

ASANTE MARIAMU

Because albinism shouldn't be a death sentence



2012 ANNUAL REPORT

ASANTE MARIAMU, A NON-PROFIT 501(C)(3)

Message from the Executive Director

What Have We Been Up To?

It has been a roller-coaster year for Asante Mariamu. From winning our first major grant to our first volunteer trip to Africa - we pushed to make a difference. Sometimes that difference was more personal and internal than expected, but our experiences have helped clarify our vision and identify our goals.

Our organization centers around personal relationships, and started because of the deep connection we made with Mariamu Staford in 2009. The personal relationships secured in Tanzania with our partner organizations and the bonds we created with students with albinism are also critical to our success. Our small circle of Board members contracted and expanded in 2012. We said goodbye to Linda Wood and Shawn Covell, two of our original Board members; and welcomed Beth Connors, Mary Filicetti, Paula Levin-Alcorn and Liz O'Dell Wehling to our ranks.

Most of the highlights from this year involve the work we did at the Kabanga Protectorate Center in Western Tanzania. Home to over seventy children with albinism, the center has become a refuge from the violence against people with albinism in the region. In the following pages, we hope that you learn more about our work in 2012, what drives us, and our dreams for the future. Love and peace,



Susan DuBois

Founder and Executive Director

Asante Mariamu

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Message and Vision

Our Perspective is to be Positive

The issues facing people with albinism in East Africa are serious and life-threatening. At times, the stories we hear and tell are inhumane and heartbreaking. But the human spirit is amazing, and despite teenagers with skin cancers and a black market in body parts, we find courageous people who inspire us with their spirit, and children who have captured our hearts with their dreams. We choose to focus on this spirit, and balance the tough stories with ones of hope and strength. The message reinforced in all we do is: *“Watu wenye ualbino ni Binadamu kama sisi,”* which means “People with albinism are just like you and me.”

Our organization is named after Mariamu Staford, shown here in her cap and gown. Four years after surviving a brutal attack that should have killed her, she graduated with honors with her certificate in knitting from the Imani Vocational Centre. This triumph of spirit exemplifies our perspective.



Awareness, Relief and Empowerment

One of our most important goals is to raise awareness about the condition of albinism, and the issues facing people with albinism in East Africa. It is important to educate the general population about the scientific basis for albinism, and we have created educational material in both English and Swahili to dispel the myths that surround the condition. We also educate people with albinism and their families on how to stay safe in the sun, and provide direct relief in the form of sunglasses, hats, long-sleeved shirts and sunscreen. Asante Mariamu also provides low vision devices, and the training on how to use the magnifiers and monoculars. Finally, we work to empower people with albinism by supporting educational efforts.

Our Board of Directors

Our work is very serious, and we are dedicated to making a difference - however, we try not to take ourselves too seriously.

Dr. Beth Connors

Beth is a private practice audiologist with over 19 years of experience and a knack for getting things done. In 2012, she arranged for over fifty hearing impaired children in Tanzania to receive hearing aids through the Starkey Hearing Foundation. Beth is married with two children and is active in the PTA. In her spare time, she loves reading, yoga and training for triathlons.

Susan DuBois

Susan has been an attorney with the Patent & Trademark Office for over 20 years, and likes non-profit work a lot more. She has written numerous grants for non-profits, and was the principal author and editor of *Raising A Child With Albinism: A Guide to the Early Years*, published by NOAH in 2009. Along with fellow Board member and husband Doug, she has two children who happen to have albinism, but they think Asante Mariamu is just a coincidence. Susan loves to travel, garden and cook complicated meals. She is also a proud member of the all-women, Afro-Brazilian samba-reggae percussion band, Batala.

Doug DuBois

Doug is a Program Analyst with the federal government with over 20 years experience. He currently works with GSA to increase small business participation in government contracting. Doug also served on the Board of Directors for the National Organization for Albinism and Hypopigmentation from 2006 - 2012. He loves music, reading, following sports with his son and coaching basketball.

Mary Filicetti

Mary could be called the most useful person in Asante Mariamu, as she is a teacher of the visually impaired, and a Certified Orientation and Mobility Instructor for Fairfax County Public Schools and Columbia Lighthouse for the Blind. A shared passion for the field brought her to Asante Mariamu, and Kabanga School in Tanzania. She is active in her church, Westminster Presbyterian and is part of a Hawaiian dance ensemble.

Zuraidah Hoffman

An accomplished triathlete, mom of two and public relations whiz, Zuraidah has been with Asante Mariamu from the very beginning. She loves telling stories, and is responsible for the overall design of our website. Originally from Malaysia, Zuraidah has more than 20 years experience in the communica-

tions industry, and is currently a senior communications advisor for the National Rural Electric Cooperative Association.

Paula Levin-Alcorn

Paula is a licensed clinical social worker, specializing in the fields of maternal and child health, brain injury and immigrant issues. She is currently a Case Manager at Brain Injury Services, but has more fun as a children’s yoga instructor. She serves on the Board of Directors for the Congregation Etz Hayim, is active in PTA and other area organizations. Paula has a Masters in Social Work from the University of Maryland School of Social Work; and lives in Arlington, VA with her husband Bob, 3 active children and 1 gentle greyhound.

Diane Vogel Raful

Diane is an attorney specializing in civil rights, education and government grants, who transitioned to journalism in the late 1990s. For the past decade, she was the Managing Producer of Washington D.C.’s award-winning midday public radio show, The Kojo Nnamdi Show. Now a media trainer and consultant, Diane brings her vast list of contacts together for the common good. Diane loves to travel, and enjoys bowling with friends and scuba diving. She lives in Arlington, Virginia with her husband Mitch and two adorable rescue dogs, Mort and Trixie.

Elizabeth O’Dell Wehling

Newly married, Liz is the fresh-faced dynamo who reminds the rest of us what it’s like to be 20-something and on fire to change the world. Liz has her Masters in Education, and served two terms as an Ameri-corps VISTA before becoming the Volunteer and Donation Drive Coordinator for The Salvation Army National Capital Area Command. Liz loves country music, her dog Buttercup and her husband Will.



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DRAFT Financial Statement

How We Raise Money

As a small non-profit, we raise most of our money through individual donations. In 2012, we were awarded a grant for \$15,271 from the Dorothea Haus Ross Foundation. We strive to keep administrative costs low by donating our time and services, and paying for travel out of our own pockets.

2012 Budget

Overall Income: This includes donations received through our website and by direct solicitations. It also includes income from our first grant, and it captures the value of donated supplies. Our in-kind donations included low vision devices, sunscreen, hats and sunglasses received from our SunDrives.

Direct Cash Donations:	\$4,560
In-kind Donations:	\$3,870
Grant:	\$15,271
Total Income:	\$23,701



Overall Expenses: Each person closely associated with Asante Mariamu donates their time and expertise. Our program expenses are limited to classroom building and renovation costs, hosting albinism awareness events, baggage fees for supplies, medical staff and supplies, school supplies, low vision devices and other sun-protective gear. Our administrative costs include postage, printing costs, insurance and website hosting.

Program Expenses:	\$20,560
Administrative Expenses:	\$2,405
Total Expenses 2012:	\$22,765

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2012 Service Projects and Programs

Support of the Kabanga School and Protectorate Center

Our work with the Kabanga School began in 2011 when we successfully initiated a program with the Tanzania Red Cross Society where students with albinism, their families, teachers and administrators worked together to determine what was in the best interests of the students. In the first year, we provided the school with a computer and dining hall furniture. In July of 2012, seven Asante Mariamu volunteers traveled to Kabanga. We used grant money to rebuild two classrooms, create a poultry project, support a sewing cooperative and build sanitary washing stations. We also brought a teacher of the visually impaired to work with the students on how to use low vision adaptive devices to access print media. In addition, we sponsored a Tanzanian dermatologist to spend one month at the center; providing education, awareness and basic medical care. Each person with albinism at the center received a hat, sunglasses, toiletries, sunscreen and an adaptive vision device.



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Albinism Awareness Day

During our trip to Tanzania, we partnered with the Catholic Diocese of Kigoma to host an “Albinism Awareness Day” in the Kigoma region. This was the first event of its kind in Western Tanzania, and it brought together over a thousand people, many with albinism. Local politicians attended, along Ministry of Health officials flying in from Dar es Salaam. We provided educational material, genetics lessons and sun protective gear - but most importantly, we provided a platform for the general public to see and hear that “Watu wenye Ualbino ni Binadamu Kama Sisi,” or “People With Albinism are Just Like You and Me.” One long-term benefit from this event was that it helped people with albinism from rural areas connect with others and form relationships. The highlight of the event was when the Kabanga Children’s Choir sang a song they wrote themselves entitled “Why Are We Refugees in Our Own Land?”

Radio Public Service Announcements

Asante Mariamu produced a series of public service announcements that aired on Radio Kwizera before and after the Albinism Awareness Day. Radio Kwizera is a regional community radio that reaches 6 million people in Western Tanzania, parts of Rwanda, Burundi and the Democratic Republic of Congo (DRC). Founded by Jesuits in 1995, RK is known for its promotion of a culture of peace as well as local, regional and international news. Asante Mariamu produced three stories for the air, all focusing on our core message of education, empowerment and dignity for people with albinism.

Domestic Awareness Programs

One of our most important jobs is to raise awareness around the world about the plight of people with albinism in East Africa. For a small organization, our impact has been quite impressive. Our work has led to stories on NPR, in many national newspapers and on the National Geographic website. In addition to this widespread exposure, we work with religious groups, scout troops, school clubs and civic organizations to raise awareness, collect donations and gather supplies. Our volunteers host “SunDrives” all over the United States to provide life-saving sun-protective gear. We believe that this part of our mission is critical to our success.

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Our Partners

The National Organization for Albinism and Hypopigmentation

NOAH is an advocacy organization based in North America devoted to offering information and support to people with albinism, their families and the professionals who work with them. NOAH creates a strong sense of community by hosting a biannual conference and a summer camp, by creating publications and hosting local events for people with albinism and their families. NOAH was an early Asante Mariamu supporter, and the two organizations work together to promote a global awareness of albinism.

Under the Same Sun

UTSS promotes the wellbeing of persons with albinism in Tanzania through advocacy and education. Based in Canada, UTSS maintains an office in Dar es Salaam and works with government officials and others to promote equality. Our organizations work together to support Mariamu Stafford, and collaborate on various awareness initiatives.

Positive Exposure

Positive Exposure utilizes photography and video to transform public perceptions of people living with genetic, physical and behavioral differences – from albinism to autism. Many of the images on our website are from the talented Rick Guidotti, who works to promote a more inclusive, compassionate world where differences are celebrated.

Tanzania Red Cross Society

The Tanzania Red Cross Society office located in the Kigoma region was an early champion of people with albinism. Led by Jane Chagie, TRCS staff members partnered with Asante Mariamu to refurbish classrooms, create a poultry project and a sanitary washing station. In addition, the TRCS acted as a fiduciary for Asante Mariamu in administering grant money.

The Catholic Diocese of Kigoma and Kabanga Hospital

Asante Mariamu partnered with the Catholic Diocese of Kigoma to host the first Albinism Awareness Day in western Tanzania. In addition, they facilitated meetings with various stakeholders to determine a plan of action for supporting the students with albinism at Kabanga.

Stichting Afrikaanse Albinos

SAA is a Dutch charity that works to provide sunscreen and sun protective clothing to people with albinism in several African countries. Asante Mariamu has provided them with culturally relevant teaching materials to distribute, and the two organizations have worked together to provide supplies for the students at Kabanga, and for people with albinism in rural western Tanzania.

Regional Dermatological Training Centre

Part of the prestigious Kilimanjaro Christian Medical Centre, the RDTC is the preeminent dermatological training school in East Africa. It is also the site of one of the earliest albinism assistance programs. Dr. Alfred Naburi has been educating people with albinism in the Moshi region since 1993, and has seen a marked decline in skin cancer rates. An RDTC dermatologist worked with Asante Mariamu to provide medical screenings, albinism awareness and education to the children in the Kabanga Centre, and also at the Albinism Awareness Day.

Washington-Lee High School

Located in Arlington, Virginia, this school has made a long-term commitment to support students with albinism in Uganda. The students raise money to sponsor tuition and also provide Rafiki Packs to individual students. In addition, they host awareness events, gather supplies and speak to various student groups on behalf of Asante Mariamu.



What's Next?

Asante Scholars

We strongly believe in the importance of providing quality educations for children with albinism, as a way to empower them to have a vital future as leaders in their communities. However, as a small grass-roots organization, we have to be very careful with our budget. We can reach many more people with awareness campaigns and by providing sun-safe supplies than we can by providing scholarships to a specific number of children. Nonetheless, we have decided to support a select number of students each year, both in primary school and secondary school. We will also refer students to our partner, Under the Same Sun, which has a much more extensive scholarship program.

Rafiki Packs

One of our new projects is to provide children with albinism with a small backpack filled with vitally important items, including a long-sleeve shirt, a brimmed hat, sunglasses, pens, pencils, sunscreen and a magnifying device. Each pack will also include a short note from a friend of Asante Mariamu, and a small toy for really young children. We are distributing these packs in Uganda and Tanzania through our partner organizations, and in person on volunteer trips. The term “rafiki” means “friend” in Swahili, and we are hoping to encourage our donors to feel more connected to kids in East Africa by sponsoring Rafiki Packs for specific children.

New Partners

2013 marks a significant expansion for us, as we will now be working in Uganda. A new relationship will allow us to provide scholarships, sunscreen, adaptive devices, educational materials, and awareness information to people with albinism in Uganda. Our first Asante Scholar is Caro Christine Makeme, a 16 old girl from the Bupoto region; who is an extraordinary student, ranking at the top of her class. We are very excited about this new partnership, and have sent Rafiki Packs to 42 children with albinism in the first three weeks of 2013.

July 2013 Volunteer Trip

Plans are underway for our next trip to Tanzania in July of 2013. We will visit the Kabanga School and follow up on the projects we started last year. In addition, our volunteers will travel north to the Lake District area and hold an Albinism Awareness Day in that region. Our trip will once again include a vision teacher as well as a dermatologist.