

FAQs ABOUT STEM CELL TRANSPLANTS

from David Liebman

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Folks

Most of you are aware by now of Michael Brecker's situation. The first e mail that went out asking for blood donation has been corrected and includes info that you should know. Please refer to this for any action you want to take.

We are all praying for him; he is aware of this and thanks everyone. At this point he is doing ok having finished one round of chemo.

Peace

Lieb

Susan Brecker's heartfelt plea elicited an outpouring of support for Michael—and an outpouring of questions. As there is outdated and conflicting information on the web concerning the stem cell transplant process that can assist Michael and so many others, we assembled a list of frequently asked questions—a hybrid of material found throughout the web in addition to new information. Before contacting Michael's management office with your questions, please review the following. Thank you for your support.

Q01: What is a bone marrow or blood stem cell transplant?

A: It's a potentially life-saving treatment for patients with MDS, leukemia, lymphoma, and other blood diseases. The transplanted healthy stem cells from a donor replace a patient's unhealthy blood cells that have been destroyed by chemotherapy.

Q02: Are these the same stem cells about which there exists so much controversy?

A: No. Those are *embryonic* stem cells---which are completely undifferentiated. Donors would be providing *blood* stem cells where the extent of differentiation is only the specific type of blood cell that will form.

Q03: Does my blood type matter?

A: Not at all. The testing is for genotype (tissue type) and not blood type.

Q04: Who can be tested?

A: Donors must be between the ages of 18 and 60, in good general health and be free of chronic diseases. For example, volunteers with serious asthma, Hepatitis B or C or most forms of cancer (regardless of whether in remission) cannot be accepted.

Q05: What is the procedure?

A: Testing only takes a couple of minutes and, at worse, is as painless as giving blood. Blood is drawn for testing and a consent form is filled out. In some instances, a buccal swab (a sterile Q-tip which is rubbed along the wall of your inner cheek to collect cells) is used.

Q06: Does a person's race or ethnicity affect matching?

A: Because tissue type is inherited, patients are most likely to match someone of their same race and ethnicity. There is a special need to recruit more donors who are, for example, African Americans, Native Americans, European Jews, Armenians, Hawaiians, Pacific Islanders, Asians, Hispanics and Latinos. The reason why there are greater number of donors needed for these groups is as a result of either purges of the population (genocide, etc.) and/or relatively few people in the group in the international registry. A match for Michael would be most likely come from those of Eastern European Jewish descent.

Q07: Where do I go to get tested?

A: Contact the NY Blood Bank [212-570-3441 / 310 East 67th Street] and make an appointment for HLA typing. If you're not in NY, go to www.marrows.org or call 1-800-MARROW-2 to find the donor center nearest you. Marrow.org will assist donors who wish to join the national registry. We hope that you will join the national registry, however, if you do not wish to join the registry [see Q13] or it's difficult to make it to a blood center, private kits are available from Tepnel Life Codes [800-915-3695]. Order the "HLA [A][B][DR]" kit for \$140. You will need to have a small vial of blood drawn. Indicate to Tepnel that your test is for "Michael Brecker" and they will know to whom to forward your results.

Q08: How much is the testing and who pays for it?

A: The test generally cost \$40 to \$95 depending on the donor center and the laboratory that completes the test. Testing at the New York Blood Center is just \$40. However, if you're African American, Hispanic, Native American or Asian testing is free at *any* donor center that's part of the National Marrow Donor Program network [800-MARROW-2]. More than 100 centers throughout the country—including the New York Blood Center are part of the network. Following the initial testing, all medical expenses are paid for by the patient or the patient's insurance.

Q09: What is the test for?

A: The test is to determine whether a tissue-type match exists between the donor and the patient. More specifically, potential donors [and the patient] are given an HLA or Human Leukocyte Antigen test. Antigens are found on the surface of infection-fighting white blood cells (leukocytes). A match between specific donor and recipient antigens is critical to having a successful transplant (i.e., where the two immune systems will not go to war with one another). Should you see your HLA results, the numbers indicated are the identifying gene-pair markers (alleles) that are responsible for your "A" antigen, for example, to be different than someone else's "A" antigen. In the fortuitous event you're deemed a good match after three specific antigens are compared, you will be asked for a second blood test.

Q10: What are the chances of my being selected?

A: As you might imagine, given the number of genes that need to match, the overall chances are quite low...but the more people tested, the more likely there will be a perfect match awaiting everyone.

Q11: Has Michael's family been tested?

A: Yes, both his siblings and children---none match. There is also a rumor afloat [04AUG] that a match has been found for Michael....regrettably, this is inaccurate.

Q12: How are patients actually matched with donors?

A: The results of blood samples from donors or umbilical cord blood units [see Q17]

are added to different registries. The registries are then searched for a donor whose tissue type matches that of their patient.

Q13: Can I be tested to be a donor only for Michael?

A: Yes, but on behalf of Michael, we hope that you would not embrace this alternative. Explains Michael, “I hope to encourage as many people as possible to get tested not just to assist me, but to help thousands of others who are either facing or who will be facing the same challenge with which I’m now confronted.”

Should you nonetheless wish to make a donation only for Michael, private kits are available from Tepnel Life Codes [see Q07].

Q14: Is there a difference between a bone marrow transplant and blood stem cell transplant?

A: Yes...and no. As a result of new technologies, the term “bone marrow transplant” is in part a misnomer. In earlier years marrow *had* be extracted from a donor’s marrow. Today at leading cancer centers like Memorial Sloan Kettering, the collecting process rarely occurs this way. A donor is simply connected to a machine through an IV that separates and harvests the blood stem cells from the donor’s blood before the blood returns to the donor through a second IV. Instead of being tethered to a machine for a few hours, some folks still prefer direct marrow collection---where medical technology has also improved. Following anesthesia, marrow---which continually replenishes every 4-6 weeks---is withdrawn using fine hollow needles in the hip. A sore bottom may result for a few days. In short, whatever the brief discomfort of whichever method that’s used—it’s nothing compared to the virtue and humanity of potentially saving a life.

Q15: Can I take my name off the donor registry at any time?

A: Yes, being on the registry just means that you may be asked to be a donor. It is *strongly* preferred, however, that you remove your name from the registry if you feel you may be disinclined to be a donor. Nothing may be as heartbreaking as someone having to learn that there exists a perfect match to save the life of a loved one...and the donor changed their mind about being a donor. Being a donor is not deleterious to your health. While we hope that you become a donor, please do not add your name to any donor registry if you’re not prepared to step-up when the opportunity presents itself.

Q16: If I am a match, who pays for the necessary procedures?

A: If you are a match, the patient's insurance pays for the entire procedure---there is no cost to you. This includes the cost of the physical you will receive to ensure that you're in good health.

Q17: I've heard about "cord donations" and stem cells from umbilical cords—what's that?

If you or anyone you know is having a child, inform the obstetrician that you would like the umbilical cord to be delivered to a cord blood bank where it is tested and where the blood stem cells are frozen for future use in the event of a match. The collection does not pose any health risk to the mother or baby and does not affect the birth process in any way. The cord would otherwise simply be disposed of.

For further information on donating umbilical cord donations:

<http://www.nationalcordbloodprogram.org>

For ordering a private HLA kit:

http://www.bonemarrowtest.com/getting_tested/pricing_kit_ordering/index.asp

For further information on whether you qualify as a donor:

http://www.marow.org/HELP/marrow_eligibility_guidelines.html

For learning where to get tested at a National Marrow Donor Program blood center:

http://www.marow.org/cgi-bin/NETWORK/map.pl?ctr_typ=DC