



20th October 2021

The Pharmac Review Committee
C/- Sarah Davies, Head of Secretariat, PHARMAC Review
83 Molesworth Street, Wellington
Phone 021 324615
Sarah.Davies@health.govt.nz

Kia Ora Koutou

Lung Foundation New Zealand (LFNZ) is a non-government organisation (patient advocacy group) dedicated to increasing survival for lung cancer.

Following our participation in the patient group meeting hosted by The Pharmac Review Committee on 16th July in Wellington, as a member of CANGO (Cancer Non-Government Organisations), we have taken the opportunity to provide some words from a very brave lung cancer patient to add context to our submission of 16th July 2021.

Maggie Fagan of Tauranga is one of more than 2000 patients diagnosed with lung cancer every year in NZ. Maggie tells us how she is coping the best she can with her diagnosis. Sadly, her cancer journey has been more challenging, because of the lack of access to standard of care treatments in public health.

Access to healthcare should be a human right not an entitlement that needs to be paid for...

30 patients with lung cancer die prematurely every week in NZ, primarily because they cannot get access to a standard of care treatment (a targeted therapy and/or immunotherapy), unless they can self-fund.

Maggie Fagan - October 2020

Maggie Fagan - October 2021





Maggie Fagan - 18 October 2021

It doesn't seem long since I wrote my submission in June (below) but I have had changes already. I got 14 months from tarceva (erlotinib) as my first line treatment. I have now had to move on to second line tagrisso (osimertinib) which would have been first line had I lived in Australia, UK, EU, USA and the bulk of the other OECD countries.

We cannot afford to pay for access to osimertinib (a drug made by AstraZeneca), which I believe is about \$13,000 a month, paid every other month until I've paid \$93,000. Cancer robbed me overnight of my income as a midwife of 35 years. We now live off one income and savings. We import from Bangladesh a generic version of osimertinib which still costs me \$700 per month. Meanwhile NZ and Pharmac now save \$1400 a month that my pharmacist told me Erlotinib costs.

If I had received AstraZeneca's tagrisso (osimertinib) from the start I would very likely have had a longer disease free progression than I got with Tarveva. I know there have been submissions for years and I beg you to fund this for all those people who are about to get this lung cancer diagnosis.

It could be any of you on this hearing committee, it doesn't discriminate and it changes your life, your hopes and your plans and it decimates families. The one thing we shouldn't have to worry about is funding life-saving drugs, the world has moved on from erlotinib and we must too.

After delivering up to 1000 babies in my career I just want the chance to hold a grandchild of my own. Every cancer patient has something they are holding on for, osimertinib is the gold standard that every country should aspire to, do not leave us behind. Give people some hope for their future. Photos included were taken a year apart, life changing.

Maggie Fagan - 22 June 2021

Today is my 1st Cancerversary. I am 57 this week. Yay, because I wasn't meant to see today. A year ago today I was diagnosed with stage four non small cell lung cancer. How did that happen I've never smoked but apparently 10% of us who get it have never smoked. It's more prevalent in women and it's generally found when it's too late. The focus and blame continues to be directed (stigmatised) towards people who smoke. That isn't my story. I only had subtle signs for a month, such a short time and there is no stage five. The prognosis was dire. Imagine not seeing the coming Christmas.

However, a tumour mutation that only 1:6 have, earned me a targeted med, a tyrosine kinase inhibitor (TKI), a once a day pill, which means I'm still here. NZ's Pharmac funds the drug tarceva (erlotinib) that the rest of the modern world has left behind for something better.

But fingers crossed it keeps working for as long as possible, because there's the rub at some stage the sneaky cancer will work out how to get round it. Any further meds, I will have to fund myself for \$11,000 a month, if I want to stay around longer. So every cancerversary is a huge celebration. Each generation of tki's gives us more hope and longer with our families.

I think what Pharmac doesn't see is that stage 4 does not define us, it doesn't describe a steady decline towards death. The meds kindly developed for us gives us our lives back, we are living in reverse and unlike everyone else we get more days to live every day we take our tki's.

Our symptoms improve and we get a reprieve. The science is strong and the evidence is clear. I read the last committee recommendation at the last refusal. You made it sound as if I was on my deathbed and that it would be a waste of resources. This is far from the truth. Please fund this next generation tki osimertinib for us.



Patient Support

Peer support is vital and it is one of the support services Lung Foundation New Zealand facilitates for patients and carers throughout New Zealand. Many kiwi patients are well informed about their diagnosis and they are also active members of peer support groups hosted abroad, for example in the USA, where all modern treatments are funded.

Pictured below is stage four lung cancer patient, Ashley Rickles of the USA. Ashley is celebrating four (4) years of progression free survival, having had access to tagrisso (osimertinib) as first line treatment at the time of diagnosis.

Ashley Rickles is one of the lung cancer patients Maggie Fagan is in contact with and draws inspiration from. Says Ashley "I surely hope everything works out for you Maggie. You may absolutely share my photo and my story. Please keep me updated. Sending only good vibes your way."

Tomorrow is my four year cancer anniversary.
Just had scans and all is stable while
continuing the almost FOUR YEAR trek on
Tagrisso as a first line. Don't lose hope!!



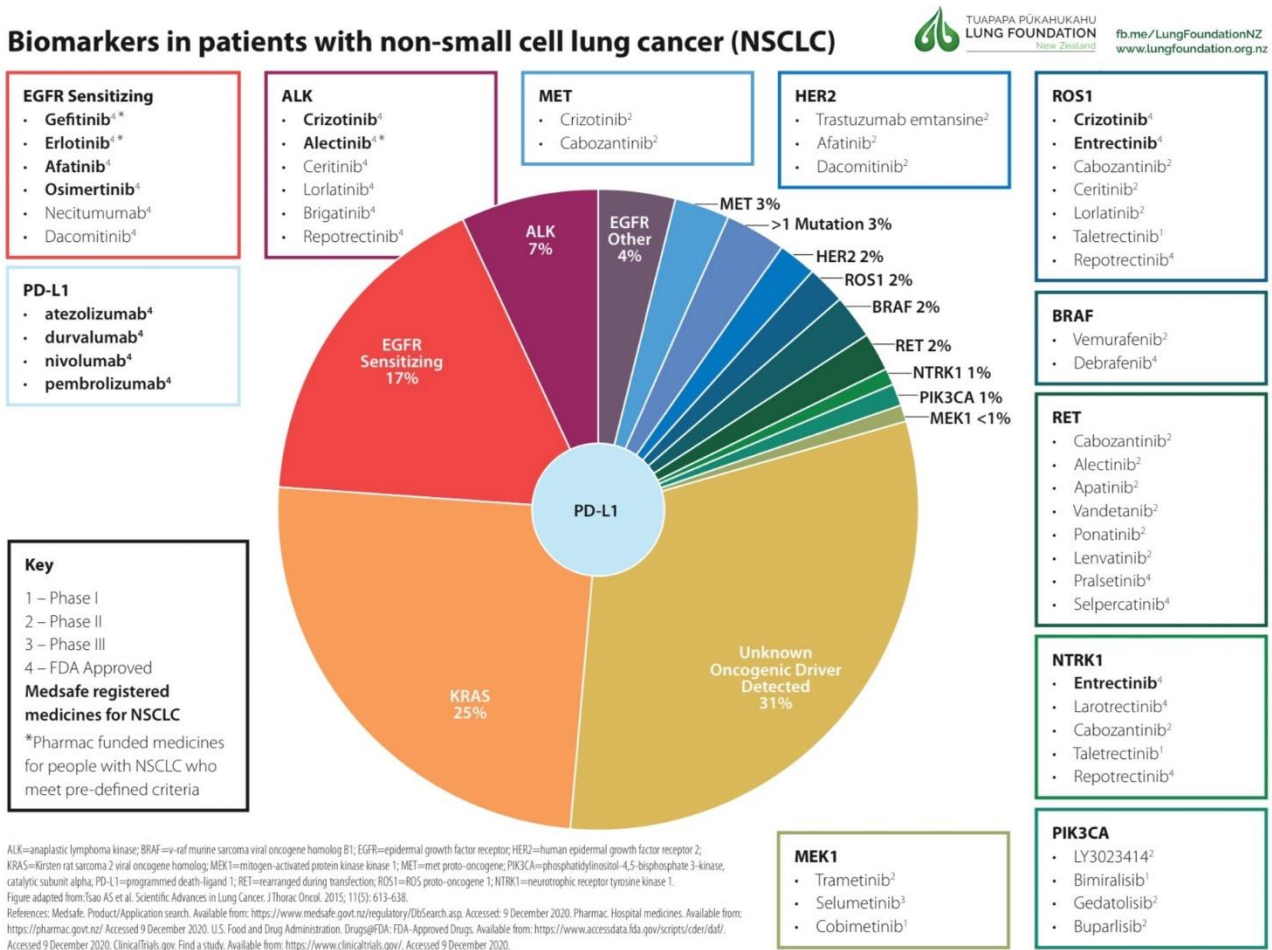
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14 comments



Enclosed below is an infographic which illustrates just how far behind NZ is with reimbursing treatments that would be life changing for our patients.

<https://lungfoundation.org.nz/wp-content/uploads/2021/01/ROC00470-Lung-Biomarker-Graphic-7.0-1.pdf>



What we want you to know about the burden of lung cancer in Aotearoa

Lung cancer kills more people in New Zealand every year, than breast cancer, prostate cancer and melanoma cancer combined.

Every day 5 people die of lung cancer and a further 6 people are diagnosed with lung cancer.

There is a major intersection with other determinants of health, including a quadrupled risk of suicide for lung cancer patients compared to the general population.

Lung cancer causes extreme inequity for Maori

Lung cancer registrations and mortality rates are FOUR times higher in Maori women and nearly THREE times higher in Maori men.

One Maori dies of lung cancer every day in New Zealand.

Lung cancer is the leading and second highest cause of death in Maori females and males respectively.



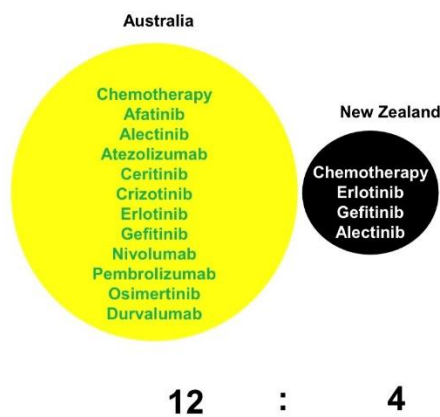
Comparing treatment of Lung Cancer with Australia

Following is a report that compares the treatment of Non-Small Cell Lung Cancer (NSCLC) in New Zealand, with Australia and Europe (NSCLC = 85% of all lung cancers). Whilst dated February 2020, this report is still current for the medicines that are currently reimbursed for lung cancer in New Zealand.

It is disgraceful, that NZ funds just a third of the treatments funded in Australia for what is our BIGGEST CANCER KILLER. Ultimately it is this lack of access that is causing so many patients to die prematurely (unless they have money to self-fund access in private clinic and then face another chronic illness known as financial toxicity).

<https://lungfoundation.org.nz/wp-content/uploads/2020/04/Non-Small-Cell-Lung-Cancer-Treatment-Guidelines-NZ-Compared-FINAL-28-February-2020.pdf>

New Zealand publicly-funded⁴ NSCLC treatment options compared with Australia: as at 28 February 2020



New Zealand publicly-funded⁴ NSCLC treatment options compared with Australia: as at 28 Feb 2020

1. Chemotherapy
2. Erlotinib
3. Gefitinib
4. Alectinib



Source: Australian Pharmaceutical Benefits Scheme

Note: Line of therapy not shown for ALK/EGFR

1. Scovrono SL. Metastatic squamous cell non-small-cell lung cancer (NSCLC): disrupting the drug treatment paradigm with immunotherapies. *Drugs in Context*. 2015;6:212289. doi:10.7571/dic.212289

2. Misha A, Desai S, McCormack R. EGFR mutation incidence in non-small-cell lung cancer of adenocarcinoma histology: a systematic review and global map by ethnicity (mtdMap). *American Journal of Cancer Research*. 2015;5(9):2892-2911

3. Paul Hoffman. ALK in Non-Small Cell Lung Cancer (NSCLC) Pathology, Epidemiology, Detection from Tumor Tissue and Algorithm Diagnosis in a Daily Practice. *Cancers* 2017, 9, 107; doi:10.3390/cancers9080107

4. <https://www.pharmas.govt.nz/medicines/resources/pharmaceutical-schedule/> (accessed Jul 18)

5. <http://www.medicare.gov.au/medicare/medicare-benefits-schedule/1-ARCEWA6> Roche

6. <http://www.medicare.gov.au/medicare/medicare-benefits-schedule/1-ARCEWA6> Astra Zeneca

7. <http://www.medicare.gov.au/medicare/medicare-benefits-schedule/1-ARCEWA6> Astra Zeneca

8. Gandhi et al. Pembrolizumab plus Chemotherapy in Metastatic Non-Small-Cell Lung Cancer. *NEJM* 2018





Lung cancer screening

Despite, lung cancer being New Zealand's biggest cancer killer, we do not yet have a national lung cancer screening programme in place...

Participants (including the writer) that attended a lung cancer screening symposium held earlier this year were told screening for lung cancer is some ten years off being implemented in Aotearoa.

What for equity?

Considering the extreme inequity suffered by Maori, who die prematurely as the result of lung cancer and NZ's responsibility to Maori (captured in Article 3 of the Treaty), the crown clearly has responsibility to protect the health and wellbeing of Maori from illness and premature death, so they can enjoy the same quality and level of health as others in Aotearoa.

Lung cancer petition

The writer delivered a petition to Parliament in 2019 with the support of hundreds of patients and carers right across NZ. This petition was signed by 7618 good people who care about lung cancer.

https://www.parliament.nz/en/pb/petitions/document/PET_86322/petition-of-philip-hope-for-lung-foundation-new-zealand

Sadly, the response to this petition by the Health Select Committee, does not acknowledge the entirety of the petition, nor did it even consider recommending a number of easy to introduce solutions, which would go along way to improving well-being and prevent the premature death of our most vulnerable patients.

Q. Why have we made reference to this in our submission to the review committee? Because, NZ's thrift funding policies and the culture of Pharmac impacts all stages of the continuum of care.

Successive governments have prevented access to countless medicines in the public system by employing thrift policy settings which has seen systemic underfunding continue.

Q. Why is NZ not prepared to invest in modern medicines that are the standard of care?

FACT: Access to treatment is access to life....

We need to treat the person, not just the condition. The vital role of precision led healthcare (informed by molecular testing) and access to the right treatment at the right time, is life changing for patients and far superior to standard chemotherapy in mono-therapy.

NZ's drug buying agency needs to negotiate supply agreements for multiple new medicines with increased frequency (for each condition), much faster and with transparency.

Delaying reimbursement to push prices down is an OUTDATED model that is causing countless patients to die prematurely, or suffer the unnecessary side effects of outdated treatments. Many of these patients re-enter the hospital system which is already strained and at capacity...



New Zealand employ's a third world approach to the detection, treatment and care of lung cancer and mesothelioma and our failure to reimburse standard of care treatments (targeted therapies and immunotherapies), all of which are life changing for patients, sees NZ falling further and further behind comparable counties of the OECD.

An instrument of government, Pharmac is now institutionalised, it is slow, bogged down by years of its 'unfit for purpose' thrift thinking and intransparent practises, which have largely remained unchallenged, enabled/led by individuals and committees too compliant or unsupported to question the status quo...

Naku noa na

Philip Hope
Chief Executive

LFNZ is an advocacy partner of the International Association for the Study of Lung Cancer (IASLC).
<https://www.iaslc.org/patient-advocacy>