

From: [Kelly Cobb](#)
To: [1115 Waiver Renewal](#)
Subject: OHP 1115 Medicaid Waiver Comment
Date: Wednesday, December 29, 2021 8:10:06 AM

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Dear Interim Medicaid Director Hittle,

As the parent of an adult child with epilepsy, learning of the OHP plan to severely restrict the formulary is alarming to say the least. My daughter has what is called medically refractory epilepsy. That means that her condition does not respond optimally to treatment. As a result, more than 10 medications, and two implant devices, have failed to fully control her seizures. She currently takes 3 different seizure medications, and still has at least 8 seizures a month. The thought of having her care options reduced to one arbitrarily chosen medication is mind-boggling.

We were fortunate to be able to have employee-sponsored health coverage when she was a child, but my heart goes out to those who do not have that option, and depend on OHP for their child's care. Mental health treatment is such an integral part of epilepsy treatment. I know for a fact that without psychiatric support, my daughter's condition would be markedly worse than it is today.

Epilepsy is a complicated, multi-faceted, very individualized condition. There is simply no one medication or treatment for every person who lives with it. Please do not so severely limit the options for treatment. The consequences for those who need a combination of medications could be life-threatening. That is not hyperbole. It is fact. Seizures can be fatal, and making sudden changes to medication, because you have no other option, could have dire consequences.

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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