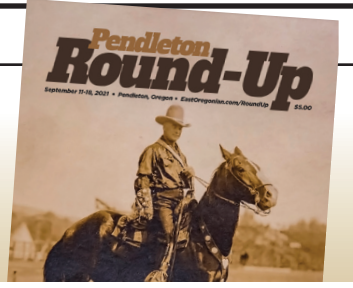


INSIDE

GET OUT THE BOOTS AND COWBOY HAT, THE PENDLETON ROUND-UP IS BACK



SAVING PROVIDENCE

Hermiston family races to raise \$400K to treat daughter suffering from genetic disorder

By WIL PHINNEY
For the East Oregonian

HERMISTON — The hazel eyes of Providence Grace Rector dart back and forth behind thick lenses in round red frames. Her face constantly twitches, but otherwise it is without expression. Her arms are constantly moving, unintentionally. Her little legs are strapped at the ankle to the footrests on her wheelchair.

Providence means “protective care of God,” which is reflected in the strong faith of her parents, Miranda and Jason Rector, but they know a contribution from science will be needed to find the medical miracle their daughter needs.

And now, two-and-half years after their daughter was diagnosed with Early Infantile Epileptic Encephalopathy-37 (EIEE-37), the Rectors and other parents like them are hopeful — and optimistic — that a potential study of gene replacement therapy could one day lead to a better quality of life for their children.

In August, with the help of Rare Village Foundation, a fundraising platform for families of children with rare diseases, three mothers — one from Croatia, one living in the United Kingdom and one in Colorado — established a nonprofit called “Finding Hope for FRRS1L” (pronounced “frizzle”). In less than 24 hours more than \$100,000 was raised, and within five days the total had doubled.

Miranda, who is enrolled Chippewa from the Turtle Mountain Band of Chippewa Indians of North Dakota and also Puerto Rican. People in Puerto Rico, where several children with EIEE-37 live, have given more than \$50,000.

What FRRS1L is

FRRS1L is the name of a protein-coding gene contained in all cells of the brain. It helps send messages between cells. The gene disorder, which results in loss of function for that gene, is a mutation triggered by the combination of each parent’s damaged DNA. The disorder produces epilepsy, progressive dyskinesia (abnormal



Audrey Bailey/Contributed Photo

The Rector family of Hermiston, in a photo taken in the fall of 2019, includes Miranda, Jason, Providence and Joshua. Providence had recently turned 2 years old. “It was a big celebration for the family, as it is every additional year we get with her,” Miranda said.

movements), developmental delay, poor muscle tone, brain volume loss, and gradual loss of responsiveness to the environment.

Children with this gene disorder develop, albeit with delays, until about ages 1-2 when they begin having seizures that cause regression. Within months, or even weeks, children lose their ability to move, speak, eat orally, and control their head and their body. Babies with the FRRS1L gene disorder grow up to be wheelchair bound, non-verbal, tube-fed and in need of constant care.

For Providence, it took just three months to go from a crawling baby to one that is trapped in a body overtaken by seizures and involuntary movements.

Fundraising promising

In August, the three women

helped create the fundraising page www.FRRS1L.ORG and mobilized other families. The exact number of children in the world living with FRRS1L gene disorder is unknown, but in a Facebook support group, parents of 14 FRRS1L children have started to raise funds. Miranda Rector is helping the group with public relations.

The initial goal was \$100,000 in the first month, the amount needed by Dr. Berge Minassian, a gene therapist at the University of Texas-Southwestern, to compose a team of researchers.

Maniassian told parents he would investigate possible treatments, but he advised them that it would require at least \$400,000 to fund the project up to clinical trials.

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Miranda Rector/Contributed Photo

Providence rests from extreme exhaustion due to respiratory distress, para-influenza, and uncontrolled seizures during her June 2020 hospital stay at Dorenbecher Children’s Hospital at Oregon Health and Science University in Portland. She is pictured with a gastrostomy-jejunostomy tube that prevents the risk of aspiration during coughing fits. A G-J tube is a single tube that passes through the abdominal surface, into the stomach and down into the second part of the small intestine.

Where are the workers? Workers in short supply amid year of explosive job growth

By SUZANNE ROIG
The Bulletin

BEND — With record job growth in Oregon, Whitney Keatman never imagined she would have problems finding workers for her Scott Street location of Sparrow Bakery.

And she didn’t. It was getting them to stay that has plagued her long time Bend business.

In the past year Keatman, a co-owner, made 117 job offers and most were accepted. But after just three months, only about 42 workers remained. The bakery needed a minimum of 20 workers at the Scott Street location and by the end of this summer there were six.

So last week, she made a hard decision: She will close the bakery at the Old Iron Works Arts District.



Dean Guernsey/The Bulletin

Co-owners of Sparrow Bakery in Bend, Whitney, left, and Jessica Keatman with their sons, Brooks and Abel are at the Scott Street bakery location, which is closing due to a worker shortage.

“We’ve been struggling for seven years with moments of success,” Keatman said. “Over the years

we’ve had on again and off again good managers. When you don’t have the right management, you

EDITOR’S NOTE

Today starts part one of a five-part series by EO Media Group to publish over the next five weekends, looking at the issue of the lack of workers for jobs in Central and Eastern Oregon; why workers are not returning to previous-held jobs; and how businesses are pivoting to function without being fully staffed.

have a hard time retaining workers. “It’s common for people to come and begin training and then get another job offer that comes with wages,” Keatman said. “There’s no allegiance. It’s a competitive market for employers.”

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