

Elizabeth Graver
from *Awake*

A long road leads to it. There is no sign. No Indian name on a wooden plaque, no Go Slow Children, just a left turn off the highway, a right turn off a single lane tar road, then a dirt road appearing before the headlights of the van, the unfurling of a path we never thought we'd find. Max in the back, that first year, his arms pale in his short-sleeved shirt, his face pressed to the window. Are we almost there, Mom? Yes, I think we're almost there. Ian at the wheel, leaning toward the dashboard. I sat next to him, my penlight tracing our path on a map. We were late. We'd gotten slightly lost, my fault. Behind Ian, his head on a rolled-up sleeping bag, Adam slept.

What I remember of that trip, our first trip there, was a sense of moving toward a place I'd been wishing for--quietly, almost unconsciously--for the past nine years, even as I'd thought it didn't exist and never would. What I remember, too, was the feeling of entering a made-up story, for I'd often told Max about a land where night was day and day night, where children ran outside when the sun went down and flowers bloomed white so you could see them in the moonlight. As we drove up the dirt road, a deer stepped out of the woods, and Ian slammed on the brakes. For a long moment, then, we all stared, human and animal, the deer so close you could see the flare of its nostrils, the raised tendons in its neck. Be careful, I said to Ian after the creature plunged back into the brush. Be careful, please. It was something I said too often in those days. I am, said Ian. I always am.

A startled deer. It stopped to look; we all looked back. Be careful. Already in my mind it was a story for Max, to help him remember as he--if he--grew up.

It was after ten when we pulled up to the camp. The lodge was dark and massive, built of wood. In the driveway we saw mini-vans like our own, and station wagons, and a smaller car or two. Lanterns hung on poles along the drive and swayed in the breeze, making it look festive, like a wedding. The license plates were from everywhere, Arizona and Quebec, Illinois and Alabama, all of us come like pilgrims, clutching hard our hope. Ian parked the van and turned off the motor. Are we there, asked Adam sleepily. From behind, I felt Max's hand on my neck. He'd crept close, his fingers twining through my hair. All right, said Ian. Shall we go check it out? But we just sat, my hand on top of Max's now, pressing down. From inside the lodge came the sound of voices and a child shrieking, then a piano being played by someone who didn't know how.

Who knows how long we might have sat there if a figure hadn't appeared on the front steps and waved. Ian rolled down the window and said hello.

"You must be Ian and Anna." The man came over and stood by Ian's door, then looked into the back of the van. "And Max and Adam. Welcome. Hello. I'm Hal. Were the directions okay?"

"Perfect." Ian flicked on the overhead light.

I leaned across him. "We got a little lost, but not because of the directions. I missed a sign. Sorry we're late."

"No no." Hal shook his head and handed Ian a heap of cloth--four blue T-shirts, it turned out, printed with a glow-in-the-dark Camp Luna above a winking crescent moon. I'd seen his

picture on the web site, but of course he looked different in person, his face more animated. "You're not late," he said. "You're just in time for dinner." Then, as suddenly as he'd come, he turned and disappeared inside.

Ian followed. First Ian, then Adam, then Max. Max wore a fanny pack around his waist with Who, his stuffed owl, zipped inside. We left our bags in the car. None of us wore the shirt. I went last, making my way up the stone steps into the entry hall, wishing Max had stayed behind to hold my hand. Over the years, I had become more, rather than less timid. Now I felt like a new girl at a school dance, filled with both curiosity and queasiness: the camp would live up to our expectations; we'd be disappointed; Max would make friends, or else turn away and sulk. The other children would be--

Here I had to stop a moment. The other children would be what? Hurt. Scarred. Dying. Some of them would be dying--if not now, then over the next few years. I'd known this before, but never so strongly as when I stood on that threshold. It was as if we'd been separated years ago from a tribe we'd never asked to join, and now here it was, a reunion, a gathering--come in come in, you're family--but what was this family? A fluke in wiring. A random, costly mix-up in some DNA.

It was Hal who came to get me. I must have seemed dazed. He looked at me; I looked away. He touched, I think, my arm, and the moment, well, the moment passed like any other, as most beginnings do.

"Are you all right?" he asked.

"I'm fine." Suddenly, oddly, I was. I smelled food cooking and heard laughter coming from inside. "I can't believe we're finally here," I said. "Max has been waiting for so long."

Hal nodded. "Alida, too. My daughter. Do you want to meet her?"

I followed him into a central room with high ceilings and a huge stone fireplace. People turned briefly to look at us, then returned to their conversations. A woman walked by with a pot of steaming soup, her round face flushed. I scanned the room. In the corner, squatting over a stuffed animal, was a small girl with dark hair that fell nearly to her waist. As we approached, I saw that her skin, at least in the dim light, looked normal. She wore the blue camp shirt and a red polka-dotted skirt.

"Hi monkey." Hal touched the top of her head. "I've brought you Anna Simon, Max's mom."

She looked up.

"Hi there," I said.

She put her hand on her father's foot. "Where's Max?"

"Max is--" I saw him standing across the room, next to Ian and Adam, and another man and boy. "That's him, right over there."

"The Max I know"--she pushed her bangs off her face and turned to look-- "takes his boat to an island where there's monsters in the trees."

I nodded. "He likes that story, too."

"But he's got straight hair and no XP. And a mother."

"This Max has a mother, too." Who, I wondered, did she think I was? "And a father and brother. Adam. He's here, too. He's thirteen. How old are you?"

She scanned me up and down, her eyes, like her father's, so dark brown they seemed black. Then she pulled on his arm. "Tell her, Daddy."

"You don't know how old you are?" Hal asked.

"No, but in days, tell her. In minutes."

"You're . . . over two thousand days old. More minutes than I can count. You're six."

"Am I older than Max?"

"Max is nine," I said. "In boy years. In girl years, you might well be older."

Hal laughed. "She's on to us. Come, let's go meet him."

"He's a little shy--" I started to say, though I'd vowed not to step in for Max. But already they were walking across the room.

Picture your child as one in a half a million, with a condition so rare that it takes months, after he's born, for it to be correctly diagnosed. Picture the white cotton weave on his blanket when you put him in his car seat under a tree, how within minutes, the open weave of that cloth has imprinted itself on his skin like a tattoo, a rising, welting rash. Allergies, says the doctor, prescribing cortisone, but meanwhile the infant is still swelling, blistering, his eyes squeezed shut, his mouth an open ring of pain. Picture the hike you take with your baby strapped to your chest, a rocky climb to the top of a mountain in New Hampshire, the fresh young family, the older boy who clambers, sturdy, up the rocks. How the new one cries and cries, howling so hard that as you rush back down the trail, you can think only of wanting to tuck him back inside you, return him, unbirth him.

Tests and speculations, then, charts and results, until—finally--a name. Xeroderma Pigmentosum. You've never heard of it. The words are twisty, warty, on your tongue. Xeroderma Pigmentosum. XP. Flawed DNA repair system. Hypersensitivity to ultraviolet light. Skin cancer, eye cancer at a thousand times the normal rate. Only a thousand known cases worldwide. The X moves into your house. The P moves in. You gather up the facts, gather up the children. A new planet, this, and you, it seems, the only people on it. Once, you were a lover of light, a traveler of lands. Now you darken the windows, batten the hatches, close the doors. Slowly, as time passes, this begins to feel like all you've ever known. You grow accustomed to the dark. You live— you often even love--your life.

Then picture this:

A room, a house full of children like Max. They looked fine. Yes, some of the kids had faces dusted with dark freckles, or pockmarks on their chins, or crutches. And yes, one boy wore thick, owlsh glasses and squinted when he spoke, and another child had blisters on her lips, but really, unless you knew, this could have been any group of kids, girls with butterfly clips in their hair and cut-off shorts, boys in backwards baseball caps, kids bare-legged, dark-skinned, light-skinned, curly or straight-haired, chattering with each other like old friends. I sat on a high wooden chair in the corner and watched. It might have been a church social, or a birthday party, or a camp that specialized in archery or arts and crafts. Only the parents looked a little different--hovering, maybe, or extra animated, buoyed up by the newness of this place, this group.