

MORE THAN A DIAGNOSIS

MADISON APPLE



Nicole Apple, Madison's mom, shared Madison's story with us as part of our *More Than a Diagnosis* series.

Getting to Know Madison

Before cancer became part of her family's story, Madison Apple was simply a happy, energetic six-year-old girl with a BIG personality.

She loved doing cartwheels and flips at gymnastics, playing with her friends and her younger sister, Amelia, and taking trips to the beach. According to her mom, Nicole, Madison was “very extroverted and loved the attention and spotlight. Always singing and acting, craving an audience!”

People would often tell Nicole, “God has big plans for this girl!”

But then something changed.

Madison began experiencing intense pain in her upper leg—pain so severe that she would scream and cry at night. Her doctor initially attributed it to growing pains. Within a week or two, Madison developed a slight limp.



Nicole's instincts told her something wasn't right. She scheduled an appointment with an orthopaedist, where an X-ray was taken. The lesion in Madison's leg was missed, and the family was told to give it a couple of months and return if she wasn't improving.

But a mother's intuition told Nicole otherwise.

"Something is wrong!" she remembers thinking.

The following day, she took Madison to her pediatrician. Blood work revealed abnormal white blood cell counts, and Madison was referred to a pediatric orthopedic specialist at UNC. After additional X-rays and blood work, Madison and her family were immediately sent to the University of North Carolina Emergency Department.

Nicole remembers the moment the orthopedic specialist gave them the news she would never forget:

"Your child either has bone cancer or a very dangerous infection that is causing this lesion in her femur that will require immediate treatment."

Nicole dropped Madison and her husband off at the emergency department before driving her younger daughter back to Pinehurst.

"I was in a complete daze," she recalls. "I just remember crying and thinking, *how can this be happening?*" It felt like an out-of-body experience, that I was watching the nightmare of someone else's life."

When the Diagnosis Finally Came

For approximately four months, Madison was treated for osteomyelitis, an infection within the bone. During that time, however, the lesion doubled in size.

After additional testing and another bone biopsy, Madison's family finally received an answer.

It wasn't an infection.

Madison had Langerhans Cell Histiocytosis, or LCH, a disease in which abnormal immune cells multiply and can damage tissue and form tumors.

“It was a day we will never forget.”

Nicole, Madison's mom

“My husband and I were driving to work together when the doctor gave us the shocking news over the phone. We drove to work in silence, having to then see our own scheduled patients.”

She remembers breaking down several times that day.

“Why did God choose Madison? Why is HE giving this sweet, innocent girl this horrible trial?”

Ultimately, Madison began treatment for LCH, but the journey to that point had already taken a tremendous toll on the family.

“I wish we had known what Madison's diagnosis was in the beginning without wasting multiple months treating an infection that wasn't there,” Nicole says.

Madison had endured visits with multiple subspecialists, difficult needlesticks, sedated imaging and two bone biopsies of her femur. At one point, her orthopedic surgeon wanted to remove the lesion and replace the affected area with cadaver bone.

“It was such a whirlwind at the time,” Nicole remembers.

When Cancer Changes Everything

The diagnosis changed far more than Madison's medical care. It changed the rhythm of everyday life for the entire family.

"I grew increasingly depressed knowing my daughter was suffering and I couldn't fix it," Nicole says.

Madison could no longer do gymnastics. She couldn't participate in field day or PE at school. Even walking became increasingly difficult as her limp became more noticeable.

She was told to use crutches at all times and eventually rode around the house on a small scooter because even walking caused her pain.



Even in the hospital, Madison's BIG personality was still shining through

For Madison's younger sister, Amelia, who was about five years old at the time, the situation was difficult to understand.

“She understood Madison had a ‘boo boo leg,’ but didn't understand the extent of the situation,” Nicole explains. “She understood she could no longer run and jump and cartwheel with her, but didn't understand how serious the issue was.”

Amelia missed her fun, energetic sister. At the same time, she struggled with seeing so much attention focused on Madison.

“Like any sibling, she was also jealous of how much attention Madison was getting,” Nicole says. “This jealousy would cause Amelia to act up to get attention, even if it was negative attention at times.”

For Nicole, simply getting through each day became a challenge.

“It was challenging to get up every day and put a smile on my face not knowing my child's fate,” she says. “As a parent, putting a brave face on for my kids and patients was a full-time job when all I wanted to do was sulk and feel sorry for Madison and our family.”

Work became challenging. Family and social events were missed. Life became a constant balancing act



between caring for Madison, supporting Amelia, working and trying to keep going.

A Village of Support

In the middle of so much uncertainty, kindness came from places the family expected—and sometimes from places they didn't.

The family leaned heavily on their faith, prayers, friends and family.

Neighbors immediately began packing suitcases, snacks and games for hospital stays. Family members watched Amelia and helped keep some sense of normalcy in her life. Coworkers helped with patient loads and surprised both girls with toys and crafts.

But for Nicole, faith was at the center of it all.

“Most of all, we had our FAITH,” she says. “We prayed and saw God working in all the little day-to-day wins. We cherished the blue skies, the birds singing, uplifting songs on the way to the hospital.”

One of those “day-to-day wins” came at a pivotal moment in Madison's treatment.



Madison was preparing to undergo sedation for a PET scan and chemotherapy port insertion when an email arrived from Dr. Anish Kumar, an LCH specialist at Cincinnati Children's Hospital.

He suggested an oral chemotherapy treatment rather than the traditional port chemotherapy and steroid treatment.

The option meant fewer side effects. Madison would not lose all of her hair, would not need to leave school for an entire year, and would not need to have a port inserted into her chest.

"In our hearts, we knew GOD was responsible for this email from this amazing man just at the perfect moment," Nicole says.

Support also came through Live Like Madison.

Someone from Nicole's workplace connected the family with Laura Fedak and Live Like Madison. Laura met with Nicole and her girls, answering their difficult questions with grace and kindness and giving Madison a basket filled with items to make hospital stays a little more bearable.

"Laura is one of the strongest women I know," Nicole says.

For Nicole, one of Laura's smallest gestures became one of the most meaningful.

Laura sent her a letter welcoming her into what Nicole describes as "the group no one wants to be in—the childhood cancer mothers family."

"It sounds horrific, but I've read and re-read that letter so many times," Nicole says. "I'm forever grateful for that letter and Laura's guidance and words of encouragement and hope."

Looking back, Nicole doesn't believe there was just one person who made a difference.

"It was really a village of people," she says.

Family and friends, other parents who understood what they were experiencing, teachers who helped with schoolwork, church groups, patients who prayed for Madison, and medical providers all played a role.

And among them was Dr. Kumar, whose expertise helped guide Madison's treatment.

"We are forever indebted to him and his organization at Cincinnati Children's Center."

**"It was
really a
village of
people."**

Nicole, Madison's
mom

Moments of Hope

Even in the midst of fear and uncertainty, there were moments that brought the family hope.

One of those moments came while Madison was in the hospital awaiting the results of a PET scan that would determine the extent and severity of her diagnosis. Madison had been sedated for the imaging and was very sleepy and nauseous afterward.

Nicole and her husband tried to prepare themselves for what the doctor might say. They researched her bloodwork and worried about what the results could mean.

"I remember fighting back tears, unsuccessfully at that, while watching Madison hovered over the toilet and

giving her what she called a ‘bird bath’ to help her feel better,” Nicole recalls.

Then the doctor and his staff came into the room with smiles on their faces.

Although Madison did have cancer, the news was better than the family had feared. Her LCH was considered the best-case scenario—single system, single site with favorable outcomes.

There was also hope surrounding Madison's treatment.

Although the oral chemotherapy treatment recommended by Dr. Kumar was novel and not typically used for LCH, the doctor who presented the PET scan results was optimistic about the documented

treatment studies and was willing to speak with Dr. Kumar about using the treatment in Madison's case.

For a family that had spent months searching for answers, that moment brought a welcome sense of relief.



Madison Was Still Madison

Cancer changed many things about Madison's childhood, but it didn't change the little girl her family knew and loved.

Madison continued to show a resilience and optimism that amazed her mom.

"I'll never forget when she told me,

"It's okay, Mommy. Don't cry. I'll be okay. I'm strong."

"Children are amazing!" Nicole says. "They are stronger than we ever are or will be."

Nicole saw that strength again at Madison's school Christmas concert. Despite the pain and the limp that had become part of her everyday life, Madison walked onto the stage and sang her heart out.

"I sobbed like a baby in the audience watching her in amazement."

For Nicole, moments like that offered a reminder that beyond the appointments, tests, treatments and uncertainty was still the same little girl who loved gymnastics, singing, performing and being in the spotlight.



Looking Forward

Today, Madison is 10 years old and has just started fifth grade at Episcopal Day School in Southern Pines, North Carolina. Her family is thankful to be able to watch her continue growing, learning and simply being a kid.



“Her prognosis is very good,” Nicole says. “It can come back, but typically presents with pain, so we just have to be watching out for bone pain. We actually saw her oncologist yesterday at UNC, but so far, so good.”

For Nicole and her family, those words—“so far, so good”—carry a lot of meaning after everything Madison has experienced.

“Looking forward, we are just so thankful and just trying to live in the moment,” Nicole says.

The experience has changed the way the family looks at everyday life. Nicole encourages other families to slow down, appreciate the simple things and make time for the people they love.

“Enjoy the sunrise and sunsets. Appreciate the simple things in life more. Take the time off work to go on vacation, eat the dessert before dinner, appreciate the laughter and good times. Go to church every Sunday, pray more, spend valuable time with friends and family.”

When she thinks about Madison's future, Nicole hopes her daughter continues to grow into the resilient, kind and compassionate young woman she is becoming.

“I hope Madison appreciates the little things. I pray she continues to be resilient and brave. I pray she remains healthy and strong. I hope she continues to be kind to friends and shows empathy and compassion to those who are suffering.”

Nicole is looking forward to watching Madison become a young lady, make new friends and discover new hobbies.

“I am looking forward to her continuing to show kindness and friendship to others. I pray she continues to be honest and grows in her faith.”

And for the future of children everywhere, Nicole has one final hope:

“I pray that childhood cancers become a thing of the past. I pray scientists continue to find treatments for this devastating disease. No one should have to go through this, especially not an innocent child.”

**Madison is more than her diagnosis.
She is a daughter, a sister, a friend—and
a girl determined to keep shining.**



Her story is still being written.

EVERY CHILD HAS A STORY.

More Than a Diagnosis

