

bcrc-wa what's news

Issue 7
Sep 2015

NEWSLETTER OF  breast cancer
research centre - WA



Prof. Arlene Chan
Director – BCTU
Vice-Chair – BCRC-WA

Welcome to Issue 7.

Our Cold Caps study is one of our many studies that we are about to commence.

The incidence of chemotherapy – induced alopecia is a debilitating side effect and it is one that we hope we can learn more about through this study using a device that cools the scalp.

Lindi Beckett has a passion to help other cancer sufferers and has taken the lead in creating a GoFundMe page for this purpose. Please help support this important study as all proceeds will be coming to BCRC-WA.

Breast Clinical Trials Unit Manager, Jeannette Devoto, discusses our Area trial this issue. This study enters its second phase this month and if you are interested in finding our more, please read about it in this issue.

We understand that there is a lot of misinformation online and in this issue Tracie Ernenwein, Research Nurse, discusses how important it is to discuss your concerns with only trusted professionals.

For us here at BCRC-WA, we appreciate all the hard work and tireless commitment in the recent

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fundraising events and morning teas. Many of the fundraising efforts mentioned in this issue are in memory of loved ones and the generosity we have seen is a testament to these women's lives. We are privileged to have cared for them and known them.

Mind-Bender



What mathematical symbol can you put between 2 and 3 to make a number greater than 2 but less than 3?

Answer: A decimal point!



A special recognition to **Hudsons Coffee** who have generously donated catering and coffees at our PYNKS meetings as well as other BCRC-WA functions.



Like us on Facebook and share us with your friends

 facebook.com/bcrc-wa

Meet the BCRC staff



Introducing:
Tegan Willsher
Position:
Project Officer

What does your role involve?

I have been working at BCRC-WA as a project officer for five years and during my time I've had the opportunity to work on a range of projects from everything from data entry to website management. I love that this job allows me to use my vocational skills to help those with breast cancer.

As the BCRC-WA Project Officer, I have a number of roles, which keep me very busy. My main role at BCRC-WA is to manage studies. This includes designing and managing databases, liaising with doctors and patients and collecting data. At the moment, the projects I am working on include PATIPS-A, SPIM and the Helen Sewell Tumour Bank. I manage our Facebook page, which keeps Friends of BCRC-WA up-to-date with everything that is happening at BCRC-WA. It also acts as a platform of encouragement for those who have breast cancer. Lastly, part of my job is to do some administrative duties such as, editing articles for newsletters and managing our online donations.

Tell us about yourself..

I have a pretty busy life, juggling postgraduate studies and two jobs so I really value my spare time. When I'm not working or studying, you can usually find me at coffee shops or the beach (when it's hot) catching up with friends. On Friday nights, I volunteer at my local church where I mentor teenagers and teach them how to play in a music band.

Area Clinical Trial

BCRC-WA is conducting a trial for patients with metastatic breast cancer to understand how a regular tailored exercise program can impact on fatigue levels while undergoing either chemotherapy or hormonal therapy.

BCRC-WA's Breast Clinical Trials Unit (BCTU), in conjunction with the Mount Physiotherapy Centre have now completed the first part of the study to ensure that the program works well and is safe for patients to undertake.

In September, the second part of the study will begin. Patients will be allocated, at random, either to the exercise arm of the trial which involves attending two 50-minute exercise sessions per week with the Mount Physiotherapy Centre located at Chelsea Village on Stirling Highway in Nedlands.

The exercise program will have a duration of 6 weeks. The other patients will be randomised to the "control arm" and they will not attend any exercise sessions. At the end of the 6-week program, a comparison will be made between the two groups to see if the exercise program assists in reducing fatigue levels. We will also look at whether the exercise regimen has any



impact on depression and chemotherapy related side effects.

To date, the patients that have participated in Part One of the trial have enjoyed the program. Please contact Prof Chan or BCTU (info@bcrc-wa.com.au or 9483-4643) if you are interested in participating.

Jeannette Devoto
Unit Manager
BCTU

*The only person you should try to be better than...
is the person you were yesterday*

In loving memory of Kate

On July 28th, the family of Kate Miloro, who passed away after battling breast cancer for almost 5 years, joined together with family and friends to hold a fundraising morning and afternoon tea for the Breast Cancer Research Centre-WA.

Kate's children, Rose, Thomas & Sam and husband Mark wanted to mark Kate's first birthday since her passing with a gesture of support for cancer sufferers. Her family also wanted to remember the enormous courage shown by Kate in fighting her illness and for the beautiful life she led.

The \$4,500 raised by family and friends on the day is a testament to all who knew Kate and held her in such high esteem. She was loved by so many and her legacy will live on. Her loving family will make sure of that!

Kate's family want to thank sincerely all who offered their support to events leading up to the morning and afternoon tea including the Kalgoorlie friends of Kate who ran a high tea at the Kalgoorlie races and to Brookfields who ran a quiz night in support of BCRC-WA. These events were hugely successful too.

Mark Miloro



Lord Howe Island: The ultimate prize

After months of hard work from Karen and Brian Taaffe and the offices of BCRC-WA, we are proud to announce the winner of the raffle prize to Lord Howe Island.

Libby Reading was extremely thrilled to win this prize (pictured) and exclaimed upon winning that she had never won a big prize like this before, only a bottle of wine. Libby has excitedly booked her trip and is planning to do all the tours and fun activities that came with this prize.

Karen and Brian Taaffe have proudly handed to our office just under \$10,000. We would like to thank Karen and Brian Taaffe for approaching our office in their quest to help raise funds for our clinical research. Also a big thank you to everyone who sold raffle tickets on our behalf through their friends and workplaces.



Brookfield Annual Charity Quiz Nite

Brookfield GIS-WA held their Annual Charity Quiz Nite at the Aviary on Monday 27th July in support of Breast Cancer Research Centre - WA.

Brookfield received a request via letter from Mark Miloro. In the letter Mark asked Brookfield to help fundraise for BCRC-WA in commemoration of his wife, Kate Miloro, who lost her battle against breast cancer in February this year leaving behind their three children aged 11, 15 and 17.

Mark opened the event with his children and said a few words of thanks; he also explained that 1 in 10 women are expected to develop breast cancer in WA, with around 2000 new cases diagnosed each year.

The event was a success with over 90 attendees of Brookfield GIS employees, their subcontractors and clients. Quiz master for the night was John Hadfield, a technician from Brookfield and it was

his local Liverpool accent and multi-cultural questions (Liverpool and soccer) that kept everyone entertained we hear!

With donations for raffle prizes and silent auctions, they raised a staggering \$5900 on the night. In addition, Brookfield GIS has additionally contributed \$500.00 making the total donation \$6400.00.

It is with gratitude that we acknowledge this kindness of both Mark Miloro and the team at Brookfield GIS.



Fundraiser High Tea at the Races 2015



Kalgoorlie Boulder Racing Club recently organised a very successful “High Tea at the Races” helping to raise funds for Breast Cancer Research Centre-WA.

Everyone enjoyed a fun packed day in their pink and purple outfits and mingling with their friends, joining in with the silent auctions and the first class entertainment.

Importantly, there was a moment’s silence while a tribute slide was shown paying tribute to those we have lost, the survivors and all the fundraising events over the years held in the Goldfields. An education stand was made available with information and newsletters on the current clinical trials that are in place at BCRC-WA.

A big thank you to the Committee Team who organised the event, Kalgoorlie Boulder Racing Club, the Lions Club Kalgoorlie for the catering and the contributors who donated so generously.



Photograph taken by Lynn Webb





Photographs supplied by Lynn Webb & KBRC

Lindi's Fight Like A Girl Campaign with GoFundMe

Chemotherapy-associated hair loss is one of the most debilitating side effects of chemotherapy for women with early and metastatic disease.

Here at BCRC-WA we are hoping to commence a study to give women with breast cancer the opportunity to avoid losing hair during chemotherapy treatment using a cold cap device. The main aim of the trial will be to assess for the effectiveness of the cold cap device in women about to commence chemotherapy; with a focus on its effectiveness across different types of chemotherapy drugs used. This study will be conducted by members of Breast Cancer Research Centre-WA (which include doctors, nurses and trial staff). The protocol will be reviewed by an independent ethics committee and once approved the study can commence inviting suitable patients to participate.

Lindi Beckett is our shining star in this, who as a patient, knows what it is like to fight a breast cancer diagnosis. She contacted our office and said she would like to raise some money for others affected by breast cancer and once she had heard of our Cold Caps study, she said she wanted to get involved in any way she could to ensure this study gets up and started. After discussions with the BCRC-WA office and Prof Chan, and with a lot of enthusiastic ideas being thrown around Lindi decided to start a GoFundMe page with 100 % proceeds coming to Breast Cancer Research Centre-WA.

Lindi herself a professional photographer organised her fellow contacts to organise a photo shoot. The photos are beautiful testament of Lindi's nature, strength and desire to help others in need. We would like to thank Anel Photography, AVS Photography and Liesl Cheny Photography for permission to use the photo in our newsletter. If you are interested in finding out about this study please contact our office via phone 9321 2354 or email info@bcrc-wa.com.au. If you would like to donate to this cause please go to www.gofundme.com/breast-cancer-wa





Pynks

POSITIVE • YOUNG • NURTURING
KIDS/FAMILY-FOCUSSED • STRENGTH-GIVING

*Do you have secondary cancer?
Like to talk to like-minded people,
who really understand?*

Pynks is a support and information group for younger women and those who are young at heart. Pynks provides facts and topics relevant to advanced secondary breast cancer.

For more information telephone **9321 2354**
or email info@bcrc-wa.com.au



Pynks is a BCRC-WA initiative

If it seems too good to be true, it probably is.

As a breast cancer research nurse, it's important to me that patients with breast cancer receive accurate and reliable information so that they can make informed choices about their care.

I hear patients say time and time again that they are confused and overwhelmed by the amount of conflicting information available to them online and through their personal networks.

When trying to decide which articles deserve our attention and which ones we should skip, I suggest to my patients that they watch out for the following "tricks" commonly used in media reporting:

1. Taking research out of context

This one is a common source of confusion for patients, and occurs when information is rooted in research, but is either incomplete or incorrectly applied to broader areas. A recent article I read had the headline "Essential oils stop cancer in its tracks", and went on to detail how cinnamon, thyme and chamomile can effectively knock out cancer. It referenced a link to a research article from 2010, but when I tracked down the article, sure enough the original researchers were optimistic about the use of essential oils on a few cancer cells in the lab setting, but their conclusion was that further research was required, and not that "cancer was stopped in its tracks".

2. Catchy headlines or bold statements

Catchy headlines are great for grabbing our attention, but without reading the article in its entirety and understanding who said what, we can easily be misled. Another recent article from the West Australian talked about exciting new research into the effects of exercise on cancer survival. The article quoted a local academic as stating that exercise had good results in reducing the negative effects of chemotherapy, and that more research was needed in order to more fully understand the chemical effects of exercise on cancer and which



exercises were the most beneficial. These assertions are widely accepted and generally undisputed by the experts. The sentence that stood out as a catchy bold-texted caption, however, claimed that exercise had similar benefits to chemotherapy. The author of the news article, not the expert, then followed on to write the unproven and

unreferenced claim that exercise improves cancer survival as effectively as chemotherapy or radiation.

3. Quoting unreliable sources of information

Watch out for this one, it is really common. It's always great to read an article that seems well-researched and contains references to back up the claims, but are those references valid? I read an article just yesterday about breast cancer remedies that referenced only other articles by the same website. The other articles in turn, were again referencing only their own articles, and so on. Another thing to check is the author him or herself. Are they an expert in the field and do they have any vested personal or financial interests in the ideas or products in their article?

4. Personal stories

Personal stories can be touching and can move us to action, but there are two big dangers in basing any health or cancer treatment decisions on other people's stories. First, we are all different and one cancer treatment does not apply to all. Your specialist will tailor your treatment to you personally, based on things like, your own family history and your type and stage of breast cancer. Interventions that might be helpful to one person can actually be quite harmful to another. Secondly, other people's stories are sometimes exaggerated or even completely false – think of Belle Gibson who amassed a huge following based on her fraudulent claims that foregoing medical treatment in lieu of healthy eating cured her brain cancer.

If, after considering the above, you are still in doubt about something you've read or hear, remember to write down your concerns and ask your specialist, GP, breast nurse, or other trusted professional at your next appointment. Remember the old adage, if it seems too good to be true, it probably is.

Tracie Ermenwein

Research Nurse

Eat Well, Feel Well

An initiative of Breast Cancer Research Centre WA

Providing you with both complimentary and paid services which will assist you in maintaining a healthy lifestyle.



Healthy Weight, Healthy Life

Healthy Weight, Healthy Life offers early breast cancer patients a free service to assist them with nutritional issues while on treatment.



Symptom-Less

Symptom-Less is a free service that offers advanced breast cancer patients advice on how to deal with symptoms related to their treatment.



Individualised Sessions

Individualised Sessions lets patients meet individually with a dietitian and the service will be specifically tailored to the patient's needs.

PYNKS

Our PYNKS group met up recently to have a morning session with Jewellery Designer, Liz Briggs.

Liz's passion is colour and she showed us techniques on making bangles and how not to be afraid to incorporate multiple colours in our pieces.

It is a fantastic skill to be able to put colours together successfully and Liz was so enthusiastic it made us feel brave in our bead choices. A fun exercise we did was to make a bangle for the person on our left and when handing it over we were to say a positive comment about them.

A lot of fun and hilarity was heard throughout the session and Liz has offered her services to us again in December for a Christmas themed event. Thank you Liz for offering your expertise and time to our group. To find out more about Liz Briggs, Jewellery Designer, please go to www.etsy.com/au/people/lizbriggsdesigns

If you would like to join our group and have metastatic disease please email Rochelle Hook at info@bcrc-wa.com.au or alternatively leave a message on our answering machine 9321 2354.



Pynks ladies
with Liz Briggs (right)

Clothes swap till you drop

Cath Ashton decided to celebrate the fact that her friend has finished treatment for breast cancer and thought what better way than to raise some funds for Breast Cancer Research Centre – WA.

"A group of us girls got together recently for a 'Clothes Swap Till You Drop' fundraiser for Breast Cancer Research Centre – WA.

We charged each person a fee to come along. We had some nibbles, drinks, lots of laughs and more importantly we raised \$160.00 for BCRC-WA! Basically, get your friends to bring along clothes, shoes, and bags etc, anything you don't want anymore.

I even advertised it as an event on my Facebook page. Lay the clothes out and everyone picks the clothes they like, swap clothes for free and walk away with a new wardrobe!"

Cath Ashton



Monthly Recipe

Mouth-watering Loaded Veggie Burger with Quinoa

INGREDIENTS

- 1 cup cooked quinoa
- 1 cup cooked mashed garbanzo beans (or you can use kidney, black or any type of bean you like)
- 1/2 cup grated carrots
- 1/2 cup grated zucchini (squeezed in your hands to remove excess moisture)
- 1/2 cup chopped kale
- 1/2 cup cooked corn off the cob (optional but I had some leftover)
- 4 tbsp sunflower seeds
- 4 tsp flour – regular or gluten free
- 3 - 4 tbsp chopped, flat-leaf parsley, stems removed
- 1 tbsp nutritional yeast
- 1 tsp chia seeds
- 1 tsp cumin
- 1 tsp soy sauce
- 1/2 tsp salt
- 1/2 tsp pepper

METHOD

Place all of the ingredients in a large bowl and stir well to combine. Make patties by forming the mixture into five or six large, packed balls. Work each ball individually with your hands until the ingredients stick together. Add a bit more flour if too wet and more crushed beans if you need a little more binding. If you want to make these ahead of time, stop here and refrigerate.

Next flatten each one into the shape of a burger and set aside.

Place a skillet over medium/high heat and add your favourite cooking oil - just enough to cover the bottom of the pan - and heat until hot but not smoking. It also works firing them on the grill.

Add the burgers to the pan and cook on one side until you get a nice brown sear (about 1 minute) and flip. Sear the other side and then stop here if you plan to freeze them. Cook for 30 seconds then cover the pan, lower the heat to medium/low and cook for another 2 or 3 more minutes until warm throughout.

Alternatively you can just flip the burgers and finish them in a 350-degree oven for about 10 minutes until the underside is brown and the inside warm.

Serve on your favourite roll with your choice of toppings, or place on a bed of mixed greens for a gluten-free option.

Respecting Privacy

Never assume that your friend or relative who has just been diagnosed with breast cancer wants everyone to know.

Once you have disclosed the news to someone, then it can never be undone. You need to be very respectful of people's wishes in this area. Some people with breast cancer are very private and want to disclose to each person individually themselves.

If they lose hair during chemotherapy, they may wish to 'lay low' until it grows back or hire/buy a convincing wig. It is very important to first ask your friend/relative who they don't want to know, who they would like you to tell and what information they would like you to pass on!

Be very reliable on this, no matter the temptation to tell others or disclose more detail.

Excerpt from **BCRC-WA's "Power of Words"**



What to say:

"Cathy, would you like me to let anyone know on your behalf? What would you like me to tell them?"



What not to say:

"Cathy told me she has breast cancer. I thought you should know."

Art Exhibition

Mr Remo Galli, a retired gentleman, contacted the office of Breast Cancer Research Centre - WA recently with a wonderful idea to help raise funds for our clinical research into breast cancer.

He was so grateful for the care of his daughter Franca, under the care of Prof Chan, he proposed putting on an exhibition of his paintings with 100% of the proceeds being directed to BCRC-WA. Mr Galli emigrated from Rome in 1961 making his home in Perth with a very busy building business and renovation company. Once he retired, he was able to enjoy creative activities that he was too busy to enjoy before such as composing music and doing acrylic paintings.

The two day event at the Laguna Veneto Club in Dianella was a complete success. \$1085 was raised and Mr Galli hopes to host this event again before the end of 2015. Mr Galli, we appreciate your kindness, support and passion for your craft. Your commitment in helping with the diagnosis, treatment and support of women and men with breast cancer is admirable.



Mr Galli, Franca and member of Mt Lawley Mr Michael Sutherland



Volunteer Helper Ieuan Hook





RENEW

RETURN TO NORMAL AND WELLNESS

- ✓ Exercise effectively and safely
- ✓ Aid in reducing breast cancer treatment related side-effects
- ✓ Improve cardiovascular fitness
- ✓ Facilitate your recovery and return to wellness

Book Today!

Individual or Group sessions (max 4)

Phone **9200 3922** or visit Mount Physiotherapy,
Chelsea Village, Stirling Highway in Nedlands

**RENEW is a BCRC-WA initiative
in collaboration with Mount Physiotherapy.**



MOUNT PHYSIOTHERAPY



breast cancer
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Striving to improve outcomes
for patients with breast cancer.



breast cancer
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Help us get the
word out there
about the amazing
work of BCRC-WA!