

February 3, 2009

290

State of Connecticut General Assembly
Committee on Insurance and Real Estate
Legislative Office Building
300 Capitol Avenue
Hartford, CT 06106

To the Members of the Insurance and Real Estate Committee in support of S.B. 290
An Act Concerning Health Insurance Coverage for Bone Marrow Testing:

As the parents of a 3 year old child who has undergone 2 separate bone marrow transplants from two separate donors, we feel strongly that no man, woman or child should ever be denied a bone marrow transplant because of the \$52 registration fee to be tested for the National Marrow Donor Program.

At 6 months of age our son Matthew was diagnosed with a rare genetic condition called Osteopetrosis. Basically this is a condition where Matthew's body lacked ability to remove old bone matter and his body literally started crushing his bone marrow cavities, optic nerves and ear canal. The only way to stop this horrible condition is through a bone marrow transplant.

We spent 143 days living at Memorial Sloan-Kettering Cancer Center in New York, during which time Matthew underwent two rounds of chemo and two separate transplants – as the first one failed. We were extremely fortunate to have found two separate donors, but unfortunately we watched far too many children die because they were not able to find a donor. Matthew would have died if we had not found our donors.

Cost and education are the two biggest hurdles facing those charged with the responsibility of registering donors. No law can be passed requiring an individual to be educated, but one can be passed relieving them of their financial burden to register. As with any other medical "test", health insurance companies should take the responsible and logical approach to cover the once-in-a-lifetime cost to register to be a donor. Without such a wide-reaching support mechanism, more people will needlessly suffer.

Obviously three other New England states have clearly seen that this is the proper course of action. The American Family Life Assurance Company of Columbus, GA (AFLAC) has also seen this as the right thing to do. Unfortunately, as a supplemental insurance company and in those limited states that it is available, one has to purchase the policy to be covered under their "bone marrow donor registration benefit".

We have put together our own information web site that tells more of our experience and speaks directly to the responsibility we feel to do everything in our power to ensure anyone who is eligible is registered to be a donor. **Please feel free to visit www.MatthewWelling.org.**

With all that is wrong with our health care system today, I can not conceive of anyone not wanting to do the right thing – and that is requiring the cost to register to be a bone marrow donor be covered by basic health insurance.

We regret that we are not able to speak with the committee in person, but we welcome any future opportunity to do or communicate further.

Thank you.

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