

## RAIGEN

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"I didn't know what to do anymore. I didn't know what avenue to take. All I knew was (Raigen) was getting worse and losing weight and not eating," Makenzie said. "I'm very thankful for (the nurse practitioner) because she finally said, 'We cannot leave this alone anymore.'"

Two weeks later, Makenzie and Jaymes walked Raigen through the emergency room doors of Providence Sacred Heart Children's Hospital in Spokane, Washington. Raigen stayed in the hospital for four nights and five days. Heather Way, Makenzie's mom and Summerville resident, said the hospital visit was particularly "devastating" for Raigen. But the family knew they needed answers, and so they stayed.

Raigen soon worsened, her condition classified as "failure to thrive," a pediatric term used to describe a patient's weight loss or inability to gain weight. The same GI who prescribed Raigen's antibiotics months before visited her in the hospital once he realized she wasn't doing well. Two days in to her hospital stay, he gave Raigen a test to determine if she really did have gastroparesis.

To test the sphincter, or valve, connecting the stomach to the small intestine, Raigen had to empty her stomach — she wasn't allowed to eat or drink anything for nine or ten days.

"She could have a sip of water, some bites of popsicle and that was it," Makenzie said. "She kind of got a little

depressed, as anybody would."

The GI determined Raigen did in fact have gastroparesis, which is a fairly uncommon disorder affecting only about 50 out of every 100,000 people, according to the National Institute of Diabetes and Digestive and Kidney Diseases. While many people can treat their symptoms by simply changing their eating habits, Raigen's case is serious enough to warrant a feeding tube that bypasses her stomach and reaches directly into her small intestine while she waits for surgery.

But the gastroparesis did not explain her excruciating headaches. A neurologist suggested Raigen get an MRI. They thought she might have a brain tumor.

Makenzie and Jaymes prayed for their little girl as she went through the MRI scanner. Over the past year and a half, they've prayed to God to help them find the answer to what was plaguing Raigen. Only, they never dreamed it would come to this.

Doctors approached the couple a few hours later, delivering the good news that Raigen did not have a brain tumor. They did find something, however, but they weren't exactly sure what.

"We were left for like four to six hours and my husband and I didn't know what to think," Makenzie said. "They thought they would have to do another MRI, which would be hard on Raigen, given that they have to completely put her under."

But a pediatric neurologist stepped in and interpreted the results so Raigen, and her parents, wouldn't have to go through that suspenseful suffering again.



Raigen plays doctor dress-up with "Poley" to help her cope with her upcoming surgeries.

Courtesy photo

The neurologist diagnosed Raigen with type II Chiari malformation — a congenital brain development disorder that pushes the cerebellum, the bottom part of the brain that controls balance, down into the upper spinal canal, causing pressure and blocking the flow of brain fluid.

Chiari malformation is found in at least one out of every 1,000 births, although researchers believe it is even more common than that due to some people never experiencing symptoms, according to the National Institute of Neurological Disorders and Stroke. But because Raigen has type II, her symptoms are more severe and her risk

of brain damage is higher than for people with type I. To treat it, she would have to go through brain surgery.

"It was a relief. My husband and I were like 'oh, we weren't crazy,' but we didn't want it to be anything," Makenzie said. "It's hard when you know your kid is in pain and there's nothing you can do."

On March 1, Raigen will have the sphincter connecting her stomach to her small intestine clipped open, and on March 25, a part of her skull will be removed to relieve her headaches.

"I have a lot of mixed feelings. I'm very ready to get past this and have this as a distant memory. It's just hard having your kid in the hospital, let alone in surgery and in pain," Makenzie said. "The stomach one I'm not quite as worried about because it's pretty straightforward. The Chiari one, though, we're very nervous about just because it's our child's (brain)."

Raigen is scared of her surgeries too, and says a special prayer to calm her nerves.

"She says, 'God, please come into my heart and take all of the worries away from my surgery,' so we know it's on her mind a lot," Makenzie said.

Raigen has a few other coping mechanisms that help her work through her fears.

"All of her babies and all of her stuffed animals are

having surgeries. They get pokes, and they get really sad, and then they're all better after the surgery," Makenzie said. "We're told that's the way she's processing, and it's actually pretty cool for a 3 year old to be processing this instead of just shutting down."

Raigen also likes to play make-believe with the pole that holds up her bag of liquid food. Because she's allowed to unhook her tube for only two hours out of 24, the pole is almost always by her side. She's decorated it and affectionately calls it "Poley."

"(Poley) is a moonicorn today," she said during a FaceTime call on Thursday. "In the morning, he's gonna be a horse."

Despite the fun she's trying to make out of her circumstances, Raigen is tired of being tied to Poley. She wishes she could go to dance class every night because during her rehearsal, she's allowed to disconnect from Poley and just be.

"The doctor said I can go to ballet and be unhooked," she said, then nodded her head enthusiastically when asked if it's her favorite time.

"I'm thankful she gets to continue her ballet for now... The doctors basically said she needs some kind of normalcy," Makenzie said. "The first time we went, we were sitting in the car, and she says to me, 'Mommy, I really wish I didn't have to have this tube. I wish my friends didn't have to see it.' And I told her, 'Your friends who love you might ask you questions, but if they're your friends, they'll love you no matter what.' She said, 'Okay, Mommy,' and that was it. Now if a friend asks, she just tells them."

Being the social butterfly that she is, Raigen misses spending time with other kids her age. Poley makes it difficult to travel, and too much social time exhausts her into the following day. That's why when Le Bebe Cakes Coffee Shop and Bakery in La Grande hosted a Disney princess themed tea party fundraiser for Raigen on Sunday, the guest of honor herself couldn't make the four and a half hour drive down from Spokane for the event.

Arla Herbel, a Union County resident, photographer and lifelong friend of Makenzie's, wanted to do something special for the family, so she pitched the tea party idea to Spring

Roberts, owner of Le Bebe, who has also known Makenzie for a long time.

"When I found out about Raigen's surgeries I wanted to help. Having kids of my own, I realize that expenses come behind every door," Herbel said. "So I approached (Makenzie), and asked if my business, Arla Marie Photography, could do the fundraiser for her."

More than 20 kids attended the tea party, with special guests Elsa and Anna from the Disney movie "Frozen" making an appearance. So far, the event has raised more than \$600 for Raigen and her family, with donations still coming in.

"We took lots of pictures, and they were all shared with Raigen's mom," Roberts said. "We wanted her to know that we felt like (Raigen) was here with us in spirit."

Makenzie shared the photos with Raigen later that day.

"She was kind of sad she wasn't there because who doesn't want to go to a tea party when you're 3?" Makenzie said with a laugh. "She loves all the sparkles and Elsa and Anna just thrill her soul, so her face was really excited."

After her surgeries in March, Raigen is looking forward to dancing ballet without having to tuck her tube into her outfit, playing with friends and especially eating all the food she wants. She has a few choice meals in mind already.

"(Pizza) and ice cream! Like this much," she exclaimed as she held her arms out wide. "Chocolate ice cream and pineapple pizza."

Makenzie and Jaymes, though, are eager to leave all of this in the past, although they acknowledge they've learned and grown a lot from Raigen and her resilience.

"It's definitely been a journey for my husband and I. It's sometimes hard to put your kids in the trust of God. All of this stuff happened, and we kind of had to then live it, in the sense of now it's something we have to actually do instead of just say," Makenzie said. "My prayer was just for God to show up — show up to these appointments, show up for us and the doctors so that we can figure this out. I believe that he is the one getting us through this, and I believe that's why Raigen is so strong and tough."

## WILDFIRES

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the end result," said JB Brock, emergency services manager for the county.

The group is focusing its efforts on La Grande for now, said Dylan Howell, the committee chairman, but if its efforts are successful, the committee will expand its reach to get more Union County communities involved.

The program the group is using, called Firewise USA, teaches people how to adapt to living with wildfire and encourages neighbors to work together and take action now to prevent future losses. The program gives a lot of information, Howell said, but participants don't need a fire science degree to understand it.

"The program is the best tool we have to communicate with the public to prepare for wildfires," he said.

Howell said there is a growing number of people in the community who are concerned that La Grande and the area surrounding it are vulnerable to wildfires.

In addition to cleaning up around their homes, the program emphasizes the importance of having a family plan for what to do if a wildfire forced them out of their home.

At Wednesday's meeting, the committee discussed how to get the word out about the program and its importance to the community. The suggestion of giving presentations at local schools and sending students home with information for their parents was a favored strategy.

Howell and the other participants at the meeting are seeking homeowners in the southern and western parts of La Grande willing to become Firewise certified, which means they would remove the debris around their home to make it safe from fire. Interested homeowners may send an email to lgwuicommitee@gmail.com.

The La Grande Wildland Urban Interface Committee meets at 1:30 p.m. on the second and fourth Wednesday of the month at the fire station. The meetings are open to anyone in the community who wants to learn more about how to protect our corner of paradise.

## US Senators seek answers on wildfire prevention during shutdown

U.S. Sens. Ron Wyden, D-Ore., Dianne Feinstein, D-Calif., and Jeff Merkley, D-Ore., led a group of their colleagues in seeking answers from the U.S. Forest Service on the recent Trump shutdown and its impact on the agency's critical wildfire prevention and fuels treatment efforts — answers that are especially pressing with the threat of another shutdown looming.

According to a press release from Wyden, in addition to Wyden, Feinstein and Merkley, the letter to U.S. Forest Service Chief Vicki Christiansen was signed by U.S. Sens. Tom Udall, D-N.M., Martin Heinrich, D-N.M., Maria Cantwell, D-Wash., Patty Murray, D-Wash., Catherine Cortez Masto, D-Nev., Jacky Rosen, D-Nev., Kamala Harris, D-Calif., Bernie Sanders, D-Vt. and Michael Bennet, D-Colo.

The senators highlight-

ed the importance of the agency's hazardous fuels work, as well as the narrow window of opportunity to complete often weather-dependent efforts, in preparing communities for the upcoming fire season, according to the release.

"While climate change is a significant driver of these severe wildfires, high fuel loads also contribute to their deadlines. Western states count heavily on reducing hazardous fuels to lessen the threat of wildfires to their communities. As the largest landowner in many western states, the federal government has a duty to ensure that this essential forest work gets done," the senators wrote in the release.

"Congress has repeatedly increased appropriations for hazardous fuels work, funding hazardous fuels at \$430 million for the fiscal year 2018, which is used for

critical fire preparedness activities and fuels treatments like prescribed burns and forest thinning," the release continued. "Prescribed burns, in particular, are weather-dependent and have a narrow window of opportunity for fuels treatment, relying on cool, damp weather conditions that occur in winter months. We have seen reports that the government shutdown curtailed the ability of the Forest Service to conduct fire prevention and fuels treatment activities."

In addition to requesting the Forest Service provide information on hazardous fuels treatments affected by the shutdown and its plans to ensure their timely completion, the senators are also seeking answers on firefighting hiring and training, fire research and the economic impacts on tribes.

— Ron Wyden staff



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