

# UPFRONT

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## TALKING TO TREVOR SMITH, BREAST SURGEON

BY SUE CLARIDGE

**Trevor Smith's concerns and outspokenness about some breast cancer issues may make him a bit of a maverick. But this father of two isn't into arm-waving or an aggressive demeanor. Instead he communicates his concerns and his passion quietly and calmly.**

Last November, Trevor Smith published an article in the New Zealand Herald and amid the comments that were bound to stir up the breast cancer community – particularly those who vigorously promote mammograms – perhaps his most important messages were lost.

It was a thought provoking article, and I have to admit, it poked some of the big issues that I'd like to have a poke at. The article came in the middle of our own series on mammography and it seemed like a great opportunity to delve a little deeper and find out what drove Trevor Smith's foray into the popular press.

So here he is...

### ON BREAST DISEASE

"If you go out with an extreme message a lot of people will take it at face value."

"That's the trouble with the current campaign. It says breast cancer is what's going to kill you. YOU'RE ALL GOING TO GET BREAST CANCER!" he says in a voice loaded with capital letters and exclamation marks. He talks about the emotiveness of the awareness campaigns.

"Your mother, your sister, your daughter.

Who will be next." He quotes some of the campaign text from memory, and calls it a campaign of terror.

"Every October I have women of 26, 27, 28 in here in tears, saying 'I have to have a mammogram, I've just read the Next magazine. Look! Here's a 26 year old who is dying!'"

After listening to the symptoms and making a careful clinical and ultrasound examination I say, 'but you've just got some hormonal breast pain. Don't worry.' But 'no, no,' she insists 'I have to have a mammogram.'"

"Where are they getting this message? That a 26 year old with no family history... They are getting it from a campaign that promises that a mammogram can save your life. From a campaign that uses young role models to front their advertising."

Trevor doesn't only treat breast cancer. "Probably one in 20 people I see is a breast cancer patient, the rest have a range of symptoms due to common non-cancerous conditions."

"Ironically, the focus is always on breast cancer, but 90% of breast problems are benign. They had the National Conference on Breast Disease [in Auckland in November 2005]. There wasn't a single talk or poster presentation on anything other than breast cancer," he says, still incredulous. "And yet 90% of the women we see have benign breast conditions – breast pain, cysts, fibroadenomas, mastitis, augmentation, reductions. All those areas of breast pathology were not touched at the conference."

"It is a reflection of this focus on one condition, as if breast cancer is the only thing that ever happens to anyone."



Trevor Smith: passionate about good medicine.

"Look around, see how hard it is to find any information on breast feeding," he says by way of example.

### ON MAMMOGRAPHY

One of Trevor's big beefs with the current campaign is that they imply that mammograms will stop you getting breast cancer.

"If you want to take the comfortable view, you can say that mammographic screening is a good thing. But there is a problem and that is, that mammography is being oversold."

"The campaigns claim that it is the best thing you can do to stay well and healthy.

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Now you don't have to be a lawyer to argue the point that it is overselling it at best."

He points out that we don't know what the benefit of mammographic screening is in New Zealand, because no-one is measuring it. "We can say that perhaps it worked in Sweden in the 1980s, but are we reproducing those results here, and what data have we got and what are we collecting to show that it is working here?"

He suggests that there is another level of discussion in which we could engage: does it work at all? We could start to "unravel those original seven studies, looking at what was measured and what was found." We could argue for a week, he says, with people defending both sides.

Trevor knows that this is not a popular question to ask, not a popular view to take. And when I suggest that he would be pilloried for heading down that track, he doesn't step back from the argument and says that he is prepared to do that, and engage with the medical community over the issue.

"I've written to the *New Zealand Medical Journal* saying... just look at this data. We wouldn't start doing other public health screening on this shaky level of evidence."

"This is the paradox," he continues. "Prostate screening, for example, is discouraged by the same health department, yet many of the arguments against prostate screening apply equally to breast screening."

On the subject of young women having mammograms, Trevor points out that for every young woman with breast cancer (only

about 2% of the total number with breast cancer are less than 30 years old) there is a woman with lymphoma, osteosarcoma, etc., and we are not screening for those. Yes cancer is tragic, but screening everyone is not the solution.

While he is clear that screening mammography is not a solution for young women, he is keen that they should get the message that if you find a lump, or have other symptoms, go and get it properly checked.

#### ON PREVENTION

"There are a whole lot of things that you can do to reduce your long term risk of getting breast cancer. Which, of course, spills over into all the other diseases [cardiovascular disease, diabetes] as well. So you are getting an exponential benefit from your prevention measures; it's not breast cancer specific."

Clearly Trevor is horrified by some of the claims in the breast cancer information provided to women...

"It says in those pamphlets: 'Unfortunately, there is little that women can do to reduce their risk of cancer...' This is the other problem with the campaigns."

He is emphatic: "There *are* things that you can do, that not only reduce your risk of breast cancer but a whole host of other, equally life threatening diseases."

Trevor rates diet as one of the biggest things which contribute to disease, including cancer. "When you actually sit and talk to people about what they eat and how they

eat, you realise how little attention we pay to such a fundamental thing as what you put inside you. Compare that to the effort we make to... go and have mammograms, for example."

A one off mammogram every two years takes less effort than addressing what you eat every day of your life. But it doesn't have to be too complicated or onerous:

"Just eating less and exercising more would be a jolly good start for most people," he says. "Then we can start looking at things like anti-oxidants, selenium, folic acid, etc."

Smoking is another concern:

"I saw a woman come in for a mammogram and she was so stressed that she stood out side having a cigarette." He laughs at the irony. "You know this message is not getting through. Throw your cigarettes away and don't come for a mammogram because that will do you much more good than smoking *and* having a mammogram."

"These are things that can be tackled. To have any message suggest that there is nothing much you can do for your health, other than go and have a whole lot of tests. It's shocking. To me it's a failure of the medical system. And I really feel very strongly about it."

Ahh. That's what we need. People who feel strongly about things who are prepared to stand up and say so, people who are not afraid to challenge the sacred cows of medicine. Passion and sense.

## BCN COMMITTEE CALLING

**B**CN Chairperson, Barbara Mason, puts out the call for more to be involved.

Breast Cancer Network needs more members on the National Committee. At present we are a committee of seven.

It is an exciting and busy time for BCN with our major projects, the forthcoming national conference in October 2007 and Stop Cancer Where it Starts, underway now. However, committee members are not expected to be involved in all of BCN's activities. Some of you may have had a phone call from me suggesting you come to our May 10th Committee meeting to meet the present committee and see how the meetings are conducted. Hopefully there are others who would like to come.

If this is for you please contact our administrator, Jennifer Woodroffe, telephone 09 526 8853 or email [brcanz@xtra.co.nz](mailto:brcanz@xtra.co.nz) or phone me in the evenings 09 625 4186. Our committee meetings are held in the evening of the second Wednesday of the month at Bakers Delight, 626 Great South Road, Greenlane. Do let us know beforehand if you intend to be with us at the meeting on May 10th so that we can arrange entry to the Bakers Delight building.

*We could also do with some more Upfront proofreaders to join our dedicated team. If you have an above average command of English, regular email access and an interest in proofreading please get in touch. Copy is sent by email and it is preferable that the corrected copy is returned by email. Usually you will have about five days, but occasionally this is cut to two in order to ensure that Upfront comes out on time. Please contact the BCN office or Sue Claridge on 09 4452 966.*

**THE BREAST CANCER NETWORK THANK THEIR SPONSORS:  
COGS, Lottery Grants Board, Neville Newcomb and Nike Women's Challenge**

## From the Editor ....

Women around the country are waiting on tenterhooks for news that Herceptin will be funded for women with early breast cancer. However, it looks like it will be a long wait – another three to four months until PHARMAC makes a decision and, if they decide to fund it, a similar amount of time until it is actually listed on the schedule and available to women.

This is a big issue and I have again devoted a decent amount of column space to Herceptin. There are a bunch of very dedicated women – Anne Hayden with her petition, Libby Burgess from BCAC, Nic Russell turning her grief over her daughter's death into campaigning energy – who, together with many other women from around New Zealand, have fought long and hard to ensure women who may benefit from Herceptin don't have to mortgage their homes to get it.

Some readers may wonder why I have included a piece on the thoughts of some medical professionals who are, to date, less than enthusiastic about Herceptin. Time may very well change their views, as further studies clarify the long term effects and benefits of Herceptin, but in order for women to be fully informed, it is important to hear both sides of the story.

Personally, I am torn between the hope that this treatment – a monoclonal antibody, not a drug per se – will offer some women the chance of a longer and healthier life, and the suspicion that we need longer studies before we can be so sure that it will do what Roche says it can do. It is only a few years since aromatase inhibitors were touted as the closest thing to a cure for breast cancer, and despite the survival benefit we are also starting to see more side-effects from these drugs.

We all need hope; hope that there will be a cure out there for us, now, when we need it, that there are treatments that give women with breast cancer a real shot at survival. Importantly we also need to understand what the risks are. In the case of Herceptin the evidence to date suggests that most side effects are not serious, but there is the risk of serious heart effects for a few women. We need to push past the media hype, and the hyperbole from those who stand to gain financially from sale of Herceptin and equip ourselves with all that there is to know about this treatment – the real risks and the real benefits.

*Sue Claridge*



## LETTERS

### GETTING FLEECE

While my reason for wearing a wig is not as a result of chemotherapy, I nonetheless feel empathy with those who are obliged to seek the assistance of a wig supplier.

With my first excursion, two years ago, I tried on several types and styles and eventually settled for a short but stylish blonde little number that really did take years off me. I cannot put into words the boost it gave to my confidence as everyone who knew me remarked on my stylish new haircut!

Alas, the downside was that the average sized wig was far too small for my jumbo sized head. Despite my protestations, the saleslady assured me that wigs came in one size and were elasticised to stretch to fit everyone. So for the next 22 months I struggled with a wig that was too tight. The wig would inevitably recede from the edges as the day wore on and I was constantly having to wrench the thing down.

So, with a degree of trepidation, I recently ventured into a different Auckland wig shop and asked if they could supply a larger wig.

A similar line exhorting the virtues of a one size fits all policy were advanced but with a reassurance from the sales assistant that they would alter wigs to fit. I was unhappy with the idea that something with a stretchy spiderweb base would be chopped about so I deferred making a decision. One or two less than flattering comments about the wig I was wearing was, I assume, a call-to-action, but I was having none of it as they were charging up to \$200 more than what I had previously paid for the same brand of wig.

That night I did a little research on the internet, and lo and behold I found a company in the US that not only supplied the brand of wig with which I was familiar, but with a range of colours and a restricted number with size options from petite to large! Equally pleasing was the fact that while I had originally paid around NZ\$350 for a Gabor wig and more recently been offered the same brand from NZ\$450 - \$550, I was now able to buy a new wig online for US\$69.00! By the time air freight charges had been taken into consideration, the all-up cost was well below NZ\$200.

It was 10 days from the time I ordered my new wig until the courier delivered it. The new wig is more trendy and fun than the previous and fits like a glove. For the first outing I was able to comb it into my old style whereby the only comments I received were from people saying how much they liked my new hairdo! However, I will

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gradually allow the more casual look to emerge rather than impose a radical change.

The final bill of \$144 including freight costs for my wig has just shown up on my credit card. According to my schoolgirl math, Kiwi ladies are being fleeced to the tune of 400 - 500%.

To those ladies who have no choice but to visit a wig shop, I urge you to do a little homework on the internet first.

**Name withheld by request**

**DRUGS, SIDE-EFFECTS AND MEMORY LOSS**

I was delighted to see in your Dec-Jan issue that Mr Ian Campbell, Waikato Breast Surgeon, refers to some arguments I made in a letter you published about why I am not taking Arimidex (Aug.-Sept issue). He probably did so because of material you printed about some doctors also thinking the Aromatase inhibitor drugs are being used too soon, too widely (Oct.-Nov. issue).

I notice he did not refer to my memory loss argument. Perhaps it is thought women who have had breast cancer don't need good memories. But I actually find memory loss my most debilitating condition, the next being lymphoedema caused by surgery twice and radiotherapy on the same site and the removal of underarm healthy lymph nodes. The on-going pain makes it impossible ever to forget I have had breast cancer, even when fully clothed.

I think it is good that women now know, after reading Ian's letter, that we are being told to take a drug for which long-term effects, other than osteoarthritis, are not yet known. This is being done in many cases on the chance that it will increase our survival from metastases which we may never have. That recalls for me the excellent programme on breast implants shown on TV1 this week [Feb 2006], made by the BBC. It showed women with normal healthy breasts repeatedly being offered by surgeons different kinds of implants, despite all these being suspected of producing serious adverse reactions in some women. It was claimed these [adverse reactions] could not be proved as being caused by the implants.

**Barbara Holt, Wellington**

**PAGETS, PALS, AND POEMS**

I thought I would send some poems a friend has written for me, at each stage I have gone through with the second lot of breast cancer.

I just wanted to say how wonderful my friends and family have been with the support, love and caring they have given me as I fight this second battle. They are always there for me and it makes each day go quicker and we have so many laughs about things that would be easier to cry about. I'm sure all readers will agree with me that their support is the reason to go on fighting.

I am about to have my second chemotherapy this week (December 2005) and I am half-way – wonderful!

I had infiltrating ductal carcinoma in '97 and thought I was "cured". This year I had Paget's disease with infiltrating carcinoma Grade 2 ER/PR negative – mastectomy in August '05. So the first poem was after the mastectomy and the second poem after I lost my hair [see page ??]. I'm sure I will have further poems written about me.

Thank you for a wonderful magazine full of knowledge and hope.

**Gay Jarret, Stoke, Nelson**

**GAY ACTIVITIES**

I know a cat lady who has something that's missing,  
Wonder if it's the result of too much fondling 'n kissing?  
By nature she is happy and by name she is Gay,  
She had an operation that left her leaning over one way,  
Now we get down to the real nitty gritty,  
So this is the tale of not two, but one titty!!

**HAIR TODAY, GONE TOMORROW**

This is such a brave courageous woman, she really doesn't care,  
She's ripped out all her lovely locks and left her head all bare!  
The flies will have a skating rink to slither and slide all over,  
And the burrs won't stick to it when she's rolling in the clover!  
Looks just like smaller girly, Yul type shorter Brunner,  
But to us, this girl will always be a simply lovely stunner.  
Bald, hairy, fat, thin, we'll all love her just the same,  
And battle alongside of her as she fights to win the game.

**By Noleen Burton**

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

**BREAST CANCER RESEARCH TRUST ANNOUNCES NEW GRANTS**

**T**he Breast Cancer Research Trust has announced new research grants worth more than \$380,000. The recipients are Dr Rhonda Rosengren, Senior Lecturer, University of Otago and Dr Raymond Simpkin, Senior Scientist, Industrial Research Limited.

Dr Rosengren's research into novel therapies for estrogen receptor negative breast cancer will receive a grant of \$133,000 during the next two

years. The research into the use of hormones for controlling growth of breast cancer cells seeks to identify anti-cancer and anti-growth properties. It is proposed to use these compounds in early clinical trials in women with breast cancer. A PhD student will perform much of the research and write a thesis.

Dr Simpkin's work on the use of radar scanning for the early detection of breast

cancer will receive funding of \$250,000 during the next two years. His work is assisting the search for a new screening tool to replace mammography, which currently misses 20% of breast cancers. The aim is to build a smaller prototype of the current research prototype which is being used in clinical trials to identify breast cancer in women.

**BCN Annual General Meeting**

**WEDNESDAY, 24 MAY, 7.30PM, DOMAIN LODGE, AUCKLAND CANCER SOCIETY, 1 BOYLE CRESCENT, GRAFTON, AUCKLAND. FOLLOWING THE AGM, DR JACKIE BLUE, MP FOR NATIONAL, AND SUE KEDGLEY, MP FOR THE GREENS, WILL SPEAK ABOUT BREAST CANCER ISSUES. THIS WILL BE FOLLOWED BY QUESTION TIME.**



## HERCEPTIN REVISITED

BY SUE CLARIDGE

### WHERE IS THE FUNDING?

Medsafe, the regulatory arm of the Ministry of Health, announced on Thursday March 23, that it had provisionally approved Herceptin for the treatment of some "women with early breast cancer who test positive for the HER2 gene once they have had surgery and completed their adjuvant (additional) chemotherapy."

Medsafe have restricted its use to women who have a normal heart function before treatment starts and requires women using Herceptin to have their heart function checked by echocardiogram every three months during treatment."

Medsafe's principal technical specialist, Dr Stewart Jessamine, says New Zealand is the first country to have its medicines regulatory authority to assess and approve Herceptin as a treatment for primary breast cancer. He went on to say that "further data examining the overall safety and effectiveness of Herceptin in the long term is required before Herceptin can be considered for full consent."



Anne Hayden: passionate about funding.

PHARMAC has publicly welcomed Medsafe's approval of Herceptin, saying that it is "in a good position to move forward."

"We have already moved quickly to examine the preliminary data. The next step is to obtain advice from the cancer treatments sub-committee, and a final recommendation from PTAC," said Dr Dilkey

Rasiah, a PHARMAC spokeswoman.

In a press release issued by PHARMAC immediately after the Medsafe announcement Dr Rasiah said that, "in addition to the clinical data, an economic analysis of Herceptin and the total budgetary cost will also be important factors for PHARMAC and DHBs to consider. Because Herceptin is a drug administered in hospitals, it would be funded from DHB hospital budgets."

"At this stage we can't guarantee that Herceptin will be funded. We have to determine if the clinical data and cost-effectiveness stacks up. If it does, we then have to reach an agreement with the supplier, Roche, that could make it affordable for DHBs. Finally, DHBs will have to decide if this is something they can afford."

The *NZ Herald* reported that Herceptin would be "referred directly to PHARMAC's cancer sub-committee, scheduled to meet in April, and then back to PHARMAC's advisory board for a final recommendation when it meets in May."

In an interview with TV3 News Dr Rasiah said that if funding was approved we can expect that the treatment would be listed on the pharmaceutical schedule, and hence available to women with early breast cancer, in October 2006.

However, Minister of Health, Pete Hodgson, while enthusiastic about Herceptin, told National Radio that the treatment cost too much but he was sure the price would come down, adding "it will have to." He said that the question was by how much and that PHARMAC would negotiate with Roche, but New Zealand would not pay \$30 million a year for it.

BCAC's spokesperson, Libby Burgess, told the *New Zealand Herald* that approval of Herceptin was a "huge relief" but she was clearly disappointed and concerned that, even if funding was approved, women would have to wait until October to get it.

### PETITIONING PARLIAMENT

Devonport woman, Anne Hayden, kept wondering when someone was going to start a petition asking the Government to fund Herceptin for early breast cancer. No one did! So Anne did it herself and, with the support of BCAC and BCN, in eight weeks she



Anne presents the petition to Dr Jackie Blue, MP

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got almost 18,000 signatures. On Thursday March 16, Anne and a group of supporter's including breast cancer patients Nic Russell, Mangalika Mendis and Aletia Hudson, and Libby Burgess from BCAC, presented the petition to Dr Jackie Blue, MP for National, on the steps of Parliament.

In her speech Anne told the gathering "this petition has shown in a mere eight weeks, how New Zealanders value their women, because this is primarily a women's disease. When these almost eighteen thousand people signed, they were thinking of their mothers, aunts, grandmothers, wives, girlfriends, or daughters... Surely nearly

eighteen thousand people can't be wrong!"

Dr Jackie Blue told *Upfront* it was "a very powerful day."

"There was across-party support and I think that the political will is there to move this along and find the funding," she said. "[The petition] was important, it made an impact and I believe it will make a difference."

## IS IT THE CURE WE SO DESPERATELY WANT IT TO BE?

**W**ith all the hype and the hope it is hard for many women to understand why PHARMAC appear to be less than enthusiastic about it, why they aren't fast-tracking funding to ensure that the women who want Herceptin can actually get it.

Despite the enthusiasm of Roche, the makers of Herceptin, the media and many of the doctors who work with Her2 positive women, there are medical professionals who have urged caution.

Dr Ralph Moss, in his report *Herceptin or Deceptin*, writes that "the orthodox medical profession, traditionally averse to outbursts of hyperbole, seemed to lose all sense of proportion. Adjectives such as "revolutionary," "stunning," and "jaw-dropping" were used by some doctors to describe the latest findings. Even the word "cure" - long taboo in oncology circles - suddenly re-emerged." Dr Moss admits that the trials of Herceptin for early breast cancer "do represent an advance in the treatment of a minority of women with early-stage breast cancer." However, he emphasises that "it is a modest and qualified advance, and one which falls far short of the promotional hype that has been unleashed by the publication of these studies."

One of the most important issues covered by Moss in his paper is one that seems to have been largely ignored by the media and those pushing for funding. What women want is to survive breast cancer. What they really want is to live for years, to watch their children grow up and to be long-term members of our communities.

In the study led by Dr Piccart-Gebhart, and published in the *New England Journal of Medicine* (NEJM) study, there were 37 deaths overall in the observation group (2.2 percent) compared with 29 deaths (1.7 percent) in the group receiving Herceptin for one

year. Ralph Moss writes that "adding Herceptin to chemotherapy conferred no meaningful survival advantage in this patient population" and the authors of the study wrote that "overall survival in the two groups was not significantly different."

Other studies have shown similar, albeit slightly improved, survival benefit in the Herceptin groups. See the two tables below for a comparison of the rate of recurrence, the number of women who died, and the relative and absolute risk reduction in each of the two trials reported in the NEJM.

In the Romond study, at the completion of one year of treatment less than two women per hundred treated are alive that would otherwise have died. At the completion of one year of treatment seven women per hundred treated are disease free that would otherwise have a recurrence.

In the Piccart-Gebhart study, two hundred women would need to be treated for a

year before one woman survives that would otherwise have died within that year. At the completion of one year of treatment five women per hundred treated are disease free that would otherwise have a recurrence.

Although Ralph Moss may be seen as something of a cancer treatment maverick, he is not the only one to pour cold water on the Herceptin hype. An editorial in the *Lancet* said that "the best that can be said about Herceptin's efficacy and safety for the treatment of early breast cancer is that the available evidence is insufficient to make reliable judgments. It is profoundly misleading to suggest, even rhetorically, that the published data may be indicative of a cure for breast cancer."

Alan Cassells, co-author of the book *Selling Sickness*, and a drug policy researcher at the University of Victoria, also has concerns at the way in which Herceptin is being marketed to vulnerable women wanting a

**From the Romond paper (NEJM, Volume 353:1673-1684 October 20, 2005). Observation at the end of one year of treatment:**

	Control Group	Study Group	Relative Risk Reduction	Absolute Risk Reduction
Participants	1679	1672		
Deaths	92	62		
Deaths as %	5.4%	3.7%	31.5%	1.7%
Recurrence	261	133		
Recurrence as %	15.5 %	7.95 %	48%	7.55%

**From the Piccart-Gebhart paper (NEJM, Volume 353: 1659-1672 October 20, 2005). Observation at the end of one year of treatment:**

	Control Group	Study Group	Relative Risk Reduction	Absolute Risk Reduction
Participants	1693	1694		
Deaths	37	29		
Deaths as %	2.2%	1.7%	23%	0.5%
Recurrence	220	127		
Recurrence as %	13 %	7.5 %	42%	5.5%

cure. He makes the distinction between lack of recurrence – which is driving the Herceptin hype – and the ultimate goal of survival, which is what a “cure” really is, and also has concerns about the rate of cardiotoxicity:

“For every 100 women getting Herceptin, between two and four more will survive, but three more women will also develop congestive heart failure while on this treatment, which is also potentially fatal. Hmm, still a wonder drug? Should we be paying \$40,000\* a year to maybe help one in a 100 women who have this type of breast cancer?”

Additionally, the *Lancet* criticised the methodology and conclusions of the two studies published in the *New England*

*Journal of Medicine (NEJM)*. The Herceptin doses, and when they were administered to participants, were different and this made comparisons between the studies difficult.

Both the *Lancet* and Moss raised concerns about the heart damage that Herceptin can cause. Although the studies found a relatively low percentage of women were affected, they also rigorously screened participants. Herceptin was already known to have a toxic effect on the heart muscle and the researchers did everything they could to reduce the incidence of cardiotoxicity and screened out any woman who had prior signs of heart insufficiency. It is reassuring to know that Medsafe have addressed this issue and that New Zealand women will

be tested regularly for heart function.

Health economists have also weighed into the debate. In a paper in the *Annals of Oncology*, Mattias Nyet and colleagues said that “the question is not whether a technology is cost effective in itself but whether it results in better outcomes than a certain comparator or benchmark.”

While Herceptin will give some women a very real chance of a better and longer life. Unfortunately, not all Her2+ women will benefit, and women contemplating having this treatment, however it is funded, should be making truly informed decisions about this treatment.

*\*A conservative figure and in Australian dollars..*

## GOING PRIVATE – CAROL'S STORY

BY SUE CLARIDGE

Carol Mitchison has breast cancer. When she was diagnosed her sister undertook some research on breast cancer treatment on Carol's behalf, and found out about Herceptin. Although Carol didn't think Herceptin would be an option she did ask her oncologist about it and discovered that she was Her2+.

The stumbling block was, as for most women, cost. And there was another problem. Carol lives in Gisborne. The crazy thing is that, while women whose Herceptin treatment is funded (because they have metastatic disease), receive their treatment at Gisborne hospital, Carol has to travel to Palmerston North every three weeks to get hers!

This isn't some nasty trick. These are the rules. If you pay for Herceptin and get it as a private patient you have to have it administered in a private oncology unit. And guess what – Gisborne doesn't have a private oncology unit. Oh, it has private hospitals, but no private oncology unit and the nearest one is in Palmerston North - which is where Carol has to go, every three weeks.

Never mind that Herceptin is administered by IV and the local doctors or nurses could do that. Never mind that the local hospital is happy to do it, and does do it for public patients. They just are not allowed to. Those are the rules.

Carol is philosophical about the situation. She feels fortunate that she has managed to pay for it privately and, although she says there was no community fundraising involved, she'd rather not



Carol receiving her Herceptin,  
accompanied by Cheryl

discuss the details. She did admit that it was a very difficult decision to spend that amount of money – a sense of guilt, perhaps – but she has a sixteen year old daughter and being around for her is a priority, as it would be for any mother. And the cost provided a very real incentive to go to the gym and get into shape after the chemo. After all, the five kilos she lost saved her \$12,000.\*

When I spoke to Carol she had literally been home for only an hour after her sixth 900 km round trip to Palmerston North. She must take two days off from her job as the administrator at the Gisborne REAP. She has a very sympathetic employer - “absolutely wonderful”

“They have been fantastic, very supportive,” she says.

Carol is very upbeat despite the weariness from her latest journey. She stays at the Cancer Society owned Ozanam House in Palmerston North, which saves her money. Her oncologist, Richard Isaacs is great and she is getting the treatment that may give a better chance of survival.

But it is still a long journey to make on top of the stress of the last year battling this disease. It's a trip she mostly makes on her own. Between when I spoke to her and when *Upfront* is printed she will have made another two trips down the east coast and across to Palmerston North. There are another nine to go!

*\* Herceptin doses are calculated on the patient's weight so the heavier you are the more Herceptin is needed and the greater the cost.*

## THE RISKS OF LIVING DOWNSTREAM

### A Stop Cancer Where it Starts Update BY GILLIAN WOODS

**T**he second Stop Cancer Where it Starts leaflet was included with the December issue of *Upfront* and was also referred to a number of health practitioners for comment. Thank you to those who replied – further comments from our readers would still be appreciated. Replies indicated that the leaflets would be welcome in a number of women's health clinics; an ideal place to offer information about breast cancer risk reduction to well women. We would be pleased to supply readers with leaflets, to be placed in situations where younger, well women can access the information. Contact us if you know of a suitable place.

Our sub-committee is now preparing a resource kit for use in approaching local bodies to clean up local environments. It is heartening to hear that in Canada more than 80 cities and towns have banned "cosmetic" spraying of lawns, in an effort to reduce their citizens' exposure to toxic chemicals. In the UK a very interesting website – [www.nomorebreastcancer.org.uk](http://www.nomorebreastcancer.org.uk) – is

**"A narrow focus on lifestyle – like a narrow focus on genetic mechanisms – obscures cancer's environmental roots. It presumes that the ongoing contamination of our air, food, and water is an immutable fact of the human condition to which we must accommodate ourselves."**

Dr Sandra Steingraber

Living Downstream: An Ecologist Looks at Cancer and the Environment  
Virago UK 1998 p262

sharing information about the influence of environmental chemicals on breast cancer risk. In the USA, two large breast cancer organisations are working to raise awareness of the environmental links to breast cancer, and taking long term action to get this risk reduced. Information from the Breast Cancer Fund can be accessed at [www.breastcancerfund.org](http://www.breastcancerfund.org) and from Breast Cancer Action at [www.bcaction.org](http://www.bcaction.org). These groups have funded a major report called *State of the*

*Evidence*, edited by Nancy Evans, available on the Breast Cancer Fund website. We recommend this report for its thoroughness and balance.

Recent contact with La Leche League has been encouraging; BCN has common ground with this group of dedicated younger women. La Leche promotes breast feeding as beneficial to both baby and mother, and their volunteers give assistance to women who are breast feeding. The key point that both organisations agree needs to be widely known, is that breast feeding up until the age of about 30 reduces the mother's breast cancer risk. Some research suggests it reduces risk for the baby in later life as well. We think it is disgraceful that breast milk world-wide is contaminated with man-made toxic chemicals. Even so, research consistently shows it to be best for baby's health in many ways.

*If Stop Cancer Where it Starts is of interest to you, we would love to hear from you. Please contact us at the office on 09 526 8853 or ring Gillian on 09 489 5470.*

## WEBSITES TO WATCH

**[WWW.PEDIATRICS.WISC.EDU/PATIENTCARE/BREASTCANCER](http://WWW.PEDIATRICS.WISC.EDU/PATIENTCARE/BREASTCANCER)**  
**[WWW.MYPARENTSCANCER.COM.AU](http://WWW.MYPARENTSCANCER.COM.AU)**

These two websites approach the same issue from different directions.

The first, a University of Wisconsin Medical School webpage on common child reactions to breast cancer and how to help provides information for adults on how to talk to children about their mother's breast cancer. It includes information on common reactions, how to approach the subject with different aged children, the impact on teenagers and what needs to be discussed with the daughter of a mother with breast cancer and what she needs to know as she grows into adulthood. The site is easy to navigate, uses straightforward language and ideas, and has numerous links and additional resources.

The second site, My Parent's Cancer, is a resource for children whose mum has breast cancer. It has sections that cover the sorts of questions children of all ages will have: What is cancer? What will happen? What about me? Personal stories, poems and discussing grief are also included. There is a glossary of medical jargon, links to other sites and resources. The site even has the option of a blue or pink style... It is an easy to navigate, well set out site that is designed with children in mind, and was clearly compiled with input from children whose parents have cancer. Although it is aimed at young people facing the trauma of a parent's illness, it would also be very useful for a parent needing to communicate with their children about breast cancer.



## MAGGIE IS STILL WAITING

**MAGGIE PIMM IS STILL WAITING FOR HER NEW BREAST. SHE HAS BEEN WAITING SINCE DECEMBER 2004.**

**U**pfront told Maggie's story in our December 2005 issue (*Upfront* 64). At that time we spoke to a number of health professionals about the delays in delayed breast reconstruction. Clearly, pressure on the health dollar is behind such problems; there is a constant demand for plastic surgery services and women with breast cancer are competing for these services along with other deserving New Zealanders.

However, it is also clear that women who required delayed reconstruction, because of the post-mastectomy treatment they must have, are being unfairly disadvantaged when compared to women who can – and do – have reconstruction immediately after their mastectomy. In fact, this inequity is Counties Manukau District Health Board policy as evidenced by a letter from Gordon Davies, Deputy Director General, DHB Funding and Performance in the Ministry of Health. In his letter, Mr Davies said "CMDHB advises that the higher priority groups for plastic surgery include: immediate breast reconstruction for breast cancer." Delayed reconstruction patients are not on their priority list.

When I spoke to Maggie in March she was angry. She does not understand why some women have had the operation, while she still waits. She feels she has been "fobbed off" by the health authorities, including the Minister of Health, Pete Hodgson, and the lack of progress is leaving her depressed. It is clear from Mr Hodgson's letter to Maggie, that his understanding of the problem is limited and it seems he has not had the best advice from his staff – he seems to think that it was Maggie's choice to delay reconstruction rather than it being forced upon her by the advanced stage at which her breast cancer was detected.

His February 2006 letter also told Maggie that only four women had had delayed reconstruction surgery at Middlemore since April 2005, but he would



Dr Jackie Blue

not say how many women had been removed from the waiting list.

Dr Jackie Blue, Breast Physician and now a member of the National Opposition, was horrified when she heard the details of Maggie's story and the way in which she has been treated. "They have just treated her as a number... No wonder she is hopping mad," Jackie said.

"I can see why [Maggie] is so unhappy," she continued. "She has had delayed surgery deliberately because of her condition, in fact, she has followed the orders and been very patient. And then she was bumped off the waiting list – that's not right."

"[Maggie] hasn't completed her surgery yet," Jackie said, clearly implying that reconstruction was part of Maggie's treatment, not merely cosmetic. "No wonder she is angry and frustrated."

*Upfront* asked all four hospitals doing breast reconstruction under the public health system what their figures were for the operation and how many women were on the waiting list. At Middlemore a number of women have been removed from the waiting list and some of those were then reinstated although exact figures were not available. Currently 13 women are on the waiting list. Waikato have 135 women on their waiting list and removed a further 33. Hutt Valley hospital have 46 women on the waiting list and none have been removed or referred

back to their GP. Christchurch did not respond to our request for information

However, it may be unfair to make such a direct comparison. Annie Tyson, Clinical Manager at Middlemore, points out that their plastic surgery department is different from the other three hospitals. Middlemore serves a considerably larger population and has a very high acute surgery load. These are patients who require immediate surgery (e.g. burns patients) and because of this elective surgery is delayed. In other areas the waiting lists are smaller simply because the hospitals serve smaller populations and don't have the same high level of acute surgery cases

Annie says that staff at Middlemore are concerned that they have to choose between one patient group and another. They don't like this situation and would like to be able to provide women with their breast reconstructions, but they simply do not have enough resources, particularly in the way of doctors with sufficient expertise, to carry out more operations.

The national scoring tool for plastic surgery is what is keeping Maggie from having her operation – she doesn't score highly enough. Pete Hodgson acknowledged that the scoring system needs review and that there are "marked differences in the way that the scoring tool is being used." Annie Tyson indicated that the review will be undertaken this year, and Alison Barber of the Ministry of Health advised *Upfront* that the review would be guided by medical ethics and best practice principles of transparency, evidence-based, procedural fairness, consistency and reliability.

Although the Ministry of Health have placed the responsibility for deciding who gets priority for plastic surgery squarely on the shoulders of the District Health Boards (DHBs). Irrespective of any review, those decisions are driven by a lack of resources. It is simply not good enough for the MoH to blame the DHBs for the waiting lists when the funding comes ultimately from the government. The DHBs are simply doing the best they can with the limited resources available to them. The bottom line, as always, is that there is not enough money to go around.

## **ANCHORS AWAY FOR ENCORE!**

BY JANE BISSELL

### **THE YWCA ENCORE EXERCISE PROGRAMME IS SETTING SAIL FOR NEW HORIZONS.**

**Y**WCA Encore is an exercise programme designed for women who have experienced breast surgery at any time in their lives. Gentle floor and pool based exercises, conducted within a safe, secure and fun environment, rebuild flexibility and strength. Participation in the programme can also help restore the self-esteem and confidence that is often lost after surgery for breast cancer.

Already well established in Australia, the programme has been running in New Zealand for a year but only in Hawkes Bay and Auckland. That is set to change following the success of a YWCA Encore Coordinator Training Course held in Auckland in February. Fifteen new coordinators will soon be introducing the programme to communities from Kerikeri to Christchurch. This is an accomplishment NZ Encore Programme Manager Marlene Sorby is rightfully proud of.

"I am absolutely confident that the integrity and professionalism of the Encore programme is assured with these fifteen wonderful new coordinators," said Ms Sorby. "Planning for the training course – the first to be held in New Zealand – took several months. It is a new programme and the group from which to draw participants was not large. But it was a great success, and we are so grateful to The New Zealand Breast Cancer

Foundation for their financial support which helped make the training a reality."

Nicole Kinnear, National Programme Manager for Australia, supported the Auckland course. "YWCA Encore attracts the most remarkable and dedicated women as

Training Manager/Australia.

Over the four days, participants learned how to set up, publicise and run a programme, and became familiar with the floor and pool exercises. Guest speakers offered information on breast cancer surgery, lymphoedema, grief and loss, and group management. The fifteen were then assessed on their exercise work and received a course completion certificate at the end.

"I am amazed at what a bunch of resourceful and energetic women we are," said Ms Cummins. "Watch this space. Encore is set to become a household name!"

Ms Sorby has plans for a second training course in 2007 and a coordinators' conference in 2008. She hopes to deliver 20-30 courses in ten centres nationwide during 2006,

adding five more locations in 2007.

So it's 'anchors up and hoist the sails' as YWCA Encore sets a course for new ports of call. This growth will bring opportunities for more women to access the physical and emotional benefits the programme offers, so providing another invaluable support for the recovery from breast cancer.

For information about YWCA Encore and programme schedules, please check the YWCA website, [www.akywca.org.nz](http://www.akywca.org.nz) or call 0900 36267 or (09) 375 9249.



The Encore course participants including Marlene Sorby, Julie Cummins, Jane Bissell, Mary Macheras-Magias and Nicole Kinnear in the front row.

coordinators," said Ms Kinnear. "The new team in New Zealand is no exception. The four-day training course was rigorous and intense but the overwhelming desire to bring the programme to their local communities saw the coordinators take on the challenge in a most positive way. We are delighted to see that YWCA Encore, and breast cancer survivors in New Zealand, will be in such good hands."

The fifteen women were instructed by NZ National Encore Trainer Julie Cummins and Mary Macheras-Magias, National Encore

## **BREAST EVENTS TO COME**

- **30 April, 2006 – Run to Heal for women's health (Allison Roe Trust)** – Auckland, 5km & 10km Run/Walk at Auckland Domain Bandstand, 8.45 am. For more information go to [www.runtoheal.co.nz](http://www.runtoheal.co.nz) or phone 09 527 2104.
- **10 June, 2006 – Breast Cancer Advocacy Coalition Forum**, Tamaki Campus. For more information contact Claire Doole, phone (09) 378 7684 or email [the.claire@xtra.co.nz](mailto:the.claire@xtra.co.nz).
- **30 June 2006 – Breast Cancer Research Trust Fire and Ice Ball**, 7:00 pm at the Langham Hotel, Auckland, Tickets: \$195.00 per person. To purchase tickets please contact Caroline Ocego on 09 845 5603 or 0800 227 828 or by email [bcrf@etconline.co.nz](mailto:bcrf@etconline.co.nz).
- **Community Breast Health Seminars** – New Zealand Breast Cancer Foundation educational presentations on breast health awareness: 10 April – Alexandra, 11 April – Twizel, 12 April – Wanaka, 3 May – Manukau, 4 May – Pakuranga and Papakura, 2 – 4 May – Christchurch, 9 May – Whangarei, 10 May – Kerikeri and Paihia, 11 May – Wellsford, 16 and 17 May – Waiheke Island, 30 May – Glenfield, 31 May – Takapuna, 1 June – Browns Bay. For more information and a list of venues go to [www.nzbcf.org.nz](http://www.nzbcf.org.nz), phone 0800 902 732 or email [enquiries@nzbcf.org.nz](mailto:enquiries@nzbcf.org.nz).
- **26-28 October 2007 – BCN National Conference for Women with Breast Cancer**, Grand Tiara Conference Centre, Rotorua. Contact BCN for more information or go to [www.breastcancernetwork.org.nz](http://www.breastcancernetwork.org.nz) for updates.

## THE PINK DANCE

BY MARIE HASTINGS

What a marvelous night we had at the Ceroc Pink dance.

Rob and Angela, of Ceroc East and South held a fundraising dance for BCN on the 11th of February, and we all had such a lot of fun. Everyone got into the pink theme: men had pink t-shirts, nail polish, pink pegs on their shirts or in their hair, and one man even sprayed his beard iridescent pink! Along with the ladies in their pink sparkly tops, it was quite a sight. Jeff was a character – he wore a blow up suit with a pink tutu and pink pegs in his hair and danced all night.

In the beginning Rob and Angela taught us all how to dance Ceroc. All ages and dance abilities joined in. There were some very good dancers who were great to watch, while the BCN ladies were selling tickets, cold drinks and sausages from the sausage sizzle, as well as dancing occasionally themselves.

Thanks to Rob and Angela's generosity, Vodafone and BCN volunteers the evening was a huge success on every level. Rob auctioned off a Vodafone-donated Warriors shirt, complete with signatures, and that raised quite a bit of money. Bakers Delight donated some hot cross buns and Vodafone has offered to match the money raised from the dance. Every one was very generous and the BCN conference account has benefited hugely.

And finally, if you enjoy dancing go along to a Ceroc dance; you will have a great time!



A huge thank you to Rob and Angela for their generosity.



Jeff got into the spirit of the occasion.

Ceroc is French jive, a funky partner dance generally done to chart, nightclub and swing music. It originated during the Second World War when American GIs based in France introduced Jive to the dance scene. The French adapted it and described it as "C'est Le Rock", hence the abbreviated Ceroc (pronounced "say-rock"). (It can be danced to other music, too.)

In January 1980, a Frenchman named James Cronin started classes in London, which are now enormously successful. Angelique Meyer, a New Zealander living in London at the time, attended a few classes and was hooked! She trained to teach Ceroc and decided it was just what New Zealand needed. There are now branches throughout New Zealand, Australia and Europe.

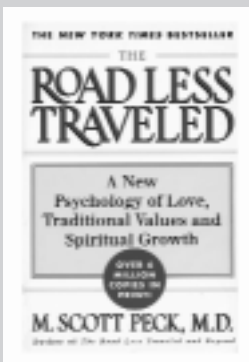
While Ceroc is a partner dance, people don't need to bring a partner as people swap as they dance. Ceroc burns the calories, keeps people fit and is just the kind of healthy and fun exercise we all need, including those who have had breast cancer.

BCN member Claire Ryan has been involved with Ceroc behind the scenes for several years, through her sister Angela and her partner, Rob. Angela and Rob offered to run the Ceroc "Pink Dance" for BCN to help raise money for the National Conference. Our huge thanks go to Angela, Rob, Vodafone and Bakers Delight for their support.

## BOOKWATCH

### THE ROAD LESS TRAVELLED

BY M SCOTT PECK, MD - FIRST PUBLISHED BY TOUCHSTONE, 1980  
REVIEWED BY GILLIAN WOODS



A late-comer to this book, I was quickly hooked into an initial speed read followed by a thoughtful re-read. Scott Peck begins his book with the words, "Life is difficult," and "... is full of pain as well as joy." I suspect many readers will immediately identify with this. He says that acceptance of this truth is important – it frees us from moaning about difficulties, enabling us to meet and solve problems, find meaning in life and grow spiritually. Not new ideas, but it may help to

read the book with acceptance of this bottom line.

What follows is a guide to help people achieve spiritual and mental growth, in sections on discipline, love, religion and grace. However, a reader does not have to believe in God or belong to a religion to gain from this book, but to have an open mind and be willing to understand more about themselves and their relationships. The author draws on his experience of clinical

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psychiatry and psychotherapy, providing stories and examples from his practice – altered, of course to provide anonymity.

The stories illustrate some important things a child needs to learn from its parents in order to become a well-adjusted adult. There is the example of the adult who hasn't learned to delay gratification and the one who procrastinates. Peck also tells of experiences with his own journey and with his family. He often uses language that portrays his Christian background, such as the chapter entitled 'renunciation and rebirth', which may mean that older readers or those from a church background are more comfortable with the style. But the ideas for balancing one's life, for giving, and putting one's self aside make everyday sense in a personal journey of growth and love, so would hopefully not be an obstacle to younger or very secular people. I was very surprised on talking

about the book with my 30 year old son who was not brought up in any church, that he had already read and enjoyed it, having had it presented to him by his boss, the head of a large IT business.

The section on love is interesting, as it describes some of the things that love is not, such as dependency, and discusses differences between falling in love and 'real' love. It presents a mature and considered view of love, a goal to aim for. Why would I recommend this book? It helped me identify some of what I need to progress my own spiritual/mental journey, with illustrations of how this knowledge might be applied in relationships with others. As such it was an inspiration and I will always be glad I got around to reading it. This book and others by M Scott Peck are readily available in libraries and bookstores. Being enormously popular, they have been reprinted several times.

## **BREAST CANCER ADVOCACY COALITION FORUM**

The Breast Cancer Advocacy Coalition (BCAC) Forum is to reconvene on the 10th of June, 2006, at the Tamaki Campus. The Forum will bring together the twelve member groups and invite new groups who have come into the breast cancer arena since the last Forum in November 2004. There will be a stimulating programme and discussion of emerging issues in New Zealand, with speakers from Australia – Lyn Swinburne of Breast Cancer Network Australia and oncologist Nicole McCarthy – and local breast surgeon, Dr Belinda Scott. Libby Burgess, chair of BCAC, will be fresh back from a conference in Italy on consumer advocacy. Groups will be invited to send two participants to this exciting and important update. For more information contact Claire Doole, phone (09) 378 7684 or email the.claire@xtra.co.nz.

**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)**

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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, Anne Iosefa, Gillian Woods.

### **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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donation \$ \_\_\_\_\_

☐ Please tick here if you have experienced breast cancer.

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