



Opponent Testimony for Senate Bill 17

Ohio Senate Government Oversight and Reform Committee

May 6, 2021

Dear Chair Roegner and Members of the Senate Government Oversight and Reform Committee,

Thank you for the opportunity to submit testimony in opposition to Senate Bill 17 (SB 17). My name is Tiffany Sammons, and I am the Ohio Rare Action Network Volunteer State Ambassador for the National Organization for Rare Disorders (NORD), and the mother of a child with a rare condition. NORD is a unique federation of voluntary health organizations that is dedicated to helping the 25-30 million Americans living with a rare disease. It is estimated that 1 in 10 Ohioans have a rare disorder and many of them could be negatively impacted if the Ohio Legislature were to approve SB 17.

I am deeply concerned by the impact that SB 17 would have on patients. As a rare disease advocate, parent, and caregiver, I have seen firsthand how essential Medicaid coverage is to many individuals with rare disorders. Medicaid coverage provides low-income rare disease patients with access to disease screening, preventive care, and medical treatment so that they can manage their complex conditions. If enacted, this legislation would put harmful and unnecessary barriers between patients and these services in the form of additional income eligibility verifications and work requirements. Medicaid paperwork is already complicated enough and failing to navigate the new requirements that this legislation creates could have serious – even life or death – consequences for people with rare, acute, and chronic diseases. If the state finds that an individual has failed to meet requirements, then they will be locked out of the Medicaid program for at least six months. For rare disease patients who often require daily, weekly or monthly medications or other care, this sudden disenrollment in Medicaid coverage could result in their being unable to meet with their provider or get prescriptions filled, leading to hospitalization or worse.

Many people with rare diseases have complex and costly health care needs and may also struggle to work due to their medical condition. According to NORD's recent *30-Year Barriers to Access Survey*, 76% of rare disease patients report some or great financial burden and 62% of



adults have had to miss work as a result of their rare disease. For all patients with a rare condition, the Medicaid program provides an assurance that if their disease increases in severity and they are unable to work they will still be able to access necessary treatment. For myself, and other parents of a child with a serious condition, the Medicaid program means that my child will not lose access to critical care if we lose our jobs. This aspect of the Medicaid program is especially vital during these difficult economic times.

Thank you for your consideration of my testimony. I feel that SB 17 would negatively impact the health care system as a whole and would do nothing to improve the sustainability and quality of the Medicaid program. If enacted, this legislation would divert funds and resources away from patient care and cause potentially thousands of patients to lose access to preventative care and routine visits. I urge this committee to reject SB 17, and I hope that we can all work together in order to improve access to affordable and adequate health care for Ohioans with rare disorders.

Respectfully,

Tiffany Sammons
Ohio Volunteer State Ambassador
Rare Action Network