ACT & SE NSW BREAST CANCER TREATMENT GROUP

NEWSLETTER

ISSUE 8 DECEMBER 2008

The Breast Cancer Treatment Group

At the beginning of 2008 it was my privilege to take over as Chair of the Breast Cancer Treatment Group. I thank and acknowledge the contribution of Dr Paul Dugdale to the group as the previous chair during 2006–2007. I would also like to welcome back Professor Jane Dahlstrom, who has kindly taken up the role of Deputy Chair. On a sadder note in early 2008, the group noted with regret the death of Dr Denis Dyason. Dr Dyason was one of the original surgeons to participate in the BCTG and was a much respected and liked surgeon in the ACT. His humour and character will be greatly missed by all.

This year marks 11 years of data collection by the BCTG. This data is at present undergoing verification and 'cleaning' which will enable the writing of the 10 year report. The number of patients recruited to the project is now over 3400 which is a remarkable number given that participation in the project by clinicians is voluntary. This voluntary contribution of time and effort is continually underestimated but is the single most important factor that has allowed the group to collect high quality and comprehensive information on breast cancer patients. As the number of breast cancer patients recruited to the BCTG project increases, the issue of funding and manpower to maintain the database will become increasingly more important.

This year has seen several informative and interesting presentations. In March Dr Nicole Gorddard, a Canberra based medical oncologist, gave a presentation on chemotherapy for early breast cancer. She highlighted new approaches to chemotherapy and current areas of research. The current regimens available as well as differences and consensus between individual medical oncologists were also covered, which the group found most helpful. In May, Dr Karen Luxford from the National Breast and Ovarian Cancer Centre spoke to the group. She gave an overview of the NBOCC as well as emphasized the need for collaboration between numerous groups, including community, health and political representatives.

continued on page 4

IN THIS ISSUE

Data Collection Sub-committee

Report from the Chair

2008 marks the 11th year of the Breast Cancer Treatment Project. As detailed in this newsletter, a large amount of data has been carefully collected and collated. As a result of this long effort, several manuscripts for peer reviewed publication have been prepared. For the first time, outcome information collected over the past 10 years has become useful. Presentations have been made to the Treatment Group, to The Canberra Hospital, and the Royal Australasian College of Surgeons (RACS) detailing the outcomes of care as the results have become available.

The project has demonstrated generally high quality breast cancer care. More importantly treatment outcomes appear good, with 5 year overall survival from invasive breast cancer of greater than 90% within the region. The collected information has also been of assistance in tracking the use of new technology. For example, the early introduction of sentinel lymph node biopsy over the last few years has reduced the risk of complications for women with no axillary lymph nodes involved. The data collection has supported the Group in documenting the introduction of the technique.

In the coming year our challenge will be to use the information gathered to inform women and men, health authorities and clinicians about breast cancer care in the region, trends, and differences. We hope this will aid clinicians refining their practice, and assist health authorities in planning for the future. The information is also useful for research into breast cancer, and members of the Group have recently completed an important study looking at the influence of multi-centric breast tumours on the risk of lymph node involvement. We expect further significant reporting activity in 2009, including a monograph report on the 10-year data-set.

I would like to thank the sub-committee members for their patience and hard work during the year. I also thank our project officers, Yanping Zhang and Robyn Bradley, for conspicuous dedication through the year, particularly the arduous task of cleaning and collating the follow-up data. Finally, I acknowledge the hard work of individual clinicians, from whom the data originates, and all of our participating men and women, who trust us with their personal information. I believe the effort has been very worthwhile.

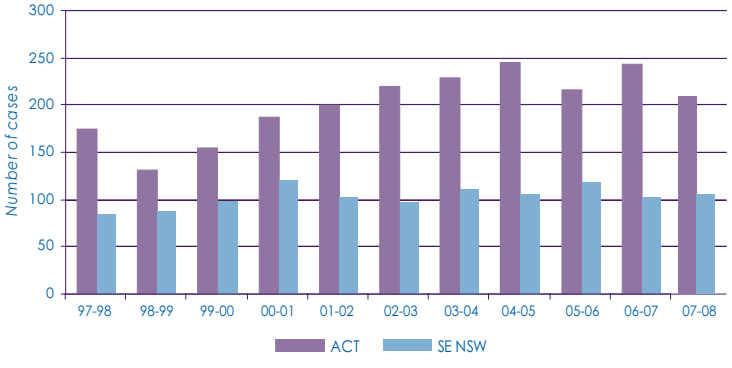
Paul Craft
Medical Oncologist

Important results from 11 years of Data Collection

The Breast Cancer Treatment Quality Assurance Project has been successfully running for 11 years now, and over 3300 women and men with breast cancer from the ACT and surrounding regions have agreed to have their information included in the BCTQA project (**graph 1**).

Graphs 2–6 provide information for all patients (n=3166) who have given written consent and have a completed data collection form. The tables summarise the results of patients with invasive and DCIS disease and their treatments. The last figure (graph 7) shows preliminary results of 10 years' follow-up data for women with unilateral invasive breast cancer (n=2364) who underwent initial surgery between 1 July 1997 and 30 June 2007.

Graph 1 Breast Cancer Cases in ACT & Surrounding Regions. 1 July 1997–30 June 2008, n=3351

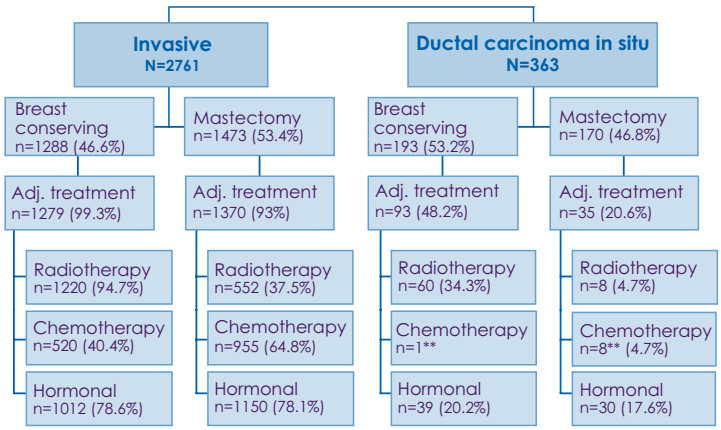


Graph 2 Characteristics of Patients and Tumour (n=3166*)

Age at diagnosis (median)	57.2 years	Range 22–95
Gender	N	%
Female	3146	99.4
Male	20	0.6
Menopausal status		
Pre-	813	25.7
Post-	2047	64.8
Peri-	271	8.6
Unknown/Male	35	0.9
Diagnosis		
Invasive carcinoma	2790	88.1
In situ disease only	376	11.9
Tumour extent		
Distant metastases at diagnosis	50	1.6
Synchronous bilateral tumours	225	7.1

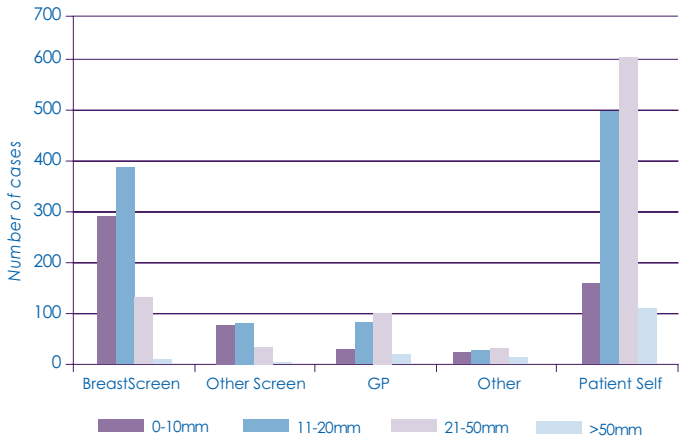
** Participants have given written consent and have a completed data collection form.*

Graph 3 Breast Cancer Treatment in ACT and SE NSW, n=3124

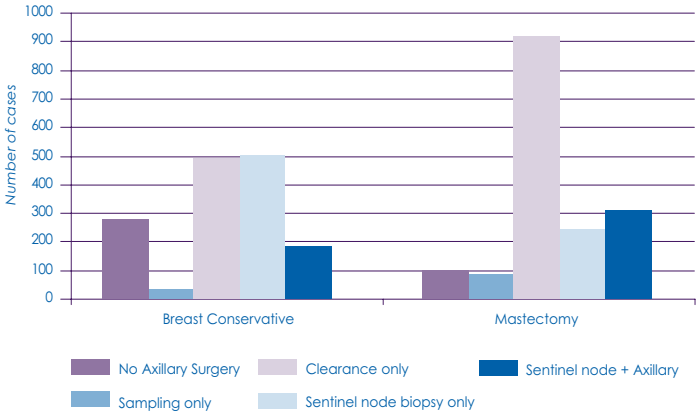


**Excluded are patients who have not undergone surgery, n=42*
*** These patients had contralateral invasive breast cancer.*

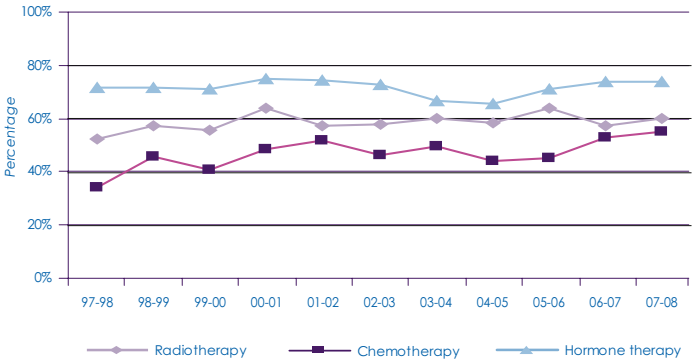
Graph 4 Method of Detection and Tumour Size



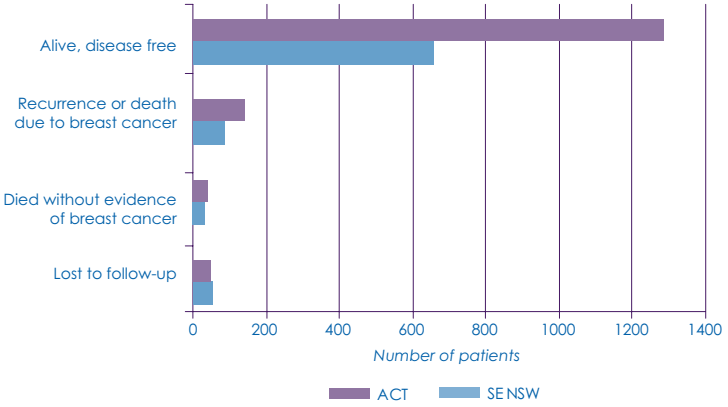
Graph 5 Axillary Surgery



Graph 6 Post-operative Adjuvant Therapy



Graph 7 Breast Cancer Outcomes, n=2366*



** For women with unilateral invasive breast cancer and their initial surgery between 1 July 97 and 30 June 07.*

The Breast Cancer Treatment Group Continued from page 1

Dr Luxford also highlighted the recent name change of the NBOCC to include ovarian cancer as well as recent publications including the 'Recommendations for the use of Sentinel Node Biopsy in early (operable) breast cancer' and 'Recommendations for the use of taxane-containing chemotherapy regimens for the treatment of early (operable) breast cancer'.

The August meeting generated considerable debate as the group discussed a potential collaboration with Biogrid, a multi-state multi-institution group that is collecting data on many diseases, including different cancers. Canberra was recently accepted as the 'ACT Node' for Biogrid on the 8th October 2008 and the BCTG has been invited to participate and to contribute data as part of the ACT node. Although the BCTG supports the project in principal, no consensus has been reached to date regarding the provision of retrospective data by the group to Biogrid. This is largely due to very valid concerns raised regarding privacy and consent issues. At the same meeting Dr Paul Craft presented the 9 year results from the BCTG project. Work on a formal publication of this data is under way with Professor David Roder, a senior epidemiologist from South Australia assisting with the complex data analysis.

Finally, in November, Dr John Eden gave a presentation to the group on the management of menopausal issues in breast cancer patients. Dr Eden is a Reproductive Endocrinologist and Gynaecologist and is also the Director of the Sydney Menopause Centre.

Notable presentations elsewhere were: Dr Paul Craft, who presented 'Outcomes of breast cancer treatment – first report from the Breast Cancer Treatment Group' at grand rounds at The Canberra Hospital; and Dr John Buckingham, who presented 'A Regional Approach in Australia to quality and safety in breast cancer management: 10 years on' as a poster at the annual scientific congress of the Royal Australasian College of Surgeons in Hong Kong.

The BCTG has also agreed to participate in the NSW Breast Cancer Tissue Bank. This project, which is funded by the NHMRC, the National Breast Cancer Foundation and the Cancer Institute of NSW, will collect blood and tissue samples as well as other information on the treatment of breast cancer patients. It aims to use this information primarily for research. Together with ongoing contribution to the Royal Australasian College of Surgeons Breast Cancer Audit and future participation in Biogrid, this will allow data collected by the BCTG to provide a significant contribution to national and perhaps in the future, international research. Such ongoing collaboration will firmly establish the group as a significant presence in breast cancer research.

As always the BCTG acknowledges the support of the meeting sponsors to allow us to invite interstate and local speakers to address the group. I am also grateful for the ongoing hard work done by Robyn Bradley and Yanping Zhang to keep the project running so smoothly. Finally, I wish to thank all the members of the BCTG for their continuing interest and participation and I look forward to seeing you at next year's meetings held in the Drawing Room at University House, Australian National University on **Monday March 23, May 4, July 27 and October 19 at 6.00pm**.

Dr Carolyn Cho
Chair of the ACT & SE NSW Breast Cancer Treatment Group
General and Breast Surgeon based at Deakin, ACT

DATA COLLECTION: Now and the Future

Data collection and analysis is becoming the 'must do' for health care across the national and international spectrum.

We in the ACT have led the way with our Breast Cancer Treatment Group Project. For eleven years we have been collecting data and now we are in a position to analyse this with a median five year follow up. We are able to show that our treatment matches our established guidelines that we set up at the beginning of the project. Also we are able to offer five year survival and recurrence data. Important regional differences have been observed.

On a national scale the RACS Breast Cancer Database has been going for less time but understandably has a lot more patients. However, their participation rate is much less than our 96% and it is hard to interpret data when only selective cases are submitted by the surgeons.

Groups such as NBOCC are recognising the importance of data collection. They are strong supporters of the surgical RACS audit and have pushed the RACS to try and get higher participation rates.

Recently I was at the American College of Surgeons Annual Meeting and they have established a programme to collect surgical data from hospitals. They recognise this as important to measure performance. They have established computer programs, performance benchmarks and hospital infrastructure required. However, because of costs involved there are only a small number of hospitals involved.

It is clear we need to look at long term outcomes to establish performance level and prove we are providing adequate care. Individuals should have help from hospitals and health authorities to do this if all levels of health care want to improve their performance by looking at their outcomes.

John Buckingham
Breast Surgeon

Events of 2008

March Presentation to the BCTG

Dr Nicole Gorddard, Staff Specialist in Medical Oncology and Lecturer, ANU Medical School addressed the group on the topic of *Adjuvant Breast Cancer Chemotherapy–Update and is there any consensus?*

Congratulations to Dr John Buckingham for presenting on behalf of the BCTG, the poster *A regional approach in Australia to Quality and Safety in Breast Cancer Management: 10 years on.* This was well received by participants at the Royal College Annual Meeting in Hong Kong in May.

May Presentation to the BCTG

Dr Karen Luxford, National Breast and Ovarian Cancer Centre (NBOCC) acknowledged the importance of research projects like the BCTG, and explained the expanding role of the NBOCC.

In May, Dr Paul Craft presented the first report on outcomes of Breast Cancer Treatment at the Canberra Hospital Grand Rounds on behalf of the Breast Cancer Treatment Group.

Managing endocrine and menopausal issues in women with breast cancer

As a recent newcomer to the BCTG, as a consumer representative for Breast Cancer Network Australia (BCNA), I found Professor John Eden's talk about managing endocrine and menopausal issues in women with breast cancer of immediate relevance. In its support role for women (not to forget men) following a breast cancer diagnosis, BCNA is constantly looking for additional ways to disseminate practical advice to manage problems occurring following treatment. Professor Eden, from the Sydney Menopause Centre, provided such advice. I made note of some of these and have suggested that BCNA might like to follow up on Professor Eden's work (and others from the centre) to ensure that women are aware of the latest information. As a national organisation with a membership of more than 31,000 women across the country, BCNA is in a good position to do this. It was also good to learn that the results of new studies on the use of topical oestrogen are soon due. Using such products women always have to balance risk with benefit. More knowledge of risks is welcome news.

Guest speaker was Dr John Eden from the Sydney Menopause Centre November 2008

Geraldine Robertson
Consumer Representative

The Annual National Breast Cancer Study-Classes of Standardised Treatment in Beijing

It was my second time to present a seminar on the Quality Assurance Project to the Annual National Breast Cancer Study classes of Standardised Treatment in October. Since 1999, this program has been organised by the Chinese Academy of Medical Sciences, National Cancer Hospital in Beijing for junior doctors from many of the hospitals around the country who specialise in surgical oncology.

I described how the Breast Cancer Treatment Group data collection project was set up following the Australian breast cancer management guidelines, and introduced our Project online information and publications. The audience was impressed by the successful achievements of the Quality Assurance Project. In particular the high participation rate and the response rate to follow-up requests was recognised as being extremely valuable.

The Program convenor, Professor Zhang Baoning, wished to hear more news about the Project and he offers a warm welcome to Australia's breast cancer doctors to attend the program in future years.

Please contact me if you are interested in these Beijing programs. Yanping.Zhang@act.gov.au or phone (02) 6205 0967.

From the GP's desk

Breast cancer will, for a long time to come, remain a huge challenge for the patient, their family and all those involved in their care. Like all other cancers it has the spectre of serious illness and even death. In addition, it has a specially sensitive psychological aspect due to the sexuality attached to the breast.

Loosing a breast, either fully or partially, evokes serious grief, particularly in younger women. Our breast are intrinsically linked to how we define our femininity. From time immemorial we have celebrated, decorated, enhanced and loved the female breast. Artists have painted them and composed poetry about them. In our times breast worship has become a cult. Fortunes are spent to make them a perfect fit to some fictitious ideal model.

How, in this climate, can a woman still feel good about herself and believe that her partner still loves her when she loses this most important symbol of her femininity? The reality however is mostly very different. It is often very moving to watch men desperately trying, with great love and caring, to convince their partners that it is them they love and that the pain and suffering they will have to endure only enhances their desire to be close to them. For those couples, where this can be communicated and received, the illness and the prolonged treatment brings them closer together. It is THE most important support the women can have through this whole ordeal.

The surgery, however, is only the first step towards the healing. Unfortunately many women have to go through months of chemo and radiotherapy followed by hormonal manipulation to avoid recurrence. HRT is no longer available to her to help her with post menopausal symptoms.

While these treatments have greatly increased the chances of survival and even cure they also have their own inherent problems. The anti-oestrogenic effect of the medication can leave a woman fatigued and lacking the vitality she once had. It can result in vaginal dryness and lack of libido clearly impacting on her sexuality. She can feel less resilient to stress, more irritable and easily hurt by the perceived attitude of others.

It is indeed a very hard road to travel. Having overcome the hardships and risks of the chemotherapy, women often find the impact of the treatment often remains for months and even years. With time a new equilibrium can be achieved and women adapt to an altered hormonal milieu. At that point, she and her family can look to the future with a sense of conquest and pride of having survived and grown together through the experience.

As a female GP I feel honoured and privileged in having the opportunity to travel with my patients for some of the way. They have taught me a great deal more than what I could ever impart on them. I am truly grateful to all those who have trusted me through this challenging period in their lives.

Marie-Ange Nambiar
General Practitioner

Thank you to all General Practitioners and Practice Staff for your most valuable contribution to the BCTG Quality Assurance Project

In preparation for the *Breast Cancer and Treatment in ACT and Surrounding Regions–Quality Assurance Project–10 year report*, during 2008 more requests than usual were sent to you in order to catch-up on missing and 'lost to follow-up' information. This was on top of the usual annual /biennial follow-ups. The enormous effort by all of you – GPs, Practice Nurses and Practice Managers – has been greatly appreciated by the Quality Assurance Project team. *Thank you!*

Pink Ribbon Breakfast

This year's Pink Ribbon Breakfast was held on Monday 27 October, 2008 at the National Museum. Special guest Professor Jane Dahlstrom spoke on 'the role of the Anatomical Pathologist in breast cancer diagnoses'.

The diagnosis of breast cancer is the domain of the Anatomical Pathologist, but the pathway from the breast tissue to the final report is convoluted with many steps.

Dr Dahlstrom showed us that breast tissue can be acquired through needle biopsy, core biopsy and surgically before arriving at the lab for many days of processing. There can be as many as 80 slides per breast case.

In the ACT, breast cancer diagnoses are presented at multidisciplinary meetings where radiologists, radiation oncologists, medical oncologists, surgeons, breast care nurses and Anatomical Pathologists come together to review cases and decide on the best practice treatment approach. This is not done for all areas of cancer diagnosis, or in fact, in all areas of Australia.

The role of the Anatomical Pathologist need not end in the laboratory. Pathologists are not only involved in teaching medical students but also in cancer research, for example in the Breast Cancer Treatment Group and Quality Assurance Project of the ACT and surrounding region. This impressive project is currently preparing the 11th year report which aims to present data that may help shape the best practice treatment guidelines for breast cancers according to their stage, type, location and hormone receptor status. This important work in its tenth year is possible thanks to the commitment of the many GPs, surgeons, oncologists, and breast care nurses that donate their time to providing information for data collection. Yanping Zhang and Robyn Bradley are instrumental in pulling this data together as accurately as possible.

I have been a medical student under the mentorship of Jane Dahlstrom since 2004 and am privileged to also be a part of the BCTG and Quality Assurance Project through the help of Bosom Buddies. We are very fortunate to have someone like Jane Dahlstrom working for, teaching and supporting breast cancer research in the ACT. Thanks Jane!

Anita Hutchison

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If you have any enquiries or comments about the project, please contact the Cancer Treatment Quality Assurance Project office, ACT Health Building, 1 Moore St (GPO Box 825), Canberra ACT 2601
Any clinical queries should be directed to Dr Paul Craft at the Canberra Hospital on (02) 6244 2220.
www.health.act.gov.au/Research/Breast Cancer Treatment

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