### A once-weekly injection

For people with hemophilia A

Hear from the community about a different treatment option



LEARN MORE



# **OneVoice**

Caring for people with bleeding disorders in developing countries one at a time

May 2019

### Welcome!

Save One Life is pretty adventurous! In addition to Chris Bombardier's amazing Seven Summits success last year, we continue the adventure fundraisers with another bike ride by Chris Siestrup, from Canada to New Mexico (<u>Lost on the Tour Divide</u>), a <u>bike ride</u> near Boston to honor Barry Haarde, and another <u>hike up Kilimanjaro</u> (with yours truly)! Please consider making a donation to support Save One Life through these fundraisers!



Starting Save One Life was an adventure in itself. But 18 years later, we are boldly increasing our visibility, reaching more people in need, and expanding our donor and sponsor base. We're grateful to each person who sponsors a child, or contributes to one of our other four amazing programs: college scholarships, micro-enterprise grants, summer camps and now, Project SHARE.

Thank you! Gracias! Asante sana! Shukria! Let's keep the adventures going!

Laurie

### **Community Bike Ride is Almost Here!**



Join Us on Sunday June 23

Barry Haarde was the first person with hemophilia, HIV and hepatitis C to cycle coast-to-coast. That initial journey was named Wheels for the World and was the first of six amazing rides by the Texas native. Sadly, Barry passed away unexpectedly last year.

Fortunately, his legacy continues with Wheels for the World: <u>Lost on the Tour Divide</u>! Chris Seistrup, a cyclist with hemophilia B, will honor Barry's memory by raising money to support Save One Life while racing the Tour Divide.

In honor of Barry and to support Chris, Save One Life and the New England Hemophilia Association (NEHA) are hosting a bike ride in Ipswich, MA on June



23. Two different courses will be available to riders: a metric century (62 miles) and quarter century (25 miles).

Please join us! Registration is \$50 and snacks and lunch will be provided.

For more information, to register, or to contribute in honor of Barry or Chris, please use the buttons below.

Chris Seistrup (top) and Barry Haarde on one of their many rides!

**Register to Ride** 

**Donate** 



## CHALLENGE 2019

### Laurie Kelley and Team Climb Kilimanjaro Again!

Laurie Kelley is heading to Tanzania to climb Mt. Kilimanjaro, the highest peak in Africa, for the third time! Laurie will be joined by seven other climbers on this incredible adventure.

Climbers will first stop in Kenya to meet with the Jose Memorial Hemophilia Society, a Save One Life program partner. They will travel around Nairobi, visiting families that are being helped by Save One Life programs and see first-hand how difficult it is to live in a developing country with a bleeding disorder.

After visiting Kenya, the team will head to Kilimanjaro to undertake the huge challenge of climbing to an elevation of 19,340 over 6 days! Each climber is fundraising on their own to raise \$10,000 for Save One Life. Please help support these climbers and their amazing efforts by clicking the link below and donating to a team member!

**Support Our Climbers!** 

### **Supporters To Date:**

### Team Mike Adelman

Juli Adelman, Beth Allen, Grant Belsham, Kevin Blake, Neha Chawla, Anne Blake-Dreher, J Dabrowski, Christina Fairbrother, Linda Folkman, Kent Johnston, Carrie Kohs, Terence Leuchars, Cynthia Okin, Martin Rose, Dara Roth-Edney, Myra Ryan, David Schaaf, George Stern, Daphne Taylor, Viscadia Inc, Matt Wallach, David Zaritsky

#### Team Ric and Wendie Chadd

Sharon Bachorski, Jill Buccella, Brittany Chadd, Joseph DiStefano, David Eckman, Cher and David Gonzalez, Jeff Griffith, Britni Harris, Mark Helm, Thu Le, Carla Lockwood, Kasey Roberts, Elizabeth Schauermann, Kevin Shaughnessy, Kim Simonson, Nicol Vargas

### Team Myles Ganley

Aptevo Therapeutics, Grant Belsham, Charlene Cowell, Angel Dunlap, Sherry Ganley, Eric Green, Laura Lierman, Michael Pascale, Maria Schwarz, Sue Schwarz, My Tran

### Team Laurie Kelley

Douglas Mildram

### Team Sam Palmer

Michael Adelman

#### Team Shannon Peterkin

Dan Boyle, Paul Odonnell, Sullivan Dental Center, Mark and Sasha Zatyrka

### **Visiting the Nepal Hemophilia Society**

### By Nitya Bhattarai

Never once in my life did I consider hemophilia treatment centers (HTC), like the one I go to at Yale Hospital, a blessing. It seemed straightforward: I would go once a year, staff would check in on me, we'd converse a little, and I'd be on my merry way. I never thought to thank the countless people who worked to take care of my rare bleeding disorder, including doctors, nurses, physical therapists, and social workers. And I never realized that for the many families affected by bleeding disorder in Nepal, comprehensive care is all but a dream.

The Nepal Hemophilia Society (NHS) is the national bleeding disorders organization in Nepal, a developing country, with a goal to provide better care for people with bleeding disorders. It has an office at Anamnagar, Kathmandu. It is in a small house, similar to those surrounding it. There are a couple of small rooms where they host various meetings such as Save One Life fund distributions.

To read more about Nitya's journey click here!



Nitya visiting the Nepal Hemophilia Society Youth Group

### Program Updates



Look at the difference your factor donations make! Samuel of Venezuela was the recipient of one of Project SHARE's April factor shipments. His face says it all!

Without our donated factor, Samuel would suffer from bleeds.

donated factor to patients in countries with little or no access to this life-saving medicine.

In April alone, SHARE shipped over 730,000 units of factor to 8 countries, including Venezuela!

Because of this, our supplies are getting low. If you, or

### Welcome New Sponsors

Nancy Carroll Reina Castaneda April Cook Lauren Davis Tessa Field Stephen Flynn Cynthia Galpin Jonathan Gealt Britni Harris Rizwan and Arpana Khan Regina Legere Tom Malone Jennifer Millian Joseph Montesano Ryan Newman Bernadette Ochap James Redquest Kelley Roberson Nicholas Self Maggie Touchette Vanessa Yoerger and Friends (FL Genetech)

### Sponsors Adding Beneficiaries

Michael Adelman
Christine Barnes
Shari Bender
Rhoda Bender
Monica and Tom Dickey
Pauline and Tom Dwyer
Leslie Jacobsen
Len Lambert
Douglas Mildram
Joan Osip
Laureen Temple

A Child to Sponsor

someone you know, has unused factor they can donate to our program, please let us know.

Project SHARE 2019 Donations to Date (IU):

Jan: 1,062,025Feb: 845,646

• March: 547,423

• April: 730,263 (8 countries!)

• May to date: 488,737

Year total: 3,674,094

### To donate factor, click here.

### **3 Scholarships** averaging \$987 each:

• Honduras: David (Microbiology)

• India: Sourav (Masters of Science, Zoology), Subham (Aruyvedic Medicine and Surgery)

### **Micro-Enterprise Grants** in Pakistan averaging \$480 each:

• Nusrat, to purchase two goats for breeding and sales

 Saeeda, to start a door to door business selling socks, leggings and undergarments for women and children

• Salma, to sell ladies undergarments and unstitched clothing



A sponsorship is just \$35 a month! Please sponsor Walter from Honduras

Walter is 21 and has severe hemophilia A. He had very limited access to factor while growing up. He is unable to walk due to his untreated bleeds.

He has been in a wheelchair since he was five. He had to drop out of school in the 7th grade.

Walter and his sister live on their own most of the time. Their father left, their mother died from lupusrelated complications, and their grandfather is an alcoholic who often disappears.

Can you imagine how your sponsorship could help Walter?

### **Thanks to Our Recent Donors**

### **Mission Support**

Anonymous
Bayer HealthCare Pharmaceuticals Inc.
Rhoda and Michael Bender
Bioverativ
Robert Brown
Kristy and Christopher Burns
Chelsea Delong
Alex Douglas
James and Marsha Fairbanks
Hemophilia Alliance of Maine

Daniel Imamura

LA Kelley Communications
Andrew LaRocco
Stephanie Lasister
Derek and Krisdee Nelson
Maarten Nieboer
Joan Osip
Jill and Christopher Packard
Hannah Russell
Greg Vennemann

### **Micro-Enterprise Grant Program**

AmerisourceBergen Foundation Douglas Erickson Michael Wegner

### **Scholarship Program**

Kin Kam Michael Wegner

### Wheels for the World: Lost on the Tour Divide

The Alliance Pharmacy
Aptevo Therapeutics
Bayer HealthCare Pharmaceuticals Inc.
Evi Butler
William and Emily Cobb
Peter L Eldridge

Mary Feist
George King Bio-Medical
Charles Glasel
Rose and David Gott
Ryan Kleinschmidt
Eric Nadelberg
Michelle Sahli

# If you like our mission, please donate today. Every dollar counts!

### **2019 Corporate Sponsors**

### **Diamond**











Gold





### Silver







### **Bronze**





### Your Save One Life Team



Chris Bombardier Executive Director



Jenn Brockway-Peirce Program Manager



Kristy Burns
Finance and Operations
Manager



Heather Klee Sponsorship Manager



Jodi Weeks Development Manager



Marelle Hart European Liason



Usha Parthasarathy India Coordinator



Andrew Mesrobian Intern

www.saveonelife.net

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