



June 17, 2020

Nathan Checketts
Medicaid Director
Utah Department of Health
Medicaid and Health Financing
PO Box 143106
Salt Lake City, UT 84114-3106

Re: Utah's Premium Partnership for Health Insurance (UPP) Premium Reimbursement Increase

Dear Director Checketts:

The National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on the state's Section 1115 Demonstration Amendment to increase the premium reimbursement amount for Utah's Premium Partnership for Health Insurance (UPP) program.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We believe that all patients should have access to quality and affordable health care that is best suited to their medical needs. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. In service of that mission, NORD supports this proposal to increase the premium reimbursement limits for the UPP program.

This waiver amendment would allow the state to increase the maximum reimbursement amount from \$150 per enrollee per month, to a higher amount, through the state administrative rulemaking process, rather than by waiver amendment. NORD agrees that increasing the maximum premium reimbursement amount will allow more low-income individuals to purchase and retain health insurance coverage. In addition, we believe that this program may become more necessary in the context of the ongoing COVID-19 public health and economic crises.

Access to comprehensive health insurance is essential to ensuring that patients are able to receive timely, medically necessary health care. If someone without health insurance is exposed to COVID-19, they are less likely to seek testing or treatment due to fears about the cost of care. This puts all Utahans, but especially rare disease patients who may have compromised immune systems, at greater risk.



The UPP program has the potential to assist low income families to retain their employer-sponsored coverage, or afford COBRA insurance in the event that one or more members of the household lose their job due to the economic impact of COVID-19. Retaining employer coverage allows for the continuity of provider networks, medications, and physicians, which is of particular importance for individuals with rare diseases. Many rare disease patients require frequent medical care, and may have already incurred considerable out-of-pocket spending in the first half of the calendar year. Facilitating the extension of employer coverage relieves such individuals from having to start a new plan, with new cost-sharing amounts and patient out-of-pocket contributions that reset to zero.

NORD recognizes that there is enormous pressure on the state to reduce costs during this economic crisis. However, we believe that this program provides an essential service, and should not be delayed. Affordable health insurance is critical to ensuring that rare diseases patients, and others with serious and chronic conditions, are able to access their health care. We urge the state to proceed with this waiver amendment to increase premium reimbursement limits.

Thank you again for the opportunity to submit comments. For questions regarding NORD or the above comments please contact Corinne Alberts at calberts@raredisease.org.

Sincerely,

Heidi Ross, MPH
Director of Policy