

April 2, 2017
Senate Committee on Judiciary
Chairman Floyd Prozanski
Oregon Legislature
900 Court Street, NE
Salem, OR 97301

Hello Chairman Prozanski and members Senate Judiciary Committee,

My name is John Silver. I am a Pulmonary and Critical Care Medicine Physician at the Santiam Hospital in Stayton, Oregon and the Director of their Intensive Care Unit and inpatient Pulmonary services. Our hospital catchment area is the Santiam Canyon and eastern Willamette Valley from Silverton to Lebanon on the east side I-5. I am a volunteer medical advisor to Adrenal Insufficiency United which has over 3,900 members and was started by Mrs. Knapp and Norgaard to optimize and improve national standards of care for patients with Adrenal Insufficiency.

I also have a rare medical disorder, Primary Adrenal Insufficiency (PAI) also known as Addison's Disease – an autoimmune form of Primary Adrenal Insufficiency. PAI is defined by the inability of the adrenal cortex to produce sufficient amounts of glucocorticoids and/or mineralocorticoids. PAI is a severe and potentially life-threatening condition due to the significant role of these hormones in energy, salt, and fluid homeostasis. PAI was first described by Thomas Addison in England approximately 150 years ago, and is therefore commonly termed Addison's disease. Cortisol deficiency results in a decrease in feedback to the hypothalamic-pituitary axis and subsequent enhanced stimulation of the adrenal cortex by elevated levels of plasma ACTH.

Only about 400 Oregonians have this disease which involves primary failure of the adrenal glands ability to produce cortisol and fludrocortisone. Taking replacement hormones on a daily keeps me in excellent health but others are not so lucky. When faced with seemingly minor illnesses like viral gastroenteritis or trauma can put me and others at risk of Acute Adrenal Crisis. The treatment is immediate delivery of intravenous steroids and fluids without delay.

Today, I am here to testify in support of SB 215. SB 215 creates a data base called ORDER (Order for Rare Disease Emergency Response).

Many patients with rare disorders (Addisons, Acute Intermittent Porphyria, Acquired Hemophilia) can have unusual presentations and require urgent therapies that astute academic or busy community hospital ER physicians may not have encountered and have not treated. Having an easy link to a computerized order set for complex patient's illness with a set of order guidelines written and suggested by how that patients specialist(s) would approach the patient would provide help to the onsite physicians at the distant hospital. It does not create liability as the document would not be all encompassing for all circumstances and all presentations and the ordering specialist(s) would know that in crafting such a document.

As an example:

A patient with Primary Adrenal Insufficiency (Addison's) like myself might have orders like the following on file in case I needed minor surgery, major surgery or a major Adrenal Crisis causing presentation to the ER or ICU:

Table 3
Hydrocortisone adjustments for medical procedures

Procedure	Preoperative needs	Postoperative needs
Major surgery	Start hydrocortisone infusion (100 mg over 12 h) just before anaesthesia	Continue hydrocortisone infusion (100 mg over 12 h) until able to eat and drink. Then double oral dose for 48+ h, then taper to normal dose
Labour and vaginal birth	Start hydrocortisone infusion (100 mg hydrocortisone over 12 h) at onset of labour	Continue hydrocortisone infusion until delivery (100 mg over 12 h). Double oral dose for 24–48 h after delivery, then taper to normal dose
Minor surgery and major dental surgery	100 mg hydrocortisone before anaesthesia given as a bolus intramuscularly or subcutaneously or as hydrocortisone infusion for the duration of surgery	Double oral dose for 24 h, then return to normal dose
Invasive bowel procedures requiring laxatives	Hospital admission overnight with 100 mg hydrocortisone intramuscularly or subcutaneously and fluid (isotonic saline), repeat dose before start of procedure	Double oral dose for 24 h, then return to normal dose
Dental procedure	Extra morning dose 1 h before surgery	Double oral dose for 24 h, then return to normal dose
Minor procedure	Usually not required	Extra dose (e.g. 20 mg hydrocortisone) if symptoms persist

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As an ICU physician, I am personally involved in the care of many patients with complex critical illnesses. Early identification of those patients with rare disorders and the specialized approach to those patients that isn't always available in medically rich resourced environments can only improve patient care. Having patients electronically flagged in an ORDER system (as with the POLST system) upon ER or ICU presentation will allow orderly transfer of data and care as a best patient practice and save lives. In ER and ICU medicine there is a "golden hour for resuscitation" during which the right therapy and the maximal therapy must be initiated or morbidity and mortality increase significantly.

I ask that you help save lives and vote yes to advance SB215 onto the next step in this legislature session.

Sincerely yours,

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