

Help pours in for siblings with rare disorder

Over \$250k cash and other gifts donated after bakery featured Lang family on social media

Goh Ruoxue

All three of Mr David Lang's children were born healthy, zipping through development milestones as they grew up.

Justina, the eldest, could name 100 objects in a picture book at the age of one. Timothy, the middle child, would try and read everything he could. Titus, the youngest, could solve a Primary 2 mathematics problem when he was in kindergarten. But as they each grew older, they started falling more frequently when running, spoke less, and had seizures.

Initially, Mr Lang, 63, and his wife, Mrs Lang Loo Geok, 62, suspected attention deficit hyperactivity disorder.

Doctors attributed the falling to clumsiness and teachers thought they had behavioural problems.

But it turned out to be Niemann-Pick disease type C, which causes cognitive and physical functions to degenerate. There are an estimated 500 cases diagnosed worldwide, according to the National Niemann-Pick Disease Foundation. It is fatal and incurable.

In 2004, Timothy died at the age of 10. Titus, now 24, and Justina, 30, are unable to walk, stand, sit without support, talk, eat, drink or swallow their saliva. They are tube-fed and breathe through tracheostomy tubes.

Because they require round-the-clock care, Mr Lang and his wife take turns waking up every few hours to clear their secretions and change their positions.

Two domestic helpers, Ms Thelma Mendez Ortega, 39, and Ms Jocelyn Nuguit, 34, who have been with the family for five and 10 years respectively, care for the children and do household chores.

Every month, the family needs about \$7,000 to \$9,000 for medication, utility fees, medical check-ups, and the helpers' salaries.

But Mr Lang is the sole breadwinner and his take-home pay as a lecturer at Singapore Bible College is \$4,600. He is also on a year-by-year employment contract and can be asked to retire with a few months' notice.

Then, Ms Thrina Low, 56, the owner of Bakery Brera & Fine Foods, stepped in.

Ms Low heard of the Lang family through Christian website Salt & Light in 2018. She thought of Mr Lang when she wanted to feature fathers who are caregivers on her bakery's social media platforms for Father's Day last month.

After she found out the family lives near the bakery in Empress Road, she visited them regularly, bringing pastries and other essentials dropped off by her customers.

The bakery hires staff with special needs and mental illnesses.

Since featuring them on her bakery's social media platforms, donations have poured in.

As at Tuesday, cash donations had surpassed \$250,000. This is on top of groceries, food, cookware and electronic items like laptops and phones donated by more than 2,000 people, many of whom gave anonymously.

Said Ms Low: "David is a very resilient man and his story was something I could not imagine anyone going through. I was very happy to chip in since I had been wanting to help anyway."

Said Mr Lang: "Most of those who give do not know us or have never met us and yet they gave so sacrificially at a time when many suffer loss of income or face uncertain futures."

One of the donors, Ms Ashley Kwong, 36, raised \$1,600 with nine friends. She had asked that they donate the money they were going to spend on her birthday to the Langs instead.

The visual merchandiser said: "Day-to-day caregiving is not an easy burden and I wanted to help."

Associate Professor Stacey Tay,



Bakery owner Thrina Low (in white) with the Langs - (clockwise from top left) Mr David Lang and his wife Loo Geok, their son Titus and daughter Justina - in their home last week. Ms Low visits them regularly, bringing pastries and other essentials dropped off by her customers. ST PHOTO: KUA CHEE SIONG

who has treated Justina for more than two decades, said: "This is a rare genetic condition where both parents may carry an abnormal copy of the gene. In carrier parents, the risk of having an affected child is 25 per cent for each pregnancy."

Another donor, who wanted to be known only as Mr Bert, 40, said he donated \$50 and plans to make monthly contributions.

He said: "I don't want it to be a one-off thing but a continuous donation. Hopefully, with all this money, we can ease David's burden as he approaches retirement."

Said Mr Lang: "We are deeply grateful to every single one who gave. The gifts, big or small, come at a very appropriate time."

Interested donors can donate to Mr Lang via PayNow at 9628-3554 or to his POSB bank account at 501-02804-5.

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The Lang family at Disney World in Orlando, Florida, in 1997. All three children (from left) Titus, Timothy and Justina were diagnosed with Niemann-Pick disease type C. Timothy died in 2004, when he was 10. PHOTO: COURTESY OF DAVID LANG

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MR DAVID LANG