

Testimony of Elizabeth O'Leary

Mother of Alice O'Leary diagnosed with Cerebral Palsy, Neonatal Seizures/Convulsions,
and Middle Cerebral Artery Ischemic Stroke, Esophoria

HB49 as Introduced by the Governor

House Finance – Health and Human Services Subcommittee

March 23, 2017

Dear Chair Romanchuk. Reps. Sykes, LaTourette, O'Brien and Sprague,

Thank you for your time today. My name is Elizabeth O'Leary. When our daughter Alice was born she suffered a major stroke that damaged the majority of the left side of her brain. She suffered seizures for her first twenty-four hours. She was diagnosed with cerebral palsy. Alice has significant weakness on her right side and right hand was tightly fisted for a long time with her thumb tucked in. (PICTURE).

Although I stand before you on behalf of my family, I also stand here for all of the children of Ohio who rely on the Children with Medical Handicaps Program and the Ohio Department of Health for a system of care. Please keep this program within the Department of Health, please keep this program in-tact.

At eight months we enrolled Alice in constraint therapy. For those of you unfamiliar, the therapy puts a plaster cast from her shoulder to the tips of her fingers on her strong arm. Alice underwent OT with her cast three hours a day, five days a week for four weeks. The goal is to force the weak side to move. Since that therapy Alice has undergone constraint about every ten months. One constraint round totals 22 OT visits.

I work and my employer provides private health insurance. Our coverage allows 25 PT and 25 OT per year. With one constraint our OT max is almost reached. The 22 visit constraint therapy costs about \$12,000.00. One forty-five minute OT sessions costs

\$236.00. At a minimum Alice requires 44 OT visits per year, upward to 66. Our CMH coverage came in around the same time as Alice's first constraint therapy and I cried with relief. Under CMH have been covered for 50 combined PT/OT visits per year.

The additional therapies provided by CMH are vital and have ensured that Alice has made extraordinary improvements. My private insurance will not cover the necessary therapies and would be an extraordinary expense for our family. After five rounds of constraint therapy, this is our girl. (PICTURE)

Under the Governor's proposed budget, November 21, 2017 is D-Day when our CMH coverage ends. Our family will not qualify for Medicaid under the proposed financial guidelines. The other day Alice said to me, "Mumma, I am going to keep getting casted, and casted, and casted and casted until Righty is just like Lefty." If Alice is given the proper therapy coverage, I have no doubt that she will accomplish this goal.

The proposed changes to CMH drastically reduce the eligibility requirements to families like mine. Please allow the program to continue and remain with the Department of Health because this system of care for is vital for not just Alice and for the many children who have hope and a future to improve. Like this (PICTURE). In closing, Mr. Chariman and Committee Members, thank you for protecting Ohio's children by allowing this program to continue providing services to all families. Thank you for the opportunity to share my family's story. I am happy to answer any questions you may have.





