

BIRGIT CREDITS CLINICAL TRIAL FOR “FEELING GREAT”

Birgit Anthony, who was one of the first people to go on a clinical trial in Australia for azacitidine (Vidaza®), describes the drug as “really quite a miracle”.

“It’s been very good for me and has given me quality of life and hopefully many years of healthy living,” said Birgit, 64, of Wodonga.

“One of my doctors recently told me that without it I would have had serious health problems by now.

“Before I went on the trial, cleaning the shower or making the bed was exhausting for me. Now I can swim a kilometre in 50 minutes which I do three to four times a week.”

Prior to her diagnosis with myelodysplastic syndrome (MDS) at the end of 2008, Birgit hadn’t been well for two years. She’d been to doctors often about her symptoms of extreme tiredness, having no energy and lots of bruises.

It wasn’t until March 2008 that her doctor said something wasn’t right with her blood and told her to come back in six months, when he’d check everything again.

After being prescribed antibiotics for a chest infection in May, Birgit went to Europe on an eight-week holiday to visit family and friends in June.

“I could hardly do anything on this particular holiday and I couldn’t come home quickly enough,” she said. “I had no energy and went to bed each night after dinner.

“People I’d seen three years earlier said – ‘I don’t know what’s happened to you’, and when I came back, my husband got a bit of a shock because I was so pale.

“At first I put it down to getting older and dismissed it, but I had a lot of unexplainable bruising.”

She went back to her GP in October and was sent off for a blood test.

“I’ll never forget it – I got a call from the hospital to come in straight away for a blood transfusion because my haemoglobin was dangerously low.”

Following blood tests and a bone marrow biopsy, Birgit was diagnosed with an aggressive form of MDS in November 2008 and referred to a haematologist in Melbourne.

“I was very sick and my prognosis wasn’t very good,” said Birgit. She was offered two treatment options – radical chemotherapy or a clinical trial for azacitidine.



Birgit Anthony has been on azacitidine for two years

“I knew absolutely nothing about the trial but decided to give it a go. There was a research centre for the trial in Wodonga and I was the first person to go on it there - on 12 February 2009.”

Birgit’s treatment regimen is two injections of Vidaza each day for seven days, followed by a 21-day break, before starting the cycle again. This month she completes the 24 cycles that make up the two-year trial. During the first 10 months of the trial, Birgit also took thalidomide.

She said the azacitidine treatment takes four months to take effect, so to “bump up” her blood levels at the beginning of the trial, she had a blood transfusion in February and another in April 2009.

“At the end of May my blood counts came up, and up and up. My haemoglobin got to 14.4 at one stage, but is usually around 12 – 13. I haven’t had a transfusion since April 2009 – that’s 22 months!”

When the treatment is administered, and for a day to two afterward, Birgit has some temporary nausea which she says “is no big deal and is handled quite well with anti-nausea medication.”

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NEW CLINICAL TRIAL WILL COMBINE LENALIDOMIDE AND AZACITIDINE



Principal investigator, Melita Kenealy

A new clinical trial will study whether adding lenalidomide (Revlimid®) to azacitidine (Vidaza®) is better than using azacitidine alone in patients with myelodysplastic syndrome (MDS), chronic myeloid leukaemia (CML) or acute myeloid leukaemia (AML) at low levels.

The MDS4 trial, due to open soon with approximately 160 patients from 30 hospitals in Australia and New Zealand, will be run through the Australasian Leukaemia and Lymphoma Group (ALLG) and supported by Celgene.

Azacitidine has been approved by the Therapeutic Goods Administration for patients with higher risk MDS and some with CML and AML. Previous international studies of azacitidine have shown positive responses in about half

the patients treated, with an improvement on average in the survival of people treated with this drug compared to other standard treatments (such as low intensity chemotherapy, high intensity chemotherapy or best supportive care alone).

In this trial, azacitidine is given as an injection under the skin (subcutaneous) for seven days each month. Side-effects include an initial lowering of blood counts (with some people needing increased transfusions in the first couple of months), abdominal upset and reactions at the site of injection.

Half the people on the study will be randomly assigned to receive the combination treatment of lenalidomide and azacitidine. Lenalidomide has also been shown to improve blood cell counts, particularly red cells, in a proportion of patients. It is a tablet taken once a day for three weeks every month. The most common side-effects are lowering of blood counts, fatigue and abdominal upset.

To ensure it is safe to take part in the trial, potential study participants will undergo several screening tests.

Patients on the study will be monitored regularly and will have up to five bone marrow biopsies in the first year, to assess the bone marrow response. There is an option to take part in additional scientific studies aimed at learning more about how these drugs work and who benefits the most. This will involve up to seven extra blood and bone marrows tests in the first year.

The study treatment will last for 12 months. For patients who tolerate the treatment and whose doctor feels it would be best to continue, the azacitidine can be continued longer term.

For more information about the study, visit www.anzctr.org.au (search request number 335266) or speak to your haematologist who may contact Dr Melita Kenealy (the principal investigator) if they need more information.

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“I feel great and have all the energy in the world,” said Birgit, for whom 2010 was a fantastic year. She’d travelled with friends to Darwin and through Central Australia and climbed part of Uluru and to the top of Kings Canyon.

“All my holidays are planned around the treatment and we plan our life around it too.

“I’ve been assured that the medication will continue to be provided to me,” said Birgit, who had bone marrow biopsies in June and October last year.

“These showed there was very little disease left,” she explained.

“A fellow diagnosed around the same time as me chose not to go on the trial because he was concerned about negative reports of the side-effects.

“He told me he’s very sorry about that decision. The trial was closed after it got the required 80 patients and he is waiting for the drug (azacitidine) to be approved. Every two

weeks he has a transfusion of four units of blood.”

Birgit was “over the moon” when her oncologist told her about earlier trials of the drug in New York that have been going over 10 years.

“He said ‘there’s good news and bad news’. The good news was these patients are still alive today and the bad news – I would have to be on this medication for the rest of my life.

“I’m glad to have had the opportunity to get on this clinical trial at the right time. It’s been a great experience for me and I’m very thankful.”



Birgit on her 63rd birthday in 2009

PBS LISTING WIN FOR AZACITIDINE

The lives of hundreds of Australians with MDS will be improved significantly when azacitidine (Vidaza®) becomes available through the Pharmaceutical Benefits Scheme (PBS) this year.

People will have access to the treatment when it is PBS-listed by the Federal Government on February 1.

“This is good news for more than 600 people in Australia who are living with MDS,” said Dr Anna Williamson, General Manager – Policy & Advocacy at the Leukaemia Foundation.

“The Foundation has been in dialogue with government to support the listing of this drug,” Dr Williamson said.

“This decision means azacitidine will soon be available for people who have intermediate and high risk forms of MDS,

where the disease is most progressed and has the highest impact on quality of life.

“People with MDS who are treated with azacitidine are likely to survive longer and spend less time going to hospital for regular blood transfusions,” she said.

MDS HOT TIP

Having sub-cutaneous injections of azacitidine can leave welts on the skin that takes some time to resolve. A study has shown that rubbing evening primrose oil on to the injection site may greatly reduce this side-effect.

WARREN BEAT MDS WITH A TRANSPLANT

Warren Carney’s blood group used to be O+, but following a bone marrow transplant in July 2009, it’s now B+ - the same as his brother, who was his donor.

“I thought that was a good omen,” said Warren, 62, of Lake Macquarie.

Diagnosed with MDS in 2008, Warren hasn’t taken any MDS or transplant medication since October 2010 - the month he competed in the Australian Transplant Games in Canberra, bringing home a gold medal in the singles and silver in the pairs in lawn bowls.

“Everything’s great,” he says. “MDS is still in the back of my mind but I’m getting on with life.”

It’s ironic that having a heart attack in 1998 actually helped Warren beat MDS a decade later.

After his heart attack, Warren went on a healthy diet and a regular fitness routine that saw him at the gym three times a week. He took up bowls and went bushwalking and bike riding too.

“I was pretty fit, I felt quite well and was surprised these things (MDS) were happening.”

His health was being monitored regularly and in 2006, a standard blood test showed Warren’s blood counts were low. He was referred to a haematologist and in early-2008 a bone marrow biopsy showed he had MDS – a condition he hadn’t heard of.

“I was told the only cure for my MDS was a bone marrow transplant, but it wasn’t necessary at that stage,” said Warren.

After his diagnosis, he took vitamin B6 to help raise his haemoglobin levels and prednisolone to boost his immune system.

His two brothers and two sisters were tissue-typed and his older brother, Garry, had matching bone marrow. Warren was also referred to St Vincent’s Hospital in Sydney where the bone marrow transplant process was explained to him.

In early-May 2009, when Warren’s blood levels reached a critical level and he began bruising a lot and got blood blisters in his mouth and sores, he started having blood transfusions, weekly initially, then twice a week.



Warren Carney, right, is now the same blood group as his brother, Garry

“But in June my red blood cells and platelets weren’t holding, so it was necessary for me to have a bone marrow transplant. I was told that a transplant at 60 could be a problem,” said Warren.

Although daunting and traumatic, the transplant, in July 2009, went very well.

“I’m still here,” Warren joked. “The success was put down to me being fit and healthy and Garry’s very good bone marrow match.”

For Warren and Margaret, his wife of 40 years, their time in Sydney was made easier by visiting family members and friends.

During the transplant, Margaret sat with Warren each day during his four weeks in hospital. After he left St Vincent’s, they stayed at the Leukaemia Foundation’s accommodation complex at Waverton for another four weeks as Warren revisited the hospital three times a week.

While in Sydney, the Carneys used the Leukaemia Foundation’s patient transport service a few times, which was a strange twist of fate as Warren had spent 12 months as a volunteer driver for the Foundation back in 2004.

Twelve months after Warren’s transplant, the Carneys went to the Whitsundays for a family holiday and as Margaret recently retired, they have many more travel plans. They’re off to Tasmania in March and are looking forward to going to Western Australia.

EDUCATION AND SUPPORT PROGRAMS

NORTHERN TERRITORY		
11 Feb		Leukaemia, Lymphoma, Myeloma & Related Blood Disorders Support Group, Eat at Martins Café, Coconut Grove, Darwin

VICTORIA		
27 Jan (also 24 Feb; 31 Mar; 28 Apr; 26 May)		Blood Cancer Information & Support Forum, Geelong West Town Hall, 153 Pakington St, Geelong West
27 Jan (also 24 Mar; 26 May)		South East Melbourne Blood Cancer Information & Support Forum, Clayton Community Centre, Cooke Street, Clayton
10 Feb (also 8 Apr; 9 Jun)		Mornington Peninsula Blood Cancer Information & Support Forum, Mornington Library, Vancouver St, Mornington
15 Feb (also 19 Apr)	11am-1pm	Shepparton Blood Cancer Information & Support Forum, Shepparton RSL, 88 Wyndham St, Shepparton
24 Feb (also 24 Mar; 21 Apr)	10-11.30am	Barwon Blood Cancer Information & Support Forum
24 Feb	10am-12noon	Horsham Blood Cancer Information & Support Forum, Grains Innovation Park Conference Centre, Horsham
24 Feb (also 31 Mar; 28 Apr; 26 May)	TBA	Blood Cancer Information & Support Forum, Geelong
24 Mar	10am-12noon	Ballarat Blood Cancer Information & Support Forum, 128 Doveton St North, Ballarat

SOUTH AUSTRALIA		
24 Jan (also 28 Feb; 28 Mar; 30 May; 27 Jun)	10-11am	TQEH Carers' Coffee Group, TQEH main building, 2nd floor dining room, Adelaide
28 Jan (also 25 Feb; 25 Mar; 29 Apr; 27 May; 24 Jun)	10.30am-12noon	Carers' Coffee Group, Palais Café, opposite RAH, Adelaide
10 Feb Reynella (also 10 Mar; 14 Apr; 12 May; 9 Jun)	10.30am-12noon	Southern Metro Coffee Group, Reynella Youth Centre, 10 Main South Rd, Reynella
15 Feb (also 15 Mar; 19 Apr; 17 May; 21 Jun)	10.30am-12noon	North East Metro Coffee Group, Salisbury East Neighbourhood Centre, 28 Smith Rd, Salisbury East
17 Mar (also 21 Apr; 19 May; 16 Jun)	10.30am	Strathalbyn Coffee Group for patients & carers, Ruffino's, 15 High St, Strathalbyn
23 Mar		Patient Education Session: <i>Blood Products</i> , presented by Bev Queded (Red Cross), BioSA Incubator Conference Centre, 40 – 46 West Thebarton Road, Thebarton

WESTERN AUSTRALIA		
11 Feb (also 11 Mar)	10am-12noon	Bassendean coffee morning, Blue Dog Café, Bassendean. Support for patients & carers
21 Feb	1.30-3pm	Patient support group, Monastery, Leederville
25 Feb (also 25 Mar)	10am-12noon	Tarts coffee morning, Northbridge. Carer support group
31 Mar	11am-2pm	<i>Taking Control and Getting Back Into Life</i> , Perth
9 Apr	9:30am-4:30pm	WA Patient Conference , The Boulevard Centre, Floreat, Perth

NEW SOUTH WALES / ACT		
1 Feb (also 5 Apr; 7 Jun)	10-11.30am	Patients/Carer's Coffee Morning, Nourish Café
3 Feb (also 3 Mar)		Thursday Chat, Port Macquarie
3 Feb (also 7 Apr; 2 Jun)		Haematology Support Group, Wilders Bakery, Booroowa St, Young
8 Feb 8 Feb (also 8 Mar; 12 Apr; 10 May)	10am-12noon	Tuesday Chat, Coffs Harbour Haematology Support Group, St Benedict's Parish Centre, Narrabundah ACT
10 Feb (also 10 Mar; 14 Apr; 12 May)		South Coast Haematology Support Group
16 Feb (also 16 Mar)		Wednesday Chat, Tamworth. The Education Room, Cancer Clinic Building, Tamworth Base Hospital
22 Feb		Tuesday Chat, Taree
1 Mar (also 3 May)	10-11.30am	Patients/Carer's Coffee Morning, Leukaemia Foundation Hunter office

TASMANIA		
15 Feb (also 15 Mar; 19 Apr)	11am-1pm	Launceston Blood Cancer Information & Support Forum, Leukaemia Foundation office, Lower Ground Level, office suite, 4/216 Charles St, Launceston
16 Feb	11am-1pm	Taking Control seminar series: <i>Centrelink Payments</i> , Bellerive Yacht Club, 64 Cambridge Road, Bellerive, Hobart
8 Mar	11am-1pm	Taking Control seminar series, <i>Emotional Support</i> , Bellerive Yacht Club, 64 Cambridge Road, Bellerive, Hobart
23 Mar	11am-1pm	Taking Control seminar series, <i>Perpetual Trustees</i> , Bellerive Yacht Club, 64 Cambridge Road, Bellerive, Hobart
5 Apr	11am-1pm	Taking Control seminar series, <i>The Role of the Social Worker</i> , Bellerive Yacht Club, 64 Cambridge Road, Bellerive, Hobart

For more information, visit: www.leukaemia.org.au (education & support programs section) or call: 1800 620 420

REGISTER FOR WORLD'S GREATEST SHAVE 2011

We are looking for thousands of brave Australians to register to shave or colour their hair to raise funds for the 13th Leukaemia Foundation *World's Greatest Shave* on March 10-12.

World's Greatest Shave is our biggest fundraiser. It generates almost half the income the Foundation needs each year for the National Research Program and to provide the free services that support thousands of people who are impacted by a diagnosis of leukaemia, lymphoma, myeloma and related blood disorders.

This is a seriously fun event and our fundraising tips make it easy. Raising \$120 is an easy goal and provides two nights accommodation at one of the Foundation's patient and family accommodation facilities for a regional Australian who has to relocate to a metropolitan centre for life-saving treatment.

So, get a team together at work, home, school or your sports club, and when the time comes, plan your own team event or head to one of many public shave events organised across the country. Sign up now at www.worldsgreatestshave.com or by calling 1800 500 088.

OUR VISION TO CURE AND MISSION TO CARE

The Leukaemia Foundation is the only national not-for-profit organisation dedicated to the care and cure of people affected by leukaemias, lymphomas, myeloma and related blood disorders.

The Foundation provides emotional support, accommodation, transportation and practical assistance for these people. It also funds research into cures and better treatments for leukaemias, lymphomas, myeloma and related blood disorders.

The Foundation receives no direct ongoing government funding and relies on the continuous support of individuals and corporate partners to provide its services and to fund its research programs.

To find out more about the work of the Leukaemia Foundation and how we can help, phone 1800 620 420 or visit www.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.