

BHAVI 2024 Guardian: Peter Ash, MA

BHAVI Awards Committee

Brain Health Alliance, Ladera Ranch CA, USA

BHAVI Symposium online 9 October 2024



Peter Ash and Friends



“People with Albinism: Not Ghosts But Human Beings”

United Nations Office of the High Commissioner on Human Rights

“Meet the Champions of the Albinism Cause: Discover inspirational stories told by persons with albinism, their supporters assisting them medically and those advocating for their human rights.” albinism.ohchr.org
UnderTheSameSun.com
Peter Ash, Founder



Honoring Mr. Peter Ash



BHAVI 2024 Guardian of Truth and Integrity: We honor and thank Mr. Ash as our 2024 Guardian in recognition of his devoted service to people with albinism in support of the health and wellbeing of these individuals who face discrimination and death in countries around the world.

Hearing about atrocities committed against children with albinism in Tanzania, [Mr. Ash](#) founded [Under the Same Sun](#). The work of this charitable organization helps to save lives of these children with albinism. As a person with compassion for humanity who cares for others and who has albinism himself, Mr. Ash began his mission of helping children in Tanzania. His organization Under the Same Sun has created safe places to learn and given new life to these children. Mr. Ash has worked to bring the plight of those with albinism to the United Nations and to advocacy groups across Africa and the world. His work has saved lives and provided hope, education, opportunities, and a brighter future for people with albinism.

People with Albinism Face:

- Staring strangers
- Ostracism and bullying
- Rejection by their families
- High risk of skin cancer (Wright et al. [2014](#))
- Risk of becoming victims of murder in countries where people believe a person with albinism is a ghost or bad luck
- Risk of being murdered for profiteering *to sell their body parts*

The Genetics of Albinism

- People with albinism have skin and hair without pigments like melanin, the biochemical that creates the variety of color tones we see across humanity. Albinism may be associated with a visual impairment relating to a lack of pigment in the eyes. (Liu et al. [2021](#); Federico et al. [2023](#); Galli et al. [2023](#))
- Most causes of albinism are genetic and almost all of those are *autosomal recessive* in inheritance. The birth of a child with albinism should not target the mother, causing her to be 'rejected' by the family, since both parents must be carriers of a pathogenic variant. (Montoliu et al. [2013](#); Fernández et al. [2021](#))
- Some people with forms of albinism have partial loss of pigment and have lighter colored hair, eyes, and skin than their family.
- Other pigmentary disorders, including vitiligo, are not strictly genetic, but may be caused by contributing factors related to the immune system and environment.

Autosomal Recessive Inheritance

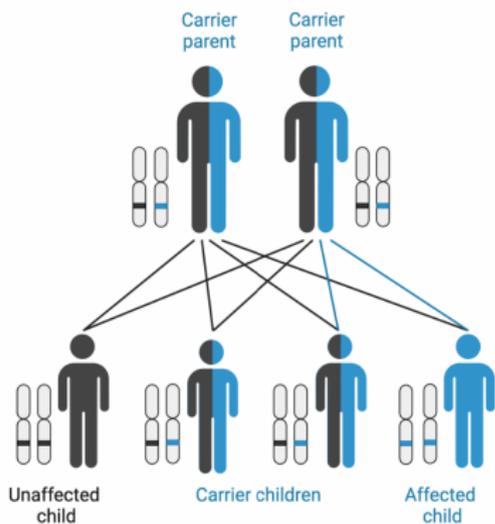


Diagram by Melissa Hardy reprinted [CC BY-NC](#).

- If both partners are carriers of a pathogenic variant in the *same* disease gene, there is a 25% chance with each pregnancy of having a child affected with the disease.
- If both partners are carriers of a variant in *different* disease genes, there is very low increased risk to have a child affected with either disease, although the child can be a carrier for one disease, or the other, or both. (There are some digenic presentations!)
- Males and females are equally likely to be carriers and are equally likely to have the disease.

Peter Ash, a Short Biography

- Peter Ash was born in Montreal, Canada, the youngest son of three siblings. One of his older brothers also has albinism.
- He obtained a Bachelor of Arts degree in theology from Peace River Bible College and a Master of Arts degree in counseling from Providence Theological Seminary. He worked as a pastor and as an entrepreneur and businessman. Along the way, he moved to Vancouver, married, and became a father.
- In 2008, he read about the [killings of people with albinism](#) in Tanzania. The compelling video evidence documented by newswoman [Vicky Ntetema](#) about the horrific trade of body parts from murdered people with albinism sparked Mr. Ash's activism.
- Within a year, he was in Tanzania advocating for people with albinism. His work spread across Africa and around the world.

Peter Ash, a Gallery



Vitiligo

- People with vitiligo (Jan et al. [2023](#)) may face the same ostracism and discrimination as people with albinism.
- [Michaela DePrince](#) was born in Sierra Leone and was put in a cruel orphanage as a toddler after her mother died. She was called a word that meant she was the least of the orphans due to her pigmentation.
- She was adopted by an American family along with her best friend from the orphanage.
- She became a celebrated ballerina with the Boston Ballet, the Dance Theatre of Harlem, and the Dutch National Ballet.
- Unfortunately, she died at age 29 in September 2024.

Michaela DePrince, Ballerina (1995–2024)



The United Nations and African Albinism Network

- The advocacy of Peter Ash and Under the Same Sun brought the plight of people with albinism, especially those in Africa, to the United Nations.
- Over the past 11 years, Under The Same Sun has brought together a global association of advocacy groups including the United Nations.
- The African Albinism Network grew out of that association of advocacy groups.
- Note that albinism is not solely found in Africa, although there are more carriers of some types of albinism who are of African descent.
- Albinism can be found around the world.

The Global Alliance for Albinism



January 2020, Paris France

Advocacy for Albinism

- Under The Same Sun
- Learn More about Under The Same Sun
- 10 Years of Under The Same Sun
- Africa Albinism Network
- Global Albinism Alliance
- UN Champions of Albinism
- Urgent Calls for Protection (2024/06/19)
- US NLM on Albinism
- UK NHS on Albinism

Cited References



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Fernández, Almudena et al. (May 2021). "Genetics of non-syndromic and syndromic oculocutaneous albinism in human and mouse". In: *Pigment Cell and Melanoma Research* 34.4, pp. 786–799. ISSN: 1755-148X. DOI: [10.1111/pcmr.12982](https://doi.org/10.1111/pcmr.12982).



Galli, Jessica et al. (Apr. 2023). "Oculocutaneous albinism: the neurological, behavioral, and neuro-ophthalmological perspective". In: *European Journal of Pediatrics* 182.6, pp. 2723–2733. ISSN: 1432-1076. DOI: [10.1007/s00431-023-04938-w](https://doi.org/10.1007/s00431-023-04938-w).



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Wright, Caradee Y., Mary Norval, and Richard W. Hertle (Oct. 8, 2014). "Oculocutaneous Albinism in Sub-Saharan Africa: Adverse Sun-Associated Health Effects and Photoprotection". In: *Photochemistry and Photobiology* 91 (1), pp. 27–32. DOI: [10.1111/php.12359](https://doi.org/10.1111/php.12359).

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