From: Kristin Spurkland
To: 1115 Waiver Renewal
Subject: OHP 1115 Medicaid Waiver Comment
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Dear Interim Medicaid Director Hittle,

As someone diagnosed with epilepsy in adulthood, I know how important it is to have options when it comes to seizure drugs. Had I been limited to the first drug I tried, I would have faced an impossible choice: seizure control or the ability to work. On my first drug, the dosage the controlled my seizures left me so nauseous and dizzy that literally could not stand. Because I was able to change medications, I now have a medication that controls my seizures while allowing me to work and be an active participant in my community. There is no "one size fits all" medication when it comes to epilepsy.

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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