

# OneVoice

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

#### www.saveonelife.net

May 2017

#### Greetings!

People with hemophilia often face limits in life, more so when they live in developing countries. But one person has shown to the extreme what is possible with proper treatment.

As our community anxiously watched his climb via Facebook, sending good wishes and prayers, Save One Life board member and Colorado resident Chris Bombardier overcame extreme fatigue, cold and even despair with the help of his expert guide and amazing sherpas to summit Mt. Everest on May 22. He captured the attention of the global bleeding disorders community and has helped to highlight the disparity in care between developed and developing countries.



Save One Life president Laurie Kelley and board member Chris Bombardier at Everest base camp, with the famous Khumbu icefall in the background.

I had only a glimpse of what he endured as I trekked with him for nine days to base camp, staying three days to experience life at high altitude as the climbers prepared for their challenge. It's not glamorous or easy. We all were sick at some point. But for Chris, it was worth it to show the world that people with hemophilia *can* reach their goal.

During his journey Chris challenged our community to sponsor children and raise funds for needy families of the Nepal Hemophilia Society. We are proud to have received 79 pledges for sponsorship and over \$13,000!

Join me in congratulating Chris on an extraordinary, superhuman achievement! This climbing season on Everest claimed ten lives, including a top Swiss mountaineer. We are grateful Chris stayed safe throughout his adventure.

### Welcome New Sponsors!

Shelby Barnhart-Guillory Stephanie Bauman Shannon Brunston Celia Cates Frin Cirelli Virginia Chandler Sarah Christman Comprehensive Health Education Services, LLC. Connecticut Hemophilia Society Laura and Bob Curtin Cameron and Crystal Dueck Alden and Brianna Dunlap Sarah Dwyer Jennifer Empson Angelie Garcia Cole and Christina Goddard Tracy Hallock Jessica Hen Lisa Hewitt Michael Holland Stormy Johnson Iona Kahu Judy Kauffman Jay and Bev Labe Miguel Lara Laura Lierman Bekkah Lyman Kathryn MacKay Tammy Marsh Nicholas McRae Cindy Mills Robin Monin Kelley O'Hara Amy Polo Gerald and Rebecca Reed Stephanie Rogers Kate Ruegg Lynette Seaton Kathy Secinaro Sarabeth Spasojevich William Triant Larry and Jane Tyler Kirk and Cindy West Sharon Whalen Michelle Willen David and Pam Williams Arthur and Gail Whitcomb In honor of Margaret Whitcomb Amanda Wolgamott

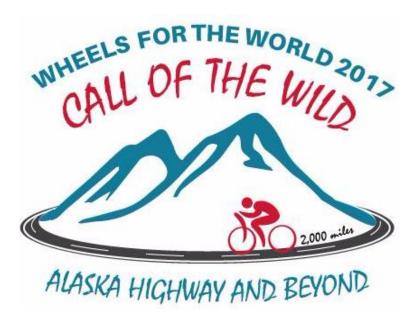
We thank these current sponsors who took additional beneficiaries:

We especially want to recognize <u>Octapharma</u>, which sponsored Chris's climb and a documentary about his trip that will be released by James Patrick Lynch and his company, Believe Ltd., in 2018.

Thank you again for your support!

Laurie Kelley and the team at Save One Life

To read Chris's postings: <u>Adventures of a Hemophiliac</u>
To see a gallery of photos of the trip: <u>Nepal Adventure</u>



Guess who is getting ready to ride?

Yes, our very own Barry Haarde will follow the "Call of the Wild" with his 6th Wheels for the World ride, this time starting in Canada on the Alaska Highway!

His ride begins in just about two weeks--on June 12!

Barry's goal is to raise \$30,000. If you would like to support your favorite cyclist,

#### Donate here!

We thank our corporate sponsors for supporting Barry and Save One Life:

Silver: Bioverativ

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### Adam Tyler's 2 for 1 Challenge



Adam Tyler

In honor of Chris's historic dimb, Adam committed to sponsor one child for every two sponsored of the 32 we had available in April.

Adam's campaign surpassed our expectations! Not only did all 32 children get sponsored, but 13 more for a grand total of 45–a fabulous result, guaranteed to please Chris!

Thank you, Adam and everyone who responded and sponsored a deserving child.

### A Child to Sponsor

Save One Life beneficiaries face the tough challenge of poverty with a bleeding disorder.

An annual sponsorship is \$264. Save One Life sends 90%, or \$240, overseas to assist the beneficiary and her/his patient organization.

Show someone you care! Please **sponsor** today!

### Ghana

The Haemophilia Foundation of Nigeria (HFN) and the Ghana Hemophilia Society (GHS) became program partners of Save One Life in 2013. From April 22 - May 3, executive director Martha Hopewell returned to assess progress, meet beneficiaries and enroll new families.



New beneficiary Gabriel Oliesegbo (with pink sandals) and his family in Nigeria.

Martha's first stop was in Lagos, Nigeria, where she went directly from the airport to a meeting of the Lagos chapter of HFN. Within two hours of arrival she enrolled five new beneficiaries. The next day she visited the homes of beneficiaries with our key contact and the president of HFN, Megan Adediron.

One beneficiary of note was 13-year-old Usman Hassan, who has lived with his 67-year-old grandmother ever since he was a baby.

Usman's grandmother has lived in the same 10' x 10' tenement room, sharing toilet and cooking facilities with 20 other families, for 30 years. In the past year, not only Usman,



Pitu, 11, Cambodia

### Thank You Letters

I am overwhelmed to know that my scholarship has been approved. It will be a great help for me to carry on my studies this year. By the end of this year I hope to apply for my master's degree. Without your help this would be impossible.

Sourav Dutta Honors zoology student Kolkata, India

For a moment I forgot I have a disorder! I try to forget this as much as possible...but this time I really forgot!

\*\*\*\*\*\*

And this is because of what I just accomplished with your help! I combined my microenterprise grant with my own earnings to buy an electric keyboard that will allow me to make a living performing music.

Thank you! You made me happy and you do the same for so many others with hemophilia.

Keep up the good work!

Razvan Barbuta Musician Romania

## Save One Life at HFA Symposium



Cyclist Barry Haarde visits development assistant Jodi

but her daughter and seven additional grandchildren have been living in this room, stretching the family finances and causing her to be in arrears for rent. When we told her that she could use her sponsorship funds to pay the rent, she burst into tears. "I only thought I could use the money for school books!" she declared. We answered that it's more important for Usman to have a roof over his head first! She later called Megan, filled with gratitude that



Usman and his grandmother, who supports her family by producing and selling yam flour.

we were able to relieve her of this terrible worry.

Martha and Megan traveled to the Amaku Teaching Hospital in Anambra State in south-central Nigeria to visit one of the country's five HTC centers, managed by a dynamic hematologist, Dr. Tessy Nwagha. During the visit patients arrived with various concerns, including a teen with a bleed and infection in his arm from an intramuscular injection.



Dr. Tessy Nwagha attending to patients in south-central Nigeria.

Our program partner, Megan Adediron, is to the right.

In Ghana, Martha traveled with Charles Afful, Save One Life scholarship recipient and program officer of the GHS, to visit families around Kumasi and Accra.

Weeks (left) and sponsorship manager Tricia Sico (right) at our booth

Hemophilia Federation of America held its 2017 symposium in Providence, RI from April 6 to 9.

We thank HFA for inviting us to participate! We enjoyed interacting with all the visitors to our booth, especially our current sponsors! We were also pleased to welcome nine new sponsors, who took a total of 14 beneficiaries!

We look forward to exhibiting again in 2018.

### LeadUP!

Nitya Bhattarai, a high school junior from Orange, Connecticut, is a young man with hemophilia. A cycling enthusiast, Nitya decided to participate in the 2017 Five Boro Bike Tour in New York City, raising \$850 for Save One Life along the way!

Nitya also enjoys playing volleyball and pick-up soccer, and looks forward to becoming a pharmacist one day.

Thank you, Nitya, for sharing your compassion with your blood brothers around the globe!



Nitya Bhattarai at the start of his tour

2017 Goals: Update

### Goal 1: 1500 sponsorships

To Date: 1420 sponsored beneficiaries (94%)



Executive director Martha Hopewell and GHS program officer Charles Afful having a conversation with beneficiary Theophilius Anash from Ghana.

A particularly memorable visit was to a family of five boys, all with hemophilia. With the exception of two boys, all also have different fathers, none of whom are present. An older boy died from a bleed, and one additional older son was born without hemophilia.

Their mother, along with the boys' grandmother and great-grandmother, is a sharecropper--growing and selling vegetables. The boys' aunt and her children also share their three-room home. which costs \$7/month. No father supports the family. Besides their meager income from farming, this family of over 20 depends on the sponsorship money they receive for each boy from Save One Life. We plan to assist the family with a microenterprise grant to sell salt.



Amos, the eldest of five brothers with hemophilia, walks with damaged knees from bleeds.

### Goal 2: 40 scholarships

To Date: 15 scholarships awarded (37%)

Goal 3: 12 micro-enterprise grants (MEGs)

To Date: 9 MEGs awarded (75%)

**Donate Now** 

2017 Corporate
Sponsors

We acknowledge these corporations for their valuable operational support in 2017:

**Diamond** 



**Platinum** 





Gold







The AmerisourceBergen FOUNDATION



Our key contact for the Ghana Hemophilia Society, Charles Afful, with his mother.

Charles himself has a story to tell. Considered to be bad luck by his family, which didn't understand hemophilia, Charles languished at home for seven years until a compassionate pharmacist offered to pay for his education. At age 15, he resumed fourth grade at school. Today, at 27, he is expecting to graduate from nursing school in June. In addition to visiting hemophilia families and performing home and hospital infusions of factor, he is the sole caretaker of his 70-year-old mother, who is recovering from a stroke.

### Smile On Summer Fund Camps

Save One Life provided grants to two program partners in the Philippines for camps in April and May.

Hemophilia Advocates of the Philippines organized their first national camp on April 22-23 near metro Manila. More than

154 attended from around the country. They also hosted eleven international guests—including eight from the United States, one from India and two from Iran. Participants shared their experiences and learned more about proper hemophilia care and advocacy work. In addition, 40 learned how to self-infuse!



Mayette Charvet teaching self-infusion techniques to Julian Andiova, Jr. and onlookers.

### Silver





Specialty Infusion Group



**Bronze** 





Congratulations to Hemophilia Advocates of the Philippines for a successful first national camp.

Blood Brothers Aid fulfilled it's mission "To Give, To Share, To Empower One Another" at its third family camp on May 20-21. Forty participants relaxed, played and strengthened their bonds as a supportive hemophilia community. Raymund Nanos, organizer of the camp, remarked that the campers who had the most fun were the women!



A happy group of hemophilia campers with Blood Brothers Aid.

### **Your Save One Life Team**









Martha Hopewell, Tricia Sico, Kristy Burns and Jodi Weeks

### **Stay Connected**





### Text | Link

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