

State of Connecticut
SB290
An Act Requiring Health Insurance Coverage for Bone Marrow Testing

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290

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First, I would like to thank you for taking the time to read my statement regarding the above mentioned bill that is before you today.

In August of 2005, I approached my New Hampshire State Representative, Nancy Johnson asking her if it would be possible to have a bill written that would ask New Hampshire based Insurance Companies to cover the cost of tissue typing their insurers who wish to join the National Marrow Donor Program Registry. In May of 2006, the State of New Hampshire passed the bill, affording many more New Hampshire residents the opportunity to become a member of the Registry.

I am so excited that the State of Connecticut, where I grew up, is now addressing this important issue. I became involved with the NMDP in 2004 when my 14 month old grand-niece Carsyn Gilloren from Beacon Falls, CT was diagnosed with AML, a form of Leukemia that is usually found in adults over the age of 50. In order for her to survive, we were told that she needed a bone marrow transplant. I had heard of the disease but knew nothing of what it entailed. Testing began on her immediate family members to see if anyone was a match. I will never forget that day in September of 2004 when I got a call with the news that Avery, Carsyn's four year old sister, was a perfect match.

As I learned more about Leukemia, I realized that Carsyn was one of the lucky ones. She had a donor. I remember thinking, how devastating it must be to be diagnosed with Leukemia or any other disease that required a transplant and not being able to find a donor. I called Dana Farber Cancer Institute / Children's Hospital in Boston to find out how I could help put more people on the registry. I learned that bone marrow drives needed to be planned and set about doing just that. I was told the cost would be \$65 per person and planned a raffle to make sure that we raised enough money so that the people who responded would not have to pay to become members of the NMDP Registry.

I was amazed during this whole process of planning a bone marrow drive how uneducated our community was regarding bone marrow transplants, the simple blood test (now cotton swab) involved in getting on the registry and the commitment one makes when they become a member of the National Marrow Donor Program Registry. I did not realize the importance of bone marrow and I am sure that if this disease hasn't hit you close to home, you probably don't either. The time and effort it takes to plan a successful bone marrow drive is enormous. I know that if I did not have to worry about raising enough money to cover the cost of adding donors to the registry, I would have been able

to put more effort into educating my community on the importance of being a donor and the responsibility that comes with this decision.

It has been my mission since our bill passed in New Hampshire to instill in our young adults the importance of giving of oneself for something one believes in. When a young person turns 18, I want them to think of two things: "I need to register to vote and I need to become a member of the NMDP Registry." We all know that every vote makes a difference and every bone marrow donor has the potential of making a difference in someone else's life.

I have watched Carsyn grow healthier each day because she was lucky enough to have her sister Avery as her donor. I have worked closely with Terry Chase of Alton, NH during the numerous drives held to find him a donor. Patients and family members must work tirelessly to plan drives in hopes of saving their loved ones life. The cost of putting a person on the registry pales compared to the cost of treating patients while they wait in hopes of finding a donor. The more people on the registry, the more likely that a donor can be found and the road to recovery can begin.

I ask that you sit back for a moment and imagine that you or someone you love has been diagnosed with a disease that requires a bone marrow transplant. Look into your heart and ask yourself this important question, "What is a life worth?"

It's worth a vote YES in support of SB 290!

Thank you again for your time.

Sincerely,

Christina L. Maiorino