

Melodee's Story...

Melodee has been a potter since 1990. Melodee and I have been together since 1988. She began her study under the experienced tutelage of Jolet Fozel at Indiana University's School of Arts. Jolet is a local artist who pretty much motivated Melodee to create unique earthen pieces by hand. While honing her skills, Melodee enrolled in a variety of pottery courses. I remember how excited she was after her first couple classes with Jolet. She simply could not find enough time to work on the wheel at Indiana University so I quickly purchased her a pottery wheel of her own so that she could do more work at home. Not too long after that, her first kiln was purchased and what a scary day that was when we fired that thing up for the first time!



I have never seen Melodee so interested in any one thing as she is in pottery. I enjoyed watching her competency in the art of pottery grow, year over year. However, Melodee's journey was not altogether continuous and it was far from easy. Because many times she had to discontinue her joyful pursuit of pottery while she recovered from intense rounds of chemotherapy to battle her progressive [Non-Hodgkins Lymphoma](#).

In the year 2000, following 3 failed clinical trials ([University of Michigan](#), [New Jersey's Garden State Cancer Center](#), [Burzynski Institute in Texas](#)) and a 16 year continuous battle with this cancer, Melodee underwent an [Allogeneic Bone Marrow Transplant](#) at the [Cleveland Clinic](#), to literally save her life. Her Lymphoma was progressing rapidly through the most intensive chemotherapy that could be administered conventionally. We

really had no other medical option left except to pursue this very risky procedure. Melodee was dying and we needed to take drastic measures.

A search for a compatible donor was performed world-wide by the [National Donor Marrow Donor Program](#) and only one person was found matching her DNA markers! All the Cleveland Clinic would tell us is that her donor was a white male of about 38 years in age. We saw him as an angel. The transplant procedure itself is really very simple. It is the [myeloablative](#) chemotherapy, followed by her almost 4 month stay in an air tight hospital room that really tested us, both physically and spiritually. Myeloablative chemotherapy is the administration of dosage so high as to literally kill a patient's existing bone marrow. As Melodee's bone marrow (the source of the immune system) was roughly 90% invaded by the Lymphoma cells, the only potentially curative route was to literally give her a new immune system. But first, the bulky tumors and her bone marrow needed to be killed.

This was one of the most frightening moments for me, as her husband. With her [white blood cell count \(WBC\)](#) at zero (normal is 12 - 14), she was vulnerable to any type of infection that a normal person could tolerate. Her hospital room was actually pressurized to bring clean air into the area at all times. It was quite a clean-room set-up but it was necessary to keep her alive.

Two weeks after the intensive chemotherapy, Melodee's bone marrow arrived from somewhere in the continental U.S. and was dripped via IV into her central line catheter that was surgically implanted into her heart. The whole process took only about 15 minutes and was relatively anticlimactic. Then, a most difficult time of waiting, for both her and me, followed. Basically, we were waiting to see if the new bone marrow from her unknown donor, of a completely different blood type, would miraculously engraft in her own marrow. Her doctor told me that they would wait no longer than 4 weeks to see if her white blood count would start to rise. If at that point, there was no indication of successful engraftment, they would re-infuse her own, cancer-laden [stem cells](#) that were extracted from her at the onset of this process. This was the back-up plan and boy did I hate the sound of that.

During this terrible waiting period, I recall waking every morning at about 4AM to rush to the hospital. Her blood chemistries were usually available between 4:30 to 5:00AM. The engineer in me was tracking those vitals like a hawk, watching closely for any sign of any improvement. I would rush to the hospital to see her numbers, only to be disappointed by the zero WBC reading. As week 4 approached, I was becoming extremely worried. Her WBC was still at zero and I was fearing not only about engraftment failure, but about her ability to fight off simple illnesses that

could literally kill her. After all, she had no immune system to fight disease. She was also very weak and on a [Morphine](#) drip for pain.

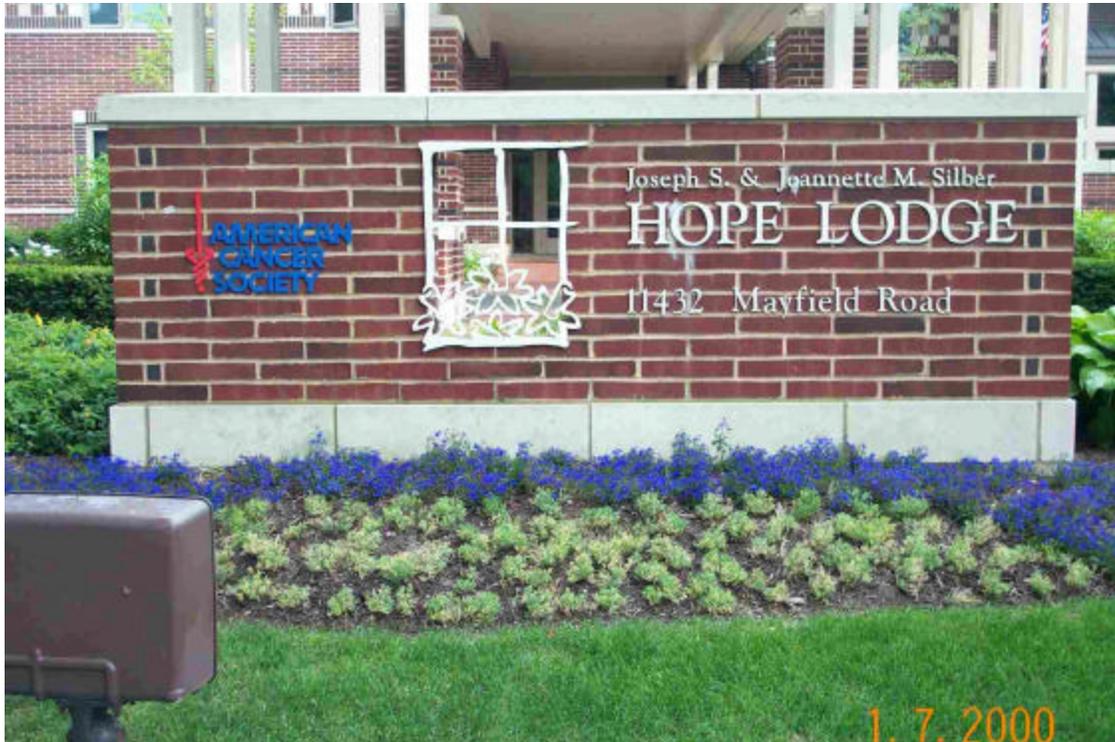
I recall bumping into her doctor at the beginning of week 4. I asked him what we were going to do and he compassionately told me to be patient. He also started to administer [Neopogen](#), a white blood cell growth factor designed to boost her immune system. But my patience was pretty much gone and a new, higher level of panic was overtaking me. I continued to pray, as hard as I have ever prayed.

Wednesday. I awoke as usual at my 4AM hour, having been exhausted from reading a book the night before about St. Jude that my mother had sent to me. I had asked [St. Jude](#) for his intercession. As the "forgotten" saint, I figured he would understand my plight. I rushed over to Melodee's hospital room and rounded up the nurses to see her chemistries.

But what I saw this time was indeed our first miracle. Her white count had moved to 0.3! Though her doctor cautioned me that this could merely be a slight increase that would later subside, I was happy for the moment nonetheless.

The next day, her count stayed about the same. And the next day, it was still around 0.3. I was becoming disillusioned once again. But by Saturday, her numbers began to increase, slowly and then more quickly. Day after day her white count increased until by about week 8, she was reading above normal levels. I recall her WBC climbing as high as 20!

Needless to say we were both ecstatic. Her doctor informed us that her white blood cell count was artificially high due to the Neupogen growth factor. He cautioned that he did not want her WBC to remain so high, as other, more serious ramifications would result. Nevertheless, with some of her numbers being marginally improved, he somewhat reluctantly released her into my care at the Hope Lodge. The [Hope Lodge](#) is a wonderful and beautiful [American Cancer Society](#) hospice at the [Cleveland Clinic](#).



When I brought Melodee back to Hope Lodge, I was so proud. She could not walk so I helped her around. She was really tired and wanted to rest but I just had to introduce her to all of my friends at Hope Lodge. I wanted everyone to finally meet my wife. But Melodee still needed around the clock care and that is what the Cleveland Clinic trained me to do. So, I became a nurse. This involved managing over 60 pills per day, several IV feedings, multiple medications, vital signs, etc. Our room looked like a pharmacy. When I look back at the photos, I don't know how we did it. However, the three clinical trials leading up to this actually helped with my aptitude.

Melodee had to stay in Cleveland for six months following the transplant. As we lived almost 4 hours away in Indiana, I stayed with her as long as I could, with her mother filling in for me when I ultimately had to return home. William, that beautiful German Shepherd on the HandsNClay home page, was a mere 3 month old puppy when Melodee and I had to depart for the transplant. He obviously stayed behind and my mother, bless her heart, raised Melodee's endearing little friend for us while we were away.

Melodee's high white count quickly got the best of her and she came down with [Graft vs. Host Disease](#). This is an ugly side effect of a transplant, especially with an unrelated donor, where the new immune system begins to battle with what is left of the old immune system. It is difficult to manage and is a primary cause for loss of life during such a procedure.

Melodee became very ill quickly. She could not keep anything down and was becoming very dehydrated. She was also running very high fevers, a classic sign of Graft vs. Host.

She was quickly readmitted to the bone marrow ward and remained there for 5 weeks, undergoing intensive steroid ([Prednisone](#)) infusions to suppress the new immune system. Graft vs. Host was very painful for Melodee as it is for all transplant patients. Fortunately, she remembers very little of this due to another morphine drip. Seems strange to want to suppress the new immune system but that is the only known way to battle this disease. If left unchecked, it would soon kill her liver and other vital organs. I recall these 5 weeks as being some of the loneliest in my life. Melodee was asleep most of the time and when she was awake, was hallucinating due to the Morphine. I was very much alone and very much afraid for her, and for us.

But as the weeks went by, her WBC count fell, almost too far. It fell to around 4! This did cause her symptoms to subside but the side effects for Graft vs. Host would also prevent her from eating solid food for quite some time. Her doctor told us he needed to find a happy medium where her new immune system felt comfortable in her body. He was happy with a WBC of 4 for a while. However this time, the rest of her chemistries were severely disrupted. Upon her release from the hospital, she required daily infusions of red blood cells and plasma. Her body simply could not produce the red cells that she needed. As time progressed, her doctor was starting to fear engraftment failure. I was horrified once again, or perhaps I was horrified all along but my anxiety levels grew more intense.

Then, about one month after all of this, and amidst daily blood infusions, etc., Melodee started to see spots or "[floaters](#)" in her vision. She said there were millions of them. Obviously this concerned us. Since we saw her doctor about every other day, we told him of these new symptoms and he was immediately and gravely concerned. When we asked him what the possibilities were, he remarked that possible causes could be that the cancer has metastasized to her brain! This was the most worried I had ever seen her doctor. But he also told us this could be other things, though he was not very convincing of that.

So, he referred us to a young ophthalmologist who very abruptly announces to us that Melodee's vision floaters were likely cancer that had metastasized to the brain. He wanted to draw fluid from Melodee's eyes to confirm. We were crushed. We simply could not believe what we were hearing at this point in the process. We followed up with her doctor once again. Melodee was refusing to let this young eye doctor draw fluid from her eyes, and I supported her in this. I asked her doctor, if it was cancer

in the brain, what could we do? He said all that could be done would be to install a port into her head for direct infusion of chemotherapy into the brain cavity. Even with that, the prognosis was only a few months, at best. Cancers of the central nervous system are very lethal.

If I were ever to define the absolute lowest point in my life, it had to be this time. For the next several weeks, I literally began preparing myself emotionally to helplessly watch my wife worsen and likely pass away. We had both fought so long and so hard but I could not even begin to comprehend how to help her through what looked to be an inevitable situation. But I mustered the strength to search the internet for a physician who specialized in ocular cancers (cancers of the eyes). As I searched Google, can you believe that the man with the most relevant hits was actually practicing at another hospital in Cleveland and he was literally 200 feet from Hope Lodge?! I made an appointment for Melodee to see him. And what a pain it was to get our insurance to approve an "out of network" visit. This was the last hassle we needed at this moment. I scheduled the appointment without the endorsement of our insurance companies. But that is a story for another day.

Melodee and I visited this ophthalmologist at his office. He was a very kind and experienced man who looked into Melodee's eyes with his microscopic tools. He looked for a long time and finally told us that he did not believe it was ocular cancer. But he did not know for sure what it was. He said that drawing fluid from the eye would tell us conclusively, but he also told us that he would not do that right away. He recommended waiting a few weeks to see if the floaters changed at all. Though we left his office feeling slightly less panicked, we were still very scared. We did not know what we were dealing with and now we had to wait. And usually, with Lymphoma, time is not on your side.

So as the waiting game proceeded, I fell into a depression. Looking back on this event, I now recognize that that was what happened to me. But I did my best to stay strong for my wife. I recall sitting with her on the back patio at Hope Lodge. We would sit in the sun because the transplant left her very cold all the time. Because she originally noticed the floaters upon looking at the sun, I would ask her to verify their existence for me. I must have bugged the hell out of her asking her to count the floaters in her eyes. But she always did so without a hint of resistance (well, there was a little). She always reported to me that they looked the same. I was losing hope and wondering what the next symptoms would be.

I can't exactly recall all of the events, and the sequences in which they happened during this time. But I do vividly remember leaning so hard on my mother through this. I did not want Melodee to feel the utter panic in my soul for her, so I did my best to bottle it up, pouring it onto my mother

whenever I spoke with her on the phone. My mother is a wonderful woman. She has propped me up more times than a mother is required to do so.

I recall speaking with mom from a pay phone in Hope Lodge so that Melodee, who was sleeping in the room, would not hear me. I was telling mom that I was losing it, and that I was trying to find a way to come to peace with the thought of losing my beautiful wife. Mom cried with me and then offered a great idea to me. It was a distraction but we needed that. As it had been almost half a year since we had been home, she volunteered to bring both grandma and William, the hyper little puppy that she was raising for us, to Toledo, a halfway point between our home and the Cleveland Clinic. So although we were not supposed to leave the Cleveland area, we made the trek to see mom, grandma, and William at a pet accepting hotel in Toledo.

The only way for me to describe that weekend was that it was all so surreal. Everything looked gray. I remember pulling into the hotel that Friday evening. Mom had just arrived and had William on a leash out in the yard. Melodee and I jumped out of the car to greet everyone. Good ole William, now about 70 lbs., showed that he had never forgotten about us. He licked Melodee so completely that he knocked her wig right off. The emotions at the point were so high. Seeing all of them made us forget for just a split second about Melodee's worsening condition.

Since William was too young and uncontrollable to be left alone, we lived in the hotel room all weekend. What a mess it was! I remember talking to God and telling him that I wanted him to freeze time. I would be perfectly happy living in this dingy old room forever, so long as I had my family, and my wife, with me forever. But that weekend, as great as it was, was also very miserable for me personally. I believed that this would be the last time my mother, grandmother, and William would get to see Melodee. I was really struggling at this point. The drive back to Cleveland was one of the most difficult I had ever made.

Now I don't remember exactly when we saw Fr. Voors, our parish priest, but I know it was amidst this whole mess. We snuck home, which we later found out was really a stupid thing to do because Melodee became very, very ill and I knew that the local hospital could not treat her. But I knew Melodee needed to get home, at least for a brief spell, for her state of mind. We were home long enough to have a very quick Sacrament of the Sick administered by Fr. Voors. This quaint little ceremony occurred in the back of the church, with my mother and grandmother present. But what I remember the most about this sacrament was how beautiful it was. I felt the warmth of God come over us and it was indescribable.

But Melodee soon became very ill once again with her second round of Graft Vs. Host disease. So, another trip to the Bone Marrow ward at the Cleveland Clinic followed. She was admitted for another several weeks. The steroids controlled her symptoms and she was released, once again, into my care. She was much weaker upon her release than any other time.

And finally, I remember that wonderful day that followed some time after that. It was one of those days where we were sitting on the back patio at Hope Lodge, warming ourselves in the sun like a couple of cats in a window seat. Like a broken record, I asked my wife to look toward the sun to give me a verification of the "floaters."

She peered toward the brightness, looked over at me, and frantically (but excitedly) told me that there were fewer! I asked her if she was sure. She smiled ear to ear and said, "Yes!"

Day by day, the floaters diminished. By the third week, they were gone. Another obvious miracle! And finally, I had to return to work. I felt like I was being ripped away from my wife. After all, we had been through so much together and I was her nurse. But I knew she was in good hands with her mother. I showed her mother how to operate her infusion pumps and her IV's, and I was off for home. My brother in law accompanied me on the drive home that day. I was glad for this as I did not want to be alone. However, when I got home, the house was so empty and cold that it scared me. I called my mother and asked her to come over, and of course, she did. And good ole William was there too! It was great to see him again.

A New Beginning for Us and for HandsNClay

It has been almost 4 years since the Cleveland episode. Once Melodee came home, it took her about a year and half to get back to normal, though her normal self of today is not her normal self from before the transplant. And one of the worst things about all of this is that she neither had the strength, nor was she allowed by her doctor, to work on her pottery while she recuperated.

But Melodee, God willing, is doing great now. In fact, in 2003, she walked a mini-marathon for the Leukemia and Lymphoma Society and was the number one fund raiser in our state! She was the only Bone Marrow survivor to participate in this huge event. But she finished, and I was extremely proud of her.

If I know my wife, she will not want me to keep her story posted on her web site. She is very humble and I love that about her. However, I will convince her that her story is an inspiring one that needs to be told to all who are willing to listen. And she will begrudgingly agree that the story should remain on this site. If this story helps to inspire just one person who is fighting cancer, or who has lost a loved one from this relentless disease, then the posting was worth the effort. Melodee has spoken with many people preparing to undergo a transplant and she is always willing to share her experiences, from her perspective, with others.

So HandsNClay has once again become Melodee's passion, and now, for the most legitimate of reasons. This is what she loves to do, more than anything, and the Lord has now given her the opportunity to teach classes. If you ever get the chance to meet my wife, either on the phone or in person, you will quickly understand how extremely fortunate you are to make her acquaintance. When you hear her laugh, you will wonder how someone can be so happy all the time?

But perhaps this letter helps to explain who Melodee is and why she is. Having known her and loved her long before all of these battles consumed our lives, I can tell you she has always been that special.

As such, HandsNClay is committed to the eradication of cancer and similar immune disorders. We donate 5% of each net sale to the American Cancer Society's Hope Lodge in Cleveland, Ohio. We know that Hope Lodge directly helped us in our fight against Lymphoma, and they continue to compassionately help others who are facing similar battles today.