**From:** Haile McIntosh
**To:** 1115 Waiver Renewal
**Subject:** Scared for my loved ones
**Date:** Wednesday, January 5, 2022 8:34:33 PM

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Interim Deputy Director Hittle,

I am writing to you regarding the Oregon 1115 Demonstration Waiver for the Oregon Health Program (OHP). My name is Haile McIntosh and I am a caregiver in Oregon who has clients and loved ones who have epilepsy. I am deeply concerned by the potentially life-threatening effects these proposals could have on them.

In agreement with Epilepsy Foundation Oregon, I will uplift and quote their concerns:

"We support Oregon's request to provide multi-year continuous enrollment for children under six and continuous eligibility for all beneficiaries ages six and over. Unfortunately, this waiver also contains multiple proposals that would undermine access to care and needed medications for people with epilepsy. We are very concerned with the new proposed closed formulary for adults, as well as Oregon's proposals to continue the waiver of retroactive eligibility, continue to waive the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit for children over the age of one, and continue to use of a Prioritized List of services that relies, in part, on a quality-adjusted life year."

I am writing to say that I strongly Oppose transitioning to a Closed Formulary for adults. The implications that the state could offer and cover just one drug per therapeutic class is so dangerous. All of the people I know who have epilepsy take several different kinds of seizure medications and they are all critical to effectively managing their health. I know that this is common across the population of people who live with epilepsy. Limiting the availability and access to these medications could absolutely be devastating and life threatening to my loved ones, as they would not be able to afford all of the medications their bodies have become reliant on if some of them were no longer covered.

I strongly Oppose Continuing to Eliminate Retroactive Coverage.
Again, to quote and agree with Epilepsy Foundation Oregon,

"Retroactive eligibility allows people with epilepsy who have either been newly diagnosed or need a new treatment regime to begin treatment right away, avoiding delays in lifesaving care and without the burden of medical debt while they work on eligibility paperwork."

I also Oppose Prioritized List and Use of Quality Adjusted Life Years and Restricting coverage for treatment under Early and Periodic Screening, Diagnosis and Treatment (EPSDT).

I agree with the following statements presented by Epilepsy Foundation Oregon regarding my opposition:

"We urge OHP to abandon the use of the QALY and work with Disability Rights Oregon, Epilepsy Foundation Oregon, and other disability rights organizations to develop a better way to allocate scarce Medicaid dollars and care for people with disabilities in an equitable way."

"We strongly support the removal of the restrictions to the EPSDT benefit to allow children full and equitable access to healthcare, in keeping with the purpose of the EPSDT benefit."

I am scared for my loved ones and angry and tired of the ways the state continues to display an interest in profit over care for human beings. With all the compassion you can muster up, please consider supporting continued life and essential, baseline care. This proposal is unacceptable. We are writing history and we have to be doing better.

Sincerely,

Haile McIntosh