

Hansard transcript

## **Petition of Belinda Hodson for the Thyroid Association of New Zealand: Help thyroid patients get treatment that works**

Health Committee

5 May 2021

### **Members**

Dr Liz Craig (Chairperson)  
Dr Tracey McLellan (Deputy Chairperson)  
Dr Elizabeth Kerekere  
Dr Anae Neru Leavasa  
Sarah Pallett  
Chris Penk  
Dr Gaurav Sharma  
Penny Simmonds  
Simon Watts

### **Witnesses**

#### **Thyroid Association NZ**

Belinda Hodson, Lead Petitioner, Administrator and Member  
Ann Bradley, Administrator and Member  
Louise Champion, Member  
Isabel Bennett, Member

#### **Ministry of Health**

Andrew Connolly, Chief Medical Officer, Ministry of Health (in an acting role at the ministry on secondment, employed by Counties Manukau DHB)

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- Craig            OK, so we now move to the petition of Belinda Hodson and the Thyroid Association of New Zealand: Help thyroid patients get treatment that works. Welcome. So you've probably seen how we roll. We've got 15 minutes for your submission. Also, if we get a few more questions, we can go for a slightly longer period of time, but we've set aside 15 minutes, and then we've got the ministry to follow on afterwards with their presentation. So I'll hand over to you to introduce your team.
- Hodson        Thank you, Dr Craig. Kia ora koutou. We really appreciate that this is the first time we get to be heard. So, thank you. I'm Belinda. This is Ann Bradley, Louise Champion, Isabel Bennett. I'm going to be speaking to you and taking questions, and they're supporting me.
- Thousands of patients feel vulnerable today because our health is at stake. We've spent six years knocking on the doors of agencies like the Ministry of Health, trying to raise awareness that patients aren't getting the help they

need. Our position is backed up by international patient petitions and endocrine authorities like Anthony Toft, who is highly respected worldwide. However, agencies like the ministry have closed the door on us, and that's why we're here.

Thyroid disease has many causes, affecting people of all ages and ethnicities—80 to 90 percent are women. It is more common than diabetes and heart disease. Left untreated, thyroid disease influences onset of illnesses like cancer and heart disease. One hundred and forty-six thousand New Zealand patients take thyroid medication and are on this for life because there is no cure. We believe 70,000 patients or people out there remain undiagnosed. You've got our submission. Here's the problem.

In New Zealand, diagnostic and treatment practices are maintained through medical training and ongoing education. These work for some patients, but they don't work for all patients. Endocrinologists in America, Britain, and Europe recognise this and, worldwide, thyroid diagnosis and treatment is undergoing change. But New Zealand is lagging behind. This leaves patients with a problem, and there are two types of problems.

The first is that thousands of patients have found alternative treatments that work much better for them. However, these treatments are unaffordable to many, and those patients who can afford them fear being taken off them. Not all doctors know about them, because they are not taught about them. Those that do feel they have to prescribe under the radar because of fear of unauthorised practice. For example, the four of us and 10,000 hypothyroid patients only get symptom relief on medications containing thyroid hormone T3. We've had terrible trouble finding a prescriber. On the standard treatment, Levothyroxine, I suffered hair loss, debilitating fatigue, weight gain, brain fog, low blood pressure, high cholesterol, crippling pain, and many other symptoms. Sustaining employment was difficult. Changing my medication to T3 turned this around, and I've been symptom-free for 13 years.

T3 is not Pharmac-funded; Levothyroxine is. I pay \$14,000 every year for treatment, and I don't get insurance either. We fear that once our doctors retire, the next clinician who takes over will switch us back to Levothyroxine or reduce our dose of T3, forcing us back to a life of terrible symptoms. We have good reason to be afraid, because the Medical Council did exactly this to patients in 2014.

That's the first group of patients. Then there's the second group. Thousands of hypo- and hyperthyroid patients don't know their care is being mismanaged, because their GPs don't know that what they are told to do is suboptimal. And because the doctor doesn't know, they tell patients their symptoms are the "new normal". Many are told symptoms are due to other causes. This includes patients making up or imagining their symptoms. Some accuse patients of non-compliance with their medication. Others test patients for other illness or ply them with Pharmac-funded medications or therapies like antidepressants that don't work. Patients who ask for alternative treatments are told "it's dangerous", "there are no studies", "stop reading

pseudo-science”, or “patients who report benefits on T3 are hysterical”. This is degrading. The four of us have all been there. It took 15 years, seeing eight doctors and endocrinologists, before I got a diagnosis.

Our association educates patients to ask doctors for the right blood tests and treatments. We help thousands of patients do this. Two thousand, one hundred and forty-seven doctors have prescribed alternative thyroid treatments because they recognise that standard treatments don't work for all patients. No one knows the cost of mismanaged care. It's not being measured. We think the cost of consults, tests for other illness, and Pharmac-funded medications that don't help patients is big. Studies that monitor the impact of medical practice on patients have not been done either.

The right doctor education, widening access to T3, and thyroid hormone tests could reduce the overall cost to the health system and return patients to good health and employment like the four of us. Instead, New Zealand is going in the opposite direction. Proposed changes to the Medicines Act aim to further restrict access to T3, and it is difficult for doctors to order thyroid hormone tests in most circumstances.

The Ministry of Health is up next. They might tell you that thyroid disease is uncommon, but Levothyroxine, the standard treatment for hypothyroidism, is one of the most frequently used drugs worldwide. They might tell you they know diagnosis and treatment is undergoing change, but won't authorise alternative approaches until there is conclusive proof. Endocrinologists in America, Britain, and Europe say withholding alternative treatments while waiting for gold-standard proof causes harm. In Britain, endocrinologists say that when T3 is withdrawn, the hypothyroid symptoms that return are so severe that some patients contemplate suicide.

The ministry might insist that patients' complaints on the standard treatment is always due to other physical and psychological causes. This has been disproven by endocrine authorities in America, Britain, and Europe. That's why endocrinologists in other countries are prescribing alternative treatments but New Zealand is lagging behind.

And, finally, the ministry might defend the status quo or say their experts are more authoritative than ours. In February 2021, endocrinologists who develop guidelines in America, Britain, and Europe published consensus statements that support our case. The ministry and other agencies we've approached have failed to meaningfully engage with the medical evidence we cite.

To this, we also say: where does the patient's voice sit in all of this? It won't help patients to maintain the status quo. It won't help patients if guidelines and medical training are reviewed without input from our association, the doctors who are helping us, and unbiased oversight.

So finally, this brings us to you. Without your help, the situation won't change. We face the same problems as endometriosis patients and patients harmed by surgical mesh. Parliament helped these patients by encouraging the Ministry of Health to hear from patients about their experiences. A

restorative justice process followed, raising awareness at the Medical Council and Royal Australasian College of Physicians that mesh protocols practised by their members were harming patients—and remember, they didn't think they were harming patients before they petitioned Parliament. We face the same problems, and we are asking Parliament to encourage the ministry to run these processes for thyroid patients. Raised awareness is needed as impetus for change. This really will help us.

We understand it's hard to hear things aren't working, and we're empathetic. We want to leave blame behind and work in good faith with medical professionals and the Ministry of Health on solutions so that all patients get the help they need and doctors use approaches that work for everyone. We hope the Ministry of Health do too and help you help us to make this happen.

Craig Thank you. Thank you for your submission. I've got a couple of questions here.

Watts Firstly, thank you all very much. I can sense it in the way in which you talk and articulate and the significant amount of information that you've provided that you guys are on a lifelong crusade—I think would be the right word—in order to improve this situation. You said, "Where does the patient's voice sit?" Well, the patient's voice needs to sit in the centre of the system in terms of health. I think we would all agree around this table that that is critically important. So to articulate what you're wanting from the ministry, very clearly, is you are asking for an inquiry into thyroid diagnosis and treatment.

Hodson Yes.

Watts Is that correct? Just be very clear. Walking out of here today, when the ministry come in after you, what do you want?

Hodson What we want—yes, we do want an inquiry. What we want is two things. There is actually a relationship problem between the endocrinologists, who developed the guidelines and medical training, and the patients, and there isn't a lot of listening, and so that relationship needs to be healed. So that's why we are asking the Ministry of Health to give patients like us an opportunity to tell our stories, so they become aware of the reality for the patients who don't get what they need.

A restorative justice process followed for mesh patients after they did that, and we think that that will help us, because what they did is they got people from the Medical Council and the Royal College of Physicians to actually sit there and listen to the reality for patients who didn't get the help that they need. And patients are being harmed, and they don't acknowledge it. They don't want to acknowledge it because they've been doing the same thing for the last 30 years, and that needs to change. I hope that answers your question.

Penk Thank you very much, Madam Chair. My question is sort of along similar lines, so if you can treat it essentially as a supplementary to that of my colleague. Again though, please allow me to salute you for your advocacy and

your courage, indeed, in speaking to your petition. Obviously, it affects you personally but also many, many others.

I suppose my question's a slightly different angle, from the point of view that I don't understand from reading your submission—it might be something that I've missed. Is it simply a lack of understanding in terms of, you know, that connection between those who are prescribing—it's probably the wrong word, but, you know, setting the policy, essentially—versus the lived experience? Is there a reason for that? I mean, is it a cost pressure, so far as you can understand, or is it that you haven't been able to have your voice heard sufficiently to be taken seriously in that way?

Hodson It's all of those things. Also, one of the things that Toft says, who's right at the top of the food chain, is that the motivation for the current guidelines and education we have has not followed the normal path for other medical diseases. So if you look at all the science of thyroid physiology, there's a lot more sitting out there that hasn't been incorporated into the design of randomised control trials, and the patient's voice hasn't been put into that either. People like myself who don't do well on the standard treatment—we have not been properly studied.

Penk OK.

Hodson So those are big factors. So the listening is really important. And at the moment, there's a lot of argument in the international endocrinology community about research, because a lot has come out in the last decade challenging what's been historically done. So that's why it's even more important that patients like us are listened to.

Penk Understood. That's helpful. Thank you.

Hodson And we represent thousands of patients.

Pallett Thank you, Madam Chair. Sorry, did you want to add something?

Champion I was just going to say that our practitioner education is related to that as well, so there's a lack of—

Penk So it's literally in medical schools to teach.

Hodson They don't understand it, yep.

Champion There is a very, very small amount of education that is provided.

Bradley I can say that 30 years ago, I got better treatment from a GP, a more thorough examination, that I wouldn't get now because they're not trained in it. And my mother, who had the same condition—she was on a better treatment and better treated than I am now. So a lot's being lost. The rules have changed—it's got worse. We expect in the modern day and age for our treatment to be much improved.

Penk It's just disheartening but a helpful detail. Thank you.

Pallett Thank you so much for your very comprehensive submission and for your courage and advocacy in coming forward. That's much appreciated. I actually had an approach from a constituent with this particular issue, so I'm

particularly interested in this. And I just wanted to ask—and this is probably one of those daft questions, right? Is there a simple and inexpensive way to determine whether Levothyroxine is going to work for patients who are diagnosed with thyroid disorders?

Hodson Yes, you trial them on medication. So you trial them on the medication, but it's not—thyroid disease is very, very complex. So a lot of the doctors that really know how to do this in New Zealand—and there's less than 20 of them, and they're about to retire—they go through a lot of symptom assessment, physical exam. The blood tests don't pick up all the symptoms. Then they go into the blood tests. Then they start with one medication. If it doesn't work, then they move to another one. So it's quite a staged process. Yeah.

Pallett So you're perhaps advocating for more specialist care at that point?

Hodson Yeah. I mean, my doctor is a specialist. He's not an endocrinologist, but he specialises in this. And, you know, it's a really—the physiology is really, really complex because it's a hormone. So, you know, he's spent years working with patients and studying and reading and learning and trialling. You know, I know that there's real medical professionals like to my right. Let's just run this test and get a treatment because they're time-pressured, right? But actually, it's a lot more complex than that. Yeah.

Bradley One of the other problems that I've struck over the years—as I said, I've been a patient since I was in my early 20s—they now don't run the full gamut of tests. So they're relying on a TSH test. If it's in a normal range between A and B, you're fine and the other tests aren't done. So my doctor will send for a TSH test, a T4, and a T3, and the local DHB will just do the TSH test and they won't do the other tests. So other people aren't getting the full range.

Craig OK. Well, thank you very much for a very comprehensive submission. Now, you're welcome to stay for the ministry's presentation next, and obviously we'll have some questions there as well. So thank you very much.

Hodson Thank you very much.

Craig Andrew, welcome and thank you for attending. So we've set aside 15 minutes for your submission, and we would love to have some time for questions during that. I'll hand over to you to introduce yourself.

Connolly Thanks, Madam Chair. Andrew Connolly. For the committee's knowledge, I am a general surgeon and therefore originally trained in endocrine disease, but I don't practise as a specialist in that area. I'm in an acting role at the ministry. I'm employed by Counties Manukau DHB.

I'd first like to acknowledge the petitioners, and I suspect we'll find that from a clinical point of view I have a lot of commonality with their comments.

For the benefit of the committee, just the history—and as you're aware, Pharmac make the decisions. In 2018, I'm advised that Pharmac last explored this issue, and at that stage we know the result was not to recommend the funding of T3 or anything other than T4. The importance, I think, of time has been, as we've heard, that the world has moved somewhat, and there is this growing knowledge that some patients—and I don't know the

proportion, but some patients—actually lack an enzyme to allow the breakdown of T4 to T3. Hence why, I think, some patients are gaining benefit from T3. I should also state that I did chair the Medical Council. I was involved in discussions around one practitioner and, in fact, we found no case to answer. So I just put that on the record. Possibly a practitioner who has been referred to here.

The history of introduction of new drugs and technology obviously should, from a medical standpoint, involve randomised controlled trials. I would agree with the petitioners that a criticism of many of the trials have been that they did not go on to sub-analyse or further explore that group of patients who failed to have benefit from T4. There is, and indeed the *Thyroid* publication in February of this year does refer to ongoing trials in that area. Pharmac have advised they would be open to receive a new application, and they use the term “if new evidence can be considered”. I don’t know the time frame for those trials, but, in summary, it does, I think, raise important questions about how new treatments are introduced and changes made to our array of pharmaceutical items. The Pharmac review may be another opportunity for the petitioners to raise concerns.

In terms of lab testing, it is correct that if the TSH, which is a marker of thyroid function, is in the normal range, most laboratories without a specialist endocrinologist request will not test for T3. T3 and T4 is available routinely if required and, I’m informed, is routinely provided in cases of overactive thyroid disease. Internationally, yes, various international agencies certainly cover the role of T3, and it’s not seen as witchcraft. It’s, I think, simply a case of how it fits into the New Zealand health system and how the funding arrangements currently are problematic.

The concern clinically from endocrinologists—and this is anecdotal—is the overactivity of the thyroid, of course, is as risky as underactivity, and therefore there are concerns about patients not being adequately monitored and so forth, which I think raises the debate around whether the lab tests are the most effective way forward. So, hopefully, that has helped the committee understand where we currently are. But Pharmac are happy to reconsider. Thank you.

Craig            So in terms of the relationships with the patient being at the centre of—you know, having a voice and thinking about clinical guidelines, clinical pathways, where are we up to in terms of updating those and considering new evidence?

Connolly        A very good question. Thank you. Obviously, the patient should be the centre of any of these discussions. I think in public practice and for any patient who does not have the remotest chance of that type of cost that we’ve heard about, probably, unfortunately, the discussion does focus on treatments that are available and funded. However, the Health and Disability Commission did some years ago make it clear that we have an obligation to raise options that patients may wish to consider, including non-funded treatments.

In terms of the guidelines, the Best Practice Advocacy Centre out of Otago handle guidelines for general practice. The Royal Australasian College of Physicians, via their endocrine section, would handle the guidelines for

endocrinology practice. The role I can provide at the ministry is through meeting with the colleges and to stimulate this discussion. Similarly with the Medical Council, because the council, in conjunction with the Australian Medical Council, credential the specialist training colleges.

Here, that would include exclusively the role of our Medical Council regarding general practice. Historically, those processes have not got into the nitty-gritty of the curricula of each college. It's more around their ability to train and their effectiveness as trainers. But I think when accreditation does occur, there are opportunities for patient groups to feed into those processes, and I'm very happy to raise with the council how they advertise that opportunity. I'm not sure when the general practice college is next due, and the RACP is probably within the next couple of years.

Leavasa            Thanks Andrew. I'd like to acknowledge the petitioners today as well. So my background is a GP. I've treated many of our thyroid disorders in the community. My question is: just in terms of the speciality of endocrinology, what is your sense then—maybe I've missed that in your talk—of where they sit at the moment then in terms of the evidence? I know our petitioners have presented on one paper. So I guess, is there a consensus from the endocrinologists at this point?

Connolly            Broadly speaking, the ones I've spoken to in preparation for today are certainly more conservative and are awaiting the trials, and I think that highlights the concerns of the petitioners. I think we're quite well served for endocrinology as a workforce. A lot of their thyroid work is involved around cancer diagnosis and working up thyroid nodules and so forth. I think, as we heard from the petitioners, one of the problems with particularly an underactive thyroid—and I'm sure you saw this in clinical practice—is whether we believe the lab tests, if you're on the fringe of the normal range of the lab test. And I think that's where differences between the endocrinology community and the current practitioners who are prescribing T3 probably starts to lie around that—are you better to be in the high normal versus the low normal and that type of debate. Frankly, I don't see an obvious solution to that debate until probably we see better evidence from the trials.

Bradley/Hodson      Come and talk to us.

Watts                Look, I guess I'm encouraged to hear, Andrew, in terms of the review by Pharmac in terms of the funding being part of a solution here, and I'm keen to see that progress through. Also around the clinical pathway aspect. I think, you know, you think about triple therapy in other aspects. What is that type of pathway so that we've got standard care in terms of reducing variation is also important. I guess clinically, just for us around the table, what is the consequence on individuals of not managing a thyroid disorder? Because I understand mental health, hypothyroidism—all of that. Can you give us a 30-second flavour of the social consequence of why this is important?

Connolly            Well, it can be catastrophic. If you're hypothyroid, you completely lack energy; don't want to get out of bed, which starts to affect your mental wellbeing; falling asleep at work; weight gain. And obviously, if you're pregnant and you're hypothyroid, the fetus is at significant risk. At the other



end, hyperthyroidism has major effects on particularly the heart. And one of the concerns about this debate around being in the high-range versus the mid-range comes around what's called atrial fibrillation, which is where the heart beats irregularly, which can predispose to strokes and so forth. Overactive thyroid, again, can lead to mental health issues. A bit like that rabbit in the headlights is probably the easiest way of describing it: hyperactive, so on and so forth.

As we heard with the petitioners, I think there's general acceptance, including from the endocrine community, that there are patients for whom T4 is not necessarily the solution or hasn't worked as desired. I think my personal feeling is that getting the issue around whether T3 should be funded is probably the key factor, as opposed to a complete lack of understanding about the role of T3.

Watts Thank you for your clarification.

Craig Thank you. Now, we are at time, so thank you for your time, and thank you, Belinda and team, for raising this issue with us. And thank you, Andrew, for coming and presenting. We will take the time now to consider your submissions. Thank you very much.

**conclusion of evidence**