

SB 544

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

My name is Jennifer Knapp and I'm co-founder and director of Adrenal Insufficiency United. I'm sure those of you here remember me from 2015.

While some of you may assume I am the one who as requested this bill I'm not. It was requested by constituent of Senator Riley's who is also a member of our adrenal insufficiency group. I'd like to take this opportunity to thank Senator Riley and Annette for bringing this issue to the attention of the committee once again.

A quick description first.

Adrenal Insufficiency occurs when a person is unable to make adequate levels of Cortisol. In an emergency an injection will help prevent death and/or permanent disability. This bill would ensure the availability of all to receive this life saving medication.

One major flaw in the opposition's testimony is that adrenal insufficiency is rare and only 7 people may need the injection in a year. These are exactly the same numbers given in 2015 and are just a wrong as they were back then. This is quite concerning to me as it shows that information we have provided in the past has not been reviewed or taken into consideration.

A pediatric endocrinologist from Dorenbechers testified for our companion school bill in 2015. She stated that at Dorenbechers alone they had 100 adrenal insufficient patients and that there were likely many more yet to be diagnosed. In fact the numbers of patients with adrenal insufficiency is rising.

Since this is a life long condition the actual numbers of 420 per million as stated in medical journals such as the Lancet and even some EMS magazines are a more accurate representation than the numbers being given by those opposed to this bill. That's over 1700 Oregonians with adrenal insufficiency.

Our FB Support group has over 8,000 adrenal insufficient patients from around the country. Surveys we have done indicate that 75% of patients will use their emergency injection.

Those opposed to this bill state that patients should work with their local EMS agency. This is all well and good, but makes the assumption that a patient will never leave their agencies borders. My daughter travels to different parts of the state, yet those Lane County protocols don't go with her.

The opposition also makes it sound easy to work with local EMS agencies. While that may be true for some not all are like that. It took me 4 years of pushing to get Lane

County to enact protocols similar to my co-founder's time frame was for Clatsop County.

Back in 2015 we did listen and try to understand the issues and concerns brought up with the bill in 2015. Those same concerns are the ones expressed in the written testimony submitted to OLIS for this current bill 544.

In 2015 our bill was gut and stuffed leaving us with a bill requiring the Oregon Health Authority to provide information about adrenal crisis to EMS agencies around the state. While I am grateful for this and see that it has made a difference because more Oregon counties have enacted protocols for adrenal insufficiency since our bill in 2015.

However, the introduction of this similar bill shows that our work is not done. Those with adrenal insufficiency are still in danger because not all are able to get their injection during an emergency and a solution to this issue is still necessary.

To address the concerns of the 2015 bill we tried a different approach in 2017, a bill for a rare disease database. While we'd thought we'd found an existing platform that would provide a solution, The Emergency Department Information Exchange. Collective Medical Technologies which runs EDIE has been supportive and initially thought it would be easy to incorporate rare and chronic conditions, but challenges have stalled the process. While I'm still hopeful it will be viable in the future it is not and we need a solution for those with adrenal insufficiency and other rare or chronic conditions.

We need to help all who need specialty medications and focus on a solution rather than reasons it can't be done. That's why I'm back again here in 2019 with SB 452. That's why all of us from the adrenal insufficient and rare disease community will keep coming back. If your loved ones life was at stake you wouldn't give up either. Let's find a solution this year!

Thank you for your time.

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Jennifer Knapp

Adrenal Insufficiency United