Statement from EveryLife Foundation for Rare Diseases
House Committee on Energy and Commerce Markup:
May 13, 2025

Chair Guthrie, Ranking Member Pallone, and Members of the Committee,

The EveryLife Foundation for Rare Diseases is alarmed by the proposed Medicaid cuts in the FY25 budget reconciliation language under consideration by the Energy & Commerce Committee. Reductions in Medicaid funding, as well as the introduction of complex work reporting requirements and other burdensome administrative mandates will devastate the rare disease community by slashing life-sustaining care and benefits.

The rare disease community utilizes Medicaid for diagnoses, treatments, durable medical equipment, home healthcare, and caregiver services for highly complex, chronic health conditions. The estimated $715 billion in cuts to the Medicaid program over ten years will impact eligibility pathways, benefits, and overall access to healthcare. The proposed cuts will decrease the availability of home and community-based services waivers and could eliminate important programs such as Katie Beckett waivers, resulting in people losing their healthcare coverage due to complicated work requirements.

Medicaid is a lifeline for millions in the rare disease community, providing benefits often unavailable through other payers. The CBO estimates that at least 13.7 million people will lose health insurance over the next ten years. Collectively, the proposed changes to Medicaid will decrease funding to states, increase administrative costs, and result in rare disease patients and families losing coverage and benefits.

Despite the inclusion of language exempting 'medically frail' individuals and caretakers for disabled individuals, burdensome work reporting requirements will harm our community. Experiences with work reporting requirements in Arkansas and Georgia, as well as Medicaid unwinding, demonstrate that coverage losses occur, not because of ineligibility, but because of challenges in understanding and complying with the reporting processes. Many in the rare disease community rely on optional benefits and waiver programs to receive critical coverage unavailable from any other insurance provider. When federal funding for Medicaid drops, those who depend on the program's waivers suffer. Medicaid keeps parents in the workforce and children at home. The proposed cuts to Medicaid, magnified by projected coverage losses for those who purchase insurance on the marketplaces, will force states to make choices that are counterproductive to the health and well-being of families and the health of our economy.

We call on Congress to reject policies that will terminate healthcare and harm rare disease patients and families. The rare disease community relies on Medicaid and is counting on Congress to protect our access to life-sustaining health care.