

Written Testimony for the Proposed H.B No. 5918, An Act Concerning Private Duty Nursing for Severely Disabled Children

My name is Jennifer Reilly and I am with my husband, Greg Perna. We are here to tell about our personal struggle with the CT State and Federal Healthcare Systems. We hope by telling you our story that you will provide Private Duty Nursing Coverage under Husky Plan B and offer supplemental healthcare services to medically fragile children despite their family's income level. Furthermore, that the state clearly and properly informs parents of medically fragile and special needs children about the state and federal services available to them.

Our daughter, Riley June Perna, has several medical disabilities, the list is tremendous. Her medical conditions include Cerebral Palsy, Bilateral Hearing Loss, Cortical Vision Loss, Hypoxic Ischemic Encephalopathy, Bronchopulmonary Dysplasia, Congenital Hypotonia, Subglottic Stenosis, and Tracheostomy and G-Tube Dependence. In laymen's terms, Riley has severe damage to the basal ganglia area of her brain which results in a lack of hearing, poor vision, lung disease and low muscle tone. She cannot sit independently, crawl, walk, talk, suck, swallow or close her mouth. Due to this long list of medical issues, having a great support system in place is paramount to her future development. It literally takes a small army to care for our daughter.

At the root of her care is the 24 hours of private duty nursing she receives in the home combined with intense physical, occupational, speech and vision therapies. Riley requires 24 hour skilled nursing care to safely manage her tracheostomy, maintain airway clearance, oversee her nutrition, administer medications & perform chest airway clearance therapy. Unlike other children with a trach, Riley does not have the strength to clear her airway on her own or effectively communicate when she is in distress. Thus, the absence of a skilled nursing professional would be life threatening as she could suffocate on her own secretions and die.

Since her birth, Riley has required Private Duty Nursing Care 24 hours a day that our private insurance covered. Throughout Riley's life we pursued state and federal assistance options to supplement our private insurance but we were consistently denied due to our income. My husband and I both work in order to help pay for supplemental therapies to help strengthen Riley and give her the best chance for a high quality of life. Hopefully it will result in the removal of her trach, her being able to communicate and sit and walk independently.

In December of 2012 we were informed that our private insurance would no longer cover Private Duty Nursing. We were terrified for Riley's well-being and immediately took action. We appealed to our private insurance company and simultaneously, contacted our Connecticut Healthcare Advocate. They along with our local state representative pleaded to the Department of Social Services to waive their three month no insurance rule so Riley could become eligible for Husky Plan B. However, they denied our plea and informed us that Husky Plan B, as of December 2012, no longer covered Private Duty Nursing. Consequently, we were disappointed and very scared for our daughter. What were we to do? Quit our jobs and go on welfare so she could be eligible for the medical attention she needs? Private Duty Nursing costs over \$400,000 per year & our combined salaries do not cover that cost; not to mention all of the costs associated with Riley's medical needs. For example, Riley also requires durable medical equipment to live which costs approximately \$36,000 year.

We felt we were running out of options and time. My husband and I were faced with the decision of whether to put our daughter in a skilled nursing facility that our insurance may or may not cover, to quit our jobs so we would be eligible for other Husky plans, or to hire non nursing professionals at a lower cost & train them. These were not viable options to us because Riley would not thrive in a facility environment, she would severely digress. We were not willing to terminate our jobs and live on a savings that would quickly run out in the hopes we would be eligible for other husky plans, and we did not feel it was in Riley's best interest to hire unskilled care givers and risk her life. Thus, we feverishly explored and sought out every Connecticut government agency & organization for help, convinced that there had to be something out there for Riley. However, every call we made it seem that either people were misinformed or could not guide us in a direction that would help Riley. Finally, with the help and guidance of well-informed individuals, we discovered the Department of Development Services has a waiver for severely disabled and medically fragile people like Riley. Through determination, persistence & guidance, Riley became eligible for the DDS waiver, which resulted in the continuation of her medical services. Our fortitude and unwillingness to give up proved the "system" could work effectively.

But what about the other children like Riley? We are writing (speaking) to you today so you can understand our struggle and know there are so many parents like us in this situation. We strongly urge you to reinstate Private Duty Nursing under Husky Plan B, to make the information and services readily available to parents of severely disabled and medically fragile children, to provide a support system to these parents & help "negotiate" and understand the "system." To provide services to all children like Riley, despite their parent's financial status, so they can safely live & thrive in the home. For we all know that, in most cases, the home is the best place for the child to live and grow. We ask you today, as tax-paying middleclass parents who are financially stable yet not rich enough to afford the proper care for Riley and not poor enough to receive state services, why should we be punished for trying to get the best medical attention for our medically fragile children? Why should middleclass parents or any parent have to "jump through hoops" to figure this out on their own? In the end, the child is put at risk and suffers the most in the long term.