

What's news

HELLO FROM PROFESSOR ARLENE CHAN



Welcome to the Winter Edition of our Newsletter. It is hard to believe just how quickly this year has gone, as I reflect on the progress we have made and goals we have yet to achieve.

In June this year we welcomed the news that a drug called Nerlynx, which has been shown to reduce the risk of recurrence in HER2-positive early stage breast cancer patients, has recently been approved by the Therapeutic Goods Administration (TGA) for sale in Australia. This is another positive step forward in the fight against breast cancer. Of course, there's still a lot of work ahead, and we will continue to work hard in order to achieve the ultimate long term goal to have Nerlynx reimbursed on Medicare.

In this edition you will find our article on 'Should all women recommended to have chemotherapy be advised to use a "cold cap"?' This article was the result of a study that I developed here at BCRC-WA to evaluate the success of hair-cooling in women receiving different types of chemotherapy. I am hopeful that the results will help women about to embark on chemotherapy, decide on whether they should use the scalp cooling device or not. You can read more on [page 5](#).

In this edition we also feature a patient story from Margaret Irvine who during the time of her diagnosis and treatment qualified to become a lawyer and was later admitted to the Western Australia Bar at the Supreme Court. An incredible achievement during a very challenging time. You can read more on Margaret's story on [page 4](#).

This May, many of you fundraised and supported BCRC-WA at the HBF Run for a Reason. We thank you all for your efforts and we

are excited for our next community event, the Chevron City to Surf in August. What a great way to give to charity while keeping active and well throughout the year.

We are also pleased to let you know that PYNKS, our group for women living with metastatic breast cancer, are now meeting every second Tuesday of every month for an informal 'Coffee & Chat' catch up, held at the Bodhi Tree Coffee Shop in Mt Hawthorn. For more information on joining our PYNKS for a coffee and chat see [page 6](#).

Once more we would like to thank all our donors, contributors and those who have supported us thus far in 2019.

I look forward to sharing results of other studies and projects that we are currently doing at BCRC-WA.

Prof. Arlene Chan
Medical Oncologist MB BS,
FRACP, MMed (Palliative Care)

EVENTS

JUNE

PYNKS COFFEE & CHAT
JUNE 11

ITALIAN CLUB LADIES NIGHT
FUNDRAISER
JUNE 21

CHEMO WISE
INFORMATION SESSION
JUNE 27

JULY

PYNKS COFFEE & CHAT
JULY 9

SOMETHING PINK FUNDRAISER
JULY 13

CHEMO WISE
INFORMATION SESSION
JULY 25

AUGUST

ITALIAN CLUB GALA NIGHT
AUGUST 10

CHEVRON CITY TO SURF
AUGUST 25

CHEMO WISE
INFORMATION SESSION
AUGUST 29



INTRODUCING
Cynthia Gregory



We're delighted to welcome
Cynthia Gregory, Senior Study Coordinator

I joined the Breast Clinical Trials Unit in January 2019. As a Senior Study Coordinator, my role is to support, facilitate and coordinate trial activities for patients and provide assistance to fellow colleagues when needed. Currently I am coordinating the PATINA, NEKTAR, TVEC, MonarchE trials among certain others.

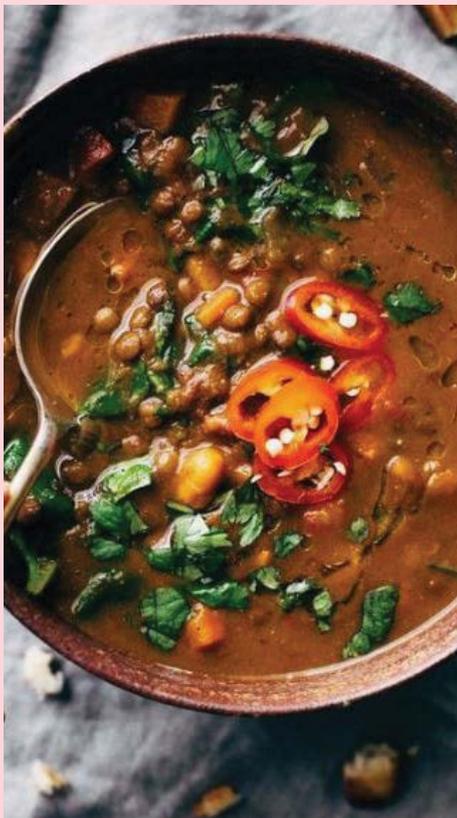
I really enjoy the ability to interact with patients in this role while making sure patient trial activities run smoothly. I feel blessed and thankful for this opportunity to be able to work with a very passionate team to help those undergoing breast cancer treatment.

I'm originally from India. I have a Masters and PhD in Biochemistry with specialization in Biochemistry of Metabolic Disorders.

Having worked as a post-doctoral research fellow at Sir Charles Gairdner Hospital and Royal Perth Hospital, I have gained extensive experience in coordinating and conducting clinical trials.

I have worked in different areas of research targeting metabolic disorders such as cardiovascular diseases, hypertension, diabetes and cancer.

WINTER RECIPE



Moroccan Sweet Potato Lentil Soup

INGREDIENTS

2 cups sweet potatoes, peeled & cubed into small pieces
1 cup carrots, chopped
1 cup onions, chopped
1 cup celery, chopped
1 red bell pepper, diced
6 cloves garlic, minced or pressed
1 ½ cups green or brown lentils, rinsed & picked over
1 ½ teaspoons each of coriander & cumin powder
1 teaspoon curry powder (or more to taste)
½ teaspoon each smoked paprika, ground cinnamon & turmeric
1/8 teaspoon ground nutmeg
6-7 cups low sodium broth (vegetable or chicken)
2 ½ cups baby spinach, roughly chopped
¼ cup lemon juice or lemon wedges for serving

METHOD

1. Place the sweet potatoes, carrots, onions, celery, red bell pepper, garlic, lentils, spices, and 6 cups of broth into a slow cooker. Cover and cook on the low setting for 6-8 hours or on high for 4-6 hours. Check the lentils for doneness. If you're lentils have been in the pantry for a while, note that they'll take a bit longer to cook through.
2. Place half the soup into a blender along with a little additional broth (½ cup or so) and blend till smoothish. Alternately, you can use an immersion blender directly in the slow cooker but be sure to not blend all of the soup if you want it to have a chunkier texture. Add the puree back into the slow cooker. Stir in the baby spinach and lemon juice. Cover the slow cooker, unplug it, and allow the ingredients to sit for 30 minutes or so until the spinach wilts down.
3. Season with salt, pepper and curry powder to taste as desired. Thin with additional broth to desired consistency. Serve warm with whipped greek yogurt, fried pita bread, and tons of fresh herbs (parsley or cilantro) on top!

CEO CORNER



This year has commenced really well and it has been great for us in so many ways. It is comforting to note the increasing support we are receiving from patients, families, friends and the wider community. This allows us to plan long term in maximising better patient outcomes.

A lot has happened in the last few months and it all augurs very well as we move towards our integrated breast cancer centre.

Recent Developments include:

- More breast care nurses
- Ongoing oncology fellows
- Psychological services

We continue to work through a model that will result in best outcomes for patients and patient feedback is constantly

being accessed for this world class, one stop shop on track to open in the first half of 2020. Hollywood Private Hospital has been a great partner and we plan to maintain this synergistic relationship long term.

We would like to extend our thanks to all our supporters. We are pleased to be considered a leading charity whereby every donation dollar has a direct impact on the future of breast cancer treatment.

The Board and Management strive to ensure the highest levels of governance and accountability. We ensure that donations go to patient research, treatment and support, where they count most.

BCRC-WA has an unflinching commitment to increasing levels of care and knowledge of the causes and management of breast cancer, aiming to cure and prolong life.

BCRC-WA is reshaping the future of breast cancer treatment.

**Carmelo Arto
Chief Executive Officer**

Save the Date
Gala Night
10 AUGUST
with guest speaker
PROF. Arlene Chan

LADIES NIGHTS

DATES: 21 June & 1 November

AT: 7pm, 1934 Ristorante 235 Fitzgerald St, West Perth

BOOKINGS ONLINE: trybooking.com/BAMD1

MAG'S STORY



My name is Margaret Irvine, but I'm known as Mags.

My story begins with the birth of my daughter and a fear that I had breast cancer which I told and was dismissed by a GP who was not my usual doctor.

I think, like all stories of super heroes (and my beautiful Amazonian warriors, we're all heroes) so let's start at where it all goes wrong and how we made it right.

Fast forwarding 4 months, I went back to my normal GP with real concerns that I had felt a lump. She wasted no time and referred me to Perth Radiological Clinic at Mount Hospital who confirmed there was a problem and asked me who my breast surgeon was. I thought I had a blocked cyst.

She recommended Specialist Breast Surgeon, Dr Peter Willsher and Medical Oncologist, Professor Arlene Chan at BCRC-WA, and this was reinforced by my lovely GP.

I went through a whirlwind of emotions. I wanted to see my kids grow up, I had so much still that I wanted to do and asked the question, why me? I cried and I threw tantrums.

I consulted with Dr Peter Willsher and asked him to give me the chance to see my children (Molly was 18 months, and Scott was 8 years old) grow up. He gave me a 10 year plan to work towards... and there was hope. He was direct, and explained the road ahead would be rough, but I would get there.

I had my surgery within a week and I felt like my world had spun out of control, however, I remembered Peter's plan and stuck to it.

I followed up with chemo treatment and a cold cap trial by the amazing (and folks she is truly amazing) Prof. Arlene Chan. I had just started 2nd year law at Murdoch University when I was diagnosed, and I asked if I could carry on with my degree... "absolutely", she told me, "do not take this lying down, you fight it."

My gorgeous, long curly hair fell out and it broke my heart. I continued with the cold cap trial and before chemo finished, my hair was growing back.

I continued my degree with my husband Craig and my best friend Andrea and family supporting me, my friends dragging me to university, the lecturers helping me, my colleagues and friends at Legal Aid supporting me unquestionably throughout the treatment, and never once treated me differently. Before I knew it, I was through radiotherapy. My hairdresser Cat, made me look like myself again and we cried.

Through my treatment, I had completed my Law degree, graduated with distinction and

started a new job in Legal Aid with the kindest, inspirational and most compassionate people you could ever wish to work with and I'm looking forward to a career as a solicitor.

So, my Amazonian sisters, for you are all heroes, I wish you courage and strength and the support of the wonderful team that I was so fortunate to have at BCRC-WA. Kick the alien invader to the kerb and if I can leave you with one thought, it is "connect".

Connect with your family, friends and colleagues as time is short and precious, love, laugh and cry together, it will give you the strength you need.

Most of all connect with yourself, you are strong, you are a super hero, you are going to get through this and it will be tough, but you are going to survive. Watch stupid movies through chemo, make the radiologists turn the radio up and sing along and look in the mirror every morning and say, "I am strong, I am loved and I have a lot more to do in this life", you can do it.

Mag's battle against breast cancer is common amongst Australian women. Research is the key to higher cure rates and longer survival rates. BCRC-WA is at the forefront of this research. Join with us and share in our vision to continue this vitally important work.

Please donate today to our end of financial year June Appeal, and help us to directly increase survival rates and cure rates.

Go to bcrc-wa.com.au/ways-to-help/ or call +61 8 6500 5501

COLD CAP

Should all women recommended to have chemotherapy be advised to use a “cold cap”?

Chemotherapy-induced alopecia (CIA) or hair loss is one of the most commonly occurring and distressing side effect of breast cancer treatment.

Studies indicate that even with the knowledge of temporary hair loss, more than half of respondents describe this symptom as being burdensome, as well as an outward sign of cancer associated with negative self-image and feelings of depression and anxiety.

Although CIA is almost always reversible after chemotherapy, current options to prevent CIA from occurring are limited.

Scalp cooling (SC – a device which women wear on their heads during chemotherapy) to reduce the degree of CIA has been utilised for over 40 years. Studies have shown it to be safe (i.e. using SC is not associated with higher rates of breast cancer recurrence) and is currently the most effective technique in reducing CIA when compared with no scalp cooling.

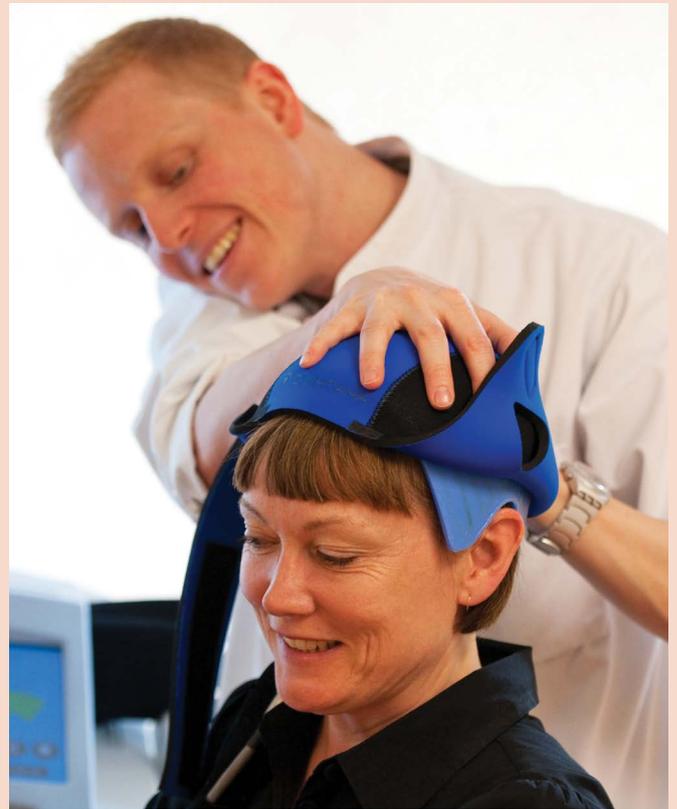
Despite consensus in the literature that scalp cooling is effective, several variables have been suggested to influence its success. These include hair thickness, type and dose of chemotherapy treatment, scalp temperature that can be achieved with the device and cap fitting technique.

It has been suggested that lowering the scalp subcutaneous tissue to 22 C is necessary to prevent alopecia, with laboratory studies, suggesting that temperatures of 14 C - 18 C may be even more effective.

The study that we did at BCRC-WA was to see how effective SC is when women are recommended different types of chemotherapy, in an effort to inform future patients as to whether they should use SC or not. Further we explored whether the degree of success in minimising the amount of hair loss, could positively impact on mood and body image. Finally, we tested whether lowering the SC temperature beyond the usual setting of 5°C could lead to greater effectiveness.

Our study results confirm that women recommended to have a particular type of chemotherapy (viz. anthracyclines) have high rates of hair loss and many patients did not persevere with using SC. Patients who receive another type of chemotherapy called taxanes, experienced the highest rates of minimal hair loss and all patients in this group used the SC for all cycles of their chemotherapy, which also reflects the good tolerability of the device.

Although our study did not show having minimal hair loss was associated with with improved mood and body image, we would routinely recommend the use of SC to women being recommended for taxane-based chemotherapy. For patients who are to receive anthracycline-based chemotherapy, an



individualised approach should be taken, balancing the low rates of effectiveness and longer treatment times against the importance of hair loss perceived by the patient. Lowering the scalp temperature did not appear to be more effective, so 5°C remains the recommended temperature setting. We continue to monitor all patients that entered the trial to ensure that scalp metastases do not occur at a higher than expected incidence.

The complete findings of our study can be found as a pdf on our website at <https://bcrc-wa.com.au/research/current-trials/>.

We would like to acknowledge the donation of the Digitana Scalp cooling device by Ashley and Martin.

**Prof. Arlene Chan
Medical Oncologist
MB BS, FRACP, MMed
(Palliative Care)**



THANK YOU FROM BCRC-WA

Travelling With Cancer



Patient of Professor Arlene Chan, Marianne Stevens, first encountered the devastating effects of breast cancer 32 years ago. Then, 8 years ago, she had a second encounter when she discovered she had a lobular cancer.

Marianne says that without Professor Chan, she doubts she would be here.

Marianne is also a published author and has recorded her journey with cancer in the three books she has written and published. Her third book "Travelling with Cancer" has just been published.

Her other books are her autobiography 'What a Life!' and a novel entitled 'A Villa in Umbria.'

Marianne is a wonderfully positive person and her latest book tells the tale of how she has lived and travelled while undergoing treatment for breast cancer.

Her story is nothing short of inspiring.

Marianne's book can be purchased from [Amazon](#).

PYNKS
A group for women living with Metastatic Breast Cancer

For more information please email info@bcrc-wa.com.au



THANK YOU FROM BCRC-WA

Macca's Rotto Swim



Raised \$35,896

Highly regarded worldwide and one of Western Australia's iconic events, the Rottne Channel Swim is a 19.7km open water swim from Cottesloe Beach to Rottne Island.

David McCarthy nominated BCRC-WA as his chosen charity. Supporting a cause close to his heart, David completed the swim in 6 hours and 40 minutes and was also the top fundraiser for the event.

In addition to over 600 hours of training leading up to the swim, David was working as a financial planner and studying full time to complete his Masters of Financial Planning.

David, his wife Chelsea and their two children, Hamish and Jesse have experienced huge support from their family and friends, many from rural Western Australia.

Chelsea is having treatment for metastatic breast cancer under the care of Professor Chan. The family wanted to contribute in a practical way to the world class research and support services conducted by BCRC-WA.

A Desire To Give Back



"I am one of more than 13,500 women in Australia diagnosed with breast cancer each year. More than 2,680 women are dying from this disease annually in Australia, and around 1 in 8 Australian women will develop breast cancer at some point in their lifetime.

It is a deeply personal and life-changing journey. From a position of health and gratitude for life, what has become most important to me, is that I want to give back," said Deb Ford.

Deb with her husband Maurice, established 5 Rooms Retreat holiday accommodation, with the sole intention of raising funds to donate to breast cancer research. They want their contribution to help increase survival and cure rates for men and women with breast cancer. To this end, half of all their profits will go to BCRC-WA.

5 Rooms Retreat is located in Margaret River and is entirely off grid, using renewable energy sources to power the eco lodge. Further information: www.5roomsretreat.com.au/

No Hair - More Care



Raised \$5,590

"That moment when someone realises that losing their hair is suddenly a reality. My dear friend was diagnosed with breast cancer in late 2018," said Sarah. Sarah shaved her head in March and raised significant funds for BCRC-WA through her 'No Hair-More Care' fundraising campaign.

"I realised that the impact of a breast cancer diagnosis is much bigger than losing hair. My friend is so strong and a fighter. It has been my privilege to be with her through a number of doctor appointments, tests and surgeries. I did this as an act of support and love for her."

CONSIDERING DONATING TO BCRC-WA?

Thank you to the following organisations for their generosity

- Lifecare Fremantle
- Paypal Giving Fund Australia
- Raising Hope
- St Joseph's Victoria Square Ex-student Association
- Whitford Catholic Primary School Group of Parents
- 101 Club Hillside Garden Village

There are many ways to help us achieve our aims at BCRC-WA.

What are we trying to achieve now and in the near future?

- Establish our new comprehensive breast cancer centre
- Continue our ground breaking research via clinical trials
- Find new and better treatments for breast cancer
- Enhance patient wellbeing and increase survival rates
- Become an education/information hub for patients, GPs and the community

Why we need your help?

- To help establish our new centre
- To facilitate our care and support in the form of:
 - More metastatic (advanced) breast cancer nurses
 - More early breast cancer nurses
 - An additional two oncologists

Donate today

You can donate by going online to www.bcrc-wa.com.au or by contacting us on (08) 6500 5501 or info@bcrc-wa.com.au

BCRC-WA is self funded.
We do not receive any government funding.

Thankyou x



A gift in your Will is a gift of hope.

Remembering BCRC-WA in your Will is a very special way you can support our world class breast cancer research and education. With your help, we can improve survival rates and minimise the impact of breast cancer.

A clearly written and up-to-date Will ensures that your estate is distributed according to your wishes. Please let us know if you have already included BCRC-WA as a beneficiary in your Will. It helps us plan for the future and also allows us to thank you.

For more information and confidential enquiries, please contact Ann Chan, Fundraising & Bequests Coordinator on (08) 6500 5501 or email fundraising@bcrc-wa.com.au



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