



BREAST CANCER ACTION GROUP NSW NEWSLETTER

October 2010 Issue 77

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Message from the Chair

With the Breast Cancer month of October still fresh in our minds, our November newsletter will inform you of activities and information that may not reach the news headlines or Facebook. My apologies for this short message, I have been out of Australia for 2 months and at times computer communication has been difficult.

BCAG NSW AGM

This year seems to have sped by and it is again time to plan for the AGM which will be held on Thursday 9th December, see details on this page. We will need to discuss the effect of our shrinking committee, my frequent absences from Australia and plan for the future.

BCAG NSW has been advocating for and informing women for 13 years. We occupy an important consumer reference point within the state. We have taken part in a number of important initiatives (see below). However, to continue this work we need a strong, energetic committee. Please do come to our AGM. We need to hear the voices of **YOU**, our members, to support us in continuing our role.

Health Consumers NSW

While our BCAG committee has been reduced in size in recent years, our previous and present committee members have a habit of moving into different theatres of action where our message of consumer participation at every level can be spread far and wide. Sally Crossing, our Past Chair, now Chair of Cancer Voices NSW, has spread her wings further to initiate a new organization, Health Consumers NSW, with another consumer colleague of both Sally and myself, Betty Johnson.

NSW is the only state without an independent consumer "voice" in health. With a state election early next year, this new organization will link many health related organizations to influence health policy and health service provision for the people of NSW. BCAG NSW has been proud to be part of this new initiative. We thank Sally and Betty for their energy and drive to establish this very important organization.

National Lymphoedema Practitioners Register

With this Newsletter, you will receive a brochure advertising the National Lymphoedema Practitioners Register. The register went live on 1st July and the organizing committee have been working to fine tune the website and to encourage lymphoedema practitioners to register.

Breast Cancer Action Group NSW Annual General Meeting for 2010

The 2010 AGM for BCAG NSW will be held on

Thursday 9 December
at

The Cancer Council NSW
(Bernie Banton Room Level 6)

153 Dowling Street Woolloomooloo
at 5.30 pm

A nomination form for positions on the Executive is enclosed for completion for those that wish to nominate. We are looking for new blood and new ideas!





The website can be found at www.nlpr.asn.au

There have been minor changes to the Google maps display (the Google maps were paid for by BCAG NSW) to make it easier to read the names of practitioners and to search for them. More practitioners are now eligible to register as the ALA has increased the number of education courses for lymphoedema practitioners that are considered satisfactory for registration. Bridging courses are also being developed for practitioners that are considered for satisfactory for registration.

There are now 122 lymphoedema practitioners listed - 26 in NSW. The numbers listed for other states and New Zealand are ACT 2; NT 2; Queensland 32; South Australia 7; Tasmania 1, Victoria 28; Western Australia 8; New Zealand 6.

This is a good start, but we do need more Practitioners listed on the directory so that consumers can find a suitable practitioner.

Please spread the word to your lymphoedema practitioner and to other health professionals that you come in contact with. Tell them how important the register is to you and to other consumers. We hope that the register can be used to strengthen the argument for increasing lymphoedema services in the public health sector.

Ask your lymphoedema practitioner if they have registered and if they have not, ask them why not.

There is a survey form at the back of this newsletter. Please do fill it in and return it to us. We need to know how you feel about the register, and how your practitioner feels to further improve it.

Launch of the National Women's Research Register – Register 4

We have been involved in and are supporting this initiative of the National Breast Cancer Foundation. See article about this online breast cancer research platform in this newsletter on page 9.

NSW Cancer Plan 2011-2015 Developed by the Cancer institute of NSW

We have taken part in consultation workshops to assist in identifying where needs exist and to critically review the overall strategic direction for the Cancer Institute NSW's programs such as BreastScreen.

Roberta Higginson, Chair

Stereotactic Biopsy- My experience

Earlier this year my Breast Cancer Surgeon suggested I have a biopsy as an abnormality had appeared on my annual mammogram. Mammograms can show differing 'abnormalities', they can be a dense irregular shaped mass, micro-calcifications or a distortion of breast tissue or structure.

So I needed a biopsy, that's fine I thought, I'd had one some years earlier and in the bigger scheme of things I recall it as reasonably painless. So I proceeded to book the appointment for the biopsy at the referred imaging centre. Other than the time and day confirmation and no talc or deodorant instructions, there was no further information offered.

Imagine my surprise however when I arrived to be told that the biopsy that I was about to undertake was mammographically guided, not ultrasound as I had presumed. Hence as the radiology assistant explained the procedure in great detail, I cursed myself for making assumptions that all biopsies were the same, when in actual fact I should have perhaps asked more questions when booking the appointment. Or was it the responsibility of the surgeon or radiology firm to make it seemingly clear what the procedure entailed?

I was seated by the assistant and told that the procedure would take close to an hour and that for the greater part of the hour my breast would be positioned in a digital mammogram machine whilst the machine took digital images in preparation for the biopsy. So my breast with scar tissue deeper than a ravine (three lumpectomies) was to be compressed in the digital mammogram machine and I was to keep as still as possible, just charming I exclaimed!

After a good half hour, the assistant announced that the imaging was successful and that the doctor was on their way to perform the biopsy. It was then they administered a local anaesthetic to numb the breast and the doctor made a small incision and subsequently took several core samples from the area with the micro-calcifications. I then had to wait for another 10 to 15 minutes in the care of the radiology staff before I was permitted to be collected by someone to drive me home. I was completely unprepared for a stereotactic mammographically guided biopsy and confess to failing to undertake any research prior to the procedure or to take painkillers to get me through the procedure.

I later discovered that the best practice for a mammographic biopsy is to give the patient the





local before they are positioned and compressed in the digital mammographic machine, not seconds before the actual biopsy samples are extracted. This practice is to ensure that the patient feels no discomfort other than some pressure, sadly this was not my experience and I would encourage others to demand best practice principals should they require a stereotactic biopsy.

Overwhelmingly however, the benefit of stereotactic biopsies is that they are less invasive and less expensive than open surgical biopsies, in general they are relatively quick and fairly simple with a very short recovery period. The even better news is that the results were clear.

Catherine Green

Reconstruction – what to watch for

Editor’s Note: *As breast reconstruction is an issue for many women following surgery for breast cancer BCAG NSW asked one of its Executive to look at the costs of breast reconstruction in both the public and private hospital systems. Cynthia Murphy’s article follows. Cynthia has undertaken breast reconstruction :*

There have been various schools of thought over different aspects of reconstruction, private vs public, immediate vs delayed.

Private health insurance allows you to choose your surgeon and your hospital (most of the time) and enables you to schedule your surgery around various aspects of normal daily life.

Medicare does not allow you to choose your surgeon (for the majority of cases) and sometimes the waiting times for surgery - as it is classed as non-urgent, can be quite long (anywhere from 6-12 months at present for NSW public hospitals). The upside is, no cost for a tissue reconstruction (speaking from personal experience), however the recovery time is long and drawn out - for a bilateral TRAM reconstruction.

I suppose I have been blessed in a way, I had my surgery time booked quite quickly in relation to my initial surgery for the mastectomy. In regard to reconstruction, it was all too much to deal with at the beginning, and we decided to look at it twelve months down the track after we had dealt with surgery, chemotherapy and radiotherapy.

6 months after the completion of my treatment, the appointment was made with the plastic surgeon, and we discussed the options available - implant surgery, TRAM flap surgery, as I was not eligible for implants, our only option was to go with the TRAM reconstruction (bilateral).

So, to present date, all surgery has now been completed, and I have been asked to do some research into the various costs associated with reconstruction.

As we did not have any health insurance at the time of my diagnosis, we were advised to go through the public system for my reconstruction. Throughout the whole process, from the time of diagnosis to the final chapter of reconstruction, I have had no major problems with any of my treatment. We had the occasional hiccup, but nothing really major to write home about.

In order to get some idea of what a private patient would pay, I spoke with my plastic surgeon’s office about reconstruction costs, for private patients, they were unable to give me any estimates, due to the different types of reconstruction, and also levels of cover with each and every health fund. One surgeon advised that for a bilateral TRAM reconstruction, without health cover, we would be up for approximately \$10k, just for the surgeon’s fees. Whew!!

Listed below are some of the costs associated with different reconstructions, thank you to the ladies from the Aussie Breast Cancer Forum for allowing me to use some of the information.

“I had an Latissimus Dorsi flap reconstruction:
First operation - Insertion of tissue expander - plastic surgeon expenses totaled \$2,710.55. Medicare Refund totaled \$2,260.55. Out of pocket \$450.00.

Next operation - Removal of tissue expander and replace with permanent prosthesis (implant) - plastic surgeon expense total \$789.00. Refund total \$72.46. Out of pocket \$717.00.

Also in same operation had right breast reduction mammoplasty - plastic surgeon expenses totaled \$1,351.00. Refund totaled from Medicare: \$891.90 Private Health fund: \$212.75. Total: \$1,104.65. Out of pocket \$247.00.
Anaesthetists and hospital stays were fully covered. So all in all (apart from one or two plastic surgeon consultations totaling about \$100.00 each, claimed some of that back from Medicare) Total out of pocket expense is approximately \$1,414.00. (Keeping in mind that \$247.00 included





in that total was for the breast reduction of the good breast) Bringing down the cost of my unilateral latissimus dorsi flap recon to \$1,167.00. The Plastic Surgeon allowed me to pay in instalments as well over a few months.”

“For those looking at surgery in the public system, you “can” insist that only a consultant does your surgery. Obviously for minor surgery it's not a big deal but with something major like a reconstruction, you are entitled to ask for the most experienced/skilled person and to refuse consent for registrars to operate on you. Just write it in on the consent form before you sign

BUT...on the down side, the range of types of reconstructions available to you in the public system may be fewer than if you shop around for private plastic surgeons...for eg, the DIEP (a 2-stage tummy-based recon which does *not* take any muscle from the stomach, just other tissue) was not available at the (tertiary level) hospital I attended.”

“left breast reconstructed using the latimuss dorsi procedure - \$3,000.00
 Insertion of tissue expander - \$3,000.00
 Right breast reconstruction using lat dorsi (after skin sparing mastectomy which I had to pay my other surgeon to do in addition) - \$3,000.00
 Insertion of tissue expander\$3000.00
 Anesthetist fee - \$4,400.00
 Medicare and Private health insurance rebate was only \$2,058.11.

Then in May I've just had the exchange surgery and this cost me \$4,505.00 to have both expanders changed for permanent implants.
 The Anesthetist Fee was \$1,375.00
 Medicare and Private health insurance rebate was only \$889.68.” **Cynthia Murphy**

Editor's Notes:

There are many websites that can be accessed but few actually give the cost – it is very individual – choice of reconstruction, surgeon, hospital etc etc.

A couple which give more general advice about reconstruction are as follows:

www.bci.org.au – type ‘reconstruction’ in the search box

www.plastic surgery.org.au (Australian Society of Plastic Surgeons)

www.australianplastic surgery.com.a

‘Baby Docs’ at Royal North Shore Hospital

Yesterday I participated in an annual activity BCAG NSW is involved with called ‘Baby Docs’.

This involves several volunteer breast cancer survivors talking to second year medical students from Sydney University who are studying a breast cancer module in their course.

The morning was facilitated by Professor Stuart Dunn one of their lecturers and after he introduced us to the group, detailed the issues they were to canvass. The students were divided up and each of the six volunteers was allocated to a group.

These med students are a different group from those we have seen in the past. Now students studying medicine at Sydney University are required to have completed a degree prior to acceptance into medicine. So that they are a lot more mature, quite a few are married, and some have children. A very different group to those of the past who had gone into medicine straight from school.

The aim of Baby Docs – we call them that, as after all they are doctors in the making - is for the students to question the volunteers about their experiences with breast cancer, from diagnosis, through treatment into survivorship, and their information needs at each part of the journey; who helped them, where they sought information, and their decision making.

The group I scored were smart, empathetic, very intelligent and in my view will make excellent doctors either as GPs or specialists – it is too early to define their futures. However amongst the six students allocated to me four were going in 2011 to Port Macquarie for a rotation, one was staying in Sydney and one was going to Orange for his rotation. Increasingly they are being exposed to patients or in this case cancer survivors, which from all reports they enjoy – at least that is the feedback we get.

Sally Crossing speaks to the larger group of year 2 med students about cancer consumer advocacy – in more general terms, but the couple of hours we spent with the students were enjoyable, and we feel we are giving back to the next generation, as well as educating future doctors.

BCAG NSW has also conducted Baby Docs at Royal Prince Alfred Hospital. Both sessions (at RNSH & RPAH) are normally held in November but this year were held towards the end of October 2010.





If any member of BCAG would like to be involved in assisting with this activity, please let us know, via the website info@bcagnsw.org.au, with your name, phone number, email address etc. You do not have to be a long term survivor – we would really like a few women who are perhaps closer to their original surgery than people like the editor, who is nearly ten years down the track, and sort of feels that she is really out of date with the advances in treatment for breast cancer !

Some might ask how will they be expected to remember all that was said. That is not the issue in my mind. If they remember just one thing from the couple of hours, it will all have been worthwhile.

It does not matter if you have metastatic breast cancer or have had early breast cancer it is of interest to the students. We would really like some more women to become involved with this activity.

Sally Hodgkinson

Australian Cancer Trials Online

www.australiancancertrials.gov.au

A new website will be launched at the COSA (Clinical Oncological Society of Australia) meeting in Melbourne on Wednesday 10 November 2010 by Minister Mark Butler. It provides consumer friendly access to clinical trials registered with the main Australian and NZ clinical trials registry and clinicaltrials.gov, a leading international database.

While Australian Cancer trials Online will encompass trials relating to all cancers, breast cancer trials, across the spectrum of treatment modalities will be a major contributor. Australian Cancer Trials on Line is a joint development between Cancer Voices NSW and Sydney University, funded by the National Health & Medical Research Council and Cancer Australia.

The idea for Australian Cancer Trials Online was promoted by Sally Crossing AM, Foundation Chair of BCAG NSW. Cancer consumers, particularly breast cancer consumers, had told us that finding clinical trials which were suitable for them, was not easy. Sally's tireless efforts over the past three year's culminate in the launch of this user friendly website.

Australian Cancer Trials Online will provide not only an avenue for consumers to check out what clinical trials are available, but they could then raise with their oncologist to see if they are eligible to participate. Consumers will also be able to see trials in which their oncologist may not be

participating and how to contact those trials. It will also provide an easily understandable avenue for clinicians as well. A further aim is to increase participation in Australian clinical trials through better information.

It will be launched by the Federal Minister for Mental Services & Ageing the Hon. Mark Butler MHR.

A bookmark with access information, for you to keep or share, will be mailed with this Newsletter.

FEEDBACK: TELL US WHAT YOU THINK OF AUSTRALIAN CANCER TRIALS ONLINE!

BCAG NSW invites its members to provide feedback when they visit this new website. This can be done online or directly to us at info@bcagnsw.org.au.

The concept behind the website was raised by consumers who needed it - now we have it, please help us to keep on refining it so it meets our needs as closely as possible.

A Chance to Have your Say

If you have any comments about the Newsletter, or about any issue that you would like to see addressed in the future, please let us know either via email at info@bcagnsw.org.au or via post to PO Box 5016 Greenwich NSW 2065.

We are only a few months out from the next NSW State Election. As a consequence, please let us know early of issues you would like to see addressed by the current state government or the opposition, that if agreed to for implementation might influence your vote. BCAG NSW will be happy to pass them on !

Please let us know either via email to info@bcagnsw.org.au or by post to POBox 5016 Greenwich NSW 2065.

See item on page15 from Ann Clydsdale

CAT Courses for 2011

For information on consumer advocacy training courses, please contact the Cancer Council NSW on 02 9334 1859 or via email to advocacy@nswcc.org.au.

It is understood that one course will be held in southern NSW, dates and venue to be advised, and two in Sydney during 2011.





RESEARCH

The Editor was at the Garvan Medical Research Institute recently discussing breast cancer research with Dr Alex Swarbrick, a researcher at the Garvan. I asked him to write a short article on types of breast cancer and the following is Alex's contribution

Molecular classification of breast cancer

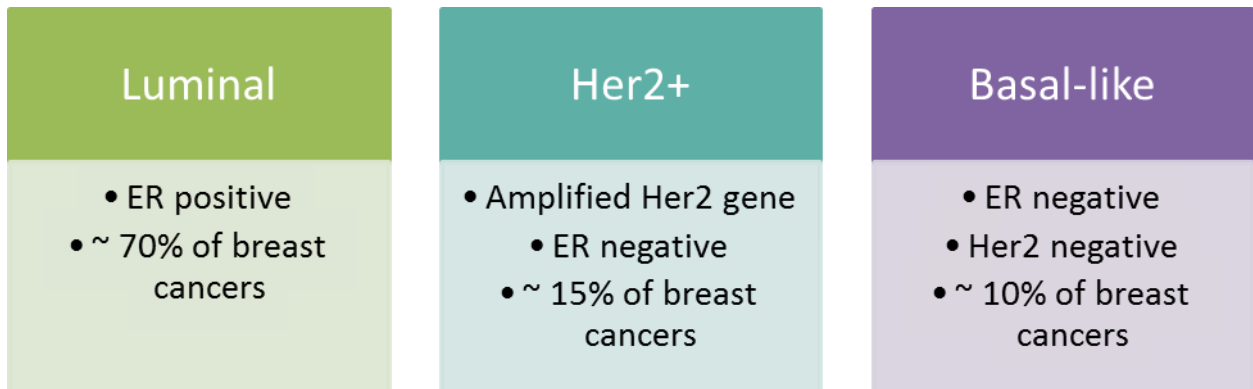
There have been significant improvements in outcome from breast cancer over the past two decades due to earlier diagnosis and the use of targeted therapies especially hormonal therapy for oestrogen receptor expressing breast cancer. However breast cancer is a diverse, complex disease and despite these advances, there are still women with breast cancer who have a poor prognosis. This article summarises some recent advances in our understanding of the genetic diversity of breast cancers and their implications for the future of breast cancer management in the clinic.

Pathologists, doctors who study the cellular and molecular basis of disease, have known for more than 40 years that breast cancers come in many different varieties. They have developed names for them that match what they see down the microscope, such as ductal carcinoma or lobular carcinoma. Pathologists have also defined cancers based on grade (how aggressive the cells look) and stage (how far cancers have spread). From these observations, it is clear that breast cancer is in fact many diseases with major differences in the underlying behaviour of these cancers. A better understanding of the classes of breast cancer is essential to improving our ability to predict patient prognosis, use current therapies more effectively and to the discovery and development of the next generation of breast cancer drugs.

Recent advances in technology have allowed researchers to analyse the genes produced by breast cancers, with the hope that this genetic pattern will allow them to distinguish different types of breast cancer on a 'molecular' level. Using this approach, Charles Perou and colleagues in the United States studied the genomic pattern of hundreds of breast cancers. Their work, and that of many more subsequent studies, has identified at least 6 clearly distinguishable 'subtypes'. These groups not only have similar genomic patterns, but also have similar clinical features, and a number of these correspond to groupings that pathologists had previously identified based on their appearance down a microscope. The three major groupings are shown in the figure below.

The luminal subtypes express the estrogen receptor (ER) and so are commonly treated with anti-estrogens such as Zoladex (scientific name is Tamoxifen) or aromatase inhibitors such as Arimidex (Anastrozole) combined with chemotherapy. The Her2 subtype is characterised by overproduction of the Her2 receptor tyrosine kinase. These tumours depend on Her2 for their growth and in recent years therapies that specifically block Her2 action have been developed. These include Tykerb (lapatinib) and Herceptin (Trastuzumab). When combined with chemotherapy, these drugs are effective in slowing or blocking tumour growth in a proportion of women with Her2-positive breast cancer.

The basal-like breast cancers express neither ER nor Her2, and breast cancers in women carrying BRCA1/2 mutations have a similar genomic make-up to basal-like breast cancer. There are no currently approved targeted therapies for basal-like breast cancer, however a number of experimental drugs are in development for basal-like breast cancer, such as the 'PARP inhibitors'.



The major genomic subtypes of breast cancer





Research continued

This new genomic approach is being used to further refine the subtypes of breast cancer, and there is evidence that each of these groups may be resolved into finer levels of detail. At least 8 subtypes of breast cancer with unique clinical behaviour and genomic makeup may now be defined, and this number may expand over time.

It is important to understand that while these studies have not yet changed clinical practice, they have significant potential to do so in the future. Understanding the genomic diversity of cancer is the foundation for the coming age of ‘personalised medicine’ and ‘pharmacogenomics’. This will involve firstly the development of new drugs for breast cancer and secondly the ability to tailor therapy to patients based on the genomic features of their cancer. Ultimately, these developments should increase the effectiveness of therapy while reducing side effects for patients.

The Garvan Institute is committed to the development of personalised medicine, which will be a major focus of the new Kinghorn Cancer Centre (KCC), a partnership with St Vincent’s Hospital Sydney. Due to be completed in 2012, the KCC will bring together clinicians and researchers to drive the translation of fundamental research into clinical practice. **Alex Swarbrick** (a group leader in the Cancer Research Program of the Garvan Institute of Medical Research, 384 Victoria St, Darlinghurst NSW 2010.)

Older Women May Need More Information about Breast Cancer Screening

Mammography is considered the current gold standard in breast cancer detection, but women over 70 do not always get the screening exam. A new study finds that these women want more information about breast cancer and would like to continue to be encouraged to receive screening for the disease. The majority of women in the study believed that their risk of developing breast cancer was no longer significant.

The study, conducted in the United Kingdom, consisted of surveying 400 women aged 70 and older. About 75% of the women surveyed found that they would like more information on breast cancer.

In the UK, women between the ages of 50 and 70 are advised to receive breast cancer screening every three years, but women over 70 are no longer invited to receive screening.

Because women over 70 were no longer advised to receive screening, the study found that the majority of these women assumed that they were no longer at risk of developing breast cancer. There has been contradictory research about the benefits of screening for breast cancer in older women. In older women, other causes of death may reduce the benefit of breast cancer screening.

However, as medical research advances and women

are living longer, breast cancer screening can help detect the disease early in these women, when the chances of successful treatment and survival are the greatest.

In the study, 75% of the women thought they would benefit from continued breast screening and would receive screenings if advised.

Sarah Woolnough of Cancer Research UK issued the following statement: “We believe that more must be done by governments, the health service and charities to ensure that older women are well informed about their risk of breast cancer, the screening programme and the treatment options available to them. We want health professionals to be more proactive in telling women that they can ask for a mammogram after they stop getting invitations and explaining the pros and cons.”

In the United States, the National Cancer Institute recommends that women begin receiving screening mammograms every one to two years at 40 years of age and every year once they reach 50 years of age. In 2009, the U.S. Preventive Services Task Force issued new breast cancer screening guidelines. The guidelines recommend biennial screening mammography for women aged 50 to 74 years.

The Task Force concluded that the current evidence is insufficient to assess the additional benefits and harms of screening mammography in women 75 years or older. These guidelines have been controversial in the United States. Therefore,





Research Continued

it is important that women talk to their doctors to develop an appropriate breast cancer screening regimen based on their individual medical situations.

Additional Resources and References

The study appeared in the May 2010 issue of the British Journal of Cancer, <http://www.nature.com/bjc/>

Cancer Research UK press release, "Over 70s want more information about breast cancer screening," <http://info.cancerresearchuk.org/>

Reprinted with thanks from BCAG Victoria

Media Release



Increased risk of other cancers for relatives of women with early onset breast cancer

Close relatives of women diagnosed with breast cancer before the age of 35 years are at an increased risk of developing other cancers, according to a University of Melbourne led study, published in the British Journal of Cancer today.

Professor John Hopper, Director of Research from the Centre for Molecular, Environmental, Genetic and Analytic Epidemiology at the University of Melbourne, a lead investigator in the study, said these are surprising and novel findings which could be pointing to the existence of a new cancer genetic syndrome.

"The results suggest there could possibly be undiscovered genes causing breast cancer in these young women, and perhaps other cancers in their families," Professor Hopper said.

Every year in Australia, more than 300 women are diagnosed with breast cancer before the age of 35 years. This is approximately one in 40 of all breast cancers.

In the largest population based study of its kind, scientists studied 2200 parents and siblings of 500 women diagnosed with breast cancer before the age of 35 from across three countries, Australia, Canada and the United States.

After excluding families with mutations in BRCA1 and BRCA2, the two known major breast cancer

susceptibility genes, they found that close relatives were at increased risk of not only breast cancer, but also of cancers of the prostate, lung, brain and urinary tract.

The results showed:

- Fathers and brothers had a 5-fold increased risk of prostate cancer.
- Mothers and sisters had a 2-fold increased risk of ovarian cancer as well as a 4-fold increased risk of breast cancer. Close relatives also had a 3-fold increased risk for brain cancer, an 8-fold increased risk for lung cancer, and a 4-fold increased risk for urinary tract cancers.

"We wanted to find out what caused the early onset of breast cancer in these women and found some results we weren't expecting regarding their relatives," Professor Hopper said.

"The results of this study could help scientists discover new cancer susceptibility genes that explain the risk of early-onset and other cancers within some families," he said.

"Our next step is to conduct larger studies to further clarify these results."

Women aged in their 20s and 30s who have breast cancer, or anyone with a family history of early onset breast cancer, can call 1800 090 990 for further information and/or if they wish to participate in this research

Or for confidential cancer information and support call Cancer Council Helpline 131120

For more information contact

Rebecca Scott, Media officer University of Melbourne 0417 164 791

STOP PRESS:

At COSA (Clinical Oncological Society of Australia) 8-11 November in Melbourne it was established that those who have transferred from Herceptin (Trastuzumab) to Tykerb® (lapatinib), will be able to resume the use of Herceptin if their oncologist so recommends.

The restriction that applied preventing resumption of use of Herceptin after Tykerb **will be removed from 1 December, 2010.**

There is no change to the Medicare late stage metastatic breast cancer (Herceptin) fund.

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REGISTER 4 *for the Cure*

Become part of an Australian first

You may have heard recently about Australia’s first online community for volunteer breast cancer research participants, Register4. They’re currently putting out the call for women to join up, so we thought it was time to put this initiative under the spotlight and answer a few questions about who they are and what they’re all about.

Giving research a helping hand

The initiative was set up in October 2010 by the National Breast Cancer Foundation (NBCF) in response to the growing need for volunteer research participants. According to their website - register4.org.au - they’re aiming for one million members. It’s not about letter-box drops or stuffing envelopes either - Register4 members are invited to participate in a range of peer-reviewed, science-based research projects. The commitment could be anything from answering a few questions to something more involved - from once or twice a year, to once every few years. As a voluntary initiative, the decision to take part is always the participants.

Unlocking the answers by focussing on the individual

The simple fact is that breast cancer is still the most common cancer affecting Australian women, and over the last few decades its incidence has been on the rise. There could be something unique about any of us that holds answers to the big questions researchers are asking. By joining Register4, participants have the potential to make a tangible impact on the path of Australian research and the health of women around the world.

Finding the right people is critical

It can sometimes take years for researchers to find the right people to participate in their work. Register4 is a way to help fast track this process. A similar initiative called Army of Women was launched in the US towards the end of 2008. After one year they had over 323,000 members and had successfully recruited all of the required participants for 18 breast cancer research studies. In many cases it took only 24 hours to recruit all of the people the researcher required.

How to get involved

- Sign up at register4.org.au by answering a few simple questions about yourself such as name, address and country of birth. It’s free to join.
- Invitations are sent to the Register4 members who meet the project criteria when participants are needed.
- If the member agrees to take part, the researcher makes contact and it goes from there.

If breast cancer has touched someone you know, or if you’re a supporter of Australian medical research, visit register4.org.au to find out more about what you can do.

Who should join

- All kinds of women from all different walks of life (you don’t have to have had breast cancer).
- Men are welcome.
- Members must be aged 18 or over.
- It doesn’t matter where you live (though the type or frequency of projects may vary).

An insert is included with this newsletter that gives more detail on this initiative.





NBOCC NEWS August 2010

By now everyone will have heard, I feel sure that the Chief Executive Officer of NBOCC Dr Helen Zorbas is now the Chief Executive Officer of the recently amalgamated groups Cancer Australia and NBOCC. BCAG NSW supports the amalgamation of these two organizations, and believes that it is a win for both, and also for cancer in general and breast cancer in particular.

New chemotherapy recommendations to guide health professionals in the treatment of women with advanced breast cancer

National Breast and Ovarian Cancer Centre's (NBOCC's) new clinical practice guidelines, *Recommendations for use of chemotherapy for the treatment of advanced breast cancer*, are now available.

The new topic-specific recommendations supplement NBOCC's comprehensive *Clinical practice guidelines for the management of advanced breast cancer*.

The inclusion of recommendations about the incorporation of trastuzumab, bevacizumab or lapatinib with chemotherapy will assist clinicians in assessing the role of these targeted therapies in the treatment of women with advanced disease. The recommendations also provide updated advice on duration of chemotherapy and the use of taxanes and antimetabolites.

The new clinical practice recommendations were developed in consultation with multidisciplinary stakeholders and are endorsed by the Medical Oncology Group of Australia, the Royal Australian and New Zealand College of Radiologists (Faculty of Radiation Oncology) and the Royal Australasian College of Surgeons.

NBOCC's *Recommendations for use of chemotherapy for the treatment of advanced breast cancer* are available to download at www.nbocc.org.au or call Ornella Care on 02 9357 9421

New resource to support breast cancer awareness workshops for Aboriginal and Torres Strait Islander women

NBOCC's new *Well Women Workshop Community Education Resource* is now available to support Aboriginal and Torres Strait Islander women to

promote breast cancer awareness through locally-run workshops, health organisations and individual health professionals working with Aboriginal and Torres Islander women. The workshop for well women promotes breast awareness and the importance of early detection in surviving breast cancer, encouraging Aboriginal and Torres Strait Islander women to be proactive about breast health.

The resource includes advice for the workshop organiser, presenter notes, resources to organise and run the workshop, including NBOCC's *Looking after your breasts – what every Aboriginal and Torres Strait Islander woman should know* DVD, and health promotion materials.

The resource has been developed in consultation with Aboriginal and Torres Strait Islander health workers and Indigenous women to ensure the information is delivered in a culturally-appropriate manner.

For further information on running a *Well Women Workshop* in your local community or to order the resource, please contact [Janice Peterson](mailto:Janice.Peterson@nbocc.org.au) (ph. 02 9357 9415).

NBOCC NEWS October, 2010

Starting a conversation about secondary cancer

At National Breast and Ovarian Cancer Centre's Pink Ribbon Lunch in Melbourne (15 October), over 350 guests gathered to hear about the information and support needs of women living with secondary breast cancer in Australia.

New research from NBOCC has found that approximately 7,000 women alive today have been diagnosed with secondary breast cancer.

At the Pink Ribbon Lunch, the Hon Nicola Roxon MP, Minister for Health and Ageing, launched a new NBOCC resource, [Finding the words: Starting a conversation when your cancer has progressed](#). The resource encourages women with secondary breast and ovarian cancer to start discussions about their needs, including quality of life, treatment, emotional and social support with their families and healthcare team.

The new resource is one in a suite of NBOCC resources for women with secondary breast cancer. [Guide for women with secondary breast cancer](#) and [When the woman you love has secondary breast cancer](#) A CD is also available.

NBOCC resources are available to download from www.nbocc.org.au or by phoning 1800 624 973





Meeting the rural challenge

NBOCC again hosted the popular Pink Ribbon Breakfast in Sydney on Australia's Breast Cancer Day (25 October), with a focus on *Meeting the rural challenge*.

Of the 14,000 women who will be diagnosed with breast cancer in Australia this year, approximately 30 per cent will live outside major metropolitan cities.

Due to the complexity of cancer treatment and the location of many specialist cancer services, many rural women need to travel away from home for at least some of their care. This may result in them making treatment decisions based on practical or logistical factors such as time spent away from home, rather than on the evidence about best practice care.

For example, women in rural areas are significantly more likely to undergo mastectomy compared to women in cities and the proportion of women who have a breast reconstruction following mastectomy is approximately three times higher in women from major cities compared with women from regional and remote areas.

Through the *Supporting Women in Rural Areas Diagnosed with Breast Cancer Program*, funded by the Australian Government, NBOCC is undertaking three streams of work to support women from rural Australia diagnosed with breast cancer and the health professionals who care for them:

- Providing the latest information on advances in breast cancer care for rural health professionals through educational initiatives
- Linking families during treatment via 'Stay in Touch'
- Improving knowledge and skills of Aboriginal and Torres Strait Islander Women and health professionals.

For further information, visit www.nbocc.org.au.

Helping women in rural areas stay in touch

NBOCC is pleased to announce the successful roll-out of a new and innovative program, *Stay in Touch*, to connect families when travel away from home is required for radiotherapy treatment for breast cancer.

Using online video communication technology via Skype, *Stay in Touch* provides laptops with access to mobile broadband to connect women face-to-face with their families when their breast cancer treatment requires them to be away for extended periods of time.

The program provides a means of overcoming the emotional impact of separation from their family by connecting them to home when they travel to receive radiotherapy. Families can share daily life, with women able to see and speak to their loved ones back home, bringing them closer during this difficult time.

Stay in Touch is currently available at the following sites:

- Adelaide Radiotherapy Centre, Flinders Private Hospital, Southern Adelaide Health Service, Bedford Park SA
- Alan Walker Cancer Care Centre, Darwin NT
- Bendigo Radiotherapy Centre, Peter MacCallum, Bendigo Vic
- Capital Region Cancer Service, The Canberra Hospital, Canberra ACT
- Illawarra Cancer Care Centre, Wollongong Hospital, Wollongong NSW
- Radiation Oncology, Sir Charles Gairdner Hospital, Perth WA
- Radiation Oncology Associates, Mater Hospital, North Sydney NSW
- Radiation Oncology Queensland, St Andrews Hospital, Toowoomba QLD
- Riverina Cancer Care Centre, Wagga Wagga NSW
- Royal Brisbane and Women's Hospital, Brisbane QLD
- Townsville Cancer Centre, Townsville QLD
- William Buckland Radiotherapy Centre, Gippsland Cancer Care Centre, Latrobe Regional Hospital, Traralgon Vic

Stay in Touch is a project of the *Supporting Women in Rural Areas Diagnosed with Breast Cancer Program*, funded by the Australian Government and delivered by NBOCC.

For more information on *Stay in Touch*, please contact [Janelle Webb](mailto:Janelle.Webb@nbocc.org.au) (02 9357 9414) or visit www.nbocc.org.au/sit.

Clinical practice guidelines: Recommendations for the use of bisphosphonates

NBOCC is currently developing a new topic-specific clinical practice guideline, *Recommendations for use of bisphosphonates for advanced breast cancer* and is inviting stakeholders to participate in the external review of the guideline.

The guideline recommendations have been developed by a multidisciplinary working group, including clinicians and consumer representatives. They are based on a Cochrane review about the use of bisphosphonates for breast cancer and an NBOCC systematic evidence review.





If you would like to participate in the external review, the draft guideline is available on NBOCC's website: www.nbocc.org.au The external review closes on 22 November.

For further information or to provide comment, please contact [Emma Lonsdale](mailto:emma.lonsdale@nbocc.org.au) (02 9357 9417).

Report to the Nation: Breast cancer 2010

On 15 October, NBOCC released *Report to the Nation: Breast cancer 2010* to provide a comprehensive picture of current knowledge about breast cancer in Australia.

Report to the Nation: Breast Cancer 2010 brings together in one user-friendly online document: an overview of key breast cancer statistics, breast awareness and early detection, risk factors and breast cancer research highlights. Download the Report from the NBOCC website www.nbocc.org.au

Staff Change at NBOCC/Cancer Australia

Dr Sue Sinclair (formerly at the Cancer Institute NSW) is now the General Manager of NBOCC.

A CLINICAL PRACTICE GUIDELINE DEVELOPED BY NATIONAL BREAST AND OVARIAN CANCER CENTRE (NBOCC)

This document supplements guideline recommendation 25 (page 10) and information about follow-up care (pages 97-102) contained in the NBCC* *Clinical Practice Guideline for the Management of Early Breast Cancer*, 2nd edition 2001. *(NBCC—was the title of the National Breast Cancer Centre in earlier days.)

Our Founding Chair Sally Crossing AM ,was a member of a panel at NSW Parliament House at a very well attended forum on the issue of Dying with Dignity on Friday 29 October, 2010. It was facilitated by the Cate Faehrmann MLC of the Greens who are planning to introduce a bill titled Right of the Terminally Ill Bill 2010.

Sally Crossing's contribution to the Panel follows:

The concepts of dying well and a "good death" were once very popular. Everyone aimed to do this, and even expected it. It meant dying with dignity, with one's loved ones around and at peace with the idea. Sadly this is often no longer a likely expectation, very often the reverse.

I have metastatic / incurable breast cancer which will sooner or later (I'm working on later) cause my death. That's Ok - I can handle that and so can my family, more or less. And then I may be lucky and slip away in a drug induced stupor with no pain at all. Or I may not. I have also watched my father dying in a way that he hated and which negated his life long values of dignity and control a death

On the way to death, I may loose any kind of quality of life, my remaining dignity and spend considerable time in pain. I would like some choice in this (possibly represented by a bottle of something locked away in my bathroom cupboard), so that if the law is not changed, I won't be at the mercy, or the lack of mercy of others - others who cannot help me because of our out-dated legislation or their own beliefs.

Something has gone badly awry. Medical science has extended our lives, and often improved their quality - but the end still comes, we may just take longer to get there. While medical miracles and improved technology can save us from the ravages of all sorts of illness and even death, we have not, as a society, kept up with the non-medical part of death and dying. In fact, there has been a creeping medicalisation of what really belongs in the largely personal worlds of ethics, morals, faith and philosophy. And our legislation has become out of touch of this realm.

I lead a consumer advocacy organisation called Cancer Voices NSW. Our members want legal choices open to them when they become terminally ill. We have watched and listened to the various arguments, trying to understand how we can arrive at an outcome which allows accommodation of all views; ie from those totally *against* assisted death choices to those who wish to face the end of their lives differently, with choice, dignity and control.

Accommodation must of course include safeguards against abuse - as achieved in other jurisdictions where reform has occurred. It seems to me that we have succumbed to legislation which reflects the ideological views of a few, and of those who fear that safeguards cannot be provide to protect the weak. Cowardly of our society.

People who are facing the unrelenting and debilitating destruction of their quality of life should be able to make an informed decision about its continuance or not. They should be able to implement this decision by seeking expert assistance. Yes, we need legislative change which reflects the needs and wishes of the many, yet respects the beliefs of those who do not agree.

As a civil society we expect people to make informed decisions all through life. We educate





and encourage them to do this. We praise and commend patient autonomy in self management of illness and medical conditions, and indeed of our psychosocial state. But quite illogically, *not at the end of life*, when we are expected to submit to preferences, religious beliefs and legislation which negates all this, just when we need it most.

We know that our options for dying with dignity and control have been reduced, and some see this as an erosion of human rights. In Australia it has become impossible to access the "best" and most humane drugs to end life - although we allow them for our four-footed friends. It is now almost illegal to *think* about ending your life in the manner you wish, let alone buy a book or ask for assistance or advice from those competent and willing to provide it. Thank goodness for Amazon.com. Suicide is not illegal, but help is - does this really make sense?

For now we are supposed to feel more comfortable when the dying person loses autonomy, responsibility and respect, in the interests of prejudices or fears of the few. As I said, I am not concerned about death itself, but the dying time. But being an optimist and fully of sound mind, I remain hopeful that reason will prevail and the law will be changed so I can seek assistance and advice when, and if, I need it. When that happens, the dread will vanish and I will approach my dying with comfort, dignity and control.

Sally Crossing AM

TIT BITS

Treatment: Invasive surgery for breast cancer queried

In the [biggest trial](#) yet to compare removing selected lymph nodes and the more aggressive procedure of removing them all, North American researchers found patients whose breast cancer was in an early stage did not need the more interventionist surgery to live longer.

US and Canadian scientists monitored 5611 early breast cancer patients whose disease had not yet spread to their lymph nodes. About half were assigned to get both surgeries. The other half had operations to remove only some of their lymph nodes. Most patients in both groups also received other treatments such as radiotherapy. After tracking the patients for eight years, doctors found no difference in the patients' survival rates.

John Benson of Cambridge University called it a "seminal" paper that should help treat most early-

stage breast cancer patients. "It will now be difficult to justify (using aggressive surgery) when there is no marked difference in survival," he said.

[The Australian](#) 22/09/10 pg 3

Risk: Paternal link to female cancers

Daughters can inherit a genetic risk of breast cancers from their father as well as their mother. Although the risk can be passed equally, many families only look to the maternal side for genetic mutations. [The Lancet Oncology](#) reported that because their father's family history is often overlooked, many women who might have inherited the mutated gene could be missing a chance for genetic testing and early diagnosis.

[Australian Financial Review](#) 28/10/10 pg 74

Risk: Cancer fear leads women to a dangerous remedy

Women frightened by links between hormone replacement therapy and breast cancer are turning to an unproven, expensive and possibly fatal alternative, a top medical expert has warned. A study in the latest [Journal of the American Medical Association](#), found menopausal women who used combined hormone therapy (oestrogen and progestin) to treat symptoms had an increased risk of breast cancer and breast cancer-related death. Professor MacLennan, Head of Obstetrics at the University of Adelaide, said the study was "statistically dangerous", only applicable to a minority of women, and ultimately was scaring women into using imported Chinese alternative medicines that were five-to-six times more expensive and associated directly with four deaths.

Professor MacLennan said the study found using progestin for more than seven years was linked to an increase of eight breast cancer cases per 10,000 women per year but that experts had already "pinpointed the problem and avoided it" by minimising the use of progestin.

[Adelaide Advertiser](#) 27/10/10 p.1.

Treatment: New hope on cancer

Australian scientists have hit on a new combination of drugs capable of stopping the growth of the most aggressive, and difficult to treat, type of breast cancer.

The research, still in an early phase and conducted in cancer cells grown in the lab and not in the human body, points to a way to stop the growth of aggressive "triple negative" breast cancer. This cancer is most commonly seen in young women and accounts for about 15 per cent of all 12,000 cases of breast cancer diagnosed in Australia every year. The work of the director of the Royal North Shore Hospital's Kolling Institute, Professor Robert Baxter, and researcher Dr Janet Martin pointed to using previously tried drugs such as Gefitinib and Erlotinib - in unison with a new and experimental approach.

[Canberra Times](#) 26/10/10 pg 5; [The West Australian](#) pg 11





and researcher Dr Janet Martin pointed to using previously tried drugs such as Gefitinib and Erlotinib - in unison with a new and experimental approach. *Canberra Times 26/10/10 pg 5; The West Australian pg 11*

Risk: Research linking HRT to cancer 'flawed'

Menopause specialists have slammed [new research](#) linking hormone replacement therapy to increased breast cancer deaths, saying the evidence is flawed and alarmist.

Results published last week from a study of more than 16,000 post-menopausal women found that those who had taken combined oestrogen and progesterone HRT were more likely to die from the disease.

It comes from a new analysis of the 2002 study which first linked the drugs to breast cancer and prompted women across the world to stop taking hormone drugs.

But Professor Henry Burger, emeritus director of Melbourne's Prince Henry Institute, told *The Sunday Age* the 11-year, US government-backed Women's Health Initiative trial was now widely acknowledged as flawed, and the latest results from it perpetuated unnecessary fear.

The Sunday Age 24/10/10 pg 5

Treatment: Secondary cancer new battle line

Health experts say survival rates for breast cancer are now about 90 per cent but more needs to be done for thousands of Australian women who have a less promising prognosis because their cancer has spread.

The National Breast and Ovarian Cancer Centre is launching new resources today for women who have secondary breast cancer, recognising not all women beat the disease but they still need options to maintain their quality of life for longer.

New research by the centre has found that about 7000 women alive today have been diagnosed with breast cancer which has spread to other organs, and their five-year survival rate is about 40 per cent. This compares with an 88 per cent five-year survival rate for breast cancer overall, and a 97 per cent five-year survival rate when breast cancer is diagnosed early and has not spread outside the breast.

West Australian 15/10/10 pg 19

Screening: Unproven breast tests could put lives at risk

Cancer specialists warn that private clinics offering unproven breast screening methods as a "safe" alternative to mammograms could be putting women's lives at risk. Clinics selling Botox, liposuction and spray tans are increasingly providing breast cancer screening that uses thermal imaging and "electrical impedance" technology.

The methods are being marketed to women as

young as 20, with claims they can detect cancer years earlier than mammograms. Experts say the technologies are not backed by sufficient scientific evidence and those offering tests often have little medical training.

Cancer Council education and research director Terry Slevin said commercially driven breast-check clinics were popping up around Australia. "There's a prospect of women becoming very confused about what is or isn't proven, valid, scientifically rigorous breast-cancer screening and I worry that that will lead to some women being diagnosed with breast cancer at a much more advanced, dangerous stage than might have otherwise been the case if they'd used more reliable technologies," Mr Slevin said. Harry Hemley, Victorian president of the Australian Medical Association, said there was no reliable evidence to show that digital infrared thermal imaging or MEMs were accurate screening tools for breast cancer.

Sunday Age 19/09/10 pg 3; Sun Herald pg 14

Treatment: We lead world on breast cancer

Australia leads the world in improving the survivability of breast cancer, an expert and author on the subject said yesterday.

Professor John Boyages, a specialist with more than 25 years experience in the diagnosis and treatment of the cancer, said breast cancer mortality had reduced by at least 35 per cent in both Australia and the UK in a little over two decades.

"I think we've done very, very well in Australia," Professor Boyages said. "Firstly, we have a fantastic breast screening program that has been going now for 20 years and early detection is very important. "Over those years we've also had better treatments as well."

Daily Telegraph 14/09/10 pg 9; Adelaide Advertiser pg 10

Prevention: Preemptive surgery to beat cancer

WASHINGTON: Women with a genetic predisposition to breast or ovarian cancer can dramatically reduce their risk of developing either by having preventative surgeries, a study shows. The research tracked nearly 2500 women with certain genetic mutations. It found pre-emptive mastectomies or surgeries to remove the ovaries or fallopian tubes nearly eliminated the incidence of either cancer.

"This is the first study to prove women survive longer with these preventive surgeries and shows the importance of genetic testing when there is a family history of early breast or ovarian cancer," said Virginia Kaklamani, a co-author of the study. The research looked at 2482 women with mutations of the BRCA1 or BRCA2 genes, which significantly increased their chances of developing ovarian or breast cancer. It found that women with mutations in either gene who opted for prophylactic mastectomies effectively eliminated their risk of breast cancer.

[The Australian 02/09/10 pg 10](#)





Problems for Rural Patients in Sydney

The latest issue of the Breast Cancer Action Group Newsletter asked for members to voice their concerns on any issue of concern to them. I would like to submit the following.

I am a YWCA Encore Co-ordinator in Bathurst, and, as such, probably have more contact with breast cancer patients than the “average Joe, or Joan”. I have become increasingly concerned by the reports brought back from Sydney by our participants who have had to travel and stay there for radiotherapy treatment. These reports relate to the deterioration in services at the Jean Colvin Centre. One of the recent patients was in a very good position to make a comparison between “then” and “now” as she has recently returned home after undergoing radiotherapy for the second time in four years.

I have to say at the outset that I have no personal experience of the Jean Colvin Centre as I had a mastectomy and did not require radiotherapy.

The Jean Colvin Centre has, in the last couple of years, ceased to be classed as a Hospital and is now apparently a hostel. This has implications for the fees charged to clients as not all Health Funds will cover costs now. It also has implications for the level of care. No longer is there a Registered Nurse on the premises to check on patients, change dressings or do all the things that the nurse used to do. If patients become ill overnight, the blanket instruction is to call a taxi (not an ambulance) and go to the hospital (presumably, St. Vincent’s).

Another area of complaint involves the meals. They are apparently of very variable quality. My informants are at pains to point out that some of the meals are tasty and nutritious, but more often of poor quality and dubious nutritional content. They are no longer cooked on the premises but brought in frozen and heated up, which may or may not be done adequately. Sometimes the meal supply is inadequate and some miss out. Also the meal presented often bears no relationship to that ordered on the daily menu form. Special diets -- diabetic and vegetarian-- are not catered for and even gluten -free meals for coeliacs may take some days to access. I am sure all the Committee members would agree that when patients are undergoing treatment as demanding as radiotherapy that they need proper nutrition.

Patients are supposed to be able to opt for a “no meals” option, but cooking their own meals is difficult as the kitchen facilities are only available to them from 1-3pm and 6-8pm, and refrigerator space is limited. There is apparently only one microwave oven available in the kitchen.

It would seem that there is inadequate screening to employ appropriate staff. The Manager is very distant and evidently spends most of her time isolated in her office, reluctant to see clients and listen to their concerns. The comment was made to me that she seems to have no empathy with or understanding of, vulnerable people. Apparently one of the kitchen staff was drunk one night and failed to appear, to heat and serve meals, which was ultimately done by another staff member and a client.

I know I am relating this second- hand but the number of complaints about the standard at Jean Colvin has been too great

to be dismissed as simply the whinges of one or two disgruntled clients. It has also been in stark contrast to the glowing reports I used to hear when I first became involved with Encore six years ago.

Cancer patients from the Central West who require radiotherapy have no option at present but to travel to a metropolitan centre for their treatment--- which is why so many women from rural and regional areas with breast cancer opt for a mastectomy, instead of the breast-conserving surgery so often recommended by their surgeons. This situation is present in most areas in Western NSW. Of the six new cancer centres mentioned in the last BCAG newsletter, only one is this side of the Sandstone Curtain, the one planned for Tamworth. Even with the one planned for the new Orange Hospital, there are large areas of the state which will remain unserved.

No one expects a cancer treatment centre to be established in every town but there should at least be one in each geographic region. That way, even when patients would still have to travel and stay for their treatment eg from the far west of the state to Orange, because the distance is that much less, the psychological distance, and hence their distress, is less. The Great Dividing Range is not just a geographical feature-- it is an enormous psychological Divide.

In the absence of such regional centres, high quality and supportive accommodation in Sydney is desperately needed. With the closure of Ecclesbourne at Double Bay the availability of such facilities is even further limited. Rural and regional patients already have an enormous cost and time burden to shoulder to access treatment. They don’t need to be made feel second-class citizens on top of that.

While on the subject of facilities, or lack thereof, in regional and rural areas, I have been concerned since my own diagnosis six and a half years ago, about the lack of treatment options in regional areas which are taken for granted in metropolitan areas. While chemotherapy can often be administered locally, under supervision of visiting specialists, after -surgery care is often missing. For example, I have an elderly aunt living in Inverell, who suffers severe lymphoedema. As far as I can ascertain, the nearest therapist is in Tamworth, a distance of some 240 kms. So her condition remains untreated. I would not imagine for a moment that hers is an isolated case. If it is possible to arrange itinerant specialists, why is it not possible to have teams of therapists, including a Breast Care nurse, making regular visits to rural centres?

I know this submission began as a concern about accommodation for non-metropolitan patients and has morphed into a general concern about facilities available in regional and rural areas but I thank you for taking the time to read it.

Ann Clydsdale
YWCA Encore Co-ordinator

THANKS
BCAG NSW thanks the
Cancer Council NSW for its assistance in printing
and posting the BCAG NSW Newsletter.
The help is greatly appreciated





National Lymphoedema Practitioners Register Survey

www.nlpr.asn.au

Please circle Yes or No

1. Have you previously looked up the site? Yes No

2. Do you find it easy to access the names of practitioners? Yes No

Comment

3. Is your lymphoedema therapist listed? Yes No

If No above, can you please tell us why the practitioner is not registered.

4. Do you find the information for consumers satisfactory? Yes No

Comment

5. Please tell us what changes to the website you would like to see

.....Name (optional)

Please return survey form to PO Box 5016 Greenwich NSW 2065

