MEDIA RELEASE
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Kiwis with cystic fibrosis don't have time to wait

A Parliamentary petition started by Carmen Shanks urging the Government to publicly fund Trikafta (a medicine that treats the underlying cause of cystic fibrosis) was presented to Labour MP Shanan Halbert, today. Mr Halbert accepted the petition on behalf of the Chair of the Health Select Committee, Dr Liz Craig.

The petition, signed by 43,234 people, represents those people with cystic fibrosis, their families, whānau, friends, colleagues, and the New Zealand public who believe there is a huge injustice over the lack of access to Trikafta in Aotearoa. Mr Halbert will present the petition to Parliament on Tuesday. Carmen has also requested an urgent hearing by the Health Select Committee into her request.

"After 18 months of hard work and raising awareness for cystic fibrosis, this petition is the culmination of efforts that represents the undeniable need for Trikafta. As a mother with cystic fibrosis who has now reached the life expectancy of a person with cystic fibrosis in New Zealand, I have had many nights holding my baby with tears rolling down my cheeks. I would search for answers to the questions many don't have to think about daily – will my baby remember me? Will I be around long enough to make sure he is on the right path? Will anyone love and care for him like I do? For me, Trikafta will mean more time with my two beautiful children" says Carmen.

16-year-old twins Lili and Manaia Graham shared their experience of living with cystic fibrosis and the life-changing benefits that they have had with Trikafta. "A miracle happened, and we got Trikafta, for the short period of time we've had it it's been a life-changer. We're planning goals, a future, we've been applying for jobs, we've been running around keeping ourselves busy because now we have the energy to. We are no longer coughing because we are no longer breathless. Why do CF patients have to be on the verge of dying for their lives to be saved" says Lili on behalf of her and her sister.

Cystic Fibrosis New Zealand Chief Executive, Lisa Burns says, "Trikafta needs to be funded now. Ongoing delays mean that people with cystic fibrosis continue to struggle, they are sick now, and they are in hospital now. Some have already left New Zealand to access Trikafta overseas or are planning to do so, while others have had the option of a lung transplant taken away. Trikafta is their last hope."

Sam Churton, a Kiwi living with cystic fibrosis shares what Trikafta means to him. "Trikafta to me is a passport to enter the world everyone else already lives in. Cystic fibrosis is limiting my social life, family life, work life, my alone time. It isn't just a full-time job, it's overtime, day and night, 365 days of the year. Trikafta has the ability to change that; to open up a world where not everything I do is affected by my illness. I love my life, I have a great family and amazing, understanding friends that I would love to be able to see more of, instead of constantly being in hospital on a bed wasting away the best years of my life that I want so badly to be living. I want to get back to working full time and contributing to society and Trikafta will help me achieve that goal. I don't have any other options and my health is quickly deteriorating, so in short Trikafta means everything to me."

People with CF, their families and whānau juggle the challenges of demanding daily treatments, increasing hospitalisations, multiple medications, while some desperately wait for a life-changing phone call from the transplant team. Every Kiwi, whether they have cystic fibrosis themselves or they are a mother, father, partner, husband, wife, or sibling, must find a way to live with this cruel condition. And even after enduring all of this, only half of those with cystic fibrosis in New Zealand will reach the age of 31 years.

"We did think there was hope" says Lisa.

In October, Pharmac's expert clinical advisers (its Respiratory Subcommittee) recommended a high priority for funding Trikafta and estimated that 388 people would be eligible.[1] They concluded that Trikafta would provide substantial improvements in quality of life and an expectation of substantial prolongation of life, as well as enabling those with cystic fibrosis to live almost normal lives. Pharmac called Trikafta a "paradigm-shifting treatment" and said publicly that it "wants to fund the medicine".

"The reality for our CF community is that five months on, we're going backwards. Trikafta still isn't funded, and Pharmac has told us they can provide no clear timeframe for a decision. While there continues to be a lack of urgency, the health of people with CF like Sam continues to deteriorate and some will die. This is completely avoidable," says Lisa

"Cystic Fibrosis NZ is very concerned about the ongoing delays and the actions of Pharmac ahead of the budget being released in May," Warwick Murray, Chair for Cystic Fibrosis NZ says. "We urge Pharmac to take the advice of its clinical experts – the Respiratory Subcommittee - and give Trikafta a high priority for funding for all those aged 6 years and over who would benefit. We want Pharmac to make a proactive decision and prioritise funding for Trikafta as soon as its budget for next year is confirmed."

Cystic Fibrosis NZ urges Pharmac to act now and negotiate with Vertex (the manufacturer of Trikafta) to agree a fair and reasonable price for the 388 Kiwis who would benefit. We also urge the Government to give Pharmac the budget needed to fund Trikafta as soon as possible. With Trikafta funded in 30 countries around the world and Australia now confirming access from 1 April, surely New Zealand can too.

Trikafta is an investment in the future and lives of people with cystic fibrosis. Trikafta would provide major economic benefit and would reduce the burden on New Zealand's healthcare system with fewer hospitalisations and lung transplants, alongside a reduction in daily treatments.

Speaking on behalf of the CF community Lisa says "Cystic Fibrosis NZ supports Carmen's petition for public funding of Trikafta and her call for an urgent hearing by the Health Select Committee. Kiwis with CF and their families don't have time to wait, it is torture for those who can see the benefits of Trikafta but cannot access it."

[1] Record of Respiratory Committee of PTAC – meeting held 26 August 2021, paragraph 3.57.

It is based on eligibility for all those aged 6 years and older with cystic fibrosis including:

- those who are heterozygous or homozygous F508del mutation; and
- a G551D mutation or other mutation responsive *in vitro* to elexacaftor/tezacaftor/ivacaftor.

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For more detailed information please refer to the Cystic Fibrosis NZ media kit.