

Upfront U Kaiora

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

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A BETTER WAY OF SCREENING HIGH RISK WOMEN

BY SUE CLARIDGE

“MRI IMAGING NEEDS TO BE AVAILABLE FOR HIGH RISK WOMEN.”

This was one of the recommendations from the workshop for women with a family history of breast cancer at the First National Conference for those affected by breast cancer.

Although magnetic resonance imaging, or MRI, has been around since the 1980s, the recommendation from the conference workshop is not a simple one to implement. It is loaded with issues which include the fact that genetics and familial breast cancer are fraught with emotion and fear, and that MRI is, as yet, a very costly procedure.

MRI FOR EARLY DETECTION OF BREAST CANCER

MRI has benefits over mammography for detecting breast cancer because it is very sensitive and can “see” tumours that mammograms can’t, particularly in young women because they often have denser breast tissue than older women. The procedure itself is also very safe compared to mammography because it doesn’t involve the use of ionising radiation. Having said that, MRI is not without its adverse impacts.

MRI is not very specific; that is, many of the “abnormalities” that it picks up are not cancer but normal changes in the breast tissue. These are false positives, and while ultimately these changes in breast tissue are found to be non-malignant, they must be evaluated. This means more imaging and biopsies, and the attendant anxiety for the woman, until it is determined that there is no tumour.

Cindy Zaistoff from the Northern Regional Genetics Service, says that the fear induced by repeated false positives can cause



A magnetic resonance imaging machine

some women with a BRCA gene mutation to consider a prophylactic mastectomy, rather than go through the anxiety each time they have a scan.

Despite its ability to pick up very small tumours and its value in detecting breast cancer in women with dense breasts, there are many reasons why MRI will not replace mammography and ultrasound. As well as the high number of false positives, MRI is very, very expensive (approximately \$1800 per procedure) and very time consuming for both the woman, and the radiologist and other staff.

However, Dr Barbara Hochstein, a consultant radiologist currently working in Rotorua, told the 2007 conference that “MRI is a useful tool for integrated imaging as an adjunct to mammography and ultrasound within a breast imaging team. It is useful in local staging of known breast cancer, differentiating between scar tissue and a recurrence, evaluating silicone implants, and the response to neoadjuvant chemotherapy, in which women

are given chemotherapy prior to surgery.”

“It is also particularly useful for screening the small group of women who are at very high risk; the approximately five percent of women with breast cancer who have BRCA gene mutations. These women develop interval cancers more frequently than others, cancers that are often more aggressive, and mammography often misses such tumours,” Dr Hochstein said.

The United Kingdom and Australia have protocols in place for the use of annual MRI for these high risk women, and in early 2007 the American Cancer Society issued new guidelines recommending annual MRI for high risk women (see box on page 2).

WHY DO WE NEED MRI?

Traditional screening using mammography is problematic for young women who are at high risk of developing breast cancer. Young women typically have denser breast tissue which makes it difficult for a mammogram to pick up a tumour. Women with a

strong familial history or who have the BRCA gene mutations are also more likely to develop interval cancers – those that develop between mammograms – and to have aggressive, fast growing cancers. MRI can pick up very small tumours in dense breast tissue before such tumours will be seen on a mammogram. Because high risk women are more likely to have fast growing tumours, MRI allows detection as early as possible.

At the 2008 American Society of Clinical Oncologists annual meeting, Dr Christina Kuhl and her colleagues presented the results of a three year prospective study comparing mammography, ultrasound and MRI.

The study team investigated the respective contribution of the different imaging modalities, alone or in different combinations, for early diagnosis of familial breast cancer. The

687 asymptomatic, high risk women underwent a total of 1,679 annual screening rounds and 27 breast cancers were diagnosed. Thirty three percent of the cancers were found on the mammograms, and 48% with mammogram and ultrasound used together. When MRI was used on its own, 93% were found, but when MRI, mammography and ultrasound were combined 100% of cancers were found. Interestingly 52% of the cancers only showed up on the MRI (that is they were not detected by either mammography or ultrasound).

The study suggests that as many as 50% of tumours in high risk women could be picked up by MRI that would not be picked up by mammography, at least not early enough to make a difference to the woman's prognosis.

The results of another study, published in the *New England Journal of Medicine* in 2007



Genetics counsellor Cindy Zaitsoff

led to suggestions that MRI should be used for screening the contralateral breasts of women who have had a diagnosis of breast cancer. With 2600 women a year being diagnosed with the disease, and at \$1800 a scan, the cost of MRI clearly puts it out of reach for screening of all breast cancer patients within the public health system.

However, Dr Barbara Hochstein told *Upfront U Kairora* that MRI is cost effective for high risk women.

For young women who have children, who are productive members of the community, the social cost of breast cancer, and the flow on costs to the community make MRI a cost effective way of reducing the burden of the disease on both the health system and the wider community.

“High risk women all need MRI every year from the age of 30, if you are going to use the recent American guidelines,” Dr Hochstein said.

It is hard to assess exactly how many women a year in New Zealand would meet the criteria for MRI screening for high risk women. However, extrapolating from the number of women she counsels, Cindy Zaitsoff from the Northern Regional Genetics Service, suggests that the figure could be around 100 to 120 women (with the highest level of risk), a relatively small number compared to the number of women diagnosed with breast cancer each year.

THE BARRIERS TO MRI USE IN NEW ZEALAND

Access and cost are the two main barriers to high risk women having access to MRI scans in New Zealand.

With breast MRI only available in three

AMERICAN CANCER SOCIETY GUIDELINES FOR MRI SCREENING IN HIGH RISK WOMEN

The American Cancer Society recommend breast MRI and mammography yearly beginning at age 30 for women with a high risk of breast cancer. This population includes women who meet at least one of these criteria:

- known BRCA1 or BRCA2 gene mutation,
- strong family history of breast or ovarian cancer,
- a 20% or greater lifetime risk of breast cancer,
- women who have received radiation therapy to the chest between the ages of 10 and 30,
- women with a first-degree relative with the BRCA1 or BRCA2 gene mutation who have not had testing themselves,
- women who have, or may have, a family history of a cancer syndrome that increases their risk of breast cancer.

WHAT IS MRI

Magnetic Resonance Imaging, or MRI, uses magnets that emit radio waves to produce a three-dimensional view of the breast and the underlying structures and vessels. Special breast coils are used and the patient has to lie on her stomach for an hour while up to 10,000 images are taken. An intra-venous contrast dye – gadolinium – is used. Tumours grow new blood vessels and the gadolinium dye shows up the increased concentration of capillaries associated with a tumour, enabling them to be detected in a way that doesn't happen with mammography, which instead shows up differences in tissue density. The analysis of the MRI images involves the dynamic study of the blood flow in the breast tissue.

Breast MRI is the most demanding of MRI procedures. To be of benefit in the detection of breast cancer, the MRI machine must be up-to-date and use special breast receiver coils to obtain the 1 – 2 mm accuracy. A dedicated computer programme is also needed because of the complexity of natural breast processes. It is a time-consuming process for both the staff and the woman.

The gadolinium can rarely cause adverse reactions such as anaphylaxis, and cannot be used in pregnant women, and those with severely impaired kidney function in whom it can cause irreversible kidney damage.

centres – Auckland, Wellington and Christchurch – many women need to travel to obtain MRI scans.

“The very nature of this particular test requires that it is performed by people who consistently carry out the procedure to a high standard and that this standard is maintained,” Dr Hochstein said. “Breast MRI at a high volume centre is best; it is not an examination to be done by someone who only does a few.”

Cindy Zaistoff from the Northern Regional Genetics Service, agrees, saying: “You need to make sure that if high risk women are having surveillance, it is good quality.”

New Zealand needs protocols and guidelines for breast MRI, as is the case in the US, UK and Australia, and Dr Hochstein says we must establish accredited centres. And both Barbara and Cindy say that more experienced staff is a must.

Distance from a specialist MRI centre is a major barrier, and Dr Hochstein believes that unfortunately for some women, extensive travel to attend an MRI centre is going to stop them participating in such screening. However, given need for high-tech equipment and experienced staff, it is unlikely that this issue is going to be any better resolved than is currently the case for breast cancer treatment for which many rural and



Consultant radiologist, Dr Barbara Hochstein

provincial women already need to travel.

WHERE DO WE GO FROM HERE?

How do we, as a community, go about ensuring that those women who can benefit most, have access to breast MRI?

First, the women who would benefit need to be identified; to that end, both Barbara Hochstein and Cindy Zaistoff say that geneticists and genetic counsellors need to be involved. We also need to have a set of guidelines, protocols and criteria for high risk women, along the lines of the American Cancer Society guidelines. Cindy suggests a multi-disciplinary, team approach is needed to develop these guidelines.

In Australia a pilot study was undertaken to work out the protocols and get a programme working before the Federal Government was

lobbied to make MRI available throughout the country. Barbara Hochstein believes that a similar approach here might work. We already have a high risk MRI clinic in Wellington which has public funding for 40 scans a year, and could possibly function as a “pilot” for making MRI publicly available and funded at two or three other centres in New Zealand.

Although the situation in New Zealand is fairly ad hoc, because there are no guidelines, Cindy says that MRI is becoming more available.

“But we need to make sure that those who really need it are getting access, rather than those with a lesser need exhausting the available funding,” she told *Upfront U Kaioara*.

Both Barbara Hochstein and Cindy Zaistoff believe that while MRI offers considerable benefits for women who are at high risk of breast cancer, the procedure is a double edged sword for the women who have it. The benefits of MRI only outweigh the disadvantages in a very small group of women.

However, it has the potential to significantly alter the prognosis for high risk women with aggressive and fast growing tumours by picking up cancers long before conventional mammography can. For this reason, it is important that MRI is made available for this small group of women.

From the Editor....

It is hard for the rest of us to imagine what it would be like to be a young woman with a strong family history of breast cancer, or confirmed BRCA gene mutations.

Although the risk of breast cancer is high for these families, many women with the BRCA genes never develop breast cancer, and for those that do, medical advances and research continue to offer them increasingly better outcomes. However, some of the advances that offer the best chance to those at high risk of breast cancer are inequitably available and the harms must be balanced against the benefits. In June we looked at prophylactic mastectomy, an option that some women consider in their plan to beat breast cancer. In this issue we take a look at MRI – a procedure that is much better than mammography at picking up very small breast cancers in young women or those with dense breast tissue, at a very early stage, offering better outcomes for high risk women. But using MRI for high risk women is not that simple. It is an extremely expensive procedure compared with mammography, and its high rate of false positives causes considerable anxiety for some women. Its cost effectiveness as a screening tool needs to be carefully considered in the context of a seriously cash-strapped public health system, which already fails to serve women with breast cancer as well as we all think they should be served. And finally, high risk women and their families need so much more than a great screening tool. They need support, information and counselling if they choose genetic testing. They need compassionate and sensitive, and up-to-date health professionals who will assist them to deal with, and make the best decisions possible for their continued surveillance and health care, without their greater risk for, and anxiety about, breast cancer dominating their lives more than is absolutely necessary.

The Faces of Breast Cancer

In the February 2009 issue I plan to do a series of articles on the faces of breast cancer. We often publish the stories of the women (and men) with breast cancer. These are our most important stories and represent the first face of breast cancer. But many others are affected by breast cancer – husbands and partners, daughters and sons, mothers, fathers, sisters, brothers and friends, GPs, breast care nurses, breast physicians, radiologists, oncologists, breast surgeons and support people. I would like to hear from a whole range of people who are affected by breast cancer – I would like your story! If you would like to contribute please let me know. I am happy to ring and talk to you, or if you would like to write your story and send it in, I'd like that, too. It doesn't have to be long – it just has to be your story, your experience. Please get in touch: ph me on 09 445 2966 or phone the BCN office on 09 360 0090, or email me at sclaridge_bcn@clear.net.nz

Sue Claridge

PUBLICLY FUNDED MAMMOGRAPHY

In the last issue of *Upfront U Kaitia*, we brought you an article from Dr Madeleine Wall, Clinical Leader, BreastScreen Aotearoa, on mammography for survivors. In a follow-up to that article we have a table that sets out the groups of women who are eligible for publicly funded or “free” mammograms: women with breast symptoms, high risk women including women who have previously had breast cancer, and women between the ages of 45 and 69.

	SYMPTOMS (lump or nipple discharge, etc)	HIGH RISK (previous breast cancer, family history, biopsy)	AGED 45 - 69
How to get referral for a mammogram	Not all women with symptoms need a mammogram. Visit your GP	GP or Hospital specialist	Self enrol, phone: 0800 270200
Pathway to appointments	Yes – on basis of clinical urgency.	Individualised surveillance advised by your GP or hospital specialist	Appointments allocated to 2 yearly re-screens first, then new women
Initial test	Clinical examination by GP (only followed by referral for imaging if necessary)	Mammography and clinical exam	Mammography only
Where will I have the mammogram?	Hospital or private radiology contracted to DHB	Hospital or private radiology contracted to DHB	BSA fixed site or mobile
Who will organise if extra tests are needed	GP/hospital/radiology practice	GP/hospital/radiology practice	BSA clinic
Recall for repeat mammograms	No	Recall dependent on GP and radiology service Regular annual	Yes by BSA Regular 2 yearly



LETTERS

KUDOS FOR BCN FROM TWO CLARKES

I've been getting the BCN newsletter for several years now and, as a breast cancer survivor myself, I think its educational emphasis is just so important. I love the lists of recommended reading and the great articles on research findings, as well as the stories of women managing their lives after breast cancer. All in all I think it's a great magazine for supporting women and keeping us up to date with what's happening in the world of breast cancer.

I think BCN is very worthy of my donation and am happy for you to use it wherever you need it, either to help with your on-going expenses or to enable you to do something you'd like to do but perhaps have been unable to because of a lack of funding.

Best wishes. I look forward to my next great newsletter!

Regards,

Ann Clark

Ed.'s note: Many thanks from the BCN Committee to Ann for her wonderful donation.

Instead of sending my lovely friend, Jenny, flowers after her recent breast cancer surgery I decided to pay her first year's subscription to *Upfront*, which I have thoroughly enjoyed over my past eleven-plus years. I know she will too.

Helen Clarke - Grateful Upfront Reader
Hamilton

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

BREAST CANCER IN THE FAMILY

BY SUE CLARIDGE

Sharyn has 13 siblings; four brothers and nine sisters. Six of her sisters have had breast cancer. The eldest, Heather, died from metastatic cancer in her liver after having had bowel, ovarian and breast cancer. The breast cancer returned twice, but Sharyn doesn't know which primary cancer caused the liver metastases.

The cancer susceptibility seems to come from her father's side. Her paternal grandmother had stomach cancer, a brother has leukaemia and several of her aunts have had breast cancer. Despite this, the other five sisters have so far survived their encounters with breast cancer, and Sharyn, the youngest at 54, has somehow kept the disease at bay.

But she doesn't just ignore breast cancer; Sharyn plays an active role in making sure that even if she can't stop it she gives herself a good chance of surviving it. She has annual mammograms which started in her early forties, and has regular tests and examinations for bowel and ovarian cancer. Early in her surveillance for breast cancer a lump was found, but to her relief a biopsy showed it to be benign.

Her other sisters are also under heightened surveillance for breast cancer, with annual mammograms as is recommended for women with high risk.

With such a strong familial involvement, two of Sharyn's sisters were tested for the BRCA genes. Both were negative. About seven years ago Sharyn was invited to be tested as part of some research. However, she was never given her results and there seems to have been a communication problem regarding this. Although it is not always understood, participants rarely receive individual results from research studies and this seems to be what happened in Sharyn's case. Certainly, Sharyn did not ever receive her results, even after the intervention of her breast surgeon, Mr John Collins, who was also unsuccessful in obtaining them (see box at right for more information).

Although Sharyn was angry about not getting her results at the time, she has moved on and her life isn't ruled by the spectre of breast cancer in her family or finding reasons for it.

Before we began talking about her family history and the role that breast cancer plays

in her life, I explained to Sharyn about breast MRI. She had had a back MRI several years ago but knew little about breast MRI. I explained the benefit of MRI over more conventional mammography when used for women at high risk of the disease, particularly those with a strong family history.

"I would love to have MRI," Sharyn said. "It



would be good knowing that if there was anything there it would be better at picking it up."

When she has a mammogram she is always a little worried about whether or not enough films have been taken to ensure that everything has been thoroughly checked. She prefers to know everything and if she did develop cancer, would want to know as early as possible so that something could be done about it. And although she doesn't have medical insurance she would be prepared to

pay for the MRI herself, to ensure that she has the best surveillance possible.

"I'm sure that my GP doesn't know about it," Sharyn said when talking about her own lack of knowledge about MRI use in the early detection of breast cancer.

"I've been very lucky with everyone looking after me. I've had very good specialists and my GP is very good. I'm sure if she knew about MRI she would have told me about it."

This raises possibly the most important point in our conversation. GPs are at the coal face of community medicine. It is to their GP that most women first go with any health concerns. All the guidelines and protocols in the world won't ensure that high risk women get the best surveillance and assessment if the GPs don't know that breast MRI is available and recommended for these women. It is critical that, when mapping the way forward with breast MRI in this country, GPs are informed so that they can recommend and refer for MRI, women at high risk of breast cancer.

Ultimately, Sharyn seems to cope very well with her family history and the knowledge that breast cancer could be in her personal future. She is positive, upbeat, and doesn't seem given to stressing about it. But she sees a need for more information, support and more counselling for women like her. After all, as we have so often heard from women in "the club", knowledge is power.

GENETIC TESTING

There are specific protocols surrounding genetic testing for the BRCA gene mutations that significantly raise the risk of both breast and ovarian cancer among carriers. After all, discovering you have the genes have considerable implications for the emotional and physical health of the women and their families.

Cindy Zaitsoff of the Northern Regional Genetic Services says that all people who want to be tested undergo genetic counselling first. Results are not withheld in a clinical setting, although testing is only offered to eligible families and individuals due to cost and difficulty in interpreting results. If members of a family had already tested negative for the BRCA gene mutations, a blood sample from a woman without breast cancer would not be tested as the results would not add further to the knowledge gained from earlier tests on the family. Genetic testing is only undertaken with the full informed consent of the individual. If you would like more information about genetic testing for the BRCA gene mutation or you have a strong family history of breast cancer and would like to know what your options are please contact your regional genetic services:

- Northern Regional Genetic Services (Auckland): Phone toll free 0800 476 123
- Central Regional Genetic Services (Wellington): Phone toll free 0508 364 436
- Southern Regional Genetic Services (South Island): Phone toll free 0508 364 436

PINK PILATES PROPAGATES

In October, physiotherapists throughout New Zealand are heading to Auckland to attend the first Pink Pilates Education and Certification Training programme.

The course will provide physiotherapists with the knowledge to help maximise recovery and improve the quality of life for those affected by breast cancer.

The Pink Pilates programme is designed to facilitate recovery from breast cancer surgery and reconstruction surgery (see *Upfront 77, February/March 2008*). It aims to reduce treatment related side effects such as lymphoedema, shoulder problems, scar tissue formation, fatigue, depression 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.

“Throughout the world there is a huge lack of information given to women about maximising their recovery after breast surgery,” says Lou James, the Pink Pilates founder and programme director. Lou is committed to promoting healthy lifestyle choices based on the latest medical research. She hopes that the Pink Pilates programme will help to raise awareness of the importance of prescribed rehabilitation for every person undergoing surgery or treatment for breast cancer.



By November 2008, Pink Pilates will be available to women with breast cancer in Dunedin, Christchurch, Wellington, Gisborne, New Plymouth, Mount Maunganui, Hastings, Tauranga, Hamilton, South Auckland, Central Auckland, West Auckland and Whangaparaoa.

Upfront U Kairua and Lou James of Pink



Pilates plan to bring readers more information on the Pink Pilates programme in the December issue of the magazine, including who to contact in your area. In the meantime, if you would like more information on Pink Pilates, visit www.pinkpilates.co.nz or email info@pinkpilates.co.nz.

WEBWATCH:

BEST BREAST CANCER WEBSITES <http://www.bestcancersites.com/breast>

This site describes itself as a guide to the world's best and most popular breast cancer websites for information and support for those whose lives have been touched by breast cancer, and for their partners, friends, relatives, caregivers and health providers.

The site was created by Ed Everest because “there was no simple guide to the various cancer websites and cancer forums on the internet” and people “newly diagnosed with cancer could spend many hours searching the internet for appropriate websites and still not find the best websites for their particular purposes.”

The site is, perhaps, too simply structured. It is basically a single page which one has to scroll through to find information. However, Ed begins with what he regards as the three best cancer sites and from there the listings appear to be chronological as Ed finds them and posts information on his website.

Where the greatest benefit lies is in the summary of each site, the active link through to that site, and often some critical information that you need to get the most out of the site to which he refers. For example, how to navigate or find specific breast cancer information. If you don't want to read the whole page but find it difficult to find what you are after you could use your browser search tool (try Ctrl F) and type in a word, e.g. chemotherapy.

Best Breast Cancer Websites provides links to websites on younger women, men, hereditary breast cancer, inflammatory disease, advanced breast cancer and how to tap into forums on many topics. The site comes highly recommended from BCN Committee member Gillian Woods and certainly seems to be a valuable filter for those wanting to find information on breast cancer on the web.

STOP CANCER WHERE IT STARTS UPDATE

BCN has recently made progress on three of the recommendations to come out of the Environment, Lifestyle and Breast Cancer workshop at last year's First National Conference for those affected by breast cancer:

- that expectant mothers should also be educated about environmental influences on breast cancer development;
- that Public Health and Plunket nurses throughout the country should be educated; and
- that councils should be approached by residents and rate payers and asked to ensure that safe alternatives to harmful chemicals are used.

BABY BOTTLES



Source: kahanaboy, MorgueFile.com

In June, BCN wrote to the College of Midwives and Plunket asking for their help to reach both new and experienced mothers to inform them about the dangers of the endocrine disruptor bisphenol A (BPA) in polycarbonate baby bottles. We hoped that they would be prepared to incorporate information on BPA into midwife training and ante-natal classes and/or for the information to be circulated by newsletter or journals in order to be available to midwives

The College of Midwives agreed in August to place excerpts from the material we sent in the next issue of Midwifery News, and to distribute the articles to the five Schools of Midwifery to add to their resource lists for undergraduate students. They also suggested further ways that we might pursue for getting the message about breast cancer prevention out to mothers and other young women.

In the letter, BCN explained that we promote breastfeeding as the best option for both

baby and mother as breastfeeding is known to reduce the risk of breast cancer. However, many breastfeeding mothers use baby bottles – for water or expressed breast milk, and the information on BPA is as relevant for them as it is for mothers of bottle fed infants.

The challenge is to educate all mothers as to why glass and bisphenol A-free plastic containers are the safest products to use for the long term health of their babies.

Evidence for a change back to glass baby bottles came at the October conference from scientist Dr Maricel Maffini, of Tuft's University in Boston. She made it very clear that the bisphenol A in polycarbonate plastic has an oestrogenic effect on developing babies from as early as in the womb. Minute amounts of BPA can alter hormones and cellular environments in the human body, particularly during periods of rapid cell growth, for example, in foetal, infant and adolescent development stages. Indeed, scientists at the Liggins Institute in Auckland recently stated their belief that early exposure to bisphenol A is likely to increase the risk of breast cancer. We believe there is a need to take notice when highly regarded scientists have publicly stated during scientific presentations that they do not have plastics in their kitchens for the sake of their children's health.

BCN also supplied articles on the dangers of endocrine disrupting chemicals in plastics to the Auckland Women's Health Council newsletter and the Maternity Services Consumer Council newsletter.

TAKING PREVENTION TO YOUR COUNCIL

BCN have produced a leaflet for *Stop Cancer Where it Starts* projects in local communities. The information in the leaflet is designed to help people decide if they would like to take the project to their local or regional councils.

The first third of the leaflet discusses the issues:

- the need to address causes of breast cancer and the incidence of the disease;
- stopping cancer where it starts and the action being taken elsewhere in the world;

- breast cancer in New Zealand;
- the concepts of environment; and
- wide spread chemical exposure.

In discussing the wider environment the leaflet points out that this includes the home, school, workplace, our sports venues, streets, vehicles, buildings, industries, farms, beaches and waterways. Chemicals and plastics are a common factor in pollution of the wider environment. Chemical influences on our health from these sources are largely beyond an individual's control BUT local, regional and central government can act to reduce chemical exposures.

The remainder of the leaflet covers how to go about approaching your council regarding reducing chemical exposure in your community. In brief the leaflet covers:

- How to begin:
 - learn about what local councils do,
 - read the relevant sections of the District Plan,
 - get in touch with local environmental groups – they may offer support as well as information and guidance learned from their experience with council.
- Phone the council – find out which departments deal with environmental matters and public health.
- Find someone to help you with the project and accompany you to the council.
- Set the goals, and make a plan.

The leaflet recommends that once you have an understanding of how your council operates, make a plan, setting just one or two goals rather than tackling lots of things at once. Familiarise yourself with information from BCN, your library and reliable websites. If you decide to speak out at a public council meeting you should make notes for yourself listing your most important points, and it's a good idea to provide councillors with some written material. Please contact BCN for help with resources for this purpose.

The steps are largely the same for regional councils as for local councils, but the areas of jurisdiction are different.

If you would like a free copy of the leaflet please contact the Breast Cancer Network by post, phone, fax or email.

From the Project Desk...

THE QUESTION OF TRANSPORT

As readers probably remember, a number of recommendations were made at the 1st New Zealand National Conference for those affected by breast cancer for the National Committee to follow up.

Recommendation 48 - "that patients be provided with better information on the travel subsidies available" was one of five recommendations from the workshop for Rural Women. This column will go some way to addressing the issue of travel subsidies.

Since 1 January 2006 'The National Travel Assistance Scheme' has been in place - this scheme is administered by the Ministry of Health and contributes towards your travel costs if certain mileage and number of visits requirements are met. Reference to the policy can be found on the website: www.moh.govt.nz. The scheme works on reimbursement of costs, so keep all your receipts and apply after the event.

You can also request a brochure by phoning the Ministry of Health on 0800 281 222.

An enormous amount of work went into developing this policy by many

women and their supporters from the Bay of Plenty/East Cape region.

The scheme has some tight parameters and for this reason, may not meet the requirements of all our rural women. If you are interested in working with BCN to take this issue further please contact our administrator, Jennifer, on 09 360 0090.

Other assistance is available from Work and Income New Zealand and your local Cancer Society. Your local Citizen Advice Bureau or Family Support Centres will know if there are local shuttles or other transport to the cancer treatment centre, and may even make your booking for you.

Assistance from Work and Income is income tested and most likely in the form of a 'Disability Allowance' (a dreadful name) to a maximum of \$54.05 per week. You will need to discuss this and apply for assistance at your nearest WINZ office. The limits for the income test may surprise you so check out www.winz.govt.nz >map(manuals and procedures)>deskfile.

Each Regional Cancer Society has slightly different criteria so please do not hesitate to contact your local branch to see if you qualify for some assistance.

Progress with other conference recommendations is featured in our Stop Cancer Where it Starts article in this issue. BCN has also discussed the recommendations from the workshop for women with secondary cancer with Sweet Louise. It is very pleasing to learn that Sweet Louise is developing an on-line journal and forum for their members and is now able to offer services to some areas outside of Auckland.

It is also good news to know that the well-known Breast Health NZ website already has a monitored forum where anyone can log in and raise issues they are concerned about or would like debated. See www.breast.co.nz and click on Forum.

We are aware that younger women (and older women!) use social networking websites and blogs extensively - so go to it and join in the Breast Health forum. And in our rather unusual featured web site this month there are links to many such sites.

BCN needs more volunteers, helpers and committee to progress the conference recommendations. Please let us know if you can help with one of these.

Gillian Woods

HELP NEEDED! BCN NATIONAL COMMITTEE NEEDS MORE PEOPLE NOW. CAN YOU JOIN US AND HELP KEEP BCN AND ITS PROJECTS GOING AHEAD? EVEN IF YOU ARE OUT OF AUCKLAND PLEASE GET IN TOUCH IF YOU WOULD LIKE TO JOIN IN.

Please call Barbara on 09 6254 186 (evenings) or Jennifer at the BCN office on 09 360 0090.

And a reminder to update your records with BCN's new address and phone number: Breast Cancer Network (NZ) Inc, PO Box 46018, Herne Bay, Auckland 1147. Phone 09 360 0090, Fax 09 360 2180, Email admin@bcn.org.nz

VITAMIN CANCER HOPE

A preventative pill for breast cancer, based on Vitamin E compounds in palm oil, could be available within three years.

USA pharmacologist, Dr Paul Sylvester from the University of Louisiana, has been researching nutrition and cancer, in particular the benefits of vitamin E, for more than 20 years.

"There is a family of compounds within Vitamin E. Tocopherol is the compound that is abundantly found in vitamins but the rarer form of Vitamin E, tocotrienol, only has a few natural sources and one is palm oil. We have found that the tocotrienol derived from palm oil can attack cancer in its

early stages without the usual harm to surrounding healthy cells. It not only stops cells from dividing but will also kill the dangerous cells."

Dr Sylvester said a study has been conducted into mouse models with the breast cancer gene HER2 being treated with a daily tocotrienol supplement. "It significantly inhibited growth of the tumour in the animals," he said. "Now we believe we can develop a daily supplement for the prevention of breast cancer in women."

Source: *Sunday Mail*, Brisbane, 7 September 2008



COVER YOUR BREASTS BY ALISON RENFREW

FIRST EDITION PUBLISHERS

REVIEWED BY JUNE NORTHCROFT GRANT, SURVIVOR

Alison Renfrew is a member of the “fold”, an ever-increasing “elite” group with first-hand experience of breast cancer and its ramifications. I happened upon Alison's on-line diaries by accident and then became intrigued by the correspondence flowing back and forth between Alison and her friends, as new entries were posted for all to read.

Her book, *Cover Your Breasts*, is not a diary, but is about the journey, illustrated with the e-mail dialogue on specific topics about everything to do with living with cancer, such as going bald, anxiety and depression, God is good and life isn't fair, breast reconstruction, and a plethora of relevant breast cancer specific topics. Reading the book brought back a flood of feelings and scenarios that all survivors have experienced in one way or another.

I met Alison at the inaugural Breast Cancer Conference in Rotorua in October last year, and she was every bit as cool as I had imagined after reading her very personal and intimate thoughts and feelings that a girl only shares with her husband and her very best friends (and sometimes, not even your husband). I came to the conclusion that Alison Renfrew had a really good story to tell and I wanted to know more about her. Alison is a great “get on with it Kiwi girl” so her attitude to the whole ugly business of getting, and the ensuing getting rid

of cancer, is tempered with sadness, humility, humour; in fact, the whole gamut of human emotions. Alison's family and friends are central to the plot, sharing every step of the journey by way of daily emails of support and being there when the going got tough.

The book offers not just a story of hope and survival but some really practical ways of achieving both physical and fiscal imperatives when dealing with the trauma of diagnosis and treatment for cancer. At the end of each chapter, Alison offers a “most important message” by way of rounding up the experience in a few succinct, anecdotal wisdoms, born of the knowledge of the survivor. This is a read-it-all-at-once book; I found it was like eating peanuts, once I had started I couldn't stop. With the statistics in New Zealand revealing that one in nine women will get breast cancer in their lifetime, this book is important to pass on to your friends, your daughters and anyone else who would benefit from knowing what living with cancer is really like.



GENETICS SERVICES STUDY

Helen Gu, a research student at the University of Auckland who is working with the National Institute for Health Innovation at the University, is undertaking a study on genetic services in New Zealand. The National Institute for Health Innovation is led by Prof Jim Warren and is concerned with health information systems, clinical decision support and quality of health information.

As part of the study, Helen is collecting stakeholder perspectives on New Zealand genetic services and is keen to talk to breast cancer patients and families, who may or may not have had some experience with genetic testing.

Helen is particularly interested in people's views on the management of genetic information; thus participants may not necessarily have had experience with genetic testing. However, breast cancer patients with either a familial history of the disease or known BRCA gene mutations in their family may have particular views on the way in

which genetic information is managed.

The study's ultimate goal is to improve the human genetic variation knowledge management performance in New Zealand genetic services. For instance, effective management of genetic information through the genetic service system might improve the quality of New Zealand genetic services; and might help contribute data into global genetics knowledgebase. The current research is designed to understand the perspectives of various stakeholders for New Zealand genetic services.

Participants will take part in an hour long interview which will cover the following topics:

1. What are your experiences with genetic services? How is genetic testing information delivered to you (including the availability and benefits of genetic testing, the testing report, and the interpretation of testing results)?
2. What do you think would be the appropriate means (methods, requirements, limits) of distribution for genetic testing results?

3. What changes would you like to see in handling and managing genetic information?
4. What are the current and potential challenges from your point of view?
5. Any further comment on New Zealand genetic services? (For example, any issue on ethics, privacy, informing clients, and legislation relevant to genetic services?)

This study is expected to provide valuable insights into genetic information management support, and the nature and benefits of this support. The study may also address current and potential knowledge management issues, such as requirements for appropriate distribution of genetic testing results where research needs must be balanced against individual confidentiality concerns.

The information obtained from participants will remain confidential, and readers who are interested in participating in the study are invited to contact Helen Gu for further information:

Yulong (Helen) Gu: 09 3737599 ext 89232
or ygu029@cs.auckland.ac.nz

CLEAN GREEN AND HEALTHY

The *Upfront U Kaioira* review of what you should and shouldn't be putting into and onto your body.

ORGANIC SHAMPOO AND CONDITIONER



I started using Organic Instinct natural shampoo and conditioner about two years ago. It is made by Australian company Natural Instinct and is sold in organic stores here. Their products contain NO: sodium laurel sulphate, petroleum, artificial fragrances and colours, harsh detergents, animal derivatives, harmful chemicals or parabens.

It is the first shampoo and conditioner I have used without having to regularly change to a different brand; all other shampoos and

conditioners seemed to cause some sort of build up of product leaving my hair dull and not feeling as clean as it should. Organic Instinct is a great basic product that fulfils all of my needs – no nasties and does the job. It is made from natural plant extracts and derivatives and includes lavender and jojoba oils, vitamin E, grapeseed extracts and extracts from nettle, chamomile, burdock, rosehip and horsetail.

It has very little smell other than a mild, slightly herbal soapy smell, and I use it for my children as well as myself. The shampoo and conditioner come in 200ml and 500ml bottles and a one litre pump bottle. While the smaller sizes are typically fairly expensive compared with normal supermarket and pharmacy brands, the one litre bottle is very economical and compares well at \$25.00 (\$6.25 per 250ml).

The Natural Instinct range includes household cleaners (which I am yet to try) and other personal care products such as cleansers, moisturisers and sunscreen (which is also great). I highly recommend this product and if you can't find a local store that stocks this range you can buy online from Albany store Naturally Organic - www.naturallyorganic.co.nz – where I buy mine from.

Reviewed by Sue Claridge

MEDITERRANEAN-STYLE BAKED EGGPLANT



I didn't really like eggplant until a friend cooked a sort of vegetarian version of the Greek dish Moussaka, traditionally made with lamb mince and eggplant. The recipe below leaves out the meat and is delicious, but you could add the meat for meat lovers or just for a more substantial main dish.

Serves 6

2 large or 3 smallish eggplant

Olive oil

4 large tomatoes or a 400g can of tomatoes

2 tspn tomato paste

2 medium onions

¼ tsp cinnamon

¼ tsp allspice

2 garlic cloves finely diced

¼ cup water or stock

salt and pepper to season

1 cup fresh wholemeal breadcrumbs

(Vogels is good)

grated cheese for topping

1. Cut the eggplants into 5mm (¼") thick slices. Layer them in a colander, sprinkle with plenty of salt and leave for 30 minutes.
2. Rinse the eggplant slices in several changes of cold water. Squeeze gently with your fingers to remove the excess water, then pat them dry.
3. Heat some of the oil in a large frying pan. Fry the aubergine slices in batches until golden on both sides, adding oil if needed. Leave them to drain on kitchen paper.
4. If using fresh tomatoes, plunge them into boiling water for 80 seconds, then refresh in cold water. Peel away the skins and chop roughly.
5. Heat some oil in the fry pan and add the chopped tomatoes, cinnamon, allspice, tomato paste, parsley, garlic, water/stock, pepper and bring to the boil. Reduce the heat, cover with a lid and simmer gently for 15 minutes. Season with salt to taste.
6. Arrange alternate layers of eggplant slices and tomato mixture in a shallow oven-proof dish, finishing with a thin layer of the tomato mixture.
7. Spread the fresh breadcrumbs over the top and sprinkle with the grated cheese. Bake in the oven 20 minutes or until the cheese is melted and golden and the dish is hot through.

CORRECTION: The soup recipe in *Upfront U Kaioira 80* was missing the measurements from two of the ingredients. The recipe should have read:

½ cup orange lentils

½ cup pearl barley

R E S E A R C H A N D N E W S U P D A T E

**12 MONTH COURSE OF
HERCEPTIN REJECTED BY PHARMAC**

Pharmac announced on the 7th of August that it would not fund 12-month courses Herceptin, and political reaction has varied, suggesting that Herceptin may become a political football in the lead up to the November election.

While opposition parties have called on the Government to pay for 12-month courses of Herceptin for women with breast cancer, the Greens say politicians don't have the expertise to make drug-funding decisions.

The Green Party's Sue Kedgley said Pharmac's decision would be a bitter blow to many women but politicians should respect Pharmac's independence.

"We can't have politicians intervening to decide which drugs should be funded and which should not," she said.

"Politicians do not have the clinical expertise to make decisions about which drugs to fund. However much we might wish to interfere, we must leave it to the experts to decide."

Health Minister David Cunliffe says he can't lawfully direct Pharmac to fund anything, but National is promising that the government will fund the 12-month courses if it wins the election.

Following a legal challenge mounted by eight breast cancer patients – the Herceptin Heroines – the High Court earlier this year ordered Pharmac to consult on whether it should extend treatment to 12 months.

The court found insufficient consultation had been undertaken into the possible benefits of the longer course and instructed Pharmac to start over again.

Pharmac chief executive Matthew Brougham said a fresh review of the science and other information had failed to convince the agency that 12-month treatments offered any additional benefits over the nine-week treatment, but that Pharmac remains open to re-evaluating its position if new evidence emerges.

"This could include results from the SOLD study, an international Herceptin clinical trial which Pharmac is helping to fund, or results from other clinical trials," he said

Source: *New Zealand Herald*, various media releases.

RADIATION DELAYS RESUME

The *New Zealand Herald* reported in early September that the Auckland DHB had resumed sending patients to Australia for radiation therapy and is also sending some to Waikato Hospital. Its waiting times for patients of "lower acuity" have risen to at least 12 weeks from the decision to use radiation.

One woman told the *Herald* that her oncologist had advised that her wait would be as much as 15 weeks.

The DHB attributed the increase to breakdowns of the radiation machines, a big rise in patients needing urgent care, and staff losses exceeding recruitment.

The *Herald* reported that the Auckland DHB declined to comment on the risks of increasing delays, referring the question to the Ministry of Health.

The Ministry's principal adviser on cancer control, Dr John Childs, a radiation oncologist, said: "What's been published suggests

that if you have treatment within 12 weeks of surgery there's no clear evidence of a problem ... once you get beyond 12 weeks there may be some slightly increasing risk."

Source: Cancer patient faces longer delay, *New Zealand Herald*, 11 September 2008

**LIDOCAINE GEL MAY EASE
DISCOMFORT DURING MAMMOGRAPHY**

Researchers from Idaho in the US have concluded, in a paper published in the July issue of *Radiology*, that premedication with 4% lidocaine gel significantly reduced discomfort during screening mammography, and reduced discomfort may improve the likelihood of future mammographic screening and early detection of breast cancer.

Four hundred and eighteen women who expected "substantial discomfort" during screening mammography were randomised to receive one of twelve treatments before screening; the treatments involved various combinations of ibuprofen, acetaminophen, 4% lidocaine gel (Topicaine), and matching placebos.

Lidocaine applied to the breasts and chest wall was associated with less discomfort during mammography, relative to placebo or no gel. Women with less discomfort were more likely to be satisfied, and those who were more satisfied were more likely to plan to undergo mammography the following year. However, lidocaine itself was not associated with satisfaction and future mammography plans.

Ibuprofen and acetaminophen did not significantly affect discomfort.

The authors say that women could apply the lidocaine at home. Yet, they note that the "magnitude of the reduction [in discomfort] may need to be balanced against the cost of the gel."

Source: *Radiology* 2008;248:765-772; Physician's First Watch for July 22, 2008

**BONE DENSITY MAY HELP
PREDICT BREAST CANCER RISK**

Measuring a woman's bone mineral density can provide additional information that may help more accurately determine a woman's risk of developing breast cancer. That is the conclusion of a new study published in the September 1, 2008 issue of the journal *Cancer*. The study's results suggest that incorporating bone mineral density tests with current risk assessments might significantly improve physicians' ability to predict breast cancer risk in older, post-menopausal women.

Studies have found an association between higher bone mineral density and higher breast cancer risk, and bone mineral density tests have been proposed as a potential addition to breast cancer risk models. Researchers from the University of Arizona studied approximately 10,000 post-menopausal women (average age 63) taking part in the Women's Health Initiative. They assessed the women's initial bone mineral density level as well as their score on the Gail risk model, a well known and commonly used tool that estimates five year and lifetime risk of invasive breast cancer for women 35 years of

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age or older. They then followed the women for an average of approximately eight years, noting which women developed breast cancer.

As expected, the study found that women with a high Gail score had a 35 percent increased risk of developing breast cancer compared to women with a lower Gail score. But the study also found a 25 percent increase in the risk of developing the disease with each unit

increase in total hip bone mineral density t-score. While the two scores were independent of each other, women who had the highest scores on both assessments had a much higher risk in breast cancer.

The findings suggest that adding bone mineral density to currently used risk assessment tools may significantly improve the prediction of breast cancer risk.

Source: *Cancer*, 2008 Sep 1; 113(5):907-15.

BREAST EVENTS to come

- **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
- **16th-18th November, 2008 – Psycho-Oncology New Zealand conference**, Palmerston North Convention Centre. Winds of Change: Ideas, Innovation, Initiatives. Contact Sue Peck, SP Conference Management, PO Box 4400, Palmerston North or phone 06 3571466 or email suepeck@xtra.co.nz.

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

ADMINISTRATOR: Jennifer Woodroffe; MAGAZINE EDITOR: Sue Claridge.

PATRON: Lois Muir.

HONORARY LIFE MEMBERS: Wendy Steenstra-Bloomfield, Barbara Holt, Dell Gee, Jennifer Clark.

COMMITTEE MEMBERS: Barbara Mason, Anne Iosefa, Gillian Woods and Linley Rivers

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 U KAIORA send your name and address to:

BCN (NZ), PO Box 46018, Herne 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) 09 360 2180 or email us at admin@bcn.org.nz .

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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

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