

Upfront U Kaiora

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

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LOSING YOUR MIND WITH CHEMO? BY SUE CLARIDGE

For most women who have been through pregnancy, it is not a new concept that the brain can behave rather strangely. Pregnancy brain, pregnancy mush brain, baby brain – call it what you will, there seems to be a pronounced change in cognitive function for many women during pregnancy. And it doesn't necessarily end when baby pops out; if the hormones don't continue to wreak havoc on the way your mind works, the sleep deprivation certainly does.

I have heard that the changes in a woman's cognitive function during pregnancy and after birth are to do with protecting and nurturing the baby – everything revolves around ensuring the baby's survival and less "important" matters take a back seat.

All very plausible, but what is behind chemotherapy induced cognitive impairment – or "chemo-brain".

CHEMOTHERAPY AND BRAIN FUNCTION

It would be fair to say that up until relatively recently – about the last ten years – the medical profession hasn't taken complaints about "chemo-brain" terribly seriously. I don't doubt that there are probably a few "dyed in the wool" health professionals who still don't.

In a paper published in the July 2000 issue of the *Journal of Clinical Oncology*, the authors wrote that many of the side effects of adjuvant chemotherapy are well documented in the medical literature but that "more subtle side effects, such as possible changes in memory or cognitive ability, have received little attention, even though many women complain of subjective changes in memory and the ability to think clearly during and after chemotherapy."

In an article in the Autumn/Winter issue of *pink magazine*, Dr Michael Jameson, a Medical Oncology Specialist at Waikato Hospital who has a specific research interest in cognitive



changes with chemotherapy, says that for many years chemotherapy was used only in people with advanced cancer and it had "such a profound effect on the physical health of a person that any of the mental effects were thought to be part of the emotional reaction, fatigue and the effects of the cancer".

With recent improvements in chemotherapy drugs meaning that patients tolerate the treatment relatively more easily, he says that the non-physical effects have become more obvious.

In what has been described as a pivotal article, published in 1998 in the *Journal of the National Cancer Institute*, van Dam et al reported on a randomised trial that compared cognitive functioning and quality of life of breast cancer patients after high-dose and standard dose chemotherapy with no chemotherapy. They found that high-dose patients showed significantly more cognitive impairment than those receiving either standard-dose adjuvant chemotherapy (fluorouracil, epidoxorubicin, and

cyclophosphamide) or no chemotherapy. The neurotoxic effects were observed approximately two years after the last chemotherapy course, "suggesting that long-term cognitive deficits result that may impair the quality of life of breast cancer survivors."

A 1999 study published in the journal *Cancer*, found that cognitive impairment is unaffected by anxiety, depression, fatigue, and time since treatment.

However, another study published in *Cancer*, in 2007 found that "even before chemotherapy, a subgroup of patients with breast cancer showed cognitive compromise that was unrelated to anxiety or depression. During chemotherapy, cognitive function remained stable in most patients, improved in a subgroup, and deteriorated in another subgroup."

The possibility that women who suffer cognitive effects are somehow predisposed to chemotherapy or even exhibit such symptoms before chemotherapy was raised at the 2008 American Academy of Neurology Meeting by Dr David Darby from Melbourne, Australia. He said that women newly diagnosed with breast cancer show cognitive impairments in learning before starting chemotherapy, but, the researchers found that impairment did not appear related to increased anxiety.

"It suggests there is something special about women who have chemotherapy, before they even have chemotherapy," Dr. Darby said, but he offered no explanation of what that might be.

BRAIN-FADE ON A DAILY BASIS

Dr Jameson facilitated the "Brain Fade With Chemotherapy" workshop at the Breast Cancer Conference in Rotorua last October, and reported on the experiences of women attending

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the workshop in the Autumn/Winter issue of *pink magazine*. He said:

“Most women in the audience (admittedly a self-selected group who wanted to hear more about this issue) had found that the effects of chemotherapy on their brain function had a very significant impact on their lives. One woman remarked that, when at her worst, she had paid the same bill several times because she couldn’t remember if she had paid it. She had to put “Post-it” notes all over her home and office to remind her of what she had to do, and take notes in a diary all the time. Others had to change their jobs because they couldn’t function sufficiently well any more (especially where the job was intellectual). The most moving and profound aspect of the workshop for me was the relief for those attending to finally have an opportunity to share their experiences without people dismissing them.”

COPING WITH CHEMO-BRAIN

Research into the cognitive impacts of chemotherapy continues. Dr Jameson says that research is underway both here and internationally. In this country research is being undertaken at Waikato, Tauranga and Rotorua Hospitals with “women having chemotherapy for early stage breast cancer,



Dr Michael Jameson

looking at cognitive function before, during and after treatment to see how much each person is affected and how quickly and completely this recovers.”

Until research provides a greater understanding of the problem there are some things that can be done to help women cope. First and foremost, women need to be told about the possibility of “chemo-brain” before chemotherapy commences. This will give them a greater understanding of the possible impacts on their lives and enable them to “forgive” themselves if they cannot mentally perform at their former level.

Dr Jameson also recommends a good diet, saying that “the brain needs the full range of nutrition to help it function well and repair any damage from chemotherapy. Specific nutrients that are especially important to the brain include the omega-3 fatty acids found in fish oils, and selenium.”

In his *pink* article and the recommendations from the conference workshop, Dr Jameson advocates exercising the brain with crosswords and reading, keeping fit and healthy, getting enough fresh air and enough sleep.

“Using some of the tricks other people have found (taking notes to remind you of important things, keeping a diary, etc.) can also help to manage the problems.”

While “chemo-brain”, “brain-fade”, “mush brain” – call it what you will – has a significant impact on the lives of many chemotherapy patients, women undergoing treatment can rest assured that they are not alone, there are ways to manage, and at least now, it is being taken seriously enough for a considerable amount of research to be undertaken on the problem.

Ed’s Note: the Autumn/Winter pink magazine carries the full article – Chemotherapy and the Brain by Dr Michael Jameson, referred to in this article.

From the Editor....

It is never a slow day in the breast cancer world – at least not from my perspective as the editor of *Upfront U Kaiora*. There is always something happening, new information coming out, new initiatives starting up. I don’t doubt for a moment that the advocacy movement has contributed to changes in breast cancer care over the past thirty years.

In this issue you get a bit of a sense of how much is happening and how much women with breast cancer have to think about and consider. It is all a bit daunting for a newly diagnosed woman, but you only have to look at the Breast Events column to see the scope of things that are happening in communities around the country. Our News and Research briefs give a feeling for how hard people are working around the globe to make things better for women. And it is not just about women with breast cancer, as regular readers well know. BCN has been working on the *Stop Cancer Where It Starts* project for some years now – trying to make sure our daughters and

granddaughters don’t have to go through the same battle. This issue of *Upfront U Kaiora* heralds some changes – or additions. BCN is committed to acting on the recommendations that came out of the First National Conference. We will have a regular report on what BCN is doing in that regard in our new column *From the Project Desk...* Breast cancer and the environment has long been dear to the hearts of those entrusted with guiding the organisation, right from the early days with Barbara Holt and Wendy Steenstra Bloomfield at the helm. The response to the environmental workshop at the conference confirmed this is a major concern for women. In recognition of that we have two new columns on keeping healthy – reviews of cosmetics and cleaners, and a healthy recipe. Remember, this is your mag – we try to respond to your needs, but we need your feedback and your involvement and these two columns, together with the *Letters and Breast Events* columns are great ways for you to stay involved.

A handwritten signature in cursive script that reads "Sue Claridge".

THE BREAST CANCER NETWORK THANK THEIR SPONSORS:
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LETTERS

CARE REQUIRED WITH LYMPHOEDEMA

Recently I was a day stay patient in hospital for a procedure which required a general anaesthetic. My patient medical notes stated that I'd had breast cancer on the left side. The staff were also asked not to use my left arm and I wore a bright pink LYMPHOEDEMA ALERT bracelet which stated 'No blood tests, Blood Pressure No IV or injections into this arm'. The staff were all professional and kind and I heard the anaesthetist in theatre remind the staff not to use my left arm for any reason. I felt relieved and safe.

I was not only upset but also angry when I was aware in recovery that the blood pressure cuff was on my left arm and felt very tight. I have had problems from time to time with lymphoedema and while it is not life threatening it can be a problem and debilitating, necessitating massage and cost.

I was given to understand that most doctors at the hospital don't believe blood pressure cuffs cause a problem and if used on the affected arm, nothing would happen. I want to believe that this is not their attitude.

I've accepted apologies, but suggest that perhaps the only way to ensure this doesn't happen if you have to go to hospital and have a general anaesthetic is to write with bright marker pen from the shoulder to the wrist. 'Do not use this arm except in an emergency.'

Christine Rule
Auckland

HERCEPTIN AT THE CONSUMER FORUM

Readers may be interested in a few remarks made about the drug Herceptin at the Consumer Forum I attended in Wellington in July (not included in my article about clinical trials in this issue). Dr Fran Boyle, speaking about researchers turning obstacles into stepping stones, used Her2 receptors as her example, saying 20% of women with breast cancer have more active Her2 receptors than other

women. From 2005, Herceptin has been used to treat early breast cancer in these women with a 3-weekly injection. She informed us there is a trial – ALTO – for a drug called Lapatinub, taken orally, which is more effective than Herceptin in treating cancer in the brain but a long way from the clinical stage yet.

US Consumer advocate Ms Margo Michaels thought the current Herceptin trial (I presume the one trying to discover whether it should be taken for [9] weeks or 12 months) was struggling, although breast cancer advocates promoted it, because doctors were the best advocates. (I presume this means some doctors, for financial reasons, don't want to upset patients who think they need the drug for the longer period.)

On entry to the Forum, we consumers were each handed a copy of a cancer treatment survey from IMS Health which began: "We are interested in finding out how people who have been diagnosed with cancer feel about access to cancer drugs in New Zealand, and their views on meeting the costs of these treatments." It had a series of questions with mainly forced choice answers, including whether we had ever asked a doctor about a possible treatment not mentioned to us, who we thought should pay for the cost of cancer treatments in NZ and how much we would be prepared to pay for them ourselves. At question time, a woman who objected to being given this survey, asked who was responsible for it. Dr Boyle told us it was produced by Roche, the makers of Herceptin, because they wanted patients to be told about all available treatments by their oncologists. She thought there could be a test case soon, with a doctor taken to court for not telling a patient about all their available options.

This to me suggests the need for consumers to be aware of how they can be manipulated by companies whose main objective is profit.

Barbara Holt
Wellington

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

YOUR NETWORK ON THE MOVE

Last month saw Breast Cancer Network packing our considerable stuff into boxes as we moved to our new office in Richmond Road, Grey Lynn. Thanks to the willing helpers who transported and sorted it.

It is with excitement and anticipation that we 'shift house' and move on.

We have had many years of wonderful support from Bakers Delight in providing us with an office. We thank them once again for their generosity and support, which was also a vital component of our 1st National Conference in Rotorua 2007, and wish them every success with their expanding bakery business.

Readers please note our new address and contact details:

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Phone 09 360 0090 • Fax 09 360 2180 • Email admin@bcn.org.nz

CORRECTION: The cover of the last edition of *Upfront U Kaitiaki*, Issue 79 June/July, was incorrect and had not been updated from the previous edition, Issue 78. The remainder of the pages were headed with the correct edition details. We apologise for any confusion caused by the error.

POST-TREATMENT BREAST CANCER SURVEILLANCE

BY DR MADELEINE WALL, CLINICAL LEADER, BREASTSCREEN AOTEAROA

Women who have been treated for breast cancer are at increased risk of developing breast cancer again. This may represent a recurrence of the original cancer in the same breast, in regional lymph nodes, or in distant organs as metastatic disease. Alternatively, a new primary breast cancer may arise in the previously treated, or the other (contralateral) breast.

RISK OF A NEW PRIMARY BREAST CANCER IN THE CONTRALATERAL BREAST

Among treated women, the risk of a new contralateral breast cancer ranges from two to 7.8 times the risk of the average woman developing breast cancer for the first time.¹ Although the estimates vary according to the study and population assessed, the highest risk occurs in those women who also have a strong family history of breast cancer. Each year after treatment, about six to seven in 1000 treated women will develop a new cancer in the contralateral breast.¹ Risk is reduced in treated women on hormone therapy (e.g. Tamoxifen or aromatase inhibitors) and to a lesser extent by regular exercise and avoiding obesity.

RISK OF RECURRENCE IN THE TREATED BREAST

For any given tumour type and stage, overall survival following breast cancer is equivalent irrespective of the treatment surgery, whether that was mastectomy or breast conserving surgery (BCS) and radiotherapy. However, the risks of local relapse in the breast are greater in those who had BCS and radiotherapy compared with those who had mastectomy, if they were younger than 40 or had large or higher grade tumours. Annually, about five to ten in 1000 women previously treated with BCS will develop either recurrent cancer, or a new primary in the treated breast. This risk persists for at least ten years after treatment and probably longer.²

POST TREATMENT SURVEILLANCE

Given the risks delineated above, what is the role of regular surveillance?

METASTASES

A Cochrane review updated in 2000,



confirmed that intensive surveillance to detect metastatic disease early (e.g. regular bone or liver scans or blood tests such as CEA) does not influence survival.³ Consequently, it is now unusual for asymptomatic women to have to undergo these tests for metastases routinely.

Therefore, it is widely accepted that, in addition to monitoring treatment side effects, the primary role of regular surveillance of women post-treatment is to detect treatable relapse or new disease early.

SURVEILLANCE FOR THE EARLY DETECTION OF TREATABLE LOCOREGIONAL RECURRENCE OR A NEW BREAST CANCER

What effect on survival will recurrence or a new primary have, and can surveillance or early detection improve the survival odds? The limited evidence available suggests that long term survival following a second primary breast cancer is similar to that of women with their first breast cancer, and is dependent on the same factors; that is, the stage and grade of disease and quality of treatment. Survival following BCS recurrence is also dependent on the stage and grade of that recurrence.⁴

Randomised controlled trials of screening mammography in average risk women 50 years and over, have demonstrated that popu-

lation based two-yearly screening can reduce breast cancer deaths by 35%. Intuitively, it follows that early detection of recurrence or a second primary in breast cancer survivors should also lead to increased survival. On this basis, many breast cancer treatment guidelines have advised annual surveillance mammography and clinical breast examination.⁵ However, it is only in the last year that definitive evidence has been published confirming that annual surveillance mammography reduces breast cancer mortality in women diagnosed with treatable locoregional recurrence or a new breast cancer.^{6,7}

WHAT ARE THE GUIDELINES IN NEW ZEALAND FOR SURVEILLANCE OF WOMEN AFTER BREAST CANCER TREATMENT?

Existing guidelines on "The Surgical Management of Breast Cancer" (RACS section of breast surgery in New Zealand, 1997) and Guidelines for Primary Care Providers on the Early Detection of Breast Cancer (1999) do not cover the most recent evidence and are now outdated.

A multidisciplinary group including breast cancer survivors is currently drafting guidelines on the "management of early breast cancer". Surveillance and care of

women post-treatment will form a part of these evidence-based recommendations. The group is convened by the NZ Guidelines Group under contract to cancer control in the Ministry of Health. It is expected that these guidelines will be available in early 2009.

PUBLICLY FUNDED NEW ZEALAND SERVICES – WHAT IS AVAILABLE FOR NEW ZEALAND WOMEN?

The Ministry of Health funds DHBs to provide to individuals referred by community-based practitioners (GPs): “diagnostic mammography for asymptomatic women regardless of age who have had a previous breast cancer” There is some evidence that this publicly funded service is not being provided consistently around the country. This may be because GPs and women are not aware a service is available. The Ministry of Health has recently reminded DHB CEOs that this service is part of the Ministry of Health -DHB contract.

HOW DO YOU ACCESS FREE SURVEILLANCE MAMMOGRAPHY?

Free surveillance mammography is important for women who have been discharged from hospital outpatient services following breast cancer treatment. You need a referral from your GP for a “diagnostic mammogram for high risk surveillance because of a previous breast cancer.” These GP referred mammograms are not provided by BreastScreen Aotearoa but at either the local hospital radiology department or at DHB contracted private radiology services.



Dr Madeleine Wall

Women who were treated for breast cancer five or more years ago, and who are aged 45-69, may re-enroll to receive a regular mammogram every two years within BreastScreen Aotearoa (Phone 0800 270 200). For mammography in the alternate years, these women can be referred by their GPs to the DHB community (GP) referred radiology services.

Those women, who are still attending post treatment outpatient appointments with an oncologist or surgeon, should continue to receive their regular mammograms at their local hospital.

BREAST AWARENESS

It should be remembered that even when there is annual surveillance mammography available, 30 to 40% of recurrences are detected by women themselves.⁸ Therefore, it is important that breast cancer survivors promptly seek medical advice should they notice anything new or unusual in the breast or axilla (armpit).

CONCLUSION

For the period 1998 to 2003, New Zealand's five-year breast cancer survival rate of 83.5% was not significantly different to the OECD average.⁹ Although higher than the survival rates for UK and France, New Zealand's rate was lower than Australian, Canadian and US rates. One likely reason for this difference is that national breast screening only began in New Zealand in 1999, and has yet to reach all eligible women. The improvements in breast cancer survival, most marked in countries with long established breast screening participation, have resulted in growing numbers of women who require long term, high quality, evidence based surveillance. The development of new guidelines to cover surveillance, and implementation of these in the future, should enable that need to be met. In the meantime, breast cancer survivors should know that surveillance mammography is publicly funded.

1. Risk Factors for Breast Cancer, NZHTA, www.nsu.govt.nz/Health-Professionals/1051.asp
2. *British Medical Journal*, 2008; 336: 107-8.
3. *Cochrane Database of Systematic Reviews*, 2000, Issue 4.
4. *Journal of Clinical Oncology*, 18, 8, 2000: 1696-1708.
5. Breast Cancer Surveillance Guidelines. American Society of Clinical Oncology. www.jco.ascopubs.org
6. *Breast Cancer Research and Treatment*, 2008 Apr 18.
7. *Journal of Clinical Oncology*, 2007; 25 (21).
8. *British Journal of Cancer*, 2007, 97, 1632-1641.
9. Health at a Glance 2007: <http://www.oecd.org/health/healthataglance>

HEALTHY LIFESTYLE TRIGGERS GENETIC CHANGES

Comprehensive lifestyle changes including a better diet and more exercise can lead not only to a better physique, but also to swift and dramatic changes at the genetic level, US researchers have found.

In a small study, the researchers tracked 30 men with low-risk prostate cancer who decided against conventional medical treatment such as surgery and radiation or hormone therapy. The men underwent three months of major lifestyle changes, including eating a diet rich in fruits, vegetables, whole grains, legumes and soy products, moderate exercise such as walking for half an hour a day, and an hour of daily stress management methods such as meditation.

As expected, they lost weight, lowered their blood pressure and saw other health improvements. But the researchers found more profound changes when they compared prostate biopsies taken before and after the lifestyle changes. After the three months, the men had changes in activity in about 500 genes -- including 48 that were turned on and 453 genes that were turned off.

The activity of disease-preventing genes increased while a number of disease-promoting genes, including those involved in prostate cancer and breast cancer, shut down, according to the study published in the journal *Proceedings of the National Academy of Sciences*.

CLAIMING OUR BREASTS – THE GOVERNMENT PROSTHESIS SUBSIDY BY JANE BISSELL

A well-timed explanation of the government's Breast Prosthesis Service Payment (BPSP) and the benefits it offers can provide women with valuable options to support their recovery from breast cancer.

THE SUBSIDY

The BPSP is available, "to people who have undergone a partial or full mastectomy, either unilateral or bilateral, and/or have undergone a lumpectomy, have congenital needs or have undergone reconstructive surgery, as specified by a specialist or general practitioner" (Ministry of Health brochure 'What you need to know about Breast Prosthesis Service Payments', 31 March 2005). It is used to purchase breast prostheses/forms and associated products (e.g. bras). The Ministry has information at <http://www.moh.govt.nz/moh.nsf/indexmh/healthpac-claims-breast> and an enquiry line on 0800 458 448. The brochure mentioned above is widely available and can also be obtained by calling the 0800 number.

Claimants receive up to \$600 per four year period (begins on the date of purchase and ends four years from that date) or \$1200 for bilateral and may choose to spend more at their own cost. Unspent funds are cancelled at the end of the four year entitlement period. Current debate centres on whether the \$600 is adequate and if it should be paid every two years, more in keeping with the 'rate of use and disposal' of lingerie by women who have not had breast cancer surgery.

PROSTHESIS BENEFITS BEST EXPLAINED AT DIAGNOSIS

John Biesebroek, Managing Director of Lanka Imports (NZ) Ltd, is the sole importer and distributor for the Anita range, supplying breast prostheses and after care products to women throughout New Zealand. John and his team believe a pre-op appointment with a fitter/consultant can be beneficial and that information about the subsidy, suppliers, and the benefits of a prosthesis should be discussed with women at diagnosis or immediately post surgery. Critics say suppliers are pushing their product at a time when women are vulnerable,



The team from Anita: Maureen Walker, Elaine Hill, Trish Spencer-Inight

but the psychosocial benefits of this entitlement are many and women do need to be aware early on of the choices open to them.

Janice Wood is a Breast Nurse at Auckland's North Shore Hospital and she informs women of the subsidy pre-surgery. "We show them a prosthesis and mastectomy bra," says Janice, "and explain that the current subsidy is \$600, rolling over every four years as long as they have not had reconstruction. Prior to discharge we give them written information about suppliers, the subsidy brochure from the Ministry of Health and another explaining the physical benefits of wearing a prosthesis for balance. We provide women with the subsidy certificate and a temporary soft prosthesis to wear until they are sufficiently healed to be fitted for their permanent prosthesis at around five to six weeks post-op. Women are encouraged to get the permanent prosthesis and not just continue to use the 'softie' because the shape and weight is more natural and will make them feel more confident about their appearance."

PSYCHOSOCIAL IMPORTANCE

Most women know about the subsidy but are not always aware of how a prosthesis can help restore self image, confidence and improve posture. This lack of information

may increase the emotional distress and physical vulnerability many women experience post surgery, making it difficult to summon the courage to make an appointment. Even for those who know what to expect, the first fitting can be an emotional experience.

Trish Spencer-Inight, Maureen Walker and Elaine Hill are specialist fitters with Anita BreastCare. Trish has been in the lingerie business for over fifteen years. "It can be quite early on when women come to us," says Trish. "Some are here five days after surgery but others could be five years or more. I remember one lady who had looked down at herself without her breasts but had never looked at herself straight on in the mirror. She told me that she just cried because she hadn't actually looked at herself that way since her surgery. We have to be aware of all those things."

Specialist fitters manage the subsidy claim for each individual, guide them through the sensitive process of being fitted and explain product care. Compassion, sensitivity to the needs and emotional responses of each woman and helping them to relax, feel comfortable and be themselves are primary concerns. Women at risk of developing post surgical lymphoedema are given information about the condition and the use of preventive compression garments. Fitters have expressed con-

cern over how little some women know about lymphoedema and what to do if it occurs.

Maureen Walker believes women could still be better informed about the after care services available to them. "Some women have their operation, are sent home and then come to us, feeling so alone. No one has discussed the fitting of a prosthesis with them and they're apprehensive. We're trying to work more closely with all support groups, breast care nurses and cancer societies to tell women about our service and that we're not just here to sell a product – we're

here to help. We want all women to know they do have choices and options." Maureen lost a best friend to breast cancer and working with Anita BreastCare offered her an opportunity to do something good for other women. "It was a shock losing my friend so suddenly - the cause is dear to my heart."

Elaine Hill has experienced breast cancer herself. She understands the need for control over the fitting process so has a real empathy for women. "Your rapport with each lady can be totally different," Elaine says. "Sometimes

they are angry, or reserved, even ashamed but once they know that I am a survivor they relax and I can get along with them so well. I try to focus on the bright side and what there is to look forward to. It's all about the after care of breast cancer, helping and encouraging women to lead a totally normal life. And there's that wonderful moment when you've fitted them, they look in the mirror and say, 'I'm normal again!' and they give me a big hug and say I've made their day. That's very gratifying for us as specialist fitters."

THREE SUPPLIER/STOCKIST DETAILS

Anita BreastCare is in Silverdale (north of Auckland) with independent stockists throughout the country. Call 0800 264 822 or (09) 427 5283 to make an appointment or for the stockist nearest to you (North and South Islands). Anita stocks the 'Anita Care' range of prostheses, bras and swimwear. All Anita prostheses can be safely worn in salt water, thermal pools and spas. Email at anita.nz@lanka.co.nz or view the 'Anita Care' range by visiting the website www.anita.com/nz/en and clicking onto the 'Anita Care' logo.

Naturalwear has shops in Auckland, Milford, Hamilton and Wellington with a stockist in Tauranga and travels throughout the North Island. For more information, call Naturalwear on 0800 612 612. Email an enquiry to naturalwear@xtra.co.nz. Naturalwear stock their own brand of product and also Amoena and Silima.

Smith and Caughey's has been fitting women at their downtown Auckland store, 261 Queen St. for over thirty years. "We work hard to make women feel at ease and try to create a warm, secure environment where they can relax," says specialist fitter Ann Harray. They feature a selection of prostheses and bras from the Amoena and Anita lines, and a wide range of other special bras and swimwear. Call Ann or Pauline in the Lingerie Department for an appointment on (09) 916 0844.

THE CLAIM PROCESS

1. Patient informed by specialist/Breast Nurse of subsidy, receives supplier details and explanation of how fitting and benefits of a Breast Prosthesis will help with recovery.
2. Patient provided with subsidy medical certificate (this should state medical condition and include patient's NHI #) and referral letter required to lodge initial claim at first fitting appointment (not required for future claims).
3. Supplier selected and appointment made.
4. Specialist fitter explains product options, fits prosthesis, bras, etc.
5. Supplier makes subsidy claim on client's behalf. (Client can make the claim themselves – call 0800 458 448 for advice).

STOP CANCER WHERE IT STARTS

ERMA DISAPPOINTS OVER ENDOSULFAN

BY SUE CLARIDGE

New Zealand's Environmental Risk Management Authority (ERMA) is currently undertaking a reassessment of the use of the pesticide Endosulfan. In late June it announced that the reassessment application includes preliminary recommendations that endosulfan be prohibited from aerial use, domestic use, and for air-blast application to citrus, and also that increased restrictions and controls be placed on all other uses.

In a press release issued on the 30th of June, Green MP, Sue Kedgley expressed surprise and disappointment that ERMA had not recommended that the use of endosulfan be banned in this country.

Endosulfan is banned in 55 countries

because of high toxicity to humans and nearly all other organisms, and its persistence in the environment. In New Zealand the pesticide is widely used in vegetables and berry fruit, on citrus and on sports grounds to control earth worms. In a recent survey, residues of endosulfan were found in 50 percent of New Zealand tomatoes. Endosulfan has been linked to breast cancer, birth defects, behavioural conditions and Parkinson's disease. It affects the central nervous system, and long term exposure has also been shown to affect the kidneys, liver and reproductive systems.

"[ERMA's] decision jeopardises the health of New Zealanders, our aquatic ecosystems and, with many western

countries banning endosulfan, our international reputation," says Ms Kedgley.

"It is well known that endosulfan is highly toxic to aquatic life; it does not break down, and is readily passed along the food chain. Levels in mammals at the top of the aquatic food chain, such as whales, dolphins and seals, are increasing."

Ms Kedgley said that she had been confident that ERMA would do the only safe and ethical thing and recommend it be banned. She says she will ask the Minister for the Environment to 'call in' the reassessment application, and make a final decision on whether or not to allow this pesticide to continue to be used in New Zealand.

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In a monograph on endosulfan, Pesticide Action Network campaigner, Dr Meriel Watts, says that "Endosulfan contaminates breastmilk, adipose tissue, placental tissue and umbilical cord blood, meaning that the unborn child is exposed, and then re-exposed on birth through breast milk – both exposures taking place at critical periods of development where oestrogenic substances, such as endosulfan, can have a profound life-long impact."

In a press release issued on the 2nd of June, Breast Cancer Network expressed their dismay at ERMA's announcement saying

that they are "very disturbed that ERMA has not recommended a ban on the use of the pesticide endosulfan in New Zealand." The press release went on to say that "ERMA should have been guided by the decisions of the 55 countries that have already banned endosulfan. By reducing endocrine-disrupting chemicals such as endosulfan in the environment we would have a better chance of reducing the incidence of breast cancer in our country, at present one of the highest in the world."

However, ERMA's recommendations are not final and the Authority has called for public submissions on the continued use of

the pesticide. BCN is sending a submission. Unfortunately, submissions close on the 8th of August, prior to distribution of *Upfront U Kaiora*. However, BCN members and readers who feel strongly about this matter are urged to communicate their views to their local MP and to the Minister for the Environment, the Honourable Trevor Mallard.

More information on the reassessment of endosulfan use can be found online at <http://www.ermanz.govt.nz/search/registers.html?id=23290>. Dr Meriel Watts' monograph on endosulfan can be found at <http://www.organicnz.org/page/campaign-endosulfan>

From the Project Desk...

Welcome to the first of what will be a regular column to update you on our progress with the recommendations that came out of the First National Conference for Breast Cancer.

A BIT OF BACKGROUND:

The conference was held in October 2007 at the Distinction Hotel and Conference Centre in Rotorua. There were more than 450 attendees, and on the Saturday 18 workshops were held. The workshop participants made a total of 63 recommendations for the BCN Committee to consider and take forward. One workshop in particular was in hot demand: Environment, Lifestyle and Breast Cancer. This, of course, was a great fit with the major project we have run for sometime called Stop Cancer Where It Starts. As a result of the recommendations from this workshop the subcommittee, has started work on new ways of reaching younger women with information about reducing breast cancer risk.

WHAT HAS HAPPENED SO FAR?

As a Committee we have had three planning days, the focus of which has been to identify those recommendations where we felt we could make a difference.

To date 12 recommendations have been identified and work is continuing on these. A third leaflet in the *Stop Cancer Where It Starts* range will be published in the near future. We have had discussions with breast care nurses at North Shore Hospital, have supported the first Samoan Women Survivors Support Group, and have had discussions with rural women with breast cancer regarding the specific issues that they face.

One of my particular jobs has been looking at transport assistance, I am happy to report that there are many avenues for assistance in this regard; an in depth report on what is available will be in my next article.

The wide-ranging conference recommendations are our special opportunity to make a difference. Will you consider

joining our BCN team? If you have writing or accounting skills, or can use Dreamweaver or Contribute software or have design skills, or if you enjoy committee work, and lastly if you are one of those rare people who have some week-day hours to spare, we need you now. The Committee will not mind being swamped with emails or phone calls on this matter phone 09 360 0090 or email admin@bcn.org.nz.)

NOT QUITE ABOUT THE CONFERENCE...

While not directly related to the conference a big project has been our move from premises sponsored by Bakers Delight to leased office space in Grey Lynn, Auckland City (see page 3 for details). By the time you read this I hope we will be well settled in 'our new home' Until next time, keep safe.

Best wishes

Vicki
Project Officer

CAUTION URGED ON "SIMPLE TEST" FOR BC RISK

Women as young as 18 could have a simple mouth swab to determine how likely they are to develop breast cancer but doctors warn the results could cause serious psychological stress and would not identify all women at risk.

The test, being developed at the University of Cambridge, would tell if a woman was carrying any of seven newly

found genes linked to breast cancer. It would also test for the two high-risk genes, BRCA1 and BRCA2, discovered a decade ago.

The researchers said women deemed high-risk could be advised to have regular mammograms or choose to have their breasts removed. Those not carrying any of the genes could wait until the age of 60 before having screening.

The executive director of the NSW Breast Cancer Institute, John Boyages, said yesterday that, while advances in diagnosis were welcome, the mouth swab should be treated with caution. "They have now found seven genes linked to breast cancer but there could be 27 that we don't know about yet, so it gives women false reassurance," Professor Boyages said.

Sydney Morning Herald, 27 June 2008

ON TRIAL BY BARBARA HOLT

A REPORT FROM THE WELLINGTON CONSUMER FORUM ON CLINICAL TRIALS FOR BREAST CANCER

A Consumer Forum held on the 5th of July, and chaired by Sue Guthrie (the NZ representative on the Consumer Advisory Panel of the Australian NZ Breast Cancer Trials Group (ANZBCTG)), was organised by ANZBCTG, BCAC and the Cancer Society of Wellington, and was sponsored by Avon Ltd. About 50 women and a few male partners attended and heard from three cancer medical specialists, one consumer advocate from Australia and another from the US. The ANZBCTG has been meeting since 1978 when it ran two trials; it now runs 60 trials with continuous support from the Australian Government. The risk of dying from breast cancer is now half what it was 30 years ago. However, only 9% of the Group's applications in New Zealand are funded by the New Zealand Health Research Council.

Associate Professor Fran Boyle, a Sydney medical oncologist and Chair of the Group's Scientific Advisory Committee, believes systemic (drug) treatments given these days are responsible for the better survival rates. She said there are now five different methods of blocking oestrogen in women who have had breast cancer. She suggested some of the drugs' supposed side-effects, such as osteoporosis, might be the result of low Vitamin D. New Zealand women can get Zoladex which suppresses the ovaries. The SOLE trial is looking at the possibility of women being on aromatase inhibitors for longer than five years. Another trial – BEATRICE – for women with receptor-negative breast cancer is looking at the prevention of blood vessel growth in cancer. Currently trials involving New Zealand women include IBIS Parts I and II investigating Tamoxifen versus aromatase inhibitors.

Mr Ian Campbell, Clinical Director of the Breast Care Centre at Waikato Hospital, said it is now thought that as many as 60-70% of women with breast cancer do not need an axillary dissection because a Sentinel (lymph) Node Biopsy is pretty accurate. However, a few uncertainties remain such as the best radiotracer to use, the best injection site, its role in DCIS, whether it should be done before or after adjuvant therapy, and

the significance of any micro-metastases found. The SLN biopsy is thought to miss about 7-9% of affected lymph nodes. The SNAC2 trial being held in NZ now tests the false negative rate and any reduction in survival. A lot more women are needed for this trial, the pay-off being absence of pain, reduced arm movement or numbness.

Dr Carol Johnson, a Wellington radiation oncologist trained in South Africa, said radiotherapy treatment produced a 70% reduction in breast cancer metastases, but it needed fine tuning in trials to decide who not to treat and what to treat, with help from new technology, new discoveries like bio-markers and other new chemistry. The TROG 07.01 (BIG 3-07) trial is looking at radiotherapy for DCIS, exploring the dose and boost area. A post-mastectomy trial – LNI-3 – is investigating whether a woman with one to three affected nodes should receive radiotherapy. Other possible trials include one for elderly women with breast lumps up to two centimetres to find out whether they should have the whole breast treated by radiotherapy, and whether those with inflammatory breast cancer should have a mastectomy or radiotherapy.

Linda Reaby, Australian Professor of Nursing, who co-ordinates the Consumer Advisory Panel of the ANZBCTG, has a strong family history of breast cancer and had both her breasts removed after her diagnosis at the age of 45. She said Professor Forbes, chairman of ANZBCTG, forecasts it will be 2040 before we eliminate breast cancer. Linda had been told there is no other group in the world like CAP for consumer-involvement in trials, although a lot of grants committees now require consumers on their protocols committees. Ms Reaby spoke of research that found 97% of women who participated in trials said they had had good treatment in them, but 85% of women with breast cancer were not aware they could enter trials. In Australia, 10% of women with breast cancer participate in trials. CAP sees a need to get GPs excited and educated about trials by lobbying them and through the CAP newsletter IMPACT and a recruitment

brochure. It does not endorse all trial protocols, believing the quality of life of women in trials is important.

The final speaker was Margo Michaels, the Executive Director and President of ENACCT, an Education Network to Advance Cancer Clinical Trials in Silver Spring, USA, funded by the Lance Armstrong Foundation. In their work to help people understand more about clinical trials, ENACCT suggests they ask the simple question: *Is there a trial for me?* In the US children have a 70% participation rate in trials, and this was offered as a reason why children's cancers were being treated more successfully than adult cancers.

Ms Michaels said that various myths about clinical trials (they are not the way to get good care; they are only for people with advanced disease; and no one benefited except the researcher) should be corrected. She believes that these days patients in clinical trials are never given anything other than what is appropriate treatment. The provision of informed consent, having the right to drop out, scientific reviews and Data Safety Monitoring Boards resulted in trials being a positive experience. In the US, 85% of patients are never told about trials, although 75% would have entered one if they had been. One of the benefits to patients was they could be the first to benefit from a new drug regime. The risks were treatments not always being better than existing ones and unexpected side-effects.

The main message I took from the panelists at this forum, only the second held, was the need for anyone who knew a new breast cancer patient to advise them to ask their doctors whether there were any trials in which they could participate. Although there was question time when some good ones were asked, in my view it was insufficient. A forum is *a place for public discussion*, and I hope CAP makes sure at the next forum, attendees get more time to express their viewpoints.

For accurate information on specific trials, visit www.anzbctg.org.au.

STOP CANCER WHERE IT STARTS

WHAT'S IN THAT CRÈME?

BY SUE CLARIDGE

THE LOW DOWN ON COSMETICS AND PERSONAL CARE PRODUCTS

When someone puffs a lungful of cigarette smoke in your face or you are subjected to a sooty black blast from the rear of a badly tuned car in front of you, you are left in no doubt that you are ingesting a whole lot of nasty chemicals. It smells bad, it tastes bad and for the sensitive among us (the author included) you can quickly develop a headache or sore eyes, or worse.

But when it comes to cosmetics and personal care products (cleansers, shampoos and conditioners, soaps, even tampons and pads) it is hard to imagine that they could be doing any damage. After all, they smell nice, they are “clean”, and make you look better and feel better about yourself. It is no accident that the “Look good, feel better” campaign for breast cancer patients involves make up and hair treatments that give women a great boost.

But are these products as healthy and benign as you're inclined to believe?

The idea that cosmetics and personal care products may have hidden dangers is not a new concept, but it has finally made its way out of the “lunatic fringe” shadows and hit the mainstream. As I pondered how to begin this article this morning (21 July) the *New Zealand Herald*, no less, ran a full page feature on cosmetics in its Green Pages, including the startling information that:

“It is thought that women ingest as much as 2kg of chemicals a year from the cosmetics and skincare they use - and there are no rules or regulations governing their ingredients.” (*Actually, we knew about the lack of regulations bit but the 2 kg was a bit of a shock!*)

I breathed a small sigh of “relief” tinged with exasperation upon reading the next paragraph:

“Attention has particularly been drawn to the use of parabens as preservatives in beauty products, which some studies have linked to cancer, and phthalates, the industrial chemicals used in many cosmetic products and linked to birth defects.”

Relief that finally these concerns were getting some mainstream exposure and exasperation that many of us have been talking and writing about this for quite some time. As an author, the only publication interested in my articles on this several years ago was *Organic New Zealand*, and even last year another magazine would only publish my article on environmental oestrogens and breast cancer after getting confirmation from a research scientist that I wasn't completely barmy for suggesting that endocrine disrupting chemicals could be found in many everyday products including cosmetics.

This article marks the beginning of a new column designed to help you make better decisions about the cosmetics and personal care products you use – helping you to *Stop Cancer Where It Starts*. So to kick us off I thought there was no better place to start than to paraphrase the *New Zealand Herald's* “9 ways to green your cosmetics.”

1: READ THE LABEL

Most of the ingredients in cosmetics are unregulated chemicals; find out which are the most important to avoid and read the labels. If the ingredients aren't listed (even the ones that aren't the “active” ingredients) don't buy it.

2: ALUMINIUM-FREE DEODORANT

Aluminium has been found to cause skin irritation, and there are links between aluminium exposure and neurodegenerative diseases such as Alzheimer's. Anti-perspirants prevent the body from eliminating toxins through perspiration. Try products without aluminium – but check for parabens as well (see below) – or try rock crystal which is made from natural salts.

3: TOOTHPASTE

Many popular brands contain chemicals such as parabens, titanium dioxide for whitening, and high levels of fluoride. But natural toothpastes are available, and many people find that using a bit of baking soda will do the trick as well.

4: HAIR CARE

Look out for products containing petroleum products and sodium laurel sulphate, hair dyes and other products with carcinogenic coal tar (especially some anti-dandruff shampoos), hairsprays and gels containing petroleum derivatives, formaldehyde and phthalates.

5: PETROLEUM-FREE PRODUCTS

Mineral oil, paraffin, and propylene glycol are basic ingredients in many cosmetic products. Look for products that use alternatives such as beeswax.

6: TANNING

Many of the common “commercial” sunscreens contain oestrogenic chemicals – many contain more than one. Try organic sunscreens (commonly available up to SPF 30 in health and organic stores) and/or cover up in the sun and stay out of the midday heat. Remember, sun exposure is necessary to make vitamin D.

7: NO ANIMAL TESTING

Look for the Humane Cosmetics Standard (HCS) label on products to check that they are cruelty free. It is the world's only international standard for cosmetic or toiletry products that are not animal tested.

8: ORGANIC PRODUCTS

If going organic choose certified organic where possible. Many products labelled “organic” or “natural” may contain only one or two organic ingredients among a pile of less friendly ones.

9: ORGANIC TAMPONS AND SANITARY PADS

Toxic Shock Syndrome is not the only health danger in these products. The chlorine bleaching and dioxin residues are also a problem. Try 100% cotton tampons and sanitary pads, organic if possible, or washable pads and a mooncup.

If you have ideas to share, cosmetics, personal care products or cleaners to recommend (or avoid), or even a healthy recipe (see below for our first), we would love to hear from you. We will run this column every issue but will ultimately rely on readers to keep it going. Please phone, write or email the BCN office, or email me, Sue Claridge, at sclaridge_bcn@clear.net.nz.

GOLDEN VEGETABLE SOUP SERVES 6 FOR A HEARTY LUNCH

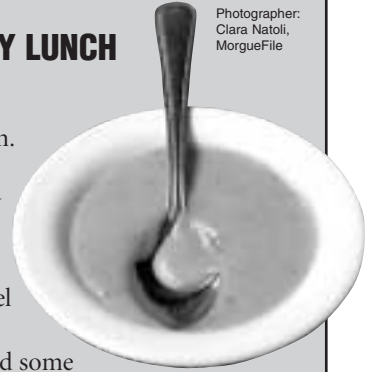
INGREDIENTS

cup orange lentils
cup pearl barley
2 onions
2Tbsp olive oil
2 tsp mild curry powder
250- 300g pumpkin
3 medium carrots
2 medium potatoes
Several stalks of parsley
1 small leek
Salt, pepper
turmeric to taste
Water

METHOD

1. Wash the lentils and pearl barley in a large pot of cold water and drain.
2. Add about 1 litre of fresh water and simmer for 1 hour. While simmering, use a processor to roughly chop the onions and fry gently in the oil until transparent. Add curry powder and cook for 2 more minutes.
3. When the lentils and barley are ready, peel and chop the pumpkin, process to a fine pulp with about half a cup of water, and add to pot. Peel or scrub the carrots, process with water in the same way and add to pot.
4. Add the onions and spices to the pot, season with 1t salt, turmeric and some ground black pepper. Bring back to simmering point.
5. Process the potatoes nearly to pulp with more water, add to pot, and stir. Simmer 10 – 15 minutes. It will thicken quickly and need stirring regularly to prevent sticking. Add a cup or more of water or stock to thin to your liking.
6. Five minutes before serving, cut the leek into thin rounds and chop the parsley, add to pot. Simmer a further 5 minutes or so.
7. Taste and add more salt if needed.
8. Serve with toast or rolls.

Each serving contains plenty of protein and 1/3 onion, 40-50g pumpkin, carrot, 1/3 of a potato, 1/6 of a leek, – probably at least 3 serves of vegetables.



Photographer:
Clara Natoli,
MorgueFile

RESEARCH AND NEWS UPDATE

BREASTSCREEN AOTEAROA COMMUNICATIONS CAMPAIGN 2008



June Northcroft Grant (Te Arawa, Tuwharetoa, Tuhourangi/Ngati Wahiao) is one of the women featured in the campaign and is a breast cancer survivor. June, seen here with her grandchildren, made a major contribution to the Rotorua conference in 2007 and will be familiar to the readers who attended.

To support the breast screening programme, a new communications campaign to encourage women to have regular breast screens will begin on 17 August 2008.

The campaign has been designed to raise awareness of breast screening, increase calls to the 0800 number and support the programme and providers in their efforts to reduce the number of women who die from breast cancer.

The campaign, which includes television, radio and print advertising, also seeks to dispel myths and reduce barriers that stop women from being screened. The messages in the campaign are straightforward, supportive and informative. Maori and Pacific women feature throughout the ads. The ads encourage women to make an appointment to have a breast screen, and tell them how to do this.

The priority audience for the campaign is Maori and Pacific women who are in the target age range of the programme (45-69) and who have

never been screened or who do not screen regularly (every two years).

The ads will be run in places where Maori and Pacific women are most likely to see them, and include TV3, Maori Television, iwi radio stations, Nui FM radio network, Mana Magazine, Tu Mai, and Spasifik. A public relations campaign will encourage media to include stories wherever possible – in news stories, on talkback radio, etc.

BREAST CANCER PATIENTS CAN HAVE NORMAL LIFE EXPECTANCY

Breast cancer patients whose cancers are discovered early when they are small can expect to live as long as women who never get the disease. The latest figures from British researchers show that five years after diagnosis, those women who were treated when their cancers were at an early stage and responded well to treatment could expect a normal life span.

That is good news for women since 61 percent of breast cancers that are discovered through screening are small. Other criteria included the cancers be classified as low grade and not spread to the lymph nodes.

The odds have also improved for women who are diagnosed with invasive breast cancer. In Great Britain, their 15-year survival rate has climbed to 86 percent.

“Huge strides have been made and more women than ever are surviving breast cancer,” said Professor Julietta Patnick, director of the National Health Service Breast Screening Programme. “Many of these have benefited from early detection through routine screening.”

BREAST EVENTS to come

- **4 September, 2008 – BCRT Cirque Fire**, Fire & Ice Gala Dinner. An evening of luxury, glamour and thrills - indulge in the opulent Louis Roederer Champagne Hour and dine under The Big Top while the circus continues to unfold before your eyes. Book your tickets now to avoid disappointment: events@bcrt.co.nz or ph 0800 227 828.
- **24 September, 2008 – 2008 Montana World of Wearable Art™**. Tickets to the Dress Rehearsal, a special preview evening of the renowned Montana World of Wearable Art Awards Show will once again be sold to raise funds for The Breast Cancer Research Trust. Tickets are \$70 (inc GST). Bookings can be made via The Breast Cancer Research Trust website at www.curebreastcancer.org.nz or by phoning 0800 227 828
- **16-19 October 2008 – Moving On From Cancer**, Full residential retreat for women. Run by Anne Scott and Ruth Stanley at the Aio Wira Retreat Centre, Waitakere City. For more details contact Ruth Stanley (09 256 0305) or Anne Scott (09 521 5567) or email cancersurvivorretreat@yahoo.co.nz.
- **18 October 2008 - Putaruru Think Pink Party** to raise money for the Waikato Breast Cancer Research Trust, 6.30pm - 2.00am, The Plaza, Kensington Street, Putaruru. For more details go to www.putaruruthinkpink.co.nz
- **7th - 9th November 2008 -Three-day Instructors Training course for The Lebed Method**, Focus on Healing Through Movement and Dance, in Wellington. International trainers Heather Ruck and Kim Thornton. Limited numbers. To enrol, please contact Naena Chhima at naenac@cancersoc.org.nz or Di Graham 04 934 3083 or 027 460 1313 or di.g@paradise.net.nz. For further information about the Lebed Method go to www.healingtherapy.us

Breast Cancer Support group in central Auckland meet every third Wednesday of the month at Domain Lodge, 1 Boyle Cres, Grafton. Please note: the meetings are now held in the afternoon, 1pm -2.30pm. If you have had a breast cancer diagnosis recently or years ago, you are most welcome to attend. For further information Ph Christine 416 7114 or Joan 6303031.

Deadline for next issue's Breast Events Column is 20 September, 2008.

VISIT THESE SITES FOR MORE BREAST INFO! www.breastcancernetwork.org.nz www.breast.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.

PATRON: Lois Muir

STAFF: Administrator, Jennifer Woodroofe and Newsletter Editor, Sue Claridge.

HONORARY LIFE MEMBERS: Wendy Steenstra-Bloomfield, Barbara Holt, Dell Gee and Jenny Clarke

COMMITTEE MEMBERS: Barbara Mason, Anne Iosefa, Gillian Wood, Liz Williams and Vicki Blacklock.

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

TO JOIN BCN

To become a member & receive a regular copy of UPFRONT send your name and address to BCN (NZ), PO Box 46018, Heme Bay, Auckland 1147 - \$25 survivors/supporters, \$20 unwaged, \$30 professionals, groups & libraries.

For further information, phone our office on (09) 360 0090 fax us on (09) 360 2180 or email us at brcanz@xtra.co.nz.

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

Address _____

Phone Home (0) _____

Work (0) _____

Fax (0) _____

Email _____

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