

Submitter: Vanessa Lara Urueta
On Behalf Of:
Committee: Senate Committee On Human Services
Measure: SB646

Feb 6 2023

To the Oregon state legislature.

My name is Vanessa Lara, I am the mother of a 7 year old child with development disability.

My daughter has a mitochondrial disorder found on the FDXR gene.

Even though she had global development delays and optic atrophy, healthwise she was stable until June of 2022.

Dayami went in to respiratory failure and sepsis.

She had to be intubated and eventually got a tracheostomy to be able to come off sedation.

She was hospitalized up until Sep 2 and we came home with a ventilator, vest therapy and cough assist. She also developed urinary retention and requires straight cathing every 4 hours.

My daughter lost all her skills she had prior to this and now she qualifies for more hours due to how much needs she has and how medically fragile she is.

We live in a rural town away from children's hospital and there is no nursing agencies in our area that work with pediatrics and not to mention the tracheostomy.

Dayami requires around the clock care and someone stays up at night to monitor her.

My husband and I take turns he does the night shift and I have my mom to help me during the day as there is multiple things that require 2:1 care.

When I became a paid DSP it was a big relief to our family financially given the fact that there was no one else that would feel comfortable doing what we do for her and I wouldn't be able to have a job outside of the house.

Sincerely, Vanessa Lara