



Ahepa Bone Marrow Donor Registry 2010-2011 Report

Our enthusiasm, dedication, hard work and 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 goal is 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:

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

1. **To date there have been Five Ahepa Marrow Donors who have successfully donated to patients worldwide in need of a life saving marrow transplant.**
2. **In the spring of 2007, one of our Ahepa donors successfully donated for a boy in his mid-teens with acute leukemia.**
3. **In September 2008, another Ahepa Marrow Donor successfully donated for a marrow transplant for a man with chronic myelogenous leukemia.**
4. **In January 2009, another Ahepa Marrow Donor successfully donated for a marrow transplant for a man with acute leukemia.**
5. **In April 2009, our 4th Ahepa Marrow Donor successfully underwent Peripheral Blood Stem Cell collection for a woman with Hodgkin's Lymphoma.**
6. **In June and July 2009, two additional Ahepa Marrow Donors underwent Peripheral Blood Stem Cell collection – for two patients in need of transplant**
7. **In May 2011, another Ahepa Marrow Donor successfully underwent Peripheral Blood Stem Cell collection for a man with acute leukemia.**
8. **The Ahepa Bone Marrow Donor Registry currently has 10,543 active donors, and with the additional recruited through the NMDP we have more than 16,000 active donors.**
9. 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. In 2008, there were more than 9,000 searches performed in our Ahepa Marrow Registry for patients worldwide in need of a life saving marrow transplant. In 2009, there were more than 11,000 searches performed in our Ahepa Marrow Registry for patients worldwide in need of a life saving marrow transplant. **In 2010, there were more than 12,000 searches performed in our Ahepa Marrow Registry for patients worldwide in need of a life saving marrow transplant.**
10. In 2011, there were more than 13,000 searches performed in our Ahepa Marrow Registry for patients worldwide in need of a life saving marrow transplant.
11. During 2008, there were 153 Ahepa Donors requested for further follow-up testing, of which 79 Ahepa Donors completed such testing. During 2009, there were 87 Ahepa Donors requested for further follow-up testing, of which 49 Ahepa Donors completed such testing. During 2010, there were 91 Ahepa Donors requested for further follow-up testing, of which 45 Ahepa Donors completed such testing.
12. During 2011, there were 73 Ahepa Donors requested for further follow-up testing, of which 35 Ahepa Donors completed such testing.
13. We have technologically 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.

DRIVES: In January 2008, 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 March 2008, another family of a young woman, 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 National Hellenic Invitational Basketball Tournament in Oak Park, Ill., and were able to obtain 50 new donors.

The Ahepa Bone Marrow Registry continues to strengthen its registry, while also galvanizing our new affiliation with the National Marrow Donor Program since the last 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 2008.**

These drives were conducted to find a life-saving match and transplant for Joanna. We organized 65 drives: 33 drives in the Chicagoland area, but also included five drives in Indiana, seven drives in Michigan, three drives in Colorado and two drives in the following states of New York, North Carolina, Texas, Arizona, Ohio, Pennsylvania and one drive in Massachusetts, Florida, Connecticut, Minnesota, Nebraska, and California. **These drives recruited over 2,114 new donors!**

During October 2008, a young Chicago native and Filipino man named Leo, who is married, has three young daughters, and is suffering from acute leukemia, contacted us. Unfortunately, Leo's leukemia had worsened, and he was in dire need of a match and transplant. Because of his ethnicity, the Ahepa Marrow program was able to assist his family in obtaining funding through the NMDP as well as organizing multiple drives for him. The first drive for Leo began November 29th 2008, where we recruited 61 donors at Swedish Covenant Hospital in Chicago, Illinois. Over the next three months, we set up an additional 11 drives, and we were able to recruit **313** donors. **Unfortunately, Leo passed away December 24th 2009.**

TOURNAMENTS: Our **Inaugural Ahepa Marrow National Invitational Basketball Tournament** took place from March 12th-15th 2009 in Chicago, Ill. We conducted drives at North Park University and Northeastern Illinois University, and recruited **87** new donors. We raised a net amount of **\$18,677** during the event, which translates into covering the cost for **359 new donors**. Our 4th annual NHIBT Ahepa Marrow Drive took place in Oak Park, Ill. on March 28th 2009. We recruited 8 donors. A month later our 4th annual GMMT Ahepa Marrow Drive occurred on May 2nd 2009, and we recruited 1 donor. Our 2nd Annual **Ahepa Marrow National Invitational Basketball Tournament** took place from March 10th-14th 2010 in Chicago, Ill. In January, we conducted drives at the Greek Embassy in Washington D.C. and recruited 30 donors. During the 2nd Annual Ahepa Marrow tournament, we added 82 new donors. These new donors potentially may be a match to save someone's life. The goals of the tournament were to promote education, raise awareness of the marrow transplant process, recruit eligible donors, promote fellowship, participate in philanthropy, and serve as a national fundraising event. We were able to conduct successful drives at North Park University and Northeastern Illinois University, and recruited a total of **82** new donors during the tournament. We raised an amazing net amount of **\$20,000** during the event, which translates into covering the cost for **384 new donors**. Our 5th annual NHIBT Ahepa Marrow Drive took place in Oak Park Illinois on April 10th 2010. A month later our 5th annual GMMT Ahepa Marrow Drive occurred on May 22nd 2010, and we recruited 1 donor.

One of these donors might be the life-saving match that a desperate patient with Leukemia or Lymphoma is looking for, and the tournament may help save their life! Thus, our tournament motto is "A Tournament That Saves Lives!"

Last year, our three-point contest raised funds for the AHEPA Marrow Donor Registry. In 2010, our three point contest raised an additional **\$1,000** which was donated to Yano, a young boy from North Carolina suffering from Neuroblastoma. Our three point contest in 2009 raised an additional **\$1,250** which was donated to Niko Bezanis, who suffered a severe spinal cord injury from a diving accident last summer. We also succeeded in fulfilling our goals of increasing the Ahepa Marrow Program's awareness and visibility by giving out close to 1,000 AHEPA MARROW T-shirts and 750 AHEPA MARROW Tournament books. The tournament was a huge success because of the enormous amount of dedication and commitment from our 30 committees, over 250 volunteer pool, as well as four Event sponsors, ten Platinum sponsors, ten Gold sponsors, twenty-five Silver sponsors, and over one hundred Bronze sponsors.

To date the continued and combined efforts of the Ahepa Marrow program has allowed us to recruit a total of 15,865 active donors. Although our Ahepa Bone Marrow Registry has 10,543 active donors as of June 24th, 2011, we have also recruited additional donors in the National Marrow Donor program. Through these efforts of increasing the donor pool, raising funds to continue organizing 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.

It would be regretful of me 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. This includes but is not limited to 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, the YAL, and student volunteers as well as all the priests and parishioners who supported our combined efforts.

In the summer of 2008 because of the tremendous dedication of all involved in the Ahepa Marrow program, we were happy to announce that a 10 out of 10 match was found for Joanna. Joanna underwent a successful marrow transplant on July 15th, 2008 at MD Anderson in Houston, Texas. She returned to Chicago 100 days post transplant in October 2008, and she is cancer free. We were very fortunate to have Joanna and her sister Anastasia take on a lead role in our drives during our 1st Ahepa Marrow National Basketball Tournament. Joanna was an inspiration to everyone involved in our tournament including participants, coaches, spectators, and volunteers. We want to personally thank everyone for participating in 2008 Ahepa Marrow Drives. We were able to conduct over 65 drives and have recruited over 2,114 donors in two weeks. Although some of you were disappointed at times because you might have only recruited a few donors, while others had over 100, it is imperative to understand that every drive is successful whether we recruit 1 or 100 donors. It is important to remember that one never knows where that one donor who matches for someone may turn up. All of our volunteers should feel very proud and a sense of gratification because of everyone's hard work. Thank you for volunteering, and joining the crusade to "fight the fight" to save lives.

FINANCE: Our income for 2008-9 was \$44,831, and our expenses for 2008-9 were \$48,025, which were predominantly laboratory fees for testing. Financially in 2008, we continue to raise funds through the support of Ahepa Chapter's Canister program, Greek Ladies Philoptochos Society, Ahepa National Housing Grant (\$5,000), the Daughter's of Penelope Society, and numerous individual donations. We also had St. Nicholas Greek Orthodox Church (\$1,780), and William Spyropoulos PTA, Flushing, New York (\$1,500). We also had significant donations from the Hempstead, New York community, who donated \$19,358. In comparison financially in 2007, we raised 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). Our expenses in 2007 were \$84,131 of 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 cope with the 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 under-represented 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 to support the Ahepa Marrow Donor program by providing funding, either by an outright donation, volunteering or by participating in the canister program.

On a sad note in 2008, Dr. Peter V. Paulus, our Past Supreme President, as well as the first chairman of the Ahepa Bone Marrow Registry suddenly passed away in Ocala, Florida in December 2008. Dr. Peter will be greatly missed by all of us. We all thank him and his family for his dedication and love for the Ahepa Marrow program, and for his wise council and inspiration he provided to all of us.

Additional announcements can be found at www.AhepaMarrow.org. We are also planning for our 5TH Annual Ahepa Marrow National Invitational Basketball Tournament from March 6-10th 2013 in order to promote awareness, education, and fundraising so that we can continue to have resources to fulfill our mission. We would like to thank all dedicated volunteers, co-chairpersons, Ahepa Chapters, participants, coaches, sponsors, facilities, businesses, sponsors of the book, sponsors of the banners, individuals who joined the marrow registry at the tournament event and during the year, and all the individuals who have in some way assisted the Ahepa Marrow program in its mission of saving lives!

Thank you for your continued support and financial assistance,

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