Support superheroes like Lincoln this Phristmas

Lincoln is four, he lives in Palmerston North with his sister Harriet, and parents Kayne and Joelle. Lincoln has cystic fibrosis, he was diagnosed as a newborn. He is a superhero in our eyes, and soon he will be in yours too. When Joelle was told about Lincoln's limited life expectancy, her world fell apart. *"No mother deserves to learn their precious newborn will live a short life and suffer so much, and there's nothing they can do about it."* 

## A day in the life

Lincoln is too young for Trikafta, but it will become an option for him in the future. Right now, his daily treatment routine consists of sitting and breathing through a nebuliser that will help him cough, followed by percussion physio. His treatment doubles during winter. "We call his physio tap taps. We use a tablet and headphones to keep him occupied, he will watch Power Rangers which is his thing at the moment," says his dad, Kayne.

Lincoln has to take Creon, a digestive enzyme, almost every time he eats. He's had to learn to make decisions around food. "Lincoln knows that he needs Creon with ice cream, but not with an ice block, so he'll choose the ice block."

Unexpected hospital admissions are something CF families need to navigate. "There have been ups and downs, like a two-week admission over his birthday last year. Having to pin him down for them to try to

get an IV line in was tough. The hospital is not a great place for a 3-year-old who wants to charge around."

## **Sibling superpower**

Being a sibling of someone with a chronic condition is not easy. "Harriet is a wonderfully responsible and protective big sister to Lincoln. Her understanding and patience never ceases to amaze us, Harriet knows that sometimes the CF has to take priority," says Kayne. The Dunlops talk about cystic fibrosis as being separate from Lincoln. "We have Harriet, we have Lincoln, and we treat the CF"

## Hope for the future

Kayne's wish for Lincoln for the future is simple "Our wish for Lincoln has always been that he could live a normal life so that he can grow up, play sport, have a family, and hold down a job. Trikafta will be a big part of that because the extension of life it offers could pretty much enable this to happen. Our wish is that there's always support around Lincoln to help him navigate his way through life with CF."

Joelle's dream for her 4-year-old son is one that many parents get to take for granted "My son deserves to live with the freedoms of his sister, his cousins and his friends".

**Reviving the CFNZ Central Districts Branch** The support that the Dunlop's received from CFNZ in

the early days was the driving force behind Kayne and Joelle restarting the CFNZ *"Lincoln will have his own story,* Central Districts Branch.

> They are passionate about being able to provide the same level of support, advice, and experience to other families whose lives are affected by CF. "Being able to connect with six families in the region

fairly quickly has been good for them and for us" says Kayne.

"CFNZ has been a great support for us from the start. We have derived great value from the families within CFNZ who have offered titbits of advice, a sympathetic ear, and in some cases simply someone else who understands all the various aspects of having a child with CF.

The resources that CFNZ provide to the families to help them along their journey, help to ease the pressure and provide support, often when things are the toughest, not least the support of the social workers and their help navigating the health system."









The need has never been greater, you can make a real difference by supporting today.

my husband and daughter will too. This is Lincoln's cross to bear, but in young, blissful ignorance we carry the weight for now, and if I could forever, I would."