

**CHRISTOPHER H. SMITH**

4TH DISTRICT, NEW JERSEY

CONSTITUENT SERVICE CENTERS:

MONMOUTH  
112 Village Center Drive  
Freehold, NJ 07728-2510  
(732) 780-3035

OCEAN  
405 Route 539  
Plumsted, NJ 08514-2303  
(609) 286-2571; (732) 350-2300

MERCER  
4573 South Broad Street  
Hamilton, NJ 08620-2215  
(609) 585-7878

2373 Rayburn House Office Building  
Washington, DC 20515-3004  
(202) 225-3765

<http://chrissmith.house.gov>



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## Stem Cell Therapeutic and Research Act of 2015

*Urging Passage of H.R.2820*  
*U.S. Rep. Chris Smith*  
*(Excerpts of Floor Remarks)*  
*September 8, 2015*

Mr. Speaker, Maalik was diagnosed with Hurler Syndrome at 15 months old—a rare and life-threatening metabolic disorder. He had a curved spine and could not walk. After receiving an umbilical cord blood transplant facilitated through the Carolina Blood Bank, Maalik is running around and expected to have a normal lifespan. His mother Krystal told the Herald Sun newspaper in North Carolina, “My son is extremely happy now... He’s energetic, and more independent. The transplant saved his life.”

In like manner, bone marrow donations provide lifesaving transplants to treat diseases like blood cancer or inherited metabolic or immune system disorders. Clara was only 4 months old when she was diagnosed with acute myeloid leukemia. John had registered with the National Marrow Donor Program (NMDP) Be the Match as a bone marrow donor when Clara was only 17 days old. It turned out he was a perfect match for Clara. John’s donation saved Clara’s life, she is now a thriving 2 year old.

Valentina was 10 months old and only 13 pounds – and diagnosed with severe combined immunodeficiency (SCID). Her doctor treated her with chemotherapy followed by a cord blood transplant. 5 months after the transplant Valentina weighed 21 pounds and doctors credited her strengthened immune system from the stem cells in cord blood.

Jennifer, 45, was suffering from acute myeloid leukemia but unable to find a matched bone-marrow transplant. Because of the high rate of tissue type diversity among racial and ethnic minorities it can be difficult to find a matched bone marrow transplant, but umbilical cord blood

can be successfully used for treatment with a less perfect match of tissue type. After undergoing chemotherapy and radiation she received a cord blood transplant, and is now living cancer free.

Not only has God in His wisdom and goodness created a placenta and umbilical cord to nurture and protect the precious life of an unborn child, but now we know that another gift awaits us immediately after birth. Something very special is left behind—cord blood that is teeming with lifesaving stem cells.

Breathtaking scientific breakthroughs have turned medical waste—post birth placentas and umbilical cord blood—into medical miracles treating more than 70 diseases including leukemia, lymphoma and sickle cell anemia.

As a matter of fact, Dr. Joanne Kurtzberg of Duke University and President of the Cord Blood Association told Chairman Pitt's Health Subcommittee on June 25 that sickle cell anemia can be "cured" with cord blood transplantation and that "it has become one of the optimal donor sources for patients with sickle cell disease" because it doesn't have to be perfectly matched.

H.R. 2820 under consideration by the House today reauthorizes through 2020 the Stem Cell Therapeutic and Research Act of 2005 a law that I sponsored a decade ago joined by Artur Davis of Alabama; legislation that cleared the Senate with the incomparable help of Senator Orin Hatch. That law built upon the excellent work of our distinguished late colleague Bill Young of Florida to facilitate bone marrow transplants and created a brand new national umbilical cord blood donation and transplantation program.

Special thanks to both Chairmen Upton and Pitts for their outstanding leadership and help on this bill, as well as the strong support by Ranking Members Pallone and Green. I am deeply grateful to original cosponsors Ms. Matsui, Mr. Jolly and Mr. Fattah for their important contributions.

Today, Mr. Speaker, under the National Cord Blood Inventory Program (NCBI), contracts are awarded to cord blood banks to collect cord blood units donated after mothers give birth. These units are then made available through the C.W. Bill Young Cell Transplantation Program also called the Be the Match Registry. The Program provides a single point of access, enabling those in need of lifesaving transplants to search for a match via an integrated nationwide network of bone marrow donors and cord blood stem cells. The Program's Bone Marrow and Cord Blood Coordinating Centers makes information about bone marrow and cord blood transplant available to donors and patients, and the Office of Patient Advocacy helps support patients and families dealing with a life-threatening diagnosis. And the Stem Cell Therapeutic Outcomes Database tracks results.

Americans willing to volunteer are the heart of the success of this program. In reauthorizing it we are grateful for the adult donors willing to donate bone marrow or peripheral

blood stem cells, as well as mothers who donate their babies' cord blood through public cord blood banks.

There are 13 public banks contracted through NCBI, including the New Jersey Cord Blood Bank in my home state, which collects cord blood from [5 participating hospitals](#).

According to the Health Resources and Services Administration (HRSA), every year 18,000 people in the US are diagnosed with illnesses for which blood stem cell transplantation from a matched donor is their best treatment option. Of this number, only about 30% have a sibling who can be the ideal matched donor, so about 12,600 people annually depend on the programs made available by this law to find an unrelated adult marrow donor or cord blood unit for treatment.

Cord blood transplants have accounted for about one half of the growth in stem cell transplants since NCBI was established in 2005. More NCBI units have been released for transplantation with each successive year since the program's inception.

In addition to currently treating more than 70 diseases, cord blood units from NCBI banks are also made available for research on future therapies. In groundbreaking research, Dr. Kurtzberg of Duke University also testified last June that "in addition to use in patients with malignant and genetic diseases, cord blood is showing enormous potential for use in cellular therapies and regenerative medicine. Cord blood derived vaccines against viruses and certain types of cancers are currently under development and in early phase clinical trials. Cells, manufactured from cord blood units are being developed to boost recovery of the immune system. Cells regulating autoimmunity (Regulatory T cells) are also in clinical trials. These approaches, which often utilize cord blood banked in family banks, may help patients with Type 1 Diabetes, as well as other diseases."

Dr. Kurtzberg further testified that she and others are developing uses for cord blood to treat acquired brain disorders. "Over the past six years" she said "we have initiated trials of autologous (the patient's own) cord blood in babies with birth asphyxia, cerebral palsy, hearing loss and autism..."

Dr. Kurtzberg has also said "We've learned that when donor cells are infused into one's body, they go to the brain and help heal the brain. When a child has a brain injury around birth, we can use their own cord blood cells to correct the damage that's occurred."

Dr. Jeffrey W. Chell, CEO of NMDP/Be the Match noted that for many diseases including blood cancers and sickle cell disease, cellular therapy is the best hope for a cure. He told Chairman Pitts subcommittee that the patient population "rising the most quickly is the elderly population...growing by double digits every year, and the reason for that is the medical

conditions for which transplant is often the only cure tend to occur in older populations for diseases like acute myeloid leukemia, myelodysplastic syndrome, myelofibrosis and others.”

Last year, Mr. Speaker, I visited Celgene Corporation of Summit , New Jersey to learn of their extraordinary efforts to use cord blood to heal diabetic foot ulcers and how they’ve turned amniotic membrane—an old placenta—into wound management that has now advanced past stage 3 clinical trials to the approval and regulatory filings stage.

H.R. 2820 authorizes \$265 million over five years and will ensure that thousands of present-day and future patients benefit from the exciting field of regenerative medicine.