



# Breast Cancer Support Inc.

Newsletter

October 2011

## Report from the Chair



**Having just returned from seven weeks overseas**, I'm still running to catch up with BCS's activities during my absence.

My thanks to Jane Bissell and the Committee for the work they have done, not only to keep things ticking over but also to move projects forward while I've been away – and for not disturbing my time with my family too much in the process! This month's newsletter is evidence that no-one has been resting on their laurels, and there are some exciting initiatives happening.

To mark Breast Cancer Awareness Month, BCS and our sister organisation, Breast Cancer Network NZ, are proud to announce the launch of an online forum for young New Zealand women with breast cancer.

The forum is hosted by Breast Cancer Network Australia on its website, and you will find details about how to sign on to it on page 3. I encourage you either to join yourself, or to tell any younger women attending your Breast Friends' group about it. We hope that it will be a catalyst for younger women experiencing breast cancer, where they can connect with one another, share information and experiences, and provide each other with friendship and support. The more young women who use it, the more useful it will be, so please spread the word!

Also high on our list of things to feel excited about is the BCS-sponsored retreat 'The Nurturing Journey' from 18–20 November. This is a new departure for us, and is being offered free to BCS group members in the peaceful surroundings of the St Francis Retreat Centre. Set in three hectares of old parkland in Hillsborough, this is one of my all-time favourite places: an oasis of calm in the midst of life's busy-ness. I can highly recommend it (and the food is good too!), so why not treat yourself to a couple of days of uninterrupted 'me' time? If you are interested in attending, please contact Jane or your Group Co-ordinator for more information as soon as possible.

In August Jane Bissell attended two very worthwhile events south of the Bombay Hills: a networking meeting with a number of regional cancer support organisations in Tauranga, and a conference addressing life *after* cancer, organised by the Wellington Cancer Society. Her reports on these events highlight recent developments in cancer care, and how both support organisations and the medical profession are changing to meet the long-term needs of people diagnosed with cancer today. Read the issues raised at the Wellington conference on page 2 – perhaps discuss them at monthly Breast Friends groups and let us know what you think. After all, it's us they're talking about.

With best wishes,

Deirdre Parr

**Breast Cancer Support Inc.**  
PO Box 10150  
Dominion Road  
Auckland 1446

**Web: [www.breastcancersupport.co.nz](http://www.breastcancersupport.co.nz)**  
**Email: [admin@breastcancersupport.co.nz](mailto:admin@breastcancersupport.co.nz)**  
**Phone: 0800 BreaCanSupport (0800 273 222)**

### Inside this issue:

Report from the Chair	1
'I'm still standing' Life after cancer Conference	2
The Nurturing Journey Retreat	2
BC Support Networking Meeting	3
New online Forum	3
Supporting BCS	3
Breast Friends News	4
A lymphoedema story	6



*BCS gratefully acknowledges the support of our primary funders and sponsors, the NZ Lottery Grants Board, COGS, the ASB Community Trust, the Guardian Trust, and Zeald.com. We also thank the team at Alpha Copy Centre for their support of BCS and to Zonta for keeping us well supplied with the 'moon cushions' that are of such comfort to our ladies.*

## **'I'm Still Standing' – Life after Cancer Conference Wellington 20 August 2011**

Jane Bissell attended this fascinating conference on behalf of BCS, hosted by the Wellington Cancer Society on Saturday 20 August. The focus of the one-day conference was survivorship after cancer, an area that is receiving increasing attention and consideration by all medical professionals involved in the wide spectrum of cancer care. The focus of care for cancer has always been on diagnosis and treatment with conventional medicine but now discussion is focussing on what happens afterwards. Defining the needs of long term survivorship and wellbeing are now considered to be a vital component of a recovery from cancer and the hope is to establish supportive strategies and care programmes within the national health system as an integral part of cancer care. The conference was introduced by Dr. Simon Allan, Medical Oncologist, Palmerston North Hospital and he defined survivorship as the process of living with, through and beyond cancer. Challenges to survivorship include linking into ongoing support once discharged from specialists, trying to stay 'healthy' ("I have learned that to be healthy is to live with the health which my body has allowed me" - quote from a patient), and navigating the three phases of survivorship: acute, transitional and remission( cure with or without consequences). The key note address was given by Professor Bogda Koczwara, Medical Oncologist, Flinders University, Adelaide. Entitled "How can survivors change the world?" she stressed that the stories of cancer survivors are already changing the world. "It is not just about surviving the tumour," said Ms Koczwara, "it is also about the physical, mental and social survival." She quoted from a recent support group survey of patient needs and the need for information ranked higher than the need for support : more information about treatment choices and side effects ranked highest, then living with cancer, talking to doctors, followed by supportive care. Information empowers choice so it is of greater value than support alone. Presentations covered a wide range of topics associated with aspects of survivorship including the importance of exercise in a recovery from cancer, Māori models of whanau care, a comprehensive review of the psychosocial issues facing cancer survivors, the integration of survivorship care plans into conventional medical care and the vital importance of communication between the patient and all of those involved in his or her care throughout the entire cancer journey, from diagnosis, through treatment and recovery and beyond.

Jane noted some key points from the conference:

1. Importance of exercise came through in almost every lecture; clinical proof now supports benefits of exercise improving overall survival outcomes for cancer patients. Exercise should be 'prescribed' as part of cancer treatment and should be introduced/discussed at diagnosis time.
2. Importance of communication at all levels (e.g. specialist to GP) – listening with empathy and understanding, not sympathy – and providing appropriate information at the right time.
3. More emphasis to be placed on supporting treatment side effects e.g. weight gain, bone loss, chemo brain etc.
4. More emphasis on discussing fertility, sex/intimacy issues.
5. More discussion and support available for information – the gathering, sharing, how-to-find – with particular reference to treatment options and side effects impact.
6. National support strategies are needed for long-term survival issues – there is currently no unified approach to this issue, only pockets of support throughout the country – and patients need to be 'linked in' to these services.
7. Patient care plans – development of comprehensive 'take-away' resource for patients, listing all cancer medical history etc, plans for ongoing 'survivor' care, follow ups etc.

The conference presentations can be viewed on the [Wellington Cancer Society website](#).

## **The Nurturing Journey Retreat 18-20 November 2011**

**St Francis Retreat Centre, Hillsborough, Auckland**

Breast Cancer Support is pleased to offer *The Nurturing Journey Retreat* for those women currently attending any of our six Breast Friends Support Groups. The two-day retreat will provide time for you to relax, share and heal in the peaceful settings of the Retreat Centre. Register by Friday 14 October 2011—please email [support@breastcancersupport.co.nz](mailto:support@breastcancersupport.co.nz) to receive further information and registration details.



## Breast Cancer Support Networking Meeting Tauranga 3 August 2011



Breast Cancer Support Services Tauranga hosted a lunch networking meeting with representatives of their Trust, the Rotorua Breast Cancer Trust and Breast Cancer Support Auckland in August. Over a shared lunch, each group outlined their general programmes, activities, upcoming events and plans for the near future. Jane Bissell from BCS joined Julie Blake (Coordinator, BCSS Tauranga), Kath Vickers (Chair, BCSS TRG Trust), Barbara Hely (BCSS TRG Trustee), Marie Hills (BCSS TRG Trustee), Dell Gee (Rotorua) and Dianne Toulmin (Rotorua) to talk about the activities of each group, sharing ideas for everything from fundraising activities to extending services to provide support for people living with other cancers. The Rotorua Breast Cancer Trust is already hosting a regular Meditation Group open to both men and women living with cancer. The Group is proving to be very successful, providing not only the relaxation of meditation but a supportive environment for sharing and fellowship. BCSS Tauranga is a well-established organisation supporting women experiencing breast cancer. They offer some services to the wider cancer community as well, for example, the popular morning tea group at the Cancer Centre at Tauranga Hospital. BCSS volunteers take in home baking to serve with tea or coffee to patients receiving chemotherapy. Patients appreciate the company and the morning tea helps pass the time. For further information, the Rotorua Breast Cancer Trust can be emailed at [rbct@paradise.net.nz](mailto:rbct@paradise.net.nz) and BCSS Tauranga can be contacted on (07) 571 3346 or emailed at [bcsstga@clear.net.nz](mailto:bcsstga@clear.net.nz).

## New online forum for ‘Young New Zealand Women’

Breast Cancer Support and Breast Cancer Network (NZ) are very pleased to announce the establishment of an online group for *New Zealand Young Women*. The new Forum is kindly hosted by the Breast Cancer Network Australia (BCNA) and can be accessed by visiting [www.bcna.org.au](http://www.bcna.org.au). The Forum follows through on two of the many recommendations that emerged from the 2007 Rotorua Conference organised by BCN (NZ): ‘that technology be used to connect young New Zealanders experiencing breast cancer’ and ‘that an online group be implemented’. To join the online group, please begin by going to the BCNA site, click onto *Join our network* and create your online profile. The site does not currently recognise New Zealand post codes so please enter 3124 in the post code section. Once you have set up a profile, you can search for online groups using the *Find Groups* facility. Enter the keywords *New Zealand* into the Keywords Search box and then scroll down to locate the *New Zealand Young Women’s Group* page. Once you reach the page, you can then register your interest in joining the group. This group is open to women who have experienced breast cancer and is currently facilitated by Breast Cancer Support. If you have any problems registering or would like further information, please contact BCS at [support@breastcancersupport.co.nz](mailto:support@breastcancersupport.co.nz)



### Supporting BCS

***BCS gratefully acknowledges the support of our members and donors. It is through your generosity that we are able to provide our support services to women experiencing a diagnosis of breast cancer. Would you like to become a member of Breast Cancer Support or make a donation? Please complete this form below and post back to us at Breast Cancer Support, PO Box 10150, Dominion Road, Auckland 1446, or call us on 0800BreaCanSupport (0800 273 222) for more information. Thank you!***

Name.....

Phone(0 )..... Mob.....Email .....

Address.....

My membership/donation is enclosed:

Individual membership (\$20)  Group (\$30)  Unwaged (\$15)  Joint (\$30) I enclose a donation of \$.....

I am a breast cancer survivor  I would like to volunteer - please contact me

Please contact us for further information on 0800 BreaCanSupport (0800 273 222) or email us on [admin@breastcancersupport.co.nz](mailto:admin@breastcancersupport.co.nz). **Donations over \$5 are tax deductible.**

## Breast Friends – News from our Support Groups

*Our Breast Friends groups have enjoyed some great meetings so far this year with informative and inspirational speakers, social events and more. Those attending enjoy fellowship and the support of others who have 'been there too.' If you would like to know more about any of our six groups in Auckland, please call us on 0800 273 222.*



*Lynne Melton spoke to Central about book restoration .. and in August Central members packed daffodils for the Cancer Society's Daffodil Day.*



*Central's Christine Rule has written and published a collection of short stories.*



*East Members had a go at scrap booking.*



### Central (from Christine Rule)

In July we were pleased to welcome a new lady from Iran and one of our Members gave birth to a baby girl on June 29th and we are thrilled to announce that mother and baby are doing well. Our guest speaker was group Member Lynne Melton who shared her hobby of making books and small boxes, ideal as attractive gifts. Lynne also restores damaged books and showed us samples of marbling both with water and oil based paints and explained the purpose of the individual tools which she uses for her work. Some of the covers are made of beautiful soft leather. The afternoon concluded with afternoon tea, much laughter and talk.

Our group is grateful for the use of rooms at Domain Lodge for our meetings and so in August we offered to pack the small daffodils for the Cancer Society in preparation for Daffodil Day. By the end of the session, we'd packed 9000 daffodils into plastic bags containing 50 daffodils in each. Although women can multi task it is not easy to speak and count but laughter and counting is possible!

Rough weather in September was no deterrent for the 17 women attending. Our first guest speaker Kaye Hatton explained the basics of scrap-booking and had prepared some very useful hand-outs for us. Scrap-booking can be therapeutic after an illness or operation and is a wonderful way to capture the lives of children and family, old and young. Iona MacDonald gave us a brief description of the book *Depression: Natural Remedies that really work* which she co-wrote with Professor Shaun Holt and Group Coordinator Christine Rule presented her new book of thirty-four short stories, *Lost and Found*.

### Hibiscus Coast (from Barbara McLean)

July saw a low-key meeting as we knew many of the group would be unable to attend due to school holidays, but twelve of us braved the winter chill! We talked about new treatments, in particular one a Member of the group is undertaking called GcMAF, which seems to have hugely exciting possibilities, so we will be following her progress with interest over the next few months. The discussion ranged over a number of health issues, from aromatase inhibitors and their side effects through alternative medications to Lipex, and on to Lymphoedema and the lack of therapists in the Waitemata Health Board area. The highlight of the discussion was when Juliet announced that the Orewa Rotary have made funds available for testing for the BRCA gene in families with a history of breast cancer. Once again the group enjoyed a good discussion meeting in August. We followed up with our Member who is having the GcMAF treatment and discussed the theory that cancer can result when the digestion is impaired. This led to a spirited analysis of the digestive process! We also discussed bras and prostheses and indeed had so much to say for ourselves that the meeting ran well over time, ending up with small groups still chatting in the sun in the car park until nearly 1pm!

### East Auckland (from Jennifer Woodroofe)

Fourteen ladies attended the September meeting of the East Auckland Breast Friends and our topic was one we had not covered for three years, making scrapbooks! We had piles of magazines, travel books, craft books and other associated paper material for the ladies to do what they wished. One lady did pictures of animals in hers, another did places but most chose to do something that would appeal to a child. Naturally, they did not get finished, so the ladies took them home to finish off and give away. We had a great meeting, and lots of chatter with several items of interest for the group to discuss.

### West Auckland (from Marie Goudge)

The seventeen women attending our July meeting were challenged to think about the extra ramifications of a breast cancer diagnosis on young women. The women were guided by Rosemary

## Breast Friends – News from our Support Groups

Geard who recently attended a Conference in Australia which concentrated on the impact that breast cancer can have on women younger than 45. Many issues surfaced, including: Where is my peer support? How and when do I tell a potential partner I've had breast cancer? Will I be able to have children after chemotherapy? Should I consider having some eggs preserved? Who will look after my children while I have treatment? Will my boss be sympathetic? Should I try to soldier on without telling anyone at work? How can I spare my elderly parents this worry?

It was clear that younger women did have specific issues that applied to them only.

It may have been a cold August night but there was warmth a-plenty when the West Auckland women met at Stan and Marie Goudge's home for a "Pot Luck" meal and social evening. In the relaxed atmosphere there was much sharing and supporting of each other. Mr. Mystery, the magical entertainer (Stan Goudge) and Mr. Bright Eyes, the white rabbit, provided entertainment. The owner of a beautiful diamond ring was puzzled as to how her ring could end up in a locked set of boxes when she had carefully given it to her friend to hold. Everyone went home feeling warmer and a little more confident because of the friendship and hospitality they had experienced.

September saw us all hearing about the joys of Dragon Boating! Robyn Gamble, Lynn Simmons and Toni Girver from the Pink Dragons team spoke with passion about their chosen sport. Paddling in the fresh air is the ideal way to discard the tensions that build up from our busy life styles. The camaraderie is strong and the exercise improves fitness. Women from all backgrounds and all ages belong to the Pink Dragons but the bond that these women have and the affection they feel for each other springs from their common meeting point – breast cancer. It was lovely to have little Max with us too. Max is the infant son of one of our members. His little fresh face and frequent smiles sent ripples of innocent happiness around the group. Max, you remind us there are a lot of good things to be enjoyed in life. We adults often make things so complicated. You charmed us all and when you got tired you went to sleep. Perhaps we could learn from you!

### North Shore (from Jenny Short)

It was the usual cold grey, miserable evening one becomes used to in July, so we didn't expect a great turnout. People often prefer to hunker down near the fire on those nights. However, to our surprise we had a gathering of twenty ladies: some new and keen to make contacts, others old friendly faces wanting to renew acquaintances and share experiences. But all of us were eager to meet Megan from Pink Pilates, to hear what happens at a Pilates session, learn how it can help us and to find out how to join her Pink Pilates group. Best of all, we were able to try some exercises with her there and then. Because we had such a good turnout, there were not enough mats for all to do the floor exercises, so we exercised in a standing position instead. I can attest to the fact that standing can be very effective as well. Megan is a great teacher. Some of our members are already participating in her group and are reaping great fitness benefits.

### Auckland South (from Jill Mellow)

In September we enjoyed a talk given by one of our members who had recently returned from a visit to Melbourne. She had gathered a collection of Australian booklets and pamphlets from the Cancer Society and had also picked up a DVD called *Just take it day to day: A guide to surviving life after cancer*. The DVD explores what it is like to finish cancer treatment and then move on. People who've been through cancer tell their stories and the DVD includes information from health professionals, who comment on emotional and physical changes after treatment.

*Disclaimer: The views expressed in this newsletter are those of the individual contributors and do not necessarily reflect the views or policies of Breast Cancer Support Inc.*

*West Members enjoyed a 'pot luck' dinner in August ..*



*...with a special appearance from Mr. Bright Eyes and Mr. Mystery.*



*Members of the Pink Dragons dragon boating Team visited West in September.*



*For information, contact the Ascot Radiology Pink Dragons by emailing [info@pinkdragons.org.nz](mailto:info@pinkdragons.org.nz)*



*For information about Pink Pilates, [visit the website](#) or email [lou@pinkpilates.co.nz](mailto:lou@pinkpilates.co.nz)*

***Would you like to join one of our Groups? Phone us toll free on 0800 273 222.***

## Emily's Lymphoedema Story



Approximately six weeks after my mastectomy I noticed that my arm was swollen (over 5 cm larger than my other arm initially). I visited the breast care nurse who measured my arm with a bioimpedance machine. My reading was initially normal but I was referred to the hospital physiotherapist who specialises in the management of lymphoedema. I say 'management' because lymphoedema is a chronic condition resulting from lymphatic dysfunction or disruption. It is often difficult to diagnose and manage but the bioimpedance machine gives health practitioners more information.

It was at least another month before I was finally diagnosed with lymphoedema and a few more weeks before I got my first compression garment. Unfortunately, I was only given a compression sleeve which made my hand worse and the glove, when I received it, fitted incorrectly. All the while, my arm was causing me great discomfort. I was annoyed over the slow diagnosis as I have read that if lymphoedema is picked up early and treatment/management begins straightaway, the results can be good for many people. Throughout my chemotherapy I saw a physiotherapist weekly and she demonstrated correct lymphoedema massage techniques. I massage my arm every morning for around 15 minutes and most nights for one hour. Massage makes a huge difference but it's important to know what you are doing and seek professional guidance from a trained lymphoedema therapist.

My lymphoedema was still unmanageable as I went through radiation treatment. Under the public health system I was entitled to one compression garment every six months which was concerning because the compression garments I had weren't doing the job. At this stage, I could barely hold a pen in my fingers so I decided to seek private help.

I researched the [www.lymphoedemanz.org](http://www.lymphoedemanz.org) website for a qualified lymphoedema therapist and fortunately had someone recommended to me. I visited this lymphoedema therapist every week during my radiation treatment and for the next five months on a regular basis. The private treatment wasn't too expensive and my therapist worked, in consultation, with my hospital based physiotherapist. Treatment involved massage, bioimpedance measurements and I trialed a hydroven massage machine at home every morning for a week under the therapist's guidance. I'm not sure this worked well for me.

I was horrified one day when I developed cellulitis in my arm from what I suspect was a n insect bite. This was treated at my local A&E Clinic over three days with IV antibiotics. (I sought immediate medical advice—if delayed it normally means a hospital admission). Lymphoedema does put you at a higher risk of developing cellulitis.



By May 2011 my lower arm was still very large and becoming fibrotic (the tissues swell with protein-rich lymph and cannot drain properly). My lymphoedema therapist is very qualified in this area and I agreed to try binding for one week. My arm was bound 24/7 and it took all my will power not to rip it off after the first half hour. It was incredibly prickly and uncomfortable. Each day I visited my therapist so my arm could be checked and rebound. I believe it made a measurable difference (size of arm and comfort levels) for me. The following week I was fitted with a new custom made compression 'all in one'

sleeve and glove. It is amazing and has made all the difference to the way my arm feels and functions on a daily basis with lymphoedema. Although it looks tricky to put on it is really straightforward. These garments require regular hand washing and are replaced after about six months.

In September 2011 I started swimming again for the first time in a year, great exercise for lymphoedema. I have been advised to go often but only do a little to start with. This is hard advice to take but lymphoedema is such a difficult condition to live with and manage so I always take the advice of my therapists. I also use a mini 'rebound' trampoline (lymphasizer) two/three times a day. Another breast cancer survivor told me about this and I can do it 'rain or shine'. I had all my bras refitted and the straps across the shoulders and back lengthened to reduce pressure on my affected arm. I will only ever see the one undergarment specialist from now on as the advice and guidance I receive from her has made a huge difference to my lymphoedema condition.

After nearly a year and many hours with both private and public lymphoedema therapists and physiotherapist, I believe I have finally 'got to grips' with helping myself manage my lymphoedema. I still have regular checkups with my occupational therapist at Waitemata Health who is trained in the management of lymphoedema. She is reassuring and I always leave my appointments feeling positive.