



BREAST CANCER ACTION GROUP NSW NEWSLETTER

February 2011 Issue 78

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Message from the Chair

February 2011

A warm welcome to another New Year. We have reached our 14th year of action in NSW.

New Editor

We are still in urgent need for a new Newsletter Editor. Our Newsletter is our means of communicating with our members and as such it is a vital role in our organisation. We need a person who can compile the articles into a neat format similar to the one before you. Thanks to Sally Hodgkinson who has so ably edited this newsletter. You will have two previous editors to assist you in the learning process. Please ring Roberta on (02) 94984838 for more details.

Annual General Meeting

Our AGM was held on Thursday 9th December. It was very pleasing to see a number of our "old" committee members attending and we are delighted to welcome Jacqui Booth as a new committee member.

The AGM was held at the offices of the Cancer Council of NSW and we thank them for the use of their comfortable rooms. Ms Gill Batt from the CC NSW was our guest speaker and her talk was very well received. She spoke of how 'lucky' those with breast cancer are compared with people who experience other cancers. As someone who has known people who are diagnosed with other cancers, such as brain, pancreatic and others too numerous to mention, I do agree that our support networks, survival rates, emphasis on Best Practice and the Clinical Trials that underpin them have improved markedly and are more advanced compared to other cancers. As a committee, our role is clearly Breast Cancer focussed. However, many initiatives flow through to other areas in medicine and we very much encourage this process. The movement of so many of our committee members into Cancer Voices highlights just how committed we are to spreading our good fortune. Gill also spoke on City - Country differences in early breast cancer outcomes. To stimulate discussion, we used an article in *"The Breast"* 19(2010) 396-

401. This article was recommended to me by Dr John Buckingham, one of the researchers, from The Canberra Hospital. I have served on a committee with him for 5 years. I understand that John, a breast surgeon, is not practicing at present. However I wish to thank him sincerely for the excellence with which he has worked to improve the experiences and outcomes for women diagnosed with breast cancer in his area. The article examines the management and outcomes of women with early invasive breast cancer treated in rural areas and metropolitan Canberra over a 9 year observation period between 1997 and 2006. It found that women in rural areas were less likely to receive post operative radiotherapy after breast-conserving surgery, or to undergo axillary lymph node surgery or sentinel lymph node biopsy. Recurrence rates and mortality rates were also slightly higher. There was also an increase in non-cancer related mortality for women in rural areas. This study supports initiatives supporting rural-based surgeons to adopt new procedures such as sentinel node biopsy and suggests that the new procedures may help optimise rural breast cancer treatment and outcomes.

Gill also spoke of the excellent services that the Cancer Council NSW offers to rural people. It is certainly a major asset and I strongly suggest that country (or City) people having problems accessing treatment or other services try the CC NSW. (The Cancer Council NSW Helpline phone number is 131120)

March is Lymphoedema (LO) Awareness Month

Unfortunately, lymphoedema is still a significant concern to many of our members and as usual, country people usually have less information and fewer practitioners to choose from. Thanks to Annette who has compiled the data on LO that is presented later in this newsletter. March is LO awareness month. You can help by raising the issue within your own circles, friends and medical practitioners. You can help to spread the word. People need to know what lymphoedema is, where they can access good quality information and what they can do to help themselves. The Australasian Lymphology Association is promoting the awareness month. They are the peak





professional organisation promoting best practice in lymphoedema management, research and education in Australia and New Zealand. The ALA have also fostered the public register of LO practitioners which is now available on line at www.nlpr.asn.au The number of practitioners continues to increase. NSW now has 28 practitioners and a number of them are available at more than one address. BCAG NSW continues to encourage more practitioners to join the register and consumer pressure needs to be maintained to accomplish this aim.

Reliable consumer information can be found on the following web sites

National Breast and Ovarian Cancer Centre

www.nbocc.org.au

National Lymphoedema practitioners Register

www.nlpr.asn.au

Westmead Breast Cancer Institute www.bci.org.au

We thank Dr Annette Clement and her group from the Lower Mid-North Coast for the survey they conducted on lymphoedema. It shows a lack of information prior to treatment and limited treatment options and information. You will find the survey results under Lymphoedema Issues later in this newsletter.

Lymphoedema continues to be a major issue for cancer survivors in NSW. We need to be involved in each Local Health Area to ensure lymphoedema treatment is funded in public hospitals under the changes that will occur under the proposed new Federal State funding arrangements. However, at present, details are not available. Please continue to let us know what is happening in YOUR local area so we can coordinate a State approach.

The results of the election for the 2011 committee were as follows:

Chair BCAG NSW: Roberta Higginson

Deputy Chairs: Cynthia Murphy & Elisabeth Kochman

Secretary: Cheryl Grant

Treasurer: Sally Hodgkinson

Committee: Sally Crossing
Geri Hill
Catherine Green
Jacqui Booth
Rosanna Martinello (Young BCAG)



Guest Speaker at the BCAG AGM on 9 December 2010 Ms Gill Batt, Divisional Director of Cancer Information and Support Services

**Learn about advocacy, and how to commit it !
CAT courses Dates & Venues for 2011**

11 and 12 March: Sydney (CCNSW Head Office)

8 and 9 April: Young (closing date 8 March 2011)

3 and 4 June: Sydney (CCNSW head office) (closing date 3 May)

To apply, please head to <http://www.cancerCouncil.com.au/advocates/workshops>

or contact the Cancer Council (Policy & Advocacy)

on 02 9334 1406 or

advocacy@nswcc.org.au to be sent an application in the mail

Cancer Voices NSW recommends that anyone interested in taking part, speaking up, developing and promoting policy for improvements, writing about their ideas or concerns, being a CVN consumer representative on committees, working parties etc - in general joining the action to improve things for people affected by cancer - should sign up for this excellent introductory course





Lymphoedema Support Group of NSW Information day and AGM

To complement Lymphoedema awareness month, the Lymphoedema Support Group of NSW will hold an Information Day and AGM on 9th April at the Aerial Function Centre at the University of Technology, Sydney. Cost is \$30 for members and you can access the member discount by joining when you register. Attendance at the AGM only, is free. At time of writing, guest speakers are still being finalised. There are two confirmed speakers. Ms Louise Koelmeyer is a lymphoedema practitioner who has recently been involved in research into the effect of upper limb lymphoedema on the psychosocial well-being of breast cancer survivors. Louise works with our partners at Westmead Breast Cancer Institute and the study looked at psychosocial themes like fear/anxiety, empowerment/control, self esteem/embarrassment, participation in everyday activities and frustration. Ms Brenda Lee is a lymphoedema practitioner who will talk about Clinical Best Practice in regard to lymphoedema. To find information on other key speakers or an application form to attend the Information Day, visit the Lymphoedema Support Group of NSW website at www.lymphoedemasupport.com

See back page of newsletter for a poster to advertise the Information Day, which you can put up on hospital, GP or library notice boards. There is also a flyer with details and an application form for the Information Day.

Directory of Breast Cancer Treatment and Services

Our much loved Directory of Breast Cancer Treatment and Services is temporarily off line. It was produced by collaboration between BCAG NSW and the Breast Cancer Institute Westmead, was first published in 2002 and allowed women to work with their GPs to access the most appropriate clinicians. The clinicians working in the field of Breast cancer were identified through the Health Insurance Commission which then sent these clinicians letters asking them to register with the directory. Unfortunately the Health Insurance Commission is refusing to continue this procedure, quoting “privacy Issues”. We are working with Westmead BCI to resolve these issues and we remain confident that we can resolve them.

Live Public Forum “Surviving Breast Cancer”

The Westmead Breast Cancer Institute is conducting a live public forum at Westmead and satellite broadcast to country areas entitled “Surviving Breast Cancer” in February. It is a forum on health

and well being after treatment and it explores the emerging evidence on the importance of lifestyle choices that influence the risks of recurrence. It will be available as a free web stream and podcast from www.rhef.com.au

They also sell a DVD “Living with Lymphoedema”, hosted by Sandra Sully. The DVD has been previously reviewed in our newsletters.

Clinical Trials

A reminder that clinical trials underpin all advances in treatment for breast cancer and a well done to Cheryl Grant, our expert on Clinical Trials. Her story appears later in the newsletter. Have you joined Register 4, an initiative of The National Breast Cancer Foundation www.register4.org.au Australian Cancer Trials, a partnership between Cancer Australia, the University of Sydney, The Australian New Zealand Clinical Trials Registry and Cancer Voices NSW is the place to find cancer clinical trials you may wish to participate in www.australiancancertrials.gov.au

Communication - hearing the voice:

During the year we engaged in public discussion via the media as issues arose. Gene Patents have been a major issue and in 2009 Janet Green was invited to appear before the Senate Community Affairs Reference Committee, following a submission made earlier. We are very pleased to report that *The Patent Amendment (Human Genes and Biological Materials) Bill 2010* was introduced into the Australian Senate in November.

The sponsors of the Bill are Senators Heffernan (Liberal, NSW), Coonan (Liberal, NSW), Xenophon (Ind, SA) and Siewert (Greens, WA). Senator Siewert is also the chair of the Senate Community Affairs References Committee which has been investigating the impact of gene patents on the Australian healthcare system for the past two years. The Committee has tabled its Report. The same Bill, sponsored by Peter Dutton MP and Rob Oakeshott MP, will be introduced in the House of Representatives in February 2011.

To complement the above, The Federal Court in Sydney has now set a timetable for hearing a case which will determine the legality of patents over human genes. We will continue to advocate for our members in this vital area.

The successful “Babydocs” program with Sydney University continued. Committee members and BCAG reps took part in all relevant stakeholder seminars and workshops throughout the year.





Publications: we continued to provide informed comment on various publications for women with breast cancer, for the National Breast Cancer Centre, the Cancer Council NSW and the NSW Breast Cancer Inst.

Treatment

Treatment options for women living with HER2+ secondary breast cancer: On December 1st the PBAC decision to modify the PBS restrictions on the use of Tykerb® (lapatinib ditosylate) takes effect. This amendment will allow clinicians to personalise treatment decisions for their patients and use Tykerb at the most appropriate time, as established by clinical evidence and according to the registered indications of use for women with HER2+ secondary breast cancer.

Breast reconstruction: we have published articles in our newsletter this year on breast reconstruction issues.

Watching briefs, consumer representation and opportunistic action continued in other areas. During the year, BCAG NSW has worked closely with Cancer Voices NSW in areas of mutual interest, .

Research

The Australian Cancer Trials on Line, launched in November, allows consumers access to clinical trials which may be suitable for them and should also increase participation. Clinical trials inform Best Practice and lead to better outcomes for consumers. The idea was promoted by Sally Crossing. Go to www.australiancancertrials.gov.au

New initiatives

Health Consumers NSW: Last week the NSW Minister for Health, Carmel Tebbutt, announced funding for the establishment and initial operation of Health Consumers NSW. This new non-government patient advocacy group will be the peak health consumer’s organisation in NSW and our very own Sally Crossing the Public Officer. BCAG NSW was an enthusiastic initial supporter of this initiative and we look forward to working with other interest groups to represent the views of health consumers in our state. (Editor: An item appears on page 15 regarding Health Consumers NSW).

Register 4: The Breast Cancer Foundation’s on line community for volunteer breast cancer research participants is now up and running. Have you registered? Participants do not have to be breast cancer survivors. A cross section of our community is required. This initiative is long term, but it has the potential to inform Best Practice for those diagnosed with breast cancer in the future.

Governance: BCAG NSW Committee and Executive

Committee Members: Roberta Higginson (Chair), Cynthia Murphy (Deputy chair), Cheryl Grant (Secretary), Sally Hodgkinson (Treasurer), Sally Crossing, Geri Hill, Elisabeth Kochman, Catherine Green, Amanda Adrian and Rosanna Martinello (Young BCAG NSW).

We have been meeting on Thursday afternoons, 5pm, at Venue Pizza restaurant, corner Hunter a and Phillip St Sydney. The meeting comes first, followed by pizza and a glass of wine. The timing ensures we finish about 7 PM so we can make our way home in the early evening. Between meetings, the regular business of BCAG NSW is conducted by email and phone. This includes organising consumer representation, monitoring activities, and compiling the NSW contribution to the newsletter. We welcome the attendance of interested members at our Committee meetings during the year as it adds to our “resource”. Please contact us if you wish to attend.

Thankyous -Thanks to all those energetic people who have helped us to make a difference. Thanks to our Committee members, our consumer reps and our hundreds of supportive and appreciative members!

Roberta Higginson, Chair BCAG NSW

6th December, 2010

The BCAG 2011 Executive Committee together with two former Committee Members, Bev Noble and Tess Mallos an the Guest Speaker Gill Batt, Director Information & Cancer Support Services at the Cancer Council NSW





As breast cancer patients often undergo radiology and various forms of diagnostic imaging, we are printing two of the position papers prepared by Cancer Voices NSW and published on the CVN website. www.cancervoicesnsw.org.au. These are on Radiology & Diagnostic imaging and Radiotherapy Issues. Also included is the list of the Medicare rebates available for radiology and diagnostic imaging, as well as a list of the locations in NSW where radiotherapy facilities are available.

Radiology & Diagnostic Imaging

ISSUE:

Modern Radiology includes a number of diagnostic imaging modalities. These are CAT or CT (Computer Assisted Tomography); Mammography; MRI (Magnetic Resonance Imaging); PET (Positron Emission Tomography and Ultrasound. All are expensive and many are not eligible for a Medicare rebate when used in relation to certain cancers.

BACKGROUND:

Use of the diagnostic imaging modalities such as MRI & PET have been shown to provide a much better delineation/diagnosis of disease especially in the metastatic situation.

MRI has an additional advantage in that it does not use ionising radiation. This means that cancer patients who frequently undergo these types of scans are not subject to extraneous radiation.

PRESENT POSITION:

Of those radiology services listed above, **mammography** is provided through the BreastScreen program free of charge to asymptomatic women (those with no symptoms) between the ages of 50 to 69 years of age on a two yearly basis. Generally women after a diagnosis of breast cancer have to access mammograms through a private radiology service and have to meet the gap between the Medicare rebate and the actual cost.

CAT or CT as it is often called, is generally available with a Medicare rebate for diagnostic purposes associated with cancer. However there may be a considerable gap to be paid.

MRI scans are only available with a Medicare rebate for certain cancers, but not for the major cancers such as breast or prostate. MRI is available for women aged under 50 considered at high risk of breast cancer.

PET scans with a Medicare rebate are only available to a very limited number of cancers, and not for the major cancers such as breast or prostate. A table showing which cancers can access Medicare rebates for PET scans and MRI is attached.

Cancer Voices NSW has, in its submission to the federal Minister through the Review of Diagnostic Imaging((Department of Health and Ageing), sought to have these anomalies rectified by the (Medical Scientific Advisory Committee (MSAC).

RECOMMENDATIONS:

That MSAC recommend and the Minister extend Medicare rebates for MRI and PET scans to all cancers for improved methods of detection and diagnosis.

Cancer patients with a health care or pension card should seek to exercise their rights to be bulk billed for such scans, and for all radiology fees associated with their cancer.

RANZCR should publish on its website which of its members offer bulk billing or reduced gap fees for cancer patients

Where such scans are to be delivered in a private radiology/diagnostic imaging practice, patients should seek an upfront quote as to the cost and if this is considered excessive, they should request referral to a public radiology/diagnostic imaging facility.

Sally Hodgkinson January 2011

Editor's Note: We are aware that on the lower mid-north coast there was an issue where women were charged for mammograms and other radiology following treatment for breast cancer, by private radiologists, because of a lack of public radiology facilities, except in Newcastle. A number of women could not afford the up front cost on a pension.

Many of these women particularly pensioners, were unable to afford the up front cost, due to the lack of public radiology facilities. Dr Annette Clement, (a retired GP) who is active as the Cancer Voices representative on the Hunter & New England Area Cancer Clinical Services Network raised the issue. It was determined that the Private Radiology practices in Newcastle were already bulk billing cancer patients, where the referral form indicated the investigation was cancer related. Consequently the Private Radiology practices in these towns were requested to, and have agreed to bulk bill patients where radiology requested is cancer related. A good result for cancer patients.





RADIOLOGY & DIAGNOSTIC IMAGING - MEDICARE REBATES

(NOTE: Blank entry indicates those cancers which have no rebate for MRI or PET)

Item	MRI	PET (Nuclear Medicine)	Medicare Number
Prostate –early/ advanced			
Lung –early/ advanced		FDG# PET identification of a solitary nodule; and for staging of NSCLC capable of curative treatment	61523;61529
Head & Neck		Whole Body FDG PET for staging of biopsy proven newly diagnosed or recurrent head & neck; evaluation of suspected residual H&N after definitive treatment, suitable for active therapy	61598;61604
Oesophageal		Whole body FDG PET for staging of oesophageal or GEJ cancer, considered suitable for active therapy	61577;61580
Melanoma		Whole body FDG PET for eval. of suspected metastatic or recurrent malignant melanoma suitable for active therapy	61553; 61556
Brain	of brain or meninges; scan of skull base or orbital tumour; stereotactic scan of brain with fiducials; acoustic neuroma ¹ ; pituitary tumour ¹		63001;63007; 63010; 63040; 63043
Breast	Mammography for women >50 at high risk ⁷		63464;63467 ⁸
Central nervous System	Scan of head and spine for tumour		63111
Spine	Tumour ^{2,3} cervical spine & brachial plexus		63154;63204; 63271;
Bone	Tumour ⁴		63301
Heart & great vessels	Tumour ⁵		63388
Scan of body	Adrenal mass, resectable ⁶		63461



Cervical	Scan of pelvis for staging of cervical cancer ⁹		63470;63473
Rectal Cancer	Pelvis for initial staging ¹⁰		63476
CoLOrectal		Whole body FDG PET for evaluation of suspected metastatic, or recurrent cancer in patients suitable for treatment	61541;61544;
Ovarian		Whole body FDG PET for evaluation. of suspected metastatic or recurrent ovarian cancer, considered suitable for active therapy	61565;61568;
Unknown Primary		Whole body FDG PET for evaluation of squamous cell carcinoma of unknown primary involving cervical nodes	61610;61613
Renal			
Bladder			
Pancreatic			
Neuroendocrine			
Liver			

1. Only 3 MRI scans permitted in any 12 months
2. Scan of one region or two contiguous regions
3. Scan of three contiguous regions or two non contiguous regions, only 3 scans permitted in any 12 months
4. Excludes tumours arising in breast, prostate and rectum
5. Only 2 scans permitted in any 12 months
6. Only 1 scan permitted in any 12 months
7. Only 1 scan permitted in any 12 months - also subject to identification of high risk issues eg. No of 1st degree relatives &/or gene testing for breast cancer gene mutation
8. Designed for folLOw up of abnormalities diagnosed by a scan under item 63464
9. Only one scan permitted in any 12 months
10. Only one scan permitted

FDG is an analog of glucose given to patients which is detected by the PET machine
 From: www.mbs.gov.au dated July 2010

Australian Cancer Trials Website - now for the roll-out

www.australiancancertrials.gov.au

BCAG NSW hopes you used the bookmark sent with the last newsletter to check on what this consumer initiated (Cancer Voices NSW initiated!) website can do for you. Or for someone else you might know who is wondering about suitable, open clinical trials. Or just to get an idea about what sort of clinical trial research is being done in Australia at the moment.

Cancer Voices NSW remains part of the project team through Sally Crossing who is a Principal Investigator. We are keen to hear feedback from people who have visited the website - positive and negative feedback welcomed.

The next advocacy challenge is to make sure that promotion of the website is maximised - not much use spending three years on development and evaluation if it's not known about - by patients, specialists, GPs and researchers. **Sally Crossing**





RADIOTHERAPY ISSUES

ISSUE:

Treatment with radiotherapy is a major part of cancer treatment, whether part of potentially curative treatment, or for palliative purposes. Access to public radiotherapy service in rural and remote areas is often difficult, time consuming and costly. Some major centres can only offer private facilities, disadvantaging those who cannot afford them.

PRESENT POSITION:

The majority of public radiotherapy facilities are located currently in the urban areas of New South Wales ie. Sydney Newcastle and Wollongong. There are private facilities located in Sydney, Wagga and Gosford and a new private facility at Macquarie University Private Hospital. A new public facility is to open in Orange in early 2011. (See list of **Radiotherapy facilities in NSW** following item.)

As a result of the Commonwealth Government's commitment of \$560 million from the Commonwealth Health and Hospitals Programme NSW will open three public new radiotherapy centres in 2013 at Gosford, Nowra and Tamworth. These new facilities will be incorporated into Integrated Cancer Centres at these sites. These Commonwealth funds are supplemented by contributions from the state.

Currently only about 35% of newly diagnosed cancer patients in NSW receive radiotherapy despite radiation oncologists and the NSW Cancer Institute considering that radiotherapy should be received by a minimum of 52% of such cancer patients, the internationally accepted benchmark. This benchmark is accepted as NSW Government policy as set out in *Optimising Cancer Care in NSW*¹

Additionally many cancer patients would benefit from being included in a radiotherapy trial, as this would mean they receive treatment free of charge (a major financial benefit to patients) and close monitoring. Involvement in radiotherapy trials is often not offered to patients, who would benefit, by their radiation oncologists. This may be due to a lack of easily accessed radiotherapy facilities. (see TROG website (Trans Tasman Radiation Oncology) www.trog.com.au.)

New Linear Accelerators became operational at Port Macquarie and Coffs Harbour in 2007, and at Lismore in 2010. Second Linacs are being installed at Port Macquarie and Coffs Harbour to supplement the single units currently operational, due to demand/usage.

Despite all these developments providing more access to regionally based radiotherapy facilities, there is still a demand from the Tweed and Albury Wodonga areas for such facilities. While regionally based facilities will ease the access situation for many cancer patients, more complex cases may still require treatment at urban centres.

Even with these regionally based centres there is a need to ensure that patients receiving treatment at these centres have access to suitable affordable accommodation available nearby to the facility, as well as any necessary transport assistance. (see also separate paper on IPTAAS).

Recommendations:

- **NSW Government to plan for further investment in public radiotherapy facilities to improve accessibility across the state over the next 10-20 years to match population increase and cancer diagnosis increase.**
- Radiation Oncologists should consider, in conjunction with their patients, whether the patient might benefit from inclusion in a radiotherapy trial.
- Radiotherapy facilities must be accompanied by suitable affordable accommodation for patients undergoing treatment, since radiotherapy is generally not a one off treatment. Additionally there should be adequate financial assistance to travel to these facilities.
- If faced with using private radiotherapy facilities, patients should request a quote of the likely gap cost of treatment, and if this is considered excessive, they should request referral to a public radiotherapy facility.
- Patients holding health care or pension cards should investigate whether they can access bulk billing at private radiotherapy facilities. If not, then they should request referral to a public facility.

Sally Hodgkinson updated January 2011

¹ *Optimising Cancer Care in NSW*, NSW Department of Health 2003

**Sites and number of Linear Accelerators:
– see page 9**





Radiotherapy Locations in New South Wales as at January 2011

Sydney:

Public Linacs:

Liverpool Cancer Treatment Centre	(4 Linacs)
Macarthur Cancer Treatment Centre	(2 Linacs)
Nepean Cancer Care Centre	(2 Linacs)
Prince of Wales Hospital	(3 Linacs)
Royal North Shore Hospital	(3 Linacs)
Royal Prince Alfred Hospital	(5 Linacs)
St George Cancer Care Centre	(3 Linacs)
St Vincents Hospital	(1 Linac)
Westmead Hospital	(4 Linacs)

Private Linacs:

Sydney Adventist Hospital Wahroonga, Sydney Radiation & Oncology Centre	(2 Linacs)
Mater Misericordiae - Crows Nest, Radiation Oncology Associates	(2 Linacs)
St Vincents - Radiation Oncology Associates	(1 Linac)
Macquarie University Hospital	(2 Linacs)

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Newcastle:

Public Linac:

Newcastle Mater Misericordiae Hospital	(5 Linacs)
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Wollongong:

Public Linac:

Illawarra Cancer Care Centre	(3 Linacs)
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Regional NSW

Regional Public Linacs:

Coffs Harbour - North Coast Cancer Institute	(2 Linacs)
Port Macquarie - North Coast Cancer Institute	(2 Linacs)
Lismore North Coast Cancer Institute	(2 Linacs)
Orange [to be operational in early 2011]	(1 Linac)

To be operational in 2013 Gosford Integrated Cancer Centre	(2 Linacs)
Shoalhaven (Nowra) " "	(1 Linac)
New England & North West Tamworth	(1 Linac)

Regional Private Linacs:

Gosford - Central Coast Radiation Oncology Centre	(1 Linac)
Wagga Wagga - Riverina Cancer Centre	(2 Linacs)

Sally Hodgkinson updated January 2011





RESEARCH RELATED ISSUES

Cancer patients given chance in a trial

run -Amy Corderoy and Julie Robotham Sydney Morning Herald—reprinted with permission date 10 November 2010.



For Cheryl Grant, getting access to a medical trial meant grabbing hold of the hope she would survive her breast cancer.

"I wanted to get the latest treatment and give myself the best chance of surviving," the 59-year old librarian said.

"When you are first diagnosed you are really petrified because even though the statistics say you have a good chance it doesn't mean treatment is going to work for you, and the trial gave me some reassurance."

Ms Grant is one of the few cancer patients in Australia - about 6 per cent - who participate in clinical research. In her trial, an international team of researchers tested different methods of administering chemotherapy and followed her progress for 10 years, finishing last month.

"It really gave me a sense of empowerment that I was dealing with my cancer," she said. "I really felt I was doing something positive not only for other women but also for myself."

It helped to know all her tests and treatments would be reviewed by researchers, she said.

More cancer patients will be able to seek out trials that could help them after the launch today of the first national online matching service to link individuals with researchers.

The Australian Cancer Trials website allows patients to search by type of cancer and how far it has progressed, and see whether trials are accepting new patients.

The chairwoman of the advocacy group Cancer Voices NSW, Sally Crossing, who helped develop the website, said cancer specialists recognised access to clinical trials, in which responses to treatments are painstakingly monitored, was important for patients. Such trials were often the only way of getting cutting-edge therapies.

"But people don't know they exist, and their doctors don't know they exist," Ms Crossing said. Without a centralised system, it was also hard to match individuals with studies whose eligibility criteria - in terms of age, disease type and stage or previous treatments - were often strictly defined.

The chief executive of Cancer Australia, Helen Zorbas, said participation rates for cancer trials were about three times higher in countries such as Britain.

"We really want to improve the participation rates in Australia," she said.

The website, which will be hosted by Cancer Australia, contains more than 1000 clinical trials that are now recruiting patients in Australia. www.australiancancertrials.gov.au

Using Quality of Life Measures in Breast Cancer Clinical Trials

Quality of life measures tend to be most useful for clinical decision-making in trials in which quality of life is the primary outcome, according to a recent study published online January 7 in *The Journal of the National Cancer Institute*. Volume 103 Issue 3

There has been increasing interest in the value of patient-reported symptom assessment in trials and their potential usage as primary or secondary endpoints in new trials. Both the World Health Organization and the U.S. Food and Drug Administration have endorsed quality of life, but they are not always incorporated into trials because of the additional resources needed for data collection. But quality of life measures remain important for women who have completed therapy and many have symptoms such as fatigue, cognitive complaints, sleep and sexual problems, and neuropathy. At the other end of the spectrum, for advanced breast cancer patients on palliative





RESEARCH RELATED ISSUES contin.

treatments with toxicities, it would be important to determine if any observed survival benefit is outweighed by that burden. To determine how quality of life measures are used in clinical trials, Julie Lemieux, M.D., of the Université Laval in Québec, Canada, and colleagues, conducted a literature search for articles that reported a randomized clinical trial of breast cancer treatment in which quality of life was an endpoint.

Their review included 190 randomized clinical trials—103 on biomedical interventions, and 87 on non-biomedical interventions, such as psychosocial interventions like the effect of group therapy on patient outcomes.

The authors found that QOL measures were most useful for clinical decisions in trials using non-biomedical interventions. They also found that quality of life measurements should be included as a secondary endpoint in adjuvant therapy trials only when the medical outcome is expected to be about the same, or if the study focuses on a vulnerable population such as the elderly; or tests a new intervention for which quality of life information needs to be obtained. They should also be included in metastatic breast cancer trials when a minimal survival difference is expected; or treatments have substantial differences in toxicity.

They also write that when QOL is not the primary endpoint of a trial, “QOL results should ideally appear in a companion article published at the same time as the traditional medical outcomes article so that a full view of the risks and benefits of the intervention can be presented at the same time to clinicians.”

In an accompanying editorial, Patricia A. Ganz, M.D., of UCLA, writes, “The large increase in the number of published studies identified in this high-quality systematic review reflects the increased acceptance of the patient’s voice in assessing the outcome of trials as well as the participation of expert QOL investigators in the design, conduct, and analysis of clinical trials.”

Ganz also writes, “Inclusion of well-validated measures of relevant symptoms should be a high priority for assessing the burden of breast cancer treatments, whether in survivors of breast cancer or in women with advanced disease receiving palliative care.”

Source Cochrane Collaboration

NATIONAL BREAST CANCER FOUNDATION—ANNUAL RESEARCH DAY February 4, 2011

The National Breast Cancer Foundation held its annual research day on February 4, 2011. There were reports on a number of interesting studies that the Foundation is funding or has funded in the past few years.

I have selected just the trial title and a few words about the trial to give a ‘taste’ of the work funded by donations to NBCF. This may encourage readers who wish for more information to obtain the booklet from NBCF via the website www.nbcf.org.au or by phoning Jessica Harris on 8098 4827 (direct) (02) 8098 4800 (switch) or email: jessica.harris@nbcf.org.au

These Research Milestones are:

1. A group of expert scientists and clinicians (known as the EMPathy Breast Cancer Network) has been awarded \$5 million over 5 years to find a cure for secondary breast cancer. This project is led by Professor Erik Thompson of the St Vincent’s Medical Research Institute Melbourne.
2. Dr Andrew Redfern of Royal Perth Hospital is exploring the effects of proteins that decide the fate of cancer cells treated with anti-cancer drugs.
3. A program shared by general practitioners and specialists is being trialled for women treated for early breast cancer. The Shared Care Demonstration Project is offering shared follow-up care at four hospitals in South Australia, New South Wales and Victoria. This demonstration program is being run by the National Breast & Ovarian Cancer Centre.
4. A small but risky investment by NBCF has resulted in the identification of breast cancer cells that can self renew. Dr Alex Swarbrick (from the Garvan Medical Research Institute Sydney) received a Novel Concept Award from the NBCF in 2008 to LOOK for evidence that breast cancers contain cells that are able to self renew. Recent research has suggested that these cells (known as stem cells) are resistant to therapy and are responsible for the movement of cancer to other sites in the body. (Dr Swarbrick wrote the article “**Molecular Classification of Breast Cancer**” that appeared in the last BCAG newsletter for 2010.)





5. For women who have had a diagnosis of breast cancer, bra discomfort is a barrier to complete recovery. Professor Julie Steele from Wollongong University, following survey of breast cancer patients found that a large percentage were forgoing beneficial exercise because of brassiere discomfort. The results will help design new bras which will be tested for support, performance and comfort. The final results will ensure breast cancer survivors are able to enjoy the health benefits associated with regular exercise.

6. Integrating the ancient Chinese Practice of Qigong into modern Breast Cancer care. Research suggests that up to 84% of people with breast cancer are using complementary medicines, however there is little scientific evidence of how effective they are. NBCF has funded a study, led by Professor Stephen Clarke, to perform a randomised controlled trial to examine the value of focused exercise, in the form of Medical Qigong, for breast cancer patients following adjuvant chemotherapy. It is common for these women to experience a decreased quality of life due to increased tiredness, poorer cognitive function, lower levels of satisfaction with sexual life, and inflammation after they have completed their treatment. With the help of 170 women diagnosed with breast cancer, Stephen and his team are comparing the effect of a Medical Qigong program as part of routine care. The results of this study will be used to develop clinical practice guidelines for the use of Medical Qigong in comprehensive cancer care programs in hospitals. It will also contribute to our understanding of the science of Medical Qigong.

7. Linking Mammograms to genes involved in Breast cancer. A study funded by NBCF has confirmed for the first time a link between two risk factors for breast cancer. Researchers from the University of Melbourne have made use of current breast cancer screening methods to identify a link between two risk factors for breast cancer; inherited genetic faults and mammographic density (shown by the amount of white area seen on mammograms). This unique study aimed to discover if recently identified genetic faults associated with increased breast cancer risk are also associated with mammographic density by studying pairs of twins and their sisters from over 900 Australian families. "Prior twin studies have suggested that in theory there is a genetic link between mammographic density and breast cancer. For the first time, we have been able to identify some of the genetic faults involved," says the leader of the study, Professor John Hopper.

8. Men from families carrying faults in a gene involved in breast cancer are at increased risk of prostate cancer. A woman who inherits a fault in the gene BRCA2 has a much higher than average risk of developing breast and ovarian cancer. In a pioneering study funded by the NBCF, Australian researchers studied male relatives of women with faults in the BRCA2 gene, using the kConFab (The Kathleen Cunningham Familial Cancer Foundation) resource of breast cancer families. Heather Thorne and her team identified men in these families who had prostate cancer, tested them for inherited faults in the BRCA2 gene and performed genetic analysis of the prostate tumours. After examining this data the researchers estimated that the risk of prostate cancer for men with a fault in the BRCA2 gene is four times the risk for men in the general population.

Register 4

Readers will recall that in the October Newsletter there was an article on the NBCF's Register 4 (For the Cure). An update on how registrations are going was obtained from NBCF recently. There have been 20,000 registrations in the six weeks since the official launch at the end of October. As at 2 February 2011 there are 20,784 registrants of whom 20,415 are women, 364 men and 5 transgender. So the register is able to accept anyone who wishes to register. Please consider registering at www.register4.org.au.







Sally Crossing and Sally Hodgkinson both members of the NBCF Community Advisory Group attended the farewell function for NBCF CEO Sue Murray that was held at Doltone House in Pyrmont, which was a really great occasion, and a fantastic celebration of Sue's contribution to NBCF and Breast Cancer specifically was had by all. A couple of photographs follow:



NBCF Research Manager Sue Carrick, Sally Crossing AM, Founder Chair of the Breast Cancer Action Group NSW & member of the NBCF Community Advisory Group, and Professor Don Iverson of Wollongong University who is involved with the direction of the NBCF research priorities.



Sally Hodgkinson Treasurer BCAG NSW & member of the NBCF Community Advisory Group listening intently to the speech made by the Chair of the NBCF Board Mr Greg Paramour in recognition of Sue Murray's contribution to NBCF since its establishment.



Briefing on Establishment of *Health Consumers NSW*

Background

In early 2010, Sally Crossing and Betty Johnson approached the NSW Minister for Health to assist in the funding of an independent voice for NSW health consumers. NSW was then the only Australian state without a peak organisation to reflect the views and interest of existing health groups within its state.

Initial meetings were held in July and August 2010, attended by people representing twenty organisations. Participants agreed on the establishment of Health Consumers NSW (HC NSW), its objectives, its membership criteria, that an Interim Committee should progress a Constitution based on the agreed principles and that state funding should be sought to enable establishment as soon as possible.

Current position

HC NSW has since developed a constitution, been incorporated and has registered its business name. On 25 November, the Minister announced an initial grant to assist in its establishment, the development of a three year budget proposal, and for commencement of operations. HC NSW has entered into an auspicing agreement whereby Alzheimers Australia NSW will host the new body until long term funding is assured.

The main objectives of the organisation are to:

- Provide an independent, informed and representative voice for health consumers in NSW
- Provide an independent source of advice and information to the NSW Minister for Health
- Influence decision-making to achieve better health and wellbeing outcomes and a better health system
- Increase effective consumer participation across the health system
- Develop the capacity of health consumer representatives to participate in health policy and health system decisions and development
- Work with all aspects of health, including the social determinants of health, as well as all aspects of the health system including public, private, allied health, non government and community health
- To improve equity, access and health outcomes for health consumers in NSW

The set-up project will see

- Development of a database of potential members and stakeholders in order to invite them to join as members, associate members or as “Friends”
- Development of communication systems for interaction with the membership - via email L0ops, a newsletter and an interactive website.
- Development of a budget and funding application to NSW Health for the first three full years of operation
- Scoping HC NSW membership for those issues of interest and concern which are best progressed at state level
- Developing a process for nominating informed consumer representatives
- Scoping of training options for use by HCNSW to build the capacity of nominated consumer representatives to effectively participate in decisions affecting NSW health consumers
- Helping to plan the first General Meeting of Health Consumers NSW at which the Board will be elected
- Development of the organisation’s operational structure, policies and & processes
Providing general secretariat support required including arrangement of meetings, venues and travel

Responsibilities

An Interim Committee will oversee operations during the establishment phase, and recruit a Co-ordination Officer to provide the secretariat and management roles for HCNSW. The Co-ordination Officer will be responsible to the Interim Committee until a Board has been elected at the first General Meeting, according to the Constitution.

Pictured beLOW Betty Johnson AO & Sally Crossing AM





TIT BITS

Prevention: HRT hope on breast cancer

Hormone replacement therapy could protect some women against breast cancer, according to controversial research which suggests a certain form of HRT lowers the risk by at least a third. The study at the University of British Columbia LOKed at the effect of oestrogen-only HRT, which is prescribed to women who have had their womb removed. The findings have been criticised for potentially causing confusion among women who have been warned for several years that HRT causes a slight rise in the chances of developing breast cancer.

Treatment: Breast cancer hope

A US study by the Massachusetts General Hospital Cancer Center has found a new drug combination could help women with early breast cancer. Using two drugs that more precisely target tumours doubled the number of women whose cancers disappeared compared to those who had only one of the drugs. It was the first test of herceptin and tykerb together for the early-stage disease.

Treatment: Drug may protect ovaries of cancer patients

Melbourne doctors are to trial a drug that could protect the fertility of young women who receive toxic cancer treatments. IVF fertility specialist Kate Stern said she hoped to recruit 80 women with non-Hodgkin's lymphoma to test whether a drug used to treat gynaecological conditions such as endometriosis could protect their ovaries for pregnancy later. Dr Stern, who is also head of endocrine and metabolic services at the Royal Women's Hospital, said the drug, goserelin, was believed to ward off the toxic effects of chemotherapy on ovaries but had not been tested for this purpose. She said that although young women diagnosed with cancer could try to freeze their eggs or ovarian tissue before receiving treatment, it was a more invasive procedure and could carry more risks compared with using a drug such as goserelin.

Risk: Breast cancer link to hormone intake

Women who take hormones to treat the symptoms of menopause not only have an increased risk of breast cancer but are also more likely to die of the disease, research has found. A US study of more than 16,000 post-menopausal women, published yesterday in the [Journal of the American Medical Association](#), found a higher rate of invasive breast cancer and death in those who had taken estrogen and progesterin compared to those on a placebo. Cancer Council of NSW epidemiologist Karen Canfell said rates of breast cancer in women aged more than 50 dropped 9 per cent - the equivalent of

about 800 cancers - between 2001 and 2005. She said the new study showed that lives had been saved by women limiting their use of HRT.

Risk: Breast implant scare

US health officials are investigating a possible link between breast implants and a rare form of cancer, as Australian authorities also monitor risks associated with the saline and silicone devices. The cancer, known as anaplastic large cell lymphoma, attacks lymph nodes and the skin and has been reported in the scar tissue that grows around an implant. The US Food and Drug Administration asked doctors to report all cases of the cancer so it could better understand the association. It learnt of 60 cases of the disease worldwide, among the estimated five million to 10 million women with breast implants. Cancer Council SA chief executive Professor Brenda Wilson said the issue was being followed with interest and it was too early to advise against implants.

Book Review:

“Pretty is What Changes” by Jessica Queller Published by Vintage Books/Random House 2008 Jessica Queller is of Askenazi Jewish extraction who at age 34 is single and living in Los Angeles where she is a writer for television scripts, and tests positive for the BRCA gene mutation. The book spends a fair amount of time recounting her mother's death from ovarian cancer, after she had had breast cancer at age 52. Whether the mother Stephanie Queller, had the BRCA gene is not revealed - possibly she had never had the test which would have identified it, but in all likelihood she passed it on to two her two daughters Jessica and Danielle, given that the chances of inheriting are 50 -50. Jessica recounts how she went in apparently 'blind' to the implications of genetic testing without any counselling, and was forced to face the consequences.

Jessica goes through the trauma of trying to make a decision to have prophylactic surgical removal of her breasts, and to have an immediate reconstruction, as eventually does her sister, all the while wishing she was able to have a child, before she needed to have her ovaries removed, to limit her chances of developing ovarian cancer. All in all the book is an interesting read, but not especially cheerful, as it concentrates on a lot of breast cancer issues that could be somewhat depressing for some readers. **Sally Hodgkinson**



Providing the voice of people affected by cancer: Cancer Voices NSW celebrates the first ten years

Cancer Voices NSW, the state level consumer advocacy group, celebrated its tenth anniversary in October 2010. We had plenty to celebrate as readers of our quarterly newsletters will know (all on our website and most searchable at www.cancervoices.org.au).

Some of our achievements are overt - eg a Comprehensive Cancer Centre with public radiotherapy for the Central Coast, IPTAAS distance reduction, identification of gaps in the medical oncologist workforce, the Australian Cancer Trials Online website, funding of our principal research priority -speeding up tailored cancer treatment. Some are more “covert” - quite often it’s a matter of inserting an idea into an organisations planning process, fanning a little from time to time and watching a nice strong flame eventually appear. This has been the case for a number of consumer initiatives developed with stakeholder organisations.

Our programs have become robust and offer a translatable template:

- Consumer Reps Program, based on trained informed CVN members nominated to decision-making committees in response to electronic requests through our website.
- Consumer Involvement in Research Program: similar but specialising in providing the consumer view to researchers and research funders.
- Area Cancer Services Program: Regular across-NSW teleconference networks about Local & regional issues and ideas which shape advocacy direction.

While CVN began in 2000, the movement for an independent voice for people affected by cancer has spread across Australia and nationally. We are proud to be the “big sister’ amongst the Cancer Voices family. The Breast Cancer Action Group movement inspired our establishment and helped us to hit the ground running.

We have remained independent of government and industry, using the good will and commitment of cancer consumer advocates who want to see a real difference made for people like themselves. Advocacy and Research Training for cancer consumers, run jointly with the Cancer Council NSW, underpin our ability to participate effectively.

To mark our achievements over our first decade, and our “persistence pays” staying power we:

- celebrated at a tenth birthday party at the Cancer Council NSW on 25 November 2010
- will publish a booklet to record the Cancer Voices decade
- distributed 5000 new informational leaflets to members, partners, stakeholders, politicians and other decision-makers
- contacted our stakeholders, supporters and friends about plans for the next decade

So, keep Cancer Voices NSW in mind when you need the view of people affected by cancer - for media inquiries, when planning cancer (treatment, support & information) services, when developing a research project, or when reviewing information resources. Use our “Request a Consumer Representative” electronic form on the website to be matched up with a suitable nominee.

Better still, join us via the website as a Member group, an Individual or an Associate Member.

If you’d like to know what our members think about specific issues raised by our members, there are 26 Position Statements on our website. We aim to reflect and promote the views and needs of people affected by cancer through our extensive membership, networks and partnership with decision-makers.

Yours sincerely

Sally Crossing AM

PO Box 5016, Greenwich 2065

Chair, Cancer Voices NSW





NEWS FROM NBOCC—December 2010

The National Breast and Ovarian Cancer Centre (NBOCC) news for December 2010 follows:

Breakthrough in feasibility of breast cancer staging for population-based cancer registries
National Breast and Ovarian Cancer Centre (NBOCC) is pleased to announce the release of the *Breast cancer staging and treatment report...* [more »](#)

Seeking nurses to participate in psychosocial care study
Implementation of NBOCC's *Clinical practice guidelines for the psychosocial care of adults with cancer* are being assessed by The University of Sydney's School of Psychology, who are inviting cancer nurses across Australia to complete an online survey which aims to explore psychosocial care for adults with cancer in Australia... [more »](#)

National Breast and Ovarian Cancer Centre at COSA
NBOCC was well represented at the successful Clinical Oncological Society of Australia (COSA) Annual Scientific Meeting held in Melbourne in November... [more »](#)

Annual Report 2009-10
NBOCC's *Annual Report 2009-10* is now available to download from NBOCC's website... [more »](#)

Season's greetings from NBOCC
The Board and staff of NBOCC extend our thanks for your support in 2010 and wish you all the best for the Festive Season. The NBOCC office will close on Friday, 24 December and re-open on Tuesday, 4 January 2011... [more »](#)

BREAST CANCER: Issue 38
This edition includes commentary by Professor Shih-Chang Wang on 'Comparative effectiveness of MRI in breast cancer (COMICE) trial'... [more »](#)

OVARIAN CANCER: Issue 11
This edition includes commentary by Dr Greg Gard on 'Outcomes of fertility-sparing surgery for stage I epithelial ovarian cancer: a proposal for patient selection'... [more »](#)

Lymphoedema Issues

In the October issue of the Newsletter there was quite a bit of information about the Australian Lymphology Association Register which had gone on

line. Since then we have had a couple of comments in relation to lymphoedema issues which support the Association's activities.

One very positive comment from a city based BCAG member was as follows, and I quote from her email:

"Dear All
thanks to the BCAG newsletter and flyer about this directory, I was able to find an excellent lymphoedema practitioner recently. I highly recommend the website to others
Regards
Sharyn

ps Although I did note that there are very few practitioners listed, but I have a feeling that there are not too many!"

A country BCAG member Dr Annette Clement surveyed her support group and the results follow:

"Herewith the results of above survey.

27 women took part during the monthly meeting of the Local Breast Cancer Support Group and results are quoted as percentages.

1. **Were you given any information about Lymphoedema by anyone BEFORE any treatment?**
Answer - 100% NO!
2. **AFTER treatment were you informed about a. The possibility of lymphoedema occurring, both how and why, and by whom?**
Answer - 52% YES - received this info by reading brochures, the internet or by talking to a physiotherapist but no info from surgeons or oncologists etc.
- b. **The prevention and treatment of lymphoedema by exercise, massage, elastic garments etc?**
Answer - 28% YES - accessed this from Encore and 2% from a "buddy" at the Mater.
- c. **Were you informed from where/whom this treatment could be obtained?**
Answer - 7.4% YES - received this from the breast care nurse, physio and care-plan nurse.
- d. **Were you informed of any cost for this treatment?**
Answer - 100% No.
- e. **Were you told that you may be required to travel to receive this treatment?**
Answer - 100% No
- f. **Were you/family member/carer/friend educated in massage therapy to help prevent or treat lymphoedema?**
Answer - 22% Yes - from either Encore programme,





Answer - 22% Yes - from either Encore programme, buddy or physio.

g. Any other comments?

Answer - 100% agreed that not enough information is provided across the board which left each patient to try to obtain this through the literature

My country correspondent who lives on the mid north coast and is an active member of Cancer Voices NSW as well as a BCAG member provided the following additional information regarding lymphoedema services in her region.

“Other info re availability of treatment for lymphoedema”

The Lower Mid-North Coast, which involves public hospitals in Taree, Gloucester and Bulahdelah and a private hospital in Forster/Tuncurry has no public treatment for lymphoedema.

The only service available is by one private physio who works in Forster.
I got her to Look back over a 2 month period about her work with lymphoedema.

No. of consultative treatments - 27
Patients were referred from:
Taree, Gloucester, Newcastle, Sydney, Bulahdelah, Forster and Tuncurry.
Patients referred by G.Ps, Breast nurses, Oncology nurses or themselves.
Pensioner reductions in cost were in place
The greater majority of those treated were breast cancer patients

This just a small snapshot but it probably mirrors other rural areas. The Hunter and New England Area Health Service (H&NEAHS) Lymphoedema Working Party has been involved for many months and hopes to eventually improve services in the whole area.”

The survey and the information about lymphoedema services in the H&NEAHS probably reflects the paucity of such services in rural and remote NSW. So we need more therapists to sign up to the Register, there is undoubtedly plenty of work out there for them, not only with breast cancer patients.

BREAST CANCER SPECIALIST WEBSITE

BCAG & BCI (Breast Cancer Institute) are meeting on 10 March to reassess the hosting, maintenance and updating of our joint Directory of Breast Cancer Specialists

APOLOGY TO YWCA

In the October Newsletter, I wrote a letter critical of the situation at the Jean Colvin Cancer Centre. In it I identified myself as a YWCA ENCORE Co-ordinator, only to explain why I had contact with a large number of women who had experienced breast cancer. I would like to categorically state that at no time was I representing YWCA NSW or YWCA ENCORE, and deeply regret any implication that I was. The views I expressed were entirely my own and that of the women who had contacted me about their experiences there.

While on the subject of the JCCC, there is some dispute about the presence or otherwise of Registered Nurses, but the new CEO of CanAssist is aware of problems at the centre and is taking steps to address them, which is gratifying to see.

Ann Clydsdale

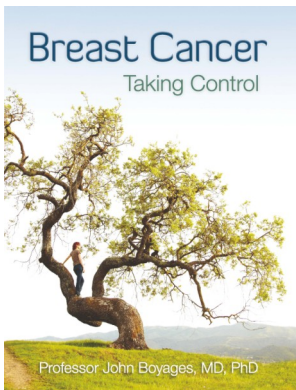
THANKS

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

STOP PRESS

The Lymphoedema Support Group of NSW is very pleased to announce that Dr Mark MaLOuf, a leading vascular surgeon in Sydney, will be a key note speaker at the Information Day on Saturday 9th April. Dr Malouf. His topic ? Lymphoedema.





BOOK - SPECIAL OFFER FREE OVERNIGHT COURIER TO YOUR DOOR FOR BCAG MEMBERS FOR \$34.99, a saving of \$18.20

Go to:

<http://www.breastcancertakingcontrol.com/BCAG.html>

***Breast Cancer: Taking Control* by Professor John Boyages, MD, PhD; Boycare Publishing; rrp: \$39.99 Available at all good book stores (e.g Dymocks, Amazon, Borders) or online at www.breastcancertakingcontrol.com/BCAG.html**

Professor John Boyages, MD, PhD released his first book *Breast Cancer: Taking Control* in September 2010 and it has been a great success with very few copies left in the shops.

“This book will help you when life suddenly feels so out of control. It provides you with the right tools, directions, and equipment to let you take control, maximise your survival, and find your path to recovery,” says Prof Boyages.

In *Breast Cancer: Taking Control* he walks you slowly through the stress and confusion of diagnosis, treatment, and life after breast cancer.

“There is a whole chapter on hormonal treatment and another one on fertility, menopause and sexuality. These are all important issues for women who take Tamoxifen or Aromatase Inhibitors or receive other treatments”, says Prof Boyages. The section on sexuality was reviewed by Dr Krychman, one of the world’s leading experts on the subject.

This book is the culmination of lots of research, peer and patient review. Learn how to:

- Identify the 20 “Control Points,” important decisions or steps you must make to navigate the medical maze
- Find and research the right treatment team for you
- Identify the key questions to ask your treatment team
- Identify the treatment choices for your breast and armpit
- Understand when you really need chemotherapy, hormonal treatment or “targeted” therapy
- Find and cope with menopause, sexuality and fertility after treatment

Breast Cancer: Taking Control also includes

- 125 photographs in Full Color and 28 graphically designed diagrams
- 20 colour-coded "Control Points" with detailed flow charts
- "Traffic-light" colours guide you through treatment phases
- Clear end of chapter "Warning", "Tip" and "Remember" icons and summaries,
- 75 hand-picked web links and 15 real-life patient stories
- Detailed Glossary, Key References and index, Plain English personal style with garden and other analogies to explain your breast cancer and its and a Insightful and informative, this book provides up-to-date treatments and is an excellent resource for patients and caregivers.

About the author: Professor John Boyages, MD, PhD is an oncologist and the founding director of the Westmead Breast Cancer Institute in Sydney, Australia. He has over 25 years experience and following his studies at the University of Sydney and Harvard Medical School, he published over 130 clinical research articles and treated thousands of breast cancer survivors. In 2006, he received a National Medical Media Award for outstanding service to the community.





PINK PADDLERS IN PETERBOROUGH

As some of you will know, but many will not, dragon boating has become an increasingly popular sport in Australia and especially for breast cancer survivors. It started in Vancouver, Canada, over 10 years ago as a result of an experiment by a sports physician to see whether vigorous exercise was as bad a risk for lymphoedema as most doctors and therapists thought. It was proven to either make no difference or to cause improvement and markedly improved the participants' physical and mental health.

When the experiment was over, the women refused to stop and Dragons Abreast (under various names) was born. It started in Darwin a couple of years later, thanks to Michelle Hanton, and has since spread throughout every state. At the highest level, some of our members are very fit and competitive and have paddled for Australia in the general sporting teams - the training is very rigorous and most of us are not prepared to do this. The majority of survivor paddlers paddle for the pleasure of it, the open air exercise and the companionship, not only of friends, but of friends who understand if we are unwell or down. The emphasis of DAA clubs is to do no harm and we are always encouraged to pull our paddle in and rest if necessary. You don't need to be fit to paddle and we have followed it by a dash to the nearest coffee shop for breakfast/brunch and a chat.

I have been paddling for about 5 years and have paddled in various parts of Australia and in Penang. The biggest event of the year for dragon boating is Chinese New Year at Darling Harbour. The Saturday is for club competition and the Sunday for Dragons Abreast and corporate teams.

In 2007 we had an international regatta in Caloundra, Queensland which was such fun that, when Peterborough, Ontario, Canada proposed to host one in June, 2010, there was great excitement. Mainly because of financial and time constraints, we only fielded 18 paddlers (a full boat has 20) plus 9 supporters and began training. All through autumn we trained at 6am in Blackwattle Bay (yes, it is hard lifting a large boat down a slippery ramp in the dark) and then did the normal club practice at 7.30, plus Tuesday and Thursday nights.

We all made our own ways to Canada, but most met in Toronto to see Niagara Falls, fortunately on a glorious warm sunny day and then drove to Peterborough. There were 1000 pink paddlers plus supporters plus about 1000 volunteers who looked after us wonderfully and the whole city was decked out in pink ribbons and dragons. Australia had the highest number of teams (14) after Canada; there were also teams from USA, UK, South Africa and Italy, and one paddler from NZ.

The weather was varied; for the march through the city and the opening ceremony we had sun and warmth; for the first day of racing we had freezing rain and wore every layer we had of thermals and rain gear; and the sun shone on us on the third day and closing ceremony. We were given a huge gala dinner in the most amazingly decorated football stadium followed by a disco dance! Between races we wandered along the row of tents, making friends and exchanging club and country pins.

We came about half way in the final results - our final race, coincidentally, was composed of all Australian teams, NSW and Queensland. Since we paddled one light (we had one Canadian paddler) and were not a selective team as many were, we were happy with this result.

After the regatta, we all scattered, with a number doing the Rockies with or without an Alaskan cruise. A fellow paddler and I went to Montreal and Quebec and practised our French!

If you live anywhere near a DAA team (you can find one on www.dragonsabreast.com.au go and have a look. Most clubs have a newbies day where you can try it and you can paddle three times without committing yourself. A warning, though, the risk of addiction is quite high. **Geri Hill**

See pictures of the paddlers on page 22





The Sydney contingent at the Peterborough Dragon Boating Festival



Dragon Boats on the water

The Paddlers Support Crew



The Australian Paddling Team and Supporters





