



**Written Testimony of Dr. Jeffrey W. Chell before
the House Appropriations Subcommittee on Labor,
Health and Human Services, Education, and Related Agencies
March 8, 2017**

Good morning Mr. Chairman, and other distinguished members of the Subcommittee. My name is Dr. Jeffrey Chell and I am the Chief Executive Officer of the National Marrow Donor Program (NMDP)/Be The Match. We operate the C.W. Bill Young Cell Transplantation Program (Program) through three competitively bid contracts with the Health Resources and Services Administration (HRSA). These contracts include the Single Point of Access and Office of Patient Advocacy, the Bone Marrow Coordinating Center, and the Cord Blood Coordinating Center. Collectively, these contracts allow NMDP/Be The Match to operate the national Be The Match Registry and provide life-saving unrelated blood and marrow transplants using individual adult donors and cord blood units. Through our affiliation with the Medical College of Wisconsin, known as the Center for International Blood and Marrow Transplant Research (CIBMTR), of which I am the executive director, NMDP/Be The Match also holds a subcontract for the Stem Cell Therapeutic Outcomes Database. We also work closely with the cord blood banks that receive critically important funding directly through the National Cord Blood Inventory (NCBI) grant program. I would like to thank Chairman Cole, Ranking Member DeLauro, and all of the Members of the Subcommittee for inviting me to speak with you today. On behalf of 565 Network partner organizations and everyone at NMDP/Be The Match, we also want to thank you for maintaining the Congressional commitment to patients fighting blood cancers and other disorders whose only hope for a cure is a bone marrow or cord blood transplant. For each \$1 million the Congress adds to the Program, 10,000 donors will be added to the registry. For each \$1 million it adds to the NCBI, an additional 667 cord blood units will be collected and stored. As you can see, these dollars go directly to saving lives. Because our funding has been flat for more than a decade, for FY2018, we ask that the Congress modestly increase the funding for the Program by \$5 million above last year's amount to allow us to

replenish the registry as volunteers age off and continue our efforts to increase the ethnic diversity of the registry as patients are most likely to find a match within their ethnic group. We also ask that the Congress increase the NCBI funding by \$5 million over previous years, consistent with last year's numbers from this Subcommittee, to fund the collection of additional cord blood units. These units have been exceedingly helpful in providing life-saving stem cells for patients who are difficult to match. The Congress has authorized both national registry and NCBI, most recently unanimously for another five years in December 2015.

As I testify before you today, I am reminded that it was the foresight of the House Appropriations Committee in the mid-1980s that created the Program on which Americans rely today. Through the leadership of the late Congressman Bill Young, the Congress decided to establish a national registry where men, women, and children with leukemia and other fatal blood disorders could find an unrelated donor to save their lives. Since the Congress made the important decision to establish the registry 30 years ago, NMDP/Be The Match has formed a highly successful public-private partnership and has made great progress. We are honored to serve as the steward of this critical national resource. Today, the Be The Match Registry remains the single point of access for both cord blood units and adult volunteer donors. This assures that physicians will have access to any potential donor or cord blood unit regardless of where they are located across the globe in order to perform adult stem cell transplants that can cure more than 70 different diseases or conditions, including blood cancers and sickle cell disease. The Be The Match Registry has grown to include nearly 16 million donors and more than 238,000 cord blood units, including 93,000 NCBI units. Through international relationships, NMDP/Be The Match has access to more than 29 million potential donors and 721,000 cord blood units worldwide.

But, the C.W. Bill Young Program is more than the national registry. Through the Office of Patient Advocacy, we assist patients and their families in navigating the complexities of health insurance and help them overcome logistical, psychosocial and informational barriers throughout the transplant continuum. We also work closely with donor and collection centers through the Bone Marrow Coordinating Center to recruit and retain volunteer potential donors, produce a comprehensive plan for donor retention, and identify ways to increase operational efficiencies. This work includes engaging with insurers, employers, and States in striving to ensure that volunteer donors have no out-of-pocket costs when they are chosen to donate. We similarly provide financial and educational support to public cord blood banks as the manager of the Cord Blood Coordinating Center and provide guidance to HRSA in the administration of the NCBI program to determine optimal composition of cord blood inventory. Through the Stem Cell Therapeutic Outcomes Database, we facilitate cutting edge research to improve patient outcomes and find innovative ways bone marrow and cord blood can be used to save lives. We provide patient services, caregiver support, and financial support through the Be The Match Foundation and help patients maintain healthy lives after transplant.

Our focus is on patients for whom cellular therapy is the best hope for curing their diseases and is often the only therapy available with an intent to cure. Today, we are able to treat patients with cancers and pre-cancers, such as leukemia, Myelodysplasia, and lymphomas; bone marrow failure disorders, such as aplastic anemia and immunodeficiency syndromes; and genetic diseases, such as sickle cell disease. To treat these diseases, we infuse bone marrow, peripheral blood stem cells, or cord blood cells into a patient after having eliminated his/her current

irreversibly diseased or damaged bone marrow. These new cells restore the patient's ability to make healthy blood cells and provide a new immune system to attack cancer cells. Finding the best match possible is important because if donor stem cells are not the same HLA type as the recipient they will recognize the recipient as being different and attack, leading to rejection.

Because we collect data on all transplants, we have been able to improve patient outcomes and reduce the complications of transplantation. During the last 20 years, the one-year survival rate for these patients has increased from just over 40 percent to 70 percent. Access to multiple cell sources allows us to find the best match possible for patients. Initially focused only on bone marrow, the Program today also allows physicians to select peripheral blood stem cells and cord blood, as well as bone marrow, as the source of the adult stem cells used in transplant.

However, more can be done. The need for transplants is increasing, especially among Americans 65 years and older. With the growth in knowledge from each transplants, we now are able to successfully transplant patients well into their 70's. The increase in the number of transplants for older Americans, and minority patients significantly increases the need for more volunteer donors and cord blood units. While NMDP/Be The Match facilitated transplants have grown by 200 percent overall and 250 percent for minorities since 2006, there is more work we can do in this area too. Only about half of Americans who could benefit from a transplant get one. With the federal dollars you allocate, we continue our efforts to expand the diversity of the adult volunteer donor registry and increase the number of minority cord blood units on that registry. During the last 5 years cord blood has been the product source for about 21 percent of

all transplants and 37 percent of minority patients who received a transplant relied upon cord blood.

Even though NMDP/Be The Match has improved the ability of those needing a transplant to find a match, there are other barriers that continue to make access difficult. These non-match barriers to access and care have a profound affect on our ability to make transplant therapies accessible to all. Language, literacy, finances, insurance, geography, lack of knowledge, and predisposition by general hematologists and oncologists towards non-transplant therapies all have an impact. NMDP/Be The Match continues to work with patients, physicians, community leaders, and others to address these problems as well.

Federal funding remains critical to continuing to provide access to transplantation. We need to continue to recruit new potential donors both to improve access for minority patients and to renew the current list of donors with younger donors. Grafts from younger donors have shown improved clinical outcomes. The funds for the Program and the NCBI allow us to continue to improve the chances of every American needing a transplant to find a match and provides the critical infrastructure that allows NCBI cord blood units to be used to save lives. We thank you for your ongoing support of the Program and the NCBI. While we understand the difficult budget situation, we also know that any additional funding for these programs will help provide the cure for a patient who has no other options. Thank you again for allowing me to testify before you today.