

# What It's Like To Raise Two Daughters With Dwarfism

*Mother Nicole Luk shares her story to mark Jeans for Genes Day - by marie claire*

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When 7-year-old Maddy Luk takes a trip to the playground, she's known for her brave and adventurous spirit.

"She'll go nuts, she'll climb things that I'm thinking, you shouldn't be doing that, but she does it anyway," her mother, Nicole Luk, explains.

Maddy was born with Diastrophic Dysplasia, a rare form of dwarfism that causes bone deformity and severe joint pain.

According to the [Children's Medical Research Institute](#), the disorder can drastically restrict movement in the body and tends to worsen with age.

When Nicole was 17 weeks pregnant, she received the news that the baby she was carrying had abnormalities. Doctors would not be able to predict if the complications would be fatal until 30 weeks into the pregnancy.

“That was the scariest time. I was really frustrated because I wanted doctors to be able to tell me, ‘This is what it is, and this is what’s going to happen’,” Nicole says.

“We knew the best case scenario would basically be dwarfism. Some physical challenges but quite a normal life in terms of physical outcomes.”

At the time, Nicole and her husband Bernard felt “overwhelmed” by the news. “It was almost crippling. We were having conversations about whether to start talking about funeral arrangements now, when we had no guarantee how things would turn out.”

Fortunately, doctors confirmed Maddy’s final diagnosis of Diastrophic Dysplasia.

The disorder is passed on genetically, and while Nicole and Bernard’s eldest daughter Lana was not affected, their youngest, Briella, was also born with the condition.

“Briella has huge advantages having an older sister with the same condition because she has been able to copy the way that Maddy does things,” Nicole explains. “They do have a really special bond.”

All three girls were born in Hong Kong where their parents were living at the time.

To date, Maddy has required surgery to repair her cleft palate. Doctors anticipate she will need multiple orthopaedic surgeries on her bones as she grows. She will also have surgery for her spine and likely joint replacements as she gets older.

But her condition and hospital visits have become “very normal” for Maddy.

“I’ve always tried to be very open and upfront about what the doctors need to do, but put it in as positive light as possible,” Nicole explains.

“Sometimes I think she has a greater acceptance of it than I do, for her, it’s just normal.”

This week, Nicole took her daughter for a spinal checkup.

“Every time we go to a spinal appointment, Maddy asks me in a really cheerful voice, ‘Are they going to cut my back open today?’”

“She asks it in a really positive and upbeat way, which is quite incredible.”

Nicole and her family are part of official fundraising efforts Jeans For Genes Day on August 4, in support of the Children's Medical Research Institute. In a happy coincidence, the date also marks Maddy's seventh birthday.

Read the full story here <https://www.marieclaire.com.au/jeans-for-genes-day-maddy-diastrophic-dysplasia>