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Meet Caroline: A childhood leukemia survivor

Hear from Caroline as she celebrates her high school graduation.

Video Details →

Caroline Watters's problems began almost from the moment she entered this world, in November 1999, when she was born both premature and anemic. For the first two years of her life, she was in and out of doctors' offices, but no one could conclusively establish what was causing her dangerously low blood platelet counts. That all changed when she was diagnosed at the age of two with myelodysplastic syndrome (MDS).

Before the diagnosis, Caroline's parents, having grown unhappy with the care provided by the blood specialists at Caroline's local hospital, decided to switch her to a hematologist at New York University (NYU) Medical Center. After conducting many tests, including a painful bone marrow biopsy, the new team concluded she was suffering from idiopathic thrombocytopenic purpura (ITP), an autoimmune disease in which the patient's body attacks its own platelets. However, Susan Watters, Caroline's mom, had done enough online research to believe that Caroline's symptoms did not match those listed for ITP.

"I went onto a Web site for ITP families," Susan recalls. "The more I learned, the more I said to myself, 'This isn't what Caroline has.' Call it mother's intuition, but it just didn't add up."

As a result of Susan's doubts, in the summer of 2001 Caroline's care was transferred to Margaret Karpatkin, MD, a member of the Division of Pediatric Hematology/Oncology at NYU. While Caroline was bruising on a regular basis and her platelet counts continued to be very low, all of her blood tests continued to be inconclusive. Hoping to discover an underlying cause of the problems, Dr. Karpatkin recommended that another bone marrow biopsy be performed. Caroline's father, Sonny, initially refused, remembering the painful experience Caroline had suffered through the first time.

"Looking back now, after all of the tests and procedures we went through, it seems silly," Susan explains. "But at the time, we didn't want to subject Caroline to any more pain."

During a Thanksgiving trip to upstate New York, Caroline took a turn for the worse, growing very weak and lethargic. Upon the family's return to their home in Queens, New York, Caroline's blood counts were found to be dangerously low. Fearing the worst, Sonny and Susan consented to have

home in Queens, New York, Caroline's blood counts were found to be dangerously low. Fearing the worst, Sonny and Susan consented to have doctors perform another bone marrow biopsy. The results showed that Caroline had myelodysplastic syndrome (MDS), a group of diseases that affect the bone and bone marrow — certain types of which may develop into acute myelogenous leukemia (AML). Unfortunately, Caroline's MDS was considered a precursor to AML and, as a result, needed to be treated with the AML treatment protocol. She was admitted to the hospital that same day and remained an inpatient almost continuously for the next eight months.

In AML, a change in the DNA of an immature white blood cell, called a myeloid cell, causes the cell to grow and multiply uncontrollably in the bone marrow. Eventually, these leukemia cells infiltrate the body's organs and interfere with their function. To combat the growth and spread of leukemia cells, the patient is treated with chemotherapy, which is given in several stages. The first stage, called induction therapy, seeks to kill close to 99 percent of the abnormal cells and to allow normal blood cell production to resume, in a process called remission.

Opting for a Clinical Trial Protocol

Caroline was started on a clinical trial treatment protocol to test a drug regimen designed exclusively for her subtype of precursor AML. For Caroline's parents, deciding whether to have Caroline participate in a clinical trial was relatively easy. "We asked if going on the trial would help Caroline's chances," Susan says. "When they said it probably would, our decision was made."

During the remission induction phase, Caroline, who was at increased risk for infection due to low white blood cell counts, was placed in isolation for eight weeks. This meant that all visitors, including her parents, had to wear gowns, masks, and gloves when they came to see her to reduce the risk of infection. Her older sister, Lisette, was not even allowed to visit. Susan, a graduate student in education at NYU at the time, managed to continue with her classes while sleeping at the hospital with Caroline almost every night. Sonny visited after work, before returning to the Watters's home in Queens, where Lisette was being cared for by her grandmother.

For patients with AML who have matched donors, the next phase of treatment following remission induction is bone marrow transplantation. During this procedure, doctors administer high doses of chemotherapy to kill any remaining leukemia cells, and then implant an entirely new, cancer-free blood forming system in the patient. To optimize the chances of success, the individual donating his or her bone marrow needs to have a tissue type that closely matches that of the recipient. Otherwise, there is a significant likelihood that the patient's body will reject the donor cells.

A Perfect Match

Fortunately, Lisette was a perfect match for her younger sister. (Only 25 to 35 percent of siblings are perfect matches.) Susan remembers the nurses breaking into applause at the good news. Susan and Sonny decided to ask Lisette, who was four years old at the time, if she was willing to donate. Without hesitating, she said, yes, she wanted to help her little sister get better.

Caroline was transferred to Memorial Sloan Kettering Cancer Center for the transplant. But before the transfer took place, she began to notice a pain in her abdomen, the cause of which was unidentifiable on scans. Because Caroline had been through so much without complaining, the Watters knew it had to be something serious. Arriving at Memorial Sloan Kettering, they discussed Caroline's new symptoms with Richard O'Reilly, Chair of the Department of Pediatrics and Chief of Pediatric Bone Marrow Transplant Service. Dr. O'Reilly thought that Caroline most likely had a cyst that was not showing up in the scans. He ordered a battery of more detailed scans, which revealed a large, fluid-filled cyst tucked behind her sternum.

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>
> Susan Watters
> Caroline's Mother

Caroline was immediately scheduled for surgery with Michael La Quaglia, Chief of the Pediatric Surgical Service, who drained and removed the cyst. As Caroline healed from the procedure, her doctors worried that the cancer would return before she could receive the transplant. If it did, she would need to go through another round of chemotherapy to get the cancer back into remission — an outcome which is much more difficult to achieve on the second try.

Fortunately, Caroline recovered from the surgery before the cancer returned, allowing her doctors to proceed with the transplant. The procedure would be performed under the guidance of Farid Boulad, Medical Director of the Pediatric Day Hospital and an oncologist specializing in pediatric bone marrow transplantation.

In preparation for the procedure, Dr. Boulad informed the Watters of all the potential side effects and complications — including the possibility that Caroline would not be able to bear children as an adult due to the intense chemotherapy that is required to kill the remaining bone marrow cells prior to transplantation. Sonny found this possibility so upsetting that initially he wanted to call off the transplant, but Susan and other family members convinced him that this outcome was preferable to losing Caroline.

A Successful Transplant and a Setback

The transplant took place on May 17, 2002. The procedure — both the bone marrow harvest from Lisette and the intravenous transfusion of the bone marrow stem cells into Caroline — went smoothly, though it would take some time before doctors knew whether Caroline's body would accept the new tissue. In the interim, Caroline, susceptible to infection and excessive bleeding, was confined to an isolated hospital room, as she waited for the transplanted bone marrow to migrate to the cavities of the large bones, engraft, and begin producing normal blood cells. Two weeks later, Dr. Boulad pronounced the transplant a success.

Caroline had not been eating after the transplant, and the Watters had convinced her doctors that she would do better at home. Once it became clear that the transplant had engrafted, Caroline progressed quickly and by the sixth week was allowed to return home. Because she needed to continue receiving intravenous fluids, a visiting nurse made regular visits to the Watters's house to help Susan monitor Caroline's condition, change the dressing on her IV port, and administer medications. (Before Caroline began treatment, a central catheter line, known as a Broviac port, was surgically inserted in her chest, eliminating the need for doctors and nurses to repeatedly access veins, which can become painful.)

Susan had grown so accustomed to the inpatient setting, the transition from the hospital to her own home was a difficult one for her. At the end of September, Caroline's Broviac port had become infected, causing a spike in her temperature. "We had been in the hospital for so long that we didn't know quite how serious this was until we reached the hospital. They informed us that she was on the borderline of having a serious septic infection," Susan remembers. As a result, Caroline returned to the hospital for two weeks, during which her doctors treated the infection with IV antibiotics.

Five Years Cancer Free

Once Caroline was home again she recuperated quickly, and before long she was living the life of any healthy three-year-old. In May 2007, she officially commemorated five years of being cancer-free, a milestone that the Watters celebrated with great appreciation.

Throughout Caroline's treatment, Susan says she never once believed that things would not work out for the best. "I think I subconsciously put myself into that mindset," she reflects. "I don't think I would've been able to handle it otherwise." In many ways, Susan explains, the entire process was harder on Lisette. Not only had she been suffering from the daily absence of her parents and sister for seven months, but she was asked to go through an uncomfortable procedure at an age when she was too young to fully understand its necessity.

But Lisette, now a cute, confident, and articulate nine-year-old, says she would not have had it any other way. "Anytime somebody finds out what happened and asks me about it, I tell them that I feel good that I was able to help."

And Caroline, today a beautiful, energetic, and healthy seven-year-old, expresses appreciation for her sister's generosity. "I feel really good about it. It makes us feel closer."

Advice for Other Families

Asked what advice she can give other families considering a bone marrow transplant for their child, Susan offers a number of practical suggestions. "For most people — not all, but most — I think it's therapeutic to talk to someone about what they're experiencing. That was the case for me. I went to any and every event offered at Memorial Sloan Kettering for parents, just so I could talk to other parents experiencing what we were going through."

Still, Susan understands that everyone copes in his or her own way. “My husband would tell you that his coping mechanism was driving on the Long Island Expressway. It gave him time to think about everything and process it.”

In the years since Caroline’s treatment, Susan says that she’s “found a real family among other parents of children who are either going through something like what we experienced or who have already experienced it.” In fact, Caroline and the entire Watters family have become involved with camps specially designed for children with cancer. Both Caroline and Lisette attend Sunrise Day Camp, where Susan is on the advisory board. Additionally, each year the Watters volunteer at Camp Sunshine, a camp for children with life-threatening illnesses and their families.

Susan tells the story of a recent summer spent at Camp Sunshine, on an afternoon when Sonny was working along the camp’s waterfront. “One of the parents came up to him and said something along the lines of, ’It’s great that you’re helping out, but you’ll never be able to understand what we’re going through.’ He pointed to Caroline, playing in the water, and replied, ’Actually, that little girl right there is my daughter and she survived cancer.’”

Update

Caroline returned to MSK in June 2018 to take part in the Department of Pediatrics’ annual Convocation, which celebrates students graduating from high school who were treated at MSK. An avid performer, Caroline sang “Rise Up” by Andra Day during the ceremony. She has appeared on HBO’s “Girls,” auditioned for Broadway productions, and recently wrapped her first independent film role. In high school, she traveled the world with her school’s show choir and performed for the pope and former President Barack Obama. Caroline began her freshman year at Lafayette College in the fall of 2018.

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