



July 12, 2005

The Honorable Patty Murray
United States Senate
173 Russell Senate Office Building
Washington, DC 20150

Dear Senator Murray:

We are writing with regard to **H.R.2520**, the “**Stem Cell Therapeutic and Research Act of 2005**,” which has been received in the Senate from the House. We support the creation of a national umbilical cord blood registry, and urge you to ensure that the enabling legislation requires transparency of program operations, and safeguards to protect against the exploitation of poor and minority women as potential donors. Furthermore, the cord blood program should directly address healthcare disparities faced by people of color in Washington State and the nation.

As an organization dedicated to advocating for mixed race people and families, the MAVIN Foundation became involved with blood and marrow donor recruitment because we learned of the terrible odds mixed heritage people now face if they need an unrelated transplant.

In 2001, five-year-old Nicole Howard was diagnosed with a rare form of leukemia. Because of her mixed race heritage—Japanese American and Caucasian—her Seattle doctors estimated that at least 55,000 people would need to be registered in order to find her match. In response, we launched MatchMaker, the only national program dedicated to mixed race marrow donor recruitment, retention and education. Unfortunately, a match has not yet been found for Nicole, but we have registered nearly 10,000 people to the National Marrow Donor Program (NMDP) Registry, and continue this work on behalf of her and thousands of other waiting patients.

We are excited by the prospect of a national cord blood program because we have seen how cord blood transplants save lives. After not one of the seven million donors on the worldwide registries was a match for our three-year-old focus patient, Dakota Kwiecinski, an unrelated umbilical cord blood sample saved his life. Like Nicole, Dakota’s multiracial heritage—Navajo and Caucasian—had complicated his search.

But our excitement is tempered by the reality faced by Nicole, Dakota, and other minority patients, who too-often receive inferior healthcare. A 2002 report by the Institute of Medicine found that even when insurance status, income, age and severity of conditions are comparable, people of color in the United States are less likely to receive even routine medical procedures and experience a lower quality of health services.¹ Despite the growing diversity of Washington State and the nation, too little is being done to level the

healthcare playing field for racial and ethnic minorities, with tragic results. We feel that H.R.2520 does too little to address this issue, and could even exacerbate it. H.R.2520 fails to address the many barriers facing people of color, both as potential donors and as potential transplant recipients. Furthermore, the NMDP's own statements acknowledge that focused cord blood collection may be unsuccessful in finding matches for minority patients.² We feel strongly that a national program funded by taxpayer dollars must operate based on accurate, unbiased information, via a transparent process that includes stakeholder participation. Without strict adherence to these principles, we fear that an unregulated cord blood industry's drive for customers could generate misleading information and could contribute to the exploitation of minority women and communities of color, who have higher birthrates but less access to specialty healthcare.

Instead, we hope that you will support legislation and funding that would enable the following:

- Improved access to all healthcare services for poor and minority patients, including blood and marrow transplants
- A dramatic increase in minority (including mixed race) representation in the National Marrow Donor Program (NMDP) Registry
- The dissemination of culturally-relevant recruitment, retention and education programs and materials to expectant parents of racially and ethnically diverse backgrounds
- The provision of culturally and linguistically appropriate services to patients, many of which are already protected under Title VI of the Civil Rights Act
- Educating healthcare providers to inform expectant parents about blood and marrow donation, as well as umbilical cord blood donation
- Increased overall funding for health programs

Fortunately, we do not have to move forward blindly. We can learn lessons from *existing* umbilical cord blood programs, including the National Heart, Lung and Blood Institute's (NHLBI) now-completed Cord Blood Transplantation Study and several public programs across the nation. By reviewing their demographic data and track records, we can identify best practices to organize a national cord blood program that serves all Americans equally.

Thank you very much for your consideration. Please do not hesitate to contact us if you require additional information, and thank you for your commitment to ending healthcare disparities faced by communities of color.

Very truly yours,



Matt Kelley
Founder/President



Nicki Carrillo
Program Manager, MatchMaker Bone Marrow Project

¹ The Report Summary can be found at <http://www.iom.edu/report.asp?id=4475>

² http://www.marrows.org/PATIENT/cord_blood_transplantation.html