

To Chair Monnes-Anderson and Committee Members,

I want to share my story and encourage you to move forward to pass a SB 770 for Single Payer health plan.

I have two children who were born in 1991 and 1993. My husband and I are healthy individuals who expected to have two perfectly healthy children, which we did, with the exception that they both had a metabolic disorder known as PKU. This disorder is caused by both parents carrying a recessive gene. Neither my husband or I had any known history of this in our families. It also can cause severe mental retardation if not caught and treated from birth.

We have been so fortunate in that when my children were born medical science understood the disease and there were laws in most states to test for it at birth. The unfortunate irony was that even though the medical community knew how to treat it, insurance companies were not willing to cover medical formula that the kids needed to drink for life. There was a technicality that was used to call the treatment “food”, rather than medicine. We, unlike, many families that we knew, had health coverage through Kaiser Permanente. They were one of the few health care carriers that covered the medical formula until Oregon passed a law to change that.

I have lived with the worry since my kids were born that they would at some point in time lose healthcare coverage because of their “Pre-existing” condition. I also have worried that they wouldn’t have healthcare period once they were unable to be insured by us. Again, we were lucky; the ACA enabled us to cover them until they were 26 years old.

My son moved to Florida for work, in that state his supplement which is a new product is not covered. He is now paying for it out of pocket.

Healthcare coverage has been a dark cloud and stressor for my family since they were born. We have been fortunate, but I know many have not been so lucky. It’s time for Oregon, and in my view, the whole country to stop punishing people who have health issues, causing financial burdens and difficult choices. Healthcare should be for all individuals. I urge you to move forward with single-payer healthcare, and pass SB 770.

Sincerely,

Mary Jo Mann