The Breast Cancer Treatment Group is now in its 15th year. The ongoing support of the participating breast cancer specialists and general practitioners is as important now as ever given that breast cancer outcomes are best measured in decades. At the time of writing this report there are 4530 notified cases of breast cancer in our region since 1997. The amount of work required to obtain consent from those diagnosed and then to collect baseline and follow-up information to maintain the Quality Assurance Project Database is considerable. The contribution of general practitioners is particularly appreciated as follow-up continues into periods when those treated for breast cancer are discharged from specialist follow-up and at a time when GPs are asked to complete follow-up forms for specialists no longer able to participate.

Throughout this period, Yanping Zhang has been the Data Manager. On behalf of everyone that participates in the BCTG, I would like to congratulate Yanping on her amazing contribution over a period of nearly 15 years and thank her for her diligence, her dedication to the project (and therefore to those diagnosed with breast cancer) and her integrity.

I would also like to commend Robyn Manda Bradley, Project Officer, on her enormous contribution.

The data collection, cleaning and pathology audits would not have been completed without the generous contribution from the John James Foundation.

Their donation to the BCTG meant that Margaret Bentley could be employed as a casual medical officer to undertake these tasks in collaboration with the Project team.

The Breast Tissue Bank Officer, Elaine Bean, has also provided valuable support in maintaining up-to-date and accurate data – this collaboration will hopefully continue to strengthen into the future.

This year we have had some very interesting presentations from interstate and local speakers. I would like to thank A/Professor Peter Graham, Professor Kathy Tucker, A/Professor Paul Craft and Dr Nicole Gorddard for their presentations – all of which were excellent and thought-provoking.

I would like to conclude on a sad but inspirational note and honor Dr John Buckingham who passed away earlier this year. I enjoyed John’s presence at our numerous multi-disciplinary meetings and was inspired by his commitment to his patients and his vast knowledge about breast cancer. I have shared many tears with women that I have seen this year who were cared for by John. Part of his enormous legacy is this Breast Cancer Treatment Group. His energy will, no doubt, continue to be present as the project goes from strength to strength.

BCTG meetings for 2012 will be held in the Drawing Room, University House, ANU 6.10pm on Monday 20 February and 6pm 14 May, 20 August and 12 November.

Angela Rezo
Chair, ACT & SE NSW Breast Cancer Treatment Group
Data Management Sub-Committee Report

This year the Data Management Subcommittee lost one of its most valuable members with the tragic death of Dr John Buckingham. John had been an enthusiastic member of the committee since its inception in 1997. His wise counsel was missed during the year. A number of research projects that John initiated, including a large study of the influence of surgical margins on outcome, will be continued to completion by other committee members and co-investigators.

The last 12 months have seen continued activity of the Group’s ongoing community based audit of cancer treatment. Accrual to the project remains steady with around 300 new subjects enrolling each year. A consequence of this is the exponential rise in the number of breast cancer survivors included in the follow-up phase of the project. Maintaining the data quality in these circumstances is a massive challenge to our project staff, and they continue to do a great job. As the audit data has matured a number of research projects have been completed. In the past year three papers have been published in the international journal The Breast, as detailed under Publications in this newsletter. More importantly, there are four approved projects well underway, in terms of project data being extracted and any further information being acquired by the researchers. These include a study of progress and prognosis after breast cancer recurrence, studies of Ki-67 expression and of the Rad 21 gene expression using archival tissue blocks, and the margin study initiated by Dr Buckingham.

In addition to our two effective and highly productive staff members, I would like to thank the Subcommittee members for their support, advice and patience during the year. We look forward to a similarly productive 2012.

Paul Craft
Chair, Data Management Sub-Committee

John James Memorial Foundation Donation

The Breast Cancer Treatment Group would like to express their sincere gratitude for the generous donation from the John James Memorial Foundation. This cheque was presented to the Chair of the BCTG, Dr Angela Rezo, the Chair of the BCTG Data Management Subcommittee, Dr Paul Craft, and the BCTG Quality Assurance Project Manager, Yanping Zhang, by the CEO of the John James Memorial Foundation, Mr Phil Greenwood at the most recent meeting of the BCTG at the ANU.
The latest from 14 years of data collection

To date, nearly 4,600 new breast cancer cases have been notified to the Project, with 93% of patients agreeing to include their information in the Project database. While these numbers have grown steadily in the past, they have dropped slightly in the year 2010–11, reflecting the importance of getting all clinicians and breast care nurses involved (Graph 1).

The number of selected women with invasive breast cancer undergoing radiotherapy, chemotherapy and hormonal therapy has remained fairly constant over the years, (Graph 2). While hormonal therapy was undertaken by 70% of patients and chemotherapy was undertaken by 30% of patients in 1997–98, the difference in these proportions have become narrower over the years.

There have also been interesting trends for selected types of hormonal therapy: while the proportion of tamoxifen cases have fallen markedly since the early 2000s, aromatase-inhibitors have been on the rise until recently (Graph 3).

After 14 years of follow up, our results show some promising outcomes, with 76.5% of patients being alive and disease free to date (Table 1). Of the 403 deaths, 60% were due to breast cancer.

### Table 1: 10-year dataset of patient outcomes with 14 years of follow up

<table>
<thead>
<tr>
<th>Current status</th>
<th>Number of patients</th>
<th>Percent of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alive, disease free</td>
<td>1,530</td>
<td>76.5%</td>
</tr>
<tr>
<td>Alive with disease</td>
<td>67</td>
<td>3.4%</td>
</tr>
<tr>
<td>Deceased due to breast cancer</td>
<td>242</td>
<td>12.0%</td>
</tr>
<tr>
<td>Deceased due to other causes</td>
<td>161</td>
<td>8.1%</td>
</tr>
<tr>
<td>Total</td>
<td>2,000</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Note: Including only female patients with invasive breast cancer, with surgeries performed between financial years 1997–98 and 2006–07. The data exclude 371 cases lost to follow up.
What is a quality assurance project, and how does it differ from clinical trials?

Before I started my current job as a co-ordinator and data manager for the Breast Cancer Treatment Quality Assurance Project, I worked on randomised clinical trials at the Medical Research Council in Cambridge and at the National Health and Medical Research Council in Sydney. Throughout my experiences, it has been interesting to compare and contrast these two approaches as they apply to health research.

Quality assurance projects are an essential part of healthcare service and delivery. The role of quality assurance projects is to evaluate and monitor current services and practices within the healthcare system with the aim of improving health outcomes. Quality assurance projects, such as the Breast Cancer Treatment Group’s Quality Assurance Project, are conducted to answer questions such as:

- **How well do local practices conform to national, best-practice guidelines?**
- **How well do current outcomes measure against standards nationally and elsewhere?**
- **What solutions can be implemented to improve healthcare quality?**

Quality assurance projects share a number of similarities with clinical trials. Both involve a team of investigators, protocol development and design, data collection instruments and a data management system. Both also rely on patient participation through informed consent, as well as an ethical approval and review process.

Clinical trials are a set of procedures in medical research that monitor the effectiveness, safety and efficacy of treatment interventions, for example, new drugs, medical devices, or treatment protocols. They are often used to compare two or more treatment interventions, generally done through randomised controlled trials (RCT). By randomly assigning patients to different treatment groups, RCTs allow investigators to eliminate any bias associated with each group and study the treatment intervention in isolation. The data collected by clinical trials allow healthcare providers, industry and regulators to make evidence-based decisions about the implementation of the treatment intervention under study.

Yanping Zhang  
Coordinator/Data Manager,  
BCTG Quality Assurance Project
Breast Cancer Risk Assessment Models used in the ACT Genetics Service

There are two consistent questions a clinician working in cancer genetics must ask for every patient during the workup of a personal and/or family history of breast and/or ovarian cancer:

“What are her chances of carrying a mutation in a high risk gene such as BRCA 1 or BRCA 2? and “What are her risks of developing breast and/or ovarian cancer with or without such a mutation?”

In the last 2 years, staff at the ACT Genetics Service have used breast cancer risk assessment models as part of the standard workup for a person with an individual and/or family history of breast and/or ovarian cancer. Prior to this time, assessment was based on the National Breast and Ovarian Cancer Centre (NBOCC) Tricolour chart, where personal and/or family history and numbers of affected people placed an individual into a low, moderate or high breast cancer risk category.

People who were in the high risk category and affected with breast and/or ovarian cancer were eligible for genetic testing of the BRCA 1 and BRCA 2 genes. There was bias towards being able to offer genetic testing to large families, regardless of the number of unaffected family members.

Our knowledge of the importance of other risk factors, such as tumour pathology, has improved. This has meant the NBOCC guidelines have been superseded in the cancer genetics clinic. As genetic testing of the BRCA 1 and BRCA 2 genes is not a medicare rebatable item, cancer genetics clinics around Australia use genetic testing eligibility criteria to triage families who are most likely to harbour a mutation, conscious of a limited testing budget. Each service employs a model they feel meets the needs of their service, often dependent on resources available for data entry. Most Services aim to offer genetic testing to families who have at least a 10% chance of a mutation being detected.

There are several new and improved risk assessment models available. Each have their advantages and disadvantages. Which one is incorporated into clinic depends on the focus of the model in delivering the assessment required to answer the questions posed above.

The models currently being used and audited within the ACT Genetics Service are the following;

1) Manchester scoring system for BRCA 1 and BRCA2 testing (pathology adjusted version)
2) Cuzick – Tyrer model
3) BOADICEA model – Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm.

1) Manchester Score

The Manchester Model is a quick and effective guide for predicting the chance of finding a mutation in a person affected with breast and/or ovarian cancer. It was developed in 2003 as a simple scoring system to facilitate accurate selection of families for BRCA 1 and BRCA 2 testing. The 2009 version incorporates pathology information. A score is assigned to individual features such as age of diagnosis, gender and type of cancer with adjustments to the score based on the pathology of the tumour i.e. a triple negative breast tumour has a greater score attached to it than an ER/PR/HER2 positive tumour. The model can be used within the clinic consultation to give feedback to the patient in “real time”. A score of 16 and above (equates to a 10% cutoff) is required for eligibility for genetic testing of the BRCA 1 and BRCA 2 genes.

2) Cuzick – Tyrer Model

The Cuzick-Tyrer Model is a computer generated breast cancer risk assessment model for women unaffected by cancer but with an assumption that their family may harbour a mutation. The model is based partly on a dataset acquired from the International Breast Intervention Study and other epidemiological data. The model requires data entry pertaining to family cancer history, personal information, hormone/reproductive factors and personal breast disease. Breast density is not included. It is not used to predict the likelihood of a BRCA 1 or BRCA 2 mutation.

...continued on next page...
3) Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm (BOADICEA) Model

BOADICEA is a computer generated risk assessment model specifically developed to assist the cancer genetic clinician in predicting breast and ovarian cancer risk for a patient, whether affected with cancer or not. It is also predicts the likelihood of finding a BRCA 1 or BRCA 2 mutation in a family. It was developed by a group in Cambridge UK, who have derived a susceptibility model based on segregation analysis. The model has a bias towards UK data presently and has not incorporated tumour pathology features, however a version is being developed which will use Australian data and incorporate tumour pathology.

It takes the most time of the three models to fulfil the data entry requirements. An advantage of this model is its ability to breakdown the risk of breast cancer and ovarian cancer into different age ranges i.e. risk in the next 12 months, next 5 years, next 10 years and over a lifetime until age 80. It also considers the effect of the size of the pedigree, taking into account affected people and unaffected people and their age and gender.

In the future, new risk prediction models are likely to result from examination of a range of high risk genes as well as single nucleotide polymorphisms in several genes associated with lower risks to provide a more accurate individual prediction. This will assist clinicians in being able to give an individual advice regarding risk reducing medication and lifestyle choices to prevent disease.


Linda Warwick
Senior Genetic Counsellor/Team Leader, ACT Genetics Service

Table 1. Comparison of Risk Assessment Models used at the ACT Genetics Service

<table>
<thead>
<tr>
<th>Model</th>
<th>Manchester</th>
<th>Cuzick-Tyrer</th>
<th>BOADICEA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast/ovarian cancer risk assessment</td>
<td>No</td>
<td>Yes (unaffected only)</td>
<td>Yes</td>
</tr>
<tr>
<td>Assessment of likelihood of a BRCA 1 or BRCA 2 mutation</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Incorporates some breast pathology features</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Incorporates some hormonal/reproductive factors</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Personal information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>age</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>BMI</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>ETOH intake</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Family history</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Computer generated data</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
New “state of the art” assessment tool for lymphoedema available at Calvary

Thanks to a donation from The Lidia Perin Foundation, Calvary Health Care ACT has purchased two Bioimpedance machines.

Bioimpedance is an evidence-based technology that offers the potential to prevent the development of secondary lymphoedema after breast cancer surgery by early detection of any increase in extracellular fluid in the tissues. It can detect changes before they are visible or measureable by other detection methods. It does this by indirectly measuring the amount of fluid in the tissues in the “at risk” arm compared to the other arm.

Recent research has demonstrated that very early detection can prevent this condition from becoming permanent if appropriate management is instituted as early as possible. At Calvary, the Breast Care Nurses use the smaller of the two units to get a baseline reading on women attending the public pre-admission clinic. Women who have undergone axillary dissection and attend Calvary for their follow-up in the physiotherapy department will have their bioimpedance measured as part of their routine assessment process. This will be measured at their ongoing visits throughout the year following their surgery. Any significant change from the baseline will indicate the need for prompt initiation of treatment strategies such as compression and instruction in self massage and exercise.

It is anticipated that women who are developing lymphoedema will be diagnosed earlier with the new technology so with early treatment their lymphoedema may be prevented from becoming a chronic condition.

Bioimpedance measurement has already been found to detect significant reductions in extracellular fluid after self management strategies have been undertaken. This information then provides extra encouragement for patients to continue with these strategies.

The lymphoedema physiotherapists at Calvary believe that the Bioimpedance technology will add to the effectiveness of the service provided to women who have been treated for breast cancer in the ACT and surrounding region.

Gemma Arnold
Senior Lymphoedema Physiotherapist,
Calvary Health Care Bruce

Lymphoedema physiotherapists and Calvary Breast Care Nurses with the new Bioimpedance technology.
Adjuvant Radiotherapy: The long and short of it

In an article Variation in the management of early breast cancer in rural and metropolitan centres: Implications for the organisation of rural cancer services1 A/Prof Paul Craft and his fellow authors found that outcomes for women in rural areas were inferior to those of women in metropolitan areas (ACT and SE NSW data). It is difficult to pinpoint the reasons as to why this discrepancy exists. One of the differences found in the study, was that women were less likely to have breast radiotherapy after breast conservation surgery. The number of women who did not receive radiotherapy increased with increasing age for example, 2.7% of women between the ages of 60-69, 10.1% of women between the age of 70-79 and 45% of women over the age of 80 did not receive breast radiotherapy. Leaving home for radiotherapy for periods of up to 7 weeks is very difficult for many women in rural areas. Radiotherapy to the breast can be given with equal efficacy and side effects using shorter schedules. There have been numerous studies and now clinical practice guidelines that support shortened treatment schedules so that treatment can be completed within 3-4 weeks rather than 7 (2,3). Women who can safely be given these shorter courses of radiotherapy are those who:

- are older than 50 years
- have tumours less than 5cm in size
- have cancer that has not spread to the lymph nodes
- have not undergone adjuvant chemotherapy

Other women not included in this list may have a discussion with the radiation oncologist about the merits of a shorter course of treatment taking into account their individual circumstances. Hopefully all women living in rural regions, who have had breast conservation surgery, will consider a consultation with a radiation oncologist regarding the benefits and scheduling of a course of radiotherapy. Steps like these may help to improve outcomes for these women.


From the GP’s Desk

I have now worked as a rural GP in this area for 11 years. Breast cancer is a very significant disease burden for my community. I feel like I see a patient with it every day in some capacity. It is so common and can be devastating.

Breasts are such an important part of the female ideal. They can be a defining aspect to female sexuality and nurturing. We are mammals, mammals have mammary glands. Modern media seems obsessed with superficial beauty, and the idealised female form.

Breast cancer is so common that it affects almost every extended family in some way. Accurate long term follow-up is essential. We must continue to learn about how this disease behaves, which treatments work, what effects survival rates, and whether treatments have unexpected adverse effects. Knowledge is power.

We all hope that we are on the verge of new highly effective treatments. However, even now we are doing well. Surgical advances allowing breast preservation, accurate sentinel node identification, and breast reconstruction, have made an enormous contribution. Adjuvant chemotherapy and radiotherapy are now established mainstream treatment. Accurate tumour typing, and receptor status helps guide our specialist colleagues. We have become better at understanding the psychosocial and psychosexual aspects of a diagnosis.

GPs remain close partners at all stages of the disease. We advocate screening and then deal with the unexpected result. We are the first port of call for the anxious revelation of a lump. We help our patients through the challenging maze of treatment. We coordinate ongoing care. And sometimes, fortunately more rarely now, we are at the bedside for the final stage.

I am always very happy to spend a few moments filling out the BCTG patient follow up forms. These purple forms can save lives and help reduce suffering. To my GP colleagues, keep up the good work, answer the simple questions and send the forms back. Thank you.

Dr James Langley, Surf Beach Surgery

Angela Rezo, Radiation Oncologist
Followup forms

The Quality Assurance Project office welcomes follow-ups at any time. If you would like your list checked please contact the Project officer (02) 6205 1542 who will be pleased to provide copies of missed follow-ups. If you have loose purple forms on your desk, the postal address is:

Confidential:
Cancer Treatment Quality Assurance Project
Screening and Support
ACT Health
Reply Paid 825
CANBERRA ACT 2601

Thank you for your most valued support!

The Breast Cancer Tissue Bank

The Breast Cancer Tissue Bank Project has now entered the second year of operation in Canberra. Royal Prince Alfred Hospital, Westmead Hospital, Royal North Shore Hospital, St Vincent’s Hospital, John Hunter Hospital, Port Macquarie Hospital and Liverpool Hospital are the other centres in NSW involved with this collaboration coordinated by the Westmead Millennium Institute. The project is supported by grants from the NHMRC, the National Breast Cancer Foundation and the Cancer Institute NSW. As of the October 2011, 339 participants have been recruited through the Canberra collection centre from patients in the ACT and SE NSW region. Matched clinical data collected from patients also participating in the Breast Cancer Treatment Group Project have been uploaded to the Tissue Bank database. The Breast Cancer Tissue Bank had about 4580 enrolled patients with 74746 available biological samples from across all the collection centres as of the same date. The demand for specimens for translational research projects has been high and proposals undergo a vigorous peer review and merit assessment process before access is granted to researchers.

www.abctb.org.au

A/Prof Desmond Yip,
Principal Investigator, Breast Cancer Tissue Bank,
ACT Collection Centre

Thank you

Jen Dalton and Annie O’Neill are the ACT Specialist Breast Care Nurses based at Calvary Hospital.
Monday to Friday 9am-5pm
(02) 6201 6672

Thank you to all the Specialist Breast Care Nurses, including Jenny Garner at Bega and Bronnie Taylor at Cooma for their continued support of the Breast Cancer Treatment Group Quality Assurance Project.

Thank you to Bosom Buddies for their generous and continued support of the Breast Cancer Treatment Group Quality Assurance Project which this year enabled data on DCIS to be reviewed.

Thank you to AstraZeneca 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.
March

**Associate Professor Peter Graham** presented an excellent talk entitled “The Timing of adjuvant aromatase inhibitors and radiotherapy”. This was a summary and update of the TROG 08.06 trial STARS (Study of Anastrozole and Radiotherapy Sequencing). At the beginning of the presentation he commented that his slides wouldn’t “answer all the questions” but it certainly gave us a head start in understanding the complexity of hormones and radiotherapy interactions. The primary question hoped to be answered by the STARS trial is whether commencing anastrozole prior to and then concurrently with radiotherapy improves local control rates as compared to commencing anastrozole after radiotherapy. Most oncologists in Australia generally hold off commencing aromatase inhibitors in patients until after they complete treatment because of the uncertainty of how the two may interact.

Prof Graham described some interesting preclinical data that suggests that aromatase inhibitors may actually improve outcomes when given prior to and with radiotherapy. The STARS trial is therefore a very important trial that may significantly change clinical management. Fortunately it appears to be enrolling well and we look forward to the results of this trial answering an important question.

*Lisa Sullivan, Radiation Oncologist, TCH*

May

Linda Warwick with special guest speaker **Dr Kathy Tucker** from the Hereditary Cancer Clinic, Prince of Wales Hospital, Sydney at the May meeting. Dr Tucker spoke about genetic testing prior to commencing adjuvant treatments in high risk women.

September

**Paul Craft** presented Breast Cancer Treatment Outcomes in ACT and SE NSW. The data that was discussed in the BCTG member’s article in ‘The Breast’ entitled Variation in the management of early breast cancer in rural and metropolitan centres: Implications for the organisation of rural cancer services was presented. This very relevant article can be located in the publications list on the BCTG webpage of ACT Health.

November

**Nicole Gorddard**, medical oncologist, presented a very comprehensive review of Breast Cancer Follow-up and Shared Care Models.

Publications


Poster

**Female Breast Cancer in the ACT: A review of new research**, Claire Behm and members BCTG.
In memory of John Buckingham

It is with deep sadness that we advise of the passing of Associate Professor John Michael Buckingham on 29 March, 2011 in Canberra at the age of 63. Much has already been written and said about John's contributions to surgery, teaching and research in our region and beyond. We would like to acknowledge his contributions to the ACT and SENSW Breast Cancer Treatment Group Quality Assurance Project. John was one of the founding members of the Breast Cancer Treatment Group in 1997, and a valued member of its research subcommittee. He was passionate about the project and spent much personal time assisting with data collection form queries to ensure “clean” and useful data. He was the main driving force behind many of the research projects the group undertook. This work has generated a number of publications that have contributed to further knowledge in breast cancer management. I recall on more than one occasion John ringing me at 7.30 am in the morning to discuss a potential research project. His enthusiasm never waned even when it was clear he would not be alive to see them all to completion. He will be missed.

Written by Prof Jane Dahlstrom, Senior Staff Specialist, Anatomical Pathology, ACT Pathology and Professor of Anatomical Pathology, Australian National University Medical School.

The BCTG newsletters, reports, publications and information of interest can be found at: www.health.act.gov.au/Research go to Breast Cancer Research
Contact Details

Any clinical questions should be directed to Dr Paul Craft at the Canberra Hospital on (02) 6244 2220.

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Website

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