

# A family's life changed in an instant

Baby's seizure launches an ongoing medical nightmare

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East Oregonian

PENDLETON — Morrow County sheriff's deputy Todd Siex stiffened as a call crackled over the radio in his police pickup. The dispatcher reported a baby was having a seizure at a Lexington residence.

Siex (pronounced "Six") checked the location on his mobile computer and saw the address was his home, where he lived with his wife, Deona, grown daughter, Lindsey Hodges, and his 11-month-old granddaughter, Oakleigh. His stomach in a knot, he drove from Irrigon to Pioneer Memorial Hospital in Heppner to meet the ambulance carrying the little girl.

Earlier that morning, it had been a normal day inside the house. Until it wasn't.

It was Dec. 8, 2019, and Deona was preparing the home for the baby's first Christmas. Oakleigh had come into the world as a seemingly normal, healthy baby girl on Dec. 28, and the family imagined a magical holiday with the child. Lindsey had just returned home from her job as kitchen lead at Heppner Elementary School. Her mother cleared off the top of an armoire for decorations. Oakleigh stood in the playpen happily observing.

Then the baby toppled over and lay still. The women rushed to the playpen.

"She was facedown and unresponsive," Hodges said.

The initial stillness erupted into a seizure that would continue for more than an hour and launch a medical

nightmare that persists two and a half years later.

"We were all so scared, and it seemed like time was standing still," Deona said. "Oakleigh was having a grand mal seizure and they could not get her to stop seizing."

## 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



Kathy Aney/East Oregonian

Umatilla County sheriff's deputy Todd Siex smiles as he tries to contain his exuberant 3-year-old granddaughter, Oakleigh Hodges, on June 11, 2022. Despite having Dravet syndrome, a seizure disorder, Oakleigh is in constant motion.

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 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 Oakleigh already had a pediatrician and therapist.

They adjusted professionally 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 know 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."

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