Did you know there are 137 different types of blood cancers and related blood disorders?

Kai Ashton is one little Australian who, at only two years old, was diagnosed with a rare blood disorder called hemophagocytic lymphohistiocytosis (HLH).

HLH is a life threatening immunodeficiency that primarily affects young infants and children, although it can develop at any age.

Kai’s mum, Tori, says everything in their life has changed since her son’s diagnosis in December.

“Kai started to show signs of being unwell when he was around six months old,” Tori said. “He constantly seemed to have a cold and runny nose but we were told they were just childhood viruses,” she said.

“He was very unwell on his first birthday and developed a rash. We were told, after another trip to emergency, Kai had a viral infection.

“But we knew it was something more serious and 45 minutes after being sent home from emergency Kai had a seizure and stopped breathing.

“It was terrifying. Kai needed to be intubated and doctors were thinking it may have been meningococcal.”

Blood tests finally revealed the seriousness of the situation and Kai’s parents were told their son had leukaemia and he may only live another 24 hours.

“We were in total shock but things got more complicated when doctors, after further tests, changed the diagnosis to HLH, a disease we had never even heard of,” Tori explained.

“All we knew was that our little boy was fighting for his life and we felt helpless.

“We threw a few clothes into a bag and Kai was rushed to Lady Cilento Hospital in Brisbane where he spent 10 days in ICU in a coma.”

Soon after, the rollercoaster ride of treatment began: chemotherapy and later a bone marrow transplant from an unrelated donor.

“It has been a really tough road and our lives have been totally turned upside down. Everything is different,” Tori said.

“I had to give up my job to be with Kai, and Kai’s dad visits most days from the Gold Coast where he works.

“We can’t go to the park or shopping centre because Kai’s immune system is compromised.

“We had to give up our home on the Gold Coast because we were...continued on page 2 ➤
told we’d be in Brisbane for a long time for Kai’s treatment. We’ve now been here for 265 days.”

For most of that time Tori and Kai have been staying at the Leukaemia Foundation’s ESA Village.

“I cried when we were offered a unit – I was so grateful,” Tori told Blood Cancer News.

“It’s really the most amazing place; a clean and safe environment where we have found amazing support and community.

“We’ve met wonderful people who have become close friends. We’d celebrate with those who were finishing treatment and support each other through the highs and lows.”

This is the third edition of Blood Cancer News and we thought it was the right time to ask you if you are enjoying the new format.

We’d love you to take a moment to fill in the enclosed survey and let us know what you like about Blood Cancer News and how you think we could improve it. Your opinion is really important to us.

We are committed to supporting you - one of the 35 Australians diagnosed every day with a blood cancer or blood disorder - along with your family and carers. And we don’t just want to support you through treatment but for as long as you need us, whether it is months or years after your diagnosis.

Blood Cancer News is one important way we can offer that support by providing useful information about treatments and research, tips on health and wellbeing and stories from people whose lives have also been affected by these diseases.

Thank you to the patients who shared their stories in this edition. Little Kai, our cover story, was only two when he was diagnosed with a rare blood disorder, hemophagocytic lymphohistiocytosis. We have also included lots of information that will be of interest to many patients, such as our articles on mucositis, understanding your blood counts, fertility preservation, as well as the many recent research breakthroughs.

If you need free support or information we’re just a phone call away on 1800 620 420, or you can visit us at leukaemia.org.au.

Barbie Hartigan
Director of Support Services
Leukaemia Foundation in Queensland

continued from page 1

Now more than 160 days post-transplant, Tori still doesn’t know when she will be able to take Kai back to the Gold Coast, where they will live with Kai’s grandparents.

“Kai is doing well but it’s still too much of a risk to take him home. His temperatures can spike very suddenly and he’s had two sepsis infections. Now he is dealing with graft versus host disease (GVHD),” she said.

“Kai is on two types of steroids and three different kinds of creams that have to be rubbed into his skin.

“We’re just taking one day at a time and life is all about Kai. We are just concentrating on doing whatever it takes to make Kai well.”

WHAT EXACTLY IS HLH?

Hemophagocytic lymphohistiocytosis (HLH) is a rare disorder of the immune system primarily affecting young infants and children, although it can develop for the first time at any age. Common symptoms are fevers, an enlarged spleen, low blood counts and liver abnormalities.

At least half of the patients with HLH will also experience inflammation of the brain, which can lead to a wide variety of neurological problems.

The symptoms result from an overactive and poorly controlled immune response. This abnormally intense immune response results in prolonged and highly elevated levels of cytokines (molecules that, in minute quantities, normally regulate immune functions). This so-called hypercytokinemia is potentially damaging to all the major vital organs. The hallmark of hypercytokinemia is hemophagocytosis, the process for which the disorder is named.

According to a large, population-based study published in Sweden, HLH was estimated to occur in 1.2 cases per million children, which corresponds to 1 in 50,000 births.

Our thanks to the Histiocytosis Association

WHAT DO YOU THINK?

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Our thanks to the Histiocytosis Association
‘MAJOR BREAKTHROUGH’ PROVIDES OPPORTUNITY TO SAVE LIVES

Research partly funded by the Leukaemia Foundation has made a genetic discovery that will help to identify and monitor people at very high risk of developing blood cancers.

The discovery was made by Professor Hamish Scott and his research team at the Centre for Cancer Biology in South Australia and published in the Blood journal.

The research presents a major breakthrough for families with a history of blood cancers. Mutations in the gene DDX41 are significant in families where myelodysplastic syndrome, acute myeloid leukaemia and lymphoma are common.

Professor Scott and colleagues founded the Australian Familial Haematological Cancer Study to help those with a genetic predisposition to blood cancer. To date, the study has involved more than 100 families.

The research, using the very latest gene sequencing technologies, is part of an international collaboration with the University of Chicago that discovered mutations in the DDX41 gene.

“This is the first gene identified in families with lymphoma and represents a major breakthrough for the field,” Professor Scott said.

“Researchers are recognising now genetic predisposition to blood cancer is more common than previously thought, and our study shows the importance of taking a thorough family history at diagnosis.

Proteins ‘speak to each’ to drive blood cancer

Research funded by the Leukaemia Foundation has uncovered a new insight into the most common sub-type of leukaemia in infants.

Peter Mac researchers have made an important advance in our understanding of mixed lineage leukaemia (MLL).

More than 80 per cent of infants under 12 months diagnosed with either acute myeloid leukaemia (AML) or acute lymphoblastic leukaemia (ALL) also have a sub-type of these diseases, MLL, which has a poor prognosis.

“Every other disease I’ve treated in my time as a haematologist has had one, if not many, new drugs come along to improve treatment,” said Peter Mac’s Professor Mark Dawson. “But this has not generally been seen for leukaemia - and for AML in particular it is none, zero.”

Professor Dawson’s team, along with international collaborators, have found the role of two proteins, which are known key regulators of MLL. Previously unknown, the research shows two proteins – BRD4 and DOT1L – depend on each other to progress the disease.

Drugs targeting both of these proteins are currently in separate clinical trials. Dawson’s research indicates combination therapy involving drugs that target both proteins at the same time may be effective in combating the disease.

“We’ve always known these leukaemias needed these regulators but what we didn’t know was why, and we didn’t know they spoke to each other to drive the disease,” Professor Dawson said.

“The good news is we don’t have to develop new drugs in light of this research because they’re already in clinical trials.”

Professor Dawson’s findings were published in Nature Structural & Molecular Biology.
If you’ve just received the shocking news you have blood cancer, the topic of preserving your fertility may seem unimportant.

However, it’s important the risks and opportunities in the area of fertility are all discussed before treatment begins. Patients who are still in child-bearing years, regardless if they already have children or not, should be informed of how their treatment may affect their fertility as part of their consent for treatment.

The impact on a blood cancer patient’s fertility depends on many risk factors including age, diagnosis, treatment plan, previous medical history and clinical status at the time of presentation. Chemotherapy, radiotherapy and surgery treatment may significantly impact a patient’s fertility potential.

Fertility preservation (FP) in cancer aims to maximise the chances of a patient being able to have their own biological child in the future. Most FP options require the process of Artificial Reproductive Techniques (ARTs) after treatment — processes that are commonly used to treat infertility in the general population.

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Depending on the age of a newly diagnosed cancer patient, they may or may not have considered their decisions about having biological children in the future so introducing, at a stressful time, the possibility of this not being an option can be very overwhelming.

If risk to future fertility is not discussed with patients prior to treatment, then finding out after treatment they may not be able to have their own children can be almost as devastating as the diagnosis.

Ideally, FP should be carried out prior to commencing any treatment but this can be problematic for patients who are too sick, need to start treatment immediately or whose health may suffer further if treatment is delayed to allow FP to take place.

For male patients who are post-puberty, the FP process can be fairly straightforward and effective and involves storage of sperm samples. Samples can either be produced at home or hospital and taken directly to the fertility clinic or produced directly at the clinic’s private rooms. The semen produced is then frozen and stored — a process known as semen cryopreservation. Patients should be referred to a fertility specialist as soon as possible for consultation but semen cryopreservation can be undertaken without the consultation.

For post-pubertal female patients, the FP journey is more complicated but options may still be available for successful live births post treatment. The established options for female FP are oocyte and embryo banking.

Both procedures require patients to undergo controlled ovarian stimulation (COS) in order to harvest oocytes. For patients without a partner willing to undergo FP, oocytes are cryopreserved at this stage. Patients in established relationships may undergo embryo development with the oocyte and their partner’s sperm and the embryos are then frozen and stored.

All patients need to be aware that their fertility status is unknown during treatment so contraception should be recommended to avoid pregnancy.

Unfortunately, there are no public fertility clinics in Queensland so all stored samples — semen and ovarian tissue — will incur storage fees at private facilities. These costs can be as much as $480 per year.

Patients who have been unable to undergo any FP prior to treatment may benefit from a post-treatment fertility consultation. Fertility clinics will arrange for patients to have discussion with a fertility specialist so each patient is aware of their available options. Patients need to be aware that just because they are not able to conceive a child does not mean that they cannot be a parent. There are other options out there for prospective parents.

Thanks to Anita Cox for contributing this article. Anita is a Youth Cancer and CNS Nurse Consultant at the Cancer and Blood Disorders clinic at the Gold Coast University Hospital. She recently won our $5,000 Adem Crosby Nursing Award, jointly supported by Team Adem and the Leukaemia Foundation.
In 2001 Bronte Hutchinson was mustering cattle in Clermont when she became ill and was diagnosed with chronic myeloid leukaemia (CML). At only 22 years old, Bronte was faced not only with a life-threatening disease but also the knowledge that it could end her chances of having children.

Bronte shares her story with Blood Cancer News about having a family after leukaemia treatment.

When I was diagnosed with CML I was immediately given chemotherapy and told, as a side effect, I might not be able to have children. In a short time my disease turned to acute leukaemia and treatment became even more serious. I’m not sure if I asked my specialist about harvesting eggs, or if he suggested it, but he said that my eggs were probably infertile anyway.

Nevertheless, he referred me to a wonderful fertility expert and it was decided to take a slice of ovarian tissue as there wasn’t time to harvest my eggs as I urgently needed to start treatment.

The problem with the ovarian tissue plan was that it had never been done, but it was taken in the hope that one day it might be possible. This was not to be the case.

We were fortunate to have our names put on the egg donor registry prior to getting married in 2003. A suitable anonymous donor contacted us in early 2005 and we began the process of making embryos, which were then frozen and quarantined for six months. We then went immediately to Brisbane for my uterus to be prepared for a baby. After two unsuccessful embryo transfers, our beautiful Jack was born in May 2006.

One thing my fertility specialist didn’t tell me was that I would be unable to breastfeed. I couldn’t understand why my milk was drying up until my paediatrician told me I needed medication to breastfeed. By then, I had almost no milk and had begun bottle feeding anyway.

When Jack was 12 months old, we decided to try for a second baby. We had several embryos left but only one survived the thawing process. We knew our chances were low but it still hit pretty hard because we thought there wasn’t any chance of getting another donor. At the time there were over 200 women waiting for an egg donor. We went home deflated.

A friend approached me about donating her eggs. After much thought we agreed, although in the end she decided she couldn’t go ahead with it. It was a tough time, but I’m glad she decided before we got further down the track.

In 2008 it was suggested we advertise for a donor, which we did six times in various publications. In 2010 we were in the process of running our last ad when two other friends approached me about donating their eggs. I was a bit apprehensive, but told them we had one last ad to run before we’d think about their generous offer.

After no replies to the ad, we were deciding about our friends’ offers when the fertility group called. They found a donor for us! I couldn’t believe it. We wasted no time and started the process again. Our second embryo transfer was successful and I cried with the nurse when she rang with the news. In June 2011, our cheeky Nate joined the family.

Despite the challenges of the process, we are so delighted to have two beautiful boys and will be forever grateful to our egg donors and everyone else involved in the process.
CELEBRITY CHEFS TEMPT TASTEBUDS OF CHEMO PATIENTS

Our popular Cooking for Chemo live demonstration was recently held in Brisbane in front of a hungry audience of around 50 blood cancer patients and their carers.

Celebrity chefs Ben Macdonald, a Masterchef finalist, and Billykart’s Ben O’Donoghue entertained the crowd while whipping up a delicious selection of modified dishes designed to tempt the tastebuds of patients feeling the effects of chemotherapy.

Ben Macdonald easily identified with the audience’s dietary needs having gone through treatment himself for leukaemia more than a decade ago.

Dietician Peter Rhodes and a Leukaemia Foundation Support Services Coordinator, Amanda Ferguson, were also on hand to discuss nutritional requirements and provide hygiene tips.

The audience were treated to gourmet samples and many were keen to give the recipes a go at home.

The demonstration was broadcast live on Facebook and a Cooking for Chemo recipe booklet is available for download at leukemiaqld.org.au/cookingforchemo. Happy cooking!

Our thanks to the fantastic chefs for volunteering their time and recipes, Golden Pig Food & Wine School and Icon Cancer Care for their support.

Cooking for Chemo is a national support program that gives blood cancer patients undergoing chemotherapy and their carers new ideas for eating well during treatment. The easy, tasty, nutritious recipes have been selected to suit altered appetites, taste, food tolerance and lifestyle.

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BANANA & HONEY SMOOTHIE

Serves 1

This smoothie can be made with any kind of milk, including nut milk. To make nut milk, soak 1 cup of almonds in water overnight. Drain, then blend with 4 cups of water and 3-4 dates. Pass through a nut bag or a very fine sieve.

Ingredients

1 cup milk of choice
1 ½ bananas
1 cup of ice
honey
pinch cinnamon

Directions

Place milk, banana, a tbsp of honey and ice into a blender and pulse until smooth.

Squeeze more honey into the glass so that it lines the side of the glass. Pour in the smoothie and enjoy.

Download the recipe book now at leukemiaqld.org.au/cookingforchemo

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MUCOSITIS AND MOUTH CARE

By Elise Button, Acting Nurse Researcher, Cancer Care Services, Royal Brisbane and Women’s Hospital; and PhD Candidate, School of Nursing, Queensland University of Technology.

WHAT IS MUCOSITIS?

Mucositis is a common and unpleasant side effect of cancer treatment, including chemotherapy and radiation. It causes painful ulcers and inflammation of the mouth and throat. Certain chemotherapy drugs, such as methotrexate, especially in high doses, are known to cause mucositis. Most people who receive high-dose chemotherapy or undergo a stem cell transplant (especially if they receive total body irradiation) will get mucositis to some extent. Mucositis usually occurs 5-10 days after treatment starts and can last for several weeks.

Mucositis is caused when the lining of the mouth thins, sheds dead cells and becomes red and inflamed, which may cause ulcers.

It’s important to note everyone reacts differently to cancer treatment and people develop mucositis in varying degrees.

HOW IS MUCOSITIS MANAGED?

KEEPING THE MOUTH CLEAN

You may not be able to stop mucositis from occurring completely, but you can do certain things to help reduce the severity. The most important thing you can do is keep your mouth clean by brushing your teeth and using mouthwash. This will help remove debris and keep the mouth moist and clean. Brush your teeth with a soft toothbrush or a child’s toothbrush 2-3 times a day and mouthwash 3-4 times a day. If you wear dentures, you will need to make sure they fit properly and remove them if they’re uncomfortable. If you develop mucositis, it’s important to continue to keep your mouth clean. If it’s too painful to brush, or brushing causes bleeding, use a foam sponge to clean your teeth.

PAIN RELIEF AND EATING

Oral mucositis can be very painful and can lead to trouble speaking, eating, swallowing or even opening the mouth. During treatment your nurses and doctor will look in your mouth often. Let them know if you have mouth ulcers or any problems with your mouth. There are many options to relieve pain caused by mucositis including sucking ice, using medications placed directly in the mouth, pain relief tablets and medications injected under the skin or into the vein.

Avoid irritating foods that are spicy, hot, dry, acidic or coarse. Some people eat a soft diet while they have mucositis.

OTHER CONSIDERATIONS

Mouth ulcers can become infected, cause fevers, or lead to infections in the mouth. One of the most common infections is oral thrush, and looks like a coating of white spots in your mouth and on your tongue. Oral thrush is treated with anti-fungal tablets. Some people are prescribed these tablets to prevent it from occurring.

It’s often a good idea to see your dentist before you start treatment, if possible. Sometimes dental work is needed prior to starting chemotherapy. Ask your cancer doctor if you should see a dentist before you start treatment and if they can recommend anyone.

As well as chemotherapy causing mucositis, having a weakened immune system will place you at risk of developing mouth ulcers and mouth infections.

WHEN WILL IT GO AWAY?

Mucositis gradually goes away when chemotherapy is complete, the bone marrow has recovered and white blood cells are growing again. Although mucositis can be very unpleasant, the benefits of chemotherapy usually outweigh this. Some people continue to experience taste changes and/or a dry mouth. You must let your cancer doctors and nurses know about any ongoing problems in your mouth.

A HEALTHY DIET

There is no evidence that any specific type of food can cause or cure blood cancers or related disorders. There is evidence however that a healthy and nutritious diet can help your body to cope better with effects of cancer and treatment.

It’s important to talk to your treatment team before making major changes to the foods you eat or before taking supplements (for example vitamins, minerals, herbal preparations or protein drinks). Dietitians and doctors are the most qualified people to talk to about your individual food needs.

Download our Eating Well booklet at leukaemia.org.au.
Our oldest patient accommodation facility, Herston Village, will be receiving a much-needed refurbishment this year to ensure regional and rural families have somewhere safe to stay in the city during blood cancer treatment.

The 14 one- and two-bedroom units in Brisbane have been a crucial part of supporting patients since 1989. However, since then, the village has been in continuous use. To ensure we can continue to provide a safe and comfortable home-away-from-home within walking distance of hospital, it is vital we carry out a major refurbishment.

To complete this important project we are relying on the generosity of the community to raise more than $2.25 million. The Australian Government has already pledged nearly $1 million through the National Stronger Regional Fund.

Our Herston Village Support Services Coordinator, Sheila Deuchars, said the refurbishment will make a huge difference to families impacted by blood cancers like lymphoma, leukaemia and myeloma.

“I know how grateful people are when they come to Herston Village at such a difficult time and receive free accommodation and emotional support,” Sheila said. “But if we’re to continue to offer modern, comfortable accommodation for many years to come the facilities are in urgent need of a major refurbishment.”

In the last three decades over 1,700 patients and their families have stayed at Herston Village. While most patients stayed an average of four months, some needed to stay for more than a year.

If you’re interested in helping us to raise the money to complete our urgent Herston Village refurbishment, please contact Lindsay Stokes on 07 3318 4458 or email lstokes@leukaemia.org.au.

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**THANK YOU FOR LIGHTING THE NIGHT**

Thank you to the many thousands of Aussies who took part in Light the Night, the Leukaemia Foundation’s annual fundraising walk to help more Australians beat blood cancer.

This year, our walkers were striving to raise $2 million to improve survival rates and quality of life among those impacted by lymphoma, leukaemia and myeloma and related blood disorders.

Without the help of those taking part in our fundraisers like Light the Night, the Leukaemia Foundation wouldn’t be able to continue to fund its life-changing research and patient support programs.

Find out more at lightthenight.org.au

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**CUTTING RED TAPE GIVES GREEN LIGHT TO DRUG ACCESS**

The Australian Government has announced its commitment to improving the way medicines are assessed for use in this country.

We welcome the reforms and recognise their importance in cutting red tape and, most importantly, helping blood cancer patients get early access to potentially life-saving drugs.

The reforms are a direct response to the Medicines and Medical Devices Review, which was tasked with improving and finding alternative ways to rapidly assess the safety and effectiveness of new medicines so that they can be utilised by the Australian healthcare system sooner.
Born and bred in Far North Queensland, Lyn Chiozzini’s leukaemia diagnosis meant leaving behind loved ones for months of treatment in Brisbane.

Working in a local cafe, Lyn, 54, thought frequent trips home to nap were simply a sign of getting “old and tired”. Suffering from chronic rheumatoid arthritis, she was used to having regular visits to the doctor. But when her blood tests started showing her neutrophils were steadily dropping to a dangerously low point, she was sent to the haematologist.

“I just thought perhaps it was anaemia or low iron levels. Cancer didn’t even cross my mind,” she said.

“My husband, Gino, came with me to the appointment and we were in total shock when I got the diagnosis.”

Lyn was diagnosed with acute myeloid leukaemia (AML) in October last year and her treatment began in Cairns. During her first round of chemotherapy, Lyn contracted pneumonia. She then spent three days in intensive care after developing a lung infection. After her third round of chemotherapy, Lyn was sent to Brisbane for a stem cell transplant.

All Lyn’s family, including two children and four grandchildren, live in Moresby, a small town south of Innisfail, but she says Gino was there for her “every step of the way”.

“Fortunately the Leukaemia Foundation gave us a lot of information about what to expect and organised accommodation for us at their Herston Village, near the Royal Brisbane and Women’s Hospital,” Lyn said.

“It was so overwhelming when we arrived. It was such a huge hospital and everything felt so unfamiliar.”

None of Lyn’s four siblings were a match for the stem cell transplant so a 39-year old American man became her unrelated donor. Following her transplant, Lyn enjoyed a relatively smooth recovery and spent only 15 days in hospital.

“Don’t get me wrong, I got very sick during the chemotherapy leading up to the transplant. I was warned the melphalan would knock me around, and it did!” Lyn explained.

Lyn says fatigue is still the most prominent side effect of her cancer but she knows she is growing stronger each day.

“I have been given a second chance at life and I’m not taking that for granted. I’m grabbing it with both hands.”

AML Handbrake

An Australian discovery shows how AML can be stopped in its tracks by targeting a protein required for cancer cell growth.

Their research, partially funded by the Leukaemia Foundation’s National Research Program and performed at the Walter and Eliza Hall Institute in Melbourne, reveals targeting a protein called Hhex could eradicate AML in laboratory models.

Dr Ben Shields and Dr Matt McCormack say their findings could be used to develop new drugs to treat AML.

US Approval for Venetoclax

A powerful anti-cancer treatment co-developed and trialled in Australia has been granted approval by the US Food and Drug Administration (FDA) for use in patients.

The announcement recognises the drug venetoclax is a successful therapy for patients with chronic lymphocytic leukaemia (CLL). Clinical trials have shown venetoclax is effective at killing cancer cells in people with advanced forms of CLL when conventional treatment options had been exhausted.
Staff at the Leukaemia Foundation were thrilled recently when little Sam Ross and his mum, Amanda, paid them a visit. The pair spent 11 months at our ESA Village in 2014 while Sam was going through treatment for blood cancer.

With her six-year-old now cancer-free and full of energy, Amanda Ross said their family was getting on with life in Bundaberg, although she can’t help but reflect on the impact that childhood leukaemia has had on their whole family.

“I remember it was during Sam’s first week of kindy. I picked him up from swimming lessons and when I removed his sun shirt I noticed some strange purple marks on his back and arms,” Amanda told Blood Cancer News.

Confused and worried, Amanda took Sam to her family doctor where he was diagnosed with acute lymphoblastic leukaemia (ALL) in February 2014.

It wasn’t long before the pair were flying to Brisbane for immediate treatment at the Royal Children’s Hospital.

Sam’s diagnosis became even more serious when doctors discovered he had the much rarer T-Cell strain of leukaemia. He was also found to have a rare genetic mutation that Amanda said his doctors had not treated before.

When treatment induced serious side-effects and didn’t seem to impact the disease, doctors recommended a bone marrow transplant, which took place in August 2014.

Fortunately Sam’s brother, Ryan, was a match and on the day of his transplant, Amanda said Ryan watched the procedure and knew he had played a special part.

In December 2014, 100 days after the transplant, Sam was given a clean bill of health and the family were able to go home for the first time in 10 months.

Since going home Amanda says it has been wonderful to watch Sam begin school and for the family to enjoy holidays together again.

She said they still have regular trips to Brisbane for medical checks and it gives them a chance to drop in at the Leukaemia Foundation’s ESA Village.

“We will always be incredibly grateful for the support we received,” Amanda said. “There are no words to describe what it means to have that kind of support.

“We’re so grateful to have Sam with us. All of the staff at ESA commented on how much he had grown and how well he looked. We feel truly blessed.”

A small, early-phase trial of engineered immune cells saw 27 of the 29 trial participants with advanced B-cell ALL go into remission.

This extraordinary result came when the patients, who were resistant to multiple other forms of therapy, had their T-cells (disease-fighting immune cells) genetically engineered to fight their cancers. The study was the first CAR T-cell trial to infuse patients with an even mixture of two types of T-cells (helper and killer cells, which work together to kill cancer).

They received the cells in Seattle through the Fred Hutchinson/University of Washington Cancer Consortium. When their responses were evaluated a few weeks after the infusion, a high sensitivity test could detect no trace of cancer in the bone marrow in 27 of 29 participants.

This experimental therapy harnesses the power of the immune system to fight cancers by genetically engineering patients’ T-cells with a synthetic receptor molecule called a CAR (chimeric antigen receptor) that empowers the T-cells to recognise and kill cancer cells that bear a specific marker, called CD19.

The Leukaemia Foundation is cautiously optimistic about the use of CAR T-cells in the treatment of ALL. There have been some issues leading to poor outcomes in some clinical trials that need to be fully explored. This therapy is complex and should not be seen as the cure-all for all patients.
An Adelaide research team has made a world-first breakthrough in the early detection of resistance to a common treatment for chronic myeloid leukaemia (CML).

Former Leukaemia Foundation PhD scholar Dr Laura Eadie at the South Australian Health & Medical Research Institute (SAHMRI) and the University of Adelaide’s School of Medicine has developed a new test that she believes could be adopted by doctors worldwide.

Offering hope for people with CML, Dr Eadie said the test will help personalise the treatment strategies that can be used for people with CML; helping doctors preemptively change the treatment strategy before a person relapses, loses response to their therapy, develops mutations or experiences disease progression.

Dr Eadie said one in five people with CML are resistant to the leading treatment of their condition.

“About 20 percent of people have a poor response to Glivec, the drug which targets the mutant protein that causes their leukaemia, however until now we haven’t fully understood why,” said Dr Eadie. “Unfortunately, this means that one in five people could be receiving treatment that ultimately is not benefitting them,” said Dr Eadie.

The study looked at the role of P-glycoprotein, a protein that pumps many drugs — including Glivec — out of leukaemia cells.

The research team’s work shows, for the first time, that assessing a person’s levels of the P-glycoprotein soon after they start receiving Glivec therapy will help to predict their long-term response to the drug.

Crediting her Leukaemia Foundation-funded PhD scholarship as the platform for her science career, Dr Eadie says the Leukaemia Foundation’s supporters have helped with the progress of her research into CML.

Dr Anna Williamson, Leukaemia Foundation Head of Research and Advocacy said the organisation is proud to see one of its PhD funded scholars, continuing to unravel the mysteries of CML.

“Dr Eadie’s research in CML is changing our understanding of the development of resistance to standard treatments in some people,” Dr Williamson said. “For the one in five people who develop resistance, Dr Eadie’s discoveries may enable the treating team to change strategies to ensure each person continues to respond to treatment.”

Scientists at the Wellcome Trust Sanger Institute in the UK have found acute myeloid leukaemia (AML) is not a single disorder but at least 11 different diseases, explaining the differences in survival among young AML patients.

Published in the New England Journal of Medicine, the ground-breaking study on the genetics of AML could improve clinical trials and the way patients are diagnosed and treated in the future.

Doctor Peter Campbell, co-leader of the study, said, “We have shown that AML is an umbrella term for a group of at least 11 different types of leukaemia. We can now start to decode these genetics to shape clinical trials and develop diagnostics.”

The study, which examined 1,540 patients with AML, looked at 100 genes known to cause leukaemia to find any common genetic themes behind the development of the disease. From here, 11 major groups were identified with different constellations of genetic changes and distinctive clinical features.

The study showed there was a unique combination of genetic changes driving patients’ leukaemia, explaining why survival rates among AML patients are so variable. This research has improved the ability to predict whether certain patients can be cured with certain treatments, opening up the possibility of new clinical trials designed to develop the best treatments for each AML subtype.

People newly diagnosed with the rare subtype of AML, acute promyelocytic leukaemia (APML), can now access arsenic trioxide (Phenasen) through the Pharmaceutical Benefits Scheme (PBS).

An Australian clinical trial demonstrated the effectiveness of arsenic trioxide (ATO) in combination with the standard therapy in Australia. ATO is also PBS listed for the treatment of relapsed APML.
Hodgkin lymphoma patient Lisa Burges was going through her first round of chemotherapy when she decided to audition for this year’s season of X Factor.

After chemotherapy in the morning, Lisa walked down the esplanade in Cairns, her home town, and wowed the judges with her rendition of Angel by Sarah McLachlan.

Although she didn’t progress into the second round of auditions, the 33-year-old described the moment as “the most fantastic experience”.

“During my first round of chemotherapy I was pumped full of steroids and very awake,” Lisa said.

“At three in the morning I was flipping through Facebook and saw X Factor auditions were being held in Cairns that day. I just thought, why not!”

After moving to Cairns a year earlier from Dalby, Lisa began singing professionally at shows around north Queensland, as well as teaching aqua aerobics and swimming.

But she noticed changes to her voice quality and breathing, attributing it to anxiety. Despite the symptoms, Lisa kept working.

“My husband, Simon, was not working at that stage so I just kept going,” she said. “I spent a lot of time resting while I was at home and eating as healthily as possible to try and increase my energy.”

Other symptoms included a rash on Lisa’s upper arms that were put down to anxiety and she was prescribed medication. She also thought that her regular night sweats were due to Cairns’ humid climate.

It wasn’t until Simon’s birthday in April this year, when Lisa’s struggle to breath hindered her from joining in on the day’s activities, that she finally admitted there was something wrong.

After a chest X-ray identified some complications, Lisa was sent for a CT scan which confirmed a diagnosis of Hodgkin lymphoma.

One lung was completely filled with fluid and a mass the size of a two-litre milk carton went from Lisa’s collar bone, across her throat and down into her chest.

“The pressure of this mass had not only caused two broken ribs, but had pushed my heart to one side and completely flipped it over,” Lisa explained.

“I could tell from my doctor’s face that he was pretty horrified at what he was seeing.”

Lisa’s treatment began immediately in the Cairns Base Hospital, with six litres of fluid being drained out of her lung.

Chemotherapy then commenced and Lisa said she was so grateful for the support of Simon and their parents.

“Simon was just beginning a new job which was so difficult for him, so we were very grateful our parents rallied around us and gave us much needed support,” she said. “I also had wonderful friends who helped us through this tough time.”

When Lisa’s hair began to fall out after the second round of chemo, she hosted a party.

“My friends and family came and we had nibbles and champagne - although I drank apple juice - and everyone had a little chop of my hair before a hairdresser friend shaved it all off.”

After Lisa’s third round of an intense chemotherapy regime, BEACOPP (bleomycin, etoposide, doxorubicin, cyclophosphamide, vincristine, procarbazine, and prednisone), a pet scan revealed her tumour was inactive.

“It was such a relief, but I must admit I wasn’t as happy as I thought I would be. I cried a lot; it was just a really emotional time.”

Lisa is thrilled that her voice is “as good as ever” and she is now getting through the final stages of treatment so she can get on with her life.

While Lisa says her experience with lymphoma has made her see so many things with new eyes, she said she now has a totally new appreciation for the incredible ability the human body to deal with illness and heal.
Early clinical data on BGB-3111 encouraging

Early results from a phase I clinical trial using BGB-3111 – a new treatment for relapsed non-Hodgkin lymphoma (NHL) and chronic lymphocytic leukaemia (CLL) – shows the drug is well tolerated and effective as a single-agent therapy.

BGB-3111 is a second generation BTK inhibitor. It blocks the signalling pathway that leads to growth inhibition and cell death in malignant B-cells.

Dr Constantine Tam, consultant haematologist at Peter MacCallum Cancer Centre and the study’s principal investigator, presented initial clinical data on BGB-3111 at the American Society of Hematology annual meeting.

Based on preclinical and clinical data, Dr Tam said BGB-3111 has led to good responses among some patients.

“It has produced rapid and durable responses as a monotherapy in different types of B-cell malignancies,” said Dr Tam about the trial, which so far has around 113 people enrolled.

“Phase I expansion is at 160mg twice a day and 320mg daily, with good tolerance and good responses. So far our results have been very good. Patients have had good responses, but we need more patients.

“We’re now getting to very high doses of BTK inhibitors with what seems like very mild side-effects, suggesting that when you have a drug that’s very selective and able to hit the target very accurately, you can give very high levels of the drug and not have many side-effects.

“What we don’t know is whether hitting the target (BTK) harder will result in patients having even better results from treatment. Only time will tell.”

Once the safe dose level is ascertained, BGB-3111 will be used in larger phase II and phase III studies to compare it against the best available therapies.

“Maybe by hitting the target harder, you can get even more effect from the drugs, thus maximising the effect of BTK inhibitors as a class of drugs – that’s where we hope to take this,” Dr Tam said.

A second study, combining BGB-3111 and obinutuzumab, is currently enrolling, while a third study of BGB-3111 and BGB-A317 (a PD1 inhibitor) is seeking ethics approval.

When Victorian vet Peter Younis relapsed three years ago, he opted to go on a clinical trial for a targeted therapy rather than having another course of chemotherapy.

The trial is for the experimental drug BGB-3111, which is effectively managing Peter’s rare form of lymphoma, called Waldenström’s Macroglobulinaemia (WM). It involves taking four capsules a day, and every two months he makes a day-long round trip from Port Campbell, where he lives in south west Victoria, to Melbourne for tests.

“I’ve had an excellent result – I’m alive, happy and have no side-effects,” Peter said.

“A big advantage is that I can just continue with my normal life. It’s unbelievably simple and non-disruptive for someone who has an active life,” explained Peter, a vet who works mainly with cattle. He’s also a surfer and a musician who plays in a band, the Swamp Apostles.

“This was such a better way of having treatment than sitting in a chemo chair for a day and going through the sickness afterwards.”

Peter’s diagnosis with WM 13 years ago was an incidental finding when he had blood tests following kidney stone treatment. The results showed a very high level of protein. Further investigations revealed high paraprotein and a bone marrow biopsy found he had WM.

Principal investigator of the BGB-3111 trial, Dr Constantine Tam

Peter Younis
Development of new myeloma drugs made the world of difference

Ken Guy recently spoke at a Leukaemia Foundation myeloma support group at the Sunshine Coast. He shares his myeloma story with Blood Cancer News.

My GP first mentioned the possibility of myeloma to me in July 2001. It was a routine visit as I’d run out of blood pressure medication.

My doctor said he’d been looking at records from my previous GP which showed I’d been steadily building up protein in my system since 1994. My first thought was, ‘I’ve been eating too many eggs’! However he went on to explain there was good and bad protein and unfortunately mine wasn’t good. That’s when the bad news hit: ‘I don’t wish to alarm you but I suspect multiple myeloma’. I knew any disease ending in ‘oma’ was cancer so while I didn’t know anything about myeloma, it didn’t sound good!

Forty eight hours later, after numerous tests and an MRI, the worst was confirmed. What do I do? The prognosis at that time for myeloma was only four to five years. Do I just submit to that sentence or do I move forward in a totally positive way? Moving forward was the only way to go.

The first step for me was to get onto the internet and learn all I could about myeloma, as I’ve always believed that knowledge is power. I became an online member of an international myeloma support group for patients, carers and doctors. I soon began my chemotherapy: VAD (vincristine, adriamycin, and dexamethasone), fed intravenously into my system via a pump I wore on my trouser belt.

My clinical hematologist wasn’t happy as the chemo failed to plateau the disease to his target figure. So the next step was to have my stem cells collected in a process called aphaeresis. Close to four million cells were collected in a plastic bag over two days and sent to the Brisbane’s Wesley Hospital to be deep frozen at minus 150 degrees until I needed them back.

In February 2003 I was admitted to a special ward at the Wesley and hit with a drug called melphalan, which reduced my immune system to zero!

A day or two later my stem cells were re-infused. I was told this process was the start of my second life, a serious and truthful claim. By the time I was discharged from hospital three weeks later I’d lost 17 kilos. My next step moving forward was to wait patiently as my immune system re-built itself. The whole process, including two collapses, was no picnic but it gave me five years of my cancer being stabilised.

Myeloma remains incurable but the development of drugs since 2000 has been truly remarkable and of outstanding benefit to me. However by late 2008 when the myeloma began to increase again, my specialist in Brisbane arranged for me to receive the latest myeloma drug, Revlimid, on compassionate grounds. I began taking Revlimid in January 2009 and am extremely pleased to report my disease is under control.

While I realise everyone’s cancer experience is very individual, I sincerely recommend maintaining a positive attitude. From an original prognosis in 2000 of four to five years, I continue to enjoy life - 16 years later.

More about lenalidomide (Revlimid)

Lenalidomide is an immunomodulatory drug and works by modifying the immune system. Lenalidomide, which is related to thalidomide (Thalomid), was approved in Australia in 2007 as a treatment for myeloma which has progressed on another therapy.

The cost of lenalidomide is subsidised by the government under the Pharmaceutical Benefits Scheme (PBS) for patients with progressive myeloma after at least one other treatment (thalidomide must have been tried) and who have either received or are unable to receive a stem cell transplant.

Ken Guy
A small Australian study has provided evidence the immune systems of people with myeloma may play an important role in why some of them survive much longer than others.

A key finding of the research, published in the Blood Cancer journal, showed those who live more than 10 years after their myeloma diagnosis have a more robust immune function compared to others with myeloma.

The long-term myeloma survivors also had certain killer immune cells that were more common and divided more readily. They also had more helper cells (which promote immune responses) and fewer regulatory cells (which suppress immune responses).

The researchers concluded that understanding how the immune system behaves in long-term survivors may provide insights helpful for the development of immune-based myeloma therapies.

Previous evidence has shown the immune system is impaired in patients with active myeloma. Components of the immune system – including T-cells, B-cells, natural killer cells and dendritic cells – are considerably altered.

Immunomodulatory drugs, such as thalidomide, lenalidomide and pomalidomide, boost a patient’s immune system to better enable it to attack and destroy myeloma cells.

T-cells – a particular type of white blood cell – help the body identify and kill various types of microbes and cancers.

Two distinct types of T-cells – killer (or CD8) cells and helper (or CD4) cells – work together to mount immune responses.

Killer cells can directly kill infected or cancerous cells, and helper cells secrete proteins that aid in the development of killer cells. Helper cells are further divided into subsets based on the type of proteins they secrete.

In this study, Australian researchers focused on T helper 17 (TH17) cells that secrete interleukin-17. Regulatory T-cells are helper cells that suppress immune responses and previous studies regarding the frequency and role of regulatory cells in people with myeloma have had mixed results.

Long-term survival with myeloma is often defined as survival of 10 years or longer after diagnosis. Several factors such as younger age, lower tumour mass, and response to therapy have previously been associated with long-term survival.

Consultant Haematologist at Princess Alexandra Hospital Dr Peter Mollee provided some valuable insight on how the immune system impacts on a myeloma diagnosis during our National Myeloma Day seminar in Brisbane earlier this year.

He also gave an update on some of the latest myeloma drugs available and those currently being trialled in the United States. Leukaemia Foundation Support Services Coordinator Amanda Ferguson shared some advice on coping with fatigue, while exercise physiologist Molly Shevill, from Aspire Fitness and Rehabilitation, rounded off the day with some interesting evidence on the benefits of tailored exercise programs.

Those in our audience who had participated in our Fit to Thrive exercise program were able to attest to the improvements in their own health. National Myeloma Day was on May 18.

To view these talks go to our YouTube channel at leukaemiaqld.org.au.

A prospective Australian study assessing a new non-toxic compound to treat residual myeloma is a world-first in blood cancer. Dichloroacetate (DCA) targets the metabolic difference between normal cells and cancer cells.

While DCA has been available for 10 years its use has been minimal, according to Dr James D’Rozario, Senior Staff Specialist at The Canberra Hospital.

“Background work has shown DCA inhibits a number of different cancer cell lines, including myeloma,” he said.
MDS patient, John Meagher, said being part of a trial that allows him to have his azacitidine injections at home, rather than travelling to hospital for seven consecutive days each month, has been life changing for he and his wife, Jean.

Diagnosed with MDS in 2012, John first joined a trial which combined azacitidine and lenolidomide. After the trial John continued on azacitidine on compassionate grounds.

“We would arrive for our early morning appointments at the Princess Alexandra Hospital, but the drug was not released from the pharmacy until 10am as it has a shelf life of only a few hours,” the 80-year-old explained.

“We would also have to wait for half an hour after I took an anti-nausea drug before the injection. We could be waiting anywhere between two to four hours for seven days every month, which was very tiring and frustrating.

“Jean would have to drive us through peak hour traffic to get to the hospital and then we would try to find free parking so we didn’t have the extra expense of paying for hospital parking.”

Azacitidine has fewer side effects than standard chemotherapy and works by restoring a more normal pattern of gene activity, which allows the bone marrow to function more effectively.

In patients with higher-risk MDS, azacitidine has been shown to improve survival, increase blood counts, reduce the requirement for blood transfusions and reduce symptoms of the disease.

In 2014, Brisbane’s Princess Alexandra Hospital began a trial, recruitment for which is currently on hold, that saw some MDS patients given the drug at home.

“The nurse phones so I can take my anti-nausea drug and be ready for the injection when it arrives.

“When I first started the drug, the injections were always put into my stomach which left painful welts and was very uncomfortable. Now the nurse rotates the injections in my stomach, legs and arms, which has been much better.”

The PA Hospital is running a trial giving a select few MDS patients their azacitidine injections at home rather than hospital in a bid to improve patients’ quality of life.

The trial co-ordinator at the PA Hospital, Keryn Hales, says the trial began at the end of 2014 with funding from Celgene and Queensland Institute of Technology.

“MDS patients needing azacitidine are in quite a unique situation because the drug is very expensive and has a very limited shelf life,” Keryn said.

“Once the drug is made up it will only last for three to four hours.

“Patients not only have to make their way to the hospital for seven days out of every month, but they often had to wait around for several hours to receive their injection.

“MDS patients are often elderly and may be unwell, so travelling can be very difficult. If you add to that the financial burden that comes with parking and other costs such buying lunch, it can cause a lot of stress.”

Under the trial, new patients have their first two cycles of azacitidine in hospital, which allows doctors to watch carefully for possible side effects. Patients are also surveyed about how difficult they found coming to hospital and what costs they incurred.

A team of dedicated acute care nurses then visit patients’ homes to administer the drug.

Then after six home cycles, patients are surveyed again to gather data on whether the home injections have improved their quality of life and financial situation.

Recruitment for the trial is currently on hold.

**IN-HOME AZACITIDINE INJECTIONS TRIALLED BY PA HOSPITAL**

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**RUXOLITINIB LISTED ON PBS**

A new drug, ruxolitinib (Jakavi®), has been listed on the Pharmaceutical Benefits Scheme for the rare blood cancer myelofibrosis (MF).

The listing is for the treatment of those classified by IPSS, DIPSS, or age-adjusted DIPSS as having:

» intermediate-2 or high risk MF; or
» intermediate-1 risk MF with severe disease-related symptoms and who are resistant, refractory or intolerant to available therapy

MF affects four in every 100,000 Australians and can cause debilitating symptoms that affect a person’s quality of life.

**NEW DRUG TAKES FOOT OFF MAST CELL DISEASE GAS PEDAL**

An experimental drug called midostaurin may reverse organ damage in people with a serious disorder called systemic mastocytosis.

These symptoms can include an enlarged spleen, which can weigh up to 10kg, pain under the ribs, abdominal discomfort, bone pain, itchy skin, fatigue and night sweats.

The cause of the disease is unknown.

It develops when the pathways that regulate blood cell production are disrupted, causing the body to make blood cells that are faulty and do not function normally.

Now people with MF who meet the eligibility criteria can have affordable access to ruxolitinib which targets and blocks the proteins that control the production of blood cells and play a role in MF and its symptoms.

Royal Adelaide Hospital consultant haematologist Dr David Ross said fatigue was a major problem in all stages of the disease.

“Patients with higher symptom burdens may also suffer from itching, sweats, and bone pain,” Dr Ross said.

“Enlargement of the spleen can cause abdominal pain and make it difficult to eat a full meal. Some patients have low blood counts and need regular blood transfusions.

“Explaining a diagnosis of myelofibrosis to a patient can be difficult because the name doesn’t tell people much, but symptomatic myelofibrosis is a serious blood cancer for which our standard treatments have been largely ineffective.”
WHERE DO BLOOD CELLS COME FROM?

Blood cells come from the bone marrow, a spongy layer that is found inside the long and flat bones of the body, for example the long bones of the arms and legs, the breast bone, the shoulder blades and the pelvic bones.

The bone marrow provides a home to protect immature blood cells (or stem cells) as they grow and develop into mature cells. When cells are fully mature and able to do their normal job, they are released from the marrow to circulate in the blood stream.

WHICH BLOOD CELLS ARE CHECKED BY YOUR BLOOD COUNT?

A blood sample is used to count - literally - the numbers of mature blood cells in the circulation. Doctors are mostly interested in the number of white blood cells, red blood cells and platelets that you have.

WHAT DO WHITE CELLS DO?

There are several different types of white cells, all of which function in various ways to protect the body from infection. A group of white cells called neutrophils, for example, protect the body by eating microbes and other potentially risky particles. They produce pus and help to alert you to the fact that an infection may be present, for example by causing pain, swelling and redness.

White blood cells are important as they provide the body’s main protection against infection. When the number of white cells, specifically neutrophils, is low, this is commonly known as neutropenia.

ARE WHITE CELLS AFFECTED BY TREATMENT?

Yes, very much so. White cells normally only live for between 7 or 8 hours in the blood stream, after which they need to be replaced by the stem cells in the bone marrow, which grow to produce new white cells. Because of this need for billions of neutrophils to be made each and every day, some of the marrow cells have to be continuously dividing. When you are given chemotherapy the marrow cells are affected and are not able to keep up with the demand for new white cells.

WHAT DOES HAVING A LOW WHITE CELL COUNT MEAN TO ME?

Having a low white blood cell count means that you have very few white cells in circulation. This can make it unsafe to give chemotherapy because of the risk of infection. When your white cell count is very low, simple infections that you would normally shrug off can become very serious very quickly. For this reason, it is very important that you alert your doctor or nurse if you have a temperature or feel unwell. If you have had previous problems with infections please tell your doctor before starting treatment.

WHAT DO RED BLOOD CELLS DO?

Red blood cells give the blood its deep red colour. Their most important role is to carry oxygen around the body. Oxygen is needed by every cell in the body and red blood cells transport it to them. If the number of red blood cells is low, then less oxygen is circulated and you may begin to feel tired, short of breath or light-headed.

ARE RED CELLS AFFECTED BY TREATMENT?

Red cells live for about three to four months and therefore the marrow doesn’t need to divide very often to make new ones. For this reason, although some may be destroyed by treatment, it usually takes several courses of chemotherapy before your red cells become affected. When the number of red cells is low, this is known as anaemia. Anaemia is usually corrected by having a blood transfusion or can correct itself.

WHAT ARE PLATELETS AND WHAT DO THEY DO?

Platelets help your blood to clot. You have seen how when you cut your finger the bleeding stops after a short while. This happens because platelets stick together and form a “plug”. In just the same way as you would use a plug to keep water in the sink, platelets are there to keep the blood in our arteries and veins by stopping any leaks if we damage ourselves.
ARE PLATELETS AFFECTED BY TREATMENT?

Yes. However, platelets have a slightly longer life span than white cells, so it is a little less likely to see severe drops in numbers in the blood count. On average, platelets live for about a week, so bone marrow replaces them by dividing from week to week - the daily demand is not as high as it is for white cells. There are about 1400 million platelets in your bloodstream - lots more than white cells.

HOW WOULD I KNOW IF I HAD A LOW PLATELET COUNT?

Since platelets are designed to stop us from bleeding, you might notice that you bruise more easily or more commonly that your gums bleed more than normal when you brush your teeth. There are no medicines that can help your platelet count to recover but if you needed one, you could have a transfusion of platelets. A low level of platelets in the bloodstream is called thrombocytopaenia.

HOW LONG MAY IT TAKE FOR MY COUNTS TO RECOVER?

In most cases, blood counts are usually at their lowest about 7-14 days after chemotherapy. Before having a further cycle of chemotherapy, your blood count will be checked to see if it has recovered sufficiently and it is safe to give you chemotherapy. If the blood count is still low, your hospital may recommend postponing your treatment for a short time (usually a few days or a week) until your blood count has recovered. Sometimes, it is necessary to give you a small injection, or course of injections, under your skin to stimulate the production of blood cells in your bone marrow. These injections are called “growth factors” and have very few side effects.

THE IMPORTANCE OF BLOOD COUNTS

A blood count allows your doctor to check how many blood cells you have available, and therefore to decide whether you can receive your next course of chemotherapy safely.

It also helps your doctor to decide whether you need antibiotic treatment to prevent or fight infection, a platelet transfusion to prevent bleeding, or a red blood cell transfusion to help you feel better and have more energy.

A small syringe of blood can reveal a great deal.

LYMPHOMA AWARE

We marked World Lymphoma Awareness Day with a series of free education and support events across the state, including in Brisbane, Gold Coast, Sunshine Coast, Townsville and Cairns.

Haematologist Dr Jason Butler spoke in Brisbane about how our immune system helps guide and personalise treatments. Julie Allen, a former lymphoma patient, also shared her own experiences with the disease.

You can watch their presentations at youtube.com/leukaemiaqld.

YOUNG PATIENTS CHAT OVER LUNCH

The Leukaemia Foundation hosts free 20/30 Chat groups throughout the year for people in their twenties and thirties affected by blood cancer. The meeting offers the opportunity for younger patients to relax in an informal environment, enjoy a light lunch and chat to others on a similar journey to their own.

The invitation is open to those with any blood cancer or related disorder, including lymphoma and leukaemia, at any stage of their treatment or beyond.

Our Support Services Coordinator, Kate Arkadieff, said many people who came along found talking to people of similar ages in a relaxed atmosphere was comforting and helpful.

“These younger patients have to deal with some fairly unique issues and 20/30 Chat provides a chance for them to share their experiences or simply listen to others over lunch,” she said.

The next 20/30 Chat will be in Brisbane on December 3. Contact us on 07 3055 8233 qldsupport@leukaemia.org.au to join the group.
## WHAT’S ON

Find out more about an event near you by contacting us on 07 3055 8233 or qldsupport@leukaemia.org.au. We will send out invitations closer to each event.

### 2016

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We don’t receive any direct government funding and rely on the generosity of the community to support patients when they need it most. If you would like to make a donation to help others affected by blood cancers, visit leukaemiaqld.org.au.

Would you like to receive this newsletter or invitations to our seminars via email? We would also love to know what you think about Blood Cancer News.

Contact us:
- 1800 620 420
- leukaemia.org.au
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Disclaimer: No person should rely on the contents of this publication without first obtaining advice from their treating specialist. If you do not wish to receive future editions of this publication please contact the Leukaemia Foundation Support Services Division on 07 3055 8233.