NORD®
National Organization for Rare Disorders

Alone we are rare. Together we are strong.®

September 2, 2026

The Honorable Sarah Huckabee Sanders
Governor, State of Arkansas
State Capitol Building
Little Rock, AR 72201

Dear Governor Sanders,

On behalf of the more than 30 million Americans – approximately 1-in-10 Arkansans - living with one of the over 10,000 known rare diseases, the National Organization for Rare Disorders (NORD®) thanks you for your leadership and for Arkansas's longstanding commitment to Medicaid expansion, providing coverage for many rare disease patients. We were disappointed to learn that CMS denied Arkansas's ARHOME waiver renewal application. We support your administration's request to CMS for a two-year extension of the program and urge you to continue coverage for the Medicaid expansion population.

With a more than 40-year history, NORD is the longest-standing patient advocacy group for the more than 30 million Americans living with a rare disease. An independent 501(c)(3) nonprofit, NORD is dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 355 patient organization members, is committed to improving the health and well-being of people with rare diseases by driving advances in care, research, and policy.

Nearly half of adults covered by Medicaid expansion are permanently disabled, have serious physical or mental conditions, or are in fair or poor health.[1] For many people with rare diseases and other complex or chronic health conditions who may find their lives and their families' lives upended by the debilitating nature of their conditions, Medicaid is often the only pathway to care. According to national hospital discharge data, Medicaid and Medicare covered more than 70% of adult rare disease inpatient stays. Among children hospitalized with a rare disease, Medicaid alone was the primary payor for more than half of all visits (50.1%).[2]

Rare disease patients face unique challenges that make uninterrupted health coverage especially critical. Fewer than 5% of the 10,000+ known rare diseases have any FDA-approved treatment, and the average time from symptom onset to diagnosis, i.e., the "diagnostic odyssey," is 6 years. Medical expertise is often limited to a small number of providers nationwide, symptoms may fluctuate and not fit neatly into traditional disability criteria, and for many patients, clinical trials are the only available therapeutic option.

[1] Brantley, Erin, et. al. Myths About the Medicaid Expansion and the 'Able-Bodied'. Health Affairs Blog. (Online) March 2017. Available: http://healthaffairs.org/blog/2017/03/06/myths-about-the-medicaid-expansion-and-the-able-bodied/

[2] Navarrete-Opazo A, et al., Can you hear us now? The impact of health-care utilization by rare disease patients in the United States, *Genetics in Medicine* (2021), https://www.gimjournal.org/article/S1098-3600(21)05167-4/fulltext

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Even a temporary disruption in coverage could have serious consequences for these patients and for the state overall. Hundreds of studies examining the impact of Medicaid expansion have found that expansion is linked to increased access to coverage, better health outcomes, and financial benefits for providers and states[3].

Medicaid is a lifeline for rare disease patients, the caregivers who support them, and many others that provides not only access to health care, but the stability necessary to manage complex and often lifelong conditions and to remain engaged in the research that rare disease progress depends on.

NORD recognizes that Arkansas is navigating difficult decisions due to CMS's denial of the ARHOME waiver renewal and amidst many new federal requirements and guidance. We support your administration's efforts to continue the ARHOME program and sustain coverage for this population, including the 1-in-10 Arkansans living with a rare disease and many others with complex health needs who depend on it. NORD stands ready to partner with Arkansas in ways it sees fit to respond to the ARHOME waiver denial and the forthcoming decision on Arkansas's extension request.

Thank you for your time and consideration. For questions or more information, please contact NORD Associate Director of State Policy Carolyn Sheridan at csheridan@rarediseases.org.

Sincerely,

Kathryn Lowell

Kathryn Lowell
Executive Vice President, Government Affairs
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[3] Madeline Guth and Meghana Ammula. "Building on the Evidence Base: Studies on the Effects of Medicaid Expansion, February 2020 to March 2021." May 6, 2021. Available at: https://www.kff.org/affordable-care-act/building-on-the-evidence-base-studies-on-the-effects-of-medicaid-expansion-february-2020-to-march-2021/