From: Marissa Mireles
To: 1115 Waiver Renewal
Subject: OHP 1115 Medicaid Waiver Comment
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Dear Interim Medicaid Director Hittle,

There is no one medication is the end all, be all. When I was first diagnosed with epilepsy, I started on a medication that was commonly used and it worked. Eventually though, I started breaking out in small hives and I was always itchy. I ended up being allergic to that medication. At the age of 18, I was finally able to get a medication that I could take. That worked with my body - I wasn't allergic to, or didn't have any problems with. I'm grateful that Medicaid is able to purchase my medication because otherwise, I wouldn't be able to get this medication. A necessary medication for my health, and to continue a healthy life and lifestyle is $500. I cannot afford that. It took me three medications to find the one that I can actually take. My brother also has epilepsy, and his is severe. Medicaid won't pay for his medication, and we cannot afford $700 to get him it every month. With cost of living and a bad economy, $700 barely covers the rent. How're we supposed to be able to cover that? Unfortunately, because we cannot, and Medicaid won't, he has to live a lifestyle paranoid. Paranoid he's going to be at work and have a fourteen, yes I said fourteen, minute seizure. Paranoid that anytime he yawns, he's not getting enough sleep so he has to cut his work time in half and life in half, so he does not put himself at risk of having a seizure. That is not a way to live. Limiting people with epilepsy to ONE covered medication, is limiting our future. We do not want these medications, we NEED them.

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 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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