

# **CLL Advocates New Zealand (CLLANZ)**

## ***Getting started: challenges & lessons***

Dr Neil Graham FRACP, FRCP  
Founder & Executive Director, CLLANZ

19 September 2019  
CLL Horizons 2019, Edinburgh

# Personal story

- MB ChB FRACP FRCP
- Consultant physician for thirty years
- Keen outdoors & family man
- CLL diagnosed at age 50



# My CLL

- Night sweats, colds
  - L=24 b/l, 11q-
- Watch and wait
- Chlorambucil
- FCR 6/4 → 8/2

- Dinacyclib
- Avoid SCT
- Ibrutinib

**5 years on: continuing remission**

# My CLL

- Complications
  - Respiratory failure
  - Bone marrow failure
  - Gonadal failure
  - Adenocarcinoma lung



# NZ Cancer Scene

## Registration and funding of medications



# Pharmac

- 20+ years existence - recognised internationally for **effective negotiation re drug prices**
- In the new era of (expensive) cancer medications response has been delay/non funding - **‘rationing by delay’**
- No rapid access scheme
- An obsolete model

# Pharmac

- Ibrutinib: NZ is the **only country of 45 where it is not funded**
- NZ **ranks last out of 24 OECD countries** for market access to modern medicines
- NZ invests **5% of total health budget** to publicly fund medicines – in most other countries it is 10 – 15%

# Comparisons - our nearest neighbour



If cancer treatments available in Australia  
had been funded in NZ, **we would have avoided  
3631 deaths from cancer** in the five years to 2017



# Motivation for establishing CLLANZ

- Advocacy for funding modern treatments
- Also, patient support, education, and information/database
- Aim was not to duplicate but complement, and partner with related groups

# Support/infrastructure required

- Membership of CLLAN
- Research on international groups
- Project management
- Trust deed
- Appoint trustees
- Achieve charitable status
- Bank account
- Fund-raising & support
- Website
- Facebook
- Links & partnerships, incl other NZ patient advocacy groups
- Media relations
- Membership drive
- Launch

# Supporters & funders

**Florence Petersen  
Leukaemia Trust**



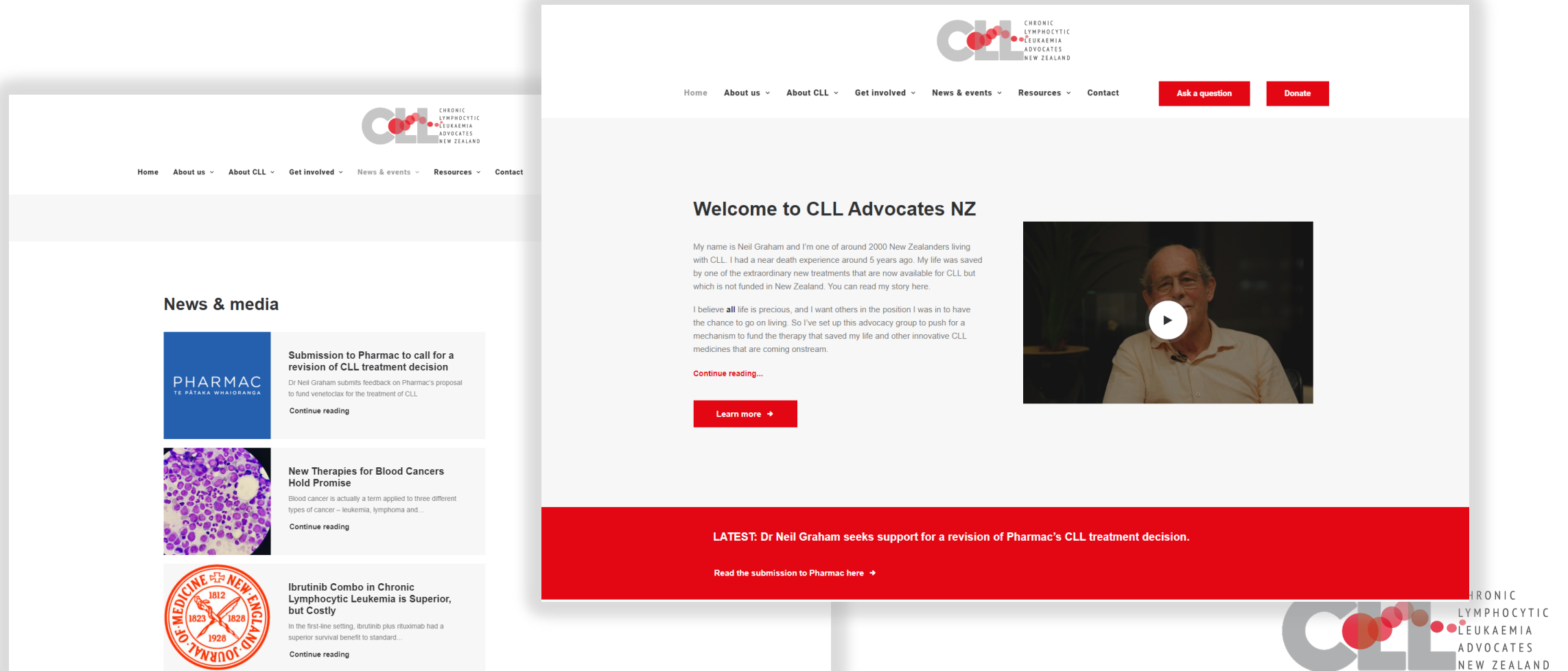
**Bay of Plenty  
Medical Trust**



**Leukaemia Care**  
YOUR Blood Cancer Charity

# Work to date

## Website [www.clleadvocates.nz](http://www.clleadvocates.nz)



# Work to date

## Facebook Group

The screenshot shows the Facebook group page for 'CLL Advocates NZ'. The page header includes the group name, a search bar, and navigation links like 'Home', 'Create', and 'Notifications'. The left sidebar contains a menu with 'About', 'Discussion', 'Members', 'Events', 'Photos', 'Units', 'Moderate Group', and 'Group Quality'. The main content area features the group's logo, which consists of the letters 'CLL' in large grey font, followed by 'CHRONIC LYMPHOCYTIC LEUKAEMIA ADVOCATES NEW ZEALAND' in smaller text. Below the logo are buttons for 'Joined', 'Notifications', 'Share', and 'More'. The 'NEW ACTIVITY' section shows a post by Neil Graham, a founding member, dated April 28. The post text reads: 'UPDATE our website is now available and you can find it at: www.cladvocates.nz. For those with CLL, there is a cost share programme for the medication ibrutinib being run by Janssen for access to this medication. The advice is to talk to your Haematologist, who can then contact Gene Pateman or Felicity Bonham at Janssen, and details and costs can then be given to you. Details of this are on the website.... See More'. The post has 3 comments and has been seen by 14 people. On the right side of the page, there are sections for 'INVITE MEMBERS', 'MEMBERS' (19 Members), 'SUGGESTED MEMBERS' (Loren Szeto, Ann Phillips, Sam Forsyth), and 'DESCRIPTION' (Tell people what this group is about).

This screenshot shows a specific post by Neil Graham, a founding member, 22 hours ago. The post text is: 'In the last few days, I have made a submission to Pharmac in regard to their proposal to fund venetoclax for treatment of CLL, but not ibrutinib. The medical evidence supports both these drugs being available for modern management of CLL. They work in different, but complementary ways. Venetoclax has advantages in some CLL clinical scenarios of this quite variable disease, but is inferior to ibrutinib in a number of CLL disease settings, such as 11q deletion, and bulky lym... See More'. The post has 4 likes and 4 comments. Below the post, there are three comments: Deborah Templer (22h) says 'Thank you so much for your work and the information.'; Wendy Delich (21h) says 'I also cannot thank you enough for the work you are doing for us all. All the best at the conference'; and Suzanne Walker (20h) says 'This is great news'. At the bottom, there is a comment by Andrew Schorr (11h) that says 'We'll discuss the drugs post iwcll in 9/28 in Patient Power town meeting from Dallas. You can watch from Down Under. Join us!'. The bottom of the post area has a 'Write a comment...' input field with icons for emojis, photos, GIFs, and stickers.



# Work to date

## March on Parliament





# Work to date

## Presenting petition





# Work to date

## Petition and hearing



**New Zealand Parliament**  
Pāremata Aotearoa

Language: English, Māori

Search: [Advanced Search]

Parliamentary Business | MPs and Electorates | Get Involved | Visit and Learn

**Parliamentary Business**  
Bills and Laws  
Select committees  
Hansard (Debates)  
View all

### Petition of Neil Graham for Chronic Lymphocytic Leukaemia Advocates New Zealand : Fund life-saving treatments for chronic lymphocytic leukaemia

Home » Parliamentary Business » Petitions

Published date: 7 May 2019

[Get notifications](#)

#### Petition request

That the House of Representatives call on the Government to approve additional budget for Pharmac to fund ibrutinib and venetoclax at international guidelines, to allow patients with aggressive Chronic Lymphocytic Leukaemia (CLL) to remain alive and well.

#### Petition reason

Around 2000 NZers have CLL, an incurable cancer that can be indolent but often becomes life-threatening. Ibrutinib and venetoclax, sometimes combined, can provide complete remission from aggressive CLL (incl 17p del), allowing patients facing death to resume full, productive lives. OS at 6 years for patients on ibrutinib at 1st line is 88%. Ibrutinib (regd in NZ since 2015) is funded in 44 of 45 countries of similar or lower wealth, the exception being NZ. NZ has no guidelines for treating CLL.

#### Petition progress

What do the symbols mean?

Op	Cl	Pr	Re
Open 07/05/19	Closed 05/05/19	Presented 07/05/19	Reported

Number of Signatures: 1041

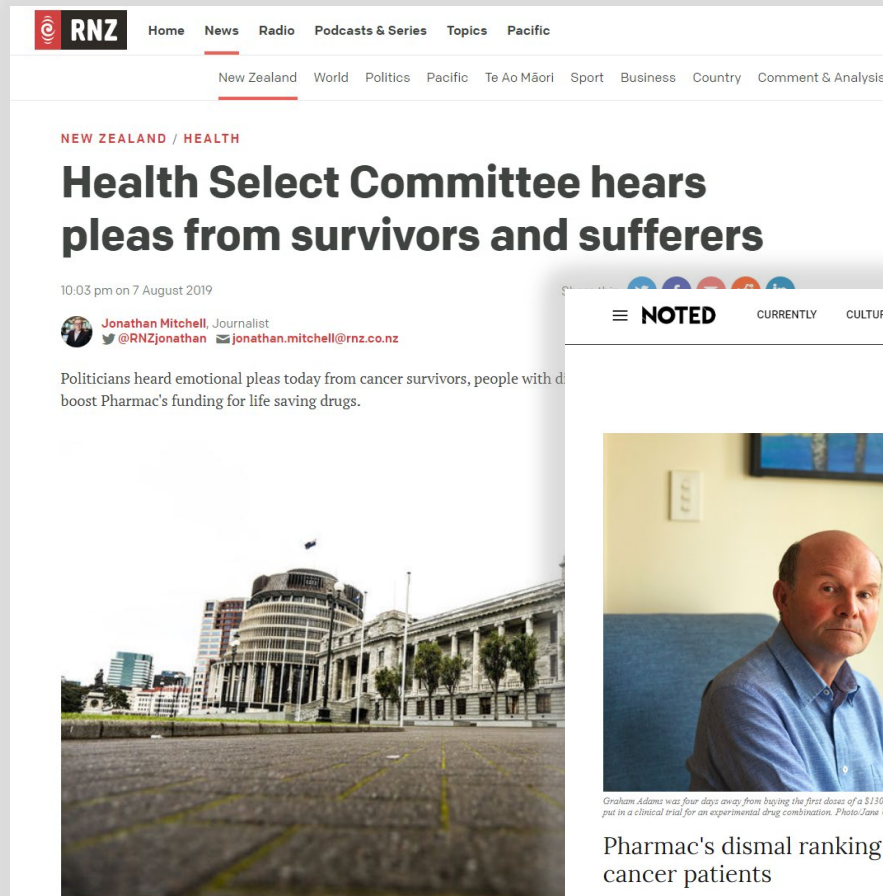
**1041 signatures**





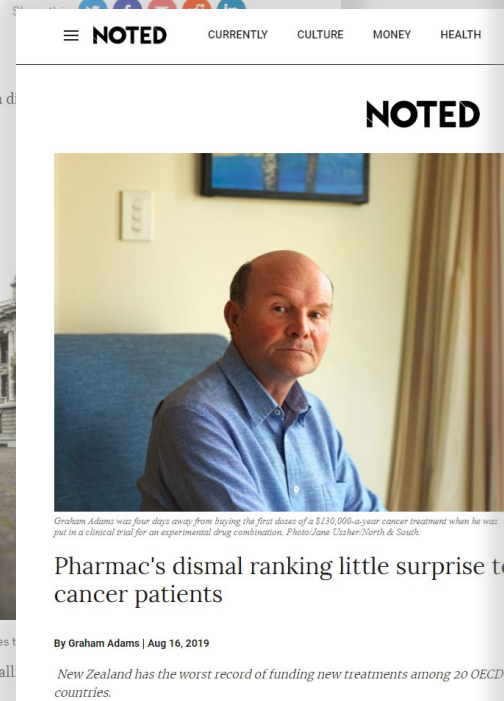
# Work to date

## Media engagement



The Health Select Committee at Parliament was presented with petitions calling on medicines... Petitions were presented to the Health Select Committee at Parliament - call... including for breast, lung, ovarian cancers, along with multiple myeloma.

Emily Beswick and her daughter, Stella, travelled 500 kilometres from Camb...



The news this week that New Zealand has been rated the worst among 20 OECD countries for funding modern medicines and pharmaceutical...



Pharmac urged to fund new breast cancer drugs that are potentially life-changing for breast cancer patients. More than a 100 women marched last year in support...

"Why does New Zealand need to... MP Maggie Barry, that was the... dozens of life-extending – and

Emotions ran high during Wednesday's hearing after plea from those suffering from cancer, politicians from both sides of the

Boiled down, the pleas were simple: fund more drug funding and do it quickly.

With his voice breaking and needing the committee his access to unfund... leukaemia "saved his life" but others had not been so lucky.



Watch: A cancer drug advocate held back tears presenting to the Health Select Committee. Credits: Newshub

National MP Maggie Barry is promising cancer drug advocates she will continue to push for an inquiry into Pharmac's spending on life-extending medicines.

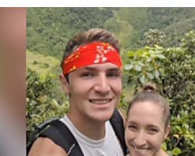
MPs at the Health Select Committee heard from a range of campaigners calling for Pharmac to fund more medicines, from those that deal with lung cancer, to ovarian cancer, breast cancer and leukaemia.

Neil Graham, a medical specialist, presented to the committee over his petition calling for funding of life-saving treatments for chronic lymphocytic leukaemia.

- **National promises \$200 million cancer fund**
- **Hundreds demand Government funding for cancer drugs**
- **Greens and ACT scoff at National's cancer agency plans**



More From Newshub



Waikato gang boss sentenced to life in prison after husband falls into volcano



McLaren Falls manslaughter

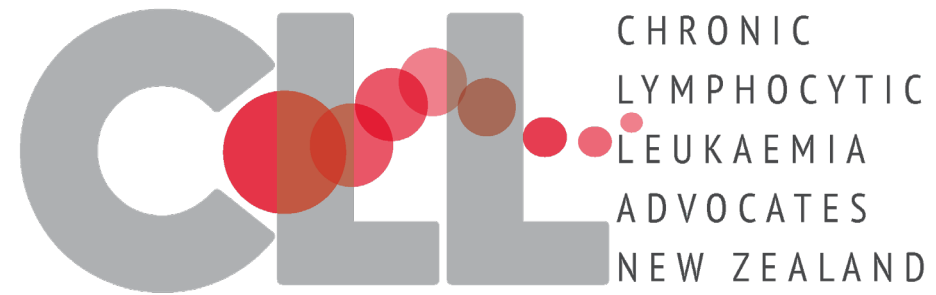
# Other work to date

- Submission to Pharmac (this week)
- Membership drive and some dialogue has started, and support has been offered
- International links established
- Patient question videos
- Online & in-person launch planned



# Challenges/lessons

- Making something happen
- Good project management is key
- Funding is a future issue
- Links to others' sites have been valuable
- Keep focus tight, grow as per need and feedback
- Political issues
- Help from multiple individuals
- Seizing opportunities – petition, march, submissions etc



**[clladvocates.nz](http://clladvocates.nz)**