



“ALBINO” VS “PERSON WITH ALBINISM (PWA)”

OFFICIAL POSITION OF UNDER THE SAME SUN (UTSS)

As a group advocating the dignity of persons with albinism, UTSS prefers the term “Person with Albinism (PWA)” and its similar variants over the term “albino.”

This is not only because of the historically derogatory use of “albino,” but also because the term, PWA, puts the person before their condition.

That said, we understand that the world is currently in transition from the use of “albino” to PWA hence, in some rare instances, we might be forced to use albino if the use of PWA compromises a relevant and important message being conveyed.

REASONS FOR OUR POSITION

- **Albino**
 - **Albino is a word that captures both a person and her condition**
 - **Therefore to use the word albino is to equate the person to her most visible aspect: albinism**
 - **This equation of person with visible condition is contrary to global efforts to advance the dignity of *all* persons**

- **Albinism**
 - **causes not only pale skin, hair and eyes**
 - **It is also a mal-formation of the eye structure**
 - ***As a result, persons with albinism have a visual disability that causes legal blindness**

- **In Canada and several countries of the world, PWA are registered as legally blind and are a part of the community of persons with disabilities**

Analogies to help you understand our position

“Negro:”

This is a word that on its own seems innocent. It merely means black in some languages. Yet the historical treatment of the word and the people to whom it referred, has rendered it an offensive identifier.

“Hey, (insert genetic condition!):”

If I cannot appropriately yell across the street: “Hey blind man!” Or “Hey! Genetic heart condition,” then yelling across the street, “Hey albino!” is equally offensive. As the world advances the dignity of all persons, no one with a disability should be referred to solely by their genetic condition.

The gentle remark: “He is albino:”

Contrary to what you see in movies and hear on the street, it is not respectful to say to your friend, “Hey, look at that albino clerk.”

As the world advances the dignity of all persons, no one with a disability should (even with the most polite tone and intent) be referred to *solely* by their disabling condition. Rather, you may say for example, I think that clerk has albinism.

With your freedom of speech, language becomes an easy and powerful way to help.

---Play your part today.

Speak your contribution to the dignity of personhood!

REFLECTIONS ON ALBINISM

“Albinism is etched in our imagination, yet the condition is rare enough in daily life that it has no human face. We carry the condition; the world carries its weight and meaning. Such deep-set words are hard to extract. Still, it’s hard sometimes not to resent albinism’s role as one of the last unmitigated means to marginalize and ridicule, especially as we are so swift to parse out people from their condition. It’s no longer “Idiot Savant,” it’s Savant Syndrome, not “Siamese twins,” but conjoined. Not “albino,” therefore, but person with albinism. In the beginning was the word. It’s still here. One day, education will dispel ignorance and decency drive it out altogether. Until then, please refer to my condition, and use my name.”

ANDREW LEIBS

WRITER AND PERSON WITH ALBINISM