

The Beacon Returns

After a period of absence, we are delighted to announce the return of **The Beacon**, a twice-yearly newsletter dedicated to sharing news, ideas and perspectives relevant to our Waldenström Macroglobulinemia (WM) communities across Australia and New Zealand (NZ).

The ambition of *The Beacon* is simple: to explore global WM research, information and developments through an Australian and New Zealand lens, while sharing the opportunities, challenges and experiences that matter to our WM communities across both countries.

The Beacon is intended to be a conversation rather than a broadcast. While this first edition will introduce you to WMozzies and WaldosNZ, alongside some exciting events on the horizon, future editions will be shaped by our community. **We warmly invite readers to contribute ideas, submit articles, suggest topics and share feedback.** Your involvement will help ensure *The Beacon* reflects the interests, experiences, and concerns of the people it represents.

We look forward to this new chapter for *The Beacon* and to building a newsletter that informs, engages and connects people across Australia and New Zealand. Together, we hope *The Beacon* will become a valuable forum for discussion, insight, and shared experience.

He waka eke noa - we're all in this together.

The Beacon Editorial Board

Andrew Warden, Peter Freese, and Mel Arnold.

Who Are We?

[WMozzies](#) (Australia) and [WaldosNZ](#) (New Zealand) are volunteer-led, community-based groups providing advocacy, support, and connection for people affected by WM. Our Group Leads are also [International Waldenström Macroglobulinemia Foundation](#) (IWMF) international affiliates, representing our local WM communities within the wider global WM network.

Peter Freese – WMozzies Group Lead



Peter Freese

Peter Freese took over as lead for WMozzies in February 2026. Taking over the role from David Young who had served as Leader for the previous 5 years. Peter is based in Sydney and has been a WM patient since 2014. His primary intent as WMozzies leader is to revitalise the organisation so that it can continue to be a vital and supportive part of the WM community. A key focus will be to continue to develop the sense of community within WMozzies and their partner organisations such as IWMF and Lymphoma Australia.

Mel Arnold – WaldosNZ Group Lead

After leading WaldosNZ since 2017, Lea stepped down as Group Lead in April 2026, passing the torch to Mel. We warmly thank Lea for her dedication and the community she has helped build, and are delighted she remains an active member of the WaldosNZ committee.



Lea Hullett

Mel Arnold lives in New Zealand's sunny Bay of Plenty with her husband and four children, aged 6–12. Diagnosed with WM in 2020, she is

currently receiving compassionate access to Zanubrutinib as her second-line treatment. Alongside her advocacy work, Mel is undertaking a PhD focused on improving how health services respond to the supportive care needs of people and their whānau (families) during the early stages of the cancer journey. She is passionate about helping our WM community to feel informed, connected, supported, and empowered to navigate their journey with hope.



Mel Arnold

WaldosNZ committee: Dr Ruth Spearing and Dr Samar Issa (Medical Advisors), Mel Arnold, Lea Hullett, Rick Robinson, and Barney Stephenson.

Andrew Warden – WhiMSICAL Investigator

After leading WMozzies (2016-21), Andrew has been focused on his role as the Chief WM Patient Investigator in WhiMSICAL Registry. Diagnosed with WM in 2003, he is currently being treated with Zanubrutinib following 3 other previous WM treatments. He is married with a son and daughter and has six grandchildren, all born after his WM diagnosis.



Andrew Warden

Want to support your local WM community?

Volunteers needed!

We are looking for **state/regional representatives** across Australia and New Zealand to be a friendly local point of contact for people with WM and their families. The role involves connecting people with information, support networks, answering the occasional question (non-clinical support), and helping facilitate local **coffee catchups, WM walks, or informal get-togethers.**

Given the rarity of WM, contact may only be occasional, but simply being a reassuring local connection can make a huge difference.

If you would like to help, **we'd love to hear from you.** We are registering expressions of interest now, with further details to come.

Peter - WMozzies: wmozzies@outlook.com or
Mel - WaldosNZ: waldenstromsnz@gmail.com

Let's ensure no one navigates WM alone.

What's happening in our WM community?

Forbidden Pharmacy Campaign (NZ)

WaldosNZ is honoured to walk alongside 17 patient charities in the Forbidden Pharmacy campaign, highlighting New Zealand's medicine access crisis, and calling on the government to increase medicines funding through Pharmac.



WaldosNZ Mel Arnold & Ruth Spearing, BCNZ CEO Tim Edmonds, alongside other campaign representatives (Focal Point Photos).

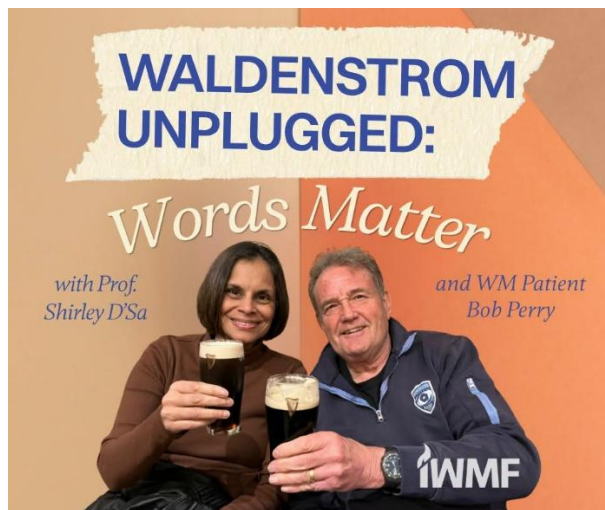
While we've long advocated for access to important WM treatments such as BTK inhibitors (BTKi), they remain out of reach for most kiwis. This campaign gave us an opportunity to put a spotlight on zanubrutinib and what funded access could mean for people living with WM in NZ.

Check it out here: www.forbiddenpharmacy.org and sign our open letter to government.

Living with Bing-Neel in NZ?

Pharmac has confirmed that people with Bing-Neel syndrome (a rare neurological complication of WM) may be eligible for ibrutinib through the NPPA pathway. This news has been shared with haematologists. If you have Bing-Neel syndrome and are approaching treatment discussions, we encourage you to ask your haematologist whether this pathway may be an option for you.

New Waldenström Podcast!

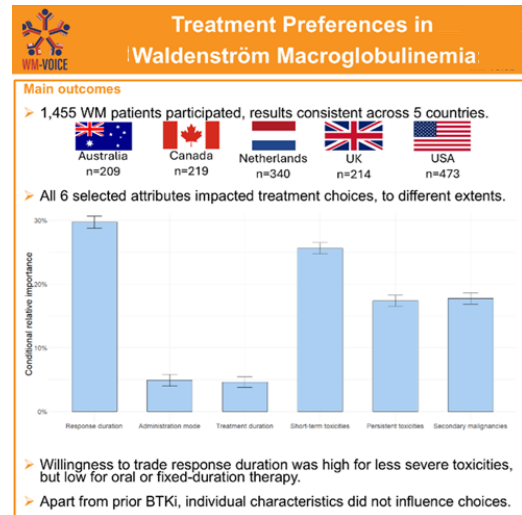


A must listen for all things Waldenström! Launching this September 15th! Listen on [Spotify](#) or other participating streaming platforms!

WM Voice Study

Some readers may remember taking part in the [WM-VOICE study](#), an international study designed to understand what matters most to people with WM when making treatment decisions. A total of 1,455 people with WM across several countries completed an online survey comparing hypothetical treatments with different benefits, side effects, modes of administration and treatment durations. Results showed that a longer-lasting response was most important, followed by avoiding severe short-term side effects. Persistent side effects and the risk of secondary cancers were also important, while

whether treatment was taken orally or by infusion, and how long treatment continued, had less influence on treatment choices.



The findings centre the patient voice to help inform shared treatment decisions, future WM drug development and clinical trial design. Thank you to those who contributed.

WhiMSICAL App



Driven by Andrew Warden, Dr Ibrahim Tohidi-Esfahani and Prof Judith Trotman in Sydney, [WhiMSICAL](#) is an international patient-led research initiative that enables WM patients to contribute information about their health, treatment and quality of life over time. More than 700 people across 23 countries are already taking part, helping researchers better understand the real-world experience of living with and being treated for WM. A new WhiMSICAL mobile app has just gone live at the [Apple App Store](#) and [Google Play](#) for download in Australia only, making it even easier to participate. We are currently liaising with the NZ Ethics Committee to enable NZ as the next country to go live with the WhiMSICAL App. The value of WhiMSICAL depends on people with WM getting involved. The more of us who participate, the stronger the evidence we can build to support WM research, treatment, and advocacy. We would love your support. Visit www.whimsicalstudy.com for more info.

WM Clinic



WM specialist consultations are available through the WM Clinic at [Haematology Department](#) in Concord Hospital, Sydney (video consultations available). **Specialists: Prof Judith Trotman, Dr Ibrahim Tohidi-Esfahani, and Dr Janlyn Falconer.** Consultations provide WM-specific advice on diagnosis, treatment, and management and are intended to complement care from your treating haematologist, with correspondence provided to your treating team following consultation. For fees, contact the clinic below.

Referrals & enquiries:

SLHD-ConcordHaematologyAdmin@health.nsw.gov.au
+61 2 9767 5757

Other WM specialists can be found on the [IWMF WM Physician Directory](#).

Strengthening our WM Community

WMozzies and WaldosNZ share a common goal: to ensure people living with WM and their families have access to information, support, and opportunities to have their voices heard. As our communities grow, we are looking at how we can strengthen connection and better complement the support available. We would love our community to help shape what comes next. **What would you like to see more of? What information, support, events or opportunities would be most useful to you? Please get in touch - we would love to hear your ideas.**

Looking for more WM information and support?

The IWMF has a volunteer-based telephone and e-mail [LIFELINE](#) intended to address specific WM questions. The LIFELINE is staffed by WM patients and caregivers who are willing to share

their experiences in specialised areas. Visit: www.iwmf.com/lifeline-and-one-on-one-support/

Visit the websites below for further WM information, resources, and support. Contact WMozzies/WaldosNZ to discuss your support needs, and to **join the email database to stay up to date with news and events.**

Coming Up

WM Education Workshop | 19 Oct 2026

1.30pm – 3.00pm

Auckland (NZ) and online

We are excited to invite you to our WM Workshop in October, bringing our community together to hear from leading WM specialists **Dr Shirley D'Sa and Professor Judith Trotman**, ask questions, and connect with others. Hosted by Blood Cancer NZ, this **free workshop** will be available online (for NZ and Aus patients), with some in person availability. **See here for forum flyer and more details: insert link.**

WMozzies Education Forum | 25 Nov 2026

Sydney (Aus) and online

In conjunction with Concord Haematology, WMozzies is also planning an Australian forum in Sydney, with opportunities to learn, connect and help shape the future direction of the WMozzies community. The forum is expected to include speakers, discussion sessions and informal opportunities to meet others in the WM community. *More details coming soon.*

Click the following links for further blood cancer support groups and webinars:



Newsletter design and template generously supported by [Seed Studio NZ](#).