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Darren and Nancie

There is never a good time for disease to strike. But for chef and restaurant owner Nancie Simonet, the phone call that woke her up before dawn one morning in January 2003 could not have come at a worse time. The call would eventually lead to a diagnosis of a blood disorder known as

One morning in January 2000, could not have come at a worse time. The call would eventually lead to a diagnosis of a blood disorder known as [myelodysplastic syndrome \(MDS\)](#) and a life-saving stem cell transplant.

At age 42, Nancie was seven months pregnant with her first child. The voice at the other end of the line belonged to her obstetrician, who had received alarming results from a standard prenatal blood test. Nancie had extremely low levels of platelets, a type of blood cell that is essential for coagulation. This meant she would be at risk of bleeding to death if she were to injure herself.

A Puzzling Bone Marrow Condition

Nancie and her husband, Darren, immediately drove to a hospital near their home in Milford, Pennsylvania. At the hospital, Nancie had new platelets infused into her blood and underwent a series of exams. In the course of the following months, she was misdiagnosed with one blood disease after another. “From lupus to ITP to aplastic anemia,” Nancie recalls. Her doctors put her on several different treatments, but none seemed to work.

“At that point, I didn’t even care what was happening to me,” Nancie says. “All I could think about was my baby — I was so afraid of losing her!” She and Darren had been longing for a child and Nancie had gone through a number of unsuccessful pregnancies.

Several times a week, Nancie needed to have new platelets infused into her bloodstream. “Time and again my gums would start bleeding, and I would run to the hospital for a transfusion,” she recalls. “The first time it happened I was in a panic. I felt as if my body were deteriorating completely.” She was eventually transferred to a hospital in New Jersey, where her daughter, Sophia, was born on April 6.

“Sophia’s Caesarean delivery was a big affair,” Nancie recalls, “with a large team of doctors and nurses involved. They were concerned I would lose too much blood.” To her parents’ joy and relief, little Sophia was as strong and healthy as any baby when taking her first breaths.

However, Nancie’s condition began to worsen soon after the delivery. Her bone marrow ceased to produce red and white blood cells as well as platelets, causing extreme fatigue, as well as various inflammations and infections. “The situation was getting desperate,” Nancie says. “My doctors still couldn’t figure out what I had. Finally, an oncologist I had been seeing here in town gave me the phone number of a specialist at Memorial Sloan Kettering Cancer Center, advising me to seek help there.”

A Diagnosis and a Turning Point

The specialist Nancie’s doctor recommended was James Young, of Memorial Sloan Kettering’s Adult Bone Marrow Transplant Service. “My first consultation with Dr. Young was a turning point,” Nancie recalls. “After reviewing the results of my bone marrow biopsy, he suspected that all the previous diagnoses I’d received were wrong. Darren and I immediately felt that he would be able to help us.” A bone marrow biopsy is a procedure in which a sample of bone marrow tissue is removed, usually from a patient’s hip bone, and examined under the microscope.

Dr. Young diagnosed Nancie with myelodysplastic syndrome (MDS), a group of diseases that affect blood stem cells in the bone marrow. Today, most cancer experts classify MDS as a form of cancer because it produces a large population of abnormal cells from a single abnormal cell. In approximately one-third of patients, the disease will progress to [acute myeloid leukemia \(AML\)](#), a type of blood cancer.

Dr. Young explained that Nancie’s condition was serious but curable. To get well, she would need to undergo [allogeneic stem cell transplantation](#) — a challenging procedure during which she would receive new blood stem cells from a healthy patient’s blood or bone marrow.

Once Nancie’s friend Ellen found out that Nancie would need to drive to New York City on a regular basis, as well as learning of her need for childcare and other unforeseen expenses, Ellen immediately went to work putting together a fund raiser in their community. All the local restaurants and specialty shops came together to prepare a feast, while local musicians entertained and staff volunteered to create the most memorable night. Guests poured in and the response was nothing less than miraculous. “I am so very fortunate to live in a small town like Milford. Even now I think about the generosity of friends and strangers and I am overwhelmed,” says Nancie. Guests were even signing up to be tested as a possible match.

Two Years of Waiting

For patients requiring an allogeneic transplant, every effort is made to find a donor whose tissue type closely matches that of the patient. The patient and the donor need to share a number of genes, called HLA genes. This reduces the risk that new immune cells, which form in the patient after the transplant, will recognize the patient’s tissues as foreign and attack them — a serious complication known as graft-versus-host disease.

Nancie has three siblings, but none of them matched her tissue type, nor did any of her other relatives. So, her Memorial Sloan Kettering doctors began searching national registries for a volunteer donor. Combinations of HLA genes vary extensively between individuals, making close matches between unrelated people rare. In Nancie’s case, the search for a potential donor lasted for more than two years.

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"Darren and I waited and waited, hoping each day that a donor would show up," she says. "Meanwhile, I had to manage my disease and have constant transfusions at my local and New Jersey hospitals."

When it was time for me to move home, I was even reluctant to leave my nurses, in whose care I had felt so safe and at ease.

Nancie Simonet

Finally, Dr. Young identified a suitable donor who was registered with the National Marrow Donor Program. But one problem remained: the donor was a US Army Special Forces Green Beret stationed in Iraq.

"We had no choice but to wait until he came home on permission," Nancie explains. "The first time that happened was in July 2005. My doctors had prepared my body for the procedure, and everything was ready. But at the last minute, they couldn't proceed with the transplant. My liver enzymes were too high. I felt so miserable going home that day, knowing my donor was on his way back to Iraq!"

At Last, New Bone Marrow

Nancie was finally able to have her transplant on the next occasion that her donor was back in the US, in October 2005. During the first part of the procedure, called myeloablative therapy, Nancie received three chemotherapy drugs over nine days to destroy her immune cells, which otherwise could react against her donor's stem cells and reject them. After one day of rest, she received the stem cells that had been harvested from her donor's blood and that would build her new bone marrow.

Nancie had to stay in the hospital eight weeks after the transplant while her immune system developed. "That wasn't nearly as bad as I had thought," Nancie says. "All the physicians on my treatment team were taking such good care of me, and the nurses were just wonderful. Someone was always there to check on me or sit by my bed if I were having a bad night. When it was time for me to move home, I was even reluctant to leave my nurses, in whose care I had felt so safe and at ease."

There were several setbacks during the long recovery process that followed. "The side effects of the chemotherapy were grueling," Nancie recalls. "I developed mouth sores that were very painful. I had high fevers. I vomited constantly."

Four Years Later

Nancie has now made a full recovery and is busy running The Waterwheel Café, a popular restaurant and live music venue she launched twenty years ago. With Darren's help and a dedicated staff, she managed to maintain the establishment throughout the long course of her illness. She is also the mother of three — her daughter Sophia, now six years old, and her stepchildren, Dustin and Morgane, who were 9 and 14 years old when Nancie had her transplant. Looking back, she recalls that a strong determination to sustain her life and her family was what most helped her pull through the difficult years of disease and treatment.

"After Sophia was born, I was determined to be there for her first day of school," she says. "It became my mantra, something I would repeat to myself in my worst moments of despair."

Nancie has developed a long distance friendship with her donor, Joshua, who lives with his family in Las Vegas, Nevada. "I was so eager to find out who he was and to thank him," she says. A year after her transplant, Memorial Sloan Kettering's Bone Marrow Transplant Service helped her to obtain the consent necessary for her to contact Joshua. (After a patient has a transplant from a donor identified through a national registry, both the patient and the donor may choose to remain anonymous or may choose to meet each other by mutual consent.)

"Nancie's long-term prognosis is excellent now that she's made it this far out. We are very pleased and happy to have cured her."



James W. Young
Bone Marrow Transplant Specialist

“When I received the call from Memorial’s BMT service office with Joshua’s information I remember how just hearing his name brought me to tears. The first time I phoned him was such an emotional moment,” she recalls. “I had so many questions about his experience, and we talked for many hours. He taught me how to use Facebook so that we could exchange photos of ourselves and our families.”

“Joshua and Dr. Young are my biggest heroes,” adds Nancie. “Each in their own way, they gave me back my life.”

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