HEARING BEFORE THE UNITED STATES HOUSE OF REPRESENTATIVES COMMITTEE ON ENERGY AND COMMERCE, SUBCOMMITTEE ON HEALTH

Summary of Testimony of Amy Ronneberg
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- National Marrow Donor Program (NMDP) has been entrusted as a federal contractor to HRSA to operate the federally authorized C.W. Bill Young Cell Transplantation Program (Program) that coordinates bone marrow, blood stem cell, and cord blood transplants nationwide. The Program houses the American registry of volunteer blood stem cell donors and the National Cord Blood Inventory (NCBI).

- The success of this lifesaving Program relies on federally overseen infrastructure that ensures a seamless national system—from a searchable registry and targeted donor recruitment, coordinated cell transport, and the continuous tracking of patient outcomes to improve results and save more lives.

- The C.W. Bill Young Cell Transplantation Program current authorization expires on September 30, 2026. The Stem Cell Therapeutic and Research Reauthorization Act of 2025 (H.R. 5160) reauthorizes the Program for another five years.

- Sustained Congressional support has improved outcomes, increasing match rates from 50 percent five years ago to 99 percent today for adult blood cancer patients.

- In its first 33 years, the Program facilitated 100,000 transplants; since 2019, it has enabled nearly 50,000 more—demonstrating the scientific advancements and systems modernization that have expanded lifesaving access to transplant.

- The Program relies on altruistic young, healthy volunteer donors. As previous donors age out, continued federal support ensures robust recruitment of additional young donors, to maintain the strength of the registry.

- The Program has never missed a delivery, due to strong collaboration with federal agencies including TSA, CBP, CDC, FDA and even the Departments of State and Defense.

- Please reauthorize the C.W. Bill Young Cell Transplantation Program to avoid disruptions to life-saving care.

Chairman Guthrie, Ranking Member Pallone, Subcommittee Chairman Griffith, Vice Chair Harshbarger, Ranking Member DeGette, and Members of the Subcommittee, my name is Amy Ronneberg. Since 2020, I have had the honor of serving as Chief Executive Officer of National Marrow Donor Program (NMDP). I lead the organization in advancing our mission to save lives through cell therapy and create a world where every patient can receive their life-saving bone marrow transplant. Our work is carried out through a true public/private partnership with the federal government. We have been entrusted with operating C.W. Bill Young Cell Transplantation Program (Program), which coordinates life-saving bone marrow, blood stem cell and umbilical cord blood transplants to patients facing blood cancers and disorders. This Program houses the American registry of volunteer blood stem cell donors and the National Cord Blood Inventory (NCBI). It also seamlessly coordinates and facilitates the timely delivery of life-saving cells to patients and their care teams, provides end-to-end support to patients and their loved ones throughout the transplant journey, and tracks the outcome of each U.S. bone marrow transplant to improve future treatments.

On behalf of the entire team at NMDP and each critical partner in the transplant process, I thank the members of the Health Subcommittee for the opportunity to testify and to share the successes the Program has achieved over the past five years. As a committee, your leadership has sustained a Program that has impacted nearly 150,000 patients.

Congress' ongoing investment and oversight of a nationally coordinated infrastructure ensures consistent, accountable, and reliable outcomes for patients, no matter where they live. In each of your home districts, there is someone who has joined the registry, a volunteer blood stem cell donor who has already said yes to save a life, or a patient who has seen their blood cancer or disorder treated or cured because of the Program.

A special thank you to the Program's long-time champions Representatives Chris Smith and Doris Matsui, along with Representative Bilirakis, Representative Dingell and a growing list of bipartisan cosponsors, for their leadership on the Stem Cell Therapeutic and Research Reauthorization Act of 2025 (H.R. 5160) to reauthorize this Program for another five years. They have been tireless champions for patients whose lives depend on a bone marrow transplant.

The Program's success is thanks in large part to Congressional vision and its decades-long commitment to patients with blood cancers and blood disorders. And it started out of the love of a child, Laura, who was fighting leukemia and needed a bone marrow transplant but had no matching donors in her family. Her parents agreed to the groundbreaking idea of using an unrelated donor's cells for the transplant, not just to support their daughter but every family in their shoes. They found a champion in Republican Congressman C.W. Bill Young from Florida, to ensure nationwide access to this life-saving option.

Like Laura, 75% of blood cancer and disorder patients do not have a fully matched donor in their family and must rely on a stranger to save their lives. The Program expands the availability of unrelated volunteer adult blood stem cell donors and high-quality cord blood units, increasing the likelihood that every patient can find a match. There are more than 75 blood cancers and disorders that can be treated and cured with a transplant.

In our first 33 years, the Program facilitated 100,000 transplants – and since 2019, that number has grown by nearly 50,000. That's an increase of more than 30% in lives impacted since the last reauthorization. This wouldn't be possible without the continued commitment of Congress. Unlike other medical treatments, there is no waitlist for bone marrow or blood cell transplants, only the availability of a suitable genetic match and the willingness of an altruistic donor to step forward.

Further, five years ago, during the last reauthorization cycle, only 50 percent of people looking for a match could find one. Today, thanks to recent scientific advancements, demonstrated in part by high impact, peer-reviewed studies facilitated by the Program, physicians can now find a suitable donor match for adult patients with common blood cancers in 99 percent of cases. This acceleration reflects the power of sustained investment, innovation, and efficiency improvements that are dramatically expanding access and improving outcomes for patients.

It's remarkable how far we have come. Starting with searching index cards in physicians' offices, the national registry has transformed into one of the world's most responsive modern, searchable databases to support doctors and patients, when time is critical. The American registry now spans over 9 million potential U.S. donors, something once considered unimaginable. Through a single, searchable platform the Program integrates 43 million donors and 760,000 cord blood units worldwide for fast filtering to expedite a patient to transplant.

Because donors inevitably age off the registry, maintaining its strength requires continuous recruitment of young, healthy donors. This ongoing process is a core responsibility of the Program and relies on sustained Congressional support. Each year, through NMDP's robust recruitment efforts, the Program brings forward a new generation of altruistic volunteer donors—individuals willing to give a stranger a second chance at life. This ongoing growth is not accidental; it is guided by data, science, and a clear national purpose. The Program conducts rigorous, periodic scientific analyses to assess how well the U.S. inventory of adult donors and cord blood units meets the needs of patients across the country. These analyses inform efficient, targeted recruitment strategies and help ensure the registry continues to evolve to meet the needs of the American people.

Taking healthy cells of a stranger to save the life of another? People said it couldn't be done. And yet we did it, and we keep doing it, again and again.

There are no shortcuts in this life-saving Program, from donor recruitment and matching to secure cell transport and patient recovery; every step must be done right, every time. Once a donor is identified, NMDP coordinates and facilitates every step—from donor medical clearance to the secure, time-sensitive transport of life-saving cells by trained medical couriers, often across states or countries. After transplant, patients and caregivers receive critical support through their recovery, while a national outcomes database, maintained by NMDP's partner at the Medical College of Wisconsin (MCW), drives continued research, accountability, and improvement in patient outcomes.

Through natural disasters, 9/11, global events and routine travel roadblocks, I am extremely proud that we have a pristine record having never missed a cell delivery. This success is due in part to our strong federal government collaboration. As a federal contractor to HRSA operating under Congressional oversight, NMDP can move life-saving cells swiftly, safely, and efficiently from donor to patient by working in close partnership with several federal agencies. More than 90 percent of the time, donors are in a different city, state, or even country than the patients, requiring clearances and access that only our federal government can provide. By working hand in hand with agencies like the Transportation Security Administration (TSA) and Customs and Border Protection (CBP), in some cases the Departments of State and Defense. NMDP ensures cells move securely through complex logistics and remain viable for the waiting patient and their care team.

Even during extraordinary circumstances like the COVID-19 pandemic, this coordinated federal partnership ensured cells arrived on time, every time. This included securing waivers to the

European travel ban and the U.S.–Canada border restrictions for medical couriers and collaborating with Department of Homeland Security (DHS) Cybersecurity and Infrastructure Security Agency to designate donors and couriers as essential critical infrastructure workers. Together, these efforts ensured that patients could continue receiving timely, life-saving` treatment despite unprecedented global disruptions.

In short, this work depends on a federally authorized, nationally coordinated infrastructure, supported by Congressional oversight and interagency collaboration, to enable uninterrupted access to life-saving donors. The federal Program has stayed true to its nearly 40-year-old promise, matching patients with unrelated donors, giving them the best chance for longer, healthier lives. And its future—its ability to reach the next child, the next family—relies on Congress.

Reauthorization is a commitment to ensuring that life-saving care remains available to patients across the United States. Thank you again for your longstanding commitment to this Program and your leadership to save patient lives.

With the current authorization set to expire on September 30, 2026, I respectfully urge Congress to pass the Stem Cell Therapeutic and Research Reauthorization Act of 2025 without delay to ensure the seamless continuation of this critical Program.