

Case studies (some names have been changed to ensure confidentiality)



Beatrice

98% of people with albinism in Africa die from skin cancer well before they reach the age of 40. Excluded from employment and living in poverty, they lack access to basic medical care, never mind life-saving surgery. Many like Beatrice don't have the basic knowledge about their condition needed to protect themselves or the money for suitable clothes, hats or sunscreen.

Beatrice has benefited from the cryosurgery that Advantage Africa introduced to Uganda in 2015 and subsequent skin clinics and sunscreen.



Cherish

In East Africa, the body parts of people with albinism are believed to create great wealth. Limbs, hair and nails are in high demand by witch doctors and their clients.



On two occasions a witchdoctor tried to break into the mud home of 6 year-old Cherish in order to abduct her. Following the second attempt, she and her guardian fled from their home. Cherish is now being looked after by a foster family.



Lesah

When this picture was taken, Lesah, (pictured here with her uncle) was 16, weak and six months pregnant. She was forced to drop out of school after she was raped by her teacher. The teacher was ashamed - not because he preyed on a pupil in his care - but because of the derision that having sex with someone with albinism attracts.

Lesah's sister died when she was 6 years old from skin cancer and her own skin is rough, dry and covered with painful weeping sores.

Advantage Africa helped her recover from this trauma by supporting her from its Severe Hardship Fund for people with albinism.

Her skin was checked by a health professional and she was provided with the a protective hats and sunscreen that she couldn't afford herself. She is now back in school, and her baby is well cared for by her family.



Ibrahim, Faruk, Rashid and Ismail

Before Advantage Africa came to their village, these four brothers with albinism had never owned sunscreen or wide-brimmed hats and didn't know about the importance of protecting themselves from the intense sun. Our dermatologist has told us that all four of the boys had small developing cancers which needed urgent attention. This were then treated with cryotherapy.



Here, Peter talks to the boys about the importance of wearing their hats whenever they are outside and gently shows them how to apply sunscreen to all exposed areas of their skin.

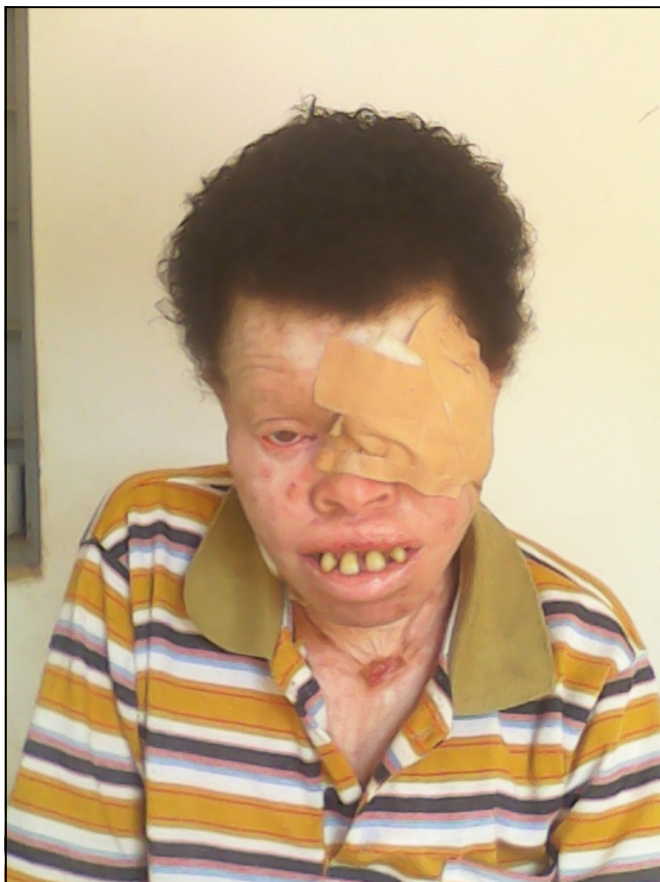


Miriam

Miriam is only 20 years old but sun damage and solar elastosis on her neck means she looks many years older. The bullying she experienced made her drop out of school. She married young but when her husband was ridiculed because of his choice of bride he became violent and almost killed her. Then he left her - destitute and with a young baby.

Until recently she has no means to earn an income and was fearful of what the future holds.

Advantage Africa helped Miriam and her daughter get back on her feet through our Severe Hardship Fund.



Justine

Justine is a single mother in her late twenties who was diagnosed with severe skin cancer around her eye, on her neck and on her chest earlier this year. With support from Advantage Africa she has had life-saving surgery and skin graft operations.

She has now been declared free from cancer. Following after-care support by our dermatologist to monitor her wounds and keep them free from infection, Justine has returned home to her family with great joy and celebration.



Simon

Simon (pictured here with his new hat and sunscreen) is four years old. He has four siblings with albinism, including the baby pictured left with their mother. The family lives in extreme poverty in a small, rural village in Busoga region. An attempt was made to abduct Simon's older sister as she was walking the three-mile route to school. Their parents have become aware that witchdoctors are targeting their children and they are very fearful for their safety. As a result none of the children have been allowed to go to school since the attempted abduction and they all stay confined within their small compound where their relatives can keep an eye on them. They are living isolated, fearful lives with no chance to learn or make new friends.

Advantage Africa is addressing such cases locally and nationally. The celebration of International Albinism Awareness Day on 13th June has reached out to around 10 million people through national media with a message about upholding the human rights of people with albinism and ending their persecution.



Julia

It's a common belief in Uganda that people living with albinism are ghosts. Julia was abandoned by her parents when she was very young and both adults and children avoided her. Now aged 12, Julia is being cared for by loving foster mother Rebecca (pictured) and she has been able to start school.



The lack of pigment in the eyes of children with albinism means they have varying levels of visual impairment. They struggle to see the blackboard unless allowed to sit up close, but not all teachers understand this or make any allowance for their condition.

When a teacher refused to let her join his class, Julia was forced to repeat a school year. Her experience is typical of the exclusion, discrimination and loneliness faced by children with albinism in Uganda that's being addressed by Advantage Africa's project.



Sharik

Sharik's mother says she 'lost her esteem' when Sharik was born because of the stigma of albinism. The community said her child was 'a caterpillar'. Her husband's parents 'chased her around' and her husband left her but she remained 'grateful to God' for her child.

At school Sharik faced bullying and 'could be beaten up when he crossed the road'. But his family's determination and love for each other enabled him to overcome such prejudice. Over the years, they have changed the understanding and attitudes of those around them towards people with albinism and 'now everyone wants to be his friend'. Sharik represents youth and his local District on the SNUPA committee. He is always ready to stand up and speak, as he does here to teenagers at his old school, about 'no magic, no witchcraft, just albinism'.



Eliza

Eliza was diagnosed with a basal cell carcinoma in 2010. Before then she had never used sunscreen or hats and didn't know how to protect herself from the sun. She lived in extreme poverty and had no means to undertake the fairly simple procedure of having the cancer removed. The cancer spread and slowly covered her entire face. IN the last few years of her life she would hide away from people beneath a scarf and eating and drinking were painful and difficult. The level of intervention and facial reconstruction Eliza needed required international expertise, significant funds and Eliza's potential separation from her family.

Eliza wa a recipient of Advantage Africa Severe Hardship Fund and we ensured she had the painkillers, (including morphine) and emotional support that she needed before she died. In the final year of her life she went on national television to call for action on behalf of people with albinism, especially the provision of sunscreen to prevent skin cancer.

Her case highlights the importance of sun protection and early intervention. Through education, training, sunscreen, hats, protective clothing and early detection of removal of skin cancer with cryotherapy, Advantage Africa aim to ensure that nobody with albinism in Uganda, finds themselves in such a desperate situation.

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