

From: Chris Higgins
Sent: Monday, 14 October 2024 12:38 pm
To: [REDACTED]
Cc: Maree Roberts; [REDACTED]
Subject: implementing the rare disorders strategy

Hi [REDACTED] **Manager- System Enablers, Strategy, Policy and Implementation, MoH**

Thanks for your call this morning letting us know that it's highly unlikely that there'll be a meeting this year of the Rare Disorders Strategy implementation group, due to the challenges in securing Te Whatu Ora's engagement at a time when they're prioritising their current reset, and despite Manatū Hauora's best endeavours.

As we discussed RDNZ was intending to use cues from the implementation meetings to inform our advocacy in respect of the Strategy. We'll now go ahead and forge our own pathway in consultation with the other two implementation agencies – Pharmac and HQSC – and will continue to engage with Te Whatu Ora where we can. We're having constructive discussions with Pharmac already, and I'd be grateful if you could let us know the contact details of who within HQSC has the RDS portfolio.

No doubt you'll let us know if things change re the meeting of the RDS implementation group.

Ngā mihi

Chris

Chris Higgins
Chief Executive
Rare Disorders NZ

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[REDACTED]

From: Chris Higgins
Sent: Friday, 11 October 2024 11:54 am
To: Maree Roberts (Deputy Director-General- Strategy, Policy and Legislation, MoH)
Cc: [REDACTED]
Subject: RDS implementation group

Hi Maree

I'm following up to ascertain how things are going with arranging a first meeting of the RDS implementation group. You'll see from the emails below that I'm not hearing from either [REDACTED] or [REDACTED], so thought I'd contact you.

Ngā mihi

Chris

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From: Chris Higgins
Sent: Thursday, 10 October 2024 2:48 pm
To: [REDACTED]@health.govt.nz>
Subject: FW: Follow Up Health New Zealand Response to Rare Disorders Strategy

Hi [REDACTED] Manager- System Enablers, Strategy, Policy and Implementation, MoH

I tried phoning you earlier this week re progress with the RDS implementation group meeting. You'll see from the emails below that [REDACTED] was expecting to have things arranged before the end of September. Since then we haven't heard anything so I'm reaching out again to see how things are going.

We're expecting that the outcome of the meeting will inform what RDNZ's advocacy will look like in 2025, and we're hoping therefore that it could be arranged to take place no later than mid-November

Ngā mihi

Chris

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From: Chris Higgins
Sent: Monday, 30 September 2024 10:01 am
To: [REDACTED]@health.govt.nz>
Cc: [REDACTED]@raredisorders.org.nz>; [REDACTED]@raredisorders.org.nz>; [REDACTED]@health.govt.nz>; Maree Roberts [REDACTED]@health.govt.nz>
Subject: RE: Follow Up Health New Zealand Response to Rare Disorders Strategy

Kia ora [REDACTED]

Checking in to see how arrangements for the cross agency meeting are shaping up

Ngā mihi

Chris

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From: [REDACTED] <[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>

Sent: Wednesday, 11 September 2024 2:36 pm

To: Chris Higgins <[REDACTED]>

Cc: [REDACTED] <[\[REDACTED\]@raredisorders.org.nz](mailto:[REDACTED]@raredisorders.org.nz)>; [REDACTED] <[\[REDACTED\]@raredisorders.org.nz](mailto:[REDACTED]@raredisorders.org.nz)>; [REDACTED] <[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>; [REDACTED] <[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>

Subject: RE: Follow Up Health New Zealand Response to Rare Disorders Strategy

Kia ora Chris,

Thank you for following up, I hope you are well.

I can confirm that planning for the cross-agency meeting is progressing well. I'm still in the process of finalising a few specifics, including locking in a date.

Once these details are confirmed, I'll be in touch with the meeting information. I aim to get back to you by the end of next week.

I appreciate your patience as I work through the final details.

Ngā mihi nui

[REDACTED]

[REDACTED] (she/her)

Policy Analyst

System Enablers

Strategy, Policy & Legislation | Te Pou Rautaki

Ministry of Health/Manatū Hauora

133 Molesworth Street Thorndon, Wellington 6011



From: Chris Higgins <[REDACTED]>

Sent: Wednesday, September 11, 2024 1:21 PM

To: [REDACTED] <[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>

Cc: Maree Roberts [REDACTED]@health.govt.nz>; [REDACTED]@raredisorders.org.nz>;
[REDACTED]@raredisorders.org.nz>; [REDACTED]@health.govt.nz>

Subject: RE: Follow Up Health New Zealand Response to Rare Disorders Strategy

Kia ora [REDACTED] Policy analyst, MoH

I'm further following up on the email thread below and asking how things are going with setting up the cross agency meeting? If it could occur before the end of this month that will be appreciated by us at RDNZ, and be consistent with the time frame indicated by [REDACTED].

Manager- System Enablers, Strategy, Policy and Implementation, MoH

Ngā mihi

Chris

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From: Chris Higgins
Sent: Tuesday, 10 September 2024 4:32 pm
To: [REDACTED]@health.govt.nz>
Cc: Maree Roberts [REDACTED]@health.govt.nz>; [REDACTED]@raredisorders.org.nz>;
[REDACTED]@raredisorders.org.nz>; [REDACTED]@health.govt.nz>
Subject: RE: Follow Up Health New Zealand Response to Rare Disorders Strategy

Thanks for this update [REDACTED]. Manager- System Enablers, Strategy, Policy and Implementation, MoH

We were more concerned that Te Whatu Ora had declared that its implementation of the RDS was to be put on hold, rather than pace per se, and we'll go ahead with an expectation that Te Whatu Ora will be willing to commence implementing the Strategy where it can after all.

In the meantime we'll look forward to hearing from [REDACTED] re the cross agency meeting.
Policy analyst, MoH

Ngā mihi

Chris

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From: [REDACTED]@health.govt.nz> Manager- System Enablers, Strategy, Policy and Implementation, MoH
Sent: Monday, September 2, 2024 8:36 AM
To: Chris Higgins [REDACTED]
Cc: Maree Roberts [REDACTED]@raredisorders.org.nz>; [REDACTED]@raredisorders.org.nz>; [REDACTED]@health.govt.nz>
Subject: RE: Follow Up Health New Zealand Response to Rare Disorders Strategy

Kia ora team,

Thanks for your email Chris, I hope you are having a lovely break.

I can confirm Maree had a discussion with one of her counterparts at Health New Zealand on the importance of the Rare Disorders Strategy, and the message was acknowledged and understood. Obviously HNZ are in a challenging place at the moment, so we are being thoughtful about expectations for how fast the Strategy can be delivered on in the short-term.

As I said to Chris on the phone a few weeks back though, I suggest you continue to use your networks within Health New Zealand to keep the conversation moving on individual parts of the strategy.

Policy analyst, MoH
Finally, [REDACTED] has been away for the last week, but now she is back will be continuing to organise a cross-agency meeting to discuss the Strategy in the next month or so.

I hope your meeting with support group leads goes well today.

Ngā mihi nui
[REDACTED]

██████████ (she/her)
Manager, System Enablers
Acting Manager, Health System Stewardship
Strategy, Policy and Legislation

██████████
██████████ [@health.govt.nz](#)
Manatū Hauora, 133 Molesworth Street
Thorndon, Wellington 6011



From: Chris Higgins ██████████
Sent: Thursday, August 22, 2024 2:07 PM
To: ██████████ [@health.govt.nz](#)
Cc: Maree Roberts ██████████ [@health.govt.nz](#); ██████████ [@raredisorders.org.nz](#); ██████████ [@raredisorders.org.nz](#)
Subject: RE: Follow Up Health New Zealand Response to Rare Disorders Strategy

Hi ██████████ Manager- System Enablers, Strategy, Policy and Implementation, MoH

I'm following up on the email thread below and the conversation you and I had last Thursday, and enquiring as to whether we can have an update please.

As you'll be able to appreciate rare disorders support group leads are keen to have an update on the outcome of the paper Tim presented to Te Whatu Ora's ELT, as per his presentation to the support group leads hui on 2nd August. We're hoping that things have progressed beyond the position Tim communicated in his 14th August email below and that we'll have something more positive by way of feedback to the support group leads when we next meet with them on 2nd September.

I'll be on annual leave from the end of this week, returning to work on 10th September, so can you please include ██████████ in any reply.

Ngā mihi

Chris

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From: [REDACTED] <[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>

Sent: Thursday, August 15, 2024 10:32 AM

To: Chris Higgins <[\[REDACTED\]@raredisorders.org.nz](mailto:[REDACTED]@raredisorders.org.nz)>

Cc: [REDACTED] <[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>; Maree Roberts <[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>; [REDACTED] <[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>

Subject: RE: Follow Up Health New Zealand Response to Rare Disorders Strategy

Thanks for taking my call just now Chris.

As discussed, we will talk with HNZ to understand the issue more fully and come back to you shortly on how work might progress going forward.

Please feel free to call me at any time, I'm always happy to chat.

Kind regards

[REDACTED]

[REDACTED] (she/her)

Manager, System Enablers

Acting Manager, Health System Stewardship

Strategy, Policy and Legislation

[REDACTED]

<[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>

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From: Chris Higgins <[\[REDACTED\]@raredisorders.org.nz](mailto:[REDACTED]@raredisorders.org.nz)>

Sent: Wednesday, 14 August 2024 2:28 pm

To: Tim Wood <[\[REDACTED\]@tewhatauora.govt.nz](mailto:[REDACTED]@tewhatauora.govt.nz)>

Cc: Sarah Clarke <[\[REDACTED\]@tewhatauora.govt.nz](mailto:[REDACTED]@tewhatauora.govt.nz)>; [REDACTED] <[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>; Maree Roberts <[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>; [REDACTED] <[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>

Subject: RE: Follow Up Health New Zealand Response to Rare Disorders Strategy

Kia ora Tim

Thanks again for participating in the support group leads hui on 2nd August, and for getting back to us re the outcome of your submission to the Te Whatu Ora ELT. Both are very much appreciated.

The Rare Disorders Strategy clearly obligates Te Whatu Ora to contribute to its implementation, with Manatū Hauora having a lead role in overseeing and monitoring its implementation. I'm not sure that it's open to Te Whatu Ora to opt out of its obligations for any reason, even temporarily, and RDNZ will accordingly be interested in Manatū Hauora's perspective.

In any case much of the content of the Strategy does not introduce "new substantive programmes of work" for Te Whatu Ora – rather it's about existing services to people with rare disorders being provided more effectively as part of a process of continuous improvement which hopefully pervades everything that Te Whatu Ora does. RDNZ will therefore continue to engage with Te Whatu Ora services to be part of bringing about improvements where we can, and we'll keep you and Sarah as our primary Te Whatu Ora contacts informed. In this context it will be helpful if we can organise a meeting to discuss further – say mid to late September?

Thanks for preparing the paper that was submitted to the ELT. Despite RDNZ's frustration with Te Whatu Ora at that level I hope there'll nevertheless continue to be good faith opportunities to continue to dialogue among ourselves, as we have been doing to date

Ngā mihi

Chris

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From: Tim Wood [REDACTED]@TeWhatuOra.govt.nz> Group Manager, Planned and Unplanned Care, Health NZ
Sent: Wednesday, August 14, 2024 1:24 PM
To: Chris Higgins [REDACTED]
Cc: Sarah Clarke [REDACTED]@TeWhatuOra.govt.nz>; [REDACTED]@health.govt.nz>
Subject: Follow Up Health New Zealand Response to Rare Disorders Strategy

Kia ora Chris

Thank you for the opportunity to meet with you and your members on Friday 2nd August. I trust my presentation and responses to the questions were helpful and informative.

Health New Zealand | Te Whatu Ora Executive Leadership Team this week considered my paper on the rare Disorders Strategy and implementation options. As you will be aware from the media coverage and my presentation the Health New Zealand Commissioner is leading a reset of Health New Zealand. While this reset is underway there is a hold on introducing new substantive programmes of work. Thus, at this time Health New Zealand will not be initiating any actions in response to the Strategy. Once the reset has been completed the Executive Leadership Team can then consider the timing of any response to the Strategy.

I appreciate this will be a disappointment to you and your members. The decision reflects the importance of the reset and does not reflect on the need to respond to the Strategy.

Noho ora mai

Tim Wood (he/him)
Group Manager Planned & Unplanned Care
Living Well | Commissioning

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Health New Zealand | Te Whatu Ora
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