

marie claire

AUSTRALIA

DREAMS FOR GENES

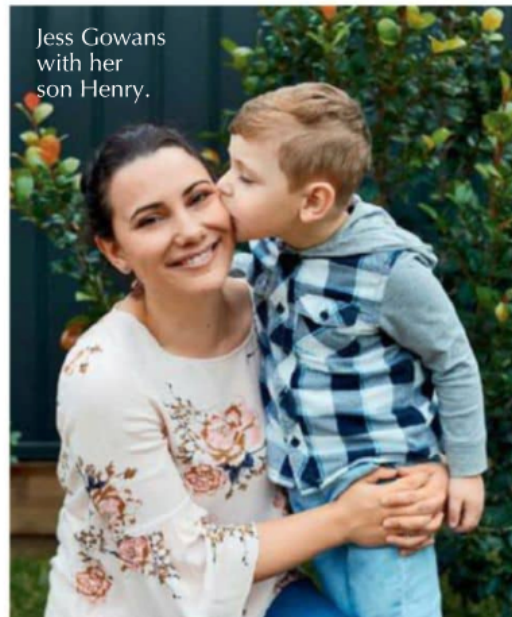
Imagine being told your children have a serious genetic disease, with no cure. Jess Gowans, whose son Henry, five, and daughter Rosalie, three, both have a condition called LCHAD deficiency, reveals what family life is like

How did your life change when you found out about your children's diagnosis?

I thought being a mum would involve wonderful days filled with the quiet confidence of being my children's main carer. However, I quickly realised it involved difficult days in the hospital, confusing conversations with doctors and uncertainty about the future. Henry and Rosalie have difficulty converting fat into energy, so when their energy levels run low it can destroy their muscles – including their heart. I must ensure that the day-to-day care of their LCHAD deficiency is maintained, that everyone who looks after them is educated, and the kids know how to care for their bodies. We fit in many medical appointments and have to keep the kids feeling positive about them.

You've set up a support group around genetic disease, as well as returning to work as a psychologist. What drives you?

For me, it's been about finding something that can give me resilience and hope. It's to show my children they have the gift of choice in their lives; choices that people with 'regular' health have.



Jess Gowans with her son Henry.

They can experience the normal things children their age do by learning about their disease and how to manage it. I never want them to feel like they're a victim to their disease.

How has Jeans for Genes helped?

I was asked to take part in the 2018 campaign, which showcased the amazing resilience of children and their fight to lead long, healthy lives. This year, Henry became one of the faces of the campaign. The most important part of being involved in Jeans for Genes is seeing my son develop confidence and pride in himself, and talk about his LCHAD deficiency. To have a child with a rare and chronic disease can be isolating and frightening. To know there is work going into treatments and cures provides a platform of hope. *Jeans for Genes day is on August 2.*