

Family trip to help boy, 3, with rare condition

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At 3 years old, Benjamin stands 33 inches tall and weighs around 23 pounds. He is learning to walk and is always smiling.

Diagnosed with Cornelia de Lange Syndrome (CdLS), a rare genetic disorder, what lies ahead in Benjamin's future is unknown.

His parents don't know whether or not he will ever speak, go to school or have true mobility.

"But Benjamin is always having fun," Zach Robbins, his father, said. "Many doctors just don't know anything about this disorder."

CdLS is the result of a genetic mutation and about 1 in 10,000 children are born with it, according to the CdLS Foundation.

In an effort to learn more about the severity of Benjamin's case, he and his parents of Loves Park will soon be traveling to Philadelphia.

"The CdLS Foundation is out that way and we are trying to see the specialists while we are out there," Robbins said.

Robbins hopes that the trip will help doctors evaluate Benjamin's needs so they can share a treatment plan with local physicians.

"We are trying to coordinate all of our appointments so we only have to go once," Robbins said.

To help raise funds for the family's trip, a spaghetti dinner is to be held at the Eagles Club, 302 State St., Beloit.

Dinner will begin at 3 p.m. Saturday and cost \$5 per plate. There also will be a silent auction, bake sale and 50/50 raffle.

"It is going to be a good time," Robbins said. "We've been working really hard to get everything together."



All smiles

Loves Park parents Zach Robbins and Julia Dale are hosting a spaghetti dinner fundraiser for their son, Benjamin. Born with a rare genetic disorder, Benjamin will soon be traveling to Philadelphia to see physicians who know more about his medical condition.

Neither Robbins or Benjamin's mother, Julia Dale, have any knowledge of CdLS cases in their family.

"We really need to find out why Benjamin has gastrointestinal issues and why he stops breathing sometimes," Robbins said.

Robbins admits that daily life can be difficult because the family never knows what to expect, but they keep a positive attitude.

"We never really know where we are at with anything," he said. "But it keeps us all stronger and closer."

For more information on the Spaghetti Dinner or to make a donation for Benjamin's care, visit www.gofundme.com/h3q1xk.