‘Living well beyond breast cancer’
BCNA forum, Cairns, Queensland

BCNA hosted a forum in Cairns on Saturday 14 September with a focus on 'Living well beyond breast cancer'. More than 160 women, supported by partners, family and friends came along to the Cairns Convention Centre.

The forum was hosted by BCNA CEO Maxine Morand. Guest speakers included Dr Sue Fraser, Dr Carrie Lethborg, Olympian and breast cancer survivor Raelene Boyle and local breast care nurse Helen Rogers, BCNA Community Liaisons Mena Crew and Zoe Dunn took part in a dynamic panel discussion.

Reflection from Zoe Dunne, BCNA Community Liaison

Innisfail Breast Cancer Support Group was lucky enough to attend the ‘Living Well beyond Breast Cancer’ Forum in Cairns on 14 September.

Maxine Morand, BCNA’s CEO opened the day with a talk about her double entry into the breast cancer world: Not only did she step into the shoes of Lyn Swinburne, BCNA’s founder, but she was also diagnosed with breast cancer.

Dr Sue Fraser, a breast care physician then talked about the latest in treatment and care, giving insights into new directions and ideas on treating breast cancer.

Natalie Halse talked about the help BCNA and her community has provided to the women in the ‘Pink in the Tropics’ support group. She presented BCNA with a cheque for $5,000, a fabulous donation from local business that has a connection with breast cancer. Well done ladies!

A panel of 3 local ladies (myself included) were then asked questions about the different roles we play in our local area. Heather Rogers the Queensland Health Breast Care Nurse wears many hats. She is involved with an exercise program specifically designed for ladies post breast cancer surgery, Encore. She is also the local coordinator for Mummy’s Wish, an assistance program for ladies with cancer who have children under the age of 12. Mena Crew spoke of her work as a BCNA Community Liaison. She also encouraged ladies to join survey groups such as Register 4 and the BCNA Review and Survey group. I spoke about the role our group plays in assisting ladies in our area; one program we have is to provide ladies with a $75 bra voucher to assist with out of pocket costs.

Dr Carrie Lethborg talked about ways to improve emotional and physical wellbeing after breast cancer. A question was asked about how to deal with the dreaded people who either have the ‘cure’, know the worst cancer horror story, or tell you that all you need to do is stay positive. Dr Lethborg’s advice is possibly the best I have ever heard, tell them thanks but they are really not being helpful. This is something most of us seem to have to deal with and a tool to handle this is wonderful.

The opportunity these events provide to ladies in rural or remote areas (we had ladies from as far away as PNG attend) is boundless. Networking with ladies in surrounding areas, resources, practical help and new contacts are always made.

Lastly, came Raelene Boyle whose honesty and humour is an inspiration to everyone. To say she is a living legend is an understatement! She has the ability to walk in to a room and create an air of fun and excitement whilst still being truthful about the realities of breast cancer.

Thank you to BCNA, you are always there to support us as individuals or groups and manage to make it seem like the miles between us are smaller every day.

Summary of questions from the audience answered by Dr Susan Fraser, Breast Physician, President of the Australasian Society of Breast Physicians.

1. ***Is the Ki-67 test the same as the Oncotype DX test?***

   The Ki-67 and Oncotype DX tests analyse different things, but both provide you with information that can help your medical oncologist determine whether chemotherapy will be beneficial to you.

   The Oncotype DX test analyses 21 genes within the woman's tumour to predict the likelihood of the breast cancer recurring. If the test shows a high risk of recurrence, chemotherapy may be recommended. If the test shows a low risk of recurrence, chemotherapy may be able to be avoided.

   The Ki-67 test measures the number of cells that have a protein called Ki-67. The more Ki-67 present, the quicker cancer cells are dividing and creating new cells. A higher test score shows that the breast cancer is more aggressive and more likely to recur, therefore chemotherapy may be recommended.

2. ***You mentioned LVI in your presentation? What does this mean?***

   LVI stands for lymphovascular invasion and is measured when a sample of your tumour is sent to the pathology laboratory. LVI measures the likelihood of your breast cancer to spread into blood vessels and lymph nodes, which is how cancer spreads to other parts of the body. If a woman's LVI score is higher, this means that her breast cancer is more likely to spread to other parts of the body, and in this case, chemotherapy may be recommended.

3. ***In what situations is a sentinel node biopsy performed instead of an axillary clearance?***

   Sentinel node biopsy is used for most women. If, during the procedure, the sentinel node is unable to be identified, a limited axillary dissection will be recommended.

   An axillary dissection may also be recommended if the tumour is larger, if there are multiple tumours in the breast or if we know before surgery that there are positive/affected lymph nodes.

4. ***For how long should women take an aromatase inhibitor?***

   When aromatase inhibitors were first developed, it was recommended that women undergo treatment for five years. Nowadays, it is sometimes recommended that women undergo aromatase inhibitor treatment for seven to 10 years, although some women opt to continue treatment for longer.

   When recommending whether a woman's aromatase inhibitor treatment should be extended, her medical oncologist will consider a number of things, including the risk of the original cancer, any side effects the woman is experiencing, and the woman's personal preferences.

5. ***How often should women have bone mineral density (DXA) tests?***

   Women undergoing aromatase inhibitor treatment should have a bone mineral density (DXA) test before they begin treatment. This is called a 'baseline' test. Additional bone mineral density tests should then be completed throughout treatment to see if a woman's bone mineral density changes over time. The number and frequency of tests will depend on the results of her previous tests.

   There are certain drugs that can be prescribed if a woman has low bone mineral density to help strengthen her bones.

6. ***You mentioned that there is a link between obesity and breast cancer. Could you please expand on that?***

   Professor Kathy Pritchard, an academic oncologist from Canada, presented on this topic at the recent Ninth Scientific Meeting for the Australasian Society for Breast Disease (held alongside the BCNA Cairns Information Forum).

   Professor Pritchard explained that a higher body mass index (BMI) is linked to breast cancer and, in particular, to oestrogen receptor positive (ER+) breast cancer in postmenopausal women. Fat cells make an enzyme called aromatase, which produces oestrogen. It is thought that obese women are at a higher risk of developing breast cancer, or of their breast cancer recurring if they have had a previous diagnosis because the higher number of fat cells in their bodies results in more oestrogen circulating in their bodies.

   Other factors which may increase a woman's risk of developing breast cancer, or a recurrence of breast cancer include high levels of blood glucose, insulin and leptin. Women can reduce blood glucose levels by losing weight. There is also evidence to suggest that Metformin, a drug used to treat diabetes, may reduce women's risk of developing breast cancer, although more research on this is required.

7. ***I am post-menopausal and am wondering under what circumstances I should consider removing my ovaries?***

   Ovary removal can be considered for women who have a strong family history of breast cancer or known gene mutation (e.g. BRCA1/2) that puts them at an increased risk of breast and ovarian cancer. The best thing to do is to speak with your GP, who can refer you to a genetic counsellor.

8. ***Can you tell me about the drug Zometa? I have osteoporosis.***

   Zometa is a bisphosphonate, which is a type of drug that is used to strengthen bones. Some women on an aromatase inhibitor or tamoxifen experience low bone mineral density and are treated with Zometa. It is given intravenously (IV) either once or twice per year. It is regularly prescribed for women who have low bone mineral density as a result of breast cancer treatments and is very effective.

9. ***When should I consider genetic testing?***

   Genetic testing can be considered if you have a strong family history of breast and/or ovarian cancer. That is usually two or more relatives on the same side of the family who have been diagnosed.

   If you have one relative with breast or ovarian cancer, or two relatives on different sides of the family, this is not considered a strong family history.
   If you are considering genetic testing, start by talking with your GP, who can refer you to a familial cancer centre if appropriate. Genetic testing is only available to those who fit a strict eligibility criteria which your GP can talk with you about. You can get tested if you don't fit the criteria, but it will cost you around $2,000. This is not advised, as if you don't fit the criteria it is very unlikely that you have a known genetic mutation.

   It's also worth noting that only five to 10 per cent of all breast cancers are caused by a strong family history or a known genetic mutation.

10. I have heard that tamoxifen can be taken for 10 years. Can you tell me more about this?

Evidence from large international clinical trials has found that 10 years of treatment with tamoxifen is better for premenopausal women with hormone positive breast cancer than five years. If you would like to know if you would personally benefit from additional years of tamoxifen treatment, it's best to speak with your medical oncologist. Whether ten years of tamoxifen is recommended will depend on the risk of the original cancer and your personal preferences for extending the treatment.

11. There seems to be a lot of research into hormone receptor positive breast cancer, but very little into triple negative breast cancer. Do we know what causes triple negative breast cancer.

There is actually a lot of research into triple negative breast cancer. We know that it is linked to BRCA1 gene mutations, and is common in younger women. We also know that triple negative breast cancer responds extremely well to chemotherapy.

Research also shows that, up to five years after diagnosis, the risk of recurrence is higher for women with triple negative breast cancer than for women with hormone receptor positive breast cancer, but that after five years, women with triple negative breast cancer actually have a lower risk of recurrence than other women.

We are unsure what causes triple negative breast cancer.

12. I take Arimidex and experience hot flushes and issues with sleep. I have heard that a drug called Effexor may be helpful. Is it true that Effexor may also make me feel depressed?

Effexor is an antidepressant that can be used in low doses to effectively treat hot flushes. As its primary purpose is to treat depression, it is unlikely to cause you to feel depressed.

Regular exercise can also help to relieve hot flushes and improve sleep.

13. When having a yearly review, is it best to have a mammogram or ultrasound?

After a breast cancer diagnosis, most women will have an annual check-up that includes a screening mammogram and a clinical examination. Women with dense breasts may be recommended an ultrasound in addition to a mammogram, as mammograms can be less effective in women with dense breasts. Dense breasts tend are more common in younger women, Asian women, women who have not breastfed, and women with a genetic predisposition to dense breasts.

14. Can women return to BreastScreen after a breast cancer diagnosis?

As the BreastScreen program is run individually by each state and territory, it depends on where you live. In Queensland, women can return to the BreastScreen program five years after their breast cancer diagnosis. In some states, such as Victoria, women can never return to BreastScreen after their diagnosis.

15. ***I was diagnosed at 79, and don't think there is enough information to let women know that they are still at risk once they are older than 69.***

    BreastScreen stops sending women reminder letters once they turn 70 , and women can sometimes assume that this means they are no longer at risk, which is incorrect. The Government has now extended the age at which women receive the reminder letter to 74 years of age. A woman's risk of breast cancer increases with age.

16. ***I was diagnosed at a young age. At what age should my daughter start screening? We have no other family history.***

    If you were diagnosed before 50, your daughter is at moderate risk. Annual screening will usually be recommended, and should begin when she is five to 10 years younger than the age you were when diagnosed.

Summary of questions from the audience answered by Dr Carrie Lethborg, Clinical Leader Cancer and Chronic Illness, St Vincent's Hospital, Melbourne.

1. ***Are there any written resources on emotional wellbeing after a breast cancer diagnosis?***

   The Cancer Council's *Emotions and cancer* booklet provides information and practical advice on coping with common emotions after a cancer diagnosis. You can order a free copy by phoning the Cancer Council on 13 11 20, or you can download a copy from the Cancer Council website.

2. ***How do I deal with people who insist on providing advice on cancer, for example 'you must only eat certain foods', or those who tell you horror stories about people they know who died of cancer?***

   I hear this complaint quite a lot from people with cancer. People tend to provide advice because they care about you. However, if it isn't helping or is causing you stress, try telling them that their advice is not helping you and is actually causing you added stress. If you feel uncomfortable telling them directly, ask someone else to speak with them for you.

3. ***I have an issue with the word 'survivor' and don't like being referred to as one.***

   Those diagnosed with cancer have mixed views on this word. The important thing is to find a way to describe yourself that you are happy and comfortable with.

   (Another member of the audience then added: '*I find it helpful to say "Actually, I had breast cancer, but it has been removed. I no longer have breast cancer*"'.