

COLUMN | DAN MCGOWAN

'A worry you didn't even know was possible': Raising a child with a rare, deadly disease

By **Dan McGowan** Globe Columnist, Updated March 13, 2024, 8:58 a.m.



Erin and Jaymes Vazquez pose for a portrait with their rambunctious son Landon at their home in Warwick, R.I. ERIN CLARK/GLOBE STAFF

W ARWICK, R.I. — Landon Vazquez is on a sugar rush, jumping between his Mario Brothers Lego set in the living room, a Bluey lego set in the family

room, and canisters of Play-Doh in the kitchen at the frenetic pace of any five-year-old with a vivid imagination and a stomach full of Sour Patch Kids.

Soon he'll dump a box of Mario-themed stuffed animals on the floor and lie down among them in his brown sweater and jeans. There's a mischievous smile, his deep brown eyes light up, and you realize he's not taking a rest; he's plotting his next move. And sure enough, off he goes.



Landon Vazquez played with his Mario-themed stuffed animals after getting home from kindergarten. ERIN CLARK/GLOBE STAFF

It's the kind of behavior you'd expect from a kindergartner after a day at school, but the palpable look of relief on the faces of Landon's parents, Erin and Jaymes, is a reminder that this type of energy has been anything but ordinary for their oldest son over the past year.

Sometime last April, Landon developed what seemed to be a standard cold that he just couldn't kick. His dry cough was persistent, but his parents' biggest worry was that he

was unusually exhausted, unable to climb the stairs in their Warwick, R.I., home and preferring to sit on the sidelines at soccer practice.

So their pediatrician recommended a series of tests, and it turned out Landon had dangerously low hemoglobin levels. A blood transfusion was ordered. Iron supplements were prescribed.

“When I tell you they ran test after test,” Erin recalls. “They thought he might be anemic.”

Landon started to feel better later in the spring, but the symptoms crept back up. He wanted to sleep all of the time. His skin appeared to have a yellow tint. His hemoglobin levels dropped again, so another transfusion followed.

Just before school started in August, Landon’s dry cough returned. While sitting in the parking lot of their pediatrician’s office, he vomited — and Erin immediately noticed the blood. He was rushed to Hasbro Children’s Hospital and ended up in the ICU for 10 days. He got a bronchotomy, and a biopsy was ordered on his lungs.

The diagnosis: Idiopathic Pulmonary Hemosiderosis, or IPH, a rare lung disease that causes bleeding in the lung air sacs and can be fatal without proper therapy.

The Vazquezes live on a quiet cul-de-sac in Warwick’s Cowesett neighborhood, five minutes from I-95 but tucked away in enough woods that they regularly see deer run through the backyard. One can imagine Landon and his two little brothers some day building forts and playing hide-and-seek for hours on end.

Erin, 34, works in human resources at Hasbro, and Jaymes, 36, works at a Porsche dealership. They bought their two-story colonial during the pandemic, shortly after Landon was born. They’ve since had two more boys: Derek is two, and Brooks is just five

months. A Google image search of the house shows a large Mario balloon attached to the lamp post in the front yard.

Experts can't quite pinpoint the cause of IPH, and a cure hasn't been developed. It's so uncommon that experts at the University of North Carolina are only now beginning to track cases through a registry they're developing, and they're hesitant to offer an estimate of how many people in the US have the disease.

"I would argue that we don't really know how many cases do exist," said Dr. Eveline Wu, a pediatric rheumatologist and immunologist at the University of North Carolina Children's Research Institute.

Wu and Dr. Timothy Vece, a pediatric pulmonologist at the institute, are leading the effort to work with hospitals around the country to begin tracking IPH and Idiopathic Pulmonary Capillaritis (IPC), a similar disease.

"There is so little research on these conditions that we don't know what we don't know," Vece said. Wu and Vece are not treating Landon, but they are working with Erin and Jaymes to raise awareness about the disease.

"What I've learned is, don't Google it," Erin said, a warning she wishes she had followed.

There's no sugarcoating this. While some patients' disease goes into remission, others have complications such as acute shortness of breath, severe anemia, and pulmonary fibrosis. They can have massive bleeding in their lungs that choke their airways, sending them into shock, severe respiratory distress, and heart failure.

If IPH isn't diagnosed and the patient doesn't begin a therapy regime, "these children can be presented with life-threatening experiences," Wu said.

That's why Landon's treatments are frequent and extensive.

Every month, he packs his Mario Brothers bag and spends three days at Boston Children's Hospital where he receives an infusion of steroids and antibodies. Much of his February school vacation was spent at the hospital, and his April vacation will be spent the same way.

His parents haven't explained to Landon everything that's happening to him, but he knows something is different. He has been frustrated because he had to spend a lot of time indoors this winter to avoid catching a cold, and at school, he uses his own coloring pencils and glue sticks.

"He knows he has sick lungs," Erin said.



Jaymes Vazquez watched his son Landon make a carrot out of Play-Doh. ERIN CLARK/GLOBE STAFF

Erin and Jaymes remain cautiously optimistic. Landon is bursting with energy right now, but they know that can change in a heartbeat.

Most parents look forward to grabbing a moment of rest when their children tucker themselves out after playing or a day at school. But when Landon seems even a little fatigued, his parents worry that his lungs could be bleeding.

The stress can be overwhelming. Every time Landon comes down with even a slight cold, or they think he's napping too much, his parents worry that his hemoglobin levels may be dropping. They're always on high alert.

"For a sniffle, we have to go to the doctor," Erin said. "I'm not a person who typically worries a lot. Now it's a worry you didn't even know was possible."

Despite their own heartbreaking anxiety about their son, Erin and Jaymes are the kind of people who still want to do everything they can to help other parents who are in a similar situation.

It starts by trying to find them.

Relatives have helped Erin and Jaymes establish a nonprofit called [Breath of Hope RI](#), and they've already raised nearly \$50,000 to help the University of North Carolina build a registry of others with the disease and, eventually, find a cure.

In Warwick, the whole community has rallied behind the Vazquez family. The principal at Cedar Hill Elementary School sent an email to every parent encouraging them to support Breath of Hope RI. After a recent visit to Boston Children's Hospital, a neighborhood parade was organized to welcome Landon home.

"We're just trying to make people aware," Erin said.

At the University of North Carolina, Drs. Wu and Vece said they hope to have a registry established by the end of the year. That will give hospitals around the country the ability to input information about similar cases.

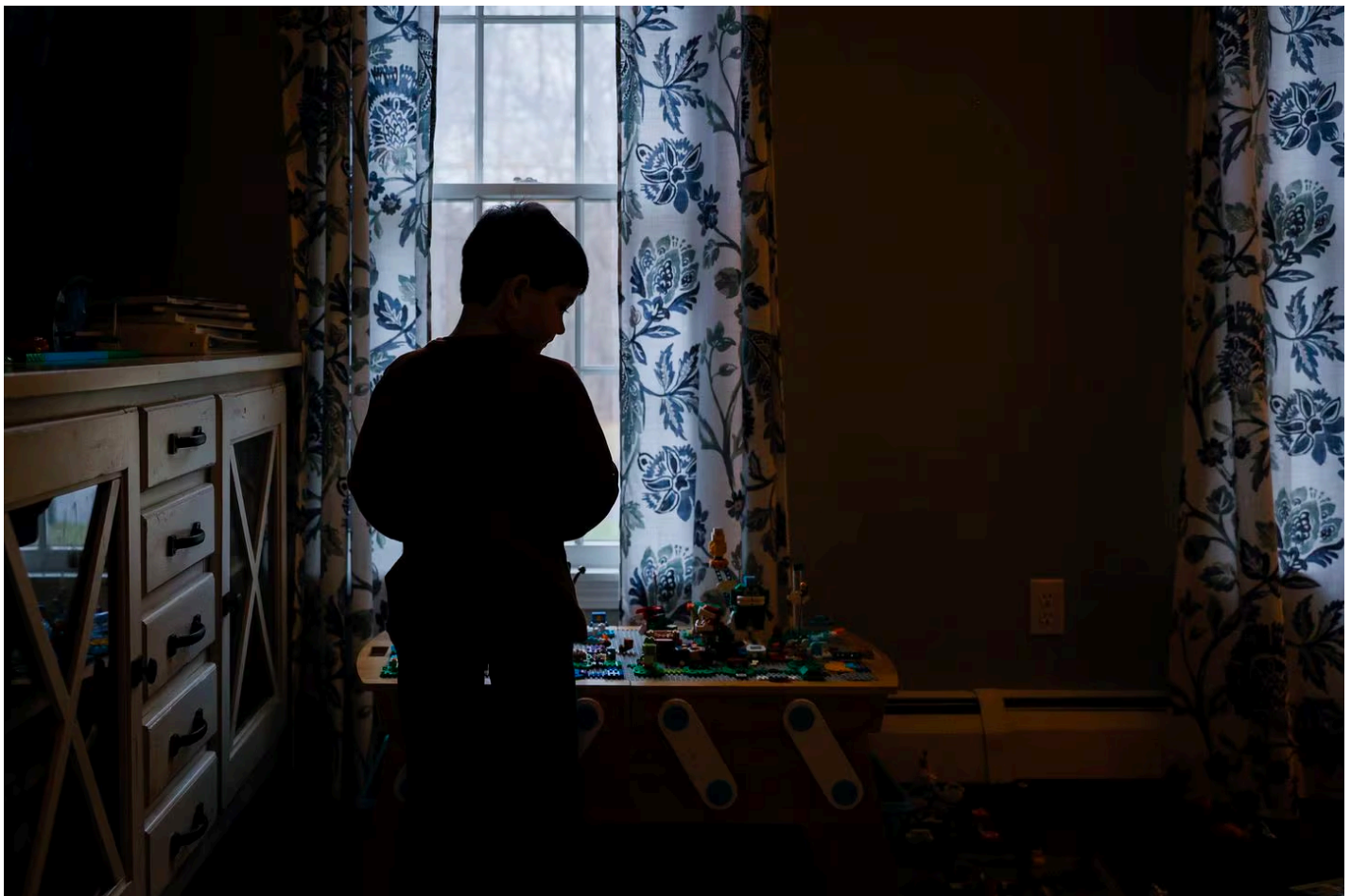
The trouble, they acknowledge, is that diseases like IPH and IPC can easily be misdiagnosed. And the rarity of the disorders makes them difficult to research.

“The goals with this registry will be, how can we help families get closer to a diagnosis and better understand long-term impacts?” Wu said.

Wu and Vece said they believe the Vazquez family can make a real difference by shining a spotlight on the disease.

“It’s really inspirational,” Vece said. “They just want to help kids.”

Meanwhile, in his happy world of Legos and Bluey cartoons, Landon laughs and plays as Erin and Jaymes hope and pray that someone, somewhere, helps their kid.



ERIN CLARK/GLOBE STAFF

To learn more about the Vazquezes' nonprofit and to donate, visit [Breath of Hope RI](#).

Dan McGowan can be reached at dan.mcgowan@globe.com. Follow him [@danmcgowan](https://twitter.com/danmcgowan).

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