

# OneVoice

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

### www.saveonelife.net

May 2016

#### Greetings!

An important contribution Save One Life makes to the global hemophilia community is our field visits to developing countries, where we can be the eyes and ears to better understand conditions that people with hemophilia face. We share our observations with the World Federation of Hemophilia to further our collective capacity to respond to needs.



Laurie Kelley Founder and President

It was with great pleasure that I recently visited the "Pearl of Africa," Uganda, in

eastern Africa, to assess the readiness of the Haemophilia Foundation of Uganda (HFU) to join Save One Life. Together with HFU's executive secretary, Agnes Kisakye, I toured the country to visit families and met with the executive committee to discuss our programs.

I was distressed by the extreme poverty I witnessed, and elevated by the resourcefulness and dedication of HFU, and Agnes in particular. I'll be pleased to report to the WFH that Uganda is doing a great job of raising public awareness of hemophilia and educating families. There's much to hope for in the coming years!



Laurie Kelley with the Ssempa Family and Agnes Kiskye of HFU

Read more about my trip and enjoy my pictures,

Laurie Kelley and the team at Save One Life

### Mission In Action: First 2016 Distribution of Funds

Save One Life distributes sponsorship funds twice a year--in May and December. This month we sent **over \$170,000** to 1,200 beneficiaries registered with 41 program partners. We also sent: **\$3,850** for two camps--one in India and one in the Philippines, **\$1,000** for a microenterprise grant in Romania, and

**\$1,300** in special gifts given by sponsors—including \$200 to help one beneficiary in Kenya buy a camera for his college courses and \$500 to help another family in the Philippines rebuild their home.

On behalf of our beneficiaries everywhere, thank you for your generous support!

## Welcome New Sponsors!

Anna Bainbridge Veronica Idoate Robert Massie and Anne Tate Denver and Megan Parler Justin Sheffield

We thank these current sponsors who took additional beneficiaries:

BDRN--Bleeding Disorder Resource Network Kristy Burns Helen Floyd Dawn Hunter Glade Nelson

### A Boy 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 his patient organization.

Show someone you care! Please sponsor today!



Hossain, 12, Bangladesh

A Successful School Fundraiser

### A Busy 15th Anniversary Season Ahead!

opportunities to participate and show your support for the good work we do! Mark your calendars!

#### Date: August 12 Wheels for the World Party

Barry Haarde will begin his 5,000-mile adventure in Everett, Washington on July 17. Part I of his journey will cover Idaho, Montana, Wyoming, South Dakota, Minnesota, Wisconsin and Michigan. Part II will begin in Portsmouth, New Hampshire and head



south along the eastern seaboard states right to the very end--Key West, Florida! He looks forward to meeting with members of our community along the way. If you would like to arrange a welcome for Barry along his route, you can contact him <a href="here">here</a>. For New Englanders, we will celebrate the launch of Part II in Portsmouth on August 12. Details to follow!

Barry's goal is to raise \$50,000. Thanks to Baxalta, Biogen, The Alliance Pharmacy, George King BioMedical and others, we have reached 80% of our goal! We need just \$10,000 more to proclaim success. To donate to Barry's cause, click <a href="here">here</a>.

#### Date: July 26 International Community Luncheon

Save One Life will be exhibiting at World Federation of Hemophilia's upcoming congress in Orlando. On this special occasion when many of our program partners will be gathered in one place, we will host a luncheon in their honor. Board member and sponsor Chris Bombardier, president of SABHA, Inc. and sponsor Shanta Kalyanasundaram, and president of the Hemophilia Alliance and sponsor Joe Pugliese will speak at this event. Thanks to Bayer HealthCare for being a silver sponsor.

Date: August 2 CEO Challenge



(EO CHALLENGE 2016

President Laurie Kelley will lead an intrepid team, including Save One Life board member Eric Hill and his son Andrew, BDI Pharma president Rich Gaton and his family, VP of Emergent BioSolutions

Michael Adelman and Dr. James Palmer from the Hospital of the University of Pennsylvania up Mt. Kilimanjaro. The team's fundraising goal is \$50,000. To support your favorite climber, click **here**.

### Date: September 29 15th Anniversary Gala

Mark your calendar for THE event of the year! Come celebrate our 15th year of extending compassion, sharing resources and bringing hope to over 1,500 people with hemophilia around the world!

The gala will take place at the Manhattan Penthouse in New York City. We will fete our many sponsors and donors who have made Save One Life's accomplishments possible since 2001. We will also announce our Sponsor of the Year and the winner of our 2016 Inspiration Award. To receive an invitation to the event, click <a href="here.">here.</a>



Dutch students raising funds for Save One Life.

On April 27 the citizens of The Netherlands celebrate King's Day, which is the birthday of their reigning monarch, King Willem Alexander. The children of the Dutch section of the European School in Luxembourg marked the occasion by organizing a flea market, with all the proceeds to go to Save One Life.

The children sold toys and treats, and raised over \$1,800!

We thank our Europe Liaison, Marelle Hart, for suggesting Save One Life to the school, Principal Hans van Wissen, faculty, parents and most of all the Dutch children of grades 1-5 for a successful fundraiser!



Delicious treats for sale during King's Day at the European School in Luxembourg.

# Welcome New Board Members

### **Mohammed Hoque**

Mo, originally from
Bangladesh, is a field care
coordinator for Cottrill's
Specialty Pharmacy. A person
with severe hemophilia A, Mo
lives in Warren, Michigan and
is an active member of the
Hemophilia Foundation of
Michigan.



Mohammed Hogue



### **Words of Thanks**

On behalf of the Ghana Hemophilia Society and our families, we are very grateful for the offer of sponsorship! You are making our patients happy and bringing hope to them. Thank you and may God bless you.

Martin Boakye, President Ghana Hemophilia Society

Last year I had several severe bleeds in my bicep muscle, which compressed the nerves and caused me to lose the functionality of my hand. My hand muscles contracted, leaving me with a permanent disability. I missed my exams and couldn't attend classes

regularly. I am slowly getting back to my studies. It's hard, but I am trying! It's not my nature to give up!

Most of us who have hemophilia in developing countries are not fortunate enough to sustain a normal life. Our disability raises the burden for our families that are already below the poverty line. It's hard for us to contribute to the family economy without finding suitable jobs that don't require physical labor...and such jobs require education!

I would like to extend my deepest gratitude for trusting me with your scholarship support. I paid my tuition fee and bought school books. The way you help us with scholarships is CRENZ

Ashrit is earning a bachelor's degree in social sciences

immense! People like you make this world a better place to live! I promise that your investment will someday help me achieve a quality, independent life.

Ashrit B.K., 25 Nepal

I would like to thank you very much for the micro-enterprise grant. Romania does not offer many opportunities, and those we have do not pay much money. Your help means a lot, and will allow me to fulfill my plans. Thank you!



Razvan is planning to organize a wedding band

But that's not all! I understand that you help many other people with bleeding disorders all the time. As a patient, I know how special it is to be supported by someone, in any way! It's a big step ahead. It's always an act of kindness which helps a lot. For this reason as well, I say thank you. May God give you many days and strength to do such

beautiful things for people in need.

Razvan Barburo, 23 Romania Myrish came to the United States with her family from the Philippines in 2014. A mother of twin boys with severe hemophilia A, Myrish is a Program Manager at the Center for Public Leadership at the John F. Kennedy School of Government at Harvard University.



Myrish Cadapan-Antonio

### In Memoriam

We are sorry to share news of the passing of Cesar Fernandez, Sr. from the Philippines, on December 24, 2015.



# 2016 Corporate Sponsors

We acknowledge these corporations for their valuable operational support:

**Platinum** 





Gold





### Save One Life Outreach in Europe

Save One Life welcomes sponsors from other countries—today we have 26 international sponsors from Canada to Qatar to New Zealand! Most, however, live in Europe, and we would like to see that number grow!

We are pleased that Marelle Hart, a mother with two sons with hemophilia, has stepped forward to be our first volunteer Europe liaison. Based in Germany near the Luxembourg border, Marelle has already reached out to hemophilia groups, filmed a local news presentation for World Hemophilia Day and involved a school in raising funds Save One Life.



Marelle Hart with her sons and husband, Anton Roodhuijzen



Silver









### Your Save One Life Team









Martha Hopewell, Tricia Sico, Lani Aldrich and Kristy Burns

### **Stay Connected**





### Text | Link

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