CLL news.

For people with CLL or SLL & their families

Leukaemia Foundation
VISION TO CURE
MISSION TO CARE

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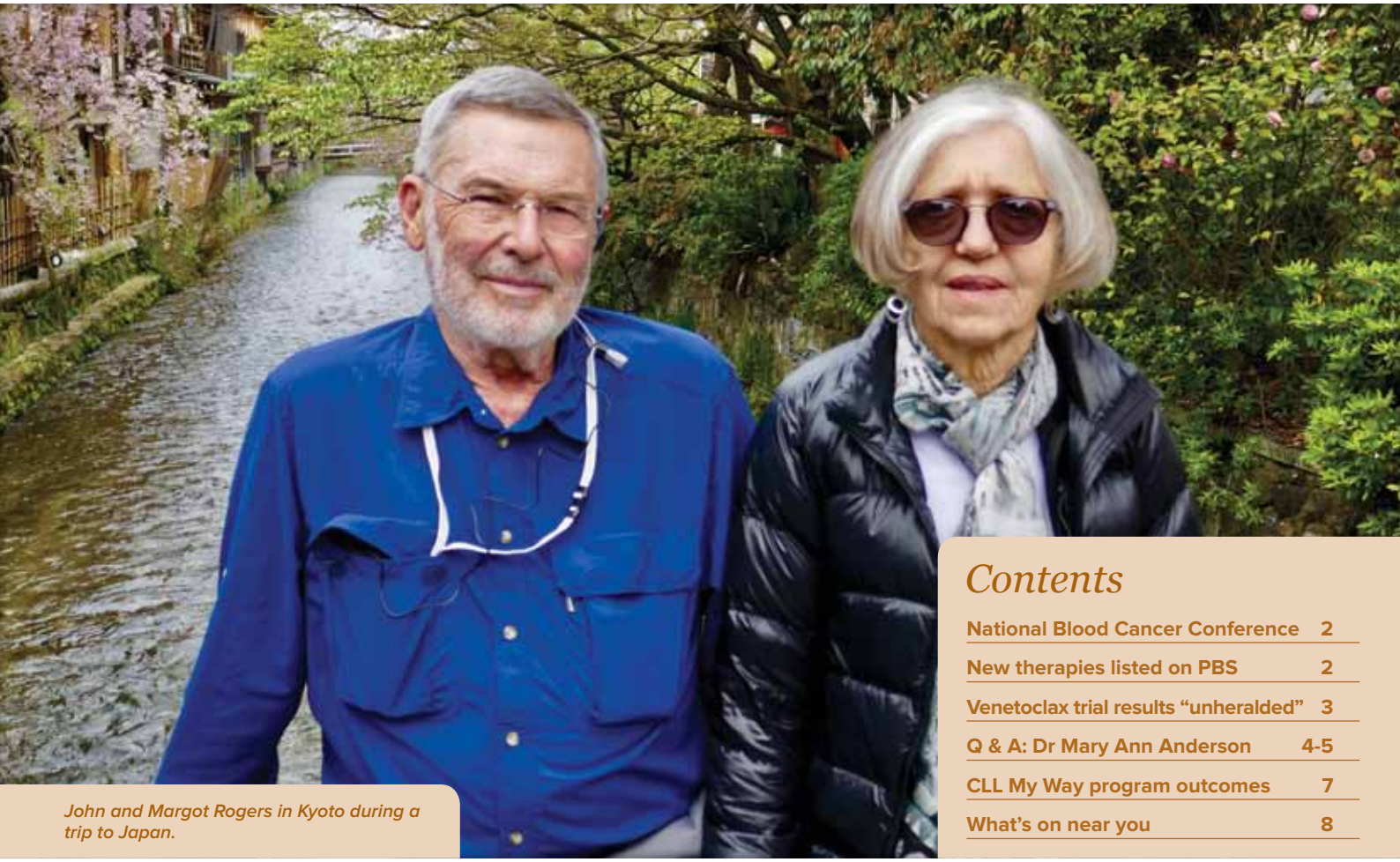

John and Margot Rogers in Kyoto during a trip to Japan.

Contents

John's on a venetoclax trial but not on treatment

Dr John Rogers AM is one of the first Australians with CLL to successfully stop treatment on a clinical trial for venetoclax, and two years later – he's still in remission.

At the start of the trial, just hours after having his first dose on 9 July 2013, John noticed a response.

"I knew by feeling the glands in my neck that it had an effect," said the now retired geneticist and psychotherapist, 77, of Melbourne.

Six months later his bone marrow was clear of CLL.

"It was great news but I wasn't officially in remission until 19 February 2016, when there was no evidence of enlarged lymph nodes on a CT scan... my lymph nodes had been as large as 10cm each!"

John stopped treatment on 29 March 2016 – two years and nine months after going on the trial for a combination of venetoclax (called ABT-199 at the time) and rituximab.

His original start date for the trial was in mid-December 2012 but at the last minute there was a seven-month delay.

"I was due to start on the Monday and on the Friday [before] they suspended the trial... two people on the trial had died in North America, from tumour lysis syndrome," said John.

His initial reaction to the suspension was distress but also pragmatism.

"There was nothing I could do about it."

"I knew by feeling the glands in my neck that it had an effect."

More than 20 years earlier, John had been diagnosed with lymphoma and treated with high dose chemotherapy. It was an experience that changed his life.

"Having a lymphoma gave me the courage to do something I had always been keen on doing," he said.

"I had a strong interest in grief and loss and life-threatening disorders," said John, who had previously worked with Elizabeth Kübler Ross[1], training as a staff member in her workshops.

He decided to resign from his position as director of Clinical Genetics at the Royal Children's Hospital and started training as a psychotherapist. Then he divided his time, working in private practice with a special interest in psycho-oncology, and in genetics at the RCH.

"I learnt two lessons from having lymphoma. One was the ability to say 'no' and the other, to be more pragmatic about life and live each day as it comes."

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National Blood Cancer Conference – 8 September

The Leukaemia Foundation's first-ever national Blood Cancer Conference for people living with blood cancer brings together leaders in blood cancer research, treatment and wellbeing.

They will share their knowledge and expertise on Saturday 8 September at the Melbourne Convention and Exhibition Centre, so save this date as this conference is designed for you.

If you would like to be kept updated on information about the conference, please register your interest on our 2018 conference website here: **http://bit.ly/lfBCC18**

Even if you are not able to attend, we are committed to ensuring this important education opportunity is available to you as all the key conference sessions will be recorded and shared on our website.

To stay up-to-date with details about the day's program and key speakers, you also can join our Blood Cancer Conference 2018 Facebook group: **http://bit.ly/BCC18fb**

Idelalisib and ibrutinib available through the PBS

Two new oral therapies for CLL and SLL listed on the Pharmaceutical Benefits Scheme (PBS) provide much needed treatment options without financial burden.

Idelalisib (Zydelig®), an oral PI3 kinase delta inhibitor, has been available on the PBS since 1 September last year for the treatment of relapsed CLL and relapsed SLL.

It is used in combination with rituximab for adults with CLL/SLL who are no longer responding or have relapsed to at least one previous treatment. Their condition also must be CD20 positive, they must be inappropriate for chemo-immunotherapy and have a total cumulative illness rating scale (CIRS) score greater than 6.

The active ingredient in idelalisib belongs to a group of medicines called antineoplastic agents. Idelalisib blocks the effects of the PI13K-delta enzyme. It affects the growth of cancerous lymphocytes (a type of blood cell), causing them to die.

And from 1 December last year, ibrutinib (Imbruvica®) has been subsidised through the PBS, also for those with CLL/SLL whose disease has progressed despite treatment with standard therapies and who are unsuitable for treatment with fludarabine. They can access the treatment for $33.80 per month ($6.30 per month for patients with concession cards).

Ibrutinib is a target oral therapy, known as a Bruton's Tyrosine Kinase inhibitor, that works by blocking signals to the protein critical to the growth and survival of leukaemia B-cells.

Associate Professor Constantine Tam, who has been involved with clinical trials for ibrutinib, said the drug had been studied extensively in Australia and overseas.

The Clinical Lead for CLL at the Victorian Comprehensive Cancer Centre described ibrutinib as a paradigm shift for how patients with CLL are treated, and it better equipped clinicians when standard therapies failed to halt disease progression.

"The clinical results are impressive, with ibrutinib inhibiting the cancer in many pre-treated patients where other treatments have failed," said Assoc. Prof. Tam.

Results of a Phase III clinical trial published in the *New England Journal of Medicine* showed ibrutinib significantly improved progression free survival, overall survival and overall response rates in patients with previously treated CLL compared with ofatumumab.

Michael says the MURANO trial was life-saving

Michael Brown hasn't had an overnight stay in hospital for anything related to CLL since being recruited, literally from his hospital bed, to go on the MURANO trial in early-2015.

"It's been a bit of a lifesaver," said the retired engineer, 77, of Canberra about his treatment with venetoclax and rituximab on the trial's investigational arm. *(See story on adjacent page.)*

His CLL diagnosis dates back to 1995, when he was working for the Department of Defence, and in 2006 he had his first treatment – a course of chemotherapy (fludarabine and cyclophosphamide).

Since then Mike's health has not been good and a dose of pneumonia grounded him in Calgary during a trip to Canada.

"This was a clear and alarming indication of what was going to happen to me if I couldn't do anything about the CLL," he said.

"To go on the trial, I had to be sufficiently sick, yet have prospects of getting good results."

Mike was "quite confident" during the trial that it was going well.

"I had blood samples taken every month and the results were very encouraging. I felt very well after the treatment and still do," he said.

Mike stopped taking venetoclax early this year but is still on the trial, which involves ongoing monitoring with a blood test every three months.

"The trial was effective except my immunity didn't respond, so I have monthly infusions of immunoglobulin," he said.

"I had a bone marrow biopsy six months ago and there's not much in the way of evidence of CLL.

"I'm getting on with life but do have other maladies not associated with CLL."

Mike Brown: "I'm getting on with life".

Continued on next page.

Venetoclax trial – "exciting", "unheralded" and "extraordinarily effective"

Progression-free survival of relapsed and refractory CLL patients on the experimental arm of a venetoclax trial was "unheralded" according to the principal investigator at Canberra Hospital, Dr James D'Rozario.

The international multi-centre MURANO trial tested the effectiveness of the Australian-developed drug, venetoclax, combined with rituximab. This was compared to standard therapy – the immuno-chemotherapy combination of bendamustine and rituximab.

The Phase III trial, which opened in 2014, has since closed to recruitment but analysis is ongoing.

The control arm had six cycles of bendamustine and rituximab, and the investigational arm had an induction phase of venetoclax combined with rituximab over six months, then two years of maintenance on venetoclax.

All 389 patients on the trial, at 109 sites in 20 countries, have finished treatment and are in the follow-up phase.

"... overall progression-free survival in the experimental arm was unheralded."

"At our site, all the venetoclax patients are still in remission and under observation," said Dr D'Rozario, Head of Haematology at Canberra Hospital where there are 16 patients on the trial – evenly split between each arm.

"None of those who had the venetoclax and rituximab combination has relapsed, which is a microcosm of the published data in the *New England Journal of Medicine*."

Dr D'Rozario said several patients at his site on the control arm had relapsed.

"A couple of them have been salvaged with another relatively new agent, ibrutinib, which is one of the other big advances in CLL," he said.

"They weren't put on venetoclax as the trial design did not include a crossover option for patients whose disease progressed on bendamustine, and it's not yet on the Pharmaceutical Benefits Scheme (PBS), so is not widely available.

"MURANO was the first big Phase III study and overall progression-free survival in the experimental arm was unheralded.

"After two years, the experimental arm extended progression-free survival from 36.3% to 84.9%, meaning the vast majority of patients who received the venetoclax appear to be having much more durable remissions requiring no further treatment for at least 24 months.

"Hopefully these results give more impetus to venetoclax being more widely available, specifically regarding PBS listing in Australia," said Dr D'Rozario.

"The bottom line is that the trial shows the combination [venetoclax and rituximab] is extremely active and far superior to other currently PBS-funded therapies for CLL.

"There's a general feeling that venetoclax's activity as a single agent, is probably a peg or two superior to ibrutinib, but that's not yet clearly established.

"The idea of improving results still further with combination therapy (e.g. ibrutinib and venetoclax) is currently being tested in trials that are ongoing. Some preliminary results, released in December at the American Hematology Society annual meeting were very promising with the approach showing an increased likelihood of eradicating all the leukaemic cells in the body – 'minimal residual disease negativity'.

"The other big message is this drug is extraordinarily effective in the subgroup with 17p deletion that traditionally has had a very grave prognosis irrespective of what treatment they've had.

"The response rate in that group and the duration of the remissions we're seeing are unheralded in either the first-line or second-line setting. It's extremely exciting," he said.

"I think there may be a potential role for venetoclax in first-line treatment for these patients given that all the patients on this study were relapsed and the results with the 17p deleted group."

Dr D'Rozario said a big issue with venetoclax in the early studies was serious grade IV tumour lysis syndrome (TLS), due to the BCL inhibitor being so effective.

"A head-to-head comparison between venetoclax, idelalisib and ibrutinib... is the next important work to be done."

"There had been a couple of deaths overseas, so everyone was a bit anxious."

Stringent monitoring and a dose ramp-up were key parts of the study design and the side-effect profile is "very acceptable".

"The incidence of TLS on the MURANO trial was not significantly different between the two arms," said Dr D'Rozario.

Dr James D'Rozario.

"In particular, the concern about TLS and infections is certainly no worse than standard therapies.

"Ongoing observation of trial patients indicates neutropenia and TLS, if it is to occur, is more likely during the first six months when venetoclax was given with rituximab. Thereafter, infection rates were similar in the two groups and generally acceptable.

"This is important because at the moment standard treatment in older persons who are more susceptible to side-effects is where the unmet need is, so there's a potential role for venetoclax in this group."

Dr D'Rozario concluded saying caution surrounded all the new CLL agents emerging at breakneck pace "because there is only three to four years of real experience".

"We still need to work out how and when to best use these new agents to ensure maximum overall benefit for all CLL patients.

"A head-to-head comparison between venetoclax, idelalisib and ibrutinib, and the effect of combining these new agents as well as ascertaining the optimum length of therapy, is the next important work to be done," said Dr D'Rozario.

The Leukaemia Foundation provided funding for early work on the precursor to ABT-199. This research, undertaken by Dr Kylie Mason, Professor Andrew Roberts and collaborators at the Walter & Eliza Hall Institute (Melbourne) through the Foundation's National Research Program Grants-in-Aid 2010 and 2012, assisted in the development of venetoclax.

Continued: Michael says the MURANO trial was life-saving

Mike's decision to go on the trial wasn't difficult.

"I'm inclined to accept the assurances of specialist practitioners as they have the best available knowledge and experience.

"There were options but they were not as attractive and I was getting quite sick at the time and spending some nights in the hospital. I am confident I made a good decision to participate in the trial.

"I'm a lot better now than before the trial, with a remarkable improvement in my every day health," he said.

Q & A with Dr Mary Ann Anderson

At the Leukaemia Foundation-hosted New Directions in Leukaemia Research (NDLR) conference in Brisbane in March, Dr Mary Ann Anderson, a clinician scientist at the Walter & Eliza Hall Institute of Medical Research (WEHI), shared a story about the development of venetoclax (Venclexta™). It involved research by thousands of people over 30 years resulting in a paradigm shift in the treatment of CLL that is "tangibly changing people's lives".

Q How did you become interested in blood cancer research?

What struck me as a haematology registrar was – we have great treatments and can cure some people but there are many diseases where patients don't have good outcomes. I found it particularly challenging when we didn't have therapies for people and couldn't help them. The natural next step in my career was working to get better treatments for those people. The only way to do that is through research, so I went into a PhD. I've been extremely fortunate to be involved in the development of a new drug that has helped a lot of people and I've fulfilled my career goal doing that. Sadly, we still have unmet areas of need that means I'll be employed for some time in the search for better treatments.

Q What was your presentation at NDLR about?

I shared a wonderful story about the development of a new drug called venetoclax (formerly known as ABT-199) that I've only been involved in for the last seven years but which started in 1984 when a protein called BCL2 was discovered. Over the 80s and 90s, BCL2 was shown to be pivotal in driving cell survival, keeping cancer cells alive inappropriately, making cancers develop and being insensitive to chemotherapy. Researchers at WEHI, in collaboration with AbbVie and Genentech, developed a molecule that selectively binds to the abnormal BCL2 protein to take out its function. I started my PhD in 2011 and together with Professor John Seymour and Professor Andrew Roberts at Peter Mac and Royal Melbourne we gave venetoclax to the first three patients in the world. We knew within hours that this drug worked. They all had dramatic and rapid clinical responses.

Q Describe your role in the discovery process.

I started my PhD six months before we dosed the first patient. In the laboratory, I tested CLL cells against venetoclax and they died very sensitively, suggesting the drug may be effective. I also looked at how the cancer cells were dying and found evidence this was a result of BCL2 being inhibited by the venetoclax. That's what we call an 'on-target' effect. Then we gave it to a person and saw almost instantaneously that it was working. As well, using translational cells taken from these trial patients prior to dosing, then 8 and 24 hours after dosing, we could see the cells were dying via apoptosis (through the inhibition of BCL2), so we recapitulated in the lab what we were seeing in the clinic and vice versa.

Q How did you feel when you saw the ventoclax response in the lab?

It's important you don't get carried away. To me it's... 'ok, it works in the lab, that's great; will it work in people?' It was only when we gave it to the first few people, and saw their white cell counts falling from 40 to 2 in a matter of eight hours, that I allowed myself to think - 'wow, we really might be on to something here'. I was really lucky, it was only a matter of six months from seeing it work in the lab to actually seeing it work in a person. There was also a lot of work at AbbVie to test its safety and a lot of other work by colleagues to underpin the safety of the drug.

"Without many patients... donating their cells so we could study them in the lab, we would not have these drugs."

Q What was your involvement in the first venetoclax studies?

Looking after patients was my main role in the early phase studies where safety is the primary consideration and end-point. Patients must be monitored really closely and often have other health issues as well. It was day-to-day medical work, made richer by the fact I was taking cells from my patients and looking at how they died in the lab in response to this drug. I'd see the patient and look at their cells in the lab, then see the patient again the next day. For me the two really played off each other, so I was hopefully better informed about my patients and how they might respond by my laboratory work, but at the same time I was being driven to do my laboratory work by seeing the patients and how well they were responding. These patients voluntarily agreed to donate their cells for research purposes. Without many patients over decades donating their cells so we could study them in the lab, we would not have these drugs. That's something that should never be underplayed, the importance of patients altruistically donating their samples for science that has given us these new discoveries.

Dr Mary Ann Anderson: "The thing that gets me up in help people".

Q What was the outcome of that first venetoclax trial?

It was a very successful Phase I clinical trial. In contrast to most Phase I studies, we showed venetoclax works in about 80% of CLL patients and we can get rid of all evidence of disease in 20% of them. The way we think about CLL is radically changing as a result of this new therapy. We no longer just want to control the disease. For the first time people are wondering if we can cure CLL with tablets rather than going on to allogeneic transplant. The main side-effect we identified was that all three of the first patients who received this drug developed a complication called tumour lysis syndrome (TLS) – where cancer cells are destroyed too quickly. While you never want to see complications, for a first-in-human trial, this was both worrying and extremely exciting, and an incredibly powerful indicator that the drug was working too well. We've got protocols to manage the risk of TLS now and it is rarely seen.

Q What's happened since?

Many patients relapse after about two years on venetoclax as a monotherapy. In the next suite of trials we combined venetoclax with monoclonal antibodies such as rituximab or obinatuzumab, or with other novel agents such as ibrutinib.

the morning is finding new and better ways to

Patients on combination therapy achieve deeper responses. Rather than a partial response, they're achieving a complete response, and instead of just achieving a complete response, they're actually clearing all evidence of disease; a state we term minimal residual disease (MRD) negative. These deeper responses correlate with longer periods before patients relapse. In some patients, we can actually stop treatment and some have enjoyed prolonged periods without treatment, where the disease has not come back. It's starting to remind us of what happened with CML*. It's very early days, we don't yet have strong evidence that it's safe or the right thing to do, but it's something we're starting to explore in our clinical trials.

"We knew within hours that this was a drug that worked."

Q What other areas of research are you are working on?

In the lab I'm trying to identify which patients are more likely to have good responses and also those who are more likely to have bad responses. We are doing a series of molecular tests to see if there's a way we can prospectively identify the patients who aren't going to do as well, and selectively target those patients for more intensive therapy. I'm also interested in trying to understand why resistance develops so we can look at targeting it more effectively. We don't yet have a good biomarker (a laboratory test that predicts for a poor outcome) so another approach is looking at the micro-environment. CLL can sit in the bone marrow, lymph nodes and blood. There's strong evidence that CLL in a lymph node is protected from death by any agent due to its environment. The stroma (tissue) and blood vessels help to keep the CLL cells alive and sustain them. When we look at CLL cells on an artificial stroma, in an artificial micro-environment, they are resistant to death by venetoclax. Early evidence from my colleagues suggests you can overcome this effect of the microenvironment niche by combining venetoclax with ibrutinib.

"We always hope the next venetoclax is around the corner."

Q What aspect of this research excites you the most?

The thing that gets me up in the morning is finding new and better ways to help people. A few years ago I'd have to say – "I have nothing for you". Now I'm saying to more and more of my patients – "I actually have something that can help you, a new drug, with good evidence that your disease will respond".

Q What is the role of clinical trials?

They are essential and have different roles in different patient groups. When patients get to a point where there aren't any conventional therapies, then a Phase I trial is particularly attractive. They are always ethically approved, based on evidence the drug is likely to be safe and effective. That doesn't mean they will be and sadly sometimes they're not. But we offer Phase I studies to people who have no other options and occasionally we find a venetoclax and we give people a prolonged period of disease-free survival. We always hope the next venetoclax is around the corner. To people asking if they should go on a clinical trial I say: "it may help you and we really genuinely hope it does but if it doesn't help you it will help people down the line". Knowing a drug by itself doesn't work is still valuable information, so we don't use it on other people going forward. For patients on a trial, there are elements of 'there is something in it for me' because they might get a drug that will work, as well as altruism because they're helping science and those people who come after them. It's often easier to sell larger Phase II and III studies to patients where the drug has good safety evidence and a signal of efficacy. But as a basic scientist I find Phase I studies the most inspiring. They're the ones where people are in the most need and that are bringing the next big thing to our attention.

"... as a basic scientist I find Phase I studies the most inspiring."

Q What is the next big thing?

I think it's going to be combinations. We're already doing trials of combination therapies – monoclonal antibodies with novel agents, dual novel agent therapies, and potentially the holy trinity, as John Seymour puts it – two novel agents and a monoclonal antibody, or potentially down the track, even combining chemo-immunotherapy with novel agents. That's where I think we'll end up, with these very deep responses and potentially options of cure. There are always new drugs in the pipeline and it remains to be seen how they all fit together. A challenge is integrating evidence from lots of different trials, to find out where in a patient's journey we should use these agents. They've been used traditionally in the relapsed/refractory setting but maybe they'll be more effective in the frontline setting.

** Treatment-free remission is possible for many people with CML.*

Venetoclax – a 30-year story

1984:
BCL2 protein discovered

2011:
First patient dosed with venetoclax

2016:
Venetoclax FDA-approved in the U.S.

2017:
Venetoclax TGA-approved in Australia

"It's decades and decades of work by very many clever and very intelligent people – chemists, structural biologists, basic science biologists, translational scientists and clinicians.

"It's work at places like the WEHI and by industry like Abbvie and Genentech and in academic research hospitals like Peter Mac and Royal Melbourne.

"It's a body of work that's taken thousands of people, in a rich variety of backgrounds, to come to fruition."

Continued: John's on a venetoclax trial but not on treatment

John had six-monthly follow-up blood tests and in 2002 the results showed an elevated lymphocyte count, which turned out to be CLL.

"They were watching me at that stage. Then in 2010, we thought it was necessary to have some treatment due to the large glands in my abdomen.

"I was offered fludarabine but was concerned about how sick it was going to make me. I preferred a gentler approach and had a course of the old fashioned treatment, chlorambucil, for several months."

John's next treatment was a monthly infusion of rituximab which he had for a couple of years until it stopped being effective.

"The glands in my abdomen keep enlarging and I looked nine months pregnant," said John.

He had low dose X-ray therapy to his abdomen in November 2012. This made it a little easier for him to breathe and he was "worked up" at the Peter MacCallum Cancer Centre for the venetoclax trial with "blood tests, a bone marrow test, CT scans and heart scan".

"This was an oral drug that was easy to take... it was amazingly simple."

"I realise how fortunate I have been to participate in a trial with such an outstanding outcome, REMISSION," said John and he describes venetoclax as "quite miraculous".

"This was an oral drug that was easy to take and, compared to CHOP[2] which were intravenous drugs that made me very sick, it was amazingly simple," he said.

"And it was quite interesting because I started at 20mg. Professor John Seymour came and gave me the tablet.

"When he came around again at the end of the day, he asked, 'what do you think?'

"I said, I think the glands are softer. He felt my neck and said 'I think you're right'.

"The next day I went from 20mg to 50mg and it was clear that it had an effect even at that very low dose. I suppose I have the advantage of being a doctor – I knew by feeling the glands in my neck."

Over three weeks, John's daily dose was gradually increased to 400mg before he began having monthly rituximab infusions for six months, and in 2015 his venetoclax dose was reduced to 300mg, based on the results of other studies.

"The trial had its own demands involving time and travel to Peter Mac. Participating was easier as I am retired," he said. *(See breakout box.)*

John's decision to stop treatment more than two years ago was made in conjunction with Prof. John Seymour.

Margot and John with their grandson, Sam, at Kata Tjuta National Park in Central Australia last year.

"I looked at the figures. There was not a lot of information. About 11 people in the world had stopped the treatment at that stage. Not all were in remission. Some had stopped because they couldn't tolerate it or didn't want to continue.

"There was a small handful that had stopped and I was reassured that if the CLL reoccurred I could recommence the treatment.

"I can't say I felt confident, but I thought it was reasonable to stop, and I stopped cold turkey.

"I'm still part of the trial and every three months I go back to Peter Mac for a review and blood test (which I have a few days before the review).

"They're carefully monitoring how things are going but that's all remained normal.

"I thought it was reasonable to stop, and I stopped cold turkey."

"After the last blood test I am still officially in remission and have no enlargement of lymph nodes clinically. I've stopped having CT scans. I was having them every three months but eventually they decided that was unnecessary," said John who is enjoying life.

"I do some reading, some writing, pick up grandchildren from school, try and keep fit, walking and swimming. I enjoy film, theatre, classical music, time with friends and overseas travel and holidays."

Last year John and his wife, Margot, took one of their four grandchildren, Sam, to Central Australia.

"We promised we'd take him when he was 10 and we got there a week before his birthday."

John Rogers: About being on the clinical trial

"I think there's nothing to fear in a trial. You have to be prepared to do the work and comply with the things they want you to do.

"I had to keep an accurate diary of the time I took the [venetoclax] tablets each day and the food I had for breakfast. This was not difficult and my visits to Peter Mac reduced as the trial proceeded.

"At the beginning of the trial, frequent attendance at hospital was necessary. I was an inpatient for a few days as it was the start of dose escalation and they took blood every four hours so they could monitor me closely.

"You need a bone marrow biopsy to go on the trial and bone marrows are done at various times afterward. The way they were done, they were never a problem.

"CT scans are so quick and easy and even though you have contrast media with them, they also are no problem. Blood tests could be a challenge as my veins are bad from previous chemo. It was necessary to find the best blood collector!

"The follow-up, at one level, is simple. I don't think anybody should be put off by the investigations they will have along the way.

"Having a strong, supportive partner makes the journey easier."

[1] *Psychiatrist and author of* On Death and Dying.

[2] *Lymphoma chemotherapy regimen (cyclophosphamide, hydroxydaunorubicin, vincristine, prednisolone).*

Future support outcomes on the way from CLL My Way research

In a unique collaboration, the Leukaemia Foundation has mapped the CLL patient journey, identified unmet needs and is now working on new and different forms of support.

The CLL My Way wellness pilot program was developed by the Foundation with support from Janssen and the CLL Australian Research Consortium.

This two-arm intervention study involved 64 people with CLL from Queensland and New South Wales, including 16 people on the new oral therapy, ibrutinib (Imbruvica®).

Evaluation of the program revealed people with CLL have a lower quality of life (QoL) than the general population and other cancer patients, that is mainly related to fatigue, their older average age and physical limitations. This included those on watch and wait (who had not yet had any treatment) and this group generally felt unsupported.

Study participants who had relapsed and were taking ibrutinib claimed they did not have an adherence issue taking their oral therapy every day at the same time. They consistently reported ibrutinib had less side-effects and was a lot easier to manage, compared to their experience with chemotherapy.

"What we were shocked to find is how many people, when diagnosed with CLL and recommended watch and wait, were not referred to the Leukaemia Foundation," said CLL My Way coordinator, Sheila Deuchars.

"Haematologists tend to refer patients to us only when treatment starts or if a patient reports the need for support to their doctor.

"At the CLL Horizons conference, the concept of being diagnosed with cancer and not being offered treatment, and the conflict and anxiety this can cause patients was widely discussed," said Sheila who attended the conference in Europe in 2016.

"The Leukaemia Foundation strives to provide the best support services to patients at all times and getting referrals is an issue we are addressing," she said.

Carer, Debbie Prescott, casting her vote.

People with CLL, carers and Leukaemia Foundation staff at the testing day at our ESA Village patient and family accommodation centre in Brisbane last month.

Following up on these pilot findings, and with additional funding support from Janssen, an interview-based study delved deeply into how people felt about their diagnosis, being on watch and wait or active treatment, and how well they were supported.

This ethics approved research, led by an innovation company, asked 25 people with CLL to tell us their stories during immersion interviews earlier this year.

The patient data gathered was used to map their CLL journeys and identify missed opportunities and areas of need.

Analysis of what they said about their experiences with CLL provided 1200 insights, explained study principal investigator, Dr Peter Diamond, the Leukaemia Foundation's Head of Support Services – SA/NT.

These poignant points were grouped into themes that led to the development of new ideas, which were then individually tested with 25 CLL patients and five carers in Brisbane and Sydney.

"We had 10 innovative service offerings that we 'pitched' to each attendee, asking: what do you think, how could it be better?" said Dr Diamond.

"We've identified needs of people at different times in the disease/patient journey."

For example, the QoL scores of those on watch and wait were poorer than those on active treatment, as summed up by the following statement: "*You just told me I've got cancer, but I've got the 'good one', yet I'm fatigued and I'm susceptible to infection*".

"We're going to come up with an action plan dedicated to these people who are being actively monitored," said Dr Diamond.

Leukaemia Foundation Support Services Coordinator, Brenda Kirkwood and Dr Peter Diamond, Head of Support Services – SA/NT with one of the innovative service offerings.

"We need to change the mindset around watch and wait and a better description for this stage is 'observe and learn'.

"This is the time to learn about CLL and options – exercise, diet, practical things – so they have some control over their disease and are doing something to help overcome fatigue which is a topic CLL patients want more information on.

"They find it hard to hold down a job because they get so tired," he said.

"Eating the right food is a big thing for this group of people too and many of them feel isolated and alone. They want to connect to other people with CLL who are at the same stage as them.

"And we've also identified that many of these people are in psychological distress," said Dr Diamond.

A report is now being prepared and we'll let you know the outcomes in the next issue of *CLL News*.

NEW SOUTH WALES / AUSTRALIAN CAPITAL TERRITORY

Sydney Metro

18 Jun	10-11.30am	St George Blood Cancer Education & Support Group (also 30 Jul, 27 Aug, 24 Sep, 29 Oct, 26 Nov)
19 Jun	10am-12pm	Liverpool Blood Cancer Information & Support Group (also 17 Jul, 21 Aug, 18 Sep, 16 Oct, 20 Nov)
20 Jun	11am-1pm	Westmead Blood Cancer Education & Support Group (also 25 Jul, 29 Aug, 26 Sep, 31 Oct, 28 Nov)
20 Jun	2-4pm	Randwick Support & Education Group

Australian Capital Territory & Southern New South Wales

4 Jun	11am-1pm	Goulburn & Surrounds Blood Cancer Support Group (also 9 Jul, 13 Aug, 10 Sep, 8 Oct, 12 Nov, 10 Dec)
12 Jun	10am-12pm	Canberra Blood Cancer Support Group (also 10 Jul, 14 Aug, 11 Sep, 9 Oct, 13 Nov, 11 Dec)
28 Jun	4-6pm	Bega Valley & Sapphire Coast Blood Cancer Support Group, Merimbula (also 23 Aug, 18 Oct)
20 Jul	1.30-3.30pm	Moruya & Surrounds Blood Cancer Support Group (also 21 Sep, 16 Nov)
28 Aug	5.30-7.30pm	20/30 Chat, Garran (also 27 Nov)

Central Coast

28 Jun	10-11.30am	Gosford Blood Cancer Education & Support Group (also 26 Jul, 30 Aug, 27 Sep, 25 Oct, 29 Nov)

Central West & Far West

6 Jun	10.30am-12pm	Dubbo Blood Cancer Education & Support Group
7 Jun	10.30am-12pm	Orange Blood Cancer Education & Support Group
14 Jun	10.30am-12pm	Mudgee Blood Cancer Education & Support Group (also 9 Aug, 11 Oct, 13 Dec)

Hunter

5 Jun	10am-12pm	Newcastle Blood Cancer Education & Support Group, Mayfield (also 7 Aug, 2 Oct, 4 Dec)
12 Jun	10am-11.30am	Port Stephens Blood Cancer Education & Support Group (also 14 Aug, 9 Oct, 20 Nov)
3 Jul	10am-12pm	Newcastle Blood Cancer Education & Support Group, Shortland (also 4 Sep, 13 Nov)

Illawarra & Shoalhaven

4 Jun	10am-12pm	Shoalhaven Blood Cancer Information & Support Group, Bomaderry (also 9 Jul, 13 Aug, 10 Sep, 8 Oct, 12 Nov, 10 Dec)
6 Jun	10.30am-12.30pm	Wollongong Blood Cancer Information & Support Group, Fig Tree (also 4 Jul, 1 Aug, 5 Sep, 3 Oct, 7 Nov, 5 Dec)
25 Jul	10am-12pm	Bowral Blood Cancer & Support Group (also 26 Sep, 28 Nov)

Mid North Coast

18 Jun	10-11.30am	Port Macquarie Blood Cancer Education & Support Group (also 16 Jul, 20 Aug, 17 Sep, 15 Oct, 19 Nov, 17 Dec)
28 Jun	11.30am-1pm	Coffs Harbour Blood Cancer Education & Support Group (also 26 Jul, 23 Aug, 27 Sep, 25 Oct, 22 Nov)

New England

12 Jun	10.30am-12pm	Armidale Blood Cancer Education & Support Group (also 10 Jul, 14 Aug, 11 Sep, 9 Oct, 13 Nov, 11 Dec)
19 Jun	1.30-3.30pm	Tamworth Blood Cancer Education & Support Group (also 17 Jul, 21 Aug, 18 Sep, 16 Oct, 20 Nov, 18 Dec)

QUEENSLAND

Brisbane Metro

28 Jul	9am-3pm	It's all about me, *Adapting to Change* (also 27 Oct)
4 Aug	9am-12pm	It's all about me, *Nutrition* (also 3 Nov)
11 Aug	9am-3pm	It's all about me, *Exercise & Relaxation* (also 10 Nov)

QUEENSLAND (cont.)

Regional Queensland

5 Jun	10am-12pm	Coffee, Cake & Chat, Mackay
7 Jun	10am-12pm	Coffee, Cake & Chat, Gold Coast (also 15 Nov)
8 Jun	10am-12pm	Coffee, Cake & Chat, Toowoomba (also 7 Sep)
21 Jun	9.30-11.30am	Coffee, Cake & Chat, Mt Isa
6 Jul	10am-12pm	Coffee, Cake & Chat, Sunshine Coast (also 12 Sep, 9 Nov)
13 Sep	10am-12pm	Cairns Patient Information Seminar (also 6 Dec)

SOUTH AUSTRALIA

Adelaide Metro

19 Jun	10am-12pm	Northern Adelaide Support Group, Evanston (also 21 Aug, 16 Oct)
20 Jun	10.30am-12.30pm	Strathalbyn Support Group (also 18 Jul, 15 Aug, 19 Sep, 17 Oct, 21 Nov)
26 Jun	10.30am-12.30pm	Men's Group, Adelaide (also 28 Aug, 30 Oct)
30 Jul	10am-12pm	CLL/CML Support Group (also 24 Sep, 26 Nov)

Regional South Australia

4 Jun	5.30-6.30pm	Mount Gambier Support Group (also 6 Aug, 8 Oct, 3 Dec)
12 Jun	10am-12pm	Port Lincoln Support Group (also 14 Aug, 9 Oct)

TASMANIA

Northern Tasmania

12 Jun	10.30am-12pm	Blood Cancer Support Group, Launceston

Southern Tasmania

13 Jun	11am-1pm	Cooking for Chemo
21 Jun	11am-12.30pm	She Shed, Battery Point (also 19 Jul, 16 Aug, 20 Sep, 18 Oct, 22 Nov)
8 Aug	11am-1pm	Hobart Blood Cancer Support Group (also 8 Sep, 10 Oct, 14 Nov, 5 Dec)

VICTORIA

Metro Melbourne

17 Jul	10.15-11.45am	Northern Suburbs Blood Cancer Support Group, Hawthorn (also 16 Oct)
2 Aug	10.15-11.45am	Bone Marrow & Stem Cell Transplant Support Group, Hawthorn (also 1 Nov)
8 Sep	8am-5pm	Leukaemia Foundation Blood Cancer Conference, Melbourne
9 Nov	10-11.30am	Berwick Support Group

Barwon & South West

19 Jun	10-11.30am	Barwon Blood Cancer Support Group (also 14 Aug, 9 Oct, 11 Dec)
5 Sep	10-11.30am	Warrnambool & South West Blood Cancer Support Group (also 28 Nov)

Grampians

13 Jun	10-11.30am	Ballarat Blood Cancer Support Group
19 Jun	11am-12.30pm	Horsham Blood Cancer Support Group

Loddon/Mallee

12 Jun	10-11.30am	Bendigo Blood Cancer Support Group
18 Jun	1.30pm	Mildura Blood Cancer Support Group

WESTERN AUSTRALIA

Perth Metro

21 Jun	1-3pm	Perth Metro Blood Cancer Support Group (also 16 Jul, 20 Aug)

Albany

8 Aug	10am-12pm	Albany Blood Cancer Support Group
21 Jun	1-3pm	Perth Metro Blood Cancer Support Group (also 16 Jul, 20 Aug)

Bunbury

7 Jun	10:30am-12pm	Bunbury Regional Blood Cancer Support Group (also 5 Jul, 2 Aug)

Peel

18 Jun	10.30-12pm	Peel/Port Kennedy Regional Blood Cancer Support Group, Greenfields (also 19 Jul, 23 Aug)

Join the CLL My Way Network closed group on Facebook: https://www.facebook.com/groups/CLLMyWay
Visit www.leukaemia.org.au for our latest Education and Support Program Event Calendar.
To register for an education or support event, freecall 1800 620 420 or email info@leukaemia.org.au

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