

Upfront U Kaiora

OFFERING INFORMATION, HOPE AND INSPIRATION TO THOSE AFFECTED BY BREAST CANCER

• PFOA and non-stick cookware page 6 • Rural Women page 4 • Faces of Breast Cancer page 8

ONE JOURNEY – MANY PEOPLE

REPORT ON THE UICC REACH TO RECOVERY INTERNATIONAL BREAST CANCER SUPPORT CONFERENCE

BY JULIE BLAKE, COORDINATOR, BREAST CANCER SUPPORT SERVICE TAURANGA TRUST

The 15th Annual Reach to Recovery (RRI) conference was hosted by Cancer Council Queensland in Brisbane, from 11 – 15 May 2009. It was an opportunity for staff and volunteers from Breast Cancer Support Service Tauranga Trust (BCSSTT) to attend an international breast cancer event, to share knowledge and experiences, learn from others and strengthen support services.

The conference provided a unique opportunity for volunteers, breast cancer survivors, advocates, family members and health professionals to join together and forge a lasting partnership to achieve the best for those who have experienced breast cancer.

BCSSTT has been a member of the UICC Reach to Recovery organisation for eight years. Our support visitor training programme is accredited by RRI and follows its principles and guidelines. Eight women attended from the Bay of Plenty, the most from any region in New Zealand, and we were pleased to meet up with a few others from Auckland, Christchurch and Hamilton to represent New Zealand. We are sure that “us Kiwis” did this with enthusiasm and style!

The conference programme was a very full four days for all of us, as we decided to include the pre-conference workshops to ensure that we got as much out of the experience as we could. And because many of the sessions ran concurrently we assigned everyone to different sessions so we could cover as many topics as possible.

The first day focused on Survivorship, covering such subjects as Benefit Finding and discovering a “new normal” after breast cancer; meeting the needs of breast cancer special interest groups; lymphoedema and breast cancer; quality of life after breast cancer; young women –



Breast Cancer Support Service Tauranga Trust delegates to the Reach to Recovery Conference.

fertility and early menopause; Women Power – women can change the system.

Day two was on Capacity Building – the matching of resources to services, ensuring adequate facilities are available, together with programme development and implementation. Sessions were about determining the needs of those going through the breast cancer journey and making sure those needs are being met at each stage of diagnosis, treatment and post-treatment, as well as those living with advanced breast cancer.

The final day was about Peer Support and this was the day where our group got to see ‘how we measured up’ and what we could do to improve our services. I can report from these sessions that the service BCSSTT provides within our community is comparable in quality to what is being provided in other developed countries. We adhere to the RRI mission and guidelines and our process of patient referral and follow-up, including communication with relevant health professionals is as good as, if not better than many other groups that work in

other developed countries. However, we did pick up lots of ideas and resources which, over the coming months, we will assess to see if any are relevant to our community.

With over 600 women attending from 47 different countries, it certainly opened our eyes to the global breast cancer scene. One of the lasting impressions that touched us all was the difference in breast cancer detection and treatments for women from developed countries compared with those from developing countries. While the incidence of breast cancer is highest in westernised countries (Western Europe, North America and Australasia), intermediate in the Mediterranean, South America and Eastern Europe and lowest in Asia and Africa, there is a distinct difference in five year survival from nearly 80% in developed countries to about



Sally, a BCSSTT support visitor dancing with one of the delegates from Kenya.

44% in developing countries. Women in developing countries often present with later stages of disease due in part to the lack of screening programmes, poorer education, lack of access to health care, cultural taboos and the stigmas attached to cancer. For many women, especially in male dominated societies, their greatest fear is that their husbands may abandon them.

We met many wonderful women from

some of these developing countries and listened to their sometimes tragic stories. It certainly made us all feel grateful for the level of care that women with breast cancer receive in New Zealand. We are fortunate to have so many groups that advocate on behalf of women and although it is not always a smooth road, together these groups persevere to achieve the best possible outcomes.

Finally, the women who attended would like to thank our sponsors – Medex Radiology,

Roche, Naturalwear Maceys and Smarta Fashions, who made it possible for staff and volunteers to attend and experience this wonderful conference. And thank you to our Board of Trustees for allowing us this opportunity for learning from a host of quality international speakers as well as the many women who attended from every corner of the globe.

SWEET LOUISE CELEBRATION IN WELLINGTON BY JANE BISSELL

Over 200 people are expected to attend a special event in the capital on 16 September as Sweet Louise celebrates the launch of its services in Wellington.

The evening event will be held at Samuel Marsden Collegiate School in Karori and many local business leaders, medical professionals, MPs and other dignitaries are expected to attend. A special invitation will be extended to many breast cancer survivors, too, and a Sweet Louise member will be one of the guest speakers at the launch event.

Expanding to the capital is a landmark event for the organisation, an achievement Executive Director Jennifer Clark is understandably proud of. "This is the beginning of our move to offer services throughout the country and has been possible only because of the generous support of the New Zealand Breast Cancer Foundation and the support of a large number of local friends of the Louise Perkins Foundation, led by Ginny Morrison."

Sweet Louise was established in 2005 to help women living with secondary breast cancer. Inspired by Louise Perkins – an Auckland woman who lived a vibrant and full life for many years with advanced breast cancer – Sweet Louise offers women practical services and complementary therapies through a free, voucher based system. Women can enrol as Members in the programme to receive an annual allocation of vouchers which they can use for many services such as home help, counselling and emotional support and complementary therapies such as massage, Reiki and reflexology. Sweet Louise sources local service providers to offer women a wide range of practical assistance and enjoyable experiences. Members can attend monthly meetings and special events, building a strong sense of fellowship and community.



Members' Meetings offer time for creativity, fun and socialising over morning tea – children and grandchildren welcome!

Sweet Louise has now helped over 360 women since its establishment in Auckland in 2006 and it is expected that the new Wellington service will increase member numbers by at least 50. Women are encouraged to enrol with Sweet Louise via the website (www.sweetlouise.co.nz) or contact the Support Coordinators on 0800 11 22 77 for more information.

From the Editor....

Activism and lobbying for women with breast cancer has, over the last two or three decades, made a huge difference in the lives of women diagnosed with the disease. From the early days in the US of “making the personal political”, individuals and organisations all over the world have made a difference. At the forefront of this “making a difference” has been the women with breast cancer fighting for more research, better detection and diagnosis, better treatment, longer and healthier lives and reduced mortality and prevention.

In New Zealand in 2009, there is a plethora of breast cancer organisations and it is clearly difficult for the public to know who is who and what we all do. However, what the public do see is the hand out asking for money. And we all know just how imperative money is if we want to do anything for women with the disease, whether it be risk reduction, better treatments, equitable access to care, raising awareness, supporting women with advanced breast cancer, or the ‘Holy Grail’ – a cure for breast cancer!

There is hot competition for the charity dollar and if you want to increase your claim on that limited pot of money you need to stand out from the rest. However, it strikes me that you need to do that in a way that doesn’t alienate or demean the very women you are trying to help. In the last few weeks, a billboard campaign by one of New Zealand’s most well known breast cancer charities, with the very noble mission of finding a cure for breast cancer, has succeeded in alienating many women who have had breast cancer. It is hard to know if their provocative billboards will succeed in bringing them any more of the cash they need towards achieving their mission, but it certainly has made people sit up and take notice – for all the wrong reasons.

Unfortunately, because the public can’t always differentiate between one breast cancer charity and another, other breast cancer organisations have had to field complaints from angry and upset women and men who feel that this campaign trivialises their personal and very traumatic battle with the disease. I have no doubt that this campaign was undertaken with the best of intentions, but one wonders how much market research was done and whether or not women with breast cancer were consulted. In our letters column, Sue McLeod asks of breast cancer charities “do you have any breast cancer women on your boards, trusts, management teams?”

I am involved with two breast cancer organisations, and both have women who have had breast cancer at an executive management level. There are a lot of women out there who have had breast cancer, and my experience is that they are generally very willing to share their experiences and thoughts in the name of making things better for other women.

It isn’t that hard to get out there and ask what the women themselves think. BCN did it with the 2007 conference; we got out there, right around the country, and asked what women wanted from a conference. Such a comprehensive exercise may not have been necessary for an advertising campaign – perhaps just a few women with breast cancer on the management team would have been enough.

It is hard to know if the public faces of breast cancer – all the various organisations – have been damaged by this campaign. But it seems clear that alienating women who’ve had breast cancer, and their families, friends and supporters, could make those people think twice about giving next time the hand is out and this won’t help any of us achieve our aims. I believe there is room for all the breast cancer groups in this country. We all offer something different and aim to support women and improve their lives in different ways. Perhaps, what we need is more women who have experienced breast cancer at the board tables, a little less of a spirit of competition among the groups for public money and a lot more of a spirit of co-operation.

Note from the Committee: BCN relies largely on community funding grants and individual private donations and bequests, and does not run a public appeal for donations.



PINK PILATES EDUCATION AND CERTIFICATION TRAINING COURSE

The 2009 Pink Pilates Education and Certification training course is to be held in Auckland on the 21st to 23rd of August. Twenty physiotherapists from Invercargill to Whangarei will be attending the course, run by Pink Pilates founder, physiotherapist Lou James and Breast Physician Dr Sonja Freese.

The Pink Pilates physiotherapy training course is designed for qualified physiotherapists. This very special three day training course has been carefully developed to help physiotherapists understand the entire breast cancer process from diagnosis to treatment, recovery, prevention of treatment side effects, and contraindications.

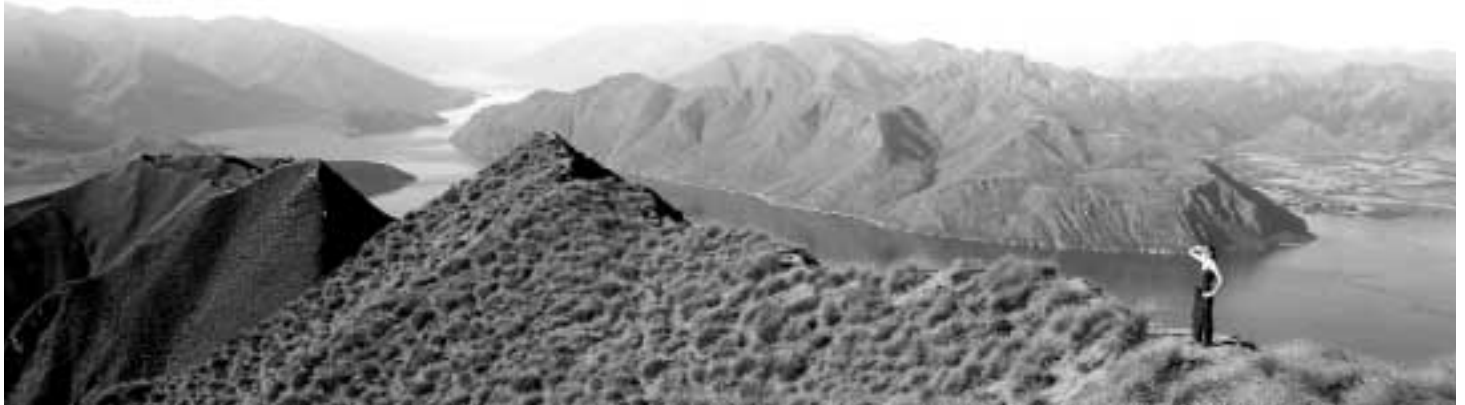
The Pink Pilates programme is designed to facilitate recovery from mastectomy, lumpectomy, and breast reconstructive surgery including TRAM flap, LAT flap and breast implant reconstruction. It aims to help reduce the risks of treatment-related side effects such as lymphoedema, shoulder problems, scar tissue formation, fatigue, and weight gain. The programme is dedicated to helping women diagnosed with breast cancer regain their physical strength, improve their body confidence and incorporate exercise into their lifestyle.

After breast cancer surgery many women are surprised by the symptoms there are experiencing and desperately need information about what to do after surgery to help themselves. Some women have very smooth recoveries with minimal discomfort, but some women experience disabling effects after surgery.

The medical tests, surgery and other treatments that follow the diagnosis, intensify a woman’s feelings of ‘a loss of control’. It is the role of a Pink Pilates physiotherapist to teach clients what they can do to help themselves to feel strong again; help clients understand why their bodies are reacting to the surgery and treatments in certain ways; provide information to help them feel more in control of their bodies and their lives again. While every woman’s experience is unique – there is a range of common physical and emotional responses which will be addressed in detail during the training programme.

THE TYRANNY OF DISTANCE: BREAST CANCER IN RURAL NEW ZEALAND

BY SUE CLARIDGE



Living in the country has many advantages over living in the city, but, as participants in BCN's First National Conference in October 2007 attested, this is not the case when one is faced with a serious illness.

The "tyranny of distance" was a phrase coined by author Geoffrey Blaney, in a book by the same name, highlighting the extent to which isolation has shaped and moulded Australia's development. It is an apt summation of the impacts on rural and provincial New Zealanders when dealing with a serious

illness. In fact, distance from providers of the required treatment and care, and the hardships imposed by that distance, were the main issues of concern among women attending the Rural Women workshop and remain the main concerns among those interviewed for this article.

This "introduction" to the issues facing women with breast cancer living in the country will consider the challenges in accessing medical services, treatment and care and in subsequent articles we will

attempt to reach some conclusions about how their needs can be best addressed.

CANCER IN RURAL AND PROVINCIAL NEW ZEALAND

There is no clear cut classification of rural and urban and various definitions are used. Thus it is hard to accurately characterise who we mean when we talk about rural and provincial New Zealanders with breast cancer. Originally based on population numbers, the modern classification is determined not only by where a person lives but the proportion of the usually resident population whose workplace addresses are within a larger urban area, giving rise to three urban and four rural categories (main urban, satellite urban, independent urban, rural with high moderate and low urban influence, and highly rural or remote).

According to Hayley Bennett and her colleagues, who investigated the effect of urban versus rural residence on stage at diagnosis and survival for women with breast cancer in New Zealand (*New Zealand Medical Journal*, 2007), of all the women who were diagnosed with breast cancer between 1998 and 2002, 73.3% resided in the main urban areas, 3.3% in satellite urban communities, 13.3% in independent urban communities and 10.2% collectively in rural and remote areas.

There are six cancer centres in New Zealand: Auckland, Hamilton, Palmerston North, Wellington, Christchurch and Dunedin. According to the research by Bennett et al. just under a third of the cohort of women they studied lived within ten

CONFERENCE RECOMMENDATIONS

These are the main issues facing rural women as set out by the conference participants, and the recommendations for improving the outcomes for women with breast cancer, now and in the future.

Issues and Discussion Points:

- access to public transport and funding for travel;
- lack of resources;
- phone and internet coverage;
- distance for family and friends to travel while the patient is having treatment;
- information regarding treatment options;
- treatment may involve more than one district health board and the problems associated with that.

Recommendations

- Health care professionals need to be informed that rural patients need all information packs provided at the first visit and that GPs are not always the "first stop".
- Privacy legislation prohibits volunteers being able to offer help as they are not permitted to be informed of women in their areas – this aspect needs to be addressed.
- There is a need to co-ordinate equipment between DHBs as patients may be left hundreds of kilometres away and cannot be nursed appropriately.
- Patients need better information on the travel subsidies available.
- Although rural women understand the restrictions imposed by cost, rural patients' needs must be considered at local and central government and policy making level.

kilometres of a cancer centre, one third lived between 11 and 50 kilometres away, 15% lived between 51 and 100 kilometres away, while 22.3% lived over 100 kilometres away from a cancer centre.

In another study by Dr Robin Haynes and colleagues (*Social Science and Medicine*, 2008) New Zealanders diagnosed with five common cancers between 1994 and 2004 were investigated for the combined effects of ethnicity, deprivation and geographical access to health services on the likelihood of survival. The researchers found that for breast cancer patients half lived within 2.1 minutes travel time of a primary health provider (e.g. GP), and half lived within an hour's drive of one of the six main cancer centres, but that there was a small number of patients with a very high travel time.

DISTANCE AND SURVIVAL

International research has identified that there are urban-rural health disparities and research in Australia, the US and Canada has found that people living in regional and remote areas have higher mortality rates than people living in urban and suburban areas; one of the major contributors to high death rates is cancer. Bennett et al. refer to research that has found both later stage at diagnosis and poorer survival in rural residents. For example, a study of over 60,000 patients in Scotland diagnosed with one of six common cancers, found that increasing distance from a cancer centre was found to be associated with poorer survival.

However, the studies by Hayley Bennett et al. (2007) and Robin Haynes et al. (2008) in New Zealand both concluded that there is no disparity in outcomes between rural and urban breast cancer patients. Bennett et al. found that there was no statistically significant difference in stage at diagnosis or survival. Haynes et al. found that while there were disparities based on ethnicity (poorer outcomes among Maori versus non-Maori) and residing in an economically deprived area, "there was no evidence that people living furthest from a GP or from a cancer centre were diagnosed at a later stage in the disease than those living closer."

The only survival disadvantage was the

already well known poorer survival associated with later stage at diagnosis, which in itself was not associated with distance from primary health care or a cancer centre.

THE ISSUES FOR RURAL AND PROVINCIAL WOMEN

While it must be comforting for women in rural and provincial New Zealand to know that they are at no greater risk than city dwellers of being diagnosed with more advanced disease, or dying from breast cancer by virtue of where they live, the distances that they must travel to obtain treatment, are nevertheless, disruptive and difficult, and impose hardship on many families.

We talked to three women from different parts of the country about those issues that were of greatest concern to them because of their geographical location. Pauline, Robyn and Lesley are all women who live some distance away from their nearest cancer centre. While all live near a primary health provider – their GPs – all three had to travel some distance to obtain all the treatment that they were recommended to have, and all received their treatment under two or more district health boards. The fact that they do not live in one of the six cities with a cancer centre has imposed a certain level of hardship, disruption and difficulty beyond that which the majority of women suffer, and hint at even greater difficulties that must be endured by other women. Yet none live anywhere that other New Zealanders would conceivably consider to be "the back of beyond".

The main issue for all three is the amount of travel that women must endure to have radiotherapy. While regional hospitals perform mastectomies and can deliver chemotherapy treatment, radiotherapy is only done at one of the six cancer centres and some women, like Lesley in Gisborne, must

travel six hours or more and are treated under three district health boards. Some of our smaller cities – like Gisborne – have no plastic surgeon for breast reconstruction and have only a visiting oncologist

Robyn lives in Ohope, just outside of Whakatane, and facilitated the Rural Women workshop at the 2007 Conference. She has been very involved in breast cancer support in the Whakatane region. She says that distance is always an issue for women in the country. She is also seeing an increase in numbers of younger women with breast cancer, and she says that for younger women with families the hardship imposed by having to travel several hours to a cancer centre is even greater than that experienced by older women.

The further away from an urban centre a woman is, the more difficult it is for her to access psycho-social support. There are fewer breast care nurses, and they may be attached to the regional hospital or radiology provider, which for women in small urban and rural communities, may be some distance away. Pauline raised concerns about communication and access to information regarding treatment options. As someone who is not particularly computer literate and doesn't feel comfortable resorting to the internet for information, this was a problem.

A 2008 New Zealand Institute for Rural Health discussion paper reported that according to the 2006 census only 70% of the New Zealand population has access to broadband and rural populations are less likely to have timely access. The same paper also found that while there is a National Transport Assistance Programme that subsidises the cost of transport for those living away from one of the six cancer centres it is inadequate and does not resolve issues of access to health services for rural New Zealanders.

In the next edition of *Upfront U Kaiora* we will take a closer look at life for women with breast cancer outside the big cities. We will hear more from Robyn, Lesley and Pauline and if you live in rural or provincial New Zealand – that is, more than an hour from one of the six cancer centres in Auckland, Hamilton, Palmerston North, Wellington Christchurch or Dunedin – we'd be interested in talking to you about your concerns. Email Sue Claridge on sclaridge_bcn@clear.net.nz or phone on 09 445 2966.

STOP CANCER WHERE IT STARTS

THE STICKING POINT WITH NON-STICK SURFACES

BY SUE CLARIDGE

Possibly regarded by many home cooks as the best thing since sliced bread, non-stick cookware has been a wonder-invention in the kitchen.* Non-stick surfaces, the best known of which is Teflon® by DuPont, is manufactured from the chemical polytetrafluoroethylene (PTFE), a synthetic fluoropolymer of tetrafluoroethylene, and is a solid fluorocarbon compound consisting entirely of carbon and fluorine.

Although manufacturers claim that products made with PTFE are completely safe, at high temperatures the normally stable PTFE begins to break down and give off several fluorocarbon gases. These degradation products can be lethal to birds, and can cause flu-like symptoms in people and this starts to happen at 200°C. The manufacturers assure consumers that it is highly unlikely that these products would be generated in amounts significant to health at temperatures below 250°C. Given that the compound is used in cookware that is designed to be heated this is somewhat problematic specially as the safety and stability of the product is reliant on consumer compliance – that is, consumers don't allow their cookware to get too hot!

As some indicator of how hot 200°C or 250°C is, cooking fats, oils, and butter will begin to scorch and smoke at about 200 °C and meat is usually fried between 200–230 °C. However, empty cookware can exceed this temperature if left unattended on a hot element.

SO WHAT PRECISELY IS THE CONCERN?

The United States Environmental Protection Agency's scientific advisory board found in 2005 that perfluorooctanoic acid (PFOA), a chemical compound used to make PTFE, is a "likely carcinogen."

In a fact sheet on PFOA the World Wildlife Fund wrote that:

"Information has come to light recently, concerning the potential developmental, reproductive and systemic toxicity of PFOS. PFOS has been shown to affect the neuroendocrine system in rats and other rodent studies have demonstrated maternal and developmental toxicity due to PFOS, with a



host of birth defects and compromised survival in newborns. PFOS has been shown to accumulate in the liver and to cause toxicity in this organ (hepatotoxicity). There is also evidence that exposure to PFOS and PFOA may cause thyroid dysfunction, which, during pregnancy, can lead to many developmental problems. The US EPA also considers both PFOS and PFOA to be carcinogenic and occupational exposure to PFOS has been correlated with increased incidence of bladder cancer.

Interestingly, DuPont settled for \$300 million in a 2004 lawsuit filed by residents near its manufacturing plant in Ohio and West Virginia based on groundwater pollution from this chemical, a chemical that is not currently regulated by the Environmental Protection Agency.

In January 2006, DuPont, the only company that manufactures PFOA in the US, agreed to eliminate releases of the chemical from its manufacturing plants by 2015, but did not commit to completely phasing out its use of the chemical. DuPont also stated that it cannot produce PTFE without the use of the chemical PFOA, although it is looking for a substitute.

The Environmental Working Group (EWG), a non-profit organisation that aims to use the power of public information to protect public health and the environment, wrote in a May 2009 document on PFOA that "as a result of PFOA contamination of consumer products and the environment, nearly all Americans have been polluted with this persistent chemical toxicant that resists degradation, accumulates in living tissues, and remains in the human body for many years."

Among a wide range of human and animal health impacts, the same document summarised the evidence for the role of PFO in the development of breast cancer.

In a two year study reported in 1987 the incidence of mammary fibroadenomas in rats treated with PFOA was significantly higher than that in study controls (42% in the low dose group versus 21% in the controls) In a 2002 review of this study, EPA determined that these findings were significant and relevant to humans, declaring the increased incidences of mammary fibroadenoma to be statistically significant.

The EWG went on to say that:

"The link between PFOA exposure and breast cancer is further supported by the fact that PFOA is an endocrine disruptor and a known mammary toxicant with transgenerational effects. In animal studies, gestational PFOA exposure is associated with altered mammary gland development in dams and female offspring. Female mice orally dosed with PFOA during pregnancy had a significant reduction in mammary differentiation, with delays in normal epithelial involution and alterations in milk protein gene expression. Female pups exposed to PFOA in utero displayed stunted mammary epithelial branching and growth. These findings are of great concern for human health, since toxic chemical exposures during early periods of development are particularly critical to later risk of developing breast cancer."

While it may be some time before we have categorical proof about any damage non-stick cookware may do to our health, and any role PFOA or PFTE has in the development of breast cancer, as always, the precautionary principle is a good one to keep uppermost in our minds.

* See our Teflon® quandary in our Clean Green and Healthy column page 10

Resources:

<http://fluoridealert.org/ca/ewg-may2009.pdf>

www.ewg.org/node/21726

<http://assets.panda.org/downloads/perfluorinatedchemicalsfactsheet.pdf>



LETTERS

THE BCRT BILLBOARD

Having cruised around the breast cancer world since 1996 it beggars belief that the likes of a prestigious breast organisation and a well known advertising agency could dream up a billboard stating:

SERIOUSLY, BREAST CANCER'S NOT A BIG DEAL

Are they looking for community support, or peddling a new slant on money gathering with a personal version of hope?

What do they take women for – air heads who haven't noticed that we have a very high breast cancer rate and some 650 women die annually. That we haven't pushed for mammography ages to be dropped, established networks, support groups, held conferences, prepared strategies to take on manufacturers of toxins in the environment, drug agencies for drugs, timely reconstructions and even dragon boats.

Believe it or not our heads are well and truly out of the sand; we know how bad it is, and that money is required to improve outcomes.

The biggest takers of the PINK BC charity purse, and you know who you are, have thrown our concerns into a competition between yourselves. Raising money by peddling hope mixed with fear has left us asking "where have the millions gone that you have received from the kind hearted public?"

We also ask "do you have any breast cancer women on your boards, trusts, management teams presenting a point of view that is different from your corporate industry-driven culture of the disease?"

We know that breast cancer hurts the very fabric of society; it is not strictly a matter that only concerns, surgeons, researchers, treatment providers and fundraisers. You cannot solve the big issues alone.

By not having representation of women who have or have had the disease on the trusts, the foundations, then you are opening yourselves up for criticism. It would be hard to argue that your intentions are in all women's best interests and not driven by a desire to be a notch above other organisations.

The 2009 breast cancer scene could now be described as having developed its own unique style of a very dysfunctional family that requires some discipline, honesty and open co-operation.

I am reminded of a wisdom heard many years ago:

"Where there is life there is hope, and where there is dirt there ought to be soap"

A new bar of soap is required.

Sue McLeod

Diagnosed in 1996 at 49

Editor's note: The New Zealand Breast Cancer Foundation have been as concerned as BCN about the BCRT billboard campaign and as one of New Zealand's highest profile cancer charities have been assumed by some members of the public to have been involved. In an interview with the New Zealand Herald (28 June 2009) Breast Cancer Foundation spokeswoman Suzanne McNicol said the billboards belittled sufferers and survivors.

The editor reserves the right to edit, abridge or decline any letters without explanation.

NEW TARGETED TREATMENT FOR BRCA CARRIERS WITH BREAST CANCER

BY ALISON VOGEL

A recent paper in the *New England Journal of Medicine* describes a first stage study (Phase One trial) of a new type of cancer treatment drug. The drug, Olaparib, was used in a variety of different types of cancers. Sixty patients were included in the first part of the study, of whom 22 had the BRCA mutations. A second group was then enrolled, all of whom had the BRCA mutations. The patients had a variety of types of cancers including ovarian, breast and prostate. All the patients had had considerable treatment prior to the trial.

Olaparib is a type of biological therapy called a PARP inhibitor and is a new approach to treating cancer in carriers of the BRCA gene mutations. Tumours that emerge in BRCA patients carry a DNA repair defect that is not shared by the normal tissues of the patient. Olaparib inhibits that DNA repair mechanism by blocking a protein called PARP. A cell with a faulty BRCA gene relies on PARP to keep its DNA healthy. So, when Olaparib stops PARP from repairing DNA damage, the cancer cells die. If the treatment works, the cancer should either stop growing or shrink. Because the defect is tumour specific the PARP inhibitors selectively kill tumour cells while sparing normal cells.

This trial focused on working out the appropriate dose range, determining safety, and side effect profiles by looking at effects in samples of blood mononuclear cells, plucked hair cells and in tumour tissue. Objective anti-tumour activity was only found in carriers of the BRCA mutations, all of whom had ovarian, breast or prostate cancer and all of whom had received multiple treatment regimens. The drug is taken by mouth, and was associated with less severe side effects than standard chemotherapy, although some patients had problems with nausea, gastrointestinal side effects and fatigue.

The findings are early, and phase two and three trials are needed to assess effectiveness and short and long term side effects. It is promising however to consider that this new approach may target the same molecular defect, but may be effective for cancers affecting different organs.

Sources: Fong PC, Boss DS, Yap TA, et al.: *Inhibition of Poly: (ADP Ribose) Polymerase in Tumors from BRCA Mutation Carriers*. *New England Journal of Medicine*, July 9 2009; 361.

FACES OF BREAST CANCER

THE TRIALS OF A RESEARCH NURSE: JENNI SCARLET

Jenni Scarlet's journey with breast cancer began when her mother was diagnosed with breast cancer; Jenni was 21 and had not long finished her nursing training. Her two sisters were only eight and eleven at the time. Their mother's cancer initially responded to treatment and she remained well for around seven years.

"This was a very personal and powerful experience and made me understand more fully the impact of cancer on a person's life and that of their family. I was grateful my sisters were another ten years older when they lost their mother".

Jenni is now a research nurse specialising in breast cancer research, but her varied nursing career spans 30 years. When she first started working at Waikato Hospital she worked part time in the Oncology inpatient ward, while completing an undergraduate degree in Social Sciences at the University of Waikato. Although she initially wanted to further her career in psychology – she went on to gain ten years clinical experience in mental health – she was inspired by some of her lecturers and papers in research, and eventually decided to pursue post-graduate studies in research.

It was around the time she completed her research studies that she had a chance meeting with local Waikato breast and general surgeon – Ian Campbell. Ian was keen to set up a research position at the Waikato Breast Care Centre. After successfully applying for the new position, Jenni worked closely with Ian, supporting his vision to develop and grow research and clinical trials, as part of the landscape of care and the total breast care service offered in the Waikato.

Jenni has worked in her current position, based at the Breast Care Centre at Waikato Hospital, for 11 years. Her main role is to coordinate breast cancer clinical trials. However, over the years Jenni's role has diversified and she is also the co-ordinator of the Waikato Hospital-based breast cancer research office, overseeing day to day operational aspects and the supervision of six other research and audit staff. In 2000 Jenni became Secretary of the Waikato Breast



Wildfoodie: Jenni (left) and friend at the Wild Food Festival, Hokitika about to eat chocolate covered huhu grubs.

Cancer Trust (WBCT), a charitable trust that was established to administrate/enable breast cancer research and education, in the greater Waikato region.

A significant amount of establishing and running clinical trials involves writing applications to gain management, ethical and other approvals before a clinical trial can be commenced. Some trials require total or additional funding to cover the costs of research, and securing funds through grant applications is another of Jenni's roles.

"I couldn't fulfil my role without my nursing background," Jenni explains. "The completion of research forms requires detailed knowledge of medical conditions and their diagnoses and treatment, and there are many nursing skills called upon in the role – a listening ear or assisting a doctor colleague with a biopsy."

Some of the clinical trials Jenni has coordinated include evaluating the treatment of a pre-cancerous condition called ductal carcinoma in situ, testing new anti-oestrogen

drugs (the aromatase inhibitors Anastrozole, Letrozole and Exemestane), and the initial introduction of sentinel node biopsy to early breast cancer surgery. With her mental health background, Jenni has also been keen to be involved in research evaluating quality of life (run in conjunction with drug treatment trials to look more closely at the impact of side-effects on quality of life) and improving the communication of complex treatment options.

The gradual improvements made through research are long lasting and, hopefully, far reaching. Through the participation of New Zealand women, and their courage in testing new and experimental treatments, questions about breast cancer are answered, leading to improvements in the care of other women around the world diagnosed with this disease. The women of today do "stand on the shoulders" of women who have participated in clinical trials of yesterday, and there are many women today who take part in research with a view to helping future

generations of women. As a member of the co-operative Australian New Zealand breast cancer research group (the ANZ Breast Cancer Trials Group), the Waikato Breast Care Centre works with other international cancer and breast cancer research groups.

“Some of the clinical trials we participate in have 7,000 or 8,000 or more women participating around the world – this is an incredible effort from these numbers of women and staff!”

One of the other major projects Jenni has been involved with is the establishment of the Waikato Breast Care Register (WBCR). The Register is an extensive audit with an overall aim of evaluating how well Waikato-based treatment services and staff provide care and treatment.

“We want to ensure women receive the best possible care. The data will enable us to continue improving the quality of care for those diagnosed with breast cancer in the greater Waikato region,” she says.

The Waikato Register is modelled on the Auckland Breast Cancer Register (an initiative of the Auckland Breast Cancer Study Group). The workload and maintenance of the WBCR continues to expand as new cases and follow-up information are included. As data matures many questions will be able to be asked and answered, and this database will be an invaluable resource going into the future.

“The New Zealand Breast Cancer Foundation needs to be acknowledged for their support of this extensive project,” she told *Upfront U Kaiora*.

Jenni sees her position with Waikato Breast Cancer Trust as very privileged.

“Not only do I get to meet many wonderful and inspiring women, I also get to experience

incredible generosity from individuals, communities and businesses such as Annah Stretton and the Stretton Group. The WBCT has numerous sponsors and each and every one of these individuals and businesses has been vital to the progress we’ve made.”

Community based fundraising is another necessity and fundraising opportunities take Jenni to Bejewelled Bra Balls, Fine Homes Tours, Triathalons, Antique Fairs, and Pink Walks. In March she volunteered along with family, colleagues and staff from the National Bank, to assist with car parking at the Balloons over Waikato event. In October 2008, three very enthusiastic Putaruru women enabled the hosting of the Putaruru Think Pink Party which saw many individuals and businesses from the local Putaruru community, and the greater South Waikato area, get behind the breast cancer cause, raising \$70,000 for the research programme!

Jenni is humbled by this sort of generosity and says it makes her and her colleagues feel hugely supported in their work.

“It makes me personally feel very committed to making donations work in the spirit in which they were given. It is heartening to see that a sense of community is still very much out there, judging by the level of generosity received for our research programme and women affected by breast cancer”.

“I know it sounds corny, but I find it satisfying to feel as though I can make a difference through what I do,” Jenni says.

“I am inspired by the many women I’ve met over the years, particularly my mother and grandmother, who faced their cancer diagnosis with dignity and courage, and the many patients who have taught me about ‘living.’”



BOOKWATCH

A CANCER PATIENT'S GUIDE TO OVERCOMING DEPRESSION AND ANXIETY. GETTING THROUGH TREATMENT AND GETTING BACK TO YOUR LIFE.

BY DEREK HOPKO AND CARL LEJUEZ

A New Harbinger Self Help Workbook, 2007, Oakland.

Reviewed by Alison Vogel

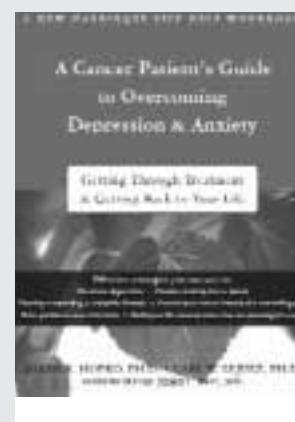
Anxiety and depression are very common problems for cancer patients with depression, occurring in up to 20 to 50% of cancer patients at some point.

This book is an evidence based workbook based on behavioural activation treatment principles, designed to be worked through over a ten week period. Behavioural activation treatment is based on reducing avoidance. This

is associated with improved prognosis (for example, by helping overcome barriers to coping with treatments) and better quality of life. It focuses on identifying strengths as well as problems. The workbook provides guidance for problem solving difficulties, and building skills in negotiating social relationships. It includes strategies to deal with common problems, such as anxiety about follow-up appointments. I found it helpful working through the questionnaires – especially as they enabled me to identify a lot of areas where things were going right, as well as clarifying those things that were still an issue. This is a practical book, with a realistic appreciation of the limitations that may be experienced during cancer treatment, and the multiple life changes, sense of powerlessness and lack of control that often accompany a diagnosis.

The techniques learnt can be used in many difficult life situations. The workbook does require a commitment to face up to difficult feelings, and to look honestly at how you are spending time. The underlying premise is that there are some things that NEED to be done, even though we may not feel like doing them. As we tackle and get through the tough tasks, and motivate ourselves to take action, our feelings and mood will improve over time. The workbook is realistic about the need for support and for setting reasonable goals. Specific strategies that are explained include sleep hygiene, progressive muscle relaxation, mindfulness and self hypnosis techniques.

Available from the Cancer Society library and public libraries.



CLEAN GREEN AND HEALTHY

THE *UPFRONT U KAIORA* REVIEW OF WHAT YOU SHOULD AND SHOULDN'T BE PUTTING INTO AND ONTO YOUR BODY AND AROUND YOUR HOME.

TEFLON® – A QUANDARY IN THE KITCHEN

Like many health-conscious people, BCN Committee member, Gillian Woods, doesn't like to use Teflon® coated products. She writes:

"Recently we decided to upgrade from our aged, well-used toasted sandwich maker to something new and state-of-the-art. What a disappointment to find that the only models available were nonstick coated. Why a disappointment? Because we have in the last few years, achieved a Teflon®-free kitchen, due to our concerns about its safety. Well, we made a big compromise and bought the gadget anyway. Every time it is pre-heated before cooking, visible fumes are released. I guiltily wonder what they contain – are they the highly toxic fumes known to be produced by degradation of Teflon® at high temperatures, or are they just burnt traces of fats that have escaped the cleaning process? Teflon® is said to be safe only when not heated above 260°C. How can I tell what temperature my toasted sandwich maker reaches? It is known that fumes from overheated Teflon® kill birds. I wonder what do they do to humans, especially little humans like my three year-old grandson?"

Surely there must be an alternative for a toasted sandwich maker.

The coating that was once hailed as the housewife's best friend and indeed, appeared to be a sort of miracle in the kitchen, is now suspected of causing harm under a variety of circumstances. It is now found in the bloodstream of every American, and some of its components virtually never degrade in the environment. What is more, it is found in coatings just about everywhere – carpets, wrapping material, and I noticed recently it is even hailed as a wonder component of toilet cleaners – helps to resist stains! What next?"

Despite the fact that Dupont claim that Teflon® is completely safe

they and other manufacturers have agreed to phase out perfluorooctanoic acid (PFOA)* – an endocrine disruptor – currently used in the manufacture of Teflon®, by 2015.

In 2006, Marian Burros, a food writer and columnist for The New York Times, tested eight high-quality non-Teflon pans to find out which came closest to being "non-stick" and found that enamel-coated cast iron ranked number one, with old-fashioned cast iron pans a close second – but even the winner needed at least a film of oil.

Shirley Corriher, a well-known food consultant, says the secret to non-stick cooking lies less in the pan than in the cook's ability to wait. Her advice for frying anything – chicken breasts, salmon steaks and, yes, even eggs – in any type of pan:

1. Heat the empty pan first to give the food a hot surface to cook on and not in.
2. Pour in a tablespoon or two of oil, and tilt it around.
3. Put in the food, which will sizzle like crazy and stick to the pan.
4. Resist the urge to chisel the food loose for at least 90 seconds until it lightly browns – at which point it will release all by itself.
5. Repeat on the other side.

"The big secret is to leave it alone," Corriher says.

However, all this doesn't solve the 'toasted sandwich maker problem'. Toasting a sandwich in a normal frypan is only a part-solution as it only works for contents such as ham, that aren't going to leak out all over the place. If any readers know of a Teflon free toasted sandwich maker we'd really like to hear from you.

* See *Stop Cancer Where It Starts* page 6

GUACAMOLE PLUS

This guacamole is enriched with fibre from the peas and cancer-fighting phytochemicals from the garlic, salsa, scallions, and lemon.

INGREDIENTS - MAKES 2½ CUPS

1 cup frozen green peas or 1 cup drained and rinsed canned peas	1 scallion, minced (optional)
1 ripe avocado, peeled	juice of 1 lemon
½ cup mild salsa	½ teaspoon cumin
1 clove garlic, minced, or	1 tablespoon fresh cilantro (coriander), chopped (optional)
1 teaspoon chopped garlic	salt and pepper, to taste

METHOD

If using frozen peas, blanch peas in boiling water for two minutes, then cool with cold water and drain. Cut avocado into large chunks. Mash avocado and peas together using a potato masher or fork, or, if a very creamy texture is desired, in a food processor. Mix in salsa, garlic, scallion (if using), lemon juice, cumin, and cilantro (if using.) Add salt and pepper to taste.

From *The Survivor's Handbook: Eating Right for Cancer Survival* by Neal Barnard



NUTRITION INFORMATION

Per 1/2-cup serving:
 Calories: 76
 Fat: 4.4 g
 Saturated Fat: 0.6 g
 Calories from Fat: 96.8%
 Cholesterol: 0 mg
 Protein: 2.4 g
 Carbohydrates: 8.4 g
 Sugar: 2.2 g
 Fiber: 3.2 g

From the project desk....

Conference Recommendation 30: That more information be available to women with metastatic disease, particularly on the BCN website.

It is with pleasure that we can tell you there is now a section on the BCN website *Living with secondary breast cancer*. Our thanks to Kristine, Gabrielle, Joan and Kashi who have shared their stories, and to Jane Bissell, who conducted interviews and wrote the articles for us. There are eight sections on the page including *Feelings and secondary breast cancer*, helpful articles and *Resources within NZ*. We will be adding to this site, and as always we value your comments and ideas. Visit www.bcn.org.nz. Please pass our website address to women you may know, who have secondary breast cancer.

Conference Recommendation 13: That education of New Zealanders regarding environmental influences on the development of breast cancer be addressed and implemented as a key priority.

Our brochure, *Reduce Your Breast Cancer Risk*, designed to provide information for young women about reducing breast cancer risk, has been sent to all breast care nurses and is soon to be distributed through organisations whose services reach young women. BCN is approaching several organisations at present.

Conference Recommendation 18: That there be more widely available literature on the subject of Environment, Lifestyle and Breast Cancer.

Dr Robert Scragg's talk on Vitamin D and Cancer at the AGM in May is now available on our website.

October, Breast Cancer Awareness Month

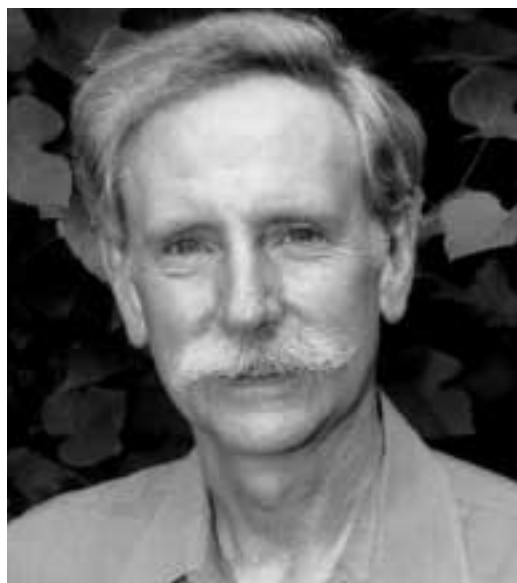
During October BCN want to do as much as we can for women who have experienced breast cancer and for the groups who support them. If a breast cancer group anywhere in New Zealand would like an article from previous issues of *Upfront U Kaiora* for a handout please let us know. We will email a PDF or Word copy to you and under this arrangement you may make as many copies as you need without breaching copyright. Several groups took advantage of this offer last year and found it helpful to have extra articles when people were seeking information. 'Watch this space' for further resources for groups coming soon...

National Committee update

The newly appointed BCN National Committee has six members, and is looking for more. Can you help? Website and writing skills, chairmanship, medical knowledge, events, projects, fundraising, newsletter mail-outs, proofreading – your input will be welcome. People outside Auckland with Skype are welcome to offer for committee. Meetings are currently held on the third Monday of the month in the evening. The team consists of Barbara, Carmel, Linley, Anne, Sue and Gillian. Our administrator, Jennifer, has just returned from a super holiday overseas, and we thank Carmel and Sam for keeping the administration flowing smoothly in Jennifer's absence.

Your BCN Committee

DIET, NUTRITION, AND CANCER — DON'T TRUST ANY SINGLE STUDY



Dr Walter Willett

Dr Walter Willett, from the department of nutrition at Harvard School of Public Health in Boston, and well known for his work on diet, nutrition and cancer, told the American Association for Cancer Research's 100th Annual Meeting that no conclusions should be made about diet and cancer on the basis of a single study. Several studies on diet and cancer presented at the meeting run counter to the accumulated body of evidence, and some of the comments based on these studies are untrue or premature, he said.

Dr Willett presented an overview entitled 'Diet, Nutrition, and Cancer: The Search for Truth,' in which he reviewed many of the associations that have been suggested by epidemiologic studies. These include consumption of red meat, meat cooked at a high temperature, a high-fat diet, and alcohol all increasing the risk, and fruit and vegetables decreasing the risk. However, much of the evidence for these links is rather weak, he said; the most robust evidence supports a link between obesity and an increased risk for cancer.

"The estimate that diet contributes to around 30% to 35% of cancers is still reasonable," Dr Willett said, "but much of this is related to being overweight and inactive."

"At this point in time, being overweight is second only to smoking as a clear and avoidable cause of cancer," he

CONTINUED ON PAGE 12

CONTINUED FROM PAGE 11

said. "People should stay as lean as they can, recognising that it is more difficult for some than for others."

Beyond this clear message about obesity, there are only hints from the rest of the data. One of the main limitations of all of the studies so far is that they have looked at a specific time of life — for example, women after menopause — and they have had fairly short follow-ups, often less than 10 years. "So what we are looking at are little slices of life," Dr Willet said, whereas the effect of diet is lifelong, and might be particularly important in the years before adulthood (e.g. during adolescence).

BREAST EVENTS to come

- **16 September – Sweet Louise Wellington Launch**, Samuel Marsden Collegiate School, Karori, 7.30pm. Call 0800 11 22 77 or email info@sweetlouise.co.nz for more information.
- **23 September – The 2009 Montana WOW® Awards Dress Rehearsal show** to raise funds for BCRT. Contact The Trust on 0800 227 828 for more information.
- **16 October - BCRT COUTTS Mercedes-Benz Golf Day** - Friday 16th October, Titirangi. To reserve your place please contact Rebecca Hendl-Smith ph 0274 666 921 or email rebecca@breastcancercure.org.nz.
- **29 October – (Thursday) Hamilton Pink Walk for breast cancer awareness**, 5pm Innes Common, Hamilton Lake, go to www.pinkwalk.co.nz for more information.

Breast Cancer Support would like your readers to rejoice with them on the launch of their website, www.breastcancersupport.co.nz. BCS sees this as a forward step towards reaching the needs of women looking for support, encouragement and hope after having received a breast cancer diagnosis. Comments from readers are welcome.

VISIT THESE SITES FOR MORE BREAST INFO! www.bcn.org.nz www.breast.co.nz www.breastcancersupport.co.nz

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BCN VITAL STATS:

Breast Cancer Network (NZ) Inc. – established in 1993 is an organisation for women with breast cancer and their supporters. It aims to promote increased efforts to prevent and cure breast cancer- by advocacy, education, information and networking.

ADMINISTRATOR: Jennifer Woodroofe; MAGAZINE EDITOR: Sue Claridge.

PATRON: Lois Muir.

HONORARY LIFE MEMBERS: Wendy Steenstra-Bloomfield, Barbara Holt,

Dell Gee, Jennifer (Jenny) Clark

COMMITTEE MEMBERS: Barbara Mason, Anne Iosefa, Gillian Woods, Linley Rivers, Sue McLeod and Carmel Clark.

BCN gratefully accepts any bequests. For more information please contact the office.

TO JOIN BCN

To support the work of BCN & receive a regular copy of UPFRONTU KAIORA send your name and address to: **BCN (NZ), PO Box 46018, Herne Bay, Auckland 1147 (Office 300 Richmond Road, Grey Lynn.)** Membership – \$25 survivors/supporters, \$20 unwaged, \$30 professionals, groups & libraries. For further information, phone our office on (09) 360 0090 fax us on (09) 09 360 2180 or email us at admin@bcn.org.nz.

Name: Miss/Mr/Mrs/Ms/Dr _____

Address _____

City _____

Postcode _____

Phone Home (0) _____

Work (0) _____

Fax (0) _____

Email _____

• **\$25.00 individuals** • **\$20.00 unwaged** • **\$30.00 professionals, groups and libraries**

Amount enclosed : membership \$ _____

donation \$ _____

Please tick here if you have experienced breast cancer.

I am interested in helping with BCN activities

I agree to BCN (NZ) contacting me by email with news, information and updates

Age Group (Optional - Please circle applicable group)

(Under 45)

(45 – 49)

(50 to 69)

(Over 70)

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