MPN NEWS

For people with **MPN & their families**

Leukaemia Foundation
VISION TO CURE
MISSION TO CARE

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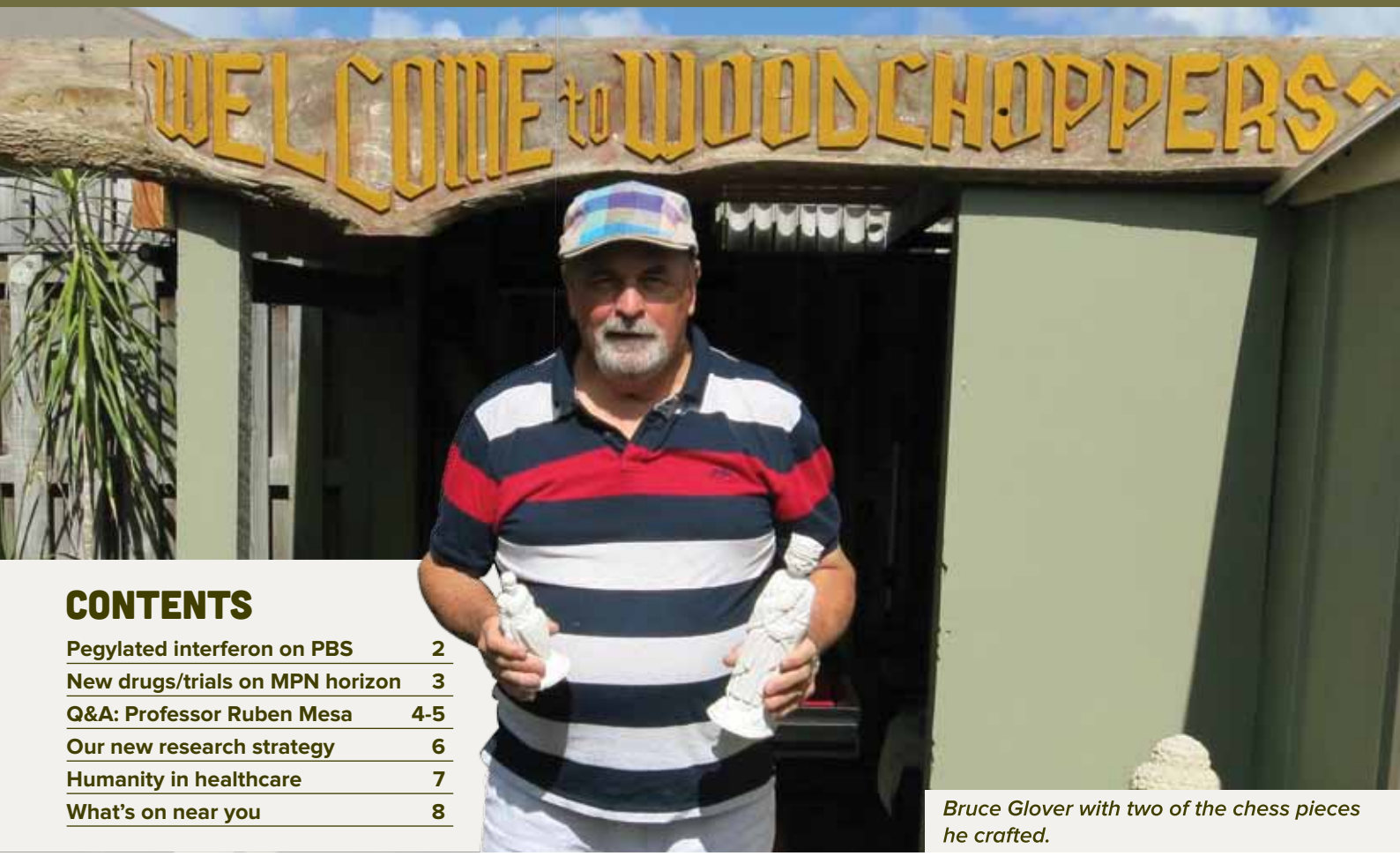

Bruce Glover with two of the chess pieces he crafted.

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BRUCE'S MASTERPIECE CHESS SETS PROVIDE A MEANS OF THERAPY

Being diagnosed with MPN gave Bruce Glover the time to revamp his artistic skills and find a new strategy to cope with living with a blood cancer.

That was three years ago, when Bruce had a fast-paced lifestyle and worked hard as a business owner in the mining and international business development sector.

"Having to undertake a massive lifestyle change and not understanding my condition, I didn't know what to do," said Bruce, 66, describing his reaction to his diagnosis with deep vein thrombosis (DVT) and then polycythaemia (rubra) vera (PRV) in February 2016.

To take his mind off things, Bruce recommenced crafting the masterpiece chess sets he had worked on as a hobby for years, providing a means of personal therapy and turning a negative situation into a positive one.

Prior to his diagnosis, Bruce's main symptoms were cramps in his feet. His doctor thought he had diabetes, but tests continually came up negative.

He changed doctors and when more blood tests and an ultrasound revealed he had DVT, Bruce was immediately admitted to hospital. Then a bone marrow biopsy and further blood tests confirmed he had PRV, which hit Bruce and his family "like a tonne of bricks".

So he could be closer to his family, especially should his condition worsen, Bruce relocated to a different part of the Gold Coast to live with his daughter and grandchildren.

His treatment began with hydroxyurea, to get his blood count under control, and which he continued taking for almost two years.

He also had frequent venesection, initially weekly and decreasing to every two months until his last one in July last year, when it was discovered that Bruce's pulse was erratic, jumping between 28 beats to 170 beats per minute.

Bruce was admitted to hospital again so his cardiologist could monitor his heart.

After getting the all clear, Bruce's blood count reversed against expectations, and a third bone marrow biopsy, in December 2018, showed his PRV had progressed to myelofibrosis.

Continued on page 6.

PEGYLATED INTERFERON NOW ON PBS

After seven years advocating for the PBS-listing of pegylated interferon alfa-2a (Pegasys®) Nathalie Cook, 54, went to her local Melbourne pharmacy on August 1 last year to have her script filled.

Thanks to her unrelenting efforts, peginterferon (Pegasys) is the first-ever consumer-instigated PBS drug listing in Australia, and it has unrestricted access.

"It was really exciting and the response from the MPN community was absolutely overwhelming," said Nathalie, a dietitian who was diagnosed with essential thrombocythaemia (ET) in 2008.

"So many people have contacted me and recently a Sydney GP thanked me for what I'd done to get Pegasys on the PBS. She had a young patient who wanted to get pregnant and couldn't have hydroxyurea (HU) because it's teratogenic [can disturb development of an embryo/fetus]."

Clinical guidelines developed

Once peginterferon was PBS listed, Nathalie said there was a time lag before haematologists knew it was available for MPNs.

"Then, having had no experience using it in MPN, they didn't know what doses to prescribe," said Nathalie.

At Dr Cecily Forsyth's instigation, a group of Australian haematologists got together and wrote clinical guidelines for the use of peginterferon in MPN, covering the different diseases – ET, polycythaemia vera (PV), myelofibrosis (MF) – and conditions, e.g., pregnancy.

"I was asked to write a section on how Pegasys got listed," said Nathalie, who was among the eight co-authors of a paper that is about to be published in *Internal Medicine Journal*.

Nathalie's interferon experience

In 2010, Nathalie's diagnosis progressed to PV and when she began treatment on interferon alfa-2a (Roferon-A®) the following year, she had lots of side-effects.

"I started calling Roche [the manufacturer], asking about their intentions for getting Pegasys on the PBS.

"They said they had no plans, there was no data and it was not TGA-approved," said Nathalie, but she kept on calling Roche.

"The reasons I wanted peginterferon was its ability to improve the outcome by preventing progression to MF.

"And it's a better drug. Interferon (IFN) is a hormone produced by the body in response to viral infections. In MPN, IFN stimulates the immune system to control the disease, is not leukaemogenic (doesn't cause acute leukaemia) and won't promote progression, as I believe HU does."

At the end of 2012, Nathalie started on Pegasys, supplied by Roche on compassionate access on a year-by-year basis, then indefinitely under a grandfather ruling after a co-payment system began. "This co-payment system made me even more determined to get it on the PBS. I felt really bad that I was getting it and other people either couldn't get it or had to partially pay for it.

"I continued to annoy Roche," said Nathalie*.

Benefits of peginterferon

"My first bone marrow biopsy 10 years ago showed mild fibrosis. The next one, four years later, showed mild-moderate fibrosis. I've been on interferon now for eight years and the most recent bone marrow biopsy (last September) found minimal evidence of fibrosis.

"This confirmed IFN had reversed the fibrosis that was developing. That's what the papers I had read said it was capable of doing, and that's why I was so keen to use it," said Nathalie.

"My haematologist said if she didn't know I was JAK2V617F positive she couldn't tell from my recent bone marrow that I had MPN!

"The most important thing in MPN is to start IFN early. You need a really small dose as ongoing treatment for many years, to slow progression of the disease and prevent fibrosis.

Nathalie Cook.

"The aim is to prevent the bone marrow progressing to MF, to reduce the risk of transformation to acute leukaemia. Once people have advanced MF, there's limited benefit in IFN."

After each fortnightly treatment with peginterferon, Nathalie gets mild side-effects a few days later.

"I feel a bit tired, have a slight headache and achy joints. I feel like I've got mild flu, so I take a Panadol. But it's a lot better than Roferon. I know, I've tried both," she said.

"I still have MPN. There is actually no known cure, but the IFN is controlling the disease and my blood counts are within normal ranges."

** In the February 2017 issue of MPN News, read how Nathalie got peginterferon on the Pharmaceutical Benefits Advisory Committee's radar.*

Associate Professor David Ross described the Pegasys listing as "... one of the most exciting things to happen in MPN in Australia in a long time; to have that drug listed 20 years after it was developed."

THANK YOU!

One of our blood cancer support coordinators received this 'Thank you' email from a patient with PV she visited.

"Thank you for dropping in to Liverpool Hospital last week to see me. Today I received the booklet and newsletters you sent me in the post and have sat down and done lots of reading and research.

"Although I knew about the Leukaemia Foundation prior to being diagnosed with polycythaemia vera about six years ago your visit last week was the first time I properly found out about the support available to me and the booklet you sent about MPNs was very informative and gave me information I didn't already know.

"You have helped me discover a whole new world of information and support!"

NEW DRUGS AND TRIALS ON MPN HORIZON

Several trials are in the pipeline for MPN in Australia. One is for a new drug, fedratinib, and another is a 'platform trial' – a new concept that tests multiple different drugs.

Fedratinib – an alternative to ruxolitinib for some people

Associate Professor David Ross describes fedratinib as "a JAK2 inhibitor that is more selective than ruxolitinib".

"Fedratinib has shown promising Phase III clinical trial efficacy results, similar to ruxolitinib, but with some different side-effects. Ruxolitinib inhibits both JAK1 and JAK2 and it remains to be seen whether there are clinically important differences between inhibitors that target only JAK2 versus those that target both enzymes," said the consultant haematologist at Royal Adelaide Hospital and Flinders Medical Centre.

"The development of fedratinib was stopped because of neurological toxicity in a very small number of patients.

"The problem was a rare condition called Wernicke encephalopathy, which is related to a deficiency of vitamin B1 (thiamine)," said Dr Ross.

Fedratinib is being resuscitated by its new owner (Celgene) in a new study comparing fedratinib with other available therapies for myelofibrosis (MF). Thiamine levels will he monitored carefully.

"We already know that the drug works," said Dr Ross.

The study is expected to open later this year for people previously treated with ruxolitinib who had a suboptimal response or intolerance.

Dr Ross said having two drugs in the same class that were slightly different could benefit a number of patients for whom one drug may be better than the other.

"It's good to have something new in the pipeline," he said.

Platform trials

A platform trial is a study opened in a particular disease in which different drugs and experimental ideas are progressively tested on this common platform.

This is a relatively recent idea, according to Dr Ross, that speeds up the time it takes to open a trial because the trial has already been approved. The contracts are in place and some common elements, such as data collection time points and outcomes to measure, have been specified.

This is how it works. When you add drug A to the common platform, a protocol amendment describes details specific to that drug, which is then tested in 15 to 20 people. When this study closes, you plug in drug B, with the extra details specifically related to that drug.

"It means you can get a rolling clinical trial that is pretty much always open," explained Dr Ross.

"I think the concept is very useful. Both academic researchers and drug companies are interested in this approach.

"Myelofibrosis is the biggest, obvious area of need in the MPNs. MF patients are very sick and severe MF can be very distressing, but that doesn't mean there aren't areas of need in essential thrombocythaemia (ET) and polycythaemia vera (PV)."

First Australian platform trial in MF

A platform study for investigator-initiated trials in MF in Australia is expected to get off the ground within 12 months.

A group of Australian investigators has received funding of $1.6 million over five years through the Australian government Medical Research Future Fund's low survival cancers and diseases project.

Lead investigator for the research project, *Improving Survival in Myelofibrosis*, is Professor Andrew Perkins from the Australian Centre for Blood Diseases (Monash University). The co-investigators, representing

Associate Professor David Ross.

most Australian states, are David Ross, Steven Lane, Cecily Forsyth, Andrew Wei, David Curtis, Jake Shortt, and William Stevenson.

"Our study will enrol people with MF and perform genomic profiling to look for mutations they may have in addition to JAK2, CALR, and MPL," said Dr Ross.

"They would be streamed into whatever clinical trial was open at the time that looked promising, based on their mutational profiling.

"The ultimate idea is to target therapy better.

"We think one of the reasons why we haven't made a lot of progress in MF is that the disease is actually very diverse. It's not just one disease.

"Some people have very slow growing MF and live for 20 years, while others get very sick very quickly and may die in two to three years," said Dr Ross.

"Although they all have MF, the behaviour of the disease can be very different. If we could better understand the biological features that caused these differences, we might be able to pick the right therapy for the right patient."

EXPERT TIPS FOR NEWLY DIAGNOSED

Here is some important advice for people who are newly diagnosed with an MPN.

These tips are from a treatment team assistant who is passionate about educating patients and other health professionals about MPNs.

She creates a one-on-one connection with her MPN patients and recommends that they:

- ask their haematologist/oncologist, within the first few visits, for resources to better understand their disease, and
- are not afraid to ask questions until they fully understand their diagnosis.

Q&A WITH RUBEN MESA

Professor Ruben Mesa spoke at a *Living with MPN Now and Into the Future* seminar in Sydney last year. During his career, the Director of UT Health San Antonio MD Cancer Center (Texas, U.S.) has become an international expert in MPNs. We asked our MPN community what questions they wanted us to put to Dr Mesa. Here is a summary of his responses. His complete answers can be viewed on YouTube: bit.ly: https://bit.ly/2sx9SGu

Q Do all people who are JAK2 positive have MPN?

If we surveyed the general population, scattered individuals would have the JAK2 mutation. But the presence of the JAK2 mutation in someone we suspect to have an MPN generally indicates they do have an MPN; there's a very low false positive rate.

Q Are MPN Unclassified and MPN Not Otherwise Specified early stages of MPN or sub-types of the disease?

Historically, we classify individuals with MPNs as either having essential thrombocythaemia (ET), polycythaemia vera (PV) or myelofibrosis (MF). The difficulty is that there are people who fall in between the cracks of those three, and that's where the other terms exist. Those individuals exist along the MPN spectrum but don't fall into any of the three groups.

Q What is your response to a patient who transformed from ET to PV in <5 years and asks: "Is this to be expected or instability with my condition?"

It could be that the individual had PV the entire time but for some reason (e.g., iron deficiency) they did not have an increase in their red blood cell count. The main difference between ET and PV, particularly in those with the JAK2 mutation, is a difference in the elevation of their red blood cell count. Some have argued that JAK2-mutated ET and PV are so similar, they should not be considered separate diseases.

Q In PV, is there any relationship between spleen enlargement and disease progression?

As we track a patient with PV, the spleen can enlarge as a sign of progression towards MF. So yes; if there is dramatic enlargement of the spleen, then I'm concerned about progression, but a modest enlargement of the spleen doesn't mean that progression has occurred.

Q In MPN, will there be targeted therapies that switch off mutated genes?

We have some targeted therapies such as JAK inhibition therapies. A variety of different technologies are being investigated to target the specific mutations such as gene editing using the CRISPR technology. A current limitation is that for many people with MPN there may be more than one set of genes involved, so editing just one gene may not eradicate the disease.

Q An 82-year old who has had MF for two years asked about new treatments and research underway.

There are many new treatments and research is underway for patients with MF, certainly more than several years ago. In addition to ruxolitinib, a range of other JAK2 inhibitors is being tested, and combination approaches are looking at adding other drugs alongside the JAK inhibitors.

"How you feel is just as important as your blood counts."

Q Are there any developments with the CALR mutation? Is CALR a forgotten brother of the JAK2 mutation?

The CALR mutation is an area of intense focus. It is a different mutation in that it may be open to certain types of treatment that might not be applicable for JAK2. The JAK2 mutation is located deep within a cell while CALR has a presence on the cell's surface that might make it amenable to being targeted in different ways to JAK2. At the moment, none of our medicines are specific for a JAK2 mutation versus a CALR mutation. But I can definitely say that people are specifically looking at distinct treatment options for CALR-mutated patients.

Q Someone with JAK2+ early-PV asks: "Why is there not early intervention when I'm in better health, rather than waiting till my symptoms are worse and I'm not well?"

I'm empathetic about the stress of watching and waiting with PV, but it reflects the limitations of the therapies available to us. I do think in the future we will treat all patients with MPNs from the time of diagnosis. Whether it makes sense to do that now, with hydroxyurea, interferon or ruxolitinib, I don't know. For some folks, maybe. Treatment from the time of diagnosis is limited now, because of our therapy options, but that will evolve.

Q How long can a patient with secondary MF take ruxolitinib?

Whether a patient can take ruxolitinib is independent from whether they have MF or PV. There are patients who have been on ruxolitinib since 2007 and there does not seem to be any cumulative negative side-effect over time. So in theory... indefinitely.

Q A person with PV, who has noticed a significant decrease in eye function, asks: "Are there possible negative side-effects of treatments on the eyes?"

MPNs can impact vision but it is in the minority and a haematologist and an eye specialist would need to be involved. Interferon can theoretically have eye-related side-effects through inflammation or other types of problems. It's not common but can occur and may be a strong reason to discontinue interferon and go on to a different therapy.

Q Another person asks if unbearable tension headaches could be due to the interferon she's had since 2013?

Headaches are always a complex thing to sort out. MPNs can make headaches worse and MPN treatment can aggravate them. Medications also can help by improving the blood counts that might trigger headaches. When it comes to medication-related side-effects it is difficult to know. Sometimes the only way to know is by taking a break from the medication and using an alternative way to control blood counts, to see if the headaches really resolve.

Q A patient with PV, JAK2 and DVT since March 2016 has a range of issues – constant tingling through his body, foot numbness and cramps, low iron, and irritability – asks: "Is there a solution or does one have to accept all this as a way of life?"

Iron deficiency might be aggravating many of these symptoms. Uncontrolled symptoms in PV can be a reason for starting a therapy or changing to different therapies. I would not accept feeling poorly with PV and would work through changing medications to improve things further. Once the medications are optimised, we would try to improve the symptomatic benefit through yoga, physical activity and nutrition.

Q Another person with debilitating fatigue, breathlessness, constant pain and who struggles to perform everyday duties, asks how best to convey her MPN symptoms to her medicos. "They look at my bloods and me and tell me how well I'm doing!"

MPN patients have several challenges. They feel different from what their blood counts reflect and may be less ill than the other [acute blood cancer patients] their haematologist sees in the clinic, and by comparison they don't get the same intensity of treatment. We are working collaboratively to develop an app to allow individuals to track their symptoms so they can be shared with their specialist. How you feel is just as important as your blood counts.

Professor Ruben Mesa and Leukaemia Foundation blood cancer support coordinator, Greg Zotos.

Q Several people asked about itching, which they find distressing, especially in contact with water. "Is there a remedy for the itching and prickling I get with MPN?"

Itching is a real, biological symptom of MPN, caused by white blood cells migrating to the skin. Water can be a trigger and some people find alternative ways of drying helpful; air drying or avoiding rubbing motions. UV light can be beneficial by calming down the white blood cells under the skin but must be balanced against the risk of skin cancer. Certain antidepressants have an anti-itch benefit because of the inhibition of serotonin and while some anti-histamines are beneficial they have a sedating effect. For a patient with PV who has failed other things, ruxolitinib is a strong consideration.

Q Dr Mesa, you and your team are investigating the effectiveness of complementary therapies to help with issues like fatigue, night sweats and itching. What therapies are you looking into?

It was clear that solely adjusting the medications of MPN patients was not normalising things. I'm fortunate to lead a group of collaborators investigating a spectrum of different treatments. Our group has helped identify the difficulty of MPN symptoms, their classification and understanding. We're looking at physical activity, yoga, meditation, nutrition, and a cognitive therapy called acceptance and commitment therapy; a form of mindfulness which attempts to manage a key stressor of an MPN – the uncertainty of the future – so it doesn't ruin your day-to-day life.

Physical activity is crucially important and incredibly helpful in MPNs. Not just the activity of daily life but uninterrupted physical activity for at least 20 minutes, such as sustained walking without stopping.

Q Someone with PV, JAK2, whose platelets are 27 and spleen is 17cm said: "I've read more in the last two hours about the disease than I had for 20+ years. Why are we left in the dark?"

There's a lot of accurate information out there, but not all of that is specific or relevant to you. So not only taking information but framing information for what it means to you is a key part and it's important that all the information you digest is done in partnership with your haematologist.

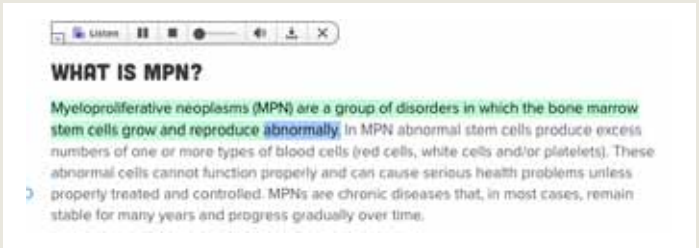
LISTEN TO OUR ONLINE CONTENT

The Leukaemia Foundation has installed a 'text to speech' service on our website so people visiting leukaemia.org.au can listen to the content of our webpages and online PDF and word documents.

From our research, we understand that during treatment many people experience some difficulties with concentration, reading and information retention (often known as 'chemo brain').

The Leukaemia Foundation has installed an online product called ReadSpeaker so people can now choose to listen to information about all the different blood cancers including MPN. Also, our support services, our disease information booklets, even this issue of *MPN News!*

The listening tool is not only useful for those affected by chemo brain, but also people with low literacy, vision impairments, English as a second language, and others who just prefer to listen to our content rather than read it.



To activate ReadSpeaker, click on the 'Listen' icon; usually found at the top left of the page you want to read. When in 'play' mode, the words that are being spoken are highlighted.

You can also download the audio as an MP3 file, or highlight text and listen to a translation through Google translate.

OUR NEW RESEARCH STRATEGY INVESTS IN INNOVATION

The Leukaemia Foundation's new research strategy supports medical research that drives rapid advancements in treatments, encourages the careers of promising scientists and discovers new diagnostics and novel therapies.

Giving Australians with blood cancer access to global clinical trials is another key aim.

CEO, Bill Petch said this new research framework came from consulting with the Leukaemia Foundation's stakeholders over the last two years.

"We have turned our attention to investment in innovation – in diagnosis, treatments and improving quality of life across the blood cancer spectrum," said Bill.

"And by forging new, strong, research partnerships with leading research agencies, including HSANZ, Cancer Australia, the Centre for Blood Transplant and Cell Therapy's Centre of Research Excellence, our new research program is powered for maximum impact.

"Our research priorities are understanding the biology of blood cancers, tailor-made therapies to treat each patient's cancer and the psychosocial aspects of blood cancer.

"Other key areas will include innovative clinical trials, new therapies and prevention research which includes investigating risk factors and possible causes of blood cancers."

Our current (2017-2019) multi-million dollar funding commitment to research will grow over coming years in line with generous support from the community.

Bill Petch, Leukaemia Foundation CEO.

To find out more about our new research program visit: **www.leukaemia.org.au/research**

CONTINUED: BRUCE'S CHESS SETS PROVIDE A MEANS OF THERAPY

"I've been told if it's not controlled it can be fatal, and can further progress to acute myeloid leukaemia," said Bruce.

"The good news is... some people I've met have been 'virtually cured,' which is a source of inspiration."

Having MPN has had a major effect on Bruce's business and daily activities and changed his mental outlook.

"Fatigue is the catalyst for this change. I start feeling very tired around 2pm, then I'm out for the count," said Bruce.

"When I wake, it feels like I've been under an anaesthetic and it takes almost a half hour to come to my senses."

At first, Bruce's reduced ability to function got him down. But as a firm believer in positive thinking and the power of the mind, he was able to persevere.

"You do go through depression at times, but you have to try and keep positive. You can't rely on other people to inspire you. Positivity has to be self-motivated," he said.

No longer able to do many of the things he wants to, such as playing golf, he now makes the effort to keep personally busy with other activities.

Bruce had to drastically cut down his work schedule due to his treatment plan but that in turn freed up time and enabled him to pursue one of his passions.

Earlier in his career, Bruce was a master craftsman patternmaker and model maker and although he had long aspired to making a large and unique chess set, he'd never had the time.

"I started handcrafting the chess pieces a long time ago, but it was more of a hobby," Bruce explained.

Making an entire chess set takes him around two months. So far, he has completed two sets, is working on a third, and hopes these "unique works of art" can be utilised to raise funds for MPN research.

"When I'm making the chess sets, my mind is in the alpha level and I can spend up to five hours on something and not notice time passing by. It is a really positive natural therapy for keeping my mind positive," said Bruce.

"I feel for me this is my best positive healing process. I'm not concentrating on my pain or personal issues and challenges, and simply enjoy the moment.

"My advice to others with an MPN is to do something creative or something they get a lot of personal enjoyment from. This can be substantially beneficial," said Bruce.

He also benefits from regularly attending the Leukaemia Foundation's Coffee, Cake and Chat social groups for people living with MPN, both in Brisbane and on the Gold Coast.

He said the people he meets at these get togethers are a constant source of inspiration. In particular, two people with PRV who he keeps in touch with, he describes as his "blood sisters".

"I think talking to other people with an MPN is really helpful. I take my hat off to the Leukaemia Foundation for arranging things like this."

Bruce is also writing a book which he hopes will inspire others going through hardship in their lives. It's about the importance of having a positive mindset and his belief in controlling your mind.

"If you can control your mind, you can control anything," said Bruce.

"I thought, now I've got MPN I realise the importance of completing my book as it could help others with blood cancer."

Bruce's diagnosis has given him a fresh outlook on life and has allowed him to appreciate life more.

"I wake up in the morning, take my dog, Moet for a walk and celebrate another day. I no longer take things for granted in my life and appreciate everything around me more."

TALKING HUMANITY IN HEALTHCARE WITH DAVID JOSKE

As significant progress was made in blood cancer research, Professor David Joske became concerned a decreasing focus on the 'patient experience' meant the humanity in healthcare was being left behind.

Dr Joske has dedicated 20 years to humanising the treatment journey for Australians with blood cancer.

It began with his observation as a young consultant in the mid-90s at Sir Charles Gairdner Hospital (Perth) that "we were making a meal of this business of managing people with cancer".

"I witnessed a lot of distress with delays with appointments and poor communication," he said.

"My colleagues and those in nursing felt we were getting less and less time with our patients. We couldn't express that we cared for them... we tended to make people feel they were on a production line.

"I have pretty much dedicated my whole professional life since then to trying to find ways to improve the cancer journey."

A chance comment from a patient in 1998 prompted Dr Joske to challenge the status quo; to embrace a more personal, open-minded approach to care.

"A lot of my patients were trying complementary and alternative therapies but felt they couldn't discuss them with their medical team," explained Dr Joske.

"This wasn't acceptable and created a barrier between me and my patients. I needed to become a doctor who showed an open mind on this."

Reading up on an area traditionally rejected by modern medicine, Dr Joske found more evidence than he expected in the field of complementary therapies.

Not complementary medicines (herbs and supplements) which Dr Joske believes are "best avoided in mainstream treatment" but diet, stress and exercise, which he said are "terribly important".

The chance came to develop and introduce a new approach to mainstream care with the opening in 2001 of the Cancer Support Centre at Sir Charles Gairdner Hospital with:

- A quiet meeting place where volunteers from all walks of life assist with patient queries.
- Information and resources for patients on support services, like those provided by the Leukaemia Foundation.

Professor David Joske's 'Humanity in Healthcare' presentation at the Leukaemia Foundation's National Blood Cancer Conference (Melbourne, September 2018) can be viewed at: https://bit.ly/2RFQHnJ

- A range of safe and supervised complementary therapies, "that major medicine had rejected for thousands of years", including acupuncture, yoga, music therapy, massage, reflexology, aromatherapy, Qigong, craniological massage and hands-off massage techniques.

The therapies were not only offered to patients, the effects were measured because there was a lot of push back and scepticism.

"The best answer was to gather as much evidence as possible" said Dr Joske.

"Even the most sceptical general practitioners will respond to good quality evidence if you can provide it."

There is a huge demand for these complementary services. The centre sees 100-150 people each week and as it grew and research progressed, it became Solaris Cancer Care in 2006, then the Cancer Support Association with an off-health campus facility where the focus is on survivorship initiatives.

"I have pretty much dedicated my whole professional life since then to trying to find ways to improve the cancer journey."

While Dr Joske is a big advocate for complementary therapies, he acknowledges that traditional treatments like chemotherapy are an essential part of a patient's treatment journey.

"I regard chemotherapy, which is still the main part of most people's initial treatment, as an investment, like a bank loan," he said.

"It's a long-term investment and you make the investment in terms of the short-term costs; feeling crappy, needles, drips, blood tests, and all the visits to hospital.

"But the return on investment can be life itself... so the short term all-in cost on the immune system is well worth it."

Dr Joske said the key to surviving and thriving through a diagnosis is the patient realising they have the right to manage their cancer in a way that is best for them.

"As I've matured as a consultant with the grey hair, I've come to see this topic as the lifestyle management of your cancer. I talk to people under my care with a very open mind on what they want to try," said Dr Joske.

"We're going to improve cure and remission rates, but there's always that personal experience: the worst day of your life where you're told you have cancer.

"You have to get your head around your life changing forever, then come up with how you're going to manage your situation."

Dr Joske's most important advice is to exercise.

"In the bad old days we told cancer patients, when they felt tired during treatment, they needed to rest. Turns out that was not good advice," he said.

"Then we went through a phase of telling people to go on walks. Turned out that wasn't going to cut the mustard either.

"What's needed is some resistance exercise as well, because cancer drugs and steroids tend to dissolve muscle and the only way to get muscle back or to maintain it is to use it."

WHAT'S ON NEAR YOU

NEW SOUTH WALES		
Sydney Metro		
20 Mar	2-4pm	Randwick Blood Cancer Education & Support Group (also 17 Apr, 15 May, 19 Jun)
25 Mar	10am-12pm	St George Blood Cancer Education & Support Group (also 29 Apr, 27 May, 24 June)
27 Mar	11am-1pm	Concord Blood Cancer Education & Support Group (also 24 Apr, 29 May, 26 Jun)
27 Mar	11am-1pm	Westmead Blood Cancer Education & Support Group (also 24 Apr, 29 May, 26 Jun)
19 Apr	10am-12pm	Liverpool Blood Cancer Information & Support Group (also 18 Jun)
Regional New South Wales		
28 Feb	10-11.30am	Gosford Blood Cancer Education & Support Group (also 28 Mar, 30 May, 27 Jun)
5 Mar	10-11.30am	Newcastle Blood Cancer Education & Support Group, Charleston (also 7 May)
6 Mar	10.30am-12.30pm	Wollongong Blood Cancer Information & Support Group (also 3 Apr, 1 May, 5 Jun)
11 Mar	10am-12pm	Shoalhaven Blood Cancer Information & Support Group, Bomaderry (also 8 Apr, 13 May, 10 Jun)
13 Mar	10-11.30am	Port Macquarie Blood Cancer Education & Support Group (also 10 Apr, 8 May, 12 Jun)
27 Mar	10am-12pm	Southern Highlands Blood Cancer & Support Group (also 29 May)
2 Apr	10-11.30am	Newcastle Coffee & Chat, Shortland (also 4 Jun)
4 Apr	2-4pm	Penrith Coffee, Cake & Chat (also 6 Jun)
QUEENSLAND		
Brisbane Metro		
11 May	10am-12pm	20/30 Chat, Paddington
18 May	11.30am-2pm	MPN Support Group, Jindalee
Regional Queensland		
8 Mar	10am-12pm	Blood Cancer Coffee, Cake & Chat, Toowoomba (also 7 Jun)
15 Mar	10am-12pm	Coffee, Cake & Chat, Sunshine Coast (also 21 Jun)
10 Apr	10am-12pm	Coffee, Cake & Chat, Tweed Heads
SOUTH AUSTRALIA		
Adelaide Metro		
20 Mar	10am-12pm	Northern Adelaide Support Group, Strathalbyn (also 17 Apr, 15 May, 19 Jun)
2 Apr	10am-12pm	Carers' Support Group, Adelaide (also 4 Jun)
3 Apr	10am-12pm	Women's Support Group, Thebarton (also 5 Jun)
11 Apr	10am-12pm	Amyloidosis/MPN/MDS Support Group (also 13 Jun)
23 Apr	10.30am-12.30pm	Men's Group, Adelaide (also 25 Jun)
Regional South Australia		
6 Mar	6-7.30pm	Mount Gambier Support Group (also 5 Jun)
14 Mar	10am-12pm	Southern Community Support Group, Noarlunga Downs (also 11 Apr, 9 May, 13 Jun)
18 Mar	10am-12pm	Port Lincoln Support Group (also 17 Jun)
TASMANIA		
Northern Tasmania		
8 Mar	10.30am-12pm	Burnie Blood Cancer Support Group (also 10 May)
12 Apr	10.30am-12pm	Launceston Blood Cancer Support Group (also 14 Jun)
Southern Tasmania		
20 Mar	11am-1pm	Hobart Blood Cancer Wellbeing Seminar (also 15 May)
11 Apr	10.15am-12pm	Hobart Blood Cancer Support Group (also 20 Jun)

VICTORIA		
Melbourne Metro		
28 Mar	10.15-11.45am	Bone Marrow & Stem Cell Transplant Support Group, Hawthorn (also 27 Jun)
11 Apr	2-3.30pm	Carers Session
18 Apr	10.15-11.45am	Northern Suburbs Blood Cancer Support Group, Hawthorn
10 May	10-11.30am	South Eastern Suburbs Blood Cancer Support Groups, Berwick
15 May	2-3.30pm	Young Adults Health & Wellbeing Workshop - 20/40
23 May	10-11.30am	Eastern Suburbs Blood Cancer Support Group, Croydon
Regional Victoria		
19 Mar	10-11.30am	Ballarat 18-65yo Blood Cancer Education and Support Group (also 16 Apr, 21 May, 18 Jun)
27 Mar	10-11.30am	Barwon Blood Cancer Support Group (also 30 Apr, 25 Jun)
27 Mar	11.30am-2.30pm	Wellbeing Seminar, *Getting Back into Life after Treatment,* Geelong
1 Apr	10-11.30am	Bendigo Blood Cancer Education and Support Group (also 3 Jun)
15 Apr	10.30am-12pm	Mildura Blood Cancer Support Group (also 17 Jun)
30 Apr	10-11.30am	Geelong Support Group, Hamlyn Heights
29 May	10-11.30am	Warrnambool & South West Blood Cancer Support Group
WESTERN AUSTRALIA		
Perth Metro		
1 Mar	10:30am-12pm	MPN Coffee Morning
4 Mar	2-3.30pm	Perth New Diagnoses Support Group (also 1 Apr, 6 May, 3 June)
18 Mar	1-2.30pm	Perth Metro Coffee & Chat (also 5 Apr, 20 May, 17 Jun)
Regional Western Australia		
21 Mar	10.30am-12pm	Peel Coffee and Chat (also 11 Apr, 16 May, 6 Jun)
4 Apr	10:30am-12pm	Bunbury Coffee and Chat (also 6 Jun)
8 May	10am-12pm	Albany Blood Cancer Support Group

MPN INFO SESSION

The Leukaemia Foundation hosted an information session for people living with MPN and their families earlier this month in Sydney, dedicated to supporting them through their MPN journey.

The event held at the Royal North Shore Hospital was booked out well in advance and the 50 attendees were keen to hear more from experts about how they can live well with MPN:

- Dr Cecily Forsyth, haematologist, spoke about the treatment and diagnosis of MPN in Australia.
- Dr Renee Eslick, haematologist, spoke about the lifestyle changes following an MPN diagnosis.
- Dr Sue McConaghey, clinical psychologist, touched on coming to terms with an MPN diagnosis.
- Dr Carmel Sullivan, general practitioner, went through the health benefits of yoga.

Leukaemia Foundation
VISION TO CURE
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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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