**Oral 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 cord blood and marrow transplants using individual adult donors and cord blood units. 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 the 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 and provide the only hope for a cure for patients with one of 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. We have facilitated more than 80,000 transplants since the inception of the program and more than 6,200 transplant per year.

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.

However, more can be done. The need for transplants is increasing, especially among Americans 65 years and older, significantly increasing 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. New indications, such as curing sickle cell disease, also drive the need for more volunteer donors and cord blood units. 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.

Even though NMDP/Be The Match has improved the ability of those needing a transplant to find a match, 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.

Federal funding remains critical to continuing to provide access to transplantation. 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.