

13 July 2020

SITREP for the National Marrow Donor Program

The Request

National Marrow Donor Program (NMDP) asks that the House and Senate act in concert to ensure the timely enactment of legislation to reauthorize the C.W. Bill Young Cell Transplantation Program (the "Program") before Program authorization lapses on October 1, 2020. This would be a simple five-year reauthorization of this noncontroversial Program. As further evidence of its bipartisan nature, the Program's authorization has never lapsed since it was first enacted in 2005. Failure to timely reauthorize would have potentially catastrophic impacts on NMDP's operations and the patients it serves.

Situation Summary

NMDP operates this federally authorized Program that matches unrelated volunteer bone marrow donors with patients in the United States and abroad who have been diagnosed with leukemia and over 70 more otherwise fatal blood disorders and diseases. Under contract with the Department of Health and Human Services/Health Resources & Services Administration, the Program is charged with providing equal access for all patients in a need of a life-saving cellular therapy. In addition to matching donors and patients, another of the Program's primary missions is coordinating the delivery of bone marrow domestically and internationally to patients in the United States and abroad.

NMDP's status as operator of the federal Program places NMDP in a unique posture allowing it to perform its obligations to the country and the patients it serves. In the event the Program's authorization lapses, NMDP's ability to successfully accomplish its life-saving obligations is threatened. The most foundational aspects of NMDP's operations, including its ability to transmit and receive critical donor and patient information between and across the members of its network, including the donor centers, bone marrow collection centers, and the hospitals where patients receive their transplants, hinge on NMDP's status as the operator of the Program. If the Program lapses, that status lapses along with it, threatening the critical infrastructure that now allows this life-saving activity to continue unabated.

Moreover, as outlined below, these concerns are substantially magnified by global pandemic.

The Current Situation – Global Pandemic

The impacts of the Covid-19 pandemic to the Program have been significant and far-ranging. As one example, increasingly restrictive domestic and international travel bans and border closings, and the declining availability of scheduled commercial passenger aviation service on international and domestic routes, have created near catastrophic barriers to NMDP's ability to timely facilitate transplants for patients in dire need. Those patients, who are in the midst of treatment protocols, suffer from conditions that have deteriorated to the point that a bone marrow transplant is the only course of treatment that will save their life.

During the pandemic, NMDP has thus far been able to mitigate any disruption to its mission while completing 1,600 lifesaving therapies without missing a single delivery. It has been able to do that, in material part, because of its designation in Federal law as the nation's bone

Operated by the National Marrow Donor Program®



marrow registry. Unfortunately, that designation will lapse with the expiration of the Program's Federal authorization on September 30, 2020.

Thanks in large part to the authorizing statute, NMDP was:

- Granted a waiver in March from the Director of the Centers for Disease Control to the European Travel Ban that was 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.
- Received CISA classification by the Department of Homeland Security as Critical Infrastructure 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 into and out of countries that have closed their borders to international travel.
- Granted temporary 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 United States.

The NMDP's ability to call upon our Federal partners in these extreme circumstances, and NMDP's standing in the eyes of foreign governments where we must operate, will be compromised after September 30th if Program authorization expires. This unnecessarily puts at risk NMDP's ability to continue to ensure the timely delivery of life-saving cellular products to otherwise terminally ill patients here and throughout the world.