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SUPPORTING EDUCATION IN CHILDREN AND ADOLESCENTS WITH HEMOPHILIA: THE EXPERIENCE OF SAVE ONE LIFE

On February 21, 2022, Dr. Paul Farmer, founder of Partners in Health, died unexpectedly in Rwanda at age 62. He was an extraordinary visionary, leader, physician and humanitarian. He was my hero and role model. Originally from western Massachusetts, like me, he attended Harvard University and became an internationally renowned infectious disease expert. He counted Bill Gates and Bono as colleagues and friends, as well as the poor of Haiti. He helped rebuild Rwanda's healthcare system following the genocide, and decided to live there. And he created the best hospital in Haiti, revolutionary in concept, which excels today in its service to the poor. Save One Life, the nonprofit I founded, also serves the world's poor. We had just partnered two years ago

with Farmer's hospital, Hôpital Universitaire de Mirebalais, to bring the first ever hemophilia program to Haiti. For Paul Farmer believed, as we do, that every life counts, and every person deserves healthcare. Ironically, the seeds for Save One Life were sown during the Rwandan genocide. I had just given birth to my third child in March 1994, and had just watched the movie "Schindler's List," which ends powerfully with Oskar Schindler receiving a ring from the Jews he saved, inscribed with "He who saves one life, saves the world." That phrase, both from the Talmud and the Koran, never left me. Schindler had always said, "Just one more... just one more," as he saved Jew after Jew from certain death. I grieved for the Rwandans, as I am sure Farmer did, and only wanted to adopt an orphan. Just one. I felt so powerless to help; perhaps saving one child would ease my suffering and give a new life to a baby who lost its family. I was not able to adopt the Rwanda orphan I so badly wanted, but I eventually founded Save One Life so that people like me – a regular mother of a child with hemophilia – could try to save one life: a child with hemophilia in a foreign land, where no treatment existed. It was a way to show gratitude for all the life-saving medicine to which my child had access. It was also a daunting task, requiring days, months, years of my life, and a lot of money, to get it off the ground. It had not been done before in hemophilia. But this idea - that we can focus our help on one person - touched others in the US hemophilia community, and made them feel more empowered to do something to help. One person in a developed country, with access to factor, could indeed directly help another, one-to-one. To know a child's name, his birthday, his family; to be able to give him money to help him go to school, or have nutritious food, or wear better clothing. We would give them that bridge, that conduit. It was beneficial that I had founded a publishing company in 1990 focusing on hemophilia; I had literally thousands of US families in my database. And pharmaceutical representatives and CEOs, and specialty pharmacies and HTC's. Thousands. I reached out and the response was amazing. We collected unwanted factor; we signed up people to sponsor children in India, Nepal and Pakistan, our first countries. I traveled to these countries to form bonds with the national organizations, which gladly worked side by side with us to make Save One Life successful. Children received funds and factor. They went back to school



They stopped the bleeds. As I traveled, I saw more needs. Most countries did not have hemophilia camps, so vital for socialization and community. So we established camps in several countries, and helped fund others that were established but in need. As our children aged and graduated, another problem arose. What about college? They lacked the funds. We started the first international hemophilia scholarship fund. These children were now young adults, and many went to college. We have graduates who even became hematologists! Others, not inclined to study, wanted income to support themselves. Another idea crystallized: micro-enterprise grants, to give them a start in the business world. We were amazed when applications came in for cell phone repair shops, roadside vegetable stalls, taxi and auto-rickshaw businesses, sewing machines, and even cows, to sell milk to local villagers. And all the while we knew every single person's name, date of birth, address, and family members. My favorite part of Save One Life has always been visiting families in their homes. Accompanied by our program partners, we've been to stifling slums in Mumbai and Nairobi; to dusty villages deep in Africa; to steel-roofed homes in the hamlets of Haiti; to squatters' make-shift homes in Nicaragua. We sit with the families, share their meals, ask them about their lives. We record their stories to bring back with us. We want the haves to know how the have-nots with hemophilia live. If we can reach people's hearts through compassion, we can compel them to act too. And we can compel them to act if they believe they will make a difference. Sometimes, the



overwhelming numbers - 300,000 worldwide in need of factor, 95,000 Rwandan orphans - paralyze us. What difference could one person possibly make? But knowing a child's name and face, and a secure way to get them funding directly, makes us feel we can change that life, and change the world.

Save One Life just celebrated its 20th anniversary in 2021. Each of those individual lives add up:

- We now work in 14 developing countries, with 45 program partners.
- We have sponsored over 2,000 children individually
- We currently sponsor 1,400 children through 800 sponsors
- Since 2012, we've provided 378 scholarships to 214 students in 10 countries.
- Since 2014, we've awarded micro-enterprise grants to 183 patients in 13 countries.
- Since 2002, we've shipped an estimated \$200 million worth of factor to 78 countries.



We've been the first to visit and assess the hemophilia situation in over a dozen developing countries, and have helped to start hemophilia organizations there. Rwanda and Haiti were among our latest; something, I think, the intrepid Dr. Paul Farmer would have approved. Save One Life, I hope, compliments the current global model of hemophilia care, which is top-down: from the developed countries, factor and training goes to the health ministries and clinics, and the national organizations. We start at rock bottom, with the neediest and poorest, to assess their needs, find community leaders, and empower them. We match sponsors with a child in need. And we build from there. We apply a holistic approach: direct financial aid; registration with the national organization; factor to stop bleeds; cooperation with the medical community.

Attendance at camp; a scholarship to attend college, or a micro-enterprise grant to start a small business. We support the needs of the family as a whole, not just treat the bleeds. Farmer once quoted a Haitian axiom: “Giving people medicine... and not giving them food is like washing your hands and drying them in the dirt.” Of course, we love big numbers too. Who wouldn’t want to say that they had helped thousands and thousands lives? Yet, to capture the hearts, imagination and actions of the masses, we believe we need to focus on the one. Paul Farmer also said, “If I saved one patient in my whole life, that wouldn’t be too bad.” Paul Farmer believed in helping one at a time, in visiting patients where they lived, in revolutionizing healthcare by going against conventional wisdom, and he believed in action. Action with compassion. I hope we keep his indomitable spirit, embodied in the work by Save One Life, alive. In Rwanda, in Haiti, and in every single child with hemophilia in need.



Lauren A. Kelley is founder and president of LA Kelley Communications, Inc., a publishing company for educational books on bleeding disorders, and Save One Life, Inc., an international nonprofit that gives direct financial aid to families with bleeding disorders. She is also author of 11 books on bleeding disorders, including the first book ever on von Willebrand disease. Until 2021, she published the longest-running newsletter on hemophilia in the US, and still publishes HemaBlog, the first dedicated blog on hemophilia, since 2006.