

# Upfront U Kaiora

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

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STOP CANCER WHERE IT STARTS

## CONTINUED ATTACKS ON BISPHENOL A, BUT NO CHANGE ON THE HORIZON

 BY SUE CLARIDGE

The continued use of the compound bisphenol A (BPA) in plastics that are used in food containers and packaging is coming under increasing criticism from scientists, and in the last two months considerable criticism has also been levelled at one of the world's biggest regulatory agencies, the United States Food and Drug Administration (FDA).

On the 16th of September this year the FDA announced, in a draft assessment of the safety of BPA in food contact applications,<sup>1</sup> that current levels of BPA used in food packaging do not appear to cause health problems. On the same day, *the Journal of the American Medical Association (JAMA)* published (online) the results of study which found that exposure to the BPA in food packaging may be putting millions at an increased risk for cardiovascular disorders, diabetes and liver abnormalities.<sup>2</sup>

While the specific concern of many researchers revolves around the oestrogenic activity of BPA and its role in the development of breast cancer and male genital tract deformities among other effects, it is ironic that the link between BPA and "some of the most significant and economically burdensome human diseases" came on the day that the FDA announced that "an adequate margin of safety exists for BPA at current levels of exposure from food contact uses."<sup>1</sup>

The FDA announcement also comes only months after its neighbour, Canada, banned the use of BPA in baby bottles and the liners in cans of baby formula. As governments and regulatory agencies in the developed world (the EU, Japan, Canada, California) begin to take a harder line on the use of endocrine dis-

rupting chemicals such as BPA and phthalates, particularly in items used by babies and children, it is hard to understand the FDA's rationale. That is, until one discovers that the FDA excluded all but two of the many independent studies published on the effects of BPA, and that the only two studies that were relied upon in the assessment were industry funded.

So why would the FDA ignore a huge volume of research in favour of two-industry funded rodent studies? The plastics industry is a huge, multi-billion dollar industry worldwide and a powerful lobby group. They have also consistently denied that their products cause any harm. For example, the New Zealand plastics industry association website ([www.plastics.org.nz](http://www.plastics.org.nz)) still insist that BPA can't possibly be harmful and that our exposure to BPA from plastics is below the level deemed to be safe by the FDA.

However, Drs Frederick vom Saal and John Peterson Myers state, in an editorial in *JAMA*,<sup>3</sup> that "numerous laboratory animal studies have identified low-dose drug-like effects of BPA at levels less than the dose used by the US Food and Drug Administration and the Environmental Protection Agency to estimate the current human acceptable daily intake dose deemed safe for humans."

What the New Zealand plastics industry association also fail to point out on their website, after using the FDA report to support their case that BPA levels are safe, is that the FDA report has come in for considerable criticism since it was released and that the FDA Science Board Subcommittee on bisphenol A have released a report of their

own<sup>4</sup> which is highly critical of the original FDA report.

A number of issues or recommendations were highlighted by the Science Board Subcommittee as being of considerable concern regarding the FDA's draft assessment of the safety of BPA, including:

- that the FDA assessment should consider cumulative BPA exposure in babies;
- that the draft FDA exposure assessment has important limitations including that an inadequate number of infant formula samples were analysed;
- that the draft FDA report does not adequately explain why so many papers and studies were excluded from the assessment and specifically, the Subcommittee does not agree that a large number of studies should be excluded from use in the safety assessment;
- that several studies of effects of BPA on adult humans and animal species that were published after the draft assessment was finished should be considered for inclusion in the final assessment;
- that the weight-of-the-evidence provides scientific support for an actual safe level of BPA that is substantially below (i.e., at least one or more orders of magnitude lower than) the 5 mg/kg of body weight per day level selected in the draft FDA assessment; and
- that the available qualitative and quantitative information provides a sufficient scientific basis to conclude that the Margins of Safety defined by FDA as "adequate" are, in fact, inadequate.

The full Science Board, made up of independent advisers to the FDA, unanimously endorsed the findings of the Science Board Subcommittee on BPA, which concluded that the FDA employed faulty science when it determined that BPA is safe as currently used.

The full Board went on to recommend future, large-scale studies examining BPA exposure from a wider range of applications.

The report now goes to the FDA, which will likely respond in the next few months, said Dr Stephen Sundlof, director of the agency's Center for Food Safety and Applied Nutrition.<sup>5</sup>

If the FDA accepts the subcommittee's findings, such as a lower margin of safety for exposure for infants, the agency would likely issue new regulations.

In the meantime, Drs vom Saal and Myers in their *JAMA* editorial have succinctly summed up the problem with getting action from the agencies that have the power to regulate levels of BPA in plastics to which both we and our children are exposed:

"One factor that may be contributing to the refusal of regulatory agencies to take action on BPA in the face of overwhelming evidence of harm from animal studies reported in peer-reviewed publications by academic and government scientists is an aggressive disinformation campaign using techniques ("manufactured doubt") first developed by the lead, vinyl, and tobacco

industries to challenge the reliability of findings published by independent scientists."

While vom Saal and Myers advocate continued research they say that "further evidence of harm should not be required for regulatory action to begin the process of reducing exposure to BPA" and that "decreasing exposure to BPA and developing alternatives to its use are the logical next steps to minimize risk to public health."<sup>3</sup>

They go on to explain that "since worldwide BPA production has now reached approximately seven billion pounds [3200 tonnes] per year, eliminating direct exposures from its use in food and beverage containers will prove far easier than finding solutions for the massive worldwide contamination by this chemical due its to disposal in landfills and the dumping into aquatic ecosystems of myriad other products

containing BPA, which Canada has already declared to be a major environmental contaminant."

It seems that even if we get to the point where BPA is banned for use in food containers and packaging, the impact of BPA on human health through contamination of our environment and water resource is likely for several generations to come.

1. Draft Assessment of Bisphenol A for use in Food Contact Applications, US FDA.
2. *JAMA*, 2008; 300 (11): 1303-1310.
3. *JAMA*, 2008; 300 (11): 1353-1355.
4. FDA Science Board Subcommittee on Bisphenol A; Scientific Peer-Review of the Draft Assessment of Bisphenol A for use in Food Contact Applications.
5. FDA Spanked by Full Science Board on Bisphenol A Safety Stance, *MedPage Today*, October 31, 2008.

#### BISPHENOL A

Bisphenol A forms the polycarbonate plastic used in a wide variety of everyday items including baby bottles and sippy cups, food can linings, dental sealants and sports water bottles as well as many food containers and clear polycarbonate "glasses". Recent studies show that bisphenol A leaches from intact polycarbonate products as well as from worn or damaged plastic. For more information on bisphenol A and breast cancer see the following issues of *Upfront/Upfront U Kaiora*:

**Upfront 67 June-July 2006, pg 1**

**Upfront 76 December 2007-January 2008, pg 6**

**Upfront U Kaiora 79 April-May 2006, pg 1**

## HERCEPTIN FOR TWELVE MONTHS

Only two days after the National Party was voted into power (with the help of the Act Party) the newly-designated Minister of Health, Tony Ryall announced that National would make good on its pre-election promise to fund twelve months of Herceptin. Mr Ryall said that they will make Herceptin available outside the PHARMAC process, making money available through the Ministry of Health for funding twelve months of the drug for eligible women.

Breast cancer groups were quick to celebrate, with BCAC saying that they were delighted with the decision. The New Zealand Breast Cancer Foundation also issued a press release expressing their delight.

BCAC Chairwoman, Libby Burgess, paid tribute to the women around the country who had lobbied for the twelve month course to be funded:

"I must offer a heartfelt thank you to all of those courageous people who have battled so long and so hard to bring the evidence to light and keep this issue in the public eye. I applaud Anne Hayden, Nic Russell, Mandy Carter, Chris Walsh and the Herceptin Heroines who presented petitions to parliament and took PHARMAC to the High Court. These women stood up and represented all those affected by HER2 positive breast cancer while battling their own diagnosis. I also thank the Herceptin Riders and all the wonderful Kiwis who rallied to this cause to support our women."

Pharmac estimates that providing access to this treatment will cost an extra \$9 million per year for the first three years, over and above the current costs for Herceptin treatment in New Zealand.

**THE BREAST CANCER NETWORK THANK THEIR SPONSORS: COGS, Lottery Grants Board, Neville Newcomb, Kitchen Aid, Gregg's Women's Challenge, Lion Foundation, Perry Foundation and 300 Richmond Ltd.**

### From the Guest Editor....

In October 2007, Breast Cancer Network hosted the first national conference for those affected by breast cancer. For Breast Cancer Network it was a pivotal time and the outcome of two years intensive preparation. One of the reasons for the conference was 'to learn what women wanted to change in New Zealand regarding breast cancer treatment and care'. From the conference came 63 recommendations.

Shortly afterwards I asked Dell Gee, conference convenor, what was most memorable for her. Her response: "It was when the plane landed bringing Susan Love to Rotorua. Then the Maori welcome that followed was such a beautiful occasion, I felt it was going to go well," – and it did go very well.

For me a memorable moment of many was at the very end of the last day. At the end of the final karakia I heard everyone in the auditorium say 'amine' spontaneously and in unison. That united voice is something that I hold dear and as we work towards implementing the recommendations I am pleased to comment on progress being made by other breast cancer groups on issues raised at conference.

We applaud the work of the Breast Cancer Aotearoa Coalition who, by their preparedness to be a public face for women with breast cancer, have ensured that soon women will no longer have to pay for a year's treatment of Herceptin.

A positive meeting initiated by Heather Shotter, CEO and Suzanne McNicol, Marketing and Communications, NZBCF (New Zealand Breast Cancer Foundation), with members of BCN committee has enabled the Foundation to become aware of recommendations that we believe they can move forward.

BCN also pointed out that the general public are confused about the pink ribbon campaign, frequently thinking the proceeds go to all groups and all areas of breast cancer work, when it is actually raised for NZBCF. BCN asked NZBCF to consider appointing a consumer (patient) representative to their board of trustees and asked for information about some pink products which appear to contain unsafe chemicals. At the same time, we learned more about the Foundation's work and goals. Their recent submission to Parliament is in this issue of *Upfront U Kaioara*.

The University of Auckland held a recent daylong symposium, 'Breast cancer genetics and genomics: the impact of new technologies on breast cancer control'. Written on the agenda was a goal "to maximise the positive impact of these technologies on patient care, close collaboration will be required between clinicians, cancer biologists, bioinformaticians and patients..." Never before have I seen patients included in the desired collaborations. A consumer voice is becoming recognised as important.

And *Sweet Louise* is expanding its services to include more women – more about this in the Project report.

I suggest all readers look again at the recommendations. We have plenty of copies if you have lost yours. Can your group tackle one of the recommendations? The conference was more than just a weekend together. The women of New Zealand have shown a way forward to which all can contribute.

**Barbara Mason**

### 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 and brothers, 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: phone me at 09 445 2966 or phone the BCN office on 09 360 0090, or email me at [sclaridge\\_bcn@clear.net.nz](mailto:sclaridge_bcn@clear.net.nz)



### TIPS FOR BUYING SAFE TOYS - Know what to look for when buying plastic toys and avoid phthalates:

**S**oft plastic toys that young children might put in their mouths may contain phthalates unless they are marked "phthalate-free," "PVC-free" or "EU compliant," or they carry the CE mark (which indicates that the product is compliant with European Union regulations and therefore phthalate-free).

- Both teethingers and pacifiers sold in the United States are supposed to be phthalate-free already, though parents should purchase these items from reputable retailers.
- Recycling codes (if toys have them) may help you determine if the

items are made with PVC, which often contains phthalates. PVC plastics are marked #3. Better choices are codes #1, #2 or #5. The Breast Cancer Fund recommends that people also avoid plastics marked #6 (styrene) and #7 ("other," but often BPA-based).

- To be safe, we recommend that parents discard soft plastic toys and childcare articles that do not fall into one of the exceptions listed above. When purchasing new items, look for phthalate-free toys and make sure retailers know phthalate-free merchandise is important to you.

## ANNIE'S STORY

Annie is in her mid 70s and has the BRCA gene mutation. Although BRCA has brought breast cancer to Annie and her family, Annie was not diagnosed until she was 71 – late for a BRCA 1 carrier – and has defied the statistics. There was no breast cancer on her mother's side, and hers is a salutary lesson for all: BRCA gene mutations can just as easily be passed on from the father's side. As a result of her own genealogy research, she realises that this is where her familial cancer came from as there were several members of her father's family who died from cancer, including prostate, ovarian and breast cancer. It just wasn't talked about much, back then.

### ANNIE IS HEALTHY WITH NO SIGN OF THE CANCER – THIS IS HER STORY:

**1996:** I have taken early retirement and life is good. There is time to garden (my passion), read, swim, travel and enjoy my children and grandchildren. I received a letter today from an ex-colleague with very sad news; her only sister has died from breast cancer at the age of 45 leaving behind three children. How fortunate I am that there is no breast cancer in our family. My Mother is still alive at 94 and my Dad's sisters were all in their 80's or 90's when they died.

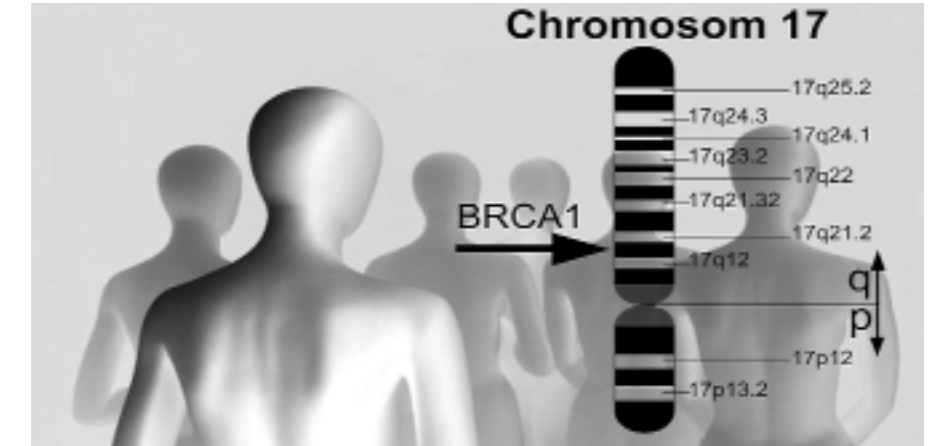
**1997:** My beautiful niece (aged 27) has just had a mastectomy. How traumatic! Losing a breast must be every woman's worst nightmare. More family research... nothing on our side!

**1998:** Julie has made a good recovery and is getting married next year.

**1999:** It was a lovely wedding and Julie looked stunning.

My daughter, Sarah, is working too hard and she looks pale and drawn. She finds a lump in her breast. The needle biopsy and mammogram show nothing of any great note. She has the lump out and it is cancerous and she has a lumpectomy. There are no clear margins and a mastectomy follows, but still no clear margin. The histology results show a widely spread triple negative breast cancer. She has radiotherapy and chemo and appears well. We have a lovely Christmas together.

**2000:** Sarah develops multiple lumps, like mosquito bites on her chest wall, and she



seems to be unable to use two of her fingers. Apart from her chemotherapy day she insists on continuing work. Headaches become a problem for her, as well as back pain. She finishes work and is put on morphine and comes home to stay with us.

Sarah died last night (aged 40) nine months after she was diagnosed and two weeks after she finished work.

Julie had a baby.

**2001:** I honour my promises to Sarah and have a mammogram and give up my daily ration of five cigarettes. My Mother dies of pneumonia at the age of 100 years.

**2002:** There is a big HRT scare at the moment, so I had better put up with the hot flushes and try to give up taking the tablets. The pain of Sarah's death doesn't lessen. It is SO out of order that one's daughter should predecease one's mother.

**2003:** Julie is tested for breast cancer genes.

**2004:** Julie is found to carry a pathogenic BRCA1 gene variant and it is suggested that I be tested. I must get around to it and also have another mammogram. The latter shows some "benign" lumps so I have an ultrasound; \$240 later I am told that I am okay and they are just "fibroadenomas".

**2005:** I have just been told that I too carry the same BRCA1 mutation as my niece. I rush to Sarah's grave, cry, apologise and generally go to pieces. Two days later I think "what about my lumps?"

I have them core biopsied and I have cancer. Next step – mastectomy and node removal (nodes are clear). Both lumps are grade 3 triple negative cancers\*. I do not have chemo or radiotherapy. Lots more research on the internet! I discover that many BRCA cancers have smooth "pushing margins" and

don't look like typical breast cancer tumours. **2006:** I have a salpingo oophorectomy – a piece of cake at my post-menopausal age!

More research. Genealogy becomes my new hobby.

I have a breast MRI in Wellington.

My other daughter, Rebecca, is tested for the BRCA gene mutation and is clear!

**2007:** Julie gets cancer in her other breast and has another mastectomy and more chemo and radiotherapy. No operations for me this year, but the heat bothers me as I get swelling on my chest wall.

I have another MRI.

**2008:** I'm tired of being prodded and squeezed, and stripping off (might feel better if I was younger but I doubt it) so decide to have a prophylactic mastectomy and get on with my life. Three months later I am almost fully recovered and have no regrets about my decision. Genetic Services have been a wonderful support for me.

My genealogy research has turned up several cases of prostate cancer on my father's side of the family as well as ovarian cancer, uterine cancer and a great, great grandmother who died of breast cancer. Getting death certificates is expensive, but essential for accuracy.

At 70+ I take one day at a time and feel I must have been dealt lots of good genes as well as a faulty BRCA1 gene. I took the contraceptive pill for years as well as HRT. There appear to be several different groups and subgroups of breast cancer and the treatment differs for each and hopefully it can only get better with more targeted therapy and less slash and burn.

\* triple negative breast cancer are cancers that are oestrogen receptor, progesterone receptor and Her2 negative.



## LETTERS

### HELLO FROM AN EX-BREAST CANCER NETWORKER IN THE UK

Hello to all of you at the Breast Cancer Network and congratulations for the outstanding things you have achieved – especially the inaugural national conference. I have read the website and it sounds as if it was a great success.

I have been away from New Zealand [in Europe and the UK] for two years now and the time has passed so quickly. I have made the most of ALL the incredible educational opportunities offered here and, as it is difficult to get a UK nursing registration here, I have spent the time doing as many courses available related to breast nursing as I could.

I have completed two University papers on the management of complex lymphoedema and qualified as lymphoedema therapist and I have also completed a course in London on Kinesio Taping for lymphoedema management. I travelled to Munich and spent three days with a bra and prosthesis manufacturing company and gained a certificate in bra and prosthesis fitting.

In Manchester I attended a very well reputed course in Myofascial Repair following breast cancer treatment. This week I headed to Leicester for a Micropigmentation Study Day, which was very interesting and I am doing a three day course on Nipple Tattooing at the end of November before we return to New Zealand in December.

While at this study day I met a very interesting woman, Glennis Hooper, a cancer survivor who has created a very interesting charity called 'Crazy Hats' ([www.crazyhatsappeal.co.uk](http://www.crazyhatsappeal.co.uk)). This charity has raised over £600,000 in six years which has been

used to support breast cancer care in Northamptonshire.

Glennis is an amazing lady and I thought would be a great speaker at a conference... I told her about [BCN's] work and she was very interested; she said she would be keen to come to New Zealand and would speak if the opportunity arose... don't know when your next National Conference is, but food for thought...

By the way have you seen the movie "Her 2" that has recently been released, it is about the struggle in the development of this drug. My husband had the privilege of meeting Lily Tarkinoff, who was instrumental in funding the development of Herceptin and involved in the movie. Her PA sent us a copy; it was great. [It would] be great to get Lily to New Zealand one day!

I look forward to getting back to New Zealand and utilising some of what I have learnt up here. I regret that at the time of my involvement [in BCN] my many family and work commitments made it difficult to offer the time to the Network that I would like to have been able to provide.

I will be happy to offer any help I can in the future.

All the best

Regards

Denise Flett

*Eds. Note: Denise was a member of the BCN Committee for several years and was a Breast Care Nurse before she left New Zealand for the UK. We all look forward to having her and her expertise back here very soon.*

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



**BOOKWATCH**

### BREAST CARE BY TREVOR SMITH

PUBLISHER: THE BREAST CENTRE LTD, AUCKLAND NZ

Reviewed by Barbara Mason

**B**reast Care by Trevor Smith, an Auckland-based Breast Surgeon, is an A4 sized book of 110 pages. What is appealing is that it has evolved from pamphlets targeted specifically for his patients. As such, it has been written to meet the needs of New Zealand women and the information is nicely presented and easy to read.

The subtitle is "Information and advice on all aspects of breast care", although it is mostly about breast cancer and it is not as comprehensive (or as expensive) as Dr Susan Love's *Breast Book*. There is more of a textbook feel to this book, with numbered paragraphs, charts and clear illustrations.

The overview of breast cancer and the treatment options is a valuable resource. BCN's *Stop Cancer Where it Starts* leaflets are mentioned and risk assessment is well covered. Breast Care does not offer information for the growing number of women living

with secondary breast cancer, and although there is a list of breast cancer groups under the heading of Support Services, contact details are only listed for a few, which from my perspective seems a missed opportunity.

However the book is a first for New Zealand women newly diagnosed with breast cancer and an excellent resource for

New Zealand breast cancer groups, and I commend it for these reasons. It can be obtained from The Breast Centre, Level 1, Ascot Integrated Hospital, 90 Greenlane Road, Remuera, Auckland, ph 09 520 9670, email [breastcentre@xtra.co.nz](mailto:breastcentre@xtra.co.nz). Cost \$25.



## MY MOTHER MADE ME DO IT! BY SUE CLARIDGE

### MY MOTHER MADE ME DO IT! SO SAYS JULIE LAMB'S FACEBOOK PAGE.

It is her first album, *Most and Least*, and her "Mother" is Darien Kerkin, who died from breast cancer in January this year. Darien was a long time member of BCN, served as the BCN treasurer and also told her story at last year's Rotorua conference.

Although the idea of doing an album, and many of the songs, date from before Darien died, and some from before she was even diagnosed with breast cancer, her death seems to have spurred Julie to turn the ideas into reality. When I spoke to her by phone at her Wellington office (Julie has followed in her mother's accountancy footsteps but after the day job plays in her band Bluzilla), she said that while the album was not "for" Darien, she was immensely sad that she didn't do it before Darien died.

At this point readers may well be wondering why *Upfront U Kaiora* is doing a story on the activities of a former member's daughter, but as Julie explained, BCN was very important to Darien.

"She believed in what the Network stood for," said Julie. "She believed in the prevention work that BCN does."

Indeed, in the time that I knew her Darien did whatever she could to reduce other women's risk of breast cancer, telling anyone who would listen, and those sometimes reluctant to hear her message, about healthy eating and not using products containing chemicals that may contribute to breast cancer. In her own words, she had become a crusader.

So, Julie has helped to continue Darien's work and chosen to support BCN with 10% of the proceeds from sales of *Most and Least*, because BCN was Darien's cause. But there is more to it than that: one of the songs

– *Cry As You Must* – is Darien's song.

It is a beautiful little ballad – a poem written by Darien for Julie when she was 19.

*I will be there*

*Because we lost in love*

*We lost to death*

*But in our loss is love and overcoming*

*In our loss is more than gain*

Although it would be easy to only pick

"I'm making use of something that she left to me," Julie explains. "It is a way to keep her with me."

"For me, what is so important about this song is that Mum wrote it for me at a time when I needed her. She was so supportive; she was that sort of person. She was there for me at a bad time in my life."

"She was such an incredible woman," she says of her mother. "She was so strong."

*Cry As You Must* will be downloadable as a single from Julie's website, and all the proceeds from this song will go to BCN.

"For me, it was the ability to translate [what she gave to me] to help with her death. Because she was such a positive woman, and she really was the things in that song, she was there for me, unconditionally..."

Although she wrote the music to go with the lyrics about five years after Darien wrote the poem, and had played it for Darien several years ago, she regrets not having made the album before Darien's death.

"Both Mum and Nanna had a lot of confidence in me," she says. In fact, it was her Nanna, who sadly also died this year, who told her to "stop singing karaoke and get on with it."

"Life is too short, so just do it!"

And "do it" she has, starting last February to turn the many years of songwriting into a debut album.

*Most and Least*, with its cross-genre mix of music – two ballads, some reggae, rock, country and funk, grounded in R&B – is more than just good music and the bringing together of the talents of singer-

songwriter and musicians. For Julie it is also a way to say thank you to Darien for passing on her strength of purpose, and for providing her with some "awesome material" for the album.



#### To help Julie's album, *Most and Least*, towards success and support BCN along the way you can:

- If in Wellington, attend the launch on Sunday, December 14, 2008 from 5:30pm at the San Francisco Bath House at 171 Cuba Street.
- Buy *Most and Least* or download *Cry as You Must* on [www.mostandleast.co.nz](http://www.mostandleast.co.nz)

Interviewing Julie little more than twelve hours after spending a weekend in the studio, I got to hear pieces from several of the songs on the album, as well as the whole of *Cry As You Must*, and I will be getting myself an early Christmas present as soon as the website is up and running and the CD is available. If you are looking for Christmas presents with a conscience for your family and friends, stop by [www.mostandleast.co.nz](http://www.mostandleast.co.nz) and buy from the comfort of your own home.

up on the sadness in the lyrics – and it strikes me as I listen to it that, as with many songs, the listener takes from the song the interpretation that fits their own story – for Julie the song is a tribute to Darien, and not about her death.

## ROTORUA IN THE PINK

Rotorua residents must feel like their city is in the national media for all the wrong reasons recently. But for the second time in just on a year (the first time was our First National Conference) the people of Rotorua have turned out to support a great cause, again confirming that the heart of the community is alive and well.

Aroha Mai, a Rotorua Cancer Support Group organised the 'Feel the Spirit Pink Walk' held on the 29th of October. Dell Gee, a long time member of the BCN Committee and one of the organisers of the National Conference last year, has been at it again, volunteering as one of the Pink Walk's organisers.

Dell told *Upfront U Kaiora* that the event had been incredibly successful, attracting more than four times the numbers that they had dared hope for on the inaugural walk for cancer. It was the main event during October's Breast Cancer Awareness month during which time Te Raukura Gallery hosted an information stand and display of art works by breast cancer survivors. It was another "collaboration" between gallery owner June Grant, who curated the Ora Creative Exhibition at the BCN Conference a year ago, and Rotorua's breast cancer

community. Works by June and Diane Toulmin who both exhibited at Ora, were featured in the gallery, among works by other artists who have had breast cancer.

Getting into the spirit of Breast Cancer Awareness month, more than 1200 people – the majority dressed in pink – turned out for the lake-side Pink Walk. Walkers started at the Village Green and walked for more than three kilometres past Sulphur Point and through Government Gardens before returning to the Green for refreshments, a sausage sizzle and live music.

"Feel the Spirit" is the council 'logo' for Rotorua and to our surprise they agreed to our request to use it – it conveyed beautifully what the walk was about and also connected as a Rotorua event."

"I must admit there have been times over the past few months when I questioned my sanity as to what I was doing but it was a great success... it couldn't have gone off more perfectly, the dark threatening sky cleared just half an hour before start, everyone was so happy, there was definitely someone looking after us," Dell said.

"We thought if we could get 300 people along we might be able to make it an annual event... We are completely over-

whelmed," another of the organisers, Bubsie McFarlane, told the *Rotorua Daily Post* on the evening of the walk.

Mrs McFarlane said that the walk was a healing journey for cancer survivors or perhaps a special time to dedicate to a family member or friend that may have passed on but the atmosphere was positive and jovial.

"People have been amazing," she said.

"We were absolutely rapt that people have come in such numbers," Dell said. "It brought the whole community together."

Dell told *Upfront U Kaiora* that one of the great outcomes of the event was the money raised. Adults were asked to make a \$5 donation but some people gave much more and more than \$6000 was raised.

"The money will be used to help ensure that local women have access to programmes such as Encore and Pink Pilates as well as assisting those in need during their cancer journey in a variety of ways not presently available in Rotorua."

With such a great response to the inaugural "Pink Walk", the organisers are looking forward to next year's event.

"People are already planning their costumes for next year," says Dell. "It's going to be HUGE!"



## LIVING WITH SECONDARY BREAST CANCER

BY KRISTINE EATON-HAMPTON

I have lived with this diagnosis for the last two years. It was not the imminent death sentence I thought that I was given on that fateful Friday in November 2006. My surgeon said he didn't know if I had weeks, months or years but they would work to get me into remission.

I am now in that space, it is scary, challenging and uplifting. I live each day and plan for the future and we do things that we may have put off in the past.

I have just celebrated my 60th birthday surrounded by friends and family and I felt loved and supported by these people who have and will continue to support me no matter what happens in the future.

I was diagnosed with secondaries before they found my primary. This is not common as they found them in my peritoneum first but I think I may have been lucky as it is not a common place for people to be looking! I went through the chemo, ugh, and had surgery to remove the little bit that was still in my breast. That was six months I would rather not repeat but I would do it all again rather than face the alternative. I am now on Aromasin (one of the Aromatase inhibitors)

My wonderful husband, Gary, supported me through this process and helped me to decide to give up work when it all got too hard. We also decided to move house about the time my chemo was ending. This was a great decision as we moved from the hill in Wellington, with the wonderful views, all day sunshine and a beautiful old villa that we had lovingly renovated but it had all day wind and steps! This house also had a mortgage and we wanted to be debt free so that I did not have to work. This was

made easier as we had been looking to move up the coast anyway and the diagnosis shortened the list of where to buy. I wanted to stay in the Wellington region so that I could stay with my wonderful doctors and we needed to be near to Mum so we could support her too.

We swapped all of the above for a flat section with a good size garden that I have been developing ever since and of course the house needed renovating, one of my other passions.

The next major event in my life was attending the Breast Cancer Conference in Rotorua last year. I had been indecisive about going, and when a friend was having a significant birthday, decided that was more important. But the party was postponed and that was my cue; off we went.

I had no idea how many people would be there or what lay ahead. It was fantastic!

I had one goal, to find out about managing the pain I was enduring with my drugs.

I found a room full of the most amazing women (and some men); it was so supportive and educating. But I also found a little group of women living with their secondaries (metastases is a horrible word). These women were amazing and we stood outside the door for the workshop that was just for us and wondered what lay ahead. It took a lot of courage for us to enter that room and I found myself standing outside holding on to a woman that I had never met, giving each other the courage to enter. We could see candles burning and didn't find that encouraging, we are alive and kicking I thought! The session was to give us hope – we had that by the bucketful – but meeting

each other was fantastic and certainly did give me more hope. When I went to the conference I didn't expect to feel special but the women in that room were special. We were the odd ones out at the conference as most women with breast cancer live to a ripe old age and don't get that diagnosis that throws your world upside down.

We were only given a short time together, and have already made suggestions that at the next conference we have the opportunity to spend a lot more time together, as we were from all over the country – Northland to Canterbury – and there are no groups outside Auckland to give us the support that we require. I look forward to *Sweet Louise* moving south!

What we realised is that now we had found each other we needed to keep in touch and we exchanged email addresses and we communicated that way.

However, I quickly realised that this wasn't the best way to keep in touch or to reach the wider group of us special ladies. Ongoing discussions with the Breast Cancer Network (NZ) have been fruitful and it now seems we are getting closer to an online forum where we will be able to communicate with each other and discuss the ongoing issues that we have.

And I did find some answers to my pain problems but I will keep that for another day and for the forum.

Thank you BCN (NZ) for listening to our needs and for the wonderful conference. I dedicate this to the wonderful women in our special group, especially Sue Ryder who spoke up for us at the conference and died recently.

## THAT PAIN IN YOUR HEAD MIGHT BE A GOOD THING

US Researchers have found that the same hormonal fluctuations that trigger migraine for many women may protect them against breast cancer.

Women who suffer from migraine had a 33% lower risk of ductal carcinoma and a

32% lower risk of lobular carcinoma than those who don't, says Dr Robert Mathes, and his colleagues at the Fred Hutchinson Cancer Research Center in Seattle.

They are not exactly certain about the biological mechanisms, but the association

between migraine and breast cancer in the population-based case-control study were primarily limited to hormone receptor-positive tumors, which suggested the link may be through hormonal pathways.

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"Given that lifetime estrogen exposure is correlated with breast cancer risk, the occurrence of migraines in women, which also has a relationship to estrogen, may be related to breast cancer risk," they wrote.

Migraines are often triggered by falling estrogen levels immediately before or during menses but stop during pregnancy when hormones run high.

Within the two study groups involving a total of 3495 women (2019 women with breast cancer and 1476 age-matched controls), women who reported a clinical diagnosis of migraine had reduced risk of ductal carcinoma and lobular carcinoma



compared with women who did not have a history of migraine.

The researchers acknowledged that the study was limited by inclusion of only

physician-diagnosed cases of migraine, because, they said, up to 59% of migraine sufferers are never clinically diagnosed. Perhaps more importantly, the data did not allow the researchers to control for use of over-the-counter drugs used to treat migraine, as non-steroidal anti-inflammatory drugs (NSAIDs) are commonly used for treatment of migraine and have been linked to lower risk of breast cancer (see Painkillers and Breast Cancer Risk on page 11).

Mathes RW, et al "Migraine in Postmenopausal Women and the Risk of Invasive Breast Cancer" *Cancer Epidemiology, Biomarkers and Prevention* 2008; 17: 3116-22.

## From the Project Desk...

### From the conference workshop: Secondary Breast Cancer - Living with Hope in your Heart

Recommendation 31 – "That participants in the workshop form a support network (via email/phone)"

Recommendation 32 – "That BCN develop a 'chat room' or an online message board facility on their website"

In *Upfront U Kaiaora*, issue 81, BCN wrote, "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." Over the last two months further progress has been made regarding the online forum.

Following discussions with Jennifer Clark, *Sweet Louise* CEO, all women with secondary breast cancer will be able to participate in the forum via BCN. There is one stipulation and that is *Sweet Louise* must have confirmation from a health professional that the woman does have secondary breast cancer. If you would like to participate in the forum, and do not live in Auckland, please email [admin@bcn.org.nz](mailto:admin@bcn.org.nz) or phone 09 360 0090 or write to BCN, PO Box 46018, Herne Bay, Auckland 1147 with your contact details and the contact details of your health professional.

(Note: Joining *Sweet Louise* – [www.sweetlouise.org.nz](http://www.sweetlouise.org.nz) – is only possible for those living in the areas where Sweet Louise can administer their voucher system and offer personal support. At present this is Auckland and soon Tauranga and Northland.)

At the time of writing, the on line forum is being tested by Sweet Louise members and we can expect it to be up very soon. Please do still contact us so that we can have the above

registration process completed in readiness for the launch.

**From the Environment, Lifestyle and Breast Cancer workshop:** Recommendation 14 – That consumer products endorsed as being in support of breast cancer (e.g. "pink ribbon" tagged products) should have no harmful chemicals added.

Sue McLeod, a BCN Committee member, has found that Leaderbrand lettuces and salad greens are free of endosulfan, as are all the products from Leaderbrand; this is good news!

Sue has also obtained more information about bisphenol A (BPA). Sue wrote to Watties regarding BPA in can linings. Although we received no assurances that anything would change, they wrote "We are naturally closely watching developments with the global position on lacquers to assess if there are suitable alternatives to epoxy resins made using BPA". There is as yet no easy substitute for BPA for can linings. There are different linings used for different purposes but they all have BPA. This is not good news!

With the barbecue season coming up we looked at what sort of plastic is used for tomato and barbecue sauce bottles and most is now recycle number 7 – i.e. polycarbonate which has BPA, which should be avoided. There are products in glass, and in number 1 plastic which is much better, so there is still a choice. Are there any readers who would like to write to the companies that are using better alternatives to polycarbonate, such as glass and number 1 plastic, and encourage them to keep going with it and report back to us if they get a response?

**Barbara Mason**

## **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](mailto:admin@bcn.org.nz)

## CLEAN GREEN AND HEALTHY

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

### SUNSCREENS REVIEWED BY SUE CLARIDGE

During my research on environmental oestrogens I was horrified to find that many sunscreens contain not one but multiple chemicals that are oestrogenic. Given that I have fair skin, and two children whom I want to protect not only from skin damage, but also exposure to environmental toxins, I made an almost instant shift to organic sunscreens.

Most organic sunscreens use a physical barrier, such as zinc or titanium oxide, together with natural plant extracts that block UV rays or have skin nourishing properties.

As with "mainstream" sunscreens, organic sunscreens must provide an SPF rating. There are an increasing number of organic sunscreens available in health shops and organic shops and they are relatively easy to find. Many such retailers also sell online.

I have used both **Natural Instinct Natural Mineral Sunblock** with an SPF of 30+, and **NOM 100% Natural Suncare** with an SPF of 25. Natural Instinct uses zinc oxide and NOM uses titanium oxide together with a range of naturally derived compounds. The NOM ingredient list sounds more natural with aloe extract, walnut oil, vegetable emulsifying wax, rose hip oil, squalene (a natural shark or fish oil), vitamin E, cocoa butter and natural fragrance. On the other hand the Natural Instinct sunscreen list reads like it is straight out of a chemistry text, but the label assures that each ingredient is naturally derived (e.g. natural mineral derived, vegetable/palm derivative, etc.)

In my experience, both are good and work well. Both are also reasonably priced, at the lower end of the price range so the boxes are ticked on the four main criteria for me: non-toxic; no oestro-

genic ingredients; high degree of protection; and value for money.

#### OTHER SUNSCREENS WORTH CHECKING OUT INCLUDE:

**Absolutely Natural SPF30 Sunscreen:** purified water, zinc oxide, wheatgerm, lavender oil, citric acid, seaweed & buckwheat extracts, glycerin and xanthan gum.

**Ecostore Sunscreen SPF 25+:** zinc oxide, carrot and sesame oil, shea butter & essential oils.

**Soleo Organic Sun Cream SPF30+:** grapeseed oil, macadamia oil, green tea extract, roman chamomile extract, sunflower oil, capric/caprylic triglycerides (plant oil derived), beeswax, lecithin, vegetable oils, cucumber extract, tocopheryl acetate (vitamin E) – active ingredient: zinc oxide.

**Living Nature Daily Defense SPF15:** aqua, zinc oxide, jojoba oil, wheatstraw extract, avocado oil, Sclerotium gum, grapefruit seed extract, NZ flax gel, manuka honey, bitter orange oil, patchouli oil, cistus oil, vitamin E, manuka oil, tea tree oil, totara extract, lemon myrtle oil, limonene\*, eugenol\*, linalool.\* (\*Component of essential oils).

**Dr Hauschka Sunscreen SPF 30 for children:** aqua, Rosa canina extract, titanium dioxide, Persea gratissima oil, tricaprylin, alcohol, Prunus amygdalus dulcis oil, Pyrus cydonia seed extract, Macadamia ternifolia seed oil, Mesembryanthemum crystallinum extract, Sesamum indicum oil, Olea europaea oil, Polyglyceryl-3 polyricinoleate, glycerin, stearic acid, aluminium hydroxide, sucrose distearate, Rosa canina seed extract, Parfum, Limonene\*, citral, geraniol, linalool\*, coumarin, citronellol\*, lecithin, oryzanol, Manihot utilissima, Starch, glyceryl oleate, esculin, propolis. (\*Component of essential oils)

## PASTA WITH AVOCADO CONTRIBUTED BY GILLIAN WOODS



### INGREDIENTS

- Pasta of your choice – 2 cups dried
- OR 1 packet of fresh ravioli
- Extra virgin olive oil – 2 tsp
- 2 ripe avocados
- Lemon juice – 2 tblsp
- Half a small pot of basil pesto
- 150 gm unsweetened low fat yoghurt
- Freshly ground black pepper to season, salt if needed
- Dash of sweet chilli sauce
- Grated parmesan cheese or
- chopped parsley to garnish – optional

1. Cook the pasta according to the packet instructions, drain and toss in the olive oil.
  2. While the pasta is cooking, mash the avocados with a fork, add the lemon juice, pesto, chilli sauce and sufficient yoghurt to bring the mixture to a creamy texture. Season with black pepper.
  3. Toss the hot pasta in the sauce, garnish if you wish, and serve immediately with a salad as a luncheon dish or main meal.
- 4 serves.**

Quantities in this recipe are not very important – more or less of any of the ingredients can be added to suit the number of serves required and to suit your taste.

## AN OPEN LETTER TO ALL NZ PARLIAMENTARIANS

### - FROM THE NZ BREAST CANCER FOUNDATION

#### October is Breast Cancer Awareness Month – Wear a Pink Ribbon and Show Support

The New Zealand Breast Cancer Foundation aims to reduce the number of New Zealanders who die from breast cancer and improve outcomes and quality of life for those affected by breast cancer. The Foundation has two Breast Health Educators who travel nationwide presenting free breast health awareness seminars to the public. Public feedback on breast cancer services is often passed on to the educators and The Foundation's Medical Advisory Committee. This year's feedback has highlighted the following three issues:

##### 1. Inadequate management of NZ women with significant breast symptoms

NZ women – of any age – who have significant breast symptoms are sometimes not being referred by their GP to a DHB for breast investigation; these women are advised to attend BreastScreen Aotearoa (BSA). This is inappropriate, and could potentially lead to significant diagnostic delay and will change overall mortality figures for BSA. In addition, it appears a number of DHB contracts have insufficient funding for breast investigations, and DHBs are reluctant to inform GPs (and women) of the contracted funding.

Recommendation: Funding to DHB providers who have diagnostic breast symptomatic services needs urgent review. GPs should have ready access to these services and inform women accordingly.

##### 2. Unavailability of annual DHB diagnostic mammograms for high risk NZ women

In Dec 2007, Hon David Cunliffe provided a letter to The Foundation stating that high-risk women eligible for DHB diag-

nostic mammograms would be entitled to access them. However, availability of these mammograms appears to be lacking due to insufficient DHB funding. GPs appear unaware of their availability, and the criteria for eligibility.

##### Recommendation:

- (1) Ensure availability of annual DHB diagnostic mammograms for NZ high-risk women and ensure GPs nationwide are informed of their availability, as well as knowledge of the high-risk criteria for referral.
- (2) Increase access to digital mammography services.

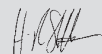
##### 3. There is gross inequality in the availability of immediate and delayed breast reconstruction for women following mastectomy. Some DHBs fund reconstruction, many do not make it available.

Recommendation: Ensure the availability of breast reconstruction in all DHBs.

On behalf of The New Zealand Breast Cancer Foundation we ask you to consider these recommendations for the improved health of New Zealand women and to wear the enclosed pink ribbon to show your support for The Foundation during Breast Cancer Awareness Month.



Dr Belinda Scott  
Chair  
Medical Advisory Committee



Heather Shotter  
Executive Trustee  
NZ Breast Cancer Foundation

*Thanks to The New Zealand Breast Cancer Foundation for speaking out on women's behalf and giving permission for BCN to publish this letter - Ed.*

## RESEARCH AND NEWS UPDATE

### PAINKILLERS AND BREAST CANCER RISK

Regular use of common painkillers such as aspirin and ibuprofen reduces the risk of breast cancer, according to an international study. The research, which looked at information from 2.7 million women, found that aspirin cut the risk by 13%, while ibuprofen lowered it by a fifth. However, experts warned long-term use of painkillers can have serious side-effects.

There have been many studies looking at the role of painkillers in breast cancer, and the latest is a review of 38 of these, combining their results to give a more reliable picture. Both aspirin and ibuprofen are Non-Steroidal Anti-Inflammatory Drugs (NSAIDs), and it is their ability to interfere with inflammation in the human body which appears to be the key.

Two body chemicals which help produce inflammation, COX1

and 2, are thought to play roles in the development of cancer by influencing how cells divide and die, the production of new blood vessels that can "feed" tumours, and influence the body's immune responses. It appears NSAIDs inhibit these chemicals.

Women taking either aspirin or ibuprofen regularly had a 12% lower chance of developing breast cancer compared to those who did not use them at all, while regular ibuprofen use appeared to have the biggest effect. However, the researchers warned against women adopting painkillers as part of a cancer prevention lifestyle.

"We don't recommend the routine use of NSAIDs for breast cancer prevention until large randomised trials confirm these findings," said Dr Mahyar Etminan, from the University of British Columbia who led the research.

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Takkouche, B. et al. Breast Cancer and Use of Nonsteroidal Anti-inflammatory Drugs: A Meta-analysis, *Journal of the National Cancer Institute* 2008 100(20):1439-1447.

**VIGOROUS EXERCISE DOES IT FOR POST-MENOPAUSAL WOMEN**

Postmenopausal women may lower their risk of breast cancer with vigorous physical activity, a study from the US National Cancer Institute has found in a recent study.

Unfortunately, anything less than vigorous activity had no influence on postmenopausal breast cancer risk, and the benefits were limited to lean women, defined as having a body mass index of less than 25.

During 11 years of follow-up, women who reported the highest levels of activity had an almost 20% lower risk of breast cancer

compared with women who exercised the least, the researchers reported in the journal *Breast Cancer Research*.

Recent reviews have suggested that increasing physical activity is linked with a reduced risk of breast cancer risk. However, authors of the reviews called for more research to identify specific characteristics of physical activity that contribute the most toward risk reduction.

In the latest research looked at 32,269 women who completed health surveys from 1987 to 1989, 1993 to 1995, and 1995 to 1998.

The surveys included questions about physical activity during the previous year and offered a list of physical activities categorized as non-vigorous or vigorous. Examples of non-vigorous exercise included washing clothes, lawn mowing, and walking. Vigorous activity included scrubbing floors, chopping wood, and running or fast jogging.

Leitzmann MF, et al., Prospective study of physical activity and risk of postmenopausal breast cancer, *Breast Cancer Res* 2008; 10.

## MERRY CHRISTMAS

The BCN Committee wishes all members and their families, supporters and sponsors a very happy Christmas and holiday season.

**VISIT THESE SITES FOR MORE BREAST INFO!** [www.breastcancernetwork.org.nz](http://www.breastcancernetwork.org.nz) [www.breast.co.nz](http://www.breast.co.nz)

*The opinions expressed in the various UPFRONT U KAIORA articles are not necessarily those of the Breast Cancer Network (NZ) Inc.*

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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 (Jenny) Clark

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

*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](mailto: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

Breast Cancer Network (NZ) Inc., 300 Richmond Road, Grey Lynn, Auckland. Phone: (09) 3600090 Fax: (09) 3602180 Email: [admin@bcn.org.nz](mailto:admin@bcn.org.nz) Web: [www.bcn.org.nz](http://www.bcn.org.nz)