

ABC NEWS

Jeans for Genes raising funds and giving hope to Illawarra child unable to grow ABC Illawarra

By Chloe Hart

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PHOTO: Ruby Collins, who has Russel-Silver syndrome, has a long road ahead of her says her mum.
(ABC Illawarra: Chloe Hart)

Four-year-old Ruby Collins has a genetic condition meaning she struggles to grow or gain weight, has a tiny uneven body and a large head.

She has Russell-Silver syndrome (RSS), a rare congenital condition and type of dwarfism affecting between 1 in 30,000 people who present with eating disorders and developmental delays.

Every day of Ruby's life is dictated by a strict care routine to keep her alive.

"She has an asymmetrical body [so] when she walks, she struggles, gets out of breath and can't make long distances," her mother Rebecca Collins said.

Ms Collins said there was little currently known about RSS and her only source of information is Google.

The bright and bubbly child also needs to wear thick glasses and shoe lifts to even out her legs and spends many hours per week in doctors' rooms.

"Ruby needs special shakes to keep her nutrients up [because] if she's not eating properly, they'll have to tube feed her and I don't want her tube fed," Ms Collins said. While Ruby has so far defied the odds related to children with Russell-Silver syndrome, her mother said she had a tough road of future surgeries ahead of her.

"She's looking at leg lengthening or leg shortening, a jaw extension, quite a few dental surgeries for crowded mouth and possibly scoliosis," she said.



PHOTO: The goal of Jeans for Genes Day is to help medical researchers make discoveries to help children like Ruby. (ABC Illawarra: Chloe Hart)

So, what is Jeans for Genes Day? If you are wearing jeans to work on Friday, you may not be aware that a gold coin donation on Jeans for Genes Day can be lifechanging for children like Ruby.

The charity raises funds for children with genetic conditions through the Children's Medical Research Institute, which works to discover cures for childhood illness.



PHOTO: Jeans for Genes raises funds for children with genetic diseases through the Children's Medical Research Institute. (Supplied: Flickr)

Every year 500 children in Australia lose their lives to childhood disease of various kinds.

"The alarming statistic is one in 20 children. That's one in every classroom in Australia or 12,000 births a year," said national campaign manager for Jeans for Genes Day Barry Kenyon.

"The money raised goes directly to the researchers at the Children's Medical Research Institute who are researching genetic causes of childhood disease.

"We are looking for the root cause of such diseases in the hope we can eliminate or at least treat a multitude of conditions." Family's other struggles Unfortunately, it is now Ruby's twin brother Riley who is now facing a health scare after also experiencing development delays and a sensory processing disorder, his mother said.

While doctors have not yet been able to diagnose him, Ms Collins suspects her son has attention-deficit disorder (ADHD) or autism.

"We still don't know [and] hopefully the doctors can get that prognosis through, so he gets all the special needs support he needs," she said.

The twins share a special bond and help each other through their struggles.

"They have sibling rivalry, but Riley is Ruby's protector," Ms Collins said.

"He looks up to her and protects her and makes sure she is fine. They are awesome."