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A Light in the Darkness

About one in a million people are hypersensitive to the sun. Peyton Madden of El Dorado, Kansas, is one of them. But thanks to a loving family and community, living with a rare disease doesn't feel so lonely.

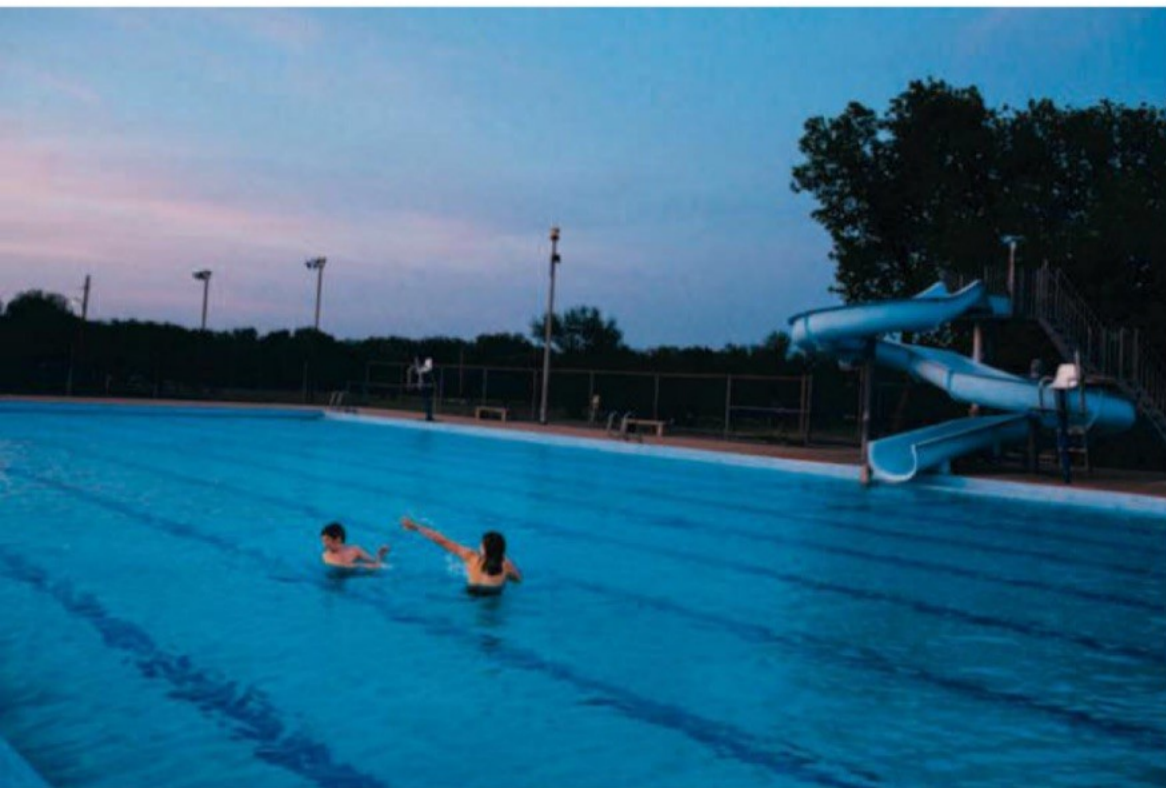
BY JEANNETTE COOPERMAN

PHOTOGRAPHS BY SARA NAOMI LEWKOWICZ

ALL PEYTON MADDEN KNEW was that the National Organization for Rare Disorders (NORD) was making a documentary. They had come to El Dorado with a film crew the day before and asked him questions about xeroderma pigmentosum (XP) and how he couldn't let sunlight touch his skin. Eleven years old and new to media, he thoughtfully answered every question, then pulled his mom aside during a break and whispered in surprise, "They're really interested in me!"

That Friday evening, though, Peyton thought they were just filming him on a bike ride with friends. Even when the American Legion guys pulled up as a sort of motorcycle escort, he figured it was "just a weird motorcycle thing"—and the crowd was for someone else's pool party.

He'd only been to the municipal pool once, wearing protective gear because he can't risk damage from



ultraviolet light. Most bodies can repair mild damage in a few hours; for Peyton, that damage is permanent and cumulative, making nonmelanoma skin cancer 10,000 times as likely and sharply increasing his risk of vision impairment and neurological problems.

Peyton pedaled a little farther with his friends, who were near bursting with the secret. And then the crowd surrounded him, and cheers erupted, and he saw the giant “Good Morning, Peyton!” sign, and it all sank in.

El Dorado had turned night into day just for him.

Overwhelmed, he did a couple more laps on his bike, a wide grin denting his freckled cheeks. “Victory laps,” thought former teacher and pool manager Steve Oltman. The mayor read a proclamation, decreeing that on August 4, 2017, “nighttime will be daytime.” When Peyton’s sister, Rylee, then 14, sang to him, Kansas State Representative Mary Martha Good had tears in her eyes—but Peyton was thinking, “Hurry up so I can shoot baskets.” The court stayed lit well into the night. The pool stayed open too, a blue froth of splashes in the park lights. Soon Peyton was starving, and Kathy Xenos (flipping name: Short Stack), a local caterer, tossed one of her famous Chris Cakes onto his plate from several feet away. “For this one night, he doesn’t have to worry,” Xenos kept thinking.

Peyton literally couldn’t stop smiling—he had to force his mouth straight just to give it a rest. The event was more than fun; it was proof that hundreds of people recognized what he has to go through every minute of his life. That night, the burden of always being different, always having to plan, got a little lighter.

“It brought out the best in everybody,” says Good. “We all share his struggle.”

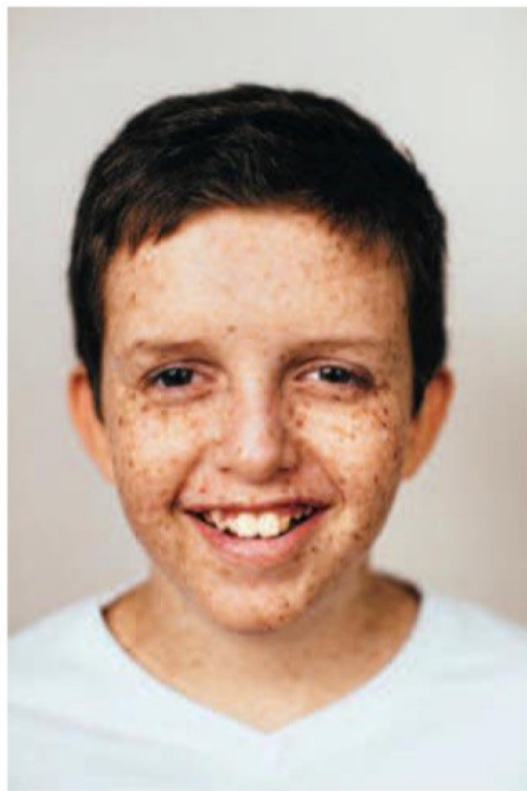
A SCHOOL MORNING: clothes, cereal, sunscreen, and 4,000 IU of vitamin D. As soon as Peyton puts on his transparent visor and hat—Sarah Madden refuses to call her son’s protective gear a “hood,” because that sounds like he’s hiding from life, and she’s determined he won’t have to—he takes out the trash.

At school, we stop in the office, where he announces with a grin, “I have a camera crew with me today.” Media savvy came fast. While he’s waiting in homeroom, his leg jitters a little, energy he can’t burn outside. I ask what’s next.

“We’re just going to stay here forever till it gets to be 8:15. Then we do our morning routine.” He likes math and science and social studies, not writing and reading. Except *Harry Potter*. He and his friend Dylan Hunter start trying to figure out how they could play Quidditch in gym class and what—or who—would be the Snitch. Peyton sticks his tongue in the corner of his mouth, mischievous. His innocence shows even in gestures, like the way he slaps his forehead over something he forgot.

In art class, he tests the Elmer’s glue on his sleeve, then starts to draw, sucking in his cheeks as he concentrates. Every time he reaches for a new color, he sharpens the pencil before using it. The kid can draw; his work is precise and beautiful, the freehand lines as straight as rulers. He wants to be an engineer.

When he and his friends work on a poster for the Renaissance Fair, I ask what superpower they’d want, thinking maybe Peyton will say he wants to be invincible, safe from the sun’s rays. Nope. “Anything I saw in a poster or on TV or my phone, I’d just be able to reach in and pull it out,” he says. Also, he wants a pet dragon.



Sarah refuses to call her son's protective gear a "hood," because that sounds like he's hiding from life.

Lunch comes early: mac and cheese and Lit'l Smokies. "You need more sunscreen?" his friend Tyler asks. Peyton reapplies three times a day, SPF 50. Teachers feel the top of his ears and say, "Nope, not enough." If a door is open, his friends walk ahead, says Tyler, "like a human shield."

Out on the playground, Peyton tugs down his visor and tosses a football. The wind is high; we're in tornado country. He and his buds move to the basketball court, where a group of kids have stretched out like they're lying by a pool. Peyton shoots baskets instead. After a while, a teacher comes over. "You hot?" Cheeks flushed, he gives a diffident shrug. "Yeah, kinda." She motions him inside, and his friends troop after him.

Finally, the bell rings, and through the jubilant blur, I glance over and see Peyton in the corner, standing in front of a closet, smearing on more sunscreen.

WE'RE WAITING FOR DARK. The Maddens' year is divided by the light: Summers just about kill Sarah and Kyle because they all stay up late playing, and then the grown-ups have to go to work the next morning. Fall is heaven, because dark comes sooner.

"The sun sets in four minutes," Rylee announces.

"It sets at 8:26," her dad says.

"Yeah. It's 8:22 now." They use their UV meter, testing for the magical 30 minutes when the sunset's afterglow keeps the world visible but the danger is gone.

Five minutes after sunset, it's safe, and Peyton's hat comes off. "Feels good," he says as he tears outside with a laser tag gun and some glow sticks.

"Light-up Frisbee, a light-up soccer ball," says Sarah. "If it glows, we pretty much have it." With her son out of earshot, she talks about their weird relationship to this most basic thing, the sun: "There are days when you feel the sunshine on your face, and it's the best thing ever. And there are other days when you walk outside and think, 'My child can't feel the sun on his face.'"

The first, unheeded clue was a smattering of adorable freckles around age 2. The serious clue came at age 3, when Peyton woke up with what looked like a sty on his lower eyelid. By the time the Maddens were able to get it removed, it was the size of a marble and reached down to the bone.

Peyton's doctor wondered. He'd treated someone with XP 30 years earlier, which was a lucky coincidence given that in the U.S. and Europe, XP affects only about one in a million people. When the growth was removed and a biopsy confirmed it was cancerous, that clinched the diagnosis. Then real panic set in: How were they supposed to get him home from the hospital? They covered the car windows with towels and blankets, and Sarah sat in back, shielding his face while he slept. They contacted the XP Family Support Group and learned how to put film over their house's windows and make Peyton a tiny



There will always be challenges: The sun, of course. Secondhand smoke. Parents edging their kids away.

hat and buy a camera that took good nighttime pictures. Sarah looked at her favorite snapshot, sun glowing on her little boy's face, and realized she'd never see that again.

Soon after, the Maddens moved to a new house (windows permanently tinted), and Sarah glared at their neighbors, half jealous, half worried for them: "People were outside all the time, and I'm thinking, 'You need to go inside!' We were new to it and overprotective." They'd barely had time to grieve all Peyton was losing. "One night Kyle and I just sat together on the laundry room floor and cried," she says.

Since then, though, they've thrown so much love at the problem, it's become manageable. Sarah was always a planner; now spontaneous Kyle has mastered the art too. As a result, Peyton has done more than they dreamed possible in those early days. "He's climbed to the top of Mayan ruins," Kyle says proudly. "We've been on three cruises." (Portholes have thick, protective glass, and Peyton stared out of them.) They've even hiked at Yellowstone.

The XP Family Support Group helped at every step. So did doctors, teachers, and anybody in El Dorado who learned their story. Which, by now, is everyone in town.

Still, the research moves at a turtle's pace. More Americans (about half of them children) live with a rare disease than with HIV, heart disease, or stroke. There are about 7,000 rare diseases, most with no FDA-approved treatment or therapy and little federal funding to discover

any. NORD gives research grants (funded by patients, families, and patient organizations), and in many cases, those grants are funding the only research being done on a particular disease.

PEYTON'S TAE KWON DO teacher, Jeff Jones, tapes the curtains shut and, after their formal greeting, whips a pool noodle toward Peyton. Peyton ducks fast, jumping as the noodle comes back low. Six months ago, he had to do push-ups on his knees; now he's strong enough to chop a board and spin into a series of side kicks. "Throw doubles," Jones orders. Sucking his cheeks in concentration, Peyton kicks five times. "Doubles!" his teacher reminds him, laughing. "There is no challenge he will not try," Jones tells Sarah.

After class, Sarah asks Peyton where he wants to eat. "McDonald's!"

Her face falls. "I'm not sure it's safe, buddy. What about Subway at Walmart?"

"Sure!" he says, like it's an even better idea.

Sometimes the Maddens go to Pizza Hut, where a waiter will see them coming and rush to shut all the blinds. At First Christian Church, all the windows have been coated, says the pastor, Stan Seymour, "so he can go anywhere without fear of the sun. Before we did that, he'd avoid any window he walked past."

Seymour helped build the crowd for the "Good Morning, Peyton!" event and has always had a soft spot for the



boy. "He's bright, not spoiled. I said to him, "There are kids all around the world who have problems, and you give them hope.'"

El Dorado's close community gives others hope too.

When the Maddens learned about a new windshield film that was entirely transparent, they installed it on their SUV so Peyton could sit in front. Good, the state representative the Maddens had come to know since the "Good Morning, Peyton!" event, winced when she heard they'd already installed it; filming the front windshield is illegal in most states. The Maddens wanted her help to change the law.

A week later, Good persuaded the El Dorado police chief and the county sheriff to meet with the family. "And don't you dare write them a ticket," she added. An hour after the meeting, the sheriff called and said, "I'm still choked up about Peyton. We've got to do this."

"I'll draft the bill," Good replied.

Peyton plans to testify before the Kansas legislators, pushing for a law that could not only let him drive a car someday but also make a difference for many others, including truck drivers at risk for melanoma.

There will always be challenges: The sun, of course. Charcoal-grilled carcinogens and secondhand smoke, which, for Peyton, are like inhaling sunshine. (Because his body can't repair the damage caused by these carcinogens, he's at risk for other types of cancer too.) Black-light nights at the bowling alley. People saying he looks "like a little beekeeper." Parents edging their kids away.

"You want to know the odds of getting this?" Sarah wants to yell after them. "I can't even win the lottery!"

XP is a genetic disorder, most commonly inherited from each parent. There's no cure. But the Maddens have high hopes for the research, because if scientists figure out a genetic repair, it could also lead to a cure for skin cancer, not to mention a slew of anti-aging remedies.

When I ask Peyton how XP has changed him, he says, "I feel like I have a lot more responsibility and, well, basically I think I'm a little bit, just a tiny bit more mature."

If he were talking to a kid who'd just been diagnosed, what would he say?

He hesitates. "That's hard. I'd probably just tell them something that would make them not sad." Such as? "I don't know." He thinks again. "This isn't from my words. It's from a movie called *Wonder*. It's about this kid who has a face deformation, and basically he's stared at a lot, like me. His sister says, 'Let them stare. You can't blend in when you were born to stand out.'"



SIX WAYS TO EXTEND A HAND

Sarah Madden's advice for connecting with families with special needs

- **Say hi and be friendly.** People living with a rare disease can feel very isolated. Being a friend goes a long way.
- **Encourage your child to befriend a child who is different.** It will be a great growing experience for your kid and help the other kid feel like part of the community.
- **Don't worry if you don't feel prepared.** A child's parents will help ensure he stays safe if you invite him over for parties or playdates.
- **Don't stare.** But there's no need to avoid eye contact either. Treat the child as you'd treat anyone else.
- **Know that it's OK to ask questions.** Most families would love to share information about their child's condition. The more people know about a disease, the better the chance for a cure.
- **Word your questions thoughtfully.** Don't ask, "What's wrong with your child?" Try, "Can you tell me more about her condition? I'm really interested in learning."