

Submitter: Brad Battles

On Behalf
Of:

Committee: Joint Committee On Ways and Means Subcommittee On Capital
Construction

Measure: SB5701

My 4-year old daughter, C. (name withheld for privacy), has Niemann-Picks Type C (NPC). It is a rare, pathogenic, progressive, autosomal, recessive, lysosomal storage disorder that prevents cholesterol from moving out of the Lysosomes and into the body for use. The cholesterol builds up and causes cellular toxicity and death. A little under two years ago when she was diagnosed, we were not sure our little girl would make it to age 4, much less school age; juvenile cases are considered the worst for this disease.

NPC can not only lead to an early death, but on the way, it leads to loss of hearing, loss of mobility, and developmental delays / disabilities. The only good part, if you can call any part good, is that C., and most children with NPC, have sunny dispositions.

But, thanks to brilliant brains, and an Expanded Access Program, she has made it to 4-years of age. And thanks to educational funding, she's started pre-school through a program funded via the Northwest Regional Education Services District (NWRESA). For two-days a week, C. goes to a pre-school, and thrives! Next year, she's supposed to go four-days a week. By Kindergarten, she may be independent enough to do some things herself!

She has an Instructional Aid who helps her use her Augmentative and Alternative Communication device (AAC) or "talker", helps her understand directions from the teacher, gets her to the restroom, and helps maneuver her in and out of her wheelchair. She has a teacher for the Deaf / Hard of Hearing to help her communicate without her "talker", and help us learn sign language. She has a Speech Language therapist to help her communicate in various methods. An AAC specialist employed at the school to help her learn to use her "talker." A physical therapist to help C.'s aid be safe in moving her. Equipment loans and physical therapy at home to help strengthen her legs so she might be able to stand. So many people, to help one child, and children like her, have a chance at some semblance of a normal life. Not just NPC kids, but those with Autism, the deaf, the blind, the disabled; all those that society leaves behind because they are not normative.

All that could disappear if Early Intervention / Early Childhood Special Education (EI / ECSE)'s \$22 million funding gap is not closed during this legislative short session. The progress my daughter has been making; the new strength her private PT has noted in her legs, the fine motor control we can see her struggling to develop to use

her “talker”, the communication she has achieved with words, sign language, and technology, all of it, gone because of legislative decisions. She gains more at a school that is partnered with NWRESA than any other school, or her mother and I, could teach her.

Restoring the \$22 million in funding will keep services at their current level; allow children who don't have the opportunity to learn, to have that opportunity. Keeping the funding short, or not bringing it up to par, will mean service cuts. It might mean that next year, instead of taking C. to school, she stays at home and loses the gains she's made. Voting "YES" provides an education for young children with disabilities, keeps a multitude of people employed, and is the right thing to do for the children of Oregon.