

It was an honour to represent CLLANZ at the Valuing Life Summit, along with our Chair, Catherine Isaac. See the full agenda here [www.valuinglife.nz](http://www.valuinglife.nz)

Hon David Seymour, Associate Minister for Health (Pharmac), opened the Summit in Parliament's Grand Hall. It was an historic occasion: a Minister fronting up and collaborating with patients and patient advocacy groups (led by Patient Voice Aotearoa), the pharmaceutical industry (led by Medicines NZ), many outstanding NZ and Australian clinicians, and senior Pharmac and Ministry of Health officials. Paula Bennett, the new Pharmac Chair, was also there for the full day, listening. This was the first ever time that all of these groups have come together, and it felt like a huge step forward

The scene was set with a very moving opening address delivered by two incredible young women: Fiona Tolich, Spinal Muscular Atrophy Advocate and now medical refugee who has been forced to relocate to Australia to access treatment; and Emma Purchase, speaking about her horrendous experience of her young husband's diagnosis with late-stage bowel cancer, the grief and crushing financial pressure of needing medicine that is funded worldwide but not in our country, and the terrible journey to his death, leaving Emma with two very young children.

Doctors treating a wide range of diseases talked about their frustration and anguish at not being able to provide the best treatments for their patients. They urged the government to recognise the wider and long-term societal benefits of keeping people healthy. Pharmac was criticised for its lengthy, unwieldy, and opaque processes. A recurring theme was the importance of patient engagement and "voice" in their decision-making processes, and indeed for all stakeholders to have their say.

One thing that surprised me was that in terms of research and development New Zealand punches well above its weight. There is a world-wide trend towards precision medicine – treating patients according to their genomics. It seems that we are well regarded for our innovation in this field, but practitioners don't have the choice of medicines needed to tailor the treatment to their patient. A highlight of the day was a discussion with a superb panel of doctors, including pioneering haematologist Rob Weinkove, Clinical Director of the Malaghan Institute. Rob is the leader of NZ's CAR-T cell therapy development, currently in trials. Read about this transformative treatment here: <https://www.malaghan.org.nz/our-research/car-t-cell/>

The workshops focused on the health technology process, improved patient engagement in Pharmac's decisions, looking at innovation and technology within New Zealand and a national medicines strategy. White papers from these workshops will be presented to the Minister.

In his opening address, Minister Seymour announced a significant increase in funding for Pharmac over the next four years. See the details here <https://www.beehive.govt.nz/release/government-saves-access-medicines> Unfortunately, it's not sufficient to fund any new treatments, and will be just enough to maintain the cost of current approved treatments. This is due to what he described as a \$1.7 billion fiscal 'cliff' created by previous governments' not budgeting for current approved treatments

continuing over the next four years. So the 140 applications for priority treatments in Pharmac's Options for Investment List, many of which are international standard-of-care treatments, will remain on the waiting list. See the list here:

<https://connect.pharmac.govt.nz/apptracker> We are so far behind the rest of the world and it was widely agreed that notwithstanding the current economic constraints, the Government should at least acknowledge that medicines are underfunded in NZ.

It was not clear what is to happen with the 13 cancer drugs the National Party promised in the election, though it seems this could be addressed separately.

The second day started with a 'breakfast with the politicians,' although Todd Stephenson and NZ First's Jenny Marcroft were the only two who attended. Todd acquitted himself well in a panel session, fielding some difficult questions.

The remainder of the morning was devoted to working out how to optimize the patient voice in New Zealand and the next steps that should be taken to use the strength we found in collaborating at this Summit.

Rachel Smalley of The Medicine Gap <https://themedicinegap.co.nz/> gave an excellent presentation on media relations and how best to engage and connect with journalists. Among many good pointers she spoke of the importance of illustrating your release or article with patient stories with lived experience, and the need to choose a journalist who is likely to empathize with the story.

Everyone agreed that going forward it was important for advocacy groups to be on the same page and that better communication was key to this. It was agreed that under the umbrella of Patient Voice Aotearoa (PVA) we could move forward as one. But there was concern about the sustainability of Malcolm Mulholland's role, given the huge amount of time he gives to keep PVA alive, organizing campaigns and being permanently on call to front to the media. Catherine raised this issue at the meeting, and suggested our individual advocacy groups could contribute some funding to help cover Malcolm's time and costs, perhaps in the form of a membership koha. There seemed to be general support for this, and it will be taken up by the major advocacy groups (CANGO) after the summit. Richard Vines, Australia's leading patient advocate and founder of Rare Cancers Australia, suggested we consider looking to pharmaceutical companies to support this.

The tone at the end of that morning was one of optimism and hope. It was a great initiative in that it allowed leading edge clinicians, researchers, government agencies, advisory committee members, patients, advocates, and other key stakeholders to come together in the same room and work constructively. It can surely only get better from here on.

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