April 27, 2020

Melody Anthony
Medicaid Director
Oklahoma Health Care Authority
Federal Authorities Unit
4345 N. Lincoln Blvd.
Oklahoma City, Oklahoma 73105

Re: 1115 Waiver Amendment - Adding the Newly Eligible Adult Group to PCMH and Increasing Care Coordination Rates for PCMH American Indian/Alaskan Native Providers (Project Number: 11-W0048/6)

Dear Director Anthony:

The National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on the 1115 Waiver Amendment - Adding the Newly Eligible Adult Group to PCMH and Increasing Care Coordination Rates for PCMH American Indian/Alaskan Native Providers (Project Number: 11-W0048/6).

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

The purpose of the Medicaid program is to provide healthcare coverage for low-income individuals and families, and NORD is committed to ensuring that SoonerCare provides quality and affordable healthcare coverage. We strongly support the State Plan Amendment (SPA) submitted on March 6, 2020 that will expand Medicaid coverage in Oklahoma to individuals making less than 138 percent of the federal poverty level ($2,498 for a family of three) beginning July 1, 2020. We urge the state to implement this Medicaid expansion as quickly as possible, as this will help provide health care coverage to an economically and often medically vulnerable population. However, the goal of expanding health care coverage in a state with an uninsured rate of 16.3% of all adults will only be met if other barriers to care included in this proposal are not implemented. These barriers would be harmful to Oklahomans with rare disease anytime; however, these barriers to access needed care are even more harmful during the current public health crisis.

Retroactive Coverage
Oklahoma has requested the authority to waive retroactive eligibility, a policy that prevents gaps in coverage by covering individuals for up to 90 days prior to the month of application, assuming the individual is eligible for Medicaid coverage during that timeframe. This is common for rare disease patients, who may suffer with symptoms for years before getting a formal diagnosis and associated treatment plan and whose eligibility status for Medicaid may fluctuate with the severity of their

condition. Retroactive eligibility allows patients who have been diagnosed with a serious illness to begin treatment without being burdened by medical debt prior to their official eligibility determination.

Medicaid paperwork can be burdensome and often times confusing. A Medicaid enrollee may not have understood or received a notice of Medicaid renewal and only discovered the coverage lapse when picking up a prescription or going to see their doctor. Without retroactive eligibility, Medicaid enrollees could then face substantial costs at their doctor's office or pharmacy. When Ohio was considering a similar provision in 2016, one estimate predicted that hospitals could accrue as much as $2.5 billion more in uncompensated care as a result of the waiver.[1] Additional uncompensated care would be especially problematic at the current time because it would add to the financial challenges hospitals are facing as a result of COVID-19. NORD opposes a waiver of retroactive coverage.

Cost-Sharing

The proposal includes cost-sharing for patients. The copays in Oklahoma's standard Medicaid program can be substantial – for example, the copay for inpatient hospital services is $10 per day, up to a total of $75.[2] Research demonstrates that low-income individuals served by Medicaid are more price sensitive compared to others, more likely to go without needed care, and more likely to experience long-term adverse outcomes.[3] NORD fears that cost-sharing could deter patients from accessing needed care, resulting in more health complications and more expensive medical bills. Many rare disease patients have complex conditions that can turn quickly into situations that require emergency interventions if left unmanaged. For example, patients with Ehlers Danlos Syndrome (EDS) often experience chest pain that necessitates careful and timely monitoring to ensure serious cardiac complications are not occurring. Implementing co-pays could deter people from seeking necessary care for their symptoms, resulting in expensive hospitalizations and in-patient procedures. NORD opposes adding cost-sharing for the Medicaid expansion population.

The core objective of the Medicaid program is to furnish healthcare to low-income populations. The totality of this demonstration application hampers that goal and NORD opposes the proposal. We instead urge Oklahoma to move forward with implementing its SPA for Medicaid expansion as soon as possible without imposing any additional barriers to coverage. Thank you for the opportunity to submit comments.

Sincerely,

Heidi Ross, MPH
Director of State Policy
National Organization for Rare Disorders

Tamra Misak
Oklahoma Rare Action Network
Volunteer State Ambassador

[1] Virgil Dickson, "Ohio Medicaid waiver could cost hospitals $2.5 billion", Modern Healthcare, April 22, 2016. (http://www.modernhealthcare.com/article/20160422/NEWS/160429965)

[2] https://www.medicaid.gov/sites/default/files/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/OK/OK-14-014.pdf

[3] See for example: Chernew M, Gibson TB, Yu-Isenberg K, Sokol MC, Rosen AB, Fendrick AM. Effects of increased patient cost sharing on socioeconomic disparities in health care. J Gen Intern Med. 2008. Aug; 23(8):1131-6. Ku, L and Wachino, V. "The Effect of Increased Cost-Sharing in Medicaid: A Summary of Research Findings." Center on Budget and Policy Priorities (July 2005), available at http://www.cbpp.org/5-31-05health2.htm.