

From: [Jordan Harris](#)
To: [1115 Waiver Renewal](#)
Subject: OHP 1115 Medicaid Waiver Comment
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Dear Interim Medicaid Director Hittle,

I'm a 28 year old epileptic who after 20 years of seizures, finally received a proper diagnosis and have almost figured out the right combination of seizure medications to control my seizures. This has required a lot of dose and medication adjustments because some medications have actually caused my seizures to become worse, increasing the level of medical care I required. For people like me, one medication alone does not provide effective seizure control and the type of medication used isn't interchangeable. For me, being limited to one type of medication could lead to an increase in seizures and result in further delay in my education, increased limitations in my ability to support myself financially by working and paying for medical costs, and a dramatic decrease in quality of life due to the limitations placed on me and the mental health effects of having uncontrolled seizures. Thank you for continuing to provide full coverage for all epilepsy medications and keeping people like me well and alive.

As a member of the epilepsy community in Oregon, I am writing to express concerns with the proposed "commercial style" closed formulary. Epilepsy is a disease or disorder of the brain which causes reoccurring seizures. Epilepsy is made up of many different types of seizures or syndromes, affects people throughout the lifespan, and can have many different causes and associated conditions. There are almost 43,000 Oregonians living with epilepsy.

I am very concerned with the state's proposal to limit coverage for prescription medications. Epilepsy medications are not interchangeable and there is no one treatment that works for everyone with epilepsy or seizures. The response to medications, including effectiveness at controlling seizures and side effects, can be different for each person. Selection of the appropriate medication to prevent seizures is determined by a number of variables, including type of seizure, seizure frequency, age, gender, and other health conditions.

People with epilepsy who have their medications switched are at a high risk for developing breakthrough seizures. Uncontrolled seizures lead to significantly increased medical costs, such as hospitalizations and treatment for complications like injuries. Uncontrolled seizures also result in lost wages and productivity, not just for the individuals living with epilepsy but also their families and communities. Access to the full range of available treatments is critical. The state should not move forward with this proposal.

I am also writing to express concern with the state's request to renew a waiver of services for children, known as EPSDT. Children with epilepsy frequently have related developmental disabilities. The current EPSDT waiver excludes treatment for disorders common in children with developmental disabilities, including and sleep disorders. Lack of sleep is a known seizure trigger and children with epilepsy are more prone to sleep problems, so lack of treatment for sleep disorders in children could result in more frequent seizures, which could result in more and stronger medications, emergency room visits, hospital stays, and lost school days.

I urge you to not move forward with the closed formulary proposal or renewal of the EPSDT waiver.

Sincerely,

Jordan Harris

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