



21 July 2020

Sarah Fitt
Chief Executive
Pharmac
PO Box 10254
The Terrace
Wellington 6143

Sent by email sarah.fitt@pharmac.govt.nz

Dear Sarah

I have been approached by local constituent s 9(2)(a) who has the rare heart condition s 9(2)(a).

s 9(2)(a) has been on a clinical trial of the drug AG10 and will be eligible to use Tafamidis early next year. This drug is known to potentially slow the progression of the disease, particularly when taken in combination with AG10.

However, when s 9(2)(a) was diagnosed with the condition s 9(2)(a) ago he was given a life expectancy prognosis of s 9(2)(a). He could not be expected to s 9(2)(a) before being able to start this potentially lifesaving trial treatment.

As Tafamidis is currently not funded by Pharmac, s 9(2)(a) is importing the drug from overseas at the cost of \$35,000 per three month treatment. GST costs of \$20,000 a year are also payable – this is a treatment that few could afford.

I have read the report stating that the Cardiovascular Subcommittee of Pharmac have recommended that Tafamidis be approved for funding for the s 9(2)(a). Their findings were “based on high health need, lack of funded alternatives and high cost of treatment”. (Record of the Pharmacology and Therapeutics Advisory Committee Meeting 22 and 23 August 2019)

The same report recommends support for Pharmac staff to engage with Pfizer, the supplier of Tafamidis internationally and to review the application of it domestically.

Is there an update available on the review of Tafamidis and the possibility of Pharmac funding that you could share with me?

I understand that Pharmac cannot fund every effective treatment, but there appear to be very compelling reasons for Tafamidis to be funded. It seems that it is the only real treatment for s 9(2)(a) with over 40 countries now offering it to their citizens.

David Seymour MP

Member of Parliament for Epsom | ACT Leader

Electorate Office: Office 2.4, Level 2, 27 Gillies Avenue, Newmarket, Auckland

PO Box 9209, Newmarket, Auckland 1149 | Telephone +64 9 522 7464

david.seymour@parliament.govt.nz

When could patients such as s 9(2)(a) hope to also benefit from publically funded Tafamidis?

Thank you for your consideration of this matter.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'D Seymour', with a stylized flourish at the end.

David Seymour
MP for Epsom

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

From: Jane Wallace on behalf of Sarah Fitt
Sent: Tuesday, 28 July 2020 12:29 pm
To: david.seymour@parliament.govt.nz
Cc: Kristen.Bartlett@parliament.govt.nz
Subject: PHARMAC response re Tafamidis
Attachments: 2020-07-21 David Seymour, MP RE_ Tafamidis - Response.pdf

Dear David

Please find PHARMAC’s response to your recent letter regarding constituent s 9(2)(a) and his use of Tafamidis.

Regards

Sarah Fitt | Chief Executive

PHARMAC | Te Pātaka Whaioranga | PO Box 10-254 | Level 9, 40 Mercer Street, Wellington
DDI s 9(2)(a) | P +64 4 460 4990 | M s 9(2)(a) | www.pharmac.govt.nz

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

From: Jane Wallace **On Behalf Of** Sarah Fitt

Sent: Tuesday, 28 July 2020 12:29 pm

To: 'david.seymour@parliament.govt.nz' <david.seymour@parliament.govt.nz>

Cc: 'Kristen.Bartlett@parliament.govt.nz' <Kristen.Bartlett@parliament.govt.nz>

Subject: PHARMAC response re: Tafamidis

Dear David

Please find PHARMAC's response to your recent letter regarding constituent s 9(2)(a) and his use of Tafamidis.

Regards

Sarah Fitt | Chief Executive

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

DDI: s 9(2)(a) | P: +64 4 460 4990 | M: s 9(2)(a) | www.pharmac.govt.nz

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

28 July 2020

David Seymour
Member of Parliament for Epsom
Via email: david.seymour@parliament.govt.nz

Dear David

Funding of tafamidis

Thank you for your letter of 21 July regarding funding for tafamidis for your constituent s 9(2) [redacted]. As you are aware, PHARMAC makes decisions about which medicines and medical devices are publicly funded in New Zealand. We do this in order to get the best health outcomes for the most New Zealanders from within our fixed budget.

The Pharmacology and Therapeutics Advisory Committee (PTAC), who provides us with clinical advice, noted at their meeting in August 2019 that tafamidis is not registered by [Medsafe](#) and that no application for tafamidis has been received by Medsafe. Although Medsafe-approval is not an explicit pre-requisite for PHARMAC funding, generally PHARMAC's preference is to fund Medsafe-registered medicines. We have reached out to the supplier of tafamidis but are still awaiting further information from them.

PHARMAC manages a pathway for considering funding for individual patients. This is called the Named Patient Pharmaceutical Assessment (NPPA). NPPA is a pathway for consideration of funding for people with exceptional clinical circumstances. Non-clinical circumstances are not taken into account when assessing NPPA applications. For example, we do not consider a patient's financial circumstances or personal preference for treatment when assessing a NPPA application. There must be a clinical need, supported by sufficient evidence, for the product being applied for.

We cannot comment on whether your constituent's clinical situation would meet the criteria for funding under NPPA. He should discuss this option with his doctor. A doctor must make a NPPA application on a patient's behalf - patients cannot make NPPA applications themselves. More information about NPPA, including forms for doctors, is available on our website at www.pharmac.govt.nz/tools-resources/forms/exceptional-circumstances/.

I acknowledge that tafamidis is funded in other countries. However, the funding and reimbursement systems between countries are often not comparable. PHARMAC must carefully assess the available evidence to make decisions about a medicine's use within New Zealand's health context. We assess all funding applications against our [Factors for Consideration](#) to ensure that every application is treated fairly.

Possible opportunities for investment in new medicines will always exceed the budget PHARMAC has available; therefore, comparative ranking is an intrinsic part of our work.

Every application that is recommended for funding is prioritised, and no one group of medicines is given priority over the others.

The relative priority of funding one medicine compared with other medicines can change over time. Details like the relative health benefits, the amount of funding available, the success of negotiations with the suppliers, new clinical data, and the mix of other funding applications being considered may change the relative priorities of funding choices. For this reason, PHARMAC is unable to give a definitive timeframe for if, or when, funding decisions will be made.

We recognise that this may not be the response you and your constituent will be hoping for. I want to assure you that PHARMAC is continuing to work hard to give New Zealanders access to medicines to help them live healthy lives.

Thank you for taking the time to write.

Yours sincerely



Sarah Fitt
Chief Executive

Subject RE Cr s s wecantwa t
Sent 11/09/2020 10 29 13 am
From Web Enqu ry<enqu ry@Pharmac.govt.nz>
To s 9(2)(a)
Cc amy.adams@parliament.govt.nz dav d seymour@parliament.govt.nz dav d carter@parliament.govt.nz ruth.dyson@parliament.govt.nz Megan.Woods@parliament.govt.nz gerry.brownlee@parliament.govt.nz

Follow Up Flag: Follow up
Flag Status: Completed

Kia ora s 9(2)(a),

Thank you for your email to PHARMAC Chief Executive, Sarah Fitt, the Chair of the PHARMAC Board, Teve Maharey, and several other PHARMAC staff members; Sarah has asked me to respond to you on all their behalf

I am sorry to hear about your difficulties with s 9(2)(a) which we know can have a significant and ongoing impact on those who have it, and their whānau

We have heard from our clinical advisors, and through regular engagement with people who treat and manage patients s 9(2)(a), about the need for further treatment options s 9(2)(a). We meet regularly with the Crohn's & Colitis NZ and appreciate their efforts to advocate on behalf of New Zealanders s 9(2)(a).

PHARMAC funds a number of medicines used in the treatment and management s 9(2)(a). These include steroids, amino salicylates, medicines that suppress the immune system, and biologics, which include infliximab (for Crohn's disease and ulcerative colitis) and adalimumab (for Crohn's disease).

We are aware that there are other biologic treatments s 9(2)(a). Ustekinumab is registered with Medsafe for treatment of ulcerative colitis. Tofacitinib is also registered with Medsafe, but only for the treatment of rheumatoid arthritis. Vedolizumab is not currently registered with Medsafe, but we are aware that an [application](#) has been submitted to Medsafe for assessment.

PHARMAC uses a robust, evidence-based approach, including seeking expert clinical advice, when assessing new medicines for funding.

We have received and assessed funding applications for both [ustekinumab](#) and [vedolizumab](#). We have compared both these medicines with, and ranked them against, other medicines that we would like to fund. Full records of the expert advice we have received on these two medicines is available via our application tracker which can be accessed via the above links. Our application tracker tells you the key steps an application has been through, and also links you to relevant published records of expert advice, consultation letters, and related notifications.

Before we decide to fund any new medicine, we generally consult publicly on the proposal. ***If you would like your email address to be added to our consultation database for gastroenterology matters, please let me know.***

We have not received a funding application for tofacitinib, but we are aware of its use internationally in treating ulcerative colitis.

PHARMAC works to get the best health outcomes for New Zealanders we can by funding medicines from within the available budget. While we recognise the challenges faced by patients and their whānau, and their understandable desire to try new treatments, our job is to look at all the evidence and make a decision that is in the interests of all New Zealanders. Possible opportunities for investment in new medicines will always exceed the budget PHARMAC has available.

PHARMAC will continue making the best choices we can, expanding available treatments for all New Zealanders based on a robust, evidence-based approach. Your feedback is very helpful to us in understanding the impact s 9(2)(a) has on New Zealanders, so thank you for sharing your personal story with us.

Kind regards

Jane

PHARMAC | Te Pātaka Whāioranga | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington

M: s 9(2)(a) www.pharmac.govt.nz

We are constantly updating our website with information about medicine supplies.
See our latest updates at pharmac.govt.nz/covid19

Subject: RE: Funding proven treatment options s 9(2)(a)
Sent: 13/10/2020, 11:16:27 am
From: Web Enquiry<enquiry@Pharmac.govt.nz>
To: s 9(2)(a)
Cc: jacinda.ardern@parliament.govt.nz;judith.collins@parliament.govt.nz;david.seymour@parliament.govt.nz

Kia ora s 9(2)(a)

Thank you for your email to PHARMAC Chief Executive, Sarah Fitt, the Chair of the PHARMAC Board, Steve Maharey, and several other PHARMAC staff members; Sarah has asked me to respond to you on all their behalf.

I am sorry to hear about your difficulties with s 9(2)(a). We know s 9(2)(a) can have a significant and ongoing impact on those who have it, and their whānau.

We have heard from our clinical advisors, and through regular engagement with people who treat and manage patients s 9(2)(a), about the need for further treatment options s 9(2)(a). We meet regularly with the Crohn's & Colitis NZ and appreciate their efforts to advocate on behalf of New Zealanders s 9(2)(a).

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PHARMAC will continue making the best choices we can, expanding available treatments for all New Zealanders based on a robust, evidence-based approach. Your feedback is very helpful to us in understanding the impact s 9(2)(a) has on New Zealanders, so thank you for sharing your personal story with us.

Kind regards

Jane



15 June 2022

Sarah Fitt
Chief Executive
Pharmac
PO Box 10254
The Terrace
Wellington 6143

Sent by email sarah.fitt@pharmac.govt.nz

Dear Sarah

s 9(2)(a)

I have been approached by local constituent s 9(2)(a) who suffers from the extremely rare, life-threatening, progressive disease s 9(2)(a).

s 9(2)(a) is dependent on regular, fortnightly infusions of Eculizumab (Soliris), a drug approved for use in New Zealand but not funded by Pharmac.

s 9(2)(a), her country of birth to continue with treatment but hopes to be able to return to New Zealand and resume her role as a lecturer at s 9(2)(a).

Are you currently considering funding any Eculizumab biosimilars?

This is particularly pertinent as I understand that the Eculizumab (Soliris) patent is due to expire later this year.

Thank you for your consideration.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'David Seymour'.

David Seymour
MP for Epsom

David Seymour MP

Member of Parliament for Epsom | ACT Leader

Electorate Office: Office 2.4, Level 2, 27 Gillies Avenue, Newmarket, Auckland

PO Box 9209, Newmarket, Auckland 1149 | Telephone +64 9 522 7464

david.seymour@parliament.govt.nz

30 June 2022

David Seymour
MP for Epsom
By email: david.seymour@parliament.govt.nz

Funding for eculizumab (Soliris) biosimilars

Dear David

Thank you for your letter dated on the 15 June 2022 about your constituent § 9(2)(a) and funding for eculizumab (Soliris) and eculizumab biosimilars

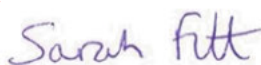
I understand the patent for eculizumab is due to expire in coming years. To date, Pharmac has not received an application for the funding of eculizumab for the treatment of § 9(2)(a). We would welcome an application to consider funding for eculizumab or its biosimilars to § 9(2)(a).

We have previously received and assessed a [funding application for eculizumab](#) (Application Tracker search: eculizumab | connect.pharmac.govt.nz) for the treatment of paroxysmal nocturnal hemoglobinuria (PNH). This application was [declined in 2013](#) (Pharmac decision on eculizumab (Soliris) funding | pharmac.govt.nz) following review by the Pharmacology and Therapeutics Advisory Committee (PTAC). The reason for the application being declined was the extreme cost of the drug and, as a result, its poor cost-effectiveness.

We take our decision-making responsibility seriously. We look after New Zealand's billion-dollar medicine budget and spend every dollar of that on medicines. While it is ultimately our role to determine which medicines are publicly funded for New Zealanders, we work with external experts when making these decisions. We're guided by robust evidence and the expertise of clinicians, the healthcare sector, and the wider public.

I want to assure you that the wellbeing of New Zealanders is at the very heart of everything we do. Pharmac staff are just like all New Zealanders, with friends, families and whānau affected by health issues. We know funded access to effective treatments is important to everyone.

Yours sincerely



Sarah Fitt
Chief Executive

Subject: re Invitation
Sent: 2/08/2022, 5:52:02 pm
From: Brian Nicolle Epsom<Brian.NicolleEpsom@parliament.govt.nz>
To: Sarah Fitt

You don't often get email from brian.nicolleepsom@parliament.govt.nz [Learn why this is important](#)

Dear Sarah,
On behalf of David Seymour MP for Epsom and my colleague Kristen , We would like to invite you to be a guest speaker at one of David’s regular community meetings.

I understood you spoke to Kristen last month and she indicated you had a willingness to speak. The format is quite simple, a 20-25 minute presentation followed by a Q and A. We get most the questions from attendees pre the meeting and forward them onto the speaker. We can also provide power point facilities if required. The meetings are of one hour’s duration and are usually held from 1.30pm-2.30pm. These are “non- political” meetings. We advertise the meetings using social media and the local newspapers. We general get a minimum of 70 or more people. I suspect that your topic will attract a larger crowd.

The following dates are suitable for David. Let me know if any are suitable for you: 12 September,16 September,26 September and Friday 14 October.

Let me know if you have any questions. I look forward to hearing from you.

Kind regards
Brian

Brian Nicolle | Electorate Agent to David Seymour MP for Epsom
Level 2/27 Gillies Ave,Newmarket
P.O> Box 9209,Newmarket 1149
Brian.NicolleEpsom@parliament.govt.nz Ph 09 522-7464 Mobile s 9(2)(a)
 Please consider the environment before printing this e-mail

,

David Seymour

MP for Epsom



21 September 2022

[address block]

[ref]

Invitation to Epsom Electorate Community meeting

On 14 October I am hosting Sarah Fitt, Chief Executive of Pharmac. Sarah will talk about the role of Pharmac in our health system and focussing on a recent review.

Before joining Pharmac, Sarah spent 12 years as Chief Pharmacist at Auckland Hospital and worked as a clinical pharmacist in the NHS specialising in HIV, intensive care, and hepatology.

Topic: The Role of Pharmac in our Health system

Time and Date: 1.30-2.30pm, Friday 14 October

Speaker: Sarah Fitt, CEO Pharmac

Venue: Gracecity Church (formerly Greenlane Christian Centre, 17 Marewa Rd, Greenlane

Questions for the speaker: I am accepting pre-submitted questions so we can maximise the time available. Please email your questions to mpepsom@parliament.govt.nz

RSVP: Please also RSVP the names of people you are coming with you for catering purposes. 09 522 7464 or mpepsom@parliament.govt.nz

I'm here to help you

My office can help you. To discuss any local or central government issues or suggestions you may have, just call my office on the contact numbers above. All such matters are treated in strict confidence.

I do hope that you can join me on the 14th.

Yours sincerely

David Seymour
MP for Epsom

3rd November 2022

To whom it may concern,

Thank you for your email on treatments for multiple myeloma and for sharing your story with me.

We currently fund thalidomide, bortezomib and lenalidomide for multiple myeloma, and do understand that New Zealanders have high expectations about having timely access to new medicines for people with cancer.

Pharmac has several applications for other [treatments for myeloma](#) that we are currently considering for funding. We have not received funding applications for elotuzumab or ixazomib.

There are a number of multiple myeloma treatments on our [Options for Investment](#) list which means they are medicines we would like to fund when we have the budget available. These include, lenalidomide for people with previously untreated multiple myeloma, and pomalidomide, carfilzomib and daratumumab for use in the relapsed or refractory setting.

Pomalidomide, carfilzomib and daratumumab are also currently being assessed for funding when used later in later lines of therapy. They have received positive recommendations from our specialist advisory committees and the next step will be to rank these as options for investment.

Unlike other countries, Pharmac works within a fixed budget, which means that we need to make difficult choices about which items to fund within the available budget. Because of this we cannot provide a definitive timeframe for if or when medicines will be funded – something we know can be difficult to hear.

In May 2022 the Government announced a [\\$191 million budget increase](#) for Pharmac over 2022/23 and 2023/24 to spend on pharmaceuticals. We are currently working our way through our options for investment list, negotiating agreements with suppliers, and we hope to fund many more treatments over the coming 12 to 24 months.

So far this year (1 July 2022 - 30 June 2023), Pharmac has funded four new treatments and widened access to 14 medicines. This has included six cancer treatments, with a further two cancer treatments currently being considered. If you would like to know more about we have recently funded you can read more about them [here](#).

It is very important we hear and listen to the voices of people directly affected by ill-health when assessing medicines. Hearing from the community, alongside clinical evidence, helps us to understand the wider impact funding treatments would have.

Thank you again for sharing your personal story with us and your feedback on the funding of medicines for the treatment of multiple myeloma.

Yours sincerely

Sarah Fitt

Sarah Fitt
Chief Executive

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From: Brian Nicolle Epsom <Brian.NicolleEpsom@parliament.govt.nz>
Sent: Tuesday, May 23, 2023 1:10 PM
To: Michelle Burton <michelle.burton@pharmac.govt.nz>
Subject: FW: Diabetes sensor funding

Hi Michelle,
On behalf of David Seymour MP for Epsom, I have received a request for information from a young guy called [redacted] s 9(2)(a) who is a diabetic. He is [redacted] s 9(2)(a) and is required to have regular two week testing for diabtetes. This is a very expensive process for a young man on limited income. However it's an important part of his life so doctors can see the patterns of his levels throughout the day and importantly helps him keep his job. It also contributes to his health eyesight, kidney function.

His request to our office was why someone like him isn't eligible for a small discreet sensor which would save him a lot of money and he would only need to have 3 months testing instead of fortnightly. He wondered why Pharmac couldn't fund this product for "high needs" people like himself. He believes that there is no Pharmac funding of this product.

Here is a description of the product: "From the moment you open the box, it's the most accurate CGM for the longest time. FreeStyle Libre 2 system meets the highest level of accuracy standards over 14 days, including superior day one accuracy compared to the other iCGM and excellent accuracy and alarm performance at low end glucose levels. 2. A small, discreet sensor that is worn on the back of the upper arm and continuously measures the glucose concentration in the body's interstitial fluid day and night.ϕ The sensor updates the glucose result every minute and stores up to eight hours of glucose readings in 15 minute intervals. It can be worn for up to 14 days and is water-resistant so continues to work while you shower, swim or exercise work." I suspect you will know the trade name for this product.

If you are able to provide me any information that would be helpful.

Kind regards,
Brian
Brian Nicolle | Electorate Agent to David Seymour MP for Epsom
Level 2/27 Gillies Ave, Newmarket
P.O> Box 9209, Newmarket 1149
Brian.NicolleEpsom@parliament.govt.nz Ph 09 522-7464 Mobile [redacted] s 9(2)(a)
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Subject: re Estradiol patches
Sent: 23/05/2023, 3:41:54 pm
From: Brian Nicolle Epsom<Brian.NicolleEpsom@parliament.govt.nz>
To: Trish Elise

You don't often get email from brian.nicolleepsom@parliament.govt.nz [Learn why this is important](#)

Hi Trish,
On behalf of David Seymour I received this email this afternoon :

I understand there has been a shortage of HRT medication in NZ - I am normally prescribed Estradiol patches but due to this shortage my Pharmacist could only provide Estraderm patches.

These patches are NOT FIT FOR PURPOSE - they are impossible to keep on and I have had to resort to using tape to ensure they stay on for the required length of time.

Pharmac has a duty to supply products that work and fulfil the need of the users - these patches do not.

Is this a matter for Pharmac ?

Kind regards,
Brian
Brian Nicolle | Electorate Agent to David Seymour MP for Epsom
Level 2/27 Gillies Ave,Newmarket
P.O> Box 9209,Newmarket 1149
Brian.NicolleEpsom@parliament.govt.nz Ph 09 522-7464 Mobile s 9(2)(a)
 Please consider the environment before printing this e-mail

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Subject: RE: Letter from s 9(2) re Special Authority for GPs to diagnose and prescribe ADHD medication
Sent: 8/11/2023, 9:49:58 am
From: David Hughes<david.hughes@pharmac.govt.nz>
To: s 9(2)(a)
Cc: s 9(2)(a); Trevor Simpson; Sarah Fitt; a.verrall@ministers.govt.nz; Shane.Reti@parliament.govt.nz; David.Seymour@parliament.govt.nz; Brooke.Vanvelden@parliament.govt.nz

Kia ora s 9(2)(a),

Thank you for your letter regarding the renewal process for stimulants used in the treatment of ADHD. Pharmac continues to work towards removing the requirement for the 2 year renewal. Given current capacity and priorities, it is likely that the changes to the schedule will proceed in the new year. I would note that the initiation criteria remain unchanged as these reflect the regulations under the misuse of drugs act. I am very happy to discuss this matter further.

Ngā mihi,
David

David Hughes (he/him)
Tumu Whakarae Haumanu | Chief Medical Officer
Director, Advice and Assessment

Te Pātaka Whaioranga | Pharmac | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington
P: +64 4 460 4990 | M: s 9(2)(a) | F: +64 4 460 4995 | www.pharmac.govt.nz

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