

# What a difference a day makes!

February 21, 2007

Ladies and Gentlemen of the State of Connecticut:

My name is Mark Lanoue. I want to thank you for the opportunity to make a difference in the lives of so many by making SB00673 and SB1014 a much-needed law. This is a cause that will inevitably benefit every person in the state and therefore also benefit our nation as a whole.

My daughter Hristianna turned three-years-old on November 14<sup>th</sup> of 2004. We took her to her regularly scheduled check-up on November 16<sup>th</sup>. She had been sick with a cold and Dr. Herzog happened to notice that Hristianna's spleen was swollen, but chose to not disclose that information yet. She told us that she would be pricking Hristianna's finger for a small routine blood sample and would likely call later with a prescription for an infection. About three hours later doctor Herzog called us at home to tell us that our daughter had leukemia. We asked her if she was sure. There was no doubt in her mind however, for Hristianna's white blood cell count was 220,000 whereas a three-year-old child's white blood cell count should only be around 9,000. This was when she also informed us that she had noticed Hristianna's spleen was swollen during the check-up but didn't want to worry us unnecessarily. She had already made Hristianna an appointment at the Pediatric oncology ward at Dartmouth Hitchcock Medical Center - this was only the first indication of how urgent the situation truly was.

Upon arrival at the medical center on the morning of November 17th, we were introduced to Dr. Larson and it was made very clear that Hristianna had leukemia - we were about to go through the initial testing phase to find out what type of leukemia she had. They proceeded to draw blood for testing and then a bone marrow tap into her hipbone. Hours later we reported back to Dr. Larson's office. Ultimately, the diagnosis couldn't have been worse. Hristianna had Chronic Myelogenous Leukemia (CML), a leukemia prominent in adult males that less than 2% of children will ever be diagnosed with. He explained to us that the disease will go through three stages: chronic, crisis, and blastic. Finding and treating leukemia in its earliest stage increases the survival rate drastically. Thank God that Hristianna's pediatrician, Dr. Herzog, found the disease in the earliest stage.

Dr. Larsen explained to us that since there are such a small percentage of children who get infected with this disease, there is little known about it in a child's body or when it might progress to the next stage. It could be three days, three months, or three years. Still, he urged us that we move as if Hristianna's disease only had three days before mutating to the crisis stage. This was yet another indication of the severity of her disease.

We next heard the words describing our daughter's fate - her only chance of survival would be a bone marrow transplant. Furthermore, Dr. Larsen informed us of how difficult it would be to find a donor for our daughter. Her genetic makeup made finding a match very slim. To make matters more difficult, Hristianna's age and rare diagnosis meant that Dartmouth would not be able to continue treatment and we were told that her care would have to be transferred to a more specialized treatment center. We chose The Dana Farber Cancer Institute in Boston, Massachusetts. We also learned that the best donor would be an immediate family member, yet there is only a 25 to 30 percent chance of a family member being a match. The entire immediate family would be tested to determine if there was a suitable match. Our oldest daughter, Cassandra flew here from Chicago to be tested as well. However, we later learned that none of

us were a proper match.

We left Dartmouth that day and while driving home, I was sickened to find myself singing along with the radio to a song that ironically couldn't have fit the situation better: *What a difference a day makes...*

I immediately found the motivation to do anything possible in order to save my daughter's life. I went to my office and began to get educated by researching Hristianna's disease on the Internet. Realizing that we had to find a donor in order to save our daughter's life would be very difficult but suddenly nothing else really mattered - expanding my business, plans for spending the summer in Greece, or even the movie we were going to see in a day or two. By default, our lives would now revolve around our daughter's disease. Every moment that passed felt like forever. I could barely talk about it without crying. My wife and I were suddenly living day to day hoping that our reality was simply a nightmare. We would talk about how we wished we could wake up and it would all go away. I was literally living life in a daze with blinders on, often finding it hard to draw my next breath.

During our first visit to The Dana Farber Cancer Institute, we met Dr. Leslie Lehmann. Dr. Lehmann is the lead doctor at Dana Farber Cancer Institute for pediatric stem cell and bone marrow transplants, which includes the 13-bed transplant ward at the children's Hospital. Dr. Lehmann reiterated to us on the rarity of Hristianna's disease as well as the slim chance of finding a donor.

We spent the next couple of months going back and forth to Dartmouth and Dana Farber for weekly blood draws - praying every time that our daughter's disease hadn't mutated into the next stage. We had not yet found a match in the national registry and knew that we desperately needed to find one for our daughter because we had a 1:50,000 chance of finding a matched donor in the general public. In order to do this we decided to conduct our own donor drives to add new people to the registry. Not only did we have the pressure to coordinate the drives, but we had to fundraise in order to pay for the testing of each individual that would be added to the national registry, a cost of between \$65-75 per person. After talking with family and church members we planned a meeting at our home for support and discussion on how to handle the situation.

Countless hours driving alone for my car business left me with many thoughts and ideas. The harsh reality was beginning to set in, but I was not going to sit and watch my daughter die without doing something about it. This was when I came up with the concept of Hristianna's Gift, Inc, a non-profit organization named after my daughter. I knew we would have to conduct donor drives at least nationwide in order to find a match for her. At that first meeting, my family, friends, and church members, came together with full support of Hristianna's Gift, Inc. Owning a car dealership gave me the idea to raffle off a car. The proceeds would help pay for donor drives, get people into the national registry to save lives, and hopefully find a donor for Hristianna. The first car raffled was a \$5000 donation from my car dealership to Hristianna's Gift, Inc. to start the organization. The raffle was a great success, raising \$17,220 for Hristianna's Gift, Inc. and we ended up raffling off five cars that year.

I soon realized just how many children with diseases like Hristianna's there are, whose parents don't have the resources that I have in order to fight for their child's life. I can only imagine coming home from work at night, sitting down to have dinner, and looking into my child's eyes knowing that she will die without a matched donor but yet not being able to do anything to help her. I have felt that hopeless feeling of knowing that all my baby needs is a matched donor to have a chance at life.

I have truly been blessed with the resources that allowed me to coordinate the fundraisers and drives in order to save people's lives. I own my own business and I have the benefit of sacrificing time away from work. However, this doesn't take away from the financial burden that this time away had on my family. I chose to fight which meant many hours per week promoting marrow drives, advertising, recruiting, fund-raising, educating, and asking every person I spoke to for any type of help that they were willing to offer. It greatly saddens me to know that so many other people don't have the luxury of taking time off work to fight for their children's lives. It angers me that they have to be faced with making this type of sacrifice. It is unjust that any person should have to find the time and financial flexibility to fundraise for the cost of HLA Typing.

Insurance companies are responsible for funding and supporting any type of cure for any disease. A bone marrow transplant is a cure and should therefore be funded by insurance companies. Having the donors' marrow type available in the national registry is the cure, without it, there is no transplant. 35 percent of people diagnosed with a disease curable by a bone marrow transplant will die because they cannot find a donor. This group of people cost the state a considerable amount of money through the time and effort they must afford in order to fight for their lives, and this has a domino effect on our economy.

For example, I am the owner of my own business, but once my daughter was diagnosed and I learned of the fight I had to endure and fundraising I had to coordinate in order to save her life, I virtually left the work force for an extended period. Not only did this cut my taxable earnings short by an estimated \$200,000, but my staff was affected as well, considering that they work on commission or piece meal for their incomes. They simply were not able to reach their potential without my job being done to its potential. With my own income, as well as my employees' incomes being cut short, none of us had the ability to spend or pay taxes into our state's economy, which means less growth in our state's economy. This is just one example. If you do not look at the big picture, then you are ignoring the facts.

No family should have to go through the financial, emotional, or physical burden of being even partly responsible for having to find a donor to save the life of their loved-one. A bone marrow transplant is no longer "experimental." A bone marrow transplant is not just a cure, often it's the only cure. This is why the cost of stem-cell testing should be funded by insurance companies, not by the family in crisis who is already paying their premiums to an insurance company for healthcare.

I strongly feel that the elected officials of the State of Connecticut owe this to its citizens to remove this burden from the families at this most difficult time.

I want to end today by praying for each one of us here today that none of us go home and find out what a difference a day makes. For I assure you, that if you do, after the testimonies you have heard today, the first thought that will come to mine will be I hope there is a matched donor available to save my loved ones life!