Better treatments...
Better lives.

ALLG News

Edition 1

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 first edition of the Australasian Leukaemia and Lymphoma Group (ALLG) newsletter - ALLG News.

Whether you are reading this as a registered Community Member of ALLG, as a supporter of ALLG, or from having seen ALLG promoted through one of our partner foundations or on our social media, we thought September's Blood Cancer Awareness Month was an ideal time to launch this e-newsletter.

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.

Simply, every new cancer treatment has only been made possible thanks to clinical trials and they are the only way we can improve treatments and patients' lives. Patients just like David, whose story you can read about in this newsletter.

Clinical trials are critical to improving the overall treatment of patients, and increasing patient access to new treatments that may not be available in Australia and New Zealand. The quality of care for patients on trials is always exceptional. On page 7 you can read Anne Hodgson's story, an Acute Myeloid Leukaemia survivor, about participating on a clinical trial.

Who is the ALLG? We're a group of doctors, haematologists and other health professionals across Australia and New Zealand working together in blood cancer clinical trials, collaborating voluntarily to research for better treatments with the aim to cure; mentoring the next generation of clinical trial researchers, and advocating for better access to life-saving treatments and trials for patients with blood cancer.

Our ALLG Members include many of the world's, Australia's and New Zealand's pre-eminent experts in blood cancer. We conduct a broad program of clinical trials to meet areas of unmet need in blood cancer. Our member haematoligists have advanced have advanced many treatments for blood cancers over the last five decades, since ALLG was established in 1973.

We collaborate with other leading blood cancer trial groups globally, opening up even greater opportunities for better treatments today for Australian and New Zealand patients that they would not otherwise have access to.

In addition, the ALLG's advocacy work continues to strive for better patient access to clinical trials. As a member of the Australian Government's Blood Cancer Taskforce Steering Committee, one of the most significant activities has been the recent launch of six new Optimal Care Pathways for blood cancer treatment and care. They set the national standard of high-quality cancer care for all Australians impacted by blood cancers. ***Learn more here.***

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***.

I look forward to sharing many of our research updates and other important news from our member clinician researchers, for you, in future editions of ALLG News.

Ms Delaine Smith,

Chief Executive Officer

www.allg.org.au

What is a clinical trial?

A clinical trial is a scientific study, or an organised test of medicines and new treatment options. The trial team includes doctors, nurses and other health professionals who carefully follow the protocol or plan of the trial. They check the health of the participating patient at the start of the trial, give specific instructions for participating, monitor the patient through the trial and stay in touch after the trial is completed.

If you'd like to know more, ***please visit the FAQs on our website*** for answers to some commonly asked questions regarding clinical trials.

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.***

Leading our blood cancer research

Since we began in 1973, the ALLG have opened more than 160 clinical trials and research projects in Australia and New Zealand. This ground-breaking research continues to influence the way doctors treat blood cancer patients globally; which in turns provides much needed hope and care to patients with blood cancers.

Our clinical trial hospital sites and doctor member researchers are key to our success, and we benefit greatly from our clinician members contributing their expertise to grow the capacity of the entire ALLG network, so that patients can more easily access trials for the chance to have better treatments and better lives.

New ALLG Scientific Advisory Chair, Professor Judith Trotman

Professor Judith Trotman MBChB, Grad. Cert. Clinical Trials (pictured) is ALLG's recently appointed Chair of the Scientific Advisory Committee (SAC) that is responsible for overseeing the scientific direction of the ALLG.

Professor Trotman is a 22-year prominent ALLG doctor member, and Head of Haematology at Concord Repatriation General Hospital NSW, where she was the Founding Director of the Clinical Research Unit 2005-2019. She is passionate about embedding clinical research in quality care; and provides global leadership in charting the role of PET scanning ***(Positron emission tomography)*** in lymphoma.

In the past 15 years, Professor Trotman has led many ALLG clinical trials and international trial partnerships.

Learn more about Professor Trotman.

Scientific Research Strategy

The ALLG launched its new ***Scientific Research Strategy*** this year to guide our future research direction and clinical trial activities. What does this mean for patients with blood cancer? Better treatments, better lives; aiming for cure.

One of the goals of the ALLG research strategy is about improving clinical practice and implementing ALLG clinical trial research findings into standard practice; for patients to have better treatments with less side-effects, and more curative options. Our trial progress is focused on delivering trials in each and every subtype of blood cancer, eg. leukaemia, lymphoma, myeloma - all types of blood cancer.

Prof Judith Trotman, ALLG Scientific Advisory Committee Chair, explained, "The Research Strategy defines the mission (the how we do it) to achieve the ALLG's vision for 'better treatments, better lives'. We will be monitoring and reporting on metrics across the trial lifecycle, and ensure we are on target to meet the five year goals within each trial program."

"As a community we are all accountable to finding better treatments that are safe, effective and well tolerated," Prof Trotman explained. "Tapping into the research strengths we have across ALLG clinical trial hospital sites is key to incorporating this research to a vibrant patient-centred clinical trial program, keeping it relevant and at the cutting edge, with results that can be implemented into clinical practice for the benefit of patients."

Prof Trotman said, "Working within a well-established Australian-New Zealand alliance, the ALLG has a platform to provide leadership in improving clinical practices for patients."

Learn more about the ALLG's Scientific Research Strategy.

11,500 patients
supported by ALLG trials from 1973 to 2021, including all ALLG trials, projects and registries.

160 trials

Our Research Reach

International clinical trial collaborations – ALLG clinical trials bringing new treatments to Australian and New Zealand patients.

About one third of ALLG's clinical trial program involves important collaborations with international cooperative trial groups, which are expanding the range of international trials we can bring to Australia. We are proud to continue a strong relationship with the Medical Research Future Fund, and with the Leukaemia Foundation that has supported our trials.

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

International clinical trial collaboration: ALLG NHL30 PETReA for follicular lymphoma

Prof Judith Trotman (ALLG's new Scientific Advisory Chair) is leading our collaboration with the UK National Cancer Research Institute, the ALLG NHL30 PETReA trial in follicular lymphoma, with the aim to improve survival and reduce side-effects of treatment for patients to have a better quality of life.

"I have been working with the Institute in the UK as ALLG Co-Principal Investigator in Australia," Prof Trotman said.

"The ALLG's strong patient recruitment to NHL30 PETReA during the COVID pandemic, which underscored the importance of doing such a study to quantify the benefits and any side-effects of antibody maintenance, has been hugely appreciated with our UK colleagues," said Prof Trotman.

PETReA assesses the benefits and toxicities of ongoing treatment in patients who have achieved complete remission after their initial immunotherapy for symptomatic advanced stage follicular lymphoma. This is of vital significance in the current COVID era where the risks of immunosuppression from maintenance therapy (treatment to avoid relapse) have increased.

There are 100 participating hospitals sites for this trial in the UK. The ALLG NHL30 PETReA trial is at eight participating hospitals across Australia and is still open to patients. Visit ALLG Current Clinical Trials and search under Lymphoma to learn more: ***https://www.allg.org.au/clinical-trials-research/current-clinical-trials/***

Studies like this enhance ties between international groups, ensuring that Australian patients will have better access to the large clinical trial studies still, which can lead to change in clinical practice, for patients to receive better the best treatment regimes.

Prof Trotman explained, "We are growing in our own trials' capabilities and the COVID era has certainly accelerated our efficiencies and agility in delivering on pragmatic, impactful trial design."

UNIVERSITY OF LIVERPOOL

International clinical trial collaboration: MM24 IsAMYP trial for AL amyloidosis

Acute Leukaemia (AL) amyloidosis is a bone marrow disorder. Misfolded proteins can accumulate in the body's tissue, nerves and/or organs, gradually causing damage and affecting function.

Dr Simon Gibbs, MBBS FRACP FRCPA (pictured) is a member of ALLG's Myeloma Scientific Working Party and a member of Myeloma Australia's Medical and Scientific Advisory Group. He is leading the **ALLG MM24 clinical trial that is evaluating a new combination of medicines for patients with AL amyloidosis.**

This is an international Amyloidosis trial, in collaboration with the French Myeloma Group Intergroupe Francophone du Myélome (IFM); our first collaboration with IFM.

The ALLG is proud to bring this important international trial to Australian patients. MM24 is evaluating three drug combinations in patients with AL amyloidosis who have either relapsed or are not better after any previous treatments. The results are being evaluated against results of another study.

There are four hospitals in Australia that are now operating this trial – Box Hill Hospital VIC, Princess Alexandra Hospital QLD, Royal Adelaide Hospital SA and Fiona Stanley Hospital WA. Six participants have already joined the trial and we aim to recruit a total of 12 patients by the end of the year. If you are interested in participating, speak with your haematologist. You can also refer to our ***FAQs*** for answers to some commonly asked questions regarding clinical trials..

ifm
INTERGROUPE FRANCOPHONE DU MYELOME

You can read David's full story here.

Acute myeloid leukaemia survivor and clinical trial participant, David Runting shares his story

In 2019, David Runting (pictured left) was just turning 57 when diagnosed with stage III Acute myeloid leukaemia (AML); a type of blood cancer where excess of immature white blood cells or myeloid line of blood-forming cells is made by the bone marrow.

As an acute leukemia, AML progresses rapidly and is life-threatening if left untreated.

David, who participated in an ALLG clinical trial, shares his story:

"Naturally the news came as a shock. Things unfolded after a review of routine blood tests with my GP following a semi-annual health check. Every other year was unremarkable so I thought this would be little different. Unfortunately, not so.

That first stint in hospital of 35 days knocked the stuffing out of me. I had been pretty well, I thought, just a couple of weeks before, then in a blur life was now in a different dimension.

While in for the second round (of treatment) I was told that I would need a bone marrow transplant (BMT). Eight out of ten Australian patients rely on an overseas BMT donor. Luckily, I had three brothers who were tested and two were found to be a match.

Agreeing to participate in clinical trials was an easy decision to make. The chances of overcoming the disease rely upon the study of and experiences of patients who have endured the effects of similar cancers, and treatments are refined based on this accumulated knowledge.

I was the beneficiary of the collaboration of patients, doctors and researchers in earlier trials, so to participate in further efforts to identify better treatments was the least I could do."

Learn more about participating in clinical trials: ***https://www.allg.org.au/clinical-trials-research/current-clinical-trials/faqs/***

You can read more about Anne's 'survivor' story here.

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 Anne Hodgson (pictured), who has volunteered as an ALLG Consumer Representative since 2010. Anne is an Acute Myeloid Leukaemia survivor. She shares her story:

"The benefits of participating in clinical trials are many and varied," Anne explained. "Importantly, often participation in trials allows patients access to drugs used in combination or prior to their general availability.

"Participation in trials may give some patients opportunities and hope that may not have been accessible otherwise," Anne said. "It also means regular and careful attention from health professionals associated with the trials, in addition to the care offered by a patient's own specialist team."

"Contributing to research today in this way, may also mean saving lives in the future and giving hope to other patients," said Anne.

"I find it most satisfyingly using my blood cancer experience in my role as a Consumer Representative to the ALLG," she said. "The contributions I make to the ALLG are many and varied and are done in the hope that, through my experience, patients diagnosed with a blood cancer travel that well-worn path just a little bit easier."

We thank Anne 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!

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

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 biggest foundations and support partners - Blood Cancer New Zealand, Canteen Australia, Leukaemia Foundation, Lymphoma Australia, Myeloma 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 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 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/

Myeloma Australia

Myeloma Australia exists to support, educate, inform, empower and bring hope to people who are living with myeloma, and their loved ones. Our specialist Myeloma Support Nurses provide information and caring support through our Telephone Support Line, Workshops & Seminars and Information & Support Group programs; our programs are delivered both online and in-person.

Our website has booklets, fact sheets, podcasts and videos available for download to help you learn more about myeloma, its treatments and living well. All of our programs and services are free and confidential. For more information, call 1800 693 566 or visit ***www.myeloma.org.au***

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