



January 26, 2018

The Honorable Seema Verma, Administrator  
Centers for Medicare & Medicaid Services  
200 Independence Avenue, SW  
Washington, DC 20201

**Re: KanCare 2.0 Section 1115 Demonstration Renewal Application**

Dear Administrator Verma:

On behalf of the 30 million Americans with one of the estimated 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) submits the following comments on the proposed extension of the KanCare Section 1115 demonstration. We understand that Kansas may withdraw this application, but we felt it important to express our strong concerns with this proposal nonetheless.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. Since 1983, we have been committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

NORD appreciates Kansas' stated goal of enhancing the lives of its Medicaid beneficiaries. However, after reviewing the proposed changes to KanCare and consulting with our member organizations, we are concerned that the work requirement proposal, and the accompanying three-year cap on eligibility, will threaten access to care for many within Kansas' rare disease community.

**KanCare 2.0 Proposal to Implement Work Requirements:**

We oppose the implementation of work requirements within the Kansas Medicaid program because we believe the exemptions to these requirements will not be nuanced or precise enough to avoid harming the health and wellbeing of Kansas rare disease patients and their families. While the list of exemptions appears comprehensive, we can still easily envision many scenarios in which individuals with rare diseases or their caregivers will be unduly subjected to onerous and inappropriate work requirements.

For example, the determination of disability included within the demonstration is, in large part, tied to the Social Security Administration's standard of disability, with one exemption described as, "[m]embers who have disabilities and are receiving Supplemental Security Income (SSI)."<sup>1</sup> Unfortunately, it is not uncommon in the rare disease community for individuals to have a great deal of trouble securing disability status from the Social Security Administration. With a scarcity of physicians familiar with rare diseases and the prevalence of undiagnosed conditions, it is often difficult, even impossible, for rare disease patients to convey the extent of their symptoms on a standard form.

Additional unwarranted applications of work requirements could arise from situations that are unaccounted for within this proposal. For example, the exemption for caregivers is stated in the

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<sup>1</sup> Kancare 2.0 Section 1115 Demonstration Renewal Application Sec. II Pg. 10

application as, “[c]aretakers for dependent children under six years or those caring for a household member who has a disability.”<sup>2</sup> Thus, while caregivers of children under the age of six or of those within the family that have a disability are exempt from work requirements, it remains unclear what would happen when that child turns six. While the caregiver may remain exempt if the child has a disability, the demonstration application does not make known how a “disability” might be determined in such a scenario.

These are just a handful of ways in which rare disease patients and their loved ones could slip through the cracks and lose access to their healthcare. In order to avoid the kind of delay or termination of care that could gravely impact the lives of Kansas’s rare disease patients and their families, Kansas would need to generate an absolutely airtight exemption process. Unfortunately, this proposal is anything but. Therefore, we would urge the Centers for Medicare and Medicaid Services (CMS) to refrain from approving this provision.

### **KanCare 2.0 Proposal to Create Three-Year Eligibility Limits:**

We also wish to express our grave concerns with the proposal to limit eligibility to three-years within a lifetime for those, “[m]embers who are subject to requirements who meet work requirements.”<sup>3</sup> Lifetime limits disproportionately harm individuals with rare diseases due to the genetic, life-long nature of their disease, as well as the incredibly expensive therapies and orphan drugs used to treat them. Rare disease patients who are subjected to work requirements, whether appropriately so or not, will suddenly find themselves entirely without coverage, despite the fact that they have adhered to the work requirements as requested.

Continuity of care is absolutely critical for individuals with rare diseases. Consequently, we strongly urge CMS to reject these kinds provisions.

Thank you for the opportunity to provide comments on Kansas’ proposed extension to KanCare Section 1115 Demonstration. Once again, NORD urges you to reject the provisions of the proposed extension detailed in this submission. For further questions, please contact me at [pmelmeyer@rarediseases.org](mailto:pmelmeyer@rarediseases.org) or 202-545-3828.

Sincerely,



Paul Melmeyer  
Director of Federal Policy

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<sup>2</sup> Ibid.

<sup>3</sup> Kancare 2.0 Section 1115 Demonstration Renewal Application Sec. II Pg. 11