

Dear Friends and Family:

You may have heard from Karen or me, during the chemo phase of this journey through MDS, that the Dacogen will work "until it quits working." After 7 complete rounds of the medicine, and after my blood counts plateaued in May, the trends have been slowly, but steadily marching downward, which is an indication that the therapy is no longer as effective. From the start, we were aware that a stem cell transplant (SCT) was a probability...some day...and that day is arriving sooner than later. After considering all the options, and on the advice of Dr. V. (transplant specialist,) we began a 2 week period of various tests which would be a major determining factor of being a candidate for the Allogeneic Stem Cell Transplantation treatment. It started with another bone marrow biopsy, my seventh, which I barely remember thanks to that wonderful "feel good" medicine, proceeded to 24 separate blood samples, a chest x-ray, a heart echo cardiogram, a lung function test, and a kidney test.

Tuesday, we went to Dallas for more consultations. Dr. V patiently and professionally explained the results of my work-up tests, all of which I passed, with exception of the kidney function, which was just out of the range of normal, but was not a deal killer. Oops...poor word choice...how about...it was not of major concern to Dr. V. (yes, I like that wording better). Other than this pesky problem of my bone marrow not making enough blood cells, I'm a picture of health. At the end of the consult, the transplant coordinator went over the timeline calendar and produced the official version of the "Disclosure and Consent for High-Dose Chemotherapy with Allogeneic Stem Cell Transplantation" form, which with other necessary forms, was written on enough paper to decimate a small forest. The very first page began with this sentence in italics: *"This disclosure is not meant to scare or alarm you..."*, and then, while reading on, I noticed that all the parts that supposedly were not "meant to scare or alarm," coincidentally **were written Bold face type**. Just imagine a script written for any medicine advertised on the evening news, and you'll get the picture. However, I signed and dated each place indicated, and by doing so I became a qualified UTSW stem cell transplant recipient... fully entitled to all rights and privileges thereof!

A modern day SCT of this type is a highly choreographed procedure, involving many skilled persons, but the key link is between me and my donor. Ironically, I signed up to be a donor at the Wild West 100 Bike Ride in 2014. Little did I know then, that I would be a recipient, and not a donor. Here's the link, if you'd like to have more information: [Be The Match Foundation](#). Thanks to BTM searching a database of around 22 million potentials, we found a perfect donor for me. We know these things about him: he is a 28 year old Canadian male with my blood type, he weighs about 155 pounds, he is a perfect 10 out of 10 genetic match, he has an intact immune system, and has previous exposure to similar viruses as I have. In addition, we have a bonus marker, which is considered a "permissive mis-match." That means something good to a really smart genetics scientist, but to me, it just means that he probably rides a Harley, and I ride a bicycle. Genetics for dummies. Karen and I have nick-named him "Dudley Do-right," since he's a Royal Canadian Mountie, and always appears just in time, shouting his familiar line to someone in distress—"Don't worry...*!//* save you!"



Here's a very simplified scenario of how my SCT will work. We will check into the hospital next Tuesday, August 28th. During the first week, while I am being given 2 different types of high-dose chemotherapy that will completely kill my bone marrow stem cells (and hopefully not me), Dudley in Canada will be given 3 daily injections to (hopefully) boost his immune system. The day before transplant, they will hook him to a machine that extracts his stem cells, and then those cells are given to a courier, who personally flies to Dallas from Canada and hand-delivers them to the blood bank for further processing. The next day, they will infuse me with Dudley's stem cells. That day is designated "Day Zero" which will be my "third" birthday—the first when I was born, the second when I was born again, and the third will be when I'm born born again. Three and four days after the transplant are 2 more rounds of chemo, and is a critical time when I'm both most vulnerable, because I will have no natural protection from various infections, and it will feel like having an amped up case of the flu which could last to day +15. Part of that sickness is from the effects of the chemo and part is due to the fact that Dudley's stem cells are making a new immune system that doesn't particularly like a body with a Texas accent; they are trying to "reject" me, so I will be taking anti-rejection medicines for a while. Best case is we are discharged from the hospital 20 days after the transplant, and then Karen and I will live in an apartment close to the clinic for another 2 months, so the recovery can be closely monitored. Whew.....well, it's actually way more complicated than that, but I left out the **BOLD type** parts of the Consent Form, because the world doesn't need any more scared or alarmed people.

Just thinking about the Journey up until now, and the complexities going forward, there are so many things completely out of our control. We are learning to stretch our faith and trust muscles to garner greater portions of strength and peace from the Lord. As we know that many of you who know us best, are praying for a miracle, I sit in true awe and reverence of God's sovereignty, provision, timing and purposes. I think about how in God's plan...28 years ago, somewhere else in the world, a baby boy was born who was so perfectly formed and matched to another person, even down to 11 incredibly complex specific molecules. I think about how God gave "scary smart" men and women the talents and abilities to use modern science and technology to bring those specific two people together at just the right time. I think about one day one of them made the choice to give the life and vitality in his very blood—to save the life of another person he'd never met. To me, all these things and more, are miracles.

The parallel between the sacrifice of Jesus on the cross, whose blood gives life to those who are spiritually dead, and Dudley giving his blood to me to save my physical life, has not gone un-noticed. Karen and I are living in a real-life-flesh-and-blood (literally) exhibition of the three things I believe God gave us at the beginning of this walk of building faith and trust. Karen and I have truly been "given a privilege"—by navigating through the maze of MDS to "watch Him work," and have been, and (hopefully) will continually be given "opportunities" to tell others of the joy of daily living an abundant life in the midst of hardship. Someday we might have the opportunity to tell "Dudley" in person how grateful we are for his gift, but in the meantime, thanks to you all, for your continued prayers and encouragements, since we will likely be facing some serious headwinds over the next few months. Each of you, for many various reasons, have made a difference to Karen and me, and we want you to know that truly you are loved and appreciated.

Remember....Greater love has no man than this: to lay down one's life for his friends,

Joe & Karen