WHAT WE SAW AT NIGHT

JACQUELYN MITCHARD
For Danny and Pamela
Hearts and minds
Être et durer
“To be and to last”
(the unofficial motto of Parkour)
“Don’t move and don’t scream too loud, no matter what you see,” Juliet told Rob and me. “Promise? On pain of death?”

“I promise,” I said readily.

Rob shot me a furious glance. I forced myself to shrug with a chilly deadpan.

What else was I supposed to do?

Juliet was a force of nature. I could ask her why we might scream. I might as well chew on air. She wouldn’t tell us. She was my best friend—in fact, aside from Rob, my only real friend—and the sum total of what I truly knew about her would have filled a teaspoon. She’d probably spent two hundred days at my house, and I’d spent another hundred at hers. None of that mattered. Still, I was always guessing at how headstrong she was and how unattainably different . . . and we were about to see that proven all over again.

Rob shivered in the Washington Wizards team jacket his father had given him. It was meant to be comforting, to include
Rob in the real world. Rob was a natural athlete, especially when it came to basketball, but couldn’t play because of what he had, what we were. He could never be exposed even to the lights in a gym during a real game. The jacket was one of thirty or so. His dad stockpiled them, being a sporting-goods buyer. They were actually a kind of mockery. But Rob’s dad was such a sweetie that he would never have realized that. So Rob dutifully rotated among the Bucks, the Bulls, the Pacers, the Pistons, and yes . . . even the Wizards.

I was wearing my leather coat and two layers of scarves. It was April 8, but Iron Harbor didn’t know it was technically spring. At two in the morning, in the brick passage-way between the Smile Doctors dentistry and Gitchee Gumee Pizza, we could see our breath every time we spoke. The temperature couldn’t have been much above freezing.

“I’m going to die,” I said. “And be cryogenized. Standing here.”

“Such a weenie,” Juliet said.

She didn’t seem to feel the cold. Ever. In a black bodysuit that made Rob stare and a black turtleneck sweater that gathered at her knees, Juliet braided up her waist-length dark blond hair and looped it into an elastic band. Along the left side of her face, from her cheekbone to her lip, she’d stenciled in iridescent face paint a line of blue stars that glowed in the faint light from the street corner.

Face paint! For a Tuesday night among the Nothings of Nowheresville, Minnesota. For the excellent true adventures of three people who had absolutely no lives.

“I’ve been called a lot of things,” I said. “But never—”

“A weenie? Consider yourself called,” Juliet interrupted with a wicked laugh. “In fact, I have called you a weenie myself.”
She had, in fact: the previous summer, when I balked at breaking into Valerie Meyercheck’s house again. After all, it was the third time. Valerie spent about ten days a year in Iron Harbor and the rest of the time whirling among her houses in Switzerland, Paris and Lake Forest. I’d finally followed Juliet inside, but I did not try on any clothes. Juliet took two sweaters, two of countless heather cashmere cardigans. Juliet insisted (and I believed her): no one who had a hundred color-coded sweaters could be sure if the moths had eaten some, or if the dear old family servant Valerie, probably called “Mammy,” had given them away to the poor.

Maybe I was a weenie.

Of course, none of us could trump what Henry LeBecque had called Juliet last fall, though we should have seen it coming for years: a “wannabe vampire.” As if she’d chosen to live the way we did. First off, how could any guy with a pulse dump Juliet, no matter what her limitations? Henry said he couldn’t stand being with a girl who basically had to go home every morning and sleep in her coffin.

He paid for it, though, a month later. Just before Halloween, the former librarian, Mrs. Taylor, died at ninety. Torch Mountain Home Cemetery happens to be a place where a lot of kids like to drink. Nobody was thinking about the fact that they would dig old Mrs. Taylor’s grave before they actually buried her, and cover it with a piece of canvas and a blanket of sod. Henry never knew what hit him. His “friends” (loyal allies that they were) took off when they heard Henry scream and tumble into a black hole. He was lucky he had his cell phone to call his parents and explain to them how he ended up alone in the deep bottom of a new grave in the snow on Halloween night. He was a weenie.
“Don’t look yet!” Juliet called back. “I have to go through this mentally before it happens.”

Biting my tongue, I watched Juliet stretch, an old habit from her days as a competitive skier. She patted her hands over her clothing, to make sure nothing was sticking out or unbuttoned. She checked her shoes to make sure the laces were tied. Then she ran off into the darkness.

Rob nudged me as we heard Juliet’s light step on the fire escape, far down the cobbled passageway. The metal was old and rusty and probably a decade out of code. Most public things ran about forty years behind schedule in Iron Harbor. Who would know better than we? People were careless enough not to lock their doors. Many didn’t even bother, much to the convenience of the only three teenagers who would be out all night, whose parents either were fine with what we did, or never bothered to stop us. Who dared to try to keep us out?

There was no fire escape, roof terrace, restaurant back entrance, abandoned cabin, deck door on a lakeside mansion, no unused boat, construction site, or gated park that Rob, Juliet and I didn’t know about—even before we all got our driver’s licenses last winter. The three of us had been born within four weeks of each other. What were the odds? January was obviously a very good month for freaks. Now the streets of Iron Harbor—all twenty of them, plus the resorts in the hills around the tiny town—belonged to us.

“What do you think she’s doing?” Rob said.

He noticed me shivering and pulled me close to him.

My heart skittered. I resisted the urge to say: Hold me tighter. My fingers flickered at the level of my chest in the ASL sign for “I want”: the one we taught my little sister to use to ask for food when she was three and spoke only baby
Chinese. But Rob didn’t see. He never saw. My sign language was from me to myself, a sort of prayer, like the way people cross their fingers behind their backs when they tell a lie.

It wasn’t a lie, though. It was the central truth of my so-called emotional life. For the past three years, Rob’s touch could brand itself in a way I would be able to feel the next morning when I lay in bed, as though I’d been bruised and there was a sort of pleasurable agony in probing the injury. Rob could pull the pin on my emotions just like that, and then leave me on fire as he walked away. He had no idea, of course. Worse: it was the effect he wanted to have on Juliet, and never would.

He hunched down on his heels and started poking at the mortar between the cobblestones. We waited.

*One, one thousand. Two, one thousand. Three, one thousand* . . .

You can think a lot in three seconds, I’d learned from being in an MRI machine.

My mother knew how I felt about Rob. I’d never told her. I didn’t have to. My mother should have been a clairvoyant on TV and made us all rich. (“I see an older man, very handsome, a thick head of hair. He’s with a baby. He wants you to know they’re both happy.”) People would have believed her. She could see through walls and straight into my skull. And phones? She could name the person at the other end of the call by the tone of my voice or who I was texting by the number of keystrokes.

A telling example of how my mom operates: about six months ago, I got dressed for the night and came down for dinner. There, at my place at our butcher block table, was this little pink bag. In the bag was a year’s supply of birth control pills.
“Well,” I said. “Uh, thanks. I was hoping for a digital camera for my next birthday. Which isn’t for quite some time. What’s the occasion?”

“Just in case,” my mother said.

My little sister, Angela, who’d just turned nine, started laughing so hard that milk came out her nose. I’d bet that Mom had sat her down beforehand with a matter-of-fact “Allie’s a young woman now,” and “sexual feelings are a part of every young woman’s process of maturity.” Having been adopted at the age of three by a single mom (who happened to have an older biological daughter with a life-threatening disease), Angie was disturbingly wise beyond her years. Either that or just disturbed.

“I hope these have a really long, uh, shelf life or whatever, because I don’t have acne and Mr. Right isn’t anywhere around,” I said. “Or even Mr. Wrong, for that matter.”

“I was thinking about Rob Dorn,” Mom said.

“So have I, but he thinks about Juliet.”

“Are they . . . ?” Angela put her fork down. Spaghetti sauce was way too volatile a condiment for this conversation.

“Most certainly negatory,” I said. “Rob has as much of a chance with Juliet as Howard.” (This in reference to a custodian of indeterminate age, who had worked at the hospital and clinic since shortly before time began. All of us knew Howard because he never really seemed to leave. Any time any of us had ever been there, he was either pushing the big rubber dumpster through the halls or lying down inside it, singing some of his favorite religious hits.)

“I just thought you should have them,” Mom said.

“Isn’t this the kind of thing you’re supposed to find hidden away somewhere? Then start crying and saying your little girl is all grown up?”
My mother sighed. “That would be conventional,” she said.

Even now, I couldn’t tell if she would be happy if I actually took the birth control pills or if I didn’t. So I kept them in my underwear drawer. I was the one who almost cried whenever I saw them, because I knew I was the last person on earth who would ever need them. . . .

Juliet’s voice came down from above like a mortar shell. “Live once!” she shouted. “Ready?”

“For a year now,” Rob muttered. “What stupid thing is she doing?”

“She’s okay,” I said, and I called softly, “Ready, Juliet!”

“She doesn’t have a light,” he pointed out.

“You don’t know that. She could have had it in a fanny pack under her sweater.”

Until recently, my little sister actually assumed that people with XP could see better in the dark, like cats. Which is absurd: on average, we probably see worse. A lot of people with XP damage their eyes with light when they’re little before they even know they have it. Rob and Juliet and I kept miners’ headlamps and little Maglites in our backpacks if we had to pick a lock or peer down a ravine or around a dark corner.

“Are you right where I left you?” Juliet called, very far away. “You have to watch every second of this. You’re my witnesses!”

I called back, “We’re right here!”

One of the things you learn pretty quickly if you live your life at night is that—unless you’re literally standing on someone’s front porch—you can pretty much be as loud as you want. No one will hear you or see you. Definitely, no one will care. We had Juliet’s dad to thank in part for our freedom, of
course. Tommy Sirocco was one of the Iron County sheriff’s deputies, and he worked the midnight shift solely because his family’s life was set up around his daughter. Whenever he spotted Rob’s Jeep, Officer Sirocco would quietly turn his squad car away to give us privacy.

I heard a shuffling and loud scraping above. Rob tensed. Juliet was making her way across the flat gravelled roof of Gitchee Gumee Pizza. The Indian name for Lake Superior is Gitchee Gumee; that wasn’t just something Longfellow made up for a poem. (Hiawatha was real, too, by the way.) The second floor of Gitchee Pizza housed the apartment of its owner and founder, Gideon Brave Bear—also a genuine Indian, a Bois Forte Chippewa; he got pissed if you used the term “Native American.” Every kid in town ate at least one meal a week at Gitchee. Fortunately, in addition to being a very good purveyor of pizza, Gideon was also a very stereotypical drunk. He wouldn’t have heard Juliet if she had been up there setting off fireworks.

We heard the scraping again, and then a few short taps.

“Juliet!” Rob cried out. “What the hell?”

Then Juliet jumped.

For a shattering instant, I thought I was a witness to my best friend’s death: a spectacular original suicide, for an audience. It was just the kind of stunt Juliet would pull. My mind slowed to syrup as I waited for her body to hit the ground between Rob and me. Juliet had always sworn she would die her own way. Not in some bed in the darkened living room of her house or hooked up to an IV in a sterile hospital . . . or after an overdose with a note pinned to her pillow, which is how many lives end for people like us.

But this wasn’t death. This was life. The moment Juliet
What we saw at night

launched herself from the roof, she became a whirling constellation. I couldn’t see her face. A long line of glow-in-the-dark blue stars, outlined in silver, soared out above our heads between the buildings, wheeling in space, completing a full circle. Then the stars were gone. She’d already landed on the opposite roof—hootling in her victory dance—when my brain caught up to my eyeballs.

Juliet Sirocco had just traversed a twelve-foot gap, twenty feet off the ground . . . while performing a front flip in mid-air. She must have shed her sweater on the roof. That explained the feverish swirl of glowing stars. She’d stenciled them on her bodysuit, all up one leg and one arm, as well as her face. Rob fumbled for the switch on his Maglite. The faint beam flickered over the roof. Juliet was punching the air and grinning down at us. I broke my promise, because I screamed. I couldn’t help it. The word exploded from deep inside: “Amazing!”

“Shut up, Allie!” Rob hissed.
“What? That was pretty amazing.”
“She could have been killed!”
I had to laugh. “What else is new?”
The three of us met in the sandbox. In the sandbox, at night.

You think of a happy child. That child is playing in the sun. She’s picking flowers in a field with the sun’s rays painting threads of platinum in her hair. She’s running with a kite, her chubby legs just a little tanned with the balmy blessings of midsummer. Think about it: even the *Sesame Street* theme song begins with the words, “Sunny day, sweeping the clouds away.”

That sunny day would kill us.

We were happy children, I suppose, but we ran to the swings to play when kids our age were listening to bedtime stories. In the hospital, I’d once overheard a toddler telling his parents he’d seen ghosts in the Iron Harbor playgrounds, the ghosts of children. I remember I was afraid to speak to the nurse after that because I thought I might cry. We hadn’t come back from the dead, but we did live in a parallel universe. It was our own country, the night country. We lived
there with our parents, many of whom chose to be Persephone and abide in the netherworld for the sake of love.

We also had each other.

I couldn’t even remember a time before the three of us were friends. So I knew from those playground days that Juliet would never stop. She was always the first to dive naked into Ghost Lake, black water so cold that it would freeze the blood in your veins. She was the first one to get a set of lock picks so that we could steal a joint from the back room of the guy who hand-loomed ugly ponchos for tourists. We got the weed but we only had one toke apiece. If you have XP, you really can’t smoke. Heat damage risk is huge. You can, however, drink. Juliet helped us celebrate the New Year last year by sneaking into the hot tub of a famous New York talk show host’s ski chalet, drinking the champagne we’d lifted from one of the twelve cases of Veuve Clicquot in his wine cellar.

But there was a flipside to Juliet’s adventurousness, the side that haunted Rob and me. She was the only one who took off, for weeks at a time, alone, away from us. First she had a legitimate reason: for four years, from ages eleven to fifteen, she managed to ski competitively. Sunlight be damned, she hurtled down the slopes swathed like a mummy in oversized goggles. But then, a year and a half ago, she’d suddenly stopped. Yet the disappearances continued. Like every month or so, for a few days or a week, we wouldn’t hear from her beyond a text saying C U Soon.

She always came back though. That was the silent mantra I repeated to myself whenever the absences seemed to reach a breaking point. Juliet always comes back.

JULIET CAME CLATTERING down the fire escape.

“Did you see me? Did you see me?” She was jumping
around like one of the Cat Dancers on the pom squad at Iron County High where we were students but never actually went.

“I saw you!” I said. “What made you do that?”

“What in the world would inspire even you to do something that idiotic?” Rob snapped. “That was screwed up, even for you.”

“What do you mean, even for me? Somebody who’s not a wuss?”

Rob rolled his eyes. “My point is: you don’t even know what you’re doing. People work out for years before they try anything like that.”

“I’ve been practicing it for months!” Juliet’s hair had come loose from its braid and cascaded around her shoulders. Her face blooming in the cold, she looked like a movie star, the only imperfection a little shadow of a cleft in her chin.

When she got mad, her eyes changed color, like somebody had retouched them with gold flecks. Juliet had no scars. Most people with XP who don’t find out until they are two or three years old have a lot of dark freckles: scary dark scars from sunburn. Rob had some on his back and neck. They found out he had it when he was one, and they were pushing him in his stroller at Disney World. Some lady looked at him. His mom thought she was going to say how cute he was, but instead she screamed, “What did you do to your baby?” Rob’s neck and back had morphed into an angry field of huge, dripping blisters.

I didn’t have any scars, either. But they found out I had it before I was born. Ironically, my dad is a genetics researcher. He had a cousin with XP, the fatal allergy to sunlight. (Clinically, Xeroderma Pigmentosum.) So they tested the unborn baby for it. And they found out—yay!—she didn’t have it.
Then she was born. Surprise! I did have it. Tests aren’t always right.

Then Dad took off.

Lots of dads do. I hadn’t seen him since I was four. He existed for me as some very nice handwriting in a few letters and a bunch of fat guilt checks that allowed us to own our house and have some nice things. Mom adopted Angela instead of latching on to some guy, which I completely admired her for, because most XP kids are only children.

What makes XP even stranger is that there are seven kinds of variations involving eight genes. Some kinds only affect your eyes and skin. But others involve cell changes from exposure to sunlight, too. Juliet and I have Type A, and Rob has Type C, but none of us have the kind that makes a child start out smart and beautiful but lose more and more every year . . . reading and drawing and words and steps just disappearing, like water into dry earth. If you can be grateful for something that’s impossible to be grateful for, I was grateful for this small blessing. And for my mom, especially. I couldn’t even imagine trying to raise a kid who was not only doomed to a life without sunshine, but also to lose her mind.

Juliet continued to pirouette before us.

“You’ve been practicing this alone? What if you hit the ground?” Rob demanded.

“What if I did?” Juliet said. “I’d die. Gideon would find me the next morning. Somebody’s going to find me dead sooner or later anyhow.”

As the douchebag Henry LeBecque pointed out, one of the truly extra-terrific things about XP is that you’re forced to live like a vampire, except you’re not immortal. Most people with XP die before they’re forty, although in every other way,
you’re totally normal. Juliet lived like she was dying. Some XP people do. Others just hide in the dark and wait.

Nobody said a word.

Juliet finally glared at both of us and growled, “I’m getting my sweater.” In a flash, she hurtled back up the rickety fire escape to the pizza parlor roof and came stomping back down, clearly outraged at Rob—and me, too, although I hadn’t done anything. “Go on and leave. I’ll walk home. I’m taking it you’re not interested.”

Her home was a long, lonely uphill hike from Gitchee.

“Interested in what?” I asked, glaring at Rob, too. “We’re not leaving you.”

“She can do what she wants,” Rob said in a toneless voice. He was shaking out the keys to his Jeep, mumbling about going home early. It wasn’t even three. We hardly ever went home before five. Then he relented. “Get in the car, Juliet.”

Her eyes sparkled in the darkness. “Don’t you even want to try it? Don’t you want to learn? I have two DVDs and some books. It’s the most incredible feeling. Like flying. Like an orgasm while you’re flying.”

“Sounds good already,” I said under my breath. I’d never flown in an airplane or had sex, at least with anybody else.

“I can show you how to be safe,” Juliet encouraged.

“Yes, I could absolutely see how safe you were up there,” Rob replied.

Juliet stopped in the middle of the street, her hands on her hips. “It’s a discipline, Allie. It’s called Parkour, Rob. It was invented, like, fifty years ago in France, and it’s based on strength, speed, skill, self-confidence and safety.” She opened her blue eyes wide. “Safety? Get it? It’s a way of getting so strong you can move as fast as you want past obstacles, or over or under them, without ever being hurt.”
“I’ve seen the videos on YouTube,” Rob said. He was already in the driver’s seat.

“One of the founders said it’s a way of touching the earth and everything on it, being part of it instead of just having it shelter you.” Juliet ran over to Rob’s side of the car. “We’ve had enough shelter, don’t you think?”

“I’ve seen the memorials too.” Rob made air-quotes. “‘He died doing what he loved.’ That’s as stupid as one of those stories about how some fourteen-year-old kid’s uncle shoots him while they’re deer hunting and everybody’s okay with it.”

Juliet kept smiling. “Everybody dies,” she said, turning her face so it was out of the light. “But not everybody really lives.”
Within a month, Juliet had converted half of Rob’s barn into our Parkour Skill Gym, with mats and parallel bars Rob’s father had scraped together from work. I wasn’t surprised by how easily Rob caved, and frankly I didn’t care. I’d become alive, like Juliet. I would wake up at sunset sick with pain in my belly and shoulders from the endless crunches and handstands. *This is how she must have felt during ski training*, I thought. And when that ended . . . what was she going do with all that excess energy? Within a few weeks, I could leg-press two hundred pounds and do a handstand on the bars.

The three of us were all over the playground at the elementary school, and then all over the bleachers at the high school. At first, we ran the bleachers sideways, skipping up one row at a time to the top, for agility. After we could do that without tripping, we would swing our way down the supports. Rob even stopped saying the word “safety” every five minutes. He was in the thick of it, too. I could hear it in his laugh.
We used the playground equipment to practice vaults until we could hurtle the little merry-go-round touching it with only one hand. (In Parkour terms: a *passement.* ) But while Juliet and Rob mastered the backflip right away, I needed a hundred tries to run up a wall and hurtle backward to a standing position. I never landed like they did. Although I will say in my defense: everything I’ve ever read says that the backflip is not really a Parkour move as much as a show-off move, since the point of Parkour is to get you quickly from one place to another, defying obstacles.

After a series of my progressively more embarrassing wipeouts, Juliet said to Rob, “She’s un-teachable. Allie, how did you ever learn to do a backflip off a pier?”

“I *can’t* backflip off a pier,” I snapped, with what little breath hadn’t been slammed out of my body.

When I finally mastered it, though, I couldn’t stop. I must have done thirty in one night.

Once in a while, we saw the beam from one of the police cars: Juliet’s dad or one of his friends. They must have thought: *Nice.* What good, clean fun we were having, just playing like the kids we were. . . .

At the beginning, my mom, who—did I mention?—has always had a problem with boundaries, would walk into my room and say, “You’re burning through the Ibuprofen. What are you guys doing out there? This doesn’t seem prudent, Allie.”

But I rarely had a cut or scrape because I soon learned to drop and roll. I would land on the balls of my feet and then tumble to a standing position. To a bystander, it would look like I’d whammed myself, but it was a way of harnessing momentum to land lightly. The feeling of being able to run to the end of a wall twelve feet up and make this controlled
dive into mid-air . . . and knowing you weren’t going to twist an ankle or break your collarbone. . . . Juliet was right about the sensation. It was a part of something magical. It was like being on the earth instead of hiding inside it. And she was right about that part, too: we’d hidden all our lives.

IN JUNE, JULIET decided we were ready to try a gap leap to a cat grab and then swing down five stories to a ten-foot turn vault to the ground. She was going to set up a camera with a filter to film us. It would be the first “Dark Stars” video feat. Dark Stars would be our “Tribe,” which is what the Parkour “traceurs” call one another. (To perform Parkour was to “trace.” Juliet had memorized all the Parkour terms in French. I had no interest in the words, so I rarely used either the French or English. I was only interested in the action.)

Our launch pad was a six-story building under construction, perched on the bluffs above Lake Superior. Juliet had chosen the spot. From there we would land on the roof of an older neighboring five-story building: Tabor Oaks, an upscale apartment complex. Then we would “lache” (pronounced la-chay): swing by one arm to the other from one balcony to the one below it. The bottom-most balconies were differently built, ten feet down and about five feet to the left or right of the balconies above—with nothing directly below them except open space.

If you missed that final move, you would plummet to the grass, thirty feet down. You’d be lucky if you only broke your neck. If you had a lot of momentum, and you kept flying, you’d eventually tumble down to the boulders washed by the waves below. I’d assumed that this was the motive behind Juliet’s choice for the Dark Stars on-camera debut: the thrill, so close to the certain death on the rocks of Lake Superior,
and also so close to a bunch of rich strangers who had no taste for adventure.

Of course, Juliet must have known we might glimpse something. Only later did I realize that she’d always known.

**OUR TRANSITION FROM** the playground to the pit—to the end of an innocence we only saw in retrospect—was abrupt. If you had asked us, Rob and I would have said that we were very mature for our age. People think that, and say that, and we were among those who would have *meant* that, what with our life-threatening illness. But in fact we were, if anything, slow to “grow up.” I thought of drinking booze and smoking weed and (eventually) having sex as big markers of adulthood. I had no idea how sheltered we really were.

It began on a Thursday, right before I fell asleep in the morning.

Juliet zinged me a text: *B ready.*

I shot back: *?*

*Something new and big We R READY! READY 4 MORE! The CHALLENGE!*

*When?*

2 *morrow!* Juliet replied.

And that was all.

Why so soon? I wondered tiredly. Why tonight?

**THAT FRIDAY MORNING,** before our epic night of “bouldering”—a Parkour word that supposedly combines the word “building” with “boulder,” from mountain climbing—I had a clinic appointment.

If I had to go to the doctor, it was usually after midnight. Many XP doctors and nurses (my mother among them) worked the red-eye shift for obvious reasons. All the patients
in the XP Family Study got free care, so we tried to make it easier for those who did the caring. There were people who’d moved all the way from Wyoming and California. The Sirococos had moved from the Twin Cities, just to bring their kids to the XP Family Study at the Tabor Clinic—the most extensive treatment facility for XP anywhere in the world. They knew it was worth the headache and expense of travel to a lackluster ski resort town, all thanks to the Tabor family.

Dr. Andrew Tabor, who was around sixty, took care of us. His younger brother, Dr. Stephen Tabor, took care of the dead. (At least that’s how I thought of him.) He did research for the XP Family Study, too, but as the county medical examiner. He dissected bodies to figure out how to prevent what kills us, which is usually skin cancer—the worst kind. Every year after New Year’s Eve, the Tabors had a big party for the XP families, and Dr. Andrew would always give the same cheery toast.

“We’re THIS close. Forty years ago, my father, Simon, could never have believed how far we would come.”

Dr. Simon Tabor, who was easily a hundred and still kicking, founded the Tabor Clinic. Why he’d decided to make XP his life’s work, none of us knew—nobody in his family had been afflicted. But half of the year-round citizens of Iron Harbor worked at the Clinic. The Tabors also owned a lot of other places in town, including the canoe and SCUBA rental places, some buildings, and the three restaurants that aren’t Gitchee Pizza. Gideon wouldn’t give in, although they tried to buy him out. He said he wanted to leave Gitchee Pizza to his son, even though he doesn’t have a son and he’s been married four times.

Sometimes, I had to ask myself why, though . . . why this whole community has grown up around the Tabor Clinic.
These families are trying to buy time, basically. Time for what? Time to be with their kids, which used to strike me as selfish if the kid was suffering. Time for the kids to have a life, which is fine, I guess, until they get old enough to know what XP really means.

People talk about “genetic engineering” and “stem cell research” and “DNA repair” like it’ll be available next week at Walmart. But even if God or the government doesn’t forbid it, that stuff takes more time than we have. It takes longer than one short lifetime. Like, ordinarily, people would say to a girl my age: You have your whole life ahead of you. Sure, you have to grow up in Nowheresville, but someday, you’ll remember the huge storms and the loon’s lonesome moans and you’ll be happy you had that girlhood. And that would all be fine except the odds are, this fairy tale doesn’t apply to me. This is my girlhood and my everything-hood. You can’t blame us for wanting to carpe that diem if our diems are numbered.

I went back and forth on this subject. Sometimes, I thought I would be better off if I’d never been born. Sometimes, I thought I would hang on long enough for somebody to find a biological switch that could turn this thing off. There were some adults with XP in Iron Harbor, sure. But not too many. And we didn’t see them much. Juliet and Rob and I were among the older patients.

When my mood was especially black, I’d think of Dennis Ackerman. He was one of my tutors—super cute and the nicest guy. He taught me math and science three nights a week. He tutored other kids who couldn’t go to regular school, too, the ones on chemotherapy or recovering from mono or what have you. But having XP himself, he had a soft spot for us.
Four years ago, at the age of twenty-five, he’d decided he’d had enough.

That morning, my mom came into my room and woke me out of a sound sleep. The look on her face was so awful, in the truest sense, as though she’d seen a vision. I was sure my little sister had been diagnosed with some awful disease, too, or that Juliet, who was still skiing competitively as a freestyle jumper, was paralyzed. In a flat voice, Mom told me that Mr. Ackerman’s mother had found him dead in his car that morning. He had shut the garage and stuffed rags in all the cracks and just let the car run until he fell asleep. I asked if he’d left a note. My mom said he had, and it said that he knew this was a lousy thing to do to his mother and his “kids,” but he couldn’t stand the wait anymore.

I more or less understood that, too. But thanks to Juliet, I had long ago vowed never to go that route.

MY FRIDAY APPOINTMENT got off to a lousier start than usual because I forgot my umbrella. Mom and I fought the whole way to the clinic. She wanted me to be more serious about my illness. I figured I was as serious as I could get about something beyond my control. With my mom being a nurse, though, she was pretty vigilant. She was over-protective. Let’s be frank: she was crazy. She would have had me bubble-wrapped if she could have.

I was so absorbed in thought about our upcoming expedition that night I just spaced on the umbrella. It wasn’t raining, of course: I needed an umbrella the size of a palm tree even when the sky was clouded over, which was pretty often in Iron Harbor.

My mom had gone out early for a run with her best friend, Gina Ricci. In addition to being my godmother, Gina was also a nurse who specialized in XP.
When they burst through the door, sweating, Mom rushed upstairs to shower. (Mom held the North American indoor record for speed-showering: five minutes from foot on the bottom step to fully clothed.) Gina gave me a kiss and slipped me a ten dollar bill. One of the benefits of having a chronic illness is frequent monetary giftage. I thanked Gina with a hug—but before my mother could slip into the shower stall, she stopped at the second floor landing and eyed my outfit.

“You’re half-dressed, Allie Kim!” she yelled.

I ignored her. That always lit her fuse. You wouldn’t refer to not carrying an umbrella as “half-dressed,” unless you were my mother. So much crap to wear just to run from my back porch to my mother’s car and then the ten feet into the clinic! You can’t have one inch of skin exposed. Not for a minute. When I go out during the day, I have gloves and veils and goggles on, so that I look like I’m studying killer bees. She dashed back down and pulled the umbrella out of the closet, shaking it at me like a sword.

My mom is good. A good mom. She so believes that I will outrun XP that I sometimes let her believe it, too. If I live to a ripe old age, her reasoning goes, I won’t want to end up looking like I was deep-fried early in life, will I?

“Allie!” she said again. My mom’s natural voice is a less-than-soothing bellow that makes neighborhood dogs howl.

“Did you hear me?”

“I’m sorry, Jack-Jack,” I told her. My mom’s name is Jacqueline.

“Don’t call me that,” she said.

“Okay, Jack-Jack,” I said.

“Someone has to take this seriously, Allie Kim!”

“Jackie, calm down,” Gina chimed in. “Allie is a very serious girl.”
“And I’m an adolescent. I’m supposed to feel immortal.” Mom shook her head. “You have bruises all over you. If Rob Dorn is—”

“He has bruises all over him, too, Mom. We’re doing this . . . mountain thing.”

“In the dark?”


Gina laughed.

“I’ll give you character,” Mom finally muttered. “And I see everything.”

“That you do,” I agreed.

She hit the shower. Gina bit her lip to keep from smiling back at me.

I jumped out of the car while Mom was in mid-resumed eruption. She would have to circle around for twenty minutes and (maybe?) park illegally and get a ticket that someone would fix for her because she worked there. By then, she’d have calmed down.

The Tabor Clinic is part of Divine Savior Hospital, which is huge, completely huge, with, like, three hundred doctors. But there were only three Tabors. At the Clinic, they call me Chinese Ginger. Gina is to blame, because she knows I am half-Chinese. But Dad must have been crossed with some hot European way back to leave me with straight auburn hair and weird amber-colored eyes. My mother is fair and Irish, although she kept the name “Kim” after they got divorced, for no reason that I could ever discern—given that I don’t look Asian and she surely doesn’t, either. Maybe it was to pave the way for Angela,
my adopted sister from China. I hoped she would last after
I was gone so my mother wouldn’t be childless.

Whenever I hinted at something like that, at the
inevitability of Angie’s outliving me, it drove my mother
savage. It either made her think I hated Angela or that I
was “giving up.” Maybe sometimes I was, but only for the
moment.

Anyhow: red hair is recessive and so is XP. Both parents
have to be carriers—not of the disease, but of the gene. The
kind that seems to occur mostly with Asian people, especially
the Japanese, was not the kind I had. This was a mercy, again,
if you can say a thing like that about a thing like XP, because
other strains leave you with an IQ of 50 by the time you’re
ten years old. The weirdest part is that the doctors can’t
explain why this happens. Sun damage should have no effect
on neurology. That’s why the Tabor family is convinced that
there is a partner gene involved.

Gina was already waiting for me in the lobby. I wasn’t
surprised she’d beat us there. She hadn’t bothered to shower.
“Ready to give up a ton of blood and skin?”
“I live for it,” I said.
“Good. Don’t spend that ten bucks all in one place.”

I GAVE UP all my samples and then went to the neurology
lab. They did a bunch of peering into my nose and eyes and
making tones I had to raise my finger if I heard. Then I went
in to wait for Dr. Andrew.

I liked him. For an older graying guy, grandpa-aged, he
always smells good and he’s super-fit, like all guy doctors
(although not most nurses, I’ve observed). I would sometimes
see him jogging when I got up at night before dinner.

He gave me a hug, per usual. “You lost weight,” he said.
“Nah, just buffing up,” I told him. I had lost a few pounds from Parkour, and although I was five-six with big shoulders and strong legs, it showed.

“Nothing else? No problems?”

“Well, I have this chronic problem with sunlight. I can’t get a base tan.”

Dr. Andrew snickered. “And how’s that career in stand-up comedy coming along?” He flashed a big fake smile that would have looked dumb on anyone else his age, but on him it was just sweet and goofy.

The drill took an eternity of two hours, like it always does. But I was grateful, as I always am, not to have to endure a full checkup every month.

Nothing about me had changed. That was good news.

Once I was home, I only had four or five hours to sleep—not enough. I was also freaking out, because hang-dropping your way down a ladder or the monkey bars is one thing, but trespassing on private property is another. Juliet kept insisting they were the same.

I texted her: 2 *Tired*.

She texted me: 2 *Chicken*.

I texted her: *Bring it*.

She wrote back: *Live once!*