The 9th Conference on Health Care of the Chinese in North America

A3M-Asians for Miracle Marrow Matches: Improving the Odds for a Life

Sharon Sugiyama, Project Director, Asians for Miracle Marrow Matches

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Abstract

Whenever I have the opportunity to talk with William Hauwa Ko, he has the most wonderful smile. However, William was very sick when we first came to know him. He needed a bone marrow transplant. William's brother and the whole family and friends joined A3M in an effort to find an unrelated marrow donor for him. But it was a stranger who saved his life. Someone who registered for the National Marrow Donor Program, (NMDP) at one of the Asians for Miracle Marrow Matches' (A3M) donor drives. Some would say that he was lucky. We think of it as a miracle.

This kind of miracle was almost impossible in 1990, when, according to NMDP statistics, just one Asian had received an unrelated transplant. At that time only about 5000 Asian potential donors were in that registry. Patients who needed a matched unrelated donor desperately searched among their friends and communities against huge odds.

The Transplant Act of 1990 requires "that a patient in a minority group have a comparable chance of finding an unrelated donor as a patient who is not in a minority group." While strides have been made, there is still a great distance between this goal and reality. Asians and Pacific Islanders (API), including Chinese, are one of the four major population groups identified as minorities for which marrow transplants occur at a much decreased rate compared to the majority population.

In the early 1990s several organizations emerged to address the serious lack of registered Asian and Pacific Islander donors which had the effect of excluding API patients from the lifesaving opportunity of a marrow transplant from a matched unrelated donor. Asians for Miracle Marrow Matches (A3M) was established in Los Angeles in 1991. A3M's activity has been focused on raising awareness, providing information and registering potential marrow donors in the Chinese, other Asian and Pacific Islander communities. Organizations similar to A3M are the Asian American Donor Program (AADP) in Oakland, California and the Cammy Lee Leukemia Foundation (CLLF) in New York. Due to limited resources, all three groups rely heavily on volunteers, particularly the participation of individuals and organizations from the various communities.

A3M, AADP, CLLF donors are held by and accessed through the National Marrow Donor Program (NMDP). Information on how to initiate donor searches in the National Marrow Donor Program will be presented in this session.

There are also donor registries in Asia which can be searched through the NMDP, namely in Japan, Singapore and Taiwan. In addition, searches may be made in Hong Kong and Korea. Participants will be provided with a list of and information about these registries.

There are now over 180,000 Asian and Pacific Islanders (API) in the NMDP registry, and to date about 155 Asian Pacific patients have received unrelated transplants. One out of every four API donors has been registered through A3M donor drives. More than half of the API donors have registered through four recruitment groups and the rest by 100 donor centers throughout the NMDP network.

A3M outreaches to the Chinese, Japanese, Korean, Pilipino, South Asian and Vietnamese communities in southern California through six ethnic task forces. Donor registration drives are coordinated with assistance from community leaders, organizations and media. Our goal is to register donors so that there is representation from the Chinese and various API populations in the national registry.

Donor search statistics are showing that as the pool of donors becomes more diverse, patient transplant statistics have increased and become more diverse. There is hope with each donor who comes up as a preliminary match for a patient and each registrant who actually donates marrow to give someone the chance of a lifetime. Still, Chinese and other Asian Pacific patients have about a third less chance of finding a matching donor than the majority of searching patients.