

## Sample Testimony, Parent

Good morning, Chairman/woman and members of the committee. My name is Mike Brame and I live in Lancaster, Pennsylvania. I am here to testify in support of HB 2718.

I would like you to meet my son, Sean. As you can see, Sean looks like a happy, healthy 10-year-old boy. But beneath his fancy socks you will find two titanium metal calves and two mechanical feet. On his right arm, instead of a hand you will see a mechanical hook. On his left hand, you will see one finger and a part of a thumb.

Sean is a living miracle. Eighteen months ago, he was injured by a teammate while playing soccer. When he fell, he broke his ankle. Our doctor read the X-ray as a sprain and sent us home to ice the injury. But 24 hours later, my wife, Carol, rushed him to our local emergency room, where she was told that Sean had blood poisoning and was dying. They couldn't maintain his airway, so Sean had to be sent to Hershey Medical Center.

Doctors tried for hours to restore blood flow to Sean's limbs, but blood clots set in and his tiny limbs began to die. Each day we walked into the intensive care unit to see more and more of his limbs turning black and blue. Six weeks after Sean was admitted to the hospital, he was stable enough to withstand the lengthy surgery needed to amputate his limbs. But even after the amputations, Sean still wasn't out of the woods. His lungs and kidneys were still compromised. He spent an additional four weeks in the intensive care unit.

Upon his release from the intensive care unit, he was admitted to the rehab center at Hershey. While there, we began to face the reality of his disability. We live in a two-story home with bathrooms and bedrooms on the second floor. We also have steps leading to our front door. We were told it would be three to four months before Sean's stumps were healed enough to even begin prosthetic fittings.

We had to make costly modifications to our home by adding a ramp and new doorknobs and locks. Sean was also forced to use a wheelchair. Since he doesn't have hands, it had to be a power wheelchair. As a result, we had to purchase a \$40,000 wheelchair ramp van.

In October 2005, Sean began the long process of prosthetic fittings. Due to his age and athletic interest, our physician wrote a letter of medical need for prosthetic equipment that could "grow" with Sean. His ankles can be pitched in a manner that will allow him to run and play the sports he loves. Our insurance company agreed to pay for the expensive equipment because Sean needed it to return to the lifestyle he had prior to his illness.

In November 2005, Sean began experiencing skin irritations and it was determined that he had a rare allergy to the material in his gel liners. As a result, he had to start all over with new sockets and liners. Once again, our insurance company, along with Medical Assistance, agreed to cover the change in equipment as long as the technicians were able to use the mechanical parts from Sean's first set of legs.



On December 23, 2005, Sean received the best Christmas gift a kid with no legs could ask for: new legs. And my wife and I received the best possible gift on Christmas Eve, when Sean walked into church with us. He's been walking ever since.

When the final tally came in for Sean's prosthetic fittings, sockets, legs, ankles, socks, liners, etc., the bill was well over \$50,000. In addition to legs, he uses a prosthetic hand on his right arm. He currently uses a myoelectric hand with a grappling hook, which allows him to open doors, pick up small items and pull a zipper. The prosthetic hand and batteries cost about another \$10,000.

My wife teaches for a local public school and her insurance coverage is excellent; to our amazement, all of Sean's major medical bills were covered. But her union is currently in the process of contract negotiations. When this contract is settled, we're not sure what type of prosthetic coverage will be available for Sean.

What concern me now are Sean's future needs. Sean can be covered on our health insurance as long as he's in school. But what happens once he turns 18 or 21 if he attends college?

Will the special equipment he needs to maintain his level of mobility be available? Will Sean be able to be fitted for the same type of equipment he has now or will he have to use less durable equipment.

Organizations such as the Shriners help provide prosthetic equipment to children, but what happens when these children turn into adults?

As a prudent parent, I have to concern myself with his future. The savings account my wife and I started after he was born was designed to help pay for college costs. Now we're worried that these funds may be needed to pay for prosthetic limbs in his adult years.

Sean has handled a very difficult situation with remarkable zeal. He sees his limb loss not as a disability but as an inconvenience. Many adults marvel at his determination. He's learned that there isn't much he can't do in this world, but he's learned he must do things differently.

In closing, I ask you to look at your children or grandchildren this evening. The next time they go to soccer or football practice, they could fall and develop an infection just like Sean. Would your insurance cover the medical bills? If not, maybe something needs to be changed.