

# UPFRONT

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## DELAYING RECONSTRUCTION BY SUE CLARIDGE

**WHEN MAGGIE PIMM WAS TOLD THAT SHE WOULD HAVE TO HAVE A DELAYED BREAST RECONSTRUCTION, SHE HAD NO IDEA JUST HOW DELAYED IT WOULD BE.**

### THE LONG WAIT

Maggie was diagnosed with breast cancer in April 2004. The following month she had a mastectomy and lymphadenectomy, but before the surgery she was told that she would need a delayed breast reconstruction because she would need both chemotherapy and radiotherapy; her body and the wound needed time to heal.

In December of 2004 Maggie had completed her chemo and radiotherapy and was looking forward to her reconstruction. In February of 2005, the North Shore Hospital advised her that there was a waiting list for delayed reconstruction and that she needed to be patient.

So Maggie waited.

In August she saw Mr Arumugam, one of two new plastic surgeons who were appointed for breast reconstruction. He explained the surgical procedures to Maggie, told her about the risks of the surgery, advised her about her expected recovery time and return to work. All the preparation for the operation was completed: Maggie's weight, height and blood pressure were measured, pre-op photos were taken for comparison with her post-op new breast, and she even filled in an anaesthesia form.

The date of the operation was of concern to Maggie. Mr Arumugam told her that the operation would take place soon after the end of September. Working as a temp, she had intended to finish on September 30th in time for the operation and seek another position once it was all over and allowing for the 30 days she would need for her recovery. If the operation was going to be delayed beyond about mid-October she was going to need to find another job in the interim.

In late August Maggie called the SuperClinic in Manukau to find out how soon

after the 30th of September her operation would be. However, the woman to whom she spoke couldn't tell her "how soon is soon" and said it could be a month, two or three.

So Maggie waited.

### A RED LETTER DAY

On the 26th of August Maggie received a letter from Chris Fleming, the manager of the ambulatory and surgical care centre – Maggie had been taken off the waiting list for surgery because under their evaluation system she did not accrue enough points. He went on to say that Maggie should be continued to be looked after by her GP and that should her condition change, her GP should contact them again in order to review the assessment.

"This last statement on its own shows that Chris Fleming knows absolutely nothing about me, or about patients with breast cancer who are in need of delayed reconstruction surgery," says Maggie.

Later Maggie was told that she had been put on the waiting list, but had to be taken off because the government doesn't want people waiting for longer than six months.

## RAISING ~~100S~~ AND 1000S FOR BREAST CANCER NETWORK



The prospect of iced pink buns got people out in their droves and thousands were raised for your Breast Cancer Network!

The Bakers Delight October promotion was a huge success with \$17,000 raised. A list of superlatives does not begin to explain how pleased we are and the Breast Cancer Network says a huge thank you to Bakers Delight, the franchisees throughout the country, BCN members and all the New Zealanders who purchased buns or made donations during this time.

This money will go towards the inaugural BCN conference for New Zealand women with breast cancer. Thank you everyone for all your support.

#### TREATMENT INEQUITIES

Our ailing health system is dealing with an increasingly aged population, an obesity epidemic, burgeoning diabetes, cardiovascular disease that just won't go away and increasing rates of cancer. Amid these issues, 2500 New Zealand women are developing breast cancer each year.

For those women with breast cancer that requires chemotherapy and/or radiotherapy, the injustice of the current system adds insult to injury. After all, their 'sisters' who, because of the stage of their disease can have their reconstructions started on the same operating table as their mastectomies, have a considerable advantage. While women like Maggie have their reconstruction delayed indefinitely.

Okay, so women such as Maggie aren't in intolerable physical pain. Their conditions aren't life threatening. But there is ample research demonstrating that, for many women, having reconstructive surgery is part of the healing process and will enhance their return to a productive and fulfilling life and restore their self esteem. What is the downstream cost to our society and to our health system from women who suffer depression, post-traumatic stress and an inability to resume lives as productive, contributing members of our society?

This system is sending a clear message to these women that their disease makes them less valued than women who can have immediate reconstruction, that they somehow deserve less than world's best practice breast cancer treatment and care.

Dr John McEwan is a health psychology specialist who, over a period of about ten years, has worked as a counsellor with over one thousand breast cancer patients. He is deeply concerned about the impact that these delays have on women needing breast reconstruction.

"Reconstruction, for women who want it, is a vital, integral part of both their physical and mental recovery," he says. In addition, Dr McEwan says that the impact of stress on the immune system is well-documented and this has implications for women's recovery from breast cancer. Thus reconstruction is



Dr John McEwan

not merely cosmetic but therapeutic.

"This is just another sad thing that shouldn't be happening," he says of the delays these women face. "There are a range of downstream costs that are pretty quantifiable; depression, decline of energy, enthusiasm, confidence and the withdrawal of able women from their workplaces." He agrees that the view from the government is short term, reducing costs now with no perception of the costs to society in the long term from the mental health effects of such policies.

#### SEARCHING FOR ANSWERS

*Upfront* sought comments on the current situation from various stakeholders, in an effort to understand what has led to these delays and how it is being addressed. The Ministry of Health advised that the prioritising of surgery and the allocation of resources is not a national policy issue but is delegated to the individual district health boards to manage, and a spokesperson for their communications department directed *Upfront* to the Counties Manukau District Health Board.

Annie Tyson, Clinical Nurse Manager at Middlemore Hospital explained some of the difficulties faced by those determining who gets priority for elective surgery. All plastic surgery cases are assessed together, so women needing breast reconstruction are

assessed alongside babies needing cleft palate or cranio-facial surgery, among others with conditions that have impacts on both physical and mental health. She also raised the issue of the availability of expertise. "We have expertise here [at Middlemore] but we don't necessarily have a lot of breast reconstructive surgeons," she said.

Changes in treatment have changed the way in which resources are used and allocated. With more immediate breast reconstructions operating theatres are tied up for longer than with just a mastectomy. "That's two teams of general surgeons and plastic surgeons out for the whole day which has meant the use of resources has increased, and other surgery is deferred," explained Annie.

Lauren Young, Communications Manager for the Counties Manukau DHB, also pointed out that acute surgical cases have to take priority, pushing elective surgery further back and deferring scheduled operations.

Annie's advice for women taken off the waiting list is to have their GP re-refer them with a strong emphasis on the woman's need for reconstruction, particularly with regards to the impact of the loss of the breast on their mental state and therefore their recovery.

Stephen Mills, a plastic surgeon in both private and public practice, is the first to admit that it is hard for women facing delayed reconstruction. But ultimately it comes down to the pressure on resources. Breast reconstruction is only available in four hospitals – Middlemore, Waikato, Hutt and Christchurch.

"It is Government policy that a patient knows with some certainty what their surgical standing is likely to be in the next six months," says Lauren Young. She says that is as far as the hospital can predict. If they will have to wait longer than six months they are taken off the waiting list and Lauren says that they can reapply. Unfortunately, there is no indication that the situation will change in the foreseeable future.

*Upfront will update readers as the response to various letters, that both Maggie and BCN have sent regarding delays in delayed reconstruction, are received.*

## From the Editor ....

I don't envy the clinical managers responsible for deciding who is next on the list for elective surgery. Our lead story this month looks at delays in delayed breast reconstruction and the impact that waiting lists for elective surgery are having on women dealing with the aftermath of breast cancer. It is hard not to see the other side of the story, the difficulties that those health professionals "at the coal face" have when there are so many deserving people waiting for their chance at a better quality of life.

While it would be wonderful if everyone could have elective surgery when they need it, clearly there are significant limitations in our public health system and this is just not possible. So, just within plastic surgery, how do you decide between a woman devastated by the loss of a breast, a toddler with a cleft palate, a teenager with very prominent ears? Is each person not equally deserving? How do you assess the ongoing physical or mental pain suffered by each and then place those individuals in some sort of prioritized list?

Over the last couple of years, I have spent quite a bit of time talking with women about their journey with breast cancer. I have absolutely every sympathy for them and am concerned that all too often the psychosocial aspects of their experience goes largely unaddressed. I have spoken with committed and passionate health professionals, from surgeons and oncologist through to counsellors. All work extremely hard to help women get through breast cancer with as much quality and quantity of life as possible. However, although these delays in breast reconstruction make it hard for some women to resume normal, healthy and happy lives, I also feel for all the other New Zealanders who must compete with breast cancer patients on elective surgery waiting lists. New Zealanders who are every bit as deserving of treatment.

I believe it is a situation that needs to be addressed by our Ministry of Health with the utmost urgency, so that thousands of people around the country can once again take up fulfilling and productive lives, potentially reducing consequent costs in the area of mental health.

*Sue Claridge*



Dr Ray Simpkin

## RADAR BREAST SCREENING UPDATE

# RADAR PROTOTYPE NOW SCANNING REAL WOMEN'S BREASTS

"Slow" was how Dr Ray Simpkin described the progress in his radar breast screening pilot study, currently underway at St Marks Women's Health Clinic in Auckland. However, the pilot study is about half completed and Ray is optimistic that the results will be positive, leading to a larger study.

At the BCN Annual General Meeting in May, Ray explained that ethical approval had been given for ten women to participate in the trials. The study cohort is taken from women attending St Marks – women whose mammograms have shown the probable presence of a breast tumour. These women undergo ultrasound examination and are asked to participate in the radar breast screening pilot study before they have a biopsy and surgery. For most women this is a particularly fraught and stressful time, and, understandably, many do not want to undergo further procedures no matter how brief and painless they may be. As a result obtaining the numbers of study participants that they need has not been easy.

Unfortunately, five of the ten women who had agreed to take part in the study pulled out before the radar screening could take place, and the research group has had to obtain permission to screen five more women\*. Ray hopes that screening will be completed by the end of the year and that no further participants will pull out of the study, otherwise he will have to apply to the ethics committee for an extension of both time and patient numbers.

Adding to the frustrations for both the researchers, and those of us waiting with bated breath for an alternative to mammography, is the processing time

of a week per patient, and a lack of funding. Despite this Ray is pretty happy with how things are progressing.

"This time three years ago we had just started, from absolutely nothing. And here we are with a working prototype and scanning patients – just three years later. For a new imaging technique that is not bad going."

Of course, he is right. Developments such as this are many years in the making and most of us are blissfully unaware of the huge investment of time, money and human resources in the research and development that leads to medical breakthroughs. Science rarely moves at speed, and discoveries that seem to have happened overnight are generally preceded by years, if not decades, of slow, methodical trial and error investigation and experiment.

The good news is that they have good sets of data for four of the patients and Ray is about to do the processing on the fifth. He and his colleagues are now looking at the images and comparing them with the patients' mammograms.

Although the first set of data looks promising, Ray says he "can't draw any particular conclusions just yet." But, assuming positive results from this study, the next trials planned for the screening technique will be three 100-patient trials undertaken at three separate sites. This will require more machines and a considerable amount of financial investment. *Upfront* will keep you all up to date with developments.

\* *Once a woman agreed to take part by signing the consent form she was counted as one of the ten patients allowed in the pilot study, even if she subsequently pulled out.*



## LETTERS

### STRESS AND BREAST CANCER

Like me you will have been surprised by [the research on stress and breast cancer].

So, like cholesterol, there is good and bad stress. Many survivors think that bitterness, sorrow, rancour, being humiliated (the bad stress?) is often not the cause, but the trigger of breast cancer.

But if it is only to have a busy life, and to have to cope with many different tasks during the day, how can they explain that this "good" stress reduces the oestrogen level?

Would you have to alter your Stop Cancer Where It Starts brochure with an entry for Life Style and Stress?

**Nicole Sabatier, Auckland**

See page 10 for story on the stress research that was published in September. – Ed.



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

## BCN NATIONAL CONFERENCE IS BECOMING A REALITY

BY DELL GEE

**E**arly in the New Year we will be involving women from around the country, in helping with the planning and organisation of the first New Zealand National Breast Cancer Conference for those who have experienced breast cancer.

Breast Cancer Network (NZ) held meetings at seventeen different locations covering all regions of the country between April and October this year, firstly to make sure that there was support for our plans to hold a Conference and also to get feedback on areas of interest and concern that needed to be covered at the Conference.

What do women want from a Conference? What stood out for me, was that above everything, they want a Conference to help make a positive difference, not only in their own journey with breast cancer but also for those that are to follow. As well as accessing information, gaining knowl-

edge and understanding, they want lots of fun and lots of laughter, and to hear inspirational stories from other survivors.

The lasting impression I have from attending the 2nd Australian Conference held in Melbourne in August 2004 is how much the Australian women had achieved since their first conference in 1998 and how empowered they had become in the process. We believe that a New Zealand Conference will be just as empowering for New Zealand women as it has been for our friends across the Tasman.

Sponsorship will play a vital part in keeping the cost of the Conference within the reach of all women wanting to attend. If you know any organisation or business who would be willing to sponsor our Conference please contact the BCN office on (09) 526 8853 or email [brcanz@xtra.co.nz](mailto:brcanz@xtra.co.nz). We would love to hear from you.



## KITCHENAID MIXER RAISES DOUGH FOR BCN

**T**he kitchen mixer donated to Breast Cancer Network by KitchenAid has sold at auction on TradeMe. The money - \$625 - will go to BCN.

BCN would like to thank KitchenAid for the donation and the opportunity to raise funds through its sale.

## SHARING THE PAIN BY NICHOLAS WHEADON

ORIGINALLY PRESENTED AT THE CANCERVOICES FORUM IN WELLINGTON, 22 MARCH 2005

**M**y first memory of knowing about cancer was sometime after I was three. My mother's younger sister was diagnosed with leukemia, and although I obviously didn't understand then what this meant, I did know that everyone was very upset for a while and that my grandparents started looking after my aunty and my cousin who was about seven.

A couple of years later when I was seven my grandma became very ill and I spent time with my Mum going backwards and forwards to Levin to visit. Grandma died of bowel cancer and, although at that time I thought I knew what it was about, I don't think I understood the affect it had on my older siblings – especially my oldest sister who was 18 and angry; Grandma was only 62 and my granddad would not talk about it or admit she had had cancer. My aunt was still sick and my grandma and granddad referred to it as "her troubles".

The following year my other grandma, in Australia, was diagnosed with bowel cancer and I spent the last four months of her life with her in her home and attended school there. However, this grandma talked to me about her life and what time we had was very precious. I had fear this time. My brother and sisters stayed in New Zealand as they were at high school and university. I went to school but each day I'd come home to see Grandma and spend the time with her. It was a very special time and it played a huge part in my growing up – each day I wondered if it was her last.

Her last week was spent in hospice – Mum and I stayed there with her. It was a hard time but the hospice staff made it that much easier and I have very good memories of this time.

Then, when I was nine, my granddad became very ill and had major surgery. He had forbidden my parents to tell me what was wrong; the following year he died of lung cancer. My grandparents had been looking after my cousin as my aunt was very unwell – it had a great affect on my cousin. None of us understood what was going on and we couldn't talk about it. I was a bit older then

and I remember talking with my brother and sisters; we were sad and we wished we'd had more time with Granddad and that he'd shared more with us.

When my aunt died later that year, my mum was angry, nearly inconsolable – my aunt, too, had chosen not to share her cancer journey with us and it made it impossible to deal with the aftermath of yet another death. My cousin became a brother – there were now five of us. Difficult times followed. My aunty hadn't really talked to my cousin and he suffered in silence and we couldn't share his grief with him.

Then my mum was diagnosed with breast cancer. I felt numb – somehow it just didn't register. However, because of the experiences with her family she decided to share it with us. We five children all reacted quite differently. She told us what it was like to have her family die of cancer and not be included in the pain. She was determined that we would share the journey and I sometimes found that very hard and became angry. My siblings are all different – both my sisters, who live overseas, unfortunately sometimes seem emotionally isolated. My brother who lives in Wellington rings mum everyday now and has done for the last three years since she was diagnosed. My other brother (my cousin) doesn't really register that this has happened – I think it seems just too much for him to cope with.

There are people here today from the medical profession, caregivers and patients.

To the patients, share your journey and share our fears. As a caregiver imagining the patient's fears is worse than knowing the fear. Also it has been made easier for me that Mum has been able to talk to me about what is happening. It makes you feel more involved and appreciated – it's not easy watching someone you love suffering and feeling unable to help.

To the medical professionals I would ask that you remember that cancer patients who have children have more than their cancer to worry about. My mum has often put us children first at a time when she should have



Nicholas Wheadon

been focusing on her own recovery. However, while she was told to look after herself, she was often too concerned about how we children were, to always do what was best for her. Her pain at having to tell us she had breast cancer was obvious.

Children who have a parent with cancer, I think, have a special set of problems. Children and parents typically have a relationship that includes as much arguing and slamming of doors and rebelling as it does care and love. Every time a young person feels angry or upset about something they feel too afraid to vent steam in case they upset their parents. If they do vent steam then parents and patients often react the wrong way. Listen carefully to what your children say.

To caregivers here today I would say that if you are feeling stressed or sad or just want to talk about it – DO SO. I know for myself that Mum sometimes talked about things and while I didn't really want to hear it, this meant I could ask questions and get answers to things that had been going around in my head.

Please don't block out your children, thinking you are protecting them. I've had both experiences and I can honestly say that an open and honest environment (no matter how much it hurts at the time) is the best one for all, not only the family and friends, but for the patients too.

## MAMMOGRAPHY PART 3 – THE RISKS AND BENEFITS

BY SUE CLARIDGE

Last month Mr Trevor Smith, a breast surgeon at Ascot Hospital in Auckland, wrote a 'perspectives' piece for *New Zealand Herald* in which he made a plea for women to be provided with balanced and appropriate information:

"As a breast surgeon I witness the tragic consequences of breast cancer on a daily basis. No effort should be spared to reduce the impact of this disease. But women are entitled to balanced information before proceeding with screening mammography. It is patronising to assume that this might be seen to cause confusion and discourage participation."

He mentions a "widely shown ad informs women that 'a mammogram is the best way to make sure you stay well and healthy for your whanau.'"

When I spoke to Trevor Smith about his article he said that he regularly sees women who don't understand how they came to have breast cancer. He says that "women overestimate what mammograms can achieve and are not aware of the limitations and associated risks. These unrealistic expectations can result in a sense of betrayal when breast cancer develops despite regular mammograms, sometimes over many years." He explained that some women believe that mammograms will stop them getting breast cancer, that it is a preventive tool, not a diagnostic tool for early detection.

In the final part in this series we will look at over-diagnosis and over-treatment, and review the studies that investigate the benefits of mammography.

### OVER-DIAGNOSIS AND OVER-TREATMENT

Over-diagnosis and over-treatment of breast cancer is explained by BreastScreen Aotearoa as "finding and treating conditions which may never have caused a woman problems had they not been detected by screening." BSA states that over-diagnosis and over-treatment account for between zero and ten percent of cancers detected by breast screening.

Women who are over-diagnosed, and thus over-treated, have cancer that will never spread



Mammographic screening – contributing to a decline in breast cancer mortality.

to other parts of the body. These women, if left untreated, would die with, not from breast cancer, and detecting and removing these cancers does not save lives. Unfortunately there is no conclusive way other than surgery, such as a biopsy, to distinguish such cancers from the others that will spread and cause harm. As a result women undergo the trauma, anxiety and surgery that accompany a positive screening result. Some of these women may be subjected to unnecessary treatment that carries with it, its own risks.

Drs Peter Gotzsche and Ole Olsen, in a review of seven randomised trials of screening mammography, found that "screening leads to more aggressive treatment, increasing the number of mastectomies by about 20% and the number of mastectomies and tumourectomies by about 30%."

In a study on the incidence of breast cancer in Norway and Sweden during the introduction of nationwide screening,<sup>3</sup> Dr Per-Henrik Zahl and his colleagues concluded "that after the introduction of screening programmes in Norway and Sweden one third of all cases of invasive breast cancer\* in the age group 50-69

are overdiagnosed – that is, without screening these cases would not have been detected during the patients' lifetime." The authors do not imply that these women were not, or should not have been treated, but they say that "women cannot make an informed choice on screening unless the level of overdiagnosis is properly explained to them."

Dr William Black says, in an editorial on the harm caused by the over-diagnosis of cancer, that over-diagnosis "plays havoc with our understanding of cancer statistics. Because over-diagnosis effectively changes a healthy person into a diseased one, it causes overestimations of the sensitivity, specificity, and positive predictive value of screening tests and the incidence of disease."<sup>4</sup>

He goes on to say that people are generally poorly informed of the possibility of over-diagnosis, pointing to a US survey of women – "only 6% were aware of... the fact that mammography could detect a form of "cancer" that often doesn't progress."

### THE BENEFITS OF MAMMOGRAPHY

Nowhere in the discussion of mammography

is the debate more hotly contested than over the issue of the benefit of screening programmes, in particular the effect on breast cancer death rates. Dr Brian Cox, director of the Hugh Adam Cancer Epidemiology Unit in Dunedin, said that "it would take at least three to five years for the effect of changes in screening to even remotely be seen in mortality rates." Trevor Smith pointed out in his *Herald* article that "New Zealand has never conducted a trial to test the efficacy of screening in our environment and we base our decisions on overseas results."

However, a review of recent international studies shows that opinion is divided.

In January 2005 a Danish study found that, for women participating in screening, breast cancer mortality was reduced by 37%, without the participants suffering severe negative side effects from the screening.<sup>5</sup>

However, as if to illustrate how polarised research opinion is, a paper published in the July issue of the *Journal of the National Cancer Institute* found that breast screening is not effective in preventing mortality.<sup>6</sup> Dr Joann Elmore, professor of medicine at the University of Washington School of Medicine, said:

"We observed no appreciable association between breast cancer mortality and screening history, [regardless of age or risk level]. Our findings may, therefore, reflect a possible reduction in the accuracy of screening as it moves from highly controlled randomised trials to real-life clinical practice."

Similarly, in January 2002 the *New York Times*<sup>7</sup> reported that the P.D.Q. screening and prevention editorial board, a panel of experts convened by the National Cancer Institute, found that there was insufficient evidence to show that mammograms prevented breast cancer deaths, although previously the same panel had said that there was evidence that mammograms prevented breast cancer deaths starting at age 40. The panel "agreed that seven large studies of mammography had serious flaws, weakening or casting doubt on the studies' validity."

However, the controversial and hotly debated nature of the panel's findings became apparent when the National Cancer Institute later went against the conclusions of the panel and said women in their 40's should have mammograms.

In the most recent research, published in

the *New England Journal of Medicine* in October 2005, seven independently developed statistical models were used to investigate the reduction in death rates from breast cancer in the United States from 1975 to 2000.<sup>8</sup> The study found that mammographic screening and adjuvant treatment have contributed almost equally to the reduction in mortality.

Senior author, Dr. Donald Berry, said that "the trials conducted to evaluate the effect of screening mammography on breast cancer mortality have been controversial. So the question was, do the findings from these studies translate into clinical practice?"

In a related editorial Dr David Dershaw, of the Sloan-Kettering Cancer Center said that the findings support the belief that screening mammography saves lives and concluded that eligible women should undergo screening.

Whatever the actual benefit of mammography screening programmes in terms of actual numbers of deaths that are prevented, the mechanism is hardly rocket science. Quite simply, detecting tumours early leads to early treatment, and a reduced risk cancer spreading to other parts of the body. There is still no cure for metastatic breast cancer and the best chance of cure and long term survival is to diagnose and treat cancer before cancer cells have a chance to spread. This benefit was discussed in research published in 2003 in which the authors found that "mammographic screening offers the potential to reduce tumor size and, presumably, breast carcinoma death, in women of all ages and density groups."<sup>9</sup> This view was confirmed in Berry's *NEJM* paper which concluded that mammography screening improves the prognosis by detecting breast cancers at earlier stages of disease.

The decline in mortality from breast cancer is something to be celebrated, no matter what is contributing to it. But understanding what is responsible for the decline in mortality, and exactly why, will help us develop better diagnosis and treatment strategies that (hopefully) will see it reduce even further. Whatever the actual effect of mammography on breast cancer mortality, it is currently the best tool we have for population-wide screening for breast cancer, although it likely that the debate over just what its contribu-

tion is to the mortality statistics will continue for some time.

Mammography is not without its risks and limitations and women should be made aware of these. Some of the risks, such as over-diagnosis, are difficult to assess and to address. BCN strongly advocates mammography and whatever treatment is recommended by a woman's medical team, to give all women the best chance of avoiding metastases even if that means some women may be over-treated. Improvements in both current mammographic screening technology and the emergence of alternative screening techniques are likely to reduce the other risks and limitations that we have considered in the previous two articles in this series.

Ultimately women should be encouraged to make informed decisions about their health and wellness, be encouraged to be breast aware and to seek medical advice if they notice changes in their breasts, and to have regular breast exams by their doctors from about the age of 30. Women should be encouraged to do whatever they can to reduce their risk of breast cancer and treat mammography as a tool for early detection, rather than perceiving it as a device that will keep them healthy.

\* *The researchers only considered invasive breast cancer and did not include cases of DCIS in the analysis. However, this article raises the issue of DCIS, a topic that we do not have room to discuss here, but that we intend to follow up in a later edition of Upfront.*

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## A SWEETER LIFE – FOR WOMEN WITH BREAST CANCER

BY SUE CLARIDGE

You wouldn't blame a man who had lost his wife after a 12 year battle with breast cancer for closing the door, turning his back on the disease. After throwing everything at the disease that medicine had to offer, you wouldn't blame a man for being bitter about losing her, only half way through her life.

But that man is not Scott Perkins.

Scott is the Chairman of *Sweet Louise*, the charity that was inspired by his wife, and that bears her name. He is passionate about the cause, and committed to improving the lives of other women with breast cancer, especially those with metastatic disease.

I have an opportunity to talk to Scott together with *Sweet Louise's* CEO, Vicki St John. Both are buoyed by the enormous success of their first fundraiser – an auction of fabulous art works, many of which were created specially for *Sweet Louise*. They are enthusiastic about the plans that the charity's Trust Board has for New Zealand women with breast cancer.

*Louise Perkins was 27 when diagnosed. Recurrence followed only two years later and she died from metastatic breast cancer at 39. However, Louise differed from most young women with the disease. Financial privilege meant that she had access to new and expensive drugs such as Xeloda and Herceptin; drugs that extended her life and vastly improved the quality of her last years.*

Scott says that *Sweet Louise* has three aims: "We want to promote complementary therapies to help improve the outcome in breast cancer patients." He emphasises that this is alongside, not as an alternative to, conventional treatment. Specifically they want to focus on the benefits of diet and exercise. "By complementary we mean anything that is not conventional medicine and with a strong bias towards having some research currency."

"Secondly, we want to provide restorative therapies that aren't necessarily specifically tied to a cancer outcome, but that are just plain good for you... these might be the simple, joyous things in life – access to holiday homes, massages, just special experiences." Scott uses the child cancer community as an example of the sorts of "restorative" activities

that are offered to children – for example, trips to Disneyland – things that are missing from the adult cancer world, the breast cancer world.

"The third thing we want to do is, over time, to be a powerful and credible advocate for world's best practice in breast cancer care in New Zealand."

SWEET LOUISE | POSITIVE LIVES WITH BREAST CANCER



ONLINE AT [www.sweetlouise.co.nz](http://www.sweetlouise.co.nz)

Vicki adds that a topline priority is social and practical help for women with breast cancer – childcare, transport, home help, preparing meals and so on. These are issues that often affect younger women, women with young families and, again, it is Louise's experience of breast cancer at a young age that drives these ideals.

While *Sweet Louise* will offer services to all women with breast cancer, many of these services will particularly appeal to younger women battling the disease.

Not only will *Sweet Louise* promote things like exercise programmes for women with breast cancer, but the services they offer will actually subsidise women on these programmes, enabling women to take part. Vicki explains the voucher system that they will operate to enable women to access their services, the

research that they are currently undertaking and the review of potential service providers.

"We want to promote services on a subsidised or free basis to breast cancer patients in a properly targeted and quality assured way, that actually brings about an improvement in their quality of life," says Scott. Using exercise as an example he explains that they intend to start in Auckland and then expand to a nation-wide exercise programme that is specifically tailored to breast cancer patients, and which will be offered to women through a number of service providers.

*Scott and Louise did a lot of their own research into Louise's care and treatment:*

*"We really pushed the boundaries. We were the first to bring Capecitabine [Xeloda] into New Zealand, which is now one of the gold standard drugs for metastatic breast cancer. We started on Herceptin in about 1998 and Louise was on it for a long time."*

*Louise was in the fortunate position of having access to both drugs before they were licenced. Scott points out that "they don't need to be licenced here for you to be able to get the drugs. As long as they are licenced somewhere else you just have to be able to pay for it."*

*"We were very lucky to have access to some great drugs and I'm sure that it made a huge difference. One of the real challenges we have got is that [these drugs] are just beyond the realms of so many people."*

This experience is clearly what drives Scott's intention for *Sweet Louise* to promote world's best practice in breast cancer care. He is unequivocal about access to the best drugs:

"There are hundreds of women in New Zealand who should be on Herceptin, and who can't afford to be, and who could have months, years of additional life."

While Scott and Vicki, and the rest of the Trust Board, are still doing the research and setting up the operational side of *Sweet Louise*, still working towards being able to offer complementary, restorative and practical services to women with breast cancer, clearly they have already progressed a long way towards their third goal – to be powerful and credible advocates for the quality of care that they believe all women with breast cancer should have.



**BOOKWATCH**

## WHEN A PARENT HAS CANCER: HOW TO TALK TO YOUR KIDS – A GUIDE FOR PARENTS WITH CANCER AND THEIR FAMILIES AND FRIENDS

By the Cancer Council New South Wales

REVIEWED BY DENISE FLETT, BREAST NURSE, NORTH SHORE HOSPITAL

**When a parent has cancer:  
how to talk to your kids**

*A guide for parents with cancer, their families and friends.*



This magazine style booklet is an excellent tool for parents undergoing the cancer experience, both for the newly diagnosed and also for those dealing with the issue of advanced cancer. It addresses the anxiety parents have in dealing with the issue of cancer with their children, and it would also be a helpful guide for grandparents, other family members and close friends in this situation.

The aim of the book is to help parents talk to their children about cancer and to maintain that dialogue throughout the cancer journey. It is simple and concise, and includes Ten ways to help your kids cope as well as a glossary of cancer words and how to explain them to both younger and older children.

It has a very useful chapter that deals with Toddlers to teenagers - what to say. This looks at what each age group should understand, from newborns, infants and toddlers, to preschool, school age children and teenagers. It offers age appropriate tips on helping the child cope and

has excellent response advice for parents. As a health professional I found some of the phrases they suggested when dealing with the issue of cancer very insightful and appropriate.

The booklet also offers information on the issues of family life after treatment and when cancer won't go away.

The chapter Getting professional help has advice about when to seek support and what is available to the cancer patient. However, being an Australian publication the services available are not entirely the same. In New Zealand I would recommend talking to your GP, Breast Nurse, Oncology Nurse or Oncologist and contacting your local Cancer Society to establish what support services are available in your region.

There are, of course, many helpful breast cancer consumer groups in New Zealand such as the Breast Cancer Foundation, Breast Cancer Network and Breast Cancer Advocacy Coalition.

## STOP CANCER WHERE IT STARTS BY GILLIAN WOODS

**U**ppfront subscribers will receive the second leaflet in the Stop Cancer Where it Starts series with this newsletter. We hope that readers will find it interesting and even inspiring, and will lend it to other family members and friends to read. The Stop Cancer Where it Starts group has consulted widely in writing this brochure, in order to give you reliable information in a clear manner. Our aim is to give you information that can improve health in the long term, and to present it in a way that does not suggest women are to blame if they get breast cancer. There are many unknowns and things outside of our control. Please ask us for another copy if you would like to give one to your doctor. Any enquiries about the leaflet should be referred to BCN.

There are factors that have been clearly shown to affect the risk of breast cancer and we think it is our job to let women know about these, especially younger women who make life-style choices that will affect their health later on. Expect to hear more about this from BCN as the project progresses.

Some of us have tried the recommended menus and increased our vegetable and fruit intake, and find that it is not impossible to double our daily intake, step up our exercise, and so on. It does, however, take commitment and a firm conviction about the benefits. Many readers have already had breast cancer and the same long-term healthy living approach is an excellent way for us to respond to our disease and treatment.

The next aim of Stop Cancer Where it Starts' is to reduce cancer-causing factors in the wider environment. The next leaflet will give an overview of this plan and what is involved in working with local bodies. We are consulting for this leaflet at present and will call on interested readers to contact us when our Action Kit is ready. In the meantime, we would be pleased to hear from you if you are interested in helping.

Stop Press: We are delighted to have received a grant from the Allison Roe Trust for printing associated with Stop Cancer Where it Starts, and acknowledge with pleasure the interest by the Trust in our project.

## RESEARCH AND NEWS UPDATE

### HIGH LEVELS OF DAILY STRESS MAY RESULT IN LOWER RISK OF BREAST CANCER

High levels of daily stress appear to result in a lower risk of developing breast cancer for the first time, but high stress may put women at risk of other serious illnesses warn researchers from Denmark.

The findings follow an eighteen year study of over 6,500 women in Copenhagen. At the start of the study researchers asked the women what levels of stress they experienced routinely in their lives, and classified the results into low, medium and high levels. Stress was defined as tension, nervousness, impatience, anxiety, or sleeplessness.

In calculating the effects of stress, researchers also adjusted the results for other factors, such as whether they had children or whether they were menopausal, which would have an influence on developing breast cancer. However, they did not account for risk factors such as family history of the disease.

Of the 251 women diagnosed with first-time breast cancer over the study period, researchers found that women reporting high levels of stress were 40% less likely to develop breast cancer than women reporting low levels of stress.

The study further found that, for every increased level of stress on a six-level scale, women were 8% less likely to develop breast cancer.

One explanation for the findings may be that sustained levels of high stress may affect oestrogen levels - which, over time, may have an influence on developing breast cancer.

Despite the findings, the authors warn that stress-induced changes in hormonal balances are not a healthy response, and continued stress may play a damaging part in other illnesses - particularly heart disease.

*Nielsen, N.R. et al., British Medical Journal, 2005;331:548.*

### LONGER USE OF TAMOXIFEN SEEMS TO BENEFIT YOUNGER WOMEN

Any additional survival benefit from using tamoxifen for five rather than two years may not be seen for more than nine years after diagnosis, and those benefits are largely confined to younger, ER-positive women.

The findings are based on a study of 1901 women with early-stage disease who were event-free after two years of tamoxifen therapy. The subjects were then randomized to stop or continue the drug for three more years.

Analysis showed that only ER-positive patients no older than 55 years benefited from longer duration therapy. In such women, a 44% drop in mortality risk was seen, whereas no change was noted in older women. The researchers said that further study is needed to definitively rule-out longer duration therapy in older women.

*M, Belfiglio, et al. Cancer. 2005 Oct 24; [Epub ahead of print].*

### A NEED FOR MORE NEEDLE BIOPSIES, MRI AND LESS INVASIVE PROCEDURES

Physicians should strive to replace traditional, invasive procedures for diagnosing breast cancer with proven, less-invasive diagnostic

methods, according to an international panel of 23 leading surgeons, radiologists, pathologists and oncologists.

They say minimally invasive needle breast biopsies and sentinel node biopsies should be performed more routinely than they currently are. In the case of breast biopsies, the experts say open surgical biopsies should almost never be done.

Consensus panel chair Dr Melvin Silverstein and Dr Henrietta Lee said "we can do things much less invasively than ever before, and doctors and women need to take advantage of these advances whenever they can."

The panel called the less invasive sentinel lymph node biopsy the "preferred method" for accurately staging image-detected breast cancer in most patients. They also concluded that evidence supports the use of magnetic resonance imaging, or MRI, in diagnosing breast cancer, saying that it can be helpful for diagnosis when mammography, ultrasound and clinical findings are inconclusive.

In the area of radiation therapy, the panel concluded that accelerated partial breast irradiation "may allow more patients to undergo breast conserving therapy more quickly, at lower cost, and with less risk of long-term complications."

Finally, the panel recommended that surgeons train in oncoplastic surgery, the combination of plastic surgery and cancer surgery, to help avoid poor cosmetic results and increase the number of women who can be treated with breast-conserving surgery rather than mastectomy.

*Silverstein, M.J., et al., J Am Coll Surg. 2005 Oct;201(4):586-97.*

### BEING BREASTFED PROTECTS AGAINST PRE-MENOPAUSAL BREAST CANCER

The results of a meta-analysis suggest that adults who were breastfed as babies may have a reduced risk of pre-menopausal breast cancer.

The researchers analyzed data from 4379 subjects who were evaluated in childhood in the late 1930s and then followed up through 2003 to assess cancer occurrence. The researchers also performed a meta-analysis of data from 14 studies that looked at the effect of infant feeding on cancer risk. In the meta-analysis, breast-feeding during infancy did not have an effect on the overall risk of breast cancer in adulthood. However, this practice was associated with a 12% decreased risk of pre-menopausal breast cancer.

*J Natl Cancer Inst 2005;97:1446-1457.*

### CO-MORBIDITY AND RACIAL DISPARITY IN BREAST CANCER SURVIVAL

While breast cancer survival rates have improved in the last three decades, racial disparities in breast cancer survival have not improved. A recent US study has found that black women with breast cancer have shorter survival times than their white counterparts, largely because of a higher rate of co-morbidities.

"Diabetes and hypertension are the two most important co-morbidities accounting for survival disparities," study chief Dr. C. Martin Tammemagi from Brock University, St. Catharines, Ontario, said.

## RESEARCH AND NEWS UPDATE

"Effective control of co-morbidities in black breast cancer patients should help improve their life expectancy and reduce survival disparities."

Advanced cancer stage, lack of access to medical care, inferior treatment, and lower socioeconomic status are likely to explain some, but not all, of this disparity.

*Tammemagi, C.M., et al. JAMA. 2005 Oct 12;294(14):1765-72.*

### EPIRUBICIN MAY CAUSE CONSIDERABLE VENOUS SCLEROSIS

Since the introduction of epirubicin to standard adjuvant breast chemotherapy regimens in the UK, many women have experienced venous access problems. In two separate reports in the *British Medical Journal* venous sclerosis was as an adverse reaction to epirubicin was described.

In the first, two women, aged 53 and 55 years, developed pain and restriction of movement of the arm due to venous sclerosis after four cycles of epirubicin 100 mg/m<sup>2</sup> given at 21 day intervals.

Both patients experienced thrombosis and sclerosis of the veins in the arm leading to pain on extension of the elbow due to tightening of the affected veins and puckering of the skin over most of the venous networks in the arm. Similar symptoms developed around the wrist; extension and flexion became painful, lasting more than three months.

The authors concluded that that "venous sclerosis may be more extensive and troublesome than has previously been recognised and that extravasation injury is merely the tip of the iceberg."

Three oncology nurse reported that an audit of 19 women receiving epirubicin revealed that only two patients reported no venous effects. The remaining 17 all reported painful, hard and tethered veins 12 of whom found the lasting effect unacceptable.

*BMJ, 8 Oct 2005;331:816 and Oct 22 2005; 331(7522):966.*

### THE POWER OF EVENING PRIMROSE OIL

Researchers have found that a substance found in evening primrose oil can help dampen down a gene responsible for 30 per cent of breast cancers and could prove a powerful weapon against aggressive forms of breast cancer.

The study, published in the *Journal of the National Cancer Institute*, focused on a substance called Gamma-linolenic acid. GLA, which appears in evening primrose oil, is a fatty acid needed to maintain normal functioning and growth of cells, nerves, muscles and organs.

GLA acts on the same receptor in tumours as Herceptin and actually boosted the effectiveness of herceptin by increasing the response of cancer cells to the drug by 40 times.

Earlier work by the same team showed that GLA also enhanced the efficacy of other breast cancer treatments, including chemotherapy and the anti-oestrogen drug tamoxifen.

Senior author of the study, Dr Javier Menendez said that the work showed that "an inexpensive herbal medicine" might regulate breast

cancer cell growth and help control cancer spread.

However, cancer organisations have been hesitant to sing the praises of Evening Primrose Oil. Hazel Nunn of Cancer Research UK said that "a lot more work still needs to be done, but gamma-linolenic acid or GLA does seem to be a worthy candidate for further investigation in clinical trials."

*Menendez, J.A., et al., Journal of the National Cancer Institute, Vol. 97, No. 21, 1611-1615, November 2, 2005.*

### CURCUMIN HALTS SPREAD OF BREAST CANCER IN MICE

Curcumin, the main ingredient of turmeric and the compound that gives curry its mustard-yellow color, inhibits metastasis to the lungs of mice with breast cancer, report researchers at The University of Texas M. D. Anderson Cancer Center.

The study that the spice appears to shut down a protein active in the spread of breast cancer to a major target for metastasis. Researchers found that the nontoxic natural substance not only repelled progression of the disease to the lungs, but also appeared to reverse the effects of paclitaxel (Taxol<sup>TM</sup>), a commonly prescribed chemotherapy for breast cancer that may trigger spread of the disease with use over a long period of time.

Because Taxol is so toxic, it activates a protein that produces an inflammatory response that induces metastasis. Curcumin suppresses this response, making it impossible for the cancer to spread. In fact, researchers found that adding curcumin to Taxol actually enhances its effect. Curcumin breaks down the dose, making the therapy less toxic and just as powerful while delivering the same level of efficacy.

Extracted from the roots of the curcuma longa plant, curcumin is a member of the ginger family. While it is not used in conventional medicine, it is widely prescribed in Indian medicine as a potent remedy for liver disorders, rheumatism, diabetic wounds, runny nose, cough and sinusitis. Traditional Chinese medicine uses curcumin as a treatment for diseases associated with abdominal pain, and it is used in ancient Hindu medicine as a treatment for sprains and swelling.

*Aggarwal, B.B., et al., Clin Cancer Res. 2005 Oct 15;11(20):7490-8.*



**STOPPRESS STOPPRESSSTOPPRESS STOPPRESSSTOPPRESS STOPPRESS**

## BIKING FOR MONEY FOR THE ENCORE PROGRAMME

Breast cancer survivor, Shelley Hanna, took part in the Lake Taupo Cycle Challenge on the 26th of November to raise money for the YWCA Encore programme. Shelley completed the 160 kilometre ride in six hours and 56 minutes, knocking 33 minutes off her last year's time. We hope to bring you more on Shelley's story in the February/March 2006 issue of Upfront, but in the meantime, if you would like to sponsor Shelley please go to <http://www.fundraiseonline.co.nz/ShelleyHanna/>

## THE PINK DANCE

Ceroc East and South is holding a Pink Dance on 11 February 2006 to raise funds for BCN's National Conference for women who have experienced breast cancer.

Ceroc is French jive, otherwise known as a funky partner dance generally done to chart, nightclub and swing music! There are branches throughout New Zealand, Australia and Europe. While Ceroc is a partner dance, people don't need to bring a partner as people swap as they dance and people don't need to dress up (though some do) as everyone can wear whatever s/he feels most comfortable in. Ceroc burns the calories and keeps people fit!

Rob and Angela from Ceroc East and South ([www.dancer.co.nz](http://www.dancer.co.nz)) run a very good show. It begins with a dance class at about 7:30 pm, where neophytes learn the basic Ceroc steps and then try them out. The more experienced Cerockers arrive later and soon the floor is throbbing and pulsating to dance music and the distinctive Ceroc style.

For more information about Ceroc go to [www.ceroc.co.nz](http://www.ceroc.co.nz). For more information about the Pink Dance contact BCN.

THE PINK DANCE WILL BE HELD AT THE EDGWATER COLLEGE HALL, 7:30 PM SATURDAY, 11 FEBRUARY 2006. TICKETS ARE \$15.00.

## BREAST EVENTS TO COME

- **RUN TO HEAL FOR WOMEN'S HEALTH (ALLISON ROE TRUST):**
  - **26 February 2006 – Hamilton, 5km & 10km Run/Walk at Innes Common - Hamilton Lake, 9.am.**
  - **19 March, 2006 – Christchurch, 5km & 10km Run/Walk at North Hagley Park - Armagh St Bridge, 9.am.**
- For more information go to [www.runtoheal.co.nz](http://www.runtoheal.co.nz) or phone 09 527 2104

**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 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.

PATRON: Lois Muir

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

HONORARY LIFE MEMBERS: Wendy Steenstra-Bloomfield and Barbara Holt

COMMITTEE MEMBERS: Barbara Mason, Dell Gee, Marie Hastings, Megan Anderson, Jenny Clark, Claire Ryan, Denise Flett, Anne Iosefa, Gillian Woods, Barbara Thatcher.

### TO JOIN BCN

To become a member & receive a regular copy of UPFRONT send your name and address to **BCN (NZ), PO Box 62-666, Kalmia Street, Auckland.** \$20 survivors/supporters, \$15 unwaged, \$25 professionals, groups & libraries. **For further information, phone our office on (09) 526 8853 fax us on (09) 526 8860 or email us at [brcanz@xtra.co.nz](mailto:brcanz@xtra.co.nz).**

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Please tick here if you have experienced breast cancer.

Please tick here if you are interested in helping with BCN activities.