

Take Action Today!

Call Your Members of Congress about Protecting Medicaid

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Call Talking Points/Story Sharing

- Good morning/afternoon. My name is [Your Name], and I'm a constituent of Representative/Senator [Lawmaker's Last Name] from [Your City/Town].
- As a constituent, and an advocate for the 1-in-10 Americans living with a rare disorder, I am reaching out to urge you to oppose proposed changes to Medicaid as passed in H.R. 1 and those currently under consideration in the Senate.
- I'm concerned that congressionally mandated Medicaid work requirements and other proposed changes to Medicaid will result in significant barriers to accessing health care treatments and services for people living with rare conditions and their caregivers. Many rare disease patients rely on the Medicaid program, and without it, they wouldn't be able to access or afford the care and lifesaving treatment they urgently need.
- Despite efforts in the bill to carve out medically fragile people and their caregivers, people with rare diseases are still at serious risk of losing coverage due to the changes that these proposals would impose on the states.
- Access to affordable and comprehensive care is vital from day one of a person's journey with rare disease; many rare disease patients face years of a difficult "diagnostic odyssey" before receiving their correct diagnosis due to the uncommon nature of these conditions.
- The diagnostic odyssey for the average rare disease patient lasts between five and seven years and is emotionally, physically and financially draining for the patient and their family.
- Please give me a moment to tell you why this is so important to me/my loved one: *In two-three minutes, please share your rare disease (or your loved ones), journey to diagnosis and/or challenges you are faced with living with or caring for someone with a rare disease, and (if personally relevant) how the Medicaid program makes it possible to receive the care needed.*
- It would be nearly impossible to legislate or regulate an effective exemption for all individuals impacted by rare diseases, including those on the diagnostic odyssey. As such, I am concerned that current proposals will likely lock many rare disease patients out of Medicaid access.
- I urge you to oppose these and other dangerous changes to the Medicaid program.
- This isn't just about me/my loved one. Many of my neighbors and fellow community members rely on Medicaid for their health care as well. Reducing access or funding would have a devastating impact on so many in our community.
- Investing in Medicaid is an investment in the health and well-being of our entire district and our state [Name State].
- I truly hope you will support policies that protect and strengthen Medicaid for all who rely on it for survival.
- Thank you for taking the time to hear my story and consider my concerns.