TUAPAPA PŪKAHUKAHU
LUNG FOUNDATION
New Zealand
Lung health for life

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12th July 2019

Louisa Wall
Chairperson
Health Select Committee
Parliament Buildings
Wellington

Kia Ora Louisa and Committee Members

Health Select Committee Hearing for Lung Cancer Petition of Philip Hope for Lung Foundation NZ

I hope this email finds you in good health and enjoying the challenges of your role.

This past Wednesday the writer confirmed with Dylan Hanna of Parliamentary Services, our cause will attend the hearing on 7th August in Wellington to deliver a presentation to the Health Select Committee, subsequent to the lung cancer petition.

However, I am dismayed (despite a request for more time) that just 20 minutes in total has been allocated to receive our submission, which we packaged into one petition that covers at least six lung cancer drugs (there are currently six drugs still sitting within Pharmac), including a request that lung cancer to be confirmed a national health priority.

Note: There were potentially seven separate petitions, however being guided by common-sense we chose to package them into one petition…

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.

The writer is very concerned the status of our petition and the process will be disadvantaged if we are not given more time to present.

Philosophy
Lung Foundation New Zealand is a values based advocacy group. The well-being of lung cancer patients and their family's are central to our advocacy, which is guided by equity, fairness and need.

We ask for your support to enable key stakeholders to assist with our presentation to the Health Select Committee, specifically;

- Trish Guttenbeil, widow of lung cancer patient, Jason Guttenbeil. Jason and Trish were central to our decision to engage this parliamentary process by planning a petition for Keytruda, but sadly Jason died before the planned launch. It was on this basis Trish Guttenbeil, supported by her whanau, handed our petition to MP Simon O'Connor at Parliament on Tuesday 7th May.

  It simply wouldn't be right if Trish and members of her whanau do not have the opportunity to attend and participate in this hearing process.

- We also have two members of our medical advisory board, who specialise in the treatment of lung cancer (they work in the public setting and also in private practice) attending at quite some cost to co-present.

  These specialists work with patients every day. They see first-hand the consequences of inequity which results in premature death of our most vulnerable.

  It is vital these specialists attend to assist with presentation to the Health Select Committee.

- Access to treatment is access to life - this is the reality for lung cancer patients.

  Despite many advances in early detection (there is NO screening in NZ for lung cancer) 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.

  Right now almost 1900 patients in New Zealand DO NOT have an effective first line treatment for advanced lung cancer.

  Lung cancer deaths in New Zealand are 83% of annual registrations (MOH 2015). Such poor survival is unacceptable for a first world nation.

  Lung cancer patients are our most vulnerable and the most disadvantaged.

  Patients really must be given the opportunity to have full and direct participation with presentation to the Health Select Committee. "Nothing About Us Without Us"

As outlined above, presentations from each of these stakeholders, build on one another and will enable the Health Select Committee to have a much greater insight and understanding of lung cancer in NZ; the scale of inequity, the disparities suffered by Maori and Pacific people, the misleading and deadly consequences of stigma, the lack of access to standard of care treatments in New Zealand and why lung cancer must be a government health priority.

Extreme Inequity
Lung cancer patients in New Zealand suffer extreme inequity and die prematurely.

Lung cancer is brutal and patients have no time to wait.

The most effective way to reduce inequity is to fund treatments that are the OECD standard of care (there are six lung cancer drugs still sitting with Pharmac) and speed up access to new innovative treatments which will keep our most vulnerable well far longer.

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).

We too are very concerned the inequities surrounding lung cancer treatment in New Zealand are extreme when Maori are considered. Lung cancer is the leading and second highest cause of death in Maori females and males respectively. In other words, the biggest source of medical mortality for Tangata Whenua in Aotearoa is being almost completely ignored…

New Zealand has singled out inequities for its indigenous people as a priory, however the lack of commitment to reduce inequalities is indefensible and unacceptable.

Article 3 of the Treaty outlines 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.

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?

Q. Will the Health Select Committee stand together and show strong and bold leadership on these fundamental issues?

Click the link below 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

Subsequent to this submission the writer also highlighted to Pharmac of the need for standard of care second line treatment to be funded for lung cancer.

New Zealand's Most Deadly Cancer is also the Most Targetable Cancer

More people die of lung cancer every year than, breast cancer, prostate cancer and melanoma combined.

Lung cancer is NZ's Biggest Cancer Killer; MOH 2015 stats; 2198 diagnosed / 1805 died.

Five people every day die of lung cancer (more than five times the NZ Road toll) and a further six people are diagnosed with this brutal disease every day.

I ask please all members of the Health Select Committee for their/your support so that our cause is given at least half a day to deliver presentations and for Q&A subsequent to the presentations.

Because the petition is sponsored by Lung Foundation New Zealand, we ask for the right of reply to submissions made by the Ministry of Health and Pharmac.

We would also appreciate the opportunity to participate in a panel discussion and Q&A together with representatives from the Ministry of Health and Pharmac. This forum would ensure responses to our submission have balance and the appropriate context.

Conclusion

The writer is very concerned the status of our petition and the process will be disadvantaged (inequity of opportunity) if we are not given more time to present, as explained above.

I ask the members on behalf of 2300 lung cancer patients and their family's dealing with this brutal disease, for your support of our request for half a day to present to the Health Select Committee.

Naku noa na

Philip Hope (Williams-Potae)
Chief Executive
Lung Foundation New Zealand Inc.

Further information relevant to this submission, is included below and referenced as addendum.

Addendum ONE:

Lung Cancer, New Zealand's Biggest Cancer Killer

- 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;
  - Lung cancer annual mortality rates are five times the New Zealand Road Toll.
- Lung cancer represents one of the largest health inequalities in New Zealand with markedly poorer outcomes for Maori and Pacifica compared to Pakeha New Zealanders.
- 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 does not discriminate - even healthy people can develop lung cancer. In fact one in five patients have never smoked.
- Just 30% of patients diagnosed with lung cancer smoke at the time of diagnosis i.e. 70% of patients diagnosed with lung cancer DO NOT SMOKE.
- There is also a major intersection with other determinants of health, including a quadrupled risk of suicide for lung cancer patients compared to the general population.
- 2019 marks the 50th year lung cancer is the Biggest Cancer Killer in New Zealand.
- 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.
- Right now almost 1900 patients in New Zealand DO NOT have an effective first line treatment for advanced lung cancer.

Treatment of Lung Cancer in New Zealand

- For 80% of patients diagnosed with lung cancer - access to treatment is access to life.
- Lung cancer is the most targetable cancer.
- Maori & Pacific lung cancer patients have a higher prevalence of the ALK & EGFR biomarker
- Lung cancer has the most number of effective treatments that are standard of care in the OECD that are NOT funded in New Zealand.
- 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).
- An increasing number of patients are importing generic lung cancer drugs, because they cannot afford to pay consumer prices for innovative cancer treatments in private practice.
- Despite lung cancer being NZ's Biggest Cancer Killer, the top 3 lung cancer drugs funded by Pharmac (2017/18) equates to just 2.3% of the top 5 cancer drugs ($122 million)

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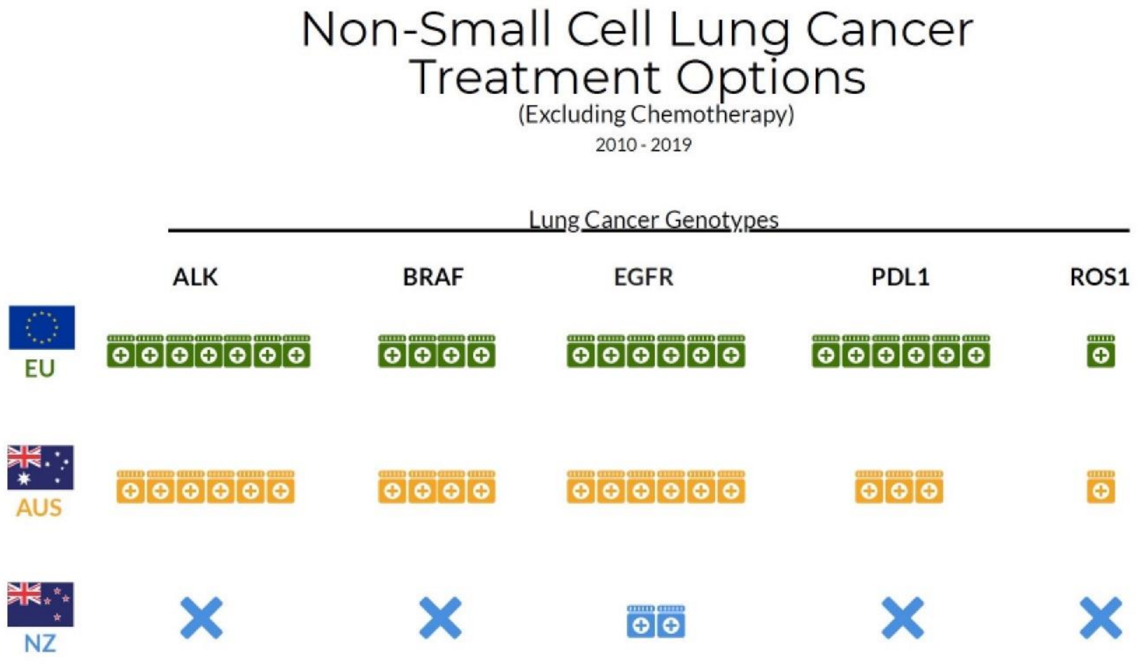
Addendum TWO:

How New Zealand Compares for Access to Standard of Care Lung Cancer Treatments

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



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

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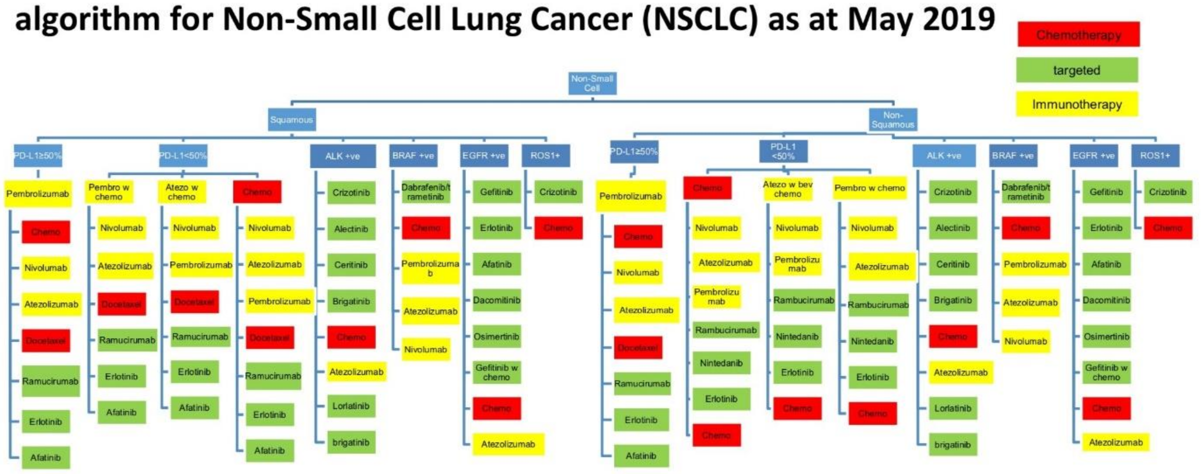
Addendum THREE:

This presentation compares; New Zealand and Australia, including the European Society for Medical Oncology (ESMO) Guidelines.

European Society for Medical Oncology (ESMO) Treatment Guidelines algorithm for Non-Small Cell Lung Cancer (NSCLC) as at May 2019



🟥 Chemotherapy
🟩 targeted
🟨 Immunotherapy

- Non-Small Cell
  - Squamous
    - PD-L1≥50%
      - Pembrolizumab
        - Chemo
        - Nivolumab
        - Atezolizumab
        - Docetaxel
        - Ramucirumab
        - Erlotinib
        - Afatinib
    - PD-L1<50%
      - Pembro w chemo
        - Nivolumab
        - Atezolizumab
        - Docetaxel
        - Ramucirumab
        - Erlotinib
        - Afatinib
      - Atezo w chemo
        - Nivolumab
        - Pembrolizumab
        - Docetaxel
        - Ramucirumab
        - Erlotinib
        - Afatinib
      - Chemo
        - Nivolumab
        - Atezolizumab
        - Pembrolizumab
        - Docetaxel
        - Ramucirumab
        - Erlotinib
        - Afatinib
    - ALK +ve
      - Crizotinib
      - Alectinib
      - Ceritinib
      - Brigatinib
      - Chemo
      - Atezolizumab
      - Lorlatinib
      - brigatinib
    - BRAF +ve
      - Dabrafenib/trametinib
      - Chemo
      - Pembrolizumab
      - Atezolizumab
      - Nivolumab
    - EGFR +ve
      - Gefitinib
      - Erlotinib
      - Afatinib
      - Dacomitinib
      - Osimertinib
      - Gefitinib w chemo
      - Chemo
      - Atezolizumab
    - ROS1+
      - Crizotinib
      - Chemo
  - Non-Squamous
    - PD-L1≥50%
      - Pembrolizumab
        - Chemo
        - Nivolumab
        - Atezolizumab
        - Docetaxel
        - Ramucirumab
        - Erlotinib
        - Afatinib
    - PD-L1 <50%
      - Chemo
        - Nivolumab
        - Atezolizumab
        - Pembrolizumab
        - Rambucirumab
        - Nintedanib
        - Erlotinib
        - Chemo
      - Atezo w bev chemo
        - Nivolumab
        - Pembrolizumab
        - Rambucirumab
        - Nintedanib
        - Erlotinib
        - Chemo
      - Pembro w chemo
        - Nivolumab
        - Atezolizumab
        - Rambucirumab
        - Nintedanib
        - Erlotinib
        - Chemo
    - ALK +ve
      - Crizotinib
      - Alectinib
      - Ceritinib
      - Brigatinib
      - Chemo
      - Atezolizumab
      - Lorlatinib
      - brigatinib
    - BRAF +ve
      - Dabrafenib/trametinib
      - Chemo
      - Pembrolizumab
      - Atezolizumab
      - Nivolumab
    - EGFR +ve
      - Gefitinib
      - Erlotinib
      - Afatinib
      - Dacomitinib
      - Osimertinib
      - Gefitinib w chemo
      - Chemo
      - Atezolizumab
    - ROS1+
      - Crizotinib
      - Chemo

NOTES: 1. lines of therapy not shown for ALK/BRAF/EGFR/ROS1
2. nivolumab/ipilimumab for TMB high included in guidelines but excluded here as registration file was withdrawn from EU

Source: Metastatic non-small cell lung cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up, *Annals of Oncology*, Volume 29, Issue Supplement_4, 1 October 2018, Pages iv192–iv237

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New Zealand Publicly-Funded Treatment Options compared with ESMO Guidelines for Non-Small Cell Lung Cancer as at 31 May 2019

🟥 Chemotherapy
🟩 targeted
🟨 Immunotherapy

- Non-Small Cell
  - Squamous
    - PD-L1≥50% (30%[1])
      - [redacted]
        - [redacted]
    - PD-L1<50% (70%[1])
      - [redacted]
        - [redacted]
        - [redacted]
      - [redacted]
        - [redacted]
        - [redacted]
      - Chemo
        - [redacted]
    - ALK +ve
      - [redacted]
      - Chemo
      - [redacted]
    - BRAF +ve
      - [redacted]
      - Chemo
      - [redacted]
    - EGFR +ve
      - Gefitinib
      - Erlotinib
      - [redacted]
      - Chemo
      - [redacted]
    - ROS1+
      - [redacted]
      - Chemo
  - Non-Squamous
    - PD-L1≥50%
      - [redacted]
        - Chemo
        - [redacted]
    - PD-L1 <50%
      - Chemo
        - [redacted]
      - [redacted]
        - [redacted]
        - Chemo
      - [redacted]
        - [redacted]
        - Chemo
    - ALK +ve
      - [redacted]
      - Chemo
      - [redacted]
    - BRAF +ve
      - [redacted]
      - Chemo
      - [redacted]
    - EGFR +ve
      - Gefitinib
      - Erlotinib
      - [redacted]
      - Chemo
      - [redacted]
    - ROS1+
      - [redacted]
      - Chemo

Source: Metastatic non-small cell lung cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up, *Annals of Oncology*, Volume 29, Issue Supplement_4, 1 October 2018, Pages iv192–iv237.

[1] Gandhi et al, Pembrolizumab plus Chemotherapy in Metastatic Non–Small-Cell Lung Cancer, NEJM 2018

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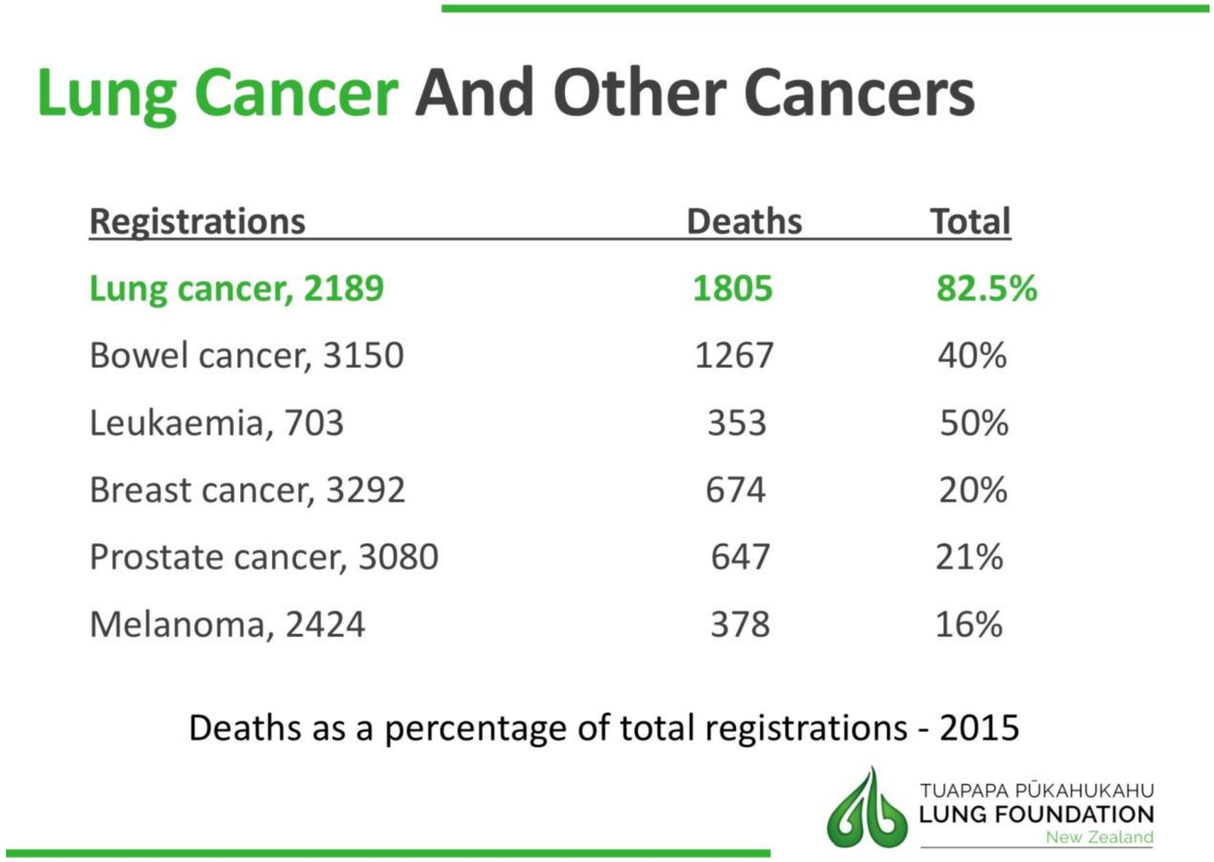
The above report demonstrates how far behind Pharmac is with reimbursing standard of care treatments for lung cancer and WHY lung cancer patients die prematurely in NZ.

Addendum FOUR:



Lung Cancer And Other Cancers

Registrations	Deaths	Total
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

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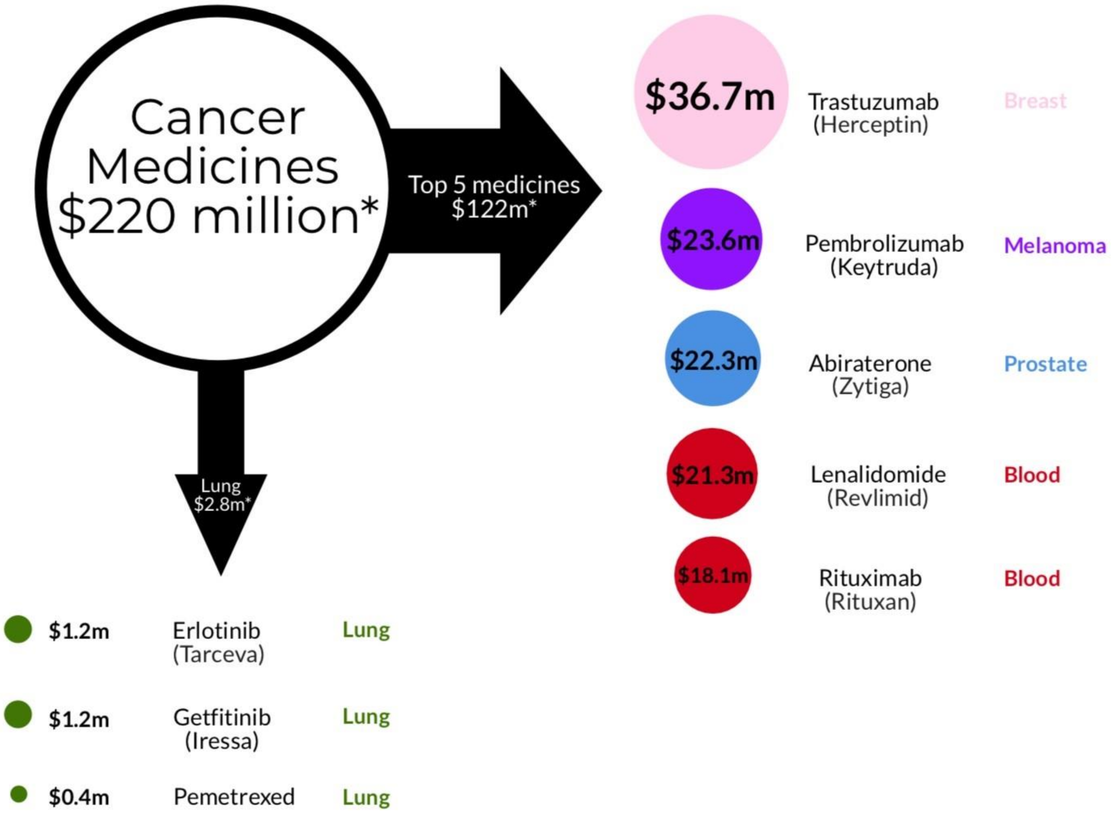
Addendum FIVE:

The infographic below illustrates a staggering imbalance with the government's commitment to funding cancer treatments and a lack of planning with introducing precision led healthcare.

Despite lung cancer being NZ's Biggest Cancer Killer, the top 3 lung cancer drugs funded by Pharmac (2017/18) equates to just 2.3% of the top 5 cancer drugs ($122 million).

This infographic also shows that Pharmac is NOT guided by equity, or burden of disease, but rather a thrift culture (the result of systemic underfunding by successive governments), which sees Pharmac funding the cheapest treatments, not the best treatments (unless there is political intervention, as was the case for the two most expensive drugs; Herceptin for Breast Cancer and Keytruda for Melanoma).



* 2017/18 gross expenditure, excludes confidential rebates

Addendum SIX:

Submission to Pharmac urging access to innovative lung cancer treatments

This submission is central to our presentation to the Health Select Committee and it includes letters from a number of lung cancer patients, who ALSO wish to present to the Health Select Committee.

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

View the full text overleaf -

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19th March 2019

Dr Marius Rademaker
Chairperson, Cancer Treatments Subcommittee of PTAC
Member, Pharmacology & Therapeutics Advisory Committee
PHARMAC
Level 9 Simpl House
Wellington

By email C/- danae.staples-moon@pharmac.govt.nz

Dear Dr Rademaker

Thank you for reviewing this submission in advance of your meeting scheduled for 5th April 2019.

We write to you and members of the Cancer Treatments Subcommittee of PTAC (CaTSoP) and Pharmac senior on behalf of 2189 patients and their families who are currently dealing with a lung cancer diagnosis.

Lung Foundation New Zealand has been informed by Danae Staples-Moon of Pharmac that the forthcoming CaTSoP meeting will include a forum dedicated to lung cancer treatments.

The purpose of this submission is to provide a voice for lung cancer patients, who need access to treatment/s to stay well and to put forward our recommendation as to the priorities for access to lung cancer treatments which we believe will best serve New Zealand's most vulnerable patients.

About us
Lung Foundation New Zealand is a non-government organisation (patient advocacy group) dedicated to promoting healthy lungs and early detection of lung disease of which lung cancer is a strategic focus.

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

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

Special Advisory Committee

Lung Foundation New Zealand (LFNZ) is informed by a Special Advisory Committee of highly respected healthcare professionals invested in improving outcomes for patients with lung cancer. Medical Director & Assoc. Prof. of Oncology, Chris Atkinson, is Chair of the Special Advisory Committee.

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

Lung Cancer, New Zealand's Biggest Cancer Killer

- 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;
    - Lung cancer annual mortality rates are five times the New Zealand Road Toll
- Lung cancer represents one of the largest health inequalities in New Zealand with markedly poorer outcomes for Maori and Pacifica compared to Pakeha New Zealanders.
    - 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 everyday in New Zealand
- Lung cancer does not discriminate - even healthy people can develop lung cancer. In fact one in five patients have never smoked.
    - Just 30% of patients diagnosed with lung cancer smoke at the time of diagnosis i.e. 70% of patients diagnosed with lung cancer DO NOT SMOKE.
- There is also a major intersection with other determinants of health, including a quadrupled risk of suicide for lung cancer patients compared to the general population.

2019 marks the 50th year lung cancer is the Biggest Cancer Killer in New Zealand.

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.

Right now almost 1900 patients in New Zealand DO NOT have an effective first line treatment for advanced lung cancer.

Treatment of Lung Cancer in New Zealand

- For 80% of patients diagnosed with lung cancer - access to treatment is access to life.
- Lung cancer is the most targetable cancer.
- Maori & Pacific lung cancer patients have a higher prevalence of the ALK & EGFR biomarker
- Lung cancer has the most number of effective treatments that are standard of care in the OECD that are NOT funded in New Zealand.
- 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).
- An increasing number of patients are importing generic lung cancer drugs, because they cannot afford to pay consumer prices for innovative cancer treatments in private practice.
- Despite lung cancer being NZ's Biggest Cancer Killer, the top 3 lung cancer drugs funded by Pharmac (2017/18) equates to just 2.3% of the top 5 cancer drugs ($122 million)

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How lung cancer compares with other cancers

Pharmac total spend for cancer in 2017/2018 = $220 million (gross spend)

Of the top 20 medicines (across all medicine groups) by gross spend in 2017/18, five of them were treatments for cancer. The top five cancer treatments funded by Pharmac equates to $122 million.

Below is the name of the medicine, condition it treats, gross spend by Pharmac in 2017/18

Transtuzumab (Herceptin)	Breast Cancer	$36.7 million
Pembrolizumab (Keytruda)	Skin Cancer	$23.6 million
Abiraterone (Zytiga)	Prostate Cancer	$22.3 million
Lenalidomide (Revlimind)	Blood Cancer	$21.3 million
Rituximab (Mabthera)	Blood Cancer	$18.1 million

Total $122 million

The top three lung cancer treatments funded by Pharmac in 2017/18

Erlotinib (Tarceva)	Lung Cancer EGFR	$1,197,494
Getfitinib (Iressa)	Lung Cancer EGFR	$1,174,417
Pemetrexed	Lung Cancer	$399,204.00

Total for lung cancer is $2,771,115.00 (just 2.3% of the top five cancer drugs funded by Pharmac)

Questions for Pharmac Senior

1. Considering the staggering imbalance highlighted above… and seeing how low the cost of pemetrexed is, we simply cannot understand WHY Pharmac took almost thirteen years to fund this treatment for NZ's Biggest Cancer Killer?

2. For 80% of patients diagnosed with lung cancer, access to the right treatment at the right time, is access to life. Knowing lung cancer is one of the most targetable cancers; why has Pharmac not yet funded any new generation targeted therapies or immunotherapy?

3. Knowing lung cancer is NZ's Biggest Cancer Killer, why hasn't there been a focus on funding lung cancer treatments to increase survival for lung cancer?

4. Given LFNZ was advised it is unlikely Pharmac will be able to fund all of the lung cancer treatments currently sitting within the Pharmac system, please clarify if a request for additional budget has been made of the Health Minister, relative to the well-being budget?

5. What portion of Pharmac's total cancer spend is used to fund lung cancer drugs? Please provide the further information so we can relate this to treatments by category?

6. Please advise the number of lung cancer patients (and individual treatments) that have been treated during the 2017/18 period? Is it possible to provide same for the top five cancers funded by Pharmac?

7. One of LFNZ's advocacy priorities is for NZ's Biggest Cancer Killer to be confirmed as a national health priority. Will Pharmac support this request?

8. Is the income derived from the rebates on selected cancer drugs, invested back into funding more cancer treatments?

   Patient and carer feedback: *Our most vulnerable patients and their families feel strongly they have been forgotten, knowing Keytruda has been reimbursed for melanoma for almost 3 years, yet Keytruda remains unfunded for lung cancer (despite the fact, lung cancer kills four times that of melanoma every year).*

Collaboration to improve outcomes
Lung Foundation New Zealand (LFNZ) collaborates with a number of sister organisations abroad, including; American Lung Association, European Lung Foundation and the International Association for the Study of Lung Cancer (IASLC) for which LFNZ is the New Zealand Advocacy Partner.

LFNZ has regular contact with and appreciates the support of the National Cancer Services Team at the Ministry of Health, including the National Lung Cancer Working Group. Our cause has had input with the various standards that have been adopted specifically to improve outcomes for lung cancer patients.

Following is the link to the "Standards of Service Provision for Lung Cancer Patients in New Zealand"

http://www.health.govt.nz/system/files/documents/publications/standards-service-provision-lung-cancer-patients-new-zealand-2nd-edn-may16_0.pdf

Below is a link to the press release by then Minister of Health on the 23rd May 2016, announcing the updated standards that will help to ensure people with lung cancer receive the best possible care…

https://www.beehive.govt.nz/release/updated-lung-cancer-standards-improve-care

The Ministry of Health have adopted good practice points and standards which include systemic therapy, one of these standards (8.1.21) states;

"Practitioners should offer treatment with targeted therapies to patients with incurable NSCLC and known targetable mutations" (e.g. activating mutations of the EGFR or ALK rearrangements etc.).

Molecular testing is key step to patients receiving the best treatment pathway. This is a standard we advocate for and is acknowledged in a number of the lung cancer patient and carer resources we have published https://lungfoundation.org.nz/resources/

Accordingly, the MOH lung cancer standards advises; all lung cancer patients should have timely access to appropriate molecular testing (standard 4.5).

Rationale - Patients with incurable lung cancer whose tumours have targetable oncogenic mutations (e.g. activating mutations of the epidermal growth factor receptor gene (EGFR) or rearrangements of anaplastic lymphoma kinase (ALK) etc.) experience the best outcomes when treated with targeted therapies. The presence or absence of mutations cannot be determined by demographic features, but only through molecular analysis of tumour tissue.

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Priorities for the Treatment of Lung Cancer:

Lung Foundation New Zealand's Recommendation to Cancer Treatments Subcommittee of PTAC.

The reality of cancer care in New Zealand, especially lung cancer, contrasts the guiding principles of the Health System, which is guided by equity, and is; dedicated to providing the best health and wellbeing possible for all New Zealanders throughout their lives; is committed to improving the health status of those currently disadvantaged; acknowledges the special relationship between Māori and the Crown under the Treaty of Waitangi; provides timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay.

What we know - **lung cancer is the most targetable cancer** and lung cancer also has the MOST Number of effective treatments which are standard of care in the OECD, but NOT funded in NZ.

Lung Foundation New Zealand's role as advocate for and on behalf of patients and carers is informed and guided by equity - we do not want to leave anyone behind.

Lung Foundation wants to see improved outcomes, right across the board for NZ's Biggest Cancer Killer. Our philosophy and our Kaupapa is all about eliminating inequity and saving lives.

We hope Pharmac supports these principles, especially considering how far behind New Zealand is with access to standard of care treatments for lung cancer.

We look to Pharmac to negotiate supply agreements for the innovative lung cancer treatments we are advocating for "without delay", ever mindful New Zealand waited 12 years and 8 months (after Australia - February 2005) to fund pemetrexed for lung cancer (funded as of the 1st November 2017).

During this waiting period, more than 15,000 lung cancer patients missed out and would have died prematurely, unless they paid for this treatment in private clinic.

Listed below are the lung cancer treatments currently sitting with Pharmac. These treatments are readily available in the OECD and they work better than standard chemotherapy; fewer side effects, improved progression free survival and quality of life.

Immunotheray treatments

- Pembrolizumab (Keytruda) MSD Products - *monotherapy first line and second line; first line combination*
- Nivolumab (Opdivo) Bristol-Myers Squibb - *second line*
- Atezolizumab (Tecentriq) Roche Products - *second line, and first line combination*

Targeted therapies

- Crizotinib (Xalkori) Pfizer New Zealand - *first line ALK (also international standard of care for Ros1)*
- Alectinib (Alecensa) Roche Products - *first line ALK (also second line for patients on first gen ALK)*
- Osimertinib (Tagrisso) AstraZeneca, Global Commercial Organisation, NZ - *second line EGFR T790M*

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Pharmac Lung Cancer Discussion

We understand during the course of its meeting on the 5th April, CaTSoP with also be discussing the lung cancer treatment landscape.

LFNZ is encouraged there will be a lung cancer discussion. We hope this forum will see participation from medical oncologists that specialise in the treatment of lung cancer (further to the existing members of CaTSoP).

Given the number of lung cancer drugs being considered, LFNZ has been advised that Pharmac may not be able to fund all of the treatments right away. We understand, it is for this reason, Pharmac have asked Lung Foundation NZ to rank the lung cancer treatments in order of priority...

We appreciate the opportunity to be consulted, and our recommendations are provided below.

It is with respect and concern we ask Pharmac to please again look at the staggering imbalance (inequity) that exists for reimbursement of lung cancer treatments which represents just 2.3% of the top five cancer drugs funded in 2017/18.

The writer seeks clarification from Pharmac, whether it is prepared to remedy this terrible inequity and WHAT Pharmac can do to address this huge inequity?

Listed below are the lung cancer treatments we consider are the utmost priority for reimbursement by Pharmac right now.

Our recommendations are guided by equity. Should these recommendations be supported, it would significantly reduce the unprecedented suffering of our most vulnerable patients, right now. Funding these treatments would meet what we consider is the biggest unmet need in cancer care in more than a decade. Please be bold!

- **Alectinib (Alecensa) Roche Products, for ALK lung cancer patients**
- **Crizotinib (Xalkori) Pfizer New Zealand, for Ros1 lung cancer patients**

Currently there are NO standard of care treatments funded for New Zealand patients with ALK or Ros1 positive lung cancer. The efficacy of these targeted therapies for the respective patients is indisputable. Chemotherapy is NO LONGER a standard of care for these patients.

A study by the University of Colorado (Pacheco 2018), reinforces the efficacy of Crizotinib followed by Alectinib for ALK+ patients, with an impressive seven year survival...

Despite being recognised as the new standard of care in the "Standards of Service Provision for Lung Cancer Patients in New Zealand" adopted by the Ministry of Health in 2016, lung cancer patients in New Zealand with the ALK biomarker, have been dying prematurely for more than four years. Pharmac received an application to reimburse ALK TKI, Crizotinib in 2015.

This treatment remains unfunded and has now been superseded by Alectinib, which was filed with Pharmac last year, following registration by Medsafe. Both these ALK TKI's are superior to standard chemotherapy. ALK patients need access to Alectinib as a matter of urgency and Ros1 patients need access to Crizotinib.

- **Pembrolizumab (Keytruda) MSD Products, for first-line setting as a combination therapy with pemetrexed and carboplatin in non-squamous patients and as a combination therapy with carboplatin and paclitaxel in squamous patients.**

KEYTRUDA is approved to treat the majority of patients with non-small cell lung cancer (NSCLC), and is foundational in the treatment of lung cancer; KEYNOTE 24, KEYNOTE 189 and KEYNOT0E 407.

KEYTRUDA is approved for the broadest set of lung cancer patients compared to any other immuno-oncology therapy. KEYTRUDA is the only anti-PD-1 therapy in New Zealand approved in the first-line setting for metastatic NSCLC - as monotherapy in patients with high PD-L1 expression (TPS ≥50%); as a combination therapy with pemetrexed and carboplatin in non-squamous patients and as a combination therapy with carboplatin and paclitaxel in squamous patients.

Reimbursement of Keytruda is central to reducing inequity in lung cancer care and it will be a huge step forward for improving survival rates for the greatest number of vulnerable patients. We consider it is absolutely essential that Keytruda be funded for first-line setting as combination therapy.

- **Osimertinib (Tagrisso) AstraZeneca, for the treatment of *EGFR T790 mutation positive non-small cell lung cancer (NSCLC).***

As has been outlined in the Phase III AURA3 trial, Osimertinib provides a progression free survival advantage of 10.1 months vs 4.4 months which is demonstrated in the Mok et al paper (New England Journal of Medicine). The improvement in progression free survival is clinically meaningful and is extremely important for lung cancer patients and their families.

Moreover, we refer to the Phase III FLAURA clinical trial, which demonstrates Osimertinib has superior efficacy to the first line standard of care EGFR drugs, as a first line treatment of EGFR mutation positive advanced non-small cell lung cancer (NSCLC). Osimertinib showed a similar safety profile, it also had lower rates of serious adverse events.

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 reduces the incidence of central nervous system metastases compared to the first generation EGFR TKI's. Brain metastases are devastating, so preventing them is really important for the patient.

Medsafe have approved Osimertinib for first line treatment of EGFR NSCLC in December 2018 and this is consistent with international standards.

Our recommendation is for EGFR mutation positive lung cancer patients to receive Osimertinib as a first line treatment (in favour of second line, which serves a smaller group of patients).

Special Note:* *We ask please that Pharmac approve reimbursement of the above treatments on the basis that all patients have automatic right to receive these drug/s, irrespective of where they are in the treatment cycle.

Letters supporting this submission are attached in the order listed. We would appreciate your time to review each of these letters/statements.

- Mark McKeage Professor, Co-Director and Medical Oncologist. Pharmacology and Clinical Pharmacology and Auckland Cancer Society Research Centre School of Medical Sciences.
- Karyn Robson, lung cancer patient and mother of one daughter.
- Rae Collins, mother and grandmother diagnosed with lung cancer.
- Lily Huang, lung cancer patient, cardio thoracic nurse and mother of two.
- Marjolein Bass, lung cancer patient and mother of three daughters.
- Bevan Leevers, carer and husband of Marjolein Bass, and father of their 3 young daughters.
- Nadine Dragicevich and Dawn Bethell (sisters) and David Coomber, lung cancer patient (dad)
- Amanda Watson, daughter and carer of Anita Reid, lung cancer patient.
- Renee Harris, lung cancer patient, mother of three.
- Radha Chand, lung cancer patient, mother and school teacher.
- Louise Ashton, mother of two and wife to lung cancer patient John Ashton.
- Kate Hodges, lung cancer patient ambassador, mother of two.
- Christine Roberts, mother of two.
- Ella and Jack Whitcombe; son and daughter of lung cancer patient Christine Roberts.
- Jeffrey Chan, carer and advocate for his mother who has lung cancer.
- Adam Codd, carer and husband to lung cancer patient Diane Codd.
- Dean Wilson, lung cancer patient, married with a 10 year old son

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Lung cancer patients interviewed - *each has a message for Pharmac*

John Ashton, 53, father of two, lung cancer patient, diagnosed July 2013

https://drive.google.com/file/d/1jyunvRfKSGfbxn91r6xqBKw3wNFtcYuH/view?usp=drivesdk

Christine Roberts, 51, mother of two, lung cancer patient, diagnosed May 2017

https://drive.google.com/file/d/1QwSf4swQXLDNA4M9qVmUHhsuZNv0lsU-/view

Karyn Robson, 40, solo mother of one, lung cancer patient, diagnosed October 2016

https://drive.google.com/file/d/14kKJ_C7xLEXNmHpmXz0oE3XjDKhGIv97/view

Kate Hodges, 49, mother of two, lung cancer patient, diagnosed July 2016

https://drive.google.com/file/d/1ln6S-HYtG6VjPwUiOAE7d4ZmiB7NTuHO/view

Dean Wilson, 43, Lung cancer patient, husband and father of one, diagnosed Dec 2017

https://drive.google.com/file/d/1KjENT5BPwjRuWzEKP3HtHzSObK4R3uu7/view

Baden Ngan Kee, lung cancer patient, father of three - NZ Herald feature (Keytruda)

- https://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=12154764
- Radio interview with Baden Ngan Kee - see attached file
- *Baden continues to respond to Keytruda.*

David Coomber, lung cancer patient talks about the need for access to Alectinib

https://www.newshub.co.nz/home/new-zealand/2019/02/difficult-situation-cancer-patient-leads-pleas-for-better-govt-funding-of-treatments.html

Conclusion
On behalf of the 2189 patients and their families, currently dealing with a lung cancer diagnosis, we urge you to reimburse the treatments recommended in this submission.

Funding these more effective treatments will increase survival for lung cancer and significantly reduce the inequity that currently exists for lung cancer patients and their families. Access to treatment is access to life!

We are most grateful for your time to read and reflect on the letters prepared by patients and carers, including viewing the number of interviews (see links).

Yours sincerely

Philip Hope

Enclosures

- letters from patients, carers and health care professionals
- Interviews (TV camera) with patients (*click on the links provided*)

Separate attachments:

- Lung cancer patient ambassador, John Ashton, PhD, Associate Professor, Department of Pharmacology & Toxicology, Otago School of Medical Sciences, University of Otago.
- Lung Foundation NZ - lung cancer advocacy position - http://lungfoundation.org.nz/wp-content/uploads/2018/07/lung-foundation_Final.pdf
- Lung Foundation NZ - Lung Cancer Patient Toolkit - http://lungfoundation.org.nz/wp-content/uploads/2018/11/LFNZ-TOOLKIT-A4-Poster-1.pdf
- Lung Foundation NZ - Know the symptoms - http://lungfoundation.org.nz/wp-content/uploads/2018/11/LFNZ-BREATHE-A4-Poster-WEB.pdf
- Radio interview with lung cancer patient Baden Ngan Kee - *Baden continues to respond to Keytruda.* ***(See attached file)***

Copy:

- Members of the Pharmacology and Therapeutics Advisory Committee (PTAC)
- Members of the Cancer Treatments Subcommittee of PTAC (CaTSoP)
- Therapeutic Group Manager, Pharmac, Danae Staples-Moon
- Medical Director, Pharmac, Dr John Wyeth
- Director of Operations, Pharmac, Lisa Williams
- CEO, Pharmac, Sarah Fitt
- Chairperson, Pharmac, Hon. Steve Maharey
- Minister of Health, Hon. Dr David Clark
- Associate Minister of Health, Hon. Jenny Salesa
- Chairperson, Health Select Committee, Louisa Wall
- Members of the Health Select Committee
- Members of the Maori Affairs Select Committee
- Spokesperson for Health, National, Hon. Michael Woodhouse
- Prime Minister, Rt. Hon. Jacinda Ardern
- Deputy Prime Minister, Rt. Hon. Winston Peters
- Spokesperson for Health, New Zealand First, MP Jenny Marcroft
- Chair of the Review of New Zealand’s health and disability system, Heather Simpson
- Health reporters
- Lung Foundation New Zealand Inc.

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29 July 2018

Committee members of PTAC

Re: Lung Foundation submission regarding alectinib and crizotinib

It is a pleasure for me to write in support of the submission from the Lung Foundation advocating for funding for alectinib and crizotinib for New Zealand lung cancer patients with ALK and ROS-1 gene rearrangements, respectively. Currently no standard of care treatments are funded for New Zealand patients with ALK- or ROS-1-positive lung cancer. Chemotherapy is no longer a standard of care for these patients.

Between 2013 and 2017, I led as the NZ principal investigator a series of clinical trials of crizotinib, alectinib and related ALK/ROS-1 targeted therapies, mainly motivated to provide access for New Zealand patients to these important medicines. Many of the New Zealand patients recruited to these trials (>25) now remain alive, well and on trial treatment for up to five years. Our experience in these clinical trials reflects the data now published and available to you about ALK- and Ros-1 targeted therapies, which are capable of inducing durable and deep long-term treatment responses, the control of central nervous systemic metastatic disease, good tolerability and the maintenance of quality of life. Unfortunately, as recruitment to these trials is now closed, this avenue for treatment access for newly diagnosed patients is no longer available.

To acquire information about the prevalence, demographic profile and current outcomes of patients with ALK-positive lung cancer in New Zealand, with others I have carried out a population-based observational study by linkage of electronic healthcare administrative databases. Among a population-based cohort of 3112 patients presenting with non-squamous non-small cell lung cancer in Northern New Zealand, 393 patients were tested for ALK gene rearrangements. The prevalence of ALK-positive lung cancer in the tested subgroup was 8.5%. ALK-positive lung cancer patients were younger, more often never smokers and more often Maori, Pacific or Asian than ALK-negative lung cancer patients. Among a group of 54 New

Zealand patients with ALK-positive advanced-stage disease, those who accessed treatment with crizotinib, alectinib or other ALK-targeted therapies lived longer (n=40; percent surviving at 2 years >80%) compared to those who did not access these new treatments (n=14; percent surviving at 2 years <10%). This study has provided data about ALK-positive lung cancer in New Zealand during a period of time when no state-subsidised ALK-targeted therapies were available there.

The testing required for identifying patients with ALK gene rearrangements may be considered by some as a barrier to implementing ALK-targeted therapies in New Zealand. To evaluate detection methodologies in a New Zealand context, with others I am undertaking a clinical laboratory retesting study comparing Immunohistochemistry (IHC), Fluorescence In Situ Hybridisation (FISH) and Next Generation Sequencing (NGS) for detecting ALK-Positive patients. IHC, FISH and NGS tests showed high concordance for the detection of ALK-positive lung cancer under local testing conditions. As IHC is quick, cheap and readily available, it will be the preferred testing methodology for detecting ALK positive patients in an equitable, cost-effective and timely manner in New Zealand. This IHC testing represents no significant barrier for the implementation of ALK targeted therapies in New Zealand in my opinion.

Feel free to contact me with questions or if you need me to provide any other information.

Mark McKeage
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13 Marvell Lane
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11/08/2018

Dear PTAC Committee,

My name is Karyn Robson.
I live in Christchurch and have a beautiful 14-year-old daughter whom I've raised pretty much by myself for the majority of her life. I also have ALK Positive NSCLC lung cancer at the young age of 40.

I was first diagnosed in 2016 when I was only 38, was cured with surgery, but a year later, it came back, stage 3B. I have NEVER smoked in my life, not even once, and have never been exposed to second hand smoke, other than out in public where strangers have smoked. I didn't drink alcohol, ate healthily and exercised regularly (running). So being told I had lung cancer and that it's going to kill me, was the biggest, most unexpected shock of mine, and my loved one's lives. I would be lying if I said I took the news well, and I doubt it will ever sit right with me. How does one EVER get used to the fact that they pretty much know, not only HOW they are going to die, but also the expected time frame you have left? I can sit here and write and tell you how petrified I am, and that I mourn for my short life on a daily basis, but unless you have this cancer yourself, I'm afraid you truly don't understand, especially the emotional pain of this awful disease. But there are others out there who share my struggle. And this is why I write to you today, for my life, for their lives.

Fortunately for me, there has been some light along this dark tunnel to death. I have been self-funding the targeted therapy drug, Alectinib since February of this year. Within only 3 months of being on it, my scans came back clear. All tumours had disappeared. My scans have been clear for the past 6 months. Long may this continue. But, I am uncertain as to how long my family and I can afford to keep self-funding this "Wonder Drug" as I like to call it. In 7 months, I have paid $45,000 for Alectinib. $31,000 of his has been through crowdfunding on Give a Little. The generosity of New Zealand people is incredible. Unfortunately, it still isn't enough though, and my parents are having to sell property to pay for my treatment. This is very upsetting for me, as keeping me alive is costing them their retirement, eating away at their savings. They are in their 70's (my father suffers from Parkinsons) and if I were to pass away within the next few years, they will be raising my child, which, as you can imagine, would be very hard work for an elderly couple, not only physically, but financially.
On Alectinib I relatively have no side effects (just occasional tiredness and aching muscles). It's just a simple matter of taking 8 tablets a day at home. Just like taking vitamins. I don't need to go to hospital for treatment. I can, and AM currently living as though I don't have cancer. Asides from the emotional aspect of my diagnosis, no one would know I have incurable cancer. I look and act just like a "normal" healthy 40-year-old. This is all thanks to Alectinib.

Alectinib has a median progression free survival of 34.8 months compared to standard Chemotherapy which is known to only give possibly an extra couple months worth of life - and what sort of life would that be? - We all know what side effects Chemotherapy offers, and that it also kills good cells as well as the cancer cells- Targeted therapies are exactly that - they target cancer cells ONLY. How can this not be the clear, obvious, and most appropriate choice in first line treatment for us sufferers?? Targeted Therapies have PROVEN to give a longer progression free survival, better quality of life, and are so easily administered, doing away with long hospital stays, using up hospital time and space. I AM LIVING PROOF OF THIS.

My oncologist has told me I am the only person in New Zealand currently taking Alectinib, and as far as I'm aware, I'm the only one at NED (no evidence of disease) status. Doesn't this alone speak volumes? There are others out there that so desperately need, and are deserving of this drug as well, but cannot afford it. New Zealand are so far behind the rest of the world in regards to cancer treatment, it's embarrassing. I belong to an ALK+ Cancer support group, and every member overseas cannot believe Alectinib, or ANY targeted therapy for our ALK mutation, is unfunded here. It is considered the first line treatment in ALK lung cancer worldwide. Why not here in New Zealand? Lung cancer is our biggest cancer killer, and the least funded because of the stigma of smokers. This is inaccurate and naive and NEEDS to change.

I truly believe (and stats have shown) that if I was on traditional chemotherapy, I wouldn't be here long enough to see my daughter grow up and become an adult. It breaks my heart (and I cry now typing this) thinking about it. My biggest dying wish is to live long enough to see her become an independent adult. I want to be given the opportunity to see all my years and years of hard solo parenting pay off. With Alectinib, I have this opportunity. I have the chance of seeing her drive a car, get into a career, maybe meet her future spouse. She currently suffers severe anxiety - this time last year she was unable to leave the house. So, I so desperately want to see her overcome her fears and blossom into a happy, confident young woman.

Having Alectinib has given me hope and light in times of darkness. It can at times, make me forget I have a terminal diagnosis, and rather, make me feel like I'm just living with a chronic illness that can be controlled.
At this stage it looks like I will be around for a few more years yet, thanks to this drug. It means my daughter has her mummy to share her successes, her highs and lows with, and to still have the one person who loves her unconditionally, which is just so incredible vital for her at this rough old age of 14, fighting severe anxiety.
It means my hard-working parents can relax, knowing that parenting duties in their retirement is postponed even longer.
I please just ask of you, to put yourselves in my shoes, my daughter's shoes, my family's shoes. If it were you, or a loved one of yours, what would you want as far as treatment goes, if money was no object? Would you be happy with traditional chemotherapy with hideous side effects and short life expectancy? Neither much quantity or quality of life? Or would you think you or your loved one were worthy and important enough for the world class efficacy of Alectinib, which offers potentially YEARS onto your life, as well as an actual LIFE where there are no hospital visits, needles and side effects? PLEASE really think about this, because YOU or your loved one could wake up tomorrow and have this awful disease. You may have it now and not know it. And if so, you are going to want and need to be on Alectinib. Lung cancer does not discriminate. As we say in my support group - If you have lungs, that's all you need to get lung cancer.
Aren't ALL of us entitled to the best possible medication? I find it disgraceful to think that not ONE SINGLE TKI is funded for ALK lung cancer in New Zealand. Not one. I am not asking for all to be funded (even though that would be ideal!), but just one. And that one, to be Alectinib.

Thank you for your time,

Kind Regards,

Karyn Robson

Me and my daughter, Danika.

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To Whom it May Concern

My name is Rae Collins. Born and raised in Dunedin, I currently live in Ponsonby, Auckland and live a reasonably active life, mainly walking, sailing - for pleasure and volunteering at the Maritime Museum, - and a bit of yoga and cycling.

I am a slim 68-year-old grandmother of 8 grandchildren - half of whom live overseas whom I enjoy visiting, and 4 who live in Wellington. I do not smoke and never have done. Until the last few months I was a healthy, working and travelling person, and was expecting to be so for the next 10 years.

Last year I suffered several upper respiratory colds - instead of one or two I normally get annually. In around late August I developed a chest cough, which never went away. It changed to a hay fever like cough irritated by the many smelly spring flowers in our area.

Towards Christmas I checked in with my GP who changed my high Blood Pressure pills, which eased my cough. However, during January, my chest did not feel quite right and after suffering odd pains - once we had to get the ambulance - and occasionally coughing up a bit of blood I went back to the doctor, who gave some blood tests and antibiotics.

Alongside, my left hip started to ache and I began to limp again. At the time I thought it was osteoarthritis and that I might need a hip replacement, as I had already had my right hip done nearly three years ago.

However, in early February I was diagnosed with Lung Cancer, which turned out to be Stage IVa adenocarcinoma of the lung. ALK mutations positive. T4 N3 M1b with T9 and left iliac bone involvement.

In addition, I have been extremely, tired, listless, lacking in energy, limping because of the pain in my hip – whether I take painkillers or not - and fading away into a gaunt, walking skeleton - I am normally around 50kg.

Alongside that, I have had to stop work because of the stress of the shock. Three days ago I commenced taking Alectinib, which is universally believed to be the most effective treatment for my condition for me to live as normal a life as possible.

Today, 3 days later, my quality of life has improved. I forgot to take any painkillers before setting off on my daily walk of over 4kms and realized that I was no longer in pain, or limping, or had shortness of breath!

However, to receive this medication, I have to pay around $6,500.00 each month, which, over my expected maximum of 4 years to live as a ball-park is $324,000.

The worry of paying for treatment has put a heavy cloud over my husband and myself. While I am grateful for having health insurance both the company and I have contributed a considerable amount of funds towards diagnosing and treating my condition.

My future is short and bleak.

- We will have to sell our home - our retirement project
- And curtail our travelling to visit family
- We will have no legacy for our children
- My husband will have a reduced quality of life when I am gone

I have some questions for Pharmac, the Government and other appropriate parties……

- Why, as a New Zealand Citizen and taxpayer, do I have to pay for my treatment?
- Why is free health treatment not available for all New Zealand Citizens?
- Why is Pharmac not funding the most effective treatments for people with cancer?
- Why is Pharmac not funding all NZ approved cancer drugs?
- What hope is there for people who cannot afford unfunded treatment - especially as more and more younger people are getting cancer and other debilitating illnesses?
- Why is Pharmac not lobbying the government for more funding if that is the issue?
- Why is Pharmac and the Government denying NZ Citizens an equal right to the best quality of care?

I understand that more people die of Lung Cancer than any other cancer in New Zealand - it even targets non-smokers such as myself.

I don’t understand why treatment of certain types of lung cancer is funded, but not others.
Why does this funding anomaly exist?
Why do we have to use all our retirement funds to pay for treatment that should be provided by the health system?

Yours faithfully,

Rae Collins

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To Pharmac

My name is Lily; the only thing I've ever smoked is a salmon but at the age of 51 I was diagnosed with stage 4 advanced lung cancer. I am alive today thanks to a targeted therapy drug called Crizotinib which is provided in most countries but remains unfunded in ours.

I immigrated to New Zealand from China with my husband in 1995, him as a Masters student and me as a senior registered nurse specialising in cardiac theatre. We arrived sharing a single suitcase of belongings, and 23 years later now own a house and have 2 adult daughters both working in the medical profession.

In my spare time, I love Zumba and playing badminton. I have always been an active and fit person; so naturally it came as a surprise when my persistent cough which slowly developed into pneumonia eventually led to a cancer diagnosis.

On what seemed like an otherwise normal Friday afternoon, I found myself sitting in my oncologist, Dr N's office listening to him explain how surgery was not a valid option and he would start me on palliative chemotherapy right away. Within a month, my life had turned upside down. I resigned from my management role in cardiac theatre and spent most of my days hooked up to a chemo drip. My hair started falling out in clumps, I had no appetite or energy. I still had all of the symptoms of my disease and occasionally coughed up blood. I was miserable.

Whilst I was on chemotherapy, Dr N was involved behind the scenes in the new buzz of targeted therapies. Considering my non-smoker status and young age, he decided to take a sample of my lung tissue and test it for mutations as a last resort.

After a second round of chemotherapy and a long wait, I had a check-up with Dr N who delivered the news that my samples had come back positive for a rare mutation called ROS1. He stopped my chemotherapy immediately and put me on Pfizer's compassionate program for Crizotinib. The last lucky patient in New Zealand to be chosen.

Within 3 days of starting the Crizotinib tablets, I noticed a huge change. I was no longer coughing and I felt my chest clear up. My body started to get used to the change, my appetite came back and I gained some weight (a blessing in disguise!). I even started part time back at work much to my colleagues' surprise.

I have now been on Crizotinib for 41 months and within that time, I have watched my oldest graduate from Otago University and start a first job. I have watched my youngest daughter finish high school and receive full academic scholarships into Auckland University. I'm now back at work full time, teaching and working sometimes operating big acute cases lasting 10 hours.

Nobody believes me when I tell them I was a palliative cancer patient only a few years ago.

Without the compassionate funding directly from Pfizer, I may have tried to access Crizotinib out of my own pocket. Although, I'd be alive, I would have no home, car, and support for my family, and no quality of life.

Lung cancer remains the single biggest cancer killer in New Zealand, taking the lives of more than 1800 unsuspecting people a year. To put things in perspective, these statistics are not nearly as high in other countries! New Zealand remains behind on providing patients with the latest targeted and immunotherapies resulting in people moving overseas to get treatment, or sacrificing what little they have to pay for a second chance at life. Whilst I feel extremely fortunate to have been included in Pfizer's compassionate program, there's a certain feeling of guilt knowing that while I've been alive and well, many unlucky people have missed out.

Recently huge steps have been made in the field of cancer research and particularly for lung cancer to combat the disparities in survival rates compared to other cancers. Whilst there are still economic and political boundaries to how these new treatments can be proudly supplied and recommended as the gold standard for patients who may benefit, it's an exciting time for supporters and advocate groups such as the Lung Foundation New Zealand who continue to work hard to bring light to our cause. I look forward to the day that for many patients, a second chance with the help of targeted and immunotherapies is no longer a wish but a reality for all.

Regards

Lily Huang

Ros1 Lung cancer patient

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Pharmac

Dear colleagues

My name is Marjolein, I'm a 43 year old mum to three young girls. Caitlyn 8, Jessica who just turned 7 and Emma 5. My husband of 11 years, the girls and I live in Lower Hutt (Wellington).

In February of 2016 I was diagnosed with stage 4 NSCLC lung cancer, this was a huge shock being a non-smoker and generally fit and healthy. I started getting wheezy, had shortness of breath and continuous coughing a few months before diagnosis which I was told by my GP was asthma, it didn't go away and got worse, then it was explained it was pneumonia. After many courses of antibiotics I was sent for an X-ray and then a CT scan of my chest which revealed a tumour on the lung. There is also cancer on my liver and spleen as well as three brain tumours. I guess I didn't present as a lung cancer candidate, being a non-smoker and fit and healthy who would have guessed this is what the outcome would be.

The oncologist at Wellington hospital explained I had 4-6 months to live and the only option available was chemotherapy which may extend my life by maybe 2 months or so. Quality of life would not be great and I would get sicker and if I started coughing up blood I could have a little bit of local radiation to the lung. Pretty horrible to hear. It was an awful time for myself and my family and friends. Being told I had less than a year to live was extremely upsetting and I would be leaving everyone behind especially my three little girls, whom really need their mum around for many years to come.

My oncologist suggested genetic testing for some forms of rare cancers and a few weeks later he called to tell me there was good news and bad news. The good news was that I have the ALK mutation, the bad news was that there are no funded targeted therapy drugs funded in New Zealand for this type of cancer. Not even one! Why is this? Even though lung cancer is the deadliest cancer in New Zealand and across the world. Yet no funded drugs for ALK. There are many TKI drugs for ALK available to patients overseas, Australia has three funded.

I was extremely lucky to meet all the criteria for a drug trial at Auckland hospital for the TKI Ceritinib. There is some travel involved going 1-2 times each month up to Auckland for check-up appointments and CT and MRI scans. Arranging family and friends to look after the children and paying for flights for the family member who comes up to Auckland with me. I have been on this trial for just over two years now and it has shrunk my cancer cells by half. I have continued staying stable and I have a VERY good quality of life. I take 4 capsules a day at home. Not daily hospital appointments for treatment.

Being able to join this trial for Ceritinib means that I have been able to be here to watch my youngest daughter start school, (she was just 3 years old when I was diagnosed), and be present to enjoy; Easters, Christmas, birthdays and Mother's Days with my family. We celebrated my middle daughter's 7th birthday this month. My oldest daughter will turn 10 next year, a milestone I am looking forward to which was not even possible to think about 2 years ago when chemotherapy was offered as the only option.

Being on the drug trial for Ceritinib means I have been able to start long distance walking again, which I was struggling with due to shortness of breath before diagnosis, even walking and completing a half marathon with my mum in February this year.

I walk in the hills 3-4 times a week doing 8 kms walks with friends and family, go on long bike rides, I can lead a pretty normal life. I can read stories to and with my girls which I was struggling with before starting my treatment. The side effects (stomach cramps and tiredness) are minimal compared to what chemotherapy would have been. I help at the school our children attend, I am able to go and watch performances the children do at school, I am able to look after friend's children if they need help. I can do all the daily tasks of running a house, enjoy working in the garden, doing little art projects with the girls, painting a playhouse for them and putting it together with my husband for the girls last Christmas. So many things I have been able to do and be part of because I am able to access Ceritinib.

Having this TKI has given me so much more time with my family than what I was originally told. The progression free survival is so much better on an ALK targeted drug such as ceritinib. Two years and counting so far for me. And there are others who have been on an ALK TKI for much much longer than that. All patients diagnosed with cancer that have the ALK mutation should be able to access these targeted drugs. I'm very lucky I made it onto this trial in Auckland. Without this trial I would not be able to afford these medicines.

Though I understand eventually ceritinib will stop working and for the next step the best course of treatment would be Alectinib which it not funded in New Zealand and would cost our family $6,500 per month. This is not achievable for us long term, this is not reality for most New Zealanders to be able to pay this each month for several years.

There should be a choice, not just for the very well to do, but for the general population. No one knows what's around the corner, is the next sore back, or cough just that or is it a symptom of lung cancer. Should we not all have the same opportunity to access quality medication, drugs that have been proven in trials that they work. I am here because of TKI drugs, because of my oncologist who looked for a trial. I am living proof these drugs have far greater efficacy and progression free survival. I don't look ' sick', I don't feel 'sick'. I am alive and living well.

Please consider my submission for funding Alectinib. This is important to our family, to our friends, to our children and to New Zealand's future patients who need this medication.

I need to be on this earth. My children need their mum. They need to be able to remember me, the longer I am alive the more they will be able to remember their mum. With Being ALK positive and having access to quality drugs such as Ceritinib, Alectinib and other TKI drugs this terminal illness can be turned into a controlled chronic illness. My initial diagnosis of 4-6 months can be changed to years if Alectinib gets funded. Just imagine, if this was your mum, or dad, another family member of friend or yourself. I'm sure you would like to be able to access the best quality cancer care and medication available.

Thank you for your time.

Kindest regards, Marjolein Baas (Phone 022 374 8093)


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JESSICA LEEVERS
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JESSICA LEEVERS
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EMMA LEEVERS
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10th August 2018

Pharmac

Dear colleagues,

My wife Marjolein whom is a mother of three young girls (Caitlyn 8, Jessica 7, and Emma 5) was diagnosed with Terminal (stage 4, Alk) Lung Cancer two and a half years ago, her life expectancy at the time was 4 to 6 months. We were lucky enough at the time to be accepted onto a drug trial for Ceritinib.

Prior to the trial Marjolein would be very tired, coughing and unable to walk long distances, thereby at times a simple task such as taking the girls to school would be very difficult if not impossible.
It took a long time (months) for Marjolein to be diagnosed due to her not fitting the assumed criteria for such a disease, i.e. non-smoker, healthy eating, etc. For the same reasons a CT scan was not undertaken as she must have asthma or pneumonia. During this time it is unknown how much the cancer grew. In my conversations with other patients on this trial, this story is common and unfortunate; most of these people are also non-smokers.

Now after two years beyond initial life expectancy Marjolein is fit, active and enjoying her girls milestones, i.e. them beginning school, their achievements both academically and in sports. It can be emotional each time she sees a milestone being reached; her tears of joy are shared by her family.

My wonderful wife has an overwhelming sense of her own mortality, nevertheless she has been an inspiration to many others on the trial. She has contacted many of these people to bring them together and give others hope by sharing her own experiences and letting them know they are not alone; for this I am in awe.

Although I am unable to fully understand what she is going through, I have another set of challenges. Mine are long-term; I need Marjolein to know the girls are going to be looked after when she is gone. How are we going fund a new drug when Ceritinib is no longer working, i.e. how many years before I am bankrupt, and what quality of care (i.e. schooling, housing, etc.) can I provide my girls when the money is gone?

Marjolein and her girls are still young. We try our best to provide a positive and happy childhood for our girls and in turn I love my wife and the girls love their mum.

The next obvious drug to help Marjolein is Alectinib, because this is the new generation ALK TKI which is regarded as the international standard of care for lung cancer patients that have the ALK biomarker. Please consider funding this drug so Marjolein and many others like her can get a chance at life.

Kind Regards

Bevan Leevers

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Pharmac

We are Nadine and Dawn and our Dad, David Coomber has Stage IV ALK positive Non-Small Cell Lung Cancer

Our father, David Coomber, was a recently retired saw doctor. His plans of overseas holidays, boating and fishing and enjoying retirement with his wife all changed as of 13th February 2017.

Dad had no noticeable cough but was experiencing, extreme fatigue along with ongoing sinus problems and migraine headaches (something he had suffered from most of his adult life). Routine blood tests also revealed high levels of liver enzymes. Our family GP had exhausted all possible diagnoses, so referred our Dad to North Shore Hospital for further tests. The chest x-ray came back clear, however a CT scan on the brain showed 3 lesions. The doctor explained there was a high chance the lesions were cancerous. We couldn’t believe it. A bronchoscopy was performed and a sample of a tumour from his Lung was sent for analysis. It was confirmed Dad had Stage IV Lung Cancer which had metastasised to his brain. A healthy, fit, 68 year old who had never smoked - we were in total and utter shock.

A few weeks later we were sitting in the waiting room at the radiology department where our Dad was to be fitted with a radiation mask. A member of the oncology team called Dad’s mobile explaining the results from his biopsy and confirmed he had a rare type of lung cancer - ALK positive. There was a clinical trial based in Auckland for trialing a targeted cancer treatment which he may be eligible for. Looking back now, we had no idea how important that phone call was.

The clinical trial at Auckland hospital/University was for a drug called Ceritinib which directly targets the tumours without the need for traditional radiation and chemotherapy. After a series of meetings and further tests Dad was accepted.

Sixteen months on and dad is still with us. The drug has worked. All lesions in his body have been stable and some no longer detected. However we have always known we would need to be prepared for the next stage when the treatment would no longer work.

Our dads most recent MRI is now showing up to 30 new slow growing lesions back in his brain. Both the Radiologist and our Oncologist have agreed the next line of preferred treatment should be Alectinib - but there is no clinical trial available here in NZ and the cost to access the medicine would be $6,500/month to our family.

Like many others in this position, we are feeling helpless and worried about Dads future and to know there is a drug available which would keep him around but may not be financially viable for us is an incredibly hard reality. After lengthy family meetings and emotional discussions, unfortunately the decision has been made for Dad to start the process of Whole Brain Radiation.

During our journey, we have made many ALK positive friends and have recently heard about Dr Camidge, a leading specialist in ALK positive, who stated patients with ALK positive are now living up to 7 years with stage IV lung cancer because of targeted therapy.

These survivors who had brain radiation are now living long enough to suffer side effects from receiving this traditional form of treatment.

The alarming thing to note is if our Dad lived in the USA, UK or Australia, he would have access to Alectinib and would only receive WBR as a last resort.

We ask you please to listen to our ALK positive patients stories here in NZ as they demonstrate the efficacy of ALK TKI's which is the standard of care NOT chemotherapy. They are real people, with so much to deal with, fighting this awful disease, when their time should be spent making memories with their loved ones.

Thank you for your time,

Nadine Dragicevich (daughter)

Dawn Bethell (daughter)

Jackie and David Coomber (ALK Survivor)

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The Cancer Treatments Subcommittee of PTAC (CaTSoP Pharmac)

Our Story – Anita Reid – My Mum living with stage 4 lung cancer

My gorgeous, health conscious Mum was diagnosed with lung cancer in June last year. The news was utterly devastating to our family. We had already lost our Dad to cancer 12 years before. We wanted our Mum alive for us and her 4 grandchildren that adored her. How could this happen to our Mum who was not a smoker and had led such a healthy and active lifestyle.

My Mum had been feeling tired – but she was 75 and was doing a lot of things. Mum led a very active lifestyle – looking after grandchildren, gardening, out with friends. Mum had only given up work in the last 3 years. Then when we were away on holiday she coughed up blood. This raised alarm bells and Mum went to her local GP. Within weeks Mum was diagnosed.

After being diagnosed with stage 4 terminal lung cancer – numerous tests were carried out and we were informed in a couple of weeks that due to the ALK mutation of her non-small cell lung cancer there is a drug available that will give Mum time and make that time worth living. The drug is Alecensa (Alectinib). The hitch is - Alecensa it is unfunded in New Zealand, unlike Australia.

Mum is responding so well to Alectinib – it is amazing! In summary, for the brain the residual focus of cortical enhancement shown in the previous scan is no longer identified, no evidence of metastatic intracranial disease on the post contrast study. For the chest, there has been further reduction in the residual multifocal abnormal soft tissue in the right hemithorax, both the upper and lower lobes. No new focal new lung lesion identified. No plural fluid. No relapse of mediastinal nodal disease. There is no lymphadenopathy in the supraclavicular or axillary regions. These is no evidence of disease relapse within the abdomen and pelvis. No peritoneal nodularity. No adrenal mass. No non-obstructed kidneys. No peritoneal free fluid. No evidence metastatic bone disease. There has been further reduction of residual abnormality within the chest. There is no evidence of disease relapse within the brain or elsewhere.

The main side effect has been constipation and the mucas lining of her nose has been altered. These are insignificant compared to how wonderful this drug is working.

The drug has allowed my Mum to LIVE!!! If Mum had had to have chemotherapy she would no longer be alive. We wouldn't have had Mum at all the birthdays in the past 10 months – how do you explain that to a six year old – his beloved Grandma and best-friend is not at his birthday because the government wouldn't help his Grandma. How do you cope with explaining to your one year old in the future this is why you don't know your Grandma – but she loved you with all her heart. If you have money in this country and you are really sick you live – if you don't have money you die.

The access to the drug costs us well over $10,000 each month. We are a middle class family. My parents have always worked. There is no mortgage on the house and Mum had enough savings set aside for a frugal retirement. We are now using this retirement fund. The next step is to sell the beloved family home. The very idea of selling the home is making my Mum upset and causing stress when she should be focusing on her health. We are lucky there is home to sell. What about the others out there who have no choice. How can my Mum who has been a tax payer all her life and a contributing member of a community be put in this position.

If we had access to this treatment with no cost we could get on with LIVING. We would not be facing the prospect of Mum selling her house and moving out of her community away from her friends. Mum needs all the strength to fight this awful battle with cancer. Mum wants to be in her home – she deserves to be LIVING in her home.

We urge – and plead – that Pharmac and those leaders in society who can make a difference - that this new generation ALK TKI be funded for others, that like Mum, are suited to this treatment. We cannot understand, as a family that heard the nightmare words - 'this is lung cancer' - that this treatment which is the standard of care in the majority of OECD countries is not funded in New Zealand. We understand that funding of an ALK TKI such as Alecensa is also consistent with the NZ Lung Cancer Standards of Service Provision which was adopted by the Ministry of Health two years ago. Why has this not been observed by Pharmac?

My Mum wants to live – she has a lot of living left to do! Lung patients want to live – and this is possible if these new treatments are funded. It is so unfair that this drug is not made available to all those that need it – and would greatly benefit.

We appeal to Pharmac to value the life of those with lung cancer otherwise much loved individuals will die unless they self-fund.

Regards
Amanda Watson
(Anita's Daughter)

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Lung health for life

14th March 2019

Cancer Treatments Sub-Committee
Pharmac

My name is Renee Harris and I am a 51 year old non-smoking female. I was diagnosed with stage 4 Lung cancer in November 2015 at the age of 48 and was confirmed to have the ALK mutation not long after that.

It took almost two months to get a proper diagnosis for my condition and that was only because I insisted time and again with my doctor to get a CT scan. She kept dismissing me and telling me 'nothing was wrong' even though I told her I couldn't breathe properly and was exhausted with the slightest exertion. I had many other symptoms which she dismissed curtly, eventually offering for me to go on anti-depressants! This was the only time I cried, with complete frustration.

In hindsight, I can only deduce from the inaction on my GP's part, that I didn't present in the typical stage 4 cancer patient way and many similar stories from other ALKie members leads me to believe that much more needs to be done in education, screening, diagnosing and treating this disease.

After diagnosis, I was so very lucky to be accepted onto a Novartis trial for an ALK inhibitor called Ceritinib. I was explained that it was a drug that had already been trialled overseas and had proven results, but this trial would be around efficacy, with or without food. Ceritinib has reduced my primary tumour and all metastases.

I have had approximately 87% reduction of disease with no subsequent progression after more than two and a half years of treatment. I would not be able to have afforded this medication if I had to self-fund it.

I have been super fit all my life, having represented NZ in volleyball and playing Combined Services sport in Basketball Softball and Volleyball throughout my career in the Air Force. I also worked out at Les Mills gym between one and three hours a day. I've eaten a healthy diet. These are typical stories I hear from other ALKie members.

Anyone can get Lung Cancer and more people die from lung cancer than any other type of cancer.

Why are we so underfunded in NZ and why do we have such poor access to medicines compared to many other countries?

I would really like for Alectinib, Brigatinib, Lorlatinib and other lung cancer drugs to be funded in NZ and not just for first line treatment. People like me have been treated successfully with a TKI already and would like a second line option.

Thank you to all those who advocate for us. We want to live and we would like these proven medications to available to us in NZ. I am a mother of three, a wife, a sister an Aunty and a friend. Attached are some pictures of my family.

Kind Regards,

Renee Harris

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ATT: Cancer Treatments subcommittee of PHARMAC

My name is Mrs. Radha Chand and I am a 60 year old high school teacher residing in Manukau, South Auckland. I have lived in Auckland since arriving to New Zealand as a permanent resident with my husband and son in 2002. I am a secondary school teacher teaching Mathematics in Auckland for the last seventeen years.

Over the last 2 years, I started experiencing various forms of seemingly unrelated symptoms, the most significant of which was a pain in my left rib and an intermittent cough. During this time, I lost a significant amount of weight, mostly in terms of muscles, had erratic changes in my bowels and became easily fatigued. I had **no history of smoking, alcohol abuse or significant family history that would be risk factors of a serious illness** and I continued to be treated symptomatically. I persisted with seeking medical opinions as I was convinced that there would be a unifying cause for all my problems. Previously I had been fit and well. The pain worsened to the point where I cried to sleep for many nights. Even with all this pain I was reporting to work every day. It was after invasive investigations like endoscopy yielded no answers when I had broad imaging done with an X-ray and CT scan that we got a diagnosis.

Towards the end of November 2018, I was informed of a diagnosis of **Stage 4C adenocarcinoma** of the right lower lobe of my lungs with an 8.5cm mass. The tumor had spread to the right upper lobe, lymph nodes and T7 left rib which explained the pain that I had been having for such a long time. I hope that you can imagine that this was a devastating diagnosis that nothing could have prepared me for. Furthermore, without treatment, this disease has a high mortality rate that I was very aware of as it is something we hear about in the media tragically affecting many New Zealanders and devastating families. The incidence of serious cancers have continued to increase in our country and the general public remains acutely aware of this.

I was referred urgently to an oncologist, Dr. Richard Sullivan, to discuss possible management pathways and in my case Targeted Therapy was an option. The genetic testing confirmed that there was an ALK mutation which made treatment using **Alectinib** an option. The treatment was a life-changing experience. **Within two weeks, the pain and cough that had haunted me for so long was gone, I could move freely, I began to gain weight (2kg), enjoy food and participate socially without becoming fatigued.**

My follow-up scans 5 weeks later showed that the tumor was less than half its original size as well. The lymph node on my rib had totally disappeared. My weight had gone up by another three kgs. Best of all, I was able to return to work when the school reopened for 2019 with the support of my employer, Pakuranga College who have done their best to accommodate me. I was fortunate to **not have experienced any side-effects** and enjoy a return to my normal, productive life that at the end of last year felt impossible and completely out of reach.

The cost of this treatment **is $6497.50 for every twenty eight days**. **Annually this would amount to $84,467.50**. For the average New Zealander with the misfortune of having a cancer diagnosis, this is a further blow. I have found it to be a daunting and frightening challenge at this stage in my life when I hoped to reap the benefits of my years of hard work. My husband and son will contribute and assist where they can but meeting this expense will remain an ongoing challenge as long as it remains unfunded. We are prepared to make the sacrifices we need to but please appreciate that this is a fight to stay alive.

We live in a miraculous time where medical science can give quality of life and hope where there was previously none. My son was a cancer biology researcher at University of Auckland in 2007 and he recently showed me how my treatment was still in development 10 years ago and held so much promise. We also live in a country that aims to make world class healthcare available to all its people. I never expected this could happen to me and similarly you may find yourselves or someone you care about needing this important treatment. Cancer sufferers can now have treatments that have more efficacy and less side-effects and we can all collectively move towards a time when we no longer lose anyone to this horrible disease. Please do not be fooled into thinking that it only happens to certain people or have preventable risk factors. As patients, we are asking for funding but what we are really getting is time and quality of life without the constant fear of how to meet the cost of our medication.

I am proof that that the treatment works and that it works well. If it can help me at my age and the advanced stage of my disease, it means that that it can help many more people. Whilst an insurance company is a business and cannot be bargained with, a government's job is to care for its people. Allowing medications that can save lives to be out of reach for its citizens over money is unacceptable. It is the antithesis of our values as a nation. Any decision that prevents life-saving health care to be unavailable to select persons due to their financial status is incompatible to my belief of who New Zealand is.

Through this letter I am making an earnest plea to get these drugs funded. I look forward to a positive response from those in power to make the change.

I would like to take this opportunity to express my sincere gratitude to the people involved in my journey. My doctors Dr. Sullivan, Dr. Ogra, Dr. O'Carroll and Dr. Siva who have had various stages contributed to my care. I am also very grateful for the love and support of my husband and son who has stood by me through all the hard times and also the tremendous moral and emotional support from family and friends.

I look forward to my next follow-up scan on 9th April, 2019 where I hope there will be further improvement in my health.

Radha Chand

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Louise Ashton
29 Howard St
Macandrew Bay
DUNEDIN 9014

14 March 2019

Cancer Treatments Subcommittee
Pharmac
WELLINGTON

Dear Pharmac,

I am the wife of a lung cancer survivor. SURVIVOR. Not a word usually associated with lung cancer, the biggest killing cancer in New Zealand.

My husband was diagnosed 5 years ago with Stage IV non-small cell lung cancer. He was 48, a fit, non-smoker, with a good job, and a bright future. All he had was a niggly cough, that just wouldn't go away.

After a CT scan revealed the seriousness of the situation, the archaic, cruel chemotherapy was applied, and like leaches applied to a dying 18th century patient of old, it didn't work. Eight rounds of debilitating, soul wrenching, hair and nail ablating agony, IT DIDN'T WORK.

Until one day after reading a magazine found in a shop on holiday, there was an article about clinical trials for these new cancer drugs in Australia. My husband rang the number listed, and it began a cascade of life extending events that led him to be genetically tested for a drug not available here in NZ. Even his oncologist had never heard of most of them.

The magic word: Crizotinib. He was genetically compatible with a drug that would enable him to survive now for over 5 years, and is still working, paying taxes, being a Dad, telling bad jokes, mowing the lawn, going to school soccer. Still here. Surviving because he received the drug on compassionate grounds. Its price is astronomical, for which not only Pharmac says it can't pay, but also says these drugs don't work. I am telling you, Pharmac, some may not, but this one, and its new progeny DO work. Come to my house and see what they can do. Open your eyes, and slip into the 21st century of new drugs. Stop quibbling about the few cents saved on some generic blood pressure or antacid pill. Heart Pills and fart pills of which there are dozens of generic forms, and a few cents here and there is meaningless.

By saying these new cancer drugs don't work, you make yourself look corrupt and blind, and the public are losing confidence in your ability to discern objectively between evidence based policy or policy based evidence.

Our children, are growing up happy, and carefree, but how long will it be before the magic wears off, and the new generation of the drug, Alectinib is tantalisingly, cripplingly, out of reach, and my children are the unwitting victims of Pharmac obstinacy?

I was a radiographer for 24 years. In those years, I saw many patients come in with port-a-caths, PICC lines and pumps delivering liquids of fierce toxicity and fierce hope in equal measure, only to read their obituary in the paper a few weeks later. I remember one man, older than my husband, fit and upright, diagnosed with Stage IV lung cancer while on holiday to visit his grandchildren in Australia. He was bewildered, and still in shock at his diagnosis. I told him my husband had the same thing. I remember hugging him, and him weeping. I remember not saying to him “It will be all right”, because we both knew it wouldn’t be. He was dead 4 weeks later. I often wonder about him, if he had stayed in Australia, or been at least tested over there, would he have survived?

I will never know.

Yours Sincerely

Louise Ashton.

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16 Coleridge Street
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Dear Members of PTAC & CaTSoP

I am a 49 year old woman, a wife and mother to 2 children aged 11 and 13. Nearly 3 years ago, in June 2016, I was diagnosed with stage 4 Non-Small Cell Lung Cancer. I was fit and healthy at diagnosis and am one of the many lung cancer patients who have never smoked.

My initial prognosis was bleak, palliative chemotherapy being the only option. Gene testing of my tumour, however, revealed that my cancer was receptive to targeted treatments giving me another treatment path. My cancer had already mutated past responding to the only government funded drug, but luckily my Oncologist was forward thinking and was aware of a drug that was being used very successfully overseas, Osimertinib.

Fortunately Aztra-Zeneca provided compassionate access to their drug because it was not yet authorized in New Zealand, and I commenced treatment in September 2016.

Since that day my cancer has remained stable and I have had a near to normal quality of life, which has given me valuable time to create memories and make future plans with my family. I am under no illusions that this drug will cure me, but I will be eternally grateful for what it has given me instead.

On 13th April 2018, the Cancer treatment Sub-committee of PTAC deferred making a recommendation regarding the funding of Osimertinib. There will be many people now in exactly the same situation as I was in July 2016, but without the chance of compassionate access from the drug companies because whilst the drug is now approved in New Zealand it is not funded, making it cost prohibitive for the vast majority of the population.

For many of us Lung Cancer patients a cure is not what we are looking for or unfortunately, expecting. We know we are living with a life limiting disease and therefore anything that can extend our life is our miracle. Osimertinib has been that for me, and it breaks my heart that this is being denied from equally deserving patients.

I urge Pharmac to fund this treatment so that all other lung cancer patients with my type of lung cancer have the opportunity to stay well for their families.

Yours Sincerely

Kate Hodges

My name is Christine Roberts Whitcombe and I am married with two children aged 13 and 14 and I'm living in Auckland.

I had a persistent cough around the beginning of 2017. I was prescribed various courses of antibiotics which had no effect on my symptoms. I returned several times to my GP realizing that my symptoms had worsened, and I now had back pain and a swollen lymph node in my neck.

A biopsy of the lymph node and a chest X-ray confirmed lung Cancer. I was diagnosed with Stage 4B NSCLC EFGR in May 2017, 5 months after noticing my first symptoms.

I have always enjoyed an active lifestyle which included many years of competitive canoeing, regular gym visits and running around after my kids. I continue to lead an active lifestyle.

I started on a targeted therapy called Tarceva (Erlotinib) on 1st June 2017. It involves taking a pill a day.
I progressed after 7 months to the T790M Mutation which is currently being treated with Tagrisso (Osimertinib). I was fortunate to receive compassionate access directly from Astra Zenica. If I had to pay for tagrisso we would have struggled to find the funds.

I was having difficulty with everyday tasks when I progressed around January 2018. Walking upstairs was a struggle as was getting in and out of bed. My back pain had returned and fluid on my lungs was creating issues with my breathing.

Once I started on Tagrisso my back pain slowly reduced over a month to almost being unnoticeable. Fluid on my lung also reduced which helped with my breathing.

My 1st CT scan showed the tumours were shrinking and my Bone Mets were healing. Subsequent CT scans showed further reduction in the tumours to almost nothing.

What excites me most about the response I am getting from my treatment Is that I can almost lead a normal life spending time with my family. I am more motivated and positive and feel less frustrated and emotional.

I have returned part time to work, contribute to our home life and enjoy holidays with the family.

I am now living every day to the fullest grateful for my health which this amazing drug has allowed me to do.

Because I have experienced both Tarceva and Tagrisso I can explain my experience here. Tarceva's side effects were far more severe compared to Targrisso. Skin problems included dryness and rash and I lost my appetite. The effect on my hair was also dry, coarse, curly and thinning and my scalp was extremely dry. Tagrisso side effects have just been the occasional diarrhoea and dry skin.

I do not understand why tagrisso is funded and is the standard of care in other OECD countries and not in NZ. Chemo seems to be the standard of care in NZ and it is not effective, and our people are dying unnecessarily. I am proof that tagrisso works and am living a relatively normal life.

I believe that Tagrisso is so effective and with so fewer side effects then other drugs that it should be fully funded by Pharmac. I believe by fully funding this drug there will be cost saving in our health system and other areas because of the flow on benefits.

I hope that Pharmac and the Government will consider our application.

Kind regards

Christine Roberts

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To Pharmac

Hello, our names are Ella and Jack Whitcombe.

We are 14 and 13 years old and we live in Auckland. Our mum Christine Roberts-Whitcombe was diagnosed with lung cancer in May 2017. We were devastated when we got the news, as we couldn't understand how our active and healthy mum could be diagnosed with lung cancer. At the time, we saw lung cancer as an "old person's disease" or "smokers disease". We now know that lung cancer can affect anyone.

What upsets us the most is that she may not be around to see us grow up, leave school or go to university. She may not even be around to see us get married and have children of our own.

Mum takes a daily pill called Tagrisso. Tagrisso is a miracle drug, which has enabled her to continue living a normal life. She is still active and finds the time to look after all of us. She runs us around for sport and music as well as working. Tagrisso has really helped her to continue being active, healthy and full of energy.

We have been told that Tagrisso will eventually become ineffective. So, she will need a new drug to treat the new mutation. This is a scary thought, as the next line will most likely not be funded.

We hope that Pharmac can fund the drugs needed by our mum and others in the same position so that kids like us are able to have their parent around for a long time.

Thank you.

Regards

Ella and Jack Whitcombe
(kids with a parent with lung cancer)

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To CaTSoP,

My mother was diagnosed with stage IV lung cancer in November 2017. She is currently taking a first generation EGFR inhibitor, however, the doctor has cautioned our family that the potency of this drug only lasts for about a year.

Our next option is either chemotherapy or Osimertinib. Osimertinib is not funded and as regular kiwis, we cannot afford to pay $10,000 a month for Osimertinib, therefore we have decided to mortgage our house in order to fund this treatment for my mother.

I am currently in my first year of my master's degree in Audiology and now faced with the decision whether to drop out in order to support my family.

The evidence is clear, Osimertinib significantly improves progression free survival and most importantly maintains the quality of life for patients compared to standard chemotherapy.

Osimertinib is used as a front- line treatment in the bulk of OECD countries including Australia.

As a country we must do better, we are falling far behind in the provision of cancer treatments compared to Australia and this is unacceptable. We acknowledge that cost is an issue, however, for thousands of families like ours we have our lives at stake. As a patient, having cancer is devastating enough, let alone also facing the guilt of having their own family struggle to be able to afford their treatment.

To the committee members, we have our lives in your hands. Please consider that your decision will not only save my mum and many other patient's lives, but also the lives of our families.

Sincerely

Jeffrey Chan.

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Dear Sir/Madam,

I am writing this letter in the hope that it may persuade you to give due consideration to approving a number of cancer treatments for public funding. Those of particular interest to me are the immunotherapy treatments, Keytruda and similar, and other targeted therapies such as Tagrisso.

On 21 December 2018 my wife Diane was diagnosed with stage 4 NSC adenocarcinoma. She is an otherwise healthy, active, non-smoking, clean living, beautiful young lady of 44 and this news was devastating, more so because we were told just before Christmas.

The prognosis was made after almost a year of frustrating interactions with various members of the medical community. Diane initially sought treatment for pain in her right chest/shoulder/back area and was referred to various gastroenterologists, physiotherapists, musculoskeletal specialists and similar, all of whom had their own views, some pretty bizarre, on what was causing the pain. Various treatments yielded no results. At no point did anybody even think to recommend a chest X-ray.

Around September of 2018 Diane developed a cough which would not go away. Again, a number of doctors visits later a chest X ray was taken. It was then recommended that she wait a month and have another X-ray. It was after this X-ray that the possibility of cancer was first mentioned at the beginning of November. This was when the world as we knew it was turned upside down.

After further frustrating waiting periods and seemingly very little progress she was finally booked for an EBUS to get a biopsy. Confirmation of the prognosis was followed by a further waiting period while the sample was tested for genetic mutations. It was confirmed on the 19th of January that Diane tested positive for EGFR mutation.

Fortunately, at this point in time there are 2 first generation treatments which are publicly funded and early evidence appears that there is some improvement although it is early days yet. We are told that at some point the current treatment will become ineffective and at that point in time we would need to look at non funded medications such as Osimertinib at an approximate cost of $7000.00 per fortnight. For all the best will and effort it is impossible to comprehend trying to sustain such a cost for any period of time, with the only option being a downturn in quality of life for our family as all monies would need to be directed toward this treatment.

This treatment and many others are publicly available in a number of other countries and I can not understand how a country like ours which prides itself on looking after its people is years behind when it comes to publicly funded treatment. The objective should not merely be to keep people alive but to provide them with the highest possible quality of life for as long as possible. These treatments have proven to be more effective on a number of levels than current treatments and offer a glimmer of hope to those of us in this position.

How any country can stand idly by while it's people suffer from this terrible disease knowing full well that there are proven treatments available that will improve quality of life and life expectancy is incomprehensible to me. Not only do I see it as unfair, I feel it is downright irresponsible and shows a callous lack of respect towards all people not only those affected at this point in time. Trust me when I say none of us know what the future holds and this can happen to anybody at any time.

Having access to these treatments would literally be life changing for our family. Just the opportunity to have a bit of normality back in our lives and to be able to focus on things that "normal" families do without thinking about all the other stuff we are currently trying to deal with is a prize worth fighting for.

I urge you with all my heart and soul, and implore you as a man fighting for his family, to push to make more treatments publicly available. I also demand, as an angry and frustrated man, that we are given the same opportunities as people in the other countries where these treatments are available.

Thank you for your consideration in this matter.

Regards

Adam Codd

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15 March 2019

Cancer Treatments Subcommittee
Pharmac

Re: Lung Cancer Treatments Review

Introduction

My name is Dean Wilson. I reside in Beachlands, Auckland with my wife, Vonja and wonderful son Jack, who is 10 years old.

On 22 December 2017, I was diagnosed with stage IV non small cell Lung Cancer. I was 42 years old.

I have never smoked. My cancer is caused by an EGFR mutation, exon 21.

Everyone we know has been shocked by my diagnosis. It has highlighted the stigma attached to lung cancer. Many people have said “but you have never smoked.” I am fit, active and lead a very healthy lifestyle.

Treatment to date

My diagnosis and treatment to date has been as follows:

Mid 2017	I had low level lower back pain for no apparent reason
Aug 2017	I fell at home and subsequently had continuous and increasing lower back pain.
September 2017	I commenced physiotherapy for a suspected ruptured disc in my lower back.
November 2017	My pain was increasing. I had an x-ray but no one picked up the tumour shown in the x-ray.
13 December 2017	I saw an orthopaedic surgeon who referred me for an MRI.
17 December 2017	I had an MRI.

18 December 2017	I was called into the orthopaedic surgeons' office. My MRI showed a large tumour in my lower spine, that had eaten away at least half of my L2 vertebrae. That day I had further scans and a biopsy.
22 December 2017	I was diagnosed with lung cancer metastasized to my spine. I was admitted into acute oncology and later released for Christmas on a high dose of steroids to reduce inflammation.
January 2018	Received SABR radiation to the tumour in my lower back.
17 February 2018	I had a partial lobectomy and several of my lymph nodes removed.
March 2018	Received news that the primary cancer in my lungs was successfully removed in surgery, but that my cancer had progressed to my T4 vertebrae and left pelvis. Commenced targeted drug therapy – Erlotinib (currently funded by Pharmac) daily.
March 2018 to present	No progression – in fact my last scan showed no detectable tumours. My oncologist has advised that I am in remission. My vertebrae and pelvis have repaired showing sclerosis.

<u>Pre diagnosis / treatment</u>

By the time I was diagnosed:

a) I was suffering constant and severe pain in my back;

b) I could barely walk due to pain, with loss of strength and feeling in my left leg;

c) I was not sleeping;

d) I could not play with my son. Bending over was impossible and even sitting to play a board game or watch television with him was too painful.

When I met the acute oncologist at Auckland Hospital on 22 December 2017, she told me I was lucky that I hadn't broken my back and was worried that the pressure on my spinal cord from the tumour would cause permanent damage. I was sent home for Christmas with steroids and under strict instructions to limit movement in case I fell again. My radiation treatment could not commence until after the qualified staff were back from their Christmas break.

<u>My current state of health</u>

The radiation I had on my spine did not reduce the tumour, but halted growth and decreased my pain a little. The lobectomy was successful in removing my primary tumour.

Since starting Erlotinib, my quality of life has improved immensely. While I have unpleasant side effects from Erlotinib, the treatment has given me my life back. I have been on Erlotinib for a year now and the results have been nothing short of incredible. In particular:

a) All the tumours in my body have gone;

b) My vertebrae and pelvic bone have repaired;

c) I no longer have any pain;

d) I have some residual nerve damage, but only feel this when I am overtired;

e) I am able to run, jump and play with my son again; and

f) I have returned to work part time.

I do suffer side effects from the Erlotinib as follows:

a) A skin rash which I manage with various oncology skin products, an antibiotic (Minocycline) I take daily and minimising skin exposure;

b) Fatigue which I manage by having a sleep in the afternoons; and

c) Diarrhoea which I predominantly manage with diet and mediation at times.

<u>Further benefits of Erlotinib</u>

If not for Erlotinib, I would at best be in a wheelchair, with a poor quality of life and at worst be in the final stages of cancer or dead.

My quality of life on Erlotinib has meant that emotionally, my wife and I, are more positively able to navigate my diagnosis. This has been so important for us, being able to continue to provide a happy (despite cancer) home for our son.

If the first few months after I was diagnosed, neither my wife nor I was able to work, due to my intensive hospital based treatments. Our son was struggling emotionally and at school because so much of our life had changed. When Erlotinib started working, our household regained normality (albeit a new normal). My wife was able to return to work and our son has returned to his usual happy and confident self.

Next steps / the future

I hope Erlotinib continues to work for me for a long time yet. Stories of people that have been on Erlotinib for years give my family real hope that I may live to see our son reach adulthood.

It is likely that I will need the drug Osimertinib when Erlotinib fails. I also understand that other OECD countries, including Australia, are now using Osimertinib as the standard first line treatment for EGFR patients. I have been told by other New Zealand EGFR patients I have met, that Osimertinib is a much kinder medicine, in terms of side effects, than Erlotinib (based on their experience with both of these medicines). I have read studies that support these assertions.

I am also likely to need Pembrolizumab in the future.

I understand the cost of Osimertinib is between $10,000 to $12,000 per month (depending on the pharmacy supplying the drug).

As individuals, we have absolutely no ability to leverage a reduction in the cost of these much needed medicines.

The prospect of having to purchase Osimertinib at $11,000 (approximately) per month and then Pembrolizumab is terrifying.

Treatment - but at what cost?

My wife and I both come from very humble backgrounds. We have worked very hard to create a financially secure home. We own a home (with a mortgage). We have savings. We have insurance (medical, trauma and life). We both have good jobs. We have no debt other than our mortgage. However, none of this is enough for us to be able to fund Osimertinib ourselves beyond a few months. We will need to incur debt or rely on the goodwill of our friends and community through crowd funding to extend and maintain my quality of life.

We worry that many New Zealanders with lung cancer, who do not have the resources we have and live hand to mouth, will simply not receive the best quality of care and die prematurely.

Even though I don't need Osimertinib or Pembrolizumab yet, the lack of funding of these drugs in New Zealand is already dictating our lives. In particular:

a) I feel like my life has been reduced to a monetary value. Is my life worth this monthly cost / burden to my family? They say yes – but at what cost?

b) Is my legacy to be one of grief and debt for my wife and son?

c) My wife worries about every dollar we spend now. She is so focused on saving money for my future treatment that we are not using our money to have days out or weekends away together for example, to create valuable memories;

d) We are looking into importing generic drugs from India or similar countries at a significantly reduced cost, but hoping they will be as effective;

e) Giving up our hopes and dreams for the future including travel, funding for our son's education and saving for retirement;

f) The emotional burden of weighing up the tipping point. At what time does the financial burden become too much?

If the drugs on the waiting list were funded

I appreciate that Pharmac has a very difficult job to do on a limited budget. However, the types of medicines on the waiting list for lung cancer has, as I understand it, fundamentally revolutionised lung cancer treatment.

The fact that there are so many lung cancer medicines on the review / waiting list that are standard treatment in other OECD countries is unacceptable, especially considering lung cancer in the biggest killer in New Zealand of all cancer types.

I know these medicines will not cure my cancer, but is it not worthwhile and important to fund these treatments to:

a) Make them accessible to all and not just those that can afford them;

b) Not only extend life, but provide better quality of life;

c) Lessen the burden on the medical system and society (less surgery, radiation and chemotherapy with people being able to continue working and contributing to society) due to better outcomes (control / remission);

d) Reduce the financial toxicity of lung cancer and not leave families with a legacy of debt;

e) Enable families to save for the other costs of cancer such as loss of income and time off work for caregivers.

Summary

These targeted drugs and immunotherapies are life changing. They are the difference between living with cancer and dying from cancer.

Pharmac, please find a way to help ease the burden on families like mine, suffering the consequences of lung cancer.

Pharmac, please bring New Zealand up to standard with other OECD countries.

If Pharmac can't see fit to fully fund these medicines, then please at the very least, find a way to subsidise them and negotiate a better price for patients.

Kind regards

Dean Wilson

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