

Submitter: Advocates For Disability Supports
On Behalf Of: Leslie Andrews
Committee: Senate Committee On Health Care
Measure, Appointment or Topic: SB538

ATTN: Legislators Please lend your SUPPORT to Senate Bill 538, or "Tensy's Law." Although parents of disabled adults can be paid caregivers, this option isn't available for children, leaving many young families with impossible choices. SB 538 would increase access to Oregon's Children's Extraordinary Needs (CEN) waiver; allow parents of minors to be personal support workers; and ensure this compensation comes from already-obligated funding. I am Tennyson Ross' maternal grandmother. For the past 2 years, I have resided approximately 6 months out of each year in our daughter and son in law's home in Sherwood, although my husband and I also reside in Hailey, Idaho. Since Tennyson was born, ten years ago, I have frequently spent several months each year in Oregon to help care for him and his siblings. I don't believe the financial and emotional hardship on extended family members is often considered in regard to nuclear families with seriously ill and terminally ill children. For 10 years my husband and I have helped supplement our daughter and son in law's income. We own their home. We have given them vehicles and helped with medical care. During Tennyson's extended hospital stays (often for weeks and months at a time), we were the primary caretaker for Tennyson's older brother, Brecken. We actually lived in our 5th wheel in Newberg for a period of over 2 years to help out. I know, from experience, that caring for a seriously ill child is MORE than a full-time job. Even with nursing care, these parents are never "off the clock." The daily and night time care is both physically and emotionally depleating. Oregon's homecare workforce shortage is well-documented. Over 90% of families report they cannot find enough caregivers to fill their authorized hours. This shortage is even more severe in rural areas, where specialized caregivers are virtually nonexistent. Tensy's Law prioritizes what truly matters: the well-being of Oregon's most vulnerable children. Thank you for your attention to this matter. Sincerely, Leslie B. Andrews, M.S.W.