

Jeans for Genes Day: The face behind the campaign



Little Henry's body can't get too hot, which means he's often stuck inside on hot days.

Henry Gowans doesn't like going to hospital but something special is making the trips more enjoyable.

Outside the Children's Medical Research Institute (CMRI) building in Westmead is an image of what he calls "Giant Henry".

That's because Henry is the one of the faces of the Jeans for Genes campaign for the second year in a row.

"We drive past CMRI on our way to see his specialists, so it gives him something to look forward to," his mum Jessica says.

"We are happy to be part of Jeans for Genes again because there is really not a lot of research being done into our children's metabolic condition, and we want to strive for better outcomes."

Henry and his little sister, Rosalie, have a rare metabolic condition known as LCHAD Deficiency.

Their bodies have difficulty converting fat into energy, and when they run out of energy it can start to destroy their muscles — including their heart.

They must be on a very strict diet and face issues in the future, ranging from loss of vision to heart problems.

Henry has just started kindergarten, and while he loves school, he knows he's not like the other kids in class.

"My school days are a bit different to other kids," he says.

"My teacher sets an alarm that tells me to drink my special formula.

"I have to have it at the same time every day to keep my energy up.

"On hot days I have to sit inside. I can't get too hot or it will make me sick."

The five-year-old from Currans Hill is one of the faces of this year's campaign, which features seven young children who are living with genetic diseases ranging from severe metabolic disorders to cancer.

Jeans for Genes is the iconic fundraising campaign behind the CMRI, which aims to find cures for children's genetic diseases.

One in 20 children across Australia face a birth defect or genetic disease.

One of the hopes that Jessica holds on to is for the kind of gene therapy being done at CMRI to one day help both her kids and others in a similar situation.

"There will always be genetic diseases. We can't get rid of them completely, but if we could find cures or better futures — then that gives us all hope," she says.

“For kids with LCHAD, there are always risks. There are long-term risks of eye, heart, nerve and muscle damage. Every year, my kids have checks to make sure there is no damage.

“My hope is that when a family has a diagnosis there will be better treatment options or even the possibility of a cure. I meet people whose children have some incredibly devastating conditions. It would be good to know there is research being done that could produce better outcomes.”

[Jeans for Genes Day](#) is on Friday, August 2, but people can fundraise for CMRI at any time of the year.

Donations made to the Jeans for Genes website from 3pm on Thursday until 6am on Saturday will be matched by a group of generous private donors, up to \$125,000.

For the second year in a row, Universal Store has also partnered with CMRI to make your jeans purchases count, with \$5 from every pair of jeans bought in stores being donated to the cause.