



# Breast Cancer Update

Issue 57 January 2007

- BRCA Trial
- PBS Changes for Early Breast Cancer
- ESMO Meeting Report
- Resources for Younger Women with Breast Cancer
- Cancer in Victoria, 2004



# BREAST CANCER UPDATE

Issue 57

January 2007

## CONTENTS

Editorial .....	3
The BRCA Trial .....	4
Longer survival with daily single agent oral chemotherapy than with a standard combination chemotherapy for silent majority with advanced breast cancer .....	4
PBS Changes for Early Breast Cancer .....	5
Report of the 31st Annual Congress of the European Society for Medical Oncology (ESMO) .....	7
Report of the San Antonio Breast Cancer Symposium .....	10
National Breast Cancer Centre (NBCC) Report .....	13
Pathology Reporting of Breast Cancer (2001) .....	13
So, I have breast cancer, what now? .....	14
Resources for Young Women Under 45 .....	15
Advanced Breast Cancer: The Role of Information .....	19
Letter to Fran .....	20
Cancer in Victoria 2004 .....	22
VCOG 30th Anniversary .....	24
Supporting Oncology Professional Collaboration in Cancer Control, 1976–2006 .....	25
Web Resource Provides Missing Link to Genetic Cancer Information .....	27
Cancer Australia Ready to Tackle National Priorities .....	27
Key Published Articles Listing—Breast Cancer .....	28
Forthcoming Meetings .....	28

This newsletter is produced by The Cancer Council Victoria's Breast Cancer Committee and sent to health professionals interested in management of breast cancer(s). The Victorian Cooperative Oncology Group's advisory committees on gastrointestinal, gynaecological, lung, skin and urological cancers also produce twice yearly cancer updates.

If you would like to have your name removed from the distribution list, or if you are interested in receiving any of the other updates please contact Mrs Noellyn Ngo, Ph: (03) 9635 5265.

\* \* \* \* \* **Last Issue – No. 56 – July 2006** \* \* \* \* \*

***The articles in the Breast Cancer Update have been published to contribute to professional debate and exchange. The opinions expressed are not necessarily those of The Cancer Council Victoria.***

## Editorial

*Dr Jacquie Chirgwin  
Medical Oncologist  
Box Hill / Maroondah Hospitals*

**B**est wishes for 2007 to all readers. I hope you will all find this “bumper” issue as full of useful information and interesting articles as I have done. Susan Fitzpatrick and her team have again done a marvelous job at identifying articles to include in the update.

This issue has again included a number of very interesting articles from consumers, including a very thought provoking “Letter to Fran” which describes with great clarity the myriad of thoughts and issues invoked by the diagnosis of an incurable, ultimately fatal illness. A special thank you to Sue Lockwood for allowing us to reprint such a personal piece. There is also a major theme of information provision for patients, including for males with breast cancer, for young women and for those diagnosed with advanced disease. The article relating to young women provides a wealth of resources to support these patients, which I am sure will be very useful for many of us.

The article on the PBS changes for breast cancer medications on the one hand is extremely encouraging, reflecting the many advances that have been made in treatment, but on the other, highlighting the “over-controlling” hand of the PBAC, who seem to think they know better than practicing oncologists how best to treat patients. They should stick to considering cost-benefit issues, rather than attempting to exert “micro-control” on the way medications are used, especially when this goes outside the evidence

base, AND has minimal (or indeed, no) bearing on the cost.

We again have reports from international meetings, including the San Antonio Breast Cancer Symposium. As this meeting is in December each year and ASCO in early June (and these meetings provide the most important new data for Breast Cancer each year), we have decided to change the publication date of the Breast Cancer Update. The December issue will now be published in January, and the June issue in July. I have also changed the colour of our update to the universal breast cancer colour – PINK!!

There is plenty else to read including about VCOG’s history and achievements. There are also a number of other useful reports, articles and lists, which appear as regular features. We are to add to this regular feature (starting in our next issue), a list of Breast Cancer Clinical Trials which are open for recruitment in Victoria. The sites that each trial is open at will be listed, together with contact details, so patients can be referred, as appropriate.

I would also like to remind all readers that we are very keen to receive any contributions, even in the form of short comments about issues of interest, for publication in the newsletter.

Thank you very much to all of you who have contributed to this interesting edition.

*Due to circumstances beyond our control, the inclusion of the SABC report has been deferred.*

### Contributions Welcome

The Breast Cancer Update welcomes contributions – conference reports, review of an area of interest, reviews of recent journal articles, clinical trial updates.

	<b>Deadline</b>	<b>Issue Date</b>
Mid-year issue	1 June	July
Year-end issue	1 December	January

Contributions should be forwarded to:

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## The BRCA Trial

*Dr Gillian Mitchell  
Medical Oncologist  
Peter MacCallum Cancer Centre*

**W**omen who carry mutations in BRCA1 & 2 genes have an increased lifetime risk of up to 85% of developing breast cancer. Tumours in BRCA1 & 2 mutation carriers do not have functional BRCA1 or 2 proteins, however their normal tissues retain normal proteins. Recent laboratory data have suggested that tumours lacking these proteins are especially sensitive to chemotherapeutic agents containing platinum salts that induce DNA interstrand cross-links. These agents, including carboplatin, are not commonly used in metastatic, sporadic breast cancers.

As most patients with high-grade breast cancers have received adjuvant anthracycline-containing chemotherapy regimes, palliative taxoid based chemotherapy has become the standard of care at the time of metastatic relapse. If the pre-clinical work on DNA interstrand cross-linking agents is confirmed in a clinical setting, an increase in therapeutic ratio for platinum based palliative chemotherapy compared to standard taxoid based therapy would be demonstrated in BRCA1 & 2 associated breast cancer.

The purpose of this randomised, phase 2 trial is to assess whether there is clinical evidence that

carboplatin alone is an active and safe therapy in women with metastatic breast cancer who are also BRCA1 or 2 mutation carriers. This will be compared to standard treatment with docetaxel in terms of toxicity, response and time to progression. The trial aims to recruit 148 patients (74 BRCA1 and 74 BRCA2) worldwide.

Trial Coordinators:

- Assoc Prof Geoff Lindeman / Dr Clare Scott, Royal Melbourne Hospital, Ph: (03) 9342 7151, E-mail: [familycancer@mh.org.au](mailto:familycancer@mh.org.au) or
- Dr Gillian Mitchell, Peter MacCallum Cancer Centre, Ph: (03) 9656 1199, E-mail: [FamilialCancer@petermac.org](mailto:FamilialCancer@petermac.org).

As women with both a BRCA mutation and measurable, metastatic disease are rare, we are seeking your assistance in accruing patients to this and other related studies in the future. We ask that you consider referring patients for these studies to the RMH or Peter Mac with the clear understanding that at the end of the study the patient will be returned to your care. It may also be feasible to jointly manage patients on study, so as to not disrupt their ongoing care from their primary oncologist during the study period.

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## Longer survival with daily single agent oral chemotherapy than with a standard combination chemotherapy for silent majority with advanced breast cancer

*ANZBCTG Media Release 15 December 2006*

**R**esearchers from Australia and New Zealand have demonstrated a rare advance in extending survival for women with advanced breast cancer, according to Associate Professor Martin Stockler, Principal Investigator for the ANZ 0001 trial.

“We were delighted by the results, especially because they were obtained using a convenient oral treatment instead of conventional intravenous chemotherapy,” Assoc Prof Stockler said. “We now look forward to planning new treatment approaches building on this success.”

Dr Nicholas Wilcken of Westmead Hospital said, "These results are particularly pleasing because the trial was rigorously conducted in accordance with the highest scientific standards – a randomised controlled trial – giving us great confidence that the results are reliable."

The ANZ 0001 trial, which was conducted by the Australian New Zealand Breast Cancer Trials Group (ANZ BCTG), included 323 women recruited at 34 centres in Australia and New Zealand. Its final results were reported on 17 December 2006 at the San Antonio Breast Cancer Symposium, the world's premier breast cancer conference.

Participating women were randomly allocated to one of three treatments:

- 107 to capecitabine tablets given for 14 of every 21 days (intermittent capecitabine)
- 107 to capecitabine tablets given for 21 of every 21 days (continuous capecitabine)
- 109 to classical CMF (a standard combination including injections of methotrexate and fluorouracil twice a month, and tablets of cyclophosphamide for 14 days each month)

The aim of the trial was to see if women treated with capecitabine would do and feel better than those treated with CMF. The underlying idea was that capecitabine would be at least as good as CMF at controlling the cancer, but would maintain control for longer because it is better tolerated and can be continued for longer.

The trial focused on women who were starting chemotherapy for advanced breast cancer, but

who were unsuited to intensive chemotherapy. These women are rarely included in cancer trials, even though they represent the majority of those affected by breast cancer. Capecitabine and other single agents are widely used in this situation, without strong evidence of their effectiveness from well-conducted clinical trials.

Capecitabine is an oral chemotherapy drug often used for colorectal cancer and further down the line for advanced breast cancer. It is closely related to 5-fluorouracil, an intravenous chemotherapy drug used in a wide range of cancers, and is the 'F' in CMF.

In the ANZ 0001 trial, overall survival was significantly longer with capecitabine than CMF. The typical survival time was 22 months on capecitabine versus 18 months on CMF. Results were similar for the two different ways of giving capecitabine. Similar proportions of women had tumour shrinkage or stabilisation on capecitabine and CMF (60%). Control of the cancer over the first six months was similar on capecitabine and CMF, but capecitabine was more likely to control the cancer beyond six months. Chemotherapy was continued for longer than six months in 40% of women on capecitabine but only 21% of women on CMF. Side effects were less severe and more tolerable with capecitabine than with CMF chemotherapy.

The coordinator of the ANZ BCTG Consumer Advisory Panel, Professor Linda Reaby, welcomed the results, saying "This is a win-win for women with advanced breast cancer – better survival and less side effects."

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## PBS Changes for Early Breast Cancer

*Dr Sue Chua  
Medical Oncologist  
Maroondah Hospital*

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**T**his year there have been several new and extended listings of drugs on the PBS for the treatment of early breast cancer. This list includes trastuzumab, docetaxel, paclitaxel, exemestane and letrozole.

After much publicity and strong campaigning from breast cancer support groups, trastuzumab

was finally approved for use in women with HER-2 positive early breast cancer on 1 October 2006 at a reported cost of approximately \$470 million over 4 years. Over 2100 women per year in Australia are expected to benefit from this change. Patients with resected early breast cancer are required to be HER-2 positive on ISH

testing, to have a LVEF greater than 45% and to have trastuzumab concurrently with chemotherapy. The government has also, for a short period, allowed patients who were having maintenance trastuzumab at 1 October 2006 to apply for funding to complete a year of treatment.

Apart from generating plenty of paperwork, the use of adjuvant trastuzumab has raised a few issues. Its use is limited to concurrent therapy with only a taxane-based regime and currently, there is no strong evidence that this is superior to sequential therapy. In fact, adjuvant trials have reported a higher incidence of cardiotoxicity when trastuzumab is given concurrently with chemotherapy than sequentially. The results from the NCCTG N9831 which directly compares concurrent (arm B) with sequential trastuzumab (arm C) will hopefully be able to answer this question when the data is mature in 2007. Difficulties in treatment decisions also arise when we have patients who are of intermediate risk and only require anthracycline therapy, and also those who are low risk such as those with small, hormone receptor-positive, node negative tumours and would not require chemotherapy. This latter group were excluded from the 4 large adjuvant trials but logic would support that they would receive some benefit. With the current government restrictions should we then administer a taxane with trastuzumab in these groups and let them suffer the side effects of unnecessary chemotherapy to obtain a years treatment? Ideally, the use of adjuvant trastuzumab should be individualised and based on the patient's cardiac function, age and risk of relapse – whether it should be given concurrently or sequentially, with or without chemotherapy and with which type of chemotherapy. It would also be beneficial to be able to use trastuzumab in the neoadjuvant setting as recent phase II trials have demonstrated significantly improved response rates over chemotherapy alone. Hopefully, future trials will help direct the use of this drug in the most effective and safest method.

Minor changes were also made from 1 October 2006 for paclitaxel and docetaxel to extend their use in early breast cancer patients who are eligible for trastuzumab. In addition docetaxel and paclitaxel were both approved for the adjuvant treatment of node-positive patients receiving an anthracycline and cyclophosphamide, with the former to be given in

combination and the later to be given sequentially. Tumours are now no longer required to be hormone receptor negative.

Recently, the PBS restriction for two aromatase inhibitors, exemestane and letrozole, were extended on 1 December 2006 to include the adjuvant treatment of hormone-dependant breast cancer in postmenopausal women. These drugs were previously listed for use only in the metastatic setting and this new listing will now bring them into line with anastrozole, which has been available for early breast cancer since December 2005. Based on the results of the IES trial, the use of exemestane has been approved for use after at least 2 years of tamoxifen to complete a total duration of 5 years of endocrine therapy. Similarly, letrozole can be used sequentially after 2–3 years of tamoxifen but can also be used as initial therapy. Despite, the significant results from the MA.17 trial, the subsidised use of adjuvant letrozole is limited to 5 years. Also, it seems illogical why they have only allowed 2 repeats for these 2 drugs rather than 5 repeats as with anastrozole as their toxicity profiles are so similar. (From 1 February 2007, 5 repeats will be allowed for letrozole.)

Early next year there may be extended use of neulasta for the treatment of early breast cancer and lets also hope that they find a better way to re-order trastuzumab for metastatic breast cancer.

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## Pathology Reporting of Breast Cancer (2001)

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A multi-disciplinary Working Party has been established under the Chair of Professor Michael Bilous, to revise the 2<sup>nd</sup> edition and produce a 3<sup>rd</sup> edition of these recommendations. The document will be produced under the auspices of ACN with the National Breast Cancer Centre (NBCC). It is hoped to have this edition published in June 2007.

*Reprinted from Wongi Yabber Nov 2006; 13(4): 3.*

# Report of the 31<sup>st</sup> Annual Congress of the European Society for Medical Oncology (ESMO)

29 September – 3 October 2006, Istanbul, Turkey

*Dr Jacquie Chirgwin  
Medical Oncologist  
Box Hill / Maroondah Hospitals*

I particularly enjoyed ESMO – Istanbul is a fabulous place to visit, I was blessed with very good company and I didn't feel I had to attend every session! I found the sessions I did attend to be very good, including some new data and many interesting discussions.

There were three presentations of new results of note:

## 1. TANDEM Study

This was a randomised study comparing Arimidex alone to the combination of Arimidex and Herceptin as first line treatment of metastatic breast cancer. All patients were offered Herceptin at progression if randomised to Arimidex alone arm. Patients must have measurable HR and HER2 positive disease. Primary endpoint was progression free survival (PFS). Secondary endpoints were clinical benefit rate (CBR), ORR, TTP, response duration and safety / toxicity.

Results were as follows:

	Arimidex alone	Arimidex + Herceptin	P value
PFS	2.4 months	4.8 months	0.0016
PFS (central confirmation HR)	3.8 months	5.6 months	
RR	6.8%	20.3%	0.018
CBR	27.9%	42.7%	
OS	23.9%	28.5%	0.325
Cardiac events	2%	13%	

Although the combination of Herceptin with Arimidex was significantly better than Arimidex alone, the benefit from Arimidex in this population of patients is well below a general HR positive population. The RR to Arimidex in the first line Arimidex vs Tamoxifen study was 21%. It is also interesting to note that the RR to Herceptin

monotherapy was 23% in metastatic disease with 29% of the population being HR positive. However, over 15% of the patients on the combination in this study did not progress for more than 2 years. So, the combination treatment is certainly superior, but concern is raised that this may represent suboptimal treatment for this patient population. It provides support for the investigation of the combination for adjuvant trials. There was an increase in cardiac toxicity and also fatigue.

## 2. CHAT Study

This was essentially a negative study. Patients were HER2 positive in first line metastatic setting. All received Herceptin and either q3/52 Taxotere (100mg/m<sup>2</sup>) or q3/52 Taxotere (75mg/m<sup>2</sup>) with Xeloda 950mg/m<sup>2</sup> bd D1-14. Overall RR was 73% and 71% respectively. Median duration of response was 9.9 and 9.8 months. The only statistically significant difference in results in the two arms (p=0.045) was TTP, being 18.2 months for TH arm and 13.8 months for THX arm. Grade 3 and 4 Neutropenia was 77% in the TH arm and 54% THX arm. There was no difference in overall survival.

## 3. BIG 1-98

Alan Coates presented 51-month data on the monotherapy arms of the BIG 1-98 study. This analysis has been undertaken to allow comparison with other AI adjuvant trials and to remove the bias created by the inclusion of data from the censored switch arms that will increase with longer follow up. 4922 patients were included in this analysis. There were 352 DFS events in 2463 patients on Letrozole, and 418 events in 2459 patients on Tamoxifen. This gives a hazard ratio of 0.82 (0.71–0.95, p=0.007). Overall survival and distant DFS were not

statistically significantly different in the two groups. The following table shows more detailed results:

	Letrozole	Tamoxifen
DFS event	14.3%	17%
Local recurrence	0.8%	1.6%
Contralateral breast cancer	0.6%	1.1%
Regional recurrence	0.5%	0.5%
Distant recurrence	7.4%	8.6%
2nd non breast malignancy	2.6%	3.3%
Death without prior BC event	2.4%	2.0%
Death	7.9%	8.6%
Systemic failure	13.4%	15.2%

A comparison between the BIG 1-98 results and those of ATAC are shown to be very similar:

	BIG 1-98	ATAC
DFS	0.82	0.83
OS	0.91	0.97
2nd primary BC	0.43	0.47
DDFS	0.87	0.84

Adverse event differences were as previously reported. Tamoxifen treated patients had more thromboembolic events, endometrial pathology, hot flushes, night sweats and vaginal bleeding. Letrozole patients had more bone fractures, arthralgias, low-grade hyper-cholesterolemia and cardio-vascular events (except ischaemia and cardiac failure). There is a 10–20% increase (of <1%) in CVS events on Letrozole, and a 40–45% decrease in thromboembolic events. A meta-analysis of the adjuvant AI trials has shown overall a HR for CVS adverse events of 1.12. For switch strategy this 1.07 and for upfront AI it is 1.42. However it must be remembered that the incidence of CVS adverse events is very low.

### Targeted treatments

#### Denosumab

Denosumab is a monoclonal antibody that binds Rankligand

resulting in inhibition of osteoclasts. It has a half-life of approximately a month and is given by subcutaneous injection. It appears that it is more effective in decreasing urinary NIX (an indicator of bone turnover), and in delaying first skeletal related event than Zometa. It is also effective in lowering an elevated urinary NTX in patients already on bisphosphonate (76% pts. on Denosumab had uNTX <50 at week 13 compared to 38% of pts. who continued on bisphosphonate). Denosumab also lowers serum calcium. Ongoing trials are looking at differing schedules, prevention of bone loss and adjuvant treatment.

#### Lapatinib

David Cameron from Edinburgh presented the results of the Xeloda +/- Lapatinib study. There were 324 pts entered (of a planned 528), all of whom had been previously treated with Anthracycline, Taxane and Herceptin, had not previously received Xeloda, had measurable disease and a normal LVEF. They all received Xeloda either alone at 2500mg/m<sup>2</sup> D1-14 q3/52, or with Lapatinib (1250mg daily continuously) at a dose of 2000mg/m<sup>2</sup> D1-14 q 3/52. The primary endpoint was TTP, and secondary endpoints were OS, PFS, RR, CB rate, safety and toxicity. Disease status was reassessed every 6 weeks. 50% of the patients were HR positive, 75% had visceral metastases and the arms were well balanced. The trial was terminated after 114 events due to highly significant benefit seen in the Lapatinib arm. Results were as follows:

12% discontinued due to SAE. There was one fatal AE in Xeloda monotherapy arm. There was a slight increase in low-grade diarrhoea and rash in the XL arm.

	Xeloda + Lapatinib	Xeloda alone	HR
TTP	36.7 weeks	19.1 weeks	0.49 (p=0.00004)
RR	21%	14%	
OS	No difference		
CNS mets progression	4	11	
LVEF drop >20%	4 (all asymptomatic)	5 (1 symptomatic)	

Maureen Trudeau from Toronto presented results with Lapatanib in patients with refractory or relapsed Inflammatory Breast Cancer. Twenty-six patients were treated and the RR was 50%. Predictors of response were *cerbB2* 3+, *perbB2* expression, IGF-IR co-expression and activated *perbB3*. PTEN status did not affect response.

Edith Perez from Jacksonville, Florida presented data on Lapatanib cardio-toxicity. She presented data on 3558 patients treated with Lapatanib, for various tumour types and healthy volunteers. 600 had received prior Anthracycline, 759 prior Trastuzumab and over 2000 had not had prior Anthracycline or Trastuzumab. Over 1,000 patients received more than 6 months and over 350 received more than 12 months of Lapatanib. A decrease in LVEF was seen in 58 patients only (1.6%) and in only 0.2% was this symptomatic. LVEF reduction was seen in 1.2% of patients with prior A, 1.7% with prior T and in 1.7% patients with no prior A or T. Average time to onset of reduced LVEF was 13.7 weeks and average duration of lowered LVEF was 5 weeks. In all cases this drop recovered including in those patients where Lapatanib was continued. She concluded that cardiac complications were of very low incidence and it may be possible to combine Lapatanib with Doxorubicin.

### Herceptin

Preoperative Herceptin: A poster reported results from 24 patients treated with 12 cycles weekly Taxol followed by FE(75)C x4. Herceptin was given concurrently, weekly with all chemo. There were 18 pathological CRs (75%); 63% of ER+ patients and 85% of ER- patients. 25% of patients had a drop of LVEF to below normal but all recovered on cessation of Herceptin. However, other studies do show that with Anthracycline and Taxane chemo preoperatively in HER2+ patients there is a high pCR rate, around 50%.

Cardiac Function Assessment on Herceptin: A poster reported a series of 52 ABC patients treated with herceptin. 37 patients developed cardio-toxicity (29% with a fall of LVEF below 50% or greater than 10% below baseline) and 8% developed symptomatic cardiac failure. In 78% of patients there was discordance between the MUGA and Echo results. The best method and schedule of assessment remains unknown.

Martine Piccart reported that in the US Herceptin adjuvant trials 19% of patients did not complete

1 year of Herceptin predominantly due to cardiac toxicity. 4.3% of HERA patients did not complete. It is estimated that for women under 60yrs 6–7% of patients will not be able to receive Herceptin if they receive Anthracyclines and 5–20% will not be able to complete one year of treatment if they receive anthracyclines. 1.3 to 4% of patients cannot receive Herceptin even without having received an anthracycline. It is important not to deny patients Herceptin with Anthracycline use, and those that do not have *topo II* amplification may be able to avoid anthracyclines. Lapatanib may also provide a solution for some of these patients if its promising early results do translate into adjuvant benefits.

### Aromatase Inhibitors

The updated results of the BIG 1-98 monotherapy arms are recorded above. There are no surprises there. Per Lonning presented the updated results from the IES study (Exemestane vs continued Tamoxifen, after 2–3 years of adjuvant Tamoxifen). These results are for 56 months median follow-up. The DFS absolute benefit remains stable at 3.5%. There is a reduction in distant, local, new primary breast cancer and intercurrent deaths in the Exemestane arm and there are no differences in benefit across all subgroups analysed. When ER negative patients are excluded, (2.5% of study population), an Overall Survival benefit is seen, with HR 0.83,  $p=0.05$ . There were reductions of 25% in recurrence related deaths, 44% in contralateral BC and 18% distant recurrence. Arthralgia was seen in 13% Exemestane patients compared to 8% of Tamoxifen patients. Osteoporosis was seen in 9.2% of Exemestane and 7.2% of Tamoxifen treated patients. Cardiovascular events were similar in both arms, but other primary cancers were reduced in the exemestane arm in particular endometrial and GI.

David Cameron presented a persuasive discussion on why upfront adjuvant AI's may well not be appropriate for all patients. The difference in DFS in the first 2 and a half years in the ATAC study favouring Anastrozole is predominantly accounted for by contralateral and to a lesser extent loco-regional recurrence reductions. There was a difference of only 10 patients in distant recurrence at this time point. (The

difference at 5 years is much greater, being 42 patients). Serious life threatening toxicities were similar in the first two and a half years but after taking AI's for longer, there was a small increased risk of ischaemic cardiovascular events (4.3 vs 3.4%). Longer duration of AI also increases the degree of bone loss. The switch studies have shown an OS advantage for patients switched to an AI after 2–3 years of Tamoxifen, of greater size than the proportion of patients lost to distant relapse by the use of Tamoxifen in the first two and a half years. There continues to be no OS advantage for patients on AI for the full 5 years. So he concluded that a survival advantage of sequential treatment may be being denied patients if they are treated with upfront AI. Furthermore by the end of the 5 years they have accumulated more toxicity issues (CVS and bone) than they would have done if treated with a sequential approach. Ideally, identification of the few patients who would be lost to the possibility of cure in the first 2–3 years is needed, and of course the results of the BIG 1-98 study will guide us further on determining the best strategy. However, until then, it may be that many of our patients will be best served by the switch strategy.

Jim Ingle's summary of hazard ratios for the adjuvant AI trials are worth noting also:

Trial	DFS	OS
ATAC	0.83	0.97
BIG 1-98	0.81	0.86
IES	0.76	0.83
ABCSG 8 / ARNO 95	0.60	
ITA	0.35	0.53
MA 17	0.58	0.61

### Tamoxifen and Venlafaxine

Jim Ingle presented on this. Further understanding of Tamoxifen metabolism has led to the discovery of the metabolite Endoxifen which is of major importance in the efficacy of Tamoxifen. CYP2D6 metabolises Tamoxifen to Endoxifen and data shows that 2-year relapse rates are affected by whether a patient is a high or low CYP2D6 metaboliser. (DFS 98% in high metabolisers and 68% in poor metabolisers. Metaboliser status is genetically determined (10–15% of the population are poor metabolisers), but is also affected by other drugs, including Venlafaxine (Efexor). The use of Venlafaxine in patients on Tamoxifen, may therefore influence the adjuvant benefit of Tamoxifen. Yet another blow to helping our patients with their menopause symptoms!

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## National Breast Cancer Centre (NBCC) Report

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### Website launched for men with breast cancer

Each year in Australia about 100 men are diagnosed with breast cancer. A diagnosis of breast cancer can be devastating for anyone, but men often face additional shock, embarrassment and isolation upon learning they have a disease they didn't even know men could get.

The National Breast Cancer Centre (NBCC) has acknowledged the need for specific information for men and in response has developed Australia's first comprehensive website for men diagnosed with breast cancer or men concerned about a breast change.

The website was developed under the guidance of a multidisciplinary working group and a number of male breast cancer survivors were involved in a review of the website and its promotion across the country. Many shared their stories with local media, which also helped to increase awareness that breast cancer is a disease that affects men too.

The website can be viewed at [www.nbcc.org.au/men](http://www.nbcc.org.au/men). A pdf resource containing the website information is also available to download and print from the site. For further information about the project, contact Ornella Care on 02 9036 3049 or e-mail [ornella.care@nbcc.org.au](mailto:ornella.care@nbcc.org.au).

## GP Education Series

NBCC is developing a *General Practitioner Education Series* to support general practitioners in the care of women with breast and ovarian cancer and in the investigation of women who present with symptoms that may be due to breast or ovarian cancer.

The first in a series of topic-specific modules is now available. The module is based on NBCC's recently revised resource *The investigation of a new breast symptom: A guide for general practitioners*. This resource was recently distributed to GPs through the Divisions of General Practice along with the revised *Advice about Familial Aspects of Breast Cancer and Epithelial Ovarian Cancer*.

Modules are designed to be implemented through Divisions of General Practice. Divisions will be provided with a facilitator's kit containing all the resources required to host their own workshops for local members.

Two additional modules will be developed over the next 12 months about breast cancer in younger women and the assessment of symptoms that may be ovarian cancer.

To order a module, contact Janice O'Brien on 02 9036 3350 or e-mail [janice.obrien@nbcc.org.au](mailto:janice.obrien@nbcc.org.au).

*Reprinted from Wongi Yabber Nov 2006; 13(4): 5.*

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## Web Resource Provides Missing Link to Genetic Cancer Information

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**M**ore than 4000 Australians diagnosed each year with a familial based cancer can now access a new online resource thanks to a collaboration between The Cancer Council Australia and the National Cancer Genetics Education Group.

The web-based family cancers facility includes information on types of family cancers, genetic testing, family cancer clinics and a searchable directory of resources.

The Cancer Council's Chief Executive Officer, Professor Ian Olver, said that in around five per cent of the 88,000 cancers diagnosed each year in Australia, an inherited faulty gene is a major contributing factor.

"Family cancer can be a difficult concept to understand and there is a lot of confusing and contradictory information around," Professor Olver said. "While the Internet has provided greater access to information, it is not always the right information.

"Our new web resource provides a centralised resource of credible, evidence-based information – making it more user-friendly and reliable for the public."

Spokesperson for the National Cancer Genetics Education Group and project manager with NSW Health's Centre for Genetics Education, Kate Dunlop, said the online resource would benefit not just consumers, but support health professionals such as GPs and others working with cancer patients.

"A busy GP rarely has the time to search through volumes of web based information to provide their patients with relevant and useful support," she said. "Now they can go to one site to get what they need and can feel secure in the knowledge they are directing their patients to evidence-based information."

The new family cancers section on The Cancer Council Australia's website can be viewed at [www.cancer.org.au/familycancers](http://www.cancer.org.au/familycancers).

*Reprinted from Wongi Yabber Nov 2006; 13(4): 4, The Cancer Council Australia Report.*

## Cancer Australia Ready to Tackle National Priorities

**A**ppointment of a Chief Executive Officer to Cancer Australia has paved the way for the organisation to become operational and address a growing list of national cancer priorities, according to The Cancer Council Australia.

The Cancer Council Australia's Chief Executive Officer, Professor Ian Olver, welcomed the appointment in August of Professor David Currow as CEO of the new agency and said he would be taking on a challenging role with big expectations from the health sector.

"The establishment of Cancer Australia is a significant development and Professor Currow's

expertise and experience will help the organisation quickly come to grips with national priorities and issues in cancer control," Professor Olver said.

"There is a real need in Australia for a central agency to coordinate and facilitate the considerable but fragmented research efforts into cancer at the national level. We also need more resourcing to develop and implement national guidelines and to accredit and credential cancer professionals and treatment centres."

*Reprinted from Wongi Yabber Nov 2006; 13(4): 4, The Cancer Council Australia Report.*

## So, I have breast cancer, what now?

**S**o, I have breast cancer, what now? is a new DVD tailored to meet the needs of women diagnosed with breast cancer. It has been developed to provide essential, yet accessible information to women and their partners and families. It offers valuable information about treatment options, the impact of breast cancer on relationships, and the availability of support services. Issues specific to young women and women in rural areas are also explored.

Interviews with specialists from all fields involved in the care and treatment of breast cancer patients, from a wide range of institutions, as well as interviews with women living with cancer, their partners and children, bring to the DVD the combined wisdom of their experiences. This DVD is a product of Monash University – Women's Health Program in conjunction with their *Health and Wellbeing After Breast Cancer Study*.

Topics covered in this double DVD (2'90 minutes) include:

- When you're diagnosed with breast cancer
- Lumpectomy or mastectomy: Surgical options

- Pathology: Understanding the different kinds of breast cancer
- Breast reconstruction: What are my options?
- The ins and outs of chemotherapy
- The experience of radiotherapy
- Hormone therapy: Why do I need it?
- Participating in a cancer trial
- What about lymphoedema?
- Managing menopause
- Genetic issues: Unravelling the mystery
- Surviving as a couple: The impact of breast cancer on my relationship
- What should I tell the children?
- Special issues of young women
- Living in a rural area
- Support for children: Kids' journeys
- Lifestyle issues and complementary therapies
- After treatment, then what?
- Moving forward: Long-term emotional issues

The DVD is now available, at a cost of \$9.95, from the Women's Health Program, Monash University on 03 9903 0827 or at <http://womenshealth.med.monash.edu.au>.

## RESOURCES FOR YOUNG WOMEN UNDER 45

### Victorian Clinical Services

**Choice Clinic, Royal Women's Hospital** offers advice, consultation and treatment for all contraceptive and sexual health needs – Ph: (03) 9344 2183.

**Fertility Clinics/Reproductive Services** offer counsellors, a fertility specialist and a specialist gynaecologist. All women are welcome to see a counsellor to discuss the impact of cancer treatment on their reproductive health.

- Royal Women's Hospital – Ph: (03) 9344 2057 / 9344 2372
- Sunshine Clinic – Ph: (03) 9356 9133
- Epping Clinic – Ph: (03) 9408 2236
- Ringwood Clinic – Ph: (03) 9871 4766
- Dandenong Clinic – Ph: (03) 9706 9995

**Jean Hailes Foundation** provides services on women's health and menopause, including alternative/ complementary therapies – Ph: (03) 9562 7771 / Website: [www.jeanhailes.org.au](http://www.jeanhailes.org.au).

#### Menopause Clinics

- Mercy Hospital for Women
- Royal Women's Hospital – Ph: (03) 9344 2183
- Monash Medical Centre – Ph: (03) 9594 2445

**Sexuality Counselling Clinic, Royal Women's Hospital** – Ph: (03) 9344 2717.

**Sexual Counselling Service, Austin Health** – Ph: (03) 9496 4732 / Fax: (03) 9496 4862.

### Books or Online Files

#### Western Breast Services Alliance Booklet: What to ask, when: Questions for younger women with breast cancer

The booklet covers issues and topics such as: feelings, body image, relationships, contraception, fertility, and menopause. It provides key questions to ask and consider when undergoing treatment.

The booklet is available electronically to health professionals on intranet sites of Royal Women's Hospital, Melbourne Hospital and Western Health. This booklet is also available in printed form from BreaCan.

#### Clinical Practice Guidelines for the Management and Support of Younger Women with Breast Cancer (2004) (Australian)

National Breast Cancer Centre 2004. This book is written for clinicians but can also be used by women. It is available as a book from the NBCC [www.nbcc.org.au/resources/resource.php?code=YWC](http://www.nbcc.org.au/resources/resource.php?code=YWC) or online from [www.nhmrc.gov.au/publications/files/cp101.pdf](http://www.nhmrc.gov.au/publications/files/cp101.pdf).

#### Dr Susan Love's Breast Book

Love, Susan M. 4<sup>th</sup> Edition. US: Da Capo Press. 2005.

#### Fighting for our future: How young women find strength, hope and courage with taking control of breast cancer

Murphy, Beth. Sydney: McGraw-Hill. 2003.

#### Sexuality and Cancer Booklet

This booklet covers the effect of cancer and cancer treatment on one's sexuality and relationship. Available free, from the Cancer Helpline 13 11 20.

#### Can I still have children? Fertility options for young women having chemotherapy and radiotherapy

Reproductive Services, Royal Women's Hospital: Women's Health Publications. 2004.

## Books or Online Files

### **No Less a Women: Femininity, sexuality and breast cancer**

Kahane, Deborah Hobler. Alameda, CA: Hunter House. 1995.

### **Sexuality and fertility after cancer**

Schover, Leslie R. Brisbane: John Wiley and Sons. 1997.

### **When a parent has cancer: A guide to caring for young children**

Harpham, Wendy Schlessel. New York: Harper Collins. 1997.

### **My mum has breast cancer, A family's journey**

Lisa Sowards and Harrison Sowards. 2006.

### **When a parent has breast cancer: How to talk to your kids**

A guide for parents with cancer, their families and friends. Cancer Council NSW. 2005.

## DVDs / CDs

### **Young Women Talking – New Information for Young Women with Breast Cancer**

*Young Women Talking* is a unique resource for young women affected by breast cancer. It includes a 20-minute DVD and supplementary booklet exploring the issues affecting young women with breast cancer as told by a group of young women, in their own words.

The women in the DVD address particular themes which reflect the unique issues that young women face such as early menopause and fertility, the impact on relationships, particularly young families and body image.

The resource has been funded by The Cancer Council Victoria and meets an important information need for young women under 45 years of age.

*Young Women Talking* also provides a brief guide for health professionals on how they may use the DVD as a resource with young women.

For further information about this resource, or to obtain a free copy please contact BreaCan on 1300 781 500.

### **So, I have breast cancer, what now? A guide for women and their families**

Produced by the Women's Health Program of Monash University.

## Information and Support Services

### **The Cancer Council Victoria**

The Cancer Council provides information and support through the Cancer Helpline, Multilingual Cancer Information Line, Look Good Feel Better Program, Cancer Support Groups and Cancer Connect (volunteers who have experienced breast cancer and have been trained to provide peer support offer telephone support to women who have been newly diagnosed). An accredited Breast Cancer Nurse answers calls and assists with enquiries. Phone the Cancer Helpline on 131120 (for all states of Australia). Website: [www.cancervic.org.au](http://www.cancervic.org.au).

### **BreaCan – Breast Cancer Support**

BreaCan is a unique service that provides breast cancer information and support for people with breast cancer, their families and friends. Trained volunteers, all of whom have experienced breast cancer, or had a close association with someone who has, assist people either face-to-face, by phone and/or email at BreaCan's city based resource centre.

Location: Queen Victoria Women's Centre, Ground floor, 210 Lonsdale Street. Opening times: 10am – 2pm every Monday, Wednesday and Thursday. Ph: 1300 781 500 (cost of a local call for country callers) / Website: [www.breacan.org.au](http://www.breacan.org.au).

## BCKOnline

Welcome to Breast Cancer Knowledge Online (BCKOnline) – your gateway to breast cancer information. This portal is the combined work of women with breast cancer and a team of Monash University researchers. It can be tailored to the needs of women under 40 or 40–49. There are over 1000 items for women under 40 and another 1000 items for women 40–49. Website: [www.bckonline.monash.edu.au](http://www.bckonline.monash.edu.au).

## Support Groups

### The Young Ones

The Young Ones is a social support group for Victorian women under 45 who have experienced breast cancer. Ph: 0411 235 964 / Website: [www.theyoungones.asn.au](http://www.theyoungones.asn.au).

### Gippsland Young Women's Telelink Cancer Support Group

An innovative telephone counselling support group for women under 45 years living with cancer in Gippsland. For more information or to register your interest contact Alma Ries, Community Health Nurse, Gippsland Women's Health Service. Free call 1800 805 448 (Mon – Thurs).

## Advocacy Groups

### Young Action on Breast Cancer (YABC)

YABC is committed to advocating the specific needs and issues which face younger women affected by breast cancer, providing a voice.

#### YABC Care Package

On Wednesday 18 October, YABC were delighted to have Terry Bracks launch a Care Package for women under the age of 40 receiving treatment for breast cancer at Western Health Hospital.

The package has been put together by young women, to help other young women with some of the basics, such as help with cleaning, child care, lawn mowing and of course some items to help pamper them. The breast care nurses at Western Hospital have enthusiastically supported the idea and will distribute the package to patients. The Care Package has been made possible through the generous donations from MOR, Jim's Services, Dial An Angel, Seddon Therapies, Arbre, Collins Booksellers as well as many local businesses. See some of the media articles from the launch on the website: [www.theyoungones.asn.au/articles\\_of\\_interest](http://www.theyoungones.asn.au/articles_of_interest).

#### YABC Young Women's Conference

Planning is underway for a two-day conference next October, titled *Up Close and Personal 2* following the successful forum in 2002. Day One will feature experts and young women's experiences that focus on fertility, menopause and sexuality; an evening celebration will follow. Day Two will feature a hypothetical session, providing young women an opportunity to hear about research and future developments, as well as a chance to participate in discussions around issues related to young women and help to set the agenda for action. Sponsorship will be provided to assist interstate and rural participation. To assist with our planning we encourage young women to write to us about the issues that are important to them and to tell us their stories. Further information will appear on the Young One's website by April next year.

Contacting YABC – Young women affected by breast cancer are invited to join YABC. E-mail: [ya-bc@hotmail.com](mailto:ya-bc@hotmail.com) / Ph: 0411 235 964 / [www.theyoungones.asn.au/young\\_action\\_on\\_breast\\_cancer](http://www.theyoungones.asn.au/young_action_on_breast_cancer).

## Websites

**Aussie Breast Cancer Forum** – An e-mail forum for sharing the experience of breast cancer and for their family, friends, carers and loved ones – [www.bcaus.org.au/forum/](http://www.bcaus.org.au/forum/).

**National Breast Cancer Centre (NBCC)** – Some information for young women can be found at [www.breasthealth.com.au/treatment/youngerwomen.html](http://www.breasthealth.com.au/treatment/youngerwomen.html).

## Websites

**Breast Cancer Network Australia (BCNA)** – The BCNA website has a section devoted to young women with breast cancer, with personal stories, information about support groups and services relevant for young women with breast cancer and their families – [www.bcna.org.au/cms/details.asp?NewsID=269](http://www.bcna.org.au/cms/details.asp?NewsID=269).

**New South Wales Breast Cancer Institute** – Has a few young women's stories – [www.bci.org.au](http://www.bci.org.au). They also have an e-mail support group for young women – [www.bci.org.au/young\\_bmail.htm](http://www.bci.org.au/young_bmail.htm).

**The American Cancer Society** – Because this is a general cancer site, it is necessary to search for young women and breast cancer. There is a lot of information available – [www.cancer.org](http://www.cancer.org).

**The Young Survival Coalition** – An international, non-profit network dedicated to the concerns and issues unique to young women and breast cancer. Through action, advocacy and awareness, the YSC seeks to educate the medical, research, breast cancer and legislative communities and to persuade them to address breast cancer in women 40 and under. The YSC also serves as a point of contact for young women living with breast cancer. Website: [www.youngsurvival.org](http://www.youngsurvival.org).

## Current clinical trials specifically for young women

There are three trials designed for young women with early breast cancer. They are all cooperative groups trials and available at various sites in Australia.

### IBCSG 24-02 SOFT (Suppression of Ovarian Function Trial)

This trial is suitable for pre-menopausal women with hormone receptor positive breast cancer when the woman's ovaries are continuing to produce oestrogen (i.e. remain pre-menopausal) after chemotherapy (if given). For the hormonal part of their breast cancer treatment women are randomised to:

- 5 years of tamoxifen alone (this is the standard arm)
- 5 years of ovarian function suppression + tamoxifen
- 5 years of ovarian function suppression + exemestane.

The ovarian function suppression can be achieved by monthly injections (reversible method of inducing menopause) or by permanent methods (eg. oophorectomy). Women can enter the trial up to 8 months after completion chemotherapy – i.e. they may have their periods stop for a while after chemotherapy and then restart and they can still be suitable for the trial.

### IBCSG 25-02 TEXT (Tamoxifen and Exemestane Trial)

This trial is suitable for pre-menopausal women with hormone receptor positive breast cancer when the doctor and woman think she should definitely receive ovarian function suppression as part of her treatment. Chemotherapy is optional according to patient and clinician preference. Randomisation for hormonal part of treatment to:

- 5 years of ovarian function suppression + tamoxifen
- 5 years of ovarian function suppression + exemestane

### IBCSG 34 POEMS (Prevention of Early Menopause Study)

This trial is suitable for pre-menopausal women with hormone receptor negative (ER and PR negative) breast cancer who will receive adjuvant chemotherapy and want to avoid premature menopause which is a common side effect of chemotherapy. Women are randomised to receive in conjunction with their chemotherapy: monthly injections of zoladex or no zoladex.

Dr Prue Francis from Peter MacCallum Cancer Centre chairs SOFT and TEXT within Australia and Professor Kelly Phillips also from Peter MacCallum Cancer Centre chairs POEMS if additional information is required. Further information on these trials can be found on the Cancer Council website – Cancer Trials ([www.cancervic.org.au/trials/](http://www.cancervic.org.au/trials/)) or on ANZ BCTG website in clinical trials section – [www.anzbctg.org/default.asp?file=clintrials.asp&TrialType=Main](http://www.anzbctg.org/default.asp?file=clintrials.asp&TrialType=Main).

## Advanced Breast Cancer: The Role of Information

*Ms Rosetta Manaszewicz  
Community Representative  
VCOG Breast Cancer Committee*

A theme which featured prominently in discussions has been that of information, or rather the lack of appropriate information. Words or phrases such as ‘power’, ‘control’, ‘empowerment’, ‘choice’, ‘decision making’, ‘comforting’, ‘less anxiety’, have all been used when describing the role of information in people’s lives. This is not to say that everyone wants or needs information all the time, or that they want or need identical information, but it does indicate how essential the ‘right’ type of information can be to the individual.

As with early breast cancer, metastatic disease is not uniform. Women are at different stages, different psychological and emotional phases. Some contemplate the future, or the lack thereof. Others are overcome by present treatments and cannot think beyond the present. Yet, the scant, available information tends to treat metastatic cancer as if everyone was at the same physical, and emotional junction. Speaking with these women reveals how far from the truth this is. Time and again comments were made about the unrealistic nature of much of what is currently available. The following quotes best illustrate this point:

“... one of the things I get frustrated at ..., even when you get the pamphlets or books, or those kits, that with advanced breast cancer you know that you’re going to die. But it doesn’t tell you what you’re going to die of, or how you’re going to die, or what effects it’s going to do on your body. None of that – so you can’t even prepare yourself. Unless you specifically ask your doctor you get no answers. It’s like the pamphlets are too frightened to tell you.”

“... I found a lot of information almost too optimistic. A lot of it was geared to people with early breast cancer ... I got a lot of information sent to me ... once again it was extremely positive. I don’t find it realistic.”

“... information is so important for me to move on. What’s hard for me is not having the information. I can face things if I have the information. Because this is what I know, this is what can happen, could happen, may happen, or may not happen. I have choices then.”

Knowing, understanding and ultimately accepting the individual prognosis was at once ‘liberating’ and endowed the individual with choices as to how to live and organise her life.

Yet, hope and how this could best be conveyed was also an essential element of the information which women felt they needed. Information could be realistic, yet not denying of hope. It could be ‘evidence-based’ without being ‘simplistic’ and uninformative. Whilst many of the women expressed the opinion that detailed scientific knowledge was beyond their understanding, and that they preferred the ‘lay version’ of events, this did not mean that there was no desire for basic ball park figures and an understanding of the rationale behind treatment recommendations. For example, one woman stated:

“But I found that what I needed was as much information ... if I know the medical facts, then I can say. I think one of the most useful things I read was an oncologist saying, ‘I can’t tell you exactly whether this will work because I’m not prescribing this cocktail for a statistic. I’m doing it for one person and according to that one person response.’ So that comes into it a huge amount. It is so important to the individual. And even the same drug. Different people will react in different ways. But I think, ... knowing the background, knowing what the parameters are, then I can come to my own conclusion.”

Such understanding is contrasted to the following situation:

“So recently he took me off Femara, just suddenly like that, and he said to me, ‘It’s not working.’ Now my tumour is oestrogen

positive, hormone positive as well as ... her2 positive, so I figure I still need some sort of a hormone and yet he says 'no, we'll just see how the Herceptin goes'. Now you're sort of left high and dry. You can't argue with him because I don't have sufficient grounds, or knowledge, to be able to say 'look I think you're wrong'. Not that I would say this, because he's obviously well versed in what he's doing, but it gets frustrating at times."

Women need information which clearly explains the rationale of all treatments. They need to know the general 'ball park' figures – what are the basic statistics and how might these relate to me? How many women have been tested? How does this drug differ to the last? Why are you recommending this? Simply relying on 'wishy-washy sentimentality', as one woman put it, was not hope inducing. If anything it was viewed as infantile at worst, and patronising, at best.

Finally, what comes through most strongly in all of these discussions, is the vital role that first hand 'experiential' information plays.

Talking with another woman in a similar situation is invaluable for the practical information provided, the emotional support, and the hope it engenders simply by knowing that someone else has been through this and you're not alone. Evidence-based medicine is fine as far as it goes. What it cannot do is address the individual situation. This is eloquently expressed by the following words: "It's only people who have been through it themselves that can really tell you what it's actually like".

Hope, trust, and understanding become the bedrock upon which many women plan their lives and their futures. Without appropriate information this inter-connectedness is shattered.

*Reprinted with permission from Breast Cancer Action Group Newsletter, Sep 2006, pages 9–10.*

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## Letter to Fran

*Ms Sue Lockwood  
Community Representative  
VCOG Breast Cancer Committee*

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**T**hanks for your card. I was really touched that you were concerned enough to write to me. I'm sorry I haven't answered you before now, but your card really challenged me to think about what I was trying to achieve by having treatment for my breast cancer. And everything seems to take a long time to do at the moment.

When I found the lump in my neck, the scans showed the breast cancer in the lymph nodes under my breast bone and in some of the breast bone itself (it's moth eaten!!!) and a small amount in one rib. It is not in any of the major organs. So it is not going to cause me any major problems for a while yet. The most recent scans have shown that the cancer has diminished a lot as a result of the chemotherapy and I will have some radiotherapy later on. Hopefully that will knock it all on the head for a while. I don't know how long the disease will disappear for, but I do know that at some stage it will appear again.

Then I'll have to deal with whatever happens then.

Now that my breast cancer has recurred, I know that at some stage, hopefully not too soon, it will cause my death. At the moment because I don't have any symptoms, apart from the problems caused by the chemo, it is hard to think about this. I know what is going to happen intellectually, but I can't really "feel" it emotionally as yet.

So when I got your letter telling me that I can "beat the bastard" and that research might find an answer I was really challenged to think about what was happening to me and how I should react to it. And I don't really know what to think.

I've seen many women die of their breast cancer. And each one has approached their sickness and death differently. But this has shown me that dying of breast cancer is not a disaster. Sure it is really sad, sure the loss for family and friends is very great and that the grief they feel is

overwhelming, and for the women with young children it is really very hard. But death is also part of life, part of living.

And life goes on. Luckily people adapt, learn to live without the person they love, after a time they often re-marry. They move on. Some sadness always remains with them, but there are other things they want to do with their lives. I guess that you, of all people understand this, probably much better than I do.

It has been a great honour to be with women as they become sicker and approach their death. I have learnt a great deal from these women and I am grateful that they have been prepared to share this time of their lives with me. One of the things I have learnt is that women are very much alive until the point when they actually die. They are interested in the world around them and what their family is doing, what their friends have been up to, they learn, and at the end, as they accept what is happening, they develop something which I call grace which enables them to deal with their family. I don't want to suggest that it is all beautiful and easy, it's not. But it can be handled in a way which gives meaning to death and comfort to those left behind.

So when you challenged me to "beat the bastard" I wondered what I was trying to beat. Was I trying to beat death, I can't do this. No-one can. Was I trying to beat it by living as long as possible: if this is what you meant, then I agree with you. I do want to live for as long as possible. But I don't want to live just for the sake of living. I want to live a reasonably active and fulfilling life. If it means that I want to live to die of something else other than breast cancer, then I'm not sure. I don't see dying of breast cancer as a disaster. It is just another form of death, not too bad, not too good. Just a death which comes to all of us.

And can cancer research help? Yes it can. I have drugs which I can use, which were not available a few years ago. And more drugs are on the way. But I also know the complexity of the way in which cancer develops is so great, that I'm not confident that research will ever solve the problem. I am convinced that it will not be in my lifetime even if I did live to 100 or more. Cancer is a very tricky disease which has exercised the minds of many very bright people for years now. The doctors talk, not of curing cancer, but of making it into a chronic disease like diabetes. I'm realistic enough to know that research has developed

treatment options which have enabled me to live for 14 years, plus a few more, with breast cancer. But there are not enough options out there at the moment for me to be confident of living with a chronic disease for many years.

I don't want this to sound as if I'm not grateful for the research effort of that I think that the research is a waste of time. The improvements I've seen make me believe that important changes are underway. But they are probably not enough to keep me alive indefinitely.

My challenge now, is to choose sensible treatments which will keep me alive for as long as possible, in a reasonably healthy and active way. I do not want the treatments to be so debilitating that I can't do the things I want to do, like walk and be with friends. I know that this will mean difficult choices, which will be distressing for everyone concerned. But I don't think I fear death. I certainly fear not being able to love a vivid and challenging life.

The really big issue is dealing with uncertainty. Because I don't know what is going to happen and when, the whole situation can be very debilitating. What I'm trying to do is set some short-term projects to do. The first was to be fit enough to run 4 kilometres in a fun run in May. I managed to do that, though I don't think I could do it now. The next is to be well enough to come to England and Sicily for Robert's wedding. Then when we get home, it will be to renovate our house. After that I'm not sure what the options might be. But I'll think of something.

However as I said at the beginning of this letter, I understand intellectually what is happening, but I'm not sure that I really understand it emotionally as yet. So all this may change over the next few months and years.

I'm looking forward to seeing you when I'm in England. I hope we'll be able to get together at some time. And thanks again for your best wishes. I keep telling women that there are no right and wrong decisions, just reasonable ones. I just hope this letter is a reasonable, considered, response to your challenging card.

*A letter sent by Sue Lockwood to a friend overseas following the diagnosis of advanced disease that Sue received earlier this year.*

*Reprinted with permission from Breast Cancer Action Group Newsletter, Sep 2006, pages 10-11.*

# Cancer in Victoria 2004

*Victorian Cancer Registry*

**T**he Victorian Cancer Registry has been a population-based registry since 1982. This was enabled by amendments to the Cancer Act in 1981, which made it mandatory for all hospitals and pathology laboratories to notify the cancer registry of the presence of cancer in patients or human tissues.

All malignant neoplasms are registered, as are in situ carcinoma of breast and cervix and in situ melanoma. Basal and squamous cell carcinomas of the skin are not registered except for those occurring in genital and perianal skin and the vermilion border of lip.

Non-melanocytic skin cancers are not registered by the Victorian Cancer Registry (or most other registries) as many are treated in doctors' surgeries using destructive techniques which preclude histological confirmation and also as they vastly outnumber all other forms of cancer.

Currently, about 250 hospitals and 50 pathology laboratories notify cancer to the registry, increasingly via electronic media. In preparing the 2004 incidence data, around 100,000 notifications were processed. In addition, death certificates are obtained from the Registrar of Births, Deaths and Marriages in computerised format on a regular basis.

The minimum data set collected for each cancer consists of:

- registry identification number
- name(s)
- residential address
- date of birth
- country of birth
- sex
- vital status
- date of last contact
- number of primary tumours
- date of diagnosis
- site of cancer
- cancer histology
- method of diagnosis.

## Overview of 2004 statistics

### Numbers

Nearly 24,000 Victorians develop cancer, other than non-melanocytic skin cancer (NMSC), each year and over 9,000 deaths are caused by it. In 2004, 13,019 men and 10,791 women presented with new cancers and 5,283 men and 4,266 women died from cancer.

### Age and sex

Cancer was very age-dependent with less than 1% of tumours occurring before age 15 and 59% in persons over 65 years. More men than women developed cancer: 121 for every 100 females. The male excess was largely due to tobacco-related cancers.

### Incidence

The standardised incidence rates were 346 per 100,000 males and 265 per 100,000 females. The cumulative rates percent to age 75 were 40.7% for males and 29.5% for females. These represented risks of over 1 in 3 for men and almost 1 in 4 for women. At least one in three Victorians will develop a cancer other than non-melanocytic skin cancer by age 75.

### Mortality

In 2004, more Victorians died from cancer (9,613 29.6% of all deaths) than from all heart disease (7,771, 23.9%). Cancer and heart disease caused more than half of all deaths in Victoria.

Age-standardised mortality rates for cancer were 125.8 per 100,000 males and 83.5 per 100,000 females. These rates are higher than those for both ischaemic heart disease (66.6 and 32.5 per 100,000 men and women respectively) and all heart disease (85.0 and 46.9 men and women respectively).

Cancer death rates for men and women continue to decrease at about 1.2% and 0.9% per year respectively.

More detailed statistics are available at [www.cancervic.org.au/cancer1/facts/vic.htm](http://www.cancervic.org.au/cancer1/facts/vic.htm).

**Figure 1. Leading Cancer Sites in Victoria 2004.**

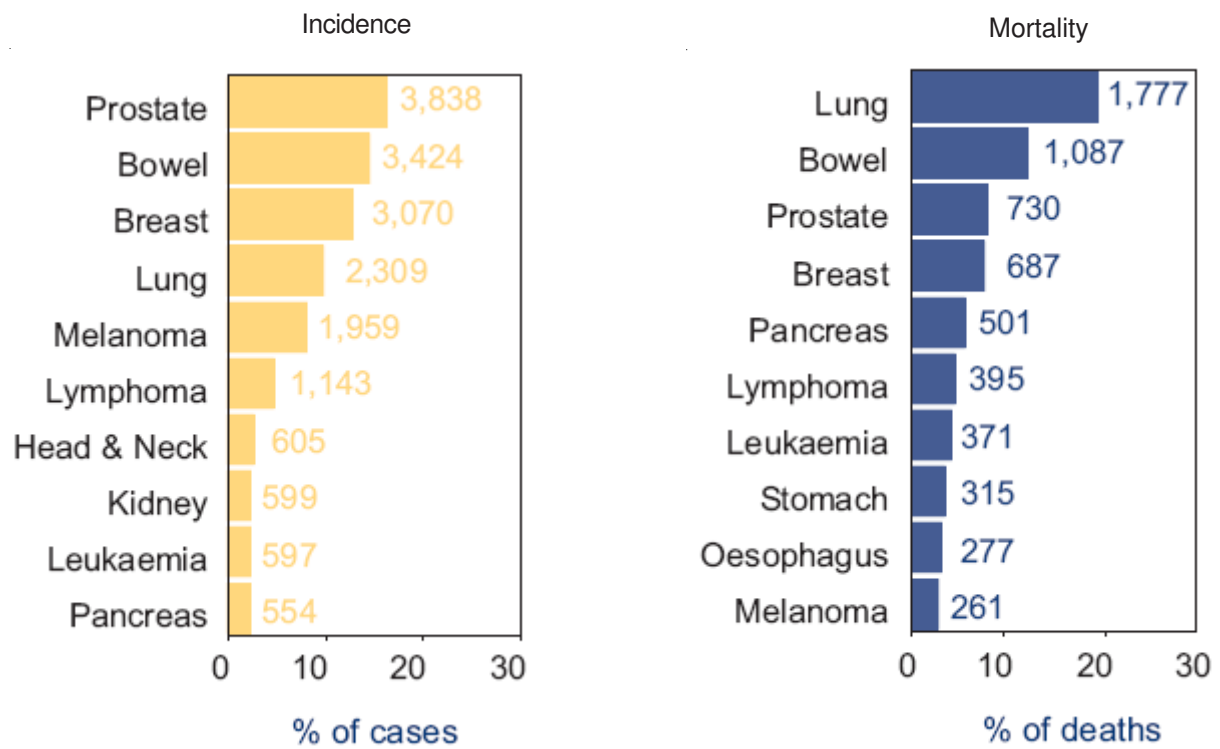
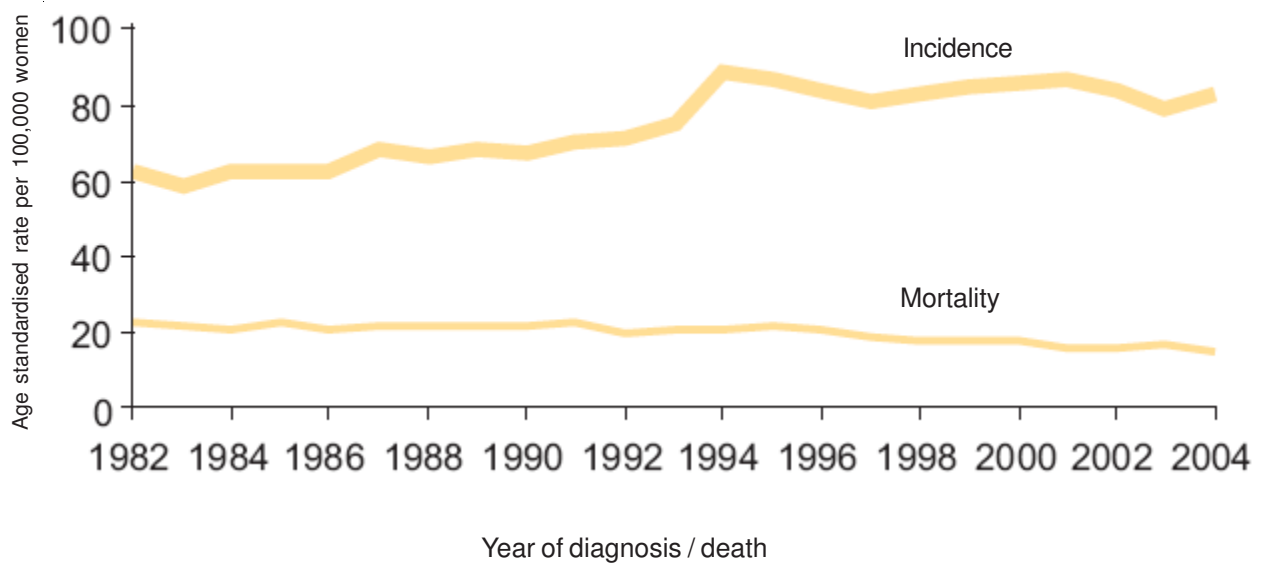


Figure 1 shows the ten top-ranking sites for cancer incidence and mortality in Victoria. The bars represent the percentages of total new cases or deaths in each site. Numbers of cases / deaths are also shown.

**Figure 2. Female Breast Cancer Trends in Victoria 1982–2004**



## VCOG 30<sup>th</sup> Anniversary

*Speech by Assoc Professor David Allen, VCOG Chair  
on 1 November 2006 during VCOG 30<sup>th</sup> Anniversary Reception*

Over the last 30 years, the Victorian Cooperative Oncology Group has developed into a body with a broad multidisciplinary and cross-institutional representation.

The aim of the group has been to prevent cancer and optimise patient treatments and care through collaboration and research. VCOG is now a forum that is of value to clinicians and of importance for patient outcomes.

The VCOG and its subcommittees have developed into an authoritative body of enthusiastic experts who work across disciplines, outside of institutional boundaries, providing clinical and research advice to the Cancer Council. The approximately 450 members of the VCOG committees make an enormous contribution to clinical research and the development of patient care protocols in Victoria.

These committees provide a necessary neutral territory for discussion and will certainly continue to grow into the future. Just last week we held the inaugural meeting of the 20<sup>th</sup> committee – the sarcoma advisory committee.

As the committees expand and strengthen further, so too will the influence and relevance of this unique forum grow in its present spirit of co-operation.

Of course the work of these committees doesn't just happen – they need to be organised, agendas prepared and circulated etc. The VCOG Secretariat, consisting of the Executive Officer Susan Fitzpatrick and her team, really is the glue that binds us together, and for all their essential

– and increasing – work, we thank them.

Every two years the Victorian Cooperative Oncology Group elects an Executive Committee that in turn elects a Chair. I am very proud to be the current chair of VCOG and the Executive Committee and I thank the members for their work and support – and in doing this I would also like to acknowledge the work of all past and present subcommittee chairs and members. And whilst I am thanking people, I would also like to mention David Hill for his constant support, and my deputy chair Ingrid Winship for her valuable contribution.

The achievements of VCOG over the past 30 years are enormous but the future looks even brighter with the new opportunities and directions that are constantly emerging. Working with the newly formed Integrated Cancer Services in Victoria is one such opportunity. And we look forward to other potential collaborations and synergies with the Department of Human Services and other relevant government departments and agencies in the future.

However, to remain relevant into the future we must always ensure that our efforts are of benefit to the Victorian community as a whole and that we keep our focus firmly on the fight against cancer.

I thank you all.

## Supporting Oncology Professional Collaboration in Cancer Control, 1976–2006

*Mrs Susan A Fitzpatrick, Executive Officer*

*Centre for Clinical Research in Cancer, The Cancer Council Victoria*

*Poster presentation at UICC World Cancer Congress, 8–12 July 2006, Washington DC, USA*

### The Victorian Cooperative Oncology Group

The Cancer Council Victoria's infrastructure support within a "neutral" environment for the Victorian Cooperative Oncology Group has enabled Victoria's cancer specialists to meet in a conducive, non-partisan environment to develop multi-disciplinary clinical management protocols and policy advice for 30 years.

The Victorian Cooperative Oncology Group is an excellent forum for communication of new cancer treatment knowledge, promoting development and implementation of evidence-based clinical management guidelines and for the collaborative design of and participation in clinical trials. It has also enabled the coordinated lobbying of governments for improved services for cancer patients and cancer clinical research funding.

*Comment from the Chair, Assoc Professor David Allen*

### Developing a unique oncology professional group

In 1975, the Cancer Council's Medical & Scientific Committee expressed concern about inconsistency in the management of solid tumours requiring chemotherapy and the then lack of suitable medical training. It formed a working group to explore all aspects of chemotherapy in Victoria.

In 1976 it was resolved to invite clinical representation from all hospitals in Victoria providing cancer therapy.

The Cancer Council Victoria provided a non-partisan environment and administrative support for the gathering.

The Victorian Cooperative Oncology Group was constituted in 1976 to:

- Advise the Cancer Council Victoria on all clinical aspects of cancer.
- Promote a range of cooperative measures to optimise cancer management.
- Contribute to the design and conduct of collaborative clinical research.
- Promote development and implementation of evidence-based treatment guidelines.

- Advocate for improved cancer services.
- Contribute to the education of the medical profession.
- Establish cancer advisory and research groups.

In 2006, the VCOG structure includes a primary committee, an executive committee, 9 cancer and 4 clinical advisory committees and 3 research groups. The Cancer Council supports the VCOG activities through a dedicated Clinical Research Centre providing administration and cancer trial coordination.

### A group with extensive cancer expertise

- 450 honorary / volunteer health professionals – medical, scientific and community.
- Inclusive, with the power to co-opt members with specialist expertise.
- Represents medicine, radiotherapy, surgery, gastroenterology, gynaecology, dermatology, ENT, genetics, haematology, neurology, palliation, pathology, psychology, respiratory / thoracic, nursing social work, etc.

- Includes 16 consumer / community representatives
- Represents 30 public and private metropolitan and regional cancer treatments centres

### **An influential role in improving cancer care**

- Supports evidence-based treatment, clinical research, equity and access to best cancer care
- Assists the Cancer Council in cancer registration (standard data items / site specific registers), knowledge dissemination (professional forums / newsletters), community education (patient information material), support (Cancer Call-In), media responses, and fundraising activities (Relay for Life, Daffodil Day etc)
- Has capacity to influence clinical practice and service provision
- Highly respected by oncology professionals in Victoria and Australia
- Has unique linkages between public and private health care professionals, institutions, government and NGOs

### **Providing authoritative advice on cancer control**

#### Advocacy / Support for

- Cancer Service Infrastructure, Bone Marrow Transplantation, Palliative Care Services, Cancer Therapies, Pain Therapies, Clinical Research Infrastructure, Standard Cancer Data Set, Professional Education, Cancer Genetics Services, Patient Resources and Support Services

#### Submissions to Government Inquiries on

- Cancer Services in Victoria / Australia, Alternative / Unproven Therapies, Mammographic Screening, Prostate Cancer Screening, Protection of Cancer Genetic Information

#### Statements / Guidelines on

- Screening for breast, bowel, prostate cancer, Handling of cytotoxic drugs, Techniques for cervical smear, Management of gynaecological, cancer, familial ovarian

cancer, non-melanocytic skin cancer, Synoptic reporting for melanoma, gynaecological and head and neck cancer, IHC testing for CRC, Gynaecological surveillance for HNPCC

#### Information for patients and families

- Expert medical advice on contact of Cancer Council information brochures.

### **Collaborating in clinical research**

#### Clinical Trials

- Initiated – Endometrial (international), Ovarian (national), Rectal (state), Breast (international, state), Pain (state), Prostate (international)
- 7% cancer patients registered in trials in Victoria
- 12% breast cancer patients in international trials

#### Treatment Surveys and Audits

- Breast (1986, 1990, 1995, 1999)
- Colorectal (1988, 1998, 1994)
- Lung (1993), Prostate (1993)
- Testes (1988–1993)
- Cervical (1982, 1986, 1987, 1992), Ovarian (1993–1995), Endometrium (1995)
- Renal Cell (2000), Bladder – Superficial (1990, 1995), Bladder – Invasive (1990–95)
- Glioma (1998–2000)
- Melanoma (2000)

#### Outcome Registers

- Insitu & Small Breast (1988–1998), Radical Prostatectomy (1997–2002)

### **Achievements**

- NHMRC Silver Volunteer Award for Health Organisation, Victoria, 2001.
- Peak oncology health professional advisory body – *Victoria's Cancer Parliament*.
- Maintained cohesive oncology health professional community for 30 years.
- Structure modelled in three other Australian states.

## Key Published Articles Listing—Breast Cancer

Title	Author & Journal
<b>Risk-reducing surgery in women with familial susceptibility for breast and/or ovarian cancer</b>	<b>Antill Y, Reynolds J, Young MA, et al.</b> European Journal of Cancer 2006; 42: 621–628.
<b>Margins and outcome of screen-detected breast cancer with extensive in-situ component</b>	<b>Kitchen PRB, Cawson J, Moore S.E, et al.</b> ANZ Journal of Surgery 2006; 76: 591–595.
<b>Modelling menstrual status during and after adjuvant treatment for breast cancer</b>	<b>Szwarc SE &amp; Bonetti M.</b> Statistics in Medicine 2006; 25: 3534–3547.
<b>Adjuvant treatment of breast cancer: Sequence and duration of hormonal therapy</b>	<b>Castiglione-Gertsch M.</b> Annals of Oncology Sep 2006; 17(10): x51–x53.
<b>Re-evaluating adjuvant breast cancer trials: Assessing hormone receptor status by immunohistochemical versus extraction assays</b>	<b>Regan MM, Viale G, Mastropasqua MG, et al.</b> Journal of the National Cancer Institute Nov 2006; 98(21): 1571–1581.

## Forthcoming Meetings

Date / Place	Meeting / Contact
<b>8–10 February 2007</b> Lorne, Victoria, Australia	<b>19<sup>th</sup> Lorne Cancer Conference – <i>The hallmarks of cancer</i></b> Website: <a href="http://www.lornecancer.org">www.lornecancer.org</a>
<b>8–10 February 2007</b> Hollywood, California, USA	<b>9<sup>th</sup> National Conference on Cancer Nursing Research</b> Organised by the Oncology Nursing Society (ONS), USA E-mail: <a href="mailto:customer.service@ons.org">customer.service@ons.org</a> Website: <a href="http://www.ons.org">www.ons.org</a>
<b>15–16 February 2007</b> Melbourne, VIC, Australia	<b>9<sup>th</sup> National Breast Care Nurse Conference – <i>Coordination of care: Breast care nurses lead the way</i></b> E-mail: <a href="mailto:Doreen.Akkerman@cancervic.org.au">Doreen.Akkerman@cancervic.org.au</a>
<b>15–18 February 2007</b> Amelia Island, Florida, USA	<b>12<sup>th</sup> Annual Multidisciplinary Symposium on Breast Disease</b> Website: <a href="http://www.cme.ufl.edu/conf/msbd">www.cme.ufl.edu/conf/msbd</a>
<b>23–25 February 2007</b> Arlington, Virginia, USA	<b>Young Survivor Coalition Annual Conference for Young Women Affected by Breast Cancer</b> Website: <a href="http://www.youngsurvivorsconference.org">www.youngsurvivorsconference.org</a>
<b>27–28 February 2007</b> Sydney, NSW, Australia	<b>3<sup>rd</sup> Australasian Redesigning Healthcare Summit – <i>Making patient journeys work</i></b> With Flinders Medical Centre and NSW Health Website: <a href="http://www.changechampions.com.au">www.changechampions.com.au</a>

Date / Place	Meeting / Contact
1–4 March 2007 Austin, Texas, USA	<b>4<sup>th</sup> Annual Conference of the American Psychosocial Oncology Society (APOS) – Promoting quality psychosocial cancer care across diverse communities</b> E-mail: <a href="mailto:info@apos-society.org">info@apos-society.org</a> Website: <a href="http://www.apos-society.org">www.apos-society.org</a>
1–4 March 2007 Sao Paulo, Brazil	<b>7<sup>th</sup> Annual Meeting of the International Network for Cancer Treatment &amp; Research</b> Institut Pasteur, Brussels, Belgium Ph: +32 2 373 9314 Fax: +32 2 373 9313 E-mail: <a href="mailto:cedric@inctr.be">cedric@inctr.be</a> Website: <a href="http://www.inctr.org">www.inctr.org</a>
6–10 March 2007 Florence, Italy	<b>4<sup>th</sup> International Conference on Tumor Micro-environment – Progression, therapy and prevention</b> Organised by AACR and ICMS Website: <a href="http://www.aacr.org/page5995.aspx">www.aacr.org/page5995.aspx</a>
14–17 March 2007 St Gallen, Switzerland	<b>10<sup>th</sup> International Conference on Primary Therapy of Early Breast Cancer</b> St Gallen Oncology Conferences, c/o Centre for Tumour Detection, Prevention and Treatment, St Gallen, Switzerland Ph: +41 71 243 0032 Fax: +41 71 245 6805 E-mail: <a href="mailto:info@oncoconferences.ch">info@oncoconferences.ch</a> Website: <a href="http://www.oncoconferences.ch">www.oncoconferences.ch</a>
15–18 March 2007 Washington DC, USA	<b>Annual Meeting of the Society of Surgical Oncology (SSO)</b> Website: <a href="http://www.surgonc.org">www.surgonc.org</a>
17–18 March 2007 St Gallen, Switzerland	<b>30<sup>th</sup> Annual Meeting of the International Breast Cancer Study Group (IBCSG)</b> Website: <a href="http://www.ibcsg.org">www.ibcsg.org</a>
22–23 March 2007 Cairns, QLD, Australia	<b>Clinical decisions, ethical challenges</b> E-mail: <a href="mailto:change.champions@bigpond.com">change.champions@bigpond.com</a> Website: <a href="http://www.changechampions.com.au">www.changechampions.com.au</a>
11–14 April 2007 Rotorua, New Zealand	<b>19<sup>th</sup> Annual Trans Tasman Radiation Oncology Group (TROG) Meeting</b> TROG Conference Secretariat Ph: (02) 9280 0577 Fax: (02) 9280 0533 E-mail: <a href="mailto:trog@pharmaevents.com.au">trog@pharmaevents.com.au</a> Website: <a href="http://trog.ranzcr.edu.au">http://trog.ranzcr.edu.au</a>
14–18 April 2007 Los Angeles, California, USA	<b>98<sup>th</sup> Annual Meeting of the American Association for Cancer Research (AACR)</b> Website: <a href="http://www.aacr.org">www.aacr.org</a>

<b>Date / Place</b>	<b>Meeting / Contact</b>
19–22 April 2007 Sarajevo	<b>1<sup>st</sup> Interconference Breast Cancer Meeting</b> Website: <a href="http://www.fecs.be">www.fecs.be</a>
24–27 April 2007 Las Vegas, Nevada, USA	<b>32<sup>nd</sup> Annual Congress of the Oncology Nursing Society (ONS)</b> Oncology Nursing Society (ONS), USA E-mail: <a href="mailto:customer.service@ons.org">customer.service@ons.org</a> Website: <a href="http://www.ons.org">www.ons.org</a>
6–10 May 2007 Melbourne, VIC, Australia	<b>Annual Scientific Meeting of the Royal Australasian College of Physicians (RACP)</b> Website: <a href="http://www.racp.edu.au">www.racp.edu.au</a>
7–11 May 2007 Christchurch, New Zealand	<b>Annual Scientific Congress of the Royal Australasian College of Surgeons (RACS)</b> Ph: (03) 9249 1273 E-mail: <a href="mailto:caroline.handley@surgeons.org">caroline.handley@surgeons.org</a> Website: <a href="http://www.surgeons.org/AM/Template.cfm?Section=Annual_Scientific_Congress">www.surgeons.org/AM/Template.cfm?Section=Annual_Scientific_Congress</a>
9–11 May 2007 Winnipeg, Canada	<b>2007 Annual Conference of the Canadian Association of Psychosocial Oncology (CAPO) – Communication, Collaboration &amp; Creativity</b> Website: <a href="http://www.capo.ca">www.capo.ca</a>
30 May – 2 June 2007 Stockholm, Sweden	<b>14<sup>th</sup> Reach to Recovery International UICC Breast Cancer Support Conference</b> Website: <a href="http://www.uicc.org">www.uicc.org</a>
1–5 June 2007 Chicago, Illinois, USA	<b>43<sup>rd</sup> Annual Meeting of the American Society of Clinical Oncology (ASCO) – Translating research into practice</b> E-mail: <a href="mailto:asco@asco.org">asco@asco.org</a> Website: <a href="http://www.asco.org">www.asco.org</a>
20–22 June 2007 Milan, Italy	<b>9<sup>th</sup> Milan Breast Cancer Conference</b> Website: <a href="http://www.breastmilan.com">www.breastmilan.com</a>
20–22 June 2007 Madrid, Spain	<b>7<sup>th</sup> Madrid Breast Cancer Conference – Changes in the treatment of breast cancer</b> E-mail: <a href="mailto:b.navarro@bnyco.com">b.navarro@bnyco.com</a> Website: <a href="http://www.madridbreastcancer.com">www.madridbreastcancer.com</a>
23–29 June 2007 Flims, Switzerland	<b>9<sup>th</sup> Joint FECS-AACR-ASCO Workshop – Methods in Clinical Cancer Research</b> Federation of European Cancer Societies, Brussels, Belgium E-mail: <a href="mailto:workshop@fecs.be">workshop@fecs.be</a> Website: <a href="http://www.fecs.be/emc.asp?pageid=1153">www.fecs.be/emc.asp?pageid=1153</a>
28–30 June 2007 St Gallen, Switzerland	<b>Supportive Care in Cancer</b> Website: <a href="http://www.oncoconferences.ch">www.oncoconferences.ch</a>

## The Cancer Council Victoria

The Cancer Council Victoria is a public institution set up by an Act of Parliament in 1936. It operates as a charity, relies heavily on volunteer support, and raises and spends \$3–\$4 per head of population annually. It is governed by the Council and Executive and other committees. Its mission is to lead, coordinate and evaluate action to minimise the human cost of cancer for all Victorians. The Cancer Council houses three research divisions (behavioural science, clinical research, epidemiology) and units undertaking public and professional education, cancer registration, cancer information and support services, anti-smoking campaign (QUIT), finance, administration and fund raising. It employs about 300 staff. The Cancer Council also auspices a cooperating network of cancer specialists through the Victorian Cooperative Oncology Group and resources an expert Medical & Scientific Committee to dispense studentships, scholarships, fellowships and research grants to other academic, research and medical institutions.

### Centre for Clinical Research in Cancer — Victorian Cooperative Oncology Group

The Centre for Clinical Research in Cancer (CCRC) formed in 1997, provides a coordinated and effective resource for collaborative clinical research and development in Victoria. The Centre provides administrative and research support for the Victorian Cooperative Oncology Group, which brings together Victoria’s cancer specialists. The Centre fosters and facilitates the development and promotion of a range of collaborative clinical measures to optimise cancer management.

The Victorian Cooperative Oncology Group (VCOG) established in 1976, provides advice to the Cancer Council Victoria, through the CCRC, on all clinical aspects of cancer control, in particular research, screening, diagnosis, treatment, palliative medicine, cancer genetics and professional education. The strategic role of VCOG is to have a ‘parliament’ of clinical cancer specialists with a view to promoting a range of cooperative measures to optimise cancer treatment in Victoria. VCOG consists of a primary committee, 10 cancer-site and 3 task-specific advisory committees, and 5 research sub-committees. These committees bring together in regular meetings approximately 450 key specialist health care professionals and scientists, representing the various treatment disciplines and centres in Victoria. VCOG has established unique linkages between public and private health care professionals, institutions and governments.

