Meet Porter

Children's Mercy

Restore the roar: Porter finds answers for rare disease

Strong, fierce and spunky — that's Porter, thriving several years into her journey with a rare disease diagnosis and treatment at **Children's Mercy Hospital Kansas**.

"You never think it will be your child until it is your child," said Breann, Porter's mom. Her family knows firsthand how difficult it can be for kids living with a rare undiagnosed condition. In 2021, Porter was just one of 74 kids diagnosed with Opsoclonus-Myoclonus-Ataxia syndrome (OMAS). This rare neurological disorder causes Porter to have rapid, involuntary eye movements and tremors throughout her body.

After two weeks of working extensively to find answers, Porter's Iowa care team called on the experts at Children's Mercy, who helped shorten the time from diagnosis to treatment. Our **pediatric neurologist Tyler Allison, MD**, began Porter's steroid treatment and infusions immediately.

"I am extremely grateful that Porter's care team at Children's Mercy is so attentive and thorough with her," said Breann. Today, Porter is a dinosaur-loving kindergartener who is back home in Iowa showing off her unstoppable "roar" and resilient spirit. Released from **rheumatology**, Porter continues to see Dr. Allison. Her team plans to taper infusions over the next year in anticipation of her entering full remission.

At **Children's Mercy Hospital Kansas**, we are committed to unlocking more answers to help more children and families access faster diagnosis, treatment and research.

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Breann,
Porter's Mom

TYLER ALLISON, MD
Pediatric Neurologist, Neurology