

## Stem Cell Transplantation: What Happens Behind the Scenes?

Allogeneic stem cell transplantation is a complex process involving transferring stem cells from a fully or partially matched donor to a patient who has received chemotherapy and/or radiation in preparation for the transplant. But what are the earlier steps involved in searching for a suitable donor, and once located, how does the entire process move forward? Find out more about what happens behind the scenes before any stem cell transplant occurs.

### Q What are your main job responsibilities?

A In my current position I do the donor searches for patients whose family members are not a match. I review the patient's HLA typing, enter that data into the National Marrow Donor Program (Be the Match®) registry and from this, I can identify unrelated matched donors or cord blood units for the recipient. Here at NIH, I work with other transplant coordinators, research nurses and research teams.

My current job is just a part of what many transplant coordinators do, but I have held those roles at Georgetown and University of California, San Diego. Many transplant coordinators take a patient all the way from first referral for a stem cell transplant right through the transplant itself. They're the touchpoint for the whole transplant team through the entire process.

Still, at any hospital a transplant coordinator may have somewhat different roles depending on the institution. At some, they may be doing what I do in addition to other things, which can go all the way through following the patients post-transplant.

### Q At what point does a transplant coordinator become involved in the process?

A They're involved right from the time a patient is referred for a transplant, so they are often the first person a patient actually meets. They contact the referring physician to get all the records and required information for screening. Screening is just what's



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Jennifer Wilder has worked in the stem cell transplant field since she became a nurse in 1999. She currently

performs unrelated donor searches for patients undergoing transplant on clinical trials at the NIH.

required to be sure a referred patient actually is a good candidate for transplant. They'll ask about family members to see who might be a possible donor, identify roadblocks that might make getting a transplant difficult for a patient. This all happens within a few days of a patient being referred.

Stem cell transplant coordinators get the HLA typing completed, send testing kits out to family members, and run searches to see if the patient has unrelated donors. After the screening visit, patients are usually back home getting their routine therapy, so coordinators follow up with the patient after their initial visit to keep them informed and get more information from them. The transplant coordinator has to keep up with what kind of treatment patients are getting back home to keep up to date with the patient's treatment and current condition. This information is all needed to help plan things that will be happening later.

The coordinator is constantly gathering all sorts of information to help the transplant team make decisions, including what to do if an optimal match is not located. It is important to follow treatment patients receive outside transplant process. For example if it's an MDS patient on azacitidine (Vidaza®) you need to know the treatment schedule and what the side effects might occur, while the search for a donor is in process. But much of this depends on the type of match that is located.

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### Q What internal (including the transplant team) and external personnel does the transplant coordinator interact with?

A Getting a patient to and through a transplant is not a one man show. It's the definition of team effort – they'd be working the whole time with every team member involved, for example, the finance department with regard to insurance, the HLA and typing laboratories, the apheresis center when related donors are involved, radiology, molecular hematology, and so much more. It's sometimes overlooked that transplants can affect every organ and system in the body so everything has to be examined and monitored. They will connect the patient with resources to help them get to and through transplant – like social work, nutrition, and counseling.

### Q What are the main steps of the entire process?

A The first phase covers the initial referral and screening. Here, the team gathers information about a patient, and the first decision that has to be made is whether the risk of transplant is less than the risk of no transplant. For patients who need a transplant from a donor, this is the time when we gather information about their relatives and do an initial search to see if they have potential matches in the unrelated donor registry, called Be The Match®.

We use HLA typing – human leukocyte antigen typing – to match donors. HLA is the part of your immune system that recognizes whether cells it sees in your body belong or not. Many people don't have a sibling match, so we look in the Be The Match® registry. The registry is anonymous – I can't see the donor's names, just their HLA typing. And the donors don't know the name of the recipient. In addition to HLA, we also consider the age, health, and other factors about the donors.

The second phase could be called the pre-transplant phase, where we narrow down the donor selection, then schedule the donor's workup and collection. We are usually working up the patient at the same time to make sure that their organs and disease status are good enough to move forward to transplant.

This is when teamwork becomes really critical – there are many people involved in getting a patient screened, a donor cleared, and getting all of the pieces onto the calendar to have the transplant happen on the day we want. Depending on circumstances, this part can take 3-6 weeks. Some of the things that can go wrong during this phase are having problems identified in the patient or donor screening that are unexpected, patients who become ill, or insurance approval problems.

The third phase would be the transplant itself. By this time, the coordinator's job is nearly done, but the

patient's journey is really just beginning. The patient is usually admitted for conditioning chemotherapy and the stem cells are infused after a few days of chemotherapy. In some institutions, the transplant coordinator follows the patient even after discharge, but many places also have a separate team that follows patients in the hospital, and then after they are discharged.

### Q Has progress in stem cell transplantation changed the job of the transplant coordinator?

A It absolutely has. The biggest changes are with the increased successes in transplanting older patients, the ability to predict donor searches, and increased safety using half-matched (haploidentical) transplants. This means there are more eligible patients and more transplants occurring all the time. Although the age for transplant candidates has gone up, still a lower donor age makes a big difference – the younger the better.

With more accurate HLA typing and improved bioinformatic systems, you can really tell almost right way if you are going to find an unrelated donor. In my 15 years doing this, this is biggest change. The search can go very quickly. When I started, I could spend months searching for donors before a decision was made about what to do.

Once I have the HLA typing, I can tell almost right way if there's a complete match or if we're going to have to look at other options like haploidentical relatives, mismatched unrelated donors, or umbilical cord blood. Having this information up front will help patients since the wait to get to the actual transplant is much shorter. This is especially good for MDS patients who might progress to AML as more time goes by.

### Q Tell us about your own role as a donor – did this inform your professional life?

A I have donated twice – once was stem cells for a patient with leukemia, and I donated my baby's umbilical cord blood to a public cord blood bank. When you do what I do – eat, sleep and breathe transplant, being a donor is incredibly meaningful for professional and personal reasons.

But the fact is under one percent of donors in the registry are actually called to donate.

Whether you work in transplant or not, becoming a donor is easy and if you get called, it will be the coolest thing you've ever done.

I always feel better about the world when I think about the 30 million people out there who have joined the registry to donate their stem cells if ever called.

I really like what I do – you get to see all the parts of a truly complex process, but you really are part of a large team of people who have the same goal. ■

## I Connected With Other MDS Patients on Social Media

**Dr. Jane Biehl**



I sat quietly in the oncologist's office. The doctor confirmed that my diagnosis was MDS and calmly stated, "The average survival term for your kind of MDS is 104 months." I felt the room spin.

I never have been healthy, and suffered from upper respiratory infections all my life. Kidney and bladder infections plagued me all through college, and I have had a severe hearing loss since birth.

In spite of these challenges, I was a consistent overachiever. I earned a master's in library science and was a librarian for 19 years. In my 40's, I went back to earn another master's in rehabilitation counseling plus a doctorate in counseling and human development services. I was a counselor for fifteen more years and I taught at three different colleges.

My life in 2010 was very full. I was slowly adjusting to the loss of my mother 18 months prior. I had obtained a gorgeous yellow lab, Sita, as my hearing ear service dog and we had wonderful adventures together. I had retired with a state pension and was working two part time jobs I loved. One was a counselor in private practice working with children with language and hearing problems, and the other one was teaching at a community college.

The only health problem I was suffering was anemia, and out of caution my family practitioner had referred me to join an oncologist.

I had a bone marrow biopsy and was diagnosed with deletion 5q subtype (del 5q) of myelodysplastic syndrome (MDS). I received alfa epoetin (Procrit®) shots for eight weeks because my white blood cell count was so low. I started a regimen of an oral lenalidomide, (Revlimid®). My oncologist then dismissed me without answering any questions or helping me at all. I left the office in tears and resolved to get another doctor. I knew that my life was going to change drastically, but never comprehended how much.

I switched to another oncologist at the Aultman Cancer Center who was much better than my first. My white blood cell counts increased from injections and I continued taking lenalidomide.

I was naïve in thinking lenalidomide would not have side effects because it was oral administration instead of IV. Little by little, the doctor helped me through the side

effects, including the diarrhea, nausea and problems with my balance. What I was totally unprepared for was the fatigue. There is no way to explain this kind of fatigue. It is more than being tired because it is constant and never goes away. This forced me to quit my job at the private practice, but I continued to teach.

Also my hearing loss dropped drastically, from the severe to profound range. As I researched more, I discovered that lenalidomide is a derivative of a thalidomide drug. These drugs are called "ototoxic", meaning poison to the ears.

My new oncologist referred me to Case Western Seidman Medical Center for a second opinion, but they felt the doctor I had (who had trained there) was all I needed. They additionally suggested the bone marrow transplant option.

Later, I went to the Ohio State Walker Center to see if there were any treatments with less side effects than what I had with lenalidomide. They suggested clinical trials, but as it turned out there were no clinical trials I was eligible for -- and I was hesitant to take that step until I knew how I would do on other drug regimens I had not yet tried.

I had bone marrow biopsies every six months, and finally the news came that I was getting worse. A bone marrow biopsy confirmed our fears, as my blast count exceeded 5%. But my doctor stated that I was still far from progressing to leukemia. She took me off lenalidomide, for a new drug, azacitidine (Vidaza®).

This adjustment to azacitidine was a nightmare as I experienced more diarrhea, fever, pain and swelling at the injection sites. I also developed esophagitis with ulcerations. Muscle aches are common side effects. But I stuck it out and slowly my situation improved!

Today, I am still on azacitidine. I have learned there are more new clinical trials out there for MDS which are working for other patients. I am now approaching the survival benchmark mentioned by the first doctor, but am determined to beat it.

My treatment facility, Aultman Medical Center, has outstanding physicians, oncology nurses and staff. I did not personally know one other person who has this disease. Now, I find through social media that there are many others.

I feel sad when people ask me when I will be done with treatment, and I tell them never. The changes in my life have all impacted me severely, but I have met so many incredible people through my MDS journey from my wonderful doctor, to the caring oncology nurses and staff, to other courageous patients. ■



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