

The following is our Ahepa Bone Marrow Donor Registry 2007-8 report that will be presented at the Order of Ahepa 2008 Athens National Convention.

Our enthusiasm, dedication, hard work and above all, teamwork, continue to bring us impressive achievements and gratification. The Ahepa Bone Marrow Donor Registry continues to strive to achieve the following goals:

- 1. Find a potential marrow stem cell donor for any individual in need of a marrow transplant.
- 2. 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.
- 3. Continue to increase the Ahepa Bone Marrow Donor Registry database (our current goal is to have 20,000 active donors), in order to improve the likelihood of finding donors for individuals in desperate need of a match.
- 4. Continue to increase the public's awareness of the desperate need to seek out donors for patients in need of a life saving transplant, by educating and sharing their inspiring stories.

- 5. Continue to raise funds in order to finance prior blood testing and future oral swab testing.
- 6. Continue to increase the public's awareness of umbilical cord blood donation.

The following are the most recent impressive achievements for the Ahepa Bone Marrow Donor Registry:

1. The Ahepa Bone Marrow Donor Registry has 11,539 active donors.

2. In 2007, there were more than 7,500 searches performed in our Ahepa Marrow Registry for patients worldwide in need of a life saving marrow transplant.

3. One of our Ahepa donors has successfully donated for a boy with acute leukemia.

- 4. Two other Ahepa donors were selected earlier this year, but in both cases, the transplant center has put the request on hold. In the first case, the transplant center decided to use a different donor, and in the second case the patient's condition unfortunately deteriorated, and so is no longer a candidate for transplant.
- 5. During 2007, there were 146 Ahepa Donors requested for further follow-up testing, of which 71 Ahepa Donors completed such testing.
- 6. During the first quarter of 2008, there were 80 Ahepa Donors requested for further follow-up testing, of which 36 Ahepa Donors completed such testing.

- 7. We have upgraded our testing to include the less invasive and more acceptable Oral Swab Buccal testing which is clearly preferred to the old blood sample test.
- 8. During the last two years, we have upgraded our testing to include 6 HLA antigens (A, B, DR), providing more useful information in the databank and arriving at better, quicker, more focused and efficient searches.

DRIVES: There were four Ahepa Marrow Drives in 2007. We also joined forces with the National Marrow Donor Program, and conducted our 2nd Annual Ahepa Marrow Team Pappas drives. These drives were conducted from May 11th through May 18th 2007, and included 22 drives, which resulted in the recruitment of 574 new donors.

Earlier in the year, a family in the St. Paul Hempstead, New York community contacted us. We conducted two large drives for a young girl suffering from acute Leukemia. On January 19th, 2008, we did a drive at St. Paul Cathedral, in Hempstead, New York, and were able to obtain 586 new donors. There was such a large turnout that we had the NMDP test an additional 526 donors, in which the Ahepa Marrow Registry picked up at an additional cost of \$24,652. Several days later, on January 21, 2008, we did another drive at Astoria, New York, and were able to obtain 630 new donors. In a matter of four days, the Ahepa Bone Marrow Donor Registry was able to test a total of 1,742 new donors with a cost of \$85,452.

During the month of March 2008, another family of a young lady, Joanna, from South Bend Indiana contacted us; the woman was diagnosed with Lymphoma and was in need of a marrow transplant. We performed our first drive for her during the NHIBT Basketball tournament in Oak Park, Illinois, and were able to obtain 50 new donors.

The Ahepa Bone Marrow Registry continues to strengthen its registry, but also develop a new affiliation with the National Marrow Donor Program this year. 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 the Ahepa Marrow registry to recruit new donors, and use NMDP Funding. This affiliation allowed us to organize our 3rd Annual Ahepa Marrow Team Pappas Marrow Drives by organizing and performing over 65 drives from May 5th through May 18th of this year. These drives are being conducted to find a life saving match and transplant for Joanna. We organized 33 drives, primarily performed in the Chicago-land area, but also included five drives in Indiana, seven drives in Michigan, three drives in Colorado, two drives in the following states: New York, North Carolina, Texas, Arizona, Ohio, Pennsylvania and one drive in Massachusetts, Florida, Connecticut, Minnesota, Nebraska, and California. These drives have recruited over 2,114 new donors

Although our Ahepa Bone Marrow Registry has 11,539 active donors, we have also recruited an additional 1,198 donors in the National Marrow Donor program. Our recent 3rd Annual Ahepa Marrow Team Pappas event (over 65 drives nationally) recruited an additional 2,114 donors through our national crusade. To date the continued and combined efforts of the Ahepa Marrow program has allowed us to recruit a total of 14,851 donors. Through these efforts of

increasing the donor pool, raising funds to continue doing drives and supporting desperate families who are truly overwhelmed by this burden, the Ahepa Marrow program gives every family and individual of Greek ethnicity a greater and fighting chance of finding a potential match. I would be remorseful if I did not thank all of our Ahepa Marrow Donor supporters and volunteers who spent countless hours helping, organizing, and participating in drives and promoting our cause. The Greek Orthodox Archdiocese of America, the Holy Metropolis of Chicago, the Ahepa Chapters and members, the daughter's of Penelope, the Greek Ladies Philoptochos Society, and the YAL

as well as all the priests and parishioners who supported our combined efforts. We are happy to announce that a 10 out of 10 match has been found for Joanna. Obviously all of our prayers and hard work have been answered. I want to personally thank everyone for participating in this year's 3rd Annual Ahepa Marrow Team Pappas event. We were able to conduct over 65 drives and have recruited over 2,114 donors in two weeks. Although some of you were disappointed because you might have only recruited a few donors, others had over 100. Every drive is equally successful whether we recruit 1 or 100 donors. One never knows where that one donor who matches for someone may turn up. I cannot stress to you how all involved pray that Joanna does well. All of you should feel very proud and a sense

of gratification because of your hard work. Thank you for volunteering, and joining the crusade to" fight the fight" to save Joanna's life!

Financially in 2007, we continue to raise funds through the support of Ahepa Chapter's Canister program (\$12,571), American Bone Marrow Registry Grant (\$11,900), Greek Ladies Philoptochos Society (\$6,050), Ahepa National Housing Grant (\$5,000), and the Daughter's of Penelope Society (\$4,482), and individual donations (\$6,696). We also had significant donations from the Hempstead, New York community, who donated \$19,358. Our expenses in 2007 were \$84,131, which \$78,827 were laboratory fees for testing. We also donated \$500 towards the George Pantazelos Memorial Fund, in remembrance of his commitment and dedication to our Ahepa Marrow Program, and particularly his remarkable accomplishments with the canister program.

We are hopeful that the Greek-American Community recognizes that the Ahepa Marrow Program is a significant and valuable asset for Greek-Americans. It stands ready to assist a patient and family deal with the unthinkable task of searching for a match for their loved one and dealing with the significant financial burden. Greek cancer patients have a difficult time finding suitable marrow donors because of the very fact that they are Greek—people of Hellenic heritage are severely underrepresented in the national and international marrow registries. These families are further burdened by the expensive nature of these tests and marrow drives. This is the sole reason why the Registry came into existence nearly 21 years ago. We are asking the Greek-American community to continue their support of the Ahepa Marrow Donor program by providing funding, either by an outright donation, volunteering or by participating in the canister program. Additional

announcements can be found at <u>www.AhepaMarrow.org</u>. We are also planning future events to promote awareness, education, and fundraising in order to continue to have resources to continue our mission.

Thank you for your continued support and financial assistance,

John Venetos M.D. Chairman Ahepa Bone Marrow Donor Registry