



Wednesday 30 September, 2020

Rt Hon Jacinda Ardern  
Prime Minister  
Parliament Buildings  
Wellington 6160  
By email: [j.ardern@ministers.govt.nz](mailto:j.ardern@ministers.govt.nz)

Cc: Hon Chris Hipkins  
Minister of Health  
By email: [c.hipkins@ministers.govt.nz](mailto:c.hipkins@ministers.govt.nz)

Dear Prime Minister,

I am writing to inform you of deeply flawed decision-making and gross obfuscation on the part of your drug-buying agency, Pharmac.

I understand that the Government prefers not to intervene in Pharmac's processes and decisions on grounds of maintaining its 'independence', but you need to be aware that this taxpayer-funded government agency is failing in its core functions, and urgently needs to be independently investigated and held to account.

I am writing to you because there is no other avenue to achieve justice for our patients on this matter, and all of our attempts over several weeks to engage with your Minister of Health have been declined. To ensure this issue is properly drawn to the attention of the public, we are sharing this letter with the media.

Recently Pharmac arrived at a decision not to fund any further drugs for the treatment of severe inflammatory bowel disease (IBD) in patients who have failed every other funded treatment. They regard it as not cost effective. The drugs we urgently need are mainstream treatments funded throughout the Western world – in 37 countries – but not in NZ. There are currently five additional drugs funded to treat IBD in other countries. There have been no new drugs funded for IBD in NZ since 2011. The options for NZ patients in this situation are multiple hospitalisations, usually through the emergency department, and irreversible surgeries to remove sections of the bowel, often culminating in permanent stoma bags. Consigning people (most of whom are children and young adults) to lives with severe pain, disfiguring surgery and social isolation is unnecessary and a heavy cost to the health system.

Dr Malcolm Arnold (President of the New Zealand Society of Gastroenterology) and I met recently with Pharmac Deputy Medical Director Dr Peter Murray and other senior Pharmac executives to attempt to understand this inexplicable and inhumane decision. We were astounded by Pharmac's lack of knowledge on current direct health costs for IBD patients failing conventional treatments, and to learn that Pharmac does not actually have the data on the most important current treatment costs. Incredibly, they asked us if we could provide the data to them!

Despite a lengthy follow-up description from Pharmac's Medical Director, Dr Ken Clark, of the organisation's cost-utility assessment methodology and its processes, it has become clear to me that the Pharmac model is deeply flawed. No matter what the processes are, if the data Pharmac puts into its models is incorrect with false assumptions, then the results of such models will also be flawed.

Even without counting the indirect health costs of ruined lives and lost productivity, we know that the treatments we are asking for are affordable when weighed against the current health system costs, including futile double

dosing of current funded treatments (eg infliximab). How is it that the rest of the Western world saw fit to fund these treatments, but Pharmac does not? Does it mean New Zealanders are worth less?

For many years I had read and believed the Pharmac-generated spin about the great job it does using data and tough negotiations to improve access to drugs for New Zealanders. However, having interacted with Pharmac staff over this specific issue, I feel embarrassed that I accepted Pharmac decisions in the past. The suggestion that we need to generate data for Pharmac to do its job, is simply bizarre. Surely it is Pharmac's role to know how and where drugs are being prescribed in New Zealand? Surely it is Pharmac's responsibility to ensure that the right data is entered into their models to ensure that the right decisions on drug access are made for New Zealanders?

In searching Pharmac's website for insight into its processes, I discovered its six strategic priorities:

- enhance key functions
- medical devices
- equitable access and use
- data and analytics
- public understanding, trust and confidence
- relationships and partnerships.

In our interactions with Pharmac on this issue, it is clear these do not apply. Pharmac has **failed to enhance its key functions**, it **denies equitable access to IBD patients** (whilst those with similar inflammatory diseases have multiple funded treatment options), it **asks others to generate the data that it needs and uses incorrect assumptions** (even though it should have these data), it **has lost the trust and confidence of the public** (30,000 signatories to a petition at present [www.wecantwait.nz](http://www.wecantwait.nz)) and has **failed to engage in meaningful relationships through a lack of transparency** in its dealings.

Dr Clark concluded his email to me by stating "...we believe we are all looking for the same end result – better outcomes for people with IBD." The actions of Pharmac to date on this issue demonstrate that this is patently untrue. If Pharmac was genuinely looking for "better outcomes for people with IBD" it would acknowledge these realities and proceed actively and urgently with the processes required to fund this medicine.

I am happy to provide you with a full record of my exchange with Pharmac, and my colleagues and I are more than willing to meet with you if that would achieve meaningful progress on this matter. My views are strongly shared by the membership of the NZ Society of Gastroenterology, the NZ IBD Nurses Group, Crohn's & Colitis NZ, and 20,000 IBD patients and their families throughout NZ. Listed below are the names of 105 colleagues/specialists who personally endorse this letter.

We are not asking you to make an exception with this case. We are asking you to investigate this indefensible decision urgently and ensure that a fair, transparent and rapid process is pursued to provide justice, fairness and compassion to New Zealanders suffering unnecessarily with this terrible disease.

Regards,



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