



Information about Albinism

National Organization for Albinism and Hypopigmentation

African Americans With Albinism

Many people ask if the incidence of albinism in non-whites is higher than in whites. The answer is no. The incidence seems higher because people with albinism born into non-white races are more instantly recognizable, and because traditional studies of albinism have been done in smaller closely related tribes where there seem to be more affected individuals.

Physical Differences

Whereas the majority of whites with albinism have pale blond or white hair, pink white skin, and blue eyes, black persons with albinism tend to have hair of a deeper, brighter yellow, cream-colored skin, and green or hazel eyes.

Although the physical problems of low vision and sun sensitivity are the same for both whites and non-whites, the social problems of non-whites are compounded. In the Caucasian races blond hair, blue eyes, and alabaster skin are considered so highly desirable that brunettes often bleach their hair or wear colored contacts. The Victorians wore white wigs and powdered their skin to a chalky white. Fairy tale heroines are said to have skin white as snow.

The same physical attributes in darker races are taboo. Individuals in these races often are ostracized because of erroneous beliefs and unfounded fears. A basic theme in

many variations in that God is delivering judgment on a family with albinism and that the individual with albinism is cursed, or is the embodiment of sin. In some religions and societies, this curse may seem true. Anyone taking as a partner a person with albinism must be prepared to suffer ridicule and disapproval from family, friends, or even the church.

Another belief is that the person with albinism is the result of incest or inbreeding. The most common myth of today is that the non-Caucasian person with albinism must be the result of mixed marriage. Those who hold this view are unaware that people with albinism existed in societies of color before those societies had any contact with Caucasians.

Peers sometimes accuse black people with albinism of "trying to pass." Indeed, some have found having albinism so painful that it is simply easier to be "white." Peers may believe that the hard-earned achievements of a black person with albinism resulted from a white teacher or supervisor favoring the him or her.

The Family of Color with Albinism

Misunderstanding of the causes of albinism is sometimes the catalyst for extra family stress. An already distrusting and jealous father may feel that his partner has cheated on him with a white man. He may be unable to accept the child as his. He may treat mother and child harshly, or even leave altogether, goaded by family and friends.

Though the mother knows that she has been faithful, only recently has blood testing allowed her to prove it. If the father stays, he may make the child with albinism the target of subtle or outright resentment. Family dysfunction such as alcoholism, drug abuse, or mental illness may compound the problems for the child.

If the mother feels "stuck" with childcare and custody, she may abuse or even abandon the child. She may endure disapproval from both races, because some people still frown upon what they assume to be interracial coupling. Mothers have reported being mistaken for baby-sitters, or in extreme cases, kidnappers.

On the other hand, many parents, after their initial shock, say they feel that their albino child is a special gift to them. They find the "golden" children attractive and welcome additions to the family, and they are quite proud of them.

School age children and teenagers with albinism often find themselves left out of extracurricular activities and social events by other black youth. Children with albinism may learn to avoid rejection by withdrawing. The child's peers then may see him or her as unfriendly or even hostile, and a cycle of isolation is set up.

Children with albinism may learn to compensate for their lack of self-esteem by striving harder in school and other activities. They tend to exceed at whatever they try. Many Black people with albinism have succeeded as technicians, legal assistants, entrepreneurs, computer programmers,

preachers, college professors . . . the list goes on and on. Once overcoming the low self-esteem brought on by early social stigma, people with albinism often become high achievers.

Coping

Coping and dealing with albinism has run the gamut from being militant in one's racial conviction to wearing dark make-up and hair color or surgically altering one's appearance to pass for white. Some may argue that these may not be coping at all. From my point of view, coping meant coming to the realization that this is exactly what the creator wanted me to be. My albinism was present with me since my creation, from the earliest stages of development in the uterus. I am a typical person with albinism. My hair, skin, and eye color are in no way different from other non-white people with albinism. To me, albinism is a situation no different than that of a redhead being born into a family of brunettes.

My other coping mechanism is the realization that albinism is an old, old "race." We have been recorded in every part of the world, in every era, in every culture known to humans. It has been said that we may represent in fact the oldest recorded genetic condition.

---Virginia Small, NOAH Director

---Reviewed by the NOAH Albinism Awareness Committee: James Haefemeyer, MD, MS, CHair; NOAH Board of Scientific Advisors; Janice Knuth, MSW, ACSW, LSW, President, NOAH 1982-1993; Charla McMillan, MS, President, NOAH, 1996-2000; Michael McGowan, President, NOAH, 2001-2002.

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