

Albinism and Race

By Marcie Pan | Monument, Colorado

Our son has OCA2 and was born with blonde hair, blue eyes, and very fair skin. We were scared at first. Nystagmus caused his eyes to swing back and forth like a pendulum, and they appeared unable to focus. To our delight and relief, we learned that his sight was intact. Still, one problem remained: he did not look like his father.

My husband is a very handsome Taiwanese transplant. His family fled China during the regime of Mao Zedong and never looked back. He has brown skin and dark eyes and hair. I am interracial, half African American and half Caucasian with blue eyes and brown hair. From our understanding and expectations, our son “should have” presented with dark eyes and hair. When our son emerged with recessive traits, we did not know why. Friends and family were similarly, sometimes disconcertingly, and often uncomfortably perplexed.



As his parents, we did not care what he looked like. We were just delighted that he was healthy. But, starting with his first unveilings through baby pictures and visits, comments questioning his appearance, such as why his eyes were blue and if/when they were going to change color, robbed attention from the good news of his birth. Instead of sharing in the excitement of our new arrival or reflecting on the beauty in his face, people remarked, “He doesn’t look like either of you.”

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Mercifully, my husband was unaffected by the controversy. But I was deeply hurt. What did these people around me mean by their comments? He was born the way God made him. Were they suggesting he was switched at birth, or worse, not my husband's son? These critiques and insinuations began stifling the joy of becoming a new mother.

Appearance aside, we needed to understand the nystagmus. Our pediatrician recommended genetic testing to provide insight. We agreed, wanting to confirm the diagnosis and ensure the proper treatment. Testing confirmed the OCA2 gene mutation, a configuration resulting in a reduction of the body's pigment (melanin) production. This explained his light features, and, more importantly to us, the state of his retinas and fundus. At least we finally had some answers.

A layer of relief came from knowing I now had the concrete, medical facts with which to repel the doubting minds of all those questioning our son's appearance. Truthfully, I hoped this new ammunition would push the shame back on the very people that perpetuated it. However, over time I came to the disappointing revelation that no diagnosis would remove the shame I felt for allowing those "friends" and "family" to strip away my

initial joy of welcoming our son into the world. I allowed their curiosity and disbelief to drive me in a desperate search for answers when the only thing I really needed to know was that my son was going to be able to thrive.

Coping with these disheartening feelings led me to the root of my susceptibility to matters of identity and appearance. These feelings grew from insecurities about my own identity, growing up interracial and struggling with my own acceptance as a child in a world still saturated in racism and categorization. That same turmoil burst through as I imagined my son inheriting the same fate: not accepted, not acceptable, not part of, not like others.

I hope people will take responsibility for their hurtful words and gossip. Some may even apologize. For now, I am not yet ready to take all of that on. I am still working on forgiving myself. My own struggle with self-worth prevented my dismissing these slights and allegations from the start. This article is the beginning of my healing journey to make sure that I never fall into that trap again.

For all the mothers out there with children that look or act "different," I am rooting for you and your child. You are both worthy of every happiness. Everyone in your life that really matters will come to agree!