FERMISCAN, OR, ‘The good, the bad and the ugly’. A possible new method of diagnosing breast cancer.

Older readers might remember a 1960’s spaghetti western called “The good, the bad and the ugly” It is a story of 3 cowboys, nicknamed, the good, the bad and the ugly, trying to find a fortune in buried coins. No single cowboy knows the location of the coins, they need to share their information to get to the treasure trove.

I was reminded of this recently by a new method of diagnosing breast cancer which has been devised. It involves using hair from women. Much of the early work on this method came from research work carried out in Australia by a researcher from the Research School of Chemistry at ANU, Veronica James.

To assess whether or not a woman might have breast cancer, it is necessary to cut 10 hairs from a woman's head. If her hair has been dyed or permed, pubic hair can be used instead. These hairs are then sent to a synchrotron and the molecular structure is analysed using the well-accepted technique of x-ray diffraction. It has been shown that hair which comes from women who have breast cancer, have a ring-like structure in their x-ray diffraction pattern. This ring is not found in hair from women who do not have breast cancer. Currently, the synchrotron being used is in America. A synchrotron is being built in Melbourne, but it is not yet set up to run this type of test. It is likely that it will be used for this purpose in the future.

Fermiscan, an Australian company, is conducting research on this technique to determine its suitability as a new method of screening for breast cancer, particularly in those women for whom mammograms are not suitable. This means young women between the ages of 20 and 50 and possibly those women who are older and or frailer, over the age of 70.¹

Some initial testing of the concept has been carried out, but Fermiscan are in the process of carrying out more exhaustive testing in Australia. With the assistance of radiology laboratories in Sydney and perhaps Melbourne, they are seeking samples from 2000 women to assess the wider applicability of the test². They have stated that, should the testing prove to be successful, they will offer the test to Australian women later in the year at the cost of AU$249³.

² http://www.clinicaltrials.gov/ct/show/NCT00419900?order=r=3
³ Fermiscan fact sheet sent to BCAG in January 2007.
All tests have limitations. These limitations can be measured in different ways. A test may produce a correct answer - that is, a woman has breast cancer and the test shows clearly that she has breast cancer. Another correct answer is that the woman has not got breast cancer and the test shows this clearly. However, a test may show that she has no breast cancer when indeed she has got breast cancer – this is known as a false negative. Or it may show she has breast cancer, when she has not got it – this is known as a false positive. This is illustrated in the table below.

<table>
<thead>
<tr>
<th>Test shows positive</th>
<th>Test shows negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Woman has breast cancer</td>
<td>Accurate result</td>
</tr>
<tr>
<td>Woman does not have breast cancer</td>
<td>False positive</td>
</tr>
</tbody>
</table>

Mammography produces both false negatives and false positives. So far the results of the Fermiscan test appear to show that there are very few or no false negative results. But the level of false positives is high, about 16%.

No-one appears to know how long it takes for a woman who has developed breast cancer to show a change in the structure of her hair and then to develop a breast cancer which is big enough to be seen on a mammogram. This is one possible interpretation of the high number of false positive test results. The woman may have breast cancer but it is not big enough to be seen clearly by mammography, or other imaging techniques. This means that it may be some time between a woman being told that she potentially has breast cancer and getting to the point where the cancer has developed to a stage where it can be seen on a mammogram, ultrasound or potentially an MRI. A third possibility is that it is a real false positive.

Fermiscan are a proactive company. They are raising funds on the stock exchange to fund the trials of this test. They have plans to offer the test in Asia. At the present time, they do not need to gain the approval of Australian authorities for this diagnostic test because the test is not regarded as a medical device by the TGA.

In summary: Good things about this test are:

- it is easy to use;
- it is being tested by clinical trials in Australia which have undergone the necessary ethics committee approvals⁴;
- it is safe
- it could enable women of a younger age and in particular in high risk groups to have a non-invasive, regular screening capability that is not available today
- the test is not yet approved for funding by government or health insurers;
- unlike current mammography, it does not use radiation
- it has the potential to be used as a monitoring test for treatment and remission status

Bad things about this test are:

- there appear to be no safeguards placed on its use in Australia by the Therapeutic Goods Administration (TGA). The TGA regulates medicines and medical devices. The test is not regarded by the TGA as a medical device, hence it is exempt from the TGA guidelines for medical devices⁵.
- Fermiscan are considering targeting women who are vulnerable, young women whom we know overestimate their risks of developing breast cancer and older women who may not be able to afford the AU$249;
- there is the potential for women to be misled into believing they can avoid having mammograms. This is not possible since one is always necessary to determine the location and nature of the tumour before surgery.

‘Ugly’ things about this test are:

- Further complicating such decision making are current results which indicate that up to 16% of tests are in fact ‘false-positives’. Women might have a diagnosis of breast cancer some months / years before any

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⁴ Personal Communication, David Young, Managing Director, Fermiscan
⁵ Personal Communication, David Young, Managing Director, Fermiscan
other sign of the cancer can be found. This is a very scary situation. It means that a woman does not even know which breast is affected. It also means that no biopsy can be done and therefore the best form of treatment cannot be found. Without knowing whether a cancer is oestrogen receptor positive or negative, or whether the tumour is HER2 positive or negative, it becomes impossible to determine which therapy options are likely to be the most effective. This can lead to anxiety and potentially the risk of extreme actions such as prophylactic mastectomies. It is easy to foresee the situation where a woman, potentially a young woman, could be pushed into having a bilateral mastectomy to prevent the breast cancer from developing before a lump can be found.

In order to get around this problem, Fermiscan are considering offering the test as a negative test, rather than a positive test. We assume this means that although they have a test which can tell women whether or not they have developed breast cancer, they will only tell women if the results of the tests are negative. Is this ethical?

If all these issues are resolved and come together, Fermiscan will have discovered the treasure trove. But until the current trial has resolved the issues and fully answered the above ‘negatives’, the test should be treated with some concern by all women and clinicians.

As well, this test needs to be carefully scrutinised by the appropriate authorities. It also seems to be inappropriate to designate this as a scientific test on the basis of the equipment used. If the test is designed to diagnose breast cancer, then it is a diagnostic test, and should be assessed as such. If a diagnostic test is being offered in Australia by an Australian company, then Australian women should be protected by a suitable assessment by Australian authorities. Because this test will be sold directly to women, it is the women of Australia who need to show some sense and to treat the test with real suspicion, until the effectiveness of the test is demonstrated and the needs of all women are protected. Beware of simple diagnostic tests - they appear to come with complex answers.

Sue Lockwood

Please note that these are my personal opinions only. I am no longer associated with the BCAG committee.

References


James VJ Changes in the diffraction pattern of hair resulting from mechanical damage can occlude the changes that relate to breast cancer. Phys Med Biol. 2003 Jul 21;48(14):L37-41


THE FERMISCAN RESPONSE

Editor’s Note: Sue’s assessment of the current situation was sent to Fermiscan with the invitation for them to respond. Following is the company’s reply written on their behalf by Dr. Peter French.

As Sue Lockwood has described, the original discovery was published by Australian scientists in the prestigious international scientific journal Nature in 1999. They reported that there were differences in the small angle X-ray scatter (SAXS) patterns of hair from individuals with breast cancer compared to healthy subjects. The SAXS patterns of hair from cancer patients contained a weak ring which was superimposed on the normal pattern obtained from healthy control subjects. This ring was reportedly observed in all samples of scalp and/or pubic hair taken from women diagnosed with breast cancer. In the paper, the following statement was made: “this may lead to a simple and reliable screening method for breast cancer using a single hair.” Subsequent papers by James and colleagues reported SAXS analysis results of blinded human samples which were consistent with the initial publication. In 2005 they reported on the results of 503 blinded hair sample analyses and demonstrated a sensitivity of 100% (no false negatives) and a specificity of 86% (14% false positives by comparison to mammography) for breast cancer.

I came across this work in 2004, and became excited by the potential that the discovery had as the foundation for a novel and reliable method for the diagnosis of breast cancer.

Fermiscan was founded to develop the potential of the scientific work for a simple, non-invasive test for the presence of breast cancer. In late 2006 Fermiscan was listed on the Australian Stock Exchange, enabling the Company to raise sufficient capital to carry out the very expensive process of taking a discovery from the laboratory to a commercial product.

The process is expensive because there are extensive safeguards and regulatory issues that need to be addressed. This process is rigorous and there are no short cuts that can be taken.

Shortly after Fermiscan commenced operations, we set up a Scientific and Medical Advisory Board comprising medical specialists, including radiologists and a breast cancer doctor. They advised us on a protocol for a robust trial of the test in the real life situation of women attending mammography clinics. The trial protocol was approved by two separate human ethics committees, including that associated with a major public hospital in Sydney, and a committee established by Fermiscan of independent medical specialists, scientists and lay people, registered with the National Health and Medical Research Council. The membership of this Ethics Committee includes Professor Ron Penny, AO, A/Professor Phillip Yuile, Professor Anne Cunningham and Dr Russell Ludowyke. Once the approval was gained, we began to recruit patients who were attending mammography clinics in Sydney and Melbourne, with the aim of comparing the mammography results with the hair results.

The trial is in progress, and the final results will not be known until mid 2007. A preliminary unblinding of the results demonstrated a good correlation between mammography and hair testing. One interesting outcome was that of the 19 women who had a biopsy as a result of positive mammogram, 10 were shown not to have breast cancer, 9 of whom were cleared by the hair test. This showed that one outcome from the trial may be that a hair test plus a mammogram may help improve the diagnostic process of mammography. This was the source of the comment about the test being used as a negative predictor of breast cancer. However, this is a preliminary result and any definitive conclusion from the trial must wait until all samples have been analysed.

Fermiscan, being a public company, works in a strict regulatory and legal framework. We will only be successful as a company if we have the support of the regulators, the medical profession and of course, the women of Australia. The trials we are conducting should provide sufficient data to satisfy the first two groups. The way the test will be positioned has not yet been finally determined as it depends very much on the outcome of the trial. One can speculate however,
that it could be used in conjunction with mammography to increase the accuracy of mammograms. A second use could be in monitoring of the success of treatment for breast cancer, which is quite difficult at the moment. Ultimately, if it passes all of these tests, it could be used as an adjunct to breast self-examination, clinical breast examination and imaging (mammography, ultrasound, MRI) to improve the ability to catch the disease early.

No pathology test is 100% accurate. False positives and false negatives are inherent in almost every test. How this is communicated to the patient is critical as to how they regard the result. This is also true for breast cancer. No one test is likely to be the answer to breast cancer, but a combination of testing regimes available to women of all ages may help to increase the overall accuracy and to reduce the impact of the disease on our community. Fermiscan is committed to developing the potential of this remarkable discovery and to use it as appropriate in consultation with the medical community and the general public. Fermiscan invites dialogue and input from the Breast Cancer Action Group and other consumer groups to ensure that the capability of the test is thoroughly understood by and appropriately communicated to all parties prior to it being launched.

Dr Peter French is the Science and Innovation Manager of Fermiscan Ltd. He has been involved in medical research over the past 30 years, at institutions such as CSIRO, St Vincent’s Hospital and the Children’s Medical Research Foundation.
BCAG Victoria is now 13 years old. Throughout this period we have witnessed many changes in the health system and its service provisions to women. BCAG has achieved many objectives and contributed to numerous projects within the breast cancer arena. In order to remain relevant and involved, it was thought necessary to not only review our past, but to set goals for the future. To this end, the steering committee held a planning day in March. With the help of facilitator, Lil, we worked through our strengths, what we do well, what influences we may be facing and how we go forward. Having a facilitator help us with the process enabled us all to contribute. We have come away with lots of work to do.

In order to assist us in working out our priorities and future directions we need to know the composition of our membership; what people see as important and how you envisage our future role. To this end we have included a brief survey on page 23 of this newsletter. Could you please fill it out and return to the address shown.

One issue that has faced us is that of BreaCan – the service that provides the special meeting place in the city where women, families and carers are able to meet with volunteers and search for information or talk with a volunteer or attend a seminar or an activity. We heard that the service was widening its brief to include a focus on gynaecological cancers. A number of issues arose for us – including adequate preparation for the volunteers and the potential for a name change. We found that there was no advisory or reference group in place to guide any potential changes. We secured a meeting with the CEO of Women’s Health Victoria (who auspice the service) to raise our concerns. Following our initial meeting a number of issues were addressed by Di Missen at BreaCan including delaying a name change and preparation for volunteers to work with gynaecological cancer issues. Work has also progressed in establishing an advisory group.

A launch of the beginning of the gynaecological service was held on May 1st. I made a brief visit and I was impressed with the level of noise coming from a group of women sitting around discussing issues facing them.

I attended the Quality Use of Diagnostic Imaging (QUDI) Research Seminar on the 4th May. I was a BCNA nominee. The QUDI Program aims to promote the quality use of diagnostic medical imaging services. One of the aims is that the services are supportive of consumer choice and empowerment. Ione of the sessions included a report on Consumer Information Strategies where two researchers showed their development of common information sheets for Radiologists to use when providing information on, for example, CT scans and MRI. Hopefully the Royal Australian and New Zealand College of Radiologists will approve their use. Another presentation was on the importance of consumer involvement in QUDI provided by the consumer representative, Ann Revell. It is pleasing to know that consumer voices are being heard.

Another forum where consumer voices were heard was held on the 23rd May. The National Cancer Nursing Education Project (EdCan) – National Standards for Cancer Nurses is a 4 year national program to develop and implement a framework, including curricula and teaching materials, that will direct the long-term workforce development of nurses specialised in cancer care. Cancer Australia has funded the project through the Strengthening Cancer Care initiative. At the forum, approximately 20 people representing cancer groups provided input into what consumers expect of cancer nurses and a discussion of the competencies that had been drawn up. This was an opportunity to meet consumers from other cancer areas and learn issues facing cancers other than breast.

The National Breast Cancer Centre has released guidelines for the use of Herceptin with early and
advanced breast cancer. The recommendations are based on a comprehensive review of all existing clinical trial evidence and include a summary of what is currently known and unknown about the drug. This may be accessed online at: http://www.nbcc.org.au/bestpractice/resources/HERG216_recommendationsforus.pdf A consumer version is in the pipeline and will be available shortly.

A number of new publications have arrived from the Victorian Department of Human Services. The titles are: A Guide to enhancing consumer and carer participation in Victoria’s Integrated Cancer Services; Achieving best practice cancer care – a guide for implementing multidisciplinary care; and Linking cancer care – a guide for implementing coordinated cancer care. In future newsletters we will include a review of the publications.

A number of BCAG members are involved in the integrated Cancer Services across the state. Each of the eight Integrated Cancer Services cover ten tumour streams with two consumers on the managing group for each stream. Southern Metropolitan Integrated Cancer Service has funding for a large project called Optimising Consumer Participation. I am Chair of the Steering Committee and Nicola Bruce is a member. This project ends in June. We will write a report of the project later in the year.

Congratulations to Nicola Bruce who has received notification that her PhD thesis has been passed, She is currently enjoying a well-earned break in France and England.

BCAG Victoria congratulates BCAG NSW and sends best wishes for their success over 10 years. A number of Victorian members will travel to Sydney to help celebrate in July.

Best wishes

Pamela Williams
Co-Chair BCAG Victoria

NEWS FROM NSW

This year, the Breast Cancer Action Group NSW celebrates a decade of providing a voice for women, and men, affected by breast cancer, by working to these objectives:

• To reduce the impact of breast cancer on the community, in terms of lives affected and lives lost.
• To improve the experience of those undergoing treatment for breast cancer.
• To encourage those with experience of breast cancer to contribute to all levels of decision-making about this disease.
• To promote and contribute to research into the causes, prevention and optimal treatments for people with breast cancer.
• To work towards ensuring access to the highest quality treatment and support services, regardless of geographical location, social or economic status or stage of disease.
• To provide a forum for women and men to share experiences and information.

The Beginning

Our first General Meeting was held on 12 October 1997 at the Sydney YWCA. It attracted 120 people, touched by the need to have a voice in making things better. The highlight of our good communication plan was a pivotal piece in the Sydney Morning Herald of 8 Oct, with a colour photo of Robyn Wicks, Sally Crossing and Vivianne de Vahl Davis at the Art Gallery of NSW chatting with a bronze torso sporting very perfect breasts. We could only muster two and three quarters between us, but it generated a lot of interest.
Hinting at our future of advocacy and information, that day we were addressed by Sue Lockwood, of elder sister, BCAG VIC, and Dr Fran Boyle, well known Sydney medical oncologist. On 10 November, twenty women who volunteered to be part of a Steering Committee, met at my house in Greenwich, another tradition which we’ve maintained. Lyn Swinburne and Sue Lockwood were able to be in Sydney then, so they attended as “consultants”. The rest as they say is History – no, Herstory!

The BCAG Victoria (founded 1994) connection made it possible for us to hit the ground running a lot faster than we otherwise would have. Over our ten years, we have shared objectives, our highly regarded and informative newsletter, and developed policies on major issues.

Working in partnership whenever possible has been a hallmark of our activities – and those partners are all key players in the breast cancer world in NSW and beyond: the NSW Breast Cancer Institute, the NSW Dept of Health, the National Breast Cancer Centre, the National Breast Cancer Foundation, the Cancer Council NSW, BreastScreen NSW, the Cancer Institute NSW.

**BCAG Women**

From 120 members in 1997, we now number 720 across NSW. Members are kept in the loop via our quarterly newsletter; offered consumer advocacy training and representation on decision-making committees, working parties, and research studies; respond to our surveys to ensure we know their views and needs, attend quarterly info sessions and let us know what we should do to make a real difference for people like ourselves affected by breast cancer.

Sally Crossing AM, has steered BCAG NSW over the decade with the help of a very able contingent of committed, intelligent and enthusiastic women. Sadly not all of “the originals” are still with us, but we miss them and honour their memories. Some names from the start: Robyn Wicks, Vivianne de Vahl Davis, Libby Manuel, Deborah Read, Nedra Orme, Pam Baber, Julie Barnett, Tessa Mallos, Greg Grennan, Denise Cole, Anny Friis, Pam Bell, Jane Redmond, Penny Schafer, Rosemary Davies

This fine band was joined over the years by Roberta Higginson, Janet Green, Rosanna Martinello, Sally Hodgkinson, Barbara Joss, Geri Hill, Ros Lawson, Bev Noble, Elisabeth Kochman, Marion Monteith, Carole Sherringham, Lesley Haysom, Sally Lynch, Kirsty Simmonds and Alex Forster.

As Committee members, these women established Special Interest Groups in the areas of Treatment, Research, Young Women, Familial, Information, Rural Women and Advanced Breast Cancer. Each reports every quarter on their issues and activities, using special email loops to communicate quickly.

**BCAG NSW Decade Highlights:**

*Information Sessions*: quarterly 1998-2006, with six one-day forums. A great array of speakers who are expert in their fields, kindly shared their knowledge

*Information Updates* in newsletters – new research, treatments, women/s experiences, advocacy, support, campaign developments

*Advocacy Topics*: access to new drugs, to multidisciplinary care, to lymphoedema clinics, access to breast prostheses, to RT services, to bulk-billing mammography, to post treatment support services, reliable & accessible information, to BreastScreen beyond the target years, to non-discriminatory insurance, to a more generous IPTAAS, for consumer involvement in research

*Publications*: Breast Cancer: Life after Diagnosis (with HCCC) 10,000 copies The Directory of Breast Cancer Treatment & Services (with NSW BCI) 10,000 copies, electronic at [www.bcagnsw.org.au](http://www.bcagnsw.org.au) and [www.bci.org.au](http://www.bci.org.au) and nationally.

*Communication*: platforms for three state elections, media responses, Conference/seminar presentations, journal
articles, “BabyDocs” program, expert comment on publications

Representation: on decision making committees – NDBC, CC NSW, TCCA, NCCI, NSW BCI

Profile (as others see us):

BCAG NSW has been described as “the conscience in the community, representing the issues of all women with breast cancer”. Our stakeholders know we carefully research before taking positions and keep close to our members needs and ideas. Our supportive Patron, NSW Governor Her Excellency Prof Marie Bashir AC says: “(BCAG NSW) has proved to be an articulate, informed and powerful voice for women who have experienced cancer”. Minister Frank Sartor wrote this year “I would like to congratulate the BCAG NSW on its upcoming tenth anniversary, and its continuing commitment to give a voice to women and men affected by breast cancer in NSW”.

Recognition:

BCAG NSW was highly commended by the NSW Minister for Fair Trading on the development of the Specialists Directory in 2002. Sally Crossing received the inaugural NSW Consumer Advocate Award in 2001 and in 2005 was appointed a Member of the Order of Australia (AM) for her work with BCAG NSW and Cancer Voices NSW.

The Workings:

As an Incorporated Association, we hold an AGM each year to elect office bearers and receive Annual Reports. Our quarterly meetings were held at the YWCA (thankyou!) until 2006, when we moved to the State Library in Macquarie Street, Sydney. Our Forums have been held in a variety of major venues, but the most popular and welcoming is the Women’s College, University of Sydney. We are all volunteers, but have managed to successfully raise sufficient funds for major projects such as the Directory, which we are planning to expand to all cancers in 2007. We seek and keenly appreciate pro bono support – such as the Cancer Council NSW’s printing and mailing our newsletters.

Changes and the future:

As our profile as advocates has increased we must remain sure that our direction faithfully reflects what women want. As an organisation we must be independent, not co-opted by big pharma, and representing only our own perspective. We need to act as a friendly (nearly always) watch–dog. We must continue to identify women’s priorities and work hard to have them addressed – whether it’s more dollars, a better tuned system, or simply drawing attention to some things which must be fixed – recognising that many good changes have indeed been made during “our” decade.

Over ten years, the advocacy scene itself has changed. In 1999, we were involved in the founding the Breast Cancer Network Australia – to whom we look to spearhead national advocacy, with our on-going assistance. The generic Cancer Voices movement has taken off in recent years, giving a voice to all Australians affected by cancer. We in BCAG NSW, a founding member of Cancer Voices NSW, have been keen to share our considerable experience in the establishing and maintenance of other cancer consumer advocacy groups, especially where issues are mutual and where the voices should be heard.

Sally Crossing
(April, 2007)
HAPPY BIRTHDAY BCAG NSW!!!!!!

The Breast Cancer Action Group celebrates its tenth anniversary this year. Sue Lockwood offers this ‘review’ of past achievements and the role of advocacy.

Breast Cancer Action Group NSW. Congratulations. Turning 10 is a major milestone. Not only have you survived, but you have thrived. And we in Victoria understand what a major achievement this is.

This article is a brief attempt at some history of consumer advocacy in Victoria and New South Wales.

The Great Silence
We started with silence. Thousands of women in Australia had experienced breast cancer, but their voices were nowhere to be heard. The subject of breast cancer and other cancers was taboo – there was no public discussion of the issue. Many women discussed it among themselves. But publicly, there was no discussion of anything to do with breast cancer. At the same time, the number of women developing breast cancer was increasing quite rapidly, while the number of women dying from the disease remained high. Despite the feminist movement which brought many women’s issues into the open, it was accepted that breast cancer was a private experience which often led to a much feared outcome; horrible, often pointless, treatments, almost inevitably, followed by death.

But We Really Knew
Women might not have spoken about breast cancer in public, but we knew what it was like. We knew about the illness, we knew about doctors who could not communicate, we knew what it was like to be passed around like a lump of meat with no-one taking an interest in the individual women, we knew what it was like to try and deal with the questions of young children, we knew that we were not being told the full story of what was happening to us – information was lacking, we knew that the treatment was often more horrible than the disease and in some cases was pointless. We weren’t all sure that we were being treated as effectively as we could have been. We knew what it was really like to have breast cancer, the psychological, social and physical traumas. We knew that the services needed to be improved. Yet we said nothing.

So weakened by life he could just pass
through the world this hospital bed,
he lies as still as someone already dead.
High-tech machines surround him now like family....

A nurse comes in to tend to the machines
Reaching across him to one of them her breast,
the left one, is momentarily pressed
into his face with pillow pressure softness

He opens his eyes as if to some memory....

Emily Dickenson

Philip Hodgins
Great Courage
But one or two voices started to be raised. A Senate Inquiry looked at breast cancer services in Australia. Some women with expertise from other areas of speaking out told the Senators just what it was like to live with breast cancer. Marcia O’Keefe had been involved with the IVF program with disastrous results. She had already spoken out on the problems with the lack of medical support for women undergoing IVF. She later developed breast cancer and was encouraged to speak up on the issues of breast cancer treatment. Her presentation, along with that of other women, was important in suggesting to the Senators some possible improvements in the current systems of care for women with breast cancer. This Senate Inquiry led in part to the development of the National Breast Cancer Centre with seed funding of $1 million. Marcia also set up the Breast Cancer Action Group in Victoria. This in turn led to the formation of the Breast Cancer Action Group in NSW.

Learning Our Trade
When the BCAGs were set up in the 1990s, consumer advocacy organisations were unheard of in the breast cancer field. There was an enormous amount of suspicion from different groups in the medical community, doctors, nurses, administrators, cancer organisations.

I remember one meeting early on in our advocacy work, when an oncologist said to Marcia and me at morning coffee during one meeting “Boy you both know what you want and how to say it.” I’m not sure what he expected but by the end of the project, a long project I might add, he was converted to the value of consumers. This sums up part of the success of breast cancer consumers, - we know what we want, and we know how to ask for it, clearly and in a reasonably non-threatening way.

Or another experience, on a committee looking at the delivery of breast cancer services in Victoria, all the specialities such as surgery and medical oncology presented papers on what they wanted. So Lyn Swinburne and I presented a paper on what women wanted. We thought it was pretty basic, but the other members were surprised, no-one had told them what women wanted before this time.

Of course we were helped immeasurably by some organisations, such as the National Breast Cancer Centre and BreastScreen Australia who were committed to the importance of the consumer voice. But it was up to us to prove our worth in presenting the views of a whole range of women with breast cancer. We did the training, learnt the skills, and then put forward our ideas, effectively and efficiently, both at the practical, policy and political levels.

Partnerships
But this work was not achieved by women alone. We worked in partnership with many different organisations and individual clinicians and doctors. It was in part the quality of our own work which helped us get our message across. But it would have been hard to get a foot in the door without the assistance of some individuals and organisations who were supportive of the consumer voice. We also decided early on, that the Breast Cancer Action Groups would work with the medical profession and organisations and not attack them from outside. This was a debate which was held in Victoria and which led to some unhappy members. But this approach has in part helped our success.
Together: Reason and Passion
BCAG VIC and BCAG NSW worked closely together on many issues. We shared information, discussed options, agreed positions on topics so that consistent messages were sent to many different committees on which women from both groups were represented. We developed a joint policy on dealing with pharmaceutical companies, we vigorously contributed to the Breast Self Examination debate – although this was high-jacked by hardline evidence based researchers; we campaigned for lymphoedema services; we railed against misleading information and suggested that every scientific article printed, should have an abstract suitable for the community; following the Women's Health Initiative debacle on the risk of women on HRT developing breast cancer, we pushed for the more accurate use of absolute rather than relative risk.

Although the issues were often the same, the priorities often differed between the two states. For example, prostheses were dealt with in Victoria a few years ago but have only just been dealt with in New South Wales. Our experience and approach was passed onto our NSW colleagues. In contrast, New South Wales has made a point of working on the iniquities of the IPTAAS system. In Victoria, we have made some more small changes, but the system still has some problems. But distances are not quite as large in Victoria, so the size of the problem is not quite as great, and does not have quite the same priority for women. New South Wales also made a great contribution by creating a Directory of breast cancer specialists. It was done in conjunction with the NSW Breast Cancer Institute. Suggestions that something similar be done in Victoria were treated with derision by clinicians. Although some are now joining in the national directory which is being developed based on the NSW directory. The Victorian and New South Wales governments followed quite different strategies to reform the delivery of cancer services, so the emphasis of both groups had to adapt to the government agendas.

But letters and articles for The Lancet and British Medical Journal, the Medical Journal of Australia have been written together. Over the years, there have been many opportunities to work together. The main one, which is generally regarded as our major achievement, is the BCAG Newsletter. This has been very successful and long may it continue.

This partnership has worked on a number of different levels over time. Newsletter editors, committee representatives and the two chairs at the time, Sally Crossing and Sue Lockwood have all worked together to make sure the relationship was as effective as possible.

Roaring Now
Now the voices of women have been heard. These voices are roaring in the community and in the medical profession and organisations. It is accepted that women have a voice as part of the overall discussion of breast cancer services. And it is accepted that there are many women and families affected, about 100,000 families at any one time.

For reason, ruling alone, is a force confining; and passion, unattended, is a flame that burns to its own destruction.....
........you too should rest in reason and move in passion.

Kahlil Gibran

We are Women
We are women hear us roar
in numbers too big to ignore
and we know too much to go back and pretend,
cause we’ve heard it all before
and we’ve been down there on the floor
and no one’s ever going to keep us down again.
Oh, yes we are wise
but it’s wisdom born of pain
yes we paid the price
but look how much we gained,
if we have to... we can do anything!
we are strong, we are invincible
we are women

With apologies to Helen Reddy
But this position is being challenged by people involved with other cancers who are now finding their voice and are demanding, quite rightly, an improvement in the services provided to their members. We have to continue to work hard in a professional way, to ensure that our voices are heard. We will also have to work with other organisations such as Cancer Voices to help make sure that we are co-operating with those other cancer voices which have arisen over time.

**Shrouds**

Many of our members have contributed to our work over time. Many have died over the life time of the two Breast Cancer Action Groups. Some are well known, while some were quiet supporters. All of them played a role and must be remembered.

Sue Lockwood
former chair BCAG VIC

I should like to call you all by name,
But they have lost the lists....
I have woven for them a great shroud
Out of the poor words I overheard them speak.
I remember them always and everywhere

Anna Akhmatova

References

Robert Frost Excerpt from: “The Road Not Taken.”
William Shakespeare: Midsummer Night’s Dream Act 3
Helen Reddy: I am woman Song lyrics.
Anna Akhmatova – Excerpt from Requiem October 1995

JUST FOR FUN: JUDY HORACEK

How can I seek to understand the world when I can’t even make sense of the TV commercials?
CRITICAL QUESTIONS FOR ‘BREAST CANCER MONTH’

Editor’s Note: Each October worldwide is Breast Cancer Month. Ostensibly, millions of dollars are raised each year for medical research. It is hard to avoid the ‘pink’ surge of publicity each year. Go to the supermarket and everything from makeup, to bread features the pink ribbon logo of the breast cancer movement. However, how many of us really know where the money ends up? Or how much actually arrives in the coffers of reputable research organisations? Has the month of October simply become another public relations exercise at best, or at worst, a marketing scam?

Below is the approach taken by the San Francisco Breast Cancer Action group. They have kindly given us permission to print the following in the hope that all who think about helping the breast cancer cause do so from a position of real knowledge rather than media hype. You may access their website at: http://www.bcaction.org/

Please note, that although the following comments relate specifically to the American scene, many of the companies, and the practices they adopt, also apply to the current situation in Australia.

Companies are increasingly using breast cancer cause marketing to reinforce their brand image and differentiate themselves from their competitors. Navigating the expanding sea of pink ribbon promotions requires consumers to ask a few critical questions:

How much money from each product sold actually goes toward breast cancer?

For example, some companies claim to donate ten cents for every item sold, or the label mailed back to the company. If a company is not giving as much as you think it should, you might choose to give directly to an organization or charity instead.

What percentage of the purchase price does this represent?

Many companies are ambiguous about the amount they donate from each purchase. For example, Ralph Lauren’s Pink Pony Products range in price from $10 to $598 in America, yet the only information given to consumers is that “a portion of the proceeds from Pink Pony products benefits the Pink Pony Fund for Cancer Care and Prevention.” The consumer has no way of knowing how much money from each product is actually being donated.

What is the maximum amount that will be donated?

Some companies place a cap on the amount they will donate, meaning that if you happen to buy the product after the cap is reached, your dollars will not go towards the charity. In 2005, Cartier’s Roadster Watch promised to benefit the Breast Cancer Research Foundation. Although each watch cost $3,900.00, the maximum amount Cartier donated from the total sales was $30,000.00. That’s less than the price of 8 watches.

How much money was spent marketing the product?

In a 2005 PR Week article, 3M touted that its 2004 breast cancer awareness effort, involving a 70-foot-tall ribbon made of Post-it Notes in Times Square, reached more than 3 million people and increased sales 80% over expectations. The article reports that 3M spent $500,000 on the
marketing campaign (no actual numbers on profits were released), but only gave a little over half of that amount ($300,000) to the cause.

**To what breast cancer organization does the money go, and what types of programs does it support?**

If research, what kind? Is it the same type of studies we’ve been doing for decades that already gets enormous financial support, or is it innovative research into the causes of breast cancer that always struggles for funds?

If services, is it reaching the people who need it most? Campaigns that are not locally focused may siphon funds away from the community and give them to larger programs that are already well funded.

If advocacy and education, do the programs make steps towards ending the epidemic? Programs supporting “breast health awareness” ignore that we are already well aware that cancer is a problem and it’s time to move from awareness to action.

**What is the company doing to assure that its products are not contributing to the breast cancer epidemic?**

Many companies that raise funds for breast cancer also make products that may be contributing to the epidemic. Is the promotion a golf tournament on a golf course sprayed with pesticides? Is $1 being given each time you test-drive a polluting car, as in BMW’s Ultimate Drive Campaign? Are the products being sold cosmetics containing chemicals linked to breast cancer?

Far too many marketing campaigns exist for it to be possible to trace the threads of profit for each, and it’s difficult to verify whether or not a promotion is legitimate while you’re standing in the store. Make the best choice you can with the information you have. If you have trouble getting answers or if you feel that a promotion is questionable, write to the company responsible, consider buying a different product, tell your friends, and/or contact BCAG.

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**LETTER TO THE EDITOR: ‘As I Contemplate’**

It’s just gone midnight & it is now my 10 year anniversary of the day I had my first breast removed.

As I sit here at my computer in the silence of the night, I am reminded of the silence of the hospital ward after surgery and the fear I felt of the unknown future & wondering how long I would survive after cancer invaded my body.

I will never forget the lift closing as I was taken up to theatre & the fear I felt as I lay on the trolley bed outside, waiting to have my breast removed.

I had no idea of the emotional & physical highs & lows that would occur in the years to come, or of the effect my cancer would have on my family, friends & myself.

I cannot let today go by without making mention of my fears of not surviving to see this day eventuate.

Today is a day of joy & sadness. Yes I’ve survived, achieved more than I could have imagined & endured much. But I am also reminded of my many friends who have not been as lucky as I have after being diagnosed with breast cancer.

It is a day for me to reflect and to say thanks, for the help you have given me in my quest to stay sane over the last 10 years.

With love & gratitude,

Tanya Cassivelidis (Wilson)
Alive and Kicking — A page especially for women with advanced breast cancer

Being a happy pessimist is OK

You're entitled, and maybe even incredibly lucky, to keep up a positive outlook, through treatments, progressions, unwanted 'new normals', etc. Research studies have shown that optimists don't live any longer than pessimists, but are happier. Pessimists are more realistic, according to the same study. But besides not believing in statistics, maybe you don't believe in research outcomes, which are based on statistical measures.

I do believe, to an extent, in statistical measures. I just don't believe that I'm locked in to be a median, mean, or within some bellcurve - I'm unique, as are we all.

I'm not sure that optimism or pessimism can be morphed so easily or authentically, if it is deeply ingrained. And since pessimism is so ingrained in me, and so frequently reinforced (see An Inconvenient Truth!), I AM doing the best I can, and it's fine with me. I don't want to turn 180 degrees and put on a cheerful expression. This is what feels right, real, and rational, to me.

Having grown up experiencing emotional and physical abuse, I developed a strong distrust of others, and a habit of waiting for the other shoe to drop. A favorite slogan of mine is: *Things could be worse... wait!* I think I've been extraordinarily fortunate to have beaten the odds against living with bcmets, and brain mets, this long, and with fairly long spells of good QOL. That's not what I expected, nor do I believe it will last.

Do I find random experiences joyful? Yes! Do I seek out pleasurable activities and delightful people? Oh yes! Do I expect to find frustration, confusion, aggravation, distress, anger, disappointment on a regular basis - watching the news, dealing with insurance and medical bureaucracies, outsourced *help* desk people, etc.? You betcha! They are there in my life at regular intervals, and I want to be mentally and physically ready to deal with them, rather than have life's inevitable negatives take me by surprise.

Unfortunately, one extremely aggravating experience is hearing *Any of us could get hit by a bus tomorrow...* I hear this remark as a trivialization of the morbid fear - not of dying (that seems to me the least of it) - of a slow, torturous downhill slide. Look, I really try NOT to get hit by a bus, every day - I cross at the lights, look both ways, give buses wide berth from inside my car, and generally have become a more safety-conscious citizen. Will these precautions save me from the likelihood of dying of bcmets or some complication of its treatment? Highly improbable!

Honestly, it's astounding to me how we all read, and react to, this online support group's postings so differently! From my perspective, the cheery bouts of NED, long intervals of effective treatment, many years of decent QOL after mets dx, are the exception, not the rule, and aren't likely to ever be my hx. I'm not bitter about that - I've already outlived my statistical expiration date, and didn't think that likely either. But I do take to heart, identify with, and imagine myself going through sometime in the not-too-distant future, the posts describing treatment failures, really bad side effects from tx s I haven't yet had, inability to tolerate treatments, calling in Hospice and foregoing further treatment, preparing to die, and the emotional pain experienced by families and friends of those who've succumbed and died.

If I hear one more Power of Positive Thinking/Rational Emotive promo, I think I'll puke! Just like some metsters wonder why so much negativity, I wonder how anyone stays positive! I sometimes want to scream: *Wake up and smell the Chemo!* But that's just me... the happy pessimist.

Reconciled to dying when the txs just aren't working any more, happy to be very much alive today, dreading awful side effects of treatments, or direct effects of the disease and further diminution of my QOL in the near future. Funny, pessimist that I am, it just doesn't even occur to me that I might get run over by a bus!!! Wouldn't it be ironic if I did!"

Sandy Greenberg
California, USA
Cancer Drugs Research or Can we have it each way?

Musa Mayer, American breast cancer advocate and writer.

Editor’s Note: the FDA is the US equivalent of our Therapeutic Goods Administration. This is a topic which has concerned the BCAGs for several years – should we advocate for access to new drugs when the evidence appears quite limited, or should we jump in and go for it in the hope that some will benefit? It would be interesting to hear your views on this article.

I’m always stunned to learn that so many people still believe that FDA approval of a new drug means that safety and efficacy have been adequately studied. But I think this is a common belief, hence the sense of anger and betrayal when safety issues emerge—as they usually do, especially with cancer drugs—and when the efficacy in a normal population (as opposed to those in a clinical trial) turns out to be far less than was hoped. The reality is that FDA drug approval always represents a trade off between early access and adequate research. People don’t seem to understand that FDA approval represents the LEAST amount of research data society is willing to accept to offer a drug for sale.

If we were to require more evidence, for example of longer term efficacy and safety, those studies will take longer, and delay approval. It would be safer for patients to wait and require more evidence, and we’d understand more about these new agents and how to use them, but the price paid for that is delayed access. FDA always gets the blame, but it is SOCIETY, not FDA, that makes the determination about how much evidence is required. FDA is tightly constrained by laws made in Congress.

In the six years I’ve been working with FDA, there has been continual pressure from patients, advocates and the pharmaceutical and biotech industry to approve drugs sooner, with less evidence. Patients and advocates want drugs sooner because for most life-threatening diseases, there are few treatments available, and they and their loved ones are dying and need treatment NOW.

The industry wants early approvals because the clock on the patent life of a new drug starts running down when it begins to be tested in humans, not when it is approved. The earlier the drug is approved, and the more people use it, the more money is to be made. And oh yes, it is about making money. Of course.

At an average investment of nearly one billion dollars per new drug, money is the engine that drives drug development. High cost, inadequate evidence—these are, quite literally, the price we pay for drug development in a market-driven economy.

Strangely, I find that it’s often the same people who are appalled at the lack of adequate research, who want drugs approved at the earliest possible moment, and fight to guarantee access for any patient who needs them. Instead, we ought to be asking ourselves: what do we as a society want?

To benefit the most people? Or to get new drugs for ourselves and those we care about? If we truly want to benefit the public good, and help the most people in the end—we’ll hold out for longer, larger multiple well-controlled studies that much better characterize safety and efficacy before approving new drugs, and we’ll carefully monitor efficacy and safety AFTER drugs are approved, which right now isn’t done in any active way.

If what we care about is getting the newest treatment at the earliest moment for ourselves and those we love—and who does not?—we’ll fight for access and approval of new drugs at earlier and earlier points in time, and live with (or die from) the unanticipated consequences this will inevitably lead to. We can’t really have it both ways...."
Dying with Dignity & Control

Note from Sally Crossing: This article appeared in the March Newsletter of Cancer Voices NSW (you can see them all on www.cancervoices.org.au). It has been suggested to us by a member of both cancer consumer organisations that we should seek your views as well.

The Cancer Voices NSW Committee has discussed the recent public debate about voluntary euthanasia (VE) around Australia and decided to work on a Position Statement about what people affected by cancer think. We see VE as one aspect of dying with dignity and control - not the whole story by any means, but worthy of serious debate. The next step is to seek guidance from our members – YOU!

Morgan Gallop Polls regularly show that 75% of Australians support VE for anybody who requests it and who is hopelessly ill with no hope of recovery. People with advanced (incurable) cancer report that their greatest concern is how they will die. They wish to die with dignity and control. You may have thought about this yourself or watched friends battle with decisions or barriers to decisions. Most of us have.

Palliation of course, may help greatly, if it is available (not all dying cancer patients can get the benefit of a palliative care team or the best palliative help), but cannot always alleviate suffering.

In our community there are religious and other moral views which can place duress on the decision-making of others. We must acknowledge that individuals and congregations have a right to adhere to these views, but not to insist that others hold them – whether through legislation or by social pressure.

As many of us will have to make some difficult decisions and plans about dying sooner or later, we in CVN think we are in a very good position to take part in the debate. We aim to produce a Position Statement on voluntary euthanasia which can be posted on the website.

This kind of decision is a very personal thing and possibly the only person who can make it is the one whose suffering has gone beyond what medical treatment can offer. And of course access to the kind of help that is necessary for those not in the medical profession is not easy.

At the moment it is illegal to assist in the death of anyone under any circumstances. In practice, caring health professionals, in consultation with the patient and his or her family, may help make an earlier, pain free release possible.

The Commonwealth recently sanctioned legislation, which came into effect on 6 January, 2007 which many Australians find disturbing.

In 2005 the Australian Government passed the most far-reaching Internet censorship laws in history. This law makes it a crime to: "use a carriage service [telephone, fax, email, internet – not mail service]: to access material; cause material to be transmitted to the person; transmit material; make material available; publish or otherwise distribute material; AND the material directly or indirectly counsels or incites committing or attempting to commit suicide; AND the person intends to use the material to counsel or incite, committing or attempting to commit suicide; or intends that the material be used by another person to counsel or incite committing or attempting to commit suicide".

Should legislation reflect what actually happens, with protection against abuse? This has been done successfully in a number of European countries. Should it not fall under the law at all, but remain in the realm of a private right?

The AMA statement is a good example of one which manages to encompass the view of their doctor members very well.

Australian Medical Association (AMA)
Medical Ethics Position Statement: The AMA believes that doctors should not be involved in interventions that have as their primary goal the ending of a person’s life. In maintaining this position, the AMA acknowledges the wide divergence of views on euthanasia and physician-assisted suicide in Australian society and amongst Australia’s doctors.
The AMA also acknowledges that, while for most severely and terminally ill people, pain and other causes of suffering can be alleviated, there are some instances when satisfactory relief of suffering cannot be achieved. The AMA appreciates that, whilst good medical practice can relieve much suffering, suffering can go beyond even the best that medical care can offer.

We certainly do not imagine that all our members will be of the same view. However, we hope to be able to make a statement on this important topic. Please think about the questions below, which are just to prompt your thoughts, and let us know what you and your group think.

What are your views about
- the need for dying with dignity and control
- the ability of palliative care to ameliorate distress
- the Commonwealth Government’s present legislation in relation to VE should there be legal protection for the medical profession when they assist us, or our loved ones, to die, in the way we would like to.
- having a choice and control power over what treatment you receive at end of life
- how to protect against abuses of freedom over how we die?

EDITOR: Thanks to CVN member Tolanda Grey, who initially raised this issue with us, suggesting that we ask the membership what they think.

More information about VE: there are a number of informative websites. ..just Google

S Crossing
– CVN Newsletter - March 2007

DR. SUSAN LOVE: ‘ON BREAST CANCER RESEARCH’

WITH cancer recurrences, the question arises: Why does this still happen? As is often the case, the answer isn’t very satisfying: not all cancers are alike, early detection doesn’t always work and treatments are still far from perfect. But there’s another problem: we keep focusing on doing the same thing better rather than trying something new. It is as if we are wearing blinders that let us see only one path and not the alternatives.

If you look at most cancer research journals you will see that our focus remains on finding smaller cancers, doing less surgery and radiation and developing new drugs to add to the old ones in an attempt to treat the cancers we detect. This approach - finding the enemy, and then slashing, burning and poisoning it hasn’t changed since I was a resident in training 30 years ago. We have certainly refined it over the years - two publications just came out that recommended expanding the use of M.R.I. scans in women who have breast cancer or are at risk for it - but, as in this situation where the additional exam only identified 3 percent more cancers, each progressive development leads to a smaller increment in benefit.

Why do we lack new approaches? One of the key problems is the way research on cancer is carried out. In the past it was common for clinicians to observe their patients, come up with a hypothesis regarding diagnosis or treatment and then head to the lab to test it out. For instance, in 1983, two Australian clinicians - one was a pathologist, the other a gastroenterologist - observed bacteria in stomach biopsies and went on to prove that ulcers were caused not by acid, as had been assumed, but by a bacterial infection. Ulcer researchers, who had spent their careers studying gastric acid, thought the idea was absurd but much to their amazement it turned out to be true. The curious clinician is becoming increasingly rare. Medicine and science have become so complicated that it is almost impossible for one person to be an expert at both. Researchers tend to take a discovery from the lab and apply it to patients; the reverse trip is more and more uncommon. More often than not, someone makes an interesting discovery in the lab and then tries to find a clinical application. There is little chance, much less
financing, for the wild idea that might prove revolutionary.

This situation is not helped by the incentives we give to young cancer researchers but not to experienced clinicians who want to test an hypothesis developed over years of treating patients. It is difficult indeed to obtain a grant to do research if you haven’t spent your career in the laboratory. As the baby boomer generation of doctors approaches retirement, we should harness their experience and wild ideas by offering training in science or partnering them with younger research colleagues. Otherwise we risk inventing and discovering without reference to actually helping cancer patients.

Another aspect of the problem is our peer review system for financing research. It works well at eliminating poor investments, but it squelches innovation and fosters the old boy network.

Organizations that give out "innovator" and "pioneer" awards claim to want to support new ideas but end up giving money to better ways of doing the same thing. And our academic and research institutions reward projects with clearly defined objectives that have a good chance of quickly leading to publications and tenure. If you have a wild idea or a completely new paradigm, forget about it.

Cancer of the cervix is one of the few cancers where we have been able to break the mould. We have moved from the Pap smear, which merely discovers abnormal cells, to a vaccine that can prevent the resulting cancer by protecting women against the virus strains that cause it. At a breast cancer conference in San Antonio last December, a leading cancer researcher, James Holland, presented evidence suggesting that breast cancer may also have viral associations. A wild idea indeed; however, rather than being greeted with enthusiasm by the attending scientists and members of the press it was dismissed. Might there be something to it? We’ll probably never know.

We need a new approach to fight this war and we need the money to do it, but, most of all, we need wild ideas to get us out of the rut of doing the same thing better.

Susan Love is the President and Medical Director of the Dr. Susan Love Research Foundation.

**RECENT RESEARCH REPORTS**

Editor’s Note: The largest oncology conference in the world (ASCO) has just been held in the United States. Presented below is one of the media reports from this conference followed by a patient’s response. The latter is presented as an ‘antidote’ to the media hype that often accompanies press releases. If you wish to view any of the other presentations – and there are many! – then log onto: [http://www.asco.org/portal/site/ASCO](http://www.asco.org/portal/site/ASCO) and follow the links from this page to ‘abstracts’.

What if an estimated 100,000 breast cancer patients got drugs that did nothing to combat their cancer, but put them at risk for heart failure and leukemia? That is the implication of new research that was presented in private session at this week’s meeting of the American Society of Clinical Oncology (ASCO) in Chicago.

The research, from Dr. Dennis Slamon, chief of oncology at the University of California, Los Angeles, suggests that the most widely used chemotherapy drugs may not benefit most women. Although the research hasn’t been published or peer-reviewed yet, it is expected to be soon.

The drugs are a common class of treatments called anthracyclines, including doxorubicin, epirubicin, and mitoxantrone. Since their introduction in the 1980s anthracyclines have replaced older chemotherapy drugs in the combination therapies given to women. Administered in the months after surgery and radiation, the chemotherapy is intended to...
reduce the chances of a life-threatening recurrence of cancer, especially in women at high risk for relapse.

Early on, researchers understood that anthracyclines could cause heart failure in some patients. Recently, evidence has accumulated about the additional risk of leukemia, which can strike years or decades after the treatment. Evidence for the effectiveness of anthracyclines versus the older drugs remained murky. Then, a 1998 meta-analysis (a study of all the previous studies) found the anthracyclines did a 4 percent better job at preventing recurrence. Despite their side effects, that study elevated the drugs to the standard of care.

Treating many to help few The UCLA research questions that treatment. Slamon played a key role in the discovery and development of the hugely successful breast cancer drug Herceptin. Herceptin, which changed the way the disease is treated, specifically targets a gene called Her-2 that is overexpressed in 20 percent to 25 percent of breast cancers (a gene is overexpressed when its effect becomes excessive in the body). Herceptin's success proved that breast cancer is not one disease, but many, with each benefiting from a tailored treatment.

In this latest study, Slamon looked at a more recently discovered gene called Topoll-2, which is sometimes, but not always, overexpressed along with Her-2. Anthracyclines stop breast cancer because they target Topoll-2. Slamon examined tissue samples from more than 2,000 women who took part in seven clinical trials. His analysis showed that anthracyclines work only in women who overexpress the Topoll-2 gene. Such women account for 8 percent of breast cancer cases. The anthracyclines - with all their side effects - have almost no effect in 92 percent of breast cancer cases.

"It seems apparent that we are treating patients who don't need the drug to get at that group who have a huge benefit," Slamon told me. "And now we need to direct our therapy and target it more specifically." "Exciting result" Even when other cancer doctors were willing to use anthracyclines only as targeted therapy, they couldn't. There is no commercial test yet for the Topoll-2 gene, although there likely will be in a few months. Nevertheless, Johns Hopkins breast cancer specialist Dr. Nancy Davidson calls the findings "an exciting result." "It's early; it's provocative. We are waiting to see it go through peer review in the usual fashion," says Davidson, who is incoming president of ASCO. "But there's a lot of buzz."

Fran Visco, a cancer survivor and president of the National Breast Cancer Coalition, agrees the work needs to be published and peer-reviewed - very soon. "This is going to be a sea change in how we treat breast cancer," she told me. "There is no reason we shouldn't be moving very quickly to publish it and quickly to figure out how we're going to implement it in practice. Women deserve no less."

And a patient's response!

This is a sobering study. It doesn't specifically apply to metsters, but I'm wondering how Pfizer (makers of Ellence - Epirubicin) and all the Adriamycin/Doxil manufacturers, will react, if/when this is peer-reviewed and published.

I wonder what I'd have chosen, had I known this info back in 1992, when I was first dx'd at Stage II, and the tx prescribed for me was CAF (standard at that time, for aggressive bc, after MRM). A 4% better job than M? Not terribly impressive, for all of Adriamycin's known toxic side effects! AND there ISN'T a reliable, insurance-company-approved diagnostic test, currently, for whether a woman's bc overexpresses the Topoll-2 gene!

In my case, Adriamycin did its toxic best on my aggressive cancer cells, as well as on many of my healthy cells, and along with the Cytoxin & 5FU, then 7 years of Tamoxifen & 3 years of Arimidex, kept any mets at least under the radar for close to 10 years. But since it's all a crap shoot anyway, I might have chosen to do w/o the Adriamycin & its ultra-toxicity if I'd have known about this study.

What I remember, viscerally, was having read up on all of the loathsome side effects I might get, and having the IV nurse say, in a sweetsy-sweet,
smarmy kindergarten teacher voice, as she hung the Adriamycin on the pole: *Now look at that - doesn't it look just like cherry Kool-Aid?!* OMG - did I want to stick that IV catheter with the *cherry Kool-Aid* drip, in HER - and where the sun don't shine!!!

What I don't like in the article: the self-congratulatory praise of Slamon, a creator of Herceptin, when Herceptin also has a possibly-lethal side effect of CHF due to left ventricle heart damage, and also doesn't work for everyone - maybe 30% of all women with bc are HER2neu++, and of us, not all have cancers that are responsive to Herceptin, and some cancers seem to acquire resistance to it after a number of months, AND it doesn't seem to cross the BBB, leaving us vulnerable to brain mets! So how come the article doesn't go into all of those caveats about Herceptin?

Again, it's great that there's a balance here, of reading material that diverse metsters find worth their while!

Sandy in Silicon Valley

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FOR INFORMATION, WANTED & THANK YOU

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Newsletter Editor – Po. Box. 281, Fairfield Victoria. 3078.

For Information: BREACAN ACTIVITIES – All BreaCan information sessions are located at :Ground Floor, Queen Victoria Women’s Centre, 210 Lonsdale Street, Melbourne.Phone 1300 781 500

Wednesday 4th July 12.00pm-1.30pm: Lymphoedema: What It Is, Treatment & What’s Available (Gynaecological Cancer Session). Judy Purbrick, Senior Physiotherapist at Mercy Hospital Lymphoedema Clinic, will be talking about lymphoedema and its association with gynaecological cancers. Women who believe they may be at risk of developing lymphoedema after gynaecological cancer surgery, or would just like to know more, are encouraged to come along with all their questions.

Thursday 12th July 12.00pm-1.30pm – Tai Chi: Talk, Demonstration & Participation Event (All Welcome) Konrad Dorn, Chief Instructor of The Art Of Harmony Tai Chi and Qigong Centre. Konrad will provide an opportunity to learn more about and experience the many health benefits of Tai Chi.

Wednesday 25th July 12.00pm-1.30pm – All About Osteoporosis (All Welcome) Libby Oldfield, Director of Fitwise Physiotherapy, will help us understand osteoporosis and it’s implications on bone density and strength. As we age, minimizing the impact of osteoporosis is vital in maintaining good posture, strong bones and preventing fractures. Libby will discuss how osteoporosis develops, symptoms, risk factors and the things we can incorporate into our every day lives to help prevent it.

Feel Good Gentle Exercise Program: Wednesdays Fortnightly – 10.30am-11.30am (All Welcome) A session of gentle exercise to tone the whole body and help the lymphatic system. Conducted by a qualified instructor, the program helps maintain upper body mobility, flexibility and a smile. Sessions are open to all ages. Women need to register and complete enrolment forms prior to attending. Dates: June 27th, July 11th & 25th.

‘Making Connections’ Advanced Breast or Advanced Gynaecological Cancer Program: BreaCan runs activities for women with advanced breast or advanced gynaecological cancer that includes information sessions on specific advanced cancer issues. If you would like to know more about what’s happening please call: Josie Scott, Coordinator – Advanced Cancer on 1300 781 500.

Please let us know if you’re coming! Call 1300 781 500 or email us at breacan@breacan.org.au to book for any session or program. For more information about BreaCan or to download this brochure, please visit www.breacan.org.au
BCAG: FUTURE DIRECTIONS SURVEY

As part of the review of the Breast Cancer Action Group begun in March we would like to hear from members. We would appreciate you providing input to the following survey.

1. Have you had a diagnosis of breast cancer? Circle – Yes ☐ No ☐

2. If you have had a diagnosis of breast cancer please answer the following questions.
   - Number of years since initial diagnosis - ________
   - Have you had a diagnosis of advanced breast cancer? Yes ☐ No ☐

3. Please circle your current age group:
   - 20 – 40 years
   - 41 – 50 years
   - 51 – 60 years
   - 61 – 70 years
   - Over 71 years

4. What do you see as BCAG’s strengths AND weaknesses? (Please jot down some phrases/sentences)
   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________

5. Which of the following BCAG activities are most significant to you? Please rank in order (i.e. 1, 2, etc).
   - Newsletter
   - Advocacy
   - Keeping members aware of new information about breast cancer
   - Representation on committees
   - Referral to relevant bodies, individuals, organisations
   - Other – Please list –

   __________________________________________________________________________
   __________________________________________________________________________

6. Are there any other activities/projects/issues/’causes’ that you would like to see BCAG undertake?
   __________________________________________________________________________
   __________________________________________________________________________

7. Any other comments you would like to make about the future for BCAG?
   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________

We really appreciate your comments. Please return BCAG,