

Peter Ash Casts High Vision for People with Low Vision in Tanzania:



UNDER THE
SAME SUN

“I have a dream that one day in Tanzania, people with albinism will take their rightful place throughout every level of society, and that the days of discrimination against persons with albinism will be a faint memory!”

- PETER ASH, FOUNDER

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Low Vision & Albinism

Making the connection between low vision and albinism was a primary focus of our education and advocacy during the most recent Trip to Tanzania. Very few people are aware of the fact that virtually all *persons with albinism (PWA)* suffer with some degree of low vision and that large percentages are legally blind.



This lack of awareness is found everywhere, not just in Tanzania. Our CEO & Founder Peter Ash and his brother Paul both have albinism. Throughout the course of their lives in Canada, they have encountered numerous medical doctors, optometrists and ophthalmologists who knew virtually nothing about the unique genetically caused condition affecting the eyes of PWA.



In Tanzania, this lack of knowledge has served to intensify the discrimination and the belief that PWA are not worth educating. What is often thought of as stupidity is simply low vision. If accommodated for, many PWA would excel in school and some even surpass the achievements of their fellow classmates with pigment.

Now here's a great story:

After hearing about the crisis of PWA in Tanzania on an ABC – 20/20 news documentary, low vision expert Dr. Rebecca Kammer promptly contacted UTSS and volunteered the services of her team to treat the eyes of PWA in Tanzania.



Dr. Rebecca L. Kammer is an Associate Professor of optometry and low vision at the Southern California College of Optometry (SCCO) in Anaheim, California.



She is familiar with the unique low vision condition related to albinism and has provided low vision care for numerous PWA including our CEO and Founder, Peter Ash.



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In preparation for her team's Low Vision Clinic (LVC) trip this June and July, she joined UTSS for a week in Dar es Salaam from May 2 – 7, 2011. During that time she ran a trial LVC in our UTSS office. The honoured patients for this clinic were Prime Minister Peter Pinda's 3 foster children with albinism along with the 10 UTSS staff who also have albinism.



To inaugurate the Low Vision Clinic and to emphasize the inseparable connection between low vision and albinism, UTSS hosted a press conference. Alongside Peter Ash and Dr. Kammer, Honourable Sophia Simba, Minister of Community Development, Gender and Children was in attendance. Upon making this connection for the first time herself, Hon. Simba said "This new awareness will revolutionize the way we understand and educate children with albinism."

Between the dates of June 19 and July 3, Dr. Kammer and her team of 5 will be providing low vision care to our Education Scholarship Fund (ESF) students in Tanzania. At this time they will be setting up 6 LVCs in 4 different locations.

Dr. Kammer has also found several optical companies willing to provide glasses frames, made-to-order prescription lenses and low vision devices AT NO COST.

Our sincere gratitude for the generosity of heart, time and resources goes out to Dr. Kammer, her team, the administration of SCCO and the eyewear donor companies, Duane Roughen from Kenmark and Collard Rose Optical. May God bless them all richly as they in turn bless children and adults with albinism in Tanzania.



ONGOING VISIONS IN TANZANIA: The Stories Continue

Manyashi is an 11 year old boy with albinism. He is a member of the first victimized family UTSS met with during our initial trip to Tanzania. Since his younger sister Mariam was killed 3 years ago, Manyashi has been:

- abandoned by his mother;
- removed from his loving grandfathers' homestead;
- placed in a government boarding school for disabled children for "safe keeping"; then removed and placed in a second offensive boarding school;
- adopted by a good foster family;
- and finally, placed into our Education Scholarship Fund (ESF) program in a high quality private boarding school along with his 3 pigmented biological siblings.

What a journey!! And it's not over.

On this trip Peter wanted to spend some time with Manyashi, chronicling the story of his young life so far.

We also wanted to help Manyashi integrate some of the fractured pieces of his life, so UTSS brought his biological family and his foster family together for a day.



Mother and stepfather



Grandpa and Grandma



Foster Father, John



Manyashi with new foster siblings



Kagera is a region in Tanzania where the killings of PWA have taken place. This Region is in the northernmost tip of Tanzania, surrounded by Lake Victoria, Uganda, Rwanda and Burundi. It is a 45 minute flight over part of Lake Victoria from the city of Mwanza to Bukoba Town in the Region of Kagera.



Just outside of Bukoba Town is a Government school for disabled children called Mugeza Mseto Primary School. There are 9 government schools like this one in Tanzania where large populations of children with albinism have been gathered for safe keeping. While UTSS Tanzanian staff has visited this school before, it was a first for the Canadian team.

These visits are always sad encounters for us since schools for disabled children in Tanzania tend to have significantly worse living conditions than schools for non-disabled children. While there, we toured the classrooms, kitchen, dorms and property.



We met the school administration and teachers as well as all the PWA students. We were able to give them sunscreen, sunglasses, treats and teach them how to apply the sunscreen and care for their skin and eyes.

A number of families from the region who were victimized by attacks or killings travelled long distances to meet us at the school and tell us their stories.





Emmanuel Festo

One of the highlights at this school was seeing the face of Emmanuel Festo in the crowd of students.

He is one of 10 survivors of machete attacks in Tanzania that we profile in our HON-OUR ROLL. Until this day we had only seen pictures of him. Peter interviewed Emmanuel and his father.

During the interview, Emmanuel wanted to show Peter how he has learned to write with his missing left arm and mutilated right hand.

On our return trip to the airport, we stopped in Bukoba town to meet Mr. Raza, a generous Tanzanian businessman and philanthropist. He has paid for the reconstructive surgeries of Emmanuel's hand. He is involved in the making of prosthetic limbs for attack victims as well as medical care for skin cancer.



Mr. Raza



One of our most disturbing moments was when Raza introduced us to a 28 year old woman with albinism who had come to his office the previous day covered with sun damage and skin cancer. He told us how much her medical care would cost and invited UTSS to share in this cost.



The most hopeful part of our trip to Tanzania is when we get to visit one of the ESF schools. The kids in these schools are the concrete results of UTSS efforts in Tanzania. This time we visited Jelly's School in Mwanza where Manyashi and his 3 siblings are attending.

While visiting and drinking pop with the kids, Peter asked how many of them knew what they wanted to do with their lives when they finished school. A good number of kids did. Peter invited them up one by one to tell him and their peers their ambitions. Among them was a business woman selling clothes, a teacher, a medical doctor and a priest. The "young priest" offered a blessing on our gathering before we departed.



Mwanza Region is the epicenter of the recent attacks and killings. On this trip we were able to do some intensive education and advocacy in the city of Mwanza.



Mwanza Church Leaders

We held 2 screenings of our documentary; *White and Black: Crimes of Colour*. One screening was with a group of church leaders and the other with a group of local officials. In both cases it was presented in their mother tongue, Kiswahili.

On Sunday morning, Peter also addressed a local church on this topic. There was not a single PWA in the congregation. This did not go unnoticed as we called them to show the love of Christ to all of God's children, not just the ones with pigmented skin.

In all 3 events, our message about albinism was revolutionary to the people of Mwanza. It was received with surprise, gratitude and promises of new openness and understanding to their fellow citizens with albinism. We hope this carries on.



Misungwi District Commissioner



Lest we think the attacks and killings have stopped, a sobering story was told at the screening with the church leaders. A young lady and her baby were among those in attendance by special invitation.

Sabina is the 22 year old mother of Meimosi, her 12 month old infant with albinism. They have managed to narrowly escape 2 attempts on Meimosi's life; one in December of 2010, and again in February, 2011. Both attempts took place in their home on Ukerewe Island on Lake Victoria where it was assumed to be safer for PWA to live.

Even if the attacks and killings in Tanzania were to stop today, the real problem of profound discrimination and ignorance as it relates to albinism is enormous. Our goal is to capture something that is way beyond our control; we hope to capture the hearts and minds of Tanzanian citizens. We know that the battle against stigma and discrimination takes generations to achieve.



UTSS is in this battle for the long haul.

PETER ASH HAS CAST A VISION; he has painted a picture that all of us at UTSS want to be in.

HOW ABOUT YOU?



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