

Submitter: Jessica Langley
On Behalf Of:
Committee: Senate Committee On Health Care
Measure, Appointment or Topic: SB538

This letter is in support of paid parent caregivers. My name is Jessica Langley and my husband Nate and I live in Albany with our two daughters. Since the birth of our youngest daughter in 2017, my husband has been unable to work anymore than part-time, as our daughter's complex medical needs, require 24 hour care and support. This has put a financial strain on our family. I work full time outside home because my employment has the best health insurance.

Our daughter was born with a congenital heart defect and requires a tracheostomy tube and ventilator for airway support. She also needs a gtube for feeding and is developmentally delayed. She is part of the DHS Medically Fragile Child Program and qualifies for over 400 hours a month of LPN/RN level care in our home paid for by Medicaid (OHP). Over the last seven years we have never been fully staffed for home nursing support. That gap in nursing support is picked up by my husband and myself. In 2020 it became impossible for my husband to work even part-time and provide care for our daughter, so he left his job for the betterment of our family.

During the COVID-19 emergency (2021-2023) Nate was a paid parent caregiver for our daughter. This was a life changing improvement to her care and we have seen great improvements to her health and development. It also provided our family with financial support and security.

This is not just parenting our child, this is providing nurse level care in our home around the clock. It keeps our daughter healthy and out of the hospital or a residential care home. Having our daughter at home is the best place for her health, development and daily living. Parents are truly the best and most talented caregivers for our Medically Fragile Children and we need to be compensated accordingly. We ask for your support of SB 538. We will gladly talk to or answer any questions this committee may have about paid parent caregivers. Thank you.