



Rare condition proves no barrier for Alaysia

This August, a Brighton family will be tying on their running shoes to support sick kids in this year's 42k Your Way challenge, raising funds for the Children's Hospital Foundation.

Four-month-old Alaysia Greaves was born with a rare genetic condition which causes muscle weakness, affecting her ability to breathe. Her condition also affects the development of her hips and feet and causes a delay in her motor skills.

Alaysia and her mum, Liselle Jose, will be pounding the pavement every day in August to complete a marathon effort of 42km to raise funds for those who supported them during a tumultuous time.

"Before having Alaysia, I wasn't aware of the Children's Hospital Foundation, but now we are so actively involved and I couldn't appreciate the work they do more," Liselle said.

With a goal of \$500, Liselle is directing donations to medical research, hoping to shed light on the underfunding of rare disease research.

"Alaysia's condition is so rare and more commonly found in adults, so there is very limited research into treatment. There is also limited information for families going through this journey, having a child with a rare disease. It would be amazing to have more of an insight to her condition, and hear stories from kids like Alaysia," Liselle added.

"Hospital can be an incredibly daunting place, especially when waiting for appointments. Luckily, I am able to take Alaysia to Kidzone – a dedicated playroom run by Children's Hospital Foundation – in Queensland Children's Hospital which makes you forget you're at hospital."

"Alaysia may not be able to run around and play with big kids toys yet, but Kidzone helps her to build on her sensory skills and learn about the world. The friendly volunteers are also a great help with information and navigating around Queensland Children's Hospital, which was invaluable when we were hospital newbies!"

Despite her rocky start to life, Liselle says Alaysia is an incredibly happy bub who is always smiling and has recently started laughing. Given the uncertainty around her condition, her family are taking treatment day by day, but regularly return to Queensland Children's Hospital for check-ups.

Children's Hospital Foundation CEO, Rosie Simpson, has commended Liselle and Alaysia for their incredible support.

"We were delighted that Alaysia and her family have decided to support other kids going through a similar journey to him by participating in 42k Your Way," she said.

"Everything we do is for kids and young people just like Alaysia, and it's a true privilege that her family is choosing to raise awareness for Children's Hospital Foundation.

"I encourage Queenslanders from right across the state to get behind Alaysia by donating or registering to go the distance for sick kids this August. I can't wait to see what the community can achieve when they come together."

To donate to Alaysia's team, visit <https://www.42kyourway.org.au/fundraisers/lisellejose/42k-your-way-medical-research>.

42k Your Way is a free, virtual event that you can do on your own, from anywhere, at any time. With every step, hop, jump or stroke, you'll be getting fit and helping sick kids like Alaysia. For more information on 42k Your Way, or to register, visit www.42kyourway.org.au/.

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About the Children's Hospital Foundation

The Children's Hospital Foundation works wonders for sick and injured kids by funding vital research, new equipment, and providing entertainment and support for children and their families in hospital. We are committed to making a difference in the fight against childhood illness and injury so every child can grow up as happy and healthy as possible. For more about the Children's Hospital Foundation, visit www.childrens.org.au

To sign up to 42k Your Way, scan the QR Code below:

