a series of high rope courses to teach confidence, awareness, trust and leadership skills. The children tried the climbing wall and the parallel beams, two very challenging courses. Some children did not finish the course, but some did, to

their own surprise and delight.

The children overcame fear and anxiety and achieved something they never thought they could. Everyone was praised even if they could not finish the course. Every child's success was reason to celebrate, but there was one child in particular that commended more attention than the rest: the only girl in the group! As she tried the climbing wall, she lost footing and asked to be lowered. The boys did not let her and urged her to try again. She did and slowly climbed all the way to the top under a crescendo of the boy's cheers. The involvement of the whole team was the key to success. It strengthened the team's spirit and the feeling of accomplishment. Her accomplishment was everyone's accomplishment.

A Talent Show on the last evening of camp gave everyone the opportunity to participate and have fun: singing, dancing and clowning around. We even staged a mock karate fight.

This year the campers had a special treat. They received hand made bears with birth certificates, from the children at Camp High Hopes in New York. The bears were so adorable that the smaller campers went to bed with them. It was so cute to see the children hug and cuddle those precious bears.

This camp was a great success because of the generosity of many organizations and individuals. We thank everyone for their thoughtfulness and kindness. 🇷🇴

Adriana Henderson is president of S.T.A.R. Children Relief and founder of Camp Ray of Hope, Romania.



Adopted bear slumber party

Meet... Lucian



Lucian Uritescu

Lucian Uritescu is a 28-year-old with severe factor VIII deficiency who lives in Romania. He has approximately six bleeding episodes a month. He visited the clinic about 25 times in the last year, requiring almost 60 infusions. He has mobility problems with his right knee and elbow, and left shoulder.

Lucian's education is incomplete; he only attended school until fifth grade. Unfortunately, he could not continue school due to his disorder. But Lucian is very intelligent; while he speaks his native Romanian, he also taught himself to read,

write, and speak English. His favorite subject is physics

Lucian is an only child. His father, Mircea, is an electrician, and earns only \$500 US a month—not much for Romania. His mother, Camelia, does not work outside of the home. The family shares two rooms in a crowded five-family urban home.

Lucian has an interest in information technology and would like to become a software engineer someday. He is an artist, and creates beautiful paintings in his spare time. He is currently unemployed. 🇷🇴

Luau for Vinkoo: A Success Story

Susan Phillips

BY SUSAN PHILLIPS



Red Nose Interact Club members from Left to right; Erica Jacobs, Sara Webber, Steven Kreschollek, Aynsley Hawkins, Mark Phillips, Marisa Guillford and Emily Warchot.

It began with a five-foot inflatable monkey and a desire to help.

“We want to make a difference in the life of a child with hemophilia,” the Red Nose Interact Club members said one day. Mark Phillips, President and Founder of the Red Nose Interact Club replied, “I have an idea. There’s a non-profit organization called Save One Life. Their mission is to help children with bleeding disorders that live in developing countries. Why don’t we hold a fundraiser to raise enough money to sponsor a child for a year?” With that, a new mission was launched.

The Red Nose Interact Club of Saguaro High School of Scottsdale, Arizona, is a school club run by 12 students and sponsored by the Scottsdale Sunrise Rotary Club. It’s dedicated to helping children with special needs, locally and internationally. The club is active with monthly events and projects.

Mark, currently a junior, began the club his freshman year. No stranger to the medical world, Mark has a younger brother, Eric, who has severe hemophilia B, in addition to several other life-threatening illnesses. Watching his little brother endure horrendous emergencies and procedures, Mark has experienced first hand the difficulties of living with a catastrophic illness. As a freshman, Mark wanted to help children with special needs. He realized he and his friends could make a difference in the lives of these special children. The Red Nose Interact Club was born.

The name comes from the 1998 movie “Patch Adams,” starring Robin Williams. The movie is based on the true story of the founder and director of the Gesundheit Institute, a holistic medical community that has provided free medical care to thousands of patients since 1971. Dr. “Patch” Adams often wore a red clown nose to boost the spir-

its of his hospitalized pediatric patients. Like Adams, Red Nose members put on red clown noses during their projects to cheer up children.

In preparation for the fundraiser for Save One Life, the teens realized they needed to select a child to sponsor. They went to the Save One Life website and printed ten photos and biographies of children needing sponsorship. Then the debating began. After 30 minutes, the teens had narrowed the list down to five of the most critical children. However, the teens were overwhelmed. They knew each child needed help, but realized they could help only one. How does one choose? Finally, in exasperation, the teens simply flipped the papers over so as not to see the faces of the children. A random number was selected and that paper was chosen. Vinkoo was the one! Vinkoo is a 17 year-old boy from India who has severe factor VIII deficiency. The teens were glad that as teenagers themselves, they would be helping another teen in a country far away.

Raising the money needed to sponsor Vinkoo would be the fun part. The teens booked a local restaurant where a fundraiser could be held. One member had a five-foot inflatable monkey and suggested a luau theme. From that moment on, every club meeting involved leis, inflatable beach balls, lobsters, and tiki masks, all in preparation for the big night.

The club members told their friends about the fundraiser, flyers were distributed around the area and in the restaurant itself, phone calls were made and e-mails sent, all in an effort to make people aware of how they could help support the club’s efforts.

The day of the event, the teens went directly from school to the restaurant.

En route, the members blew up the inflatable beach balls, seahorses, and shells, opened 140 little cocktail parasols, and separated 50 tangled leis.

Once at the restaurant, the members immediately began turning the place into a luau! Mark stood on a ladder and suspended fishing nets from the ceiling. One of the girls wove lobsters, crabs, colorful fish, and leis into the nets. The seahorses, beach balls, and puffy fish were hung in the windows, the bathrooms, over the tables, the booths and even on the walls. The five-foot inflatable monkey dangled from the ceiling. On each dining table were little Hawaiian bags with photos of Save One Life children. Little parasols were strewn in front of these bags for tips. A \$5 table was set up with assorted Hawaiian trinkets. If someone donated at least \$5 into the tiki pitcher, they could pick anything off the \$5 table to keep. There were tiki masks, coconut monkeys, Hawaiian serving trays, kids lobster grabber toys, sandal notepads, and beach balls.

The teens all wore flowered leis, bright beach hats, straw hats or pirate hats...and of course, red noses!

A poster was displayed showing the Red Nose Interact Club and the other service projects completed during the school year. Another poster highlighted a photo of Vinkoo, his family and Save One Life. Flyers and newsletters of Save One Life were passed out. A giant thermometer drawn on poster board showed a goal of \$240, one year of sponsorship, and a little fish to move up gradually as the money came in.

The restaurant manager trained the teens on how to bus tables, and bring food and appropriate silverware to the customers. Luckily the manager was wonderful and permitted the club to turn the entire restaurant into a luau!

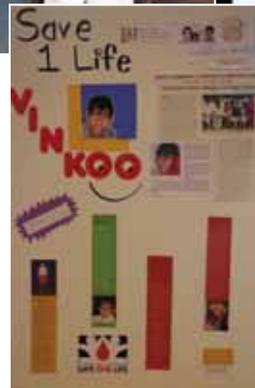
At 5:00 p.m., the cash registers flipped to “Red Nose” time. From 5:00 p.m. to 8:00 p.m., all purchases (dinner, beverages, pastries) were totaled. The restaurant gave the club 15% of all its total revenue for those hours. The more people brought in to eat during those hours that night, the more the restaurant made, and the thermometer rose. Additionally, the club was allowed to keep any tips placed in the tip bags and any donations in the tiki pitcher went directly to Save One Life.

Almost immediately at 5 p.m., friends and families of the Red Nose Interact Club started arriving. It was like one big party! Any customers who walked in the door, friends or strangers, were approached by the teens. Everyone knew about Save One Life by the time they had placed their order at the counter! There were so many people coming in, the manager kept running out of silverware, and the poor cooks were frazzled! The lines went out the door for almost two hours straight. The teens were frantically running around, delivering food to tables, wrapping silverware, and clearing tables. Mark, in a pirate hat, greeted everyone at the door and handed out little plastic fish to each child to welcome them to the event. As each person went a few more steps, they saw the Save One Life poster and were then met by another club member, wearing a huge straw hat. She explained what the fundraiser was about and showed them Vinkoo’s picture. She told them how \$5 would help Vinkoo and his family. Nearly everyone gave at least \$5 and frequently more. Anyone who donated was asked to sign a big birthday card for Vinkoo, whose birthday is in August.

The whole evening was a huge suc-



The club members saw to every detail.



cess. Everyone who attended felt good about helping a child with hemophilia. Many individuals had never even heard of hemophilia so we were able to educate them about the severity of the disease. Numerous people took Save One Life literature home with them to share with other family members.

The night finally ended and the teens scurried around, cleaning up all of the Hawaiian decorations. The manager tabulated the totals and the teens counted the donations. The manager told us our club had been, by far, the most successful fundraiser he had ever seen at the restaurant! We were very proud of our club. However, the final totals would not be revealed until the next day. Other private donations had come in the mail from people who were unable to attend the event but still wanted to help.

The next day at the Red Nose Interact Club meeting, Mark delivered news that brought smiles to the members’ faces and cheers to their lips. The club had raised \$1,900! This was enough to not only sponsor Vinkoo, but the club would be able to sponsor a second child! The total far surpassed the

goal of \$240. This meant the club would be able to sponsor two teens for four years each! The stunned silence was quickly broken by high fives, hugs and a few tears.

Now, however, came the agonizing job of choosing one more deserving child out of so many. Mark lightened the load a little when he shared with them that two individuals at the Luau for Vinkoo had each decided to adopt a child of their own! The club members roared their approval.

But, they had to get back to the serious business of selecting a second child. After much soul searching, the club chose a 16-year-old girl, Anjum, also from India, who has Von Willebrand Disease. Mark said what tugged at the members’ heartstrings the most was when they read Anjum’s dream: to have a family. The teens realized they could help Anjum’s dream come true. What a powerful realization! Twelve American teenagers would make a difference in the lives of two teenagers in India. Teens helping teens across the world! A true testament to the statement, “Caring for people with hemophilia around the world, one at a time.”

By the time you read this newsletter, four children’s lives will be changed forever and four families will believe in miracles. 🇺🇸

helped me see how blessed we are to live in the US. Hemophilia is not that bad when you have access to factor and proper treatment.

But in the developing world, it's another story. For example, I remember one night when I got a phone call from Lucian. He told me that he had just gotten mugged and had been hit in the head. He asked what he should do. It felt strange for him to be calling me. In the US, we would call our doctor or treatment center, or go to the emergency room. Lucian doesn't have those kinds of options. He asked me if he should take some of the donated factor he had on hand. I told him yes. I was not trying to play doctor but I knew his alternatives were not good. I recommended he take a larger dose than normal and to keep a close eye on his condition. I stressed he should go to the hospital if his condition got worse. He called me the next night from a pay phone at the hospital. He said he did indeed have a head bleed. Lucian was lucky; the hospital had some plasma on this occasion and he would recover. It is these kinds of events that really make me see how life is for many people with a bleeding disorder, like Lucian, in developing countries.

Role reversal

It's strange: Lucian usually ends up motivating me, because despite all he has to deal with, he still has a positive outlook on life. Lucian is an artist. Last Christmas he sent me a unique gift: a painting of an old man. I love helping Lucian, and expect nothing in return,

but when I got that painting and saw all the things he sent my son, Keeton, and me it was the best Christmas gift I got last year!

Lucian hasn't had a formal education. He wasn't able to attend school regularly due to his bleeding episodes. He is now unemployed, and lives in a small apartment with his parents and grandmother. There is little privacy. And they own very little. Days and even weeks sometimes pass before I get an email reply back from him. His Internet access for years had been through Internet cafes, which are costly. With little money, it's a problem for Lucian. Can you just imagine life without easy access to your computer? Most of us are addicted to being online; it's an easily taken for granted way of life. When it is your only access to the outside world, and it is limited, it must be frustrating.

To help defray costs, we recently began using Skype, a free telephone service provided over the Internet. We are even able to use a video link. Talk about an unreal experience, to see him and his family in a live video! I even performed a song on my harmonica, and watched their faces in surprise as I played!

To whom much is given

I have tried to live my life according to the Bible quote "To whom much is given, much is required." I cannot tell you how it feels when I get emails from my friend thanking me for helping him; to receive his Christmas gift was wonderful. My friends who do not have hemophilia would never be able to experience that kind of appreciation.

Andy Matthews



Andy stays fit with physical activities

If you get involved with Save One Life, it too will change your life. I truly believe if my parents had been able to read Save One Life's *OneVoice* to me when I was a young child, it would have given me a different way to view hemophilia. Rather than feeling sorry for myself and struggling with poor self-esteem, I could have learned how others live around the world. I could better appreciate what I had. Perhaps I would have started back then helping other kids, but it's never too late to start helping now. 🇺🇸

Editor's note: Thanks to Andy, Save One Life will enroll Lucian in the sponsorship program. (see page four) If you'd like to sponsor a child with hemophilia in the developing world, contact us today! There are children waiting for a sponsor like you.

Andy Matthews has severe factor VIII deficiency and lives in Texas with his wife Patti and son Keeton. Andy is active in the local hemophilia chapter of the National Hemophilia Foundation.

He has spent the last 17 years working in the home health care industry. He currently works as a consultant for the pharmaceutical industry, speaking out on the subject of insurance, to make patients aware of the changes that will affect their healthcare.

Andy is active, and serious about fitness. He believes that staying in good physical shape has played a key role in avoiding many complications faced with a bleeding disorder.

Andy Matthews



"To whom much is given, much is required."
Andy Matthews, wife Patti and son Keeton

Meet Our Board

Mark Zatyorka



Mark Zatyorka

Mark Zatyorka is a manager of client relations at American Homecare Federation, Inc. (AHF), a homecare company that serves individuals with bleeding disorders. He also has severe hemophilia A, AIDS, hepatitis C and severe arthritis.

Mark holds a BA in Communications from Quinnipiac University. Mark has worked for MTV Films, MTV Home Video,

VH1 On-Air Promotions, and started his own production company. Since 1990, Mark has traveled the country as an HIV/AIDS and hemophilia advocate and educator. Mark has shared his personal story to over one hundred high schools, colleges, businesses and youth groups, and has been featured on NPR, the Disney Channel, MTV, CBS, and local television and radio stations and has been published in several magazines and books.

In April 2006, Mark went on a month long, cross-country bus tour, speaking to schools and colleges about HIV/AIDS. En route, Mark met Sasha Fles, who had just returned from working in an orphanage in Africa for a year. What Mark once thought impossible, happened. They fell in love. Since then, they have dedicated their lives to helping people with chronic illnesses such as hemophilia, HIV/AIDS, and cancer, as well as volunteering for children in foster care, and at camps for children with chronic disorders, on a local, regional, national and international level. Mark and Sasha will be married in Connecticut in October.

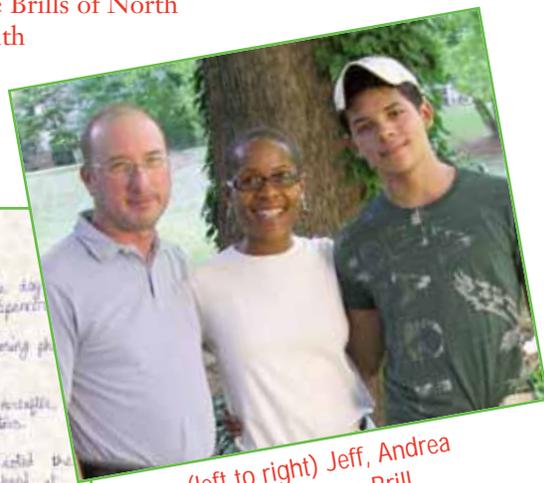
Like many people, Mark took having his health care and hemophilia medication for granted. But after learning that 80% of the world's hemophilia population has inadequate or no access to medicine, Mark knew he needed to be a part of something to change that. Save One Life was a perfect fit. He believes no one deserves to suffer through this extremely debilitating and painful disorder without medication, friendship, and support. Mark Zatyorka has been on the board of directors of Save One Life since 2007. 🇺🇸

Letters

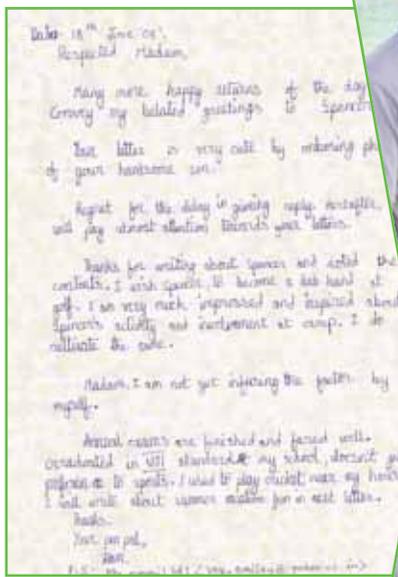
I greatly thank you for the blessings I have received from you. May God keep blessing you a lot for the help you've given to my children, Eliezer and Ezequiel, and to me. Thank you from the bottom of my heart. May God keep blessing you. The money you gave is used to purchase food and some things that they do not have, like school supplies. Thank you very much.

Eliza Valdez, the Dominican Republic.

Save One Life gives sponsors the chance to get to know families with hemophilia from other cultures, and to support them financially. For example, the Brills of North Carolina, who have a son with hemophilia, recently received a friendly letter from their beneficiary Ram of India.



(left to right) Jeff, Andrea and Spencer Brill



Original letter to sponsor



Ram and his parents, India

Thank You

FFF Enterprises of California:
\$10,000 to operations.

LA Kelley Communications
of Massachusetts: **\$5,000 to operations.**

BioRx of North Carolina:
\$2,500 to operations.

thank you 🇺🇸

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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OneVoice

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