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Out from the Shadows

In East Africa, people with albinism face a bleak fate. But Doug DuBois '89 is leading efforts that offer real hope for a better life.

By DOUG DUBOIS '89



A baby is carried by a resident at the Kabanga Protectorate Center, a government safe house for people living with albinism. The baby's mother walked 200 kilometers to find safety at the center for her child. Children born with albinism have been targets for violence in East Africa. (Photo by Susan DuBois)

Our son Nick was born in July 2000 — a big, healthy baby with a full head of white hair. We didn't think too much of it since I was a 'towhead' when I was a child and he seemed perfect to us. My wife, Susan, and I were very surprised when, just a day after being born, our baby was diagnosed with albinism, which is the recessive genetic condition defined by the lack of ability to produce melanin: the primary pigment in your hair, skin and eyes.

In the general U.S. population, 1 out of 70 carries the recessive gene, and approximately 1 out of every 20,000 person has the condition. Neither Susan nor I knew of any relatives who had had albinism, but we both carry the recessive gene. As any Biology 101 student at Illinois Wesleyan could tell you, any child we have has a 25 percent chance of having albinism. When our daughter Kate arrived two years later, she also had albinism.

As concerned parents, we did extensive research to identify the medical issues involved. People with albinism are more susceptible to sunburn and skin cancer. They also have uncorrectable low vision, which can be improved with glasses and other devices, but only to somewhere between 20/60 and 20/400. Beyond these medical challenges are social issues, such as teasing, comments from strangers and frequent stares in public. Kids with albinism often struggle with feelings of isolation and awkwardness that come from looking very different from their peers.

To help them face these challenges, Susan and I became advocates for our children. We joined the National Organization for Albinism and Hypopigmentation (NOAH) and started the process of early-intervention services to address the expected visual developmental delays. We attended albinism conferences, hosted local events and volunteered to help other families with newly diagnosed children. This led to friendships with couples who had adopted children with albinism from other countries. From them, we learned how prejudice against such children can be far more severe in other parts of the world.

But nothing could have prepared us for news stories in 2009 that began trickling out of Tanzania about how people with albinism were being murdered and mutilated. Albinism is misunderstood in many parts of the world. In certain parts of East Africa — where albinism is far more common than in the United States — it is considered to be the result of a curse. Witch doctors promote the belief that magic potions made from albino body parts can bring wealth and luck to the recipients. As a result, nearly 100 people with albinism have been killed since 2006 due to the deadly black market for albino body parts. Many others, while seriously injured, have survived attacks. Such attacks often go unreported, and local law enforcement typically failed to pursue or prosecute these cases.

The grim reality of this nightmare was brought home when we met one of the victims. Mariamu Stafford was a single mother with albinism who made her living as a seamstress in a rural Tanzanian village. One night a group of men entered her home and attacked her with machetes. Mariamu lost her arms — and, due to the trauma, her unborn baby — but she miraculously survived and also saved the life of her 2-year-old son.

Mariamu's heroic story was featured on the ABC news show *20/20* in 2009, and NOAH was inundated with calls about how to help her. ABC News agreed to fly her to the U.S. for treatment, and NOAH asked Susan and me to organize the effort in the Washington, D.C., area, where a member had arranged for her to receive donated prosthetics. Other NOAH members and family friends provided housing, meals, supplies and nursing care.

My family felt an instant bond with Mariamu when we met her at the airport. We visited her regularly during her three-week stay while she was fitted with and learned to use her “new arms,” as she called them. We worked with our congressman to introduce a House Resolution (later passed) condemning the atrocities against people with albinism in East Africa.

As Mariamu returned to Tanzania to resume her life, we realized that we could not just end our efforts with her departure. Nor could we forget her suffering. So we decided to launch a nonprofit group dedicated to help people with albinism in East Africa called Asante Mariamu — *asante* means thank you in Swahili, and we seek to honor Mariamu's dignity and bravery with our work.

In December of 2009, we launched our 501(c)3 nonprofit with no funding or experience, two full-time jobs and two young kids. Undaunted, we lobbied friends and family for help and raised funds through backyard



Mariamu Stafford (above) lost her arms in a machete attack by two men who hoped to benefit from the myth that albino body parts bring wealth or luck. After receiving prosthetic arms, she finished a vocational degree in commercial knitting. Inspired by her story, Doug and Susan DuBois launched Asante Mariamu to help East Africans with albinism. (Photo provided by Asante Mariamu)

barbecues, neighborhood concerts and bake sales. Four years later, Asante Mariamu has won several grants to help fund specific projects; formed strong partnerships on the ground in Tanzania and created a network of international organizations with similar missions that we work with to be more effective. We have directly helped hundreds of people with albinism in Tanzania, Uganda, Malawi and Kenya and educated thousands more in those countries about the true nature of albinism.



DuBois (right) led awareness days in Tanzanian villages to change misconceptions about albinism. (Photo provided by Asante Mariamu)

Asante Mariamu has organized several volunteer trips to Tanzania in which we help the people with albinism on multiple levels. Our long-term goal is to change the perception of albinism by educating the general population in the towns and villages we visit. Part of this effort involves distributing thousands of informational posters and pamphlets in English and Swahili. At each stop, we conduct an Albinism Awareness Day in which we explain the scientific basis for albinism and attempt to dispel the damaging myths that people with the condition are cursed, that their body parts can be used to make powerful potions or that killing an albino person is not really murder because they are not fully human.

We also educate people with albinism about how to best protect themselves from a danger even more deadly than the witch doctors — the omnipresent threat of the East African sun. In Tanzania, only about 2 percent of the country's albino population reaches the age of 40. Skin cancer is by far the leading cause of premature deaths. We distribute sunscreen, wide-brimmed hats, long-sleeved shirts, sunglasses, magnifying devices and medical treatment to those in need.

The dire need for this kind of assistance is evident at the so-called “protectorate” centers established by the Tanzanian government in response to the crisis of violence against people with albinism. Every single one of 70 children we met at the Kabanga Protectorate Center and School in rural western Tanzania had varying degrees of sun damage across their face and arms. Kabanga is one of the nine protectorate centers set up at residential schools for the disabled throughout the country. Protected by an armed guard and razor wire placed on the brick-walled perimeters, these centers are overcrowded and understaffed, providing little more than a chance to be safe for the residents, who range in age from infants to adults.

The children at these centers live in deplorable conditions. During Asante Mariamu's first visit to the Kabanga center, our volunteers observed that the sanitation system is almost nonexistent and the classrooms and dorms were filthy and crumbling. In 2012, Susan led a group of seven volunteers, and they spent most of their time at this center, refurbishing classrooms and building a small library.

During our most recent trip, which I led this past summer, we visited several towns and villages in the northern lake districts of Tanzania where attacks on people with albinism have been more prevalent.

Along our route, we stopped at a school started by Helena Ntambulwa, a Catholic nun who lived and worked in Wisconsin for 12 years before returning to her homeland in response to reports about the killings of children with albinism there. On the southern shore of Lake Victoria, she established a school and sanctuary that Asante Mariamu helps support.



DuBois's group distributes backpacks with sunscreen, wide-brimmed hats, sunglasses and magnifying devices to help people with the condition. (Photo provided by Asante Mariamu)

We all noted Sister Helena's careful regimen of fully suncreening the children twice daily, having them wear wide-brimmed hats and keeping them out of the sun as much as possible at midday. As a result, they had remarkably smooth and unblemished skin — proof that, with a few simple steps, these children can avoid the blight of skin cancer that has taken the lives of so many people with albinism in East Africa.

The final destination on our journey was a village near Sister Helena's school. Accompanying me were our Asante volunteers — one close friend, an Oxford University student, and three Tanzanians: a dermatologist, an albinism advocate and a translator. Along with Helena and our driver, Josiah, we all loaded into a decidedly non-4WD Toyota minivan and rode across the open plains adjacent to the Serengeti National Park in northern Tanzania.

Suddenly, we came to a halt. Neither Josiah nor Helena would admit we were lost — despite the fact that we have been meandering across this dusty terrain for over an hour, and we'd been told our destination was "just a few kilometers" from our starting point.

All seven passengers were asked to exit the van so it could make it through the dry, heavily rutted riverbed without getting stuck. As our driver, Josiah, drove off to find an alternate route, our group set out on foot toward our destination. We ended up walking the last several kilometers while Josiah circled around and joined us at the village. Sister Helena was a bit embarrassed but explained that a) she would normally walk here rather than drive; and b) "T.I.A.," which stands for "This is Africa." It explains to Western visitors how they need to readjust their Type-A, highly scheduled expectations.



To his surprise, DuBois was presented with a pair of goats as gratitude from a villager on one of his stops. He gave the goats to a school that helps children with albinism. (Photo provided by Asante Mariamu)

After presenting our Albinism Awareness Day at the village to a large and appreciative audience, one of the elders approached us. Ngongo (who we learned had 80 grandchildren, three with albinism) wished to thank us for our efforts by giving us “two gods” to take with us on our journey — or at least that’s what I thought he said. It soon became clear he was actually offering “two goats” to pick from a herd presented by one of his sons. We gratefully chose a pair, and they joined us in the minivan, though we couldn’t help but wonder how we would explain our gifts to TSA agents when boarding our flight home. Fortunately, Sister Helena offered to take the goats, whose milk would help feed the 30 children with albinism in her care. All in all, it felt like a fitting end to our journey.

When I was at Illinois Wesleyan, it never occurred to me that I couldn’t reach any goals that I was striving for, as long as I was willing to work hard and persevere. My wife Susan and I try to instill this lesson in our children, and they will have to work harder and clear more hurdles than we did. But for the children with albinism of Tanzania, the idea that they too can achieve their dreams is something they likely could not even imagine.

We hope to give them the tools, information and skills necessary to achieve those dreams. Foremost, we want them to be safe, but we also want them to be living with their families and to become leaders within their communities. Rather than living like refugees, we want these displaced children to gain an education and become self-advocates. They should not feel like they have to lower their heads in shame or fear.

That this goal is achievable can be seen in children like Israfil Muhamed. Our volunteers first met this intelligent, resilient 16-year-old boy at the Kabanga Protectorate Center in 2012. He has now returned to his home in the Kibondo district and enrolled at the Bishop Mpango Secondary School, where he is among the highest-performing students. We are sponsoring him and two other former Kabanga students to pay for tuition and fees at this school. During our visit to Kibondo last summer, we were proud to see Israfil elected as the chairperson of a new Tanzania Albino Society, one of many such advocacy groups we have helped organize across the country.



Volunteers led by Susan DuBois (right) worked to improve conditions for residents at the Kabanga Protectorate Center. (Photo provided by Asante Mariamu)

Previously Israfil didn't know that he had a future. Now his plans are to be an architect or engineer. Seeing this change in him fills Susan and me with hope that this can become reality for him and many more of these once-forgotten children. More than ever, we are dedicated to continue the journey that began with the births of our children and took on new purpose after launching Asante Mariamu four years ago.

About the author: Doug DuBois '89 majored in philosophy and political science at IWU. He is a program analyst for the General Services Administration, an independent U.S. government agency in Washington, D.C. He served as a member of the Board of Directors of the National Organization for Albinism and Hypopigmentation (NOAH) for six years.

In addition to his work in the albinism community, he has served on county advisory committees for both conservation and special education instruction. He enjoys coaching his kids' soccer and basketball teams and is active in their school district.

DuBois is returning to Tanzania this spring to lead a new group of Asante Mariamu volunteers.

To learn more about Asante Mariamu and its programs, visit www.asante-mariamumu.org.