

Families Inspiring Others

Jake and Jordyn

When Mindy Lee was sent home from the hospital with her first-born 14 years ago, she was told she had “a healthy baby boy.” Six months had passed and at each well visit, her pediatrician rebuffed her concerns about reflux, fussiness during feeding and crying while being changed, insisting it was typical baby behavior.

She persisted and visited a neurologist who diagnosed her son with Rhizomelic Chondrodysplasia Punctata, RCDP. There are fewer than 65 cases worldwide.

A few years later, daughter Jordyn also was born with the rare form of dwarfism, which affects brain function, growth, mobility and speech.

“My children are beating the odds because once they made it to age 5, they were considered long-term survivors,” says Lee, now a member of the parent advisory council at UH Rainbow Babies and Children’s Hospital.

At 14 and 11, Jake and Jordyn have become a source of inspiration for many families of children born with RCDP, and their mother has been a champion for researching effective treatments or working to find a cure.

Jake and Jordyn are unable to talk, walk independently, they are tube fed and have shortening of the arms. Between visits to dozens of doctors at Rainbow, they receive occupational, physical, speech and music therapies at home through North Royalton Schools.

Lee became president of the Ohio chapter of RHIZOKIDS International and is part of a collective effort to build resources and a support network for other families of Rhizo kids.

“They kind of learned from my kids because we were basically told that once you had an RCDP baby they will die, and if they make it to age 2 you were really lucky,” Lee says. “We have a natural history study we are really proud of that now they can see what’s typical and what’s not typical, and though a lot of the kids are the same, they are different in many ways. For a while, we had nobody. Today, Jake and Jordyn give these families hope.”

The Rockin’ and Rolling for RhizoKids — Night at The Races fundraiser will be held on Saturday, September 23, 6-11 p.m. at St. Adalbert - Keller Center 66 Adalbert Street, Berea, Visit rhizokidsohio.com

