



VISION QUEST

This family is travelling the world—
before the kids lose their vision to a rare
genetic condition

BY *Lisa Fitterman*

The Pelletier children
(pictured in Damaraland,
Namibia) travelled
to 13 countries over
the course of a year.

HIS

mouth open in both wonder and horror, Laurent Pelletier stares at the carnivorous armoured bush cricket that has landed in front of him on the picnic table. The boy is camping with his family near Fish River Canyon in Namibia, in southwest Africa. The insect, yellow and light green, has a collar of spikes and six spindly legs planted in a boxer's stance. It's as big as the five-year-old's hand.

"Can we eat it?" he asks his mom, Edith Lemay.

"I don't think so," she says, laughing.

"Can I take it as a travel companion?"

"No, but you'll meet many more."

And Laurent did, over and over again during the first few months of a year-long trip through Africa, Asia and the Middle East with his parents and three older siblings, Mia, 12, Léo, 10, and Colin, 7. Bush crickets, ground crickets, baby crickets, crickets whose chirping lulled them to sleep at night; they became talismans, part of a panoply of encounters during which the kids experienced the world in technicolour and surround sound. Imprinting memories by horseback-riding across the bright green steppes of Mongolia, kayaking on the azure sea off Cambodia, camping under the soaring brick-red peaks of Namibia and hot-air ballooning over the brown, lunar-like landscape in Turkey.

Far from their home in Boucherville,

Quebec, the children's experiences, steeped in colour, shape, touch and smell, are especially important to them. Because unless science makes a breakthrough soon, three of the four siblings—Mia, Colin and Laurent—will become blind, likely in adulthood. They have been diagnosed with a disease that has no effective treatment as it gradually robs them of their sight.

FOR THE CHILDREN'S PARENTS, Edith Lemay and Sébastien Pelletier, the diagnoses came after a four-year search for the reason why their eldest child couldn't see at night. Then a toddler, Mia banged into furniture that her mom and dad could make out once their eyes adjusted to the dark.

In 2013, when Mia was three, the family began a frustrating series of visits to doctors, none of whom had an answer for her lack of night vision. In 2015, as a last resort, a pediatric ophthalmologist enrolled the family in a research project in which their entire genome was mapped out. After two interminable years, the mapping was completed.

The family was called into the ophthalmologist's office, where the specialist gave it to them straight. "It's retinitis pigmentosa, a mutation called PDE6B," they were told. The gene was inherited from both Lemay and Pelletier, neither of whom knew they were carriers.

RP, as it is known, is a catch-all term for a group of about 50 inher-

ited genetic mutations that affect the retina, tissue at the back of the eye that interprets images in both black and white, and colour. The cells at its edges, called rods, crucial for peripheral and night vision, die first. As the disease progresses, the cells in the middle, called cones, used for seeing in colour and for everyday activities like reading, writing and driving, die off, too.

"Right now," the doctor continued, "there is no cure."

Awash with emotion, Edith stood up, excused herself and walked to the nearest bathroom, where she locked herself in a stall. *I can't cry in front of Mia*, she told

herself. *She wouldn't understand*. There, alone, she cried gasping, heaving sobs.

After a few minutes, Edith splashed cold water on her face before returning to the ophthalmologist's office, where her husband and daughter were waiting, and they talked about next steps.

While it was tempting to seek a second opinion, Lemay and Pelletier knew that genetic mapping did not lie: The results were definitive, irreversible and life changing. Soon tests would show that Colin, at the time an infant, and Laurent, yet to be born, had PDE6B, too. Only Léo, the couple's second eldest, didn't have the mutation.

ALL PHOTOS COURTESY OF THE PELLETIER FAMILY



Back: Sébastien and Mia.
Front, left to right: Laurent,
Colin, Léo and Edith in
Walvis Bay, Namibia.



"Everything we hope for our children, for their future, for what they could become, has to change," Edith said as she and her husband embraced one evening, in tears. "How will they cope?" They vacillated over explaining to Mia what her condition meant. Should they let her be a kid, innocent and unaware, for as long as possible?

A few weeks later, it just came out, part of a conversation about disabilities in general while having lunch at their kitchen table. "You know the problem with your eyes?" Edith asked Mia. "You're probably going to be blind when you're an adult." The revelation was more abrupt than Edith had hoped, but at least it was done. Edith held her breath as she waited for Mia to respond.

"Oh, that's not fun," the seven-year-old said before changing the subject.

Later that week, Mia approached her, saying she needed to keep her bedroom especially clean from then on. "In the future, I'll need to know where things are," the little girl explained.

Edith and Sébastien watched as Mia continued, unprompted, to feel her way around the house with her eyes closed to see what it was like to navigate without sight, up the stairs and down, through the kitchen, living room and basement, memorizing shapes with her

fingertips. "She is finding solutions on her own," they told each other. "We need to follow her lead."

And so the idea of a year-long trip was born, one that would show the kids the world, not through two-dimensional picture books and lectures in a classroom, but in person and close-up, from windswept vistas to waterfalls and warthogs. A trip that would show life in all its grandeur and gritty detail—while the kids could still see it.

When Edith and Sébastien first broached the idea in the spring of 2020, the kids didn't understand. A whole year away from school, their grandparents and friends? "It was hard to imagine," says Léo. "I didn't think it was real."

BEING BLIND DIDN'T MEAN THE END OF THE WORLD. RATHER, THE WORLD WOULD BE DIFFERENT.



For the next two years, Edith and Sébastien continued to work—she in health logistics and he for a financial start-up. They saved money, researched places to visit and asked their children what they wanted to do on their big trip. Mia wanted to ride a horse. Colin wanted to sleep overnight on a train. Laurent thought it would be fun to drink juice while riding a camel. Léo wanted to tour Pokémon attractions in Japan.

Clockwise from top left: Laurent and an armoured cricket; Stone Town, Zanzibar; Colin with a chameleon in Zambia; chilling at a guesthouse; Etosha National Park, Namibia; Léo and Colin learn to start a fire with the Maasai in Tanzania.

IN EARLY 2022, they were ready. Edith and Sébastien quit their jobs, rented out their home for the next year and gathered textbooks so the kids could study French and mathematics a few times a week. The rest of the time, they'd be learning from the world around them—the best teacher of all. Travelling with four children wouldn't be cheap, but they'd save money by camping, staying in hostels, guest houses and even a Mongolian yurt made from goatskins.

On Monday, March 21, they flew out of Montreal, with no set itinerary save for a meandering initial trip from the southwest coast of Africa to the east, through Namibia, Botswana and Tanzania. Once there, they would make plans on the fly. "How we adults see the world and how kids see the world is so different, and we had to respect that," says Edith. "That was clear from the start. It would have to be less about temples and museums and more about whatever caught their eye."

Over the months, that world constantly unveiled itself, sometimes in a cacophony, sometimes in a whisper. There was the shouting of hawkers selling bananas at each stop of a 24-hour train ride through Tanzania. And then there was the near-cathedral silence of Namibia's Dead Vlei. Once a marsh, it's now bone dry, with sand dunes rising 400 metres and trees that are black skeletons against a cloudless sky.

They played patty cake with uniformed schoolchildren in Botswana, and while in Tanzania they danced



with Maasai tribesmen and stayed on a banana farm. In Borneo, they went parasailing over the South China Sea. In Thailand, Mia touched an elephant, calling out in surprise at how rough it felt. In northern Cambodia, Colin, who had always been more withdrawn than his siblings, mugged like a miniature pirate while brandishing the wooden sword a guide had carved for him on the spot from a piece of mahogany they'd found while hiking.

Each day, Edith and Sébastien watched

their kids change, physically and emotionally. Mia grew taller and, on the cusp of adolescence, needed more independence. Both Léo and Colin became more confident and outgoing, unafraid to engage with strangers, kick around a soccer ball with locals and try new food, like red ants in Laos gathered from under a tree. "They taste like lemons," the kids chorused.

The family itself grew more tight-knit and protective of each other, which helped when they faced situations that

were difficult to explain. One example came when they drove past villages in Cambodia that were the sites of massacres, the "killing fields" during the genocide perpetrated by the Khmer Rouge in the late 1970s. Their guide told of how he was abandoned as an infant in

Clockwise from top left: In Turkey, an Istanbul mosque; Léo in Cappadocia. In Indonesia, Mia and Laurent in Sulawesi; and the rice fields on Flores. In Mongolia, the Orkhon River; and meeting an eagle.



Clockwise from top left: Peeling cocoa grains to make chocolate in Sulawesi, Indonesia; Laurent in a temple in Luang Prabang, Laos; Léo in a flower market in Bangkok, Thailand.

the nearby forest, likely hidden by his parents to protect him. Edith and Sébastien held their children close, to make them feel safe.

Other times, the goal was pure fun and adventure, like when the family went up in a hot-air balloon on July 1, in celebration of Laurent's fifth birthday. Or the visit in January to the Tad Fane waterfall in Laos, when the family ziplined across the gorge below.

Rarely did they talk about why they were abroad in the first place, with one exception: While travelling along a dusty Mongolian highway last summer, Laurent, who had seemed unaware of what

was to come, asked: "What does it mean to be blind? How will I cross the street? Will I be able to drive a car?"

"It's like when you have your eyes closed," Edith said. "It won't happen overnight, but slowly, over years." Being blind, she continued, didn't mean the end of the world. Rather, the world would be different. Nothing would prevent them from doing most things, including skiing, swimming or even becoming scientists who worked on cures for their condition. Laurent nodded, then went back to making up his own games to pass the time.

By the time the trip began to wind

down early this year, the family had travelled 83,700 kilometres and visited 13 countries. The kids reflected on what they had learned about the world and themselves. "There's a lot of suffering and poverty, but lots of good and interesting things, too," says Colin. "Kids are kids everywhere, just like us, but with their own customs and traditions."

Léo's take was a bit less philosophical. "I am not fond of durian," he says, wrinkling his nose in distaste at the thought of the spiky fruit he tasted in Indonesia that has a reputation for smelling like rotten eggs, old onions and raw sewage—combined. But that hasn't

stopped him from wanting to travel more. Mia nods her head. "This has been a magic year we'll remember for the rest of our lives."

RETINITIS PIGMENTOSA, which affects between one in 3,000 to 4,000 people globally, was once considered untreatable. But over the last 20 years, science has seen considerable breakthroughs. While there is not yet a cure for PDE6B, the mutation the Pelletier kids have, genetic research has resulted in the development of a successful treatment to reverse the effects of another muta-

tion, RPE65. (Basically, it's a surgical injection behind the retina.) This, says Dr. Robert Koenekoop, a pediatric ophthalmologist in Montreal, has given science a clear road map for developing treatments for other forms of RP.

Until then, science has managed to temporarily slow the progress of RP in many cases by injecting antioxidants such as vitamin A and omega-3 fatty acids at regular intervals. And, in 2022, two different studies found that acupuncture can improve vision, possibly by increasing blood flow to the retina.

EDITH AND SÉBASTIEN WANT THEIR KIDS TO LEAD FULL LIVES, WHETHER THEY'RE BLIND OR NOT.



"This is the most exciting time in terms of advances for treatment of RP. The chances of kids like these three getting help are good," says Koenekoop.

Edith and Sébastien know there is some hope. But they downplay the possibility because they want their kids to lead full lives, whether they're blind or not. The trip has reinforced what Mia showed them all those years ago when she wandered the house with her eyes shut. They will find their way.

"Today, my vision is good and I'm going to make the most of it," says Mia. "We will rise to the challenge." **R**