

From: [Anthony Cook](#)
To: [1115 Waiver Renewal](#)
Subject: OHP 1115 Medicaid Waiver Comment
Date: Tuesday, December 28, 2021 8:30:06 PM

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Dear Interim Medicaid Director Hittle,

My Name is Anthony Cook, and I have been living with epilepsy since 1980. In my travels abroad four other continents I have always been surprised by the ease with which I have been able to obtain my prescription. This can be taken out of context, as it sometimes is in the US, as being a problem with other countries' ability to keep dangerous drugs from the public. On the contrary, I have seen only professionalism and compassion from foreign doctors and pharmaceutical staff, just as I have here in the United States. Where professionalism is lacking is in the healthcare industry, and it is here that Oregon can again make an example of what good, safe and humanitarian healthcare should be. "Commercial Healthcare" is an industry which makes a profit off the needs of people. Whether you are healthy or well, rich or poor, you should feel free to see a doctor. Every friend I know in a country outside of my own, is appalled by the way our "healthcare" treats its patients. They are also confused because of the great doctors and healthcare professionals that are here. but so many can't or won't go to see because of fear of being unable to pay the bills.

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,

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