

## Giving Back

By Todd Wenzel, Golf Course Superintendent, Riverview Country Club

My cell phone rang in my pocket just like it does any number of times every day. I don't recall if I took it out to look at the caller ID or if I just let it go to voicemail. When I did check to see who had called, it was the familiar contact info for the Community Blood Center of Appleton. I assumed it was another reminder call that I was eligible to donate blood. As I listened to the voicemail I realized this was not the typical reminder call. The voice was telling me that I was a preliminary match to

be a bone marrow donor for a leukemia patient. It was a phone call that would help to change someone's life. That day was July 6, 2011.

Leukemia has affected both my mother's and father's families by claiming an uncle of mine on both sides of my family. It was the passing of an uncle in my mother's family in 1994 that spurred me to be registered on the National Bone Marrow Registry, now called Be The Match. I had been a somewhat regular blood donor prior to that time

and I knew of the existence of the registry. My uncle was fortunate to receive a bone marrow transplant from an anonymous donor but he later succumb to secondary infections as a result of the transplant. By learning more about the registry and the processes involved in transplants, my choice to join the registry became a simple one.

When I joined the list several tubes of blood were taken to do tissue typing. Today, a cheek swab is taken to collect the cells necessary to do the tissue typing. Specific antigens in the blood of the patient and donor need to match for a transplant to be successful. Up to 10 different antigens are matched when selecting a donor for a needy patient. Ethnic heritage is a large factor in determining a match. Most patients will match someone that has a very similar ethnic or racial background.

Each year in the United States, more than 10,000 patients are diagnosed with leukemia or another type of life-threatening blood disease. The best potential match will typically come from a close family member. Only 30 percent of patients needing a transplant have a family member match. The other 70 percent are placed on the National Marrow Donor Program (NMDP) registry to hopefully find a match. In 2010, the NMDP matched over 5,200 patients with the donor they needed. Depending on the specific disease being treated, the patient's doctor will request either bone marrow or blood stem cells. Blood stem cells are requested 75 percent of the time with bone marrow donations becoming less common. Peripheral blood stem cell donation (PBSC) is a process where stem cells are collected from the donor's blood through the process of apheresis. Blood is drawn from the donor and passed through a blood separator machine. Blood is spun in a centrifuge where the stem cells are separated out and the remaining components are returned to the donor. This is the process that I would undergo to donate peripheral blood stem cells to a 49 year old male suffering from chronic lymphocytic leukemia.



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During the fifteen years since I had joined the registry, I had been called twice as a preliminary match to be a donor. The first time I had been called two tubes of blood were drawn to do additional tissue testing. Neither of these times did I go beyond being only a preliminary match. After the July 6th call from the Community Blood Center (CBC), I quickly returned the call and we scheduled a July 11th appointment for a blood draw for more testing. On July 8th, the CBC called again to tell me that because of the additional blood I had given several years before, the NMDP had been able to do more testing and found that I was a perfect match with 10 out of 10 antigens matching between me and the patient. Things quickly progressed from there. At the July 11th appointment several tubes of blood were drawn to begin testing my health and to continue testing the compatibility between my cells and the patient's. I was also informed that the transplant center had requested August 30th as my date for donation and that they wanted to do a PBSC procedure. Hearing a specific date mentioned reinforced how very real this situation was.

During this first week my head spun with questions, concerns and feelings of excitement and trepidation. Would I be healthy enough to donate? What are the risks and side effects? The whole reason I joined the registry was so I could donate if I was ever called. I knew for certain I would go forward with the process if I could. At each step towards donation, every donor is free to stop the process if they decide not to donate.

On July 13th I received all of the necessary information regarding my donation from the Blood Center of Wisconsin in Milwaukee (BCW), the Be The Match facilitator in Wisconsin. This included all of the consent forms needed for donation and information about the donation process from start to finish. In addition to giving consent for the donation, I was asked if I would be willing to participate in a clinical trial for the drug Filgrastim, the drug used to prepare donors for the PBSC process, as well as donating a blood sample for research and storage with the NMDP Research Sample Repository and the Center for International Blood and Mar-

row Transplant Research. Both of these optional programs will help researchers better understand what makes transplants successful and how to best use the drug Filgrastim in preparation for PBSC donation. I consented to the optional trials in the hope that my sample and my experience with the drug can add a small part to the ongoing research.

On July 18th I traveled to Milwaukee for a complete physical, health history, a chest X-ray and another blood draw to ensure I was healthy enough to donate and that

***I knew that my discomfort and pain were no comparison to the life altering condition the patient must have been going through.***

I did not have any underlying issues that could harm me or the recipient. Within a week all of these tests came back normal and I was physically cleared to donate. Another blood draw took place on August 8th at the CBC in Appleton where 11 tubes of blood were taken. In my estimate, I had over 40 tubes of blood drawn during the entire pre-donation process.

Peripheral blood stem cells contain the same blood-forming cells as those found in bone marrow. In order to harvest enough of these cells for transplantation, more of these cells need to be moved from the bone marrow and into the bloodstream. The best method currently available for doing this is through a regimen of Filgrastim injections for five days prior to donation. Filgrastim is primarily used to increase the levels of healthy blood cells in cancer patients. The use of Filgrastim for PBSC donations is still a relatively new procedure. This use of Filgrastim is under a clinical research study under the guidance of the FDA. The most common side effects of these injections are bone pain, headaches and fatigue.

My series of Filgrastim injections began on August 26th. Each day involves three injections, two in one arm and one in the other arm. The shot itself was surprisingly painful with a very intense burning

sensation as the drug was injected. After a short period of observation for allergic reactions I was on my way home and the countdown to my donation was underway. Approximately four hours after the injections I began to notice side effects. The most obvious was a dull headache coupled with pressure in my sternum. Tylenol is the recommended pain reliever for these side effects and I found it to work fairly well. The side effects began to subside about twelve to fourteen hours after the injections. This timeframe for side effects

would tend to be the schedule for the following three days. After the second day's injections I began to experience bone pain. This pain is typically felt in the pelvis, hips, lower back and legs. These bones are where the majority of our marrow is found and it is from these bones where the stem cells were being moved into the bloodstream. I felt the most pain in my hips and pelvis with some radiating pain into my legs. It is generally difficult to describe pain, but I would relate it to what are called "growing pains" in adolescence. The pain was the most intense for four to six hours and made it very difficult to find a comfortable position to rest in. It did not matter whether I was lying down or sitting or standing, every position was painful. These continued on days three and four of the injections. The pain became greater and occurred in more areas each day. I knew that the pain would come to end after the injections and donation were finished. I knew that my discomfort and pain were no comparison to the life-altering condition that the patient must have been going through. I knew that it would all be worth it in the end.

On the day before my donation, I received my Filgrastim injections and we made the trip to Milwaukee to stay overnight and to be ready for my 7 AM donation appointment. As had been the case during the previous days, my bone pain and discomfort had become more intense. Throughout the evening the pain increased and spread throughout my back, hips and legs. Lying on the couch in the hotel room with my legs elevated seemed to be the only somewhat comfortable position to rest in.

## MISCELLANY

The pain lasted through the night this time and I had a difficult time sleeping. We arrived at the BCW at 7:00 AM and were met by the nurse that would be doing the procedure. After more consent forms and one final blood draw for immediate testing, I received my last set of Filgrastim injections. The waiting time after the last injection and before the donation could begin was one hour. The donation itself was expected to take between four and six hours. Once the donation began, I would be in the chair from start to finish. There are no options for stopping the donation for any breaks. After 45 minutes had passed, it was time to get in the donation chair and begin preparing so the donation could begin in another 15 minutes. I lay down in the chair at 8:30 AM.

To the left of my chair was the separator machine. It would be instantly recognizable to anyone that is a regular blood or plasma donor. Hanging above the machine were several bags of fluids and one empty bag that would collect my stem cells. There was an IV that would only be

used if necessary, as well as a bag of blood thinner and anti-coagulant that would be injected into my body along with the remaining components of my blood. The blood thinner and anti-coagulant would prevent the stem cells from "sticking" in my bloodstream and allow them to be harvested.

The amount of cells to be collected is based on the size of the patient. 363 cc, or just over 12 ounces, was the amount that would be drawn from me. The rate of the draw is based on the size of the donor. After some quick calculations based on my height and weight, it was determined it would take 4 hours and 2 minutes to reach the 363 cc goal. A needle was placed in each of my arms in the same way and in the same areas as would be done for donating blood. After a short delay because of a problem with the needle in my left arm, the procedure began just after 9:00 AM. Within a few minutes, the collection bag began to fill with the orange/red colored fluid that was the mixed stem cells and platelets. Due to the way that the

blood is spun and how similar stem cells and platelets are, it is not possible to completely separate the two during the collection. If the transplant center feels it is necessary, the combination could be spun again to attempt to separate the stem cells for implantation.

The next four hours would pass by rather uneventfully. The chair was reclined and comfortable, we had a TV to watch, and there was a refreshment area just outside of the room. Other than having to keep my arms straight and not being able to switch positions, it was a rather simple process. A nurse from the BCW was in the room with me at all times to monitor the process. My girlfriend Laura, who I could not have made it through the entire process without, was also at my side the entire time.

During the last two hours I did begin to feel weak and tired, a combination of the Filgrastim injections that morning as well as the donation itself. The bag continued to fill and the counter slowly clicked its way closer to 363 cc.

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When we reached the required amount, the system was slowly stopped and the needles were removed. I stayed in the chair for about fifteen minutes afterwards to gain some strength before leaving. We spent about thirty minutes in the recovery room with the representative from the BCW going over the post-donation protocol. During this time my donation was being prepared for transport to the transplant center. Due to privacy laws, we were not allowed to know anything about the patient other than his age and condition. The BCW would tell us that the transplant center where his transplant would take place was in the United States. We also learned that recipient was already prepped for the transplant and that it would likely take place early the next morning. About an hour after my donation was complete, we were on our way home and the cooler containing my bag of stem cells was on its way to the airport with a medical courier.

My recovery from the donation was a typical one. I slowly regained my strength and energy over the first two days. I did not go to work the day after the donation but I did feel up to it on the second day afterwards. I felt weak but I could tell my energy was quickly returning. The descriptive term of the day would have been "slow". Everything took a little longer to complete and I needed frequent breaks during the days after. At my one week checkup after the donation I felt I was at about 80%. I would still have a few episodes every day of sudden weakness or dizziness. Most of these would pass in less than a minute. At two weeks I felt I was completely back to normal. The only lasting evidence of my donation was a large hematoma that developed along the length of my left arm because of the problem with the needle in that arm during the preparation for my donation. Most PBSC donors report feeling completely recovered after two weeks. I will continue to have periodic checkups by phone up to one year after the donation, then once yearly for years to come. My responses will be added to the results of all other donors to continue to help researchers better understand the entire donation process.

The days and weeks after the donation left me with a strange feeling. After all of the prep work and appointments that led up to my donation, the finality of it left me feeling almost let down and empty. I knew what I had done was very important



Todd Wenzel relaxing during the 4 hour draw. Todd was the Superintendent at Riverview Country Club in Appleton until December 20th, when the club closed after 114 seasons of golf. He had been the longtime assistant for his father, Tom, at Ridgeway Country Club in Neenah.

but the suddenness of it and the resulting necessary lack of information felt strange. I wanted to know more about the recipient, about his illness, and his progress. Federal laws prohibit any contact between

a donor and recipient during the year after transplant. After one year written contact is allowed and, if both parties agree, open and personal contact can occur. If either of the parties is not from the United States things become more complicated. Many countries, especially European countries, forever prohibit any contact or divulging of any information among a donor and recipient.

During the first week of December I received my first limited update on the recipient. My donation recipient is alive and doing well and is out of the hospital. Unfortunately, the donation has not fully engrafted in him. This means that my cells have not fully taken hold and are not reproducing in the way that they should. This is a common problem early in the post donation recovery period. Having made it to three months is a good sign and hopefully we receive more news in another three months.

My desire to write this article and to speak to anyone about my experience is to raise the awareness of the need for donors of marrow, stem cells, and whole blood. I have said all along that if my experience can help to inspire one new person to join the registry or become a blood donor, then my experience would be worth it. I encourage all of you to consider joining or donating to the donor registry by visiting [www.marrow.org](http://www.marrow.org). You could help change someone's life today. ✓

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