



*My daughter,  
her albinism and  
the world as we  
now know it.*

# A Whiter Shade of Pale

*By Kara Pound*

Let's not candy-coat it. Giving birth hurts. But the outcome, a tiny person who grew inside you for 10 months, gives you this surge of adrenaline that makes you feel like you can conquer anything. So when the pediatrician on call comes into your hospital room 10 hours after your daughter is born, wearing one of those sullen doctor faces you've seen on TV, the adrenaline encourages a false sense of invincibility. You know he's preparing to tell you something serious, but you're also sure it won't be more painful than what you just went through.

He begins by asking if either my husband or I have ever had a family member born with white hair. The question doesn't make sense; people die with white hair, they're not born with it. I look at Ryan blankly, as if he might deliver the punchline. But Ryan looks as confused as I am, and the doctor's serious expression doesn't let up. He prods, "Has anyone in your family had albinism?"

The word hangs in the air for a moment: *albinism*. It seems vaguely familiar, sort of like the word "albino." I scrunch my face up in typical journalistic-style and prepare to ask a stream of questions, but no words come. I've done no research and, honestly, I have no idea where to begin. The doctor goes on to say that he's 99 percent sure our daughter has albinism. He noticed her white hair right away, and when he did an eye exam, he saw very little pigment. He points to my own fair, Irish skin and observes that it's helpful we're Caucasian, because "socially, she won't look that different from you." However, he continues, she will likely have vision problems, her hair will probably remain white and her eyes and skin will be extremely sensitive to the sun.

"Well," my husband says after a moment. "There goes my dream of her becoming a pro surfer!"

The doctor doesn't seem to get the joke. Or maybe he doesn't find it funny, but he assures us that our daughter is otherwise healthy and, in typical doctor fashion, drops his bomb and leaves the room.

For a few minutes, Ryan and I just kind of stare at each other. We laugh, I cry (he tells me to buck up after about 30 seconds) and we immediately ask for our daughter back from the nursery. The nurse says it will be another hour — the staff is still checking her over — so we start to think about how the other people in our lives will take the news.

Our parents all left the hospital about an hour earlier and went to a restaurant down the street. We begin trying to reach them. Ryan's dad is the first to answer his phone and we spare the drama and blurt out something like, "Congratulations. Your granddaughter is an albino!" He passes the news along to

the other parents at the table. They're cute and supportive and probably half-drunk, and of course just as clueless as we are about what it means.

We hang up. By now, it's nearing bedtime, and I can't believe the day I've had. I'm exhausted, my body feels like a war-torn Third World country and apparently I've just given birth to a genetic lottery winner. I do a quick Google search of albinism and look at the Wikipedia entry, but I don't truly read it. I'm not ready for what it says. But I swear that I will eventually learn everything there is to know about albinism and I will become our daughter's biggest advocate. She is named Honora Louise and she is perfect.

**A**lbinism comes from *albus*, the Latin word meaning white, and is characterized by a lack of pigment in hair, skin and eyes. It's a genetic condition, due to absence or defect of an enzyme involved in the production of melanin, and it occurs only when both parents carry the recessive gene for albinism. About one in 70 humans carries it, and in our case, both Ryan and I are carriers. I've read conflicting statistics about its frequency, but a woman who did extensive research for a "20/20" ABC special told me that among Caucasians, albinism occurs about one in 35,000 — the genetic lottery.

An absence of melanin, the stuff that colors our skin and protects us from sun exposure, obviously affects appearance. But the lack of pigment also means the retina doesn't fully form and can lead to a number of vision

defects, such as photophobia (light sensitivity), nystagmus (involuntary eye movement) and astigmatism, which results in distorted images. Honora has all three.

There was no indication of Honora's albinism before she was born. Because it's a genetic condition, it can be detected by prenatal tests, but if you aren't aware of any family history, as in our case, it's not a routine test. And until the day Honora came into my life, what I knew about albinism couldn't fill a page. I've come across

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only a few albinos in my life (a fellow student at Flagler College and a musician in a reggae band when I was on vacation in the Bahamas), and probably regarded them much as any normally pigmented person does — as a novelty. But I've never known any personally, which is doubtless due in part to their scarcity.

When Honora was diagnosed, I did a lot of research on the albinism community. One of the most prominent organizations is the National Organization of Albinism and Hypopigmentation, a group that aims to both inform and connect the albino community. (They also, incidentally, frown upon the use of the word albino, preferring the gentler "people with albinism.") A friend bought us an annual family membership, and the organization sent us an albino care package, complete with baby sunscreen and a full SPF suit. But we're waiting until Honora is older to see how involved she



Ryan and me last summer (top), and with Honora on her first day of life.

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wants to get in the NOAH community. We don't want her to grow up thinking that albinism defines her. We're hoping that instead of a disability, it feels more like a characteristic — like having red hair or green eyes.

At the same time, the temptation to reach out to others affected by albinism is strong. Within months of Honora's birth, I'd contacted the parents of some of the other albino children in the region. There are roughly a dozen in Northeast Florida. As rare as albinism is, it runs in families. For two parents with the gene, there's a 1-in-4 chance that a child will be born with albinism. Which starts Ryan and me thinking. Though neither of us is ready to talk about having another child, we can't help but think about it in terms of Honora's needs. In a world where being different is so difficult, she'll need as many allies as she can get.

Once we start to settle into parenthood, we call our close friends to tell them about Honora's albinism. I wasn't sure if some might've already guessed from the pictures we posted on Facebook; it's hard for me to know just how different she looks from other "pigmented" babies. Most of our friends just posted comments like "Wow! What a blondie" or "Looks just like mommy" (I'm practically translucent). Once we start telling people, I quietly collect their reactions. "I don't feel sorry for you because you're not crying and you don't seem upset," one friend says. Another jokes, "If nothing else, she will be MTV's DREAM candidate for 'The Real World' when that show enters its 72nd season and they shoot it on the moon." One friend points me in the direction of Skadi, the beautiful Norse goddess of skiing, winter and mountains, with snow-white hair, icy-blue eyes and pale skin.

Initially, Honora's appearance is the focal point, but there is much more to sort out. Our pediatrician refers us to an ophthalmologist at Nemours Children's Clinic in downtown Jacksonville. We bring Honora to the

appointment when she is just nine days old, and we're not sure what to expect. The ophthalmologist actually seems confused as to why we're there, which only compounds my own confusion. He confirms she has albinism, but says there isn't much he can tell us about her vision right now. He gives us pamphlets for the Blind Babies Program and Disability Services, and for a moment I'm stunned. I ask why he's giving us these when she is like any other normal baby — just a lighter shade of pale. He says we should start her in the programs early because there's a good chance she'll be legally blind.

The next nine months are filled with research and doctors' appointments. We take her all over the state, from Miami to Jacksonville, and visit every kind of physician, from geneticists to dermatologists and multiple pediatric and vision specialists. If someone has information that I don't have, I am determined to get it. The sad thing is, not many doctors are educated on albinism. It's rare and, except for a small number of serious conditions associated with albinism, isn't life-threatening. The pediatric dermatologist basically told us "the sun is her enemy" and the various ophthalmologists estimate her visual acuity to be 20/200 (legally blind), but the truth is, we won't really know until she actually tells us what she can and can't see.

I've tried to relate to the world as my daughter encounters it. Without correction, my vision is 20/400. Of course, I can put on a pair of glasses or insert a pair of contacts and see 20/20. Honora can't correct her vision. Someone explained to me it's like a camera — it's not the lens that needs correcting, like with glasses; there is something wrong with her film, the retina. And unless some crazy, experimental retina transplant surgery becomes available, she will always see this way.

As much as I resisted the idea that Honora would need the Blind Babies Program or Disability Services, we signed up. It's free, and we figured we should take advantage of any program that might help our daughter. Every week or two, a wonderful woman who works at

the Florida School for the Deaf and the Blind comes to our home and teaches Honora “how to see.” She’s by no means blind, but her world is blurry. A blue toy on a blue carpet is going to be difficult if not impossible for her to discern. So we have to be conscious of contrasting colors — white on black, green on red, orange on blue. For the first few months of her life, I encouraged everyone to wear black and white polka dots or stripes to help stimulate her vision. The vision exercises may improve her vision somewhat, but mostly the sessions are designed to help her learn to use other visual cues. Since her vision lacks depth perception, for instance, the lessons will help her learn how to determine the size and proximity of a tree, based on other variables, like light, or the presence of other objects.

The lessons are also for the parents — a chance for Ryan and me to better understand our daughter’s world. There’s a slight chance Honora will have to learn Braille, and she will likely need specialized education, with an aide assigned to help her at public school. Ryan and I will have much to learn about when and whether to get involved in her interactions with other kids; when to “educate” other kids, when to let her handle things herself. And, amid everything, we have to remember not to

overthink things. She’s just a baby, after all, still not even one year old.

I’ve come across a lot of interesting information about albinism in the past 10 months, and some terrible stuff, too. By far, the most difficult to accept is what’s happening in Tanzania, a country on the eastern coast of Africa, where some people believe albino body parts are good luck charms that bring wealth and fortune. This “misunderstanding” has led to a rash of murders, with albino kids killed and their limbs, genitals, ears, nose and tongues hacked off and sold for thousands of dollars. While albinism is still rare in Tanzania, it’s more prevalent because of inbreeding. Since 2007, dozens of albinos have been murdered or dismembered. Sometimes, their families have been killed while trying to protect them. Some escape, but because albinos have little protection against the sun, many eventually die from skin cancer.

In other parts of the world, albinos are viewed with suspicion or feared. Some cultures believe they’re magic or capable of casting spells, others think they’re retarded, deaf or sterile. In Zimbabwe, some men believe that

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## A Winter’s Tale

When Honora was diagnosed with albinism, Ryan and I instantly thought about legendary rock musicians Johnny and Edgar Winter — brothers, and both albinos. Music is a huge part of our life — Honora went to at least a dozen concerts in utero — and when we heard Johnny was coming to town, we decided to see if he would meet her. He agreed, so last October, before his show at Freebird Live in Jacksonville Beach, Ryan, Honora and I stepped into Winter’s pitch-dark, smoky tour trailer. For a guy born in Texas in 1944, being an albino has been rough. At 66, he looks more like 80 and is almost completely blind. And he never found albinism easy. Winter told us he made a conscious decision early on not to have kids, for fear that he would pass the trait to them.

“It was really hard,” he admitted. “Growing up, when I was a kid, it was really hard. Kids were pretty cruel.” Winter is a man of few words, and when I asked for advice on raising a kid with albinism he offered only this: “Just be as loving as you can. Try and help her if people bother her, and tell her it’s just one of those things that you have to go through.”

Before we left, Winter held Honora, briefly, awkwardly. A tourmate remarked that it was one of only a very few times Winter had ever held a baby. It was hard to tell for sure, but he seemed to like it.



“Just be as loving as you can.”  
Johnny Winter holds Honora, October 2009.

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having sex with an albino woman will cure them of HIV. There are a handful of world-famous albinos — reggae star Yellowman, Chinese model Connie Chiu, comedian Victor Varnado, musicians Johnny and Edgar Winter (see sidebar) — but most people will never personally know someone with albinism, and prejudices abound in ignorance.

A few months ago, our home-care vision professional set up a pizza party at the Florida School for the Deaf and the Blind. Any student with albinism was invited to attend and meet one of the newest members of their community. With the lure of free pizza, about a half-dozen showed up. They ranged in age (third grade to high school senior) and ethnicity (Caucasian, African American and Puerto Rican), but all have one thing in common. Albinos are notorious for having big personalities. They use humor to deflect the difficult and wit to manage the rest. Unfortunately, unless you know an albino personally, this isn't what's portrayed in pop culture and throughout the world. There's a lot of work to be done to dispel these myths. I hope that Honora and I will be able to help do that.

I'm by no means a saint. It's not like I sat around reading medical journals for the past 11 months. I've returned to normal in a lot of ways — going to concerts, out with friends, back to work. But there's a strange coolness involved with being the mom of an albino. Our home-care vision lady even told us “people will hold a halo over your head when you have a disabled child.” I thought that was ridiculous, but now I get it. People are constantly praising me for “being so strong” and telling us that Honora's so lucky to have parents like us. This wasn't a choice, but we're certainly not going to ignore it. If you have to drive to Miami and spend five hours at the Bascom Palmer Eye Institute because it's the best in the country, you just do it. If you have to decline invitations to the beach or an outdoor party because Honora can't be in the sun, you just find something else to do.

Like I said, I'm not a saint. I've cried and mourned the fact that Honora will never drive a car or fly a plane or read the fine print. But it's usually when I'm alone. I promised my husband — and myself — that I would never let our daughter see me cry. She will have enough to deal with — bullies, heartache, heartbreak. She doesn't need to see her mom cry about it. Unfortunately, some of those tears have manifested into anger. I've found my temper growing shorter these days, and my patience wearing thin. It's astonishing how many people comment on Honora's white hair, alabaster skin or darting eyes. Deep down, I know it's because they're not educated on albinism, but sometimes I resent that I have to be the one to do that.

In a month, Honora will be one year old. Soon she'll be 16 and then 30 and then 40. I will always look at her in amazement. Not because she's an albino or because (and I have no doubt) she will overcome many obstacles, but because she is a unique, beautiful kid who has touched so many lives and brought so much awareness to the world.

Honora, this is how the first year went. Next year will be better, and the next even better. Happy Birthday. I love you, Mom. □

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