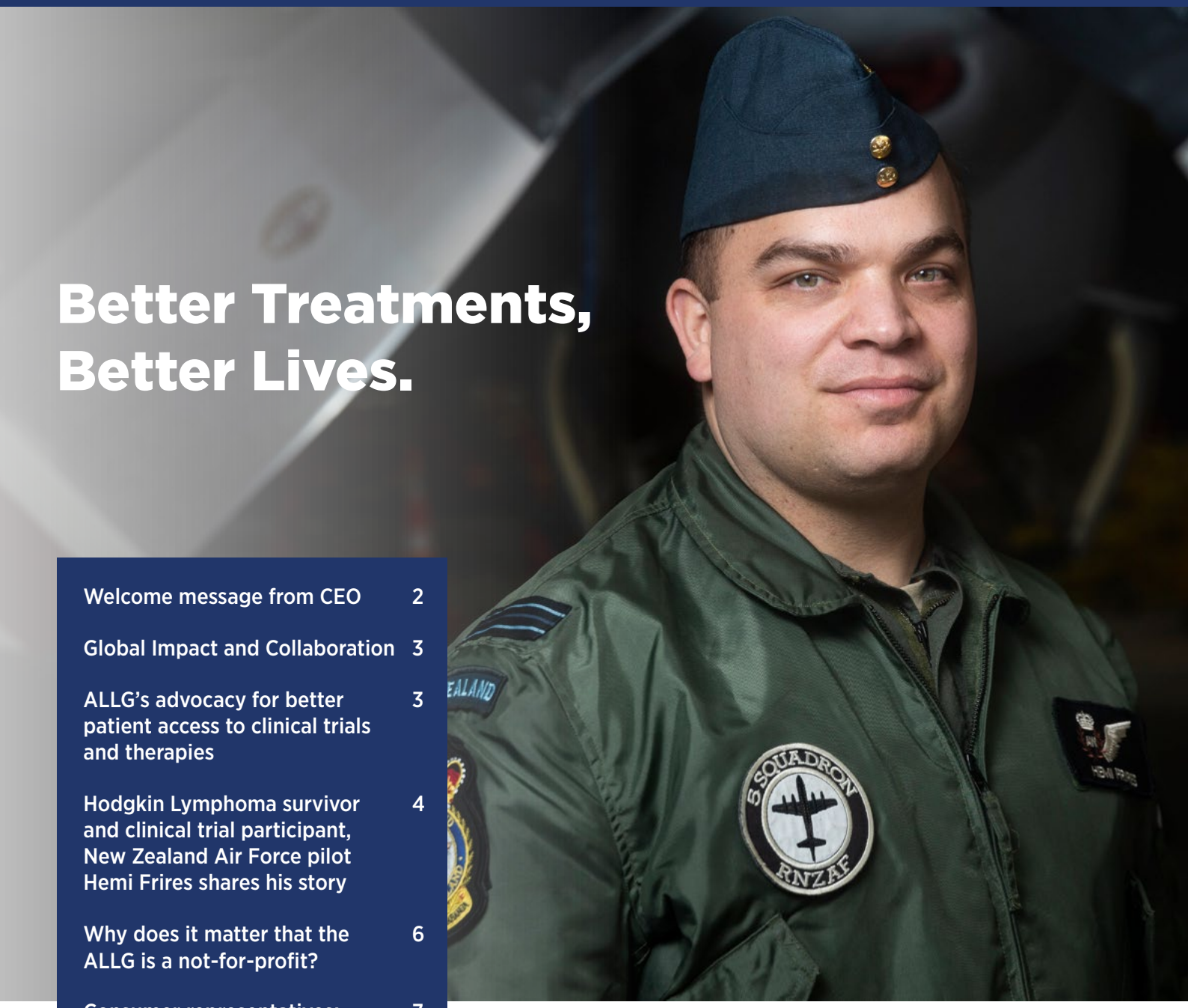
Better treatments...
Better lives.

ALLG News

Edition 2



Better Treatments, Better Lives.

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The Australasian and Lymphoma Group (ALLG)
Better Treatments... Better Lives.

https://www.allg.org.au/subscribe-to-allg-news/

Welcome

Welcome from ALLG Chief Executive Officer

Welcome to the second edition of the Australasian Leukaemia and Lymphoma Group (ALLG) newsletter - ALLG News.

You may be reading this as a member of ALLG, or as a subscriber or supporter of ALLG, or from having seen ALLG promoted through one of our partner foundations or on our social media. ALLG News is for people like you who are interested in research and our mission to create better treatments and better lives for patients with blood cancers.

Laboratory research and clinical trials are the only way to create a new wave of discoveries and to offer new medicines. Clinical trials are the engine of cancer research. Virtually every cancer treatment available to people with cancer today is the direct result of a clinical trial. Patients with hard-to-treat blood cancers often have no other way to gain access to innovative, potentially life-saving, new treatments.

Our ALLG clinical trials have advanced many treatments for blood cancers over the last five decades. ALLG aims to cure patients with blood cancers; finding more effective and less toxic therapies. We help our member doctor researchers develop better cancer treatments so that people with blood cancer can have a longer and better quality of life; helping to make a world of difference for patients and their families.

As the only non-profit collaborative clinical trials groups in Australia and New Zealand for blood cancers, ALLG has the capability to run independent doctor-led clinical trials in Australasia and, crucially, to participate in international trials; allowing us access to new drugs with the potential to make a significant impact on patient outcome.

Our international clinical trial collaborations bring new treatments to Australians and New Zealanders; including patients just like New Zealander Hemi Frires, a Royal New Zealand Air Force pilot who joined an ALLG clinical trial for the treatment of his Hodgkin Lymphoma. You can read Hemi's story later in this newsletter. We thank Hemi for sharing his story, and are delighted that he is well and back to enjoying his life and passions such as flying.

Although there has been much survival improvement in the types of Hodgkin Lymphoma, there is still much more clinical trial work to do to ensure the 20–30% of patients that relapse have better opportunities for better treatments.

Patients make a vital contribution to clinical trials and there are many advantages that patients gain by taking part. You can learn more about clinical trials, and what they involve, by visiting our website's ***Frequently Asked Questions page***. If you are a loved one has blood cancer, speak with the treating doctor about participating in an ALLG clinical trial.

If you are not already a subscriber to this newsletter, visit ***www.allg.org.au*** to join and receive our quarterly ALLG News. You can also join as a ***Community Member,*** and follow us on ***Facebook***, ***Twitter*** and ***Linkedin***.

The ALLG will celebrate 50 years in 2023. I look forward to sharing more of our research updates, our impact today and over the past half a century, and other important news from our member clinician researchers in future editions of ALLG News.

I also want to thank those of you who support our work and donate to our End of Year appeal to help us further progress our work for better treatments. ***Your donations to our blood cancer research will help Australia's and New Zealand's leading researchers end blood cancer sooner***.

Wishing you and your loved ones a safe and happy festive season.

Ms Delaine Smith,

Chief Executive Officer

www.allg.org.au

Who is the ALLG?

We are a group of world-leading blood cancer doctors and researchers based in Australia and New Zealand committed to exploring and finding better treatments for better lives of people affected by blood cancers. We do this through independent clinical trial research; collaborating voluntarily to research for better treatments with the aim to cure. The ALLG also mentors the next generation of clinical trial researchers, and advocates for better access to life-saving treatments and trials for patients with blood cancer.

You can visit ***www.allg.org.au*** to learn more and download our latest Annual Review publication.

ALLG's Mission

To improve the treatment and the lives of patients with leukaemia, lymphoma and other haematological malignancies by advancing 'leading edge' clinical trials in Australasia, and to be regarded by the local and international community as the peak research body for these diseases within our geographical areas of operation and influence. . ***Learn more.***

Global Impact and Collaboration

Participation in a clinical trial gives patients access to cutting-edge, potentially life-saving, new treatments before they become available nationally.

About one third of our trial program involves important collaborations with international cooperative trial groups, which are expanding the range of international trials we can bring to Australia and New Zealand. We are indebted to the support of the Leukaemia Foundation which has been critical to bringing many of these trials to fruition.

We continue to forge new partnerships and alliances with international cooperative trial groups, including the IFM (Intergroupe France du Myélome), UK IMPACT group, UK Myeloma Alliance, the Asian Myeloma Network and the Canadian Cancer Trials Group. These complement our existing relationships with the HOVON/AMLSG group and Cancer Research UK. These alliances are so important, especially because of the opportunities they provide for our patients to receive better treatments.

Here are a few of our international trial collaborations...

Under the guidance of ALLG member Professor Andrew Wei, the ALLG is embarking on its first collaborative study with the US where the MD Anderson Cancer Center will be a site on the ALLG AMLM26 INTERCEPT trial in Acute Myeloid Leukaemia.

ALLG Members Dr Nicole Wong Doo, Dr Leanne Berkahn and, ALLG Scientific Advisory Committee Chair, Professor Judith Trotman, have combined to bring us the UK's RADAR trial for untreated early stage Hodgkin Lymphoma (ALLG HD13).

In the Myeloma Scientific Working Party, our first collaboration with the Intergroupe francophone du myélome, led by ALLG Member Dr Simon Gibbs (ALLG MM24) opened in July this year.

ALLG Member Dr Tara Cochrane has brought a trial (HD11) from Canada's CCTG collaborative group for relapsed Hodgkin Lymphoma.

The ALLG HD10 trial, led locally by ALLG Member Professor Mark Hertzberg in collaboration in with the German Hodgkin Study Group (GHSG), was for newly diagnosed advanced Hodgkin Lymphoma. This trial finished patient recruitment with analysis of the results underway. New Zealand patient Hemi Frires, featured in this newsletter, participated in this trial and is now in full remission.

These international collaborations are opening up opportunities for better treatments for Australian and New Zealand patients.

ALLG's advocacy for better patient access to clinical trials and therapies

ALLG's advocacy work continues to strive for better patient access to clinical trials.

The ALLG has continued strong efforts to advocate for access to new medicines via clinical trials on a number of fronts in New Zealand (NZ). To help address barriers to ALLG drug trials for blood cancer in NZ, for example, a specific ALLG working group for ALLG members in NZ, the **Medicines Access New Zealand Committee** ensures that blocks to NZ participation are removed before trials open.

Medicines Access NZ Committee's work, chaired by Dr Claire Hemmaway [pictured] from Auckland Hospital NZ, includes advocating for access to therapeutic drugs, standard of care investigations, as well as funding for New Zealand sites.

The Committee has actively lobbied the New Zealand Government to try and improve a number of aspects of clinical trial conduct, including drug access. Participation in national consultations to the Health Research Council and Pharmac have given ALLG an opportunity to promote the value of clinical trial research as a mechanism for access to new therapeutics.

Photo: Dr Claire Hemmaway, Chair, ALLG Medicines Access New Zealand Committee

Hodgkin Lymphoma survivor and clinical trial participant, New Zealand Air Force pilot Hemi Frires shares his story

In 2018, Hemi Frires [pictured] was only in his late 20s when symptoms he began experiencing ended up being advanced stage Hodgkin Lymphoma. At the time symptoms developed, and the diagnosis was made, Hemi was working as a pilot in the Royal New Zealand Air Force. We spoke with Hemi about his Hodgkin Lymphoma diagnosis and the treatment he received as part of the ALLG clinical trial he participated in.
Here's Hemi's story:

"They were vague symptoms at first, fatigue and malaise, so easy to brush off and ignore but then the intense itchiness on my feet and elbows got so bad I scratched until I bled.

"There was a GP at my work. He went through a whole list of possible causes. We kept investigating for about two months, including blood tests that showed inflammation was up in my body. I then noticed inflamed lymph nodes under my collar bone. A biopsy was done. It came back as cancer.

"The news came like a bolt out of the blue. I have no family history of this.

"Although I had symptoms for a few months, my doctor thinks I may have had Hodgkin Lymphoma for a year. I wasn't completely floored. This news was shocking but, in some way, it was a relief to have a name to the problems I was dealing with.

"The symptoms then got worse over that next two months while I had to wait to get the cancer staged to look at solutions.

"A particularly tough part was supporting people who were shocked about the 'big C word', so learning to help manage that and manage expectations was really important.

"My GP referred me on to see a haematologist specialising in blood cancer, [ALLG Member] Dr Claire Hemmaway in Auckland New Zealand who took over my care. She set up a check of my organ function and ordered a PET-CT scan, which was crucial in staging what I had. It ended up as Advanced Stage 4B Hodgkin Lymphoma. Despite this, my doctor was confident I would be okay.

“My doctor recommended a clinical trial, HD10, as I fit the criteria. It seemed sensible to have a chance at an improved outcome from the trial, so I took the opportunity.

“The trial information was accessible, thorough, and discussed with my treatment team, so it wasn’t a challenge at all to get involved with or understand.

“This trial was in Auckland and seemed like a better choice for me, as it could be more effective, with a better regimen of chemo, and would be quicker. Being on the trial means they look at side-effects during and the outcomes and will follow up with me long-term.

“I started the trial in 2019. It lasted three months instead of the standard six months of treatment, with chemo every two weeks. I ended up staying with my parents during my treatment. I was really fortunate throughout to have a lot of support, and caring people.

“It took about 12 months, or most of 2019, to recover and feel okay again.

“Fortunately, it was successful. I feel really lucky to have had a good outcome and to find it hasn’t held me back from flying, just a bit of a delay, 12 months or so; so not much.

“I was able to get back to living life normally, back to work with a full head of hair, and I had some interesting experience that has helped me grow as a person.

“I am back to fighting fit, and back to flying in the Air Force.

“For anyone considering clinical trials, it’s worth looking into. For me, it was totally worth doing because a clinical trial is about testing for an improved medicine or treatment.”

We are delighted Hemi is back to enjoying his passion for flying and thank him for sharing his story about being on a clinical trial.

About the ALLG HD10 clinical trial

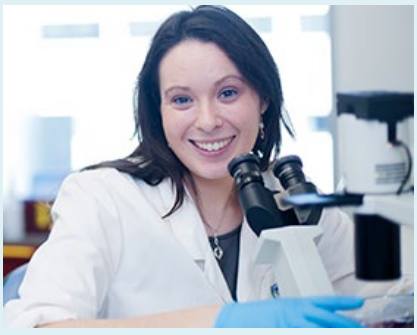
The ALLG collaborated with the University of Cologne and German Hodgkin Study Group to bring the ALLG **HD10** GHSGHHD21 trial to Australia and New Zealand. The trial was specifically designed for patients with advanced stage Hodgkin Lymphoma, offering innovative first-line treatment.

This trial was designed to assess a new chemotherapy regimen in the newly diagnosed, first line treatment setting.

The doctors leading the trial locally (for Australia and New Zealand) are ALLG members, Professor Mark Herztberg and Dr Georgina Hodges. ALLG member, Dr Claire Hemmaway, was the lead doctor at Auckland New Zealand.

For Hemi specifically, the HD10 trial provided him with the option of receiving new treatments under the safety of the clinical trial setting where close monitoring and close attention to care is given.

This trial highlights the importance of ALLG’s collaborations with international cooperative trial groups, which are expanding the range of trials we can bring to Australia via the ALLG that provide patients with more opportunities for better treatments and better lives.



Why does it matter that ALLG is a Not-for-Profit (NFP)?

Being a NFP gives us the independence to put action plans in place for all disease, not just one blood cancer type.

ALLG trials take a holistic approach in delivering clinical trials – they are not just about the drug but also about the quality of life for the patient and the opportunity to continue new discoveries through sample collections and laboratory research. We are not tied to any one specific drug or area, and can be flexible in our research approach.

We make the most of every angle possible and every opportunity for the patient and for the research benefit. **We also bring a number of new drug options into our trials for better treatments and better patient lives, with the ultimate aim of a cure for patients with blood cancer.**

Discovering new and more effective treatments with less side effects, while aiming for a cure for people with these diseases, will not only improve patients' wellbeing, but will also save more lives.

We receive no ongoing funding and rely on the support of organisations and individuals to enable our essential trial research.

Your engagement with and support of the ALLG is critical to us achieving better treatments and better lives for patients with blood cancers, whether you are a trial participant, a donor, or an advocate in helping spread the news about our work.

As a registered charitable organisation, donations to ALLG of $2 or more are tax deductible. Donations to our blood cancer research will help Australia's leading researchers end cancer sooner.

If you would like to donate to our End of Year appeal, visit
www.allg.org.au/support-us/make-a-donation/

What your donation supports

$30
Supports specialised collection kits used in clinical trials.

$60
per month
Supports express 24 hour transport of samples from hospitals to the biobank.

$100
Supports data management collection to complement samples.

$350
Supports a variety of tests used to detect disease relapse.

$1000
Supports the analysis of clinical trial samples.

$5000
Supports the implementation of trial procedures at hospitals.

You can read more about Steve's story here.

What is a consumer representative?

A consumer representative is a committee member who voices the consumer perspective (someone whose life has been affected by cancer) and takes part in the decision making process on behalf of consumers.

Our current committee of four representatives are all survivors of blood cancer and provide feedback on a wide variety of issues, such as clinical trials, ALLG website consumer information and research priorities.

If you are interested in joining the ALLG's Consumer Representative Panel, learn more here and how to apply.

Consumer Representative Panel Factsheet

Application Form

Consumer representatives; survivors' voices on clinical trials

Consumer input and feedback is an essential part of the development of clinical trials and scientific research.

Meet Steve Towell (pictured), who volunteers as an ALLG Consumer Representative.

Steve is a Mantle Cell Lymphoma survivor. He knows exactly how important the best treatments are to patients with blood cancers. His treatment saved his life. July this year marked the 10th anniversary of Steve's life-saving bone marrow transplant for his lymphoma. It was his only chance after his initial treatment had failed. The treatment worked, and Steve regained his strength. Life is great for Steve now.

Steve shares his story about when first diagnosed:

"I had a severe pain in my stomach which was getting worse, I finally made an appointment with my GP but never got there as the pain become so bad I went to the Emergency room. White cell count was through the roof and the pain was found to be from a very enlarged spleen.

"Initially I was told it was Chronic Lymphatic Leukaemia (CLL) but after more tests a confirmed diagnosis of Mantle Cell Lymphoma (MCL), stage 4, which was **the scariest news of my 44 years**. I had no idea what lymphoma was, much less this rare sub-type.

"When I had my 50th Birthday, it was a milestone that if Dr Google was to be believed I should never have reached. July [2022] marked the 10th anniversary of my life-saving bone marrow transplant. It was my only chance after the initial treatment had failed.

"I also have another wonderful annual event to celebrate now – my wedding to my love Tracy that was in March [2022].

"I've been doing some fundraising and a little public speaking, as I felt like I needed to give something back, which led me into ALLG as a Consumer Representative.

"Clinical trials are the only way we get new and better treatments. That's what the ALLG is all about. I am hoping I can do some more good work as a consumer representative and help others to get through it a little easier than I did."

We thank Steve and all of our Consumer Representative Panel members for their dedication to providing a consumer's voice and perspective and raising awareness for blood cancer and clinical trials to support better treatments, better lives. Their commitment to helping others is greatly appreciated!

Unfortunately, there are still too many people whose stories don't have the same happy outcome as Steve's. Thousands of Australians and New Zealanders lose their life to their blood cancer every year. That's why ALLG's world-leading doctors and researchers are so committed to tackling the biggest challenges of blood cancers like leukaemia, lymphoma and myeloma through our ground-breaking clinical research.

Patient and Carer Resources

For information on clinical trials, visit ALLG's ***Frequently Asked Questions***.

Our excellent relationships and continuity of support from key partners across the Blood Cancer Forum network, industry partners and philanthropic organisations have been critical to ALLG's ability to conduct clinical trials and pursue our mission to create better treatments for patients with blood cancers.

We would like to thank our long-term partners – Leukaemia Foundation, Snowdome, Lymphoma Australia and Myeloma Australia, Leukaemia & Blood Cancer New Zealand, and Canteen Australia – and our industry and philanthropic partners for their support.

You can visit our partner organisations for patient and carer resources and support services:

leukaemia & blood cancer NEW ZEALAND
Vision to Cure. Mission to Care.

Leukaemia & Blood Cancer New Zealand

Leukaemia & Blood Cancer New Zealand (LBC) is the only not-for-profit organisation in New Zealand dedicated to providing care, and supporting research for a cure, for people living with blood cancer and serious blood conditions.

LBC is committed to improving the quality of life for our patients and their families/whānau. LBC provides patient support services, funds research, provides the latest information, helps raise awareness, and advocates for patients and their families/whānau.

LBC provides individualised support to patients, runs support programmes for adults and children, facilitates education sessions, and provides emergency financial assistance.

LBC has support centres in Auckland, Hamilton, Wellington, Christchurch and Dunedin, and our team travels to other parts of New Zealand regularly.

leukaemia.org.nz

NZ Nationwide Phone Number:
0800 15 10 15.

Leukaemia Foundation®

Leukaemia Foundation Blood Cancer Support Line

If you or someone you love has been diagnosed with blood cancer, you're not alone.

Connect with an experienced Blood Cancer Support professional who can guide and support you through the emotional, physical, and psychosocial challenges of blood cancer diagnosis, treatment, and survivorship.

Call 1800 620 420
or visit leukaemia.org.au

https://www.leukaemia.org.au/how-we-can-help/

Lymphoma Australia

Lymphoma Australia

Lymphoma Australia is the only dedicated organisation who provides individualised nursing support and education to lymphoma and CLL patients in Australia. Lymphoma Australia aims to improve patient outcomes by supporting and providing education to nurses across Australia, which has resulted in 3,500 members in our nursing special interest group. We have a dedicated health literacy nurse, who has developed, updated and standardised our lymphoma subtype brochures and website to meet universal health literacy standards.

Lymphoma Australia continues to grow as an organisation as we work towards supporting all people affected by lymphoma across Australia. For more information, please visit our website or email ***nurse@lymphoma.org.au***.

https://www.lymphoma.org.au/support-for-you/

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