Ready to start planning your care? Call us at 800-525-2225 to make an appointment.
×



In June 1989, at the age of two and a half, Daniel, who had always been a good eater, started spitting out his food regularly at meals. A large, apparently healthy child who was at the upper end of the height and weight charts for his age, Daniel had never previously experienced any significant health problems. This sudden change was very troubling to his mother, Karen, who, at the time, had just given birth to Daniel's brother, Michael. "I spent all of my well-baby visits for Michael inquiring about Daniel," Karen remembers.

Karen asked the pediatrician to do a chest x-ray, believing that some sort of obstruction must be preventing him from swallowing his food. The pediatrician refused, insisting that he did not want to expose a two-year-old to what he felt was unnecessary radiation.

At the same time, Daniel began to develop recurring fevers not seemingly related to any other symptoms. While both Karen and Daniel's father, John, found these developments to be worrisome, the pediatrician reassured them that such symptoms were normal childhood occurrences. By September, Daniel's condition had worsened. He came down with a different cold or flu almost every week, but, still, the pediatrician was not concerned, blaming the continual illnesses on nursery school, which, Karen was quick to point out, Daniel did not attend. "I just thought there was definitely something seriously wrong with him," she says. "It was my mother's intuition."

Tumor Hiding — in Plain Sight

One morning in early October, Daniel woke up crying. Unable to walk or crawl, he told Karen that his knee hurt. Karen took Daniel to the pediatrician immediately, whereupon she was told to go to the emergency room of their local hospital in New Jersey to meet with an orthopedist. After a long, painful day of waiting in the ER, the orthopedist arrived. Despite Karen's pleading for an x-ray of Daniel's knee, the orthopedist, believing that a virus located in the hip was the cause of Daniel's pain, ordered x-rays of only the hip. When the x-rays came back, neither the doctor nor the consulting radiologist saw anything of concern in Daniel's hip. (Later, when Daniel was finally correctly diagnosed with neuroblastoma, doctors at Memorial Sloan Kettering reviewed these initial x-rays and identified the presence of a large tumor in Daniel's spine — a tumor that had been missed by the previous doctors, who had been looking only at the hip portion of the x-rays.)

Because Daniel's fevers had never dissipated, the pediatrician ordered a series of blood tests, the results of which all appeared normal. The pain, fever, and absence of a diagnosis continued through November, even after the pediatrician referred them to a pediatric specialist for a second opinion. Throughout this period, Daniel's doctors, suspecting arthritis, considered sending him to a rheumatologist in Manhattan, but since none of the blood tests confirmed its presence, the referral was never made. Instead the pediatrician advised Karen to treat Daniel's pain with Tylenol and told her that she could rest assured that whatever was going on with Daniel it was minor, since all the tests ruled out anything serious.

Prayers and Supplements

By Thanksgiving, Karen and John were at the end of their ropes. "I didn't feel very thankful," Karen says. She felt helpless as Daniel's fever and intense pain persisted. Karen adds, "I just prayed, 'Lord, I know I should be thankful, but please show us the cause of Daniel's suffering!'" With few options remaining, in early December Karen and John took Daniel for a painfully uncomfortable two-hour car ride to a highly recommended naturopathic doctor. The naturopath prescribed $400-worth of vitamins and supplements without even examining Daniel. "I felt so sorry," Karen recalls, "that we caused Daniel to endure so much extra pain on this long trip, in our desperation to find an answer to Daniel's suffering."

> "It was a really big help knowing that these are caring human beings helping you. "
>
> John Erd
> Daniel's Father

Reflecting on those early weeks of December, Karen and John say they noticed that Daniel's pain had moved from one knee to the other knee, then from the knees to his hip. He also started to complain of a "tummy ache." When Karen asked him to point to where it hurt, he pointed to his back. It

turned out that “tummy ache” was Daniel’s catchall phrase for “pain.”

Finally, a Doctor Who Listens

It was around this time that Karen made a conscious decision to place everything in God’s hands. When the stress over Daniel’s condition began to get the most of her, Karen concentrated on reassuring Bible verses like Proverbs 3:5-6: “Trust in the Lord with all your heart and lean not on your own understanding; in all your ways acknowledge Him, and He shall direct your paths.” “Various scripture passages reminded me that it is God who is in control,” Karen says. “After much prayer and reflection, I thought perhaps a rheumatologist has seen something like this.” In mid-December, she insisted that the pediatrician provide her with names of rheumatologists, since Daniel’s severe knee and hip pain resembled the symptoms of arthritis. As she pondered the names of the doctors and hospitals given to her, Karen prayed that God would make it extremely obvious to her where to bring Daniel.

When Karen called to schedule an appointment with Dr. Thomas Lehman, a pediatric rheumatologist at the Hospital for Special Surgery in Manhattan, the doctor himself answered the phone. The receptionist was strangely absent from her desk, Dr. Lehman explained, so while he and Karen waited for the receptionist to return, Dr. Lehman proceeded to inquire about Daniel’s symptoms. “He listened for almost 30 minutes,” Karen remembers with appreciative amazement. A further sign to Karen that her prayers were being answered, Dr. Lehman just happened to have an opening at eight o’clock the following morning. Karen could not help but think that perhaps Dr. Lehman would be the one to finally diagnose Daniel’s mysterious illness.

It was nearing Christmas when Karen and John took Daniel to the appointment with Dr. Lehman. They remember his excitement at driving across the “Christmas bridge”— the George Washington Bridge, which connects northeastern New Jersey to upper Manhattan. Almost immediately, Dr. Lehman proved to be different from Daniel’s previous doctors. “He was wonderful!” Karen gushes. “None of the other doctors had wanted to hear the full chronology of Daniel’s illness, but Dr. Lehman wanted to know everything since he was in utero.” Karen is quick to mention, too, that as a physician Dr. Lehman recognized the utter importance of listening carefully to the mother, who knows her child best.

After absorbing the details of and asking questions about every iota of Daniel’s condition, Dr. Lehman said that Daniel was exhibiting many of the symptoms of some rarer types of juvenile rheumatoid arthritis (JRA). While waiting for the results of the blood tests, Dr. Lehman prescribed Daniel the non-steroidal anti-inflammatory drug naproxen used to treat a rare form of JRA.

At Last, a Diagnosis — “Daniel Has Cancer”

Daniel appeared to improve over Christmas, but on the evening of New Year’s Day he complained that his chest hurt. When Karen and John lifted his shirt to see what was wrong, they were horrified to find that his chest was swollen like a barrel. They notified Dr. Lehman, who insisted that they bring Daniel in first thing the following morning. “And we got a phone call from his office before 7 a.m. to make sure we were coming,” Karen notes. “At that point,” John remembers, “we knew it was bad, but we still never thought cancer.”

Karen spent the day and night with Daniel at the hospital, as he received blood tests and the chest x-rays that Karen had requested of Daniel’s previous doctors six months before. Early the next morning, waking next to Daniel in his crib, Karen overheard someone in the hallway mention “the big C.” Suddenly, a voice in her head said, “Daniel has cancer.” Shortly after, Dr. Lehman walked in the room and told Karen that Daniel most likely had cancer, possibly neuroblastoma, but that it was treatable.

“After I calmed down a bit, I said I needed to call my husband, although I could barely utter the words through my tears,” Karen says. “It was such a huge shock, but it was also a great relief to finally have a diagnosis,” she adds. “The next thing Dr. Lehman told me was that he had already contacted the best neuroblastoma oncologist in the world, Nai-Kong Cheung from Memorial Sloan Kettering Cancer Center. Little did I know that he literally was the best doctor in the world!”

Dr. Cheung arrived later that afternoon having already studied Daniel’s blood samples and the chest x-rays, which showed a large mass in his chest. After more tests and scans, he told Karen and John that Daniel had advanced stage IV neuroblastoma, which is a relatively rare cancer of the nerve network that carries messages from the brain throughout the body. Dr. Cheung recommended that Daniel be transferred to Memorial Sloan Kettering to begin treatment at once. “We very quickly knew, after speaking to a number of people, that Memorial was the best place in the world to treat this,” comments John.

New Treatment Provides New Hope

When they arrived at Memorial Hospital, the Erds were informed that a new treatment protocol called immunotherapy had recently been approved for patients with neuroblastoma. This was welcome news because, at the time, no child with stage IV neuroblastoma had been completely cured

for patients with neuroblastoma. This was welcome news because, at the time, no child with stage IV neuroblastoma had been completely cured with the standard therapy. Immunotherapy uses the patient's own immune system, through the injection of what is known as a monoclonal antibody, to help fight the cancer. The monoclonal antibody attaches to a marker on the surface of neuroblastoma cells, which becomes a target for the patient's immune system to attack and kill the tumor. Daniel, at three years old, would be one of the very first patients in the world to receive this innovative protocol.

But first he would have to undergo standard chemotherapy to reduce the size of the tumor, which had invaded his knee and hip bones, a number of his ribs, as well as his spinal canal. It had taken so long to make the correct diagnosis that the tumor now blocked his spinal fluid from circulating and was crowding his organs, including his lungs, to such an extent that one of his lungs collapsed during the initial surgery to install the chemotherapy port in his chest.

The doctors informed the Erds that the entire treatment process would take eight months. To ease Karen and John's commute, Karen's parents quickly volunteered to take in the couple along with Daniel's eight-month-old brother, Michael, for what turned out to be almost an entire year. "Words cannot express how thankful we are for the prayers and support of our families and so many others throughout our ordeal," says Karen.

The Power of Childhood Resilience

Daniel was vomiting on and off throughout the night of his first chemotherapy treatment, which also happened to be his third birthday. But by the next morning, when Karen comforted him, saying, "You poor baby, you were so sick last night," he remembered nothing. He was more interested in going to the hospital playroom, which he had seen the day before. "That's the one positive thing about having cancer at that young age," Karen explains. "The younger kids do better because all they know is today," adds John.

Dr. Cheung was amazed at Daniel's almost immediate positive response to the chemotherapy. When he came to see Daniel the following Monday, he found the three-year-old happily running around the playroom, seemingly free of pain. Unfortunately, the entire process was not as easy, with Daniel experiencing various infections, including a very serious case of septic shock. Throughout it all, Karen and John asked many questions, a practice that Dr. Cheung encouraged. "He told us, 'Doctors don't know everything. In many cases, we try something and if that works, then we continue down that path,'" John recalls. "He was the most humble, selfless, caring doctor I have ever met," Karen adds.

> "Everybody in the neuroblastoma team is thrilled to know that Daniel is coping well, and that he learned the art of healing in nursing school, which will allow him to give back to those less fortunate."



Nai-Kong V. Cheung
Neuroblastoma Program Head

And it wasn't just Dr. Cheung. Once the chemotherapy had shrunk the tumor enough to allow the bulk of the remaining portion to be surgically removed, Michael P. La Quaglia, a pediatric surgeon specializing in treating children with neuroblastoma, performed Daniel's delicate surgery in August. "When we initially met Dr. La Quaglia, after listening to our story he said, 'I can't imagine what you are going through.' He was so personable and caring right from the start. It was a really big help knowing that these are caring human beings helping you," John says.

Success — Daniel as a Happy Young Adult

Between the chemotherapy, the monoclonal antibody immunotherapy, and the surgery — which together accounted for the 350 days Daniel spent in the hospital during that fourth year of his young life — the tumor eventually disappeared. "Daniel's positive attitude and compliant nature were so helpful throughout the entire ordeal," Karen remembers. There were a number of post-treatment-related health concerns, including some developmental delays, but Daniel went on to be a smart and happy child, adolescent, teenager, and, now, young adult.

Inspired by all the remarkable healthcare workers he has met during his treatment, Daniel has decided he wants to give something back and is currently studying to receive his degree in nursing. He is also an avid and talented artist, and has been actively involved in hockey, paintball, and snowboarding with his brother, Michael, and friends. Looking back on the long, twisting road that has led them as a family to the present, the Erds, fortified by their faith in God, take nothing for granted and are able to appreciate the great gift of life that is presented to them each and every day.

The Erd family dedicates this story of courage and resilience to Daniel's loving grandparents — Henry and Lida Erd, and Anton and Kay Thomasen.

Communication preferences
Cookie preferences
Legal disclaimer
Accessibility statement
Privacy policy
Price transparency
Public notices

© 2024 Memorial Sloan Kettering Cancer Center