



Breast Cancer Support Inc.

Newsletter

December 2009

Report from the Chair, Marie Goudge



Christmas is on its way. I know it will be here soon because the Christmas lilies are blooming. When we lived in Dunedin the lilies were always in full bloom on Christmas Day but in Auckland they herald the approach of Christmas by blooming in late November or early December.

For me, these beautiful white lilies with their golden stamens and sometimes overpowering perfume have another significant meaning. They remind me that it was at this time of the year I was diagnosed with breast cancer. I had a mastectomy in November 1980 and the lilies were blooming when I came home from hospital. Isn't it strange how things trigger memories? I also remember the crisp lettuce and tomato salad my husband prepared for my lunch that day. That is the best lettuce I have ever tasted. Salads were not on hospital menus in those days. Are they offered now?

Many of you have visited the BCS website – www.breastcancersupport.co.nz – since our last newsletter. It has been growing steadily with more information, photos and links being added weekly. In the last report the monthly website visits had doubled compared with the previous month. Overseas people are linking on too. All of this is very encouraging because it is offering support of a different kind to a wider range of people.

The decision to contract out some of the administration of BCS to Jane Bissell is reaping benefits for the organization. The committee is achieving so much more and has the sense of finally accomplishing some of its goals. The challenge is to keep a sufficient flow of money coming in to finance the service. At this point I mention that any extra contributions from our members and friends will be gladly received! Donations over \$5 are tax deductible.

The long awaited brochure should be ready for distribution early in 2010. It was decided that quality photographs were important if the BCS brochure was going to carry the desired message and image. We wanted to portray real women who knew about being diagnosed with breast cancer and how important peer support had been for them. We felt such women would stamp authenticity onto the brochure and perhaps give encouragement to other women travelling a similar road. An SOS for volunteers from the Breast Friends groups brought 24 women together for a special photo shoot. Marie Richards from "Photographymarie" took the professional photos. Marie had a perfect understanding of what was required and her skill and sensitivity for the occasion has provided BCS with an extensive photo bank which will serve us well.

The afternoon turned into quite a social get together with women from the Hibiscus Coast drinking coffee in the garden with those from Papakura and elsewhere. Some of the photos

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- To become a Member of BCS, or to make a donation to support our activities, please complete the form in this newsletter and post to us.
- For information about our support services, please contact us on 0800BreaCanSupport (0800 273 222) or visit our website and complete the Contact Us online enquiry form.



Coordinators met in September at Domain Lodge for a Workshop to share ideas and suggest improvements for the Groups.

A Social Evening for members of Breast Friends groups will be held at Domain Lodge Monday 14 December at 7.30pm. There will be a surprise performer, plenty of food and the good company of those attending! Please RSVP to (09) 835 1890 or (09) 274 1192.



can be seen on the BCS website.

Another social function that several of the BCS women attended was a fund raising dinner arranged by the women of the Auckland West Zonta Club. Zonta is an International organization which strives to “advance the status of women globally through service and advocacy.” Zonta is in 68 countries and has 33,000 members. The guest speaker for the evening at the Titirangi Golf Club was Liz Mitchell, one of NZ’s leading fashion designers. BCS is sincerely grateful to the Zonta Club for the proceeds from the evening which will fund a large proportion of the costs for creating the brochure.

On the 27th September the Coordinators and others who help lead the groups met at Domain Lodge for a Workshop to share ideas, collect written material, plan and suggest ways of improving the support BCS offers to women who attend the groups. The evaluation sheets collected at the end of the day suggested that the programme had been helpful and that further similar days would be appreciated. The committee is committed to supporting the leaders of the groups. They too, need to know they are “not alone”.

Last year in response to requests from members of the Breast Friends, that they would like to meet women from the other groups, a social evening was arranged. It was so successful a similar function is being planned for the 14th of December this year. It will be at 7.30pm at Domain Lodge. There will be a surprise guest performer again, plenty of food and those attending will provide the entertaining and witty conversation. All are invited and an RSVP to 835 1890 or 274 1192 would be appreciated.

Happy Christmas! May joy and peace dominate your lives this Christmas and throughout the year.

Marie Goudge, Chairperson, Breast Cancer Support Inc

Supporting BCS ...

BCS gratefully acknowledges the support of our members and donors and wishes to thank the JR McKenzie Trust, NZ Lotteries Commission, COGS and Zonta for their donations towards our work in 2010.

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 Rd, Auckland 1446, or call us on 0800BreaCanSupport (0800 273 222) for more information. Thank you!

Name

Address.....

..... Phone (0)

Email Mob

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 info@breastcancersupport.co.nz.



Clinical Trials—Improving Breast Cancer Care

(We thank Jenni Scarlet for her permission to reproduce this abridged version of her article)

What is a clinical trial?

Clinical trials are research studies where a new treatment is tested against a best available or standard treatment. In cancer care, a clinical trial is one of the last stages of a lengthy and careful process that often starts many years earlier in a laboratory. New cancer drugs are required to go through a number of safety checks before being used in humans. The testing of a new drug progresses in an orderly series of steps called phases. New drugs are first tested in people with terminal illness. If effective in terminal or advanced cancer they can then be tested in people with early cancer.

What types of clinical trials are there?

Trials are carried out to find out whether new and potentially promising ways of detecting, preventing or treating cancer are possible and if they are safe and effective.

- Detection or screening trials evaluate the best approach to find a cancer in its early stages; for example, mammograms (breast x-rays) or cervical smears.
- Prevention trials test new approaches; for example, use of medicines or healthy lifestyle changes; that may lower the risk of getting a certain cancer.
- Treatment trials test new treatments, for example, drugs such as chemotherapy or hormonal treatments. New radiotherapy or surgical techniques are also tested. Counselling and psychological support or ways of providing better communication are also part of treatment trials.

Why participate in a clinical trial?

The most common spontaneous feedback regarding why women take part in breast cancer trials is that their participation may help future generations. Participation in a clinical trial does assist with the advancement of medical knowledge. People take part in trials for a number of different reasons. They may receive a new treatment before it is widely available to other cancer patients. Evidence shows people can also have a better outcome because they have been involved in a trial, even if they have received a standard treatment. This may be because most participants on a clinical trial receive carefully and often more rigorously monitored treatment and follow-up.

What is a trial protocol?

Researchers testing new cancer therapies follow strict guidelines. Prior to starting up a trial a detailed action plan of how the research will be carried out is written. This is called a protocol. Before a clinical trial can commence the protocol must be reviewed and approved by an ethics committee at each centre or hospital where the research will take place. The ethics committee will particularly want to check that potential participants are given very detailed information and prior to approving a trial, what risk of adverse events are present, if any. The research team carrying out the trial must follow the protocol which gives instructions on such things as;

- reasons behind doing the trial,
- what patients are suitable for participation in the study and how many will participate in the study,
- how treatments will be given (e.g. by mouth, injected into the blood or muscle),
- what trial tests will be done and how often,
- how patients will be monitored, what information will be gathered and how results will be analysed and reported.

Is a trial suitable for you?

Your Oncologist (Cancer Doctor or Specialist) may suggest that you consider taking part in a clinical trial. Or if you are interested in taking part in a study but have not had this suggested, ask your Oncologist. A patient information sheet giving the detail of the research will also be given to you before you agree (consent) to take part in a trial.

Clinical Trials—Improving Breast Cancer Care (cont.)



Jenni Scarlet is a Research Nurse at the Breast Care Ctr at Waikato Hospital, specialising in breast cancer research. She is also the co-ordinator of the breast cancer research office at Waikato Hospital. If you would like more information about clinical trials, please contact BCS.

In our next newsletter, we will feature a story by BCS member Rosemary Geard who participated in a recent clinical trial.

Why are clinical trials important in breast cancer care?

All the major advances in controlling breast cancer have been the result of clinical trial research. This includes scientific proof that, for example: drug treatments (including chemotherapy and hormonal treatment) following breast cancer surgery cure some women, and delays recurrence in others; sentinel node biopsy can replace routine axillary dissection in some women with small breast cancers; targeted drug treatments benefit breast cancers which have specific features present e.g. Herceptin for HER 2 positive breast cancer

It is extremely important that all new therapies and procedures be scientifically proven and long term safety determined before they can be recommended for general or standard use. Additional tests or questionnaires to fill in regarding a patient's feelings or side effects to treatment are required to evaluate safety and impact on quality of life. This all helps with the collection of detailed and accurate information and thus the overall accuracy of trial results.

Where are the participating centres for breast cancer clinical trials in New Zealand?

In New Zealand, breast cancer clinical trials are available at Cancer Centres or Breast Clinics at North Shore, Auckland, Waikato, Palmerston North, Wellington, Christchurch and Dunedin Public Hospitals. Some cancer specialists in private clinics participate in breast cancer clinical trials.

Breast Friends - News from our Support Groups

Central Auckland

In September 19 ladies and 2 new Members met to hear Jane Carden speak about herbs – and some weeds! – and their use in cooking, simple medicinal or healing. Jane did warn us not to use herbs to excess and to identify them correctly before using them. In spite of members with broken bones, flu, and others away on holidays, we had 14 ladies at our October meeting and welcomed one new lady. Marie Goudge spoke about theatre production which was not only interesting but also entertaining. Our November meeting welcomed another new lady bringing our total for the meeting to 15. We watched the video 'Voyage of Rediscovery' about a group of women who'd had a cancer diagnosis, unknown to each other prior to setting sail on a yacht in the Sounds. Not only did they share their cancer journeys but shared wonderful experiences too.

Hibiscus Coast

8 ladies attended the September meeting. One who attended was new, less than a month out of surgery, and had heard about the group through a leaflet from the hospital. We discussed a variety of subjects, from the merits of being assertive enough to change a GP or specialist if unhappy with the level or style of treatment received, to the perennial topic of bras. Georgea had brought along the beautiful album she has created of photos from all our luncheons. She would like to make a second one of the first Relay for Life that our group took part in, plus newspaper clippings of members spreading the Breast Friends message. In October we had 17 ladies present plus Lyn Mourant, Marie Goudge and Deidre Parr from BCS. Marie and Deidre told the group about the work BCS does. They covered a wide variety of topics such as the general structure of BCS, the website and its constant need for items, Jane's role as Admin support, the upcoming brochure, funding and the need to submit all invoices to create a paper trail to prove the need for funding to possible fund providers. The discussion also included the 2010 Relay for Life. One of our new ladies had questions about reconstruction, so a couple of our younger ladies had a quiet chat with her. Both new ladies stayed on after the meeting, saying they had found it helpful to talk to others who had been through similar experiences.

West Auckland

15 women attended the September meeting. Guest speaker Mari May-Hanley, a Cancer Society Liaison Nurse reminded the women of the many services that the Cancer Society offers to those diagnosed with cancer and also the support available for their families. There is a free library, excellent booklets about specific topics and the Cancer Helpline on 308 0162 or 0800 CANCER (0800 226 237). 13 women attended the October



Breast Friends - News from our Support Groups

meeting where we evaluated the effectiveness of our Group and planned for the future. 4 women will now run the group and we discussed why we attend. One woman wrote: 'It reinforces that you don't have to be isolated – sharing is very beneficial.' In November, 15 women heard Marilyn Bellingham, the Breast Care Nurse for the North Shore and Waitakere Hospitals, speak about various breast cancer trials taking place. It is very encouraging to hear that new drugs are being developed and that the trials are looking so promising. Marilyn answered many general questions and the group was delighted to hear that breast cancer services were being extended at the Waitakere Hospital. The women from the West find it a long trek to the North Shore Hospital for all their follow up treatments. Several of the women volunteered to help with the Cancer Society's Relay for Life at Mt Smart. Almost all will attend the Social evening at Domain Lodge on the 14th December. They remember a very enjoyable similar evening in 2008. Some are planning an unofficial coffee morning in January. A ring around will ensure everyone is invited.

North Shore

In October, we held a Potluck International dinner. Everyone brought a dish that reflected their home country or background. We had a wide range of exotic delights as some of the ladies who attended were from Korea, Japan, Singapore, Malaysia, Canada and Switzerland. 13 members and 2 support people attended the November meeting at the Senior Citizens' Clubrooms in Takapuna. It was great to see young ones – in this case a daughter and a daughter-in-law – at the meetings. Of course, they not only learn more about the health of the loved one they are supporting, but also learn for themselves, hopefully, so that they can avoid problems in the future. We also had two new members and their contributions to discussion made for a very lively and informative night. Megan Clarke spoke about Pink Pilates and how it can help restore core body strength and stomach muscles after breast operations. Megan practices at Albany, sessions cost \$60 per hour but if within two years of diagnosis, the Pink Pilates Trust will subsidise these sessions so the cost is only \$10 per session for ten. A medical referral is not required to attend Pink Pilates.

Pakuranga

In September Sue Corin, a registered Lymphoedema Therapist, spoke to 20 ladies about lymphoedema. Sue and colleague Diane gave an informative talk on the lymphatic system, causes of lymphoedema, prevention and treatments. One of our 10+ year members is moving up to Orewa, so a special supper was provided by the members and a presentation made. We will miss her. In October 14 ladies enjoyed a film evening, sitting back to watch *Jonna's Body* with popcorn and ice-cream in tubs!

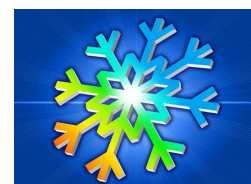
Auckland South

14 ladies and 2 men attended the September meeting. We welcomed a new lady to our group and Cathy Bray spoke on reflexology and remedial massage. She demonstrated the various points on the feet that relate to different parts of the body, saying that reflexology increases the sense of vitality and equilibrium and stimulates body processes and relieves stress. Cathy also teaches the Bowen Technique and chair massage. In October we enjoyed an evening with Deborah making Xmas Cards. She showed us how easy it was to make these cards by stamping and using a few embellishments. Deborah demonstrated the "Stampin Up" system for making cards and scrapbooks. Annette offered her home for the November meeting. Marie and Mary attended from the BCS Committee. Heather and Susan taught us how to wrap parcels and make beautiful bows. Some organised members were able to wrap and decorate their Christmas presents!

Don't forget the BCS Social Function, 14 December 2009!! 7.30pm, Domain Lodge

BCS will hold its annual Christmas social on the evening of Monday 14 Dec. for Members and Breast Friends. Mark this date in your calendar now and we'll remind you again closer to the time!

"We discussed why we attend. One woman wrote: 'It reinforces that you don't have to be isolated— sharing is very beneficial.'"



Sharon's Story



Sharon

I came to New Zealand in September 2003 aged 36 and was diagnosed a month later with breast cancer. I had a partial mastectomy in December, started chemotherapy in January and radiotherapy in May 2004. Not quite the new life I anticipated, in a life changing move half way across the world!

My experience with breast cancer was unique, no one's journey is ever the same! My family were all in the UK and I only had my partner for support. It is hard for some people to understand what you are going through and comments like 'what doesn't kill you makes you stronger' are all well and good but at times most inappropriate! I like to think of myself as a strong person but there were times when I realised how fragile my body was especially after the 4th round of chemo and 5 weeks of radiotherapy!

I felt so fortunate because we have wonderful support here in New Zealand for women experiencing breast cancer. The Breast Care Nurses and Counsellors from The Cancer Society were just lovely, so caring and compassionate. They introduced me to some of my closest friends by encouraging me along to a local support group. The Hibiscus Coast Breast Friends in Red Beach is free for women and I've met some amazing ladies there who shared their own experiences and gave me much needed information and support. This helped me to know I would be OK and I'd make it.

I volunteered to go to Sydney for radiotherapy, as resources were limited here in Auckland. I knew if I went it would allow one woman to stay at home with her family and it gave me a much needed change from 5 months of the same four walls. I had made a couple of friends who were going through the same treatment programme and one came to Sydney too. We didn't have much energy to spare but we made the most of it! Whilst in Sydney, I attended yoga classes at a local centre and I now appreciate the benefits of yoga practice. The centre offered acupuncture and other interesting healing modalities, which I tried as my body was under considerable stress and I felt the need to try and help my body. It was a special place for me as it made me realise my dream of opening a healing centre.

"Don't try to please everyone all the time.

Trust your instincts and listen to your body."

It took some time to regain my health following treatment. Conventional medicine has its place, however, I could see I would be prescribed continuous antibiotics to deal with my ups and downs with my immune system, unless I found an alternative solution. Through friends and recommendations, I started to explore complementary therapies. I took control of my own well-being and investigated what I could do to help myself.

I discovered Reiki a few years ago and was amazed at how well it worked for me. Reiki is an energy healing practice that engages your body's self-healing and helps improve immune function. Reiki is becoming recognised as a complementary therapy that can be integrated into any treatment plan for increased well-being. I was so impressed I trained to become a Reiki practitioner, which I now offer part-time. I am also a YWCA Encore course facilitator, co-facilitating programmes at Maygrove Village in Orewa.

My dream was realised in April 2009 when I opened The Sanctuary in Whangaparaoa (Auckland). We offer a variety of holistic therapies and hope to expand next year to offer yoga and meditation classes. I would like to see Health and Healing Centres throughout New Zealand offering community access to complementary therapies, yoga and meditation classes. Such healing centres provide options and choices for those wishing to enhance their well-being, especially when undergoing conventional medical treatments for illnesses such as cancer.

I have learnt it is important to ask yourself, 'What do I need to do for myself?' Don't try to please everyone all the time. Trust your instincts and listen to your body. Experience with any disease or injury provides an opportunity to learn about our bodies and tune in to what we really need physically, emotionally and spiritually. The past six years have been such a healing journey for me. I do not regret having had breast cancer as I know I would not have met such amazing people and wouldn't be where I am today. I know I am where I'm meant to be and living my dream.

For more information about The Sanctuary contact Sharon at shamor@clear.net.nz.