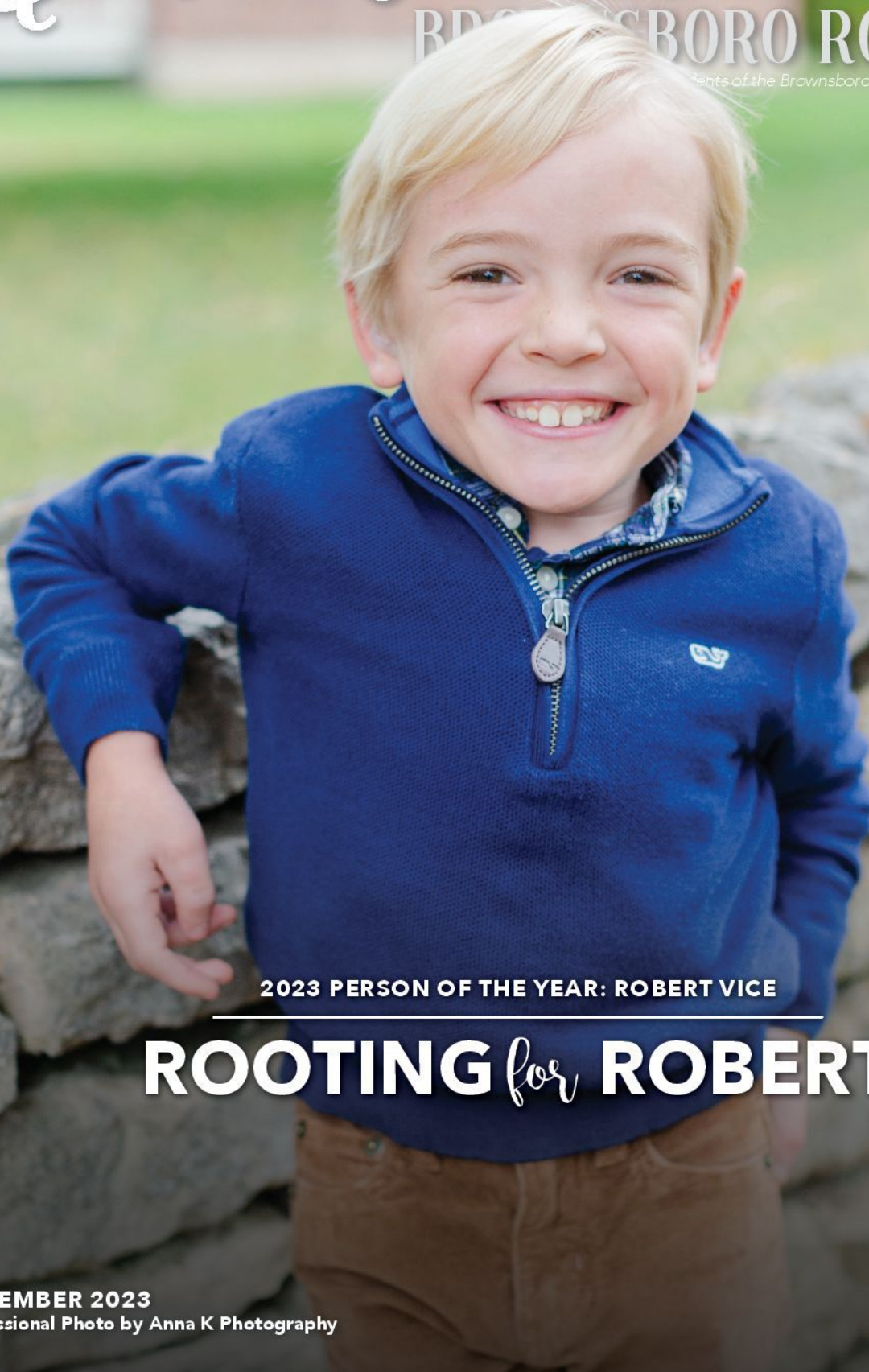


East End Living

BROWNSBORO ROAD

Highlights of the Brownsboro Road Corridor



2023 PERSON OF THE YEAR: ROBERT VICE

ROOTING *for* ROBERT

DECEMBER 2023

Professional Photo by Anna K Photography

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2023 PERSON OF THE YEAR: ROBERT VICE

ROOTING for ROBERT

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By Kelly Jarboe • Professional photo by Anna K Photography

Robert Vice's smile lights up the room.

Robert (8) lives in Rolling Fields with his sister, Anna (12), and his parents, Bobby and Helen Vice.

His days are filled with school and activities, much like any other 8-year-old boy.

However, Robert copes with something no child should have to face. He has endured hundreds of hours of medical treatments through a port, countless doctor appointments, multiple surgeries and extensive physical therapy.

Robert has Morquio Syndrome, a rare genetic condition that affects 1 in 200,000 people. The degenerative disease impacts Robert's bones, spine, organs and physical abilities.

"In April 2018, we thought we were pretty much like every other typical family with two working parents and two children," says Helen. "At the time, Anna was 6 and Robert was 2. We were trying to keep up with our kids and spend as much time together as possible while maintaining sanity!"



"Take it one step at a time."

Robert Vice

"However, on April 13, 2018, our life took a turn we could have never imagined when we took Robert to the pediatrician for a small bump on his spine," adds Bobby. "Three weeks later, Robert was diagnosed with Multipolysaccharides IVA, otherwise known as Morquio Syndrome."

The diagnosis means Robert has a shortened life expectancy and might never reach three and a half feet (42 inches) tall. The disease



primarily affects Robert's bones, but it does not stop there. He will likely suffer (and in some instances, already has suffered) from life-threatening trachea, heart, lung and spinal cord issues; hearing and eyesight loss; compromised immunity and low energy.

Children with Morquio Syndrome are missing or do not produce enough of the enzyme that breaks down certain sugar chains naturally produced in the body. The disease is severely progressive, and the effects get worse with time.

"Robert has already gone from a very coordinated 2-year-old in the 25th growth percentile to an 8-year-old who, simply put, cannot physically keep up with peers, endures hours of physical therapy, fights to climb a flight of stairs and does not register on the growth chart," explains Helen. His physical limitations include hyper-flexible, weak and painful joints along with laborious walking and a pronounced uneven gait.

Despite the challenges he faces, Robert is incredibly positive and rarely complains. He says the hardest part about having Morquio Syndrome is that everyone thinks he is small. However, he concedes being small has some advantages. "I'm good at hide and seek since I'm so small!" exclaims Robert. "I also like it because it makes me different."

Robert is in 2nd grade at Kentucky Country Day (Anna is in 6th grade there, and both Bobby and Helen attended the school as well).

He enjoys playing a wide range of sports. "I like football because I like to play with my friends," says Robert. "I like soccer because it really keeps me going, and I like swimming because it keeps me calm and feels good on my body," he adds.

Robert loves music, especially guitar, and playing with the family's Labradoodle, Maple. He also enjoys spending time with his friends in Rolling Fields. "I like being in my neighborhood because I love my friends, and they are really helpful to me," he explains.

"Everyone loves him at school," adds Anna. "He literally knows everybody at school, and he is so talkative. He's a comedian, and he makes the funniest jokes!"

"We were incredibly fortunate to immediately get in touch with leading specialists and geneticists, and we have been working ever since to ensure both of our children have great childhoods and are as unaffected by the diagnosis as possible," says Bobby.

While medication exists to help treat Morquio Syndrome, there is no cure. When Robert was 2, he had a port surgically implanted in his chest. Since then, he has undergone over 260 weekly enzyme replacement treatments through his port. Each treatment lasts six hours. Unfortunately, the current medications have limited positive effects, mostly benefitting soft tissue and energy levels, and are extremely costly.

Robert has undergone multiple surgeries. When he was 4, he had to have four vertebrae fused together in an effort to prevent his spine from severing his spinal cord. After the surgery, he spent six months in a neck brace.

When he turned 6, Robert underwent major hip and leg reconstruction in which new hips were created from grafting, pins were inserted in his ankles, and screws were put in his knees. He spent six weeks recovering in a body cast and had to relearn how to walk. Robert continues to have outpatient surgeries to remove and tweak the hardware in his legs and hips.

"Despite all of the surgeries and weekly infusion treatments, we have learned more about

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"Sometimes it hurts to walk a long way.
We are trying to get rid of that."

Robert Vice

ourselves and the goodness of others than we ever imagined possible," says Helen. "We are so blessed to have caring individuals from other Morquio families, nurses, doctors and all of our friends and family. It is amazing what the village does for our family."

The Vices are working diligently to ensure Robert and others with Morquio Syndrome have the best possible outcomes. "We are committed to making sure Robert gets the best medical care, expanding the treatment options available to Robert and others with Morquio Syndrome, and ensuring he has the fullest life possible," says Bobby.

Bobby, who is a transactional attorney and co-founder of Vice Cox & Townsend, and Helen, who works as a member of the Associate Well-Being Team at Humana Inc., co-founded A Cure for Robert, Inc. in 2020.

A Cure for Robert, Inc. (d/b/a Rooting for Robert) is a 501c3 nonprofit organization dedicated to funding research that will lead to a cure for Morquio Syndrome. Under Bobby and Helen's leadership, the organization has raised approximately \$1,750,000 to help fund ongoing research projects and clinical trials with the goal of finding a new and better treatment for the rare and devastating disease.

To date, Rooting For Robert has funded or committed \$992,000 to research projects taking place in hospitals and research labs ranging from San Francisco to London, England. Two projects have been approved for clinical trials, the first for Morquio Syndrome in nearly 15 years.

"We are working to raise money to get better medicine, so it will be all better for me and other kids with Morquio," explains Robert.

To follow Robert's journey or learn more about Morquio Syndrome and A Cure for Robert, Inc., visit www.rootingforrobert.org.



▲ This plate, made by Robert and Anna, raised \$13,000 at the 2023 Rooting for Robert fundraiser.



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PHOTOGRAPHY



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