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Sam and Bobbie Ryner are pictured with their three children.

GUEST EDITORIAL

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Guest editorial: Shining a light on Cerebral Palsy Awareness Month



Scott and Karen Alvord Mar 08, 2024 7:00 AM

March is National Cerebral Palsy (CP) month. We were invited over to take photos with some amazing Westpark friends who have experienced this journey with their middle child, Cal.

Sam and Bobbie Ryner are incredible parents to three beautiful children. Cal is now 4 years old and thriving. His role model and hero is his big brother. But Cal's journey to this point was a stressful and rocky road and the challenges are not over.

When Cal was an infant, his parents knew something wasn't right. For example, he would eventually stop breathing when he was laid down flat. Little did they know at the time, but the pressure that would build up in his brain was causing this dangerous situation. For many months, they took turns holding him through the night so he was upright in their arms.

Medical professionals didn't have the answers for them until they finally put their foot down and advocated heavily for better testing. Little Cal finally got diagnosed with Spastic Hemiplegic Cerebral Palsy. His muscles on the left side of his body are tight

and weak.

Cal's parents can't praise our wonderful Placer County Office of Education enough, speaking about how the staff got Cal into their Infant Development Program when he was only 3.5 months old. He had occupational therapy, physical therapy, vision therapy and saw a special educator. The parents are certain Cal is where he is today because of all the amazing therapists who work there! He graduated from vision therapy as well as special education services but still receives occupational therapy and physical therapy through California Children's Services. This is mostly for self-help skills such as getting dressed and undressed. He is still unable to sit with his legs crisscrossed on the floor.

The parents not only gave us permission to share the above and the following medical information, they encouraged it because it's important that others understand the extent of CP to hopefully help other families going through this or families that suspect their child has it. Bobbie added, "We're just super proud of him and everything he's been through so we love to share it with others."

Honestly, Cal is amazing. Seriously, he is. He is full of positive energy, and while he doesn't have fine motor skills, the kid runs fast and can throw and kick balls better than most his age ... which is incredible.

As you can see in the photos, Cal had a pretty big skull surgery (posterior fossa decompression surgery) where they removed part of his skull and spine to relieve pressure on his brain stem. This was because he had Chiari malformation where part of his brain tissue was in his spinal cord and his skull was pushing on his brain stem, causing many problems, including the stoppage of breathing. They were also hoping it would cure his syrinx (fluid-filled cyst) but, unfortunately, that did not happen. But it did relieve the pressure on his brain stem.

is syrinx runs through over half his spine. He also has a condition called syringobulbia, which basically means the syrinx affects his brain stem. Cal has to get yearly MRIs to check the growth of his syrinx as well as check his brain and skull growth. He may need another skull/spine surgery in the future but as of right now, he doesn't. They recently found out one of his legs is longer than the other. For now, they are just monitoring growth. His doctor at Shriners is monitoring his knees as well; they turn inward and have caused him pain. It may require Osteotomy surgery but right now, he is too young for that. But as you can guess, their journey isn't over, as there are ongoing problems medical technology can't fix ... yet.

CP is a group of disorders that affect movement, balance and posture. According to the CDC, CP affects approximately 1 in 345 children, making it the most common motor disability in children. The severity and symptoms of CP vary. Some children will need lifelong care while others can live a more independent lifestyle. About 50-60 percent of children with CP can walk without assistance. CDC's website has a lot of information on what the early signs of CP look like in different age categories under a year.

One of the benefits of sharing Cal's story is to highlight the importance of early diagnosis and intervention. Recognizing the early signs can save a child's life and improve their outcomes. For Cal and his family, this made an incredible difference. Incredible ... just like Cal!

Scott and Karen Alvord are active Roseville community members. Scott serves on the Roseville City Council and Karen serves at PRIDE Industries, the nation's largest employer of people with disabilities.



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