

## Testimony of Ben Studer

Chairwoman Schmidt, Vice Chair Deeter, Ranking Member Somani and Members of the Committee, my name is Ben Studer.

Thank you all for taking time out of your busy schedules. By being here today, you're letting families of Ohio with special needs and medically complex children know that you hear them, you see them and you're willing to help them.

I am here to tell you about my son Boone and the impact PPEC has had on his life. Boone has a rare connective tissue disorder called Epidermolysis Bullosa, EB for short. His skin is extremely fragile. He lacks a protein called Collagen 7 and any bump or friction will cause his skin to blister or sheer off. This condition isn't limited to just the outside of his body, as he also gets blisters inside of his mouth, on his tongue, in his throat, esophagus, and GI tract.

We were told from doctors that Boone would never get better. He would face extreme challenges walking and talking. He would be delayed developmentally. He would not be able to eat normal food. They said Boone would require long term care at home and his life expectancy would depend on how fast the severity of his condition progressed. I hope you can understand the level of sadness and disappointment we felt as parents after hearing the very first problem our son experienced in life, we couldn't fix.

6 months after Boone was born, due to the amount of care my son required, my wife was informed by her employer she had run out of FMLA time. She was forced to resign from her position because we were unable to find child care sufficient enough to meet Boone's level of care without Medicaid. In one of our several attempts applying for Kentucky Medicaid, Boone was denied within the first 5 minutes of our phone call. When I asked them for reasoning, we were told it was because we were able to pay our mortgage, electric, and water. It was recommended to me that if I drastically cut my hours or quit my job, only then would he be approved. When I expressed my disappointment towards this idea, as I deeply believe in my ability to work hard and provide for my family, while paying taxes to my state and country, I was told 3 words that have been engraved in the back of my mind ever since:

**"WE DON'T CARE"**

Kelsey and I struggled to help Boone reach important milestones because of EB. We kept applying for Kentucky Medicaid because my sole income would hardly allow us to keep a roof over our heads, let alone foot the bill for him to receive the assistance he so desperately needed. Once approved for Kentucky Medicaid almost 2 years into his life, Kelsey and I cautiously searched for a place that would provide Boone the opportunities to develop, learn, make friends and receive his necessary assortment of therapies. A place where my wife and I would have peace of mind knowing that he would be safe and cared for from a medical standpoint.

That's when we discovered Easterseals Redwood.

Through Boone's short time at Easterseals Redwood, Boone isn't just walking; he's running, jumping and climbing. Boone isn't just talking; he's yelling, laughing and singing. Boone isn't just eating normal food he is DEMANDING to eat normal food. All the while doing this safely and comfortably, with managed pain and medications.

Boone is breaking down barriers and THRIVING. All the early milestones we were told he would struggle to accomplish or wouldn't accomplish at all, he HAS accomplished, thanks to Easterseals Redwood.

Another benefit that stood out to us about Easterseals Redwood is the opportunity for Boone to be present in a room with children that are not medically complex but are typically developing. This unique and inclusive learning environment has really encouraged Boone to step out of his comfort zone. He is able to push his own

boundaries by seeing what activities other kids are doing and finding a way to do these things himself, despite the limitations caused by his condition.

It is imperative that families in Ohio have access to Easterseals Redwood, where children that have been told they can't or won't their entire lives are taught ways that they can and will. Where parents that have been told 'we don't care' are asked 'how can we help?'. Citizens of Ohio that can benefit from Easterseals Redwood should be able to do so, despite their Medicaid status. We can't make life any harder for children that already face an uphill battle. Parents shouldn't be forced to decide between getting the medical assistance their children need or bringing home a paycheck to provide for their family. Total government assistance isn't the American Dream. The American Dream is the opportunity and freedom for anyone, regardless of who they are or where they come from, to achieve their OWN version of success. As leaders of Ohio, you have an opportunity to send a strong message to a community way too often overlooked by society:

**"OHIO DOES CARE"**

Thank you for your time.