

My name is Oriana Horneck, and I am here with my husband, Brian, and our son, Avery. We live in Portland and the three of us support SB 646.

Avery has a rare condition called KCNA2 epileptic encephalopathy, which causes him to have multiple severe disabilities. Due to his high level of care, we've experienced the temporary paid parent caregiver program. We've seen first hand how beneficial it is for Avery, so we strongly believe in making this program permanent and including all families with attendant care hours.

While I've been his primary paid caregiver, Avery has been healthier, happier, and more integrated in his community. Avery's medical complexities combined with being nonverbal, make it very challenging to keep him safe and healthy. A caregiver must be able to differentiate his breathing patterns to know if he's nauseous, having a seizure, or so congested he's not getting enough oxygen. Meeting these needs or not, is the difference between being home and healthy, or hospitalized. Even his excellent support worker of 2 ½ years still cannot tell these differences. It's me and his Dad, who have spent nearly every day of the past 7 years caring for his needs, that are able to interpret the subtle changes that keep him healthy and happy.

Avery's increased integration in the community has been another benefit. I take him out far more frequently than any support worker he's had. We go to the playground, museums, walks in the neighborhood, sporting events, and so much more. Getting out with Avery isn't easy, so most workers choose to stay home with him. But Avery loves to be on the go and he deserves to have someone that will satisfy that desire.

To go back to the world where I am unable to be paid to care for Avery, means that he will spend his days sicker, unhappier, and less present in his community.

Avery's Dad and I are truly the best caregivers to meet his needs and provide him the best quality of life.

Thank you.