



### LaRDR Sites and Principal Investigators

*(italics = governance approval pending)*

**Alfred Hospital:** Susan Morgan  
**Austin Hospital:** Eliza Hawkes  
**Ballarat Hospital:** Geoffrey Chong  
**Barwon Health:** Sumita Ratnasingam  
**Box Hill Hospital:** Eliza Hawkes  
**Canberra Hospital:** Dipti Talaulikar  
**Concord Hospital:** Judith Trotman  
**Epworth Hospital:** Miles Prince  
**Fiona Stanley Hospital:** Dustin Hall  
**Gold Coast University Hospital:** Tara Cochrane  
**Gosford Hospital:** Tasman Armytage  
**Monash Health:** Stephen Opat  
**Peter MacCallum Cancer Centre:** Michael Dickinson  
**Princess Alexandra Hospital:** Colm Keane  
**Royal Adelaide Hospital:** Pratyush Giri  
**Royal Hobart Hospital:** Anna Johnston  
**Sir Charles Gairdner Hospital:** Chan Cheah  
**St Vincent's Hospital, Sydney:** Nada Hamad  
**Sunshine Coast University Hospital:** Manjunath Narayana  
**Sunshine Hospital:** Duncan Carradice  
**Toowoomba Hospital:** Howard Mutsando  
**Townsville Hospital:** Joel Wright

### LaRDR Steering Committee

**Stephen Opat (chair):** Monash Health  
**Leanne Berkahn:** Auckland Hospital, NZ  
**Chan Cheah:** Sir Charles Gairdner Hospital  
**Michael Dickinson:** Peter MacCallum Cancer Centre  
**Maher Gandhi:** Princess Alexandra Hospital  
**Pratyush Giri:** Royal Adelaide Hospital  
**Eliza Hawkes:** Austin Hospital/ Box Hill Hospital  
**Anna Johnston:** Royal Hobart Hospital  
**Colm Keane:** Princess Alexandra Hospital  
**Zoe McQuilten:** Monash University  
**Stephen Mulligan:** Royal North Shore Hospital  
**Jake Shortt:** Monash Health  
**Dipti Talaulikar:** Canberra Hospital  
**Judith Trotman:** Concord Hospital  
**Erica Wood:** Monash University

### Working groups

#### Chronic Lymphocytic Leukaemia

**Stephen Mulligan (chair):** Royal North Shore Hospital  
**Xavier Badoux:** St George Hospital  
**Gavin Cull:** Sir Charles Gairdner Hospital  
**Constantine Tam:** Peter MacCallum Cancer Centre  
**Bryone Kuss:** Flinders Medical Centre  
**Paula Marlon:** Princess Alexandra Hospital  
**Manjunath Narayana:** Sunshine Coast University Hospital  
**Stephen Opat:** Monash Health  
**Sumita Ratnasingam:** Geelong Hospital  
**Dipti Talaulikar:** Canberra Hospital  
**Erica Wood:** Monash University

#### Pathology Review/WHO Classifications

**Dipti Talaulikar (chair):** Canberra Hospital  
**Simone Birch:** Princess Alexandra Hospital  
**Christina Brown:** Royal Prince Alfred Hospital  
**David Ellis:** Clinpath Pathology  
**Yasmin Harvey:** Sullivan Nicolaides Pathology  
**Sam Hitchens:** University of Tasmania  
**Sanjiv Jain:** Canberra Hospital  
**Peter Jessup:** Royal Hobart Hospital  
**Surender Juneja:** Peter MacCallum Cancer Centre  
**Daniel Kearney:** Royal Adelaide Hospital  
**Beena Kumar:** Monash Health  
**Stephen Lade:** Peter MacCallum Cancer Centre  
**Kenneth Lee:** University of Sydney  
**Connall Leslie:** University of Western Australia  
**Eileen Long:** Hobart Pathology  
**Adrienne Morey:** Canberra Hospital  
**Lakshmi Nath:** Clinpath Pathology  
**Debbie Norris:** QML Pathology  
**Andrew Parker:** St Vincent's Hospital, Sydney  
**Jeremy Parry:** Fiona Stanley Hospital

#### LaRDR Team Members

**Coordinating Principal Investigator:** Stephen Opat  
**Administration:** Transfusion Research Unit  
 School of Public Health and Preventive Medicine,  
 Monash University  
**Investigators:** Erica Wood, Zoe McQuilten  
**Senior Projects Officer:** Neil Waters  
**Senior Research Officer:** Gayathri St George  
**Research Officer:** Christianto Thu  
**Research Officer:** Michelle Zheng

Welcome to the LaRDR report for 2019! We are delighted to share the registry's activities and achievements, and thank all the registry participants and supporters for your great efforts over the past year.

### MESSAGE FROM THE CHAIR

It is approaching five years since the first seeds of the lymphoma registry were sown, and it is now bearing fruit. The registry has grown quickly, with the participation of 21 sites and entry of 2381 cases at the time of writing.

There have been challenges, including rapid expansion, introduction of updated tumour classifications, and development of procedures for verification of clinical and laboratory data, and I thank everyone for their work to address these. The CLL working group under the guidance of Prof Stephen Mulligan has enabled the registry to collect a dedicated CLL dataset to provide important real-world data in a rapidly changing therapeutic landscape.

The next few years will be extremely productive with output generated through the close ties between clinicians, researchers, industry and community partners and the LaRDR team at Monash University. This success would not be possible without the dedication of all these individuals and organisations and your support has enabled the registry to flourish so wonderfully to this point. Thank you!

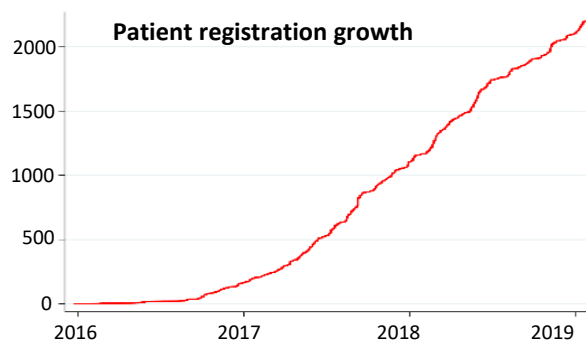
### LaRDR ACTIVITIES AND PROGRESS

**Governance and management:** The registry is overseen by the national **LaRDR Steering Committee** and managed by Ms Gayathri (Gaya) St George and the LaRDR team at Monash University's School of Public Health and Preventive Medicine. LaRDR uses an "opt off" consent model to enable maximum participation.

Lymphoma diagnoses include a very diverse group of conditions. As a quality assurance activity, a **LaRDR Pathology Review committee** chaired by A/Prof Dipti Talaulikar has been established to ensure the accurate and consistent diagnosis of cases entered into the registry, and to enable interpretation of treatment and outcomes reported by the registry. During 2019 the Pathology Review committee undertook some pilot work reviewing reports for cases of diffuse large B-cell and follicular lymphoma. Concurrently, the **World Health Organization (WHO) Classification Working Group** is working to ensure that disease classifications used in the registry are up-to-date with the WHO classifications. **The Data Validation Working Group** of Dr Allison Barraclough and Tania Cushion (Austin Health), and Dr Joshua Casan and Jing Huang (Monash Health) working with the Monash University LaRDR team, are identifying potential improvements to the LaRDR database to enhance its usability, while ensuring that the captured data are meaningful and relevant.

**Participation:** Recruitment reached over 2300 in September 2019, from 21 active sites. More sites are interested in joining. The median age of enrolled patients is 63 years, and 60% are male. Major diagnoses of participants include mature B-cell non-Hodgkin lymphoma (NHL, 72%), Hodgkin lymphoma (18%), mature T-cell and NK-cell NHL (5%), CLL (4%) and post-transplant lymphoproliferative disorder (0.5%). CLL case numbers will rise with the recent addition of a CLL-specific case report form, designed with input from the **Chronic Lymphocytic Leukaemia Working Group** chaired by Prof Stephen Mulligan to capture a more comprehensive picture of patients diagnosed with CLL in Australia.

Now that substantial recruitment has been achieved across a range of lymphoma subtypes, and follow-up is accruing, **LaRDR is preparing to provide its first data reports to participating sites.** The aim will be to provide hospital-specific data analyses twice-yearly to support benchmarking and practice improvement.



LaRDR investigators, friends and supporters met in Brisbane for the 2018 LaRDR breakfast meeting as part of the *Blood 2018 conference*. Thanks to our excellent invited speakers, Professor Steven Coutré (Stanford University), Dr Greg Hapgood (Australasian Lymphoma Alliance), and A/Prof Jake Shortt (Monash Health). During the conference Dr Michael Dickinson delivered an oral presentation “High rates of early treatment failure in patients with diffuse large B-cell lymphoma: First results from the Lymphoma and Related Diseases Registry” on behalf of registry investigators; and A/Prof Dipti Talaulikar presented a poster on the first steps for the LaRDR Pathology Review Committee.



### REGISTRY PROJECTS

**ICAN: Immunoglobulin use and outcomes in Chronic lymphocytic leukaemia And Non-Hodgkin lymphoma** is a registry-based study funded by the National Blood Authority and led by A/Prof Zoe McQuilten from the Transfusion Research Unit at Monash University. ICAN will collect ‘real world’, up-to-date Australian clinical and laboratory information on immunoglobulin and antibiotic use for LaRDR patients with CLL and NHL. The results will help to improve infection prevention and treatment for patients, and to rationalise the use of immunoglobulin therapy. Data are entered at baseline and 4 subsequent timepoints. The study offers a per patient payment for participation. ICAN recently received ethics approval and recruitment is underway.

**Melbourne Genomics Health Alliance** The *Melbourne Genomics Health Alliance Lymphoma Flagship* study, led by Dr Gareth Gregory and Prof Stephen Opat from Monash Health and the MGHA, has been examining the feasibility and value of genomic sequencing for lymphoma in clinical practice. Sequencing was conducted on 125 patients diagnosed with aggressive NHL, and the data were linked with clinical information from LaRDR to gain a comprehensive understanding of each patient’s clinical picture.

The *GELF study* explores the utility of the Groupe d’Etude des Lymphomes Folliculaires (GELF) criteria in guiding clinicians’ therapeutic decisions. This project is led by Dr Allison Barraclough and Dr Eliza Hawkes from Austin Health, and has been accepted for a poster presentation at Blood 2019 and the American Society of Hematology meeting. A manuscript is currently under peer-review for publication.

The *Australasian Lymphoma Alliance*, led by Dr Eliza Hawkes and colleagues, aims to increase national collaborative lymphoma clinical research output and facilitate engagement with international collaborators and industry. ALA and LaRDR have several joint projects, led by A/Prof Dipti Talaulikar, Dr Kirsty Rady, Dr Gohar Maqbool and Dr Zainab Ridha, including investigating outcomes of adolescent and young adults with lymphoma, and adults with Waldenström macroglobulinaemia and testicular lymphoma.



The *WhiMSICAL (Waldenström Macroglobulinaemia Study Involving Cart-wheel)* study aims to expand investigate patient-reported outcomes (PROs) and expand an international patient-derived dataset for patients diagnosed with Waldenström Macroglobulinaemia. WhiMSICAL provides a platform for patients to voice their experiences, which may assist in breaking down clinician-patient barriers. In a recent collaboration with LaRDR led by Dr Ibrahim Tohidi-Esfahani and Prof Judith Trotman from Concord Hospital, WhiMSICAL patient-entered data were compared to hospital-entered patient information captured in LaRDR. The results showed good concordance, with a high level of data accuracy and utility in both these datasets. The results were presented as posters at Blood 2018 in Brisbane, and the European Hematology Association congress in Amsterdam in June 2019.

The *T-cell Project 2.0* is a collaborative international registry with participation from Europe, United States, South America, Australia and Asia. It collects information on patients with newly diagnosed peripheral T-cell lymphoma. LaRDR will provide information for the Australian cohort. Prof Miles Prince from Peter MacCallum Cancer Centre is one of the founding members of the T-cell Project 2.0 Executive Committee. Legal agreements are being finalised and LaRDR data sharing will commence shortly.



LaRDR is working with the *Movember cancer registry platform*, a national initiative seeking to transform health outcomes of Australians diagnosed with cancer. The LaRDR team recently met with the Movember Foundation to give an overview of LaRDR and particular issues relevant to lymphomas, as part of the scoping activities for a future national cancer registry platform.

*LaRDR welcomes suggestions for analyses of registry data and new project ideas using the registry.* Please contact the LaRDR team and we will provide you with the data access policy and data request forms, and help with analysis as needed.

### To contact the LaRDR

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### LaRDR appreciates the support from these organisations

