
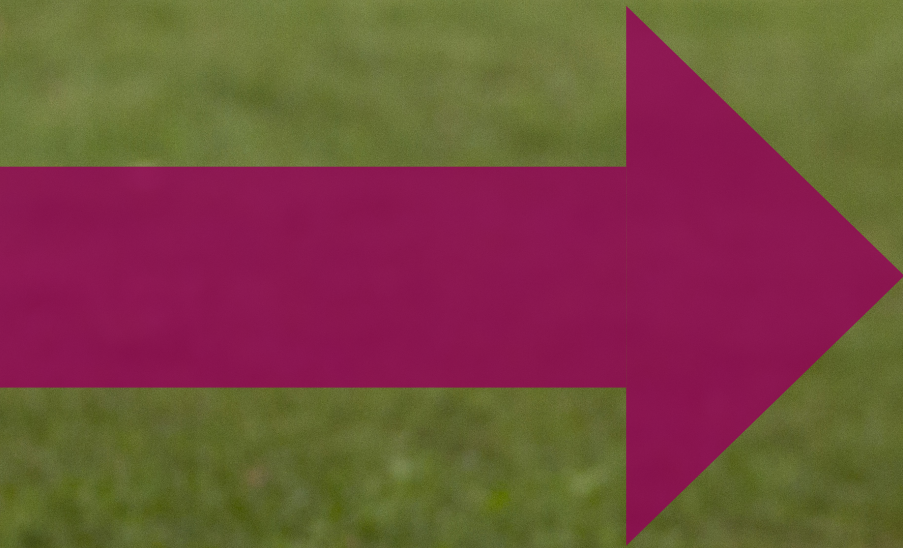


win the day

Eanes family copes
with neuroblastoma cancer



Rex Ryan runs in the race
at the second Run With Rex
event on April 11, 2015.

Tim Whaling

It was only a shudder. One-year-old Rex Ryan was a baby who sometimes looked surprised, which could be normal or even endearing in some ways. After a while, though, Rex's father, new assistant principal Casey, and mother, Eanes Elementary principal Lesley Ryan, decided to consult a neurologist about the shakes. Three weeks after that, it all seemed to have passed. Until Rex got sick, and the shuddering came back. Just from looking at

Rex, the neurologist told Mr. and Mrs. Ryan that Rex likely had neuroblastoma cancer, and Mr. Ryan, Mrs. Ryan and Rex stayed the night at Dell Children's Medical Center for tests the next morning.

"A lot of [memories] over time you lose, but at that exact moment, I can tell you who was in the room and where they were standing, how they were positioned," Mr. Ryan said. "And then the oncologist came in and said [Rex] has stage four neuroblastoma. [He] rattled off all the other stuff with the bone marrow and the bones. I just remember saying over and over, 'He's just a baby. He's just a

baby.' And I lost it. I was a mess."

On Sept. 12, 2013, Rex was officially diagnosed with neuroblastoma, a malignant tumor that develops in the adrenal gland from immature nerve cells. Mrs. Ryan's reaction to the diagnosis was not what she would have expected from herself.

"As a mother, I would've assumed that my response would've been to completely lose it and cry and yell," Mrs. Ryan said. "That wasn't my response at all. It was, 'All right. Let's fix it. What are we going to do? What are our next steps? I want to know short-term [and] long-term ramifications for

later in life.' And so I think that what we've experienced as a couple and as a family is that when one of us rises in anxiety and stress and fear and emotion that the other one balances naturally by being calm, and that is a shifting pendulum in terms of how we support one another."

After Rex's diagnosis, the Ryans decided to start a blog at posthope.org/rexstrong on which they could document what was going on in all of their lives — Rex's, Mr. Ryan's, Mrs. Ryan's and their daughter Elle's, who was in kindergarten when Rex was diagnosed.

"It wasn't anyone else sharing

on our behalf,” Mrs. Ryan said. “It was important for us to be able to share with our own voice the emotions behind what we were experiencing as well as just the factual pieces.”

Although the positivity and determination to eradicate childhood cancer are major drivers of the Ryan family, going through cancer treatment wasn’t an easy journey for them. Another purpose of the Ryan’s Posthope site was to help other people see that their family’s experience was real and that stories like theirs were all around.

“Our whole experience wasn’t just ‘Look at our cute, smiling, bald kid,’” Mrs. Ryan said. “There are days where this is grueling, and we’re afraid we’re going to lose our kid. And we’re not the only family in our city and in our state and in our world who’s experiencing this. This is a global issue. And if you think this isn’t in your backyard, you’re wrong. It is. This affects everyone.”

The Ryans have taken this frustration and fear and channelled it into activism.

“Every family has a cancer story. Everyone,” Mrs. Ryan said. “Every individual has something that has touched our lives, and

cent of funding goes to pediatric cancer. It’s infuriating. Because it doesn’t impact you until it does. Until it’s your kid. And then you’re like, ‘Wait a minute. Let’s evaluate the equity and how we’re serving the people in our nation.’”

For the Ryans, a personal struggle quickly turned into a mission to eradicate childhood cancer. They have established the Rex Ryan Endowment Fund, Mrs. Ryan has rappelled down the W Hotel in Austin for a Make-A-Wish fundraiser and they have also started Rexstrong, a community that organizes the yearly Run With Rex races, which raise money and awareness for childhood cancer research.

“When this started, statistically speaking, he should’ve died,” Mr. Ryan said. “I mean, if you look at just the simple data with his diagnosis, what his situation was, as serious as it was, he wasn’t supposed to make it. So I think all along it wasn’t just about us; it was how can we use this to get more support. And then obviously we developed a network through people at [Dell Children’s Medical Center], and even with Make-A-Wish and some other organizations. And that just kind of became something that we felt

nies. The act allows the companies to fast-track another, possibly more profitable drug for FDA approval as long as they also work on childhood cancer drugs as well.

“When Rex went through this opportunity with the immunotherapy, it wasn’t FDA approved, but through the Creating Hope Act, which is what we spoke about in Washington, this was the [third] drug that was approved in the last 20 years specific to childhood cancers,” Mrs. Ryan said. “Because we positively benefitted from resources allocated and from that research that’s out there, I think we can speak to it from a different perspective.”

The experience was one where the family could see and feel the impact of their work for childhood cancer research.

“The fact that we were invited to go to Washington, D.C., and to speak with the members of Congress was kind of one of those things [that made us think], ‘All right. We must be doing something right. We’re obviously getting his message and our family’s story out there,’” Mr. Ryan said. “When people say they know about Rex and Elle and their story, I’m proud of them. It makes you proud of your kids and what they’ve done.”

One person in the Ryan family could easily be overlooked through all of this — their daughter Elle, who is in second grade now. The entire process of treatment was just as hard on her as it was for everyone else in the family. While it wasn’t easy, Mr. and Mrs. Ryan think it has helped her to become a better person.

“Being flexible and resilient throughout [treatment] was really important,” Mrs. Ryan said. “And she did it. I think it has really enriched who she is as a young woman and as a human being. We’re very proud of her because it’s not easy being the sister to someone who’s most certainly in the light. You see Rexstrong shirts everywhere, and she was a part of that.”

Going through cancer treatment has also provided new skills for their work. Both parents work in Eanes ISD as administrators (she as the Eanes Elementary principal and he as an assistant principal at Westlake). This experience has given them not only different viewpoints in life but also education.

“It’s given us great perspective in our practice and what we do

because [we are] able to say to a student or to a parent or to a staff member, ‘Is this a big problem or a little problem? Is this something we can solve easily?’” Mrs. Ryan said. “And we could say we’ve lived through big problems. I think to be able to convey that perspective is really important because to everyone in different circumstances, it is a big problem.”

Rex is now 3 years old, and he has been in remission since Oct. 18, 2014, when his scans were clear. This definitely caused relief and happiness for the Ryans but also some confusion as to what would be in their future.

“It was strange,” Mr. Ryan said. “A strange feeling because for over a year it had been something that we had so identified with, but it was a great feeling, obviously. It’s just kind of this relief, but it was also this ‘What’s next?’ thing.”

“How do you go back to being normal?” Mrs. Ryan said.

Rex is young enough that he might not even remember his treatment, and Mr. and Mrs. Ryan would be happy for that to be the case. However, they don’t want him to forget that he’s a cancer survivor because they want him to be proud of that part of his life.

“He’ll always have scars on his chest and stomach from surgeries,” Mr. Ryan said. “I guess part of me, selfishly, always wants those scars to be there. I think that’s part of his story and part of who he is. Those are his battle scars.”

After the family’s Make-A-Wish Trip to Disney World in January, when Rex had scans soon afterwards to see if he was still in remission, they gained an appreciation for living in the moment and what they had at the time. Being at Disney World, a place thought of to be happy and joyous, while also dealing with the worries about Rex’s future was a situation with such stark contrast that it became very clear to them that the future could go a number of ways.

“I think it’s just getting that perspective, just kind of stepping back sometimes,” Mr. Ryan said. “And I think we should all do that now, even when we’re on a family trip. Taking that moment to just look around and be present [is important].”

“Win the day,” Mrs. Ryan said. “Yeah,” Mr. Ryan said. “Just take every moment and every day for what it’s worth and maximize it.”

—Madeline Dupre

“Our whole experience wasn’t just ‘Look at our cute, smiling, bald kid.’”
—Lesley Ryan

cancer had touched our lives prior to Rex being ill. [Mr. Ryan] lost his dad to brain cancer; he had glioblastoma. I had had thyroid cancer, myself; it was treated with just surgery, but everyone’s lives have been impacted somehow by someone with cancer. I think that for us [it has] just [been] funneling our advocacy towards what’s most recently really impacted us, and it’s been childhood cancer awareness. Being told that your child has cancer is unbelievable in the worst possible way you can imagine. You go through those grieving processes, and the plan you had for your kid is different than what you originally set out to have. And then you find out that only 4 per-

very strongly about, that we had a message. It’s so fortunate that [Rex] is alive and that he is here. That message is very important too. [We want] to show that with the right care and medicine and a whole lot of luck, some of these kids do make it.”

For Rex, part of that medicine was Unituxin. Rex was part of an experimental trial of the drug that led to its FDA approval. Unituxin decreases the relapse rate and increases the survival rate for neuroblastoma. As part of their advocacy, the Ryans went to Washington to speak to Congress about the Creating Hope Act, which incentivizes creating pediatric cancer drugs for pharmaceutical compa-