

AHEPA Bone Marrow Registry Makes Progress; Needs More Donors

By: Maria A. Karamitsos

CHICAGO --- Back in 2006, AHEPA answered the call to help identify a bone marrow donor for the late Steve Pappas. That year, the first annual AHEPA Marrow Team Pappas Donor Campaign took place, and 35 donor drives were organized. Many volunteers joined the effort. Unfortunately, Pappas past away before a donor was found, however, AHEPA keeps fighting the fight for future patients in need of transplant. The 2nd annual campaign consisted of 22 drives. Recently the 3rd annual campaign drew more than 2,114 new donors from 65 drives.

Fueled by interest in the fight to save Joanna, a 26-year old fighting Hodgkin's Lymphoma, the group was very pleased with this year's result. A perfect match was found for Joanna and a transplant will take place next month. The AHEPA Bone Marrow Donor Registry will continue to host drives and solicit donors to build its database. Hellenic Americans are severely underrepresented in the national and international registries. The statistics are astounding: the probability for a typical Greek American finding a match within the registry is 1 in 25,000. For some individuals with rare HLA genetic types it can be a staggering statistic of 1 in 12 million. "We encourage everyone to be proactive, get tested, and join the registry," said Dr. John Venetos, Chairman of the AHEPA Bone Marrow Registry. "We're committed to growing the registry to 25,000 to 30,000 donors, if not higher "It took 20 years to reach the 7,000 donor count, and in the last two years with everyone's support, we have already doubled the size of the registry to an impressive 14,851 donors."

The technology is advancing, and getting tested, and actually donating marrow, is easier and simpler than ever. In the past, a blood sample was taken from a potential donor. Today, they utilize the Oral Swab Buccal test, which is less invasive and more acceptable. Essentially, a Q-tip-like device is used to

swab inside one's cheek to collect a sample. Further, they have upgraded testing to include six HLA antigens (A, B, DR), which provides more useful information for the databank, which results in better, quicker, more focused and more efficient searches.

Extracting the marrow for transplant is basically effortless. In the past, the procedure was done under general anesthesia, and involved an extraction of marrow from one's hip, leaving the donor sore for several days. Today, the procedure is not only simpler, but also virtually pain-free. Now, two-thirds of all donors make their donation through a process called Apheresis. Under this new process, the donor is given medication to stimulate marrow production, and the stem cells actually come out of the bone marrow into the peripheral blood. For today's transplant, the donor's arms are hooked up to a filter machine. The machine will extract blood from the right arm, filter out the stem cells, and send the blood back into the left arm. The entire process takes three-to-five hours. The stem cells are then frozen for transplant. "Once transplanted to the recipient, the cells can find their new home quicker and engraft. They quickly develop into platelets, white blood cells and red blood cells," explained Dr. Venetos. Of 3,500 transplants performed in 2007, 2100 were done with the new process. The newer, easier process, and also a face to relate to, like Pappas or Joanna, has helped to raise the number of registered donors.

Donors remain anonymous during the first year of the transplant. There is some information that the donor is informed of regarding how the recipient is doing, but they aren't allowed to contact each other. After one year, if donor and recipient mutually agree, they can be put in touch.

AHEPA is making major strides. In 2007, there were more than 7,500 patients who searched within AHEPA's registry. A match was found for a young boy suffering from Leukemia. Earlier this year, two more donors were matched from the databank, however, in both cases the transplants were not

performed; one patient became ill with further progression of her disease and was deemed no longer eligible for transplant, and in the other case, another similar genetic donor was selected. Also in 2007, 146 AHEPA donors were initially selected for further follow-up testing; Earlier this year, 80 AHEPA Donors were initially selected for further follow-up testing. Also in the early part of this year, drives were conducted for a young girl in NY. In four days, 1,742 new donors were added to the AHEPA registry at a cost of \$87,100. The numbers are quite impressive, but AHEPA refuses to rest on its laurels.

“The AHEPA Bone Marrow Registry continues to strengthen its registry, but has also developed a new affiliation with the National Marrow Donor Program (NMDP) this year,” added Dr. Venetos. “We signed an affiliation agreement with the NMDP allowing us to be an AHEPA Marrow Recruitment group for the NMDP. The leadership of the AHEPA Bone Marrow Registry secured this affiliation, which will allow our registry to recruit new donors, and use NMDP funding. This affiliation allowed us to fund and organize our Third Annual AHEPA Marrow Team Pappas Donor Drive event. The AHEPA Bone Marrow Registry now has 11,539 active donors, and they have recruited an additional 3,312 donors in the National Marrow Donor program, resulting in a grand total of 14,851 donors to search from.

AHEPA remains steadfast in their commitment to educate the community, plus increase awareness of the registry as well as the number of donors. In their annual report, they reiterated their pledge to find a potential marrow stem cell donor for any individual in need of a marrow transplant. Also, they remain committed to provide and assist in the search process for individuals in need of a marrow transplant by searching the AHEPA Bone Marrow Registry, the American Bone Marrow Registry as well as the Caitlin Raymond International Registry. Additionally, they’ll continue their fundraising efforts to finance the initial testing for donors.

Donations of umbilical cord and placentas following the birth of a baby provide another important source for stem cells. According to the Marrow Donor Program Web site at www.marrow.org, cord blood is rich in blood-forming cells that can be used in transplants for patients with leukemia, lymphoma and many other life-threatening blood diseases. After donation, cord blood units are stored and ready for use anytime, thus providing a quick transplant option. Cord blood is also helpful to those who have difficulty finding a donor match, as cord blood does not have to match a patient's tissue type as closely as donated bone marrow does. This is a great option for patients of underrepresented ethnicities or races in the donor pool. Currently, not enough is being done to preserve umbilical cords and placentas. AHEPA is working to increase public awareness as well as making the donating process more readily available at hospitals and easier to complete.

Many young adults got involved and volunteered for this year's drive and all have signed up as donors. The chairman and his team urge all Hellenic Americans to sign up for the registry. Our ethnic group is very underrepresented, and as we have seen so dramatically with Joanna, it only takes one person to save a life. For more information or to get tested today, call Dr. John Venetos 773.989.6262 or visit www.ahepamarrow.org.