From: Patricia Durkin
To: 1115 Waiver Renewal
Subject: OHP 1115 Medicaid Waiver Comment
Date: Wednesday, January 5, 2022 12:15:40 PM

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Dear Interim Medicaid Director Hittle,

My daughter was born with charge syndrome over 41 years ago. At 25 she started having seizures. The medication that she is on now is absolutely essential for her to keep using.
She is highly sensitive to many things. She is on a special diet needing to avoid many foods she is sensitive to in allergy response and ill health response.
A few years ago our pharmacy gave us a prescription for her that was same generic medication but made by a different manufacturer. After two doses she wasn't in a preseizure state verified by doctor and pharmacist both. Since there have been times when getting only the one medication by the one manufacturer has been challenging g. Our pharmacist has been very helpful . She cannot switch medications nor manufacturer. She cannot be put on a " one size fits all" medication!!!
She has been disabled and on Medicaid and SSI since birth.
Please do not change system!

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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