

Written Testimony of Brian Lindberg

(National Marrow Donor Program/Be The Match)

Before the House Energy and Commerce Committee, Health Subcommittee

“Improving Access to Care: Legislation to Reauthorize Key Public Health Programs”

July 29, 2020

Madam Chair, Ranking Member Burgess and distinguished members of the Subcommittee, I am Brian Lindberg, and I have the honor to serve as Chief Legal Officer and Chief Policy Officer of National Marrow Donor Program (NMDP)/Be The Match. For over three decades, through a genuine public/private partnership with the federal government implemented through competitively bid contracts with the Health Resources and Services Administration (HRSA), we have been entrusted to operate the C.W. Bill Young Cell Transplantation Program (Program), which provides life-saving bone marrow and umbilical cord blood transplants to patients in need.

On behalf of those patients we serve, their family members and friends, our donors, couriers, volunteers, our Board of Directors, and the entire team at NMDP/Be The Match, I would like to thank Chairwoman Eshoo, Ranking Member Burgess, and all the members of the Health Subcommittee for the opportunity to speak with you today, and for allowing me the privilege to share with you the astounding successes of the Program over the past five years, but more specifically during the current crisis of the global pandemic.

I would also like to extend special thanks to Congresswoman Doris Matsui and Congressman Gus Bilirakis, for their leadership as our sponsor and original cosponsor in introducing H.R. 4764 to reauthorize the Program for another five years. As you know, this is

the Program that houses the national registry of volunteer bone marrow donors, as well as the National Cord Blood Inventory (NCBI) grant program and the Stem Cell Therapeutic Outcomes Database (SCTOD). Mrs. Matsui and Mr. Bilirakis have been tireless champions for patients whose only chance at life is a bone marrow transplant.

The Program was first established through a partnership with the Navy in 1986, transferred to the NIH for oversight the following year, then authorized by this Committee in 1990 and has been reauthorized in 1998, 2005, 2010, and 2015. As I prepared my testimony and reflected on the Program's history, I am reminded of the series of events that set into motion over three decades ago an effort to establish a national registry of unrelated volunteer that was led by families of patients in desperate need of a bone marrow donor, but were unable to find a matching donor in their own family. The humble beginnings of this Program include a Technology Assessment Meeting held under the auspices of the NIH just over 35 years ago today. That consensus conference, held in May 1985, concluded overwhelmingly that while unrelated donor bone marrow transplantation held promise as a therapy, it was premature to commit to a centralized national donor registry because, after all, who would join? Who would step up to donate their bone marrow to a stranger? Unwilling to take no for an answer, those responsible for the creation of this registry persisted, and by the following year the first federal dollars were appropriated to what would eventually become this federally authorized national program and national resource.

Today, the Be The Match Registry includes more than 22 million selfless volunteers who stand ready to be a life-saving bone marrow donor. It also includes more than 300,000 cord blood units, 110,515 of which are in the National Cord Blood Inventory. This valuable source of

cells also is reauthorized by H.R. 4764. Through international relationships, NMDP/Be The Match has access to more than 35 million potential donors and 783,000 cord blood units worldwide.

H.R. 4764 also authorizes our work in support of patients and families through our Office of Patient Advocacy. NMDP/Be The Match strives every day to improve the lives of patients and provide one-on-one support to these individuals and their families. Our staff offers the resources and guidance patients need throughout the transplant process – from deciding if transplant is right for them to adjusting to life after transplant.

This legislation also will continue the work of the SCTOD, a remarkable data resource that allows doctors and researchers significantly impact survival for blood cancer and other diseases while also improving the quality of life for thousands of transplant patients. NMDP/Be The Match is relentless in its search to find answers that will lead to better donor matching, more timely transplants, and treatment of even more blood diseases through transplant.

Finally, this legislation is fundamental to vision to ensure that every patient in need of a lifesaving transplant has access to a matched donor regardless of ethnic, racial, or socioeconomic background. One of our greatest areas of focus is to continue to diversify our donor base to reflect the ever-changing mix in our nation's population.

Esteemed members of this Subcommittee, as we have worked to fulfill all of these critical missions that are a part of our authorizing statute, it brings me real joy to tell you that this past December, National Marrow Donor Program/Be The Match marked the 100,000th time it facilitated a transplant in which a heroic volunteer donor stepped up to save the life of a person they had never met by making this life-giving gift of bone marrow donation. More than

100,000 patients, facing the fatal consequences of blood cancers like leukemia and lymphoma, as well as over 70 other otherwise catastrophic diseases, have been given a second chance to live by someone they had never before met. And millions of their family members, friends, and loved ones, have been given the gift of more time with them. This is due to the refusal to accept “no” for an answer by those who had the foresight 35 years ago to know that a national registry would work, must work, and needed to be established by Congress.

I can say without hesitation that this same indomitable spirit, and that refusal to take no for an answer, have served this Program extraordinarily well over the past year. In addition to celebrating our 100,000th transplant, in 2019 we facilitated more transplants than in any other year in our history.

And then global pandemic arrived.

As the members of this Subcommittee understand likely better than most, the success of this Program, and the lives of the patients we serve, rely on our ability to move bone marrow donors and the couriers who carry donated cells not only all across the country, but also across the world. The complexities of matching patients and donors result in half of our cellular donations crossing an international border.

Domestic and international travel bans, border closings, and the declining availability of scheduled commercial passenger aviation service on international and domestic routes during the COVID pandemic have created near catastrophic barriers to our ability to facilitate timely transplants for those patients in dire need. Quarantine orders, shelter in place requirements, and an ever-changing patchwork of restrictions that not only differ state to state, but local

jurisdiction to local jurisdiction as well, threaten to impede every one of these life-or-death missions at multiple points along the now tenuous path from donor to waiting patient.

Despite all of that, I am thrilled to be able to report to you this morning that throughout the course of this pandemic, NMDP/Be The Match, through grit, determination, innovation and sheer force of will has delivered more than 2,500 life-saving therapies to patients who are relying on them, without a single failure. I will admit to it being closer than we would have preferred on more than one occasion, requiring immediate assistance from different agency and foreign partners to work around unintended and often unanticipated obstacles. But even with all of this, not one patient prepped for transplant has gone without. Everyone associated with this Program understands the consequences of failure are the direst consequences of all.

In fact, despite all of these obstacles, it is remarkable to note that, in June, we facilitated more transplants than in a single month in the Program's proud history.

Thanks in large part to the national program status afforded us under the authorizing statute, we were:

- Granted a waiver in March from the Director of the Centers for Disease Control to the European Travel Ban issued by the President. The waiver was issued in "the national interest" to allow international bone marrow couriers to travel to and from the United States to deliver cellular products from abroad to U.S. patients.
- Designated with an Essential Critical Infrastructure classification by the Department of Homeland Security's Cybersecurity & Infrastructure Security Agency (CISA) for the Program to include "Donors of blood, bone marrow, blood stem cell, or plasma, and the workers of the organizations that operate and manage related activities."

- Authorized by a subcontract with the Department of Health and Human Services to use private aircraft donated to the government, renewed on a monthly basis, to deliver life-saving cells to patients when commercial flights were not available.
- Able to access support from U.S. Embassies and Consulates to liaison with host governments to facilitate timely travel authorizations for individual donor and courier travel and to coordinate private and/or humanitarian flights in and out of countries that have closed their borders to international travel.
- Granted clearance from U.S. Customs and Border Protection that ensures bone marrow and blood stem cells coming from Canada to American patients will have uninterrupted transport into the country.

The examples I've just described share two common, and two extraordinarily important, threads. First, this would not have been achieved without NMDP/Be The Match's national program status. And, second, patients in the U.S. would have died had these things not happened. Today, while we have no way to predict exactly what the next emergencies will look like, we nevertheless know with certainty that they are going to happen. Based upon the extraordinary experience of the last four months, we can safely assume that the lynch pin to the solution will be our national program status. And that is why I am before you today, urging your help to ensure timely reauthorization of this Program, in order to mitigate any unnecessary risk to patient life. These are patients already struggling to overcome great odds, and I cannot in good conscience accept an additional threatening variable without speaking forcefully on their behalf.

Because of its unassailable mission, because of its great successes over three decades, and because the Program is relied upon by more patients than ever before, we trust that reauthorization of the national registry remains non-controversial and members of both chambers of Congress, in a bipartisan manner, will once again unanimously choose to place their stamp of approval on the Program's operations going forward. But because of the wild unpredictability of the Covid-19 pandemic, and its downstream impacts that create such risk to bone marrow transplant patients, our ask of you, on behalf of the patients we serve every day, is that you move this reauthorization bill forward with speed to ensure no lapse of the Program, as it is set to expire at the close of this fiscal year. No lapse in the Program means no lapse in our national program status. And that means no lapse in our ability to move mountains in our efforts to leave no patient without the transplant that they so desperately need.

Please allow me to thank you again for the opportunity to submit this testimony and for the Committee's longstanding support for this Program that has given so many a second chance at life with their families and friends. On behalf of those who are alive today, those who are searching the national registry for a matched donor, and those who will need to look to the Program for help in the future, we urge you to once again reauthorize the C.W. Bill Young Cell Transplantation Program, and we respectfully ask that you do so prior to the Program lapsing at the end of September, in order to best ensure that the scourge of global pandemic will not unnecessarily claim the lives of patients in need of bone marrow transplant.