

# Girl in a billion

**S**tephanie Lugani, mother to two girls who attend Perform's weekly drama classes, tells us what it's like to have a 'girl in a billion' daughter, and the impact Perform has had on them.

My middle daughter Olivia is 6 years old and has a rare form of Dwarfism called Goldblatt Syndrome. Olivia is the 18th child diagnosed with this condition worldwide.

At first sight, she appears the size of a 12-month old, but once one converses with her, she impresses you with her wise words. Olivia uses an electric wheelchair full-time, which many after-school clubs found challenging to handle but Perform embraced Olivia with open arms.

Olivia's symptoms include extreme short stature, joint laxity, scoliosis, flattened vertebrae, hypermobility, neck instability, low muscle tone, narrow chest cavity, and weak tooth enamel called dentinogenesis imperfecta (DI). She cannot walk independently due to her spinal curvature and disproportionate head-to-body size. She has remained at 67cm since the age of 10 months.

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By the age of four months, we began to recognize Olivia was shorter than her peers. She was unable to lift and pivot her head, and she screamed whenever she was put onto her stomach for tummy time.

Since Olivia was nine months of age, I have been on an endless pursuit chasing consultant's opinions from around the world. After five years of an exhaustive medical search, I have now carefully selected a team of consultants across London hospitals for a holistic view of Olivia's complex needs.

Due to the rareness of Goldblatt syndrome, there is a lack of knowledge and expertise available to understand Olivia's needs and fore-see her future. Due to her cervical instability, the top neurosurgeon at Great Ormond Street Hospital is currently seeking professional advice outside of his field, namely respiratory, anaesthesiology, endocrinology, paediatrics, and genetics, to assess the risks



with performing a cervical fixation and discuss a future care plan.

Rarely can anything for Olivia be acquired off the shelf. Whether it's her school uniform, restroom facilities, or the numerous pieces of mobility equipment. I challenge people every day to think outside the box. How can we make this to suit Olivia? After months of deliberation and trial and error, an electric wheelchair and bespoke walker were carefully adapted to suit Olivia's small size. Standard toilets are too high for her to reach, so steps were built at home and school for her to safely climb up without assistance. At home, we have adapted several areas to suit her small size and to support her need of independent mobility.

Every day I fight for Olivia's inclusion in society and aim to help her develop strong confidence to face life's challenges. When we are out in public, it is easy to notice strangers' eyes staring at Olivia because they don't understand how someone so small can speak so eloquently. I make sure when people meet her for the first time they speak to her like a 6 year old, not like the baby she may appear to be. I also strive to offer her as much independence as possible. She is now able to dress herself for school, which makes her feel like she's accomplished something without mommy's help.

**Perform has been an integral part of my children's lives since they began classes two years ago.**

Thankfully, Olivia is a very bright child and has a big personality. She captures the light in the room. Her passions include swimming, reading Roald Dahl and Doctor Seuss books, creating science experiments, constructing Lego displays, coding on her computer, and singing and dancing at Perform. Perform has been an integral part of my children's lives since they began classes two years ago. Their teachers have offered them an environment for their personalities to flourish and be themselves. Every term, the catchy tunes are sung verbatim and the choreography is practiced at home, creating a very joyous atmosphere. The girls look forward to attending every class. I would like to thank Andrina, Amy and Vicky, the teachers who have offered Olivia an opportunity to SHINE.

For more information about Olivia's condition, and to follow her journey, please go to [olivialugani.com](http://olivialugani.com). ■

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