

**Proponent Testimony**  
**House Bill 141**  
**House Health Committee**  
**May 7, 2025**

Chairwoman Schmidt, Vice Chair Deeter, Ranking Member Somani and Members of the Committee, thank you for the opportunity to provide testimony in support of House Bill 141 so we can bring prescribed pediatric extended care (PPEC) centers to Ohio. My name is Amanda Lunsford, and I have lived in Ohio for the past 41 years. I am the mother of 3 beautiful children, Jenna Lynn (age 6) and my twin boys, Sameer and Saleem (age 3). In 2003, I earned my certification as a state tested nursing assistant and as a nursing assistant. I worked in a variety of healthcare settings until 2021 when my twins were born.

Shortly after birth, Saleem was diagnosed with a genetic condition called Coffin-Seris Syndrome. This diagnosis is consistent with developmental delays, difficulty feeding and respiratory problems. This resulted in Saleem requiring a G-Tube so he could sustain nutrition and oxygen so he could breathe. Saleem's needs resulted in him coming home from the hospital with oxygen tanks, a pulse oximeter, feeding pump, suction machine and boxes of supplies that he needed just to stay alive and make it through each day. He has since added a wheelchair to his collection along with a gait trainer and a stander to help him walk.

When my twins were 8 months old, their father decided that he no longer wanted the responsibility of a family and walked out on us. This left me a single parent with 3 young children who all needed childcare for me to continue working. I learned quickly that it was easy to find a place to care for Jenna Lynn and Sameer since they were typically developing and could fit wherever there was an open spot. As I called centers to see if they could manage a baby with a g-tube and oxygen, I learned quickly that finding a safe place for Saleem with staff who could be trained to care for his medical needs was going to be nearly impossible. Because there were no childcare options for Saleem, I was unable to return to my job and had no choice but to stay home with my children and collect as much government assistance as possible.

It was hard for me to not have a job since I had worked for the past 17 years and was used to having a regular income that paid the bills. It was also hard not being able to provide for my children and having to wait each month for the check from the government. I worried each month if the electricity was going to be turned off and relied on agencies to help when I couldn't make ends meet. The hardest part was looking at my children and worrying that I might not have enough money to put food on the table towards the end of every month. I always seemed to figure it out, but it still didn't stop the constant stress and worry. On top of everything, I was not getting much sleep as I had to listen for alarms in case Saleem stopped breathing or his oxygen needed to be adjusted. During the times when he had a cold, I had to suction him 3-4 times an hour so he wouldn't choke. Not to mention all the doctor's appointments and therapies I had to take Saleem to, just to help him develop and get stronger.

When Saleem was about 18 months, he had his first visit with Complex Care at Cincinnati Children's Hospital. After meeting the team and telling them how I really needed to be able to get back to work, I learned that there were many families experiencing the same hardship. I also learned that Saleem's Medicaid plan had a nursing benefit that would allow a nurse to come to our home and care for him. I was excited to hear this and the social worker started to make referrals to nursing agencies. The excitement quickly faded when nursing agencies would not pick up Saleem's case because they could not

find nurses who were willing to come to my home due to the area where I live. Because of my financial situation, I can only afford to live in an area of town where there happens to be high crime and a lot of drugs. I understand why a nurse would not want to work where I live because I don't even want to live where I live. If I were able to work, I could have saved the money a long time ago to afford deposits, a moving truck and everything needed to move my family somewhere safe where they can develop and play outside without being exposed to people doing drugs and the trash they leave behind.

After our social worker tried for 12 straight months and could not find nursing for Saleem, we had a zoom meeting with some representatives from Medicaid to try and see if there was any way an exception could be made for me to be paid as a home health aide for Saleem through his Medicaid plan. We pleaded that since home nursing options had been exhausted and I was the only trained caregiver for Saleem, that I be paid in some capacity to provide his medical care since there were no childcare centers equipped to do this and this was the sole reason why I had to remove myself from the workforce. While they were sympathetic about my situation, they could not approve this plan due to the way the rules are written. They reiterated what we already knew which was I could only be paid to care for Saleem through Medicaid if I was a licensed nurse. This was just one more punch in the gut considering my goal has been to go to nursing school, but that was squashed after learning I could not even return to work.

Three years later, I am happy that Saleem's medical needs have improved, but I am going into my 4<sup>th</sup> year without employment because there still is not a safe place for him to go for childcare. Although he now just has a G-tube and requires random suctioning, these are still skilled needs that can't be managed in a community childcare center.

While I could go on and on regarding the hardships my family has encountered due to our circumstances, I don't want to lose sight as to why we are here today. As I conclude my testimony in support of HB 141, I hope that I have represented my fellow parents well who also have children with medical complexity and are unable to work. I hope I have raised awareness that children who require special medical care should not be excluded from childcare and parents should not be penalized just because their child does not fit in with the current childcare model. Passing this bill and bringing medical childcare centers to Ohio would allow single parents like me to maintain employment and continue with their dreams and goals so they can provide the best life possible for their children.

Thank you for your time,

Amanda Lunsford