

Seizure:

Continued from Page A1

Survival and diagnosis

She said medical personnel at the Heppner hospital struggled to intubate the thrashing baby girl. Deona rode along on the medical transport plane to Doernbecher Children's Hospital in Portland, while Todd and Lindsey drove there in Todd's personal pickup. Inside the airplane, the crew worked to keep the baby alive.

"When we arrived at the pediatric intensive care unit at Doernbecher Hospital in Portland, Oaks was in bad shape, barely hanging on," Deona said. "She was dehydrated, she wasn't getting enough oxygen, and her little body was becoming hypothermic on top of everything else."

As medical personnel at the hospital worked to stabilize the baby, she went into cardiac arrest. Code blue. CPR revived Oakleigh but her condition remained unstable. Lindsey signed permission to connect the baby to a machine that pumped blood outside the body to remove carbon dioxide and bring back oxygen-rich blood. Though Oakleigh rallied, an MRI showed she had suffered a stroke during the procedure.

The family made it home for Christmas that year, but they were shaken. The little girl continued to experience periodic seizures and her neurologist eventually diagnosed the baby with Dravet syndrome, a seizure disorder that generally begins in the first year in otherwise healthy infants and affects an estimated 1 in 15,700 individuals. It was a difficult diagnosis. June is Dravet Awareness Month, a time when those affected by the syndrome reach out and try to describe their world.

Life can be nerve-racking. A rescue plan hanging on



Umatilla County sheriff's deputy Todd Siex set his granddaughter Oakleigh down June 11, 2022, after holding her for a minute. Oakleigh, who has Dravet syndrome, is in constant motion.

the family's refrigerator lists five chronological things to do until Oakleigh stops seizing. The plan is signed by her pediatric neurologist at Oregon Health & Science University.

"To whom it may concern," the letter starts.

The list starts with instructions to give a nasal medication and call 911 if a seizure begins. If that doesn't work, the emergency medical technicians have several more strategies to try. Timing is critical.

Revolving life around Dravet syndrome

More than two years since that first attack, the family has become Team Oakleigh. Last year, the trio moved from their beloved Lexington to Pendleton, where St. Anthony Hospital is better equipped and has quicker access to Life Flight and other services.

They adjusted profession-



Oakleigh Hodges snuggles with her kitten on June 11, 2022, in the backyard of her family's Pendleton home. Oakleigh, who has Dravet syndrome, seemed to be a normal, healthy infant until her first seizure at 11 months.

ally as well. Todd secured a job as a deputy with the Umatilla County Sheriff's Office. Deona commutes to her job with the Morrow County District Attorney's

Office in Heppner. Lindsey gave up her job in order to stay with Oakleigh.

Recently, the three relaxed in their new Pendleton living room and reflected. On the

carpet, Oakleigh drew with giant Crayons. She giggled as she stuck a sticker on Todd's cheek and he flashed her a silly smile. Then she picked up her pink, sparkly iPad and listened to "The Boom Boom Song" for a while. Out in the yard, she chased bubbles and cuddled with her cat.

Life with Oakleigh offers a huge dose of joy, they say, along with so much worry.

The little girl, spunky, fearless and outgoing, loves to color, swim, be around animals and spend time outside, running and squealing. She knows her shapes, alphabet, colors and animals, though she struggles with balance and speaking clearly. Every seizure knocks her back developmentally, and she must slowly make her way forward again.

"Her speech is probably behind her comprehension," Todd said. "You can see her counting, recognizing letters. Telling you what she's thinking, she struggles with that.

She gets frustrated with that, too. We can see her getting frustrated with us."

"The St. Anthony's therapy team has been amazing, and we appreciate all they are doing for her," Deona said. "She is making progress."

In it together for Oakleigh

The onset of a seizure — which hasn't happened since February — means all hands on deck and sometimes an ambulance ride, such as the one during a visit to Portland last November.

"That was the craziest ride," Lindsey said. "When we turned the corner, everything slid."

The three adults form a phalanx of sorts around Oakleigh, knowing they must be vigilant. No more camping trips in the mountains. Even driving to the Tri-Cities takes planning.

"The morbidity risk of kids with Dravet syndrome is very high," Todd said. "If you don't act and you don't how to respond to it, her chance of dying is very high."

Lindsey said she worries she can't adequately convey how quickly one must act when Oakleigh has a seizure. She's considering enrolling Oakleigh in preschool but conversations with providers leave her unsure. She wants to attend school with her daughter in case of a seizure, but hasn't received encouragement so far.

"They say, this is your time to have a couple of hours to yourself," Lindsey said.

"They think we're being dramatic," Todd said.

The three adults know people just don't understand the complexities of the disorder. Why would they? Until that day three years ago, when the call came crackling across Todd's police radio, they didn't either.

So they focus on Oakleigh and revel in her take-no-prisoners attitude about life.

"Oakleigh is truly our little miracle," Deona said. "She is such a fighter."



East Oregonian, File

Industrial facilities operate Jan. 11, 2022, at the Port of Morrow near Boardman. Oregon Department of Environmental Quality announced Friday, June 17, it increased the penalty against the port for nitrate pollution from \$1.3 million to a little more than \$2.1 million.

Fine:

Continued from Page A1

"The amended notice cites the port for additional occurrences of applying wastewater containing nitrogen to fields that already had too much existing nitrate or moisture in the soil," according to the statement. "Having too much nitrate or moisture in the soil when applying wastewater increases the likelihood of nitrates flowing down into the groundwater rather than remaining in the soil for crops to use."

DEQ also reported the port documented additional violations to DEQ in its annual report and in email and phone reports of noncompliance. The additional violations occurred between November 2020 to February 2021 and November 2021 to February 2022.

The revised fine totals \$2,100,351.

DEQ in its amended notice stated it "acknowledges that the port is committed to finding a long-term solution to the management of its wastewater that both promotes beneficial reuse and is protective of public health and the environment."

Even so, according to the notice, since DEQ issued the notice, the Port of Morrow has not submitted a plan to achieve compliance with the nitrogen loading limits in the permit. The new notice requires the port to "develop and implement an approval plan to achieve compliance with

both the nitrogen loading and moisture content limits in the permit."

Because the port already has an appeal going with the initial fine, the DEQ explained it does not need to submit a new appeal, although it can submit an amended request for a hearing.

The state environmental department also encouraged the port to collaborate with local partners to complete a "Supplemental Environmental Project" that addresses high nitrate concentrations in the drinking water in the groundwater management area. DEQ stated the port could resolve as much as 80% of the penalty through such a project.

Oregon Rural Action, an Eastern Oregon community organizing and advocacy organization, in a press release before the DEQ announced the larger penalty issued a notice that Morrow County Commissioner Jim Doherty was meeting Friday at 6 p.m. with Boardman residents in the West Glen neighborhood where most of the 60 wells tested had above the maximum contamination levels for nitrates, with dozens up to five times the level. Kristin Ostrom, executive director of Oregon Rural Action, said the DEQ penalties emphasize that people in the Boardman area have been in harm's way for a long time.

She said it was past time to get residents immediate help, emergency water, crucial information and conduct water testing to ensure access to safe drinking water.

Hotel:

Continued from Page A1

As of June 14, 25 rooms were ready to go with the other 15 rooms nearing completion. Barnett said they hope to have all 40 rooms — two suites, six doubles and 32 kings — done by next week. With a fully finished pool and sauna outside, a construction process that began in December 2021 is nearing completion.

It was a process the owners were unsure would ever happen. In fact, the group originally had a different town in mind.

"We only stopped in Pendleton on our way to see a hotel in Baker City," Mogg said, "Then we saw this hotel and knew that's what we wanted. We got really excited. After going over the numbers, we didn't even end up going to Baker City."

The three were drawn into the atmosphere of Pendleton, and talked things over with Economic Development Director Steve Chrisman. When the lodge secured a \$500,000 grant and a \$100,000 Jump Start loan from the Pendleton Development Commission, it cleared another hurdle to get things moving. The deal requires Cascadia Hospitality to pay back the loan in three years with a 3% interest rate.

Now, the owners want the hotel to serve as a way for tourists to experience the same thing they did those years ago.

"We really want to bring a new type of traveler to Pendleton," Duncan said. "Our motto is 'embrace the journey.'"

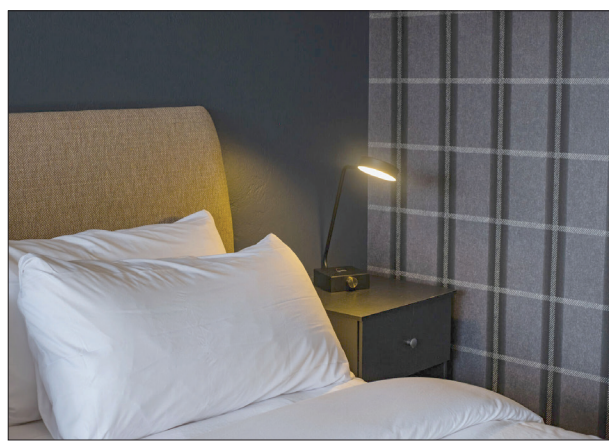
Chrisman agreed, noting the untapped potential of Pendleton outside of the town's premiere event, the Round-Up.

"The hotel will drive in adventure bikers and other travelers from all over to see Pendleton," Chrisman said. "This place has gone



Yasser Marte/East Oregonian

MotoLodge owners David Mogg, left, and Jeremy Duncan discuss the grand opening of their Pendleton hotel Thursday, June 16, 2022. "We didn't find Pendleton," Duncan remarked. "Pendleton found us."



Yasser Marte/East Oregonian

Guests could check out rooms Thursday, June 16, 2022, at the grand opening of the MotoLodge in Pendleton. The hotel has 25 rooms ready to go with the other 15 rooms nearing completion.



Yasser Marte/East Oregonian

A small wooden sauna stands poolside Thursday, June 16, 2022, at the opening of the MotoLodge in Pendleton.

from a section of town that didn't perform to a new place that will generate a lot of revenue."

And the revenue already has started. Despite not being open to the public, the MotoLodge is booked

solid for next week. With the Jackalope Jamboree coming to town June 23-25, many visitors turned to the hotel as a place to stay.

Even with the success, there's still a bit of work to do. Shipping delays leave the hotel without bed frames and desks. But those small missing pieces do little to sour the excitement for the rehabbed establishment.

The hotel is looking to rent out the pool and sauna area for parties, and plans on selling passes to come to the pool as well. Even before they open their doors, Duncan and the rest of the lodge owners have become intertwined in the community.

"A big reason that I'm excited for the whole project is because I love the owners' energy," Chrisman said, "it's infectious to me and to the community. It'll bring people in."

For the group that was not even considering Pendleton when they started their hotel journey, they could not agree more with Chrisman.

"It's not like we found Pendleton," Duncan said, "Pendleton found us."

Hotels development is having a moment in Pendleton. The new Radisson Hotel next to the Eastern Oregon Regional Airport is nearing completion.