

Submitter: Nico Pagan

On Behalf Of:

Committee: Joint Committee On Ways and Means

Measure, Appointment or Topic: HB5006

Chair Lieber, Chair Sanchez, and Members of the Committee,

My name is Nico. My 12 year old sister Nina has a genetic syndrome, epilepsy, autism, and a host of complex medical needs. My families works harder then anyone I know to keep Nina safe, thriving and living at home.

I ask for your support for SB 538, Tensy's Law—a bill that recognizes that parental caregiving is essential, skilled, and lifesaving.

In homes across Oregon, parents are providing round-the-clock medical care for their children with significant disabilities. This isn't just feeding dinner and helping with homework. It involves managing seizures, monitoring oxygen, administering medications, and operating feeding pumps—tasks that, if performed by a nurse or support worker, would be compensated.

However, if a parent provides this care in Oregon, it costs zero dollars.

That's not because the federal government prohibits it. In fact, under current federal Medicaid rules, parents can be paid for providing this level of care, and over 20 states already do. Oregon has simply chosen not to, leaving families with impossible choices between earning a living and caring for their child.

This is care that prevents hospitalizations, keeps children out of institutions, and saves the state money. But more than that—it's care built on trust, love, and the deep expertise that only a parent can bring.

SB 538 doesn't ask for special treatment. It asks Oregon to follow what Medicaid already allows and finally acknowledge the skill, sacrifice, and value of these parents' work.

Please pass SB 538 and recognize parental caregiving as a vital part of our healthcare system.

Thank you.

Nico Pagan