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**“Marrow for Tomorrow:” a community-based public health partnership in
Worcester’s medically under-served communities**

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Background:

For many types of blood diseases such as leukemia, the only hope for a cure often involves the transplantation of bone marrow—derived stem cells or of peripheral blood stem cells (PBSC).¹ Graft rejection is minimized, and patient survival optimized when donor cells are genetically identical, or nearly identical to those of the recipient. “Compatibility” of this type, as defined by HLA-antigen DNA typing, is most likely to be found within a patient’s own family. However, since only 30% of patients can actually find a suitably matched donor in their family,² unrelated donors must be sought, with the more likely matches arising from within the patient’s ethnic/racial group. The population at large poses a range of match probabilities (from 1 in 450 to 1 in 750,000),³ however a relatively low proportion of the population is accessible for donation due to lack of screening programs within their community.⁴ The shortage is especially acute in minority populations, where a far lower percentage of individuals have been screened.

Objective:

Narrowing the “stem cell gap” for all communities, focusing especially on the Black, Latino, Vietnamese, and Cambodian communities in Worcester and beyond.

Introduction:

Annually in the United States, over 35,000 children and adults develop life-threatening diseases for which a marrow or blood cell transplant could be a cure; these diseases affect families from all racial and ethnic backgrounds.⁵ Members of minority communities, however, are under-represented in national marrow registries, where far fewer potential minority donors have been screened than whites.⁶ It is more likely that a donor who comes from the same racial or ethnic group as the recipient will have the same tissue traits. For African Americans, this is particularly true, as some African American tissue types are rarely found in donors from other races and may be unusual even among other African Americans. Therefore, if the group of potential donors being searched is small,

¹ Umbilical cord blood is also being used as a stem cell source.

² <http://www.dana-farber.org/how/donatebone/minority-donors.asp>

³ <http://www.hema-quebec.qc.ca/anglais/cellulessouches/index.htm>

⁴ Switzer GE, Myaskovsky L, Goycoolea JM, Dew MA, Confer DL, King R. Factors associated with ambivalence about bone marrow donation among newly recruited unrelated potential donors. *Transplantation* 2003; 75: 1517-23

⁵ <http://www.dana-farber.org/how/donatebone/minority-donors.asp>

⁶ http://www.marrow.org/MEDIA/Facts_and_Figures/facts_figures.pdf

the likelihood of finding a match will be small also.⁷ This holds true for many minority groups, such as the Latino, Asian, and Native American/Pacific Islander communities.

Methods:

Marrow for Tomorrow (MFT) aims to increase the number of life-saving donors in under-represented communities. Understanding that community partnership is the key to community involvement, MFT is a project comprised of five main programs, each aimed at increasing the number of minority donors screened for stem cell: (1) working with health and cultural centers to schedule and implement bone-marrow recruitment drives; (2) informing at-risk populations of Worcester by teaching about bone marrow donation in public schools, of whose student bodies comprise a large minority population; (3) acting as an information gateway by distributing relevant educational materials at cultural gatherings, and by creating an educational website dealing with stem-cell related issues; (4) setting up audio-visual equipment in waiting rooms of area health centers, to play bone marrow educational video material; and (5) composing, arranging, and producing a bone-marrow promotional video for Worcester's Vietnamese and Cambodian communities.

Key to implementation of the project⁸ was assessing population needs, accessing stakeholders, and implementing objectives on a community-based partnership model.

Results:

Community-targeted public health activities were successful in both raising awareness and facilitating recruitment into stem cell donor registries. Screening objectives were met as one UMMC and two community recruitment drives were held, with minority donors better represented in the latter. Relationships were established with area health centers for future coordination of stem cell recruitment activities.

An after-school seminar was held at a local middle school, dealing with blood diseases and the important role played by stem cells in their treatment. Students were engaged in discussions of how to address the dearth of donors in the community, and seemed eager to get involved. A follow-up session was planned at the high school.

Other means of informing the community were employed. At community fairs and cultural gatherings, information was distributed to passers-by and attempts were made to educate regarding stem cell screening and transplantation. A website was developed and installed at www.marrowfortomorrow.org, which serves to both educate the public about marrow donation, and describes the present recruitment project.

For the purposes of playing bone marrow educational videos, 4 local health centers received TV/VCR sets. These locations were chosen for their access to minority populations, and for their interest and willingness to participate in educating their patients

⁷ <http://rarediseases.about.com/od/rarediseasesb/a/minoritymarrow.htm>

⁸ Supported by the Association of American Medical Colleges and their "Caring for Community" grant program, and the University of Massachusetts Medical School and their offices of Medical Education and Family Medicine & Community Health.

about bone marrow. After purchase and installation of these TV/VCR sets, they were used to play both “The Missing Piece” by the National Marrow Donor Program, and the MFT-produced Vietnamese-language video.

A Vietnamese-language stem cell donation promotional video was produced and distributed to area health centers, and repurposed for online delivery on the project website. In composing and producing the video, effort was expended to partner with members of the Vietnamese community wherever possible. This involved focus groups with Vietnamese individuals in Worcester in coordination with Worcester’s Southeast Asian Coalition. Additional involvement from the Area Health Education Council of Central Massachusetts (AHEC) facilitated translation and helped ensure the educational video retained both cultural congruence and linguistic accuracy. Doctors and nurses at UMMC were recruited to both appear in the video, and enabled contact with transplant recipients who appeared in the video to appeal for recruitment.

Discussion:

Stem cell donation remains fertile ground for public health efforts to improve outcomes in blood cancers and other disorders. Recruitment of donors from under-represented communities can be pursued most effectively with broad-based community initiatives rather than hospital-centered systems per se. A multi-faceted approach, such as that represented in the current project, may be a powerful strategy to achieve progress in this regard. Future efforts at other under-represented communities may further demonstrate the effectiveness of this approach.