

Subject: Fwd: PWS legislative

From: Lindi Kessinger

To:

Date: Sunday, June 22, 2014 9:46 PM

DADS

~~Ok... What do you think. Tried so hard to condense to 3 minutes (you might have to read quickly ;). Do I need to put it on the form letterhead?~~

I want to share only a few of the struggles that families like ours have faced daily. My 11 year old daughter was born with Prader-Willi Syndrome. Recently, after a recent sneak and binge, she complained of an upset stomach. We followed protocol for the syndrome and headed to an urgent care facility to hopefully rule out stomach rupture, which is one of the life threatening complications of the syndrome. While there, the doctor at the small facility did an x-ray that indicated our daughter needed more emergency care and a specialized scan. We went into the hospital ER with directions from the urgent care office. After showing our paperwork, we still waited an hour in the lobby while potential stroke patients and heart attack victims went inside...leaving us out in the lobby. When we were finally seen it took 7 hours to obtain the emergency scan that was needed to determine if emergency surgery would be necessary. Thankfully this time we were safe and my daughter did not die from the emergency like others with the syndrome do. While in there, the ER doctor offered my daughter chips, which proves that the doctor didn't have a clue that the situation was life threatening or that my daughter isn't allowed junk food. There was no urgency nor understanding to be sure my daughter didn't die in the ER that day.

Currently my daughter sees 2 specialists out of state, and has one doctor that flies in from another state a few times a year. When our daughter entered the public school system this year and her PWS specialist wrote a letter laying out the dangers and crisis risk involved in putting our daughter through the high stakes, high stress Staar test. Our school proceeded to tell us it wasn't an option and so we followed their protocol vs the protocol that our doctor recommended. Since mid school year our daughters emotional and psychiatric well being has been compromised. The school, though they thought they tried, put the academics in front of medical advice, and according to the Texas Education Agency, they are allowed and required to ignore sound medical advice for the sake of taking a test. The doctor we have to see for her anxiety meds is in Florida and not covered under her MDCP medicaid. We must pay our own travel to see the doctor that is one of only a few in the world that understands medication dosing for somebody with PWS. Our daughter didn't pass the test the first time, and was required to re-test....it was such a traumatic experience that I reached back out to our specialist to see about increasing her anxiety med. Sadly, due to the way they metabolize meds, she cannot go up on this med without adverse affects. One of my biggest fear is getting into an ongoing crisis situation and having to leave my daughter somewhere for months because people wouldn't follow protocol. Right now our only option is to wait it out until we can fly to Florida and get her doctor to change the script. She was prescribed another med that we were unable to obtain either since the doctor is out of state. She is on the Medically dependent childrens program, but several of her medications aren't covered because she has to have an out of state doctor who understands medication dosing in PWS to write them. We have another

medication this doctor prescribed which could help with narcolepsy symptoms, excessive daytime sleepiness, and behaviors. This medication cannot be obtained without us paying 100% of the cost.

With this syndrome we cannot trust doctors that don't understand the dosing requirements. We are forced to either have non PWS specific doctors tinker around with typical dosing or go out of state to doctors who know this syndrome and can give proper med dosing.

I share these struggles, not because they are individual struggles, but this is the life a person with PWS.

We don't fit into the traditional special needs box. My daughter at school had 3 pizza parties the last 2 weeks of school. Her teacher was using marshmallows in the classroom to motivate her other special needs kids. This syndrome is unique in that food can kill them and our world revolves around food.

For those with PWS, food can kill them...and their brain triggers like a person with a cocaine addiction.

Food in the classroom and in our world not only can kill our individuals, but puts their minds in a continuous battle. In our world, we celebrate with food, mourn with it, eat for every reason imaginable....those with PWS eat to survive. Their hunger is 7x that of a person who is fasting. My daughter's life is at stake and I cannot get educators, doctors, and often friends and family to understand the severity and what it takes to keep them safe. Her very life is in my hands and if I or one of her siblings slips up and leaves the pantry unlocked, we could lose her and have to live with that for the rest of our lives. Food is everywhere, it is lethal, and untrained individuals cannot keep our loved ones safe.

Thanks for listening to a few of our struggles,
Lindi, TX mom