Testimony by Dorothea Staursky, Volunteer and Bone Marrow Donor on behalf of National Marrow Donor Program

Chairman Aderholt, Ranking Member DeLauro and Committee Members, my name is Dorothea Staursky of Birmingham, Alabama. On behalf of the patients, family members, donors, volunteers, and staff of the National Marrow Donor Program® (NMDP) I want to thank you and the members of the Committee for your support of the C.W. Bill Young Cell Transplantation Program (Program) within the Health Resources and Services Administration (HRSA), Health Care Systems account last year. Your partnership with the Program truly saves lives. In Fiscal Year 2024, NMDP respectfully requests $35,000,000 for the C.W. Bill Young Cell Transplantation Program to improve access to cell therapies for thousands of underserved patients.

The Program has been a true public/private partnership between NMDP and Congress for more than 35 years. By establishing a national bone marrow donor registry in the mid-1980s, Congress promised patients with blood cancers, like leukemia and lymphoma and over 75 other life-threatening diseases, that they would have a way to find a life-saving donor. Thanks to this 35-year partnership, the Program has facilitated over 120,000 transplants between a matched, unrelated donor and a patient with blood cancer or disorder.

While patient's lives are changed through this program, my life was also forever altered when I received the call that I was a patient's match. In October 2018, I received a call from an NMDP representative informing me that I had been identified as the best possible match for a patient with a rare blood disease. I am speaking to you now as a two-time cell donor through the Program, as I donated peripheral blood stem cells (PBSCs) to my recipient in November 2018 and then again to the same recipient in June 2019.

I initially joined the registry because I saw a social media post about a young Greek American child who was suffering from a rare blood disease and needed a bone marrow transplant to save his life. This social media post was encouraging individuals with Greek heritage to sign up for the registry. This was the first time that I learned that ethnic background affects a patient's odds of finding a match. When it comes to matching, a patient's likelihood of finding a matching donor on the registry ranges from 29% to 79%, depending on ethnic background. Thanks to Congressional investment, NMDP has been successful in narrowing that gap, through targeted recruitment efforts, groundbreaking innovation, and assisting patients in navigating barriers to transplant.

My cells were a match for a young man with a wife and two young children. I felt a responsibility and an honor that I matched with my recipient and was able to offer him hope for a healthier life. After a full calendar year, my recipient and I were able to exchange contact information. His name was Mario, and thanks to social media and an online translation platform, we were able to connect and communicate with one another. Unfortunately, shortly after this, I learned that Mario passed away. I am comforted in knowing that I was able to give Mario more time to spend with his family and was able to give his two young children more experiences and memories with their dad.

My PBSC donations to my recipient, Mario, has given my life and work new meaning. I continue to be involved with NMDP. I have hosted donor registration drives in Alabama, Mississippi, and New York, currently serve as a volunteer Advocacy Ambassador, and recently completed my doctoral degree with a final doctoral project that focused on bone marrow and stem cell donation. Professionally, I have a career in hospital administration in a cancer center in Alabama. Every day, I am surrounded by the bravery and strength of our patients, the spirit of our family members and caregivers, and the healing work of our providers.

Empathy starts with imagination. Throughout my donor journey, from registration to donation to legislative advocacy, I imagined myself, a family member, colleague, or a friend as a patient waiting for a match in order to live. I feel that it is my personal responsibility to never cease my work to ensure that every patient has a suitable match available.

In the Greek language, the word *Philotimo* is a word that lacks a true definition; however, its meaning is great. The roots of the word *Philotimo* include *filos* meaning friend and *timi* meaning honor. *Philotimo* extends beyond friendship and honor. It encompasses the desire in each of our hearts to do good work for others. *Philotimo* is what we should all aspire to achieve. Being a donor, being an advocate, and supporting the Program is a perfect way to show our humanity by doing something out of love and honor for another human being.

This committee knows the meaning of good work. More than any other Committee in Congress, the programs you support save lives every day, such as the Program I am here to speak about today.

The C.W. Bill Young Cell Transplantation Program, authorized by Congress, has been funded by the Committee and fulfills three important missions. The first is the nation's registry, which includes more than 41 million volunteers worldwide, who stand ready to be a life-saving bone marrow donor. It also includes more than 800,000 cord blood units through NMDP and international partnerships, 115,000 of which are in the National Cord Blood Inventory, which is also funded by your Committee.

From the moment doctors search the registry for a donor, to the safe delivery of the life-saving cells to the bedsides of patients for transplant – NMDP is there every step of the way. NMDP ensures that the global network, technology, and logistical support are in place to facilitate a transplant.

The Program's second mission is to support patients and families through its Office of Patient Advocacy. NMDP works tirelessly to improve the lives of patients and provide one-on-one support to these individuals and their families. They offer the resources and guidance patients need throughout the transplant process – from deciding if transplant is right for them to adjusting to life after transplant.

Finally, the Stem Cell Therapeutic Outcomes Database is a third program component that helps doctors significantly impact survival for blood cancer and other diseases while also improving the quality of life for thousands of transplant patients. NMDP is relentless in its search to find answers that will lead to better donor matching, more prompt transplants, and treatment of even more blood diseases through transplant.

Our request this year builds upon past funding to clear a pathway for more patients, especially those from minority and geographical distant communities, to be able to access transplant services. The funding we are seeking this year will immediately increase the number of patients who enter the pipeline to receive a bone marrow transplant for a lifesaving cure, by increasing targeted donor recruitment efforts, expanding early intervention with community referring physicians upon patient diagnosis to accelerate the path to transplant, and propeling innovation to improve outcomes and establish new treatment options to ensure a donor for all searching patients, regardless of their racial/ethnic background or the complexity of their DNA, ensuring access to transplant and equal and successful outcomes for all.

The request also builds on a successful pilot program, called HLA Today. HLA Today, a program piloted and funded by NMDP, has shown outstanding early success in targeted outreach to patients diagnosed with a transplant-treatable disease. Alabama was the first in the nation to launch HLA Today in 2019, with Mitchell Cancer Institute at University of South Alabama in Mobile. Since then, the program has grown to 29 states and Puerto Rico. This free program improves the time to transplant through a simple process of providing genetic typing for patients who are newly diagnosed with a condition for which a transplant may be a potential treatment or cure. With increased Congressional support, NMDP aims to expand this program nationwide to improve patient access to treatment options.

Thank you for the opportunity to share my story and most importantly thank you for learning a little bit about my recipient. Your longstanding support for this Program is the hope that people hold onto after receiving their life-threatening diagnosis. On behalf of those who are alive today, those who are currently searching the national registry for their potentially life-saving donor, and for those who will need to look to the Program for help in the future, I urge you to fund the C.W. Bill Young Cell Transplantation Program at $35 million to immediately provide access to therapy at the point of diagnosis for all patients. Thank you.