

Edited text of update sent to selected support groups on 3 August 2018

Hi everyone,

I'm sending this to all those groups who have been "in the loop" regarding access to medicines for rare diseases over recent years. Here's an update on the discussions I've had with the Minister's office and the Ministry about funding of orphan drugs for rare diseases.

A refresh of the background:

- June/July 2017 – submissions and presentations at the health select committee for Samantha Lenik's petition. This, and pressures from others, kept the issues front and centre and helped lead to
- August/September 2017 – opposition political parties (Labour, Greens and NZ First) reconfirmed their 2014 election policies of a separate fund for orphan drugs, managed away from Pharmac and with consumer involvement in decisions.
- November/December 2017 – the policies we want fall victim to the coalition negotiations. Pharmac's briefing to the incoming minister and their orchestrated and tame review of their \$5 million pilot round for rare disease drugs, persuaded the parties that they could get better deals if they continued to manage the process.
- February 2018 – it becomes clear what has been going on behind the scenes and Collette Bromhead (NZORD CEO) challenged Health minister David Clark in a Radio NZ interview. https://www.radionz.co.nz/audio/player?audio_id=2018633019
- The Minister's comments in that interview made it clear he wants the system to deliver a better deal for those with rare diseases. But he is going down a different path to what we wanted, to get there – getting Pharmac to continue work on medicines for rare diseases and (most importantly) to hear his message that this is an equity issue that needs to be addresses as such. Equity is the core of our campaign for medicine access for rare diseases and the minister has publicly stated his support for that, and wants Pharmac to deliver on that. He will be getting advice from the ministry too, and reports from Pharmac on how things are progressing.

Next developments:

- I got to meet with the minister on 3 April and outlined how Pharmac had actually failed to deliver in their pilot round and had used smoke and mirrors to make very little to sound like a lot. Then I proposed a simple method that could be used to make real progress. The minister asked the Health Ministry official who was there, to work with me to see how my proposal could be practically implemented.
- In the following 4 weeks I had very good discussions with Ministry people – Chief Medical Officer and a policy advisor – and we agreed the summary of discussions would be written up by them, sent to me to agree on, so I could circulate to all of you as the stakeholder group with the most interest in this.
- There were considerable delays during May and June, for a variety of reasons. It was not until the end of July that we has an agreed summary of discussions between the Ministry and myself on the proposal. You will know how important precise wording can be in such matters and it was a struggle.

I'm attaching the draft of where the proposal is at now. Note that this is for discussion with the ministry only. It is not an agreed position with them. Also, this has not quite full agreement of the ministry about

final wording, but we are almost there. It is closely aligned to the Australian system where drugs that don't meet PBAC criteria for listing on their schedule (the PBS) because of cost, get referred to a separate process called the LSDP.

<http://www.health.gov.au/internet/main/publishing.nsf/Content/lsdp-criteria>

Current state of play:

The ministry has to do work internally to consult with different officials about the implications of this proposed new policy. I have asked that patient groups interested in this can be involved in discussions about that, but they are not committing to that (nor openly rejecting the idea). They will eventually give advice to the minister about the proposal.

This proposal is not in isolation from other things:

- Pharmac had stated on its website that they would “form a view by the end of the year on future use of such funding pilots”. (Website update 12 April 2018.) But they have brought this forward and, in a rush, have sent out an RFP to drug suppliers for rare diseases. The close off is 3 September with review of proposal by their new PTAC sub-committee for rare diseases, due in November.
- The minister's letter of expectations to Pharmac (done each year to outline what he wants them to focus on) is also attached for information, and has clear statements about equity and about progress on drugs for rare diseases.
- Pharmac's rushing out of the RFP is clearly because the minister has said he wants progress, and possibly also because Pharmac knows my proposal is being discussed with the ministry and is being followed with interest by the minister's office. Pharmac have a strong incentive to try and show they can deliver on this, or possibly have the responsibility shifted from them.
- Separately I have been in touch with Pharmac about work they are doing on equity which was stated as one of their “bold goals” last year. They had recently confirmed to me they are not doing any work about equity as far as what medicines get funded, is concerned. What they are talking about is equity of uptake for drugs that have been funded, and that is a very different issue, and possibly a big side-step by Pharmac. My request to meet with them is about getting clarification on this issue.
- I'm asking Pharmac for a meeting about their response to the equity issue, and to try to clear up the mixed message they are giving out about what they will actually do in response to it. I'm asking that they meet with me and Collette from NZORD together, and a couple of ministry officials who deal with medicine policy have expressed an interest in coming along to that meeting too. (I had briefed them on the contradictory statements from Pharmac).

My apologies for the long delay in getting this to you. But I guess you can see how the delays came about, and also guess at some of the likely reasons for it being such a difficult and slow process.

Any questions?

Cheers, john

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