

Malady: 'Whoever he is with, I have to make sure he is safe'

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start a conversation with local paramedics, while on shift at her job at Wet Dog Cafe in Astoria.

She asked the paramedics if they carried the specific medicine, Solu-Cortef, necessary for people with adrenal insufficiency. Without the medication, the condition can be fatal.

The paramedics said they did not carry the medicine.

Norgaard helped write protocol for Medix, comparing Solu-Cortef to insulin needed by diabetics. The medicine is now available by Medix and at Columbia Memorial Hospital.

"That is part of our daily struggle. If we go somewhere that is not Clatsop County, where we have protocol, is he going to be safe? The answer is, 'no,'" Kirsten Norgaard said.

Changing the law

The two bills that passed this session are Senate Bill 874 — requiring the Oregon Health Authority to train healthcare professionals about adrenal insufficiency — and Senate Bill 875 — allowing trained school personnel to administer medication to students.

Both bills go into effect in January.

State Rep. Alissa Keny-Guyer, D-Portland, offered her input during the final reading of SB 874.

"The most urgent need in the adrenal insufficiency community is for protocols to treat adrenal insufficiency in the prehospital and emergency department settings,"

Keny-Guyer said. "Many other states and cities have created and used protocols to save lives. We need the same in Oregon."

Norgaard credits Knapp, who took time away from her work to be in Salem full-time during the legislative session, and state Sen. Betsy Johnson, D-Scappoose, who supported the bills from Day 1.

For the first hearings in Salem, Norgaard brought her son and 9-year-old daughter, Faith Norgaard. The group personally handed out cupcakes to the lawmakers' offices. The cupcakes were in honor of a girl named Annie who died after being misdiagnosed when she had adrenal insufficiency. The girl's favorite thing to do was bake cupcakes with her mom.

"That little personal story opened so many doors," Kirsten Norgaard said.

Spending time in the state capital was an eye-opening experience for the Norgaards. Senate Bill 874 had opposition from lobbyists who claimed the medical community already knew about the condition.

Norgaard said she had a hard time explaining lobbyists to her two children.

"My little girl wondered how anyone would want her brother to die," she said. "How can you explain that?"

Staying safe

Norgaard admits she was terrified when her son started kindergarten. With the school nurse only available once a week and school staff not trained in administering the medication, she was worried

Jennifer Knapp of Eugene, who founded the nonprofit Adrenal Insufficiency United with Kirsten Norgaard, handed out cupcakes to lawmakers in Salem. The cupcakes were in honor of a girl who died from being misdiagnosed when she had adrenal insufficiency.
KIRSTEN NORGAARD — Submitted photo

what might happen if her son had a problem.

"Whoever he is with, I have to make sure he is safe," she said.

A couple of weeks ago, Tristan Norgaard had an incident that proved the importance of having adrenal insufficiency medication readily available. He was hit in the mouth with a metal baseball bat before a T-ball game. For other people who get smacked in the face with a bat, their cortisol levels start pumping at 10 times the normal level. For Tristan, his cortisol does not pump at all.

"If I wasn't there at that game, he would have gone into shock and within 30 minutes he could have been dead," Kirsten Norgaard said.

With awareness increasing across the state, Norgaard does not worry as much anymore.

She recently met a local man who said he was just diagnosed with adrenal insufficiency at Columbia Memorial Hospital.

"That is because of Tristan and the protocol we have at CMH," Norgaard said. "Because they know to find symptoms, because that is part of the protocol, they were able to save him."



Guru: Marsh wants 'one in every state, county, country'

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"I don't even want to sell flowers," he said.

Marsh said he would hand-pick the center's directors.

"I'm going to have a test, just like you have to go take a bartender test," he said, adding he has to create the qualifications because no industry standard exists. "It's going to be someone who's qualified, in my eyes, to dispense that info."

If a patient comes in with a serious health condition, he said, they could consult via teleconference with medical professionals. Patients could also get their medical marijuana cards, referrals to

suppliers, dosage protocols and even deliveries to their homes.

"I'd like to open one in every state, county, country," Marsh said. "My goal is to open them worldwide."

Spreading the word

One thing Marsh has been good at is getting attention.

He runs a website — www.thecannabisconsultants.com — which he calls the LinkedIn for resources on the medicinal use of cannabis.

In May 2012, Marsh started a Facebook page called "Cannabis Oil Success Stories" that now has more than 54,000 likes.

Marsh said he has been in-

terviewed by a Playboy.com correspondent, will be featured in an upcoming documentary by HBO's news program "Vice" and is preparing to publish a book, "Random Acts of Cannabis."

He said he has purchased 357 cannabis-related Web domains, in part to keep them out of corporate hands and available for people who want to start related endeavors.

"It's an interesting scenario that's gone from 1993 to this point," Marsh said, adding he has been telling people for the past 22 years they have receptors for cannabis. "We've treated hundreds of people all around the world."

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