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National Organization for Rare Disorders

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September 2, 2026

Arkansas Legislative Council
Hospital, Medicaid, and Developmental Disabilities Study Subcommittee
1 Capitol Mall
Little Rock, AR 72201

To the Honorable Members of the Hospital, Medicaid, and Developmental Disabilities Study Subcommittee of the Arkansas Legislative Council and Dedicated Staff,

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 holding a public hearing on this critical issue, and for Arkansas's longstanding commitment to Medicaid expansion.

We write to express our deep concern about the future of this coverage following the Centers for Medicare & Medicaid Services' (CMS) rejection of Arkansas's request to renew the Arkansas Health and Opportunity for Me (ARHOME) waiver. We understand that the Arkansas Department of Human Services has since submitted a request asking CMS to extend ARHOME for two additional years, to allow the state time to design and implement a new Medicaid model. We support this request and urge you to help ensure it is approved so that Arkansans currently covered under expansion do not experience a lapse in coverage while the state works through this transition. We further urge that any new model developed during this period fully preserve coverage for the individuals who depend on this program for access to essential health care.

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.[2]

[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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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.

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 lawmakers and other state leaders are navigating difficult decisions due to many new federal requirements. We respectfully urge Arkansas to prioritize continuity of coverage and a path forward that preserves Medicaid expansion for the 1-in-10 Arkansans living with a rare disease and many others with complex health needs who depend on it. We would welcome the opportunity to serve as a resource, however we may be helpful.

Thank you for your time and consideration. For questions or more information, please contact NORD's State Regulatory Affairs Specialist, Gretchen Frank at gfrank@rarediseases.org.

Sincerely,

Carolyn G. Sheridan, MPH
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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/