

Our family is very grateful that Laila's PKU was discovered with newborn screening. Once we were able to overcome the fear and shock of her diagnosis, the next step was to learn about what we could do to keep her healthy and protect her developing brain and tiny growing body. We have been fortunate to live in Oregon, which mandates medical formula and food coverage and have had insurance coverage for her medical nutrition since she was born. I cannot imagine a life where we would be unable to provide the nutrition our daughter needs to survive and thrive. All medical formula and foods for my daughter require that we pay our \$5000 deductible first and then we are responsible for 20% of the cost up to the out of the pocket maximum on our plan of \$6750. This does not include the cost for Kuvan, a medication that allows my daughter to eat one additional gram of protein per day and costs our health plan nearly \$8000 per month. Medical nutrition coverage has been a priority and constant consideration for our family since Laila was born. It has driven career decisions for my husband and myself to ensure that we maintain jobs that will provide the medical nutrition coverage for Laila. I have spent many hours on the phone with insurance companies, balancing medical nutrition bills, working out medical bill payment plans, and reviewing EOB's with insurance providers to ensure medical nutrition was covered appropriately over the years. Unfortunately with coverage not mandated throughout the U.S., Laila will be forced to make college, career, and relocation decisions when she enters into adulthood in eight years that are highly influenced by where she can get the medical nutrition coverage she needs. I do not want any barriers for my daughter to live her best life. I don't ever want her to sacrifice medical nutrition because of the lack of coverage or inability to afford other basics of living along with the very expensive medical formula and foods, this could have awful and long-term impacts on her health and quality of life. Providing this coverage is not just the right thing to do for my daughter, but for all of those that live with disorders that require medical nutrition to protect their health and prevent other long-term costs like hospital visits and inpatient care. It is our obligation as a nation to protect the health of the public, medical nutrition decisions should not be left to insurance companies and should have legislation to ensure coverage is equitable and accessible to all.