
From: Lisa Williams
Sent: Thursday, 1 December 2022 11:31 am
To: Alex Chippy Compton; Sarah Fitt
Cc: Jane Wright; Josh Wiles; Geraldine MacGibbon; Logan Heyes
Subject: RE: Executed agreement for Trikafta

Such excellent news Chippy – well done to you and the team. You should all be rally proud of yourselves as this has been a massive slog.

L

From: Alex Chippy Compton <[REDACTED]>
Sent: Thursday, 1 December 2022 10:15 AM
To: Sarah Fitt <[REDACTED]>; Lisa Williams <[REDACTED]>
Cc: Jane Wright <[REDACTED]>
Subject: FW: Executed agreement for Trikafta

We have an agreement 😊😊😊😊

Chippy

Ngā mihi

Chippy Compton | [she/her](#) | Therapeutic Group Manager

Te Pātaka Whaioranga | Pharmac | PO Box 10-254 | Level 9, 40 Mercer Street, Wellington
DDI: [REDACTED] | P: [REDACTED] | M: [REDACTED] | www.pharmac.govt.nz

From: Annette Kerr (she/her/hers) <[REDACTED]>
Sent: Thursday, 1 December 2022 9:39 am
To: Alex Chippy Compton <[REDACTED]>
Cc: Sabrina Barbic <[REDACTED]>; Jane Cusack (she/her/hers) <[REDACTED]>; Josh Wiles <[REDACTED]>; Geraldine MacGibbon <[REDACTED]>; Logan Heyes <[REDACTED]>
Subject: Executed agreement for Trikafta

Dear Chippy,

Please find attached the executed agreement for Trikafta. Thanks for your patience and prompt responses over the last week while we worked through the final stages, it is much appreciated.

Our comms director has been working with Jane to ensure the announcements are coordinated. I'll also make sure that our materials are shared once approved.

Again, thanks so much to you, Logan and Josh for your efforts over the past months and in deed since we kicked off discussions at the beginning of last year it's been a pleasure working towards this outcome for patients in New Zealand.

Kind regards

Annette

From: Annette Kerr (she/her/hers)

Sent: Wednesday, 30 November 2022 3:38 PM

To: 'Alex Chippy Compton' <[REDACTED]>

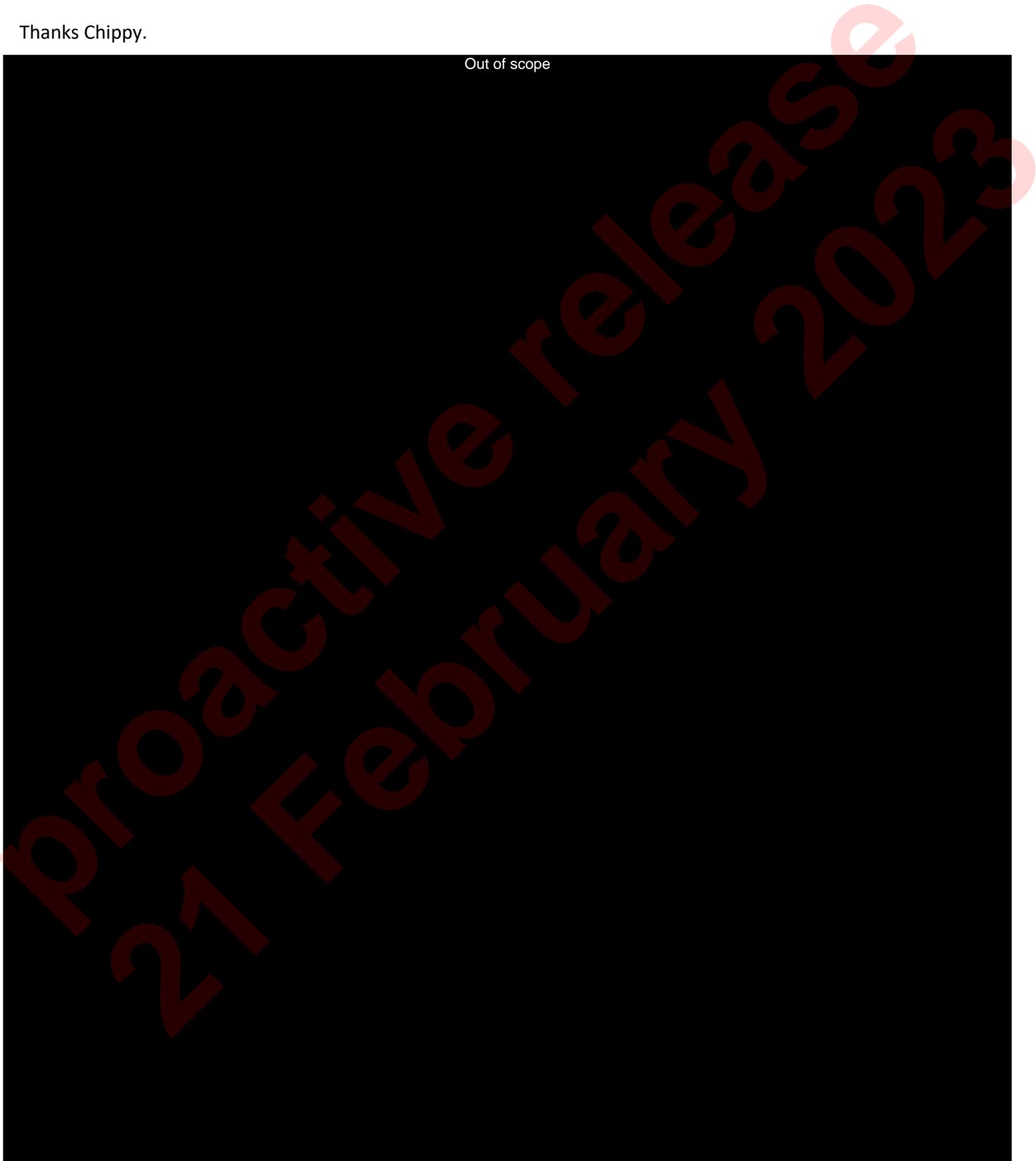
Cc: Sabrina Barbic <[REDACTED]>; Jane Cusack (she/her/hers) <[REDACTED]>; Josh Wiles

<[REDACTED]>; Geraldine MacGibbon <[REDACTED]>

Subject: RE: Confidential - draft consultation for Trikafta

Thanks Chippy.

Out of scope



proactive release
21 February 2023

From: Jane Wright
Sent: Thursday, 1 December 2022 9:41 am
To: Sarah Fitt
Subject: RE: Confidential - draft consultation for Trikafta

Yes I think I already have you down for Ed. It is a risk media wise, but we will have lined up the biggest risk Paddy so he won't leak early and I think worth telling Rachel from Stuff on Friday too so she is ready for Monday morning.

They will hold it, everyone will want the excitement of Sunday night – worst case (which is actually best case) they encourage their followers to watch Sunday night news without actually saying why

Sent from [Mail](#) for Windows

From: [Sarah Fitt](#)
Sent: Thursday, 1 December 2022 8:37 am
To: [Jane Wright](#)
Subject: RE: Confidential - draft consultation for Trikafta

Assuming it arrives today can I be on call to Ed Lee as well as Lisa Burns. Ed texted me last night. Have to say I am a little worried about giving them over 48hrs notice. Bit of a risk

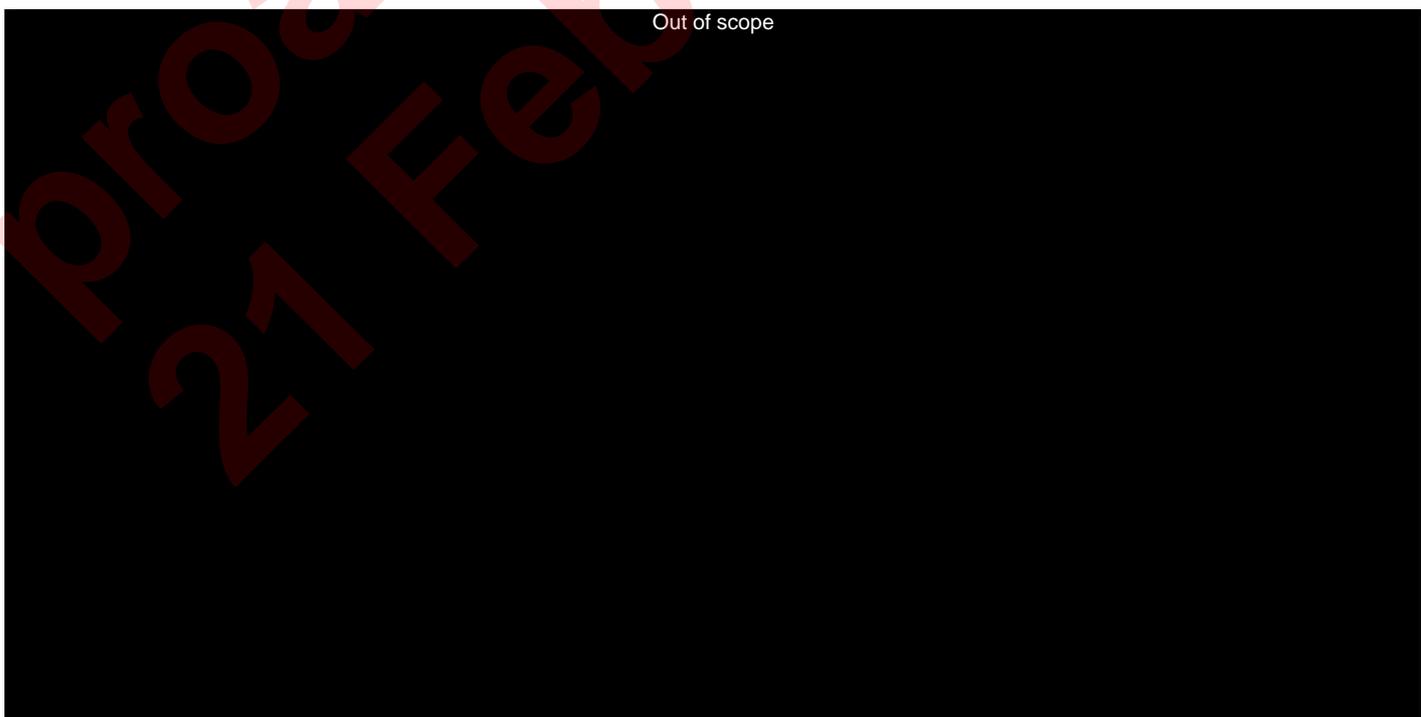
Ngā mihi,

Sarah

Sarah Fitt | Chief Executive

PHARMAC | Te Pātaka Whaioranga | PO Box 10-254 | Level 9, 40 Mercer Street, Wellington
DDI: [REDACTED] | P: [REDACTED] | M: [REDACTED] | www.pharmac.govt.nz

Out of scope



Proactive release
21 February 2023



proactive release
21 February 2023

From: Jane Wright
Sent: Thursday, 1 December 2022 9:51 am
To: Alex Chippy Compton
Subject: media release
Attachments: 2022-12-04 trikafta consult media release.obr

One last check – particularly numbers – as I know there has been some discussion on that!

Sent from [Mail](#) for Windows

proactive release
21 February 2023

From: Liz Barlow
Sent: Thursday, 1 December 2022 11:20 am
To: Jane Wright; Rosa Bach
Subject: RE: can you please put this on our website - to go live Sunday at 6pm

Do we have the consult to load?

Preview:

[REDACTED]

Link:

<https://pharmac.govt.nz/news-and-resources/news/2022-12-04-media-release-pharmac-seeking-feedback-on-funding-trikafta>

From: Jane Wright <[REDACTED]>
Sent: Thursday, 1 December 2022 10:49 am
To: Liz Barlow <liz.barlow@pharmac.govt.nz>; Rosa Bach <[REDACTED]>
Subject: can you please put this on our website - to go live Sunday at 6pm

Hi Liz, can you please put this on our website - to go live Sunday at 6pm.

Rosa, for mailchimp to go out at 615pm on Sunday

Thanks!!!

Sent from [Mail](#) for Windows

From: Liz Barlow
Sent: Thursday, 1 December 2022 11:52 am
To: Alex Chippy Compton; Jane Wright
Subject: RE: Consultation

Preview link:
[REDACTED]

Actual URL

<https://pharmac.govt.nz/news-and-resources/consultations-and-decisions/2022-12-04-proposal-to-fund-elexacaftor-with-tezacaftor-and-ivacaftor-trikafta-for-people-with-cystic-fibrosis>

From: Alex Chippy Compton <[REDACTED]>
Sent: Thursday, 1 December 2022 11:24 am
To: Jane Wright <[REDACTED]>; Liz Barlow <liz.barlow@pharmac.govt.nz>
Subject: Consultation

Consultation now approved.

Chippy

Ngā mihi

Chippy Compton | [she/her](#) | Therapeutic Group Manager

Te Pātaka Whaioranga | Pharmac | PO Box 10-254 | Level 9, 40 Mercer Street, Wellington
DDI: [REDACTED] | P: [REDACTED] | M: [REDACTED] | www.pharmac.govt.nz

Proposal to fund elexacaftor with tezacaftor and ivacaftor (Trikafta) for people with cystic fibrosis

4 December 2022

What we're proposing

We are proposing to fund elexacaftor with tezacaftor and ivacaftor (brand name Trikafta) for people aged 6 years and above with cystic fibrosis subject to eligibility criteria.

Consultation closes at **5 pm, Monday 16 January 2023** and feedback can be emailed to consult@pharmac.govt.nz

What would the effect be?

From 1 April 2023, people with cystic fibrosis would have funded access to Trikafta if they:

- are aged 6 years and above, and
- have specific mutations, and
- meet certain clinical criteria.

[About cystic fibrosis – Health Need section of the Trikafta Summary of Assessment](#)

Our expert advice indicates that treatment with Trikafta significantly improves lung function and other symptoms of cystic fibrosis. We estimate that Trikafta could give people with cystic fibrosis up to 27 more years at full health, compared to supportive care. This would significantly reduce the impact of the condition on people with cystic fibrosis, their whānau, and communities.

[Our assessment of the benefits of Trikafta – Health Benefit section of the Summary of Assessment](#)

We estimate there are more than 360 people in New Zealand who would be eligible for funded treatment under the proposed criteria.

Romaha ora, respiratory health, is one of Pharmac's Hauora Arotahi, Māori health focus areas. Our clinical advisors have told us it is likely that Māori experience worse health outcomes than non-Māori for cystic fibrosis.

[The impact for Māori and other populations experiencing health disparities – Health Need section of the Summary of Assessment](#)

Individuals would be able to access Trikafta through their prescriber. Prescriptions would be sent to and collected from Te Whatu Ora hospital pharmacies.

Who we think will be interested

- People with cystic fibrosis, their whānau, caregivers, and communities
- People interested in the funding of medicines for cystic fibrosis and rare disorders

- Respiratory physicians, paediatricians, respiratory nurses, and other clinicians and health professionals involved in the management of cystic fibrosis
- Advocacy and support groups for people with cystic fibrosis
- Te Whatu Ora Hospitals
- Pharmaceutical suppliers and wholesalers

About cystic fibrosis

Cystic fibrosis affects around 500 New Zealanders of all ages. The condition occurs when someone is born with two faulty genes, which causes the body to make abnormally thick mucus. The mucus stops organs working well and results in infection. People living with cystic fibrosis have shorter lives because of the condition. Cystic fibrosis can also cause other conditions, including diabetes and diseases of the liver and bone.

Cystic fibrosis is a chronic condition and it affects children – both of which are Government health priorities.

There is no cure for cystic fibrosis. The current treatments for most people with cystic fibrosis (known as supportive care) take up a lot of time, with many healthcare appointments and sometimes hospital admissions. This impacts people and their caregivers' ability to do day-to-day activities, such as going to school and work.

[About cystic fibrosis, the impact it has on people and their whānau, and existing treatments – Summary of Assessment](#)

About Trikafta

Trikafta is an oral medicine in tablet form taken twice a day. It supports the faulty protein to make thinner mucus. This stops the mucus blocking the body's organs. Trikafta significantly improves lung function, patient weight, and other symptoms of cystic fibrosis, reducing the likelihood of people being admitted to hospital. We expect that these benefits would allow people with cystic fibrosis to live healthier, longer lives.

Trikafta is available in two fixed dose combinations:

- for people over 30 kilograms: two 100 mg elexacaftor with 50 mg tezacaftor and 75 mg ivacaftor tablets in the morning and one 150 mg ivacaftor tablet in the evening; and
- for people under 30 kilograms: two 50 mg elexacaftor with 25 mg tezacaftor and 37.5 mg ivacaftor tablets in the morning and one 75 mg ivacaftor tablet in the evening.

Trikafta is Medsafe approved for people aged 6 years and older in New Zealand.

[Medsafe datasheet for Trikafta](#)

Why we're proposing this

The pharmaceutical supplier, Vertex, submitted an application to Te Pātaka Whaioranga – Pharmac in July 2021. The application asked us to fund Trikafta for people with cystic fibrosis who are aged 6 years and older and who have a specific gene mutation.

The Respiratory Advisory Committee and the Pharmacology and Therapeutics Advisory Committee have recommended funding Trikafta for people with cystic fibrosis who are aged 6 years and older, subject to certain criteria. They considered:

- evidence and information from the supplier
- communication from Cystic Fibrosis New Zealand
- advice from members of Pharmac’s former Cystic Fibrosis Panel.

We have heard from expert advisors and people with cystic fibrosis, their whānau, and communities about the impact of cystic fibrosis and the benefit Trikafta can have. This has helped our understanding and assessment of this proposal.

Trikafta has been ranked on our Options for Investment list since October 2021. The list includes all treatments that we would fund if the budget allowed it. Following the budget announcement in May 2022 and commercial negotiations with the supplier, Vertex, we are now able to progress this proposal.

Details about our proposal

Elexacaftor with tezacaftor, ivacaftor and ivacaftor (Trikafta) would be listed in Section B (as PCT only) and Part II of Section H of the Pharmaceutical Schedule from 1 April 2023 at the following price (ex-manufacturer, excluding GST):

Chemical	Formulation	Brand	Pack size	Price and subsidy
Elexacaftor with tezacaftor, ivacaftor and ivacaftor	Tab elexacaftor 100 mg with tezacaftor 50 mg, ivacaftor 75 mg and ivacaftor 150 mg	Trikafta	84	\$27,647.39
Elexacaftor with tezacaftor, ivacaftor and ivacaftor	Tab elexacaftor 50 mg with tezacaftor 25 mg, ivacaftor 37.5 mg and ivacaftor 75 mg	Trikafta	84	\$27,647.39

A confidential rebate would apply to Trikafta that would reduce the net price.

Elexacaftor with tezacaftor, ivacaftor and ivacaftor (Trikafta) would be listed in Section B and Part II of Section H subject to the following eligibility criteria:

Special Authority for Subsidy

Initial application from any relevant practitioner. Approvals valid without further renewal (unless notified) for applications meeting the following criteria:

All of the following:

1. Patient has been diagnosed with cystic fibrosis; and
2. Patient is 6 years of age or older; and
3. Either:
 - 3.1. Patient has two cystic fibrosis-causing mutations in the cystic fibrosis transmembrane regulator (CFTR) gene (one from each parental allele); or
 - 3.2. Patient has a sweat chloride value of at least 60 mmol/L by quantitative pilocarpine iontophoresis or by Macroduct sweat collection system; and
4. Either:
 - 4.1. Patient has a heterozygous or homozygous F508del mutation; or
 - 4.2. Patient has a G551D mutation or other mutation responsive in vitro to elexacaftor/tezacaftor/ivacaftor (see note a); and
5. The treatment must be the sole funded CFTR modulator therapy for this condition; and
6. Treatment with elexacaftor/tezacaftor/ivacaftor must be given concomitantly with standard therapy for this condition.

Notes

- a) Eligible mutations are listed in the Food and Drug Administration (FDA) Trikafta prescribing information https://www.accessdata.fda.gov/drugsatfda_docs/label/2021/212273s004lbl.pdf.

Elexacaftor with tezacaftor, ivacaftor and ivacaftor (Trikafta) would be listed as a 'PCT only – Specialist pharmaceutical' in Section B of the Pharmaceutical Schedule. This means that funded treatment could only be dispensed from a Te Whatu Ora hospital pharmacy.

We are not proposing that Trikafta be dispensed through community pharmacies at this time. This is due to the high cost of this medicine. To reduce the number of times people need to travel to their nearest hospital, Te Whatu Ora Hospitals would be able to dispense three months' worth of treatment at a time.

To provide feedback

Send us an email: consult@pharmac.govt.nz by **5 pm, Monday 16 January 2023**.

All feedback received before the closing date will be considered by Pharmac's Board (or its delegate) before making a decision on this proposal.

Your feedback may be shared

Feedback we receive is subject to the Official Information Act 1982 (OIA). Please be aware that we may need to share your feedback, including your identity, in response to an OIA request. This applies to anyone providing feedback, whether they are providing feedback themselves or for an organisation, in a personal or professional capacity.

We can only keep feedback confidential as allowed under the OIA and other related laws. If you want any part of your feedback treated as confidential, you need to tell us. Please let us know if you want to keep part of your feedback confidential, and why. Is it commercially sensitive, confidential or proprietary, or personal information? Clearly state this and tell us which parts of your feedback you want to keep confidential for these reasons. We will consider your request under our OIA requirements.

From: Jane Wright
Sent: Thursday, 1 December 2022 1:04 pm
To: David Cormack
Subject: our PR

Media release

4 December 2022

Pharmac seeking feedback on funding Trikafta

Te Pātaka Whaioranga – Pharmac has reached a provisional agreement with medicine supplier Vertex to fund Trikafta.

“Following [our budget increase in May 2022](#) and commercial negotiations with the supplier, Vertex, I am thrilled to announce today that we are initiating consultation on the funding of Trikafta for people aged 6 years and above with cystic fibrosis who meet certain eligibility criteria,” says Pharmac’s director of operations Lisa Williams.

“Trikafta has the potential to make a substantial difference to the lives of those people in New Zealand living with cystic fibrosis and for their whānau and communities too. We estimate that, if funded, Trikafta could give people with cystic fibrosis up to 27 more years at full health, when compared with supportive care. This would significantly reduce the impact of the condition on people with cystic fibrosis, their whānau and communities.

“We have been actively working towards this step in the funding process since receiving recommendations from both our Respiratory Advisory Committee and from our Pharmacology and Therapeutics Advisory Committee (PTAC) that the medicine should be funded. Our expert advisors have told us that treatment with Trikafta significantly improves lung function and other symptoms of cystic fibrosis. The evidence is clear that Trikafta can benefit people with cystic fibrosis, so we are pleased to start consultation on a proposal to fund it.

“I want to acknowledge the time that many people have put into advocating for those living with cystic fibrosis and to those who have shared their own very personal stories with us. We have heard them all, and we know there will be a lot of people thrilled to hear that we are proposing to fund Trikafta.”

The consultation is available on the Pharmac website for anyone wanting to have their say.

“Consultation is a very important step in our process,” says Ms Williams. “It’s how we check that the people who will get the most benefit from the medicines will be able to access them. If approved, we will also be working closely with our colleagues across the health sector to plan for the implementation of Trikafta.”

“We have been saying that we wanted to fund Trikafta – and now we are a step closer,” says Ms Williams.

Funding of Trikafta is proposed to start 1 April 2023.

ENDS

We are welcoming feedback on the proposed funding of Trikafta until 16 January 2023. Please email media@pharmac.govt.nz or call 021863342 if you would like to know more.

Learn more:

Trikafta is a combination of elexacaftor, tezacaftor and ivacaftor. It is a tablet, taken twice a day. Due to the wide public interest in its funding application, Pharmac has shared every milestone along our assessment and decision-making processes, starting with receiving the application:

- <https://pharmac.govt.nz/news-and-resources/news/cystic-fibrosis-medicine-applications-to-be-considered-by-pharmac-and-medsafe-in-parallel/?page=9>
- <https://pharmac.govt.nz/news-and-resources/news/2021-07-09-media-release-application-for-cystic-fibrosis-medicine-received-by-pharmac/?page=8>
- <https://pharmac.govt.nz/news-and-resources/news/2021-10-27-media-release-cystic-fibrosis-medicine-added-to-pharmacs-options-for-investment-list/?page=7>
- <https://pharmac.govt.nz/news-and-resources/news/2021-02-23-media-release-pharmacs-clinical-experts-recommend-funding-trikafta/?page=5>
- <https://pharmac.govt.nz/news-and-resources/news/2022-08-15-media-release-pharmac-shares-update-on-its-assessment-of-trikafta/?page=2>

A year and a half after receiving the application to fund Trikafta, it is only fitting that Pharmac shares this milestone too.

We are continuing to work our way through our options for investment list, trying to secure deals for as many items as we can within available funding. Since 1 July 2022 Pharmac has funded 12 new treatments and widened access to 17 already funded medicines, and there are more to come.

From: Patrick Gower <[REDACTED]>
Sent: Thursday, 1 December 2022 1:10 pm
To: Jane Wright
Subject: Re: PR and consult for you to see

Gotcha!

On Thu, 1 Dec 2022 at 13:04, Jane Wright <[REDACTED]> wrote:

Hi Paddy, Lisa is free tomorrow at 0900 – does that work for you? She could do this afternoon to if needed! The PR is below and the consult is attached. Sing out if you need anything else today. As discussed Lisa Burns and Ed Lee will be told, in confidence, tomorrow at 3pm so please keep it tight before then!

Media release

4 December 2022

Pharmac seeking feedback on funding Trikafta

Te Pātaka Whaioranga – Pharmac has reached a provisional agreement with medicine supplier Vertex to fund Trikafta.

“Following [our budget increase in May 2022](#) and commercial negotiations with the supplier, Vertex, I am thrilled to announce today that we are initiating consultation on the funding of Trikafta for people aged 6 years and above with cystic fibrosis who meet certain eligibility criteria,” says Pharmac’s director of operations Lisa Williams.

“Trikafta has the potential to make a substantial difference to the lives of those people in New Zealand living with cystic fibrosis and for their whānau and communities too. We estimate that, if funded, Trikafta could give people with cystic fibrosis up to 27 more years at full health, when compared with supportive care. This would significantly reduce the impact of the condition on people with cystic fibrosis, their whānau and communities.

“We have been actively working towards this step in the funding process since receiving recommendations from both our Respiratory Advisory Committee and from our Pharmacology and

Therapeutics Advisory Committee (PTAC) that the medicine should be funded. Our expert advisors have told us that treatment with Trikafta significantly improves lung function and other symptoms of cystic fibrosis. The evidence is clear that Trikafta can benefit people with cystic fibrosis, so we are pleased to start consultation on a proposal to fund it.

“I want to acknowledge the time that many people have put into advocating for those living with cystic fibrosis and to those who have shared their own very personal stories with us. We have heard them all, and we know there will be a lot of people thrilled to hear that we are proposing to fund Trikafta.”

The consultation is available on the Pharmac website for anyone wanting to have their say.

“Consultation is a very important step in our process,” says Ms Williams. “It’s how we check that the people who will get the most benefit from the medicines will be able to access them. If approved, we will also be working closely with our colleagues across the health sector to plan for the implementation of Trikafta.”

“We have been saying that we wanted to fund Trikafta – and now we are a step closer,” says Ms Williams.

Funding of Trikafta is proposed to start 1 April 2023.

ENDS

We are welcoming feedback on the proposed funding of Trikafta until 16 January 2023. Please email media@pharmac.govt.nz or call 021863342 if you would like to know more.

Learn more:

Trikafta is a combination of elexacaftor, tezacaftor and ivacaftor. It is a tablet, taken twice a day. Due to the wide public interest in its funding application, Pharmac has shared every milestone along our assessment and decision-making processes, starting with receiving the application:

- <https://pharmac.govt.nz/news-and-resources/news/cystic-fibrosis-medicine-applications-to-be-considered-by-pharmac-and-medsafe-in-parallel/?page=9>
- <https://pharmac.govt.nz/news-and-resources/news/2021-07-09-media-release-application-for-cystic-fibrosis-medicine-received-by-pharmac/?page=8>
- <https://pharmac.govt.nz/news-and-resources/news/2021-10-27-media-release-cystic-fibrosis-medicine-added-to-pharmacs-options-for-investment-list/?page=7>
- <https://pharmac.govt.nz/news-and-resources/news/2021-02-23-media-release-pharmacs-clinical-experts-recommend-funding-trikafta/?page=5>
- <https://pharmac.govt.nz/news-and-resources/news/2022-08-15-media-release-pharmac-shares-update-on-its-assessment-of-trikafta/?page=2>

A year and a half after receiving the application to fund Trikafta, it is only fitting that Pharmac shares this milestone too.

We are continuing to work our way through our options for investment list, trying to secure deals for as many items as we can within available funding. Since 1 July 2022 Pharmac has funded 12 new treatments and widened access to 17 already funded medicines, and there are more to come.

This e-mail message and any accompanying attachments may contain confidential information. If you are not the intended recipient, please do not read, use, disseminate, distribute or copy this message or attachments. If you have received this message in error, please notify the sender immediately and delete this message.

--

--

Patrick Gower

National Correspondent

wbd.com



proactive release
21 February 2023

From: Jane Wright
Sent: Thursday, 1 December 2022 1:56 pm
To: Nicole Bremner
Subject: Pharmac update

Kia ora Nicole, as discussed, here is our embargoed release. Let me know if you would like me to tee up any interviewees for you! Lisa is available early tomorrow morning or this afternoon even if you would like to chat with her.

Media release

4 December 2022

Embargoed

Pharmac seeking feedback on funding Trikafta

Te Pātaka Whaioranga – Pharmac has reached a provisional agreement with medicine supplier Vertex to fund Trikafta.

“Following [our budget increase in May 2022](#) and commercial negotiations with the supplier, Vertex, I am thrilled to announce today that we are initiating consultation on the funding of Trikafta for people aged 6 years and above with cystic fibrosis who meet certain eligibility criteria,” says Pharmac’s director of operations Lisa Williams.

“Trikafta has the potential to make a substantial difference to the lives of those people in New Zealand living with cystic fibrosis and for their whānau and communities too. We estimate that, if funded, Trikafta could give people with cystic fibrosis up to 27 more years at full health, when compared with supportive care. This would significantly reduce the impact of the condition on people with cystic fibrosis, their whānau and communities.

“We have been actively working towards this step in the funding process since receiving recommendations from both our Respiratory Advisory Committee and from our Pharmacology and Therapeutics Advisory Committee (PTAC) that the medicine should be funded. Our expert advisors have told us that treatment with Trikafta significantly improves lung function and other symptoms of cystic fibrosis. The evidence is clear that Trikafta can benefit people with cystic fibrosis, so we are pleased to start consultation on a proposal to fund it.

“I want to acknowledge the time that many people have put into advocating for those living with cystic fibrosis and to those who have shared their own very personal stories with us. We have heard them all, and we know there will be a lot of people thrilled to hear that we are proposing to fund Trikafta.”

The consultation is available on the Pharmac website for anyone wanting to have their say.

“Consultation is a very important step in our process,” says Ms Williams. “It’s how we check that the people who will get the most benefit from the medicines will be able to access them. If approved, we will also be working closely with our colleagues across the health sector to plan for the implementation of Trikafta.”

“We have been saying that we wanted to fund Trikafta – and now we are a step closer,” says Ms Williams.

Funding of Trikafta is proposed to start 1 April 2023.

ENDS

We are welcoming feedback on the proposed funding of Trikafta until 16 January 2023. Please email media@pharmac.govt.nz or call 021863342 if you would like to know more.

Learn more:

Trikafta is a combination of elexacaftor, tezacaftor and ivacaftor. It is a tablet, taken twice a day. Due to the wide public interest in its funding application, Pharmac has shared every milestone along our assessment and decision-making processes, starting with receiving the application:

- <https://pharmac.govt.nz/news-and-resources/news/cystic-fibrosis-medicine-applications-to-be-considered-by-pharmac-and-medsafe-in-parallel/?page=9>
- <https://pharmac.govt.nz/news-and-resources/news/2021-07-09-media-release-application-for-cystic-fibrosis-medicine-received-by-pharmac/?page=8>
- <https://pharmac.govt.nz/news-and-resources/news/2021-10-27-media-release-cystic-fibrosis-medicine-added-to-pharmacs-options-for-investment-list/?page=7>
- <https://pharmac.govt.nz/news-and-resources/news/2021-02-23-media-release-pharmacs-clinical-experts-recommend-funding-trikafta/?page=5>
- <https://pharmac.govt.nz/news-and-resources/news/2022-08-15-media-release-pharmac-shares-update-on-its-assessment-of-trikafta/?page=2>

A year and a half after receiving the application to fund Trikafta, it is only fitting that Pharmac shares this milestone too.

We are continuing to work our way through our options for investment list, trying to secure deals for as many items as we can within available funding. Since 1 July 2022 Pharmac has funded 12 new treatments and widened access to 17 already funded medicines, and there are more to come.

From: Rachael Bylykbashi <[REDACTED]>
Sent: Thursday, 1 December 2022 2:58 pm
To: Jane Wright
Subject: RE: Pharmac's media release

Hi Jane

It's great news that everything is now signed.

Can you let me know when you'd be available to talk through your media strategy? My release is not 100% finalised yet, but is close.

Kind regards

Rachael

From: Jane Wright <[REDACTED]>
Sent: Tuesday, 29 November 2022 11:48 AM
To: Rachael Bylykbashi <[REDACTED]>
Subject: RE: Pharmac's media release

CAUTION: This email originated from outside of Vertex. Do not open links or attachments unless you know the sender and believe it is safe. If you suspect that this email is a potentially malicious email, **please click on the Report Phish button.**

Pharmac seeking feedback on funding Trikafta

Te Pātaka Whaioranga – Pharmac has reached a provisional agreement with medicine supplier Vertex to fund Trikafta.

“Following [our budget increase in May 2022](#) and commercial negotiations with the supplier, Vertex, I am thrilled to announce today that we are initiating consultation on the funding of Trikafta for people aged 6 years and above with cystic fibrosis who meet certain eligibility criteria,” says Pharmac’s director of operations Lisa Williams.

“Trikafta has the potential to make a substantial difference to the lives of those people in New Zealand living with cystic fibrosis and for their whānau and communities too. We estimate that, if funded, Trikafta could give people with cystic fibrosis up to 27 more years at full health, when compared with supportive care. This would significantly reduce the impact of the condition on people with cystic fibrosis, their whānau and communities.

“We have been actively working towards this step in the funding process since receiving recommendations from both our Respiratory Advisory Committee and from our Pharmacology and Therapeutics Advisory Committee (PTAC) that the medicine should be funded. Our expert advisors have told us that treatment with Trikafta significantly improves lung function and other symptoms of cystic fibrosis. The evidence is clear that Trikafta can benefit people with cystic fibrosis, so we are pleased to start consultation on a proposal to fund it.

“I want to acknowledge the time that many people have put into advocating for those living with cystic fibrosis and to those who have shared their own very personal stories with us. We have heard them all, and we know there will be a lot of people thrilled to hear that we are proposing to fund Trikafta.”

The consultation is available on the Pharmac website for anyone wanting to have their say.

From: Liz Barlow
Sent: Thursday, 1 December 2022 3:06 pm
To: Jane Wright; Alex Chippy Compton
Subject: Trikafta

Hi

I've set the consult and media release to go live automatically at 6pm on Sunday. So if something changes between now and then, let me know so I can stop the automagic.

Ngā mihi

Liz Barlow ([She/Her](#)) | Senior Communications Advisor (Digital)

Pharmac | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington
P: [REDACTED] | M: [REDACTED] | pharmac.govt.nz

PSA Delegate | [Join the PSA today](#)

From: David Cormack <[REDACTED]>
Sent: Sunday, 4 December 2022 3:29 pm
To: Jane Wright
Subject: '2022-12-01 Pharmac messages to support the Trikafta consultation' with you
Attachments: 2022-12-01 Pharmac messages to support the Trikafta consultation.docx

Suggestions in red.

proactive release
21 February 2023

Pharmac messages to support the Trikafta consultation

Trikafta funding messages

- Te Pātaka Whaioranga – Pharmac has reached a provisional agreement with medicine supplier Vertex to fund Trikafta for people aged 6 years and above with cystic fibrosis who meet certain eligibility criteria.
- Trikafta is the brand name for elexacaftor with tezacaftor and ivacaftor. It is a tablet, taken twice a day.
- We received an application to fund Trikafta in July 2021, and it was added to our options for investment list in October 2021. Just over a year later, we are a step closer to funding it.
- Trikafta has the potential to make a substantial difference to the lives of those people in New Zealand living with cystic fibrosis and for their whānau and communities too.
- Trikafta could give people with cystic fibrosis up to 27 more years at full health, when compared with supportive care.
- Funding Trikafta would significantly reduce the impact of the condition on people with cystic fibrosis, their whānau and communities.
- The evidence is clear that Trikafta can benefit people with cystic fibrosis, so we are to have started consultation on a proposal to fund it.
- Funding of Trikafta is proposed to start 1 April 2023.
- There are more than 360 people in New Zealand who would be eligible for funded treatment under the proposed criteria.

Pharmac budget messages

- The \$191 million pharmaceutical budget increase over two years Pharmac received in May is the biggest we've had since we were formed almost 30 years ago.
- The Budget 2022 announcement means Pharmac's budget for treatments is now \$1.186 billion and next year will be \$1.245 billion.
- We are continuing to work our way through their options for investment list, trying to secure deals for as many items as we can.
- Since 1 July 2022 Pharmac has funded 12 new treatments and widened access to 17 already funded medicines, and there are more to come.

FAQs

What is happening?

Te Pātaka Whaioranga – Pharmac has reached a provisional agreement with medicine supplier Vertex to fund Trikafta for people aged 6 years and above with cystic fibrosis who meet certain eligibility criteria.

Why now? I thought your CE said you wouldn't be able to afford this right now.

All Pharmac staff are motivated to fund as many treatments as we can to achieve the best health outcomes for New Zealanders. We have been working really closely with Vertex, the supplier of Trikafta, to come to an agreement, and are thrilled we have been able to **what we think is a very good deal**.

How much is it going to cost taxpayers?

We can't share the cost that Pharmac is paying for Trikafta. We ask New Zealanders to trust that we were able to negotiate a good, fair price for a treatment that has the potential to make a substantial difference to the lives of those people in New Zealand living with cystic fibrosis and for their whānau and communities too.

What about everything else on your OFI list?

We would love to be able to fund every medicine for every condition but unfortunately that's not realistic. The budget increase we got this year is the largest in our history and has allowed us to fund many more medicines.

We are continuing to work our way through their options for investment list, trying to secure deals for as many items as we can. Since 1 July 2022 Pharmac has funded 12 new treatments and widened access to 17 already funded medicines, and there are more to come.

Why did it take so long?

We received an application to fund Trikafta in July 2021, and it was added to our options for investment list in October 2021. Just over a year later, we are a step closer to funding it. **This is historically pretty quick, which is due in large part to the budget increase we received this year which has allowed us to fund 12 new treatments since July this year, and widened access to 17.**

Have you just caved to a PR campaign?

Not at all. Pharmaceuticals can spend all they like on PR campaigns, these have no bearing on our decision making. We received an application to fund Trikafta in July

2021, and it was added to our options for investment list in October 2021. Just over a year later, we are a step closer to funding it.

These decisions are based off expert advice, not PR campaigns.

Any question about the review

We are in the process of finalising our first progress report since the review which will be made public soon.

General message

All of us at Pharmac have friends and loved ones who have illnesses. Our hearts go out to anyone in Aotearoa who is unwell. We wish we could fund every medicine for every condition, but we're doing our best to help as many Kiwis, and treat as many illnesses as possible.

proactive release
21 February 2023

From: Augusta Buchanan
Sent: Thursday, 1 December 2022 3:52 pm
To: Rosa Bach; Alex Chippy Compton
Cc: Jane Wright
Subject: RE: Consultation lists for release on Sunday

Kia ora,

The contacts in red are already in Mailchimp just not in the selected groups.

I'm happy to draft the outlook emails and pop them in the Consults drafts folder to be scheduled.

The Other GP's email is sent by Jess so won't be sent till Monday morning if that's ok?

Ngā mihi

Augusta

Augusta Buchanan ([she/her](#)) | Team Assistant

Pharmac | Te Pātaka Whaioranga | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington
DDI: [REDACTED] | P: [REDACTED] | M: [REDACTED] | www.pharmac.govt.nz

Te Pātaka Whaioranga – Pharmac will be closed from Saturday 24 December 2022 to Tuesday 3 January 2023 inclusive.

From: Rosa Bach <[REDACTED]>
Sent: Thursday, 1 December 2022 2:59 pm
To: Alex Chippy Compton <[REDACTED]>; Augusta Buchanan <[REDACTED]>
Cc: Jane Wright <[REDACTED]>
Subject: RE: Consultation lists for release on Sunday

Hi both, just checking if you need my help with anything? I see the [REDACTED] are highlighted red; I can help to set up those emails to go on Mailchimp if needed? Otherwise, happy to be hands off, but on call if needed.

Ngā mihi,
Rosa

Rosa Bach | Communications Advisor, media and social media

From: Alex Chippy Compton <[REDACTED]>
Sent: Thursday, 1 December 2022 1:10 pm
To: Augusta Buchanan <[REDACTED]>
Cc: Rosa Bach <[REDACTED]>; Jane Wright <[REDACTED]>
Subject: RE: Consultation lists for release on Sunday

Thanks Augusta, have tidied and retained two emails that do appear in other Mailchimp groups (as we don't want to be sending to those whole groups). Is there a way to add the emails in the table to Mailchimp or should I set those up in outlook?

Also had a quick chat with Jane, could we tee up for 6:15 pm (rather than 6:10)?

URL below:

<https://pharmac.govt.nz/news-and-resources/consultations-and-decisions/2022-12-04-proposal-to-fund-lexacaftor-with-tezacaftor-and-ivacaftor-trikafta-for-people-with-cystic-fibrosis>

Ngā mihi

Chippy Compton | [she/her](#) | Therapeutic Group Manager

Te Pātaka Whaioranga | Pharmac | PO Box 10-254 | Level 9, 40 Mercer Street, Wellington
DDI: [REDACTED] | P: [REDACTED] | M: [REDACTED] | www.pharmac.govt.nz

From: Augusta Buchanan <[REDACTED]>
Sent: Thursday, 1 December 2022 10:52 am
To: Alex Chippy Compton <[REDACTED]>
Cc: Rosa Bach <[REDACTED]>; Jane Wright <[REDACTED]>
Subject: RE: Consultation lists for release on Sunday

Kia ora,

I have gone through and highlighted in green the additional contacts who are included in the Mailchimp send out and don't need to be sent an email on outlook too.

The contacts highlighted in red are in Mailchimp but in a group not selected for the send out. The group they are in is commented beside their email.

Ngā mihi

Augusta

Augusta Buchanan ([she/her](#)) | Team Assistant

Pharmac | Te Pātaka Whaioranga | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington
DDI: [REDACTED] | P: [REDACTED] | M: [REDACTED] | www.pharmac.govt.nz

Te Pātaka Whaioranga – Pharmac will be closed from Saturday 24 December 2022 to Tuesday 3 January 2023 inclusive.

From: Alex Chippy Compton <[REDACTED]>
Sent: Thursday, 1 December 2022 10:09 am
To: Augusta Buchanan <[REDACTED]>
Cc: Rosa Bach <[REDACTED]>; Jane Wright <[REDACTED]>
Subject: Consultation lists for release on Sunday

Kia ora,

Consultation lists finalised (attached). Please can these emails be set up to go out on Sunday evening, 6:10 pm (@Rosa Bach/@Jane Wright shout if you are not happy with a slightly delay on the mailchimp send and we can set up for 6 pm).

I understand Mailchimp emails can be set up to go automatically. However, Rosa also has access so we may be able to work something out if we're worried about technology not playing ball.

If some of these groups still need to go out via outlook, let me know and I can set them up from the consult inbox as I will be online on Sunday to send items out.

Email subject/text included in the attached doc, Liz should be able to provide the URL to hyperlink.

Chippy

Ngā mihi

Chippy Compton | [she/her](#) | Therapeutic Group Manager

Te Pātaka Whaioranga | Pharmac | PO Box 10-254 | Level 9, 40 Mercer Street, Wellington
DDI: [REDACTED] | P: [REDACTED] | M: [REDACTED] | www.pharmac.govt.nz

proactive release
21 February 2023

Pharmac Consultation Groups

Please highlight in **yellow** which groups you would like your consultation to be sent to below, any additional emails to be sent out please list separately on page 2.

<u>Below Therapeutic Group are sent via MailChimp:</u>
Alimentary Tract & Metabolism
Allergies
Blood & Blood Forming Organs
Cardiovascular System
Cardiovascular System – Renal
Colleges & Professional Societies
Consumer Group
Dermatological
Diabetes
Genito-Urinary System
Hormone Preparations
Immunisation
Immunology
Immunosuppressant
Infections
Infections – Antiretroviral
Musculoskeletal Anti- inflammatory Rheumatology
Musculoskeletal – Osteoporosis
Nephrology
Nervous System – Anaesthetics/Analgesics
Nervous System – Mental Health
Nervous System - Drug and Alcohol Dependency
Nervous System – Neurology
Oncology Agents (includes MoH Cancer Team, Medical Oncology Work Group, INCOM membership, Cancer Society, BCAC, Breast Cancer Foundation, and CANGO – please do not note these groups as additional groups/emails to be sent out)
Respiratory
Sensory organs
Special Foods
Tender
<u>Below groups are sent via Outlook:</u>
Other – GP's (Which is sent by an MD/ Medical Directorate TA)
Community Pharmacy (Sent via MailChimp)*
Suppliers A-Z (located in outlook address book)*
Internal (PHARMAC)*
DHB Chief Pharmacists (List received from EA to Medical Director) *
Wholesalers(located in outlook address book)*

****All consultation & notifications are to be sent to the following groups unless otherwise stated***

Additional Groups/emails to be sent out by TGMs/PTAC sec:

- PTAC – Toni to send
- Rare disorders advisory committee - TGM to send (Chippy to confirm who, likely Josh CL)

- Anti-infectives advisory committee – Ben to send
- Respiratory advisory committee – Chippy to send
- Trikafta for Kiwis – Chippy to send
- Ed Lee – Chippy to send
- CFNZ – Chippy to send
- CF treaters – Chippy to send

Additional emails to be sent out by Augusta (in table):

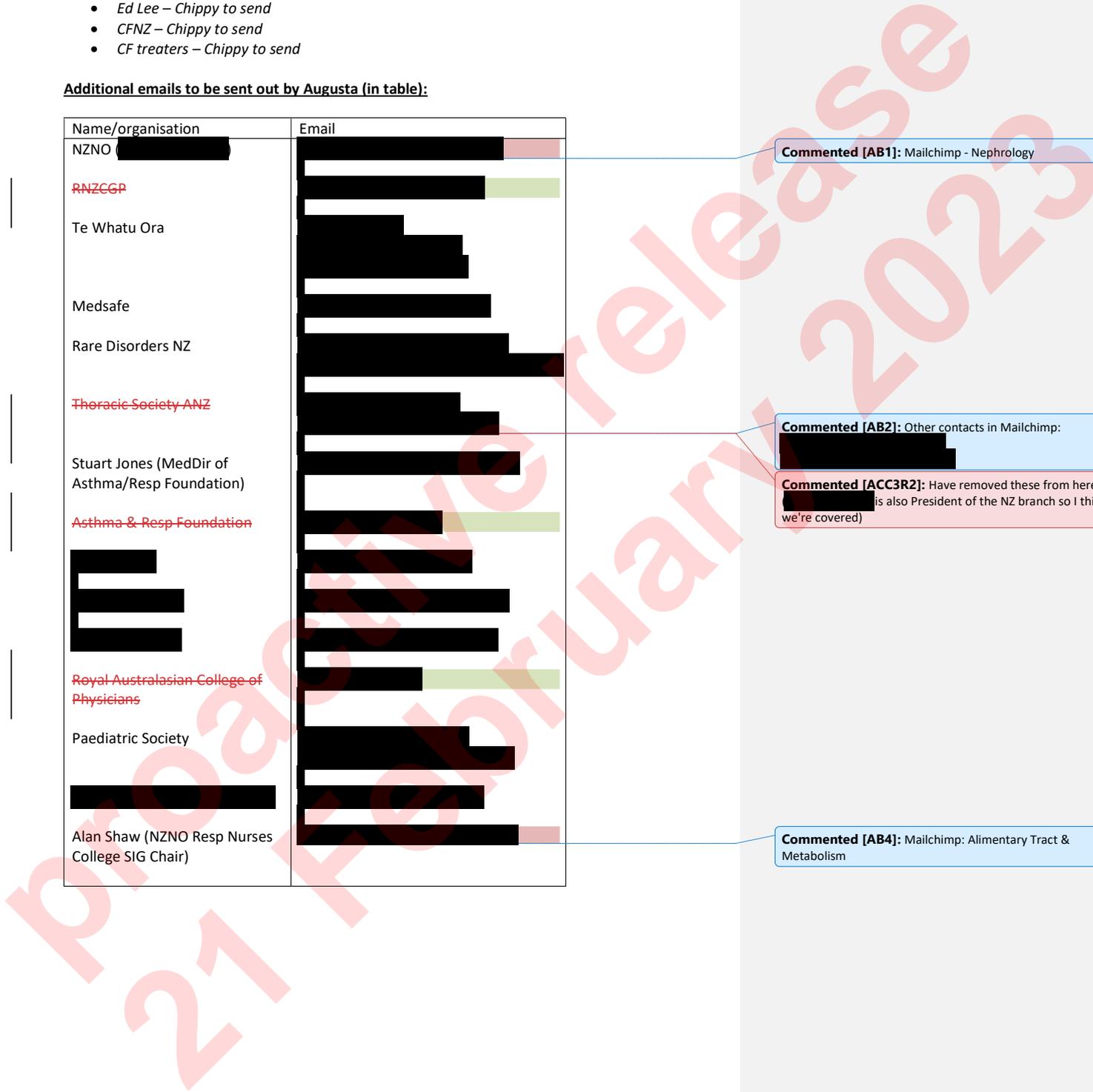
Name/organisation	Email
NZNO [REDACTED]	[REDACTED]
RNZCGP	[REDACTED]
Te Whatu Ora	[REDACTED]
Medsafe	[REDACTED]
Rare Disorders NZ	[REDACTED]
Thoracic Society ANZ	[REDACTED]
Stuart Jones (MedDir of Asthma/Resp Foundation)	[REDACTED]
Asthma & Resp Foundation	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
Royal Australasian College of Physicians	[REDACTED]
Paediatric Society	[REDACTED]
[REDACTED]	[REDACTED]
Alan Shaw (NZNO Resp Nurses College SIG Chair)	[REDACTED]

Commented [AB1]: Mailchimp - Nephrology

Commented [AB2]: Other contacts in Mailchimp:
[REDACTED]

Commented [ACC3R2]: Have removed these from here [REDACTED] is also President of the NZ branch so I think we're covered)

Commented [AB4]: Mailchimp: Alimentary Tract & Metabolism



Email to go out

Subject: Pharmac consultation – Proposal to fund Trikafta for people with cystic fibrosis aged 6 years and above

Kia ora,

We are pleased to announce that we are proposing to fund elexacaftor with tezacaftor and ivacaftor (brand name Trikafta) for people with cystic fibrosis aged 6 years and above who meet certain eligibility criteria.

Please follow [this link](#) to the consultation on our website. We welcome feedback on this proposal. To provide feedback, please submit it in writing by 5 pm, Monday 16 January 2023 to consult@pharmac.govt.nz.

Commented [ACC5]: Hyperlink from Kim/Liz

Please circulate this to others who may be interested.

Ngā mihi,

Alex Chippy Compton | Therapeutic Group Manager

Te Pātaka Whaioranga | Pharmac | PO Box 10-254 | Level 9, 40 Mercer Street, Wellington
www.pharmac.govt.nz

proactive release
21 February 2023

Key messages for Trikafta consultation

Main message

- We said we wanted to fund Trikafta – and we're a step closer now that we have reached an agreement with the supplier. We are proposing to fund Trikafta for people aged 6 years and above with cystic fibrosis who meet certain eligibility criteria.

Core message

- We have recommendations from both our Respiratory Advisory Committee and from the Pharmacology and Therapeutic Advisory Committee (PTAC) that the medicine should be funded for people 6 years and over. Our expert advisors have told us that treatment with Trikafta significantly improves lung function and other symptoms of cystic fibrosis.
- We estimate that Trikafta could give people with cystic fibrosis up to 27 more years at full health, when compared with supportive care. This would significantly reduce the impact of the condition on people with cystic fibrosis, their whānau and communities.
- We estimate there are around 340 people in New Zealand who would be eligible for funded treatment in the first full year of funding, under the proposed criteria.
- Funding would start 1 April 2023, if approved.
- We want to acknowledge the time that many people have put into advocating for those living with cystic fibrosis and to those who have shared their own very personal stories with us. We are thrilled to share the news that we are proposing to fund Trikafta.
- The consultation has been sent to health professionals, patient groups and others who we think would be interested. It is available on the Pharmac website for anyone wanting to have their say.
- Consultation is a very important step in our process. It's how we check that the people who will get the most benefit from the medicines will be able to access them.
- Following the budget increase, we are working our way through our options for investment list. Having already funded 12 new treatments and widened access to 17 medicines from our medicines budget since July 2022 (with hopefully more being added to the list next month), we are really pleased to be in a position to consider funding Trikafta too.

Media release

4 December 2022

Pharmac seeking feedback on funding Trikafta

Te Pātaka Whaioranga – Pharmac has reached a provisional agreement with medicine supplier Vertex to fund Trikafta.

“Following [our budget increase in May 2022](#) and commercial negotiations with the supplier, Vertex, I am thrilled to announce today that we are initiating consultation on the funding of Trikafta for people aged 6 years and above with cystic fibrosis who meet certain eligibility criteria,” says Pharmac’s director of operations Lisa Williams.

“Trikafta has the potential to make a substantial difference to the lives of those people in New Zealand living with cystic fibrosis and for their whānau and communities too. We estimate that, if funded, Trikafta could give people with cystic fibrosis up to 27 more years at full health, when compared with supportive care. This would significantly reduce the impact of the condition on people with cystic fibrosis, their whānau and communities.

“We have been actively working towards this step in the funding process since receiving recommendations from both our Respiratory Advisory Committee and from our Pharmacology and Therapeutics Advisory Committee (PTAC) that the medicine should be funded. Our expert advisors have told us that treatment with Trikafta significantly improves lung function and other symptoms of cystic fibrosis. The evidence is clear that Trikafta can benefit people with cystic fibrosis, so we are pleased to start consultation on a proposal to fund it.

“I want to acknowledge the time that many people have put into advocating for those living with cystic fibrosis and to those who have shared their own very personal stories with us. We have heard them all, and we know there will be a lot of people thrilled to hear that we are proposing to fund Trikafta.”

The consultation is available on the Pharmac website for anyone wanting to have their say.

“Consultation is a very important step in our process,” says Ms Williams. “It’s how we check that the people who will get the most benefit from the medicines will be able to access them. If approved, we will also be working closely with our colleagues across the health sector to plan for the implementation of Trikafta.”

“We have been saying that we wanted to fund Trikafta – and now we are a step closer,” says Ms Williams.

Funding of Trikafta is proposed to start 1 April 2023.

ENDS

We are welcoming feedback on the proposed funding of Trikafta until 16 January 2023. Please email media@pharmac.govt.nz or call 021863342 if you would like to know more.

From: Jane Wright
Sent: Thursday, 1 December 2022 4:27 pm
To: Sarah Fitt; Lisa Williams
Subject: Re: URGENT REQ T Fwd: Informing CFNZ

Thanks, will let vertex know

Get [Outlook for iOS](#)

From: Sarah Fitt <[REDACTED]>
Sent: Thursday, December 1, 2022 4:25:56 PM
To: Jane Wright <[REDACTED]>; Lisa Williams <[REDACTED]>
Subject: RE: URGENT REQ T Fwd: Informing CFNZ

No, they should hear it from us tomorrow as planned
Ngā mihi,

Sarah

Sarah Fitt | Chief Executive

PHARMAC | Te Pātaka Whaioranga | PO Box 10-254 | Level 9, 40 Mercer Street, Wellington
DDI: [REDACTED] | P: [REDACTED] | M: [REDACTED] | www.pharmac.govt.nz

From: Jane Wright <[REDACTED]>
Sent: Thursday, 1 December 2022 4:23 pm
To: Sarah Fitt <[REDACTED]>; Lisa Williams <[REDACTED]>
Subject: URGENT REQ T Fwd: Informing CFNZ

I said unlikely but I'm obliged to ask. I think she is right they wouldn't break embargo, but feels rushed. She has asked for an asap response.

Get [Outlook for iOS](#)

From: Rachael Bylykbashi <[REDACTED]>
Sent: Thursday, December 1, 2022 4:08:49 PM
To: Jane Wright <[REDACTED]>
Cc: Sabrina Barbic <[REDACTED]>
Subject: Informing CFNZ

Hi Jane

Thanks for your time just now.

As discussed, we would like to inform CFNZ today, out of respect, and to give them time to prepare their own communications. Otherwise they are going to have to be working all weekend to get themselves in order. They are very professional and I have every confidence that their CEO, Lisa Burns will not break any embargo.

Looking forward to hearing from you ASAP.

Kind regards

Rachael

Rachael Bylykbashi

Communications Director

Vertex Pharmaceuticals (ANZ) Pty Ltd

Level 3, Suite 3

601 Pacific Highway

St Leonards, NSW 2065

Australia

Mob: [REDACTED]

www.vrtx.com

We acknowledge the Cammeraygal people of the Eora Nation, the Traditional Custodians of the land on which we gather. We also acknowledge Traditional Owners of Country throughout Australia and to their continuing connection to land, sea and community. We pay respects to them and to their Elders past and present.

This email message and any attachments are confidential, may contain privileged information and are intended for use by the addressee(s) only. If you are not the intended recipient, please notify me immediately by replying to this message, and destroy all copies of this message and any attachments. Thank you.

This email message and any attachments are confidential and intended for use by the addressee(s) only. If you are not the intended recipient, please notify me immediately by replying to this message, and destroy all copies of this message and any attachments. Thank you.

From: Rachael Bylykbashi <[REDACTED]>
Sent: Thursday, 1 December 2022 5:43 pm
To: Jane Wright
Cc: Sabrina Barbic
Subject: RE: Informing CFNZ
Attachments: Vertex Pharmac Agreement Trikafta - DRAFT.pdf

Ok – thanks Jane.

Here is our release. It is still a draft but shouldn't change.

Are you able to send me your latest release as well?

And just confirming media strategy:

1. You've already briefed Paddy Gower and I can reach out to him and send him my release once approved.
2. You have also briefed Nicole Bremmer – health reporter from TV1.
3. You will also pre-brief Rachel Smalley, Megan Wilson and Rachel Thomas. I will also reach out to them on confirmation of briefing.
4. We will send an embargoed (to 6pm) release at 12 noon on Sunday to all remaining media.

Thanks in advance Jane. Let me know if you have any questions.

Kind regards

Rachael

From: Jane Wright <[REDACTED]>
Sent: Thursday, 1 December 2022 2:31 PM
To: Rachael Bylykbashi <[REDACTED]>
Cc: Sabrina Barbic <[REDACTED]>
Subject: RE: Informing CFNZ

CAUTION: This email originated from outside of Vertex. Do not open links or attachments unless you know the sender and believe it is safe. If you suspect that this email is a potentially malicious email, **please click on the Report Phish button.**

Kia ora Rachael,

I have checked with Sarah, but just wanted to let you know that we will be sticking to the 3pm zoom call tomorrow.

I still have not seen your PR, are you able to send it through?

Many thanks.

Ngā mihi

Jane Wright | Pharmac's Senior Communications Advisor, Media

From: Rachael Bylykbashi <[REDACTED]>
Sent: Thursday, 1 December 2022 4:09 pm
To: Jane Wright <[REDACTED]>
Cc: Sabrina Barbic <[REDACTED]>
Subject: Informing CFNZ
Importance: High

Hi Jane

Thanks for your time just now.

As discussed, we would like to inform CFNZ today, out of respect, and to give them time to prepare their own communications. Otherwise they are going to have to be working all weekend to get themselves in order. They are very professional and I have every confidence that their CEO, Lisa Burns will not break any embargo.

Looking forward to hearing from you ASAP.

Kind regards

Rachael

Rachael Bylykbashi
Communications Director
Vertex Pharmaceuticals (ANZ) Pty Ltd
Level 3, Suite 3
601 Pacific Highway
St Leonards, NSW 2065
Australia
Mob: [REDACTED]
www.vrtx.com

We acknowledge the Cammeraygal people of the Eora Nation, the Traditional Custodians of the land on which we gather. We also acknowledge Traditional Owners of Country throughout Australia and to their continuing connection to land, sea and community. We pay respects to them and to their Elders past and present.

This email message and any attachments are confidential, may contain privileged information and are intended for use by the addressee(s) only. If you are not the intended recipient, please notify me immediately by replying to this message, and destroy all copies of this message and any attachments. Thank you.

This email message and any attachments are confidential and intended for use by the addressee(s) only. If you are not the intended recipient, please notify me immediately by replying to this message, and destroy all copies of this message and any attachments. Thank you.

This e-mail message and any accompanying attachments may contain confidential information. If you are not the intended recipient, please do not read, use, disseminate, distribute or copy this message or attachments. If you have received this message in error, please notify the sender immediately and delete this message.

This email message and any attachments are confidential and intended for use by the addressee(s) only. If you are not the intended recipient, please notify me immediately by replying to this message, and destroy all copies of this message and any attachments. Thank you.

proactive release
21 February 2023

Vertex Announces Provisional Agreement with Pharmac for the reimbursement of TRIKAFTA® (elexacaftor/tezacaftor/ivacaftor and ivacaftor) for Patients With Cystic Fibrosis Ages 6 Years and Older With at Least One *F508del* Mutation in the *CFTR* Gene

– Under this agreement, more than 360 New Zealanders with cystic fibrosis will have funded access to Trikafta, including around 340 who will have reimbursed access to a CFTR modulator therapy for the first time –

Wellington – 4 November 2022 - Vertex Pharmaceuticals today announced that it has reached a provisional agreement with New Zealand’s medicines purchasing agency, Pharmac, for the reimbursement of TRIKAFTA® (elexacaftor/tezacaftor/ivacaftor and ivacaftor). Following a public consultation period, the agreement will cover eligible cystic fibrosis (CF) patients 6 years and older who have at least one *F508del* mutation in the *cystic fibrosis transmembrane conductance regulator (CFTR)* gene with access planned from 1 April 2023.

“Today’s announcement is a significant milestone in ensuring New Zealanders living with cystic fibrosis receive timely and sustainable access to Trikafta, including children as young as six,” said Sabrina Barbic, Senior Country Manager, Vertex Australia and New Zealand. “We are pleased that Pharmac has recognised that every eligible patient should have access and acknowledges the value Trikafta can bring, not only to people living with cystic fibrosis and their caregivers, but also the wider society.”

Pharmac will now seek public consultation on its proposal to fund Trikafta. We acknowledge this as an important step in the process and are hopeful that patients will have access to Trikafta as soon as possible.

On finalisation of the process, New Zealand will join more than thirty-five other countries - including Australia, Canada, Denmark, Finland, Spain, Germany, Austria, Slovenia, Croatia, France, Italy, and the United Kingdom - where Trikafta is broadly reimbursed for eligible CF patients.

Media Contact:

Rachael Bylykbashi
Vertex ANZ – Communications Director

M: [REDACTED]

E: [REDACTED]

Mark Blackham
Blacklands PR

M: [REDACTED]

E: [REDACTED]

About TRIKAFTA® (elexacaftor/tezacaftor/ivacaftor and ivacaftor)

In people with certain types of mutations in the CFTR gene, the CFTR protein is not processed or folded normally within the cell, and this can prevent the CFTR protein from reaching the cell surface and functioning properly. TRIKAFTA® (elexacaftor/tezacaftor/ivacaftor and ivacaftor) is an oral medicine designed to increase the quantity and function of the CFTR protein at the cell surface. Elexacaftor and tezacaftor work together to increase the amount of mature protein at the cell surface by binding to different sites on the CFTR protein. Ivacaftor, which is known as a CFTR potentiator, is designed to facilitate the ability of CFTR proteins to transport salt and water across the cell membrane. The combined actions of elexacaftor, tezacaftor and ivacaftor help hydrate and clear mucus from the airways.

About TRIKAFTA® (elexacaftor/tezacaftor/ivacaftor and ivacaftor) in New Zealand

TRIKAFTA® (elexacaftor/tezacaftor/ivacaftor and ivacaftor) is a prescription medicine approved for the treatment of cystic fibrosis (CF) in patients ages 6 years and older who have at least one copy of the *F508del* mutation in the *CFTR* gene. TRIKAFTA has risks and benefits. Use strictly as directed. TRIKAFTA is currently an unfunded medicine - a prescription charge will apply.

- Consumer Medicine information can be obtained from the Medsafe website www.medsafe.govt.nz
- Prescribing Information (TRIKAFTA New Zealand Data Sheet) for healthcare professionals can be obtained from the Medsafe website www.medsafe.govt.nz

About Cystic Fibrosis

Cystic fibrosis (CF) is a rare, life-shortening genetic disease affecting more than 80,000 people globally. CF is a progressive, multi-system disease that affects the lungs, liver, GI tract, sinuses, sweat glands, pancreas and reproductive tract. CF is caused by a defective and/or missing CFTR protein resulting from certain mutations in the *CFTR* gene. Children must inherit two defective *CFTR* genes — one from each parent — to have CF. While there are many different types of *CFTR* mutations that can cause the disease, the vast majority of all people with CF have at least one *F508del* mutation. These mutations, which can be determined by a genetic test, or genotyping test, lead to CF by creating non-working and/or too few CFTR proteins at the cell surface. The defective function and/or absence of CFTR protein results in poor flow of salt and water into and out of the cells in a number of organs. In the lungs, this leads to the buildup of abnormally thick, sticky mucus that can cause chronic lung infections and progressive lung damage in many patients that eventually leads to death. The median age of death is in the early 30s.

About Vertex

Vertex is a global biotechnology company that invests in scientific innovation to create transformative medicines for people with serious diseases. The company has multiple approved medicines that treat the underlying cause of cystic fibrosis (CF) — a rare, life-threatening genetic disease — and has several ongoing clinical and research programs in CF. Beyond CF, Vertex has a robust pipeline of investigational small molecule, cell and genetic therapies in other serious diseases where it has deep insight into causal human biology, including sickle cell disease, beta thalassemia, APOL1-mediated kidney disease, pain, type 1 diabetes, alpha-1 antitrypsin deficiency and Duchenne muscular dystrophy.

Founded in 1989 in Cambridge, Mass., Vertex's global headquarters is now located in Boston's Innovation District and its international headquarters is in London. Additionally, the company has research and development sites and commercial offices in North America, Europe, Australia and Latin America. Vertex is consistently recognized as one of the industry's top places to work, including 13 consecutive years on Science magazine's Top Employers list and one of Fortune's Best Workplaces in Biotechnology and Pharmaceuticals and Best Workplaces for Women.

From: Sabrina Barbic <[REDACTED]>
Sent: Thursday, 1 December 2022 10:02 pm
To: Sarah Fitt
Subject: RE: Thanks

Categories: To file

Hi Sarah again, I understand that your comms person has already discussed with journalists ahead of 3pm tomorrow. There could be something there in the discussion with Paddy. Again, we take your lead, fully respect and aligned with your plans

Sabrina

From: Sabrina Barbic
Sent: Thursday, 1 December 2022 19:49
To: 'Sarah Fitt' <[REDACTED]>
Subject: RE: Thanks

Hi Sarah,

Sorry to hear that. We have engaged with no one, we are fully taking your lead on this. I did reach out to Lisa today to ask if there was a willingness to bring that forward but totally and fully respect your plans

Happy to talk in the morning
Sabrina

From: Sarah Fitt <[REDACTED]>
Sent: Thursday, 1 December 2022 19:33
To: Sabrina Barbic <[REDACTED]>
Subject: Re: Thanks

CAUTION: This email originated from outside of Vertex. Do not open links or attachments unless you know the sender and believe it is safe. If you suspect that this email is a potentially malicious email, **please click on the Report Phish button.**

Sabrina

Just wanted to drop you a line to let you know a journalist here, Rachael Smalley, has tweeted tonight suggesting she knows that we have reached an agreement. Not sure how she would know but I am concerned about this as we have a clear Comms plan lined up involving our Minister, of Health ,PM etc
We plan to speak to CFNZ tomorrow at 3pm with a media release planned for Sunday evening at 6pm.
Happy to chat tonight or tomorrow morning.

Sarah
Sarah Fitt
Chief Executive
PHARMAC

From: Sabrina Barbic <[REDACTED]>
Sent: Thursday, December 1, 2022 12:57:58 PM
To: Sarah Fitt <[REDACTED]>
Subject: RE: Thanks

Hi Sarah,

I was about to email you ! I too am thankful for the position we are in and to be a step closer in serving our patients in this CF community.

The teams have worked very well together and I look forward to work continuously with you and team through implementation.

Thanks to you, Lisa, Chippy and Logan!

All the best
Sabrina

From: Sarah Fitt <[REDACTED]>
Sent: Thursday, 1 December 2022 10:54
To: Sabrina Barbic <[REDACTED]>
Subject: Thanks

CAUTION: This email originated from outside of Vertex. Do not open links or attachments unless you know the sender and believe it is safe. If you suspect that this email is a potentially malicious email, **please click on the Report Phish button.**

Hi Sabrina

Just wanted to say thanks to you and your team for all their hard work to get us to this point with the agreement, it's very much appreciated.

We look forward to continuing to work with you and the team through the next phase of consultation and hopefully, implementation next year.

Ngā mihi,

Sarah

Sarah Fitt | Chief Executive

PHARMAC | Te Pātaka Whaioranga | PO Box 10-254 | Level 9, 40 Mercer Street, Wellington
DDI: [REDACTED] | P: [REDACTED] | M: [REDACTED] | www.pharmac.govt.nz

This e-mail message and any accompanying attachments may contain confidential information. If you are not the intended recipient, please do not read, use, disseminate, distribute or copy this message or attachments. If you have received this message in error, please notify the sender immediately and delete this message.

This email message and any attachments are confidential and intended for use by the addressee(s) only. If you are not the intended recipient, please notify me immediately by replying to this message, and destroy all copies of this message and any attachments. Thank you.

This e-mail message and any accompanying attachments may contain confidential information. If you are not the intended recipient, please do not read, use, disseminate, distribute or copy this message or attachments. If you have received this message in error, please notify the sender immediately and delete this message.

This email message and any attachments are confidential and intended for use by the addressee(s) only. If you are not the intended recipient, please notify me immediately by replying to this message, and destroy all copies of this message and any attachments. Thank you.

proactive release
21 February 2023

From: Allannah Andrews
Sent: Thursday, 1 December 2022 10:53 am
To: Senior Leadership Team
Cc: Alex Chippy Compton; Geraldine MacGibbon; Jane Wright; Rosa Bach
Subject: FW: No Surprises update - Trikafta consultation
Attachments: 2022-12-04 trikafta consult media release.docx

FYI

From: Allannah Andrews
Sent: Thursday, 1 December 2022 10:50 am
To: [REDACTED]
Cc: Adelia Hallett <[REDACTED]>; Talisa Kupenga <[REDACTED]>;
[REDACTED]; Allison Bennett <[REDACTED]>;
Therese Egan <[REDACTED]>; Carol Morris <[REDACTED]>
Subject: No Surprises update - Trikafta consultation

Kia ora Anna,

This is a no surprises update for Minister Little.

On Sunday 4 December at 6pm, Pharmac is putting out a consultation seeking feedback on a proposal to fund elexacaftor with tezacaftor and ivacaftor (brand name Trikafta) for people aged 6 years and above with cystic fibrosis who meet certain criteria, from 1 April 2023 (subject to Board approval of the proposal).

Pharmac intends to put out a media release (attached to this email) to support this consultation and will share it through our social media channels. Lisa Williams, Director of Operations, will be our spokesperson and be available for media interviews.

To maximise positive, detailed, people-focused coverage of this news, we intend to share it, embargoed, with Paddy Gower (Newshub) as he has covered Trikafta since before an application was even made to Pharmac. As late as yesterday, he was sharing social media posts, asking for Trikafta to be funded.

On Friday 2 December, we will share the consultation and media release, in confidence, with Cystic Fibrosis New Zealand's CE Lisa Burns, as we know they will be approached for comment on the consultation by media. Pharmac staff will also contact the other cystic fibrosis advocates – Trikafta for Kiwis, Ed Lee and Rare Disorders NZ to share the consultation and media release, in confidence.

We will share it more widely with the media and other key stakeholders on Sunday 4 December at midday, embargoed for 6pm that night.

If you require further information about this consultation, please let me know.

Ngā mihi, nā

Allannah Andrews ([she/her](#)) | Manager, Policy and Government Services

P: [REDACTED] | M: [REDACTED] | www.pharmac.govt.nz

Te Pātaka Whaioranga | Pharmac | PO Box 10-254, Wellington 6140 | Level 9, 40 Mercer Street, Wellington 6011

PHARMAC
TE PĀTAKA WHAIORANGA

Te Pātaka Whaioranga – Pharmac will be closed from Saturday 24 December 2022 to Tuesday 3 January 2023 inclusive.

From: Allanah Andrews
Sent: Friday, 2 December 2022 11:31 am
To: Jane Wright
Subject: RE: Urgent for checking

We just ignoring the apostrophe in 'welcomes'?!

From: Jane Wright <[REDACTED]>
Sent: Friday, 2 December 2022 11:28 am
To: Geraldine MacGibbon <[REDACTED]>
Cc: Allanah Andrews <[REDACTED]>
Subject: Urgent for checking

Hey can you check this for me? It looks fine to me, it is just the numbers at the end I want double checked against your numbers. They are basing this on the 2017 numbers we gave them and then added the additional ones since the 25 October.....so I am sure it is fine

Ngā mihi

Jane Wright | Pharmac's Senior Communications Advisor, Media

Pharmac | Te Pātaka Whaioranga | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington
M: [REDACTED] www.pharmac.govt.nz

From: Nicole Salmon <[REDACTED]>
Sent: Friday, 2 December 2022 11:02 am
To: Jane Wright <[REDACTED]>
Subject: RE: No Surprises update - Trikafta consultation

Thanks Jane. This is our current draft. It is currently with SMEsinput/feedback and then will go through sign off.

Give me a call if you'd like to discuss

Ngā mihi

Nicole Salmon (she/her)
Manager External Communications and Engagement
Government and Executive Services

I do not check my emails regularly after 3pm

[REDACTED]
Manatū Hauora, 133 Molesworth Street
Thorndon, Wellington 6011

From: Jane Wright
Sent: Friday, 2 December 2022 12:08 pm
To: Geraldine MacGibbon
Subject: RE: Urgent for checking
Attachments: 2022-12-04 trikafta consult media release.obr; 2022-11-29 Trikafta consultation communications approach.obr

It was in the plan 😊 here it is! And the PR

Ngā mihi

Jane Wright | Pharmac's Senior Communications Advisor, Media

Pharmac | Te Pātaka Whaioranga | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington
M: [REDACTED] www.pharmac.govt.nz

From: Geraldine MacGibbon <[REDACTED]>
Sent: Friday, 2 December 2022 12:06 pm
To: Jane Wright <[REDACTED]>
Subject: RE: Urgent for checking

Me personally? I wasn't aware of that. Am I doing anything else? Maybe I better see the plan again, and our key messages

From: Jane Wright <[REDACTED]>
Sent: Friday, 2 December 2022 12:03 pm
To: Geraldine MacGibbon <[REDACTED]>
Subject: RE: Urgent for checking

ALSO, a reminder that you are telling RDNZ about Trikafta. You can do this anytime from 3pm today, but impt to remind them that it is embargoed to Sunday at 6pm.

Thanks!

Ngā mihi

Jane Wright | Pharmac's Senior Communications Advisor, Media

Pharmac | Te Pātaka Whaioranga | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington
M: [REDACTED] www.pharmac.govt.nz

From: Geraldine MacGibbon <[REDACTED]>
Sent: Friday, 2 December 2022 11:45 am

To: Jane Wright <[REDACTED]>
Cc: Allanah Andrews <[REDACTED]>
Subject: RE: Urgent for checking

Hi Jane which numbers are you asking about? There are a lot of numbers in that document

From: Jane Wright <[REDACTED]>
Sent: Friday, 2 December 2022 11:28 am
To: Geraldine MacGibbon <[REDACTED]>
Cc: Allanah Andrews <[REDACTED]>
Subject: Urgent for checking

Hey can you check this for me? It looks fine to me, it is just the numbers at the end I want double checked against your numbers. They are basing this on the 2017 numbers we gave them and then added the additional ones since the 25 October.....so I am sure it is fine

Ngā mihi

Jane Wright | Pharmac's Senior Communications Advisor, Media

Pharmac | Te Pātaka Whaioranga | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington
M: [REDACTED] www.pharmac.govt.nz

From: Nicole Salmon <[REDACTED]>
Sent: Friday, 2 December 2022 11:02 am
To: Jane Wright <[REDACTED]>
Subject: RE: No Surprises update - Trikafta consultation

Thanks Jane. This is our current draft. It is currently with SMEs input/feedback and then will go through sign off.

Give me a call if you'd like to discuss

Ngā mihi

Nicole Salmon (she/her)
Manager External Communications and Engagement
Government and Executive Services

I do not check my emails regularly after 3pm

[REDACTED]
Manatū Hauora, 133 Molesworth Street
Thorndon, Wellington 6011



From: Jane Wright
Sent: Friday, 2 December 2022 12:17 pm
To: Kirsty Doig
Subject: RE: No Surprises update - Trikafta consultation

Yes 😊

Ngā mihi

Jane Wright | Pharmac's Senior Communications Advisor, Media

Pharmac | Te Pātaka Whaioranga | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington
M: [REDACTED] www.pharmac.govt.nz

From: Kirsty Doig <[REDACTED]>
Sent: Friday, 2 December 2022 12:15 pm
To: Jane Wright <[REDACTED]>
Subject: RE: No Surprises update - Trikafta consultation

You don't often get email from [REDACTED] [Learn why this is important](#)

Thanks Jane, dumb question but just want to triple check, so that takes the overall number of extra funding decisions to 201?

From: Jane Wright <[REDACTED]>
Sent: Friday, 2 December 2022 12:10 pm
To: Kirsty Doig <[REDACTED]>
Cc: Nicole Salmon <[REDACTED]>
Subject: RE: No Surprises update - Trikafta consultation

Hello 😊 totals from 17/18 to date are 68 new listings and 133 widened access
For this year so far with \$191M uplift its 12 new and 17 widened

Ngā mihi

Jane Wright | Pharmac's Senior Communications Advisor, Media

Pharmac | Te Pātaka Whaioranga | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington
M: [REDACTED] www.pharmac.govt.nz

From: Kirsty Doig <[REDACTED]>
Sent: Friday, 2 December 2022 12:08 pm
To: Jane Wright <[REDACTED]>

Cc: Nicole Salmon <[REDACTED]>
Subject: FW: No Surprises update - Trikafta consultation

You don't often get email from [REDACTED] [Learn why this is important](#)

Kia ora Jane

Nicole passed this on to me. Can I just check that it's from 2017 & also has the overall funding decisions number gone up too?

The Government's funding boost since 2017 has allowed Pharmac to make an extra 189 funding decisions, including 68 new listings and the widening of access to 133 treatments, with more to come.

Thanks, Kirsty

Kirsty Doig

Principal Advisor | External Communications & Engagement
Government & Executive Services |
Te Pou Whakatere Kāwanatanga

[REDACTED]
Manatū Hauora, 133 Molesworth Street
Thorndon, Wellington 6011



From: Nicole Salmon <[REDACTED]>
Sent: Friday, 2 December 2022 12:01 pm
To: Kirsty Doig <[REDACTED]>
Subject: FW: No Surprises update - Trikafta consultation

From: Jane Wright <[REDACTED]>
Sent: Friday, 2 December 2022 12:00 pm
To: Nicole Salmon <[REDACTED]>
Subject: RE: No Surprises update - Trikafta consultation

So totals from 17/18 to date are 68 new listings and 133 widened access
For this year so far with \$191M uplift its 12 new and 17 widened

Ngā mihi

Jane Wright | Pharmac's Senior Communications Advisor, Media

Pharmac | Te Pātaka Whaioranga | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington
M: [REDACTED] www.pharmac.govt.nz

From: Jane Wright
Sent: Friday, 2 December 2022 11:54 am
To: Nicole Salmon <[REDACTED]>
Subject: RE: No Surprises update - Trikafta consultation

All looking good – the figures at the end have gone up – working through that!

The Government’s funding boost since 2017 has allowed Pharmac to make an extra 189 funding decisions, including 68 new listings and the widening of access to 133 treatments, with more to come.

I think we are at 200 now.... But will come back to you

Ngā mihi

Jane Wright | Pharmac’s Senior Communications Advisor, Media

Pharmac | Te Pātaka Whaioranga | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington
M: [REDACTED] www.pharmac.govt.nz

From: Nicole Salmon <[REDACTED]>
Sent: Friday, 2 December 2022 11:02 am
To: Jane Wright <[REDACTED]>
Subject: RE: No Surprises update - Trikafta consultation

Thanks Jane. This is our current draft. It is currently with SMEs input/feedback and then will go through sign off.

Give me a call if you’d like to discuss

Ngā mihi

Nicole Salmon (she/her)
Manager External Communications and Engagement
Government and Executive Services

I do not check my emails regularly after 3pm

[REDACTED]
Manatū Hauora, 133 Molesworth Street
Thorndon, Wellington 6011



Government welcome's decision to consult on cystic fibrosis medicine

XX welcomes the decision by Pharmac, the independent Government medicines funding agency, to consult on the funding of Trikafta for people with cystic fibrosis.

“Trikafta could make a significant difference to the lives of people with cystic fibrosis as well as their whānau. Pharmac estimates Trikafta could give people with cystic fibrosis up to 27 more years at full health, that’s a considerable outcome,” xx said.

“Many New Zealanders have advocated for the funding of Trikafta, I acknowledge their contribution in helping to make this happen.

“This latest decision is the result of the Government’s increase in Pharmac’s funding. In 2020, we said it would increase Pharmac’s budget by \$200 million. On top of that, we’ve put in \$71 million this year, and another \$120 million boost is in the pipeline for next year.

“This means better access to medicines and treatments for New Zealanders, helping people to lead healthier lives.”

The consultation announced today is the next step in the process. Funding of Trikafta is proposed to start 1 April 2023. Pharmac has reached a provisional agreement with medicine supplier Vertex to fund Trikafta for those aged 6 years and above with cystic fibrosis who meet the eligibility criteria.

Pharmac says the evidence shows treatment with Trikafta significantly improves lung function and other symptoms of cystic fibrosis. Trikafta, a tablet taken twice a day, is a combination of elexacaftor, tezacaftor and ivacaftor.

The Government’s funding boost has allowed Pharmac to make an extra 189 funding decisions, including 59 new listings and the widening of access to 130 treatments, with more to come.