
From: Jane Wright <[REDACTED]>
Sent: Thursday, 1 December 2022 11:45 am
To: Nicole Salmon <[REDACTED]>
Subject: FW: No Surprises update - Trikafta consultation

Kia ora Nicole,

In confidence, this is the background info on the now planned for Sunday at 6pm announcement. Happy to discuss and to support the drafting of a PR and messages.

Jane

From: Allanah 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

Allanah 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.

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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 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.

Did the minister give you extra money for Trikafta?

Smile coyly ...You know I can't get into budget discussions with you. You will need to talk with Minister Little.

Politicians don't make decisions on what we fund. 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 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.

Subject: Paddy Gower - IV on Trikafta
Location: Room - Hedley - Seats 9 - Lvl 9

Start: Fri 2/12/2022 9:00 am
End: Fri 2/12/2022 10:00 am
Show Time As: Tentative

Recurrence: (none)

Organizer: Jane Wright
Required Attendees: Lisa Williams
Resources: Room - Hedley - Seats 9 - Lvl 9

proactive release
21 February 2023

From: Jane Wright
Sent: Friday, 2 December 2022 11:12 am
To: Rachael Bylykbashi
Subject: Final PR

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: Friday, 2 December 2022 11:22 am
To: Jane Wright
Subject: RE: Final PR

Thanks Jane

From: Jane Wright <[REDACTED]>
Sent: Friday, 2 December 2022 9:12 AM
To: Rachael Bylykbashi <[REDACTED]>
Subject: Final PR

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.**

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- <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>

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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: Alex Chippy Compton
Sent: Friday, 2 December 2022 4:12 pm
To: Carmen Shanks
Cc: Logan Heyes
Subject: Confidential - consultation and media release
Attachments: Confidential - Proposal to fund elexacaftor with tezacaftor and ivacaftor (Trikafta) for people with cystic fibrosis.pdf; Confidential - Trikafta Consultation media release.pdf

Kia ora Carmen,

Thanks for your time on the phone.

Please find attached a confidential copy of consultation for a proposal 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, and our accompanying media release. As discussed, this is confidential until public release at 6 pm Sunday 4 December.

From 6 pm Sunday, the consultation will be available on the Pharmac website via [this link](#). We would welcome you sharing this link with others after public release of the consultation.

Feedback can be sent to consult@pharmac.govt.nz. All feedback received by 5 pm, Monday 16 January 2023 will be considered by Pharmac's Board prior to a decision being made.

Ngā mihi,
Chippy

Ngā mihi

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

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

Communications plan

Project	Trikafta consultation
Date most recently updated	28 November 2022
Communications lead	Jane Wright
Spokesperson	Lisa Williams
Reviewers	Chippy Compton, Logan Heyes, Geraldine MacGibbon
Final sign off	Lisa Williams

Commented [ACC1]: Jane as discussed, made some tweaks since this was approved following discussions with relevant TGMs

Background

Pharmac is proposing to fund elexacaftor with tezacaftor and ivacaftor (brand name Trikafta) for people aged 6 years and above with cystic fibrosis who meet the eligibility criteria. The consultation is being planned for Sunday 4 December 2022.

Advocates have been calling for Trikafta to be funded before we even had an application and have openly criticised Pharmac for not making a funding decision. Many media outlets have covered Trikafta, and much of this coverage has been very negatively slanted against Pharmac, with strong implication of a lack of caring on Pharmac's behalf, and a lack of fairness in the system for those with cystic fibrosis and their whānau.

Due to the wide interest in this funding application, we have shared every milestone along the way:

- <https://pharmac.govt.nz/news-and-resources/news/2022-08-15-media-release-pharmac-shares-update-on-its-assessment-of-trikafta/?page=2>
- <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/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/2021-07-09-media-release-application-for-cystic-fibrosis-medicine-received-by-pharmac/?page=8>
- <https://pharmac.govt.nz/news-and-resources/news/cystic-fibrosis-medicine-applications-to-be-considered-by-pharmac-and-medsafe-in-parallel/?page=9>

A year and a half after receiving its application, it is only fitting that we share this milestone too.

Communications approach

The communications team are responsible for internal communication, updating the website, social media and media, as well as advising the Ministry of Health's media team and the Minister of Health's office of the decision. The therapeutic group managers will be responsible for identifying which stakeholders need to be advised, and when, as well as communicating that to them.

Now that the Trikafta consultation is being put out, we have a strong opportunity to reset the discussion around our Pharmac model, gain favourable media coverage around this issue, and gain ground in the discussion around whether Pharmac is equitable/fair. An announcement that progress is being made on Trikafta will be important and meaningful.

We intend the consultation to go out on Sunday 4 December at 6pm.

Wider health sector

Prior to any public communications being issued we will share what we are communicating with the Pharmac Board, the Ministry of Health, Te Whatu Ora, and the Minister's office.

Supplier

We will work with the supplier of Trikafta, Vertex, to align timings and messages.

Stakeholders

There are a few groups/individuals who we know will be particularly interested in this, and who are likely to be contacted by media for interviews.

On Friday 2 December we will share the consultation and media release, in confidence, with the following people:

- Lisa Burns, Cystic Fibrosis New Zealand
- Carmen Shanks and Eddie Porter, Trikafta for Kiwis
- Ed Lee
- Michelle Arrowsmith and Kim McGuinness, Rare Disorders NZ

Also on Friday 2 December we will send an email to other stakeholders (listed below) advising that an update will be being shared on Sunday midday, which will be in confidence until 6pm.

Media

To maximise positive, detailed, people-focused coverage of this news, we intend to share it on the morning of Thursday 1 December with Paddy Gower (Newshub), provided a signed provisional agreement has been received from the supplier by this time. Paddy Gower has covered Trikafta since before an application was even made to Pharmac. He will be given a Sunday 4 December at 6pm embargo for publicly sharing it, but able to talk with the above mentioned stakeholders from Friday 2 December from 3pm.

We will also share it at the same time with Nicole Bremner (TVNZ), Rachel Thomas (Stuff) and Megan Wilson (NZME).

We will share it more widely with (our mailchimp) media on Sunday 4 December at midday, embargoed until 6pm.

When the embargo lifts, we will update our website with the consultation and media release and share both on Facebook, after sending out the mailchimp emails to all relevant consultation groups.

Lisa Williams will be our spokesperson and will be available for pre-records Sunday afternoon and for live interviews Monday 5 December.

Pharmac staff

There will be a lot of interest in this consultation from staff. We will share an update at Board Debrief on Friday 2 December.

Communications cascade

Audience	Distribution channel	Person who sends/does
Communication cascade for Wednesday 30 November		
Minister of Health, Associate Minister and Prime Minister's offices	No Surprises, which will include the communications approach and the media release.	Jane and Allannah
Ministry of Health		
Board		
Billy Allan, Te Whatu Ora Pharmacy Manager		
Nicole Salmon, Manager External Communications and Engagement, MoH		
Communication cascade for Thursday 1 December		
Paddy Gower (Newshub)	Phone call, followed by emailed media release and consult	Jane
Nicole Bremner (TVNZ)		
Rachel Thomas (Stuff)		
Megan Wilson (NZME)		

Communication cascade for Friday 2 December		
Lisa Burns, CE CFNZ	Video call, followed by emailed media release and consult	Sarah, with Chippy, Logan, and Jane
Ed Lee		
Rare Disorders NZ	Phone call, followed by emailed media release and consult	Geri
Pharmac staff	Update, following the Board Debrief	Chippy
CF Treaters (Mark O'Carroll, Cass Byrnes, Richard Laing)	Emailed advanced warning of an update on Sunday	Chippy
Respiratory Advisory Committee		Chippy
Anti-infectives Advisory Committee		Ben
Rare Disorders Advisory Committee		Josh C-L
PTAC		Toni
CAC		Mako
Te Ropu		Trevor
Te Whatu Ora, the Māori Health Authority and the Ministry of Health media teams		Jane
Communication cascade for Sunday 4 December at midday		
Pharmac staff	Te Pātaka message from Sarah, to include our media release	Jane and Cam
CF Treaters	Email with media release, embargoed until 6pm	Chippy
Respiratory Advisory Committee		Chippy
Anti-infectives Advisory Committee		Ben
Rare Disorders Advisory Committee		Chippy
PTAC		Toni
CAC		Mako

Commented [ACC2]: Assuming this call is also being made by the people below.

Friday 2 December is board day so will Lisa be available? If not, would Lisa be comfortable with the calls happening in her absence?

Commented [JW3R2]: Lisa your call. Could we do in a break with you? Or are you happy for Logan to lead? Or bring in Geri?

Commented [LW4R2]: I don't actually know Lisa B, so if someone else knows her it might be better for them to tell her. I'm happy for Chippy/Logan to make the call

Commented [JW5R2]: Sarah has asked if she can make the call

Commented [ACC6]: Moved as will no longer be phoned - instead given a heads up

Te Ropu		Trevor
Te Whatu Ora, the Māori Health Authority and the Ministry of Health media teams		Jane
Communication cascade for Sunday 4 December at 6pm		
Base content for all	https://www.pharmac.govt.nz/news/consultations https://pharmac.govt.nz/news-and-resources/news/	Liz
Media release to all	Via Mailchimp	Rosa (pre-loaded Friday)
Consultation lists (as advised by TGMs)		Augusta (pre-loaded Friday)
Hospital Pharmacists DHB GMs P&F, COOs & Pharmacy Portfolio Managers	Ask TAS to circulate	Rosh (pre-loaded Friday)
General public	Facebook	Rosa
Communication cascade for Monday 5 December		
Everyone who has contacted us previously via enquiries/OIA	Via email	EJ and Melody
CMOs	Via email	Trish
Community Pharmacists	Mailchimp community pharmacy audience list. (740) Mostly pharmacy owners.	Liz to send email

From: Alex Chippy Compton
Sent: Friday, 2 December 2022 4:43 pm
To: Mark O'Carroll
Cc: Logan Heyes
Subject: Upcoming Pharmac consultation

Kia ora koutou,

I wanted to let you know that this Sunday (4 December, 6 pm) Pharmac will be releasing public consultation on a funding proposal which we think will be of interest to you. I will email a confidential copy of this consultation to you on Sunday at midday ahead of public release.

Best Wishes,
Chippy

Ngā mihi

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

Te Pātaka Whaioranga | Pharmac | PO Box 10-254 | Level 9, 40 Mercer Street, Wellington
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From: Alex Chippy Compton
Sent: Sunday, 4 December 2022 11:46 am
To: Cass Byrnes
Cc: Logan Heyes
Subject: RE: Upcoming Pharmac consultation
Attachments: Confidential - Proposal to fund elexacaftor with tezacaftor and ivacaftor (Trikafta) for people with cystic fibrosis.pdf

Kia ora,

Later today, we will be releasing consultation on a proposal 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 find attached a confidential copy of our consultation. This is **confidential until public release at 6 pm** this evening (Sunday).

From 6 pm, the consultation will be available on the Pharmac website via [this link](#). Following public release, you are welcome to share the link with others who may be interested.

We welcome your feedback on this proposal. To provide feedback, please submit it in writing by 5 pm, Monday 16 January 2023 to consult@pharmac.govt.nz.

Thanks for your advice on and advocacy for this funding proposal. Please let me know if you have any questions.

Ngā mihi,
Chippy

Ngā mihi

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

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

proactive release
21 February 2023

From: Alex Chippy Compton
Sent: Sunday, 4 December 2022 12:04 pm
To: Carlo Marra; Carlo Marra Private; Emma Glamuzina; Humphrey Pullon; James Cleland; Janice Fletcher; Katherine Neas; Tim Stokes; William Wong (home)
Cc: Joshua Cronin-Lampe; Hanna Aulia; Ptac
Subject: RE: Pharmac consultation: advanced notice
Attachments: Confidential - Proposal to fund elexacaftor with tezacaftor and ivacaftor (Trikafta) for people with cystic fibrosis.pdf

Kia ora koutou,

Later today, we will be releasing consultation on a proposal 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 find attached a confidential copy of our consultation. This is **confidential until public release at 6 pm** this evening (Sunday).

From 6 pm, the consultation will be available on the Pharmac website via [this link](#). Following public release, you are welcome to share the link with others who may be interested.

We welcome your feedback on this proposal. To provide feedback, please submit it in writing by 5 pm, Monday 16 January 2023 to consult@pharmac.govt.nz.

Please let me know if you have any questions.

Ngā mihi,
Chippy

Ngā mihi

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

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

From: Joshua Cronin-Lampe <[REDACTED]>
Sent: Friday, 2 December 2022 3:25 pm
To: Carlo Marra <[REDACTED]>; Carlo Marra Private <[REDACTED]>; Emma Glamuzina <[REDACTED]>; Hanna Aulia <[REDACTED]>; Humphrey Pullon <[REDACTED]>; James Cleland <[REDACTED]>; Janice Fletcher <[REDACTED]>; Katherine Neas <[REDACTED]>; Ptac <[REDACTED]>; Tim Stokes <[REDACTED]>; William Wong (home) <[REDACTED]>
Cc: Alex Chippy Compton <[REDACTED]>
Subject: Pharmac consultation: advanced notice

Kia ora Rare Disorders Advisory Committee,

I'm emailing to let you know that this Sunday (4 December) at 6 pm Pharmac will be releasing a public consultation for a funding proposal which we think will be of interest to you.

My colleague Chippy (copied in) will email a confidential copy of this consultation to you on Sunday at midday. This will be **confidential** until public release.

Ngā mihi nui,
Josh Cronin-Lampe | Therapeutic Group Manager

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

PHARMAC
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proactive release
21 February 2023

From: Alex Chippy Compton
Sent: Sunday, 4 December 2022 12:04 pm
To: David McNamara; Dr Neil Whittaker; Greg Frazer; Ian Shaw; Justin Travers; Stuart Dalziel; Tim Christmas; Matthew Strother
Cc: Logan Heyes
Subject: RE: Pharmac consultation - advanced notice
Attachments: Confidential - Proposal to fund elexacaftor with tezacaftor and ivacaftor (Trikafta) for people with cystic fibrosis.pdf

Kia ora koutou,

Later today, we will be releasing consultation on a proposal 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 find attached a confidential copy of our consultation. This is **confidential until public release at 6 pm** this evening (Sunday).

From 6 pm, the consultation will be available on the Pharmac website via [this link](#). Following public release, you are welcome to share the link with others who may be interested.

We welcome your feedback on this proposal. To provide feedback, please submit it in writing by 5 pm, Monday 16 January 2023 to consult@pharmac.govt.nz.

Thank you for all your advice about this funding proposal. Please let me know if you have any questions.

Ngā mihi,
Chippy

Ngā mihi

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

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

From: Alex Chippy Compton
Sent: Friday, 2 December 2022 4:27 pm
To: David McNamara <[REDACTED]>; Dr Neil Whittaker <[REDACTED]>; Greg Frazer <[REDACTED]>; Ian Shaw <[REDACTED]>; Justin Travers <[REDACTED]>; Stuart Dalziel <[REDACTED]>; Tim Christmas <[REDACTED]>; Matthew Strother <[REDACTED]>
Cc: Logan Heyes <[REDACTED]>
Subject: Pharmac consultation - advanced notice

Kia ora Respiratory Advisory Committee members,

I'm emailing to let you know that this Sunday (4 December, 6 pm) Pharmac will be releasing public consultation on a funding proposal which will be of interest. I will email a confidential copy of this consultation to you on Sunday at midday.

Best Wishes,
Chippy

Ngā mihi

Chippy Compton | [she/her](#) | 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

From: Alex Chippy Compton
Sent: Sunday, 4 December 2022 12:04 pm
To: Mark O'Carroll
Cc: Logan Heyes
Subject: RE: Upcoming Pharmac consultation
Attachments: Confidential - Proposal to fund elexacaftor with tezacaftor and ivacaftor (Trikafta) for people with cystic fibrosis.pdf

Kia ora,

Later today, we will be releasing consultation on a proposal 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 find attached a confidential copy of our consultation. This is **confidential until public release at 6 pm** this evening (Sunday).

From 6 pm, the consultation will be available on the Pharmac website via [this link](#). Following public release, you are welcome to share the link with others who may be interested.

We welcome your feedback on this proposal. To provide feedback, please submit it in writing by 5 pm, Monday 16 January 2023 to consult@pharmac.govt.nz.

Thank you for your advice on and advocacy for this funding proposal. Please let me know if you have any questions.

Ngā mihi,
Chippy

Ngā mihi

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

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

From: Alex Chippy Compton
Sent: Friday, 2 December 2022 4:43 pm
To: Mark O'Carroll <[REDACTED]>
Cc: Logan Heyes <[REDACTED]>
Subject: Upcoming Pharmac consultation

Kia ora koutou,

I wanted to let you know that this Sunday (4 December, 6 pm) Pharmac will be releasing public consultation on a funding proposal which we think will be of interest to you. I will email a confidential copy of this consultation to you on Sunday at midday ahead of public release.

Best Wishes,
Chippy

Ngā mihi

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

proactive release
21 February 2023

From: Alex Chippy Compton
Sent: Sunday, 4 December 2022 12:04 pm
To: 'Richard Laing'
Cc: Logan Heyes
Subject: RE: Upcoming Pharmac consultation
Attachments: Confidential - Proposal to fund elexacaftor with tezacaftor and ivacaftor (Trikafta) for people with cystic fibrosis.pdf

Kia ora,

Later today, we will be releasing consultation on a proposal 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 find attached a confidential copy of our consultation. This is **confidential until public release at 6 pm** this evening (Sunday).

From 6 pm, the consultation will be available on the Pharmac website via [this link](#). Following public release, you are welcome to share the link with others who may be interested.

We welcome your feedback on this proposal. To provide feedback, please submit it in writing by 5 pm, Monday 16 January 2023 to consult@pharmac.govt.nz.

Please let me know if you have any questions.

Ngā mihi,
Chippy

Ngā mihi

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

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

From: Alex Chippy Compton
Sent: Friday, 2 December 2022 4:44 pm
To: Richard Laing <[REDACTED]>
Cc: Logan Heyes <[REDACTED]>
Subject: Upcoming Pharmac consultation

Kia ora koutou,

I wanted to let you know that this Sunday (4 December, 6 pm) Pharmac will be releasing public consultation on a funding proposal which we think will be of interest to you. I will email a confidential copy of this consultation to you on Sunday at midday ahead of public release.

Best Wishes,
Chippy

Ngā mihi

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

proactive release
21 February 2023

From: CAC (Consumer Advisory Committee)
Sent: Sunday, 4 December 2022 12:01 pm
To: CAC Members; 'Tui Taurua'
Subject: Confidential consultation
Attachments: 2022-12 Proposal to fund elexacaftor with tezacaftor and ivacaftor (Trikafta) for people with cystic fibrosis.pdf

Kia ora koutou

Please find attached a confidential copy of consultation for a proposal 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. This is **confidential until public release at 6 pm** this evening (Sunday).

From 6 pm, the consultation will be available on the Pharmac website via [this link](#).

We welcome your feedback on this proposal. To provide feedback, please submit it in writing by 5 pm, Monday 16 January 2023 to consult@pharmac.govt.nz.

Ngā mihi,
Mako

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

Contact details:

Mako Osborne | Ph [REDACTED]

Peter Alsop | Ph [REDACTED]

Jannel Fisher | Ph [REDACTED]

Trish Elise | Ph [REDACTED]

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

To: Anja Werno; Eamon Duffy; Ed Gane; Elizabeth Dennett - PTAC Member; Emma Best; Graham Mills; James Chisnall; Jane Morgan; Rhiannon Braund; Sean Hanna (Oratoa); Simon Briggs; Steve Chambers
Subject: Pharmac consultation advance notice

From: Ben Graham

Sent: Friday, 2 December 2022 2:40 pm

To: Anja Werno <[REDACTED]>; Eamon Duffy <[REDACTED]>; Ed Gane <[REDACTED]>; Elizabeth Dennett - PTAC Member <[REDACTED]>; Emma Best <[REDACTED]>; Graham Mills <[REDACTED]>; James Chisnall <[REDACTED]>; Jane Morgan <[REDACTED]>; Rhiannon Braund <[REDACTED]>; Sean Hanna (Oratoa) <[REDACTED]>; Simon Briggs <[REDACTED]>; Steve Chambers <[REDACTED]>

Subject: Pharmac consultation advance notice

Kia ora Anti-infective Advisory Committee,

I'm emailing to let you know that this Sunday (4 December) at 6 pm Pharmac will be releasing a public consultation for a funding proposal which we think will be of interest to you.

I will email a confidential copy of this consultation to you on Sunday at midday. This will be confidential until public release.

Ngā mihi

Ben Graham | Therapeutic Group Manager | Operations Directorate

Te Pātaka Whaioranga | Pharmac | PO Box 10-254 | Level 9, 40 Mercer Street, Wellington
P: 0800 660 050 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: CAC (Consumer Advisory Committee)
Sent: Friday, 2 December 2022 3:45 pm
To: CAC Members; 'Tui Taurua'
Subject: confidential advance notice of public consultation

Kia ora koutou,

I'm emailing to let you know that this Sunday (4 December) at 6 pm Pharmac will be releasing a public consultation for a funding proposal which we think will be of interest to you.

I will email a confidential copy of this consultation to you on Sunday at midday. This will be confidential until public release.

Ngā mihi,
Mako

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

Contact details:

Mako Osborne | Ph [REDACTED]

Peter Alsop | Ph [REDACTED]

Jannel Fisher | Ph [REDACTED]

Trish Elise | Ph [REDACTED]

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

From: Ptac
Sent: Friday, 2 December 2022 3:21 pm
To: Alan Fraser; Brian Anderson; Bruce King; David Hughes; Dr. Giles Newton-Howes; Elizabeth Dennett - PTAC Member; Hanna Aulia; Jane Thomas; Jennifer Martin; Lisa Stamp; Marius Rademaker; Matthew Strother; Rhiannon Braund; Robyn Manuel; Simon Wynn Thomas; Stephen Munn; Tim Stokes; Toni Broome
Subject: Confidential advance warning of consultation happening this weekend

Kia ora everyone

I'm emailing to let you know that this Sunday (4 December) at 6 pm Pharmac will be releasing a public consultation for a funding proposal which we think will be of interest to you.

I will email a confidential copy of this consultation to you on Sunday at midday. This will be confidential until public release.

Ngā mihi,

Toni

Toni Broome | Pharmacology and Therapeutics Advisory Committee Secretary

Te Pātaka Whaioranga | Pharmac

PO Box 10-254, Wellington 6140 | Level 9, 40 Mercer Street, Wellington 6011

DDI: [REDACTED] | M: [REDACTED] | P: 0800 660 050 | www.pharmac.govt.nz

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

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From: Cameron Webb
Sent: Friday, 2 December 2022 2:23 pm
To: Jane Wright
Subject: 2022-12-04 SF email
Attachments: 2022-12-04 SF email .docx

proactive release
21 February 2023

Hi everyone,

I hope you're having a lovely weekend.

As I mentioned at Board debrief on Friday, I'm thrilled to announce that we have reached a provisional agreement with medicine supplier Vertex to fund Trikafta. This has been a huge piece of work, and I want to congratulate again everyone who was involved in this work.

From 12 pm today, our media release can be published, so expect to see a few media stories coming out about this. Our communications team will pull together a wrap-up on all these stories and post it on Te Pātaka on Monday.

Ngā mihi,

Sarah

From: Jane Wright
Sent: Friday, 2 December 2022 1:51 pm
To: Alex Chippy Compton
Subject: RE: Email to advisory groups for this afternoon

You are a legend, was JUST starting to draft this too!!!!

Are you around – urgent update!

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: Alex Chippy Compton <[REDACTED]>
Sent: Friday, 2 December 2022 12:32 pm
To: Ben Graham <[REDACTED]>; Joshua Cronin-Lampe <[REDACTED]>;
Ptac <[REDACTED]>; Mako Osborne <[REDACTED]>
Cc: Jane Wright <[REDACTED]>
Subject: Email to advisory groups for this afternoon

Kia ora,

Please see below for the email (titled Email #1) which needs to go out today to your relevant advisory group (detailed below). @Mako Osborne you might already have something drafted for CAC so feel free to take or leave. Ideally this would be sent later this afternoon (eg some time after 3 pm) but if you need to send it earlier that is fine. Please log these emails in the attached folder once sent.

We will then need to send a follow up email with the details at Sunday midday. I am happy to send these on your behalf, otherwise you can set up an email to automatically go out on Sunday (drafted below as Email #2) with the consultation attached as a PDF. If you choose the latter, your computer needs to be running with outlook open for the email to go. Please let me know what you would rather for Sunday.

Chippy

- PTAC - Toni
- Rare Disorders – Josh
- Anti-infectives – Ben
- CAC - Mako

Email #1 – to be sent Friday afternoon

Kia ora <name> Advisory Committee,

From: Ptac
Sent: Friday, 2 December 2022 3:12 pm
To: Ben Graham; Alex Chippy Compton; Joshua Cronin-Lampe; Ptac; Mako Osborne
Cc: Jane Wright
Subject: RE: Email to advisory groups for this afternoon

Hi Chippy

I am happy to send my email out on Sunday. Comfortable to do the delay send and leave machine logged on on Sunday. 😊

Toni

Toni Broome | Pharmacology and Therapeutics Advisory Committee Secretary | Panels Coordinator | Health & Safety Representative

From: Ben Graham <[REDACTED]>
Sent: Friday, 2 December 2022 1:40 pm
To: Alex Chippy Compton <[REDACTED]>; Joshua Cronin-Lampe <[REDACTED]>; Ptac <[REDACTED]>; Mako Osborne <[REDACTED]>
Cc: Jane Wright <[REDACTED]>
Subject: RE: Email to advisory groups for this afternoon

Hi Chippy – Just want to confirm the subject of email #1, is it to include that the consult is about Trikafta because the body of the email does not mention it?

Ben

From: Alex Chippy Compton <[REDACTED]>
Sent: Friday, 2 December 2022 12:32 pm
To: Ben Graham <[REDACTED]>; Joshua Cronin-Lampe <[REDACTED]>; Ptac <[REDACTED]>; Mako Osborne <[REDACTED]>
Cc: Jane Wright <[REDACTED]>
Subject: Email to advisory groups for this afternoon

Kia ora,

Please see below for the email (titled Email #1) which needs to go out today to your relevant advisory group (detailed below). @Mako Osborne you might already have something drafted for CAC so feel free to take or leave. Ideally this would be sent later this afternoon (eg some time after 3 pm) but if you need to send it earlier that is fine. Please log these emails in the attached folder once sent.

We will then need to send a follow up email with the details at Sunday midday. I am happy to send these on your behalf, otherwise you can set up an email to automatically go out on Sunday (drafted below as Email #2) with the consultation attached as a PDF. If you choose the latter, your computer needs to be running with outlook open for the email to go. Please let me know what you would rather for Sunday.

Chippy

- PTAC – Toni
- Rare Disorders – Josh
- Anti-infectives – Ben
- CAC - Mako

Email #1 – to be sent Friday afternoon

Kia ora <name> Advisory Committee,

I'm emailing to let you know that this Sunday (4 December) at 6 pm Pharmac will be releasing a public consultation for a funding proposal which we think will be of interest to you.

I/My colleague Chippy (copied in) will email a confidential copy of this consultation to you on Sunday at midday. This will be confidential until public release.

Ngā mihi,
<your name>

Email #2 – to be sent Sunday midday – attach PDF consultation letter with title including 'Confidential'

Kia ora <name> Advisory Committee,

Please find attached a confidential copy of consultation for a proposal 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. This is **confidential until public release at 6 pm** this evening (Sunday).

From 6 pm, the consultation will be available on the Pharmac website via [this link](#).

We welcome your feedback on this proposal. To provide feedback, please submit it in writing by 5 pm, Monday 16 January 2023 to consult@pharmac.govt.nz.

Ngā mihi,
<your name>

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: Jane Wright
Sent: Sunday, 4 December 2022 3:30 pm
To: Megan Brodie
Subject: Re: Trikafta funding deal

Thank you!! We are really excited! Did you not get it through mailchimp? Very odd! Will look at that tomorrow but for now....

Get [Outlook for iOS](#)

From: Megan Brodie <[REDACTED]>
Sent: Sunday, December 4, 2022 3:28:15 PM
To: Jane Wright <[REDACTED]>
Subject: Trikafta funding deal

Hey Jane

I understand you have an embargoed release for me? Send it through when you can - and congrats all around on a wonderful achievement. Happy days!

Cheers,
Megan

Megan Brodie
Publishing Editor

m: [REDACTED]
e: [REDACTED]
w: www.mednews.com.au



From: Michelle Arrowsmith <[REDACTED]>
Sent: Friday, 2 December 2022 3:34 pm
To: Geraldine MacGibbon; Kim McGuinness
Subject: RE: Confidential - copy of consultation letter and media release for proposal to fund Trikafta from 1 April 2023

Thanks Geraldine for your call.

Great news for the CF community, long awaited with significant campaigning and advocacy effort by many, this will make such a difference to the treatment and care of those with CF in NZ.

We are really pleased to hear of this decision.

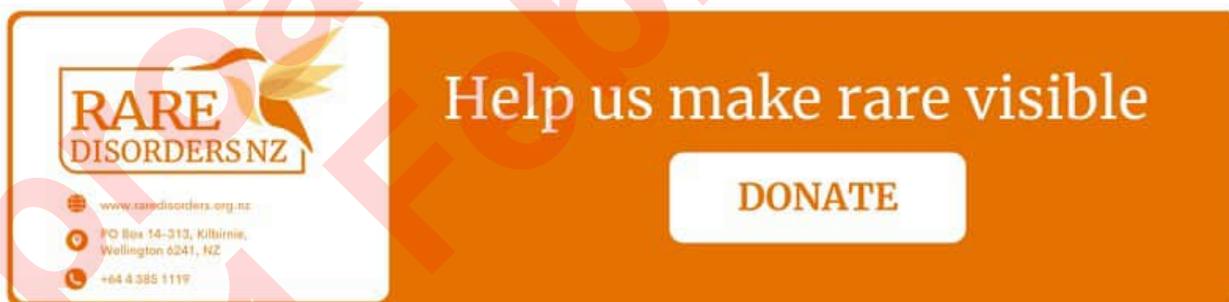
We hope that there will be more positive timely decisions for rare disorders sufferers that lead to equity in medicine access.

We appreciate you sharing this ahead of time with us, [REDACTED]
[REDACTED]

Ngā mihi
Michelle

Michelle Arrowsmith
Chief Executive
Rare Disorders NZ

PO Box 14-313, Kilbirnie, Wellington 6241, NZ
Office: +64 4 385 1119
Mobile: [REDACTED]
Email: [REDACTED]
Web: www.raredisorders.org.nz



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From: Geraldine MacGibbon <[REDACTED]>
Sent: Friday, 2 December 2022 3:23 pm

To: Kim McGuinness <[REDACTED]>; Michelle Arrowsmith

Subject: Confidential - copy of consultation letter and media release for proposal to fund Trikafta from 1 April 2023

Kia ora Kim and Michelle

In follow up to my phone calls with you both, please find attached a confidential copy of our consultation on a proposal 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, and our accompanying media release. As discussed, this is confidential until public release at 6 pm Sunday 4 December.

From 6 pm Sunday 4 December, the consultation will be available on the Pharmac website via [this link](#). We would welcome you sharing it with others who may be interested following public release.

Feedback can be sent to consult@pharmac.govt.nz. All feedback received by 5 pm, Monday 16 January 2023 will be considered by Pharmac's Board prior to a decision being made.

Please let me know if you have any questions – I'll be here for the next hour or so or you can call me on my personal number [REDACTED] over the weekend if you would like.

Ngā mihi
Geraldine

Geraldine MacGibbon, PhD ([she/her](#)) | Manager, Pharmaceutical Funding

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

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

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From: Alex Chippy Compton
Sent: Friday, 2 December 2022 4:15 pm
To: Eddie Porter
Cc: Logan Heyes
Subject: Confidential - consultation and media release
Attachments: Confidential - Trikafta Consultation media release.pdf; Confidential - Proposal to fund elexacaftor with tezacaftor and ivacaftor (Trikafta) for people with cystic fibrosis.pdf

Kia ora Eddie,

Thanks for your time on the phone.

Please find attached a confidential copy of consultation for a proposal 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, and our accompanying media release. As discussed, this is confidential until public release at 6 pm Sunday 4 December.

From 6 pm Sunday, the consultation will be available on the Pharmac website via [this link](#). We would welcome you sharing this link with others after public release of the consultation.

Feedback can be sent to consult@pharmac.govt.nz. All feedback received by 5 pm, Monday 16 January 2023 will be considered by Pharmac's Board prior to a decision being made.

Ngā mihi,
Chippy

Ngā mihi

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

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

From: Edward Lee <[REDACTED]>
Sent: Friday, 2 December 2022 5:34 pm
To: Alex Chippy Compton
Cc: Logan Heyes; Jane Wright
Subject: Re: Confidential - consultation and media release

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

Thanks Chippy, Logan. Honestly I am buzzing. I haven't been like this in years. Thank you to you both for your hard work with all of this.

Jane can you call me on [REDACTED]

Cheers,
Ed

On 2 Dec 2022, at 5:00 pm, Alex Chippy Compton <[REDACTED]> wrote:

Kia ora Ed,

Thanks for your time and kind words today. We are really excited to share the news on Sunday with the wider community.

Please find attached a confidential copy of consultation for the proposal 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, along with our accompanying media release. As discussed, this is confidential until public release at 6 pm Sunday 4 December.

From 6 pm Sunday, the consultation will be available on the Pharmac website via [this link](#). We would welcome you sharing this link with others after public release of the consultation.

Feedback can be sent to consult@pharmac.govt.nz. All feedback received by 5 pm, Monday 16 January 2023 will be considered by Pharmac's Board prior to a decision being made.

Do let us know if you have any questions ahead of Sunday's release. I will be checking emails at intervals over the weekend.

Ngā mihi,
Chippy

Ngā mihi

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

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

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<Confidential - Trikafta Consultation media release.pdf>

<Confidential - Proposal to fund elexacaftor with tezacaftor and ivacaftor (Trikafta) for people with cystic fibrosis.pdf>

proactive release
21 February 2023

From: Rachael Bylykbashi <[REDACTED]>
Sent: Saturday, 3 December 2022 9:08 am
To: Jane Wright
Subject: Otaga Times
Attachments: 9627C2FD-C98A-4067-828E-4366D52CF885.data

Hi Jane

Morning!

You've probably seen this but Fiona has followed Rachel's lead.

Kind regards

Rachael

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From: Jane Wright
Sent: Saturday, 3 December 2022 10:34 am
To: Jannel Fisher
Subject: Re: Trikafta "guess work" in the ODT too

And I confirmed that they couldn't break the embargo so I think we need to go after them. Annoyingly I'm not sure it will get anywhere.

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From: Jannel Fisher <[REDACTED]>
Sent: Saturday, December 3, 2022 10:32:47 AM
To: Jane Wright <[REDACTED]>
Subject: Re: Trikafta "guess work" in the ODT too

That's pushing it seeing they had the PR under embargo

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From: Jane Wright <[REDACTED]>
Sent: Saturday, December 3, 2022 10:21:10 AM
To: Sarah Fitt <[REDACTED]>; Lisa Williams <[REDACTED]>; Rosa Bach <[REDACTED]>; David Hughes <david.hughes@pharmac.govt.nz>; David Cormack <[REDACTED]>
Cc: Jannel Fisher <[REDACTED]>; Peter Alsop <[REDACTED]>
Subject: Trikafta "guess work" in the ODT too

https://readnow.isentia.com/Temp/138041-894287869/1747625468_20231203.pdf

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From: Kim McGuinness <[REDACTED]>
Sent: Saturday, 3 December 2022 2:59 pm
To: Geraldine MacGibbon
Subject: Re: Confidential - copy of consultation letter and media release for proposal to fund Trikafta from 1 April 2023

Hi Geraldine,

Thank you so much for your call yesterday. [REDACTED]
[REDACTED]
[REDACTED]

We can't wait to share our excitement with the rest of the CF community on Sunday.

Enjoy your weekend.

Kim

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From: Geraldine MacGibbon <[REDACTED]>
Sent: Friday, December 2, 2022 3:22:46 PM
To: Kim McGuinness <[REDACTED]>; Michelle Arrowsmith <[REDACTED]>
Subject: Confidential - copy of consultation letter and media release for proposal to fund Trikafta from 1 April 2023

Kia ora Kim and Michelle

In follow up to my phone calls with you both, please find attached a confidential copy of our consultation on a proposal 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, and our accompanying media release. As discussed, this is confidential until public release at 6 pm Sunday 4 December.

From 6 pm Sunday 4 December, the consultation will be available on the Pharmac website via [this link](#). We would welcome you sharing it with others who may be interested following public release.

Feedback can be sent to consult@pharmac.govt.nz. All feedback received by 5 pm, Monday 16 January 2023 will be considered by Pharmac's Board prior to a decision being made.

Please let me know if you have any questions – I'll be here for the next hour or so or you can call me on my personal number [REDACTED] over the weekend if you would like.

Ngā mihi
Geraldine

Geraldine MacGibbon, PhD ([she/her](#)) | Manager, Pharmaceutical Funding

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

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

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proactive release
21 February 2023

From: Jane Wright
Sent: Sunday, 4 December 2022 10:46 am
To: Adelia Hallett
Subject: RE: PR for fact-checking

Looks good to me, thanks Adelia. Apologies for not coming back on Friday, the day was a bit manic for obvious reasons.

We are putting our media release, embargoed until 6pm tonight at 2pm today. Vertex are doing the same, and so are CFNZ.

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: Adelia Hallett <[REDACTED]>
Sent: Friday, 2 December 2022 5:53 pm
To: Jane Wright <[REDACTED]>
Subject: PR for fact-checking

Hi Jane

Hon Andrew Little

Minister of Health



2 December, 2022 - DRAFT

**PĀNUI PĀPĀHO
MEDIA STATEMENT**

Govt's medicines boost paying off for New Zealanders

Pharmac's plan to fund the cystic fibrosis medicine Trikafta is another example of the Government's boost to the medicines budget helping New Zealanders, says Health Minister Andrew Little.

"Since coming into Government in 2017, we've increased the medicines budget by 43 per cent, letting Pharmac make more than 200 medicines available for thousands of people," Andrew Little said.

"Trikafta is the latest of those medicines. It has the potential to not only greatly improve quality of life for people with cystic fibrosis, but also extend their lives by up to 27 years.

“This is fantastic news for them and for their families, and comes on top of other recent announcements like a plan to fund the spinal muscular atrophy medication Spinraza and a call for proposals for late-stage lung cancer medicines.

“It shows what a difference the Government’s budget boost is making. When we came into Government, the medicines budget – like other parts of the health system – had been starved of investment, despite record population growth.

“We’re fixing that. In 2020, we promised we’d increase Pharmac’s budget by \$200 million over four years. We’ve kept that promise, and on top of that put in \$71 million more this year, with another \$120 million boost is in the pipeline for next year.

“The medicines budget is now 43 per cent bigger, under the Labour Government, than it was when we were elected in 2017. This means better access to medicines and treatments for New Zealanders, helping people lead healthier lives.”

For further information contact: Adelia Hallett [REDACTED]

Editor’s notes:

- Today’s announcement by Pharmac is the next step in the process to make Trikafta available for New Zealanders with cystic fibrosis.
- Pharmac has reached a provisional agreement with medicine supplier Vertex to fund Trikafta for people with cystic fibrosis who are aged six and over, and who meet eligibility criteria.
- Funding of Trikafta is proposed to start from 1 April next year.
- 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 201 funding decisions since 2017/18, including 68 new listings and the widening of access to 133 treatments, with more to come.

Ngā mihi

Adelia Hallett

Senior Press Secretary to Hon Andrew Little MP

DDI [REDACTED] | Mobile [REDACTED] | Email [REDACTED]

Office of Hon Andrew Little MP, Minister of Health, Lead Coordination Minister for the Government’s Response to The Royal Commission’s Report into the Terrorist Attack on the Christchurch Mosques, Minister for Treaty of Waitangi Negotiations, Minister Responsible for the NZSIS, Minister Responsible for the GCSB, Minister Responsible for Pike River Re-entry
Reception +64 4 817 8707 | Ministerial Email a.little@ministers.govt.nz | Web beehive.govt.nz | Postal Freepost Parliament, Private Bag 18 041, Parliament Buildings, Wellington 6160, New Zealand



Please note information about meetings related to the Ministers’ portfolios will be proactively released (this does not include personal or constituency matters). For each meeting in scope, the summary would list: date, time (start and finish), brief description, location, who the meeting was with, and the portfolio. If you attend a meeting with the Minister on behalf of an organisation, the name of the organisation will be released. If you are a senior staff member at an organisation, or meet with the Minister in your personal capacity, your name may also be released. The location of the meeting will be released, unless it is a private residence. The proactive release will be consistent with the provisions in the Official Information Act, including privacy considerations. Under the Privacy Act 1993 you have the right to ask for a copy of any personal information we hold about you, and to ask for it to be corrected if you think it is wrong. If you’d like to ask for a copy of your

information, or to have it corrected, or are concerned about the release of your information in the meeting disclosure, please contact the sender. You can read more about the proactive release policy at <https://www.dia.govt.nz/Proactive-Releases#MS>

Authorised by Hon Andrew Little MP, Parliament Buildings, Wellington 6160, New Zealand

proactive release
21 February 2023

From: Ben Graham
Sent: Sunday, 4 December 2022 12:00 pm
To: Anti-Infective Advisory Committee
Subject: Consultation on a proposal to fund elexacaftor with tezacaftor and ivacaftor (Trikafta)
Attachments: Proposal to fund elexacaftor with tezacaftor and ivacaftor (Trikafta) for people with cystic fibrosis.pdf

Kia ora Anti-Infective Advisory Committee,

Please find attached a confidential copy of consultation for a proposal 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. This is **confidential until public release at 6 pm, 4th December** (Sunday).

From 6 pm, the consultation will be available on the Pharmac website via [this link](#).

We welcome your feedback on this proposal. To provide feedback, please submit it in writing by 5 pm, Monday 16 January 2023 to consult@pharmac.govt.nz.

Ngā mihi

Ben Graham | Therapeutic Group Manager | Operations Directorate

Te Pātaka Whaioranga | Pharmac | PO Box 10-254 | Level 9, 40 Mercer Street, Wellington
P: 0800 660 050 M: [REDACTED] | www.pharmac.govt.nz

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