Attachment—Additional Questions for the Record

Subcommittee on Health
Hearing on
"Improving Access to Care: Legislation to Reauthorize Key Public Health Programs"
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The Honorable Anna G. Eshoo (D-CA):

1. Black patients have a 23 percent chance of finding a matching, available blood cell donor, in comparison to White patients who have a 77 percent chance. How is your program working to address this disparity and is there anything that Congress should be doing to help in your work?

Madam Chairwoman Eshoo,

On behalf of National Marrow Donor Program (NMDP)/Be The Match, thank you for your question and for providing us the opportunity to highlight our lifesaving work, in particular our efforts to better serve historically underrepresented populations. NMDP/Be The Match is dedicated to ensuring that all patients receive access to life-saving cellular therapy. To that end, in 2018, our Board of Directors and executive leadership launched a five-year strategic plan with the audacious goal to ensure that every American, regardless of ethnicity, background, age, or socioeconomic status, has an equal chance at finding a volunteer bone marrow donor, and a successful outcome from their transplant. We refer to this as *Democratizing Cell Therapy*.

NMDP works every day to democratize cellular therapy and drive equal outcomes for all. We are approaching this challenge from multiple perspectives. To disrupt the disparity, it is critical that we grow the number of Black/African American volunteer donors on the Be The Match Registry, increase the likelihood that they say "yes" when we call them to donate, and provide advanced research to address the gap in supply and demand for unrelated donors.

When it comes to matching human leukocyte antigen (HLA) types, a patient's ethnic background is of fundamental importance in predicting the likelihood of finding a match. It is far more complicated than blood typing and can be hard to match as there are many HLA markers and some HLA types are far less common. This is because HLA markers used in matching patients with donors are inherited. Some ethnic groups have more complex tissue types than others. A person's best chance of finding a donor is most often with someone of the same ethnic background. Patients who need a transplant benefit from what we refer to as a perfectly matched

8/8 antigen donor. The data indicate that genetic HLA uniqueness is becoming greater in our younger populations. In the United States, 36 percent of the population is without a single 8/8 matched donor on the registry. While match rates for White Americans are greater than 75 percent, Asian and Hispanic populations within the U.S. each have 8/8 match rates below 50 percent and Black Americans have an 8/8 match rate of less than 30 percent.

While we work to address all disparities in access, a critical focus is to increase the number of Black/African American members on the registry. Currently, we are investing ten times the funding to recruit a Black/African American donor compared to a White donor. As the nation's registry, we act ceaselessly to increase the number of volunteers on our registry, and this challenge becomes even more pronounced as the genetic makeup of our population continues to diversify. As of today, the Be The Match Registry is comprised of 42 percent ethnically diverse donors (as compared to other far less diverse international registries, including the world's second largest registry, which is a private German-based registry that is comprised of only two percent ethnically diverse donors).

NDMP/Be The Match recognizes the deeply rooted historic mistrust of medical institutions in traditionally underserved populations. Furthermore, misinformation about cost, confidentiality, and discomfort related to bone marrow and blood stem cell donation has discouraged potential donors from signing up. We are committed to sharing the facts and setting the record straight, while building trust within the community and awareness about donation. We are leveraging funds to drive awareness and action through:

- Dedicating 100 percent of our marketing resources to disrupting this health disparity and recruiting ethnically diverse donors.
- Partnerships with Black/African American Civic and Community organizations like the National Urban League Young Professionals, Sigma Gamma Rho Sorority, Inc. and 100 Black Men.
- Targeted public relations and partnership campaigns with trusted community leaders and influencers.
- Focused communications at opportune moments, such as Sickle Cell Awareness Month, Black History Month, and Juneteenth.
- A dedicated multi-channel marketing campaign in Atlanta, St. Louis and soon Chicago.
- Increased efforts with Historically Black Colleges and Universities (HBCUs), including a paid intern program to develop peer-to-peer influencer programs that drive awareness.

In addition to adding new members, we are also providing a best-in-class registry member experience so that when they are called to donate, our Black/African American registry members say "yes." To accomplish this, we are developing dedicated Black/African American marketing experiences that incorporate multiple forms of communication including personalized outreach. We have also recently launched a Donor Engagement Team that specializes in outreach to Black/African American donors to make the first contact.

Furthermore, we are committed to accompanying patients on every step of their journey. As provided for in our authorization legislation, we maintain the Office of Patient Advocacy which is dedicated to breaking down barriers to transplant for patients and their families. Our professional staff provides a full range of services that help patients navigate roadblocks that can develop throughout a patient's experience. These include financial barriers, insurance coverage issues, and logistical challenges related to the proximity to transplant centers and medical care. Many families find that their insurance doesn't cover all the costs associated with a transplant. NMDP/Be The Match Foundation raises funds to help patients cover costs and nearly 30 percent of these Patient Assistance Funds were paid out to ethnically diverse patients.

To improve patient outcomes, critical information about a patient's disease course must be provided to them as early as possible. This is why we launched our "HLA Today" strategic initiative, which provides preliminary donor search reports for patients newly diagnosed with blood cancers and disorders at no charge to providers or patients. Just last year, we saw a 28 percent increase in ethnically diverse patients, who may otherwise have gone without transplant, be referred to transplant treatment options through this initiative.

Furthermore, unlike any other registry in the world, we sponsor and support medical research to improve genetic typing initiatives to enhance the matching process and improve the outcome for mismatched donors, who have no other transplant options. We are currently investing $8.8 million over four years to address the gap in suitable volunteer unrelated donors. For patients who need a transplant but who lack what is called a perfectly matched 8/8 antigen donor, alternatives include a mismatched volunteer donor if we are able to ensure similarly successful outcomes.

We recently modeled donor availability if we were able to successfully perform unrelated donor transplants using both 8/8 and 7/8 matched unrelated donors. The impact was substantial. As previously noted, match rates vary significantly by ethnic group, reflecting a combination of intrinsic HLA diversity within populations and the ethnic composition of the registry. By expanding the potential donor pool to include 7/8 antigen matches with outcomes matching 8/8 matching donors, the ability for Asian Pacific Islanders to find a suitable donor increases from 40 percent to 85-90 percent, for Hispanics from 48 percent to 90 percent, and for Black/African Americans from 20 percent to over 70 percent.

Thus, research focused on enabling the more frequent and successful use of 7/8 matched volunteer unrelated donors would bring BTM/NMDP closer to its vision of Democratizing Cell Therapy.

We continue to support the work of the Center for International Blood and Marrow Transplant Research (CIBMTR) in maintaining the Stem Cell Therapeutic Outcomes Database (SCTOD), which also is mandated in our authorizing statute. This data is invaluable in tracking outcomes and helping doctors and researchers learn from every bone marrow transplant. It is an important way in which we measure our success at meeting our goal of a successful outcome for every patient, regardless of race or ethnicity.

As we continue to strive toward our vision of Democratizing Cell Therapy and to close treatment disparities between White patients and patients of color, we recognize that financial barriers to transplant remain a material obstacle to access to care, particularly for historically underserved populations. This is why we so appreciate your gracious inquiry about what more Congress might do to help in this work.

We know that Congress right now is undergoing a critical self-examination and taking a hard look at all ways in which we as a nation can break down barriers impeding the ability of underserved communities to receive the medical care and other services they need to improve life expectancy and treatment outcomes. Our focus as a national program is to examine ways in which we can disrupt disparities that prevent patients of color from accessing life-saving transplant and cellular therapies that cure blood cancers and sickle cell anemia. As you evaluate investments that Congress will make to eliminate health disparities, National Marrow Donor Program would ask that Congress provide funding support to eliminate all search fees for all patients and offer those services free of charge. We believe this will have the single greatest impact in moving patients onto the transplant pathway and providing a second chance at life to people who would otherwise not have access to transplant due to financial barriers. Not only will free search services substantially increase the number of ethnically diverse patients who proceed to transplant in the United States, it also will mirror the growing trend of other registries across the world, which are beginning to do the same. This will avoid the adverse impact to our national interests from foreign registries entering the United States and attempting to offer a lesser quality registry option in the U.S. market and exploiting the infrastructure investment that has been built by the public-private partnership between NMDP and the federal government over the past 30 plus years.

At a time when our nation is evaluating the impact of racial and social disparities on the availability and quality of medical care in underserved populations, we take these challenges very seriously. Expanding our partnership with Congress and federal agencies in this way will enable us as a program to focus our resources on the other ways that we as a national program, unlike our overseas competition, can build and diversify our national registry, better support patients as they navigate around the myriad of barriers that can prevent them from receiving a lifesaving transplant, support research to improve the transplant procedure and expand the list of diseases for which it is a cure.

We want to help you and the members of your Committee as you work to increase access to medical care for underserved populations. We appreciate the unwavering commitment of Congress for legislation that supports the Be The Match Registry and for the funding will be required to ensure that the full range of services are available to all patients regardless of their race or socioeconomic background. We look forward to discussing the legislative and funding requirements that will be necessary to achieve our shared commitment to provide equal access and outcomes to all of our searching patients.

Sincerely,

Brian Lindberg
Chief Legal Officer and General Counsel
Chief Policy Officer,
National Marrow Donor Program/Be The Match