

# A family's life changed in an instant

Local baby's seizure launches medical nightmare that persists two years later

BY KATHY ANEY  
Hermiston Herald

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 prepared 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 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 face down 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 individuals. It was a difficult diagnosis. June



Kathy Aney/Hermiston Herald

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.

is Dravet Awareness Month, a time when those affected by the syndrome reach out and try to describe their world.

Life can be nerve-wracking. 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," Lindsay 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."

Lindsay 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."



## Good Shepherd Outreach & Events

### June is National Safety Month

Get ready for wildfire smoke events by planning ahead! Stay up to date on local info, pay attention to home filters and air cleaners, and keep some respirator masks on hand. For more information on air quality alerts, current air quality conditions, and forecasts, visit [AirAlerts.org](http://AirAlerts.org)

### Virtual Healthy Cooking on a Budget

class for people of all ages and families who want to learn how to cook healthy on a budget! Second Tuesday of each month through November.

### Virtual/In-Person Powerful Tools for Caregivers

6-week series to show caregivers the benefit of self-care skills. Starts June 16th, 3-5pm

### Save the Date: Family Health & Fitness Day + 5K Fun Run

September 24 from 9am - 1pm at Hermiston High School

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