

Date: April 3, 2019  
From: Julie and Kevin Hall  
To: Joint Ways and Means Subcommittee on Education  
Re: Written testimony in support of OHSU's budget

Thank you for the opportunity share our experience receiving services from the Child Development and Rehabilitation Center (CDRC) at Oregon Health & Science University (OHSU).

Our daughter, Samantha, was born with a life-threatening, complex congenital heart defects. She spent a collective two and a half months under the care of OSHU medical staff in the Neonatal Intensive Care Unit (NICU), and the Pediatric Intensive Care Unit (PICU). As parents, we were overwhelmed when we brought her home, knowing that she was medically fragile, and there was much uncertainty for her care in the future. We were grateful in knowing that not only would Samantha's cardiology team be following up with us regularly regarding her heart, but also the CDRC would be monitoring her overall progress in all aspects of her development.

Samantha had a stroke in her early days of life. This went undetected for months until we started to notice that her movement on the right side of her body was limited. For some reason, Samantha's right side just wasn't catching up with her left side in development. This could have easily been ignored or written off by other doctors, but it was the keen, watchful monitoring of the CDRC that diagnosed her with Cerebral Palsy. We have seen the effects specifically in her right hand and in the right side of her mouth.

Samantha has been going to occupational therapy (OT) for over a year. OT focuses on the fine motor movements. She would go week after week to the local clinic and make slow improvements. We were pleased that she was starting to use her right hand more but also frustrated with the lack of progress. We appreciate Samantha's pediatric clinic and all of their efforts here in Salem, but they are simply not equipped or specialized to be able to advise us on the best course of action for our daughter's growth, given her medical complexity.

Samantha was watched and evaluated by the OHSU Child Development and Rehabilitation Center stroke team, a team of specialists that work with children who have had strokes. This team suggested that Samantha, given her work ethic, would be a great candidate for Constraint Induced Movement Therapy (CIMT). When presented with this option we initially said no. It would difficult to drive from Salem to Portland multiple times a week for this intensive therapy, but after a long discussion we agreed to participate. It was the best thing we could have done for our daughter. Samantha made more gains in the three week intensive therapy sessions at the OHSU CDRC than she did in the prior year at OT in Salem.

The therapists and specialists at the CDRC are top notch. They did an amazing job of getting a two year old to complete the desired tasks, while making it a fun game. Sammy would work for an hour with one therapist and be sad when it was finished because she wanted to keep playing. She went from not being able to pick up a large object (like play kitchen plastic food) with her right hand to being able to pick up small objects (like a bead) with a pincher grasp. This improvement in her fine motor skills of her right hand would not have been possible without the OHSU CDRC.

Prior to the intensive CIMT sessions, we wondered if Samantha would be able to button buttons on a shirt, tie her shoelaces or close the clasp on a necklace. While Samantha has more growth and learning before she can complete these tasks, we have hope because of the growth she has shown, and because of the therapists and specialists at the CDRC. We have hope for a brighter future for our little girl.

Looking towards the future, Samantha will probably have more intensive CIMT therapy sessions at the CDRC. It is well worth the drive to work with the best team. Samantha has so many more doors open to her with the improved use of her right hand.

Thank you for continuing to support the CDRC programs at OHSU, including the CIMT Program. Your decisions have a direct impact on parents and children living all over Oregon. You have the great opportunity to be on the same team as these wonderful children making wonderful progress.

Please support them and continue to fund the programs at the CDRC so children just like Samantha can have bright futures.

Kind regards,  
Julie and Kevin Hall