

Hidaya's Story:

In Black and White

Read Hidaya's story below and map out a pedigree of all named individuals, shading in only those affected by albinism. Then determine whether the trait is autosomal or sex-linked and whether it is dominant or recessive. Your evidence should include each individual's genotype above each symbol (O for females and □ for males) and their name below each symbol.

Hidaya was always different. Growing up in Tanzania as a person with albinism, the lack of pigment in her skin, eyes and hair made her stand out among her dark-skinned peers. She grew up in Babati where she felt relatively safe, but it was no secret what happened to albino people in other parts of Tanzania. She knew that many albino people were sometimes mutilated or murdered because of the belief that their bodies possessed magical powers. She had heard frightening stories of children's hands and other body



parts being removed because they could be sold for large amounts of money. There were still beliefs by traditional medicine men that certain body parts from albinos could help cure disease, improve fertility, and even bring good luck and prosperity. This lack of education seemed to be more common than Hidaya once thought.

Hidaya did not have anyone but her mother and cousins in their village and, as she grew older, she longed to more about her heritage. When she came of age, she asked her mother to tell her why she had no other family like the others in Babati. Her mother, Heruma, decided it was time to tell her about her past and the family they left behind. She explained that Hidaya was born in Mwanza, Tanzania. The killings and mutilations of albinos was common there and, from the moment Hidaya was born, Heruma knew she was not safe. Her father, Hatari, was outraged and claimed that Heruma had evil spirits that caused their baby

to be born this way. Heruma begged Hatari to keep their baby a secret until she could find a safe place to go with her. Hatari was embarrassed and left the village. Heruma's cousins lived in Babati and she knew this to be a safe place where no killings had occurred. Over the next few days, Heruma prepared to leave with her baby with the help of Hidaya's grandmother Afifa and grandfather Jalil. Heruma also had 2 sisters, an older sister named Kani and a younger sister named Fathi, both of whom were dark-skinned.

The trip to Babati from Mwanza was long as it was over 350 kilometers away. But Heruma knew that she would have had to travel far as, once the villagers in Mwanza learned of her baby, Hidaya would have been at risk. So she traveled as far as she could, knowing that Babati was a safer place for Hidaya. On this journey, she talked with her parents about her ancestry. Afifa said both her own mother Ituri and father Marzuku were both dark-skinned but that she had a grandmother named Rim (pronounced reem), Ituri's mother, who was albino. Afifa loved to tell the story of her grandfather Sadiki and how he fell in love with Rim even though she was an outcast for being albino. Rim was the only person in her family who had this trait. Jalil explained that he had not known anyone in his family that was albino. Heruma knew this to be true as she had never met anyone in her family that had this phenotype.

After hearing Heruma's story of her journey to Babati, Hidaya asked about her father and his parents. Heruma had only met Hatari's parents a few times as they were from Kenya, but they were dark-skinned and she knew nothing about any of his other family members.

Hidaya came to respect the local nurses and doctors who visited Babati and helped her with her condition. Like many people with albinism, she had issues with her vision and her skin was extremely sensitive to the sun. Years later, Hidaya decided that she wanted to go to Muhimbili University of Health and Allied Sciences in Tanzania where she could become a nurse and help others. While there, she met Saburi, a student from Kenya. Saburi reminded

Hidaya's Story (Continued)

Hidaya of her grandfather with his dark eyes and tall stature. Over the course of a year at the university, they fell in love and planned to get married after graduation.

Hidaya had asked Saburi about his family and whether any of its members had been born with albinism. He lived with 4 generations of his family and none had ever shown this trait. They graduated, marrying soon after, and had their first child, a son named Salmini, who was born dark-skinned. Both Hidaya and Saburi began working for the Global Medical Relief Fund which helps provide prosthetic arms and legs to children in crisis zones, like those albino children in Tanzania. Hidaya felt lucky to have escaped the pain and suffering that many other albinos experience in Africa so she felt putting her talents to work to help others was the perfect path for her. They went on to have two more children as well: Barati, a daughter, and the youngest Baraka, a son. All of their children were dark-skinned though Hidaya suspected the gene could show up in generations to come as it did with her.

Based on case studies from Stensson, E. (2008). The social stratification of albinos in Tanzania:

A case study from Babati, Södertörn University College.

For more information on how the Global Medical Relief Fund helps albino children, visit <http://www.gmrfchildren.org>