Submitter:	Clark Hansen
On Behalf Of:	The ALS Association
Committee:	Senate Committee On Health Care
Measure:	HB4113

Chair Patterson and members of the Committee thank you for the opportunity to submit testimony. My name is Clark Hansen, and I am the Managing Director of Advocacy for the Western states for the ALS Association. I am writing in support of HB 4113.

In recent years, health insurers have begun implementing new programs that prevent any patient assistance funds from counting towards patients' deductibles and out-of-pocket maximums.

Under the current system two patients with the same disease, prescription and insurance can pay vastly different prices for their medicine. The amount a patient pays is determined by their insurance company and its pharmacy benefit managers, who negotiate and set the prices they will pay.

Some insurance companies are changing their policies to no longer allow outside financial assistance to count toward a patient's out of pocket costs. Consequently, this means patients could pay thousands of dollars more at the pharmacy or risk going without life-saving medicine.

As you know, ALS is a terminal disease. It currently has only 6 FDA approved treatments. None of these approved treatments have a generic equivalent. Relyvrio, the newest and most promising ALS drug, has a cost of $158,000 per year. Its manufacturer Amylyx, has a prescription assistance program for eligible patients who have commercial insurance that can be used to eliminate their co-pay. Without this discount program, ALS patients can face prescription costs of $1,000 to $4,000 per month just for this drug. ALS patients often take other drugs to deal with the complications that come with the disease. These drugs can cost patients thousands of dollars per month. So patient groups like the ALS Association and other charitable organizations offer financial support to patients to help offset these costs. Under some of the current Insurance company programs, this support would not count as payment towards a co-pay.

Our healthcare system has many flaws that need to be fixed, but the reality is insurance companies are taking away a cost sharing tool that patients have come to rely on. Patients risk their health and treatment outcomes when they are no longer able to afford medications or ration their prescriptions to stretch their financial resources. When a patient is not initially aware financial assistance options are no longer accepted by their insurer or counted toward their deductible, it can cause a major disruption in their life.

HB 4113 will help Oregonians continue to access the life-saving treatments they need by requiring all payments made on behalf of a patient count towards their cost sharing obligations. In the case of ALS patients, pharmaceutical co-pay assistance programs do not steer patients to a more expensive drug over a cheaper option

because there are no cheaper options.
I am asking for your support on this bill.
Thank you
Clark Hansen, Managing Director of Advocacy ALS Association, Northwest Territory.