

House Bill 30, The Donate Life PA Act Testimony of Monica Forte

Good Morning. My name is Monica Forte. Thank you for this opportunity to speak to you in support of House Bill 30 – The Donate Life PA Act. I'd like to thank the members of this committee for holding this hearing and considering this important legislation, and I'd especially like to thank the members of the committee who have co-sponsored the bill.

I am here today because my family has a passionate and personal stake in efforts to expand organ donation in Pennsylvania, and that includes passing the Donate Life PA Act.

In 2005, my third son Tony was born with a rare intestinal disorder. Tony was born at a healthy weight of 7 pounds 8 ounces. At first, everything seemed fine. He looked like any other healthy and thriving infant. But within a few days, we became clear that he was very frail, and we knew something was wrong. Tony seemed very frail.

By the time he was one week old, Tony had exploratory surgery that confirmed a problem with his colon. He had something called Total Colonic Hirschsprung Disease. In simple terms, because of problems in Tony's stomach and intestines, he cannot eat, digest and process food on his own.

For Tony to survive, he couldn't eat like a normal baby. He was in the hospital the first three months of his life and had four major surgeries on his intestines before he could come home.

The first years of Tony's life were full of countless lengthy hospital visits. During these hospital stays, I would be there during the day while my husband would be there at night. We'd bring our other sons to visit their little brother after school.

Despite this, we tried to maintain a normal home life for Tony and our family. But often that's just not possible: Tony, who is now nine years old, has never gone swimming, never had birthday cake, never stepped foot in a school, and never had a full meal without getting sick.

Because Tony has difficulty digesting food, he wears a special backpack wherever he goes. An IV line runs from the backpack into Tony's chest to give him the nutrition he needs.

He cannot attend a regular school, but must attend an online cyber school from home. To avoid infections, my other sons must also be home schooled. And Tony cannot participate in other activities like most children.

The only way to give my son the childhood he wants - to attend school and be a healthy and active child – is with an organ transplant. Today, Tony is on the waiting list for a stomach, intestine and liver transplant – and he’s been waiting for more than three years.

Tony is not alone, there are many more children like him in Pennsylvania, and even more adults. There are so many children waiting for transplants. I’ve known parents whose children have died waiting.

Right now more than 8,500 people in Pennsylvania are on the organ waiting list, and that number has been rising. Nationally, the list has now exceeded 122,000.

So why, when the need is so great and the willingness to help is so strong, are so many people waiting, and so many dying? And what can we do about it?

Passage of the Donate Life PA Act would be a good start. This bill attempts to address some of the reasons why the waiting list is over 8,500 men, women and children long. The Donate Life PA Act will expand public education about organ donation, which is the cornerstone of a successful state donor designation campaign. It will increase public education through training of medical, osteopathic and nursing school students and instruction of high school and college students.

Because the more people who agree to be donors, the more organs will become available for transplant, and the more lives will be saved.

It makes improvements to the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund, which is funded through voluntary contributions from applicants for driver’s licenses, identifications cards, and vehicle registrations. And it reinforces provisions in state law that make organ transplantation a priority over other uses of organs.

You are hearing from several people today about how important it is to pass this bill. But I would like to focus on one other point: it is important that you pass this bill *right away*.

Every day and week that passes, more people, including children like Tony, are added to the waiting list. And tragically, more people drop off the waiting list because they have simply run out of time.

So I ask you to please vote to pass The Donate Life PA Act without delay. We dream of the day we can send Tony off to school with a regular backpack full of schoolbooks, instead of his IV backpack.

By passing this bill right away, you can help bring us one step closer to that dream.