

Submitter: Hannah Grist
On Behalf Of:
Committee: Joint Committee On Ways and Means
Measure, Appointment or Topic: HB5006

My name is Hannah Grist, and I'm here today to ask you to remove the ban on paying parents as care workers for very high needs children with disabilities by passing Tensy's Law, Senate Bill 538.

My son Henry is a medically fragile six-year-old. As a result of a brain injury at birth, he has severe cerebral palsy, a seizure disorder, is legally blind, and receives all of his nutrition through a surgically placed feeding tube. Henry requires skilled, around-the-clock care every single day of his life. He also has a magnetic, joyful personality and an extraordinary capacity to enjoy almost everything life has to offer. We work hard to build a life where he can thrive at home, at school, and in our community—but our ability to do that is constantly threatened by the lack of consistent and qualified in-home care.

Because of Henry's medical complexity, the State of Oregon authorizes over 200 caregiving hours per month. Yet due to the severe caregiver shortage, we are only able to use about 20% of those hours. The few caregivers we've found are usually kind, dedicated young people just starting out in life. They care deeply for Henry, but they lack medical training and cannot manage an emergency. As a result, either my husband or I must remain home even when a caregiver is present.

The truth is, we are Henry's best caregivers. We've learned how to change his feeding tube, respond to life-threatening seizures, and care for him through terrifying respiratory illnesses. And we do all of this while trying to hold down jobs.

This isn't about politics. It's about common sense and caring for children and families. Please support Tensy's Law and remove the outdated ban on parents as care workers for their children.

Thank you for your time.