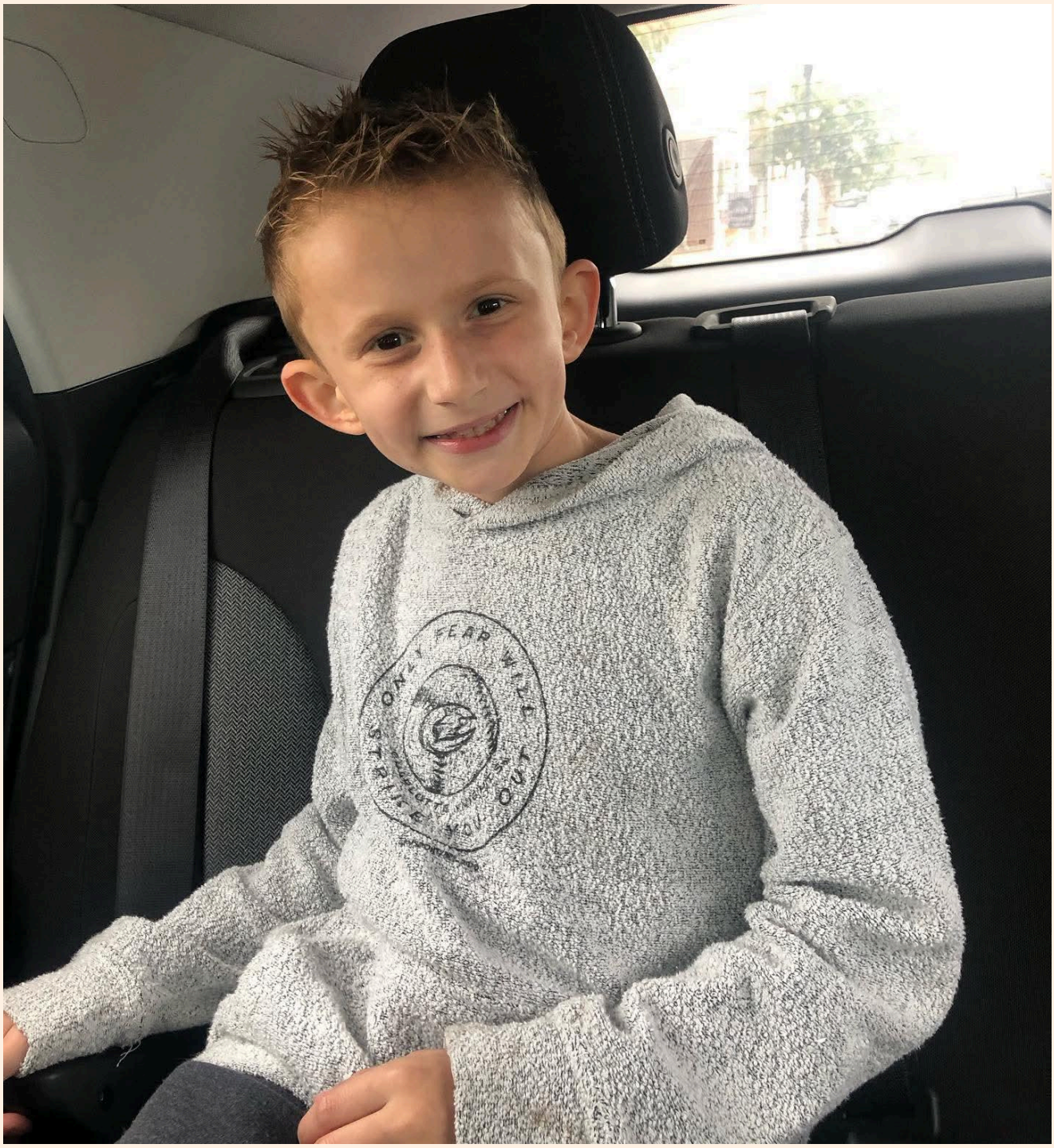
MORE THAN A DIAGNOSIS

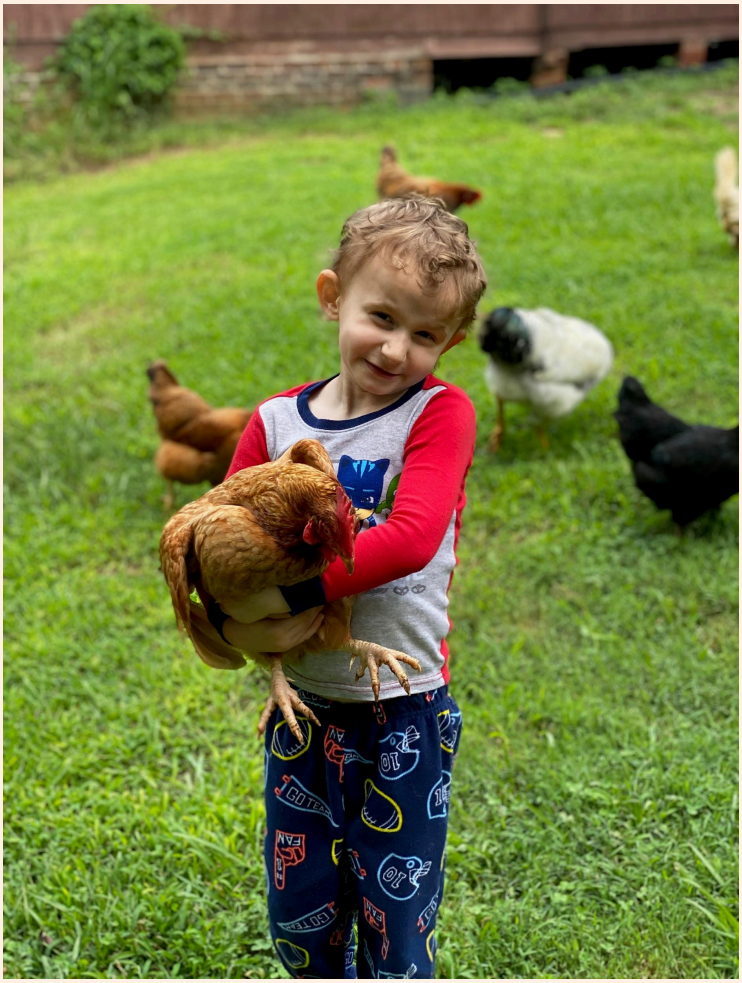
MAX LARIVIERE



Dianna Lariviere, Max's mom, shared Max's story with us as part of our *More Than a Diagnosis* series.

SIMPLY MAX

If you want to understand Max, you might want to start with a chicken.



Not just any chicken. Her name was Pumpkin, and she was Max's chicken.

When Max was little, he loved animals. He would carry Pumpkin around, and she would follow him like a dog. When he came home from daycare, Pumpkin would run to his side of the car and spread her wings, waiting for Max to scratch underneath them. If Max was outside playing in the sprinkler, Pumpkin was right there with him. The family also had a goat Max loved to play with, and trips to the zoo were a favorite. Animals were simply his thing.

His love for animals even found its way into the way he talked. When Max wanted his mom to rub his back or his stomach he said, "Pet me!" To Max, it made perfect sense.

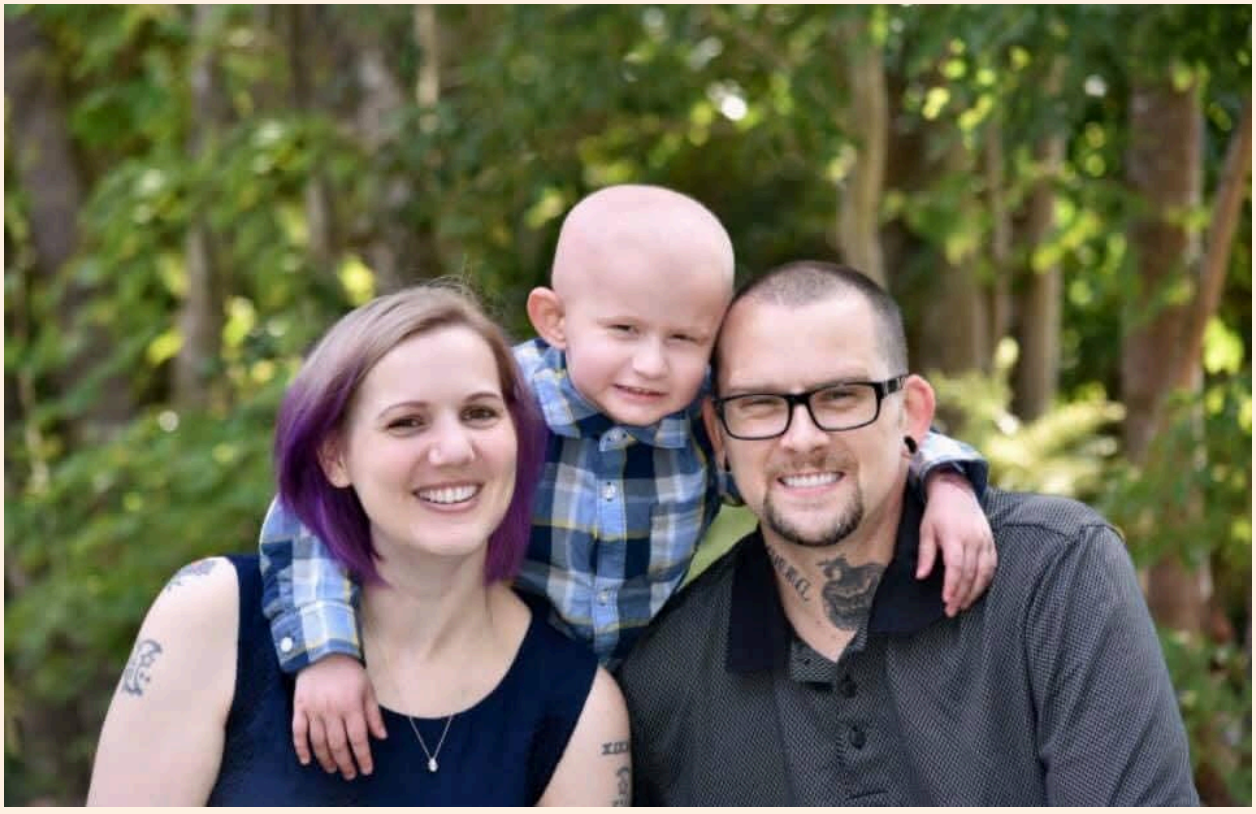
That was Max.

He was quirky and funny and laughed a lot. He was smart and very well spoken for his age and was learning

Spanish at daycare. Dianna remembers him jumping on his little trampoline on the porch while she drank her coffee. He loved being outside. He was a happy little boy, and his family was only just beginning to get to know the person he was becoming, when everything changed.

WHEN CHILDHOOD CHANGED FOREVER

Max was just shy of his third birthday, when his parents began to realize that something was wrong.



It started with bruising around his eyes— sometimes called "raccoon eyes." Max hadn't been sick. He hadn't been complaining. So when the bruising appeared, it was frightening because it seemed to come out of nowhere.

Within days, the family went from wondering why their toddler had bruising around his eyes to learning that

he had cancer called neuroblastoma throughout his body. He had extensive bone marrow involvement and multiple solid tumors. His MIBG scan—a scan used to detect neuroblastoma and comparable in some ways to a PET scan—lit up "like a Christmas tree."

The little boy who had seemed so healthy only days earlier was suddenly facing one of the most aggressive childhood cancer treatments imaginable.

A TREATMENT AS TOUGH AS THE DISEASE

Max's treatment was extraordinarily intense because of how much cancer was present in his body. His family chose to enroll him in a research study, a decision Dianna believes was critical to his survival. The study allowed his doctors to add treatments that would not have been permitted under standard treatment alone.

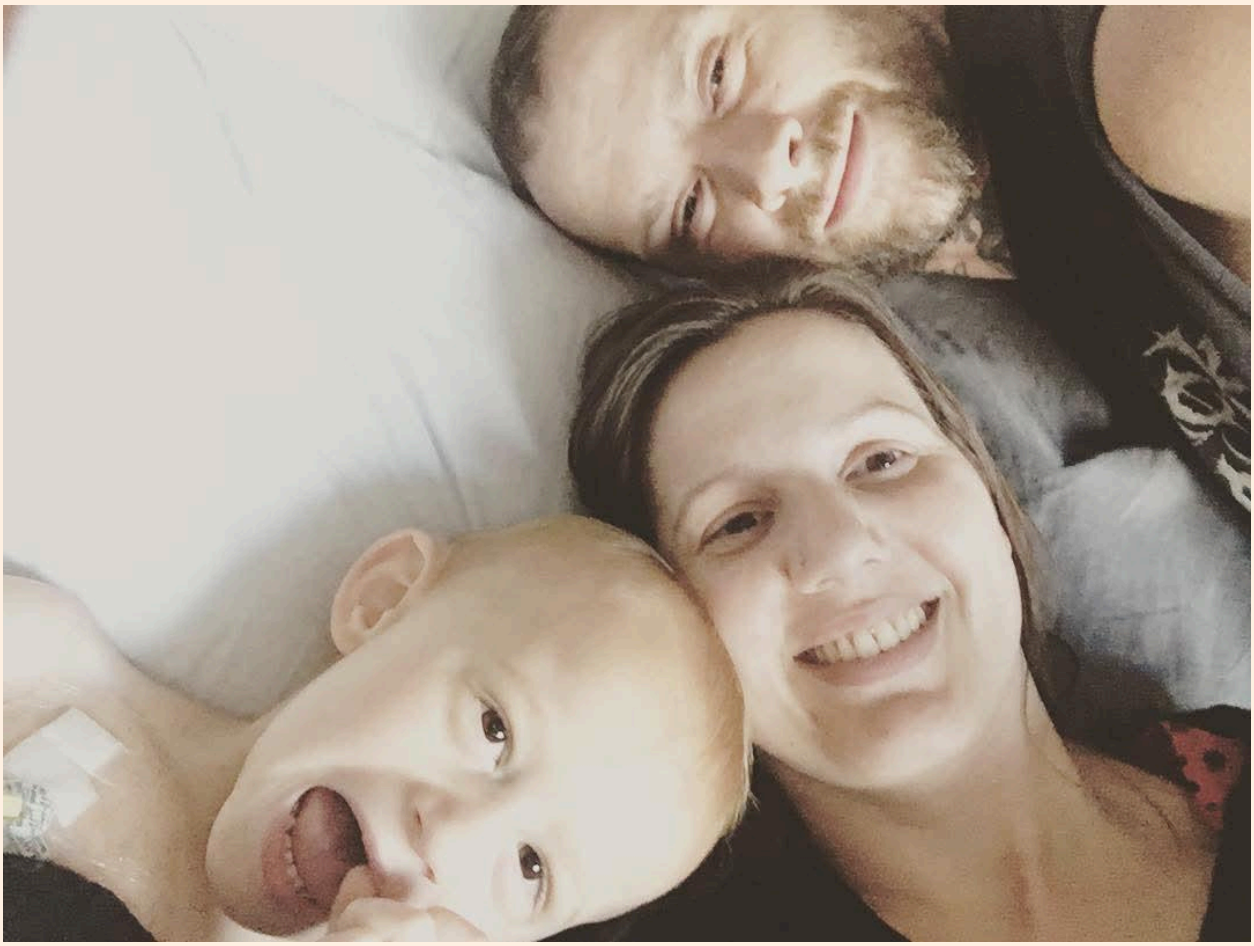
His treatment included chemotherapy, radiation, immunotherapy and a stem cell transplant. But getting Max to the point where he could undergo the transplant was not simple.

His bone disease was particularly stubborn. Dianna explained that Max's Curie Score—the measure doctors were using to assess his bone disease—was so high that it wasn't even measurable. He needed to reach a score of three or below before doctors could consider the transplant and believe he had a reasonable chance of success.

That meant more treatment.

Doctors introduced chemotherapy typically used in relapse situations into Max's initial treatment, along with additional immunotherapy, in an effort to knock down the stubborn bone disease enough for him to proceed.

Eventually, Max underwent an autologous stem cell transplant: His own stem cells were harvested and frozen before the transplant and later returned to his body as part of the treatment. The hope was that using his own cells would allow his body to recover more easily.



The treatment was successful in bringing Max to a point where there was no evidence of disease.

But the treatment that helped save Max's life would also leave lasting effects that would follow him long after his intensive treatment ended.

WHEN BEATING CANCER WASN'T THE END

Today, Max's doctors find *no evidence of disease*. But, one of the most striking contradictions in Max's story came after his cancer treatment when many health complications continued to persist.

One of the most significant is his platelet production. Since his transplant, Max's body has never produced platelets at the level of a normal, healthy child. He continues to have fewer platelets than he should, and that affects decisions about what he can safely do.

He has also experienced significant gastrointestinal problems and nutritional challenges. His body burns calories at an unusually high rate, making it difficult for him to gain and maintain weight. He needs a tremendous amount of food and protein simply to maintain his weight, but eating enough can itself be difficult because eating too much at one time can make him sick.

And his treatment left him with hearing loss, requiring Max to wear hearing aids.

His family has spent years trying to understand what is happening inside his body.

There have been appointments with specialists, tests, surgeries, procedures and countless conversations about what might help Max become healthier. Eventually, his family learned that his nutritional problems were significant enough to result in a diagnosis of *Failure to Thrive*.

And that diagnosis carries an almost painful irony.

Max had survived cancer. Now his family was fighting to help him thrive.

There have even been discussions about a permanent feeding tube if Max cannot maintain his weight.

And so the medical appointments, monitoring and questions continue, but so does the advocacy. Because *no evidence of disease* does not mean *no medical problems*.

For Max, survivorship has become its own chapter of his story

TRYING TO BE A NORMAL KID

The hardest part may be that Max doesn't want to be extraordinary.

"I just want to be normal."

Max tells his mom.

He gets winded easily. He can't participate in sports the way other children his age can. His platelet count means his parents sometimes have to consider risks that other families never have to think about.

And Max notices.

He notices the things he can't do.

He notices the things his friends can do that he can't.

He notices the hearing aids.

He notices the scars.

He notices when his body doesn't cooperate.

Sometimes he tells his mom, "Cancer ruined my life!"

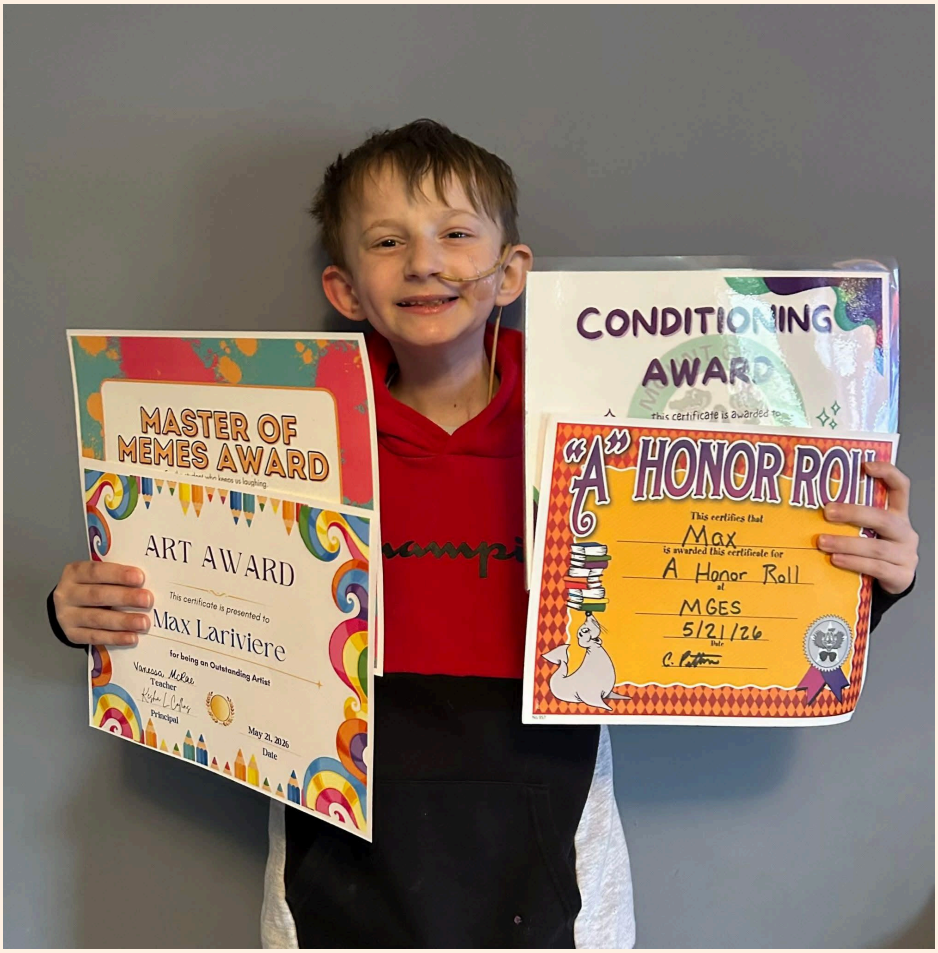
Those words are difficult for a mother to hear, because Dianna knows how hard Max fought to have that life in the first place.

Cancer also interrupted his education. Medical problems and surgeries have kept him out of school for significant stretches of time. After one surgery, he missed nearly 40 days of school because his recovery did not go as expected. He eventually had to receive instruction at home, but the support he was supposed to receive was inconsistent.

For an only child who was already isolated by his medical problems, being home while his mom worked was difficult.

But Max was smart.

He caught up.



That little boy who had been learning Spanish at daycare and bouncing on his trampoline while his mom drank her coffee was still there.

THE THINGS PEOPLE DON'T SEE

Some of the hardest effects of childhood cancer don't show up on a medical chart.

Max has physical reminders—his scars, his hearing aids, the medications he still takes, and the limitations his body places on what he can do. But there are emotional reminders, too. Dianna says Max doesn't always talk about how his body feels. He might say that he doesn't feel good or that his stomach hurts, but he rarely explains what is really going on inside.

Sometimes, though, those feelings come out in ways that are difficult for his mother to hear.

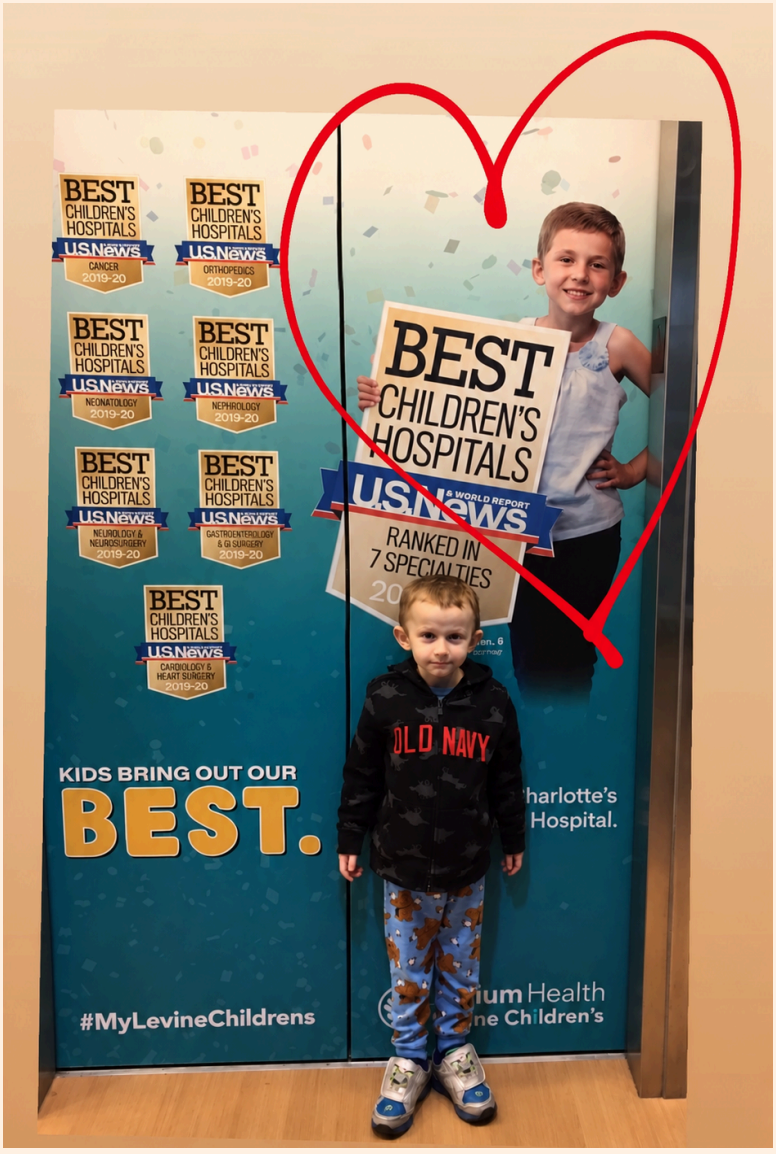
"*Cancer ruined my life*," Max has told her. He has also told her that other children make fun of him because of his scars.

And then there are the memories.

He remembers Madison Fedak.

Max was very young when they were both being treated for cancer, but he remembers coloring with Madison in the hospital playroom. They were two little kids trying to find friendship and a sense of normalcy in a place where neither was easy to find.

He remembers Madison as his friend—his best friend.



And he still has questions.

Why did God let me have cancer?

Why did God let me live when other kids didn't?

When people tell him that God must have big plans for him, Max has wondered why God wouldn't have big plans for Madison, too.

There are no easy answers to that.

Max has experienced survivor's guilt, and his family understands that some of the emotional weight of

everything he has experienced is too much for a child to carry alone. He has received counseling from someone specifically trained to work with children dealing with the trauma associated with childhood cancer.

Because surviving cancer isn't simply a physical experience.

It changes a child.

It changes a family.

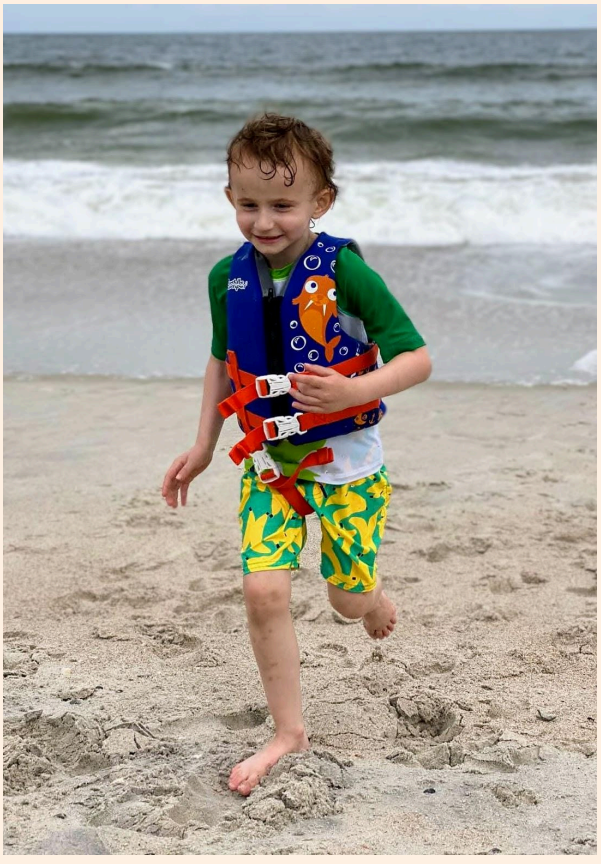
And it changes the way everyone looks at the future.

Those are the things people don't see when they look at Max today.

They see a boy who survived cancer.

They don't see the memories, the questions, and the grief he carries with him.

MAKING MEMORIES



The family isn't looking for extravagant adventures.
They're looking for ordinary ones.
A campfire.
A hike.
A weekend at the beach.
A trip to the mountains.
Swimming.
Reading books together.
Just being a family.

Recently, they bought an older pop-up camper so they can take inexpensive weekend trips without having to worry about the expense of hotels. Max has always wanted to swim more because it is easier on his joints, so they now have a pool too. It was years in the making after medical appointments and other things got in the way, but after years of waiting for the right time, the family is learning that maybe there is no perfect time–Maybe you just make the memories when you can.

A MOTHER'S HOPE

Dianna's hopes for Max are simple, even if the road ahead isn't.

She wants him to have relief from the medical problems that continue to affect him. She hopes he can avoid a liver transplant, something his doctors have been trying to prevent. She hopes medicine continues to advance. But more than anything, she hopes Max gets the normal life he wants. She wants him to have friends. She wants him to experience love. She wants him to have the opportunity to build a family someday, regardless of the fertility challenges his treatment may have caused.

She wants him to have a future that isn't defined by cancer.

And she wants other families to understand something she has learned firsthand: when a child reaches remission and has no evidence of disease, the story doesn't necessarily end.

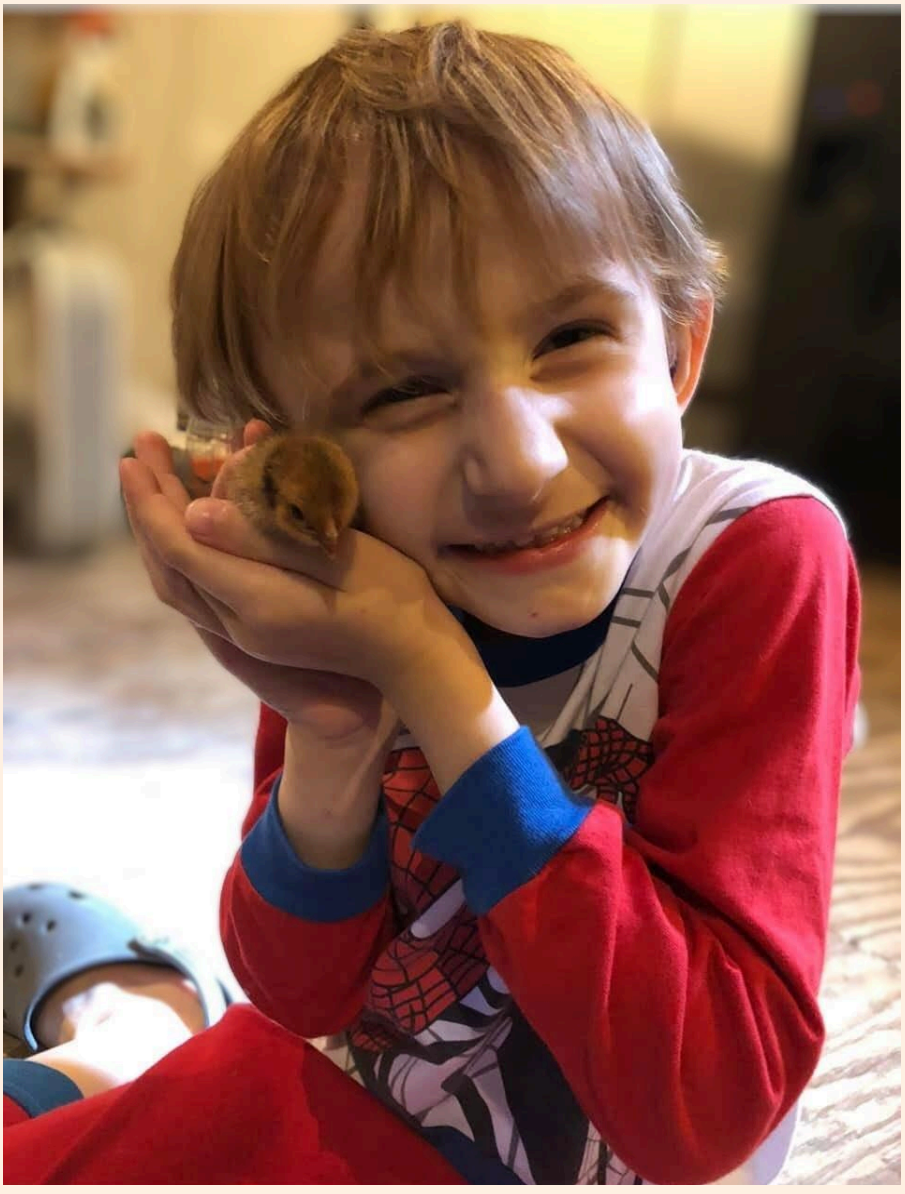
MAKING ROOM FOR CHILDHOOD

When Dianna recently asked Max what keeps him motivated despite everything he has been through, his answer was simple: *he believes in himself*.

He told her that he gets up every day and tries not to let himself be let down by the things that have happened in the past. Every day is a new day. And every morning, he wakes up hoping that his body will recover a little more.

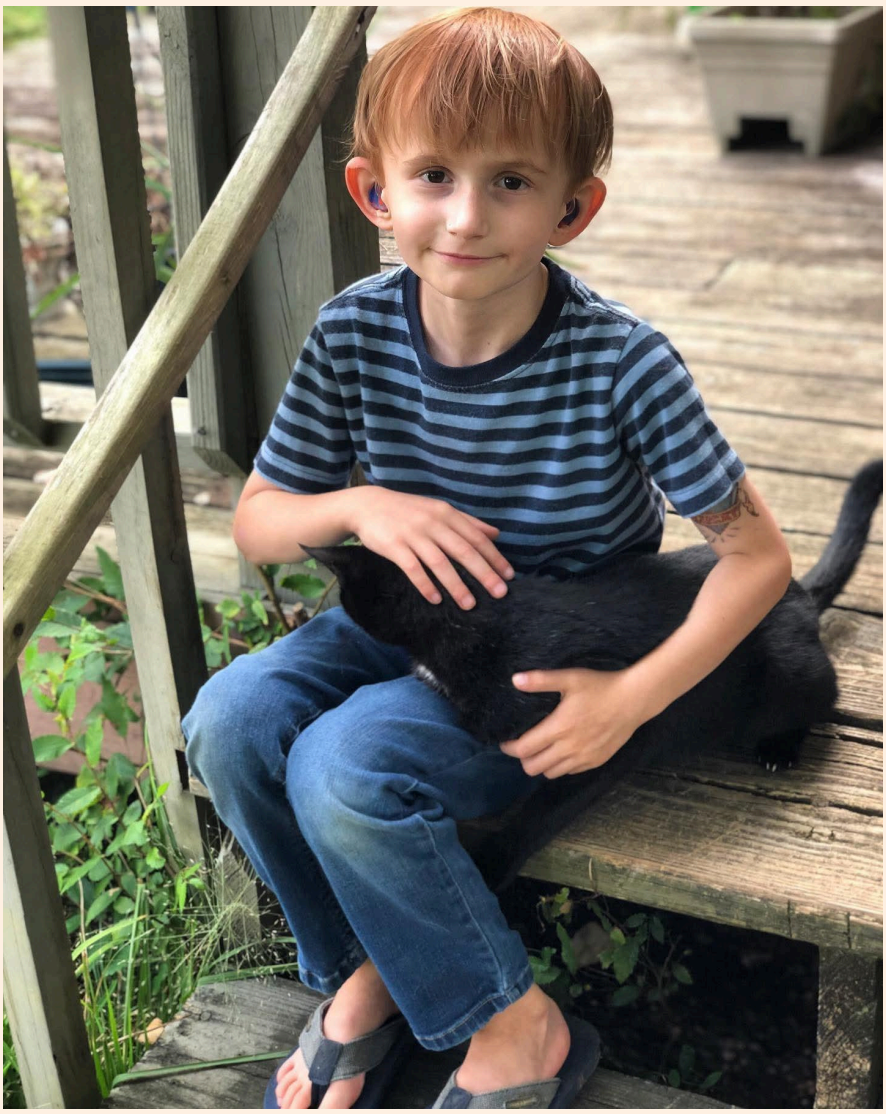
He wants to play with his chickens and goats and hike and swim and do all the other things that normal kids do.

He just wants to be a normal kid and do normal kid things.



And maybe that's what moving forward looks like for Max. Not forgetting what happened. Not pretending that it didn't change him. But waking up each morning and believing that today can be a little better than yesterday.

Max is more than his diagnosis.
He is a thinker, a dreamer, and a believer in himself.



His story is still being written.

EVERY CHILD HAS A STORY.

More Than a Diagnosis

Live Like MADISON