

SB 215 will create ORDER

(Orders for rare disease emergency response)

WHY IS IT NECESSARY?

- There are over 7,000 rare diseases identified, and the numbers continue to grow.
- Many with rare disease require specialized care.
- When unexpected emergencies occur, it is vital that health care providers have accurate information to treat the patient.
- Enabling health care providers to access this information quickly will improve outcomes and save lives.

A vision for ORDER

When a patient in the data base has an unexpected medical event ORDER will ensure they receive prompt and proper treatment.

- In private practice health care providers will be able to access the data and upload ORDERS for their patients.
- In hospitals and urgent care centers information on the patient will be available on the internet.
- In the field EMTs will be able to call medical control to access information in order to act on the ORDER.
- School nurses and/or police officers would be able to utilize the system as well.

Our Survey Results

78 Patients representing at least 18 rare disease/disorders took part in the survey.
(not everyone indicated their rare disease/disorder)

- 90%** Those who indicated that their rare disease/disorder requires specialized treatment.
- 88%** Number indicating they experienced a delay or improper treatment.
- 82%** Gave “Medical Staff were unfamiliar with the disease/disorder” as the #1 reason for the delay or the improper treatment given at the hospital.
- 22%** Indicated that proper treatment was never given.
- 80%** Patients indicated they suffered longer than necessary.
- 9%** Patients suffered permanent damage due to a delay or improper treatment.
- ONE** Number of deaths due to delay or improper treatment.

ORDER will provide a valuable tool for health care providers!

Patients will have fewer complications and better overall outcomes during unexpected emergencies.

Better outcomes = less money spent on hospital stays and/or follow up care.

Please vote yes on SB 215



Patient Examples

(In their own words: cut and pasted from the survey)

Familial Partial Lipodystrophy

Patients with Lipodystrophy have very high triglycerides and are not able to receive some emergency medications such as steroids as that could push them into pancreatitis.

CADASIL

Thrombolytic medications typically utilized in a "Stroke Protocol" can be harmful to CADASIL patients who often present with stroke like symptoms. CADASIL causes vessels to block with abnormal proteins, not a blood clot like typical stroke patients.

Addison's Disease

Our 24 yr old daughter went into cardiac arrest from an Addison's crisis. She died in our home and the EMT team had no idea how to treat her and had no medications to treat her. She had no pulse 35 min and revived to a coma status and 11 months later is permanently disabled from anoxic brain damage. Her Dr's had also dismissed the importance of having an emergency injectable kit.

Patient Examples

(In their own words: cut and pasted from the survey)

Diabetes Insipidus, Pituitary Apoplexy - Panhypopituitarism

Paramedics had no idea what Diabetes Insipidus was and kept saying "what you don't check your sugars?!?" "We are gonna check your sugars honey". ER doc pushed fluids while I was hyponatremic despite my warnings causing me to get even worse. ER wouldn't call endocrinology and didn't know what adrenal crisis was or how to treat me. ER evaluated me only for stroke despite my explanation that I was headed into adrenal crisis - they never provided me with steroids. My hydrocortisone medication was withheld causing an adrenal crisis while I was inpatient.

Collagen VI Related Congenital Muscular Dystrophy

Interventional Radiation guidance for chest tube placement.
No oxygen (hypercapnea risk).

Hemophilia B Factor IV deficiency

Must receive factor prior to evaluation or procedure: Sons injury took 8 weeks to heal likely would have been greatly decreased had he had factor immediately.

Krabbe Disease

The hospital was unable to provide the timely needed chest vest treatments do to lack of personnel trained and available. We had to get discharged so we could go home and use our own equipment. Battling respiratory aspiration infection.

Patient Examples

(In their own words: cut and pasted from the survey)

Fibromuscular Displasia of the Renal Arteries

Ruling out ruptured aneurysms depending upon the situation

Fibromuscular Dysplasia of carotid arteries

Weak neck no manipulation should be done. However, a diagnosis of Vertigo instead of stroke from FMD was treated with neck physical therapy manipulation. The stroke was undiagnosed and symptoms were dismissed by primary care physician, urgent care, and hospital who misread MRI. The patient suffered permanent damage.

Von Willebrands type 1/ hemophilia a

Need clotting medication to stop bleeding

I needed help accessing a vein and no one would help and I sat in the ER until I was able to get a room and instead of using my dose right there they had to order it which took hours