

What would you do if your newborn was diagnosed with a genetic condition with no known cure? And, even worse, your family lives on the other side of the world?

Your generous donation today will help provide the missing link in the chain of support for families separated by distance.

Dear reader,

They say raising a child takes a village.

But what if, at just three-weeks-old, your precious newborn is diagnosed with an incurable genetic illness with no known cure?

And, what if, your whole family and vital chain of support lives on the other side of the world?

That was the devastating reality for new parents, Natalie and Grady, who welcomed their precious newborn, Teddy, right in the middle of the pandemic.

Please will you donate today? Your generous gift will help provide emotional and practical relief for those diagnosed with cystic fibrosis who don't have family nearby to support them.

When beautiful baby Teddy was born December 2020, the international borders had been closed for months due to the pandemic.

Teddy's grandparents live in the UK and USA. It broke the family's hearts that they couldn't travel to meet their much-longed-for newest addition to the family.

Just two weeks after he was born, Natalie and Grady were alarmed to notice that Teddy was losing weight and failing to thrive.

After being admitted to emergency by his community nurses, the third week of the now two-year-old's little life was spent in hospital undergoing numerous tests.



It was there Natalie and Grady received the devastating news that their precious tiny baby had cystic fibrosis. Cystic fibrosis is a genetic condition that impacts the lungs and digestive system. Not only are the vital organs affected, but cystic fibrosis will impact all areas of the body throughout life.

To add to their heartbreak, Natalie and Grady were heartbroken to learn that there is currently no known cure for this insidious condition.

The relief at finally having a diagnosis was quickly replaced with the terrible realisation of the hard road the family had ahead of them.

Daily medication treatment and physiotherapy can take up to three hours. Exercise is a core part of the process to remove mucus from the body and keep the airways clear. And these chores are on top of the hectic morning routine every family experiences before they head out to work and childcare.

At such a traumatic time when the new parents should have had Teddy's grandparents to lean on, distance meant they were forced to navigate their new reality alone.

And quickly.

Receiving the diagnosis - as one Australian family will do every four days - was a moment neither parent will forget. Even reminiscing on it almost two years later brings back uncomfortable emotions.

I'm delighted to share that with thanks to donations received, their local cystic fibrosis organisation was able to step in and support the family immediately.

The new parents were given essential education on how to keep Teddy physically fit and healthy. The rigorous life-saving routine they must follow daily would begin immediately.

Information for newly diagnosed parents was also provided and gave Natalie and Grady a much better understanding of what would be involved in Teddy's care. This information was also passed on to his grandparents to answer their questions and help them become part of the journey so they could support from afar.

Because of donations previously received, the family also received invaluable emotional support from their local cystic fibrosis organisation at what was undoubtedly one of the scariest, saddest times of their lives. Just as if it was received from directly within the family unit, those living with cystic fibrosis rely on this practical and emotional support from the moment of diagnosis.

Please will you kindly donate this Christmas? Your generous gift will provide vital education needed for parents receiving a diagnosis for the first time.



With limited knowledge of what was required to keep Teddy healthy, as soon as he was diagnosed, Natalie and Grady instantly began researching.

What was relief at finally having an answer turned into shock at what this would mean for the young family's lives.

The shock turned into sadness and anxiety.

As I'm sure you can imagine, the life they'd hoped for their precious newborn would never eventuate.

Even more shocking was that there were no signs of either Natalie or Grady being a carrier. Just like 81% of parents whose child has been diagnosed with cystic fibrosis, neither had any idea that this would be the reality for their first child.

Tracing back the family tree and with no family members previously diagnosed, they informed and educated the whole family. They advised them to get tested, particularly their siblings. Stephen, did you know that for a child to be born with cystic fibrosis, both parents must be carriers? There was now a one in four chance that Natalie and Grady's siblings would be carriers as well.

Even though donor-funded research means outcomes are improving daily for those living with cystic fibrosis, life expectancy on average is still less than 48 years. Quickly learning that every day is precious, Natalie and Grady learnt to draw on the resources available and focus on nothing more than the day ahead.

Please will you donate today and give hope to Teddy, Natalie, Grady and the 3500 other families living with cystic fibrosis in Australia today?

While practical support such as a nebuliser to administer inhaled antibiotics helped make life easier for this family, Natalie and Grady are also extremely grateful for the financial subsidies provided by their local cystic fibrosis organisation for hospital parking and activities that encourage physical activity to keep Teddy's airways clear.

When Teddy was admitted to the hospital with pseudomonas, he received a Boredom Buster Bag from our charity consisting of age-appropriate toys and books as well as a beautiful handmade quilt which really cheered him up in his time of need. The quilt is something the family will cherish forever.

With his grandparents so far away, these simple yet significant donor-funded touches can lighten the mood during hospital admissions and accelerate healing allowing the patient to return home sooner.

And we simply can't provide this support to families without you.



Please will you donate one last time this year? Your kind support will provide nebulisers to children admitted to the hospital with pseudomonas and other complications arising from cystic fibrosis.

By the time you read this, Teddy will have celebrated his second birthday.

I'm thrilled to tell you that he met one set of grandparents aged 12 months, and the other set aged 14 months.

It was an emotional, sweet reunion for the family separated for the critical first year of his life.

When family can't be there, I'm proud that donor support allows Cystic Fibrosis Western Australia to step in.

From the bottom of my heart I ask you to please donate this Christmas. Your kind support will provide vital education, emotional and financial support to those diagnosed with the most common, life-shortening genetic disease in Australia.

I want to be there to improve outcomes and extend the life expectancy of those living with cystic fibrosis even further.

This is only possible thanks to support from donors just like you.

Wishing you and your family a safe and happy Christmas,

L Bayakly

Yours sincerely

Lisa Bayakly

Chief Executive Officer

PS While there is currently no cure for cystic fibrosis, advances in research mean the average life expectancy for somebody diagnosed today has now extended to just under 48 years. All donations over \$2 are tax deductible and will help improve outcomes for those living with cystic fibrosis to extend this life expectancy even further.

"With thanks to your donations, our local cystic fibrosis organisation recently helped us to get respite with a weekend away. With our own family so far away, this was a beautiful gesture that made us all feel loved and supported outside of our family unit. We know that someone will always be there for us thanks to your support."

Natalie



Please donate to Cystic Fibrosis Western Australia to help end the waiting for children like Teddy, so that they can live their lives unaffected by cystic fibrosis.

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