

My Personal Chronicle of Battling Blood Cancer: A Journey of Challenge and Hope

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I have compiled this story detailing my personal health journey to share some of my experiences and emphasize the impact of blood cancer on myself, my wife, and our family. The purpose of this outline is to underscore the significance of fundraising efforts that support ongoing research and to offer hope to those currently battling this devastating illness or who may face it in the future.

Approximately twenty years ago, in February 2003, I received a diagnosis of Thyroid Cancer. Following two surgeries, multiple radioactive iodine (RAI) therapies, and nearly a decade of treatment, involving countless scans, hospital visits, and various medications, I was ultimately declared to be in remission. That same year, 2003, I married Jessica, and our journey became intertwined. Therefore, I will refer to our experiences collectively, as we navigated this path together over two decades.

Now two years ago, in 2022, we faced another new and serious challenge when I was diagnosed with therapeutic Acute Myeloid Leukemia (t-AML). In simpler terms, AML is a rare form of blood and bone marrow cancer where blood cells fail to develop properly in the bone marrow, resulting in the production of immature cells known as myoblasts, or 'blasts.' As these blasts proliferate, they crowd out normal red blood cell, platelet, and white blood cell production, leading to symptoms such as fatigue, bruising, and fevers.

The radioactive iodine treatment I had undergone for thyroid cancer over the years had led to the breakdown of my bone marrow. In late 2021 and spring 2022, during the yearly follow-up testing, continual decrease in the number of white blood cells in my blood had been observed. We were scheduled to meet with the Department of Hematology at the Cancer Clinic in London Health Sciences Center. Naturally, in the week leading up to this appointment, we were filled with worry, asking each other if we had to go through this ordeal again. The subsequent bone marrow biopsy, conducted with only local anesthesia, involved the extraction of a sample from the back/hip area with a needle. We were informed that the results would take several weeks to come back.

The very next day, however, we received a phone call from the hematologist that changed our lives. Preliminary tests of the bone marrow indicated a diagnosis of AML. All we could hear were the words "leukemia" and "low survival rate." We were overwhelmed with noise, shaking, and tears. We had no understanding of what AML entailed, and we could scarcely formulate any questions. The doctor informed us that we needed to come to London within seven days and be prepared for up to six weeks as an inpatient to immediately commence heavy doses of chemotherapy without delay, aiming to halt the production of these blast cells in the bone marrow.

As one can well imagine, we found it nearly impossible to function for several days after receiving this news. Thanks to Jessica, my true support, we paused, talked, and discussed what this diagnosis meant for us. Together, we resolved to confront it head-on and shield our family of six

young children from witnessing our breakdown. We had no choice but to press on; it was a difficult yet necessary decision, with no alternative in sight.

Bidding farewell to our family on the front porch, with my parents present, I knew that due to COVID-19 restrictions at the hospital, I wouldn't see them again for nearly a month and a half. The chemotherapy treatments took their toll; I shuffled down the hallways leaning on Jessica, battling fevers, nausea, and overwhelming exhaustion. In a matter of weeks, I most certainly felt like and looked more like an old man. However, by the end of the induction chemotherapy, I began to feel better and regained my ability to walk without assistance.

During this period, I gained insight into my illness and learned that due to the damage to my bone marrow from previous radioactive iodine treatments, a bone marrow transplant would be necessary. While receiving the diagnosis of AML was incredibly challenging, it was equally heartening to discover that the chemotherapy treatment had been effective, reducing the blast count by 37% to undetectable levels, a rarity occurring in less than 40% of cases after the initial treatment. This indicated remission, albeit temporary, as without a bone marrow transplant, the disease would likely return swiftly.

Fortunately, a perfect donor match was found: my sister Niessa. The transplant was scheduled to take place after she had her baby in early fall of 2022. Following the consolidated chemotherapy treatment in August 2022 to keep the leukemia at bay, I returned to the cancer clinic in October 2022 for the bone marrow transplant.

Advancements in medical knowledge, training, and funding have transformed the transplant process compared to years ago. After further rounds of chemotherapy to clear my bone marrow and completely suppress my immune system, my sister's bone marrow, resembling blood, was slowly infused into me via IV. Prior to this procedure, Niessa underwent injections to stimulate bone marrow stem cell production, leading to bone marrow cells entering her bloodstream. This marrow was then harvested through a blood donation-like process, involving extracting blood from one arm, harvesting excess bone marrow, and returning the blood to her other arm. Though this process may sound straightforward, Niessa experienced significant bone pain and exhaustion in the weeks following.

Initially, the days following the transplant went smoothly, but then the intentional collapse of my immune system led to severe illness. Without any remaining immune system, even a common cold posed a threat to my life, necessitating constant monitoring by nurses. However, within days, my blood numbers improved, and the new bone marrow began to settle into my bones, initiating the production of new blood.

To grasp the significance of this medical treatment, consider the remarkable fact that I now carry my sister's bone marrow, resulting in her blood type flowing through my body. I am no longer O+ blood type but have Niessa's A Neg. This condition, known as chimerism, involves having cells from two different sources, resulting in dual DNA, a rarity in North America.

After weeks of sleeping 16-17 hours a day at home, I finally began to feel better. However, my doctor was vigilant for signs of graft-versus-host disease (GvHD) reactions. The new immune system I received has the potential to "attack" my body, which lacks its own immune defenses.

This must be managed carefully to prevent it from becoming a life-threatening secondary illness. Symptoms of GvHD, such as skin rash and significant gastrointestinal issues, emerged around Day 100 after the transplant, indicating a strong reaction that is necessary to prevent the leukemia from recurring.

Over the following year, I found myself back in the emergency room for extended stays due to GvHD reactions and additional complications such as collapsed lungs from contracting COVID-19, rhinovirus, RSV respiratory infection, and later, Pseudomonas pneumonia. With a new immune system, I had to combat childhood illnesses once again, despite being 43 years old. The risk of developing these lung-related conditions is particularly concerning, as they pose a significant threat to someone with a compromised immune system, nearly leading to intubation for life-support.

Currently, I feel the healthiest I have been in almost two years, though I still experience fluctuations due to medication, resulting in rapid weight gains followed by losses. The first-year post-transplant is the most challenging, but things gradually stabilize over time. When asked if I am better, the answer is both yes and no. Yes, I have surpassed the critical stage, but no, I will never truly return to full health. As the Nurse Practitioner aptly described it, "Marius, you are running a marathon without a destination. You can't quit; you just keep running."

Everyone's futures are uncertain, but usually, these thoughts can be pushed aside. However, I now face that reality and uncertainty nearly every day, particularly reminded by every little pain, cough, or change in how I feel. You might ask, "What is the long-term projection?" I don't have that answer; you can search for it yourself. In the meantime, I am grateful to God as the supreme Physician and preserver of life, thankful for the expert medical services and treatments I have received, appreciative of the tremendous professional care provided by the medical team, and indebted to my wife, Jessica, my entire family, and the numerous friends who offered unwavering support.

I share our personal journey not for pity or recognition but with gratitude and to raise awareness. If we collaborate to expand the medical community's knowledge, there's hope that if or when this disease returns, there will be more treatment options available, for me and others like me.

Never forget: the phone could ring for any one of us, maybe even you, one day.