

Submitter: Tara Stone
On Behalf Of:
Committee: Senate Committee On Human Services
Measure: SB646

Chair Gelser Blouin, Vice Chair Robinson, and Members of the Committee,

Hi, I delivered my son at 27 weeks 2 days pregnant. Hours after he was born he suffered a grade 4 and grade 1 brain hemorrhage. He spent 730 days in the NICU. Came home with a trach on a ventilator, oxygen, gtube, feed pump and 22 meds per day. From the beginning I have fought to get my son the best care. 5 months into our NICU stay the hospital wanted us to end care, they said there was no cure for bronchopulmonary dysplasia and that his body would outgrow his lungs and pass. I refused to end care. Instead I went online, found a hospital that specializes in BPD. 3 days later we flew by medical jet to Ohio. Guess what, after 1,236 days my son no longer has his trach. Breathing on his own. He has a long list of other things going on. 16p11.2 deletion syndrome, Cerebral Palsy, Spina Bifida Occulta, Scoliosis, Cortical Visual Impairment, Global Delay, non Verbal, Sensory Processing Disorder, well, he has a total of 33 active diagnosis in his chart currently. We are a family who utilized nursing but due to shortages we had to wait over a year for one to become available and was only available once a week. She ended up leaving and we decided to try one more nurse, on this nurses second shift, I left to run errands because that's what the state wanted us to do have someone else watch our kids and well when I got home and started his bath my son had handprint welts down his spine from our "professional" nurse the state urged us to use. The spine that has Spina Bifida, the spine that has scoliosis. The body that struggles due to Cerebral Palsy was abused by a nurse. Let that sink in. From that day on my son developed a fear of anyone that wasn't mom or dad. Being non verbal he voiced this fear with behavioral and destructive issues in home. Developed fear of being around people. He would spiral into panic in fear he would be abused again. This has taken years and allot of attention to trust his doctors and therapists again.

Due to my son being severely immunocompromised he's homebound where school and therapy come to us. We have 11 appointments weekly where I have to be present, not including his 16 specialist appointments, a procedure, labs, images or surgery every 3 months. I left my career the day Ashton was born, I stayed bedside in the NICU 22 hours per day. Having a son who requires 24/7 care and knowing my career I had there was a no phone policy, I had to schedule weeks in advance for time off and bid for vacation days. There's no way I would be able to maintain this career with how busy our weekly schedule is. When parents were allowed to start claiming hours that my son had set aside that hadn't been used in years I felt like I could finally take a deep breath knowing that my 24/7 job of taking care of my son I could financially provide for my family.

My husband was working multiple jobs now just has his one full time job since parent

pay started. When this is lifted we won't allow nurses in our home. There's no guarantee another nurse won't turn into a child abuser either. He has the most qualified caregivers already which is us his parents and we will never abuse him like that nurse. My son is thriving because of us, my son has stayed healthy because of us. My son is happy and feels safe because of his parents. I urge you to truly understand that this is our life, this is serious to us, this isn't a vacation, this isn't the easy way out for us. Try putting yourself in our shoes. Every child in Oregon just like my son who already has the hours there, their parents should truly be able to continue to claim those hours. Please pass SB 646 out of committee. This shouldn't be something that has to be thought about, chipped away, the money is there already.

My son doesn't have a voice, but I guarantee if he could talk he would beg you not to take away parent pay. Hear these innocent kids silent voices please.

Sincerely,

Tara Stone