

Donor Registries: Background

The process of searching for an unrelated donor for a specific patient begins with research into the holdings of databases of donor HLA typings that have been collected by registries in the US and around the world. In order to better understand the search process, it is helpful to understand how the donor registries developed and how they now operate.

History of Donor Registries

In the earliest days of BMT, starting in the late 1950s, the procedure was only done between identical twins, who were understood to “match” each other genetically, even before there was scientific knowledge of the immune system and DNA. This work was started in New York state by Dr. Donnall Thomas, who later received a Nobel Prize in medicine for this pioneering work in the BMT field. (Dr. Thomas went on to become one of the founders of the Fred Hutchinson Cancer Research Center in Seattle, which opened in 1972.) Further research led to the start of BMTs using sibling donors starting in 1968. The first successful unrelated BMT was done in 1973 for a child with an immune disorder, and in 1979 for a child with leukemia.

After this start, efforts began in many of the industrialized countries of the world to create registries of potential volunteer donors, in order to systematize recruitment of donors for BMTs. In the US, the passage of the National Organ Transplant Act (NOTA) in 1984, led to the creation of the National Bone Marrow Donor Registry in 1987. Start-up funding for the Registry came from both military (Navy) and civilian (National Institutes of Health) branches of the federal government. At first, the American Red Cross was contracted to operate the program, which was based in St. Paul, MN. When the NOTA was reauthorized in 1988, it authorized establishment of a registry. At that time, the NBMDR Board changed the registry name to the National Marrow Donor Program (NMDP), and administrative responsibility for it was transferred to the US Department of Health and Human Services (HHS).

In 1990, the NMDP became a separate private nonprofit organization in Minneapolis, and was contracted by HHS to operate the registry, replacing the Red Cross. Responsibility for maintaining the public US BMT donor registry resides with the Division of Transplantation of the Healthcare Systems Bureau of the Health Resources & Services Administration (HRSA) of HHS. HRSA does not operate the registry itself, but continues to contract out this federally-funded service. The selection of the registry contractor is done through a competitive bidding process, when the program comes up for renewal every 5 years. For the renewal to occur each time, Congress must pass enabling legislation that is then signed into law by the President. To date, at each renewal, the registry contract has been awarded to the NMDP. The Office of Naval Research continues to fund scientific research and minority donor testing conducted by the NMDP.

Related efforts to develop BMT programs for contingency support of military personnel exposed to radiation or chemical warfare agents, led to the creation in 1985 of a BMT research and donor recruitment program within the Department of Defense. The DoD’s C.W. “Bill” Young Marrow Donor Program is named after Congressman Young (R-FL) who was instrumental in working for its creation. Donors recruited by with this program, which is part of the NMDP Network, donate to both military and civilian patients.

On a global level, work to create donor registries began in 1970 with efforts in Germany to catalog the HLA typing results of volunteer blood donors to be used for platelet transfusions and BMTs. The first registry in the world was the Anthony Nolan Trust in the UK, established in 1974. By 1989, these pioneering efforts led to the creation of Bone Marrow Donors Worldwide, a registry of registries linked to a central international search engine. Presently international transplants facilitated by the NMDP account for 15% of both recipients and donors; the NMDP is now the largest single registry in the world.

Donor Registries Today

The BMDW database now contains typing for 11.3 million potential donors from 42 countries; 6 million of whom are listed with the NMDP in the US. There is also now an international listing of cord blood units managed by the International NetCord Foundation based in Germany, which is linked to BMDW. Of over 300,000 cord blood units typed and stored in public banks, about two-thirds are in the US. In late 2006, the NMDP and NetCord finalized a Search Exchange Agreement to link their registries so that transplant centers worldwide can simultaneously search both databases.

Consumer advocacy efforts have continued to play an important role in making sure that the US registry fulfills its mission of serving the public. Early on, BMT survivors and patient families were concerned by the registry’s sole focus on donors, while overlooking critical needs of patients and families for information and support. Their efforts led Congress to include these concerns in the Transplant Amendments Act of 1990 which led to the creation of the Office of Patient Advocacy of the NMDP in 1991. This legislation also led to the first allocation of federal funds for donor typing. Continued citizen efforts to include the recruitment of donors from under-represented racial/ethnic groups as a program priority, led to new NMDP recruitment programs starting in the mid-90s, when existing ethnic-specific recruitment groups were incorporated into the NMDP Network for the first time. Subsequently, equity goals were included into the language of the National Bone Marrow Registry Reauthorization Act of 1998, which spelled out the need for diversifying the pool of donors in the

NMDP registry.

In December of 2005, the Stem Cell Therapeutic and Research Act of 2005 was passed by US Congress and signed into law, creating the C.W. "Bill" Young Cell Transplantation Program. Under this new name (said to have been selected in honor of the ongoing work of Rep. Young to promote BMT donor recruitment, but not part of the DoD program of similar name) a national public cord blood program was added to the existing functions of the NMDP, along with the creation of the NMDP-affiliate Center for International Blood & Marrow Transplant Research (CIBMTR), a statistical center to track and report outcomes of all BMTs done in the US. Federal contracts to operate the components of the program were awarded to the NMDP in 2006,

There is also a renewed contingency planning component, now called the Radiation Injury Treatment Network.

Another part of the new program is the Center for Cord Blood, also run by the NMDP, which works with 6 designated public bank programs around the country to receive donations of umbilical cord blood for the National Cord Blood Inventory (NCBI). Our state contributes to the NCBI through the cord blood program of Puget Sound Blood Center in Seattle, which presently receives donations from births at 5 Seattle-area hospitals. Before the end of FY 2007, more banks are planned to be added to the national program, which has a stated goal of increasing the genetic diversity of donations in order to better benefit more patients.

Federal Advisory Committee

The 2005 legislation also mandated for the first time in the history of federal BMT program, the creation of an Advisory Council on Blood Stem Cell Transplantation as part of the C.W. "Bill" Young Cell Transplantation Program. The Council is to be composed of BMT health professionals from all disciplines, scientific researchers, healthcare advocates, BMT donors and recipients, patients families, and interested members of the public. The charge of this group is to study and give advice to HHS on all operational and policy aspects of the program. The deadline for nominations for the new body was February 2007. On October 2, 2007 the American Association of Blood Banks (AABB) sent a letter to HHS Secretary Leavitt expressing concern that no action had yet been taken to establish the Advisory Council.

On January 18, 2008 HRSA announced the establishment of the ACBSCT, which will hold its first meeting on Jan. 28-29 in Rockville, MD. The ABSCT membership roster may be found on HRSA's C.W. Bill Young Cell Transplantation Program website. None of the committee members represent community minority-focus organizations or BMT donor recruitment groups. A few of the medical professionals are themselves members of minority groups and have involvement in equity-related work.