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Let’s get Kalydeco publicly funded!**

**Advocacy Toolkit**

**The purpose of this toolkit is to help you take action in support of the campaign to get Kalydeco publicly funded. This toolkit is based on advice from the Tick for Kids advocacy toolkit, thank you to Tick for Kids for letting us use their information.**

**About the campaign – join us in getting Kalydeco publicly funded**

Cystic Fibrosis NZ (CFNZ) and Kalydeco for Kiwis are running a joint campaign to get Kalydeco publicly funded in New Zealand. You can find more information on the campaign in the website links listed below.

Kalydeco is an important treatment for many people with cystic fibrosis, and the evidence behind it is strong and unequivocal.

In early September PHARMAC called for applications from suppliers of medicines for rare disorders. Vertex, Kalydeco's manufacturer put in an application for Kalydeco.

So, the immediate focus of the campaign is to push for PHARMAC to fund Kalydeco through this process.

We need as many people as possible to join and help us get Kalydeco funded.

We’ve launched a public awareness campaign to raise awareness of Kalydeco and we’re encouraging people to write to PHARMAC in support of the application for Kalydeco. To raise awareness we're also asking people to help spread the word in any way they can in their community, for example meeting with their electorate MP, writing an article for the local paper, talking to local organisations etc.

This advocacy toolkit is designed to help you take action. If you have any feedback about the toolkit, or other things that would help you, let us know!

**Helpful links**

* CFNZ - [www.cfnz.org.nz/](http://www.cfnz.org.nz/)
* Link to campaign webpage - [www.cfnz.org.nz/what-we-do/avocacy/campaign-for-kalydeco/](http://www.cfnz.org.nz/what-we-do/avocacy/campaign-for-kalydeco/)
* Kalydeco for Kiwis - [www.facebook.com/KalydecoForKiwis/](http://www.facebook.com/KalydecoForKiwis/)

**How are we going to get change?**

We'll be talking with politicians (including the Minister of Health) and PHARMAC about why it's important to fund Kalydeco. But we think a key part is showing public support for funding Kalydeco. This is why the awareness campaign is so important. It means we need to go out in the community and get as many people as possible participating in the campaign and showing their support.

**How you can take action**

You can help by:

* Joining CFNZ and Kalydeco for Kiwis on Facebook.
* Holding, or participating in, a local event (see suggestions below for how to do this).
* Writing to PHARMAC (see suggestions for writing to PHARMAC below).
* Meeting with your local electorate MP (see suggestions below).
* Talking with your friends and family about the issue, posting information on your social media feed.
* Writing a letter to your local paper or drafting an article (see suggestions below).
* Participating in the sticker campaign (see suggestions below).

**Key messages you can use when taking action**

* We want to see Kalydeco publicly funded for New Zealanders with G551D Cystic Fibrosis aged 2 years and older.
* Kalydeco is the first medication that fixes the underlying cystic fibrosis defect, essentially turning off cystic fibrosis. Kalydeco represents a major breakthrough in cystic fibrosis research; current medications only treat the symptoms. Every day that Kalydeco remains unfunded in New Zealand, irreversible lung damage is occurring.
* Kalydeco works.  It is a proven treatment, that is backed up by robust data and a universal consensus that it is hugely beneficial for those with G551D cystic fibrosis.
* NZ is the only country in the OECD (with a significant cystic fibrosis population) that has not funded Kalydeco for those with G551D cystic fibrosis.
* Kalydeco alleviates many of the symptoms and issues associated with cystic fibrosis.  It is preventative as it treats the underlying cause of cystic fibrosis, preventing symptoms developing in the first place.
* There are societal and economic reasons for funding Kalydeco. The cost of Kalydeco is drastically offset through a reduction in health costs. Kalydeco prevents complications that require costly treatment. For example, the need for lung transplants is likely to be greatly reduced, as lung damage is effectively halted while on Kalydeco. Furthermore, there are important social and societal benefits from people with cystic fibrosis needing less time off work, away from school, away from their families and so forth.

**Take action**

A key part of the campaign is showing public support for funding Kalydeco. This means we need to go out in the community and get as many people as possible participating in the campaign and showing their support. The actions below are designed to do just this.

**Join the sticker campaign!**

Show your support by posting a photo of a campaign sticker on Facebook and tagging CFNZ and Kalydeco for Kiwis. The aim is to get the sticker in the coolest, most unique place! You can get stickers by contacting the CFNZ office.

**Social media**

Help us spread the word through Facebook, Twitter and other social media you’re on. Example Facebook and Twitter posts are below.

* Join me in the campaign to get Kalydeco publicly funded! [www.cfnz.org.nz](http://www.cfnz.org.nz) #KalydecoForKiwis
* Kalydeco is a breakthrough treatment for cystic fibrosis, but did you know NZ is the only country in the OECD (with a significant CF population) that has doesn’t fund Kalydeco? Let’s change this [www.cfnz.org.nz](http://www.cfnz.org.nz) #KalydecoForKiwis
* Every day that Kalydeco remains unfunded in New Zealand, irreversible lung damage is occurring. Join the campaign to get Kalydeco funded! [Insert website link]. #KalydecoForKiwis

**Organise an event to raise awareness, or attend other events/meetings in the community**

You can organise an event to raise awareness, more information on how to do this is below. Alternatively (or at the same time!) you could approach organisers of local events, or ask groups that hold meetings (e.g. Lions Clubs, Rotary), and ask if you can come along to talk about the Kalydeco campaign.

The key ask is for people to check out the campaign and write to PHARMAC showing their support.

*Things to keep in mind when organising an event:*

* CFNZ recommend that only one person with cystic fibrosis should attend an indoor event to avoid risk of cross infection.
* Timing: choose a date and time that will achieve maximum participation and provides enough time for candidates to confirm their participation.
* Venue: choose a venue that is affordable, comfortable, and has good acoustics so speakers can be heard.
* Programme: identify the format for your event. Have someone to MC and manage proceedings, time for speakers, and questions.
* Publicity: publicise your event through:
  + The CFNZ and Kalydeco for Kiwis Facebook pages, the CFNZ website and your own networks (e.g. through your social media, work, family friends etc.).
  + Email networks: e.g. local churches; schools; early childhood centres; the Chamber of Commerce; Rotary; Lions; Zonta; unions; local news media; Grey Power; Age Concern; iwi, health and social service organisations.
  + Issue a media statement before and after the event, get in touch with CFNZ and we can help you.

**Write to PHARMAC**

When writing to PHARMAC, also cc in the Minister for Health and opposition Health spokespeople. Below is a template letter you can use if you wish (and if you do use it by all means change it up as much as you like!). Personal stories are powerful so if you have a story you would like to share it would be great to include it in your letter. If you don’t have a personal story to share that’s fine too!

Here are some tips for writing to decision makers in general:

* Always be courteous: Remember you are trying to influence their thinking, not alienate them. So use courteous language. Don’t be sarcastic, judgmental, or question their motives.
* Don’t get emotive: You feel strongly enough to write to them. That carries weight, but it will also make it important to understate rather than overstate. Don’t use exclamation marks, heavy underlining, italics, or bold font. And don’t write words in capitals to make your point (GET IT!)
* Keep to the point: Like all the rest of us, they’re are very busy people. They do want to know what you think on an issue but they don’t want to hear about several issues at the same time. Keep to the point.
* Keep it short: This is related to point three above.
* State the purpose of the letter at the beginning: It is useful also to give your letter a heading that sets out what the subject of the letter is.

*Template letter*

*Dear xx*

*I am writing to urge you to fund Kalydeco for people with Cystic Fibrosis.*

*Kalydeco works and will be a game changing treatment for many people. It has proven effectiveness, backed up by robust data. In fact NZ is the only country in the OECD (with a significant cystic fibrosis population) that has not funded Kalydeco for those with G551D cystic fibrosis.*

***There’s a huge need***

*Cystic Fibrosis has huge impacts on the individual, but also their family and wider society. Managing cystic fibrosis is a considerable burden – all up a person with the condition spends many months a year in hospital as they deal with the many health issues it causes. This requires the individual (and loved ones) to spend time away from work, school and family, and as you can imagine this has a huge impact on their ability to participate in society.*

*IF YOU HAVE A PERSONAL STORY TO SHARE, YOU COULD TALK ABOUT THE IMPACT OF CYSTIC FIBROSIS*

*However, Kalydeco is game changing because it treats the underlying cause of cystic fibrosis. This in turn reduces the burden of the condition by preventing many of the health issues arising that require arduous treatment. This is obviously hugely beneficial for the individual, but also for society as a whole as people with cystic fibrosis need less time off work, away from school, away from their families and so forth.*

*IF YOU HAVE A PERSONAL STORY TO SHARE, YOU COULD TALK ABOUT HOW KALYDECO WOULD MAKE A IMPACT*

***Health benefit***

*The health benefits from Kalydeco is massive. Current life expectancy for those with cystic fibrosis is 37 years, but this is drastically improved for those on Kalydeco.*

*Kalydeco alleviates many of the symptoms associated with the condition and is preventative as it treats the underlying cause of cystic fibrosis, preventing health issues developing in the first place. This makes the condition easier to manage, helping the person with cystic fibrosis to live well and reduce the burden of the condition.*

***Costs and savings***

*There are strong societal reasons for funding Kalydeco, but there are also economic reasons. The cost of Kalydeco is drastically offset through a reduction in health costs. Kalydeco prevents complications that require costly treatment. For example, the need for lung transplants is likely to be greatly reduced, as lung damage is effectively halted while on Kalydeco.*

***Suitability***

*Kalydeco is easy to use, this reduces the possibility of reduced effectiveness due to administration error.*

***I urge you to keep talking with Vertex***

*PHARMAC has a proven track record of constructive and effective dialogue with pharmaceutical companies – I encourage you to continue talking and negotiating with Vertex.*

*I would also like to say that PHARMAC has a role to supply medicines for all New Zealanders, and this includes those with rare disorders. Within the current funding model, those unfortunate enough to suffer from a rare disorder are at a disadvantage, as access to specific treatments is very limited. Practical steps need to be in place to ensure access to medicines for those with rare disorders is increased. I would like to see Pharmac review its funding model for rare diseases.*

*Yours sincerely*

**Meet with your local MPs**

Meet with your local MPs. All you need to do is ring their local office and make a time to meet. Follow the tips above about writing to decision makers. Have your key messages clear in your mind before the meeting (the key messages at the beginning of this document may help).

Importantly, if you can include a personal story do, personal stories have the greatest impact and are a powerful way to get a message across.

**Letter to the editor**

Write a letter to the Editor – a template is below. This is a guide only, please feel free to use and amend.

*I recently became aware of a campaign to get Kalydeco publicly funded in NZ.*

*Kalydeco is an important treatment for people with G551D Cystic Fibrosis, however it’s not currently funded in NZ. In fact, NZ is the only country (with a significant cystic fibrosis population) in the OECD that has not funded Kalydeco. The evidence is clear that Kalydeco works. Kalydeco is the first medication that fixes the underlying cystic fibrosis defect, essentially turning off cystic fibrosis. Kalydeco represents a major breakthrough in cystic fibrosis research; current medications only treat the symptoms. Every day that Kalydeco remains unfunded in New Zealand, irreversible lung damage is occurring.*

*There are societal and economic reasons for funding Kalydeco. The cost of Kalydeco is drastically offset through a reduction in health costs. Kalydeco prevents complications that require costly treatment. For example, the need for lung transplants is likely to be greatly reduced, as lung damage is effectively halted while on Kalydeco. Furthermore, there are important social and societal benefits from people with cystic fibrosis needing less time off work, away from school, away from their families and so forth.*

*PHARMAC is currently considering applications for treatments for people with rare disorders. Kalydeco is one of them. I encourage you to join the campaign, more information is on the Cystic Fibrosis NZ website.*

*Yours sincerely*

**Write to your local newspaper or online forums/blogs**

Contact your local newspaper and ask if they’d be interested in including a story on the campaign. Human stories are most engaging, so it’s useful if you have a story you could base the article on. Alternatively, there may be online forums or blogs you could share your story on.

Here’s a template article, it’s a guide only so feel free to change it as you please.

*[Add name] has cystic fibrosis and would benefit from a treatment called Kalydeco, however Kalydeco is not publicly funded in New Zealand. New Zealand is the only country (with a significant cystic fibrosis population) in the OECD that has not funded Kalydeco for those with G551D cystic fibrosis.*

***Share information about a personal story and how Kalydeco would help.***

*Kalydeco is the first medication that fixes the underlying cystic fibrosis defect, essentially turning off cystic fibrosis. Kalydeco represents a major breakthrough in cystic fibrosis research; current medications only treat the symptoms.*

*“Kalydeco is a proven treatment, that is backed up by robust data. Every day that Kalydeco remains unfunded in New Zealand, irreversible lung damage is occurring” says [add name].*

*[Add more information from personal story]*

*“The cost of Kalydeco is drastically offset through a reduction in health costs. Kalydeco prevents complications that require costly treatment. For example, the need for lung transplants is likely to be greatly reduced, as lung damage is effectively halted while on Kalydeco.*

*“Importantly, there are huge social and societal benefits from people with CF needing less time off work, away from school, away from their families and so forth” says [add name].*

*PHARMAC is currently considering applications from suppliers of medicines for rare disorders. Kalydeco is one of the treatments being considered. More information on the campaign can be found here: xx*

**Call your local talkback radio**

Love it or hate it, talkback radio is here to stay. If you want to get your point of view heard it is as good as a letter to the editor. There’s at least one near you so why not use it. It is the fastest way to respond to news and events. And remember, politicians listen as a means of keeping abreast of what people are thinking or are concerned about.

When you ring you will not go straight on air. Instead you will be spoken to by a producer who will want to know your name and what you want to say. If you want to stay anonymous then explain that to the producer and your reasons for wishing not to have your name given on air.

Tips on calling your local talkback radio

* Prepare yourself before making the call. Have a main point that you are very clear on. Stick to that point and don’t ramble around the subject. It helps to write down that main point as part of your preparation. It is useful also to have a few facts at your fingertips
* Speak as you would to a friend on the phone. Keep it conversational, one-to-one. Be friendly. Don’t shout or make a public speech
* If you can, support your argument with facts or expert opinion
* Be positive and constructive. Offer an alternative way rather than be critical
* Keep it personal – use stories and experiences if you can
* Be good-natured and relaxed. Use humour if the opportunity is there
* If you get asked an unexpected or awkward question, don’t go silent. Just say something like “I would have to think about that …”
* You can also send you point of view to talkback hosts by fax or email.