

## Providence:

Continued from Page A1

The campaign was launched at 6 a.m. Aug. 22. By 6 a.m. the next day, less than 24 hours after the fundraiser began, that first \$100,000 had been committed. Within five days, on Aug. 27, donations totaled more than \$200,000 and as of Sept. 1, some 649 donations totaled more than \$281,000.

Miranda said that one of the first contributions was a \$10,000 pledge, but every "\$20 donation" is appreciated. The largest donation has been \$20,000.

"All we want to do is find a cure for these babies," she said.

Meanwhile, Minassian has contacted a group of scientists in Germany who recently completed a promising study specifically on FRRS1L gene replacement therapy in mice. Minassian was optimistic and the parents were ecstatic.

### Providence's Journey

Providence turned 4 on Aug. 4. Born without complications, at 6 months old she was unable to sit on her own or hold her head up. She was considered developmentally delayed.

Miranda started a Facebook album and Instagram account for Providence to track her medical journey, which has included eight hospital stays. Twice this spring she spent 16 and then 17 days at Oregon Health & Sciences University in Portland.

The infant was improving, albeit slowly, and by the time she was 1 year old, Providence was supporting herself sitting, her head control improved, she was eating softer foods like steamed veggies and she was army crawling around the Rector's home in Hermiston.

"That first year she was crawling, eating toast, blowing raspberries. She laughed and would grab and pull herself up," Jason said.

During a month-long trip to Colorado just after Providence turned 1, her aunt, a former special needs and preschool teacher, noticed the baby staring off into the distance. She suggested Miranda and Jason get her tested.

At Sacred Heart Children's Hospital in Spokane, an MRI came back normal, but an EEG showed Providence was having "absence seizures," which cause lapses in awareness. They are a type of gener-



Miranda Rector/Contributed Photo

**Providence at 14 months old smiles with her dad, Jason Rector of Hermiston, a month before her regression and excessive seizure activity starts.**

alized onset seizure, once referred to as petit mal seizures, meaning they begin in both sides of the brain at the same time. They begin and end abruptly but can last up to 30 seconds — so brief they sometimes are mistaken for daydreaming and may not be detected for months. An epilepsy medication, Kepra, was prescribed with hope to help, but after a few weeks seizures progressed.

Doctors ran another EEG, did a lumbar puncture and more MRIs. They poked and prodded Providence. They did what seemed to be an inordinate amount of bloodwork.

With a second medication, ONFI (a benzodiazepine used along with other medicines to treat seizures), Providence showed improvements.

"I thought we were on the right track," Jason said. "Then the seizures happened again, and it all went downhill from there."

Providence started struggling to drink from a bottle. Doctors — and the Rectors — realized even higher doses of ONFI weren't working.

"If anything, Providence started becoming more lethargic, sleepy and like she was in a haze," her mother said.

The parents consulted a feeding

therapist at Kadlec Medical Center in Richland, Washington, and in December, just before Christmas, Providence was admitted to OHSU for a gastrostomy-jejunostomy tube, which passes through the abdominal surface, into the stomach and down into the second part of the small intestine.

The family returned home, but on Christmas Day, Providence was readmitted to OHSU with more seizures and respiratory distress. Over the next four months, she returned to OHSU four more times for the same issues.

On Feb. 19, 2019, Providence was diagnosed with EEIE-37. By March, she had totally regressed. She had lost all physical abilities.

Providence no longer could play with her toys, move her arms or legs on purpose, and she had no head control. She was eating only through the J-G tube. She also developed strider and laryngomalacia, essentially losing muscle tone in her throat.

Medical equipment started stacking up. She was prescribed a Nebulizer, electric suction machine, ventilator for CPAP use, medical chairs, oxygen tanks and more.

In May 2019 she had surgery for



Miranda Rector/Contributed Photo

**Providence Rector sleeps after an MRI during her admission at Sacred Heart Children's Hospital in Spokane in November 2018. Because patients must stay extremely still during an MRI, she was put to sleep for the procedure. It was her second MRI of the year.**

a gastrostomy tube, a more permanent feeding tube that connects directly to her stomach, and a supraglottoplasty to remove tissue from her throat to help reverse the strider and laryngomalacia.

After the surgeries, Providence further regressed. Among other things, she has cortical vision impairment, meaning she has difficulty controlling her eyes. Her vision is currently around -15 corrected to a -12. She has been on seven different anti-epileptic medications; none have completely stopped the seizures from breaking through.

So now Providence relies on her parents for everything.

Miranda and Jason, both 33, didn't know what normal was when Providence was born.

"We heard comments ... 'she's not holding her head up; you might want to get her checked out,'" Miranda said. "We took her to a pediatrician who told us some kids take longer than others. 'Give it six months,' and that's what we did."

Miranda and Jason questioned their parenting skills.

"We thought it was our fault ... we didn't put her on her tummy early enough or get early intervention soon enough," she said. "Now four years into this, there's nothing we could have done that would change where she is right now."

"I specifically remember doctors telling us, 'Her condition is progressive. The studies say that quality of life is unknown but not good,'" Miranda said, noting that most children with EEIE, also known as Otahara Syndrome, don't live past the age of 2.

### HOW TO HELP

For more about Providence and the gene disorder, visit:  
**www.FRRS1L.ORG**  
**Instagram:** Hope4frrs1l  
**Facebook:** Finding Hope for FRRS1L

### Hope

The chance that gene replacement could change Providence's quality of life is what her parents hope for.

"There are no words," Miranda said. "To even dare fathom the idea that our daughter might have somewhat of a normal life. The possibility of her walking, even holding her head up on her own. Even a fraction ... that would be a huge blessing that could expand her quality of life. That's been the prayer since she started regressing."

"This new gene therapy could be the light at the end of tunnel," Jason said, "even if it could just stop the seizures and let her smile."

Successful gene therapy could also save their marriage.

"It's been rough on our family," Miranda said.

For the last six months, Miranda and Jason have seen each other as little as 15 minutes a day — from the time she returned home from work at 1:30 p.m. to when he had to leave at 1:45 p.m.

"We literally live on a schedule, her schedule," Miranda said.

Miranda doesn't hide the fact the relationship between she and Jason has been strained. She noted there are 84% more divorces for parents of special-needs children.

Jason agreed with Miranda's assessment that their marriage is "on a thread."

"I don't know the future," he said, "but it's not uncommon."

If gene therapy works, that would be fantastic. If it doesn't, the Rectors know Providence's future — maybe not their own.

"We love Providence exactly where she's at right now. Our love is vast. If this is how it will be for the rest of her life, we'll love her no matter what," Miranda said.

In the meantime, with funds being raised and a doctor eager to find a cure, Miranda and Jason Rector will be hopeful. "I know there's a child in there who knows what's going on," Miranda said.

"She's just stuck in a body that doesn't respond."

## Workers:

Continued from Page A1

### Hard time

During a year of record job growth in Oregon, employers like Keatman have had the hardest time finding workers to fill positions. Companies, particularly in the leisure and hospitality industries, across the state are scrambling to find workers.

The hospitality, hotel, restaurant and tourism-related industries added 6% more jobs this year, economists say. Hiring is more competitive than ever as employers raise wages, offer signing bonuses, referral bonuses, improved benefits, even subsidies for housing. But those incentives also have to compete against federal unemployment benefits, an increase in household income from federal stimulus funds and retirements.

Just ask Robin Clement, co-owner of Monkless Belgian Ales in Bend. Clement and her husband opened their pub just four months before the pandemic shut it down to reduce the spread of COVID-19.

Fast forward to July when tourism season in Central Oregon hits a high note and the state is reopening as COVID-19 cases wane, the Clements are scrambling to get enough workers to keep the brew pub open six days a week.

In an interview with an out-of-town worker recently seeking a lead prep cook position, Clement said she made an offer on the spot to the worker. The applicant dined with his family for dinner that night.

But the next day, he told her Clement he took another position. Because it The job he took offered slightly more money and a leadership role, something the small pub couldn't offer, Clement she said.

"It was really disappointing, but par for the course. He was one of the few interviews that I set up who actu-



Dean Guernsey/The Bulletin

**A help wanted sign at Einstein Pros Plumbing Heating Cooling Service Co. in Bend seeks workers with a starting offer of \$20 per hour.**

ally showed," Clement said. "2020 was a cake walk compared to 2021.

"Customers have little grace. Their patience is thin. It's been hard dealing with expectations."

### Tough spot

Only 32,500 eligible workers statewide are sitting out the labor market waiting for the pandemic to lift, who may have health concerns or child care issues, said Gail Krumenauer, Oregon Employment Department economist. And another 12,000 workers statewide, who had been in the leisure and hospitality industry, now are working in the transportation/warehousing and delivery sector because of higher wages and benefits, Krumenauer said. The average wage for leisure and hospitality in Oregon is about \$14 an hour but in transportation/warehousing it's \$18 to \$20 an hour.

"That's a tough spot to be in. The hiring is 1-1/2 times greater than we've ever seen," Krumenauer said. "This spring we had 98,000 job vacancies, that's a lot of what is fueling the worker shortage."

"That's a perfect storm: a lot of things happening all at once and it makes it hard for employers. Everyone's hiring."

Layer these events on top of one another and

mix in pent up demand for buying and traveling and the demand on goods and services increases, which in turn increases demand on the need for more workers, Krumenauer said.

"Expanded benefits helped families in Central Oregon and nationwide keep food on the table and a roof over their heads when workers lost their jobs through no fault of their own during this public health pandemic," U.S. Sen. Ron Wyden, D-Oregon, said in an email. "Research has repeatedly debunked the baloney that benefits discouraged work."

"What's clear in my conversations with Oregonians all over our state is that the lack of child care, housing costs, the unique challenges of service industry work and other factors are what's really keeping many people from returning to the workplace."

### Going down

The unemployment rate in July was 5.6% in Deschutes County, lower than the double-digit rates at the height of pandemic-related closures, but still above February 2020 when it was 3.3%, according to the Oregon Employment Department monthly unemployment figures. Crook and Jefferson counties too have seen their unemployment levels return to near normal levels in the months following the busi-



Dean Guernsey/The Bulletin

**Robin Clement and her husband, co-owners of Monkless Belgian Ales in Bend, opened the pub just four months before the pandemic shut it down to reduce the spread of COVID-19.**

ness closures imposed to slow the spread of the virus.

Crook County's unemployment rate was 7% in July, compared to 4.4% in February 2020. And Jefferson County's unemployment rate was 6.5% in July, compared to 4.1% in February 2020.

In Eastern Oregon, Baker County's unemployment rate was 5.4% in July 2021, compared to 8.7% the prior July. Union County's unemployment rate was 5.8% in July 2021, down from 9.4% the prior July. Wallowa County's unemployment rate was 5.4% in July, compared to 8.3% the previous year and Umatilla County was 5.5% in July 2021, down from 7.3% in July 2020.

Statewide the unemployment rate was 5.2% in July, just slightly below the national unemployment rate of 5.4%.

"There's no doubt that (the federal boost of the unemployment insurance) is constraining the supply of labor," said Damon Runberg, Oregon Employment Department regional economist. "But I don't think it is to a

significant degree.

"The labor market will likely ease some as we move into the fall, but that will be more a reflection of a reduction in job vacancies rather

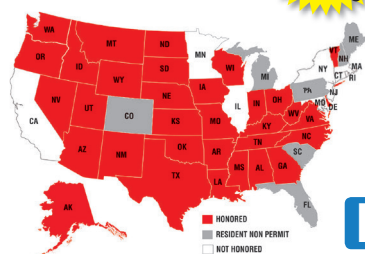
than a massive influx of workers who lost their federal unemployment insurance benefits."

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## CONCEALED CARRY PERMIT CLASS

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