**(Insert Date)**

**(Your address)**

**Dear Minister of Parliament,**

**We are writing to you as a constituent of the (…insert ) electorate. I live in (… insert suburb) our child [first name] has cystic fibrosis. Or/ my name is …. and I have cystic fibrosis**

**If our family lived anywhere else in the developed world it’s likely we would be giving him/her the new class of medicines designed to treat the underlying cause of cystic fibrosis.**

**We ask you to raise in Parliament the issue of underfunding for this illness, and our request that all types of cystic fibrosis are included in the category of “rare disorders”.**

**Five million dollars a year has been given to Pharmac specifically to fund medicines for rare disorders but this is nowhere near enough to meet people’s needs. In addition, a large percentage of the CF community don’t meet the Pharmac classification for a rare disorder. That means we are left to fight for funding for new medicines out of the general Pharmac budget.**

**This has become a real problem now because of a new era in breakthrough therapies for children like ours [child name / people like me]. For example, a therapy called Kalydeco treats the underlying cause of a rare form cystic fibrosis. It works by helping cells move salt between them, which means sufferers have better digestion, leading to improved weight gain, and also a 10 percent improvement in breathing.**

**Kalydeco is funded in all other countries that, like ours, have a high proportion of people with CF. Australia has funded it since 2014. It’s deeply upsetting that New Zealand misses out on this important drug because of lack of funding for Pharmac.**

**A similar new medicine called Orkambi has proven very effective for a large percentage of people with CF. It has been registered in most developed countries. It is funded by health insurance companies in the US and also funded in Germany and France. Recently Ireland won funding after a hard-fought campaign. The medicine has not even been registered in NZ – probably because the manufacturers have little hope of it being funded here.**

**(Please insert some personal information about your own situation including your health or son/daughter’s health – the impact on the family and how treatment with one of the new medicines could improve your lives).**

We would love to talk to you further about how cystic fibrosis affects our daily lives and how these new medicines will change everything for us.

Please help us find a way to solve this problem.

Kind regards,

(Name) Phone number and email.