

THROUGH THE
*Looking
Glass*

For much of her life, Meron Benti
has been seen as being different.
How she views herself is another story.
By Matt Jennings Photographs by Brett Simison



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MERON BENTI doesn't remember much about her early childhood in Ethiopia. What she does recall are fragments of memories: car trips to the capital city, Addis Ababa; the waiting rooms of doctors' offices; certain rooms of her house in the mid-sized city of Shashamane. The house that she rarely left, at least during daylight hours, unless it was for another visit to some new doctor.

She doesn't remember the rare occasions when she did venture outside with her family; she only knows about the people who would stare, the children who would follow them down the street, the hecklers who would suggest that her mother had committed adultery with a European, or, worse, that her mother was bewitched and Meron was the daughter of the devil. She only knows about these things because she heard them in stories told by her family years later.

She doesn't remember her first day of kindergarten, or much of kindergarten at all. Of course, she wasn't privy to the fact that the school in her neighborhood didn't want to take her, that the teachers didn't want to teach her, that she was thought to be incapable of learning in a "regular" classroom, and that the school administrators felt they had no way to accommodate "her differences." She doesn't remember what other kids said to her or if they said anything at all. What she does recall of her year of kindergarten in Ethiopia was going home at the end of the day and staying there until it was time to go to school the next morning.

"I guess I just blocked all of this out," Meron would tell me many years later.

When the school year was over, her parents made plans for Meron to move to Italy to live with her adult brother, Ayle. She would never live full time with her mom and dad again. She was six years old.

In either of these types of oculocutaneous albinism, a genetic defect disrupts the normal production of melanin, the pigment that gives human skin, hair, and eyes their color. The result for people with OCA1 or 2 is extremely fair skin, light-colored eyes, and hair coloring that ranges from white to light blonde.

Meron is the youngest of 10 children, nine of whom have dark skin. Her parents, too, are black, yet they both carry the albinism gene. Albinism is a recessive trait, which, if you recall from high school biology, means that each of her parents carries a recessive gene for the condition, but they do not manifest the condition themselves. Both parents gave Meron a copy of their chromosomes; she had a one-in-four chance of an autosomal recessive inheritance of albinism. Unlike her siblings, the odds played out differently for her.

Being different meant a move to another continent and country, to a place where her condition was better understood and medical options were more readily available. "Most people think of albinism as being 'devoid of color,'" says Murray Brilliant, one of the world's foremost experts on the genetics of human albinism. "And while this perception can lead to social stigma—such as what Meron experienced as a child and often resulting in even more dire consequences for patients in other regions of the world—the condition is defined, medically, by deficits in vision." (It should be noted that Brilliant was told about Meron and her condition in an interview. He has never met her.)

Meron's vision is severely compromised, the result of undeveloped retinas that are lacking a critical layer of pigment known as the *retinal pigmented epithelium* (RPE). One of four distinct pigmented layers in the human eye, RPE helps maintain photoreceptor cells; with a limited (or nonexistent) RPE, there are fewer of these cells at the center of each retina. The result, says Brilliant, is a degraded field of vision.

Think of a photograph with a limited number of pixels per square inch, he explains to me. "If

you enlarge the photo, the image gets pixelated, it gets blurry," he says. People with albinism may be able to see something up close—say, 10 or 20 feet away, relatively well, but as distance increases what one sees gets more and more blurry.

Meron has told me that she is extremely nearsighted, which might not be technically true, Murray notes, as albinism doesn't affect the shape of the eyeball, but the result is the same. Objects that are more than, say, 20 feet away become very blurry to her. To illustrate what this is like, she recalls standing on a street corner in Oakland, California, a few years ago. Traffic was zooming past her, and her attention was drawn to a box on the far side of the intersection. She had never seen such a contraption before, and in the middle of the box was a blurry, digitally lit hand. Then the hand disappeared and the box appeared to be empty. She stood there for about 30 seconds, just staring at the box, not even noticing that the traffic in front of her had stopped. And then the hand was back, and the rush of cars had resumed. She couldn't see the numbers counting down the time she had to cross the street.

"I REMEMBER EVERYTHING about Italy," Meron says, contrasting her recollections of living in Europe with her hazy recall of events in Ethiopia.

At six years old, she and an older sister, NAME, settled in a small village in Tuscany, where their brother was working and playing soccer on a semipro team. (Though NAME was less than thrilled about moving to Italy, too, their parents felt it was essential that Meron have a female presence in her life.)

The timing was fortuitous: just a few months prior, as Meron's parents were exploring medical options beyond Ethiopia for their daughter, her brother had struck up a conversation about his sister's condition with a neighbor in the small Tuscan village where he lived. This neighbor



wanted to help and offered both to introduce Meron to an ophthalmologist that she knew and, as an Italian citizen, to sponsor her immigration to Italy.

The ophthalmologist had a litany of eye problems to consider and treat. In addition to Meron's retinal issues, she is extremely light sensitive, the result of a reduced layer of pigment in the iris; she also has a condition called *nystagmus*, which affects both vision and depth perception. This causes her hazel eyes to dart rapidly back and forth, an involuntary movement that she no longer notices, but is evident when you talk to her in person.

She thinks that her vision issues had as much to do with her Ethiopian teachers not wanting her in their classroom as her skin coloring did, a theory that Brilliant thinks is reasonable. ("There's an assumption that one is incapable," he says, "especially when at a young age and in places where help is less accessible.")

In Italy, Meron does not recall her vision being a social or educational handicap, but there were new challenges. For the first time, she recalls being cognizant of looking different than her siblings, perhaps because *they* stood out in a predominantly white region. She recalls the sidelong glances of this "big black guy walking down the street with a little white girl." And while she reminds me that her appearance was more stark then—"I was six or seven years old, so I wasn't wearing makeup. My hair was white, my eyebrows and eyelashes were white, my skin extremely pale"—she says that people didn't really pay much attention to the albinism. "What seemed to make a difference to them was my being an immigrant," she says.

At first, she says, people assumed she was Scandinavian, but when she explained that she was Ethiopian, opinions of her grew harsher.

"I was bullied," she says, "though I guess I didn't know what that was then. I just thought people were being mean." She remembers one classmate in particular, who, upon hearing she was from Ethiopia, began to sing about Mussolini invading her country. "He told me his grandmother loved Mussolini," she says, a sense of wonder still present in her voice all these years later.

Her brother tried his best to assimilate Meron into the culture of her new home. He insisted that she learn Italian, and by the time school started in September, she was nearly fluent. And she says that while she missed her parents intensely at first, gradually she allowed her memories of them to recede. It was her way of coping with being away from them.

It was six years before she returned home for a visit. She went alone, and she has a clear memory

of walking off a plane in the Addis Ababa airport and becoming overwhelmed.

For six years, she had not seen another black person aside from her brother and sister, and now she appeared as the only white person in this bustling airport. And then there was the rush of people, not just her immediate family, but distant relatives and family friends. "I didn't recognize my brothers," she remembers. "I couldn't tell who was my brother, who was my nephew, who was a neighbor. And then my mother . . . she seemed taller than I had remembered her, so I guess I was looking at her funny, and she burst into tears. She thought I didn't remember her."

But the truth was, she says, she *did* feel estranged from her mother. Her coping mechanism had worked. "At first, it didn't feel like she was my mom."

Gradually, over her two-month stay, familial ties emerged. It wasn't exactly normal, she says ("though what counts as normal?"), but it was normalized. Being 12, though, she was also much more aware of how she was received outside of her house. She remembers walking around town with her siblings and having other kids harass her. First they would approach her asking for money ("That happens a lot in Ethiopia; people assume that if you are white then you have a lot of money"), and then when her brothers grew defensive, tipping off the others that she was with them, the remarks turned caustic.

The stories she had heard about being called a "devil child," she says, apparently were true.

MERON RETURNED to Italy, yet says that in all her time there, she never felt at home. She found herself missing Ethiopia, a feeling that intensified after another visit the following summer. "I thought about moving back for high school, but my brother told me that was a bad idea," she says. "He was probably right." So she began to cope the best way she knew how: by forgetting.

By this time, her brother, Ayle, had taken a job in the United States and had moved to Oakland. She and her sister remained in Italy and settled into a predictable routine: "She worked; I went to school," Meron says. Around this time, Meron began modeling, first for fashion students at a local university, and then with an agency. Yet she also says that she began to isolate herself from the rest of her surroundings; looking back on this period, "it wasn't that different than when I was a child in Ethiopia." She wasn't hiding exactly, but she wasn't engaging with the culture (aside from her modeling), either. She

went to school, a rigorous science academy, six days a week, and she studied all the time.

I ask her if she was sad, lonely: "You were a teenager," I say, "and, sure, this can be a time filled with adolescent angst, but it's also an age when many lifelong friendships are born."

She shrugs. "No, I still think of myself as being pretty lucky. I mean, during that time I had Facebook friends, people with albinism, who were teenagers like me, and they needed guide dogs to get around or walked with a cane. I felt fortunate that I didn't need any of that."

Meron probably would have finished her studies in Italy, had she not received a phone call from her brother inviting her to come visit him in America the summer after her third year in high school.

I ask if this was her first time coming to the United States.

"Yeah—the first and last time," she laughs. "That's when I stayed."

WHILE RESEARCHING this story, I came across a portfolio from an Italian fashion shoot in 2013 featuring Meron that currently appears on the website behance.net. Highly conceptual and stylized, the shoot is titled "Beauty and the Beast." Meron is the "beauty" in this concept, and the images of her are striking. She's sitting in a white chair, her pale skin and blonde hair accentuated by a pale peach-colored dress and an orange flower that she holds in two hands, close to her face.

"That was my favorite shoot," she tells me when I ask about it a few weeks ago. "I loved the concept."

She pauses and starts to say something, then stops.

"But . . . ?" I say.

"They were interested in having someone with very fair skin, which was fine—most of the shoots were of that nature," she says. "But in this one, they really emphasized my whiteness. They even added white makeup on top of my pale skin and my hair! It took me two days to wash it entirely out of my hair."

She continues: "I've always wanted to do something more colorful, like what we did with Brett." (She's speaking of the photo shoot for this story) "Those vibrant colors feel more like me."

I ask her if she felt that the white makeup further masked her identity in addition to accentuating her whiteness.

Again, she pauses. "I don't know if I would have phrased it that way then, but it certainly makes sense now."

Meron tells me that she had never thought about the concept of race until she came to the States a few years ago. "Ethnicity yes, race no," she says. "Race is not a concept you really think about in Italy, at least not where I was," she says, "because everyone is the same. And in Ethiopia, that's literally true. Everybody is the same race."

She first thought about this concept and how it applied to her when she was registering for high school in Oakland, where she was, once again, living with her brother.

We all know the question, a prompt to check off a box identifying one's race, only Meron had never seen such a question before.

"There were all of these choices, and I was very confused," she says. "I thought, *I'm white, but my whole family is black.*"

"So, what did you do?" I ask.

"I checked black."

The significance of her decision was not lost on her, especially as she spent more time in the U.S. "I may lack melanin, but I'm Black," she says. (The capitalization of "Black" in this instance is intentional.)

During the past few months, Meron has emailed me a handful of stories to read and videos to watch. One piece she sent me was a story that appeared on National Public Radio, titled "People of Color with Albinism Ask: Where Do I Belong?"

"When I saw that story"—she first saw it online before listening to it—"I was so excited. I thought, *Yes, finally someone understands me.*"

What she had begun to experience in the United States was that she was Black, "but not fully, if that makes sense?" she says. What she means is that the longer she has spent time in the U.S.—first in Oakland and now at Middlebury—she has grown to understand what it means to be Black in America. "I consider myself Black, but I have white skin, so people don't see me that way, at least superficially, and how you are seen can mean everything."

She continues: "I go places with my Black friends; they are looked at differently. I have seen them followed by clerks in stores, and that never happens to me. Ironically, the same treatment that Black people can have in the United States is what I experienced in Ethiopia. So I can relate, but I'm not facing that situation anymore. At least not here."

Immediately after arriving in Oakland a few years ago, she applied for asylum in the United States. The process was long—it was 18 months from the time she applied until a decision was made—but because of her personal history in Ethiopia, her application was approved. She recently applied for a green card to obtain permanent residency status, a process that

took her to an immigration office in St. Albans, Vermont, about 20 miles south of the Canadian border. After handing in her paperwork, a clerk summoned Meron back to her desk.

"I think you made a mistake," she said, sliding a form across her desk to Meron, the form where Meron had indicated her race.

"No, I didn't make a mistake," Meron replied.

"Are you sure?"

"Yes," Meron said. "My whole family is black."

"If you say so."

MERON IS NOW a sophomore at Middlebury; how she got here from Oakland Tech High School isn't all that interesting. "Google," she laughs (though she does credit a history teacher for encouraging her to apply to Ivies and the top liberal arts colleges, types of schools she had either never heard of or never given any serious thought to previously).

But her experience so far has been "amazing," Meron says. An anthropology major, Meron's focus has returned to her native Africa, though with designs that expand beyond Ethiopia. "This is strange for an Ethiopian," she laughs. "There's a joke that Ethiopians consider themselves apart from the rest of Africa." In January, she took the intensive leadership and innovation course called MiddCORE, and for her class project she came up with the idea of a summer camp in Kenya for people with albinism. She chose Kenya rather than, say, Ethiopia, she says, because not only is albinism more prevalent among the populace, but the stigmatization and associated danger that comes with it is higher.

I've learned that as bad as Meron had it in Ethiopia, there are countries in sub-Saharan Africa where having albinism can cost you your life. A recent report by an albinism advocacy organization called Under the Sun has documented hundreds of attacks against people with albinism in countries such as Malawi, Tanzania, and Kenya. (In Tanzania there were gruesome reports of killings and dismemberment.) Meron acknowledges that attempting to start her camp in Tanzania wouldn't be safe for a college student, though she quickly says she could envision starting a nonprofit that serves people with albinism in Tanzania or Malawi in the future.

And as for now, even Kenya may be too risky. Meron applied for a fellowship with Middlebury's Center for Social Entrepreneurship (CSE) in the hopes of putting her idea into action. But her application was denied, in large part because of the risk associated with the endeavor, the center's director, Nadia Horning, tells me. But to say Horning was impressed with

Meron's application would be an understatement. "This is somebody who will be an agent for social change," Horning says. An associate professor of political science with a focus on African politics, Horning has gotten to know Meron through the African student organization Umoja. Horning is the group's faculty advisor, and this year Meron is its copresident. Horning has learned the same thing that I have during the course of reporting this story: "All her life, Meron has taken a deficit, a handicap, and turned it into an asset," she says.

Though Meron did not receive funding through CSE for her project, she, along with a few other applicants, were offered a nonfunded opportunity to continue researching their project under the auspices of the center, where they would have space to work and access to advising. Not everyone who was offered the opportunity accepted, Horning says, though Meron did immediately upon the offer.

MERON BENTI has an elaborate tattoo on her back consisting of a constellation of symbols that form the shape of the continent of Africa. She says that because her phenotype does not contain any Black features, she wanted something on her body that "hinted to people that I am African." A heart symbol represents Ethiopia. The image also contains native African species such as the sankofa bird and the denkyem crocodile, as well as West African Ashanti symbols.

I joke that it's not very Ethiopian of her to be thinking so deeply about other African countries, and she laughs. She says that the symbols not only reflect her origins but also her adaptability to live in different environments. She tells me that until coming to Middlebury, she had never really met any Africans who were not Ethiopian. (The irony that she had to come to rural Vermont to do so is not lost on her, but she hastens to add that the fact that Middlebury facilitated this is one of the many reasons she loves the school.) Now these students of color from other countries, the United States included, are among her best friends.

Not too long ago, a group of students organized a Women of Color brunch, to which Meron was invited.

"I don't think they realized how happy that invitation made me feel," she says. "When people acknowledge me as being a person of color without me having to remind them . . ."

"It's your identity," I say.

She pauses.

"It's more than that," she says. "It's belonging." ■