TRIKAFTA KEY MESSAGES

Kiwis with cystic fibrosis can't wait any longer for Trikafta

- Cystic fibrosis (CF) is a serious and ultimately terminal genetic condition which affects around 540 people in NZ.
- CF causes the body to produce thick, sticky mucus which damages the lungs, digestive system, liver and other parts of the body.
- CF imposes a heavy burden, with significant quality of life, social and economic impacts on people with CF, their families and communities.
- People with CF endure a demanding and time-consuming daily regime of lung clearance and medication, together with regular medical check-ups and, over time, increasingly frequent hospitalisations. For a number of those with CF, a lung transplant may be the only remaining option.
- CF cuts short the lives of those with the condition. Only half of those with CF reach 31 years of age.
- Current treatments for the majority of people with CF in NZ treat only CF symptoms and not the underlying cause of the condition.
- CF modulators, such as Kalydeco and Trikafta, provide the first treatments to address the underlying cause of CF.
- Kalydeco is funded in NZ but only works for approximately 5% of people with CF it has provided significant benefits for the 30+ eligible people in NZ.
- Trikafta works for around 90% of those with CF.
- Trikafta provides for significant and immediate improvements for those with CF by increasing lung function and weight gain, reducing the burden of treatment, improving quality of life, and increasing life expectancy.
- Trikafta is now available to CF patients in the UK, Republic of Ireland, the USA, Denmark, Germany and Switzerland. It is currently being considered for funding in Australia, with a decision to be announced in April 2021.
- Several New Zealanders are self-funding Trikafta and, as a result, have experienced life-changing improvements in their health, well-being and ability to fully participate in life.
- Trikafta can also provide immediate and longer-term benefits for the NZ health system, through reduced hospitalisations, decreased treatment burden, and deferred lung transplants.
- Trikafta needs to be funded in NZ <u>now</u> to ensure the significant benefits to people with CF, their families and the NZ health system can be realised as soon as possible. Kiwis with CF can't wait any longer.