

## Welcome to the latest edition of the Lymphoma Nurse News!

In this edition you will find a snapshot of upcoming events, a wrap up of the inaugural Lymphoma Nursing Conference, recent COVID vaccination information, recent approvals, new initiatives within Lymphoma Australia and more!

### What are we doing at LA.

Lots has been happening at Lymphoma Australia, with lots of new projects and goals. Like you, our nurse team and our usual work practices have been impacted by the ongoing COVID pandemic. Nevertheless, we have continued to evolve and adjust our practice with our “new normal”.

A big project for our team was hosting the Inaugural Lymphoma Nurse Conference on the weekend of the 5th and 6th June. The event was based in Brisbane at the Stamford Plaza but was conducted as a hybrid conference, so we could reach nurses across the country. With more than 500 people involved, the conference was a huge success!

Topics that were covered included struggles faced in regional and rural settings, lymphoma and COV-ID 19, oral therapies, new and upcoming treatments for aggressive lymphoma. Pru Etchverry, the regional director of Lymphoma Coalition Asia Pacific was a guest presenter at the conference and provided interesting insight into the nursing role and the difference we can all make to our patients'. Pru shared the results of the Lymphoma Coalition's global study of patients which provided many interesting insights. Australian patients reported

significantly higher levels of fatigue and psychosocial impacts compared to their global counterparts. This highlighted the importance of the nursing role and the impact we can have on our patients' lives during treatment by ensuring they are well educated and aware of supportive services and how to access them.

### Some of the feedback we received...

“Knowledgeable presenters giving excellent information and reinforcing what nurses need to identify in providing treatments in respect to Lymphoma patients”

“I will use the knowledge I have gained to improve my patient assessment and education”

Watch this space, as we plan for the Lymphoma Nursing Conference to become an annual event!

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# Inaugural *Lymphoma* Nurse Conference



Brisbane Hub site attendees



Erica Smeaton & Lisa Oakman



Brisbane Hub site attendees



Brisbane Hub site attendees



# Lymphoma Australia says farewell to Donna

While it has been a time of growth for Lymphoma Australia, it has also been a time of change, we have said goodbye to Donna Gairns who has taken on a new career opportunity at Monash Health. We recognise the significant part that Donna played in the Lymphoma Australia team and we wish her well and are excited to work with her in a different capacity in the future.



## COVID safe packs are now available for your patients!

These packs include a Lymphoma Australia face mask, a social distancing badge, a Lymphoma Australia referral card and practical tips on managing the COVID risk, all packaged in a handy little reusable bag. To order some for your patients, head to our website and follow the links.

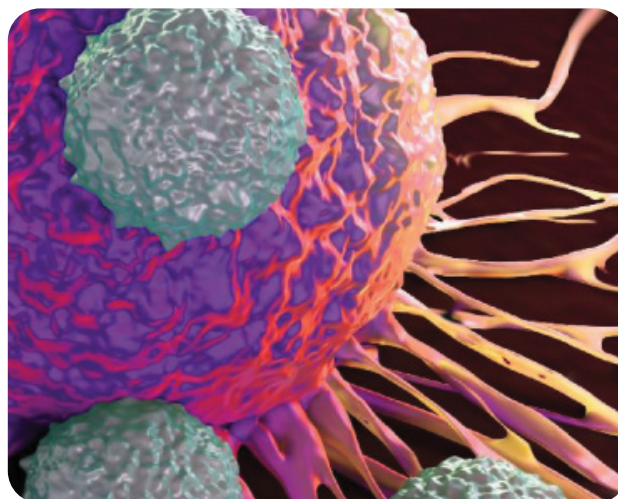


# Lymphoma and CLL pharmaceutical updates

Kite, a Gilead company, today announced that its Chimeric Antigen Receptor (CAR) T cell therapy, Yescarta® (axicabtagene ciloleucel), is now publicly funded and available to patients in Australia.

Yescarta is now funded for the treatment of adult patients with relapsed or refractory CD-19 positive; diffuse large B-cell lymphoma (DLBCL), primary mediastinal large B-cell lymphoma (PMBCL), transformed follicular lymphoma (TFL) and high-grade B-cell lymphoma (HGBCL) who meet the eligibility criteria.

Haematologist and Lead of the Aggressive Lymphoma disease group at the Peter MacCallum Cancer Centre and Royal Melbourne Hospital, Associate Professor Michael Dickinson, said: "Many people living with these four forms of non-Hodgkin lymphoma, who have either not responded to treatment or where their cancer has returned, have an urgent need for new therapy options



to treat this aggressive blood cancer." Sharon Winton, CEO, Lymphoma Australia, commented, "Until recently Australian patients with the approved four aggressive lymphoma subtypes had a very poor prognosis. To have access to another CAR T cell therapy option in Australia is very welcome news for these patients and their families."

## Health literacy update

**Did you know 6 out of 10 adults in Australia do not have the health literacy skills to access, understand and use health information effectively?**

This means 60% of your patients may not understand health-related information given to them. As a result, they may have lower medication compliance, delay reporting medical or psychosocial concerns, and have lower uptake of preventative measures. Low health literacy also makes it difficult to manage, and locate appointments.

People with low health literacy often have unexpected admissions to hospital, higher grade toxicities, elevated anxiety, stress and premature death. Frequently missed appointments can also result from lower health literacy.

People from all walks of life can have low health literacy. Therefore, the Australian Commission on Safety and Quality in Health Care, recommends a universal health literacy approach to patient resources. One recommendation of universal health literacy guidelines, is that all consumer health information be written, or spoken at a grade 6-8 level. By doing this, we can maximise the number of people we effectively reach.

At Lymphoma Australia, we are meeting this criterion by listening to our consumer groups, patients and carers, and our nursing special interest group (SIG). We then develop, or review material to meet the needs, and test these against validated literacy tools. You can be sure that when you provide your patients with our new and updated resources, that you will be supporting your patient's universal health literacy needs.

# To vaccinate and when, that is the question?

It is difficult to keep up to date with the ever evolving COVID vaccination advice for Lymphoma patients and the many fallacies that continue to circulate adding to the confusion and uncertainty amongst patients.

A recent interim analysis of the UK PROSECO study showed that some subtypes can mount a robust immunological response as early as six months post completion of treatment. However, the data also suggested that patients who are vaccinated whilst on active treatment are unlikely to develop the same antibody response with the recommendation to revaccinate 6 months after completion of anti CD20 containing treatment. At Lymphoma Australia, we recognised the ongoing clinical interest for both patients and nurses, and held a COVID webinar with Professor Judith Trotman, Dr



Juliette Raedemaeker and Dr Julianne Falconer to provide some clarity and medical evidence to inform patient decisions. We had 350 people online for the webinar and after running 45 minutes over time and with questions still flooding the Q+A, we unfortunately had to end the session. We hope to release a recording of this shortly.

## Do you want to be a *Lymphoma* Care Nurse?

Are you a nurse in Victoria, Western Australia or South Australia, experienced in haematology and looking for a change in career and a new challenge? This may be the perfect opportunity for you, as we are looking to hire a new Lymphoma Care nurse.

We are looking for:

- minimum of 5 years experience in haematology
- motivated and ability to work autonomously
- ability to travel



If this sounds like something you are interested in, please contact Erica Smeaton, the national manager [erica.smeaton@lymphoma.org.au](mailto:erica.smeaton@lymphoma.org.au)





# TAKE CHARGE

## Live well with Lymphoma/CLL

**Wednesday 15 September 2021**, Lymphoma Australia invites you to register for our FREE live webinar.

### About this event

This event is a symposium for patients and carers to access relevant and up to date information from a variety of health care professionals.

All patients and carers are encouraged to attend as you will find the information relevant, regardless of where you are in your journey.

### Topics that will be discussed during the webinar include:

- navigating the health care system
- right treatment right time?
- complementary and alternative therapies
- survivorship, and
- emotional wellbeing.



### Details

**Date:** Wednesday 15 September 2021

**Time:** From 1 pm

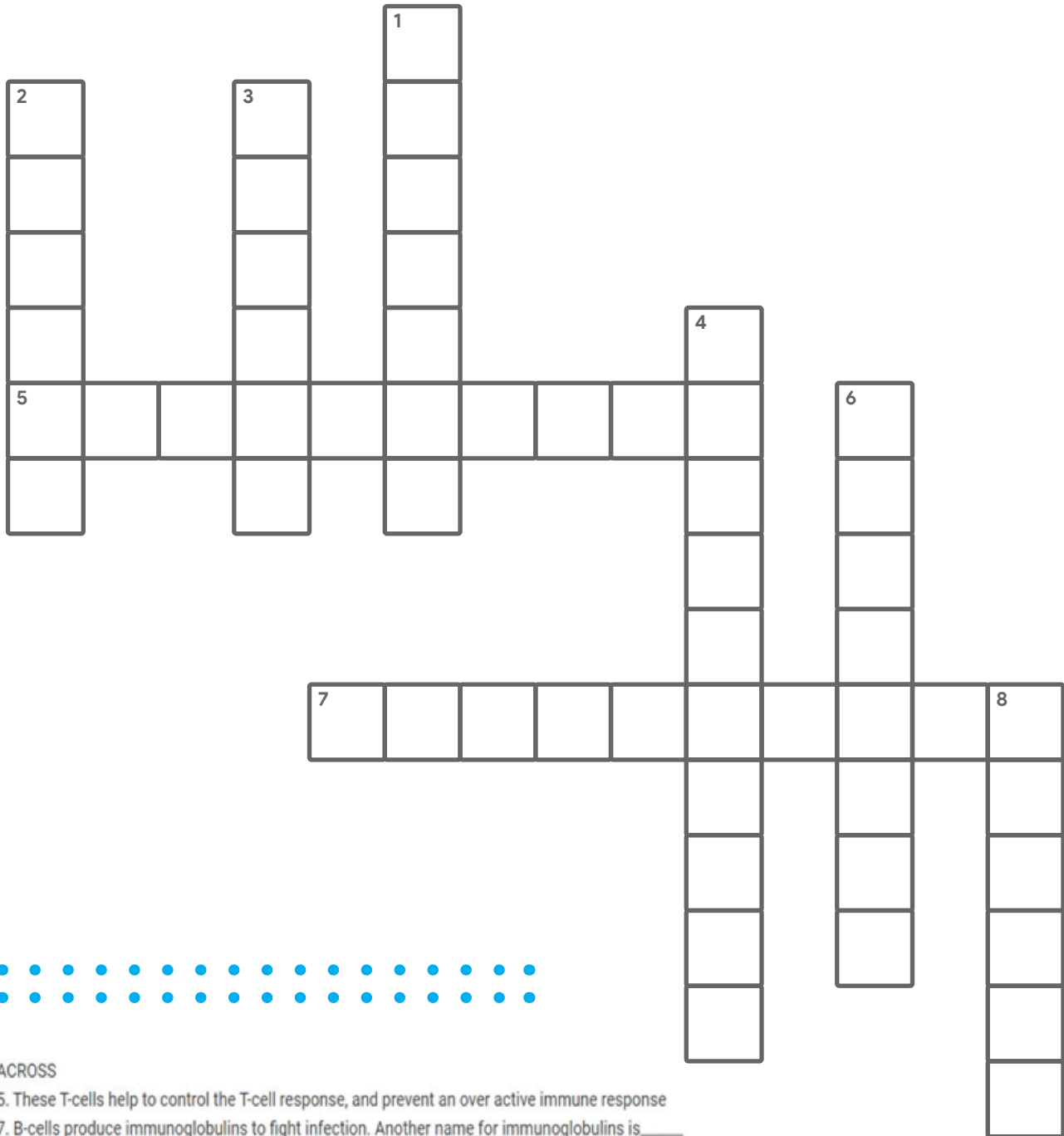
**Venue:** This is a virtual event

**RSVP:** Scan the QR code to register and you will receive an email with further information. Alternatively, if you wish to register you can also contact the nurse support line on **1800 953 081**

*Scan me!*



# Lymphoma crossword



**ACROSS**

- 5. These T-cells help to control the T-cell response, and prevent an over active immune response
- 7. B-cells produce immunoglobulins to fight infection. Another name for immunoglobulins is\_\_\_\_\_

**DOWN**

- 1. Antibodies provide what type of immunity?
- 2. Lymphocytes are an important component of the adaptive immune system because they develop an immunological \_\_\_\_\_
- 3. T-cells are produced in the bone marrow and then travel to this organ to mature and differentiate
- 4. Natural killer cells are a type of what white cell
- 6. The adaptive immune system is slow on first exposure to an antigen but on subsequent exposures is very quick and \_\_\_\_\_
- 8. B-cell lymphocytes often live in this organ while waiting to be activated

# Upcoming events/webinars



## Go Lime For Lymphoma

September is Lymphoma Awareness Month with World Lymphoma Awareness Day on Wednesday 15th September. We invite our community, families, supporters and partners and nurses and hospitals to register your interest in going lime for lymphoma. Head to our website to request your lime pack to help your team turn lime and raise awareness.

**TAKE CHARGE**  
Live well with Lymphoma/CLL

## Patient Symposium

This year, to shine a spotlight on Lymphoma we are holding a Patient Symposium on World Lymphoma Day 15th September. The focus of the event will be to "Take charge of your Lymphoma and live well with your Lymphoma/CLL". The symposium will be held online with multiple experts presenting on a variety of topics that patients will find relevant, regardless of stage they are at in their journey. We will be sending out posters for waiting rooms shortly.



## Module

T cell Lymphoma is associated with poorer outcomes than B cell Lymphoma, but treatment approaches have been extrapolated from the management of B cell Lymphoma predominantly, utilising a CHOP chemotherapy type approach. Relapsed/ refractory T cell lymphoma has significantly poorer survival with a median overall survival of 6.5months and a PFS of 3.1 months. Do you want to know more about T cell lymphoma? We are holding a T Cell Lymphoma module on the 7th September with Professor Miles Prince and Odette Buelens, CTCL NP Peter MacCallum Cancer Centre.

Do you have a patient with PTCL? Would they like the opportunity to chat to an expert? We are hosting an informal chat with Professor Miles Prince to provide the opportunity for patients and carers to ask questions and receive expert advice on PTCL.

Do you need to get in touch with our Lymphoma Nurse team to see how we can better support you and your patients? Reach out to our team and we will do our best to support you, your team and patients. Email [nurse@lymphoma.org.au](mailto:nurse@lymphoma.org.au) or call 1800 359 081.

## Connect with us...



Join our dedicated closed Facebook group for patients and carers by searching **Lymphoma DOWN UNDER**

For more information visit [www.lymphoma.org.au](http://www.lymphoma.org.au)

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