

TO: House of Representatives
Commonwealth of Pennsylvania

FROM: Elizabeth (Wertz) Evans, PhD, RN

Executive Director,
Oncology Nursing Society

Donor Mom

DATE: May 9, 2014

RE: Public Hearing HB 30 – Donate Life PA

Chairman Cutler, Chairman White and members of the committee,

Thank you for inviting me here today to speak to you about a very important subject, House Bill 30 and organ donation.

I'm here today both as a healthcare professional and the mom of an organ, tissue and cornea donor.

My daughter Amanda was 14 years old when her life was cut short. It was a heartbreaking experience for our family. There was nothing we could do to change the outcome of her life, but there was something we could do to prevent other families from feeling the same sense of loss due to the death of a loved one.

On November 10, 2001, Amanda's organs, tissue and corneas were donated to several people to enable them to continue their lives:

- Amanda's liver was given to a 12-year-old girl from Michigan;
- Amanda's right kidney was given to a 33-year-old man from South Carolina;
- Amanda's left kidney, pancreas and bone marrow were given to a 36-year-old man from southwestern Pennsylvania;
- Amanda's corneas were given to a 79-year-old woman and an 84-year-old woman from New Jersey.

Her donation gave our family a great deal of comfort. Knowing that this awful tragedy could in some way help others was very important to us.

CORE, the Center for Organ Recovery & Education, treated me and my family with dignity and respect at a time when we were overcome with grief and confusion. They took the time to build a relationship with us – a relationship that endures to this day. Our wishes, Amanda's memory and confidentiality were and remain of the utmost importance to CORE.

Organ donation saves lives. CORE saves lives. And by telling Amanda's story, I hope to help you make a decision on HB 30 that saves lives.

Amanda was a beautiful child who had a smile and a laugh that would melt your heart. We were so blessed to have her in our lives for 14 years. She taught our family so many valuable lessons about life and how to view people with disabilities.

We used to call her Amanda Panda, a nickname that was given to her by her pediatrician at the time of her first seizure. She was ten weeks old and a patient in the Neonatal Special Care Unit in a local community hospital.

Amanda had complex medical problems that were a challenge for us every day, yet seeing her seize and caring for her just became part of our routine. She was diagnosed with infantile spasms (the most serious form of epilepsy) and went on to have a history of refractory seizures (meaning they could be not controlled) as well as Lennox-Gastaut Syndrome. She only had one year of her life in which she did not suffer from seizures.

Functionally, Amanda did not speak and had an estimated developmental level of 12 to 24 months. She would laugh when she was happy and grunt or cry when she was upset. As a young child, she would sign with her hands, which made us feel like we had a secret language. Even the kids at her day care center learned the signs. It was fun to see them all adjust to this different child sitting at the same table with them.

Amanda eventually developed scoliosis (curvature of the spine) because of the low tone of her muscles. For many years we took her to see the pediatric orthopedic surgeon who followed her closely. He was (and is) a wonderful man and waited as long as he could to do surgery. On November 8, 2001, she had her back fused and bone grafting done at a tertiary, non-pediatric hospital.

The operation took a long time and went smoothly. She had no complications and got to the Pediatric Intensive Care Unit (PICU) around 5 p.m. that same day. She did well through the evening and overnight. At 6 a.m. on November 9 (approximately 22 hours post-op), Amanda went into cardiac arrest while being suctioned through her nose. She was resuscitated but had no brain function and was eventually pronounced brain dead at 1:52 p.m. that afternoon.

We made the decision to donate all of her viable organs. My family and I – including Amanda's father and our two other children (Patrick, who was 17 and Ashley, who was 9) – took solace in one thing after that tragic day.

We decided to turn our grief into something more positive. We created various memorials and projects in Amanda's memory. We tried to focus on the lives of the people who were helped by the donations of her organs and tissues.

After the recipient of Amanda's liver and our family expressed an interest to meet each other, CORE arranged for an introduction. As when we first met CORE, they showed unwavering commitment to confidentiality and professionalism. But they also treated us with the sort of kindness that the situation called for.

On July 10, 2009, we had the incredible privilege of meeting Dayna, who is now 24 years old. She was 12 when she received Amanda's liver. It is difficult to describe the emotions we experienced that day, although I surely felt Amanda's love when I hugged Dayna for the first time.

Dayna is a wonderful young lady who is bright, healthy and full of life. We are blessed to now know her and her family.

Amanda brought us all together, and we plan to stay a part of each other's lives.

Today, Amanda would have been 26 years old.

I used the following quote for many years to try to get past Amanda's diagnosis and prognosis. It's about wartime nurses and comes from the Journal of Emergency Nursing.

"I learned that you can get beyond grief. Although it will always be a part of you, I learned that you can derive lessons from negative experiences... To heal yourself, you have to give to others. That is your responsibility."

Since Amanda died, this quote has even more meaning, as I try to find a way to share the wonderful things she taught all of us and show people that good things can come from tragic circumstances. If only you know where to look.

HB 30 will not only save the lives of transplant patients, but will help more families like mine find comfort in the fact that their loved ones will live on. No family should be denied the opportunity to donate, regardless of the circumstances or place of death.

Thank you.