

SB 452

Hello Senator Monnes Anderson and Members of the Senate Committee on Health Care

I'm still Jennifer Knapp co-founder and director of Adrenal Insufficiency United and today also speaking as the former Oregon Ambassador for the National Organization for Rare Disorders.

As you heard in my previous testimony on SB 544, SB 452 is a bill to help all patients who carry specialty emergency medications and need specialized care in emergencies. I believe SB 452 addresses the issues and concerns expressed with our adrenal insufficiency bill in 2015. MO passed this bill in 2017 and patients lives have already been saved.

I have been emailing with Drs Sahni and Rostykus today and would like to clarify a couple issues they brought up.

First it is our intention that any protocols made would include the input, approval and oversight of EMS Physicans.

Second we are not expecting protocols for each rare disease, obviously with over 7,000 rare diseases we know this is impossible. Rather we are asking for protocols that will outline the circumstances in which EMS personnel would be enabled (NOT Required) to administer patient carried specialty medications or treatment needed by their patient.

In MO's bill some of their requirments are that

- A paper copy of orders from the patient's physician must be with the patient's medication
- That medications carried by the patient be clearly labeled and contain the original dosing instructions
- and That paramedics are the ones who are able to administer patient carried medications

Some the concerns expressed, do not pertain to this bill, but rather the bill we had in 2015. I think there is some possible confusion which I would like to clear up.

SB 452 is a totally different bill

- SB 452 Does Not Require any EMS personnel to administer medications rather it gives them the ability to treat without fear of recourse. ([medical practice is NOT dictated](#)) In fact back in 2012 when I first met Dr. Sahni he was president of the NAEMSP we discussed patient carried meds. At that time he indicated it might be a good solution to our problem so I was a bit surprised to read his testimony in opposition to this proposal and am curious about what has changed.
- SB 452 does not require [ambulances to carry new medications](#). In fact this bill follows the recommendation from the opposition in 2015 in which they said all patients should be carrying their own medications.

- Submitted Testimony Samuel Kim, Mike McCaskill (testimony) incorrectly categorizes this bill as an adrenal insufficiency bill. It is not this bill covers any Oregonian who requires specialized medication and/or treatment. One in ten people are living with a rare disease and even some without rare disease may carry emergency medications.
- Some written Testimony states that EMS are allowed to give patient carried medications. However at an EMS conference in 2015 an Oregon EMS director told me he WOULD NEVER AUTHORIZE the administration of my daughter's medication. When I told him she would die without it, his response was. "People die everyday." He may have well ripped out my heart because 4 years later this still makes me cry.

I was here in Salem last week to work on setting up a meeting between other rare disease directors and the EMS Community before a scheduled hearing. However I feel that since we are at the beginning of the session there is still ample time to have this meeting and am requesting a delay in any work session until all parties can meet and hopefully come to an agreement on amendments to clarify some of the concerns raised.

Thank you for your time.

Jennifer Knapp

Adrenal Insufficiency United