Albinism Awareness Month

This month, we want to bring awareness to albinism, a genetic trait that affects about 1 out of every 18,000 people. People with albinism have a reduced amount of melanin – the substance that produces pigmentation for your hair, eye, and skin – or no melanin at all. As a result, people with albinism often have white or very light blonde hair (although some have brown or red hair), white skin and eyes that are gray, blue, green or pink. Due to melanin being involved in the development of the retina, albinism affects eyesight and can even cause blindness. That means a student with albinism may need extra help and support at school.

The National Organization for Albinism and Hypopigmentation (NOAH) offers a School Kit that includes informational sheets for teachers, documents to help guide conversations between parents and educators, templates for student involvement in conversations and advocacy, thorough explanations of eye issues, and ideas for IEP accommodations. This School Kit was designed in collaboration with a team of teachers from the Texas School for the Blind and Visually Impaired.

Equity Heroes



Megan Cauthen has albinism, but her daughter Kaliegh does not. When Kaliegh asked her mother to write a letter to her classmates, answering their questions about why her mom is so white, Ms. Cauthen did more than a letter – she wrote a children's book – Nellie and Ollie: Meeting a Friend Like Me. It describes the friendship between a little girl with albinism and an albino squirrel.



Thando Hopa is a South African attorney who became a fashion model after being spotted by designer Gert-Johan Coetzee. By 2019, when she became the first woman with albinism to appear on the cover of Vogue as well as the subject of the cover story inside, Ms. Hopa had also become an activist for inclusion. She has spoken at many conferences and written articles about her experiences with albinism.



Brother Ali walks to his own beat as a hip-hop artist living with albinism. Many of his lyrics reference his unique life experiences, but his activism doesn't end behind the microphone. Brother Ali is a voice for many marginalized communities and his podcast Travelers Podcast explores cultural and spiritual topics.



Natalie Devora is the author of Black Girl, White Skin: A Life in Stories. She was senior editor for Ache: A Journal for Lesbians of African Descent and has been featured on NPR's Code Switch and The Top Of Mind podcast.



Because it is relatively rare, albinism is often misunderstood. Here are some basic facts:



Meet Migaloo, an albino humpback whale; Snowflake, an albino gorilla; an albino penguin, and one member of a large population of albino squirrels that enjoys special protections in Olney, Illinois.



If you have a suggestion for an Equity Hero theme, please email equity@isbe.net.

Photos

Natalie Devora: KALW Public Media | Megan Cauthen, WBTV | Thando Hopa: ThislsAfrica.me | Brother Ali: brotherali.com | Humpback whale: Queensland.com | Gorilla: Wikipedia | Albino penguin: iflscience.org | Squirrels: stltoday.com