

House Health  
Proponent Testimony  
HB72  
April 11, 2018

Good Morning Chairman Huffman, Vice Chair Gavarone, Ranking Member Antonio and members of the Committee, my name is Natalie Andrews, this is my husband Jason. We live in Johnstown with our three daughters and our son, Samuel. This is Samuel, he is 6 years old and in kindergarten. Two years ago we adopted Samuel from China. Samuel has a bleeding disorder called severe hemophilia. Samuel's blood clots at a rate of less than 1%. He went untreated in China for 4.5 years and sustained many injuries and joint bleeds causing permanent damage to his knees and ankles.

Here in the U.S. he is getting amazing care at Nationwide Children's Hospital. My husband is self-employed, so our family is covered under an individual market plan. To be a healthy, active 6 year old boy Samuel needs IV infusions twice a week. The medication Samuel is on is newer technology, thus more expensive per unit than other medications used to treat hemophilia. But his medication allows him longer time in between infusions, which means less units used over a months supply of the medication. Some plans in Ohio are requiring a failure on 2-3 other medications before being on his current extended-half life medicine. This would mean Samuel would have to be treated every other day, instead of twice a week.

My husband has learned how to infuse Samuel at home, which saves us countless trips to the hospital. This medicine allows Samuel to run, jump and play. He is such a happy boy! But, two mornings a week he is poked with needles. Sometimes we are able to get the needle into a vein on the first try, other times it could take up to 4 needle sticks before we have a successful poke. On average for Samuel's standard infusions he gets poked roughly 104 times a year. If he was on a less effective medication this number would be closer to 520. When my daughters were younger and they had to go to the doctor for shots, it was such a traumatic experience with tears and bribes of suckers and stickers. And that was only once a year! This is Samuel's reality all the time. If he was put on a less expensive medication and it failed him, it could be fatal.

On behalf of the Bleeding Disorders community we are asking for your support of HB72. Our community needs to have access to clotting factors they are stable on throughout their transitioning between insurance plans.

Thank You