

## Dwarfism won't hold back our children, say determined parents

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*Two of the Luk children have dwarfism, but their parents are determined the condition will not hold them back, writes Hazel Parry*

Three-year-old Maddy squeals with joy on seeing her baby sister being carried into the room. "Can I hold baby, please?" she says.

She wiggles up onto the sofa, sits down and holds out her arms as mum Nicole Luk places baby Briella into her arms.

At just 75cm tall, Maddy is not much taller than the average one-year-old. Her arms and legs are much shorter than normal, making the task of climbing onto the sofa and holding her baby sister more of a challenge.

But she beams with pride as she lovingly cradles seven-month-old Briella. "I love my baby sister," she says, after planting a not-so-gentle kiss on her sister's head.

Maddy is the first child in Hong Kong to be diagnosed with diastrophic dysplasia. Luk and her husband Bernard, who relocated from Australia several years ago, discovered their second baby had skeletal dysplasia dwarfism about 17 weeks into the pregnancy.

At the time, doctors could not say which form of dwarfism it was, and they didn't know for certain until she was born.

The couple have another daughter, five-year-old Lana, who does not have dwarfism. When Maddy was born, the Luks learned that her condition was caused by a faulty gene they both have, which gives their children a 25 per cent chance of getting dwarfism. In November last year, baby Briella was born with the same condition as her older sister.

"With Briella, we did plan the pregnancy and we were aware of the chance she would have dwarfism. We had the opportunity, if you want to call it that, of something called pre-implantation screening," says Luk.

"That is basically IVF with genetic testing on the embryos. But that was not something I felt comfortable doing, particularly as I already had a child with that diagnosis.

"I felt I had to come to a place where I could accept another child with the same form of dwarfism, and if I couldn't do that, then I shouldn't be having another child.

Nicole Luk



The systems here lack a human touch. They only see the medical condition

"Of course, we were mostly hoping it wouldn't be the case, because no one would wish their child to have difficulties in life. I guess we also saw benefits for Maddy if Briella had the same condition," she says.

There are around 200 forms of dwarfism. The most common is achondroplasia, which affects between one in every 15,000 to 40,000 births. It is the form which affects Peter Dinklage, the actor who plays Tyrion Lannister in the *Game of Thrones* series. Maddy and Briella's condition is much rarer and affects only one in every 100,000 children.

People with diastrophic dysplasia grow to an average of about 120cm, and the condition comes with a series of cartilage and bone-related problems.

Maddy and Briella were both born with a cleft palate and hearing problems. Their fingers are fused at the joints and they have "hitchhiker's thumbs".

Maddy also has severe scoliosis, or curvature of the spine, which Briella may develop as she gets older, and has already undergone surgery on her cleft palate and has grommets in her ears to help with her hearing. She will soon need corrective surgery on her spine.

Briella also has club feet, and both sisters are likely to suffer joint problems as they get older, and may need hip replacements, says Luk.

The condition does not include any mental disabilities, and Maddy already has a skill for mathematics at the kindergarten she attends.

But it wasn't easy to find a school for Maddy, says Luk, partly as a result of Hong Kong's lack of anti-discrimination laws, and because of society's failure to provide adequate support for families like hers.

"I couldn't fault the medical care," she says. "But the support was terrible. No one gave me any advice on what real life would be like."

In the absence of local support, the couple turned to the internet to link up with other families of children with dwarfism. Luk started a blog called "Holding on to Hope" [madeline-hope.blogspot.com](http://madeline-hope.blogspot.com) [1] which she continues to update to pass on her experiences.

It is this desire to provide a source of support and increase awareness of dwarfism which has made Luk very open in talking about Maddy and Briella's condition.

Strangers can be blunt in what they say, but Luk says that is usually out of ignorance.

"I get a mixed reaction. The most common one is that people think Maddy is much younger than she is, and they are amazed she is speaking and walking so well."

Some people don't realise that it is a congenital condition and suggest vitamins and other ways to make her grow; Luk knows they are trying to be helpful and tries to take it in a positive spirit.

"Dwarfism isn't something you can hide away, and only talk about when you feel comfortable with it. So if people are going to ask questions, I would rather answer those questions."

Luk is also a member of the recently formed Little People of Hong Kong [www.lphk.org](http://www.lphk.org) [2] a group which aims to support people with dwarfism and help them lead fulfilling lives.

The group's slogan is "We are little, but not less", a message they hope to get across about dwarfism to the people of Hong Kong.

Luk knows that many challenges lie ahead for her two girls, including discrimination and stereotyping.

"People with dwarfism have traditionally been seen as objects of entertainment. If you look at the way Hollywood portrays dwarfism, it is usually as a leprechaun or an angry dwarf who kicks someone in the shin," she says. "They rarely play a normal person who happens to be of short stature.

"But I think the tide is turning, and there have been quite a few reality shows such as *Little People, Big World* and *The Little Couple* which show people with dwarfism as everyday people, who have kids and jobs.

"There is still a way to go. Hong Kong, in some ways, is a very open-minded place, and in other ways, it is very close-minded.

"Hong Kong systems lack a human touch. Sometimes they only see the medical condition. I think those with disabilities here have to be twice as good as others to get a job.

"But there are people with dwarfism who are lawyers and doctors. So like any other parents in Hong Kong, we have high aspirations for all our children."

Luk also takes comfort in the fact that Maddy and Briella will be able to support each other. "As they have the same condition, they will face the same problems and be able to work together to find solutions. They won't feel so isolated."

Sitting on the sofa, Maddy is still chattering away to her sister. Luk smiles.

"Maddy is very determined. She can be very sensitive. She sometimes gets frustrated, but she is magnetic and people are really drawn to her. She is a special little thing," Luk says.

"I do want to have one more baby, although I am not quite there yet. But when I look at Briella and Maddy, I think they are so wonderful that I could have 100 of them."

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[1] <http://madeline-hope.blogspot.com>

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