



28th January 2020

Louisa Wall
Chairperson
Health Select Committee
Parliament Buildings
Wellington

Tena Koe Louisa and members of the Health Select Committee

Outstanding Questions of Pharmac subsequent to our Lung Cancer Petition

The writer acknowledges the questions asked of Pharmac by the Health Select Committee, subsequent to our lung cancer petition.

Having attended the Health Select Committee hearing on Wednesday 23rd October, at which Pharmac made their oral submission, it was disappointing no further questions were asked of Pharmac (subsequent to Pharmac's submission dated 21st October), given the writers petition urging lung cancer be declared a national health priority and in relation to the standard of care treatments, our cause has urged be funded for lung cancer in first line treatment, specifically;

Pembrolizumab (Keytruda) for patients with a PD-L1 expression (would benefit up to 1500 patients per year).

Reimbursement of Keytruda (pembrolizumab) is central to reducing inequity in care for lung cancer and it will be a huge step forward for improving survival rates for the greatest number of vulnerable patients.

The five year survival rate for lung cancer will double for patients that have access to this treatment.

We consider it is absolutely essential that Keytruda be funded for NSCLC in first-line setting, as monotherapy and in combination therapy.

Crizotinib (Xalkori) represents a new era of targeted treatment for Ros1 - a rare form of lung cancer which makes up just 1% of non-small cell lung cancer (15 - 20 patients per year).

In contrast to Pharmac's response to previous named patient applications for Ros1 patients in need of access to Crizotinib, chemotherapy is NO LONGER a standard of care for these patients.

As has been established from the Ros1 clinical trial PROFILE 1001, Crizotinib is a superior treatment for Ros1 lung cancer in comparison to standard chemotherapy. Crizotinib has far less toxicity and will significantly improve wellbeing and survival for Ros1 patients.



NOTE: *Pharmac does not need to wait for an application for reimbursement to fund this treatment which means life for patients with this rare form of lung cancer (Ros1).*

Osimertinib (Tagrisso) for EGFR (approximately 200 patients per year)

*EGFR patients, when treated with Osimertinib in **first line**, achieved 18.9 months progression free survival, compared to 10.2 months for first line EGFR TKI's, which is an advantage of 8.7 months.*

This improvement in progression free survival for ALL EGFR patients is clinically very meaningful and "especially significant" for the 40% of EGFR patients that do not progress (during first line EGFR TKI) with the T790M mutation, because these patients would NOT be eligible to receive osimertinib in a second line setting.

Globally, the standard of care for first line treatment of EGFR mutation positive advanced non-small cell lung cancer (NSCLC) is now Osimertinib (in favour of first line EGFR TKI's) as outlined in the Phase III FLAURA clinical trial.

Osimertinib greatly reduces the incidence of central nervous system (CNS) metastases, compared to the first generation EGFR TKI's (Erlotinib & Gefitinib).

Progression free survival for patients treated with Osimertinib in first line, is MORE than TWICE the first generation TKI's Erlotinib & Gefitinib.

ESMO - Magnitude of clinical benefit scale, score Erlotinib & Gefitinib at just 1, (1 being the lowest and 5 the highest), yet Pharmac considers these treatments the standard of care because they are so cheap.

Question: *Should our most vulnerable patients be given the cheapest treatments that result in more harmful side effects and premature death, or should we fund the BEST and most efficacious treatments that extend life and greatly improve well-being?*

EGFR lung cancer patients that progress with brain metastases, must then endure a terribly brutal and invasive treatment pathway, including, brain radiation and chemotherapy. These treatments have implications for the effectiveness of future treatments.

Lung Foundation New Zealand has supported countless EGFR patients who have progressed with brain metastases and we have countless surviving family members prepared to share their very painful journey which ended in the premature death of a loved one.

Note, all three treatments listed above are assessed as being efficacious and when funded by Pharmac will prevent, premature death for more than 1700 patients per year.

<https://www.esmo.org/Policy/ESMO-MCBS>



We believe the outstanding questions are as follows:

1. Pharmac says it looks to other international treatment guidelines and recommendations or key advice from similar countries. Q. How is their evaluation of cost effectiveness different from New Zealand? Pembrolizumab (Keytruda) is reimbursed by Australia for all first line lung indications (including, irrespective of PD-L1 expression) and therefore the PBAC sees this product as cost effective in lung cancer. As well as 40 other countries funding Pembrolizumab (Keytruda) for first line lung cancer, many with much lower GDPs than NZ.
2. Q. How does PHARMAC measure cost effectiveness for a drug that is extending life as opposed to a treatment that is treating a chronic condition?
3. Q. How can there be such a huge emphasis by PHARMAC on the “Factors for Consideration” which evaluates health disparity, inequity and Maori health outcomes; and yet PHARMAC has still not been proactive around investing in lung cancer treatments? These treatments have been on PHARMAC’s waiting list for many years despite lung cancer being over represented in a high needs population.
4. Q. Why is Pembrolizumab (Keytruda) still not funded? Having reviewed the PTAC and CASTSOP minutes we note MSD has put multiple funding applications to PHARMAC over three years. PHARMAC has recently made a decision to hold an RFP for non-small cell lung cancer and although it was proposed a few months ago, there has been no further evidence of the RFP announcement?
5. We ask that the following treatments be funded in first line without further delay;

Pembrolizumab (Keytruda) for patients with a PD-L1 expression (would benefit up to 1500 patients per year).

Crizotinib (Xalkori) for patients with Ros1 - a rare form of lung cancer which makes up just 1% of non-small cell lung cancer (15 - 20 patients per year).

Osimertinib (Tagrisso) for EGFR (approximately 200 patients per year).

6. In response to the writers petition, we ask the Health Select Committee and Pharmac to declare NZ’s BIGGEST cancer killer, lung cancer to be a national health priority.

Thank you for your time to review and respond to the questions listed above.

Naku noa na

Philip Hope (Williams-Potae)



Petition of Philip Hope for Lung Foundation New Zealand: Ask Pharmac to fund innovative treatments for lung cancer

Petition request

That the House of Representatives call on the Government to declare lung cancer a national health priority and to approve additional budget for Pharmac to fund lung cancer medications, including Keytruda, Alectinib, Osimertinib and Crizotinib, for all Kiwis with advanced lung cancer, irrespective of socio-economic status.

Petition reason

Lung cancer is NZ's biggest cancer killer; every day 5 people die of lung cancer. The top 3 lung cancer drugs funded in NZ represent less than 3% of the top 5 cancer drugs, despite lung cancer being the most targetable cancer. We believe 80% of lung cancer patients do not have an effective first line treatment in NZ. The impact on patients to meet the cost of unfunded drugs can cause financial crisis and increased risk of suicide.

Lung Foundation New Zealand provided a recommendation to Pharmac that was informed by research and guided by equity; to fund a number of lung cancer treatments by way of a submission dated 19th March 2019 (for first line treatment).

Click to view our 48 page submission to Pharmac -

<https://lungfoundation.org.nz/wp-content/uploads/2019/03/2019-March-Lung-Foundation-NZ-Pharmac-Cancer-Treatments-Subcommittee-CaTSoP.pdf>

Article 3 of the Treaty outlines the crown's 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.

Q. How is the government and Pharmac (an instrument of Government) meeting these Treaty responsibilities, not just for lung cancer, but ALL cancers and health in general?

Background - Lung Foundation New Zealand Inc.

About Us

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

The Lung Foundation provides information and support for lung cancer patients and carers and is devoted to advocating on a range of issues, including; prevention, early detection (screening), stigma, public access to more effective treatments, an increase in research funding and a commitment to Smokefree 2025.



Lung health for life

Our Vision

New Zealanders know how to keep their lungs healthy and they investigate symptoms of lung disease earlier.

Our Mission

To increase survival for lung cancer

Our Goals

- Promote Lung Health
- Promote Early Diagnosis of Lung Disease
- Reduce Lung Cancer Deaths

Our Values

Rangatiratanga; we have integrity, we empower people, we say what we mean.

Manaakitaka, we nurture and respect people's mana.

Whanaungatanga, collaborating to improve healthcare in Aotearoa, also serves future generations.

Ehara taku toa i te toa takitahi engari he toa takimano

My strength is not that of an individual but that of the collective

Gift Acceptance Policy

LFNZ is an independent non-government organisation and is reliant on philanthropic support to sustain its mission. We have a sincere commitment to the ethical practice of philanthropic fundraising.

View our gift acceptance policy <https://lungfoundation.org.nz/support-us/gift-acceptance-policy/>

NB: LFNZ acknowledges, inequity and financial toxicity exists in healthcare (especially for access to lung cancer treatments) and for this reason, our cause DOES NOT seek donations from patients.

Special Advisory Committee

LFNZ has assembled a Special Advisory Committee (SAC) of highly respected healthcare professionals, invested in improving outcomes for patients with lung cancer. These good people consider our cause to be their charitable priority.

Medical Director & Associate Professor of Oncology, Chris Atkinson, is Chair of LFNZ SAC.

<https://lungfoundation.org.nz/about-us/our-people/>

Associate Professor of Oncology, Chris Atkinson;

Life Member RANZCR

Life Member TROG

Scientific Advisory Board MSD

Life Member Psycho-oncology NZ

Board Member CHOMNZ

Chair St Georges Cancer Care JV Board

Member St Georges Cancer Institute Board



*Philip Hope, Chief Executive, Lung Foundation New Zealand;
Member, International Association for the Study of Lung Cancer
Member, The Union for International Cancer Control's (UICC)*

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

1. Lung cancer in New Zealand - Key Facts (Refer Addendum ONE - FIVE)

More Kiwis die of lung cancer than breast cancer, prostate cancer and melanoma combined
Lung cancer is NZ's BIGGEST cancer killer - increasing annually (2015 - 2189 Diagnosed 1805 Died)
Lung cancer deaths in New Zealand are 83% of annual registrations (MOH 2015). *Such poor survival is unacceptable for a first world nation.*

5 Kiwis die every day from lung cancer

6 Kiwis are diagnosed with lung cancer every day

1 in 5 patients never smoked - 70% DO NOT smoke at the time of diagnosis (Just 30% of patients smoke at the time of diagnosis).

NB: 5000 Kiwis die every year in NZ, the result of exposure to tobacco products (14 people EVERY DAY, or one person every 90 minutes).

How lung cancer outcomes in New Zealand compare internationally

The five year survival for lung cancer in NZ compares poorly with Australia and much worse with the other major OECD. Stats for Maori are at least 4% worse.

While there are more factors influencing survival than just available treatments, what is obvious is that there is a gap between the countries (19.4% in Australia vs 15.3% in NZ).

Also of note, is that the gap between Australia and NZ has widened over time, 2000-04 (3.4%) to 2010-14 (4.1%). Of concern, not only do Australian patients have a longer overall survival than NZ, the rate of overall survival improvement is FASTER in Australia.

Reference - Global surveillance of trends in cancer survival 2000 - 14 (CONCORD-3).

Subsequent to the period of the study, the gap in overall survival continues to grow, because NZ funds so few targeted therapies and NO immunotherapy...

New Zealand DOES NOT fund any therapies for;

- Ros1
- EGFR T790M
- PD-L1 expression (immunotherapy)
- BRAF
- Small cell lung cancer (15% of all lung cancer, although is the most aggressive and difficult to treat)
- Mesothelioma



Note: Reimbursement for ALK targeted therapy has been an advocacy priority for LFNZ since 2015 and has only just been funded (as of the 1st December, Alectinib is funded for ALK lung cancer).

2. Disparities in New Zealand 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 every day from lung cancer (Maori are just 15% of the NZ population, but represent more than 20% of total lung cancer registrations per year.
- Maori suffer extreme inequity and die prematurely as the result of lung cancer. Article 3 of the Treaty, highlights the crowns 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.
- Because Māori are more likely to present with later stage lung cancer, a targeted lung cancer screening programme (low dose CT Scan) for at risk Maori (co-designed with Maori) will reduce the disparities of lung cancer outcome between Māori and non-Māori.
- Introducing lung cancer screening for Maori is the right thing to do and it will fulfil the crowns responsibility, per the Treaty.

Treatment of Lung Cancer in New Zealand (Refer Addendum TWO)

Despite many advances in early detection and innovative treatments across the OECD, our cause is witnessing unprecedented suffering and inequity in New Zealand, resulting in premature death for the majority of patients diagnosed with lung cancer.

- Lung cancer patients suffer premature death in New Zealand, because they DO NOT have access to drugs that work (unless they can pay for treatment in private practice).
- For 80% of patients diagnosed with lung cancer - Access to Treatment is Access to LIFE.
- Right now 1700 patients in New Zealand DO NOT have an effective first line treatment for advanced lung cancer.

Detection of Lung Cancer in New Zealand

- Early diagnosis of lung cancer is critical to improving outcomes, with 80% of lung cancer cases being diagnosed at an advanced stage.
- Despite, lung cancer being New Zealand's biggest cancer killer, we DO NOT yet have a national lung cancer screening programme in place...



Addendum ONE:

Figure 2: New Zealand cancer registration rates, 2016, selected cancers, Māori vs non-Māori

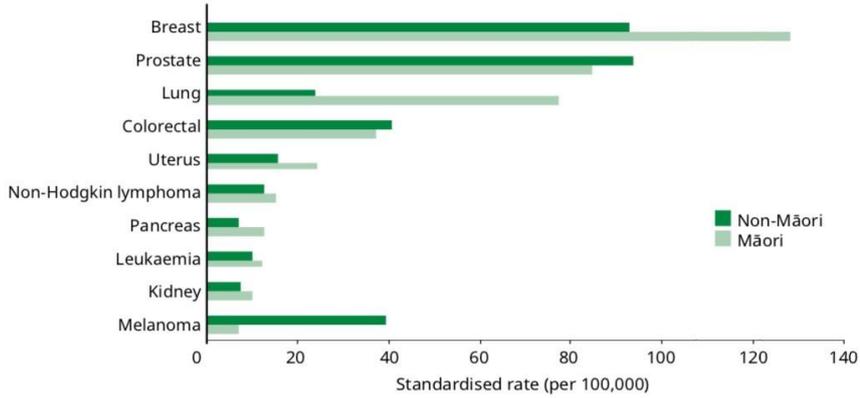
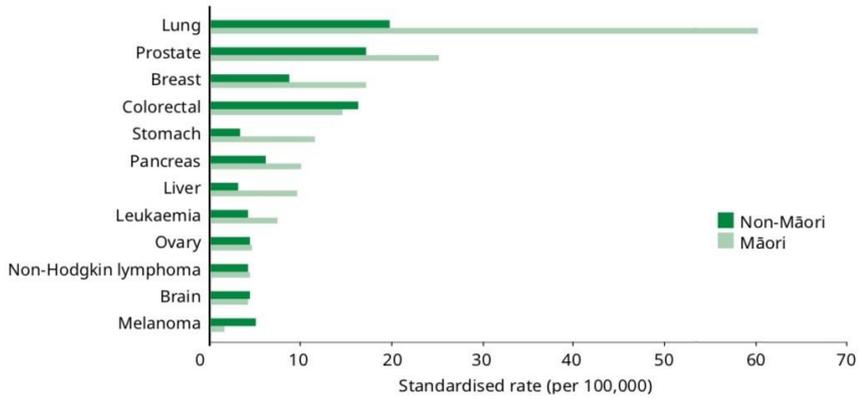


Figure 3: New Zealand cancer mortality rates, 2013, selected cancers, Māori vs non-Māori



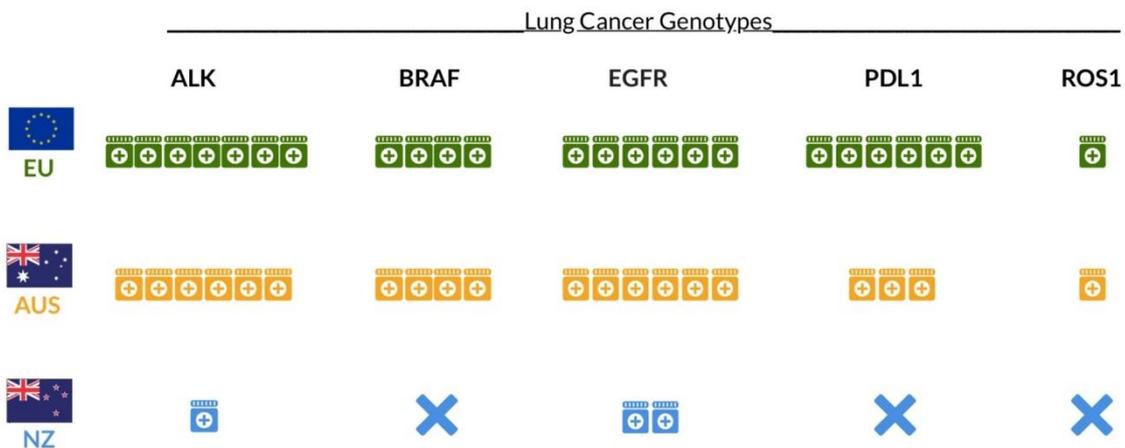


Addendum TWO:

How NZ Compares for Access to Standard of Care Lung Cancer Treatments as at 1st Dec 2019.

Featured below is an infographic that provides a comparison of the number of lung cancer genotypes funded in; NZ, Australia and the EU.

**Non-Small Cell Lung Cancer
 Treatment Options**
 (Excluding Chemotherapy)
 2010 - 2019



A comparison of the number of innovative treatments funded for each lung cancer genotype.



Addendum THREE:

OVER 1800 KIWIS DIE FROM LUNG CANCER EVERY YEAR

NEW ZEALAND'S DEADLIEST CANCER



TUAPAPA PŪKAHUKAHU
LUNG FOUNDATION
New Zealand

Lung Foundation New Zealand is a non-government organisation dedicated to promoting healthy lungs and early detection of lung disease, including lung cancer, New Zealand's biggest cancer killer.

The Foundation is devoted to supporting people affected by lung disease and provides information, support and advocacy for patients and their families.

Advocacy priorities include;

- Public access to more effective treatments
- Government commitment to early detection (includes screening).
- Increasing research funding in lung disease.
- A restated commitment (and increased investment) to making Aotearoa a smokefree nation by 2025.

What lung cancer patients want...

- Access to treatments that are readily available in other countries
- Greater transparency with respect to funding decision processes for treatment
- Not be stigmatised, because they might have smoked in the past, or have never smoked, but now have lung cancer



1 in 5 people diagnosed with lung cancer have never smoked

...TO LIVE

EARLY DETECTION AND EFFECTIVE TREATMENT WILL IMPROVE SURVIVAL

Lung cancer is New Zealand's biggest cancer killer, so treatment of lung cancer needs to be a government priority. We need more common sense in funding the provision of more effective treatments for lung cancer.

Lung Foundation NZ works with healthcare professionals, researchers, pharmaceutical companies, PHARMAC and the Ministry of Health to advocate for the needs of patients.

Small changes to the way New Zealand manages and funds lung disease and lung cancer will save hundreds of lives every year, enabling patients to enjoy a better quality of life, with their whanau.

Please support our cause



fb.me/LungFoundationNZ

www.lungfoundation.org.nz



Addendum FOUR:

Lung Cancer And Other Cancers

<u>Registrations</u>	<u>Deaths</u>	<u>Total</u>
Lung cancer, 2189	1805	82.5%
Bowel cancer, 3150	1267	40%
Leukaemia, 703	353	50%
Breast cancer, 3292	674	20%
Prostate cancer, 3080	647	21%
Melanoma, 2424	378	16%

Deaths as a percentage of total registrations - 2015





Addendum FIVE:



Philip Hope

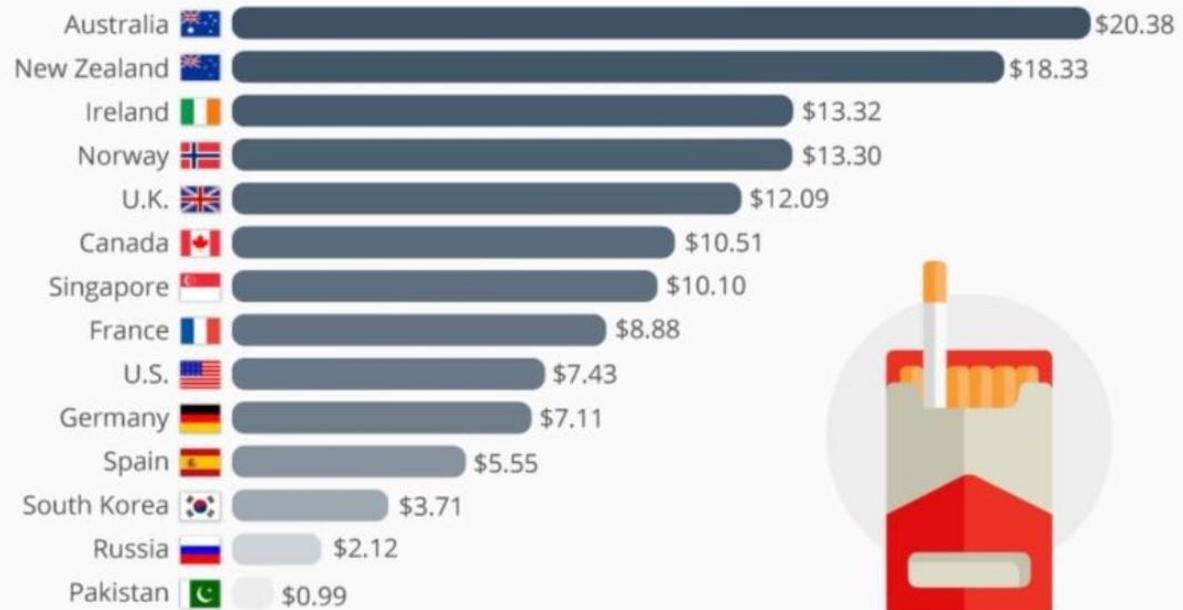
Chief Executive, Lung Foundation New Zealand (Tuapapa Pukahukahu Aot...
 5d

Tobacco taxation in New Zealand is amongst the highest in the world; Overall tax revenue has increased by 76.4%, between 2009 and 2018. In 2018 the tax revenue from both domestic and imported tobacco was 1800 \$1.93 billion (up from \$1.77 billion 1700 in 2017).

Q. Why isnt NZ directing more money into harm minimisation; cessation support; health promotion; early detection ; screening; modern medicines?

The Price of a Pack of Cigarettes around the World

Selling price for a 20 pack of Marlboro cigarettes in selected countries (Aug 2019)



@StatistaCharts Source: numbeo.com



5 · 11 Comments



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For further information, please contact;

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Visit us online <https://lungfoundation.org.nz/about-us/>

Connect with us on Facebook <https://www.facebook.com/LungFoundationNZ/>

- **Medical Director & Associate Professor of Oncology, Chris Atkinson talks about a new approach, informed by equity is a must to improve outcomes for lung cancer.**
<https://drive.google.com/file/d/1pjdZVvMtlRz5uyZGjzTVg972Q8fm7xv/view>
- **Lung Foundation's submission for the Inquiry into health inequities for Maori**
<https://lungfoundation.org.nz/wp-content/uploads/2019/11/2019-September-Lung-Foundation-NZ-Maori-Affairs-Committee.pdf>
- **Lung Foundation's response to the Governments Cancer Action Plan 2019 - 2029**
<https://lungfoundation.org.nz/response-to-the-cancer-action-plan-2019-2029/>
- **Lung Foundation NZ declares lung cancer a National Health Emergency**
<https://lungfoundation.org.nz/wp-content/uploads/2019/07/Media-Release-World-Lung-Cancer-Day-2019.pdf>
- **National lung cancer screening programme could save kiwi lives**
<https://lungfoundation.org.nz/wp-content/uploads/2019/02/2019-February-Lung-Cancer-Screening-Position.pdf>
- **Lung Foundation's submission to Pharmac in March 2019** - includes letters from patients
<https://lungfoundation.org.nz/lfns-submission-to-pharmac-includes-patient-letters-etc/>
- **Staggering imbalance with cancer treatments funded by Pharmac** - the top 3 lung cancer drugs funded by Pharmac (2017/18) is just 2.3% of the top 5 cancer drugs (\$122 million)
<https://lungfoundation.org.nz/staggering-imbalance-with-cancer-treatments/>
- Know the symptoms of lung cancer - click to view the BREATHE POSTER.
<https://lungfoundation.org.nz/wp-content/uploads/2019/04/LFNZ-BREATHE-Symptoms-Poster.pdf>
- Lung cancer Patient Toolkit to empower patients and carers to navigate their cancer journey
<https://lungfoundation.org.nz/wp-content/uploads/2018/11/LFNZ-TOOLKIT-A4-Poster.pdf>
- Make a gift - Support our fighting fund and help us save lives
<https://givealittle.co.nz/donate/org/lungfoundationnz>
- Plan an event - Help us raise awareness and funds
<https://nfp.everydayhero.com/nz/lung-foundation-new-zealand#>