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Currans Hill boy Henry Gowans, 4, is the smiling face of Jeans for Genes campaign

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Henry (with little sister Rosalie), of Currans Hill, is the face of the 2018 Jeans for Genes campaign.

FOUR-year-old Henry Gowans, of Currans Hill, is one of six young faces of this year's Jeans for Genes fundraiser however what his gorgeous smile does not show is that he and his sister Rosalie both live with a rare genetic disease.

Henry and Rosalie, 20 months, both have the enzyme deficiency, LCHAD (Long Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency).

Mum Jessica Gowans said she jumped at the chance for Henry to become one of six young faces of Jeans for Genes to raise awareness about genetic diseases and to help raise vital funds for the Children's Medical Research Institute.

“I look forward to a future when we can cure genetic diseases and not have them impact lives,” Mrs Gowans said.

Henry was diagnosed with LCHAD, which prevents the body from converting fats to energy, when he was 10-weeks-old.

Rosalie was diagnosed when Mrs Gowans was 16-weeks pregnant.

Henry and Rosalie won't eat food, are fed through a tube and face complications including possible blindness, weakening of the heart and permanent nerve damage.

They will also have to be on a strict diet for the rest of their lives.

Mrs Gowans said children were very resilient and Henry had shown her that despite LCHAD, he keeps going on.

“Even when Henry doesn't feel well, he still wants to go to prep school and he still wants to play, and he still wants to learn,” she said.

“He just wants to keep being a kid.”

Mrs Gowans said when Rosalie was diagnosed with LCHAD she went through a period of grieving again.

“I was grieving the opportunity for them to have a long and healthy life, that's the reality,” she said.

Mrs Gowans said she was right behind Jeans for Genes which this year had the theme Fight for Me, Fight with Me.

She urged people to sign up to help raise money and donate to the CMRI to help find a cure and improved management for children's genetic diseases.

JEANS FOR GENES

- The national fundraiser supports the work of the Children's Medical Research which investigates genetic defects and childhood diseases
- Sign up at jeansforgenes.org.au to take part in the campaign, which runs through to Jeans for Genes Day on Friday, August 3