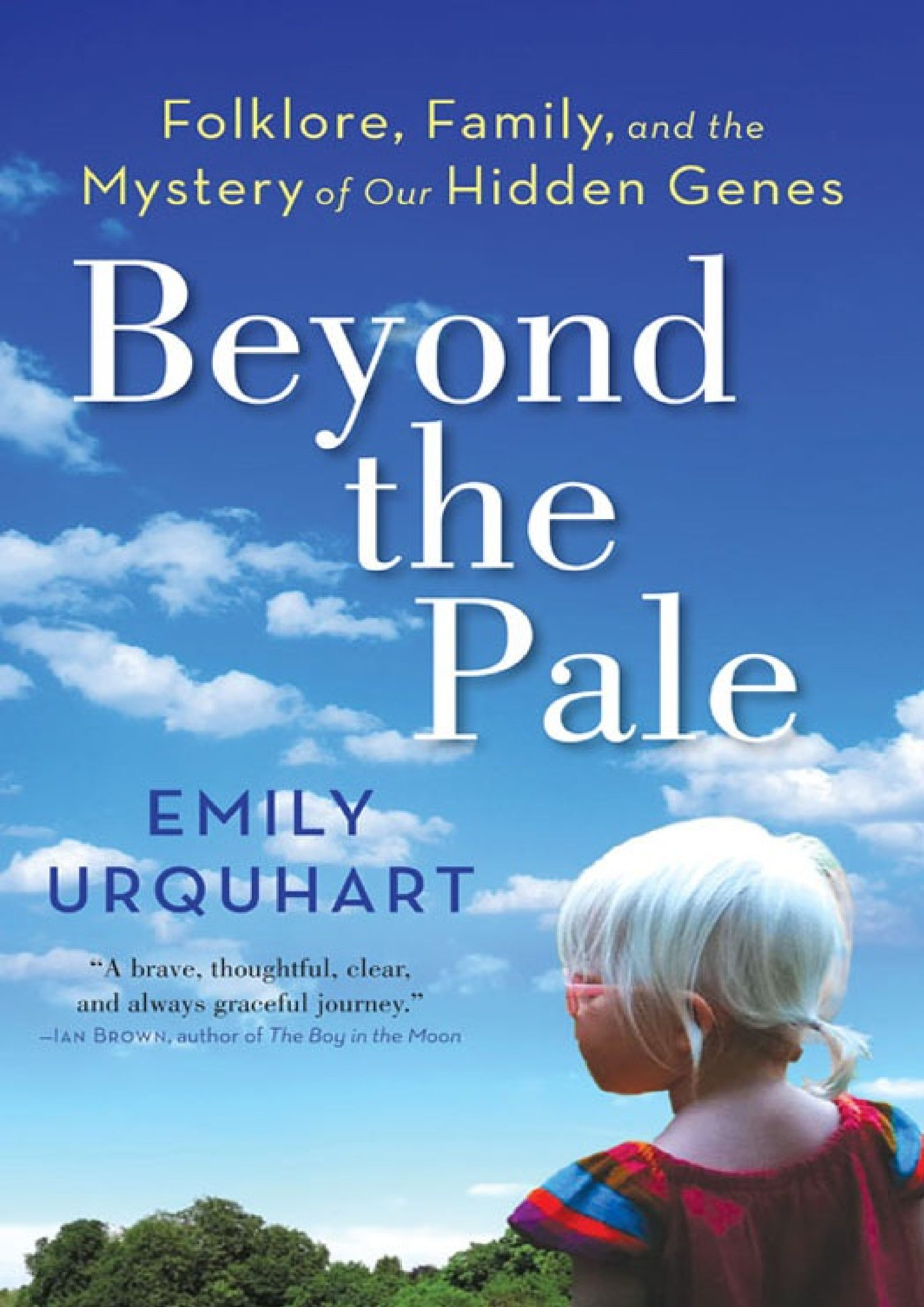
Folklore, Family, and the Mystery of Our Hidden Genes

Beyond the Pale

EMILY URQUHART

"A brave, thoughtful, clear, and always graceful journey."
—IAN BROWN, author of *The Boy in the Moon*



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EMILY URQUHART

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Dedication

In memory of Rodsella Morse Spencer, who lived not in your time, not in my time, but in the old time, and for Andrew and Sadie, my happily ever after.

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Prologue

MY DAUGHTER WAS BORN WITH A GENETIC CONDITION I KNEW NOTHING about. It was so foreign to me that I wasn't able to recognize or see it. It is a deceptively obvious medical mystery, one that crops up in both holy and medical texts and in supernatural beliefs across time. In some cultures, people like my child are revered; in others, they are seen as harbingers of evil. In my own society, they have been fodder for legends, believed to live in backwoods colonies, cloistered together, insular and removed. In the recent past, they've been exploited and exhibited like animals in a zoo. The most extreme stories are from East Africa, where people are being murdered and mutilated for bearing this disorder's recessive traits.

I study folklore, the intimate truths we reveal through the stories we tell. Legends, fairy tales, and beliefs are the screens onto which we project our fears, hopes, secrets, and desires. After my daughter was born, I felt that knowing the cultural tales about people with her condition, whether they were frightening or beautiful, would help me understand the shape of her life. Because she will encounter these stories too: on the silver screen, via the Internet, in the news, and from the lips of unpredictable strangers.

I've never met or known about anyone—family or acquaintance—who shares my daughter's difference. It can pass silently on from parent to child for hundreds of years, so I also didn't know where it came from. Then, a few weeks ago, there was a clue. A series of family photographs from the early 1900s show two women who bear a striking resemblance to my daughter.

I mined archives and census records to learn more about these people, but none of those fraying documents could identify them, or provide the human details I craved about their lives. Specifically, I want to know if these long-ago women were happy, despite living with a disability and standing apart from their peers because of their unusual, if beautiful, appearance. It's a risk-laden query because the answer will shape how I see my little girl's future.

Now I am meeting a distant relative I discovered while trying to understand my daughter's inheritance. At age ninety, she's the only connection I have to several women who lived a century ago, tangential ancestors whose lives might illuminate my child's present. My dad is driving me to this meeting; he has never met this relative either. He is calm; I am nervous. Neither one of us knows what to expect.

I tell my dad that we've passed the building. We drive around the block, then pull into the parking lot of a modest retirement residence where our cousin many times removed is expecting our arrival. My dad sits patiently by my side while I shuffle and reorder the family photos I brought with me. I think back to when I'd sat in a different car, in a colder season, years and miles from here, parked outside our doctor's office in Newfoundland. I wept in the passenger seat while my husband stared wearily out from behind the wheel. Our infant daughter was in the back, wearing thumb-less mittens and a tiny woolen hat. She was two weeks old. During our first visit, the physician

quelled my husband's fears, but on that day, our second trip to her office in a week, she acquiesced and referred us to a specialist with a long wait-list.

I'd looked out the car window and spotted a speck of steel in the gray sky. A plane rising. I wished I were on it. Turning back to see my sleeping infant, I crashed to earth. I resolved to stay there. Although we didn't know it then, inside that car, sitting in the frozen, snow-crusted parking lot, some of the answers were within us, in our cells, soon to be extracted from our blood.

Over the next three years, we consulted a slew of experts—medical, cultural, regular, and extraordinary—but the person who would teach us the most—tiny, mute, sleeping in the back seat—was our daughter. The rest we uncovered over a series of journeys. These voyages took us across North America and as far away as Africa. Each one was more harrowing than the last, and each time there was a moment when I contemplated retreat before heading forward.

Today, in autumn's pale light, my hesitation evaporates. I turn to my dad, who has been waiting quietly for my lead.

"I'm ready now," I tell him, then open the door and step outside to meet my daughter's past and her future.

ONE
DISCOVERY

CHAPTER 1

Some White

THE VISITORS COME FROM ALL WARDS OF THE HOSPITAL. THERE IS AN audiologist, a social worker, a lactation consultant, a rotating cast of doctors, and an endless stream of nurses. We have a private room, but our newly formed family of three is rarely alone. This is not unusual in the maternity ward. What is curious, however, are the nurses who visit with no service to offer. They arrive at my side, somewhat apologetically, to catch a glimpse of our newborn daughter. “Some white,” they whistle and coo into her plastic bassinet, using the vernacular emphasis that has become so familiar during my five years in Newfoundland. They say it to me, and they repeat it to one another: “That hair is some white.”

Sadie Jane is born in the usual excruciating manner on Boxing Day 2010. Overdue, she is unwrinkled and chubby, with perfectly formed features and a shock of white hair on her head. Her mouth a tiny *O* and her arms flailing, she reaches constantly for my arms, my milk, my warmth. Her eyes flutter open occasionally, but mostly they’re shut. In one of our baby’s fleeting moments of wakefulness, the ward pediatrician probes her pupils with a tiny flashlight. Afterward, she looks past me and my husband, Andrew, past my parents, fixing her gaze on the spruce-clad hills behind the hospital. “You have a very fair, very healthy baby girl,” she says. We never see that doctor again.

My child is the fairest of them all. The weight of my pride is unbearable, too big for our tiny room on the maternity ward. I stage a photo shoot on my bed, and Andrew takes the picture that will become Sadie’s birth announcement. I beam the image across the globe.

The next day, Andrew takes Sadie in his arms and goes for a walk down the hall. The nurses crowd around, making a fuss over her white hair and scolding him in the same breath. “No walking with babies in the hall! That hair! The liability!” He is heading back to our room when he overhears one of the nurses ask, “Is that baby an albino?”

They return trailed by a heavy-set nurse with dark hair and few teeth. “Is she an albino?” the nurse asks, lisping slightly, a note of alarm in her voice. “No,” I tell her firmly. The woman stares back at me, bug-eyed, bewildered. Then she lets herself into our bathroom, where she cleans the toilet, empties the trash bin, and wipes down the sink. She is wearing nurse’s scrubs, but it is clear now that she is a janitor.

As Andrew recounts this strange tale to his mother over the telephone her heart sinks. She doesn’t know what to say, because both she and Andrew’s father, Don, asked the same question when they saw the first photographs of their granddaughter. Don, a family physician in Georgetown, Ontario, grows increasingly tense as the days pass. *Why didn’t the pediatrician say something?* he wonders. He is 99.9 percent certain, as convinced as he can be without examining her, that Sadie has a genetic condition called albinism. It is stable, and there is no treatment (you can’t substitute

good genes for bad ones—at least not yet). He believes that the doctor opted to spare us, for now.

In a week's time, Don will be on a plane to Newfoundland. His role as a grandfather is not to deliver grim medical news. He is the support staff, not ground control, and he feels certain that our family doctor will say something at the one-week checkup. After that, he can offer guidance.

Albinism, a genetic disorder, is both obvious and mysteriously complex. (As with the pejorative "retard," those in the know don't use the word "albino" anymore.) People with oculocutaneous albinism have little to no pigment in their skin, hair, and eyes. They have relatively little protection against the sun; burns are quick and dangerous and may cause skin cancer.

The current understanding of the way pigment affects vision is more complicated. Normally, when the irises are faced with glare, they activate the pupils, a pair of gatekeepers that control how much light reaches the back of the eye. Without this regulation system, stray light enters through the pupil and iris, impairing the development of the retina and interfering with the optic nerve (the wiring system that connects the eyes to the brain). Albinism also affects the development of the fovea, a cluster of cones in the middle of the retina that are responsible for visual acuity. At around six weeks, almost every baby with albinism will develop nystagmus, in which the eyes dart back and forth involuntarily. We don't know why this condition is present in albinism, but it is unrelated to pigment.

What we also know is that low pigmentation results in photophobia, meaning that daylight, particularly the searing rays of high noon, can be intolerable. It resembles those initial moments of squinty-eyed discomfort the rest of us feel when exiting a dark theater into the light of day. Together, this complicated cocktail of eyesight issues is called low vision, and it is like seeing the world through an Instagram filter. The pixels are bigger, the world is a little brighter, and while it is not blurry, the finer details are lost.

There are few experts in the field of albinism. The condition falls across a spectrum of medical specialties—genetics, ophthalmology, dermatology—and most general practitioners will never see a patient with albinism during their careers. When we visit our family doctor a week after Sadie and I are discharged from the hospital, she dismisses my husband's concern about the janitor's comments. "I've seen babies this fair before," she tells us. Her file notes from our visit on January **5** list that Sadie has very fair skin, that her eyes are normal, and that she is thriving. Thriving! My maternal pride swells. My baby is flourishing. My husband, however, is not doing well at all.

Hours after the doctor's appointment, we take the dog for a walk and stop at a nearby schoolyard, where he runs in circles, chasing his doggy shadow across the floodlit snow. Sadie is tucked into her dad's coat, strung up in a contraption that keeps her close to his chest and out of the cold. We silently shuffle back and forth to keep warm. A heavy darkness fills the air between us. It followed us here, stalked us down the stairs from our apartment and along the night streets. It has been with us since we left the hospital. Something is wrong with Andrew. Later I will find him sitting quietly in the dimness of early evening. I switch the lights on, and he turns them off again.

Even his camera, a constant flashing light from Sadie's first cry, has gone dark. But when I ask him what is wrong, he cannot find the words to tell me.

My husband is the kind of person who leads the pack in a crisis. This strength, along with his height, his dark hair and green eyes, and his ridiculousness, are what had me pining to be his sidekick. But since the birth of our first child, he has come loose. He is distant, and unreachable. Parenthood exposes his Achilles' heel, shocking both of us. What I don't know is that, like his parents, Andrew is convinced our newborn baby girl has a rare genetic condition.

My in-laws arrive the next day. Don carefully examines Sadie, using the contents of his doctor's tool kit, a ritual I wrongly assume follows the birth of every grandchild. He takes on the responsibility that, as a grandfather, he had hoped to avoid. He waits until morning, when his son, so clearly tormented, comes to him. Andrew is saddened but receptive to the possibility of a problem. Later, when we are alone, Sadie sleeps in my arms while he relays his father's concerns, releasing his own bottled fear in the process. To me, the suggestion is infuriating and impossible.

When noon comes and I still have not contacted my parents, it is gently suggested that I make the call. Sitting in a rocking chair by the nursery window, phone in hand, I stare out at the familiar scene and find it distorted. The row houses, stacked one above the other up Prescott Street, the two towers of the basilica, the gray winter sky—it is all askew. I dial and wait for my mother to answer.

"There might be something wrong with Sadie," I tell her. I have a catch in my throat, and can't continue.

My mother, listening on the other end, does not hesitate.

"No one will love her any less."

I DO NOT FAIL TO NOTICE THE PECULIARITIES OF MY DAUGHTER'S ARRIVAL, but I interpret them in a completely different way. My husband is a biologist, attuned to the natural order of the world. I am a folklorist, and walking the line between fantasy and reality is my work. I believe in science, but I understand fairy tales. My new baby's astonishing white hair and unusual beauty, her immediate legion of admirers, even the timing of her arrival—a labor that stretched across some of the holiest days of the liturgical calendar—have the markings of a supernatural tale.

We mythologize even our routine birth stories. The most extraordinary reside in the world's grand narratives, from ancient Greece to the foundations of Christianity. Like the detailed version of Noah's birth, brought to public attention in the 1940s with the discovery of the Dead Sea Scrolls. In it, the boy is born with flesh as "white as snow," hair as "white as wool," and unusual eyes that illuminate the room. His father, Lamech, is disturbed by his newborn son's appearance, so different from his own. He is suspicious too. Recently, there were rumors that angels had been cavorting about with mortal women, and this child has definite angelic qualities. He consults his father, Methuselah, who in turn seeks the counsel of his father, Enoch. What Lamech ultimately discovers is that the pale flesh, white hair, and luminous eyes are attributes of the child's divine calling. "Call his name Noah," Enoch advises. "When all mankind who are on earth shall die, he shall be safe."

Texts from some of the scrolls are published in the mid-1950s, and this birth story catches the attention of a British ophthalmologist named Arnold Sorsby. In 1958, he publishes an article titled “Noah—An Albino” in the *British Medical Journal*. He writes that the narrative is “clearly not that of a miraculous child but of an albino.” To help prove his point, he includes a genetic breakdown and an adjoining diagram explaining the possible inheritance pattern of Noah’s albinism. Only in the final paragraph does he suggest that the article is a parody, when he earnestly considers the recessive genetics of angels.

I read this paper shortly after the birth of my own ethereal child (“Your baby looks like an angel!” exclaims another new mom at the hospital). I search for Sorsby online but find an obituary rather than a white pages listing. What I glean from his life story is that he edited the *Journal of Medical Genetics* for seven years in the 1960s, he was an ophthalmologist employed at London’s Royal Eye Hospital, and he specialized in genetic conditions of the eyes. All of this posits him as a person whose theories you would be inclined to take seriously. Case in point: when the first American albinism advocacy group forms in the 1980s, it takes the acronym NOAH (National Organization for Albinism and Hypopigmentation) as its official name.

I show Sorsby’s article to Dr. Daniel Machiela, a professor in the Religious Studies Department at McMaster University in Hamilton, Ontario, with special expertise in the interpretation of the Dead Sea Scrolls. He is interested but unconvinced.

“There is a metaphorical and symbolic attachment to the way he looks,” Machiela says. “And that clearly seems to be what is going on here.”

I want to connect Noah’s story to my own, so I suggest that his ancient Near Eastern parents theoretically would have had dark hair, skin, and eyes, and therefore a child born with white hair would be very unusual.

“The point in these stories is that he was not just like anyone else who was born then—the way you would expect them to be born,” says Machiela. “He stood out.”

WHEN SADIE IS FIVE WEEKS OLD, WE MEET WITH A GENETICIST, Dr. Lesley Turner. She is exquisitely gentle examining our infant daughter, and I trust her immediately. We have seen an ophthalmologist, and we understand that Sadie has characteristics of albinism, but the doctor refers us to the Provincial Medical Genetics Program for conclusive tests. Andrew and I sit at a round table in an office at the Health Sciences Centre in St. John’s, and I nurse Sadie while Dr. Turner and a genetic counselor draw our family tree—a narrative of various disasters that includes an uncle who died too young of multiple sclerosis, a brother who died even younger of alcoholism, and on both sides the shattering experience of Alzheimer’s.

Sadie has five milliliters of blood taken, half the regular amount because she weighs just eleven pounds. She is silent when the needle pierces her skin, but she pees from the shock of it. The tiny vial of blood is flown to the University of Minnesota Physicians Outreach Laboratories, where I imagine a flurry of strangers in white lab coats carrying beakers and punching codes into complicated machines. The results arrive four weeks later: Sadie has oculocutaneous albinism type 1 (OCA1) variants A and B.

In OCA1A, the enzyme tyrosinase, which converts the amino acid tyrosine into melanin, fails to carry out its assigned task. In OCA1B cases, it makes a partial effort, and there is some pigment formation: yellower hair and eyelashes, darker eyes. OCA1 occurs with one in every forty thousand births. The recessive gene can be passed on silently for centuries because both parents must be carriers for the condition to manifest. It is so rare, so improbable. Of all the gin joints in all the towns in all the world, Andrew walks into the Ship Pub in St. John's on a blustery June night. I spot him across the bar and think he looks familiar, so I introduce myself. The rest is genetic history.

It is a strange relief to succumb to your DNA. Earlier that week, I had fought back tears when a worried nurse at a lactation support session looked into Sadie's eyes and asked, "Does she smile at you? Does she make eye contact? Can she focus on an object?" No. No. And no. But with the albinism diagnosis, I throw out all of my "baby's first year" books and ignore the monthly milestones attributed to normal development. The first time Sadie reaches for an object (a garish purple dragon hanging from the handle of her bucket seat), the first time she holds my gaze, the first time she smiles back at me, these will happen on a different timeline, and they will be some of the most exciting, profound moments of my life.

When I meet with Dr. Turner a year later, I ask her how it feels to be a genetic code messenger. She considers this for a moment. In our case, she has noticed a shift toward accepting Sadie's condition since our first visit, particularly in me. In the beginning, I denied the possibility of a problem, or at least I saw it in a different way. Andrew, his earlier depression having lifted, seemed open to the diagnosis during the initial meeting.

The hardest cases are when a child's prognosis is terminal. She tells me about walking into the small room where we met the previous year and facing an entire family (child, parents, and both sets of grandparents) to deliver the news of the fatal genetic flaw. The mood was heavy. The father was weeping. Dr. Turner excused herself for a moment on the pretense of finding a few more chairs. She went to her office, put her head down, took a few deep breaths, and said, "Okay, pull yourself together."

"Then what?" I ask.

"And then I was fine to go back in."

"IT'S NOT SUPPOSED TO LOOK LIKE THIS," SAYS A FIERCE, SAD-EYED mother in the outpatient waiting room at the children's hospital in St. John's. "You get pregnant, and you have a baby, right?" She shakes her head. "I had a big bleed at thirty weeks, and it's been hell ever since." I have seen this mother before; I take Sadie to a slew of specialists with offices here, and our appointments often coincide. The woman points out her daughter, a small eighteen-month-old with a wiry build and corkscrew curls, seated at a miniature yellow table, coloring with conviction. I don't see the problem, but it turns out that no one does. She suffers from "a failure to thrive." This is the term allotted to an infant or a young child who stops developing at the same rate as his or her peers. The child's development begins in the regular way, and then there is a

change.

In European fairy lore, a newborn whose nature turns foul, who screams with colic or falls suspiciously quiet, whose chubby cheeks turn gaunt and whose bright eyes hollow, is called a changeling. It is sometimes believed that the human child is switched by the fairies for one of their own offspring. The fairies persisted in North America, stealing infants from cribs throughout Newfoundland and leaving cross, wizened, unfamiliar babies in their places.

Some scholars attribute changeling narratives to cases of failure to thrive. A supernatural explanation absolves the parents of guilt; rather than a genetic hand-me-down, it is a case of switched identity. It allows them to grieve for the stolen child, the one they had conjured over nine long months—because that child is gone, away with the fairies, and with it any preconceived ideas of parenthood.

There are no changeling stories connected to albinism because, with the exception of nystagmus—the darting of the irises, which appears at around six weeks—the condition does not develop after birth. However, the ethereal whiteness does inspire albinism lore across the globe, particularly where people typically have darker skin, hair, and eyes. In the early twentieth century, New Zealand ethnographer Makereti Papakura found that Maori people with albinism are believed to be the offspring of mortal women and supernatural men who belong to a tribe of fair-haired mist dwellers.

Around the same time, Western scholars sought to verify rumors of an “albinotic race” residing among the Cuna people of the San Blas Islands, off the coast of Panama. The theory has been debunked, but the place still appears to have a high incidence of the genetic condition. D.B. Stout, an intrepid anthropologist, takes up residence among the Cuna and discovers that, in some communities, individuals with albinism are associated with higher intelligence, godliness, and magic powers that enable them to ward off a demon that periodically eclipses the sun and moon. Stout’s successors find that Cuna people with albinism are called moon children, alluding to their mothers or fathers staring too long at the night sky during gestation.

I print the albinism-lore articles I’ve found through my university library’s database and keep them in a folder on my desk. They sit side by side with Sadie’s five-section medical binder. In some ways, what I learn about the moon children of the San Blas Islands is just as important to my understanding of the condition as the literature from our genetic counselor.

In spring we drive from St. John’s to Northumberland County, Ontario, where we plan to spend the summer at my family cottage by the lake. The ferry ride is dark and bleary. The province of Nova Scotia is a continuous scream. New Brunswick, a long, low wail. Quebec is Stan Rogers, roadside nursing, and cheese curds. Ontario, endless highway, more tears, then relief when we pull down the treed lane and see the little blue cottage that will be our home for the next three months.

My parents’ home is a short drive from the lake, and Sadie and I spend afternoons there with my mom and dad. I sit in my mom’s office, transcribing interviews I’d conducted for my dissertation, listening to the stories from a Newfoundland outport. Normally, this is where my mom writes, but lately she is more babysitter than novelist. Often I’ll wander out and find my mother reclined on the couch reading, while Sadie

lolls around on the floor beside her, thumping her heels on the ground, sucking on the lid of a yogurt container, or removing her socks. It astounds me that they can achieve this kind of parallel amusement. As the mother, and the main food source, I'm never afforded the same kind of reprieve.

My father is usually there too, working in his studio, which is a room off the back of the house. He'd recently rediscovered a series of his early tondos, circular oil paintings he did in the 1960s, along the back wall of the barn on their property. The building originally belonged to my maternal grandparents, and he must have stashed them there in the late 1970s or early '80s, having run out of storage space in our home. If my parents hadn't bought the house after my grandmother died in 2007, the paintings would have vanished—auctioned off or carelessly discarded. He's reinspired by the almost-lost work, reviving and adding to the brilliant orbs of abstract landscapes. On the afternoons we spend there, I take Sadie out to see her grandfather working on his art, dipping her head close to the colors and whisking her away before she's able to mash her fingers into the gobs of wet oil paint.

Down at the lake, we keep Sadie inside, afraid the sun will scorch her pale skin but equally frightened by the warnings against applying sunblock to a baby less than six months old. I try a few different natural brands, but they are gritty, or oily, or so zinc-filled that the lotion looks like war paint. As the sun sets one evening Andrew carries Sadie down to the edge of the water so that she can hear the waves raking the beach stones. She is awake, but her eyes are closed. She rarely opens her eyes outside unless she's peering out from beneath a floppy wide-brimmed hat. I don't know if she will grow less photophobic with time or if she will always close her eyes against the day's light.

IN JUNE, WE TAKE SADIE TO SEE DR. ELISE HÉON, THE CHIEF OPHTHALmologist at the Hospital for Sick Children in Toronto. She is a tall, handsome woman, wearing a sleeveless Anthropologie dress stamped with a bucolic landscape print. She graciously acknowledges the distance we have traveled and makes us feel like visiting royalty. She is a commanding presence, and her underlings are practically tripping on her white coattails. Even Sadie, traumatized by an earlier test involving electrodes plastered to her head and a strobe light, succumbs immediately to the doctor's charm and reaches for her arms. In faintly accented but excellent English, Dr. Héon informs us that our daughter will never drive a car.

I can no more picture six-month-old Sadie driving a car than I can imagine her using a fork. The future is slippery and hard to grasp. Sometimes I imagine approaching her teacher to discuss how to avoid flash photography on picture day. "Perhaps you would consider taking the pictures outside this year?" my future self will ask Sadie's future teacher, explaining how the flash makes her blue eyes appear red. But when I visualize this, I am standing in the foyer of my own elementary school and speaking with Mrs. Vijendren, my grade-two teacher. I have no frame of reference for Sadie's future—nor, for that matter, for my own.

After our morning at SickKids, we walk over to the Art Gallery of Ontario to see the abstract expressionist show. In the hushed world of the exhibition space, my mind

wanders. Sadie is asleep in her stroller, buried beneath the hulking gray UV shield. Several of Mark Rothko's giant color field paintings dominate a corner of the gallery, floating landscapes of shimmering hues, detail-less and yet so emotive. This is how Sadie will see, I think, in giant fields of color, as an abstract expressionist does.

A few days later, I am cornered at an afternoon gathering by an acquaintance, a tireless raconteur of questionable narratives.

"My aunt is an albino," she says. "She had to wear a blanket over her head during the day if she ever went outside, but mostly they had her working in the fields at night during rainstorms. Everyone thought she was a witch."

"Really?" I ask, unconvinced.

"You got the short end of the genetic stick," she says, shaking her head.

It enrages me that this woman is calling my beautiful baby a manifestation of poor genes. But it is the interactions during the most mundane aspects of life that wear me down. A flash mob of shoppers comes alive at the grocery store when I push my daughter along the aisles in the cart—craned necks, pointed fingers, wide-eyed astonishment. "Does she get her hair color from you or your husband?" they ask. The answer is both, of course, because it's a recessive trait.

WE RETURN TO ST. JOHN'S IN EARLY FALL, AND AFTER A CONSULT WITH our ophthalmologist, Sadie gets fitted for glasses to help control her nystagmus and improve her distance vision. Something about the pink plastic frames digging into her chubby cheeks upsets me deeply. I erupt in great, galloping sobs at the optometrist's office. Even after I pull myself together, a snivel will escape at random, like a hiccup.

Around the same time, I am roused from sleep one night by a drunk abusing the cars parked on our downtown street. His fists repeatedly rain down on hoods and trunks and windshields. The bashing of flesh on metal and glass sounds like an offbeat drum, punctuated by his raging diatribe. The next morning, I see two cars with smashed windshields on our block. Later that week, a neighbor tells me that the offender returned, leaving an envelope with $250 on the windshield of one of the damaged vehicles. Inside was a note that read, *I'm sorry I smashed your windows. I don't know what got into me.*

This outburst and the man's apology resonate with me. Some days I want to scream out my front door like a banshee and smash my world apart, then leave an apology note and get on with life.

Instead, I rub two shiny worry spots into either side of my scalp. While organizing photos from a spring vacation, I am shocked to see the round bald spots peering out of my hairline, like a second set of eyes. Motherhood, with its saggy-bodied sleeplessness and the baby's constant cry, is a foreign country. Not Tibet exactly, but certainly Denmark, or Croatia.

AT EIGHT MONTHS, SADIE BEGINS TO SPEND TIME AT OUR LOCAL CNIB (founded as the Canadian National Institute for the Blind), a center where we can use a playroom designed for children with limited sight. It is called the Snoezelen Room (an awkward

neologism that pairs the Dutch words for “sniff” and “doze”), and it conjures hazy memories of European discotheques from the year I spent in the south of France. A darkened lair, it is a wild array of flashing lights, mirrors, padded floors, lit-up toys, and beanbag chairs, under a convincing projection of stars. Another projection on the wall is of an underwater scene in the shape of a circle, as if we were peering out a submarine porthole. Sadie’s vision progresses in tandem with these visits, until one day she notices the stars on the ceiling.

Along with the music lessons, playgroups, and kids’ gym, the Snoezelen Room becomes just another new-mom-and-baby excursion. Months back, however, pushing my stroller through CNIB’s doors for the first time, I agreed with the woman I met in the hospital waiting room in St. John’s: “It’s not supposed to look like this.”

But it does. And it will. I see lots of other kids wearing sunglasses, and we live in an age of UV-proof clothing and SPF awareness. Visually impaired or sighted, we all carry technological devices that facilitate our everyday tasks. Sadie is beautiful, smart, and funny, and most important, she is loved. Her network starts with her two smitten parents and expands across family and friends, a team of doctors, and a beloved dog that waits with tail-thumping enthusiasm at the nursery door every morning. Her fans include the PhD-wielding mamas in our baby group, her sitters, the besotted employee at our local grocery store, and our postal worker, who for a year delivers weekly gift packages to the little blond girl at number 62.

Before Sadie came along, smug parents would tell me that you can only really know love when you have a child. I interpreted this to mean the love you feel for your child, which I now know is vast and indefinable. But I wonder if they meant it in a greater sense. It is the love we receive that astounds me. You never know how much people care about you until you fall apart a little and everyone picks you up, piece by piece, and puts you back together again.

I AM THE ANTHOLOGIST, AND THESE ARE THE STORIES IN MY REPERTOIRE. Occasionally, snippets of darker narratives sidle their way into my collection. I read about folk beliefs in Zimbabwe and Tanzania, where some see albinism as a curse, a contagion, or punishment for a mother’s infidelity with a malevolent spirit. In these nations decimated by disease, there are rumors that sleeping with a woman with albinism can cure HIV/AIDS.

“The same culture that can elevate me to a god can turn me into a demon,” says Peter Ash, a BC resident with albinism who founded Under the Same Sun, a Vancouver nonprofit that strives to better the lives of people with albinism in Tanzania.

Ash is a fast talker, and he rhymes off the atrocities visited on Tanzania’s albinism population in rapid-fire succession: rape, violence, dismemberment, social stigma, abandonment, orphanhood, and infanticide. He tells me about visiting a little boy who had lost a hand to poachers—a transaction set up by his parents. The poachers sell “albino” body parts to witch doctors, who believe they hold magical properties and use them for curative potions.

Ash remains remarkably objective when discussing these issues. I am less so.

Whispers of colonial judgment shroud my objectivity. “How do I interpret this?” I ask my former teacher Diane Goldstein, a folklore professor at Indiana University, and a renowned belief scholar who describes herself as a cultural relativist. She reminds me to look at the context, and says that in her own work (on AIDS legends and beliefs and, more recently, infanticide), she finds that “at the heart of these beliefs are important cultural issues that are very humane.”

And how different are these beliefs from our own? Hollywood is North America’s witch doctor, and he can also be barbaric. Such popular films as *The Da Vinci Code*, *The Matrix Reloaded*, and *The Princess Bride* all feature albino villains. Despite our perceived modernity, much of our faith and knowledge is wrapped up in make-believe.

AFTER MONTHS OF READING PARENTING MEMOIRS AND MEDICAL JOURNALS, I return to novels. I pick up Michael Crummey’s *Galore*, and in the first few pages a “bleached white” man is cut from the belly of a beached whale, to the horror and fascination of the outport villagers who witness the event. The man is christened Judah, and there is a hint of the supernatural in his muteness and whiteness. He is often referred to as “the albino.”

I have crossed paths with Crummey a few times over my years in Newfoundland. He is kind and affable, and I like how he peppers his soft-spoken sentences with emphatic curses. He agrees to speak with me about Judah’s character.

We meet in a soulless boardroom in the library at Memorial University—Crummey’s alma mater, where I am working on my PhD—and he tells me that Judah’s whiteness is not related to a genetic condition. (In the book, a doctor’s examination reveals that Judah is “not a true albino,” and Crummey jokes, “I guess given your own experience he could have just got it wrong.”) The decision was practical: Judah was bleached by the whale’s stomach acid. However, the whiteness opened up a variety of literary possibilities.

“White is the empty page,” says Crummey. “It’s the blank canvas, and so what I saw happening in the book was that Judah was the blank canvas people could project whatever they desired most—or whatever they feared most—onto. The community created Judah over and over and over again because he was blank.”

White is the noncolor, both enigmatic and profound. I think of Noah’s whiteness, symbolic of a divine path. I think of the fair-haired people who live in the New Zealand mist, the moon children on a string of islands off Panama, and the infants who went away with the fairies of Newfoundland. I think of the tiny white-haired baby who slept in her plastic bassinet while half of the hospital came to her side in awe.

I can’t go back to those few days in the maternity ward, before the janitor’s Cassandra-like prediction, before science threatened my version of the story—when I spun my own tale and accepted my daughter’s beauty as otherworldly and magical. I am not certain that we are better off for knowing the molecular story rather than the folktale, or whether there is room for both. Science can tell you how genetic anomalies and birth defects happen, but not why they happened to you rather than to your neighbor. Medical facts can rarely offer the level of comfort that stories can. At least in our personal narratives we have control. Here is the value of folklore: it gives shape to

the unknowable. This can be uplifting or dangerous, but ultimately it explains human difference in a way that science never will. Some days, I yearn for my short-lived dark age, but it is a curious nostalgia because I can't imagine life—and more specifically my daughter—to be any different, and in the end I don't want to.

WHEN SADIE IS A YEAR OLD, DR. TURNER INVITES US TO SHARE OUR tale of genetic discovery with her first-year medical students. We nervously over-prepare with a twenty-one-slide PowerPoint presentation and seven pages of notes.

The talk goes smoothly until we broach the topic of having a second child. There is a one-in-four chance of albinism, and one in two that the baby will be a carrier regardless. There is also a one-in-four chance that the gene will not be present at all. These numbers tell me as much as tea leaves or tarot cards. A second child will have this condition, or she will not.

For now, it is just a line in our printed notes: "Talk about DNA/in vitro testing." The rest of the sheet is blank because we have come to the end of the story so far. We have to look out at the fifty or so faces in the room and shrug our shoulders, helpless to fate, helpless to a wiring system I barely understand, the invisible ruler we must obey that hovers, depending on what you believe, somewhere between God, fairy tales, and science. The talk stops here. The students clap, and Sadie looks up from the third row, where she has wedged her walker between a desk and a knapsack. The clapping ends, and the students ask us questions we can confidently answer, about events that have already happened. Sadie dislodges her walker, turns, and races off in the other direction, happy to receive the students' attention, content to hear her parents' voices in the background, knowing that we are there watching her and making sure (for now) that her world is padded and safe.

Telling our story to the medical students is not as frightening as I had thought it would be. The reality is that I tell versions of this story every day. I tell inquisitive grocery shoppers, and moms at playgroups; I tell my seatmates on airplanes, and strangers at the park. I perform the narrative like a folktale, many times, and it changes depending on the context and the audience. One day, I will pass it on to the person who matters most, because it is her story, after all. I wonder how she will tell it.