

November 2020

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*Hunter and
mum Grace*

“Being told Hunter has a life-threatening genetic disease... I broke down...”

Only with your help and the help of kind people like you can we ensure families don't have to face the challenges of cystic fibrosis alone.

Dear <<FirstName>>,

“Your son has a genetic condition. He has cystic fibrosis,” Grace was told.

Grace's world came crashing down. “I felt cold and couldn't believe it. Fear, confusion, anxiety, worry... so many emotions were running through me,” she says.

It was fear that this diagnosis might mean that Hunter would never be able to have a normal, happy childhood...

...how would he cope when he starts school, will the kids make fun of him for having to take medicine when he eats? Will he be able to grow up, and start a family of his own? Find love, and explore the world?

For Grace, these early days were consumed by “a feeling I would never wish upon anyone.”

Hunter's diagnosis was a steep learning curve. “I didn't really know much about cystic fibrosis. There were so many things I had to quickly learn to help slow the damage on Hunter's body,” Grace says.

Being a first-time mum can be tough enough. When your child has a demanding health condition, it adds an extra layer of challenges.

Damp soil or sand could be full of dangerous bugs. There may be harmful bacteria in that puddle that Hunter wants to splash in. Bath toys might have unsafe mold growing inside.

Learning how to prevent infections, specific nutrition needs, and the seemingly endless

risks in the environment “can feel quite overwhelming at times.”

After a hard first few days, Jude, one of the Cystic Fibrosis NZ social workers, reached out. Suddenly, Grace told me, “I felt a sense of optimism for the future.”

“Cystic Fibrosis NZ has become a big part of our lives since the diagnosis. I started following the Facebook page and was lifted by seeing what other children and adults with CF were up to – and that there was support out there,” Grace says.



Connecting with others can make a huge difference to how you cope with day-to-day life.

“I knew I had to be strong for him, I needed to be his rock, and I forever will be,” Grace says.

At the age of three months doctors found that thick mucus was blocking the release of enzymes needed for digestion, meaning Hunter's body wasn't able to digest food or absorb nutrients properly.

Hunter was prescribed Creon, a pancreatic enzyme supplement, that would help him digest his food and get the vital nutrition he needed to grow strong.

*Hunter sleeping peacefully
- before we found out he
has cystic fibrosis*

“At three months’ old Hunter was just a baby, and all he knew was breast milk. How was I supposed to feed him these granules mixed in with apple sauce? It was hard and yet another hurdle, but with the help of our doctor and dietitian we managed to find a way that worked,” Grace says.

On the outside, Hunter looked like any other young boy. But inside his lungs there was thick, sticky mucus building up and beginning to trap bacteria.

“Chest physio was another thing we had to adjust to, morning and night. This was a mission to get Hunter to do – we had to get him to lay still while we do hand percussion on his sides, back and chest to help dislodge the mucus building up,” Grace says.

“Our lives have changed dramatically, and things aren't as simple as a normal three-year-old child running around, but we're doing okay.”



You're already a generous supporter of Cystic Fibrosis NZ. Gifts like yours are what makes it possible for people like Grace and Hunter to get the support and services they need to learn to cope with their situation and look ahead to a bright future.

There are over 540 people in New Zealand with cystic fibrosis. Less than 4% of Cystic Fibrosis NZ's income comes from the government. The rest is thanks to generous, compassionate New Zealanders like you. That's why your gift today is so important.

Will you please donate <<\$Amount>> to give New Zealanders living with cystic fibrosis the services and support they urgently need?

Your gift could, for example, provide food or parking vouchers to assist with costs during

hospital stays. It could provide access to emotional and practical support from a social worker, or information packs to help explain cystic fibrosis to friends and family.

Hunter, who turns four in November, is a wonderful boy with a cheeky, irresistible laugh.

He loves keeping fit and active, just like his mum Grace. “Every time I go to the gym, he’s always wanting to come along, or if I’m practicing some group fitness routines he wants to join in, it’s very cute!”

Hunter is a natural at taking his Creon before eating now. Twice-daily chest physio is still a challenge – but its part of the daily routine that is needed to keep Hunter healthy.

“Hunter even tries to do physio on me now, bless him.” Grace says.

“Our social worker Jude has been amazing and is always there for us. She visits us when she can, and often gives lots of helpful tips that we didn’t know. I appreciate the support available - it’s a great feeling to know there are people out there to help us if needed.”

In spite of the shock diagnosis, Grace is so grateful. “Hunter is the light of my life,” she told me. “We have a special bond and have so much to look forward to together.”

The help Grace and Hunter have received is thanks to people like you. “Knowing you have a really good support system in Cystic Fibrosis NZ has opened up a new life for us, it has changed a stressful and worrying situation into one with hope,” Grace says.

“You’ve given us confidence to tackle the future ahead of us.”

Hunter’s health has been good, Grace tells me. Minimal colds during the winter, he’s gaining weight, attends check-ups every three months, and most of all – he’s happy.

* **“I know there will be ups and downs in the future. We will eventually need to navigate longer hospital stays, more daily treatment to stay healthy, and potentially even a lung transplant,”**

“But I know there is support out there to help us along the way,” Grace says.

<<FirstName>>, I am truly grateful for supporters like you. I am grateful for your kindness and generosity to help provide vital services and support for people living with cystic fibrosis and their family.

Thank you for your compassion for New Zealanders with this genetic condition which has no known cure.

I hope you can see now how your gifts to Cystic Fibrosis NZ can make such a difference to a family living with cystic fibrosis.

Before Grace was contacted by Jude, she felt alone. She felt isolated. She didn’t know where to go for support, or even what kind of support was available.

But there is help. And because of the support of people like



Hunter is just like any other little boy and loves all things ‘Paw Patrol’

you, Grace and Hunter are getting the support they urgently need.

However, there are many more New Zealanders, just like Grace and Hunter, who need help. Every year there are between 10 and 15 babies born with cystic fibrosis, and each family will require some level of support as they adjust to their new normal.

This is why your kind gift today will be life changing for New Zealanders living with cystic fibrosis.

Will you consider donating <<\$amount>> today to give more people just like Grace and Hunter the practical and emotional support they urgently need?

Thank you for your kindness and generosity today.

Grace told me that as a mum of a child with cystic fibrosis, she felt very worried about what the future would look like.

But with the help of donations from people like you, she found that “there’s still hope and a good future ahead.”

Yours truly,



Laura Huet
Fundraising Manager

P.S. Every dollar counts and ensures individuals and families affected by cystic fibrosis can access crucial support.

P.P.S You might recognise Grace and Hunter from our recent SWEAT4CF campaign. “I want to help others who need Cystic Fibrosis NZ’s help, just like we have.”



*With your help families
don't have to face the
challenges of CF alone*