Conference Proceedings

Breast Cancer Network (NZ) Inc

Breast Cancer
Network NZ
Conference 2007

1st New Zealand National Conference

For those affected by breast cancer

Friday 26th to Sunday 28th October 2007
Distinction Rotorua

Compiled and Edited by Sue Claridge

Moving Forward Together - Ahu Whakamua Tatou

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Executive Summary

One in nine New Zealand women experience breast cancer at some point in their lives, and New Zealand has one of the highest incidence rates in the world for breast cancer. Until October 2007, there had been no opportunity for women to attend a conference relevant to their needs in New Zealand.

The First National Conference was organised by people affected by breast cancer for people affected by breast cancer from diverse communities throughout New Zealand; a forum where participants not only gained knowledge but put forward their own ideas on how to improve the management of breast cancer in this country.

The keynote speakers – Dr Susan Love, Dr Maricel Maffini, Dr Ingrid Winship and Phil Kerslake – combined with New Zealand's top breast cancer specialists in a variety of disciplines to offer a stimulating and informative plenary session programme. In addition, an inspiring and generous group of New Zealand breast cancer survivors shared their journeys through plenary presentations, and the Ora Creative Exhibition that was on show in the main conference room throughout the three days.

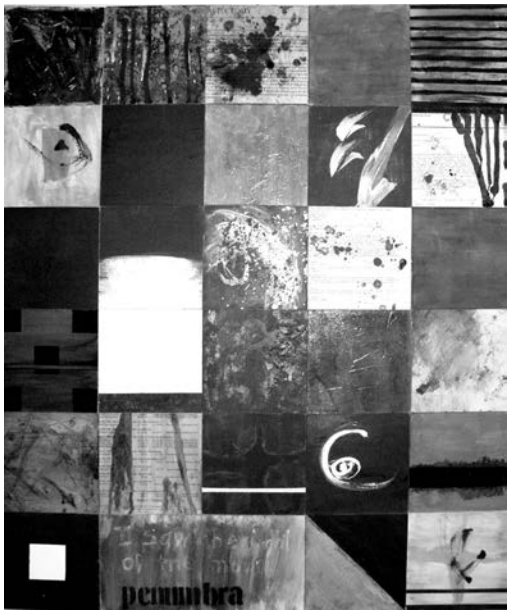
A large number of workshops were held covering a wide range of topics. They enabled the participants to contribute to lively discussions, and offer their opinions, concerns and recommendations for the way forward. As well as the discussions from each workshop being summarised in these proceedings, the outcomes of the workshops have been gathered and collated into a set of recommendations that form a seperate document - *The Way Forward.*

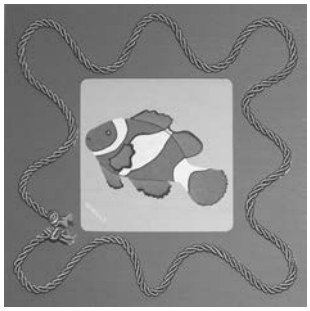
It is hoped that the First National Conference for those affected by breast cancer will make a positive difference, not only to the futures of those who attended, but in the lives of those who will follow. These proceedings are a record of the presentations, workshops and recommendations from the conference; it is an important document the Breast Cancer Network hopes will have a role in ensuring changes to policy and practice that will lead to improved outcomes for New Zealanders with breast cancer.

And now that the speakers have finished, now that the buzz of excitement and camaraderie has faded, and the emotion, the learning, the sharing, the fun, the laughter and the tears of those three days are over, we hope these proceedings will give participants an opportunity to dip back into the conference whenever they feel the need to be reminded of what we have achieved and that which we strive for in the future.

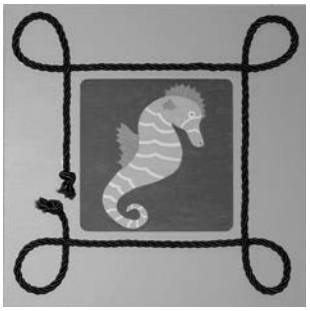
Table of Contents

Diane Toulmin





Angela Jowitt



Judy Pruden

Helen Painting

A Conference for Those Affected by Breast Cancer

In August 2004, three members of the Breast Cancer Network Committee – Dell Gee, Marie Hastings and Gillian Woods, and the Editor of *Upfront*, Sue Claridge, attended the Breast Cancer Network Australia's second national conference in Melbourne. These women returned from Australia filled with the learning, sharing, inspiration, determination and sisterhood that suffused the conference. They also shared a common reaction to the three days in Melbourne: "We want a conference, too!" One of the compelling factors was that, with their second (2004) conference, the Australians had shown how much of a difference their first (1998) conference had made.

In April 2005, BCN announced to its membership that it was their aim to organise a National Conference for women who have experienced breast cancer.

"We want women from throughout the country to gain the benefits of attending stimulating workshops, listening to addresses by top international and national health professionals on all aspects of breast cancer, and to be inspired by meeting and talking with others," BCN said in *Upfront*.

To achieve those aims requires considerable planning. BCN set about holding discussion meetings in towns and cities throughout the country during 2005, in order to gauge the support for a conference, and also to identify areas of interest or concern that may be addressed by conference speakers and workshops. BCN was particularly keen to talk to women from rural and provincial communities and involve them in the planning.

Soon after the discussion meetings began it became clear that it was not a matter of "if there is a conference" but a matter of where and when it would be held. Seventeen meetings were held from Kerikeri to Invercargill, and in December 2005 BCN announced that, yes, the conference was to become a reality.

One of the things to come out of the discussion meetings was that women around the country wanted 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 knowledge and understanding, they wanted lots of fun and lots of laughter, and to hear inspirational stories from other survivors.

In April 2006 the dates and venue were finalised and BCN adopted the theme *Moving Forward Together – Ahu Whakamua Tatou* as a guide for the planning and the outcomes of the conference.

The programme was compiled from the topics that women from around New Zealand said were the most important, and Rotorua was chosen as the venue reflecting the strong opinion that the venue should be in an easily accessible provincial area.

The person that women said they most wanted to hear speak was Dr Susan Love and it was a dream come true when Dr Love agreed to be the conference keynote speaker. Her presence at the conference was made possible by the wonderful support of The New Zealand Breast Cancer Foundation.

The discussion meetings also revealed numerous inspirational women who have had breast cancer. Together with breast cancer experts from many disciplines, it was decided to ask some of these women to share their journeys, and their strength, to help empower other women and their supporters to fight breast cancer, either through the plenary sessions, the workshops or the Ora Creative Exhibition.

From the moment that international key-note speakers, Drs Susan Love and Maricel Maffini ,were welcomed to Rotorua on Thursday afternoon, until the closing ceremony at the Distinction Hotel on Sunday afternoon, our First National Conference for those affected by breast cancer was just amazing – informative and inspiring, fabulous and fun.

All the preparation, planning, meetings and discussions, with everyone from women who might attend to the sponsors, from the speakers to the behind the scenes and venue staff, was worth it.

Ahu Whakamua Tatou – Moving Forward Together; a conference for those affected by breast cancer in the hope of making life better for those who are to follow.

Ahu Whakamua Tatou – Welcome

Survivor

Can you feel my emotions
Rising up to the air
I just can't believe I'm here
There's a deep sense of belonging
Now I'm here
When I look around the room
Knowing the miracles that have
Found me here
You're the reason I want to share

CHORUS

I'm a survivor
There's no stopping me now
A survivor
You're gonna hear me scream and shout
I have a reason to live
There's much more I can give
I'm a survivor
A survivor
There'd been a time
When giving up crept on in
When a smile became hard to give
Oh then you came and entered my life
You help me through
Through all of my downtimes
You've given me
All the support I need
It ain't over
My life ain't over
So I'm gonna live it up
I ain't given up on me
Yes I'm a survivor

Lyrics by Metua Strickland. Music by Metua Strickland and Leah Ratana.

Survivor ***was written specially for the conference as a tribute to their whanau, and sung by Metua and Leah at the opening and closing ceremonies.***

Conference Opening

The conference venue, the Fenton Room at the Distinction Hotel in Rotorua, was filled to capacity for a moving and inspiring official opening ceremony. The opening commenced in complete darkness, lighting slowly revealing a performance that paid tribute to our culture and our people.

Jenny Clark of Breast Cancer Network, welcomed delegates from all over New Zealand, and thanked them for making the effort to be there.

"This is your conference, so make the most of it," she asked of them.

The opening and welcome was officiated by Kevin Winters, Mayor of Rotorua, and Steve Chadwick, Minister of Parliament for the Rotorua electorate. Both have been affected by breast cancer.

Kevin welcomed the delegates, the speakers and other guests to Rotorua, before going on to show a broader than expected understanding of breast cancer issues by pointing out that breast cancer is not just a women's issue. He had recently found out that his own father must have mammograms, too. He lamented the impact of cancer on the whole of society.

He congratulated the Breast Cancer Network: "What you are doing here today has to be admired."

He finished by saying that he was looking forward to hearing from the guest speakers, and hoped that delegates would be supported so that they, in turn, can support their families and go forward with great courage and deal with the trauma of breast cancer.

Steve Chadwick began by acknowledging that this was a much needed conference, and that what was in place was a stimulating and inspirational programme, with a wonderful array of top speakers from New Zealand and overseas.

She formally welcomed all the speakers, congratulated Breast Cancer Network and the Rotorua organising team and then welcomed the delegates themselves.

"Most of all I want to welcome those of you who have experienced breast cancer; this conference is for you as survivors!"

She also acknowledged the theme, *Moving Forward Together – Ahu Whakamua Tatou*, by saying that specialists and doctors can't do it on their own, and that what was needed was the involvement of the women.

Most of us will be affected by cancer, if not as a patient as a family member or friend. Steve has a personal experience with breast cancer, losing her mother to the disease.

"Sharing the experience brings greater understanding for all those involved in the journey," she said.

Steve believes strongly that one of the most important things for women who have been diagnosed is timely and accurate information. Information about reducing the risk of breast cancer and access to screening were also vital in her opinion.

She acknowledged BCN's beginnings, the work that had gone into planning the conference and said she was looking forward to viewing more closely the works in the *Ora Creative Exhibition*.

She also mentioned the other work that BCN undertakes: the newsletter, *Upfront*, and the Stop Cancer Where It Starts project.

POLICY AND ADVOCACY

Steve discussed policy development and the role of governmental agencies in addressing the impact of cancer in our communities, action that is of great importance if we are to successfully reduce the toll from this disease.

She made mention of the Cancer Control Strategy which covers all aspects of cancer from prevention through treatment, to rehabilitation and palliative care.

"It reflects a shared commitment to reducing the incidence of cancer and improving the quality of life of those who develop cancer."

Steve continued to discuss recent developments in addressing cancer impact in New Zealand.

In mid 2006, work started on the formation of four regional cancer networks – Northland, Northern-Midland, Central and Southern. The networks are now all established, though some are more advanced than others."

One of the key activities for the regional networks is facilitating co-ordination in those regions to improve patient access through their cancer treatment, improving the patient pathway so that it makes progress through treatment easier. The cancer control work programme is developing guidance on support and rehabilitation during and after treatment.

Work is being undertaken to assess the range, delivery and availability of psycho-social support services. National guidelines for the treatment of breast cancer are also being developed with the aim of improving access.

Steve Chadwick concluded:

"It is fitting that [during] breast cancer awareness month, we are here together to share information, to be encouraged and moved by each other's stories. I wish you all the best for a stimulating and inspirational weekend."

"Kia ora koutou."

The Pink Ladies arrived in Titty Titty Bang Bang

Pacific Island cultural workshop

Pink Pilates

Part One: Plenary Sessions

Survivors

Lois Muir OBE, DCNZM, Patron of Breast Cancer Network

*A true New Zealand sports icon, **Lois** was inducted into the New Zealand Sports Hall of Fame in 1993. Lois represented New Zealand in both basketball and netball and coached the New Zealand netball team for an unsurpassed 15 years until 1988. She retired from coaching in 2005, and is currently Chair of the New Zealand Academy of Sport – South Island, and President of Netball New Zealand. Lois was awarded an OBE in 1984 and Distinguished Companion of the New Zealand Order of Merit in 2004, well-earned recognition for her dedicated services to netball and the administration of Netball New Zealand. Lois has experienced breast cancer, and handled her diagnosis and treatment in a characteristically positive way. As a breast cancer survivor she is a wonderful role model to women who are diagnosed with the disease and is Patron of Breast Cancer Network (NZ) Inc.*

"It's great to see you all here. Isn't it great we are all making history being part of the first Breast Cancer Network conference?"

So Lois Muir began before going on to thank the organisers for their foresight and their "mammoth effort".

Lois told of her rural life growing up, and believes that it was that life that gave her her stickability, and provided her with a "fitness programme" quite unlike that of today's elite athletes.

Lois spoke a lot of her career in New Zealand sport, commenting on how much sport had changed over that time. She talked about being addicted to and obsessed by her job as coach of the Silver Ferns, but there reached a point, standing on the sidelines when she knew she had to retire.

"You must remember, you must enjoy your work… always! You must keep going forward… always! The moment you see it a chore, life gets hard."

"To me the key to success in anything in life, is the 'how', not the 'what'."

She was diagnosed with breast cancer in 1998 while coaching the Wellington Shakers elite team and the Wellington national side, while living in Dunedin, travelling a lot and spending three to five days in Wellington each week.

She explained how she was diagnosed with breast cancer on the Thursday, flew to Wellington on the Friday and coached the Wellington team on Friday, Saturday and Sunday. On Monday she flew back to Dunedin to see her surgeon, then was back to Wellington on Tuesday and then on to Hamilton with her team to watch them play in the national championships. She told no-one but her family of the cancer. It was a long week but her focus was on other, more important things.

The Shakers placed second in the championships and she told the team during the post game de-brief that she "had had a bit of a hiccup" and that the following Wednesday she was having surgery for breast cancer.

"I said to them that I had a game plan and 'I hope I'm going to stick to it a little better than you guys did in the final' and I got a laugh out of them."

She explained that she needed to tell them about the cancer and let them know she had it under control, that she was okay, before they heard about it through the "bush telegraph".

During her talk Lois dished out generous helpings of the Muir philosophy. One of her beliefs – we can't control our lives but we can control our responses – was amply demonstrated by her own response to cancer.

Lois finished by saying that "no matter your aspirations the greater the challenge, the greater the rewards."

Te Haerenga – The Journey

June Grant *Tribal affiliations Te Arawa (Ngati Tuwhareoa, Tuhourangi/Ngati Wahiao)*

Rotorua born artist, gallery owner, business woman and entrepreneur, ***June*** *attributes much of the inspiration for her art to her close connection to Whakarewarewa. She has travelled widely overseas exhibiting and promoting Maori art. Since June's breast cancer diagnosis in 2003 she has been actively involved in raising awareness and supporting others. Last year she was involved in the advertising cam-paign for BreastScreen Aotearoa in the Waikato/Bay of Plenty area and also travelled to Denver, Colorado to participate in the Native Peoples Circle of Hope conference about breast cancer. June is one of eleven cancer survivors featured in the "Healing Journey's" DVD produced by the Cancer Society of New Zealand in 2007 and is a member of the Aroha Mai Maori Cancer Support Group in Rotorua.*

June's paintings are a visual journey that she created after her diagnosis with breast cancer in 2003. With a great deal of humour and honesty she shared both her story and her culture with the conference delegates on the opening day of the conference.

"I was at the Lion's cancer lodge when I decided that I needed something to take me out of myself," she told the delegates. "And painting was the way that I did that."

Her first painting depicts her standing in front of the Mercedes building in New York. She was lying on her hotel bed in that city, watching TV with her hand on her chest and thought to herself "Is that a lump?" That was the moment when "the penny dropped" and she realised then that she had breast cancer although it was not formally diagnosed until a few months later.

So, the first painting is about the discovery of her cancer and her journey across the ocean. It is filled with images that connect her with her ancestry and incorporates designs from the meeting house of her people.

The second painting depicts the surgery for her breast cancer. Her children are depicted at the bottom of the painting, between her legs as is the Māori tradition in their carvings. In turn, her grandchildren are held in the arms of her children. The carving depicted on the left is a guardian figure, a manaia. The top of the painting depicts the coming of her ancestors to Aotearoa in a canoe, above which is the kauae, or women's moko which indicates her matriarchal genealogy. The feather symbolises the retention of values, of things that are really, really important.

"All of you have been to that spot where you think 'what am I doing and what is really important?'" June explained. "What is my life about?"

"And that, for me, was about the things that I hold dear. I mean, I've been strolling down memory lane for five years now, because [people, family] are so important."

Her third painting is about the chemotherapy. It depicts her family's good luck "charm" – the fantail – a guardian figure. During her treatment and when she was healing she would go out for walks:

"Whenever I walked the fantails would come," she said. "And they would just be around me and alight on a branch. I would think this is just too spooky.

I'm not necessarily a very spiritual person, but they were always there, and they reminded me of my parents, my grandparents and my ancestors."

In her hand she holds a club, a whale bone club that "in the old days we used to use to kill things," June said, adding in a stage whisper "like people," before declaring to some considerable laughter that she was not proud of that part of her people's history.

"The patu was to kill the cancer, so that's what I'm holding. I've got my weapon in my hand and I'm going to beat this thing to death." Her determination clearly resonated with the audience.

She also has two big guardians on her shoulders to help her through the treatment. On the right is a Pou Rahui pole – a commemoration pole. It commemorates three of June's friends who died while she was having chemotherapy, including renowned musician Hirini Melbourne.

Her fourth painting is also about values. The treasure box, or wakahuia, at the top is guarding her head.

"If I had no brain my body would heal, I'm sure it would," she said with a laugh. "But you have to get your head right, and I kept having to get my head right while on this journey."

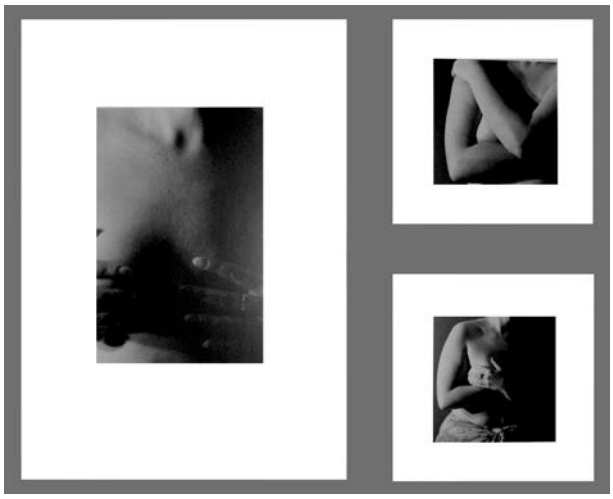
The painting is predominantly red to represent the burning of the radiation therapy. There are also a number of more subtle symbols representing family ("My father's war number: I want him on my side fighting this battle.") and her hospital number. The tiki is Ko Te Uoro – a family tiki owned by her grandmother, a guide in the Rotorua area, whose life provides obvious inspiration for June to fulfil her own potential in spite of the cancer.

"The paintings are a tribute to my family and to the trials and tribulations that we all face when we go through cancer treatment," June said in conclusion.

Sharon Saunders

Jane Wilkins

Merihyn Ruxton



Jane Wilkins

Malaga - Journey

BERNADETTE PEREIRA

***Bernadette Pereira** is a Community Development Adviser for the Manukau City Council where she works extensively with diverse communities. Bernadette is a member of the Pacific Island Health Advisory Council to the Counties Manukau District Health Board and Community Reference Group Representative to the Ministry of Pacific Island Affairs Auckland. She is also the Inaugural President for the National Council of Women Manukau Branch.*

While living in the Pacific, Bernadette was a professional youth worker and policy advisor in the Ministry of Youth, Sports & Cultural Affairs, Samoa and the Manager for the Pacific Women's Resource Bureau, South Pacific Commission. In 1995 she attended the Fourth Global Conference on Women in Beijing and as part of the conference planning was involved in formal presentations at all United Nations preparatory meetings in New York.

"I want to echo the sentiments and the lyrics of the song that gathered our spirits this morning; I am a survivor!"

Bernadette began her presentation by saying that she had made many presentations during her career, but that this was special; an emotional and history-making presentation at this, the inaugural conference for those who have survived breast cancer. She was unsure if she wanted to share her story.

For Bernadette her diagnosis was a curse that entered her wairua, her spirit. She could feel, taste and smell that it was foul. Her diagnosis was a rude awakening and she was rendered speechless for sixty minutes upon being told she had breast cancer and, she said, "for anyone who knows me they know that this is not a characteristic of Bernadette Pereira."

Cancer was never a topic for open discussion in Pacific society; it was seen as a curse and when diagnosed in a family member the "curse" was seen as a consequence of something, so nobody wants to talk about it and nobody wants to hear about it.

Bernadette found the lump in her breast in the middle of a global forum for Pacific women in 1995. She kept it a secret from even herself and felt she could not sacrifice the global forum for her own health.

When she was finally formally diagnosed she wanted to return home to Samoa to tell her mother. She tried to find a time to tell her, but her Mother passed away suddenly without Bernadette having had a chance to tell her of the cancer.

"She left, and I didn't have the time to tell her, to share the story," she told the conference, with emotion breaking her voice.

Bernadette had no-one to share her journey with and she returned to work in New Caledonia. She went to see the doctor and felt lost; she didn't have family, or people she felt could help her during that time. She turned to her brother in Wellington and told him of her diagnosis. He insisted that she go to Wellington for a second opinion. She travelled to New Zealand and had private treatment, ultimately having a lumpectomy, chemotherapy and radiotherapy. The only time she stopped and focussed on herself was the six months during her treatment.

She returned to work again in New Caledonia wanting no pity, and carried on as if nothing had happened. There is very little information in the "islands" regarding cancer and she felt she was unable to share her story there.

"Since then I made up my mind, I was going to live and I wasn't going to let this pull me down. So my journey began... it is eleven years since I was diagnosed with cancer," she said to applause.

"So, to you women out there, to all of us, I think we can learn and continue to live. I have been on this road forward, and I want people to move forward with me."

Keynote Address

Changing Paradigms in Breast Cancer

DR SUSAN LOVE

Susan M. Love M.D. *has always been a pioneer and entrepreneur. Focused on educating women about their options, Dr Love authored the widely acclaimed* Dr Susan Love's Breast Book, *now in its fourth edition. She is known worldwide as a pioneer of the breast cancer advocacy movement and lectures internationally on breast cancer, menopause and women's health.*

She is a Clinical Professor of Surgery at the David Geffen School of Medicine, UCLA, and was appointed by President Clinton to the National Cancer Advisory Board. She sits on the Boards of the National Breast Cancer Coalition, Y-ME and the Young Survival Coalition. Dr Love started the first all-women Breast Center in Boston, and developed a model for multidisciplinary breast care at the Revlon/UCLA Breast Center. She is currently President and Medical Director of the Dr Susan Love Research Foundation. The Foundation has one goal: to eradicate breast cancer within our lifetime. At UCLA Dr Love invented the intraductal catheter, and the Foundation is focusing research on the breast ducts and understanding how the breast works. Dr Love strongly feels that we now have the tools we need to get to where breast cancer starts and only need the will and resources to make prevention a reality.

ABSTRACT

Over the past few years there have been several major changes in our understanding of the disease of breast cancer which will drive treatment approaches going forward. The keynote address offered a conceptual overview of these new insights and showed how they will change prevention, screening, diagnosis and treatment of the disease.

INTRODUCTION

Susan Love began be saying how delighted she was to be here, that she didn't hesitate when asked, and having been here before would always look for an opportunity to come to New Zealand. She thanked Lois, June and Bernadette for sharing their stories, saying:

"I think it's very important to be grounded in the reality of the breast cancer experience."

It is also important to talk about the science of breast cancer.

"Patients always assume that there is a "right" or "best" treatment," she said, "that the doctor knows "the truth" and will tell it to us, that the tests are 100% accurate, and that the more aggressive the treatment the better."

"We also think life is fair, that Santa Claus comes at Christmas, that you'll meet your prince or princess and live happily ever after... There are a lot of myths that we believe."

"But medicine is really only a work in progress... there is no "one" truth. It is a search to under-

stand this disease and to figure out how best to approach it and how best to treat people."

She set out to tell the delegates how the research works and about the changing paradigms in breast cancer, and how this is changing treatment.

Research has shown us that there are different types of breast cancer – probably at least five types of breast cancer and they all behave differently. Susan explained the importance of this with considerable humour despite the gravity of the information:

"There is the 'almost-normal' kind of cancer, and that one is 'really good'; that one, it doesn't matter what you do, you'll probably be fine, because it was never going to do very much anyway."

"Then there is the really bad cancer, it's very aggressive; it doesn't matter what you do, it's so bad that our treatments are not so good for it."

"Then there are the kinds in the middle that maybe we can make a difference [with treatment]."

She explained that with screening, the reason we can only improve the mortality of breast cancer by 30%, not 100%, is because of the biology of the disease, not the sensitivity of the imaging. Thirty per cent of the tumours are there long enough for screening to detect them before they spread. The important issue is to find the cancer before it has spread because breast cancer that is just in the breast does not kill people. It needs to be in other more important organs. Mammography picks up cancer, but it is best at picking up the slow growing tumours. In the best of hands it will decrease the death rate of breast cancer by 30%. But it is far from perfect. We need a new method that is not focussed on finding cancers that are already there but which can find cells that are only "thinking" about becoming cancer, and perhaps rehabilitate them and change their fate.

The exciting changes in breast cancer treatment are in moving beyond one size fits all. For most of the history of breast cancer we have done what she terms "slash, burn and poison". Although she would have the same treatment herself if diagnosed with breast cancer, she acknowledges that it is a pretty crude approach.

"So, if we start to understand that there are different kinds of cancer, maybe we can start to look at the treatments a little differently as well."

"What we are finding out is that not only do different cancers behave differently, and have different prognoses, but they also respond differently to different treatments."

For example, in some cancers, hormone treatment works well, but chemotherapy is worthless. In other cancers hormones don't work but chemotherapy does. Then there is the grey area in between. The important development is that the researchers are really starting to refine which chemotherapy drugs should go to which patients and at what point in time. It means that patients are getting chemotherapy when it benefits them, rather than giving it to patients in whom it only produces side-effects. It is all about matching the treatment to the cancer.

SUSAN LOVE ON HERCEPTIN

Susan Love took on the controversial subject of Herceptin. Her view is that, in looking at the data, nine weeks of Herceptin treatment is probably just as good as 12 months, but at this time there is not enough data on the efficacy of the nine-week treatment regime to say it is equivalent.

"More is not always better," she said, using the example of high dose chemotherapy to illustrate her point, in which higher doses were proven not to be better and, in fact, women were adversely affected by the high dose regime. She points out that the drug companies are always going to promote a drug treatment for a longer period of time, because that is how they make their money.

"I think we have to be careful, and I think that the best thing to do is participate in a study [comparing 12 months with nine weeks]," Susan advised. "And that is how we will get an answer, but you can't assume that because they started out with a year that it is the best way to go."

ITS ALL ABOUT THE NEIGHBOURHOOD

We have always looked at cancer as if it is a foreign invader; one cell that "comes from somewhere else – outer space, maybe - and attacks your body."

The slash, burn and poison approach that Susan mentioned earlier was part of this paradigm, a paradigm that said every cell had to be killed.

"In actual fact," she said, "it's not a foreign invader but one of your own cells that goes a little off. It is part of you."

She suggested that there may be ways to change things within the patient's body. Breast cancer cells have been studied in isolation, but the reality is that they don't grow in isolation; they grow inside a human body and a breast, and interact with the other cells and tissue in the breast and body. Research has taken breast cancer cells, put them in normal breast tissue, and it has been found that those breast cancer cells behave normally. When those same cells are put back on cancerous breast tissue, they again behave like cancer.

"It's not just the cells," Susan emphasised. "It's the neighbourhood they're in, it's the local environment and the whole body, that is really important."

Some of the newer treatments - hormonal treatments such as Tamoxifen - don't kill cells as chemotherapy does, but they change the environment. There is now ample evidence that hormone replacement therapy (HRT) adversely changed the environment, and since the publicity about the risk of HRT in the development of breast cancer caused a significant drop in the use of HRT, there has been a drop in the incidence of breast cancer in the US and around the world.

Using hormone treatments such as Tamoxifen for breast cancer doesn't just have an effect while the woman is taking the drug, but the effects last for at least 15 years after stopping treatment – it changes the "local" environment for some time.

Susan Love believes that much of the complementary and alternative medicine used to treat breast cancer also works by changing the environment. Things such as exercise and meditation work by changing the environment of the whole body, which also changes the neighbourhood of the cancer cells.

"Stress doesn't cause cancer, but it certainly changes the environment in your body. It changes the hormonal status of your body." While stress may not cause cancer it may trigger cells that have been "sitting around behaving themselves" to start misbehaving.

The possibility is that some types of treatments may be able to rein in the cancer cells, to put them back under control and to force them to behave normally.

NEW APPROACHES, NEW ANSWERS

Despite these newer ways of looking at breast cancer, Susan Love still gets frustrated by the lack of progress in treatment. She has been a breast surgeon for thirty years and says that we are still doing the same things as thirty years ago, but just a little bit better.

"We're still doing surgery, but a little better, radiation a little better, chemotherapy a little better, hormone therapy a little better. But we're not doing something totally new."

And the statistics are only a little better. She says that a recent announcement showed that the death rate from breast cancer in the US had reduced in the past year by two percent.

"That's terrible! We should be reducing it by 50 percent, by 80 percent by 100 percent. Two per cent is nothing to crow about."

She points out that as a community we keep looking in the same place, where the answers are not. The only way we are going to get that level of change in the mortality figures is by looking at things completely differently. "And," she says "by getting in much earlier in the development of the breast tumour."

"Instead of trying to find cancers that are already there and trying to figure out how to get rid of them, we need to find cancer cells that are just "thinking about" being cancer... we need to rehabilitate those cells before they become cancer. We need to figure out what causes breast cancer in the first place."

All breast cancer starts in the milk ducts, but there is much that we don't know about the anatomy of the breast and the development of the breast. For example, we don't know exactly how many openings there are in the nipple out of which the breast milk drains after flowing down the milk ducts. We don't yet have an adequate understanding of the ductal system!

Research that Susan Love is undertaking as part of her ductal lavage technique for detecting abnormal cells in the milk ducts, is starting to reveal more information about what is in breast fluid, and the environment in which cancer cells develop. For example, levels of oestrogen are forty

times higher in breast fluid than in the blood, because the breast makes its own oestrogen. But again there is much we don't know about why or how or who – high risk women only or low risk women as well. Research is continuing within her research foundation on healthy women who volunteer to take part.

"Once we figure out what the conditions are that lead to cancer cells, we can change them and prevent it from happening."

The difficulty with mammography is that it does not work well in younger, pre-menopausal women who have dense breasts.

"We need a test that is really easy, and really cheap, so we can figure out who among the young women are at risk, so then we can figure out who we really need to be monitoring and who we don't. And we don't have [such a test]."

In current research, for which the Susan Love Research Foundation has just received a grant, she is looking at markers in breast fluid from young women, with the aim of developing a test that will work a little like a home pregnancy test. It will collect a drop of fluid and indicate if the fluid contains one of the markers that her research hopes to identify. This result would indicate that a woman is at higher risk, leading to more testing and investigation of the cells in the breast fluid. Susan is hoping that this will lead to treatment that could be put straight into the milk duct thus preventing cancer. She has already tested this technique in thirty women to assess safety and adverse reactions. The next step is to test the theory in women with ductal carcinoma *in situ* prior to surgery to see how well it works in treating the cancer.

"I don't know whether these things are going to work. But if we don't ***try*** totally new ways of doing it, we are never going to ***have*** totally new ways of doing it!"

Plenary Sessions

A Tapestry of Survivors

LARRY WILSON

*In a society largely unaware that males do get breast cancer, there was a huge impact on **Larry** and his family when he was diagnosed with breast cancer three years ago at the age of 50, and subsequently underwent surgery followed by radiotherapy. Larry was a supervisor for Telecom and spent a number of years travelling and doing similar work overseas before returning to NZ and now lives in Ohura where he was born.*

Larry is 'brassed off' that all the advertising and awareness-raising about breast cancer is focussed entirely on women; there is never any mention that men can get it too. When Larry found a lump he was inclined to dismiss it as 'nothing'; fortunately his wife insisted that he get it checked out and breast cancer was diagnosed. If the news was a shock to this bloke's "bloke", the reaction of many of his friends ranged from disbelief to insulting. He was accused of being a liar, asked if he was "on good drugs," asked if he was a homosexual, or "informed" he must have had a sex change "because only women get breast cancer."

"Mentally, it's like being a big macho male, and finding you've got a "woman's" disease; it's quite shattering really."

"The idea that I had breast cancer was very, very hard to accept," he said. "But with the help of a lot of people, I got through it."

He worries that the general lack of awareness leads to it not being diagnosed in men until it is too late and has metastasised. Now, Larry's male friends check their own breasts for signs of breast cancer, so his own experience has, at least in his own circle of friends, raised awareness of the disease among men.

SHELLEY HANNA

When Shelley Hanna was diagnosed with breast cancer she had just started Masters swimming after years of being 'too busy' with work and babies. At the time she feared her days of competitive swimming would be over virtually before they'd started, but with the encouragement of her surgeon she was soon back in the water. Swimming helped her to feel better during the long months of chemotherapy. Over the next few years she exceeded her expectations, eventually winning three gold medals in her age group at the NZ Masters Games in 2004. Motivated to help others in their recovery, she worked with the YWCA to set up the YWCA Encore programme in New Zealand.

When Shelley was diagnosed with breast cancer in 2000 at the age of 41, it was the culmination of several difficult years. She had been the primary 'breadwinner' – working fulltime and doing a diploma in business studies – and had two young children. She had a double mastectomy (partly for fear of recurrence) followed by aggressive chemotherapy over three months.

Only three months prior to her diagnosis she had taken up Masters swimming in an effort to get fitter and healthier; it also offered her some enjoyment in life that had previously been missing.

She was really keen to get back into the pool after her surgery and her breast surgeon, John Harman, gave her the okay to do so; 18 days after her mastectomy she started swimming again. Although she couldn't lift her arm very high, once she was in the water she had an amazing degree of freedom and mobility. And because she'd had a bilateral mastectomy, she didn't feel self conscious in her swimsuit even without prostheses.

"When I got out of the pool, what was really amazing, was that the pain that I'd been feeling – which was not bad pain, but severe discomfort – was completely gone. I had no pain."

After swimming every day for a week she wondered if she was overdoing it, so took a day off. After about 36 hours the pain came back – the swimming was giving her 36 hours of pain relief!

Chemotherapy slowed her down a bit, but after the treatment finished she began training again with her team. They trained for the World Masters' Swimming Champs in Christchurch in 2002. In a four-person relay team that included Olympic swimmer Toni Jeffs, she achieved a personal best in freestyle over 50 metres, and they broke the New Zealand record for their age-group.

Her success in swimming spurred her to look for a water-based exercise programme that would help other women recovering from breast cancer, and to encourage other women to use exercise in their recovery.

Shelley discovered the YWCA Encore programme in Sydney and made contact with the YWCA in Auckland, who were interested in bringing it to New Zealand. In April 2005, Shelley and two others went to Sydney to train as Encore instructors and have been running the programme in New Zealand for the last two years.

"So, what I'd say to you is, never underestimate your [ability to recover]. Your body is an amazing thing; just trust it. And I want to leave you with a quote from [author] Tom Clancy:

> *''Nothing is as real as a dream. The world can change around you, but your dream will not. Your life may change, but your dream doesn't have to. Responsibilities need not erase it. Duties need not obscure it. Your spouse and children need not get in its way, because the dream is within you. No one can take your dream away.''*

SUSAN LAWRIE

***Susan** is a wife, mother and breast cancer survivor. She was diagnosed five years ago with HER2 positive breast cancer, soon after celebrating her 40th birthday. She was working as a Practice Nurse for a local Medical Centre, and continued to work after her surgery, while completing chemotherapy and radiotherapy treatments. However, Susan's life view changed and, wanting to make the journey a little easier for individuals and families affected by cancer, she found herself choosing to work part-time in Support Services for the Cancer Society. She also runs a support group for women with breast cancer in a voluntary capacity.*

An experience like breast cancer is often a motivator to view life through different eyes, Susan told the delegates.

"The woman you were before your diagnosis is probably not the women you are today. As Eleanor Roosevelt said: 'You gain strength, courage and confidence by every experience in which you really stop to look fear in the face.' "

She has three distinct memories of the period of time during which she was treated for breast cancer:

- her daughter's anger at her having to have chemotherapy and radiotherapy, not just the simple lumpectomy that Susan had been promised;
- leaving hospital after radiotherapy one day, when a very strong wind picked up her wig and threw it over the road, prompting her to use double-sided tape from then on; and
- being asked to be part of a patient panel at a newly diagnosed patients seminar run by the Cancer Society, forcing her to reflect on her personal story.

The last event was a catalyst for Susan, encouraging her to change her focus from practice nursing to working part time in support services for the Cancer Society. The move gave her the ability to make a real difference in the lives of cancer patients.

Susan spoke also of the journey of her own mother, diagnosed with breast cancer two years ago, emphasising the differences brought about by her mother's approach to treatment; she has embraced alternative and complementary medicine, rejecting conventional treatment including surgery. Susan is learning to allow her to make her own choices, to follow her own path, and at the same time supporting her in her journey. She acknowledges that their goals are the same although their paths diverge.

She concluded with a piece of prose that she wrote for her mother which ended:

"Know that cancer cannot shut out memories, or silence the courage. It doesn't take away hope or break the sprit. Where there is hope there is life."

LEAH RATANA-CLUBB

*In 2004, two years after her original operation and having had her cancer return twice **Leah** looked at what else she could do to help her healing and chose to use the traditional Māori Rongoa treatments. Leah is a founding trustee of Te Waiora a Tāne Charitable Trust in Rotorua.*

Leah has spent her life working in tourism in Rotorua and has travelled overseas promoting tourism in New Zealand. She has spent many hours on the stage from which she addressed the conference delegates.

Leah was diagnosed with breast cancer in May 2002, and had surgery which was followed by chemotherapy and radiotherapy. In December

2003 she discovered that the cancer had returned in the form of bone cancer in three places – one site on her shoulder and two in her rib-cage. Although the doctors could treat the tumours on her rib-cage, they said that the cancer in her shoulder had spread and they could not operate.

In early 2004, Leah decided to turn to alternative Māori treatment – Rongoa.

She went into the bush with her Rongoa practitioners to collect the items that she would need. Her treatment included a poultice made from kawakawa leaves and a medicinal Rongoa drink made from different medicinal plants. Her most unusual treatment was hauora, in which she was placed in a hangi with medicinal leaves and wet sacks. She likened it to radiotherapy saying the cancer sites on her ribs and shoulder would glow. A follow-up CAT scan revealed a reduction in the size of the tumour. By Christmas the cancer in her rib-cage had gone, although the cancer in her shoulder remains and she continues to have conventional treatment alongside the Rongoa.

Three years later, Leah has lived beyond the doctors expectations when she was diagnosed with metastatic disease.

"I've been able to have chemo, and I've had the magic pills and I still work with my Rongoa; the two walk alongside each other. And I know I don't look too good at the moment, but I tell you, I looked worse before."

Leah and her people have formed their own trust – Te Waiora a Tāne – offering Rongoa traditional Māori healing treatment, which now has treated more than one thousand patients.

BARBARA HOLT

*In August 1987, at the age of 50, **Barbara** was diagnosed with a Grade One breast cancer tumour in her right breast and had a lumpectomy followed by radiotherapy. She then served two years on the Auckland Breast Cancer Support Society Committee, and two years on the Auckland Women's Health Council. In October 1993, with Wendy Steenstra-Bloomfield, she co-founded Breast Cancer Action Aotearoa-NZ, later to become Breast Cancer Network NZ. In July 1997, they attended, with two other BCAANZ Committee members, the First World Breast Cancer Conference run by survivors, held in Kingston, Ontario, Canada. In May 2002, aged 65, Barbara was diagnosed with four primary Grade Two tumours in the same breast and had a mastectomy. Barbara currently lives in Wellington, but was born in Auckland and lived in London for one year as a teenager and eleven years as an adult.*

"My idea of moving forward after cancer is always to move to another place," she explained with dry humour. "And some medical professionals don't like it. 'If you don't stay in one place,' they have said, 'you won't get good treatment'. But I don't always agree with them."

"I think my second primary cancers may have been caused by the radiotherapy I had to my right breast after my lumpectomy. Some of us may be allergic to it."

Barbara explained how, after her first diagnosis, she quickly became involved in voluntary work with the Breast Cancer Support Society in Auckland. Partly as a result of its "rules" for dealing with breast cancer patients at that time – for example, volunteer visitors not being allowed to talk about their own breast cancer experience, or mention lumpectomy to women who had had a mastectomy – she joined forces with Wendy Steenstra-Bloomfield, whom she met at the Cancer Society's Opening-Up series of seminars. Together, they founded Breast Cancer Action Aotearoa-New Zealand, which they modelled on the San Francisco-based Breast Cancer Action. Wendy's own cancer had been missed by an old Cancer Society mammography machine and she was campaigning to have it shut down when they met. Barbara paid tribute to New Zealand's cancer researchers, suggesting we could "grow our own Susan Love."

The other reason Barbara gave for wanting to start a breast cancer organisation was, after completing a Masters Degree in Public Policy from Victoria

University of Wellington in 1980, to influence public policy. A year after Breast Cancer Action Aotearoa-NZ became Breast Cancer Network NZ in March 1998, Barbara retired for the second time (having left the Public Service in Wellington at age 50). She gave up her role as Chair of BCN, after moving to Whangarei. Just over three years later she discovered she had four new primary breast cancers in her right breast, slightly more aggressive than the first.

"So, I had a mastectomy and moved back to Wellington," she said to laughter from the audience. "And the next move may be Christchurch, if I get it again."

"I'm a twenty-year survivor, and I have been lucky," she concluded.

JULIE BLAKE – BREAST CANCER SUPPORT SERVICE TAURANGA TRUST

Julie Blake *is the co-ordinator of the Breast Cancer Support Service Tauranga Trust. The trust was formed in 1991 by a group of local women who had all had breast cancer, and were aware of the lack of support and information locally for women with breast cancer at the time. They saw and felt a need in the community and set about meeting that need.*

The Breast Cancer Support Service Tauranga Trust (BCSSTT) is a charitable trust independent of any other cancer group. They are members of the international Reach For Recovery organisation and follow it's guidelines; the BCSSTT resources and visitor training programme have been approved by them.

BCSSTT currently have 23 trained volunteer support visitors who have a wide range of breast cancer experiences across a wide range of ages. The Trust is governed by ten trustees who include two breast care nurses and a sponsorship/ marketing person. The remainder are all breast cancer survivors.

The Trust provides one on one support through their support visitors, currently supporting about 80 women each year. They also supply an information pack to all newly diagnosed women through both public and private hospitals, BreastScreen Aotearoa and health professionals. In addition, they offer support to partners and families and have regular support meetings. They also have a monthly lymphoedema meeting, a weekly meditation group and a counselling service.

Funding is a challenge and the Trust do not receive any funding from government, district health boards or other cancer groups and are reliant on community grants, donations from other groups, business and individuals and their own fundraising efforts.

A major event on their calendar is the October ASB Girls Just Wanna Have Fun walk. Three thousand women (and some men) took part in their 5th annual walk held in early October 2007, which in 2006 saw more than $12,000 raised.

JAN BENSEMANN

Ten years ago during a twelve hour shift as a nurse, Jan had a mammogram, and then an urgent assessment with a breast surgeon. She was told the same day that she had breast cancer. The experience as a nurse of caring for others, and then being cared for herself by health professionals has been profound. Five years later, Jan's doctor phoned her at work, to inform her she had been diagnosed with a second unrelated cancer, a salivary gland cancer; tough times followed this diagnosis. Jan is very involved with the New Beginnings Support Group in Christchurch and is an avid dragon boater.

Jan Bensemann: a woman, a wife, a mother, a grandmother, a sister, a nurse, a tramper, a dragon boater.

"I am a dragon!"

She is also a cancer survivor, surviving breast cancer which was diagnosed ten years ago and salivary gland cancer five years ago. She is minus part of her "boob", her lymph glands, half her teeth, and part of her neck. However, she says she is very whole, a survivor.

She lives by a number of mottos such as "long time looking at the lid."

"That excuses all kinds of behaviour – all kinds of spending and drinking and eating and ..."

Only the good die young is another saying she quotes, and admits to working very hard at being bad.

As a health professional she admits to being a good nurse but a lousy patient. She hates attending appointments and having to park in the "patient" car-park.

Jan got involved in the breast cancer support group New Beginnings at a time when she needed to feel safe and supported, and has now facilitated this group for a number of years. She is also an inaugural member of the Christchurch dragon boating team, Abreast of Life, formed eight years ago and who this year were victors in the competition against other breast cancer teams.

"A really, really important aspect of our journey is that it is an incredibly sad journey. We have lost so many wonderful women. So many wonderful dragons are now in heaven."

Jan believes that what survivors need are hope, strength, a sense of humour, tears and fears, resilience, family, friends, treatment options, sick leave, support – lots and lots of it – fun, an ability to grieve both our own losses and those of our friends, and finally information.

DARIEN KERKIN

***Darien** considers herself a breast cancer survivor even though she lives with metastases. First diagnosed in 1995 she had a mastectomy followed by chemotherapy and Tamoxifen, and continued to work as a lecturer at University and generally ignored her illness. She had always felt that she had good health, so assumed that she was going to "beat the disease" as so many women do. In August 2003, after several months of undiagnosed pain, Darien had emergency surgery for a bowel blockage and the surgeons found extensive breast cancer around the bowel. This wasn't diagnosed earlier, primarily because breast cancer rarely metastasises to the bowel. At the time her prognosis was poor but, once she was over the surgery, she felt really well again.*

When diagnosed with metastatic disease in 2003, Darien's children were told that she had two and a half months to live. She is grateful that she wasn't told that.

Darien spoke of unexpected consequences of her diagnosis. She became a bit of a hermit, because for the first year she waited to die. And it didn't happen! At the end of the year she asked herself what she was doing, putting her life on hold.

In 2006 her daughter had her third child and Darien really enjoys spending time with her grandchildren, and relishes the fact that she is still here to be part of their lives.

Another unexpected was that her breast cancer metastasised to her peritoneal cavity, which is quite rare. Surgery left her with an ileostomy and "bag", impacting considerably on her life. Subsequent problems meant more surgery and, fortuitously, the opportunity to have the ileo-stomy reversed, although she suffers from bowels that are prone to misbehaviour.

With remarkable frankness and good humour – and an apology to the men present for detail they may have preferred to go without – Darien described discovering a lump on her labia. Although initially reassured that it was just a cyst, further investigations showed it was cancerous. Her doctor told her:

"I've been a gynaecologist for thirty-five years, and this is only the second time I've seen breast cancer go to the fanny!"

This "unexpected" consequence elicited gales of laughter from the audience.

Darien's final unexpected consequence is that she has become a crusader. She had effectively a "free" stomach stapling and lost a lot of weight, weight that we all know can contribute to breast cancer.

"It really worries me when I see young women who are obese. Don't they know [about] the links to breast cancer?" she asks.

She is also a crusader for household products, environmental factors and skin care products. She harbours serious concerns about the chemicals in these products and the contribution that they may make to the development of breast cancer.

"I'm very happy with where I'm at," she concludes. "Apart from an unpredictable bowel I lead a very, very happy life, a very full life."

SUE MCLEOD

In 1996, at 49 years of age, ***Sue*** *just knew she would write her journey* – The Unremarkable Nipple - *and from there she undertook educational awareness for herself and others by establishing the NZ Community Development Trust web site www.breast.co.nz. Now addicted to breast health information, her ambition to attend the 3rd World Conference on Breast Cancer was achieved and her poster contribution,* Do Something - Stop Breast Cancer Where It Starts, *featured prominently. Healthy Options magazine printed this material in September 2002. Sue also featured on the New Zealand documentary* The Naked Breast *and gave a PowerPoint presentation,* Preventing Breast Cancer, *at the 2005 World Conference in Halifax.*

As a child Sue was exposed to "nasty" timber preserving chemicals and her health was below par for her age. As an adult in the 1960s she qualified in radiography and was exposed to gluteraldehyde; she suffered from chest problems and the health effects of chemicals, at that time, were not well understood. In 1981, she moved to Kerikeri with her husband to begin orcharding, and was exposed to most of the chemicals used in the horticultural industry, particularly orthene and simazine, both of which have been found in breast tissue.

Sue says that there have been huge improvements in the breast cancer services in Northland since 1996 when she was diagnosed. There is now a free mammography bus, satellite mammography centres, a top-of-the-line, state-of-the-art digital mammography machine in Whangarei, a breast clinic, breast surgeons well practised in breast surgery, breast care nurse and visiting oncologists.

"My aim will always be to break down the barriers, to empower myself and others with knowledge and, hopefully, to raise a smile while doing so. Last year I was sixty – and a grandmother – eleven years on. I don't call myself a survivor. I'm a thriver!"

Sue tells the audience that her journey has not just been about breasts, mammography, chemo, radiation or survival... It has been more about words, and dialogue and how the breast cancer industry has developed. It's been about how words are strung together to influence, reassure, to aid compliance, to raise money, even to insult.

She points out that the "pink ribbon" is pink because of a cosmetics company, after the original ribbon was a peach colour.

"It was originally inspired by and then borrowed from the AIDS activists. It starts with awareness but it is all about marketing, and what appeals."

"Breast cancer has been glamorised by our feminine bits," she says.

She asks why we allow this pink marketing, this pink washing of products to continue, without necessarily knowing where the money is going to go.

"I didn't intend to become an activist, it just sort of happened," she declared and went on to point out that she bought the domain name www.breast.co.nz before the porn industry could grab it.

CLAIRE RYAN

Claire *is an Auckland lawyer, a part-time lecturer in forensics and scripture, and also a keen astronomer. Among other community service positions that she holds, Claire is a Director of Breast Screen Auckland Limited and the Deputy Chair of the Breast Cancer Aotearoa Coalition. She is a member of the Breast Cancer Network, is a seven year survivor and a strong supporter of breast screening, Herceptin and thrashing Australia in all things, especially in breast cancer statistics and cricket. She acknowledges that we have a bit of work to do in both of those areas but there are signs of hope…*

Claire refers to herself and her sister-in-law as "Kylie's body guards"; Kylie Minogue was 37 when diagnosed with breast cancer, while Claire was 38 and her sister-in-law, 36. Claire had a mastectomy, chemotherapy and radiotherapy. Her oncologist told her that her chances of surviving ten years were 25%.

"In three years time I'm going to have a huge party – you're all invited because I think we'll have it at the oncologist's practice."

Claire acknowledged that she is well known for talking too much.

"The [conference] organisers were really worried about my speaking [today] for less than five minutes! So, I'm going to stop talking now."

Claire shared with the delegates a series of slides set to music (*Can You See What Our Love Has Done* by U2), of photos of people who had been mentors for her during her journey, plus some of her own illustrations.

RUKU LUCY WAIPOURI

With her family devastated by the number of their family members diagnosed with different cancers, ***Lucy*** *is looking at the ways they can start the healing process and move forward positively. Lucy was diagnosed with DCIS two years ago and had a lumpectomy followed by radiotherapy. After cancer was detected in the opposite breast this year Lucy opted to have a bilateral mastectomy and is currently undergoing chemotherapy. Lucy lives with her family in Wellsford.*

Lucy began by acknowledging her people, saying that she stood there to speak for all Māori who could not stand there. In her work she delivers health messages to her people.

"[I] come from four generations of cancer." She asked forgiveness if she became emotional but said that she had a lot to cry for.

She is one of ten siblings who grew up on a farm, surrounded by gardens and fruit trees, living a simple life and active in sports. In 1981 her father died from bowel cancer; 18 months later her mother died from stomach cancer. In that same 18 months 18 more of her whanau all succumbed to cancer and died. In those 18 months her family became professional mourners.

In 2000 her oldest brother died from prostate cancer; her youngest brother followed in 2004 and another brother in 2006. She has only one brother left. There are five sisters remaining and Lucy is the first to have breast cancer.

However, the next generation have already shown that they carry the family susceptibility to cancer. Two of her nieces have cancer, one breast cancer, and one stomach cancer. She has lost many cousins to breast and prostate cancer. Is this a maketu, a curse?

"We don't know how this has all come about, especially as we have a background of healthy living; farming, being active, being involved with sports."

Her family are on a journey looking for answers.

"We are looking for answers to our prayers, an [end] to our ordeal."

Lucy has made a pact with her family; if anything happens to her, her niece will carry on the quest for answers.

KELLY BATLEY - BREAST CANCER SUPPORT SERVICE, TARANAKI

Kelly *was diagnosed with breast cancer in November 2003 at the age of 31. As the mother of a toddler it was a huge shock and resulted in life changing decisions. BRCA1/BRCA2 mutation screening was done and the test showed that she carries a BRCA2 genetic variant that had not been reported before. Kelly resigned from her job as the Branch Manager of a busy courier company and she sought support from the Breast Cancer Support Service (BCSS) run by the Taranaki Cancer Society. After 18 months of attending support meetings Kelly was trained as a BCSS Volunteer and then was later appointed the Co-ordinator of the Taranaki BCSS. As well as her voluntary role with BCSS Kelly now works part time for the Cancer Society of New Zealand Taranaki Centre as the Events Coordinator organising events such as Daffodil Day and Relay For Life.*

Kelly and her Pink Ladies arrived at conference on the Titty Titty Bang Bang bus from Taranaki. The Pink Ladies came together for the Relay For Life and get involved in local breast cancer events; they went on to fundraise in order to get to the first national conference.

Kelly spoke first of the origins of the Breast Cancer Support Service in New Zealand, before speaking in more detail about the group in Taranaki. The Taranaki BCSS have bi-monthly evening meetings, bi-monthly luncheons and trained support volunteers.

They promote breast cancer awareness in their communities, providing free information on breast cancer to any woman who wants it. To get to the conference they held a movie night and a pre-Valentine's Day dance to raise funds. They have used that old stalwart of fundraising – raffles – and have availed themselves of "benefit" days at the local races, at which gold coin donation "entry fees" go to a charity organisation.

This year they had the first ever survivor's flag for Relay For Life – "It hasn't even been done in America," Kelly said as she showed slides of the flag.

"We called it the hands of hope. Every survivor that was involved was able to put their hand-prints on it with their name, and each year we hope to have another flag."

A recent event was "Pink Your Ride" which got off the ground when Kelly was approached by a friend from the Hot Rod Club who said he wanted to do something for breast cancer awareness.

"He said 'I want to have a parade, I want to have woman drivers in hot rods.' "

"We decided that we were going to turn Taranaki pink," Kelly told the delegates, as she flicked through slides that captured the occasion. The Topp Twins were in town at the time and took part in the parade.

"We had a lot of fun. We had sixty cars, twelve motorbikes, one push-bike, one horse, three dogs, and we raised $3894.98."

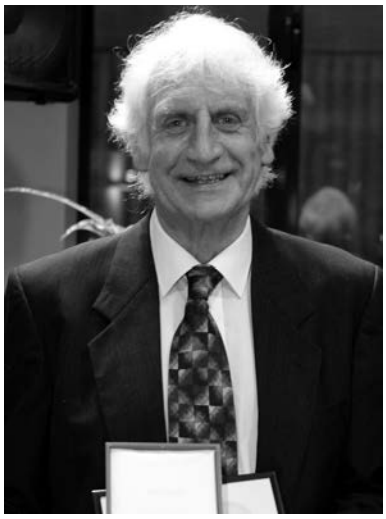
Sadly, one of the Pink Ladies who was instrumental in the fundraising, was not at the conference.

"This is in memory of Debbie. You'll be on your way up; you'll be seeing great sights. You'll join the high fliers who soar to great heights."

A sad reminder that not everyone makes it.

New Zealand's Contribution to World Wide Cancer Research

PROF BRUCE BAGULEY



***Professor Bruce Baguley** is one of this country's most eminent cancer researchers. After training at the University of Auckland he did his postdoctoral research in Switzerland. He returned to New Zealand and joined the Auckland Cancer Society Research Centre in 1968. He is currently involved on the development of new anti-cancer drugs from basic concepts to clinical trials. Through his work at the centre he has been involved with bringing eight new world-class cancer chemotherapies to trial.*

Professor Baguley was the recipient of the 2006 Sir Charles Hercus Medal in molecular and cellular sciences and technologies, for his contribution to the development of new cancer therapeutics, and was jointly awarded the Peter Gluckman Medal for outstanding research endeavours with centre co-director, Professor Bill Denny. He is also a Fellow of the Royal Society of New Zealand and an Officer of the New Zealand Order of Merit for services to cancer research.

ABSTRACT

New Zealand already has an international profile in cancer research, particularly in the development of new anti-cancer drugs, the discovery of new molecular pathways associated with some types of cancer, and in the development of innovative clinical trial strategies. At the same time, it is important to address particular national needs in cancer treatment and prevention. We need to examine the factors that contribute to high research productivity and international awareness of work in this country. Where have we come from and where should we be heading in the future?

INTRODUCTION

How do we measure New Zealand's contribution to worldwide cancer research, how do we measure our improvement in this area, and where are we going; how might we make an impression on the international cancer research?

ANALYSING OUR CONTRIBUTION

How does New Zealand's cancer research rank on the world stage? This can be assessed by the number of times that cancer research papers, published in the world's medical journals, are referred to, or cited, by other researchers in their papers. This is an indication of how other researchers value the work of New Zealand scientists.

In terms of New Zealand's contribution to cancer research, some 2000 papers have been published, and of those 46 are highly ranked; that is, they have each been cited in other papers more than 100 times. The two areas in which New Zealand cancer research have made a big impression in the medical literature are anti-cancer drug development, and understanding the genetics and molecular biology of cancer.

DEVELOPMENT OF DNA-BINDING ANTI-CANCER DRUGS

When Prof. Baguley returned to New Zealand from Switzerland in 1968 he began working with Dr Bruce Cain. Cain trained as a chemist at Auckland and Oxford universities and commenced working in cancer research in Auckland in 1956. He acquired a very broad knowledge of clinical cancer chemotherapy, and aimed to use synthetic organic chemistry to make anti-cancer drugs. He was the first of the New Zealand scientists to reach the '100 paper citation' benchmark, but he also had a vision for the future.

His initial idea was to look for anti-cancer properties in New Zealand plants, and followed this with using chemistry to produce new treatments for cancer, a novel idea at that point. He then moved onto designing new drugs that would bind to DNA. The idea of making drugs that would interact with cancer DNA has driven cancer research since then.

In 1970 Cain developed a DNA binding drug called amsacrine, that he thought would be active in cancer patients; it was first tested

in clinical trials in 1978. In 1974, Gianni Bonadonna showed that another DNA binding drug, doxorubicin (Adriamycin), was of significant benefit to patients with breast cancer. However, clinical trials of amsacrine showed it to have activity in leukaemia but not breast cancer.

In 1986, clinical trials of asulacrine, a new amsacrine analogue developed by Dr Cain shortly before his untimely death in 1981, showed activity in breast cancer, but for various reasons it was never commercialised. Several other DNA binding drugs have been tested in clinical trials since then, and there is excitement over a new drug, currently referred to as SN-28049, that the researchers are hoping may go to clinical trial next year.

All of these drugs act on the same enzyme to cause DNA damage, working like 'liquid radiation' but with particular selectivity for the cancer cell. The problem is that amsacrine works well against leukaemia, and not so well against other cancers. The key challenge is to find out what 'extra' things the drugs need to do to make them work on other cancers. Current research indicates that the "extra" things require a functioning immune system to work.

GENETICS AND MOLECULAR BIOLOGY IN NEW ZEALAND

Much of New Zealand's reputation in this area has come from the work undertaken at Otago University in the department of biochemistry. Dr Tony Reeve has been at the centre of this work which has included:

- groundbreaking research, combining clinical and molecular studies which identified a molecular basis for Wilms tumour in children;
- combined clinical and molecular studies at the University of Otago which identified a molecular basis for a familial lung cancer in Maori families.

The latter of these research areas has really put New Zealand on the map in terms of a genetically inherited predisposition towards stomach cancer.

COMMON ELEMENTS OF SUCCESS

There are a number of factors that have made the drug development and genetics/molecular biology work in New Zealand stand out internationally. Both bodies of research have come from large, multi-disciplinary research groups undertaking work which involved close co-operation with patients, clinicians and pathologists. There is also an enthusiasm and willingness to take risks in new areas. This seems to be more possible in New Zealand because of our small size, and may be harder to achieve in larger countries.

WHERE TO FROM HERE?

Prof. Baguley believes that recently there have been some amazing advances in the way that we think about cancer. Two theories that he believes are particularly important are the stem cell theory of cancer and the "seed and soil" theory.

The stem cell theory revolves around the concept that if you have a cancer, most of the cells in that cancer are unable to keep on growing by themselves; that they are destined to die. The cancer is actually driven by a very small number of cells that can't be seen. These cells are hidden but you can infer that they are there. In the breast, a single stem cell is capable of multiplying and forming a complete duct. Stem cells are nurtured within a 'niche' which protects them before they go out and differentiate into different types of tissue with different functions. When the way in which the stem cell differentiates into tissue malfunctions, the stem cell produces abnormal structures, and benign and malignant tumours can result.

The seed and soil theory concerns metastases, when breast cancer spreads into the lymph nodes. Ordinarily when a breast cancer cell leaves the original tumour in the breast it would just die. It is believed that when they move to the lymph node and flourish, it is because the lymph node has already been "prepared" creating the right environment for the breast cancer cells. Although this research is in its infancy, it is thought that cells from somewhere in the bone marrow move to the lymph node and create the right environment for the breast cancer cells.

What is needed is an understanding of the relationship between the breast tumour cells and the rest of the body.

A disturbing implication of tumour stem cell theory is that while chemotherapy can kill most of the tumour cells it may be less effective against stem cells inside the protective niche. The cancer stem cells are the ones which are resistant to therapy and can grow the tumour

again; we need to develop a strategy for treating those cells. We need some sort of "triple-whammy" approach to tackling the niches that contain and protect the tumour cells.

This may involve a combination of standard chemotherapy, the body's own immune system and vascular-directed therapy. Vascular-directed therapy involves disrupting the tumour's blood supply. Prof. Baguley is currently working on a new drug, DMXAA, which has just been through Phase II clinical trials in lung, prostate, and ovarian cancer, in which it looks quite promising. It is hoped that it will undergo trials for breast cancer soon.

In conclusion, a number of factors or conditions are needed to make progress:

- a multidisciplinary research team,
- optimal interactions among cancer patients, clinicians and scientists,
- a funding structure that is not based on profit, and
- an ability to take risks.

All of these can be achieved in New Zealand!

Working Towards a National Database

DR RUTH SPEARING

Dr Ruth Spearing *is a Haematologist in Christchurch. She has been the Chairman of the IT Sub-committee of the New Zealand Cancer Treatment Working Party for the last four years, the major aim of which has been to develop a national cancer database.*

ABSTRACT

To further improve outcomes in the treatment of breast cancer and other malignancies, it is essential we know how successful treatments are in the various sub-groups of patients. At the moment, despite the amount of money spent on cancer treatments, there is very limited data collected with regard to their success or otherwise. National data collected in New Zealand is limited to survival, which for a condition such as breast cancer, which may be a relapsing and responding condition, is not adequate for clinicians. The IT subcommittee of the New Zealand Cancer Treatment Working Party has strived to persuade the Ministry of Health of the need for a national, consistent, accurate, patient-anonymous database which can be easily analysed by those involved in making treatment decisions.

NEEDING, WANTING A DATABASE

Why do we need a database and why is there so little progress at a national level?

Ruth Spearing describes herself as a frustrated Chairman of a Ministry Subcommittee whose aim has been to get national cancer data collected, to enable progress in the management of cancer. She asked whether it is a case of slow thoughtful progress wins the race or... Is it a dream that is lost in the bureaucracy of the system?

THE DREAM

The goal has been to collect cancer data nationally to enable progress in the management of cancer. The aim is to collect information on the incidence, diagnosis, treatment, and outcomes; how well do patients do on different treatments, what treatments are the most successful; to collect a comprehensive set of nationally consistent, peer reviewed and scientifically accurate data that was able to be intensively analysed.

THE HISTORY

In 2002, the subcommittee of the New Zealand Cancer Treatment Working Party (NZCTWP) of the Ministry of Health (MoH) was convened. There was a single teleconference. Ruth admitted that she is not very good at sitting back and watching things "not being taken forward." As a result, in 2003 she became chairman of the re-formed group, and in that year a considerable amount of active work was accomplished. In 2004 a

feasibility study was undertaken, and in 2005, Ruth presented the findings of that study to the Cancer Control Council who strongly endorsed it.

"They said that this was important work, work that needed to be done if treatment of cancer was to be taken forward," Ruth told the conference.

In 2006, a business case for funding was put to Treasury. At the end of that process 90% of the clinicians involved were very despondent. They realised that, whereas they had previously worked as a close-knit team with clinicians through many specialties, the cancer registry, and the New Zealand Health Information Service, it was suddenly being taken over by the Public Health team and bureaucrats who did not have an understanding of why or what data clinicians needed to try to improve patients outcomes. There was a real concern that the database was likely not to be a tool which could be used by clinicians for their patients.

Today, in 2007, although the money needed has apparently been obtained from Treasury, the NZCTWP has not been officially informed and, to date, there has been no progress.

WHY DO WE NEED A NATIONAL DATABASE

A database would enable an audit of results and comparison of local and national results, with international results, for the equivalent stage of disease. For example, we know that early breast cancer is different from advanced breast cancer, so we need to make sure we are comparing "apples with apples".

A database would enable the development of national treatment protocols. It would also help in the evaluation of existing screening programmes and provide baseline data for new screening programmes. We need to know whether patients picked up through screening are really doing better than patients who self-present. BreastScreen Aotearoa collects some excellent data but it really needs to be combined with data on what happens to those patients after screening has identified them.

A database would also:

- enable health professionals to give locally meaningful outcome data as part of the informed consent process;
- assess why there is a difference in the outcomes in different racial groups;
- provide data to research groups attempting to answer other questions;
- enable clinicians and managers to have relevant data with regard to the patient numbers and characteristics for managing local and national services, and to ensure equity of services across the country;
- allow the effectiveness and use of expensive treatments to be assessed; and
- enable the success of the Cancer Control Strategy to be assessed.

THE EXISTING CANCER REGISTRY

New Zealand has a very good cancer registry, however, it lacks:

- accurate information on the stage of disease;
- details of treatment: surgery, radiotherapy, chemotherapy, palliative care;
- outcome data: response rates, response duration, disease free survival;
- comparative data for screening programmes to be able to compare outcomes to the same cancers picked up through self presentation;
- occupational and exposure data.

A lot of data is already collected at many points in the health system and from many sources. However, that data is not pooled. For a system to be efficient there needs to be:

- electronic cross-capture of basic information already captured by other national datasets, local clinic and pharmacy databases;
- set up so that certain fields such as stage can be overwritten by clinicians;
- collaboratively developed by all the clinical groups involved in each subspecialty (public and private) along with management and MoH representatives;
- readily accessible (ideally online) to all these groups for the purposes of data entry, analysis and interpretation as required;
- capable of being used by relevant health professionals for audits or research in an unidentifiable way, with identification of patients limited to those within their own centre.

A NATIONAL DATABASE

The national database project needs to be outcome focused. If health professionals can see meaningful outcomes, they will ensure data is entered.

The concept that was put to the Cancer Control Council was that this should be a national collection of data, that stewardship should be with the New Zealand Health Information Service, but that there should be active governance by clinicians and other health professionals, and consumer representatives.

Two levels of data should be collected: core data for all cancers (see box at right) and common data for each major anatomical site. There has been considerable enthusiasm among clinicians and there were many specialities 'putting up their hands' and saying "please could we be first."

The NZCTWP compiled guidelines for which cancer group should be the first to develop a database to see whether or not it would work. It needed to be a common cancer and one that was the subject of considerable public concern. It also needed to be a cancer in which patients and clinicians were motivated to obtain answers and therefore to collect the data. It needed to be a cancer in which there was evidence that clinicians could co-operate on evidence-based management of cancer, and had already developed collective thinking about core and common data for that cancer site/speciality. Breast cancer was the only one that really stood out.

Two years ago, Ruth would have been sure that a national breast cancer database was "only a leap away"; now she is not so sure.

"Maybe we need to step back and look at starting small and building big. Maybe we need to look at what has already been achieved by groups such as in Auckland and the Waikato and take what they have done to the rest of the country."

Core Data For All Cancers
Patient Demographics - NHI, DoB, gender, and ethnicity, etc.
Tumour demographics - Type
Stage
Health Practitioner Index
Dates of surgery, radiotherapy, chemotherapy and palliative care
Follow -up status - survival yearly

The day before her presentation – Ruth believes it was as a result of her speaking at the conference – she had a phone call from the MoH. A very positive phone call which said:

"Let's get key people together to see if we can take forward the concept of being able to extract data from local clinical information systems."

"Let's make the meeting December."

She is still unsure if it will happen, but she is sure that it will not happen unless the people affected by cancer tell the Minister for Health and the MoH the importance of them knowing how well they are doing and what is working and what is not.

Lois Muir & Barbara Mason

Dell Gee, Jackie Blue & Anne Josefa

The Value of the Auckland Breast Cancer Database

PROF VERNON HARVEY

Prof Vernon Harvey *is Associate Professor of Medical Oncology at Auckland University and Senior Medical Oncologist at Auckland City Hospital, and for twenty years was the Director of Clinical Oncology. He has been the principal investigator on numerous breast cancer trials. Over the past twenty five years Clinical Oncology at Auckland Hospital has been a major contributor to breast cancer trials run by Cancer Trials New Zealand, Australia and New Zealand Breast Cancer Trials Group, International Breast Cancer Study Group, Breast International Group, Breast Cancer International Research Group and various pharmaceutical companies. He is on many boards and advisory committees – The New Zealand Breast Cancer Foundation (medical advisory committee), Sweet Louise (trustee and chairman of the medical advisory committee), ANZ Breast Cancer Trials Group (scientific advisory committee) and Breast Special Interest Group of the New Zealand Association of Cancer Specialists (executive member). Vernon is a member of CATSOP, the Cancer Therapy subcommittee of PTAC, Pharmaceutical Therapy Advisory Committee of PHARMAC.*

ABSTRACT

The Auckland Breast Cancer Database was established in June 2000 in response to the need for a comprehensive review of breast cancer in New Zealand women. The aim was to document the incidence and nature of breast cancer in Auckland, its means of diagnosis and treatment, risk factors for recurrence and death, and rates of survival. This would allow review of patterns of care, particularly in defined patient groups and, in time, allow us to compare the processes of care with guidelines, actual with predicted outcomes and outcomes in defined subsets of patients, especially Māori and Pacific Islanders.

THE NEED FOR A DATABASE

"It seems to me, absolutely self-evident that you can't know where you are going to end up if you don't know where you are starting from," Vernon told the conference delegates.

"And we don't know where we are starting from!"

There are few data on breast cancer in New Zealand and there is a conflict between the need for data collection and personal privacy issues and laws.

"It is embarrassing for me to stand here and tell you that I cannot tell you how many patients with breast cancer were treated at Auckland hospital this year, or last year, or any other year before that."

In support of Ruth Spearing's dream and that of the NZCTWP, to have a national cancer database, the Auckland breast cancer database offers a glimpse of what might be possible.

The current Auckland breast cancer database is in its second incarnation after privacy issues shut down the first one in 1985. It took ten years of red tape before the second database could be started in 2000, and it is only now, in 2007, that it is beginning to be useful. It takes time for things to happen.

THE AUCKLAND BREAST CANCER DATABASE

The Auckland breast cancer database aims to document:

- the incidence and nature of breast cancer in Auckland,
- diagnosis and treatment,
- risk factors for recurrence and death,
- progression free and overall survival.

It allows the review of patterns of care in defined patient groups, especially Māori, Polynesian and Asian women. It also allows comparison of processes of care with guidelines, actual with predicted outcomes and the outcomes in defined subsets of patients. That information also directs future research so that treatment and care can be improved.

Currently there are just over 4000 patients whose data is eligible to be entered into the database, and because of a time-lag in data entry (because so much happens in the first six months after diagnosis), 3661 (88%) of patients have been entered into the database. Only 100 patients declined to have their data included, usually because of language barriers.

WHAT CAN BE DONE WITH THE DATABASE?

The database provides information on age, ethnicity, prognoses and relapses. The database has shown that in Auckland:

- 99% of patients are female, 1% are male.
- At diagnosis 29% of patients are under 50 years, 44% are between 50 and 65, and 27% are over 65.
- Overwhelmingly, patients on the database are European New Zealanders. Compared with census data, there are fewer Māori, Pacific Island and Asian patients than would be expected.
- In terms of detection, more women find a lump (50 to 60%) than are diagnosed through screening, and that rates for screening have been consistently between 35 and 40% of patients of the last five years.
- For women between 50 and 69 years of age the reverse is true: between 55 and 60% of breast cancers are detected through screening and 35 to 40% are detected when the patient finds a lump.
- The proportion of Māori and Pacific Island women, and, to a lesser extent Asian women, diagnosed through screening are somewhat lower than the proportion of women of European descent.
- In younger age groups (under 40) there are fewer small tumours and a greater number of large tumours compared with older women, therefore one can predict that overall younger women will have poorer outcomes than older women.
- Māori and Pacific Island women also have more large tumours and fewer smaller tumours, again leading to the prediction that these women will have poorer outcomes than women of European descent.
- Younger women, and Māori and Pacific Island women have more grade 3 tumours than older women and women of European descent.

In addition, the database contains information on the treatment given (mastectomy, partial mastectomy, radiation, etc.) and the frequency of hormone receptors and HER2 positivity. Among patients on the database, 16% had chemotherapy alone (4% declined chemotherapy), 37% had hormonal treatment (3% declined hormonal treatment), 18% had both and 24% had neither.

Only 409 patients have been in the database long enough to provide five-year outcome data. However, among those patients 12 have had a local recurrence, 38 have had metastases, 18 have had both, and eight have had a second primary cancer. Sixty five patients have died, two thirds of them from breast cancer, and there is an overall survival of those in the database of 84%. However, the five-year dataset is far too small to be particularly meaningful.

The database can be used to predict the outcomes for everyone on the database using the data on tumour grade, size, age, etc. When that data is combined with treatment information it can be used to predict how many relapses one can expect among those patients, which can then be compared with how many actual relapses occurred.

This information provides clinicians with a tool by which they can measure the efficacy or appropriateness of the treatment given to patients. If the right treatment is not being given to the right patients this will show up in the data and delivery of treatment can be improved, thus improving outcomes for patients.

Future Trends in Breast Imaging

DR BARBARA HOCHSTEIN

Dr Barbara Hochstein, *a consultant radiologist since 1990 with subspecialty skills in women's imaging, has been involved with breast imaging since 1988. She has worked in Auckland in both public and private hospitals, has been a clinical lecturer at the Auckland Medical School since 1989, organised the first multi-disciplinary breast conference in New Zealand (Auckland 1997), and was the founding Medical Advisor to the New Zealand Breast Cancer Foundation. After the commencement of the national BreastScreen Aotearoa programme, Dr Hochstein shifted to Rotorua and has been the clinical director of the Bay of Plenty sub-contracter to BreastScreen Aotearoa since 1999.*

ABSTRACT

The fundamental techniques used in breast imaging are mammography and ultrasound. Breast MRI is a relatively new modality that has become an extremely useful tool for the evaluation of breast cancer. The role of breast MRI imaging will be discussed in particular for screening of high risk women with a BRCA gene mutation. There are also new and exciting developments in breast ultrasound (elastography), which is still a research tool but may become another exciting addition to breast imaging.

INTRODUCTION

Dr Barbara Hochstein began by acknowledging that behind the images she spends her days viewing there is always a woman and her story.

Discussing future trends in breast imaging is a bit like crystal ball gazing. What is on the horizon? What is going to be the new technology? There have been announcements in the media that there are exciting new advances in technology, but except for one or two of them, they are not yet in clinical practice.

Breast anatomy explains why there are so many changes possible in the breast, in the ductal system. Proliferative changes occur at the last branch of the ductal system – this is also the site for pre-invasive ductal carcinoma *in situ* (DCIS). Invasive cancer starts here and then invades the adjacent breast tissue.

Imaging is involved both when a problem is found, for example, when a woman finds a lump, and as part of a screening programme. However, imaging cannot make a diagnosis. It only detects an abnormality in the breast tissue; a biopsy is used for diagnosing cancer.

There is a debate over mammography which can become very heated. However, we still have a very incomplete understanding of the biology of breast cancer. Because there is not only "one" type of breast cancer but up to ten different types of breast cancer, there is not "one" disease but a spectrum of disease, and some of the breast cancer changes we can see and some we can't.

The vast majority of breast cancers are the invasive ductal cancers. Most of them do enough to be seen on a mammogram, but some, such as invasive lobular cancer rarely show up on a mammogram.

Mammography does not detect between ten and 20 percent of breast cancers, and it over-diagnoses up to ten percent of the time, showing cancer where none exists. It may also be inadequate in dense breast tissue.

So what is the future of breast imaging?

The pathway from technical innovation to accepted clinical practice is long, arduous and costly. Breast imaging needs to be evidence-based, and, for all its limitations, mammography is the only modality that has been evidence-based. The research has shown that there has been a 30% reduction in mortality with mammography. There have been no randomised controlled trials (RCTs) that have evaluated ultrasound and MRI for reductions in mortality.

DIGITAL MAMMOGRAPHY

This is a relatively new technique (2000), and two machines have been installed in New Zealand with the next due before the end of 2007. This technique represents a rapid advance in mammography in which the image is captured

digitally rather than on film, and thus the data can be manipulated digitally and enhanced. Unlike traditional mammography there is no processing and no chemicals. Advantages include that it works better in dense breasts and that lower doses of radiation are used.

The disadvantages are that it is slower to read, and hard to compare with traditional analogue mammograms. There is also no ability to switch between large and small format; you need a large format machine for large breasts but it can be difficult to position smaller breasts.

There is no difference in cancer detection rates between digital and film mammography. Recent trials have shown that there is increased sensitivity in women under 50 years of age and women with dense breasts with digital mammography.

DIGITAL TOMOSYNTHESIS

This technique was announced in 2005 although it has been limited by the Food and Drug Administration in the US as an investigational tool. The first commercial unit was to be released in Chicago in November 2007.

The technique takes "slices" or images every millimetre through the breast, obtaining between 50 and 70 images in five seconds. It does not require compression of the breast, and only uses the same level of radiation as traditional mammography. This exciting technique offers much better resolution of lesions and abnormalities, allowing greater precision in detection. The minimal compression used would also encourage patient compliance.

CONTRAST ENHANCED DIGITAL MAMMOGRAPHY

This technique uses an iodine contrast agent or dye which is injected while a sequence of tomography images is taken. The speed at which the dye is taken up allows differentiation between malignant and benign tumours.

MAGNETIC RESONANCE IMAGING (MRI)

MRI has been around since the 1980s. It had an enthusiastic start in breast imaging in the 1990s but there are difficulties and obstacles. It is very costly, time consuming for the patient and time consuming for the radiologist as some 5000 images are generated. It uses an IV contrast and biopsy is also needed. The technique is very sensitive, but not very specific; that is, it picks up almost all invasive cancers but also picks up many normal changes in tissue.

MRI will not replace mammography, ultrasound and biopsy, but it is a useful tool for integrated imaging as an adjunct to mammography and ultrasound within a breast imaging team. It is useful in local staging of known breast cancer, differentiating between scar tissue and a recurrence, evaluating silicone implants and the response to neoadjuvant chemotherapy, in which women are given chemotherapy prior to surgery.

It is also particularly useful for screening the small group of wom.en who at very high risk women, the approximately five percent of women with BRCA gene mutations. These women develop interval cancers more frequently than others, cancers that are often more aggressive, and mammography often misses such tumours. The medical literature now indicates that the optimal way of screening these women is to combine MRI with mammography and ultrasound. Already, the United Kingdom and Australia have protocols in place for the use of annual MRI on these high risk women.

MR SPECTROSCOPY

In the US, magnetic resonance (MR) spectroscopy combined with MR imaging has been used. MR spectroscopy provides chemical information about cancer. As well as viewing the MR images they look for a choline peak, which is a chemical signature that most invasive cancers have. Because MRI picks up many non-cancerous changes in breast tissue, a choline peak can confirm that the lesion that is picked up on the MRI is actually cancer.

ULTRASOUND

Ultrasound continues to have an important role in detection and diagnosis, for problem solving, evaluating a palpable mass, and particularly for guiding the biopsy needle to the mass that is to be tested.

One of the developments in ultrasound is elastography or strain ultrasound, which enables the 'hardness' of the lump to be determined. The image displays the 'elastic' properties of the breast tissue, or differences in tissue 'stiffness'. This technique can differentiate between benign lesions, which always appear smaller with elastograpy than with ultrasound, and malignant lesions which always appear larger. It

is particularly useful for reducing the number of biopsies currently performed of benign lesions.

OTHER TECHNIQUES

There are some other techniques that are on the horizon. PET scanning, or positron emission tomography, uses radioactive glucose to show up malignancies. However, it is not very sensitive and many cancers are not metabolically active enough to show up using this technique, and it has not been proven to be useful for breast screening. However, it is very sensitive detecting cancers in the lymph nodes, and has great potential as a possible replacement for sentinel node biopsy. But it is early days and the technique is very, very expensive.

Two other technologies are scintimammography and optical imaging have been discussed in the medical literature but neither has been shown to be useful in breast imaging.

Finally, thermography has been around for many years, but is a controversial technique that has been largely shunned by conventional medicine and screening programmes as having insufficient data.

Screening for Breast Cancer – ensuring equity

DR MADELEINE WALL

Graduating as a doctor in 1982 ***Madeleine*** *subsequently specialised in radiology and has worked almost exclusively in breast imaging and screening for the last ten years. She was Clinical Director of the Wellington regional breast screening programme until 2003 when she became the clinical leader of the national programme, BreastScreen Aotearoa.*

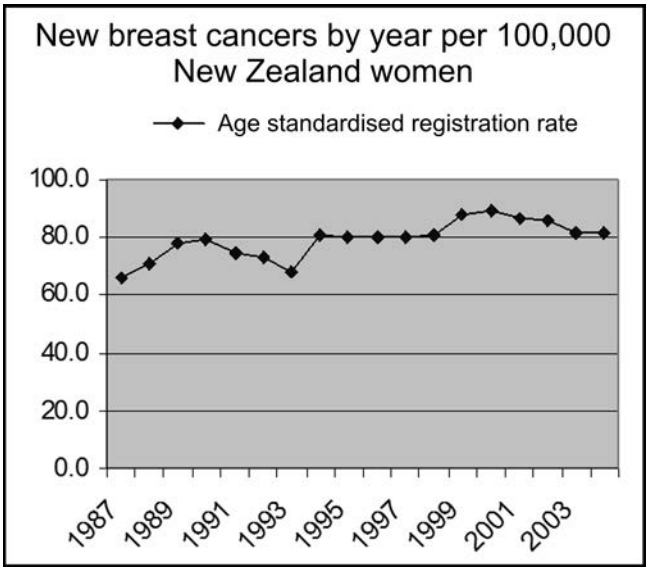
ABSTRACT

Data will be presented on those who are most at risk of developing or dying from breast cancer, appropriate screening tests to reduce breast cancer mortality and the current situation regarding New Zealand women's access to these services and what BreastScreen Aotearoa achieves.

BREAST CANCER IN NEW ZEALAND

How many women in New Zealand get breast cancer? Since the late 1980s the incidence of breast cancer has increased. Each year from 1987 to the mid 90s there was a climb in the diagnosis rate, with a spurious dip in 1993 because we did not count cases particularly well until about 1995-96.

The graph at right represents the number of new diagnoses of breast cancer per 100,000 New Zealand women since 1987. There is a bulge in the graph between 1999 and 2003 due to the implementation of the breast screening programme. This occurs because not only does breast screening diagnose cancers that would have been diagnosed that year, it also "pulls cancers out of the future" and diagnoses these



one to two years earlier than they would have been diagnosed. The rate then drops back down to the pre-screening rate as just the smaller cancers are detected.

A New Zealand woman's risk of developing breast cancer lies somewhere between the risk that Australian and American women bear (see table below). The risk is lowest in our twenties at less than one woman developing breast cancer for every 2000 women in the population, increasing to one in 32 in our 60s, after which time the risk decreases slightly.

Risk of Breast Cancer Diagnosis by Age in Australia, USA and New Zealand.

Age	Australian (AIHW)	USA (NCI)	New Zealand (MOH)
20s	1 in 2000	1 in 2500	0 – 1 in 2000
30s	1 in 250	1 in 232	1 in 245
40s	1 in 70	1 in 55	1 in 65
50s	1 in 40	1 in 40	1 in 37
60s	1 in 35	1 in 29	1 in 32
70s	1 in 30		1 in 37

RISK FACTORS

If you are a woman you are at risk of getting breast cancer and this risk increases with age. Research on the risk factors for breast cancer is continuing. A review of the current evidence was conducted by Otago University for the National Screening Unit (NSU). Risk factors for which there is strong evidence are:

- lifetime exposure to oestrogen,
- high energy (caloric) intake,
- obesity
- alcohol
- previous breast cancer, and
- dense breasts (having dense breasts confers a risk of two to four times that of other women.)

There is conflicting evidence for phytoestrogens, xenoestrogens and DES (diethylstilbestrol).

You cannot eliminate your risk of getting breast cancer but you can do things to stop your risk increasing, including:

- limiting alcohol intake,
- avoiding post-menopausal obesity, and
- limiting use of HRT.

THE RISK OF DYING FROM BREAST CANCER IN NEW ZEALAND

In New Zealand the mortality rate at five years after diagnosis is similar to Australia and Canada, worse than in the US and better than in the UK. However, these figures derive from women diagnosed prior to the implementation of our breast screening programme, and at a time when breast screening was established in three of the other four countries.

Commonwealth Fund 5 Country Comparison 2004 (numbers from 1998) - five year relative survival rates from breast cancer (figures are from 1998).

Australia	NZ	Canada	England	USA
80%	79%	78%	75%	86%

Death rates from breast cancer have been progressively declining since the late 1980s, largely because of the use of Tamoxifen to treat oestrogen positive breast cancers.

RISK FACTORS FOR DYING FROM BREAST CANCER

In New Zealand the risk of dying from breast cancer is strongly tied up with who you are and your socio-economic status. Out of 100 women with diagnosed breast cancer with the highest socio-economic status, 81 will still be alive after ten years (19 will have died). Compare that with 100 women who are the most socially deprived and also diagnosed with breast cancer. Only 67 of these women will survive ten years (33 will have

died). So, economically advantaged, least deprived women are more likely to survive breast cancer than those most deprived. This disparity is seen worldwide.

Ethnicity is another clear factor in the survival stakes. Prior to the screening programme, 78% of non-Māori women survived 10 years following a breast cancer diagnosis compared with only 55% of Māori women. Breast cancer survival is best for Asian women, followed by women of European descent, then Māori women and poorest for Pacific Island women. Ethnic differences in survival are much greater than, and are not explained by, differences in deprivation (income, education).

One of the major influences on survival outcome is the stage at diagnosis; whether the cancer is confined to the breast (localised), has spread to lymph nodes nearby (regional spread) or has already spread to distant organs (metastases). Ninety-one percent of women with localised disease at diagnosis will survive ten years, whereas for women in whom cancer has spread to the lymph nodes at diagnosis, only 60% will survive ten years.

Breast screening can change the prognosis by picking up cancer at an earlier stage. (Early diagnosis does not however change the grade or the receptor status of the breast cancer and these factors also influence prognosis.)

Clearly, screening can eliminate disparities in survival outcomes between Māori and non-Māori.

IMPROVING SCREENING UPTAKE

By all current indicators BSA is meeting the interim targets to reduce breast cancer deaths in the women it screens. However, BSA needs to ensure that it offers accessible services to at least 70 percent of women if breast cancer deaths in the eligible population are to be reduced overall. Currently, 63 percent of eligible non-Māori women are enrolled with BSA and participating in breast screening. Among Māori and Pacific Island women, the uptake is only 40 percent of those eligible.

NSU commissioned research has identified a number of barriers to women participating in breast screening. Gaining the trust of women from ethnic minorities and offering them acceptable screening experiences is a challenge all over the world. In New Zealand a few of the barriers identified relate to where BSA services are sited – which is very important for those reliant on public transport. Many women cannot take time off work for a mammogram without having to take a whole day's sick leave, so after hours appointments are important. Many are unaware that you will not be automatically invited, that each woman must enrol in BSA. Others believe cancer is an automatic death sentence and do not realise that early detection with mammography can prevent them dying from breast cancer.

Proportion of cancer picked up at each stage prior to and following the implementation of breast screening.

	Prior to BreastScreen Aotearoa	After BreastScreen Aotearoa (1999-2005)
Localised Cancer	54%	76%
Regional Cancer (spread to lymph node)	40%	23%
Metastases	5.5%	0.8%

There has clearly been a significant shift to earlier detection in those women who have regular screening within BSA compared to women diagnosed before the programme began. Preliminary data suggests that for women screened within BSA between 1999 and 2003 and diagnosed with cancer, there is a reduction in risk of a breast cancer death of about 23% for non-Māori and 64% for Māori. This data indicates that for both Māori and non-Māori alike, ten year survival is likely to be about 83%.

As an example of what can be achieved, BreastScreen South covers three-quarters of the South Island and is unique in screening over 70% of each of its main ethnic groups. It has done this by working with GPs to identify unscreened women and invite them to participate; they also follow-up with health promotion, information and support services.

SCREENING MAMMOGRAPHY

Mammography as a screening tool is far from perfect. It works best in women over 50 but is problematic in women under 50 and in women with dense breasts. Mammography does not detect all breast cancers. The ones that do not show up on a screening mammogram are called interval cancers. About 15% of cancers in screened women over 50 years and 25% in 40 – 49 year old screened women will be interval cancers that show up as a symptom, for example, a lump, between regular screening mammograms. An interval cancer may occur because:

- it was missed off the film,
- the radiologists missed it,
- it does not show on mammograms even when you can feel it, or
- it has grown quickly.

Unfortunately, we do not currently have a better tool for breast screening. Ultrasound has a lower sensitivity and specificity than mammography, although it remains an important diagnostic tool for investigating already identified problems. It may prove to be useful with mammography in screening high risk, dense breasted women. This is currently being investigated in a large US trial (ACRIN6666)

BSA advise women that learning to examine your breasts does not reduce your risk of dying of breast cancer. Breast self examination has been shown in two very large trials not to prevent breast cancer deaths, but to increase the number of unnecessary biopsies. However, apart from screen detected breast cancers, most women actually find their own cancers by chance. Even women who practise breast self exam often find their cancers by chance, in between their regular monthly exams. Self exam kits do not appear to help. There is evidence that palpation aids like Breast Chek (breast self exam kit) actually make it less likely you will find small lumps. The important thing is not training your fingers to feel lumps but to act promptly to see your doctor no matter how you find or notice a change in a breast.

Women should go and see their GP if they have symptoms; they should not enrol in BSA or wait for screening in these circumstances. Women with a breast problem can get free, more appropriate and timely care at a hospital clinic.

In addition women need to know that mammography for asymptomatic high risk women, regardless of age, is publicly funded, and requires a GP referral. High risk women include those who have a mother or sister with premenopausal breast cancer or bilateral breast cancer, or have had a previous breast cancer, or who have had a breast biopsy in the past showing an at risk lesion such as “atypical ductal hyperplasia.” These mammograms are not provided by BreastScreen Aotearoa but by local district health board services.

Sentinel Node Biopsy and SNAC Trial Results

MR IAN CAMPBELL

***Ian Campbell** is a Breast and General Surgeon at Waikato Hospital. He is the Clinical Director of the Waikato Breast Care Unit, Waikato Hospital. Ian is a Senior Lecturer for the Waikato Academic Division of the University of Auckland School of Medicine, and a member of the Board and the Scientific Advisory Committee for the ANZ Breast Cancer Trials Group. Among his many committee memberships, Ian is currently the New Zealand Representative on the Royal Australasian College of Surgeons (RACS) Breast Section Executive, Chairperson of the New Zealand Guidelines for Management of Breast Cancer, New Zealand Guidelines Group, a member of the Sentinel Node biopsy versus Axillary Clearance (SNAC) Trial Management Committee and Chairperson and Protocol Author of the SNAC 2 Sentinel Node Trial. Ian is also Chairperson of the Waikato Breast Cancer Trust and has co-authored many publications on the topic of breast cancer treatment and research.*

ABSTRACT

The status of the axillary or armpit lymph nodes remains the most important indicator of outcome for women with breast cancer and helps predict the need for further treatment (e.g. chemotherapy or radiotherapy). Traditionally, axillary node status has been determined by removal of most of the nodes (axillary clearance or dissection). This operation may lead to arm swelling, pain, some abnormal skin sensation or shoulder stiffness.

The **S**entinel **N**ode biopsy versus **A**xillary **C**learance (SNAC) 1 trial has established that for women with small, unifocal breast cancers the removal of the "sentinel" nodes (i.e. the first lymph node/s draining from the region of the breast cancer) may provide accurate information as to whether axillary nodes are involved with cancer or not. Sentinel node based management resulted in fewer side effects for women but, for those women who were found to have involved nodes, sentinel node biopsy overall missed three percent.

The SNAC 2 trial, seeks to evaluate the long term outcome of this false negative rate and whether sentinel node biopsy is appropriate for women with larger or multi focal tumours.

BACKGROUND

Axillary node dissection (or clearance) has been the standard surgical treatment following removal of a cancerous tumour. Axillary (lymph) node status remains the single most important predictor of outcome for breast cancer. It also helps oncologists select appropriate further treatment for breast cancer, such as hormonal treatment or chemotherapy, and sometimes radiotherapy.

Axillary node dissection is also therapeutic in itself. The chances of local recurrence of breast cancer in the axilla after axillary dissection are very low. It remains a controversial issue as to whether it also confers a survival benefit for some women.

The risk of cancer spread (metastasis) to the lymph nodes is directly related to the size of the breast cancer. When the tumour is less than one centimeter in diameter, the risk of axillary metastasis is around 10%; when the tumour is greater than five centimeters, the risk of axillary metastasis is greater than 70%. Overall, for women with a small breast cancer, axillary dissection is an unnecessary operation; for 60 to 70 percent of women there are no lymph nodes involved. Axillary dissection has associated potential side-effects, including infection, pain, shoulder stiffness, upper arm numbness and lymphoedema (swelling of the arm). These issues have led surgeons to try a new less invasive technique to reduce the side-effects of axillary surgery.

SENTINEL NODE BIOPSY

The sentinel node or nodes are the first lymph node/s to which the area of the breast containing the cancer drains; it is the node or nodes most closely related to the cancer. Surgeons can identify these node/s, in most women, by injecting blue dye or a radio-tracer, or both, around the tumour. A scan then reveals the first node that drains the area of the breast in which the tumour lies.

The sentinel node/s is then removed and sent to the laboratory for microscopic examination. If the node contains cancer cells, the surgeon proceeds with an axillary node dissection. If there is no cancer, no further surgery is required.

The assumptions with sentinel node-based management are that:

- sentinel node biopsy will accurately predict node status
- there are fewer side-effects than with axillary node dissection, and
- it will produce equivalent cancer outcomes.

The SNAC trials are essentially asking if these assumptions are true.

THE SNAC TRIALS

The original SNAC trial – SNAC 1 – is a multicentre randomised trial run by the breast surgery section of the Royal Australasian College of Surgeons in collaboration with the Australian National Health and Medical Research Council Clinical Trials Centre. There were 28 centres in Australia and four centres in New Zealand that took part in the study; 20 percent of the women who participated were from New Zealand.

Women were recruited to participate in this trial faster than in any other cancer trial in Australia and New Zealand. It was also the first multicentre randomised surgical study in breast cancer designed and conducted within Australia and New Zealand.

The aim of the SNAC I trial was to determine if Sentinel Node Based Management (SNBM) causes less side-effects than Routine Axillary Clearance (RAC) with equivalent cancer-related outcomes. The critical question faced by a woman with breast cancer, and her surgeon, is "does the risk of missing an involved lymph node (a false negative) with sentinel node biopsy outweigh the risk of side effects, in particularly lympho-edema, from RAC?"

Women were eligible if they had a unifocal, invasive cancer, less than three centimeters in size where no suspicious nodes could be felt in the armpit. Participants were randomised to one of two groups:

- Sentinel node biopsy followed immediately by axillary clearance, or
- Sentinel node biopsy followed by axillary clearance only if cancer is found in a sentinel node. If no sentinel node could be found then axillary node dissection was performed.

The outcomes were measured at one, six, twelve months and annually out to five years and included:

- objective outcomes rated by clinicians:
- arm swelling, sensation, movement;
- seroma, haematoma, infection (that is, side effects related to surgery).
- subjective outcomes rated by patients:
- arm symptoms, dysfunction and disability using SNAC Study Specific Scales (SSSS);
- the European Organisation for Research and Treatment of Cancer (EORTC) core questionnaire and breast module;
- the body image after breast cancer questionnaire.

SNAC STUDY SPECIFIC SCALES (SSSS)

SSSS was developed with consumers, clinicians and researchers and validated in the first 500 patients (Nowak, SABCS 2004), and was found to be more sensitive than clinician measures in all cases (Smith, Rome 2006).

RESULTS OF SNAC I TRIAL

The sentinel node was the only positive node found in 63 percent of women in which the positive nodes were found; that is, the cancer had not spread beyond the sentinel node.

The ability of the sentinel node biopsy (SNB) to detect a positive node (or sensitivity) was 92 percent; that is, SNB detected 92% of the women in whom cancer had spread to the lymph nodes. False negatives were eight percent but if non-sentinel nodes were included the false negatives dropped to five percent.

SNAC Study Specific Scales (SSSS)

7 Symptoms	3 Dysfunctions	4 Disabilities
Pain	Using hand	Dressing
Swelling	Using arm	Doing hair
Tightness	Raising arm	Working
Heaviness		Housework
Numbness	Trouble Sleeping	
Pins and needles		
How it looks		

The scale was 0 = none at all to 10 = worst I can imagine.

Sentinel Node Biopsy versus Routine Axillary Clearance

	Sentinel Node Based Management		Routine Axillary Clearance	
Sentinel node -	67%		69% →	Axillary Clearance
Sentinel node +	29% →	Axillary Clearance	25% →	Axillary Clearance
Sentinel node not found	4% →	Axillary Clearance	6% →	Axillary Clearance

If all women who participated are considered, SNB failed to identify a positive sentinel node in only three percent of cases.

A woman who has a one centimetre tumour has approximately a 20 percent chance of having lymph nodes involved. On this basis the results of the SNAC I trial indicate that for every 100 women with a one centimetre tumour, only one woman would be missed using SNB. For 100 women with a five centimetre tumour, this increases to five women being missed in a SNB.

In terms of the side-effects from the procedure, SNB offers a significant benefit to women. At 30 days post-surgery the incidence of infection and seroma are considerably less in SNB patients compared with those who had routine axillary clearance (RAC) (see table below).

Incidence of side-effects in Sentinel Node Biopsy versus Routine Axillary Clearance

Surgical Event	Sentinel Node Based Management	Routine Axillary Clearance
Infection	9%	14%
Seroma	17%	36%
Haematoma	7%	6%

These figures include the women in the sentinel node based management arm of the trial with positive sentinel nodes who went on to have RAC (33% of participants in that group) compared with the women in the control group who all had RAC.

Differences in arm mobility between the two arms of the trial diminish over time, while differences in arm swelling increase over time.

Clinically, after one year SNB continues to outdo RAC with a significant reduction in most symptoms, and it is expected that with long-term follow-up the difference will be even more significant.

In terms of how the women rated the severity of side-effects in the two arms of the study using SSSS, one year after surgery the side-effects reported by women in the SNB arm were significantly reduced.

Again, these figures include the women in the sentinel node based management arm of the trial with positive sentinel nodes who went on to have RAC.

Incidence of side-effects in Sentinel Node Biopsy versus Routine Axillary Clearance after one year .

Score	Sentinel Node Based Management	Routine Axillary Clearance
Overall	4.3	7.0
Symptoms	5.5	9.7
Dysfunction	3.5	5.6
Disability	2.8	3.4
Swelling	3.4	7.4

The scale was 0 = none at all to 10 = worst I can imagine.

In conclusion, SNB was found to be highly accurate and leads to significantly less morbidity based on both objective clinicians' measurements of arm swelling and subjective patient-rated outcome measures. However, definitive answers about cancer recurrence require meta-analysis of all randomised trials.

The Royal Australasian College of Surgeons position statement on SNB is that:

- Many descriptive studies and several randomised controlled trials have shown sentinel node biopsy to be a viable alternative to level 2 dissection for staging the axilla in smaller, clinically node negative breast cancer, with significantly less morbidity.
- The technique is accurate, but there are a small number of false negative cases. The clinical significance of this is currently unknown, and results of randomised controlled trials are awaited.
- Surgeons commencing sentinel node biopsy should audit their results against level 2 dissection, using the SNAC trial protocol as a guide, prior to offering sentinel node biopsy as standard practice.

SNAC II TRIALS

The second phase of introducing sentinel node biopsy to breast cancer surgery is referred to as the SNAC 2 trial and is very similar to SNAC I. The SNAC 2 trial will extend the work started on

SNAC 1 and will investigate the use of SNBM in women with larger breast cancers or more than one cancer in the breast. SNAC 2 will determine whether the smaller operation gives cure rates as good as axillary clearance, and if so, for which women does this apply. Does SNBM work only for small breast cancers or is it appropriate for women with larger cancers or more than one cancer? SNAC 2 will also contribute to answering the very important question, "Does sentinel node biopsy result in increased local recurrence or decreased survival, and if so, for which group of women is this the case and for whom is axillary clearance really necessary?"

IN CONCLUSION

The decision for a woman and her surgeon about whether to proceed with SNBM becomes a trade-off between the risk of a false negative sentinel node resulting in a possible consequence of local recurrence and possible impact on survival versus the increased risk of side effects associated with axillary clearance.

> *"The pivotal issue regarding the safety of sentinel-node surgery in patients with breast cancer is whether it results in a reduction in survival - even a relatively small reduction." (Krag & Ashikaga, 2003)*

Any effects on survival in the SNAC trials are likely to be small, but could be important. The final answer about overall survival will require long-term follow-up and analysis of information from all clinical trials evaluating sentinel node biopsy. With the long term commitment of women participating in the SNAC trials, and other international sentinel node biopsy trials, we eagerly await this answer.

Moving Targets – making sense of the science in clinical practice

DR JEREMY LONG

Dr Jeremy Long *is a Medical Oncologist. Originally from South Africa, he trained at the University of Witwatersrand and has been in New Zealand since 1996. He initially worked in Auckland for six months, but subsequently chose the country life of Hamilton. He completed the Australasian Fellowship in 1998. Jeremy has been a Clinical Senior Lecturer for the University of Auckland Medical School since 2000, has been the Clinical Director of the Regional Cancer Centre at Waikato Hospital since 2000, and the Clinical Director of the Midland Region Cancer Network since 2006.*

ABSTRACT

For over 100 years, targeted therapy has been used to manage breast cancer. The oestrogen receptor and the ability to modulate it through various strategies has been a fundamental premise for developing tailored treatments for breast and many other cancers. Over the last two decades there has been an explosion in the basic scientific understanding of cellular function at a molecular level in both normal and cancer cells, and this understanding has resulted in fundamental changes in the way we investigate and manage breast cancer. The job of clinicians is to interpret these changes and use the powerful weapons we now have to advise our patients on the best management for them.

INTRODUCTION

The way in which we think about breast cancer has evolved, which has helped researchers and doctors work out how they should be treating the disease. Over the years 250,000 women have been involved in clinical trials that help to answer some of the questions we have about breast cancer and how it should be treated, and to help us move forward.

We have a single common purpose: to eradicate breast cancer. So, how are we progressing towards this goal? How did we get to where we are now and where do we go from here?

Deaths from breast cancer (number of deaths per 100,000 women of population) increased steadily from the 1950s to the 1990s, at which point mortality started to decline. Mortality peaked at about 75 per 100,000 women in the UK and about 67 per 100,000 in the US; New Zealand rates lie somewhere between these two countries.

The decline has been brought about by a combination of the efforts of all health care professionals working with breast cancer – radiographers, breast surgeons and oncologists.

BREAST CANCER IN HISTORY

The connection between the ovaries and breast cancer was made in 1882 when an observational case report by Thomas Nunn was published in the medical journal, *The Lancet*. In 1889 in Germany, Albert Schinzinger proposed surgical oophorectomy (removal of the ovaries), however, it wasn't until 1895 that George Beatson performed the first oophorectomy for recurrent breast cancer in a pre-menopausal woman. In 1897, Stanley Boyd proposed oophorectomy as an adjuvant treatment for breast cancer.

Little changed in the medical management of breast cancer until 1950, when an oestrogen receptor was discovered in the nucleus of the cell. But it took another twenty years before Tamoxifen was developed and used in a metastatic breast cancer trial. It is one of the most studied breast cancer drugs – there are 23 million patient years worth of research on it – and it remains an important weapon against breast cancer today.

By the 1990s there was routine measurement of the oestrogen receptor in clinical practice, in order to decide who should have hormonal treatment. In 2000, measurement of the HER2 receptor became part of clinical practice.

The future holds the prospect of measuring or determining a whole new array of receptors and gene signatures.

So, what does it all mean?

The difficulty is that there has been enormous amount of research undertaken generating huge amounts of information over the last thirty years, presenting clinicians with the job of sifting through that information to make the best choices for the patient.

CLINICAL TRIALS

The choices are guided very well by the steady, incremental gains in knowledge and observation through carefully planned clinical trials. It is the phase three clinical trials which allow researchers and clinicians to work out what is going on. Phase three trials involve pitting a "new" treatment against the existing standard of care; if the "new" treatment proves to be better than the old it becomes the new standard of care.

Clinical trials are a slow process which builds upon positive results, gradually improving survival, reducing harm, validating bio-markers and laboratory results and working out how best to use that knowledge in the treatment of breast cancer patients. Clinical trials also confirm or refute biases and help maintain momentum.

WHAT HAVE THE TRIALS SHOWN US?

Importantly, clinical trials have shown us that breast cancer is not a single disease. It is a different disease in different women:

- pre- versus post-menopausal,
- node positive versus node negative,
- oestrogen receptor (ER) positive versus negative,
- HER2 positive versus negative,
- gene signature,
- patient characteristics.

We have moved from the microscope – which looked at breast cancer as one disease – to the genoscope, where we can actually look at lots of genes in the cancer and interpret them. In the future, we may move to the 'proteoscope' and be looking at proteins and how drugs may affect those proteins in the cell.

WHERE ARE WE NOW?

Between 1990 and 2005, risk dominated treatment selection, in which we treated all cancers with a certain characteristic (e.g. node positive) in the same way. We are now in an era in which we understand the biology of the cancer a bit better and in the last couple of years we have moved towards a responsiveness dominated treatment approach. Clinicians consider for whom will a particular treatment work, and who can be spared a treatment such as chemotherapy. For those who need chemotherapy, the question becomes which chemotherapy will work best.

THE FUTURE...

In the future we may be looking at molecular fingerprints in order to determine the best treatment. By using fluorescent dye on breast tumour cells certain gene markers can be identified, and the presence of certain gene markers determine the type of breast cancer a patient has.

Using this method researchers have determined that breast cancer is actually five or more different diseases: there are those with luminal characteristics (luminal A and luminal B), a HER2 positive breast cancer, and basal-like breast cancers. These are now all managed in slightly different ways.

In the future, clinical trials may be divided up for the specific types of breast cancer. When we find out what the molecular characteristics of the breast cancer are, we can fine tune and target the treatment, thus improving outcomes.

Breast Cancer Genetics

PROF INGRID WINSHIP

***Professor Ingrid Winship** holds the inaugural chair of adult clinical genetics in the Department of Medicine and Royal Melbourne Hospital at the University of Melbourne. She is also head of the adult genetic service at the Royal Melbourne Hospital. Ingrid is a clinical geneticist with an interest in clinical services and research into late onset genetic disorders and the inherited predisposition to cancer. She is chair of the Cancer Council of Victoria's Victorian Co-operative Oncology Group (VCOG) Cancer Genetics Advisory Group and deputy chair of the VOCG, and she combines this with her role as research director for Melbourne Health.*

ABSTRACT

Genes, genetics and the role of genes in breast cancer: an update on the inheritance of breast cancer, risk assessment and risk management, outlining the translation of research into clinical care, what a patient can know about herself, and then how much she may want to know. The intention is to create empowerment through knowledge, with informed choices about the utilisation of new technologies.

BREAST CANCER AND GENES

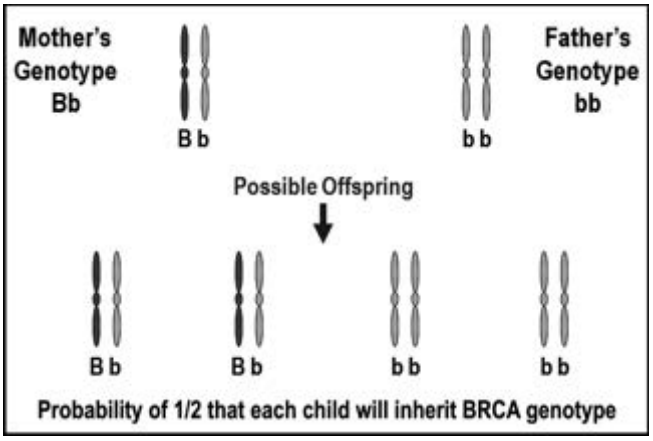
Chromosomes are inherited from one's parents and determine one's inherited characteristics; DNA, genes and chromosomes are responsible for the uniqueness of the individual. Genes are the instructions that make us who we are and we are all different from each other because of our genes.

A mutation is a change in the DNA comprising a gene from what is "normal". Such single gene alterations can pre-dispose an individual to conditions like cancer. In a medical sense, the important issue with genes is in working out where a change in a gene is just a normal variation, and where it may be related to some sort of illness.

In talking about breast cancer and genetics, and breast cancer and genes, it is important to differentiate between the genes that an individual has inherited (the basis for genetic testing for a pre-disposition to breast cancer) and the genetic information in only the breast tumour cells that is increasingly used for molecular fingerprinting for targeted breast cancer treatment.

THE BRCA GENE MUTATIONS

Everyone has BRCA 1 and 2 genes, one copy from each parent. Mutations(alterations) in these genes which cause an increased cancer risk can be inherited from either parent. In the example below, the mother has a BRCA mutation on one chromosome while the father has no BRCA mutation at all. The children from these parents will have a 50:50 chance of inheriting the BRCA mutation. Boys can inherit the BRCA mutation



in the same way that girls can, so men with the BRCA gene mutation can pass on the gene to their children. In the example in the diagram above, children with the darker gene carry the BRCA gene mutation, irrespective of gender; the females would carry an increased risk of breast cancer.

HOW CAN GENOMIC DATA BE USED?

Genetic testing can predict those at higher risk and prior to the development of symptoms if a mutation is found within their family.

Genetic testing can refine the knowledge of individual risk and risk assessment. This can mean that an individual risk can be fine-tuned from a person being a member of a high-risk family to either "you're an individual in a high-risk family who has the high risk" or "you're an individual in a high-risk family who doesn't have the high risk".

In a familial cancer/genetic clinic it is not all about the BRCA test; it is about the full risk assessment:

- risk assessment for individual and family,
- family history,
- age of onset of cancer,
- constellation of signs and symptoms,
- patterns of cancer in families, e.g. breast and ovarian cancer,
- special investigations (histology), mutation detection (test of someone with cancer to look for a mutation), predictive testing (test of family members to see if they have the family specific mutation or not).

From all this information, a risk management strategy can be formed. This strategy or risk management plan may include surveillance, intervention (chemoprevention/surgery) and other evidence-based strategies. Research is being undertaken into more targeted therapies

BREAST CANCER AND GENETIC PRE-DISPOSITION

Only about five percent of women with breast cancer have a predetermined single genetic factor or risk. Ninety-five percent of women with breast cancer have no predetermined single genetic factors. For families with the BRCA gene mutations there may be many close relatives with breast (or ovarian) cancer, many people over successive generations, cancer in young people and the occurrence of multiple tumours.

On average, for those with the BRCA1 mutation, the risk of breast cancer is 65%, and ovarian cancer 40%. The peak age of incidence among these women is under 50 years for breast cancer and over 50 years for ovarian cancer.

For carriers of the BRCA2 mutation there is an increased risk of pancreatic cancer and melanoma, and prostate cancer in men, as well as breast and ovarian cancer. On average there is a 45% risk of breast cancer and a 10% risk of ovarian cancer. The peak age of incidence among these women is under 60 years for breast cancer and over 60 years for ovarian cancer.

It must be remembered that the BRCA gene mutations confer an increased risk of cancer, but cancer is not inevitable.

GENETIC TESTING AND MANAGEMENT

Genetic management involves diagnosis, risk assessment, risk management, counselling, education and advocacy, all underpinned by multidisciplinary research.

For some families or individuals, genetic testing can be a "treasure trove" of information, for others it is a "Pandora's Box"; some people need the certainty of knowing whether or not they have the gene mutations, others prefer not to know.

Information can be empowering, offering the opportunity to make lifestyle decisions and opening up health care options. Interventions can include cancer surveillance, chemo-prevention, risk reduction surgery, and for those not at high risk, a release from early screening.

MRI is particularly suitable for screening women who are carriers of the BRCA gene mutations, in conjunction with breast examination and mammography.

One of the new technologies that is being looked at currently is pre-implantation diagnosis for embryos for parents concerned about passing the gene mutation on to their children. It is possible to test prior to implantation in an *in vitro* fertilised pregnancy and then select embryos free from the mutation known in the parent.

THE IMPACT OF GENETIC TECHNOLOGY

There are a number of big issues involved with genetic testing. There are legal, spiritual, health, psychological, biological, cultural and ethical implications for genetic testing.

Genetic information is unique (unless you have an identical twin) and personal; it is the biological essence of who you are. Obtaining information about your genes has implications not only for the individual but for a patient's family and future generations. It needs to be remembered that the information obtained from genetic testing is incomplete; we have a partial understanding of what BRCA means, but we don't know everything.

The way we interpret our genetic information goes beyond just the DNA; there are cultural and spiritual implications in our genes.

There are a number of issues that need to be considered when embarking on genetic testing.

Genetic testing is only undertaken with informed consent. Culturally, there may be issues of autonomy versus collective ownership of the information, especially for Māori. Many people may not want to find out whether or not they carry gene mutations, and they have a right to refuse testing and to not know their gene status without prejudice to ongoing surveillance and medical care. Privacy and confidentiality are paramount; genetic counsellors and testers do not want to be the cause of genetic discrimination (particularly in insurance and employment).

Another question is should children be provided with such information. The current view is that there is no particular advantage in children knowing their BRCA status in childhood, and testing is usually deferred until they have the maturity and life experience to determine for themselves whether or not they want to know.

The cost of genetic testing, and ease and equity of access are other issues which are going to be increasingly important.

The important aspect is to bring the outcomes of genetic research into clinical practice for the betterment of people's health; global, good general health for everyone in an empowering and equitable service.

Environmental Effects on Breast Cancer

DR MARICEL MAFFINI

Dr Maricel Maffini *is a Research Assistant Professor in the Department of Anatomy and Cellular Biology at Tufts University School of Medicine in Boston. She holds a PhD in Biology from the National University of Litoral, Santa Fe, Argentina and has been awarded several fellowships, including one from the World Bank. She is currently a fellow of the First Science Communication Fellow Program, sponsored by the non-profit organisation Environmental Health Sciences which aims to increase public awareness and understanding of environmental health science. Her research interests are in the field of carcinogenesis and developmental biology.*

In the field of breast cancer, she has shown that the supporting tissue of the breast is a crucial player during the process of tumour formation and tumour cell growth. Based on these observations, it was postulated that cancer is a tissue-based disease and carcinogenesis is a process

akin to development gone wrong. Dr Maffini is interested in understanding the association between exposures to environmental oestrogen-mimics during foetal life and breast cancer risk in adulthood. She is working on a model of foetal exposure to endocrine disruptors, like bisphenol A (BPA), their effect on the breast throughout life and its association with breast cancer incidence.

ABSTRACT

Breast cancer incidence is increasing at a rate that cannot be explained by genetic changes alone. Manmade chemicals acting like hormones can alter the endocrine systems in all living organisms. Endocrine disruptors with estrogenic activity, such as Bisphenol-A, have deleterious effects on the normal development of the mammary gland when the exposure occurs *in utero*. This foetal exposure may contribute to the development of breast cancer in adulthood.

INTRODUCTION

The question "Does breast cancer start in the womb?" is one that the scientists in the Department of Anatomy and Cellular Biology at Tufts University School of Medicine are trying to answer.

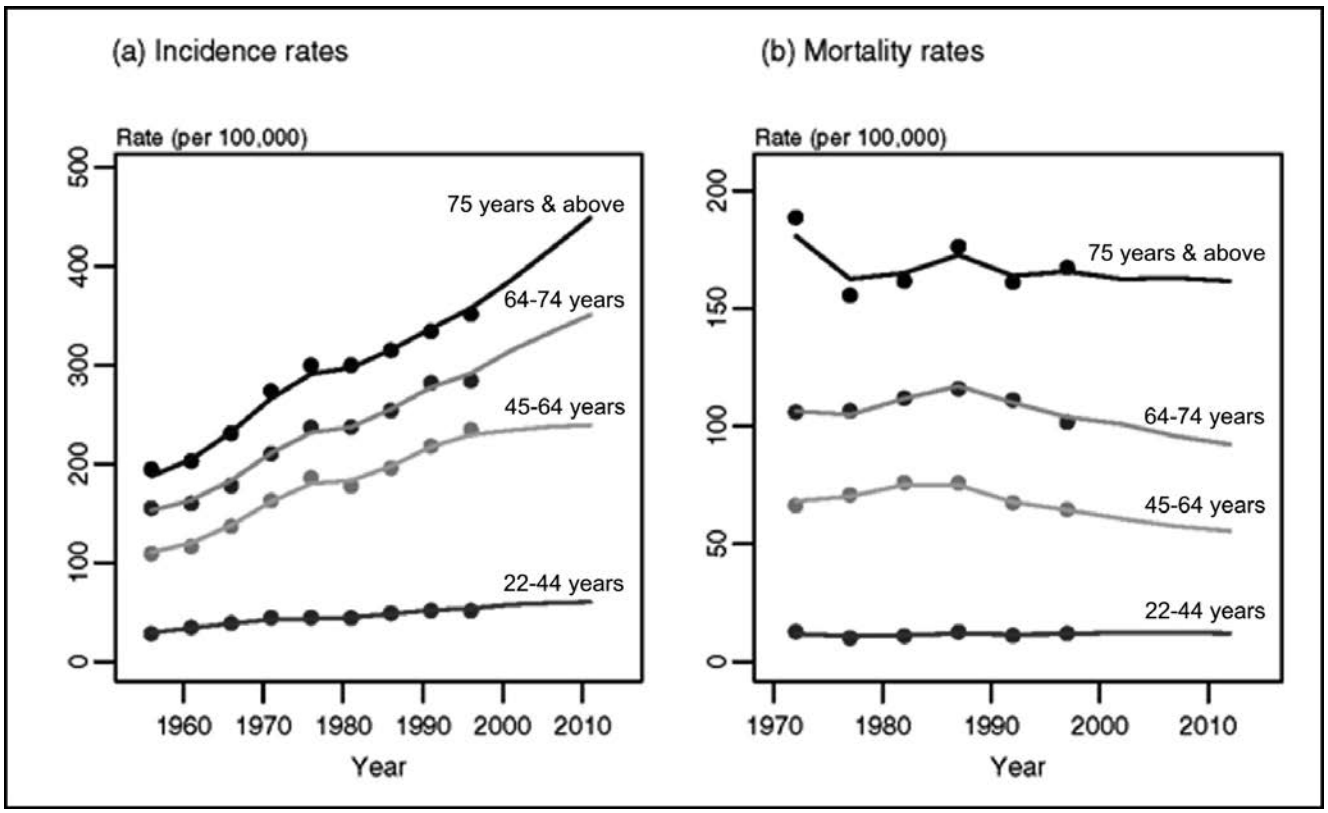
Researchers have found that tumours are not a disease of the cell so much as a disease of the organ. The environment in which the cells exist is extremely important. From this work, scientists believe that cancer results from developmental processes 'gone wrong'.

INCIDENCE OF BREAST CANCER

The incidence of breast cancer in the western world has been increasing since the middle of the twentieth century, although mortality rates have either been relatively steady or have started to decline. In 1940 the lifetime incidence of breast cancer was one in 22 women; in the 1960s it was one in 12. In the US in 2004 it was one in seven.

In the popular press the most common explanation for the increasing incidence is that it is in our genes, yet only five percent of the incidence is in women who carry the BRCA gene mutations. In addition, genetic changes do not happen fast enough for such changes to adequately explain the degree of increase that is being seen.

If it isn't heritable genetic factors, then what is responsible for the other 95% of breast cancer?



Breast Cancer in New Zealand: trends and projections of lifecycle specific rates.

THE ENDOCRINE SYSTEM AND ENDOCRINE DISRUPTORS

The endocrine system is a very powerful system that regulates growth, metabolism, reproductive health and lactation, and also how we deal with sugars. Some of the hormones in the endocrine system are testosterone, oestrogen, progesterone, thyroid hormone, insulin, growth hormone and prolactin.

Oestrogen is one of the most important hormones involved with the development of the mammary gland.

The mammary glands of mice and rats are similar to human mammary glands and these animals are widely used in research on breast cancer. For the first twenty days after birth the mouse mammary gland doesn't change or grow much. However, at puberty there is profound growth of the mammary gland which is driven by oestrogen.

It is well known that the risk of breast cancer is associated with the lifetime exposure to oestrogen. The earlier a woman enters the menarche (commencement of periods) and the later she enters menopause the higher the risk of breast cancer.

Prenatal exposure to oestrogen is also known to alter risk. Women who are twins have a higher risk of breast cancer because of the greater exposure to oestrogen *in utero*, while babies whose mother's developed pre-eclampsia, in which oestrogen levels are slightly lower, go on to have a lower risk of breast cancer later in life.

These oestrogens are endogenous hormones; that is, natural hormones produced by the body.

However, there are many man-made oestrogens to which we are exposed every day. They are in our food, food packaging and wrappers, in the water we drink, in cosmetics and personal care products, fertilisers, cleaning products. We are living in a chemical soup.

Many of the compounds to which we are exposed can interfere with the normal functioning of our own hormones. We ingest them in our food and drink and absorb them through our skin. They are even found in medical devices, a source that is particularly important in neonatal medical care. These compounds are called endocrine disruptors or endocrine disrupting chemicals (EDCs) and they have the ability to mimic or counteract the effect of endogenous hormones.

> *"An endocrine disruptor is an exogenous agent that interferes with the synthesis, secretion, transport, binding, action, or elimination of natural hormones in the body that are responsible for the maintenance of homeostasis, reproduction, development, and/or behavior."*
>
> - US Environmental Protection Agency

EDCs include oestrogen agonists/antagonists (e.g. DDT), androgen agonists/antagonists (e.g. vinclozolin), thyroid disrupting agents (e.g. PCBs), and disruptors of hormone metabolism/synthesis (e.g. atrazine).

XENOESTROGENS

Among the EDCs some of the most common oestrogenic chemicals (xenoestrogens) include:

- insecticides – DDT, methoxychlor, kepone, dieldrin, toxaphene, endosulfan, lindane;
- antioxidants – alkylphenols, butyl-hydroxy-anisole;
- plasticisers and monomers – phthalates (BBP, DBP), bisphenols (BPA);
- disinfectants – o-phenyl-phenol; and
- PCBs, sunscreens, fire-retardants.

In the early 1990s a group of clinical researchers observed that there had been a steady increase in the incidence of testicular and breast cancer over many decades. There was also a decline in the quality and quantity of sperm, and an increase in the incidence of male genital tract defects (hypospadia, cryptorchydism).

The researchers hypothesised that all these pathologies are associated with an increased exposure to xenoestrogens (Sharpe, R.M., Skakkebaek, N.E. and Davis, D.L., *et al.*, 1993)

HOW CAN WE TEST THE XENOESTROGENS HYPOTHESIS?

There are problems with epidemiological studies (which consider the impacts through observation of part of the population) not the least of which is the fact that people, in their everyday lives, are not exposed to just a single chemical. There is also no control over the period or time of exposure. Most importantly many people suffer

from chronic long term exposure to EDCs. So it is difficult to say that on a population level, this specific chemical causes this particular effect.

However, accidental and medical exposures offer insights in to the effects of xenoestrogens. In one important incident many people were exposed to dioxin following a factory explosion in Seveso, Italy in 1976. Blood was collected from people who were exposed to the dioxin and in the last five years interesting epidemiological data has been published:

- among women who were aged from infancy to 40 years old at time of exposure, individual blood dioxin levels are associated with breast cancer incidence, with breast cancer risk increasing with increase dioxin levels in the blood (Warner *et al.*, EHP, 2002);
- among women who were under 30 years at the time of exposure those with higher levels of serum dioxin have a higher risk of endometriosis (Eskenazi *et al.*, EHP, 2002);
- among women who were premenopausal at the time of the explosion, there is a statistically significant trend toward earlier menopause (Eskenazi *et al.*, EHP, 2005).

DDT is a pesticide which was introduced in the USA in 1945, and used widely with peak use in 1959. It was banned in 1972 after it was found to adversely affect wildlife. It is a potent oestrogen-mimic. Significant health impacts are seen in women with heavy exposure to DDT (e.g. women who lived on farms or places where DDT was used) under the age of twenty years. Such women have a five times greater risk of developing breast cancer. Many women heavily exposed in childhood have not yet reached the age 50 (Cohn *et al.*, EHP; 2007)

DES (diethylstilbestrol) was prescribed to between two and ten million pregnant women in the US between 1948 and 1971 for preventing miscarriage. Although DES treatment was banned in the US in 1971, it use continued in other countries until the 1980s.

Women exposed in utero developed a rare carcinoma of the vagina, had malformations of their genital tracts (H-shaped uteri), and abnormally shaped fallopian tubes, and a decreased ability to support pregnancy.

Women with prenatal exposure to DES have an increased risk of breast cancer after age 40 years (Palmer *et al.*, *Cancer Epidemiol Biomarker Prev*, 2006) and are 50% more likely to experience menopause at any given age. This effect was dose dependent (Hatch *et al.*, *Am J Epidemiology*, 2006)

Men exposed in utero had malformations of their genital tracts including undescended testes, small testes, and cysts of the epididymus. In addition, sperm quality was decreased and episodes of infertility increased.

BISPHENOL-A AND THE BREAST CANCER LINK

Bisphenol A (BPA) is the building block of polycarbonate plastic. It is found in a wide range of consumer items including baby bottles, water bottles, water carboys, food containers, dental sealants and composites, the lacquer coating of food cans (including baby formula), household glues, electrical insulation, water pipes, and wine storage vats.

In testing by the US Centres for Disease Control (CDC), BPA was present in 95% of urine samples analysed. It was also found to be present in the placenta, foetal plasma, breast milk and ovarian fluid. It was present in amniotic fluid in concentrations approximately five times greater than in the mother's blood.

The levels of exposure to BPA are extremely low and babies are subject to chronic low-level perinatal exposure.

Research has shown that pre-natal exposure is associated with advanced puberty (Howdeshell et al., 1999), altered oestrous cycles and early cessation of cyclic activity (Markey *et al.*, 2003), altered ovarian morphology (Markey *et al.*, 2003), quantitative changes on the expression of ERα and PR in the uterus (Markey *et al.*, 2005), and altered behaviour (Palanza, vom Saal, Rubin).

In order to determine the impact of BPA on breast tumour development in rodents, foetal mice were exposed in utero to environmentally relevant doses of BPA through a pump implanted under the skin of the mother mouse at day eight of the pregnancy, just before the mammary gland in the foetal mice begins to develop. The pups were not exposed to BPA after birth.

In foetal mouse pups the mammary glands of those exposed to BPA in utero were larger and the milk ducts longer. In addition there were longer term consequences. BPA dramatically altered the mouse mammary gland in adulthood

(six months); the mammary gland showed development and cell proliferation that normally only occurs during pregnancy.

In a later experiment the mice pups were exposed to BPA not only in utero but also after birth during lactation. The effects observed in the first experiment were observed earlier, so that now the mammary gland development normally associated with pregnancy was occurring at three months of age. By the equivalent of menopause (one year to eighteen months), the milk ducts were blocked with condensed fluids and there were pre-tumourous lesions.

In rats exposed to BPA, pre-tumour lesions also occurred, together with carcinoma in situ, and at a much earlier age.

In conclusion, pre-natal and peri-natal exposure to BPA correlates with increased mammary density, and an increased number of structures where cancers are thought to originate, increased sensitivity to oestrogen and the presence of intraductal hyperplasias (pre-cancerous lesions) and carcinomas *in situ*.

The US EPA considers that the "safe" dose of BPA is 50 micrograms (one millionth of a gram) per kilogram of body weight per day. Yet, the dosages used in the experiments at the Tufts University laboratory ranged from half of the EPA "safe" dose down to one two-thousandth of the "safe" dose.

THE IMPLICATIONS

Exposure to environmentally relevant doses of BPA during the peri-natal period alters normal mammary gland development. The BPA effects on mammary gland development are long lasting.

In 1981 it was shown that foetal DES exposure increased the propensity of the rat mammary gland to develop tumours, and finally in 2006 it was proven that the DES-daughters have increased incidence of breast cancer.

In 2006, researchers demonstrated that prenatal exposure to BPA increases the vulnerability of the rat and mouse mammary gland to developing pre-cancerous lesions and carcinomas *in situ*.

Will breast cancer incidence be found to increase in women exposed to BPA in utero in the next decades, perhaps 2031???

CAN WE STOP IT WHERE IT STARTS

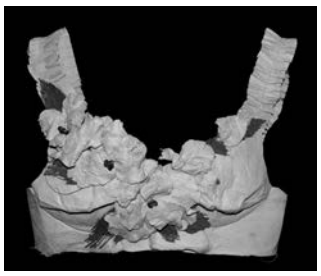
There are a number of things that we can do to reduce our risk of breast cancer.

The "easy" things:

- avoid plastics and don't microwave in them,
- buy organic produce and hormone-free meats and dairy,
- wash/rinse fruits and vegetables thoroughly,
- use pesticide-free lawn care,
- use the least-toxic cleaning products (or substitutes),
- reduce exposure to cosmetics, especially in young girls,
- avoid Teflon (non-stick pans and pots),
- avoid treating carpets and upholstery with stain-free agents,
- avoid exposure to flame retardants.

The "hard" things:

- change the way testing is done by regulatory agencies (e.g. Environmental Protection Agency),
- hold corporations responsible,
- use the precautionary principle,
- develop better testing methods to assess total body burden,
- educate the public and health care professionals about risks and ways to prevent unnecessary exposures.



Fijian Bra Art

How to Dance and Laugh Your Way to Recovery

PHIL KERSLAKE

***Phil Kerslake** is a well-known New Zealand cancer survivor, TV presenter, life coach, speaker and author. First diagnosed as a teenager, he has coped with six battles with Hodgkin's and non-Hodgkin's lymphoma over 28 years, twice recovering from stage four illnesses. Phil is the author of the highly acclaimed* Life, Happiness …& Cancer: Survive with Action and Attitude! *– a book that marries up-to-date international research with Phil's personal experiences, to tell how patients can underpin their recovery through active participation and the tactical use of psycho-social support measures.*

Phil has spoken to thousands of cancer patients, caregivers, supporters and medical professionals throughout New Zealand. In June he won one of only three international, Roche-sponsored Re-Building Lives Awards 2007 in Austria for his inspiring survival journey and for his work in New Zealand cancer support. Phil lives with his wife Gillian and their baby boy, Rhys, (born 1 July 2007) in Wellington.

ABSTRACT

Around half of all cancer patients find the emotional and psychological challenges of their experience as trying as, or even more trying, than the physical effects of the cancer and its treatments. While these aspects of the cancer experience are rarely addressed when patient treatment plans are formulated by medical teams, they can be extremely well self-managed through measures designed to reduce stress, raise mood, preserve hope and faith, create relaxation and resilience, and explore, acknowledge and release emotions. Cancer patients cope con-siderably better with their diagnoses, treatments, and recovery while improving the quality of their lives through active participation in what are collectively termed 'psychosocial support measures.'

INTRODUCTION

Phil's experience has come from many years coping with cancer. As a 19 year old in 1979 diagnosed for the first time, he was reluctant to participate in any psycho-social support measures that were offered to him. This attitude was gradually put aside over the subsequent years and a further five battles with both Hodgkin's and non-Hodgkin's lymphoma.

For him, developing a belief in the value of psycho-social support measures has been an evolutionary process, rather than a revolutionary one.

PHIL KERSLAKE – CANCER PATIENT

When first diagnosed at 19 years of age, Phil was told that he had an incurable type of non-Hodg-kin's lymphoma and that he would have up to ten years to live. The doctors took a "wait and see" approach which didn't seem to Phil like much of a strategy. With few symptoms other than lumps and bumps on his body, the biggest challenges for Phil were the emotional ones.

He got on with his life and it wasn't until the late 1980s that his cancer progressed to stage IV disease and he had to deal with major health challenges that the cancer presented. It was at the age of 28 in 1987 that he had his first chemotherapy treatment. That treatment took him into 1988 when he had a relapse and another six months of chemotherapy. He then had a new diagnosis and radiotherapy.

In 1993-94 he had a localised relapse and was again treated with radiotherapy. This was followed by ten years of remission. His disease-free life ended in 2003 with the formation of a lump in his abdomen. He was diagnosed again with stage IV disease, had another six months of chemotherapy, followed by a further relapse. This time he was treated with high dose chemotherapy, a stem cell transplant and a splenectomy.

Phil has had to cope with cancer for three decades and has had plenty of experience with the emotional and existential challenges of

cancer. At 48 he has been in full remission for three years.

THE EMOTIONAL AND EXISTENTIAL CHALLENGES OF CANCER

Phil realised early on that there are many mental and emotional issues that cancer patients must deal with, and that these were not being dealt with within the modern medical system. When he returned to hospital in 2003 nothing had changed: the mental and emotional aspects of being a cancer patient are still a significant but undertreated problem in our approach to treating cancer.

Over the years, we've seen good progress in cancer research and medical treatments, but we continue to under-acknowledge the emotional and existential challenges of cancer, and the coping and recovery-enhancing benefits of their management. Our medical system is almost exclusively focused on our physical needs – while half of all cancer patients find the emotional challenges as difficult as, or more difficult than, the physical ones.

From as early as his first diagnosis, Phil read books and research on the psycho-social aspects of cancer, coping mechanisms, and the physiological benefit of these practices on people's immune systems and recovery. This culminated in the writing of his book:

> *"Recovering from cancer becomes more achievable when mind, body and soul are all truly aligned to recovery."* –
>
> *- Life, Happiness … & Cancer: survive with action and attitude!*

The book focuses on the things that he found beneficial throughout his numerous battles with cancer.

The emotional challenges are many and varied. Cancer patients fear for their lives, usually for the first time. The treatment process takes us away from everything we hold familiar; after all, who prepares for cancer? We only know what happens and how the system works once we are in it. Despite all the life experience we might have, a cancer diagnosis sets us back to square one; we are like children.

Cancer patients have to manage the responses of others; facing our mortality creates fear in those around us. In addition, cancer patients have societal prejudices to contend with. Cancer is often viewed as more akin to leprosy and many people respond as if it is 'contagious'. There may also be employment prejudice and people treat us differently.

Cancer patients also find that the medical 'system' is not always so systematic, despite our reliance on it for our survival. And the physical deterioration and damage devastates our self-image and our trust in our bodies.

Typical existential concerns include having fewer achievements to our names than we had wanted, and wondering if we have appreciated those we love enough? Many cancer patients feel that life seemed to happen without them at the helm. They question why they haven't been more adventurous, courageous or fearless, or regret opportunities that they may have let pass by. Ultimately they question whether or not they have made any mark at all in this world?

These stresses need release, and managing the emotional and existential challenges can bring about many favourable outcomes for cancer patients.

MANAGING THE CHALLENGES AND THE BENEFITS THAT ACCRUE FROM THEM

Actively managing these challenges through expressions of 'YOU' will enhance the quality of your life during cancer, contribute to your recovery, and help you re-build an even better life after cancer.

Specifically, managing your emotional and existential challenges will:

- enable and encourage you to express your concerns and emotions;
- help ease your anxieties and depressed feelings;
- help steel your resilience, determination and positive expectations;
- encourage problem-solving behaviours;
- improve your decision-making capabilities;
- enable you to communicate better with your medical professionals and others in your support team;
- help you let go of things you may be lamenting, so as to focus on your recovery;

- help you realise you have some control over your circumstances, overcoming the deadly duo of helplessness and hopelessness.

Resilience, determination and positive expectations are, for Phil, three of the most important and powerful cancer recovery tools or characteristics you can have. The good thing is that they don't necessarily have to be innate, but can be learnt, or gained through the practice of simple emo-tional management activities.

There are numerous emotional management activities or measures that are available to cancer patients. These are expressions of an individual's creativity and spirituality.

Thousands of robust studies have shown the benefit of **meditation** and **visualisation** while coping with cancer, and both have been shown to improve the physiological ability to cope with treatment and pain.

Many cancer patients may not feel like laughing, but **laughter** truly is a beneficial therapy and is widely accepted part of therapy and recovery. Rather than waiting to feel like laughing, laughter can be induced. Phil built up his own laughter library (DVDs, etc), ensuring that he had access to things that would make him laugh. He found that even when he was almost immobile after treatments and feeling very sorry for himself, after watching a comedy his spirits were raised, he was more mobile and much more "forward looking" in his outlook.

Music is an extremely powerful and valuable tool. Phil uses music in different ways – for example, to steel him and to make him tough and stroppy before operations, and as an emotional release – and he collected music as therapy.

As with music, many people find **dance** a spiritual and therapeutic activity, as well as an emotional release.

> *"Somehow my psychological healing is intimately connected with dancing again."*
>
> - Jan Bolwell, dancer and breast cancer survivor, from *Beating Our Breasts*

For some people gardening is a very spiritual, relaxing and centring experience:

> *"... gardening and music maintain my wellbeing. I cannot live without either. The cats are also important – such a delight to have them around, doing all their catty things."*
>
> Joanna Booth – Cancer survivor, from *Life, Happiness ... & Cancer: survive with action and attitude!*

Affirmations and **affirmative language** use encourages positivity, counters negativity, including negativity emanating from doctors. Words create and reinforce images of ourselves and research has been done on words that help and words that harm; while medical professionals are much better than they used to be, some still persist with the wrong language that can be very negative.

Life path and purpose reviews:

> *"Many people suffering from cancer have an unrealised dream lurking beneath the surface. Adding the power of this dream to other healing methods after a cancer diagnosis can help stimulate the immune system and sometimes can make the difference between life and death."*
>
> - Dr Lawrence LeShan, US Research Psychologist and Author of *Cancer as a Turning Point* and *You Can Fight For Your Life*

We have to make the most of this life; why shouldn't we do what we want to do with it. Cancer often provides an opportunity to make a new life for ourselves. Planning a 'new' life during a cancer battle gives the patient more to fight for. The concept of reviewing one's life, where one is and where one wants to be, during a battle with cancer, not waiting until afterwards, is a pleasurable and exciting process, and thus can be a powerful tool.

Writing can be an emotional support mechanism. Research has shown that engaging in writing which elicits the emotions, and enables us to express our emotions has an immune system boosting action. Phil used writing in a number of ways: to express his emotions, writing 'gratitude' lists that enabled him to see that not everything in his life was all bad, as well as writing his book.

"We will always have challenges in life; cancer or something else. We shouldn't put life on hold. We shouldn't put life on hold because we have cancer, or because "what if". Life should be lived

to the full now. We only live it once, and cancer or no cancer, it moves very, very fast."

IN CONCLUSION

There are four compelling outcomes from managing your emotional and existential challenges:

1. A greatly enhanced ability to cope physically, mentally and emotionally with your diagnosis, the ensuing battle and post-treatment challenges.
2. An enhanced tolerance to the treatments, with faster recovery from them, enabling them to have optimum effect.
3. Better-functioning natural healing mechanisms, which help your body to be more resistant to the cancer and more receptive to the healing process.
4. A sense of having some control over your circumstances, which supports your fight for recovery, and enhances the quality of your life

Access to Anti-Cancer Medicines and Clinical Trials in New Zealand

PROF VERNON HARVEY

ABSTRACT

Traditionally most anti-cancer medicine (especially chemotherapy) has been available through the public hospital system. Although always considered expensive, the cost (a few hundred/thousand dollars per course) had been contained by the limited duration of treatment (< 6 months) and the restricted number of effective therapies (1 or 2). From about 1990 an increasing number of new therapies became available, providing therapy for more patients and more courses of therapy for patients with responsive tumours (4-6 courses). The newer therapies were more expensive, so the public hospital system struggled to fund them, with significant inequity of access to treatment arising around the country. By the late 1990s the situation was critical with few new therapies available and then only in some hospitals ('post code lottery').

Considerable advocacy and debate on affordability eventually led to a Ministerial Directive making ten of the most active therapies available for defined indications and establishing a process to approve new therapies or new indications for existing medicines in 2001. There will always be tension between the need for new therapies and the cost of those therapies. The problem is illustrated by the example of Herceptin.

THE HISTORICAL SITUATION

Before 1990 there were about 40 anti-cancer drugs. There were a limited number of what were regarded as 'sensitive' tumours and the only adjuvant therapy was for breast cancer, but not for other common cancers. We rarely had more than one or two kinds of chemotherapy for advanced cancer. At that time the Auckland oncology budget was about $750,000 per annum – that is the budget for chemotherapy drugs.

Between 1990 and 2000 was a particularly difficult time. An increasing number of new chemotherapy drugs became 'available' (e.g. taxanes, capecitabine, oxaliplatin, rituximab, trastuzumab), but no new drugs were funded. At that time hospitals were responsible for funding drugs from their own budgets, which were insufficient. At the same time, more tumours were considered 'sensitive' and there were now adjuvant therapies for bowel and ovarian cancer, and subsequently for other cancers. There was also a huge increase in patient knowledge and therefore their expectations. The Auckland oncology budget remained the same at $750,000 per annum.

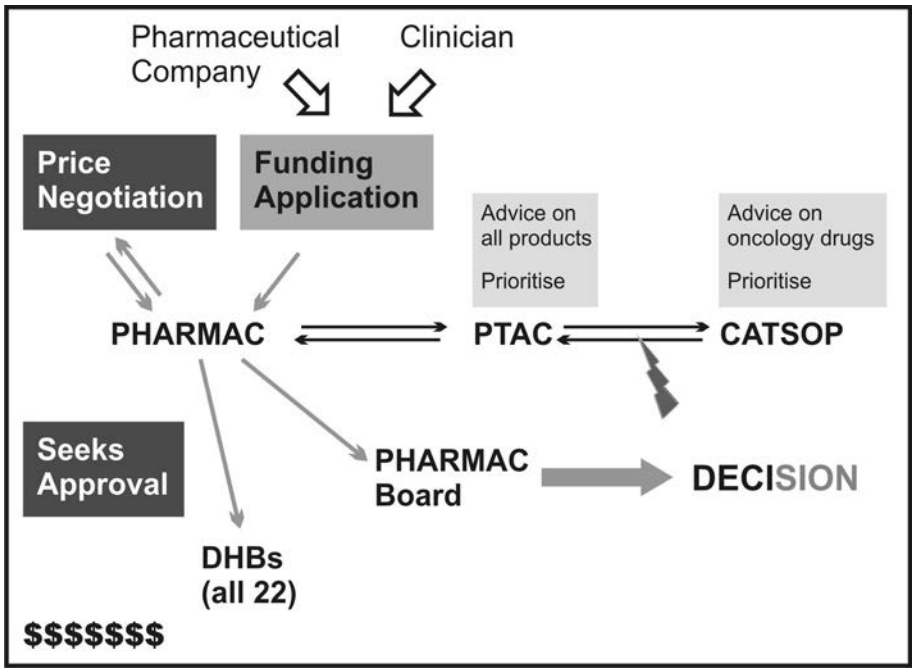
In 2000 and 2001 a crisis was reached. There was increasing pressure to use some of the new drugs, yet there was no more money. Some oncologists were more successful in persuading their District Health Boards (DHBs) to allocate money for the new drugs and this led to inequity around the country: a therapy that might be available in Hamilton might not be available in Auckland, etc. (the so-called 'post-code lottery'). A number of meetings were held with the Minis-

try of Health; the outcome was that the Minister for Health issued a Ministerial directive which approved ten new anti-cancer drugs. Those meetings also established the PHARMAC process. While there may be problems with this process, a process was clearly needed – a system that allows therapies to be prioritised. At this time the Auckland oncology budget was $1 million.

THE PHARMAC PROCESS

Since 2001, New Zealand has had what is called the PHARMAC process for new drug utilisation:

- STEP 1 – Registration:
  - Efficacy and safety is assessed by MEDSAFE and the drug is licenced for use.
- STEP 2 – Funding
  - An application is made to PHARMAC for the drug to be publicly funded within the health system.



The PHARMAC Process
(PTAC = Pharmacy Therapy Advisory Committee consisting of 12 specialist physicians; CaTSOP = Cancer Therapy Sub-committee of Pharmac)

When a funding application is made to PHARMAC, they seek advice from PTAC, who may or may not seek advice from CaTSOP. CaTSOP is not always asked for advice and if they are not asked, they cannot provide advice, and any advice they are asked for may not always be acted upon. If PHARMAC is given advice by PTAC that a drug should be funded, PHARMAC then goes into negotiation with the pharmaceutical company over the price, and they must get agreement from all 22 DHBs to fund the drug, which is problematic. In the future, funds are supposed to go directly to PHARMAC for them to decide on drug expenditure rather than to DHBs who under the current system determine if a drug will be funded.

There have been some achievements under the PHARMAC process:

- Glivec for chronic myelogenous leukemia and gastrointestinal stromal tumours,
- Aromatase inhibitors for advanced disease (and exemestane as adjuvant),
- Rituximab for non-Hodgkin's Lymphoma,
- Gemcitabine for urogenital cancers,
- Temozolimide for Glioblastoma multiforme brain cancer (adjuvant),
- Capecitabine for advanced gastro-intestinal cancers,
- Paclitaxel for node positive breast cancer (adjuvant),
- Trastuzumab (Herceptin) for nine weeks breast cancer (adjuvant).

A number of drugs have been declined including taxanes for ovarian cancer (Taxol has been approved from 1st December), 12 months of trastuzumab, bevacizumab for colorectal cancer, gefitinib for lung cancer, pemetrexed for lung cancer/mesothelioma, Liposomal doxorubicin for ovarian cancer, and bortezomib for multiple myeloma. In addition, a number of drugs have not been considered.

During that time – between 1990 and 2007 – the Auckland DHB oncology budget for anti-cancer drugs has gone from $750,000 per annum to $16 million per annum. Unfortunately, these new drugs are very expensive – hence the huge increase in the budget – yet the $16 million does not include taxanes for node positive breast cancer or the nine weeks of Herceptin that PHARMAC have approved as these costs have only been from the 1st July.

There are many problems with the current system: it is too cumbersome and slow, and PHARMAC does not always seek advice from those clinicians who have the expertise or, indeed, from the consumers. If a pharmaceutical company has not applied to MEDSAFE for a drug to be registered or for a drug to be registered for a particular use, it cannot be recommended for funding. On the financial side, price negotiations may falter, as all 22 DHBs must agree to fund the drug and there may simply not be enough money in the budget.

THE ADJUVANT HERCEPTIN STORY

Is Herceptin a wonder drug?

There are certainly a lot of people who think it is, and there has been a lot of media interest in the whole Herceptin story. Women have marched on Parliament demanding that the drug be funded. But is it really that good?

HER2 is only one of a family of four receptors in the cell wall. Trastuzumab – or Herceptin – is a humanised anti-HER2 antibody that attaches to the part of the receptor that protrudes from the cell wall and effectively inactivates it. It does so by stopping growth messages going into the cell. If those messages are not stopped they are sent to the nucleus of the cell, to the DNA, telling the cell to grow.

HER2 receptors are found on approximately 20 to 30 percent of breast cancers and they are associated with more aggressive disease. However, if you read what is presented in the media, you would be led to believe that having HER2 positive breast cancer is a death sentence, and that if Herceptin is available to all HER2 positive women half of the women might live. This is **not** correct.

Over four years the survival of patients who are HER2 negative is about 90%. For patients who are HER2 positive but who do not receive Herceptin, survival after four years is about 78%. If you give Herceptin to the HER2 positive group of patients, it returns the survival rate to where it would have been had they not been HER2 positive, that is to about 90% survival at four years.

If Herceptin is to be incorporated into a treatment regime there are a number of ways in which to do it:

- After four cycles of anthracycline, Hercepetin is started simultaneously with four cycles of Taxol and continues after the Taxol is finished.
- Herceptin is given after all chemotherapy has finished (the only way it is actually registered to be given in New Zealand, although the first method is sometimes used).
- Herceptin can be given from the beginning as long as the chemotherapy does not include anthracycline, as anthracycline and Herceptin together cause too much damage to the heart.

THE HERCEPTIN TRIALS

The global Herceptin adjuvant programme involves four trials (HERA, NSABP B-31, NCCTG9831 and BCIRG006) and more than 13,000 patients have participated, including some women from New Zealand.

In the North American trials (Herceptin started with Taxol and after adriamycin), after four years there were 12% fewer recurrences in the group that received Herceptin, and 3% more women survived after four years in the group that had Herceptin. In this trial, ten percent of those women in the Herceptin group didn't actually ever get any Herceptin because at the end of their adriamycin chemotherapy their heart function wasn't good enough. Another ten percent only got Herceptin for three months because they had problems with it. Only 70% of the Herceptin group got more than nine months of therapy.

In the HERA trial (one year of Herceptin after all chemotherapy was finished), disease free survival after three years is 6% greater in those on Herceptin, and 2.7% more women on Herceptin survived after three years than in those without Herceptin. At one year after Herceptin the number of local recurrences was reduced by 40%, the number of distal recurrences (metastases) was reduced by 40% and the overall mortality was reduced by 33% (all relative risk reductions).

The ultimate results of the Herceptin trials are that for every 50 women treated for one year, one woman's life will be saved, and one woman will suffer severe, although probably temporary, heart damage.

SIDE-EFFECTS

One of the major side-effects of Herceptin is cardiac damage. The trials have shown an

increasing incidence of heart failure over time – 4.1% after three years. However, severe heart failure is uncommon, and, at least in the short-term, it seems to be largely reversible. With Herceptin given after anthracycline, heart function declines considerably to reach a low about a year after the commencement of treatment and at three years has partly recovered, although it is still well short of normal. The implications for cardiac health ten or twenty years later are unknown.

SHORT DURATION HERCEPTIN TREATMENT

FinHER was a small Finnish study in which Herceptin was given for a short time in combination with non-anthracycline chemotherapy, but the anthracycline chemotherapy was given afterwards. There was a reduction in recurrence for patients on Herceptin, and improved survival after four years (not statistically significant). The reliability of the results in this trial is lower than in the other trials because of the smaller number of participants in the study, although the outcomes in terms of disease-free survival are very similar. There were also no cardio-toxicity problems with the nine weeks of Herceptin.

Another trial (E2958) investigated whether or not short duration Herceptin would reduce the cardiac damage; it did not appear to do so and the study was largely forgotten. However, when the original four year-long Herceptin trials were updated, the E2958 participants were also followed-up. In the trial, patients were given short duration (ten weeks) Herceptin as in FinHER, followed by anthracycline. Half the patients were then given the remainder of the 12 month Herceptin regime while half got no more Herceptin.

At five years the short duration Herceptin yielded slightly better results than the long duration Herceptin (recurrence in 23% of participants com-pared with 25% recurrence in the long duration group) and overall survival (85% survival compared with 82% in the long duration group).

HERCEPTIN AND THE FUTURE

Is Herceptin the end of the story? No; there are other biologicals that have been looked at for breast cancer – Lapatinib (another anti-HER2 therapy), Gefitinib and Erlotinib (anti-EGFR therapies) and Bevacizumab (Anti-VEGF therapy).

Theoretically, lapatinib (Tykerb) may be better than Herceptin. While Herceptin blocks only one receptor, lapatinib blocks two (HER 1 & 2). In trials to date in advanced breast cancer, there was longer disease control in the lapatinib plus capecitabine group than in the capecitabine alone group at two years. Trials of bevacizimab showed similar results with improved disease-free and overall survival at two and a half years.

A number of questions about Herceptin remain:

- Does every HER2 positive patient need Herceptin?
- What is the optimal duration of Herceptin?
- How is Herceptin best integrated with other treatments?
- Are other therapies better, or do they add to Herceptin?

The answer is that we need more studies.

A new study - the Synergism or Long Duration (SOLD) Study – will try to answer the question of whether long or short duration Herceptin is better. Half the participants will have nine weeks of Herceptin, while the other half will have nine weeks of Herceptin, followed by more chemotherapy, and then go on to complete a year of Herceptin.

The ALTTO adjuvant lapatinib study will compare lapatinib (Tykerb) with Herceptin. There are four arms of the study with all patients starting on chemotherapy followed by:

- one year of Herceptin; versus
- one year of lapatinib; versus
- some Herceptin followed by some lapatinib; versus
- both Herceptin and lapatinib for a year.

There is concern among some clinicians that one quarter of the patients in this study get no Herceptin at all.

And finally there is the BETH adjuvant bevacizumab study. In this study patients get chemotherapy followed by either one year of Herceptin or both Herceptin and bevacizumab.

HOW CAN WE IMPROVE ACCESS TO CANCER THERAPIES?

There are many ways in which we can improve access to cancer therapies. Whatever we do we have to “get more bang for our buck.” We need more money, but if we don’t have more money

we have to make sure we use what we do have to the best possible advantage.

All stakeholders must be involved in the decision-making process, including the consumers. We also need transparent decision-making processes, a problem that exists with the current PHARMAC process. Those who sit on the committees advising PHARMAC work hard to make drugs available to patients, but that process is hidden from consumers. In addition, co-operation between stakeholders is necessary in order to agree on priorities.

Panel Discussion – The Way Forward

PANELISTS: DR MADELEINE WALL - DR MERIEL WATTS - DR JACKIE BLUE - DR BARBARA HOCHSTEIN - PROF VERNON HARVEY - LIBBY BURGESS

***Dr Jackie Blue** is a Member of Parliament. She graduated as a Doctor in 1983 and practised as a GP for seven years before training as a breast physician in 1992. Jackie is a Past President of the Australasian Society of Breast Physicians; a current member of the Medical Advisory Committee for the Breast Cancer Research Trust; and a former elected board member of the Auckland District Health Board.*

***Dr Meriel Watts'** career path has included agricultural science and work as a naturopathic health practitioner. Over the last seventeen years she has worked with a number of non-governmental organisations on behalf of community and environmental interests regarding the impacts of pesticides. Since gaining her PhD in 2000 in pesticide policy, she has worked closely with Pesticide Action Network Asia and the Pacific and is highly regarded internationally as a researcher and author. A keen organic grower, her major interest is the influence of pesticides on breast cancer incidence, and she has recently published a book investigating this topic (Pesticides and Breast Cancer: A Wake Up Call).*

***Libby Burgess** is a 9 year breast cancer survivor. She chairs the Breast Cancer Aotearoa Coalition (BCAC), an umbrella group representing 23 of New Zealand's breast cancer-related groups. Libby is a member of the Guideline Advisory Team developing evidence-based clinical best practice guidelines for early breast cancer in New Zealand. She is providing a consumer perspective into the development of the Northern Regional Cancer Network under the NZ Cancer Control Strategy, and has actively campaigned in the media for Herceptin funding. Libby is a scientist based in Auckland.*

DR MADELEINE WALL

We all know, now, that breast cancer is multi-factoral, and we know the story of the "seed and the soil". Each woman will have different "seeds" and different "soil". There is no one risk factor that we will be able to avoid, enabling us to stop breast cancer. There is no single intervention that is going to get rid of it. The reality is that what is important for surviving breast cancer are the small, incremental advances in breast cancer treatment, each of which will work in some people and not in others.

For some years to come, we are going to have to look at breast cancer in this way. Yes, a healthy diet, low alcohol consumption and a number of other things will reduce your risk. Screening will work for some people, and reduce mortality by 30%. For some people, screening is no good,

but unfortunately we can't tell beforehand who will benefit and who will not, so the best thing is screening for everyone in the relevant age-range.

We still don't know who will develop breast cancer and why.

Live well, participate in screening. If you get cancer, get the best treatment you can and learn as much about it as you can. And carry on having publicly funded mammograms!

DR MERIEL WATTS

The breast cancer and environment workshop on Saturday was filled to capacity; beyond capacity, in fact. There wasn't even standing room, which indicates that there is a real thirst for knowledge about the chemicals that may be involved in causing breast cancer. Women desperately want to have information about these chemicals, in particular, information about safe alternatives.

There is a lot of information out there, but it is not getting through to the people who need and want it. Women want to take charge of their lives and remove the risk in their lives and the lives of their daughters and grand-daughters. It is vitally important to get this information into schools and to young girls, so that they have the information about cosmetics and personal care products, and how to take action before they become pregnant and have their own children. There is also the need for action at a Government level, particularly in replacing suspect chemicals with safer alternatives.

Behind all this lies a need for a systemic change in attitude among ourselves and society as a whole, particularly at a government level. We need a change in attitude towards chemicals. We are inclined to believe that they are safe unless someone can really prove that they are not. If there is evidence that they may be a problem, we need to play it safe and remove them from our environment and use safer alternatives.

We need to address the issue of evidence. The authorities say they will act when there is evidence of harm, but while that evidence is being acquired, women are still getting breast cancer, harm is still being done until sufficient evidence for action has been collected. We need to err on the side of safety for women, not on the side of protecting the chemicals and those who profit from their use.

DR JACKIE BLUE

Where do we go from here? For a start we need more conferences like this. Hopefully this is not the last; we need to hold them regularly.

Do not underestimate the power and the influence that you have in driving change; politicians ignore a group like you (the conference participants) at their peril. There will be recommendations to come out of this conference. You should all send those recommendations to your own Member of Parliament, and also individually send them to the Minister for Health.

A number of issues have arisen from discussions here at the conference, that need to be followed up as a matter of urgency:

- A national breast cancer database is vital. Without knowledge we are powerless.
- Screening is important, particularly among Māori and Pacific Island women. Reaching those eligible women who have not yet taken up the invitation to enrol in screening is a top priority in order to reduce disparities in New Zealand.
- We need to fund MRI screening for high risk women.

In addition, the Breast Cancer Network petition and submissions to the Health Select Committee, which were supported by Dr Meriel Watts and the Liggins Institute, made a big impression on the members of the Health Select Committee; I think that there will be some strong recommendations to come out in their report.

BARBARA HOCHSTEIN

This has been a very special conference, and as much as you learn from us as speakers, we learn from you, the patients.

One of the things that has been learned at this conference is that the biology of breast cancer is important, and this also explains why not everything works for all patients. We have to continue the work we are doing with screening, and continue working in multi-discplinary teams. New advances in imaging will enable more precision. However, lurking in the background is our imprecise understanding of the biology of breast cancer.

One day I may not be involved in breast imaging if things like bio-markers take over – I don't mind; I can always look at other parts of the body.

DR VERNON HARVEY

Understanding is the key; understanding the disease for you, and understanding your needs for us. There are more 'unknowns' than 'knowns'; there is no place for personal dogma and biases.

We need to keep an open mind and we need to keep looking. The answer is there, it is just waiting for us to find. The only way we will not find it is to close our minds. Some of the answers we will find will be against our prejudices, and the harder to accept for that. But we know that the biggest lessons come from the mistakes we make not the victories.

We need to use our energies wisely, we need to talk with each other and not at each other, and we need to keep inquiring. If we keep asking why, we will find an answer.

LIBBY BURGESS

We've been all really privileged over the last three days to hear the latest in breast cancer from a wide range of experts. We now know that breast cancer is at least five different diseases; that treatments are becoming more targeted and less brutal, more elegant.

Here in New Zealand we have a history of lagging behind other similar countries in our access to detection, treatment and care, to health-giving and life-saving technologies. We deserve better than this, and we can make a difference here. We've gained a lot of wisdom from our own experiences of breast cancer, and that has been evident throughout this conference. Clinicians have also acknowledged that they have gained from listening to us.

If we want to ensure that those who follow us on the breast cancer journey have timely access to world-class detection, treatment, care and support, then we need to share that wisdom with the policy makers and those who decide how our tax dollars are spent. We need to ensure that we have representation on the many decision making bodies that determine our fate.

Thank you, Vernon [Harvey], for asking the question earlier "where is the consumer in the PHARMAC process." We are bashing at the doors but no-one in there is listening to us yet!

The motto of the European Cancer Patients Coalition is "Nothing about us without us". This is a principle we need to instil in the New Zealand health system. Our involvement can empower us to use our knowledge as survivors and those living with breast cancer to reform policies and budgets for everyone's benefit.

We have a cancer control strategy and we need to ensure that its implementation is more than merely window dressing. We can achieve this if we work together, strategise together and move forward together – collectively, as survivors and those with breast cancer, and with our clinicians.

Ahu whakamua tatou – moving forward together; I think that is the key.

Breast Cancer Treatment and After: your role in the process

DR SUSAN LOVE

ABSTRACT

The most important member of the breast cancer team is the patient. How can you best participate in the decision making and what do you need to know? What do we know about lifestyle, aftercare and advocacy that can alter the outcome personally and politically?

PRACTICAL ADVICE FOR WOMEN WITH BREAST CANCER

Throughout much of the conference, and particularly in Susan Love's first presentation, there was much talk about the biology of breast

cancer. But what can women do for themselves? How can women change the outcomes for themselves, for their friends, for their country and for all women?

IMPROVING QUALITY OF LIFE

Remember that the cells live in an environment. You cannot afford to think about those cells as inevitable "terrorists that are going to blow up your body". You have to think about those cells as being able to be rehabilitated.

"They don't just have to be killed. They can be changed, controlled, put to sleep. There is some ability – maybe not 100 percent – but some ability to manage these cells ourselves."

We know about some of the things that we can do. For example, there is very good data on exercise and the role that it can play in improving the quality of life for women who have breast cancer. Strength training is good, because many breast cancer drugs – such as aromatase inhibitors – make the bones weaker, so making the muscles stronger helps reduce the risk of osteoporosis. Cardio exercise involves the release of endorphins which, if nothing else, makes you feel better. Yoga has also been shown to improve the quality of life. Any way you look at it, it is important to incorporate exercise in your life.

Stress reduction has also been shown to improve the quality of life. We were hoping that it would have greater effect by "putting the cancer cells to sleep", but it is not clear that it can do that. All of the measures that have already been talked about – meditation, music, singing dancing, laughing – make a major difference in the quality of life, if not the quantity. Another important aspect in stress reduction is community – support groups. The support and camaraderie that women gain from each other is important, and this is a way in which women can gain a lot of strength.

Menopausal symptoms are harder to manage, particularly as the traditional drugs that are used for them are not always able to be used by women with breast cancer.

"Sometimes you just have to 'reframe' things. Don't think about hot flushes as an annoyance or as evidence of the chemo, but think of them as power surges. You really have to think about it differently, that the energy is so strong in your body that it just has to come out somewhere."

Menopause gets a 'bad rap', but so much of it is about how we perceive things, and some of the words that we use indicate how we think about it. Hormone replacement therapy implies that something is missing, but what we are doing is 'replacing' something that should not be there. When doctors talk about oestrogen deficiency disease (menopause) we all feel deficient, and we don't like to be deficient. However, menopause is a normal process that has always happened to women; it is a normal part of life and we medicalise it by suggesting that women are 'deficient'.

The really powerful women in the world – Margaret Thatcher, Indira Gandhi, Madeleine Allbright, Hillary Clinton – are all post-menopausal. Menopause releases us from the reproductive domesticity that oestrogen and our fertile years imposes upon us and we can reclaim our power!

"It's a different way to think about it and it makes you feel a lot better. It shows you that how you think about things really makes a difference."

PROLONGING SURVIVAL

There is data that some of the measures discussed can not only improve quality of life but can prolong survival as well.

We had thought that diet would be the key; there have been many recent studies looking at low fat and diets high in fruit and vegetables. Unfortunately diet has not been the saviour that we thought it would be, although it is still worth having a diet that is high in fruit and vegetables and low in animal fat.

Exercise has been shown to improve survival as well as improving quality of life. You have to do a significant amount – four to five hours a week of 'regular' walking, or 30 mins of brisk walking (that produces a sweat), four to five times a week, or running for shorter times.

Observational studies have shown that those who exercise have a 50% lower death rate than those who do not exercise, although there may be other things that these women are doing, such as eating better as well. The greatest benefit is seen in women who go from doing nothing to doing something – no exercise to some exercise. The same benefit is not seen among women who are already exercising and then do more.

Body weight is an issue that the majority of women seem to struggle with but it is a crucial

factor particularly among post-menopausal women. It is important to maintain a healthy weight, or to lose weight if you are overweight, in order to decrease the risk of dying from breast cancer. Fat produces its own oestrogen, and studies have shown that women who are overweight after menopause, or after diagnosis, have a higher chance of recurrence.

"General health is important, too! Breast cancer survivors always forget that there are other things that can kill you, besides breast cancer."

"Don't smoke! It is not okay to smoke; it is one of the stupidest things you can do."

Smoking is associated with many chronic health conditions – cardiovascular disease, diabetes, lung cancer and other respiratory diseases.

"And it is the biggest cause of wrinkles!" Susan said stridently. If you only stop for reasons of vanity, it's worth it.

Finally we have to have fun. We are all going to die sometime; death is not optional. The goal is not to decrease mortality *per se* – we are all going to die! And there is no point in living for a long time with a poor quality of life.

"The goal is to live as long as you can, with the best quality of life you can have, and then drop dead, whether you have breast cancer or not."

The way to achieve this is to make lifestyle changes. The way to do it is by enjoying each day; by focussing on getting the most you can out of every minute.

If you do happen to have a recurrence, and have to deal with breast cancer again, try to participate in clinical trials. It is the only way that we make progress – the reason we know about Herceptin is because there were women who were prepared to be randomised in a trial pitting Herceptin against nothing. The reason we know that lumpectomy and radiation is as good as mastectomy is because women were willing to be randomised to one of two trial groups – lumpectomy and radiation versus mastectomy.

YOU AS A MEMBER OF THE COMMUNITY

After you have been diagnosed with breast cancer, you become a resource for your community. You become the person that other people come to, to ask about breast cancer.

"The most important thing you can do when a woman comes to you and says she has just been diagnosed is say 'take a deep breath and don't rush into anything'."

"The diagnosis of breast cancer is not an emergency; it is not going to spread that night. It has been there a long time, and you have time to express an opinion, to research things, and to figure out what is the best approach for you."

The next important thing to do is to take your most obnoxious friend to your doctor's appointment. Make a list of what you want to know and if you can't ask the questions, get your 'obnoxious friend' to ask. Later on, when you have recovered, you can be the obnoxious friend for someone else. Take a tape recorder so that you can go back and listen to what was said later on, so that you don't have to take notes or try to remember everything. It also saves the doctor a lot of phone calls.

"The most important thing is to be out there – let people know that you have breast cancer. Knowledge makes it less scary. It is powerful to bear witness to the fact that you can have breast cancer and life goes on."

BEING AN ADVOCATE

As a group, women with breast cancer are a powerful force to contend with. You really can't stop a determined group of women out to change the world. And women can change the world. Breast cancer advocacy has already changed things for the better.

Susan tells of a talk she gave in the 1990s in which she suggested that to achieve change perhaps women would have to march on the White House topless. She got a laugh, which is what she had intended, but after she had finished several women approached her and asked "when do we leave?"

"It was then that I realised that it was time we made breast cancer political," she told the conference.

Early on in breast cancer advocacy in the United States, the movement managed to acquire money from the US Defence budget for breast cancer research. Today, ten years on, breast cancer research is still funded in part through the Department of Defence. Women decide where the money goes and no research gets approved with-

out women advocates being involved. This has come about through Project Lead, a programme run by the National Breast Cancer Coalition which trains advocates to sit on the committees that are allocating grant money. It is a science training course designed to help breast cancer activists influence research and public policy processes; a seat at the table. You have to demand that right to be involved in the decision making.

We need to go beyond pink ribbons. We need to take the step towards actually making things change. Awareness is important but we also have to be sitting at the table, demanding something better. Women should be the ones to decide the agenda; they need to be on the committees and be involved in ensuring that there is change.

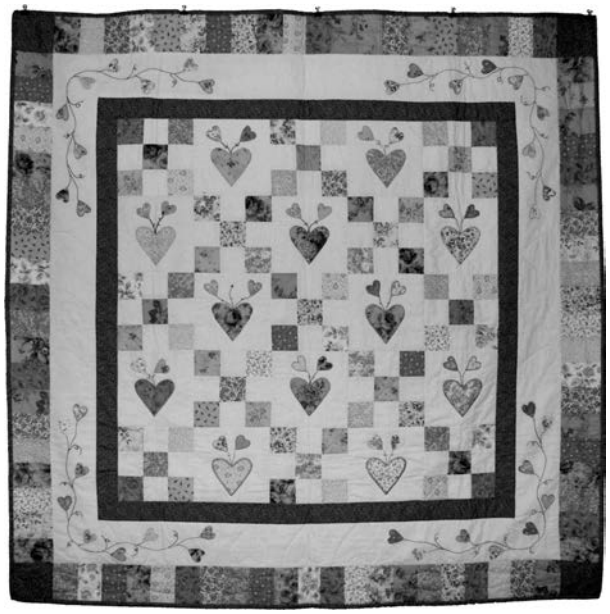
"We have to be there saying, 'this is where we want the research to go, these are the answers that we want."

"We want more research into metastatic disease... or we want more into the environment... or we want a new test that works in pre-menopausal women."

"You decide the agenda that's right for New Zealand!"

Women really can influence the change. We can stop breast cancer but we need to be bold, fearless, sassy, stroppy and obnoxious. We need to demand it, because we are the ones that care the most. To us, it really, really matters.

We **can** be the ones to make it happen and we **have** to be the ones to make it happen, because our lives, and the lives of our daughters and granddaughters depend on us stopping breast cancer.



Aorere Community Education Patchwork & Quilting Group

Catherine Hodson

Annie Fielder Munro

Yo Oliver

Part Two: Workshops
Context | Issues | Recommendations

Each workshop was provided with a form on which to record the discussion points and recommendations that arose from that discussion. The summaries presented here are based on the forms that were returned from each of the workshops.

Some of the workshops provided information and a forum for general discussion for the participants, and the 'outcome' of those workshops were those discussions. In others, recommendations and ideas for improving the quality of life for the participants were the main outcome, while in the majority of workshops specific recommendations were made for improving the detection and diagnosis and/or treatment and care, or outcomes, or psychosocial support for breast cancer patients now and in the future. These recommendations form the outcomes and recommendations for this conference – the way forward!

Fertility Options After Treatment

DR MEGAN OGILVIE

Megan Ogilvie *is a general and reproductive endocrinologist. She graduated from the University of Auckland and completed specialist training in Auckland. She undertook postgraduate training in general and reproductive endocrinology at St Bartholomew's Hospital and Middlesex Hospital in London. Megan returned to New Zealand to join Fertility Associates and to work publicly at Fertility Plus in 2005.*

Context

Breast cancer is not uncommon in young women. As childbearing is increasingly delayed in our society all the time, pregnancy options after breast cancer therapy are becoming more relevant. There are options for fertility preservation before and after breast cancer treatment, including preservation of embryos, mature oocytes and ovarian tissue as well as attempts at ovarian protection during chemotherapy. Safe pregnancy and lactation after breast cancer are possible – improvements in techniques are continuing and research is still in its early years.

Issues and Discussion Points

- Some women have not completed their families at the time of a breast cancer diagnosis; 25% of women treated for breast cancer are potential candidates for a future pregnancy.
- Endocrine concerns following breast cancer treatment include absence of periods, fertility preservation, will pregnancy be possible, and if so, will this change the risk of cancer recurring, and is lactation possible and safe?
- Chemotherapy can be harmful to the ovaries. Fertility after breast cancer depends on the chemotherapy regime used, the age of the woman, and the number of courses of chemotherapy.
- There are treatment options available that can preserve fertility: IVF and embryo freezing, freezing of mature oocytes, in vitro maturation, and freezing ovarian tissue.
- Preserving ovarian function during chemotherapy may be achieved with a drug called a GnRH analogue.
- Pregnancy after breast cancer: pregnancy does not appear to have a negative effect on survival. However only 3- 8% of premenopausal women conceive after breast cancer treatment.
- Lactation after breast cancer: if a woman has had breast conserving surgery followed by radiotherapy she can still produce milk on the affected side.
- Conclusion: there is much going on in the field of post breast cancer fertility that improves a woman's options.

Recommendations

- A woman's oncologist or a fertility specialist needs to discuss what a woman wants, the likelihood of menopause and the impact

of treatment on her fertility. Donor eggs or oocytes maybe an option for some women.

- Women should be advised to wait for three years to conceive if they are node negative, and to wait five years to conceive if they are node positive.
- Women able to and wishing to breastfeed after breast cancer should be advised not to breast feed on the side affected when they have undergone radiotherapy.

Sarah Hunter, a Registered Nurse and Doctoral candidate is interested in talking to women about fertility damage as a result of breast cancer treatment for research for her doctoral degree. Sarah can be contacted on 027 264 3502 or by email at shun044@auckland.ac.nz for more information.

Management of Menopausal Symptoms in Women After Breast Cancer

DR STELLA MILSOM

Dr Stella Milsom *is a specialist in endocrinology and reproductive medicine at Fertility Associates and at the Department of Reproductive Medicine, National Women's Hospital, Auckland. She is also a Clinical Senior Lecturer in the Department of Obstetrics and Gynaecology, University of Auckland. Her clinical and research interests include ovulatory disorders, polycystic ovary syndrome, menopause and lactation physiology.*

Context

The management of significant menopausal symptoms in a woman with a history of treated breast cancer, or as a result of treatment for breast cancer, remains a challenge for both health professionals and affected women. In general, vaginal atrophy, osteopenia and mood changes can be managed effectively and safely, but vasomotor symptoms present more of a challenge. HRT is, in general, contraindicated in these women. However, there are lifestyle, herbal and pharmacological alternatives to HRT for troublesome vasomotor symptoms.

Issues and Discussion Points

- Symptoms of menopause: hot flushes and sleep disturbances, mood changes and irritability, vaginal dryness and reduced bone mineral density.
- Vasomotor symptoms of menopause occur in 70% of women and are severe in 20%. Such symptoms are usually self limiting, lasting 6-36 months for 70% of women.
- Options for managing vasomotor menopausal symptoms for women **without** a history of breast cancer include HRT (oestrogen+/-progesterone), other hormonal therapy (tibolone, progestins), neuroendocrine agents, and complementary therapies (lifestyle and non-prescription treatments).
- Should breast cancer survivors take HRT?
- What are the alternatives to HRT?
- Management of menopausal symptoms in women after breast cancer.

Recommendations

- To cope with menopausal symptoms after breast cancer women need to optimise their lifestyle, recognise that symptoms do not last forever and to treat bone density and vaginal atrophy as required.
- Alternatives to HRT if vasomotor symptoms are significantly impairing a woman's lifestyle: complementary therapies – lifestyle changes, acupuncture, relaxation techniques and non-prescription treatments; other hormonal therapy – tibolone and progestins; neuroendocrine agents – clonidine, gabapentin, SSRIs.
- If HRT is to be used it should be an informed decision between the woman and her doctor after a full discussion of the risks and benefits.

Family History of Breast Cancer – what it means for you

PROF INGRID WINSHIP, CINDY ZAITSOFF

Professor Ingrid Winship *commenced her appointment in November 2006 as the inaugural chair of adult clinical genetics in the Department of Medicine and Royal Melbourne Hospital, at the University of Melbourne. She is also head of the adult genetic service at the Royal Melbourne Hospital. Ingrid is a Clinical Geneticist with an interest in clinical services and research into late onset genetic disorders and the inherited predisposition to cancer. She is Chair of the Cancer Council of Victoria's Victorian Co-operative Oncology Group (VCOG) Cancer Genetics Advisory Group and deputy chair of the VOCG. She combines this with her role as research director for Melbourne Health.*

Cindy Zaitsoff *is a genetic counsellor based at the Northern Regional Genetic Service in Auckland. A large part of her current role is cancer genetics, but she also has varied experience in general and pre-natal genetics and particularly in pre-implantation genetic diagnosis.*

Context

Having one or more close family members who have developed breast cancer may increase your chance of developing breast cancer over the general population risk. Family history affects our own risk and family history is assessed in the setting of a Genetics Clinic. Different options are available to manage different levels of risk, and there are issues that affect both the individual and their families regarding genetic testing for people who appear to have an inherited predisposition to develop cancer.

Issues and Discussion Points

- Very few cases of cancers are due to an inherited predisposition; only 5-10 % of breast cancers are due to an inherited predisposition and not all are accounted for by BRCA1/2 gene mutations.
- There are specific patterns in family history that suggest an inherited mutation (gene change) which predisposes to cancer within a family.
- Genetic management for cancer susceptibility involves information gathering, risk assessment, communication and education, surveillance recommendations, non-directive counselling, support, reassessment and follow-up, and genetic testing.
- Key questions include:
  - How many relatives are affected with cancer?
  - What type of cancer is in the family? Similar types?
  - What side of the family are the affected relatives on?
  - What is the relationship of the affected relative to the patient?
  - What is the relationship of the affected relatives to each other?
  - What age were the affected relatives diagnosed?
  - What is available for women at high risk of breast cancer?
  - Psychological implications of genetic testing.

Recommendations

- It is as important for risk assessment to obtain the breast cancer history from the father's side of the family as the mother's family history.
- Referral to a genetic service is important for accurate risk assessment and management recommendations.
- MRI imaging needs to be available/used for high risk women.
- An individual's DNA can be extracted from a blood sample and stored by genetic centres for use by relatives at a later date.

The Healing Power of Your Mind

BEV SILVESTER-CLARK

For more than 25 years **Bev** *has been committed to promoting health and happiness through the healing power of the mind, emotions and spirit. She works both with individuals and with groups. With her colleagues in the USA she has developed programmes applying mind-body principles to managing cancer treatment, preparing for surgery and recovery from major health challenges. She was one of the group facilitators in the St Marks study; a research project that has confirmed the great value of a mind-body approach to breast cancer.*

Context

Why do some people do so well despite a very bad prognosis? Why do others do so poorly despite a good prognosis? The mental, emotional and spiritual dimensions of a person are extremely significant in recovery from cancer. Within every individual, the mind, emotions and spirit are powerful and unrecognised resources that can make a huge difference in the healing journey. This workshop presented women with ideas on how to access this knowledge and power.

Issues and Discussion Points

- ☞ The patient needs to satisfy herself that a mind-body approach is scientifically sound.
- ☞ Women can access the knowledge and power by:
  - learning how to relax,
  - learning how to breathe,
  - learning how to meditate,
  - learning to live in the present,
  - conducting a careful lifestyle review – diet, exercise, stress patterns,
  - learning to use her imagination to talk to her body,
  - making friends with her feelings,
  - understanding the power of her unconscious belief system,
  - having a clear sense of purpose for her life,
  - celebrating her one magnificent life!

Recommendations

- ☞ That every effort be made to have mind-body approaches to the journey with cancer integrated into mainstream care and offered right from the time of diagnosis, through treatment and be available at all stages thereafter.

Brain Fade With Chemotherapy

DR MICHAEL JAMESON

Dr Michael Jameson *(FRACP MRCP(UK) PhD) is a Medical Oncology Specialist at Waikato Hospital. He was awarded his PhD for a clinical phase I trial of a new anti-cancer drug from the Auckland Cancer Society Research Centre and is currently involved in both research and clinical practice. His research interests include cognitive changes with chemotherapy, the impact of selenium on preventing cancer and modifying the toxicity and efficacy of cancer treatments, and early clinical trials of new anti-cancer drugs (he is leading trials at Waikato Hospital on new drugs developed at the Auckland Cancer Society Research Centre).*

Context

Patients receiving chemotherapy commonly complain of "chemo brain", noticing poor concentration and memory in particular. Cohort studies demonstrate measurable impairment of cognitive function in patients who had recently completed chemotherapy, and persistent changes were noted even ten years later following high-dose chemotherapy. Recent longitudinal studies

have reported marked impairment across several cognitive domains, but these appeared to be largely reversible, and studies of adjuvant chemotherapy for breast cancer suggest that there is little problem longer-term.

Issues and Discussion Points

- ☞ How does chemotherapy affect brain function?
- ☞ How do you measure "chemo brain"? It slows down metabolism, generates free radicals and causes tiredness.
- ☞ Chemotherapy and cognitive effects – memory, concentration, effects on speech and inability to multi-task.
- ☞ One effect of oestrogen deprivation is that the brain slows down.
- ☞ Knowledge of the condition is a step forward. People talking together about the issues is often the best way forward.

Recommendations

How can women cope with "chemo brain"?

- ☞ Women need to be told about "chemo brain" before chemotherapy starts.
- ☞ Women should be advised how they can help the brain function:
  - exercise the brain, e.g. crosswords, etc.
  - keep fit, stay healthy and get enough fresh air,
  - get enough sleep,
  - diet, including omega 3 fatty acids, selenium, berries, etc.
- ☞ Talk to others about "chemo brain" – find out what helped them.

Access to Care – are New Zealand women getting the best?

SUE GUTHRIE

Sue Guthrie *is a Health Information Manager from Auckland and a two year survivor of breast cancer. She is the Treasurer for BCAC and the New Zealand representative on the Consumer Advisory Panel of the Australia New Zealand Breast Cancer Trials Group. Sue has worked for the Auckland District Health Board for 12 years, specialising in clinical coding and casemix.*

Context

New Zealand's breast cancer survival rate is 28% lower than that of Australia. There are issues involving adequate access to best practice breast cancer care and treatment both across the board and for specific sectors of New Zealand society. Ensuring that all New Zealand women with breast cancer receive full access to detection and diagnostic services, medical treatment and support are a major concern for both breast cancer patients and the many consumer and advocacy groups working on their behalf.

Issues and Discussion Points

- ☞ Mammography:
  - communication re eligibility and availability of services,
  - low rates of access by Māori and Pacific women,
  - eligibility for those with a family history and previous diagnosis of breast cancer,
  - increased coverage of the national screening programme,
  - training for radiographers.
- ☞ Access to drugs:
  - consultation with consumers.
- ☞ Radiotherapy:
  - access to treatment – issues with distance from treatment centres for many women,
  - treatment delays (how long are the waiting times around New Zealand and how can these be addressed).
- ☞ Support Services:
  - sources of information – currency and accessibility,
  - private versus public sector,
  - national database and NZ Cancer Society,
  - access to breast care nurses by private patients,

- district health nurses and funding.

Recommendations

☞ Mammography:

- That there be better communication regarding mammograms and eligibility.
- That it should be patient's choice to receive results from mammograms or not.
- That state funded access to mammograms be increased to include women from 40-45 and 69-79, as in Australia.
- That mammographers are supported to continue to 'renew' existing skills to meet training requirements.

☞ Access to drugs:

- There should be full consultation with relevant, appropriate and representative consumer groups.
- There should be early and timely consultation.
- There should be time for consumers and consumer representatives to respond to proposals so that consumers may meet, reflect and consult.
- That consultation with consumers should be two-way, open and accountable.
- That consumer advice/input should be appropriately resourced.

☞ Radiotherapy:

- Community fundraising should be for equipment not buildings. Government should provide buildings.
- Delays need to be addressed as the guidelines for treatment specify that treatment be commenced within four to six weeks, while the current waiting time is 12-16 weeks.
- New machines should be provided for the Tauranga/Bay of Plenty and Hawkes Bay regions, to deal with an increasingly aging population.

☞ Support Services:

- That information provided to patients be up to date and accessible.
- That the NZ Cancer Society works to expand their provision of support services to include all regions.
- That private patients have access to breast care nurses.
- That there be improved funding for District Health Nurses.

Lymphoedema: The swollen limb

KATH VICKERS

Kathryn Vickers *is a Physiotherapist a Lymphoedema Therapist in private practice with a special interest in post breast surgery rehabilitation and lymphoedema management. She has completed three post-graduate level lymphoedema accredited courses and is a member of the Australasian Lymphoedema Association. She is also a trustee for the Breast Cancer Support Service Trust and runs a monthly lymph-oedema awareness session. She also co-ordinates the YWCA Encore programmes in the Bay of Plenty.*

Context

Lymphoedema is the accumulation of fluid in the tissue causing swelling. It may occur soon after treatment or months or years later. It may occur as result of breast surgery, radiation treatment or infection. Lymphoedema is a significant problem for many women following breast cancer treatment and can impact on health and quality of life in the years after breast cancer.

Issues and Discussion Points

☞ Rehabilitation following breast cancer treatment.

☞ Early warning signs for lymphoedema.

☞ Avoiding or managing lymphoedema.

☞ Air travel and lymphoedema.

☞ Where do women obtain advice if they are concerned about lymphoedema.

☞ Access to treatment.

☞ Access to garments; discrepancies in the funding of garments.

☞ Where do women find practitioners that specialise in the management and treatment of lymphoedema.

- ☞ Future developments for lymphoedema management:
  - Sentinel Node biopsy - reduced need to remove axillary lymph nodes.
  - Laser treatment is being used in Whangarei?
  - A bioimpedence unit is being used in Tauranga to measure and monitor arm density post-operatively to detect early onset lymphoedema in the arm.
  - Lymphoedema therapists have noticed an increase in breast oedema and the need for aspiration of fluid from the axilla.
  - More breast conservation surgery is leading to new rehabilitation protocols.
  - More medical people training in lymphoedema management.
  - Increase in exercise programmes after breast surgery and lymphoedema (YWCA Encore, Pink Pilates, Gym programme in Auckland, dragon boating, Nordic walking)

Recommendations

- ☞ There is a need for greater awareness of lymphoedema by medical staff, particularly when blood tests or IV lines are required.

Reconstruction

DR STEPHEN MILLS

Dr Stephen Mills *is a New Zealand trained plastic and reconstructive surgeon. He has a special interest in breast surgery including congenital, reconstructive and cosmetic aspects. Dr Mills is on the medical advisory committee of The New Zealand Breast Cancer Foundation. He is a senior reconstructive breast surgeon at Middlemore Hospital, Auckland and is also in private practice.*

Context

Breast reconstruction is not suitable for everyone but should be offered to all women undergoing breast cancer surgery. Breast reconstruction can be performed at the time of mastectomy (immediate breast reconstruction) or at a later time (delayed breast reconstruction). Reconstruction uses a patients own tissues or implants or a combination of both.

Issues and Discussion Points

- ☞ Partial mastectomy offers good options for breast aesthetics, but must be followed up with radiotherapy.
- ☞ For larger breasted women partial mastectomy can be combined with a breast reduction with excellent aesthetic outcomes.
- ☞ Immediate reconstruction often offers better results than delayed reconstruction as it is possible to preserve the skin of the breast.
- ☞ Skin sparing mastectomy preserves the skin of the breast but removes the breast tissue.
- ☞ Funding of breast reconstruction: there are inequities in the funding of breast reconstruction in the public health sector around the country with some areas only offering immediate reconstruction while in other areas delayed reconstruction is not funded.
- ☞ The proximity of the patient to a plastic surgery unit is a major factor in breast reconstruction options available.
- ☞ In the private sector a mastectomy plus TRAM flap reconstruction costs approximately $25,000

Recommendations

- ☞ All women should be provided with information on the options for breast reconstruction including immediate and delayed reconstruction, and should have the benefits, risks and complications of the procedure fully explained.
- ☞ General surgeons should improve their plastic surgical skill base or work in conjunction with a plastic surgeon in order to ensure improved outcomes for partial mastectomies.

Environment, Lifestyle and Breast Cancer – how important are these links, and what can be done?

DR MERIEL WATTS, DR URSULA MAKOWIEC

Dr Meriel Watts' *career path has included agricultural science and work as a naturopathic health practitioner. Over the last seventeen years she has worked with a number of non-governmental organisations on behalf of community and environmental interests regarding the impacts of pesticides. Since gaining her PhD in 2000 in pesticide policy, she has worked closely with Pesticide Action Network Asia and the Pacific and is highly regarded internationally as a researcher and author. A keen organic grower, her major interest is the influence of pesticides on breast cancer incidence, and she has recently published a book investigating this topic (Pesticides and Breast Cancer: A Wake Up Call).*

Dr Ursula Makowiec *qualified in Germany as an Obstetrician and Gynecologist, Breast Surgeon and Physician. Since the early 1990s her interest has been breast cancer, particularly prevention and early detection. Her PhD study was a comparison of breast ultrasound with mammography for screening, in order to find an additional tool for early detection which would not cause additional harm. She is very interested in the links between life-style, environmental factors and breast cancer. She currently juggles her work at Auckland's North Shore Hospital with raising two school-age sons. Ursula is also well-known in her home country for her achievements as an athlete.*

Context

Is it possible for an individual in New Zealand to reduce breast cancer risk by making changes to their lifestyle and working to influence the politics around environmental chemicals? Lifestyle factors and environmental chemicals may influence the subsequent development of breast cancer from as early as in the womb. By adhering to the precautionary principle, positive steps can be taken by individuals and at a societal level to reduce the risk of breast cancer.

Issues and Discussion Points

- Soy products.
- Risks: obesity, alcohol, smoking and passive smoking, oestrogen exposure and HRT.
- Pesticides (including herbicides), chemicals in cleaning products, endocrine disrupting chemicals.
- Diet; organic food.
- Awareness of chemicals.
- Substitution principal – finding safer alternatives.
- Labelling of products in New Zealand.
- Safe cleaning products.

Recommendations

- Education is a key issue:
  - make a submission to the Ministry of Education;
  - girls should be made aware of issues at puberty – need an info/education pack for girls at intermediate school on breast awareness;
  - expectant mothers should also be educated about environmental influences on breast cancer development;
  - Public Health and Plunket nurses throughout the country should be educated;
  - further discussion and articles through BCN's newsletter, *Upfront*;
  - promotion of issues and awareness to young people through internet sites such as Bebo;
  - Men should be included in education initiatives - so that they are well-informed to advise their daughters.
- Consumer products with a "pink ribbon" should have no harmful chemicals added.
- Councils should be approached by residents and rate payers and asked to ensure that safe alternatives to harmful chemicals are used (e.g. alternatives to endosulfan)

- ☞ The issue of environmental influences on breast cancer should be promoted both in terms of survival and prevention.
- ☞ The impact of the environment on the development of breast cancer needs to be constantly brought to the attention of the media.
- ☞ There is a need for more literature on the subject.

Managing Your Healing Team

PHIL KERSLAKE

Phil Kerslake *is a well-known New Zealand cancer survivor, TV presenter, life coach, speaker, and author. First diagnosed as a teenager, he has coped with six battles with both Hodgkin's and non-Hodgkin's lymphoma over 28 years, twice recovering from stage 4 illnesses. Phil is the author of the highly acclaimed* Life, Happiness …& Cancer: Survive with Action and Attitude! *– a book that which marries up-to-date international research with Phil's personal experiences, to outline how patients may underpin their recovery causes through active participation and the tactical use of psycho-social support measures.*

Context

Coping well with cancer is best achieved through teamwork. The patient's spouse/life partner may be their first source of logistical and emotional support, but there are many others who can play a valuable role in helping sustain them during a cancer battle. A patient's 'healing team' may include their family, whanau, friends, employers, work colleagues, medical professionals, cancer support organisations, counsellors, other cancer patients, and many others in society. The breast cancer patient can rally and coach the various members of their healing team, so that it works like a well-oiled machine in their interests.

Issues and Discussion Points

- ☞ Why team work?
  - Coping with cancer is best achieved through team work.
  - Even the most independent of people benefit from medical, emotional, logistical, employment/economic and problem-solving support.
  - Being open to support helps others cope too.
  - It is, therefore, neither selfish nor an indicator of weakness to seek and accept support.
- ☞ Who are the key members of a patients healing team? (Your spouse/significant other, adult family/whanau and close friends, your children, medical/health professionals, cancer support organisations, employer and co-workers.)
- ☞ Patients should always put their recoveries before their jobs, but may nevertheless choose to work through their treatments if this is feasible.
- ☞ Patients may benefit significantly from developing and implementing a planned psychosocial support program with the help of their cancer support organisation.

Recommendations

- ☞ Patients should consider building and managing their healing team as a part of their recovery plan.
- ☞ Patients should let people know that support is welcomed, and let them know specifically what they can do for them.
- ☞ Patients should be active participants in their treatment programs, monitoring and questioning constantly to understand the process.
- ☞ Patients should plan and even rehearse appointment discussions with their medical professionals to gain the most value from them.
- ☞ Children should be told about the parent's cancer diagnosis and the events to come, but in a careful, planned and considered way.
- ☞ Patients should connect with a suitable cancer support organisation early in their recovery process to construct a program of psycho-social support services to complement their primary treatments.

A Lesbian Perspective

DR SUE HANNA

Dr Sue Hanna *is a Senior Lecturer and programme leader of the Bachelor of Social Work Programme at the University of Auckland. Her research interests are in new and emerging areas of social work practice, and in exploring how people who experience significant trauma move forward with their lives. Sue was first diagnosed with breast cancer in 1999.*

Context

The results of a recent New Zealand lesbian health survey found lesbian women have poorer health, and delay seeking health care even from alternative health professionals. These results support overseas studies suggesting that lesbian women access health services in a different way from random samples of heterosexual women. Statistically lesbian women, who comprise roughly 3 to 5% of the total population, develop breast cancer in higher numbers than their heterosexual counterparts, yet empirical data significant to this group remains under theorised in the medical literature.

Issues and Discussion Points

- Small minority group in relationship with larger institutions in a dominantly heterosexual society.
- Who are we and does it matter?
- What are the risk factors for breast cancer for lesbian women?
- What is the prevalence of breast cancer among lesbian women?
- Differential use of the health care system.
- Lesbian life style factors.
- Support networks.
- Coping styles.

Recommendations

- It is important that information from women who identify as lesbian is collected on admission forms and is entered onto a national database so that information on the characteristics (risk factors, prevalence) of breast cancer among lesbian women are captured and reported on.
- Lesbian breast cancer survivors need to do more to publicise risk factors for lesbian woman within the lesbian community and through lesbian networks.

Cultural Aspects of Care for Maori

DR MADELEINE WALL, BUBSIE MCFARLANE

Graduating as a doctor in 1982 ***Madeleine*** *subsequently specialised in radiology and has worked almost exclusively in breast imaging and screening for the last ten years. She was Clinical Director of the Wellington regional breast screening programme until 2003 when she became the clinical leader of the national programme BreastScreen Aotearoa. Madeleine is married with five children and two small granddaughters.*

Prior to her present position as a health promoter ***Bubsie*** *worked for the Cancer Society. She works to raise awareness and encourages the community to participate in breast and cervical screening programmes. As well as being involved with the Make a Wish Foundation, Bubsie started the Aroha Mai Cancer Support Group in Rotorua and is passionate about working in this area.*

Context

That there are disparities in the health of Māori versus non-Māori is well recognised and disparities in mortality from breast cancer between Māori and non-Māori women are significant. Māori women have a 68% greater chance of dying from a disease for which we are seeing increasingly better survival in other groups. Poorer

survival outcomes for Māori women are associated mainly with later stage of disease at diagnosis, when the cancer has already spread. This highlights the need to ensure equitable access to screening, primary care and diagnostic services However, there are still significant inequities in survival, even among those diagnosed at a similar stage of disease progression. This implies that there is poorer access to timely and appropriate treatment services in Māori compared with non-Māori.

(This workshop involved a mixture of Māori cancer survivors and a large contingent of non-Māori cancer survivors who work in the health system – practice nurses, hospital oncology staff and breast screening staff).

Issues and Discussion Points

Many stories of:

- women from poorer areas who do not feel comfortable attending screening at private radiology practices.
- inequities in funding transport to BreastScreen Aotearoa Assessment Clinics.
- GPs ignoring women who present with symptoms.

Recommendations

- That there be better access to screening for women who live in lower socio-economic areas.
- That the mobile units be sited in these areas for longer periods and in places where women can access them without the need for private transport.
- There is a need for a consistent national policy on funded transport to BreastScreen Aotearoa Assessment Clinics.
- That there be greater access to Māori cancer support services such as Aroha Mai.
- GPs need to be re-educated regarding the management of women with symptoms irrespective of whether or not women have been screened. This should include how to listen to their patients.
- Update the GP guidelines.

Living With Hope In Your Heart

MEG HILLS

***Meg** is a Sister of St Joseph, a registered General Nurse, Midwife, Social Worker and grief and loss counsellor. Sixteen years ago she took up employment for what is now the Bay of Plenty DHB and in this time has worked extensively in psycho-support, education, advocacy and co-ordination of services provided to adults with cancer. In 1998 Meg and two surgeons established a dedicated weekly Breast Care Clinic which she facilitated until recently when a breast care nurse was appointed. Over the years she has walked alongside many women who have breast cancer. She dedicated this forum to her friends and mentors, Annette and Debbie, both of whom lived with hope in their hearts until the day they died.*

Context

The needs of women living with metastatic disease differ greatly from those of women with early breast cancer. Despite complex ongoing treatment women with metastatic disease seek to live full and productive lives. The journey is often fearful, lonely, frustrating and not to mention expensive! Keeping hope in your heart can be a mighty challenge.

Issues and Discussion Points

- The concept of time changes for women with metastatic disease. Time = 'now'. The present (now) is a gift to be unwrapped daily.
- Metastatic breast cancer is a lonely journey.
- Patients with metastatic disease have to work harder to access information, services and treatment, and have to constantly be pro-active.
- When you are labelled "palliative" you are no longer a 'top priority' in terms of investigations, etc.
- Those who have lived with mets for many years are such an inspiration to women who are newly diagnosed.

- A prognosis is an opinion not a prediction!

Recommendations

- That more information be available to women with metastatic disease, particularly on the BCN website.
- That participants in the workshop form their own support network (via e-mail/phone). This gave great energy as many feel very alone on their journey.
- That the BCN website develop a 'chat room' or an online message board facility for women with metastatic disease.

Cultural Aspects of Care for Pacific Island Women: Le Ula O le Ola-Lei of Life

BERNADETTE PEREIRA, PAPALII MEMA ASPINALL, ROSA WETZELL

Bernadette Pereira *is a Community Development Adviser for the Manukau City Council where she works extensively with diverse communities. She is a member of the Pacific Island Health Advisory Council to the Counties Manukau District Health Board and Community Reference Group Representative to the Ministry of Pacific Island Affairs Auckland. She is also the Inaugural President for the National Council of Women Manukau Branch. Bernadette was diagnosed with Breast Cancer in 1995.*

Papalii Mema Aspinall *JP and celebrant is the CEO of O Tua'a Sina-Sina-O-Samoa Welfare Council Inc, a community group for the elderly. She is also a Community Reference Group representative for the Pacific Island Community and the Past President of the Council of Samoan Women in New Zealand Inc. Papalii has been involved with a number of nationally organised societies like the National Council of Women as well as local community groups like ASPAIR. Papalii has a Samoan public service background as well as New Zealand legal executive experience.*

Rosa Wetzell *is actively involved with her church and is a member of St Mary's College Alumnae Samoa.*

Context

As with Māori women, there are considerable disparities in outcomes for Pacific Island women with breast cancer; mortality from breast cancer is highest among this cultural group. Pacific cultures are inclined not to openly discuss cancer; it is often seen as a "curse" on a family or a consequence of some action. As a result there is little information available to women in the Pacific Islands and in New Zealand, as with Māori, there is often a low participation in the national screen-ing programme. In addition, Pacific Island people are over-represented in economically deprived groups in New Zealand society, a known contributor to inequities in access to care and consequent disparities in breast cancer outcomes.

Issues and Discussion Points

"Pacific women at this conference are deeply appreciative of the opportunity to link our stories/journeys to all women at this conference. We need your continuing support."

Recommendations

- That a Samoan Women Survivors Support Group be formed after the conference. The initial fono will be held on the 1st of December, 2007, with the theme "Steps to reaching out."
- For the Breast Cancer Network to be part of the initial fono.
- For the Breast Cancer Network NZ to support the SWSSG in its journey in reaching out to other Pacific women.
- That the weaving of LO'le "Ola/Alofa"e Ula be continued.
- That links with mainstream services be made to scope what is available to support awareness among Pacific communities/families about people/women impacted by breast cancer.

Sexuality After Breast Cancer

ROBYN SALISBURY

*Clinical Psychologist **Robyn Salisbury** is Director of Sex Therapy New Zealand. Contrary to common expectations she does **not** wear fishnet stockings nor does she carry a whip but she will take a very matter of fact, sometimes light-hearted look at this important topic.*

Context

Studies have shown that for some there is significant impact upon libido and sexual function after breast cancer, but they also indicate that this is true for all life threatening, stress/grief related, and potentially body image changing challenges that we may meet in life. In addition to the stress/grief related impacts on a woman's sexuality after breast cancer, many treatments can cause severe physical symptoms such as changes in mood, libido, vaginal dryness and vasomotor symptoms.

Issues and Discussion Points

- ☞ There is a lack of useful information about sexual experiences – people figure it out by themselves.
- ☞ Sexuality = attractiveness + youth. How does breast cancer treatment and surgery affect this:
  - impairs body image
  - makes women feel less attractive,
  - makes women feel vulnerable, helpless, out of control,
  - generates anxiety, depression, anger, resentment,
  - loss of wellbeing, fatigue,
  - treatment side effects,
  - lowering of libido.
- ☞ How does cancer affect female sexuality. Only 15% of women express their sexual concerns to professionals.
- ☞ Female cancer affects sexuality yet the symptoms of this are rarely identified by treating physicians.

Recommendations

- ☞ Medical professionals should receive training to prepare them to discuss the side effects of treatment on our sexuality.
- ☞ Women also need to raise these issues with our medical professionals as well. Open sex up for discussion.
- ☞ Talk openly and fully with partner or a friend to work through any problems.
- ☞ Maintain non-sexual closeness – cuddles.
- ☞ Women should seek professional help if they need to.

Young Women and Breast Cancer – Psycho-social and long term survivorship issues

MAUREEN TRAINOR

***Maureen Trainor** is a Clinical Psychologist with 20 years' experience working primarily in collaboration with general practitioners to integrate psychological services into primary health care. She has always had an intense interest in health psychology, especially oncology and breast cancer. As well as private practice experience she has worked as a Student Health Psychologist at the University of Otago, the Family Court, ACC and has completed clinical work for the Police. She has a particular interest in the mind-body interface as it relates to the psycho-social aspects of breast cancer, and the importance of psychological mechanisms to ensure the best outcome for survivors of breast cancer. Maureen, herself, is a two-time survivor of breast cancer and strong advocate of the importance of increasing the quality and quantity of life for all women affected by breast cancer.*

Context

Arriving at the realisation you have breast cancer is a devastating event – particularly for young women. Younger women have been shown to experience more psychological distress than older patients including feelings of sadness, loss, anxiety and above-all, isolation. The importance of psychological mechanisms and support cannot be under-estimated as a tool for survival for young women.

Issues and Discussion Points

- Young women with breast cancer have specific issues unique to them.
- The increase in numbers of young women with breast cancer.
- What can we do to improve the support and survival of young New Zealand women with breast cancer?
  - What is the ideal support network for young women?
  - What does it need to include?
  - What can we do to promote it?

Recommendations

- That technology be used to connect young New Zealanders with breast cancer (e.g. email, internet).
- That a mentor or buddy system be implemented with women of similar age and stage being put in contact with each other.
- That an online support group be implemented.
- That services tailored for 20-45 year olds be implemented.
- That potential links with other cancer groups be investigated.
- That the needs of young women are promoted through the health sector.
- That 'look good feel better' type services are expanded.
- That a DVD of stories/experiences/step-by-step treatments be produced for young women.

Rural Women

ROBYN TOWERSEY

Robyn Towersey *was born in Invercargill, later moving to Carterton (Wairarapa) before moving to Opotiki (Bay of Plenty) in 1978 with her husband Jim and two children, David and Susan. On New Year's Eve 1990 at the age of 42, she underwent her first operation for breast cancer. This road turned out to be a little longer than was anticipated, with more bends than she had wished for at the time. She now lives in beautiful Ohope and she and her husband are the proud grandparents of two.*

Context

Living in the country has many advantages over living in the city, but is this the case when one is faced with a serious illness and many recognised support networks are some distance away? Rural women with breast cancer face challenges in accessing medical services, treatment and care.

Issues and Discussion Points

- Access to public transport and funding for travel.
- Lack of resources.
- Phone and internet coverage.
- Distance for family and friends to travel while the patient is having treatment.
- Information regarding treatment options.
- Treatment may involve more than one district health board and the problems associated with that.

Recommendations

- Health care professionals need to be informed that rural patients need all information packs provided at the first visit and that GPs are not always the "first stop".
- Privacy legislation prohibits volunteers being

able to offer help as they are not permitted to be informed of women in their areas – this aspect needs to be addressed.

- There is a need to co-ordinate equipment between DHBs as patients may be left hundreds of kilometres away and cannot be nursed appropriately.
- Patients need better information on the travel subsidies available.
- Although rural women understand the restrictions imposed by cost, rural patients needs must be considered at local and central government and a policy making level.

Cultural Perspective of Breast Awareness

MONIQUE FREDATOVICH, BETTY LING AND SUSAN HWANG

Monique Fredatovich *is the General Manager Operations WONS: Nursing, Education and Health Promotion Services. Monique has worked extensively with women and their health for the last 20 years. She discussed research on breast cancer and the Asian population.*

Susan Hwang *is a Korean Health Promoter with WONS: Nursing, Education and Health Promotion Services. Susan has worked with the Korean community on women's health issues and facilitates clinics and screening programmes for her community. Susan offered a Korean women's perspective on breast cancer, breast awareness and barriers.*

Betty Ling *is a Chinese health promoter with WONS: Nursing, Education and Health Promotion Services. She has worked extensively with the Chinese community and is a founder of the Chinese Women's Wellness Community Trust. Betty discussed what it means from a Chinese cultural perspective living in New Zealand, and the health care system, breast awareness and breast cancer.*

Context

Asian women who are new migrants to New Zealand are unfamiliar with the New Zealand health system. Language difficulties present barriers to women accessing population based health screening programmes. In the US lower rates of breast cancer incidence and mortality in comparison with other groups led both health care professionals and Asian women, themselves, to believe that they were not at risk from breast cancer. However, once Asian women migrate to western countries such as New Zealand, Australia and the US, their risk of developing breast cancer rapidly increases to meet the risk to women in their adopted country.

Issues and Discussion Points

- There are numerous barriers for Asian mi-grant women to accessing health care services: language, transport and culture and these barriers are interlinked.
- Asian women have the lowest participation rate in breast screening services.
- Asian women are often diagnosed with more advanced breast cancer compared with their Caucasian New Zealand peers.
- That myths about breast cancer exist for some Asian women; for example, that breast cancer is linked to "bad luck", and that seeking a cancer screening is merely asking for trouble.
- Some of the cultural issues for Asian women that hinder their participation in screening programmes and access to medical care and treatment include modesty, a lack of female health professionals, lack of family support and lack of understanding about breast cancer (e.g. if they wait the problem may "go away").

Recommendations

- That medical awareness information for the Asian population, in various languages, be made available.
- That an 0800 number medical language line, with interpreters in various languages, be implemented.
- That sharing information about the New Zealand medical system in the Asian languages be adequately resourced.
- That there be increased resourcing and funding for health educators and translators.

Art Therapy and Cancer Care

DENISE HERMON

Denise Hermon *is a cancer survivor and creative therapist living in Hamilton. HeARTworx Unlimited, her new business venture, has been created as an avenue through which she works to share her knowledge and passion about art and creativity as a therapeutic tool, through workshops, and with individual clients and their families. Denise has recently become involved with the 'Help me to heal' programme run by Health Journeys NZ, a retreat for people with cancer.*

Context

Art Therapy has its roots traditionally in hospital settings and goes back over 50 years when art was offered to hospitalised patients in specially set up art studios. The aim was group participation and sharing. Nowadays art also comes to your bedside through programmes such as "Arts for Health" which operates out of Waikato Hospital.

Issues and Discussion Points

- Art therapy is useful for relaxing while undertaking treatment, and can provide a useful diversion from the realities of treatment.
- Art therapy is not about having artistic ability; it is used as a way of expressing, discovering and achieving insight without words. It is process driven not results driven.
- Art therapy enables the patient to express unconscious attitudes and emotions about treatment and their journey with breast cancer. It can also give control back to the patients.
- There are more art therapy programmes available to cancer patients, e.g. Help me to heal programme – Jane Currie.
- Art therapy is available to patients, their families, and carers, from diagnosis, through, and after treatment. Art therapy can help you throughout your journey.

Recommendations

- Keep a positive outlook.
- Be an active participant in your treatment.
- Find a creative way to express yourself, whether that is through art, dance, music, writing, gardening – whatever takes your fancy.

Breast Cancer Advocacy – Making a positive difference together

LIBBY BURGESS

Libby Burgess *is a nine year breast cancer survivor. She chairs the Breast Cancer Aotearoa Coalition (BCAC), an umbrella group representing 23 of New Zealand's breast cancer-related groups. Libby is a member of the Guideline Advisory Team developing evidence-based clinical best practice guidelines for early breast cancer in New Zealand. She is providing a consumer perspective on the development of the Northern Regional Cancer Network under the New Zealand Cancer Control Strategy, and has actively campaigned in the media on a range of breast cancer issues including the need for fully funded access to Herceptin and other breast cancer medicines, provision of breast reconstruction, access to timely radiation therapy, and reinstatement of breast physicians as a recognised specialist group. Libby is a scientist based in Auckland.*

Context

How can we, as survivors, get a better deal for the women and men who will follow us on the breast cancer journey? Advocacy is a crucial step towards ensuring that the concerns and needs of those with breast cancer "stay on the agenda." Effective, evidence-based advocacy can influence the policy and decision-making that determines how much of our tax dollar is spent on health and which areas are prioritised. Those of us who have experienced breast cancer can work together to bring about positive improvements in access to treatments and care for New Zealand women and men.

Issues and Discussion Points

- What is advocacy?
  - influencing decision-makers,
  - championing an issue – getting it on the agenda,
  - identifying a problem, recommending a solution, connecting the solution with the problem,
  - changing policies, programmes, budgets,
  - changing organisations or systems,
  - educating leaders, politicians, policy makers and policy implementers,
  - building support for an issue.
- Why do we need advocacy?
  - New Zealand women have low and slow access to breast cancer treatment medicines;
  - we have one of the highest breast cancer death rates in the world;
  - resources won't be allocated to provision of world class detection, treatment and care without effective advocacy;
  - as survivors we have the first hand experience and knowledge to advocate effectively – the few doctors who advocate for us need our support and encouragement,
- How can we advocate effectively?
  - By taking a strategic approach:
  - Look outwards – identify the issue, gather the evidence, define objectives, identify advocacy targets.
  - Look inwards – gather the team, devise strategies, identify allies, allocate tasks, go for it.
  - Look ahead – review effectiveness of actions and strategy, adapt, keep at it.
- Some keys to success:
  - teamwork; sharing the load; celebrating our successes; enjoying the journey; bringing allies on board; understanding opponents.

Recommendations

- Strategic evidence-based advocacy is the key to provision of the world class standard of detection, treatment, care and support that New Zealand women with breast cancer deserve.
- Women with breast cancer in Aotearoa New Zealand need to work together and support each other to develop and undertake strategic advocacy.
- Key advocacy objectives include:
  - Establishment of a high quality national breast cancer database.
  - Development and establishment of national guidelines for detection, treatment and care of breast cancer.
  - Establishment of funding for 12 months of Herceptin treatment for women with early HER2 positive breast cancer, the international standard of care.
  - Provision of full access to other effective cancer treatment medicines.
  - Timely access to radiation therapy.
  - Provision of high quality psychosocial support and counselling for breast cancer patients and their families in the New Zealand public health system from the time of their initial diagnosis onwards.
  - Ensure a representative consumer voice on bodies that make decisions about our treatment and care.
  - Closing the gaps in access to treatment and care for Māori and Pacific women.
  - That a breast care nurse be available for support for every woman diagnosed for as long as, and whenever, she is needed.

Source of advocacy principles and strategies for this workshop: University of Kansas Community Toolbox http://ctb.ku.edu/tools/EN/index.htm.

Rongoa – Traditional Māori Healing

LEAH RATANA-CLUBB

In 2004, two years after her original operation and having had her cancer return twice ***Leah*** *looked at what else she could do to help her healing and chose to use the traditional Māori Rongoa treatments. Leah is a founding trustee of Te Waiora a Tāne Charitable Trust in Rotorua.*

** This workshop was not on the original programme and was a late addition.*

Context

Traditional Māori healing – or Rongoa – has become increasingly popular over the last twenty years, and within a health environment in which there are numerous factors impacting upon Māori health. These factors include access, cost and cultural beliefs, all of which contribute to disparities and inequities in health outcomes for Māori, disparities that are particularly evident in outcomes for Māori cancer patients. In addition, Rongoa has offered an alternative method of health care when conventional medicine has been unsuccessful, or has nothing more to offer. This is particularly pertinent to cancer patients.

Issues and Discussion Points

Te Waiora a Tāne ('the living waters of Tāne') is a traditional Maori healing service which offers Rongoa, Mirimiri, Reflexology and the Hauwai steamer. All patients are assessessed and treated holistically with regard to wairua (spiritual), tinana (physical), hinengaro (mental) and whanau (social/family) considerations. Workshop attendees were treated to a demonstration of some of the native plants and processes utilised in traditional healing.

Up to 20 percent of Te Waiora a Tāne patients suffer from cancer; many come after feeling the western system isn't enough, others defy life expectancy predictions. They are cared for by a multi-disciplinary team of volunteer healers from various tribal and religious/spiritual backgrounds. While patients are mostly-Maori, the service is open to all and local GPs are part of a PHO programme to refer their clients for traditional healing as required.

Te Waiora a Tane is part-way through a trial year with DHB and Te Puni Kokiri funding and reaching out to let more people know what it does and finding ways to make it sustainable.

Cutting the cakes

Raffle Winners

Claire Ryan, MC

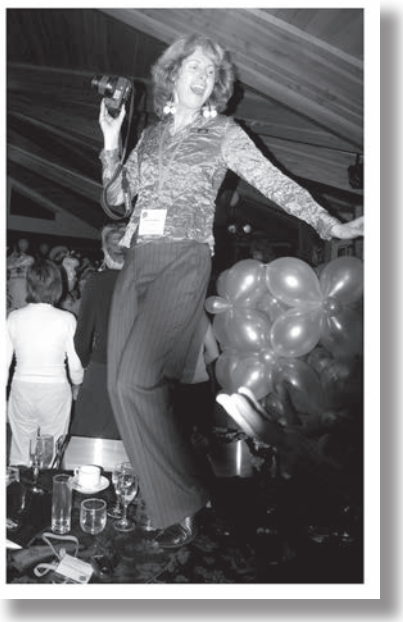
Part Three: Celebrating Survival

The Conference Dinner







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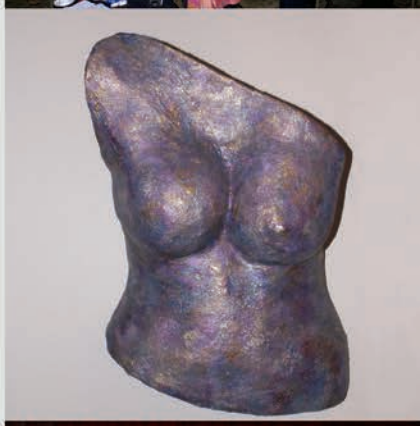
Thanks also to Debbie Wooten and her team at *The Organiser*, Haidee and the *Dynamics* team, and Vicki and *Distinction Hotel* staff for ensuring that the conference ran so smoothly.



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