

NEWSLETTER

ISSUE 9

DECEMBER 2009

BCTG Chair's Report

Once again, the year is drawing to a close! This has been an eventful and busy year for the Breast Cancer Treatment Group.

Firstly, the ten-year report has been completed. I would like to thank all the authors involved as well as the members of the Data Management Sub-committee for their considerable effort in completing this work. I also acknowledge and thank Yanping Zhang and Robyn Bradley for all their hard work on the report. It is expected that the report will be published and distributed in the near future, and this will be marked by a public launch of the document.

The ten year report is significant in many ways. Firstly, it is a comprehensive record of ten years of breast cancer treatment within a single region in Australia – the first of its kind. It has an outstanding participation rate of 96% of patients in the region, given that participation by clinicians and patients is voluntary. Secondly, the BCTG has been able to report on outcomes of breast cancer treatment. Outcome analysis has shown that in this time period, over 93% of patients are alive and over 80% alive and disease free at five years. This is matched or better than other national and international figures. Lastly, the project is ongoing and

requires continuing support both in terms of funding and participation.

Recent statistics from the Australian Institute of Health and Welfare have stated that the incidence of breast cancer continues to increase with breast cancer affecting 1 in 9 women by the age of 75 years. The mortality from breast cancer is however, decreasing. The increase in the number of cases of breast cancer has made the task of recruiting patients to the project increasingly time-intensive. Consequently the workload involved with data verification and database maintenance has also increased. This continuing work has been supported by funding from ACT Health and also Bosom Buddies.

The BCTG had four excellent speakers this year, which are detailed later in this report. We would like to extend our appreciation to these speakers as well as the sponsors of our meetings.

Later in the year, the BCTG also began a collaborative project with the NSW Breast Cancer Tissue

Bank. Following ethics committee approval, a small pilot trial has commenced recruiting patients to both the BCTG Quality Assurance Project and the Tissue Bank. It is anticipated that patient recruitment by all clinicians will commence after minor adjustments to the process.

Next year, I am very pleased to announce that Angela Rezo will take over the Chair position of the BCTG. I am sure that she will bring enormous energy and enthusiasm to the group. I thank all members of the BCTG for their support over the last two years in my role as chair, in particular Jane Dahlstrom as deputy chair, Yanping and Robyn.



Carolyn Cho

IN THIS ISSUE

BCTG Chair's Report	1
Data Management Sub Committee Report	2
Results from 12 years of data collection	3
From the GP's desk	4
Collaboration with the Breast Tissue Bank Project	5
Sexuality and breast cancer	6
What is a Specialist Breast Care Nurse?	7
Events of 2009	8

Data Management Sub Committee Report

Paul Craft has continued to chair the Data Management Sub-committee whose other members include John Buckingham (Surgeon), Carolyn Cho (Surgeon), Jane Dahlstrom (Pathologist), George Jacob (Radiation Oncologist), Janet Li (Representative of ACT Population Health) and Robin Stuart- Harris (Medical Oncologist). This year Angela Rezo (Radiation Oncologist) joined the committee.

The focus this year for the Subcommittee has been on the review of the database and completion of the ten-year report of our quality assurance project. This task has been ably led by Carolyn Cho. Other members, apart from members of this subcommittee, who helped in the preparation of the report include Ian Clark (Pathologist), Jeremy Price (Radiologist), our very hard working staff, Yanping Zhang and Robyn Manda Bradley and Anita Hutchinson, Medical Student/Intern at Canberra Hospital, employed by Bosom Buddies to complete the data audit/validation.

The Subcommittee is working with Desmond Yip, Medical Oncologist, to streamline the consent process with the commencement of the breast tissue bank in September this year. Regular updates of this project will be provided to the group.

The Data Management Subcommittee is currently completing a manuscript looking at breast cancer survival in the region based on eight years follow up. A number of research applications have been received from members of the BCTG and reviewed by

the committee this year. All the publications related to the BCTG, including all newsletters, can be found on the external ACT Health website www.health.act.gov.au – Research – Breast Cancer Research – BCTG – Publications. A list of presentations for 2009 is detailed in this newsletter.

Thank you to all the health professionals, Bosom Buddies and patients for their continued support of this project. Finally, I would like to particularly thank Carolyn Cho, who is stepping down as chair of the Breast Cancer Treatment Group at our next meeting. Not only has she ensured the completion of the ten year report but she was integral in maintaining sponsorship of our meetings and organising very interesting guest speakers in 2008–09.



*Jane Dahlstrom,
Acting DMSC Chair*

2010 dates for your diary

Breast Cancer Treatment Group meetings are held at University House, ANU in the Drawing Room from 6pm on

Monday 22 February
Monday 10 May
Monday 26 July
Monday 18 October 2010



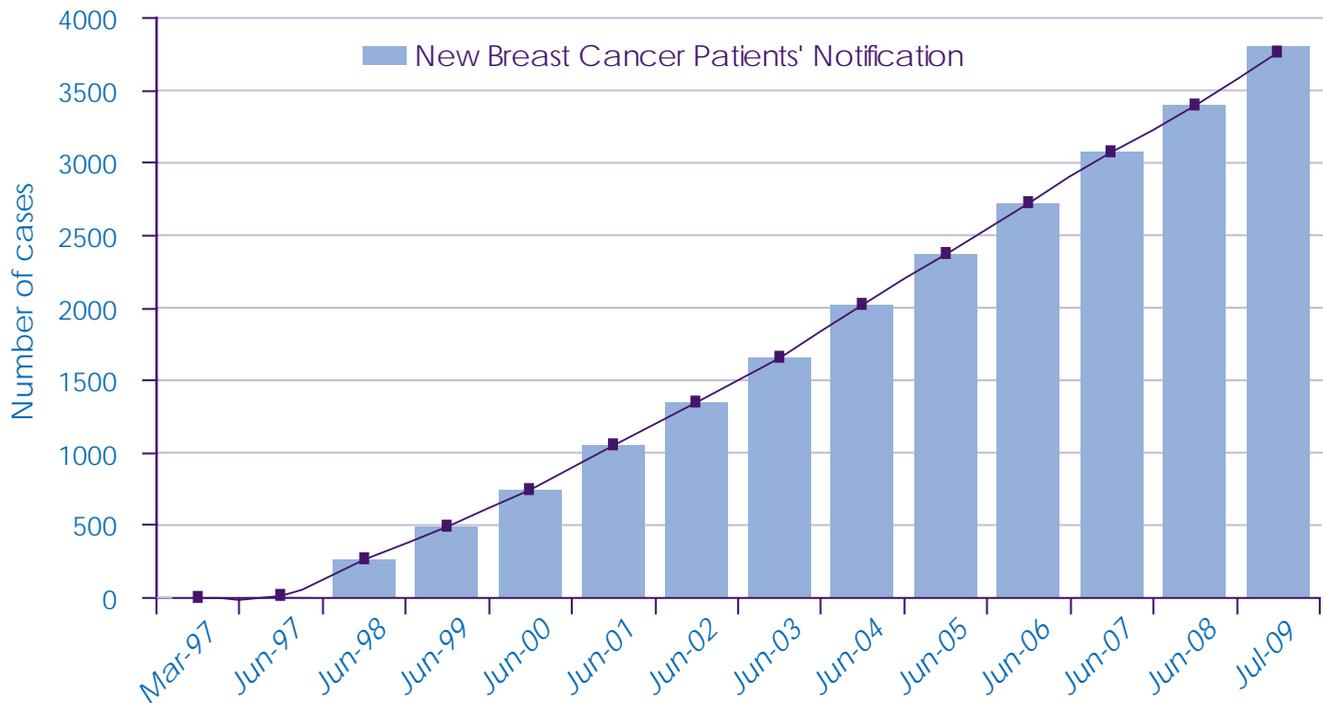
Thank you

The group would like to thank The Canberra Hospital Radiation Oncology Private Practice Fund for their generous contribution towards the publication of the ten-year report. We would also like to acknowledge and thank ACT Health Breastscreen, and all those who have voluntarily given of their time, many for the full 12 years of our operation, by providing ongoing support to the BCTG Quality Assurance Project's endeavour to collect valuable long term data. The 10 year report will be available at the ACT Health website early in 2010.

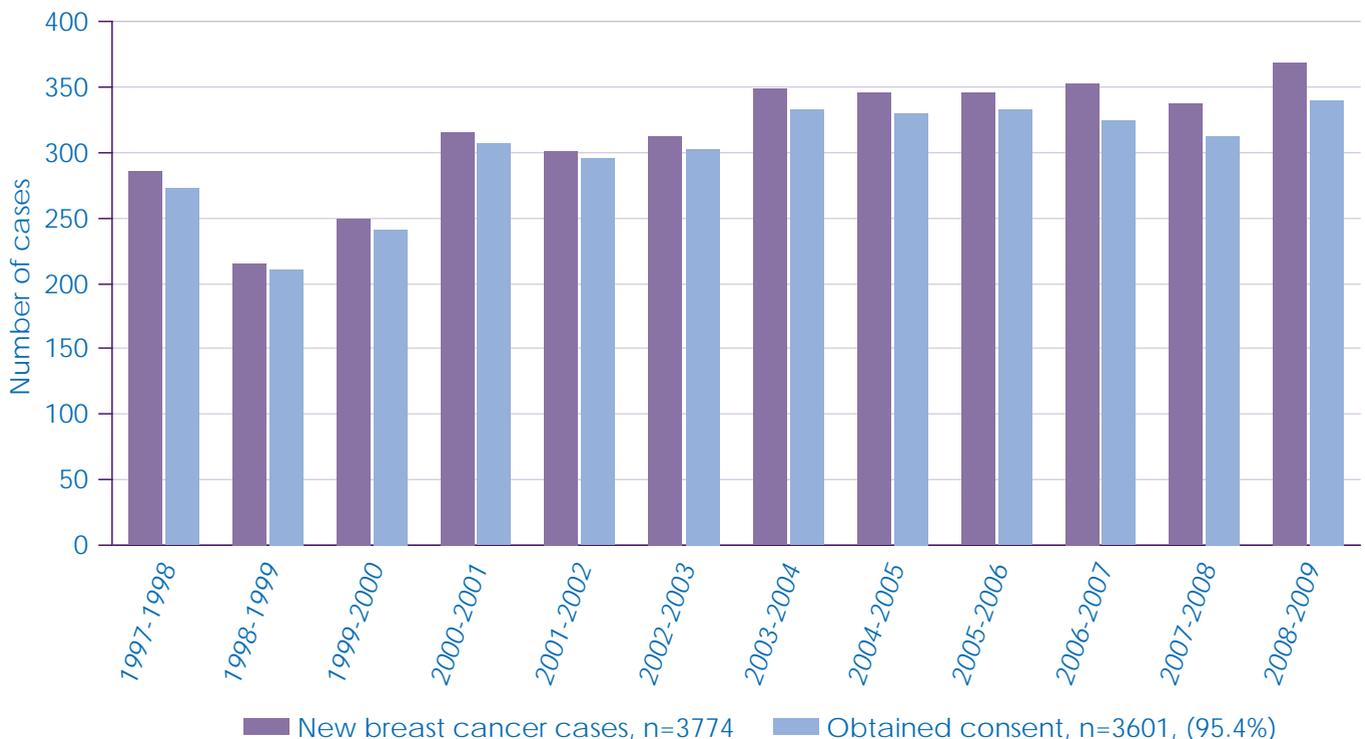
Results from 12 years of data collection

To date 3800 patients have been notified to the Cancer Treatment Quality Assurance Project. There are up to 6 follow-ups for each patient depending on the date of diagnosis. This covers up to 12 years of follow-up on the status of patients who volunteered to participate.

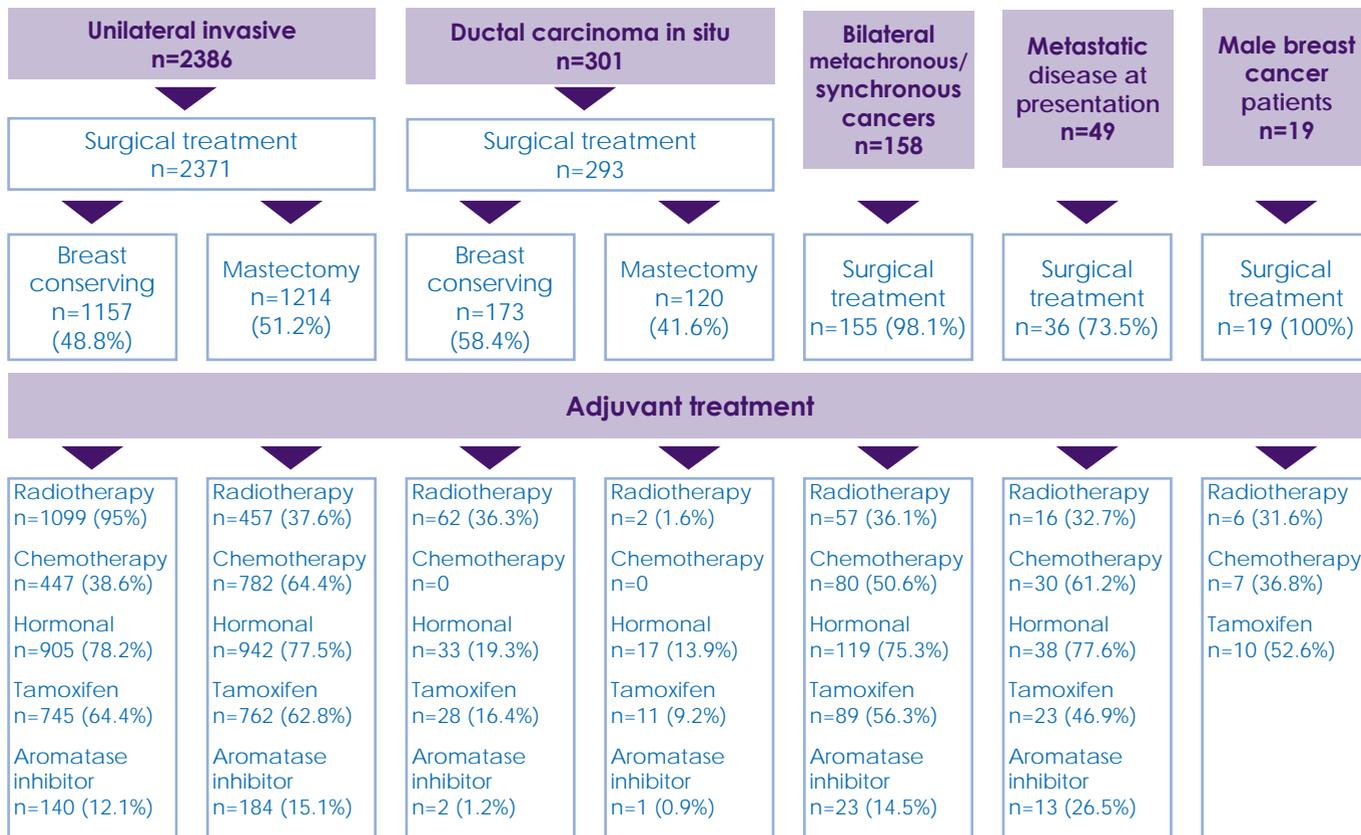
Cumulative Breast Cancer Patients Accrual (n=3870)



Number of newly diagnosed breast cancer cases in the ACT & SE NSW From 1 July 1997 to 30 June 2009



Overview of breast cancer treatment in ACT and SE NSW July 1997–June 2007



From the GP's Desk

This month will be 25 years since a member of my family was diagnosed with breast cancer. It was a younger sister who, at the age of 29 was found to have a 4cm tumour with nodal spread. This was indeed a devastating diagnosis for one so young with a prognosis that was felt to be quite guarded. The options for treatment at that time were quite limited with the conventional treatment being a radical mastectomy with adjuvant radiotherapy. But 1984 was a year of change in the treatment of breast cancer. Her breast surgeon had been impressed by some pioneering Italian studies that showed possible benefits from adjuvant chemotherapy in breast cancer. He and oncologists from the Ludwig Institute for Cancer Research had decided to undertake a clinical trial of their own looking at adjuvant chemotherapy rather than radiotherapy for tumours requiring a full mastectomy.

After much soul searching and discussion with the oncologists, and against the advice of many in the medical profession, my sister courageously agreed to be part of the chemotherapy trial and was in fact one of the first breast cancer patients treated on the trial. These initial chemotherapy protocols were different to what is now currently used. We all held our breath for the next 5 years wondering if every little ailment represented a recurrence of the cancer. But after 5 years, with no sign of disease, her oncologist gave her the all clear to start a family. In the following years, she had 2 beautiful daughters and went on to achieve much as a comedian and writer with successful radio and television shows to her credit.

continued on page 5

Collaboration with the Breast Tissue Bank Project

The Breast Cancer Treatment Group has recently collaborated with the Westmead Millennium Institute to establish a Breast Cancer Tissue Bank (BCTB) collection centre in the ACT. Breast Cancer Tissue Bank originally began in 2004 in response to widespread recognition that the availability of high quality biospecimens and data was vital to the future progress in breast cancer research. Competitive grant funding was awarded from the NHMRC, the Cancer Institute NSW and the National Breast Cancer Foundation. This project has received approval by the ACT Health and Calvary Healthcare Human Research Ethics Committees. Canberra joins the six other collection sites in NSW in this project, with the first ACT patient being recruited in September 2009.

ACT Pathology and Capital Pathology have worked closely together to streamline the

collection and processing of blood specimens from donors as well as the retrieval of breast cancer tissue specimens for the Breast Cancer Tissue Bank collection centre based at The Canberra Hospital. Breast cancer patients are being prospectively recruited through the rooms of Drs Carolyn Cho, Peter Barry, John Buckingham and Ian Davis as well as through the medical and radiation oncology outpatient clinics and rooms. It is also planned to recruit patients who have had their breast surgery in the Greater Southern Area Health Service. Drs Vlad Milovic and Robert Drielsma are also enrolling patients who are undergoing cosmetic breast reduction surgery in order to provide a control group of normal individuals without cancer.

Over 2000 individuals have now been enrolled as donors to the Breast Cancer Tissue Bank in NSW and ACT and new donors are being recruited at a rate of approximately 100 per month

across the collection centres. The BCTB project provides a valuable resource for basic science and translational researchers to investigate breast cancer causality and biomarkers that may predict the clinical behaviour of the cancer as well as response to therapies. Since the availability of materials was advertised in 2008, over 1500 biospecimens have been approved for provision to researchers. Data obtained from donors are maintained under strict confidentiality as with the Treatment Group project with the aims of both projects being complementary in improving breast cancer outcomes. www.abctb.org.au

A/Prof Desmond Yip
Principal Investigator,
Breast Cancer Tissue Bank,
ACT Collection Centre
Staff Specialist in Medical
Oncology,
Canberra Hospital

From the GP's Desk continued

As I regularly complete follow-up forms for the Breast Cancer Treatment Group Quality Assurance Project, I reflect on what has been achieved in the treatment of breast cancer over the last 25 years with 5 year survival rates now so much improved. I also reflect on the courage of the women, like my sister, who participated in the trials of these new adjuvant therapies that are now used in current treatment.

The follow-up data from GPs like myself will continue to be important in defining the outcomes from our treatment of breast cancer here in the ACT and south east New South Wales, particularly as our chemotherapy protocols and drug options are further refined.

Cameron Webber
General Practitioner, Manuka, ACT

Sexuality and breast cancer

Doreen Akkerman AM, Director Cancer Information & Support Service (CISS)

Dr Amanda Hordern, PhD, Deputy Director (CISS)

As health professionals, we care for many women who have been diagnosed with breast cancer who have to face major changes to their wellbeing and self esteem. Side effects of chemotherapy have caused them to lose their hair, they may be retaining fluid and may lie awake at night worrying about their relationship. In an ideal world, their treating team would be the place they can feel confident to ask for assistance with both the psychological as well as the physical treatment they require. However, research has shown that health professionals are reluctant to discuss sexuality, even with a young woman.

When a woman is first diagnosed, survival is the top priority, but what we have to work to ensure is that at the time she is discussing treatment with her doctor, that discussion should include information about the impact that the treatment will have on her sexuality and fertility.

A young woman who is living the breast cancer experience has different needs to an older woman. She may still want to bear children, raise children or achieve success in her career. She also may not have met her life partner or they may be still working out the depth of their relationship and intimacy will be very important.

Surgery, even a lumpectomy or partial mastectomy affects a woman's self esteem and she will often lose confidence in herself. Whilst she is receiving

treatment, which may include chemotherapy, hormone therapy and/or radiotherapy, she is confronted with the loss of hair, the retention of fluid, mood changes, a loss of libido, a dry vagina, all of which will have a detrimental impact.

We have facilitated many workshops on Sexuality and Cancer and find that participants are eager to include sexuality discussions in their consultations, but fear colleague's opinion of them. We have learned that it is essential for the senior members of the multi-disciplinary team to support the inclusion of such psychosocial support as part of the overall treatment plan.

There are solutions to many of the problems encountered as part of the treatment for breast cancer and a reading list is available from the Victorian Cancer Information & Support Service. Often, all that is needed is guidance. It is very rare that in depth sexual counselling is required.

The Cancer Council Victoria has developed an excellent resource booklet, 'Sexuality and Cancer' for patients and their partners and 'Sexuality and Cancer' workshops for health professionals and patients.

We may be contacted at

Doreen.Akkerman@cancervic.org.au or

Amanda.Hordern@cancervic.org.au

Doreen Akkerman is the Director of the Cancer Information and Support Service at The Cancer Council Victoria, the Helen Macpherson Smith Trust Fellow, and founding President and present Board Member of the International Cancer Information Service Group. Doreen was our special guest at the July meeting.



Congratulations to Dr John Buckingham

Senior Australian of the Year 2010 National finalist (ACT)

The national finalist in the Senior Australian of the Year 2010, John Buckingham has been formally recognised for his groundbreaking work with the sentinel node mapping technique which enables diagnosis of lymph node involvement with breast cancer diagnosis, and for his involvement in establishing Breast Screen ACT. The Breast Cancer Treatment Group is very fortunate to count John among its members and congratulate him heartily for this most deserved award.

What is a Specialist Breast Care Nurse?

'The Specialist Breast Nurse is a registered nurse who applies advanced knowledge of the health needs, preferences and circumstances of women (and men) with breast cancer to optimise the individual's health and well-being at various phases across the continuum of care, including diagnosis, treatment, rehabilitation, follow-up and palliative care'. (NBOCC, 2005).

The ACT Specialist Breast Care Nursing Service has recently been complemented by the appointment of a McGrath Foundation/ACT Health funded breast care nurse to care for patients in the advanced/metastatic breast cancer setting. This new position was implemented in June at the Canberra Hospital under the Capital Region Cancer Service and is jointly funded by the McGrath Foundation (2 days) and ACT Health (2 days). Kerryln Ernst, the successful applicant is on maternity leave, and Sue Perryman is currently acting in the position. Advanced breast cancer patients can be referred to the **McGrath Breast Care Nurse** via the following contact details:

Phone: (02) 6244 3896

Mobile: 0466 169 954

Fax: (02) 6244 2887

Susan.Perryman@act.gov.au (Tuesday to Friday)

The services offered by the **ACT Specialist Breast Care Nursing Service** in the early breast cancer setting (following the diagnosis of early breast cancer and during adjuvant treatment for early breast cancer) remain unchanged. i.e. 3 full-time ACT Health funded breast care nurses who are based at Calvary Health Care ACT, Bruce, and cover all public and private hospitals in the ACT and Queanbeyan.

The ACT Specialist Breast Care Nurses are available to patients at the following key points:

- Before going into hospital;
- During hospital admission(s);
- Following the first appointment with the surgeon post hospital discharge; and
- Following the first appointment with a medical and/or radiation oncologist.



Newly diagnosed breast cancer patients can be referred to the ACT Specialist Breast Care Nurses via the following contact details:

(02) 6201 6672 or

(02) 6201 6943 or

(02) 6201 6944

Fax: (02) 6201 6084

BreastCareNurses@calvary-act.com.au

The service has recently established a **Breast Care Nurse Follow-Up Clinic**. This clinic is by appointment only and is held at Calvary Health Care ACT. The follow-up clinic is located adjacent to the Zita Mary Clinic and is available to patients undergoing adjuvant treatment and/or as required. The aim of the clinic is to provide support and information at key points during the breast cancer journey, and attend to referrals as appropriate, for example, physiotherapy or counselling.

Appointments are encouraged and driven by the patients' requirements. The clinic sessions are approximately 1hr in duration, available on Mondays and Tuesdays only, and appointments can be arranged by phoning (02) 6201 6102. There is no charge for this service.

ACT Specialist Breast Care Nursing Service
Bethel Holley, Morag McNair & Jen Dalton
based at Calvary Health Care ACT

PO Box 254

Jamison ACT 2614

(02) 6201 6944 or

(02) 6201 6672 or

(02) 6201 6943

Email: BreastCareNurses@calvary-act.com.au

EVENTS OF 2009

Guest speakers

Medico-legal implications of multidisciplinary meetings
Professor David Hardman (March 2009 meeting)

Breast imaging and the use of MRI. Can it make a difference? (Do I really need it?)

Dr Georges Hazan, a Sydney radiologist.
(May 2009 meeting)

Sexuality issues after breast cancer treatment Doreen Akkerman, Director of the Cancer Information and Support Service at The Cancer Council Victoria (July 2009 meeting)

Presentation

Breast cancer treatment and outcome in the ACT and surrounding regions. Zhang Y, Craft P, Buckingham J, Dahlstrom J, Cho C and in conjunction with the Breast Cancer Treatment Group. The Australasian Health & Research Data Managers' Association 18th Annual Scientific Meeting, March 2009, Perth, Australia

Poster

Ten years of a breast cancer database in the ACT and SE NSW. Cho C, Craft, P, Price J, Rezo A, Zhang Y, Stuart-Harris R for the ACT & S E NSW Breast Cancer Treatment Group. The Australasian Society for Breast Disease 7th Scientific Meeting. October 2009, Gold Coast, Australia.

Journal Articles

Synchronous multiple ipsilateral breast cancers: implications for patient management. Jain S, Rezo A, Shadbolt B and Dahlstrom J. Pathology: Journal of the Royal College of Pathologists of Australasia, January 2009, 41:57–67.

Variation in treatment outcomes and care provided for operable breast cancer in rural and metropolitan centers. Craft P, Roder D, Buckingham J, Zhang Y, Beckmann K, Dahlstrom J, Jacob G, Stuart Harris R, Tait N in conjunction with ACT and SE NSW Breast Cancer Treatment Group, American Society of Clinical Oncology Annual Meeting Proceedings (Supplement), 2009: e11517.

Reports

Variation in treatment for early breast cancer affects outcomes: Implications for the organisation of rural cancer services. Report written by Breast Cancer Treatment Group members, July 2009.

Thank you to Bosom Buddies for their generous and continued support of the Breast Cancer Treatment Group Quality Assurance Project.

Thank you to Roche and Novartis for sponsoring the Breast Cancer Treatment Group meetings and speakers this year, and to Lyn North and staff at University House, Australian National University, Canberra, for providing the facility/resource for our meetings for many years.

CONTACT DETAILS

Any clinical questions should be directed to Dr Paul Craft, Associate Professor, Canberra Hospital, (02) 6244 2220 or contact Yanping Zhang, Project Co-ordinator, (02) 6205 0967
Email: yanping.zhang@act.gov.au or the Project Officer (02) 6205 1542 Email: Fax (02) 6205 2109

Breast Cancer Treatment Quality Assurance Project
ACT Health, GPO Box 825, Canberra ACT 2601
www.health.act.gov.au – Research/Breast Cancer



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