Newsletter name change to include SLL

Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL) are essentially the same disease; the only difference being where this slow-growing cancer occurs.

If most of the cancer cells are located in the bloodstream and the bone marrow, the disease is called CLL, although some cancer cells may also be found in the lymph nodes. If most of the cancer cells are in the lymph nodes, the disease is called SLL. The title of the Leukaemia Foundation’s CLL newsletter has been updated to – CLL News including SLL – to ensure those affected by SLL receive the most relevant information about their disease.

ROB’S RESPONSE TO NEW TARGETED THERAPY – “BRILLIANT”

Rob Domone says he was “very lucky” to find out about an international clinical trial for ibrutinib just when he needed it.

He had read about the new targeted therapy for the first time in the December 2012 issue of CLL News, soon after being told he had 17p-deletion CLL – a high-risk form of the blood cancer. He started ibrutinib last year and had an immediate response.

Tracking back to April 2011, Rob was first diagnosed with CLL after seeing his GP when he had a severe earache.

She ordered a full blood count and the report mentioned a slightly high white blood count, with a note: ‘CLL?’.

“She called me in and explained it was slow-moving and treatable. I’d never heard of CLL and was very surprised,” said Rob, now aged 65, of Sydney.

“There was no history of CLL in my family. Both my parents lived to about 90 and I’d always been pretty healthy and fit.”

Rob’s wife, Maggi, who has worked as a medical librarian, helped him research CLL on the internet, and they went together to see a specialist who suggested he take the standard approach at the time – watch and wait.

Rob, who had no obvious symptoms at the time, had his blood checked every three months and continued working – in IT at St Vincent’s Hospital. He decided to retire in November 2011 because he needed a change.

“We found out via the internet that the standard treatment for CLL was FCR – chemotherapy and immunotherapy.”

Continued on page 6...
Research Matters

LATEST RESEARCH PROJECT INVESTIGATES CLL

CLL is the focus of a research project funded by the Leukaemia Foundation in its 2014 round of annual research grants.

A Grant-in-aid (funding of $86,581 over 12 months) went to Dr Timothy Mercer (Garvan Institute of Medical Research) for Backwards splicing of cancer genes in blood disorders. Supported by the Estate of the late Shirley Miners. This grant is one of 21 research projects in the Foundation’s 2014 round of annual funding, totalling $3.6 million. This builds on the Foundation’s ongoing National Research Program of 50 research projects already in progress (worth $9.14 million), plus a $150,000 contribution to the Australasian Leukaemia & Lymphoma Tissue Bank.

In its commitment to a future where blood cancer can be cured, the Foundation currently funds 71 research projects at leading research institutions across Australia, from 2014-2019 – an investment of $12.89 million in research.

Over the next five years there also will be considerable further investment in research by the Foundation, with the addition of each year’s new round of National Research Program grants and other research funding.

1 The Leukaemia Foundation makes an annual contribution to the ALLG Tissue Bank (a total of $2.3 million since 2002).

LOOKING AT ‘SPICING’ IN BLOOD CANCER DEVELOPMENT

A research team led by Dr Timothy Mercer (pictured), from the Garvan Institute of Medical Research, is using a new technology to take a closer look at the role of ‘splicing’ in and CLL and myelodysplastic syndrome (MDS).

Splicing is an important process that occurs in our cells to produce the proteins coded for by genes. Each human gene is made up of smaller parts known as introns and exons. Splicing cuts out the introns and stitches together different combinations of exons. By alternating the combination of exons that are spliced together, a single gene can encode for multiple protein products.

However, when gene splicing goes wrong it can lead to cancer. Sequencing the genomes of tumours in a wide range of cancers, in particular MDS and CLL, has shown that the cellular machinery responsible for gene splicing is often impacted by mutations.

According to Dr Mercer, researchers don’t understand how these mutations affect the splicing machinery and cause cancer.

“Myelodysplasia and chronic lymphocytic leukaemia often harbour mutations to the splicing machinery,” said Dr Mercer.

“In preliminary research, we’ve found that splicing can proceed incorrectly backwards, building incomplete genes and tying the RNA into circular knots. Many of the genes that can be spliced backwards are critical for the cell, and involved in blood cancer development.”

Dr Mercer and his team are aiming to find whether mutations to the SF3B1 and the splicing machinery cause the backwards splicing of these genes, resulting in defective proteins that cause MDS and CLL.

If their theory is correct, it could result in an entirely new pathway by which cancer develops and that is potentially common to many cancers.

EXPERIMENTAL DRUG OPENS NEW ERA FOR CLL & SLL

People with advanced chemotherapy-resistant CLL or who are too frail to withstand treatment, have a 10-fold better chance of remission through a new drug.

The tablet, ibrutinib, is being lauded as a wonder drug by oncologists for patients who have exhausted all other options.

Results of the global Phase III clinical trial are so impressive, further trials have already begun to see if ibrutinib can replace chemotherapy and treat CLL in the same way blood pressure is managed with daily maintenance tablets.

Peter MacCallum Cancer Centre consultant haematologist, Dr Constantine Tam, said that in about 50% of people with CLL, the blood cancer was benign. But it progressed to becoming chemotherapy-resistant in the other 50%.

In the study of 391 patients worldwide, including those from Peter Mac and St Vincent’s Hospital, in Melbourne, they were given either daily ibrutinib tablets or injections of ofatumumab.

“This is the most significant breakthrough we’ve ever made in this scenario. It opens up a whole new era for the treatment of this leukaemia,” Dr Tam said.

“More than 80 per cent of patients noticed a benefit within a week.

“Their energy improved, severe sweats disappeared straight away, the swollen lymph glands in the neck started softening and blood counts improved.”

The findings have been published in the New England Journal of Medicine and presented at the American Society of Clinical Oncology and the European Hematology Association.

Dr Tam said it might be two years before the drug would be available in Australia but new clinical trials with second generation compounds based on ibrutinib are now recruiting in Australia.

1 The Leukaemia Foundation makes an annual contribution to the ALLG Tissue Bank (a total of $2.3 million since 2002).
IMPROVING ACCESS TO CLL & SLL DRUGS

These are exciting times with several emerging therapies on the horizon for people with relapsing or refractory CLL, according to the Leukaemia Foundation’s Head of Research & Advocacy, Dr Anna Williamson (pictured).

“This means that, in time, those therapies that deliver robust remissions are likely to become available as first-line therapies once good data is available from clinical trials,” Dr Williamson said.

“Having had no major improvements in the outcomes for people with CLL in the last 20 years, this is an exciting time for people affected by this type of leukaemia. There is a major unmet need for this patient group, but in the next year or two, we expect companies to register new CLL therapies with the Therapeutic Goods Administration (TGA) and submit applications to the Pharmaceutical Benefits Advisory Committee (PBAC) for funding under the Pharmaceutical Benefits Scheme (PBS).”

These include:
- bendamustine (TGA registered, clinical trials CLL)
- obinutuzumab (TGA registered, clinical trials CLL)
- ofatumumab (TGA registered, clinical trials CLL)
- ABT-199 (clinical trials for CLL)
- ibrutinib (clinical trials for CLL, CLL del 17)
- idelalisib (clinical trials for CLL, SLL).

Dr Williamson said that having this many potential new therapies becoming available within a short timeframe would be challenging for Australia’s PBAC.

AUSTRALIA’S DRUG REGISTRATION AND REIMBURSEMENT SCHEME IS COMPLICATED

The regulatory processes that make drugs available to Australians were designed to ensure drugs are safe and effective, and best value for money.

This is achieved initially through the Therapeutics Goods Administration (TGA) registration – regarding safety and efficacy, and that those therapies funded by the taxpayer through the PBS are good value for money too.

When there is sufficient evidence that a new therapy is effective and safe, the time it takes for it to become available on the PBS is increasing as technology advances and more therapies become available more rapidly.

New therapies are often effective for a defined subgroup of patients only and the use of the new therapy may need to be determined with a specific diagnostic test. (This test also needs to be evidenced as the Medical Services Advisory Committee – MSAC, see www.msac.gov.au.)

In other parts of the world – North America and some European countries – schemes have been developed that make urgently required new cancers therapies available more quickly. These include Fast Track (U.S.) and Cancer Drugs Fund (UK).

An equivalent scheme has not been introduced in Australia, however the Cancer Drugs Alliance is advocating for policy change with the Australian government to ensure Australian cancer patients can access and afford new therapies that are available in other parts of the world. (More info: www.cancerdrugsalliance.org.au)


CLL RESEARCH IN AUSTRALIA

Clinical trials often provide access to potential new CLL therapies long before they become available to most Australians.

Participation in a trial can be pivotal for people for whom standard therapies have not been or are no longer effective and for whom further treatment options may be limited.

In addition, the time it takes to gather sufficient evidence that a potential new therapy is effective, safe (needed for registration with the Therapeutics Goods Administration), and should be considered for listing on the Pharmaceutical Benefits Scheme (PBS) can be difficult to achieve.

The PBAC generally requires evidence from clinical trials that involves large numbers of people, and requires data that demonstrates the new therapy also is cost effective (‘value for money’ compared to other treatments). For many rarer CLL subtypes, the number of people affected may be too small in Australia, or the disease too slow-growing, to make it possible to collect this information within a commercially feasible timeframe.

MICHELE WANTED TO GO ON A CLINICAL TRIAL

When Michele Cooper was offered a Phase III randomised, double blind clinical trial in August, she didn’t hesitate to say – “yes, I’ll take the trial”.

At the time she was on watch and wait and hadn’t had any treatment for CLL since her shock diagnosis in March 2012, but according to recent tests her CLL had begun to progress.

“The trial just seemed like the right thing to do,” explained Michele, 60, of Burra (SA).

In 2012, when she had her cholesterol checked for the first time in her life, a blood test showed her cholesterol level was normal but her white blood cell count was very high.

Michele had monthly appointments with an oncologist in Adelaide – a 400km round trip from home – to monitor her CLL and kept working as a house parent for boarding students at a Burra high school. She also decided to play an active role in helping her body cope with having blood cancer by changing her diet, taking supplements and exercising.

“I couldn’t just sit there and not do anything. I felt a lot better in myself by controlling what I was eating, and by walking.”

A month after starting a strict diet, she had a “drastic turn around in her white blood cell count”. It dropped from 71,000 (when diagnosed) to 34,000, then hovered around 40,000-50,000 over the next 12 months.

“I understood that with CLL it was going to get worse and there was no cure. That’s what motivated me to look at what I could change to make it better for me, and to find alternatives to the standard treatment. I wanted to do a trial.

“I was very diligent, watching my bloods and thought I was coping okay. But I had a stressful year at the boarding house, wasn’t on the diet and everything went out the window. The stress of my job was a big factor and last year it all went haywire.”

Late last year, when Michele had a skin cancer cut off her hand, her artery was cut during the procedure and she ended up with a massive infection.

“I’ve been on antibiotics on and off ever since.”

Michele has worked all her life and she used her 10 years of accumulated sick leave for medical appointments and tests. In January this year she took long-service leave.

“I look back at all the things that went wrong and that’s when it began spiraling down.

“When Michele was in Adelaide for tests prior to the trial, she stayed with her daughter, Billie-Jai, who had just had a baby, was midway through renovating their house and simply didn’t have any spare room.

“It’s too hard to be there while I’m having chemo and I couldn’t keep driving back and forth from Burra.

“I need to be in Adelaide for the six months because they (the trial team) don’t know how I’ll react to the treatment so I have blood tests twice a week to check if anything is going wrong.

“Billie-Jai has been taking me to and from all the blood tests, and she mentioned that the Leukaemia Foundation had just built accommodation.

“An itchy body rash came up but I don’t have any side-effects at the moment.”

When Michele was in Adelaide for tests prior to the trial, she stayed with her daughter, Billie-Jai, who had just had a baby, was midway through renovating their house and simply didn’t have any spare room.

“It’s too hard to be there while I’m having chemo and I couldn’t keep driving back and forth from Burra.

“I need to be in Adelaide for the six months because they (the trial team) don’t know how I’ll react to the treatment so I have blood tests twice a week to check if anything is going wrong.

“Billie-Jai has been taking me to and from all the blood tests, and she mentioned that the Leukaemia Foundation had just built accommodation.

“I went a bit gung-ho, thinking I was on holidays. I started gardening, forgot I was sick, and got a leg infection. I kept pushing myself and my bloods were up,” said Michele.

She returned to work after a 10-week first term break then got a “horrible” sinus infection, which she couldn’t shake despite more antibiotics.

“My immune system was so far down.”

In July, a blood test showed her white blood cell count was nearing 100,000 and her lymph nodes were three times larger than normal. And when Michele went to Adelaide in August, she needed a blood transfusion and platelets.

That’s when she was offered and accepted the clinical trial, which she began in mid-September –idelalisib/placebo tablets twice daily, in combination with bendamustine and rituximab infused once a month for six months.

“Not many people have this as first-line therapy – it’s normally for relapse. There are only two of us on the trial in Adelaide and I don’t know if I’m on the placebo,” she said.

“As an optimist, I take each day as it comes and deal with it. I am really positive about the trial.”

Two weeks after her first course of treatment, Michele’s white blood cell count dropped from 100,000 to 9000.

“I was amazed by this result and how dramatically my white blood cells had gone down, and I’ve also got eosinophils (a type of white blood cell, part of the immune system) for the first time since last year,” said Michele.

“An itchy body rash came up but I don’t have any side-effects at the moment.”

When Michele was in Adelaide for tests prior to the trial, she stayed with her daughter, Billie-Jai, who had just had a baby, was midway through renovating their house and simply didn’t have any spare room.

“I need to be in Adelaide for the six months because they (the trial team) don’t know how I’ll react to the treatment so I have blood tests twice a week to check if anything is going wrong.

“Billie-Jai has been taking me to and from all the blood tests, and she mentioned that the Leukaemia Foundation had just built accommodation.
CLL TELEPHONE FORUM SURVEY

The Leukaemia Foundation provides specific support for people with CLL from regional and rural areas through its telephone support program.

Monthly CLL telephone forums are designed for those who can’t access the Foundation’s established education and support program and also are available for metropolitan patients, particularly those who have difficulty accessing the Foundation’s regular education activities.

To ensure our phone forums are meeting the needs of participants, the Leukaemia Foundation conducted a survey earlier this year.

Overall, respondents to the online survey “indicated a very good level of satisfaction with the CLL phone forum in general” in its current format according to Chris Hobson, who facilitates the CLL phone forums and is a Leukaemia Foundation support service coordinator.

“We sought constructive feedback on how the forum could be improved to better serve the needs of the CLL community nationally,” he said.

“They were happy with the timing of the forums – being held on Mondays, in the current timeslot (6-7.30pm EST) and the frequency (every four weeks).”

Survey respondents said they were motivated to participate in the forum for the following reasons:

• the opportunity to talk to others with CLL, share experiences and support;
• access specialist guest speakers on clinical topics related to CLL and its management;
• access up-to-date information on the latest available clinical trials and treatment options;
• information on living long-term with CLL, and managing symptoms and side-effects of chemotherapy;
• information on supportive care and complementary therapies, emotional support and coping strategies;
• input from allied health professionals;
• reducing feelings of isolation; and
• reducing fears by better understanding the condition of CLL.

“Thanks to everyone who took the time to complete the survey and for their ongoing participation in and support of the CLL telephone forum,” Chris said.

He plans to redouble his ongoing efforts to secure quality and relevant guest speakers for the CLL telephone forum throughout 2015 and continues to welcome all feedback on the CLL forum in general.

NATIONAL CLL SURVEY

The Leukaemia Foundation is about to undertake a national survey, to better understand the experience of people living with CLL in Australia. To find out more about the survey or to express your interest in participating in the survey, please contact Anthony Steele: asteele@leukaemia.org.au.

“I rang the Foundation and after initially being told they couldn’t fit me in until the end of October, they called saying a unit was available.

“I moved in just before starting the trial. It’s lovely and I couldn’t have asked for anything better. I can rest, go to the shops, see friends, do whatever I want and there’s a spare bedroom if any of my kids want to stay. And the Foundation staff are absolutely sensational.

“For the first couple of weeks I was in bed by eight and didn’t wake until seven. My body seemed to need sleep.”

Michele has four children, aged 24 to 32, and five grandchildren including “a lovely little set of twins”.

When she spoke to CLL News she was looking forward to the arrival of her sister Janine, who was coming from Streaky Bay to stay and help out.

“I do feel privileged,” said Michele referring to the resources she’s used since her CLL diagnosis – the clinical trial, blood transfusions and accommodation.

“It’s wonderful that people donate so other people can have a better quality of life.

“If I ever win money I’ll donate and give back,” said Michele who was waiting to see how she went in the $25 million draw from the night before.

As skin cancer is a common problem for people with CLL, it is important to have regular skin checks.
In October 2012, 18 months after diagnosis, Rob's white blood cell count had increased, his other blood counts were dropping, and he had a swollen lymph node in his left groin, so his specialist decided it was time to look at treatment.

At that stage a bone marrow biopsy, followed by a FISH test showed he had the 17p-deletion genetic mutation. This aggressive form of the disease occurs in around 7% of people with untreated CLL and for this group, FCR treatment is less effective.

"I had no idea there were different types of CLL, what 17p-deletion meant, or that there were clinical trials," said Rob. "I started looking on the internet to see what drugs existed and what trials were available here or overseas and found out that ibrutinib seemed the best available drug. But the only trials were overseas. Nothing was available in Australia at the time.

"I wasn't too happy but it was just a question of wait and see and maybe get on a trial overseas,"

By November 2012, the node in his groin had grown to the size of a grapefruit. His left leg had become swollen and his white blood cell count was 70 (normal: 4-11).

"It was suggested that I try FCR because I had no alternative." This is when Rob contacted the Leukaemia Foundation seeking information and he was sent a copy of CLL News. After reading an article about high-risk CLL by Dr Constantine Tam at the Peter MacCallum Cancer Centre in Melbourne, Rob sent his test results to Dr Tam.

"He was looking for patients to join an ibrutinib trial, who had 17p-deletion CLL and had tried FCR and failed," Rob explained.

"I wasn't eligible for the trial because I had to try FCR first, but at least there was a trial and there was some hope, so the timing was all good from my point of view. Dr Tam asked me to update him on my progress."

Rob had his first FCR treatment in mid-December. After his second cycle in mid-January 2013, he was admitted to hospital with fever and a zero neutrophil count.

"It took a while to find out what I had," said Rob.

They tried antibiotics, antivirals and antifungals. Finally, he was treated for a type of fungal pneumonia.

By February, the node in his groin, which had only reduced slightly during treatment, had returned to its original size.

Rob sent his latest test results to Dr Tam and was accepted on to the ibrutinib trial, one of only five people in Australia and 101 across the world currently on the three-year trial.

"I've had few side-effects, just atrial fibrillation (fast, irregular heartbeat) which I had experienced occasionally prior to my CLL diagnosis. Now I have it continuously and take drugs to slow my heart rate.

"Three weeks after starting the trial, all my enlarged lymph nodes had disappeared, they melted away, and within a few months my bloods were all back to within the normal range."

"It was brilliant. These targeted therapies are the way of the future, particularly for older people because they're much kinder on the body and have less side-effects. I'd really like to see them fast-tracked so they are available more quickly to everybody."

Life for Rob is pretty much back to normal.

"I've started sailing again, I'm back at the gym and am able to work in the garden and do a few things around the house. I just have to take it steadily and do a bit at a time," he said.

"But it's a 'new normal'. I don't have as much energy as I used to have. I get tired and can easily pick up infection, which also is harder to fight off. This is because my B-cells don't work and is typical of CLL."

To help protect him from infection, he's having intravenous immunoglobulin once a month for six months. This boosts his antibodies.

When he can, Rob joins the Foundation's monthly blood cancer support group at Concord Hospital.

"It's great to chat with other people with similar problems and it's always interesting to see how they're getting along. Last time we did some gentle yoga which I enjoyed, so I've now enrolled for a weekly course at the hospital."
BE INFORMED WITH COMPLEMENTARY MEDICINES

By Dr Lynn Weekes (pictured)

Supermarket, health food store and pharmacy shelves are packed with an array of natural, herbal and alternative medicines. So they must be safe, right?

Not necessarily. Complementary medicines like herbal supplements and vitamins are often considered less powerful than prescription medicines, but can still cause side-effects in some people, and may interact with other medicines and food.

Complementary or natural medicines should be given the same consideration as other medicines, despite the fact that information about them can often be harder to find.

An NPS survey1 of 1500 people in 2012 found 48% of respondents did not tell their doctor or pharmacist about other medicines they were taking.

One reason for this could be that people are not always aware that a complementary medicine is a medicine too. Of those surveyed, less than half considered certain vitamins and herbs to be medicines: multivitamins (23% considered it to be a medicine), echinacea (24%), and fish oil (32%). Awareness of Chinese herbal remedies as medicines was slightly higher at 41%.

Our findings also showed that complementary medicines were used by 46.3% of participants, representing just over half (53.2%) of all medicines users, 87.4% of whom used both conventional and complementary medicines. Women used more complementary medicines than men.

People may think that some doctors disapprove of complementary medicines, but this is not always the case. Health professionals know that many people use complementary therapies, and even if they are not convinced that all of them are effective, they will appreciate knowing about any you are taking. In order to treat the patient in the best way they can, a health professional needs to know about all the medicines a patient uses.

When it comes to taking any complementary medicine – whether it’s a herb, vitamin or mineral, nutritional supplement, aromatherapy product, homoeopathic or traditional Chinese medicine – it’s important to do some research on the benefits and risks first.

This is definitely not as easy as finding information about prescription and over-the-counter medicines which undergo scientific testing and have lots of publicly available information.

Complementary medicines are generally subjected to less testing and information is harder to find.

Firstly you can ask your treating doctor or pharmacist. You can also read the label and any supporting product information, but you may find this is not particularly detailed.

Lastly, there are many thousands of websites that provide information about complementary medicines. The difficulty with most is they are designed to sell products so you may only get information that increases their appeal. A limited number of sites provide both sides of the story, so look for websites that appear to present information in an unbiased way. Some of these include:

- myDr – www.mydr.com.au;

Having found your information, you need to assess if it answers the following five questions.

1. Is a medicine needed?

Medicines are not always the best way to treat or prevent a condition or illness. Sometimes other approaches may be more helpful. For example, vitamin C has not been proven to prevent or reliably treat a cold, and its effect on colds has not been studied in children. Resting at home is likely to help you or your child’s immune system fight the cold virus and prevent its spread to others. Your doctor or other health professional can advise on non-medicine options for you or your family.

2. How effective is the medicine?

No medicine is a universal cure, so you need to find out how likely it is the medicine will work for you or your family. Take fish oil supplements for example. Hundreds of studies have been conducted to determine their effectiveness in treating or preventing a variety of conditions, including some that can affect children such as attention deficit hyperactivity disorder (ADHD). But most have come back inconclusive other than for people with high triglyceride levels in their blood, heart disease or rheumatoid arthritis.

3. What are the possible side-effects?

Although complementary medicines generally cause fewer side-effects than prescription medicines, no medicine, however ‘natural’, is completely free of side effects. For example valerian a herb sometimes used for sleep problems and anxiety, can cause headaches, excitability and vivid dreams. Echinacea, used to ward off infections and reduce the duration of colds, may worsen asthma.

4. Will it interact with other medicines or foods?

Like all medicines, complementary medicines may interact with other medicines and foods, sometimes with potentially harmful effects. St John’s wort is found in many complementary medicine products used to alleviate depression. It can interact with several commonly used prescription medicines to reduce how well they work, including oral contraceptive pills, chemotherapy and epilepsy medicines. St John’s wort can also interact with some other antidepressant medicines to increase the likelihood of side-effects.

5. What is the right dose for me or my family?

You need to take enough of a medicine for it to be effective. However, you don’t want to take any more than you need, because doing so increases your likelihood of developing side-effects, not to mention a potential waste of your money. As with other medicines, the right dose may depend on whether the complementary medicine is for you or your child and the condition for which it is being used. Follow the recommendations given by your doctor, pharmacist or other qualified health care provider, or as provided on the medicine label or packaging, and don’t be tempted to take or give more than the recommended dose.

Dr Lynn Weekes is CEO of NPS: Medicinewise. Established in 1998, NPS Medicinewise enables people to make better decisions about medicines and medical tests, leading to better health and economic outcomes. NPS Medicinewise helps health professionals keep up to date with the latest evidence and provide individuals with the tools and knowledge to make better decisions.

1 Morgan TK, Williamson M, Pirotta M, Stewart K, Myers SP & Barnes J. A national census of medicines use: a 24-hour snapshot of Australians aged 50 years and older, MJA 2012; 196 (1): 50–53
HELP DETERMINE THE CAUSES OF CLL – REGISTER FOR RESEARCH STUDY

CLL, which makes up around a third of all leukaemia diagnoses, is a rare cancer and the causes of CLL remain unknown.

An epidemiological study, called The Forgotten Cancers Project, is focusing on the causes of less common cancers, including CLL, which have not been studied extensively.

The aim of the study, which is being conducted by the Cancer Council of Victoria, is to understand the roles of genes, lifestyle and early life environment as causes of less commonly occurring cancers, such as CLL.

The study is collecting a broad range of health and lifestyle information from people diagnosed with CLL and the other blood cancers. The same sort of information also will be collected from a family member of each participant.

It is a case-control study because information from people diagnosed with CLL who take part will be compared with information from people who are not affected by this disease. The aim being to identify any differences between the people with CLL and the people without, to see whether the differences may be associated with development of cancer.

The study is seeking a total of 30,000 participants (15,000 cases + 15,000 controls). People who were 18 years or older when diagnosed can register to take part in the research.

The Leukaemia Foundation supports this research project and encourages people with CLL to take part.

According to the Foundation’s Head of Support Services, Anthony Steele, it is important for blood cancers to be well represented in the study.

“If we can learn the risk factors of CLL, either genetic or lifestyle, we may be able to prevent it occurring in future generations,” Anthony said.

“We believe it is in the best interests of those with CLL to take part in this study. The more people who contribute, the stronger the research will be.”

To participate in the study, phone 1800 068 289 or email forgottencancers@cancervic.org.au.

OUR VISION TO CURE AND MISSION TO CARE FOR YOU

The Leukaemia Foundation is the peak body for blood cancer in Australia, funding research and providing free services to support people with leukaemia, lymphoma, myeloma and related blood disorders. Our free services include emotional support, accommodation, transportation and practical assistance. We also fund research into cures and better treatments.

We receive no ongoing government funding and rely on the continuous support of individuals and corporate partners to provide our services and to fund our National Research Program.

To find out more about how we can help you:
Freecall 1800 620 420
Email: info@leukaemia.org.au
Mail: GPO Box 9954 in your capital city
Website: www.leukaemia.org.au

Disclaimer: No person should rely on the contents of this publication without first obtaining advice from their treating specialist.

FORGOTTEN CANCERS PROJECT

An epidemiological study, called The Forgotten Cancers Project, is focusing on the causes of less common cancers, including CLL, which have not been studied extensively.

The aim of the study, which is being conducted by the Cancer Council of Victoria, is to understand the roles of genes, lifestyle and early life environment as causes of less commonly occurring cancers, such as CLL.

The study is collecting a broad range of health and lifestyle information from people diagnosed with CLL and the other blood cancers. The same sort of information also will be collected from a family member of each participant.

It is a case-control study because information from people diagnosed with CLL who take part will be compared with information from people who are not affected by this disease. The aim being to identify any differences between the people with CLL and the people without, to see whether the differences may be associated with development of cancer.