

**From:** John Forman

**Sent:** 19 July, 2017 3:31 PM

To all members of the Health select committee of Parliament.

This submission attempts to provide the “right of reply” that I asked for at the end of Pharmac’s responses to your questions on Wednesday 5 July.

There are many points of contention with the responses given by both the Ministry of Health and Pharmac to the petition of Samantha Lenik about funding of medicines for rare diseases. There seem to be considerable efforts on the part of both agencies to obscure or deflect many of the issues raised in the petition and related submissions from our side. Responding point by point would bog us down in detail and obscure the essential aspects of our long-standing campaign on this issue, but those points do highlight one of our central themes – that Pharmac is largely free of any effective accountability for our concerns and pleas.

We urge the select committee to dig deeper into this issue and not let the clever words of officials, mask what is a seriously inequitable situation for many patients with rare diseases. Pharmac acts according to its own will and there is no other mechanism available to us, beyond the select committee, to see that the issues are explored in a meaningful way. We are advised that they do not have a reviewable consultation process that determines whether our medicines will get onto a priority list, nor how our interests are considered by Pharmac or PTAC. We are also advised they are not subject to the H&D Code of Rights as they are not a “provider”.

Pharmac’s CEO, Steffan Crausaz, in response to questions about an “equity lens” in its decision-making, repeatedly defaulted to an “equality” perspective, where every medicine and every patient group was on an equal footing. He avoided the essence of the petition and submissions by concentrating on the “best health outcomes” at a population level, and ignored the arguments we made about the disadvantage of rarity especially where novel therapies are concerned.

The “moral position” that Steffan outlined was all about this population-wide consideration, and the simplistic utilitarian ethic of the greatest good for the greatest number. But that ignores the guidance in the Health & Disability Act about:

- reduction of health disparities for Maori and other population groups,
- ... to promote effective care or support for those in need of personal health services
- ... to reduce, with a view to eliminating, health outcome disparities between various population groups within New Zealand by developing and implementing, in consultation with the groups concerned, services and programmes designed to raise their health outcomes to those of other New Zealanders
- ... to exhibit a sense of social responsibility by having regard to the interests of the people to whom it provides....., services
- ... to uphold the ethical and quality standards commonly expected of providers of services and of public sector organisations

Pharmac's stance also misses the guidance in the Health Strategy, both the old one and the recent new one, which specifies:

- One of its aims is improved health and equity for all populations.

And the guidance in the strategy's "roadmap of actions" which mentions equity in 12 places, including:

- Planners continuously improve services to better meet these needs and improve outcomes and the equity of outcomes.

As a positive example of the principles of the Act and the Health strategy in action elsewhere in the health system, I have been involved in a recent review of the National Screening committee strategic plan and it is just FULL of emphasis on equity, and a whole lot of actions that aim to achieve this.

So why does Pharmac act so differently?

The problem is the section of the Act giving specific objectives to Pharmac which is then interpreted by them as having a narrow focus on population-wide health outcomes, with an emphasis on cost per QALY as their major decision factor.

They could have taken a more generous and equity-based approach, but they don't. They have rejected any special consideration of equity and ethics in their decision-making, despite being a purchasing agent for DHBs who do have those responsibilities specified in the Act and the Strategy.

Thus, Pharmac's rejection of equity as a basis for decision-making is calculated and deliberate. They focus on their narrow approach to the exclusion of equity principles which permeate every other part of our public health system.

The solution is not so much about getting Pharmac to change (though that would be good to see), but instead, leaving them to get on with the good work they do in getting good deals on bulk medicine purchases for the bulk of the population, and putting the responsibility for orphan drugs for rare diseases under the auspices of a separate body with its own special budget for this purpose, and with clear guidance about achieving equity for this very disadvantaged population.

This can be and has been successfully implemented in other places throughout the world. The reports Pharmac has sought on these points in the past have clearly been from chosen authors sympathetic to Pharmac's approach.

A separate fund with a separate decision maker has been endorsed by three political parties (Labour, Greens and NZ First) in the leadup to the last general election. The National party said it would look to the rare diseases fund to achieve better outcomes for rare disease patients, and we submit that exercise has not delivered as expected.

We believe we are addressing a significant and serious problem in our health system, which is gaining traction with many politicians. Please do not let Pharmac divert your attention with its clever presentation of facts, figures and arguments.

Please also note that the way Pharmac operates regarding medicines is the last vestige of neo-liberal health economics that were prominent in the 1990s and which was rejected in the 2000 Act. It is the only part of our health system where equity is deliberately excluded by an unaccountable agency, leaving us abandoned and without hope.

We submit there is a higher-level government responsibility that matters here, and the committee should report to Parliament that current arrangements (especially as interpreted narrowly by Pharmac) fail to achieve equity for people with rare diseases, and a change to the act or a significant change in policy needs to come from government, to fix the problem and produce a fair and equitable outcome for us.

Yours sincerely,

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