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## Breath of Hope

A Warwick boy, a rare disease, and a family's unrelenting hope



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151153-e07-feature02 - LandonAndLegos by Barbara Polichetti.jpg)

**Landon Vazquez and his Lego landscape at the family's home in Cowesett section of Warwick.**

(PHOTO BY BARBARA POLICHETTI)



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**By CHRISTOPHER GAVIN**

When Landon Vazquez takes the soccer field, it's hard for his mom, Erin, not to get emotional.

It's not because of the cute-factor of a bunch of 5-year-old kids running around in uniform, or even the prowess of a young athlete on display. In fact, during his first game back this season, Landon didn't even get to kick the ball, Erin recalled.

No, the emotional tug of watching Landon comes simply from watching him sprint, seemingly carefree, up and down the field.

"This is the best he's been in a very long time," Erin, 34, recently told The Warwick Beacon.

Indeed, the past year has dealt a confusing, frightening, and heart-racing saga for the Vazquez family, as Landon was diagnosed with idiopathic pulmonary hemosiderosis – or IPH – an incredibly rare and potentially deadly disease that has no cure.

So little is known about IPH that experts can't even say whether Landon's condition is one in a million, two million, three million or more.

For a while last year, all anyone knew was that something was clearly not right.

"It could have been fatal if they didn't catch it," said Emily, speaking through tears as she sat inside her family's Cowesett home. "That's the scary part."

**Landon's diagnosis**

Last April, a cold hit Landon hard.

At his first soccer practice, he could muster no interest in the game or his teammates. The same happened again the next week, even after he appeared to be on the mend.

"He again didn't seem to want to be there," Erin said. "But he was four. So you're like, maybe this isn't something that he wants to do or doesn't like, or is lazy. We were unsure."

Then another cold came on. His teachers took notice. Landon was pale.

Bloodwork showed his level of hemoglobin – the protein in red blood cells that transports oxygen – was essentially half of what it should be for his age, Erin recalled.

Sent to Hasbro Children's Hospital, Landon underwent more tests and then a blood transfusion. Doctors thought he could be anemic, Erin said. And for a short time, a remedy of iron supplements seemed to help.

But on Mother's Day last year, the boy became "pale as a ghost," said Nancy Curran, Landon's grandmother. He was unable to muster the energy to walk.

That day, Landon was rushed back to the hospital and amidst another blood transfusion, his oxygen levels dropped, requiring him to be placed on a machine to help him breathe, Curran said. He was admitted to the hospital for three days, before he again appeared to be on the rebound, Erin said.

"He was good," she said. "His energy was good. Color was good. School ended, so we weren't around any illnesses, and he was fine."

Summer rolled on. Landon turned 5 years old that August. But about a week after his birthday, he developed a dry cough – and then the fatigue crept in again.

After a prolonged nap one day, Landon woke up looking yellow, and a call to the doctor's office gave the family some marching orders: Come in, immediately.

"We drove there and the second he got out of the car he said, 'I'm going to be sick,'" said Erin, who, at the time, was eight months pregnant with her and her husband Jaymes' third child. "And he just threw up blood in the parking lot."

At Hasbro again, Landon received an x-ray exam. Doctors thought perhaps it was pneumonia, Erin recalled.

His hemoglobin dropped again, this time to its lowest levels ever. Landon labored to breathe.

"He had no color. He stopped eating. He wasn't going to the bathroom," Erin said, her voice quivering.

After days of pneumonia treatments, however, one side of Landon's lungs had not cleared up. The Vazquezes made the difficult decision to perform a bronchoscopy, and then, out of necessity, a lung biopsy.

"Once everything was done, [the doctor] could tell he was bleeding in his lungs," Erin said. "So he ended up being in the ICU for 10 days."

By then, the doctors knew they were looking at an anomaly.

"Even our pediatrician, who I love dearly, she was like, I have heard of this in school, but I really don't know much about it," Erin said.

## **What's IPH?**

Experts at Boston Children's Hospital – through which Landon now receives monthly treatments – have concluded it's IPH, while Hasbro's staff contends it could be idiopathic pulmonary capillaritis, or IPC, a closely related and very similar rare disease, according to Erin.

“They’re interrelated diseases. They present very similarly; similar symptoms,” said Dr. Timothy Vece, a pediatric pulmonologist at the University of North Carolina Children’s Research Institute. “[There are] some similarities in how we treat it but actually some pretty important differences.”

At UNC, Vece and Dr. Eveline Wu, a pediatric rheumatologist and immunologist, are working to establish a registry to track both IPH and IPC cases across the country.

Both diseases – whose causes are unknown – are commonly misdiagnosed and, given the rare nature of each, diagnoses often take a long time to determine, they said.

“There’s not a ton of clinicians who have experience with this and then there’s even less pathologists,” Vece said.

Through establishing the registry, the hope is there are markers of IPH and IPC “that we can help identify that will allow children to get to a quicker, more accurate diagnosis,” Wu said.

So far, what Vece and Wu see the most amongst IPH and IPC patients are initial anemia diagnoses with recurrent pneumonia, intermittent low oxygen, and low hemoglobin, Vece said.

“We’ve had patients who [have had] literally years of symptoms before ... they are diagnosed,” he said.

And, perhaps naturally, without a registry to date, neither Wu nor Vece can say how prevalent the two diseases are.

The FDA defines a rare disease as one that affects less than 200,000 people in the United States, Wu noted.

“We know it’s a rare disease,” she said. “But beyond that, we don’t have enough numbers to be able to accurately estimate how many new cases are we seeing per year; how many total cases do we have currently alive.”

## **Breath of Hope**

Curran knew she couldn’t just stand by, watching what happened to Landon.

“You can sit and say why me or you can get out there and say, ‘Let’s make a difference,’” she said.

After learning about the research going on at UNC through Landon’s doctor at Boston Children’s, Curran, with the help of friends earlier this year, established Breath of Hope RI, a nonprofit now working to raise hundreds of thousands of dollars to help get the registry up and running.

The new organization quickly obtained its designation earlier this year – a process Curran was told would take months, not the mere three weeks it did.

And it’s clear Curran, a retired physical education teacher, is employing the same energy required to close sales in her second career as a real estate agent to now move quickly on hitting the registry’s \$600,000 startup goal.

To date, Breath of Hope has already raised more than \$63,000.

"I can't change ... what's happened to Landon. That is concrete. That is there," Curran said. "So the best we can do is help other people who may be struggling, not knowing. And let's just not sit around twiddling our thumbs. Let's get some people going on this."

Vece said he and Wu couldn't be more grateful for the dedication and support.

"It's very inspiring to have a family like theirs kind of embrace the diagnosis and want to use the story to help others who are affected and support work like this that, again, could help answer questions for a potentially life-threatening, rare condition," Wu said.

Vece added: "I think within rare lung diseases, it's the only way that it ends up happening: These amazing families who dedicate time and resources to helping us understand it better."

With that in both heart and mind, on May 18, Breath of Hope will host a 5K run/walk at Warwick's Goddard Memorial State Park beginning at 10:30 a.m. (Registration – which is \$35 per participant but free for children under 12 – starts at 9:30 a.m.)

According to Curran, more than 200 runners were registered as of late April. The event will also have food trucks and a DJ on hand to provide some music.

Breath of Hope is also planning a golf tournament fundraiser for September.

"I'm looking for a cure for this thing. That would be a blessing," Curran said. "We're looking for things that make these kids' lives better."

## **Landon today**

These days, Landon makes trips to Waltham, Massachusetts every few weeks to receive a transfusion of antibodies and steroids. So far, the regimen has kept Landon pretty well since last fall, after he picked up RSV and COVID back-to-back, sending him into the hospital again each time, Erin said.

"He's just like himself again," she said. "He looks like himself, he acts like himself. It's as if nothing's happened. So that is reassuring."

Landon, at five years old, only knows a bit of what's going on with his body, after all. He knows, essentially, he goes to all these doctor visits to care for his "sick lungs," Erin said.

"I don't think he has any idea ... what has gone on with him, even though he's been the one living through it," she said.

Another scan is in store for later this month to check for bleeding and scarring inside his lungs. The thought of it has, naturally, left Erin feeling anxious.

She also worries about what germs could await him in the new school year this fall. Even a sniffle beckons Landon back to the pediatrician's office.

"There's still so much unknown, but he's been such a strong little guy," Erin said. "If he can get through that, we can, too."

For more information about Breath of Hope RI, visit [www.breathofhoperi.org](http://www.breathofhoperi.org)