

Welcome to the second edition of Nurse News for 2019!

Lymphoma Australia's Nurse News aims to keep nurses with a special interest in lymphoma up to date with all aspects of lymphoma care locally and from around the world.

Welcome to our second edition of Lymphoma Nurse News for 2019! The year is travelling incredibly fast and it has been a very exciting and busy few months for Lymphoma Australia. We would like to thank you all for the ongoing support and enthusiasm for the work that we are doing to support all who are affected by lymphoma in Australia.

Lymphoma Australia hosted our first patient and nurse education event alongside the national ALLG (Australasian Leukaemia and Lymphoma Group) meeting in Sydney in May. We have also hosted two international guest speakers who presented at Sydney, Melbourne and Perth for patients and nurses. We plan to host more as the year travels.

In past 3 months there have been another two medications for lymphoma that have added to the PBS listing for chronic lymphocytic leukaemia and cutaneous T-cell lymphomas. CAR -T-cell therapy has been TGA approved in Australia for lymphoma patients and vital



The Hon Greg Hunt MP with Donna Gairns, Lymphoma Care Nurse Consultant

funding has been targeted towards the first Australian Centre of Excellence in Cellular Immunotherapy (including CAR T-cell therapy).

The most exciting piece of news came on Friday 29 March, The Hon Greg Hunt MP announced that Lymphoma Australia will receive a 1.2 million dollars grant from the Federal Government to continue and develop our Lymphoma Australia Nurse Care Program.

This funding will ensure we are supporting patients and nurses across Australia to have access to information and support at the time when it is needed the most. The funding will support Lymphoma Care Nurses over the next four years.

New *Lymphoma* Care Nurse Positions

Following from the recent funding granted by the Federal Government for the next 4 years, Lymphoma Australia are excited to announce that we are looking for more Lymphoma Care Nurses to join the team!

At this stage we are ready to employ experienced haematology nurses in NSW and Queensland.

We are looking for:

- Highly motivated and experienced haematology nurses
- Two nurses to represent NSW
- Two nurses to represent Queensland
- Part-time positions (2-3 days per week)



- Minimum of 5 years working with haematology patients
- Who have a strong interest and passion of lymphoma
- Interest in education, support, advocacy and awareness for those affected by lymphoma

If this sounds like you, I invite you to contact Donna Gairns, National Lymphoma Nurse Manager and I can send you the position description; donna.gairns@lymphoma.org.au or mobile **0404 749 884**.

Fiona Stanley Hospital Nurses take the Plunge

Congratulations to the team of 10 nurses from Fiona Stanley Hospital in Perth, who abseiled down 40 storeys building to raise funds for charity! On Friday 12 April the team raised a massive \$11,000 for Lymphoma Australia. The very brave group of nurses took part in the annual QV1 Urban Descent abseil, Perth's tallest building, helping to conquer their fears to help their patients. A big thank you to you all! Lymphoma Australia appreciates your efforts.



Fiona Stanley Hospital Nurses



New Pharmaceutical Benefits Scheme (PBS) Listings

Adcetris for CTCL

The Hon. Greg Hunt MP announced the PBS listing of Adcetris (brentuximab vedotin) will be broadened to treat a rare form of cancer which affects about 150 to 200 Australian's each year called cutaneous T-cell lymphomas. Lymphoma Australia National Nurse Donna Gairns, "This is a life changer for advanced CTCL patients giving them more equitable and affordable access to this drug. No one should miss out on treatment due to financial reasons and we welcome the additional funding from the federal government."

VENCLEXTA for relapsed / refractory CLL

VENCLEXTA in combination with rituximab will be listed on the PBS from 1 March 2019 for CLL patients who have relapsed or are refractory to at least one prior therapy and who are unsuitable for treatment or retreatment with a purine analogue. Every year in Australia around 1400 people are diagnosed with CLL, making it one of the most common types of lymphoma diagnosed in Australia.

The reimbursement of VENCLEXTA for patients with relapsed / refractory CLL marks a major milestone in the clinical development journey that included the first patients in the world receiving this agent on clinical trials in Australia in 2011 after VENCLEXTA arose from a basic research discovery in Melbourne 30 years ago.

Deb Sims has worked tirelessly as a patient advocate to have Venetoclax PBS approved in Australia for all eligible patients.



Deb Simms with her children and Hon Greg Hunt MP

Education Events

In case you missed them...



Prof Mathias Rummel, Germany

Lymphoma Australia were delighted to host Prof Mathias Rummel, MD, director of the Department for Haematology at the Clinic for Haematology and Medical Oncology at the Justus-Liebig University-Hospital in Giessen, Germany.



Andrew Warden (patient), Prof Mathias Rummel and Patrick Devine (patient) – Monash Health, Melbourne

Prof Rummel is an international leader particularly in the research and management of Follicular lymphoma, Mantle Cell lymphoma and Waldenstroms Macroglobulinaemia. He provided three education events for nurses and patients in Melbourne, Perth and Sydney in March.

Thank you to all of you who attended the events and for those who could not attend, we have filmed both the Melbourne and Sydney events; links below.

“New and emerging therapies for Follicular Lymphoma and Waldenstrom’s Macroglobulinaemia”
Monash Health, Melbourne, Monday 25 March 2019

 <https://bit.ly/31yEGqw>

“New and Emerging Therapies for Follicular Lymphoma” Prof Mathias Rummel with Prof Judith Trotman

Saxons Education Centre, Sydney, Saturday 30 March 2019

 <https://bit.ly/2ZqwWoo>

Aggressive *Lymphoma* Education Day

Lymphoma Australia & ALLG, Hilton Sydney, Tuesday 7 May 2019

Lymphoma Australia hosted our first education event alongside the ALLG national meetings in Sydney during May for patients and nurses.

We had three excellent presenters who discussed “Understanding lymphoma subtypes and the treatment options” Dr Jane Estell, Concord Hospital; “If lymphoma relapses, what is the role of transplant” Dr Nada Hamad, St Vincent’s Hospital Sydney; “Understanding CAR T-cell therapy for the treatment of lymphoma” Dr Ken Micklethwaite, Westmead Hospital and Steve Towell provided his cancer story.



Dr Ken Micklethwaite,
Westmead Hospital



Dr Jane Estell,
Concord Hospital

Thank you to all who attended the day and we hope to continue to provide these events. For those who could not be there we have filmed them for you to view via our website.

Prof Steven Le Gouill, France

Prof Steven Le Gouill recently visited Australia from France and presented to patients and nurses at Peter MacCallum Cancer Centre on May 27.

Prof Le Gouill is an international leading expert on the research and particular interest in Mantle Cell lymphoma. He is the Professor of haematology at the University of Nantes, France where he is in charge of the lymphoma research program and the early phase clinical investigation in Haematology Unit. He presented alongside Dr Michael Dickinson about the management of lymphoma, new treatments and CAR T-cell therapy.



Sharon Millman (CEO), Donna Gairns (Lymphoma Care Nurse), Prof Steven Le Gouill, Dr Michael Dickinson and Mike Aikenhead (Janssen)

Thank you to those who came along. We have filmed the event for those who could not make it and it will be available on our website shortly.

 <https://bit.ly/2Zr9PKm>

Upcoming Education and Conference Events



Upcoming dates to keep on your calendar

CNSA Congress 2019

Date: 20–21 June 2019
Venue: Melbourne Convention and Exhibition Centre
Registration: www.cnsacongress.com.au

National Cutaneous Lymphoma Symposium – for health professionals

For consultants, trainees, nursing and allied health staff – sponsored by Takeda & Merk Sharp Dohme Australia

Date: 23 August 2019
Time: 08:45am – 5pm
Venue: John Loewenthal Auditorium, level 2, Westmead Conference & Education Centre, Westmead Hospital
Cost: 50 consultants and \$25 trainees, nurses and allied health

RSVP: 17 August 2019; invitation details to be emailed soon or email donna.gairns@lymphoma.org.au

Blood 2019

Date: 20–23 October 2019
Venue: Perth Convention & Exhibition Centre
Registration: www.blood2019.com

Nurse Education Breakfast – Hosted by Lymphoma Australia

“Save the date”: presenter Dr Chan Cheah, Sir Charles Gairdner Hospital

Date: 21 October 2019
Time: 06:45am – 08:15am
Venue: Perth Convention & Exhibition Centre

Meet the *Lymphoma Australia* staff members

For those who are new to Lymphoma Australia, I would like to introduce you to our current team members:

Sharon Millman CEO
Donna Gairns Lymphoma Care Nurse Consultant

Sharna Moloney Lymphoma Care Nurse Consultant
Carol Cahill Community Support Manager
Josie Cole Fundraising Manager

Lymphoma AUSTRALIA NURSE ALLIANCE SURVEY

HELP US, HELP YOU

Please take 5-10 minutes to complete our survey. Your feedback will help us to evaluate our Nurse Group and see how we can better support your needs as a health professional. To date we have only had 50 responses, that have all been helpful to hear.

 <https://bit.ly/2WNkP83>

Resources & Fact Sheets

We continue to add to our range of resources and fact sheets that are available to download and print from our website. We can also send you a supply of the books and fact sheets for your patients by emailing enquiries@lymphoma.org.au

These free resources are designed to better inform patients on a wide range of topics including detailed information about lymphoma subtypes, clinical trials, side effects and survivorship. They are also good for revision for health professionals wanting to know more.



Thank you!

Thank you for supporting Lymphoma Australia and being a part of the Lymphoma Nurse Special Interest Group. We are striving to increase membership and grow our services for you. We would like to encourage you to invite your colleagues to join. Please do not hesitate to contact me if you have any questions or suggestions.

Donna Gairns, Lymphoma Care Nurse Consultant
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Phone: **0404 749 884**

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

For more information visit www.lymphoma.org.au

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