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Clinical trials: How consumers, clinicians and researchers can initiate and participate in the best cancer trials

OVERVIEW

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These are exciting times. The last 30 years have seen major reductions in mortality from breast cancer, childhood leukaemia and tests cancer heralding what is possible for other cancers. These improvements are a direct result of clinical trials establishing the benefits of mammographic screening, adjuvant therapy, and treatments for advanced cancer and improving their effectiveness. Changes in community attitudes to sun exposure, tobacco use, and diet should cause major reductions in skin, lung, and colorectal cancer cancers over the next 30 years. Despite these major advances, about a quarter of people in the Western world will die from cancer, and many more will be affected. Why are clinical trials crucial to improving our lot?

Recent, rapid advances in cell biology, genetics, drug development, radiation biology and physics, surgery, supportive care and diagnostics have resulted in a plethora of promising new interventions against cancer. These promising new interventions have to be tried, tested and proven before they can be adopted in clinical practice. The history of medical science shows that only a precious few will translate into real improvements. Clinical trials are the only reliable way of determining the safety, activity and benefit of these promising new interventions.

The theme of this series is ‘How consumers, clinicians and researchers can initiate and participate in the best cancer trials’. Changes in the nature of scientific progress, government involvement, commercial interests, and regulatory requirements are forcing us all to rethink our roles in oncology research.

The authors were selected because of their involvement in innovative, successful projects with lessons that I thought were applicable beyond their particular area, to other areas of oncology and medicine. Authors were asked to focus on what was innovative and interesting for a general audience, and to highlight lessons applicable to cancer trials research in general. All authors made related presentations at the International Clinical Trials Symposium held at Darling Harbour, Sydney in 2002.

Alan Coates sets the scene by describing the benefits, beneficiaries and challenges of cancer clinical trials research. He concludes that cancer trials are a good buy for patients, doctors and society.

Sue Lockwood considers collaboration between consumers and clinician researchers using the example of breast cancer, and the effects of recent controversies surrounding hormone replacement therapy. She concludes with the suggestion that researchers provide a community information abstract, summarising the results of their studies for an informed lay audience.

Mark Rosenthal reflects on the strengths and innovations of the Victorian Centre for Developmental Cancer Therapeutics. The model has been so successful in cancer that it will be applied to neurological and cardiovascular diseases through the establishment of Clinical Trials Victoria, which recently received an $8 million grant from the Victorian Government.

Nicholas Wilcken describes the opportunities and challenges associated with Australia’s participation in HERA, a large international randomised trial of trastuzumab (Herceptin™). He concludes that studies like HERA raise new questions about how trials should be designed and conducted, and reinforce the need for conducting high quality clinical trials on which to base clinical practice.

Marie Malica describes the development of Cancer Trials NSW as a model for improving participation in and access to clinical trials. She emphasises the importance of collaboration, inclusion, consumer involvement and improving access and participation. She concludes that while much needs to be done, the future looks bright.

Leonie Young describes an innovative program to acknowledge the contributions of breast cancer trial participants by providing a network, education about breast cancer research and advocacy training. She concludes that increasing the community’s awareness of the benefits of breast cancer trials will also help other areas.

Life is getting more complicated, but major improvements are on offer. Many have argued, in Australia and overseas, that increasing participation and access to high-quality cancer trials is the best way to improve outcomes for people affected by cancer. Getting cancer trials on the local political agenda may be our major battle in the war against cancer. Perseverance may be the key to helping more Australians survive the war.
Clinical trials: Benefits and challenges

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Clinical trials provide the evidence basis for rational decision-making in medical therapeutics. They provide benefits to participating patients, future patients, the community, third party payers (such as governments and private health insurers) and to participating clinical researchers.

Benefits

Patients participating in clinical trials receive treatment under rigorously defined, ethically scrutinised protocols. There is some evidence that such patients survive longer than similar patients treated with similar regimens outside trials. While patients participating in clinical trials receive treatment under protocols (such as governments and private health insurers) gain knowledge about the acceptability and economical treatment while (hopefully) discarding treatments shown to be ineffective. Clinical trials provide the evidence basis for rational decision-making. They provide benefits to third party payers. Patients participating in clinical trials receive treatment under protocols that benefit the patient was a legitimate purpose of clinical trials. Early access to new and more effective regimens only benefit the patient. Modern consent forms used did not offer inappropriate inducements to trial participation. Satisfaction of helping future patients is another, purely altruistic motive for trial participation.

Challenges

Evidence from earlier trials is available to assist patients and their doctors in reaching treatment decisions. Such evidence includes benefits of treatment, side effects and impact of treatment on quality of life as judged by similar patients who have had similar treatment. From the viewpoint of government and doctors, trials provide evidence to give security that the advice offered (and paid for) is appropriate, allowing preferential use of more efficacious, acceptable and economical treatment while (hopefully) discarding treatments shown to be ineffective.

Clinical discipline in the use of defined regimens, dose modifications and documentation may as noted above lead to barriers after by patients. Although many patients in phase I trials may receive ineffective low doses, Horng et al concluded that the consent forms used did not offer inappropriate inducements to trial participation. Satisfaction of helping future patients is another, purely altruistic motive for trial participation.

Clinical trials in breast cancer

In 2002, 84% of women diagnosed with breast cancer survived five years, whereas just 10 years ago this figure was 72%. This is a great improvement, most of which is due to better detection and treatment. Much of the research providing these improvements has come from clinical trials. But 30% of women diagnosed with breast cancer still die of it, and some of those who are cured suffer ongoing side-effects of their treatment, eg lymphoeidea. It is therefore imperative that more work be done to improve outcomes. Both the effectiveness and safety of treatments must improve.

The only way to get improved outcomes faster is to increase the number of women participating in clinical trials. Greater numbers of women means faster results over a wider range of patients.

We’ve got a groovy thing goin’ baby… or have we?

Involving women in clinical trials

• may turn down the opportunity to participate in trials;
• there is another side to this litany of problems. Work done by the National Breast Cancer Centre surveying women who had been recently diagnosed and treated for breast cancer showed that most women were not invited to participate in a clinical trial. Only 6% of women were asked to participate, of these, half said yes. That is, 50% of women with whom a trial was discussed agreed to participate. So, while only 3% of women participated in trials, this was 50% of the women offered the chance to participate.

These figures indicate that the main problem is not with the women refusing to participate in a trial, but that so few women were asked in the first place. This experience is not unusual, and fits with data from other surveys.

Abstract

This paper explores how the number of women in clinical trials might be increased and the extent to which researchers, clinicians and women are currently working to improve outcomes for women. It explores the issues from the perspective of women with breast cancer, but the arguments presented here apply to other diseases. It also considers the loss of trust in the research process that results from inappropriate promotion of results. The Women’s Health Initiative trial is used as an example of how fear and loss of trust can ensue. Some mechanisms to improve trust are suggested, such as communication about potential side effects.

Introduction

Women who have been diagnosed with breast cancer want the best possible treatment for themselves and other women with the disease. Clinical trials are an important mechanism for improving treatment outcomes, so women are very interested in the results of trials. Clinicians are also interested in improving outcomes through research. They also want better outcomes for their patients, but many of them are also interested in the intellectual challenges which research provides. Both women and clinicians have an interest in increasing the number of women in clinical trials.

Clinical trials have been very successful to date

In 2002, 84% of women diagnosed with breast cancer survived five years, whereas just 10 years ago this figure was 72%. This is a great improvement, most of which is due to better detection and treatment. Much of the research providing these improvements has come from clinical trials. While there are important reasons why some women are not invited to participate, women with breast cancer as they are to researchers? There are very few trials in radiotherapy and surgery and even fewer in the area of the psychosocial study of breast cancer. Encouraging more people to participate in clinical trials might be increased and the extent to which researchers, clinicians and women are currently working to improve outcomes for women. It explores the issues from the perspective of women with breast cancer, but the arguments presented here apply to other diseases. It also considers the loss of trust in the research process that results from inappropriate promotion of results. The Women’s Health Initiative trial is used as an example of how fear and loss of trust can ensue. Some mechanisms to improve trust are suggested, such as communication about potential side effects.

These figures indicate that the main problem is not with the women refusing to participate in a trial, but that so few women were asked in the first place. This experience is not unusual, and fits with data from other surveys. Perhaps recruitment will continue to depend on those few specialists who are treating large numbers of women with breast cancer, or are working in larger specialty teams, are more likely to enrol women in trials. It is hoped that research leaders will need to support active involvement in clinical trials, most importantly access to data managers and study nurses. This may be the greatest barrier to more clinicians becoming involved. Perhaps the move to multidisciplinary teams and greater specialisation will lead to more clinicians offering women entry to clinical trials.

First, in trials we tell us what works, such as screening for breast and bowel cancers, breast conserving surgery, adjuvant systemic therapy in breast cancer and bowel cancer, radiotherapy in breast, rectal cancers and chemo-radiotherapy for cancers of rectum, lung, head and neck, cervix and oesophagus. Trials also tell us what doesn’t work. High dose methotrexate was once popular in many tumour types but comparative trials severely limited its applicability. An early attempt to justify government support for the costs of clinical trials as a good investment was based on this work. Lastrille was an ‘alternative’ medication popular in the 1980s, and more recently we have seen the influence of clinical trials in reducing the use of high dose chemotherapy with stem cell support for breast cancer.

1. The only way to get improved outcomes faster is to increase the number of women participating in clinical trials.

References

5. S Lockwood Breast Cancer Action Group Fairfield, VIC.

How can we encourage more women to participate in clinical trials?

• more relevant trials;
• increased numbers of participants; and
• increased involvement of clinicians.

Perhaps there are too few trials. It is clear that there are many trials, but they all relate to areas of interest to research scientists and clinicians. Many of these are concerned with chemotherapy and different modes of delivering therapy. Although there are important reasons why some women are not invited to participate, women with breast cancer as they are to researchers? There are very few trials in radiotherapy and surgery and even fewer in the area of the psychosocial study of breast cancer. Encouraging more people to participate in clinical trials might be increased and the extent to which researchers, clinicians and women are currently working to improve outcomes for women. It explores the issues from the perspective of women with breast cancer, but the arguments presented here apply to other diseases. It also considers the loss of trust in the research process that results from inappropriate promotion of results. The Women’s Health Initiative trial is used as an example of how fear and loss of trust can ensue. Some mechanisms to improve trust are suggested, such as communication about potential side effects.

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5. S Lockwood Breast Cancer Action Group Fairfield, VIC.
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The other side of the coin – loss of trust

From these experiences, we know some of the factors that encourage recruitment into clinical trials. They are:

- design win-win trials;
- use end points that are meaningful to participants; and
- involve consumers in all aspects of trial design and management.

We all must be very careful to nurture the trust between the community at large and the clinical community. There are many ways of doing this. Here are some suggestions.

Community information abstracts

Each research paper has a scientific information abstract that describes, in a form of code, the results of the research in such a way that other researchers can find the results. In the current world, many of the research results are of interest to the general public. It seems appropriate for community information abstracts to be written in a way that is more accessible.

These community information abstracts would be of use to many different groups as well as consumers of health services.
The HERA trial is a large international randomised trial testing the efficacy of the new biological drug trastuzumab (Herceptin) in early breast cancer. HERA is being conducted in Australia by the Australian New Zealand Breast Cancer Trials Group in collaboration with the International Breast Cancer Study Group and the Breast International Group. This is the first time Australian centres have participated in a trial of a biological agent in the adjuvant setting and is an important learning opportunity for all those involved.

Background
HER2 (also known as erbB2 or neu) belongs to a family of receptors that are located on the surface of human cells, and when stimulated they transmit growth signals to the nucleus. In many cancers, these growth pathways become uncontrolled, contributing to cancer development or progression. For example, the receptor may mutate in a way that causes it to always be “switched on.” In the case of HER2, about 15% of breast cancers are overexpressed.

Problems with an adjuvant trial
Given the activity of trastuzumab in advanced disease, an obvious question is whether or not it is effective if given as part of the adjuvant treatment of early breast cancer. An immediate problem is the required size of such a trial, since it will only apply to 15% of women with early breast cancer needing adjuvant treatment. It is important that testing for HER2 is standardised as much as possible, given the ease with which inconsistent results can be obtained. Lastly, while toxicity is always important, it is particularly so when new drugs are given to otherwise well women with potentially long lifespans. Thus intensive cardiac monitoring is a crucial part of any adjuvant trial using trastuzumab.

The HERA trial
Given all these considerations, it is clear that large resources are required to conduct an adjuvant trial. The HERA trial therefore brings together several clinical trials groups across the world, and has been designed and initiated in close collaboration with the relevant pharmaceutical company, which is providing strong financial support without impinging on the scientific independence of the various trial committees.

Two biological considerations incorporated into the design of HERA differenciate it from the concurrent American trastuzumab trials. Recent information supports the use of trastuzumab in a “weekly” schedule, rather than the usual twice-a-week schedule that has been used to date. Thus there will be the opportunity to make indirect comparisons between trials about the cost, patient acceptability and toxicity of these schedules. In addition, there are of course not yet any data on the appropriate duration of trastuzumab in the adjuvant setting, and the American trials are not testing this.

Thus HERA is a three-armed randomised trial. After appropriate adjuvant chemotherapy, 3,000 women will be randomised to either no trastuzumab, trastuzumab for one year or trastuzumab for two years. Follow-up will continue for 10 years. All breast tumour samples will require testing in a single reference laboratory. Frequent cardiac monitoring (either echocardiograms or radionuclide scans) will be carried out using the same protocol for all three arms of the trial. This is an important point, since intensive cardiac monitoring is not usually done in women having chemotherapy alone. This trial will therefore provide the opportunity to assess prospectively the level of cardiotoxicity associated with usual adjuvant chemotherapy protocols and to accurately measure any additional effects seen with trastuzumab.

Because accrual to this trial will be challenging – over 30,000 women will need to be screened – there is a deliberately pragmatic approach to chemotherapy protocols. Recognising that evidence from randomised trials supports a number of standard chemotherapy regimens, the choice of chemotherapy is left largely to individual investigators.

Lessons to be learned
Participation in this large new trial offers the opportunity to learn several lessons that will be increasingly important to clinical trialists over the coming years. As cancer treatments inevitably become more targeted, so will the requirement to coordinate large-scale tissue collection and testing. In the face of such increasing complexity, it will be important to keep as many aspects of the trial as simple as possible. Thus HERA trialists will need to employ the adjuvant chemotherapy protocols they are using.

The evolving biological agents requiring rigorous testing in randomised trials will also change the way we monitor clinical trials. For example, established clinical trialists may feel less able to scrutinise available phase II and early randomised trials of new agents before incorporating these new drugs into definitive large scale trials, and maintain an open mind about trial design and conduct.

Reference
1 DI Simmons, B Layek-Jones, Sh Sakh, et al. “Use of chemotherapy plus a monoclonal antibody against HER2 for metastatic breast cancer that relapse after adjuvant chemotherapy.” JAMA 2002;287:2023-2029
Consultation and collaboration

Comprehensive consultation was done to help develop the most appropriate model for this collaborative initiative. Consultative committees were convened to provide advice and reach agreement on all aspects of CTN – including issues of policy, procedure, selection of trials and participating centres, finance, governance and management. All committees included consumers, health professionals and researchers. CTN is now well established with consensus from all the key stakeholders on suitable policies and procedures for a fair, rigorous and inclusive selection.

Trial selection

CTN trial selection occurs twice a year, with calls for applications in March and September. Continuing review and addition to the portfolio of CTN trials is designed to ensure that the mix of cancers and treatments in supported trials reflects the experience of cancer in NSW.

The CTN portfolio now includes 47 supported trials.

Trial Selection Committee

Our inclusive Trial Selection Committee comprises 26 individuals from all relevant disciplines, including three consumers, clinicians, researchers and staff of The Cancer Council NSW. Three assessment forms are used by the committee.

At least 10 committee members review and rate each trial application using:

1. the “CTN trial and concept rating form”, an electronic form that allows raters to score each trial application against specific selection criteria developed for CTN.

A content expert and a methodologic expert do more detailed assessments using other forms.

2. the “Protocol critical appraisal form” developed by Davina Gherzi of the NHMRC Clinical Trials Centre; and

3. a modified version of the “National cancer grants ranking form”.

The results of these ratings and assessments are then summarised and form the basis of the committee’s discussions and decisions.

Trial selection criteria

To help meet the aims of CTN, selection criteria were developed and integrated into a CTN centre rating form that includes 21 aspects grouped into seven domains:

- Participation
- Access and equity
- Quality
- Economy and efficiency
- Multidisciplinary care
- Contribution to Cancer Council activities
- Overall rating

Ideal applications include substantial, realistic participation in a rational subset of CTN supported trials involving collaboration, networking and links between disciplines, centres, areas and institutions. In their application each centre outlines which trials they intend to do and their proposed recruitment figures. CTN sponsored centres are encouraged to take up new supported trials as they are approved, and patients recruited are included in the evaluation of that centre.

Vision – “research in practice”

We hope that by 2010, throughout NSW:

- Participation in cancer trials is an integral part of clinical practice.
- Everyone suitable is able to participate in cancer clinical trials, both patients and clinicians.
- World-class participation delivers world's best cancer care and outcomes.
- 90% of eligible patients are offered participation in CTN supported trials and 25% choose to take part. The targets are that everyone is given the choice, and that people are fully informed and free to choose.

What’s in the future?

Increase funding

We plan to increase the number of CTN supported study nurse/data managers to 20 FTE over the next five years, contingent on the success of our fundraising efforts with The Cancer Council NSW. We anticipate future applications to support centres will be invited annually as funds become available.

Trials initiation

Our initial focus has been to improve participation and access in NSW by selecting and supporting greater participation in ongoing, high-quality trials. The next step is to identify important gaps in our cancer trials research program, and help establish high quality trials to address them. Through this initiative, CTN will provide a genuine vehicle to support locally initiated trials and build on the intellectual contribution from NSW to the global trials effort.

A national register of cancer trials

Information about each supported trial and centre is currently available on the Cancer Trials NSW website, which is part of The Cancer Council NSW website at www.cancercouncil.com.au. We aim to work with our key stakeholders and other state cancer councils to further develop this information as a basis for the establishment of a national register of cancer clinical trials.

Education and training

Educating advocates, consumers, clinicians and researchers about ongoing trials and the importance of participation is another important strategy for increasing participation and access throughout NSW. CTN has already contributed to training of consumers, and plans are in progress for educational programs for study nurses, data managers, clinicians and other researchers.

Conclusion

CTN provides a successful, effective model for building infrastructure to improve participation in and access to cancer clinical trials, and for developing a close collaboration between consumers, clinicians, researchers and funders. Effective involvement means inclusion at all levels including trial development, management and funding, things that CTN will continue to champion in the future. CTN has only just begun and there is a long way to go, but with the continued support of CTN's key stakeholders, we are optimistic that the education and training initiatives will provide the foundation for improved participation.

Australian New Zealand Breast Cancer Trials Group: IMPACT – Improving Participation and Advocacy for Clinical Trials

L Young

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Clinical trials research

We are now in the most exciting and productive time ever in breast cancer research. The genetics of breast cancer are being unravelled, new treatments are being tested and greater understanding of the controls of cell growth and mechanisms of development of breast cancer are being explored. The most significant obstacles to new research are low recruitment to clinical trials and lack of infrastructure funding. Relying on the generosity of the community and industry, does not allow for long-term commitment. Lack of ongoing infrastructure funding makes it difficult for health professionals to make a commitment to research and the number of institutions which offer clinical trials is limited.

Community education about clinical trials research is very important if participation rates are to increase. Not only is the general community ill-informed about clinical trials research, but so are many health professionals who are in a position to advise people diagnosed with cancer.

People diagnosed with cancer should be given as many opportunities as possible to participate in cancer clinical trials research. The involvement of partners, families and friends is also important in the decision of whether to participate in a clinical trial. Therefore, the whole community needs to be informed so appropriate enquiries can be made at the time of diagnosis.

There are still many myths of how trials are conducted. Perceived uncertainty or the “guinea pig” mentality is still very prominent. Because of these misconceptions, many people still feel that by participating in a clinical trial they will be giving over their treatment to chance. People who are eligible to participate in a trial are reliant on good communication and full explanations about the trials they may be considering.

Positive community education is vital to influence decision-makers, politicians, health professionals and people in the general community who may face a diagnosis in the future. The myths surrounding cancer clinical trials research need to be openly refuted.

Consumer involvement in clinical trials research

Hanley et al recently made the following points about consumer involvement in research:

- “The consumers helped convince researchers and funders that the trial was possible and ethical.”
- “They were important in helping to refine questions.”
- “More relevant and clearer questions were… asked.”
- “They helped make a complex trial comprehensive to most patients.”
- “They provided insights into issues important to the community and patients.”
- “Their participation led to improved recruitment.”

Australian New Zealand Breast Cancer Trials Group (ANZ BCTG)

Established in 1978 to create a national collaborative approach to breast cancer research through clinical trials, the ANZ BCTG collaborates with over 500 researchers in 60 leading medical and research institutions in Australia and New Zealand and with 15 countries internationally.

The ANZ BCTG invited the inclusion of consumer representation to research planning in 1994 when a breast cancer survivor and a breast nurse counsellor were invited to become members of their Scientific Advisory Committee. They were invited both because of their own life experiences with breast cancer, and their academic expertise. They have contributed to the scientific discussion and have been responsible for reviewing and commenting on new trial protocols and participant information sheets. They also represent consumers’ perspectives on various external committees and present consumers’ viewpoints to the media, at conferences and at symposia.
The strategies for achieving the IMPACT program's aims include:

1. IMPACT Newsletter
2. Information sessions
3. IMPACT Education Program

The first aim, of recognising the important contributions made by women to breast cancer clinical trials research, is the most important aspect of IMPACT. High quality breast cancer trials are impossible without the participation of women with breast cancer.

The opportunity to network in a non-clinical environment and to meet with others who have had similar experiences reinforces how important and empowering each woman's contribution is and how much it is valued.

The ANZ BCTG wants to help consumers become more effective as advocates so that they can take a greater role in research development and planning. The information and education provided by IMPACT is designed to do this.

The IMPACT Newsletter is distributed regularly and provides information on research issues and educates readers about the research process. It also provides a vehicle for members to have a say and maintain a connection.

Information sessions are being scheduled nationwide. A brief overview of the IMPACT program and current research updates are presented. Most importantly, however, these sessions provide an opportunity for the ANZ BCTG to acknowledge the contributions of participating women to its research programs, and for participating women to meet others with similar experiences.

The IMPACT Education Program is offered to members who continue to show a commitment to the clinical trials process and an interest in learning the concepts of basic science, breast cancer research and policy issues.

The Education Program runs over three to four days. Presentations are made on subjects specifically designed to give the participants an understanding of:

• the biology of breast cancer;
• genetics;
• study design, statistics and interpretation;
• diagnosis and treatment;
• conducting clinical trials; and
• advocacy and communication skills.

IMPACT allows its members to make choices. However they choose to contribute, their participation is constructive, valued and they can continue to provide a broader consumer perspective.

What sets IMPACT apart is that it specifically aims to address issues relating to clinical trials research. Inevitably, the positive messages about breast cancer trials will carry over to the benefit of other clinical trials research. This is another positive attribute of IMPACT. There is still a long way to go to eradicate breast cancer. Advocates cooperating and striving for a common cause can help achieve this sooner.

IMPACT members will continue to make their contributions to the research process count.

Reference
1. B Hanley, A Truesdale, A King, D Elbourne and I Chalmers. "Involving women in breast cancer clinical trials: an example of successful involvement. IMPACT aims to provide a positive voice in the research process count.

Testing for familial cancer susceptibility gene mutations

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Abstract

Genetic testing is a useful means of identifying individuals who are at an increased risk of developing familial cancer. This information assists such individuals to make lifestyle alterations and consider surgical intervention to minimise their risk of developing cancer. In WA, genetic testing is conducted free of charge to the public through Genetic Services of WA who provide an integrated service. This includes pre- and post-test counselling, testing, family support and a surveillance registry.

However, the recent granting of an exclusive gene patent licensing agreement for familial breast cancer susceptibility genes threatens free of charge public testing services Australia-wide. Exclusively licensing creates a monopoly on the testing services available, and accordingly there has been a great deal of controversy over the breast cancer gene patent and licensing agreements internationally. This article explores aspects of testing for familial cancer susceptibility gene mutations, focusing on experiences with familial breast cancer.

Breast cancer is the most common form of cancer among Australian women, and it is estimated that it will affect approximately one in 12 women in their lifetime. While fewer than five per cent of all cases of breast cancer in Australia may be attributed to familial links, the risk of developing the cancer is potentially higher-risk persons (less than one per cent of the population) is six to 10 times higher than the population average. The causes of breast cancer are complicated by interactions between environmental factors such as diet, and genetic factors. In regard to familial breast cancer, currently identified environmental risk factors are thought to explain less than 10 per cent of breast cancers. This indicates there is still much to learn about why breast cancer runs in families more often than would be predicted by chance alone. The BRCA1 gene, associated with inherited risk of breast cancer other than BRCA1 and BRCA2, has been discovered in the last few years.

The BRCA1 and BRCA2 gene mutations act as tumour suppressors. Mutations in these genes lead to increased susceptibility to uncontrolled cell replication, thereby resulting in cancer. These mutations, largely specific to a family, may be passed through several members, males and females. Population-based studies conducted internationally indicate that individuals who have inherited (deleterious) BRCA1 mutations have an elevated lifetime risk of both breast and ovarian cancer. For those individuals at increased risk of developing familial breast and ovarian cancer, genetic testing may be an appropriate option to refine actual risk as a component of their risk management.
The Familial Cancer Program also operates a cancer registry that provides surveillance for women identified as being at increased risk of breast or ovarian cancer. If no mutation is found in the family, members are still encouraged to follow screening measures due to the strong family history of disease. The Familial Cancer Program also invites such individuals to join the registry in the event that a new genetic mutation is identified in the course of future research or technological development. In addition, the program provides educational initiatives for individuals to participate in approved clinical trials and research projects conducted through the Familial Cancer Program and the Breast Cancer Program at Royal Prince Alfred Hospital.

The holistic and multidisciplinary care in the BRCA genes suggested that counselling is effective in helping women through the genetic testing process, highlighting the need for a comprehensive genetic service.

An experience of genetic testing

Genetic testing for familial breast cancer mutations raises a multitude of psychosocial issues, which need to be considered before any imaging testing occurs. For example, in deciding whether or not to undertake testing the individual needs to consider the impact of the information on their own psychological coping and issues such as life insurance and employment. Ultimately, the choice is a personal one but genetics professionals can ease the decision-making process by equipping individuals with the best information about the issues involved so they can make the best choice for themselves and their family.

In response to the high prevalence of breast cancer in her family, one woman underwent a double mastectomy in order to minimise her risk of developing breast cancer. This woman states that “breast cancer has been casting a long shadow over the women in my family, it seems as if part of our family is doomed to breast cancer” and is therefore also currently considering genetic testing in order to add to the genetic knowledge in her family.

In another family, both mother and daughter undertook genetic testing through GSWA two years ago. Breast cancer has affected three generations of their family. They heard about the services offered by GSWA through a family member who is a GP and who felt that given their strong family history of breast cancer, there might be genetic factors involved. Both women were tested for breast cancer susceptibility genes, but so far only the mother has developed ovarian cancer. Other family members have also undergone genetic testing, however some have elected not to receive this predictive information.

The daughter states that she was apprehensive about having the testing done, but the counselling she received supported her from the genetic counselors and valuable written information assisted her decision-making. She also noted that the explanation of the information by the clinical geneticists was most important in assisting her decision-making. Receiving the results that she carried a mutation was “frightening but you learn to live with it”. Knowledge of the mutation has enabled her to be vigilant and prepared. The daughter states that “when I first heard we were facing our breast and we were watching closely”. Both women are undergoing regular surveillance and have been encouraged to join the Familial Cancer Registry.

Genes patents

Despite the benefits clients derive through familial cancer services such as that offered by GSWA, the ability of public hospitals to provide free-of-charge genetic services to the public is threatened by the implications of gene patenting.

Recently a US-based biotechnology company, Myriad Genetics Inc, has taken out a broad patent for the BRCA genes in numerous countries, including Australia. Myriad was granted the framework of exclusively licensing the use of its test to a very limited number of commercial genetic laboratories in specific locations.

Broad-based gene patents raise the controversial issue of whether or not it is ethical or practical to patent a naturally occurring substance, and further to make a commodity out of it. Extending beyond this ethical issue is perhaps the more critical question of whether it is in the interests of public health and research to allow gene patents, and evidence increasingly suggests it may not be.

While it is acknowledged that patents support the protection of corporate interests and are a central tenant of international trade agreements between industrialised nations, these corporate interests need to be weighed against the public good. The exercise of exclusive and monopolistic gene patents will interfere with patient care by disrupting the integrated testing, clinical and counselling services already provided throughout Australia. It may also compromise the viability and expertise of publicly-funded genetic testing services, and divert testing services away from established Australian best practice guidelines which serve to ensure the medical and psychological wellbeing of individuals undertaking testing.

Genes patents also have the potential to compromise public health by inhibiting biomedical research that could prevent an alternative genetic test from being developed. For example, a trader wanting to find a cure for breast cancer would have to negotiate with the patent holder for access to the BRCA1 and BRCA2 genes. In addition, they must also negotiate with all the other patent holders who have discovered and patented any of the hundreds of other mutations in these genes. The stimulus to patent genes in the last decade has been likened to a “genetic gold rush”. A Victorian Government report, Genetic Technologies Limited, has patented 95% of all intrinsic DNA (also known as “junk DNA”) in the likelihood that this material may be found to be important.

Internationally, there have been very few legal challenges launched against gene patents, and there certainly have been no decisive legal moves to address directly whether human genes are even an appropriate substance to patent. In the US, moves to reform legislations have been strongly opposed by a coalition introduced by Senator Lynn Rivers. The Rivers Bills aim to grant medical researchers and clinical geneticists protection from patent infringement, in an effort to prevent the impact of gene patenting on health services. In Australia, a similar course of legislative action is yet to be undertaken, and in the interim gene patents remain a very real threat to the delivery of genetic testing as a component of our public health service.

Conclusion

It is currently known that a small number of cases of breast and ovarian cancer may be attributed to mutations in various genes, including BRCA1 and BRCA2. It is expected many more genes that contribute to cancer will be identified as research advances. It is currently noted that “the better we understand them, the better we’re facing our breast and we’re watching closely”. Both women are undergoing regular surveillance and have been encouraged to join the Familial Cancer Registry.

The impact of physiotherapy intervention on functional independence and quality of life in palliative patients

El Laakso
School of Physiotherapy and Exercise Science, Griffith University
AJ McAuliffe
Zonal Quality Co-ordinator, Queensland Health, QLD
A Cantlay
Formerly Superintendent Physiotherapist, Newbury Physiotherapy Service, UK

Abstract

The Physiotherapy Department of the Royal Brisbane Hospital has conducted a review of physiotherapy services to palliative care patients in Australia. As part of this review, a trial was undertaken to investigate the impact of physiotherapy intervention on quality of life and functional level. The results indicated that the provision of an adequately resourced physiotherapy service incorporating early intervention and community follow-up can contribute significantly to the maintenance of functional independence and quality of life among patients receiving palliative care.

Introduction

In the mid to late 1960s, the concept of rehabilitation as a part of the cancer treatment process began to flourish. Dietz developed the framework of cancer rehabilitation prevention, restoration, support and palliation. Physiotherapy involvement in the treatment of cancer patients began to develop at around this time, but with involvement often limited to the restorative stage. During the 1970s, the input of physiotherapist in the support phase began to be noted. Zissis reported the usefulness of physiotherapy to maintain range of motion post-operatively, and Mayer noted that physiotherapists could implement a graduated exercise program contributing to maintenance of mobility. The role of physiotherapy in cancer rehabilitation was firmly established by the 1970s, with many textbooks devoting space to the role of physiotherapy and also of the importance of a multidisciplinary approach to palliative care. A series of publications by Doyle demonstrated the development of the contribution of physiotherapy to palliative care. anecdotal reports suggested that while physiotherapy involvement could value-add to the care of patients in the palliative stage of cancer, there was an inconsistent approach to the referral of patients to physiotherapy or even of the involvement of physiotherapists explicable in the context of the health system. One of the aims of this study was to understand whether physiotherapists were involved in palliative care services in Australia, specifically identifying the impediments to those services, and primarily (ii) to conduct an outcome study of physiotherapy to patients receiving palliative care, observing the effects of a standard physiotherapy service compared to an optimised physiotherapy service. In the context of this project, palliative care is defined as care for life for patients in the non-curative stage of the disease process.

Method

Stage 1

In order to provide a benchmark service against which to assess physiotherapy outcomes, it was necessary to understand what a constipated standard versus optimal physiotherapy practice. Prior to the commencement of the outcome study, a survey of physiotherapy services was undertaken to assess the possible options was conducted. The survey identified a number of impediments to the delivery of a quality physiotherapy service, including the fact that the average time spent in providing physiotherapy to patients receiving palliative care is less than 10 minutes. Other limitations included delayed or absent referral to physiotherapy during hospital admission, limited resources (such as equipment and funding) to provide adequate services, and a lack of community-based services for follow-up after hospital discharge. The specialised physiotherapy service examined during stage two of this study was designed to reduce the impact of the limitations identified in stage one.

Stage 2

The study was conducted over 12 months in an oncology ward of a major metropolitan teaching hospital. The subjects were patients admitted for symptom control (palliative care patients). Forty patients were randomly allocated to receive the optimal trial physiotherapy service (characterised by time and...
Subjects were allocated to the study groups in the following way. The project physiotherapist screened new admissions to the ward, and palliative patients with indications for physiotherapy intervention were identified. From this group, randomly selected patients were approached and invited to take part in the trial. These patients received the trial service by the project physiotherapist and were known as the “project group”. Patients not randomised to the project group became subjects in the “standard group” and if and when they were referred for physiotherapy during their admission. In this way, the standard group was representative of the usual process of referral for physiotherapy service delivery from the ward. Patients in the standard care group received physiotherapy from the staff physiotherapist rostered to the ward. The trial service differed from the standard service in three main ways:

1. to overcome problems of delayed referral, patients were recruited on admission by the project physiotherapist;
2. the project physiotherapist limited her patient load to ensure that each patient received adequate contact time, thus reducing the problem of limited resources; and
3. the project patients received regular community follow-up visits following hospital discharge.

Both groups received best-practice medical and nursing care appropriate to their condition.

The interventions undertaken by the project physiotherapist were numerous and varied but can be grouped into three intervention categories commonly used by physiotherapists:

a. Pain and symptom management, including transcutaneous electrical nerve stimulation (TENS), appropriate positioning of patients to reduce stress on joints and muscles and to prevent development of pressure areas, and the treatment of lymphoedema by a combination of massage, compression and exercise.

b. Education provided by the physiotherapist covered topics including safe and comfortable transfer and handling techniques to minimise discomfort and injury to both the patient and carer, and techniques to reduce work associated with activities of daily living.

c. Mobility and independence were maximised by designing exercise programmes specific to the individuals’ needs, providing gait re-education and the provision of appropriate walking aids.

The trial outcomes were assessed with respect to:

• discharge destination;
• place of death;
• functional level;
• patient satisfaction; and
• quality of life (EORTC QLQ-C30).

The functional level of the subjects was measured using a tool developed for the project that assessed nine tasks. The tasks assessed were ability to roll in bed, transferring from side-lying to sitting up, sitting, transferring from sitting to standing, standing, mobilising (walking), negotiating stairs, toileting and entering/aligning from a car. Each task was graded based on the degree of assistance required to complete the task: independent (1), use of an assistive device (2), requirement for assistance provided by a carer ie supervision only (1.8), minimal assistance (1.5), moderate assistance (1.2), maximal assistance (0.9), two people to assist (0.5), inability to move (0). A score between 0 and 27 was obtained with 27 representing complete independence in all tasks. The task was assessed for utility in a number of palliative care services prior to its use in this study.

Quality of life was assessed using the EORTC QLQ-C30 that produces scores ranging from zero to 100 for six function components and for nine symptom impact components. For the function components a score of 100 represents the best possible level of function, thus an increase in score represents an improvement in function. In the symptom impact components, a score of 100 represents the highest possible impact on QOL thus a decrease in score represents a decrease in the severity of the symptom.

Figure 1: Functional level of project and standard groups at admission, discharge and mid-survival follow-up. At mid-survival follow-up assessment there were weak statistical (p=0.09) and clinically significant differences between the project and standard groups.

Functional level and quality of life were assessed on admission, at discharge and at regular intervals following discharge.

Patient satisfaction of the physiotherapy service received was assessed at discharge and where possible, at four week follow-up and subsequent regular intervals. Subjects were asked to rate a number of factors (amount of physiotherapy received, confidence in the abilities of the physiotherapist, consideration by the physiotherapist of the patient’s wishes, understanding of advice and instructions given by the physiotherapist and helpfulness of advice and instructions given by the treating physiotherapist) on a five point Likert scale.

In order to develop standards for practice, physiotherapist workload data were collated using a simple bar-code reader. Time required for the management of various components of the episode of care was recorded when the bar-code reader was scanned across bar-codes according to the intervention strategy employed. For reporting purposes, intervention strategies were grouped into major treatment categories.

Results

Results were analysed using Wilcoxon rank data analysis and chi-square frequency analysis. While the group numbers were relatively low, resulting in weak levels of significance, there were distinct differences between groups.

Length of stay, discharge destination and place of death

Participants in the project group were more likely to be discharged home than those in the standard group (p=0.0858). Patients in the project group were also more likely to die at home (p=0.0159). There was no statistically significant difference in length of stay (LOS) between groups. Patients in the project group had a mean LOS of 17.55 days, and patients in the group that received standard care had a mean LOS of 15.6 days.

Functional level

A comparison of the functional level between the groups was performed using a post-discharge assessment score obtained at a time that was half way between the date of discharge and the date of the patients’ death. This method was chosen to ensure that the groups were comparable with respect to extent of disease and the stage of decline.

At admission and discharge, patients in the project group had mean functional independence scores of 16.5 (supervision to complete some tasks) and 15.5 while the standard group means were 14.6 (supervision with some tasks) and 14.3, respectively. The decrease in score at discharge in the project group is in the main due to the higher proportion of patients in this group who died during admission (15%). When these patients are excluded, the difference at admission is maintained at discharge (17.9). Figure one demonstrates that there was no statistically significant difference in functional ability between the groups at admission or discharge from hospital. At mid-survival follow-up assessment there were weak statistical (p=0.09) and clinically significant differences between the project and standard groups. The standard group required light to moderate assistance with all tasks, while the project group was functionally independent with the use of a walking aid in all tasks.

Quality of life

Neither the standard nor the project groups experienced significant changes in any of the function components of the QLQ-C30 questionnaire over the study period. However, noticeable trends existed within the two groups. The trend within the standard group (figure two) was towards a decline in function whereas the trend within the project group (figure three) was towards improvement in function. Comparison of the functional independence measurement tool with the physical function component of the QLQ-C30 demonstrated a weak but significant positive correlation (r = 0.629, p <
ARTICLE

For symptom impact scores between admission and follow-up, the standard group experienced a statistically significant increase in constipation (*p = 0.027) and a significant decrease in sleep disturbance (*p = 0.075). The project group experienced statistically significant decreases in fatigue (***p = 0.05), pain (**p = 0.052) and appetite disturbance (*p = 0.09). There were no significant differences in either group for the remaining symptom components.

Physiotherapist workload data

The average times devoted to physiotherapy management presented in table one.

Table 1: Average duration of intervention (minutes/seconds) for each group of patients

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<td>8:06</td>
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<tr>
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<td>4:34</td>
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<td>Follow-up assessment and treatment</td>
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<td>40</td>
</tr>
<tr>
<td>Discharge assessment session</td>
<td>Not available</td>
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</tbody>
</table>

Discussion

Length of stay, discharge destination and place of death

Examination of the length of stay data revealed that patients in the project group had a mean stay of two days longer than those in the standard group. The specific reason for this was not apparent from the analysis; however, it was noted that in general a higher proportion of patients in the project group died during admission. This may denote a difference in severity of illness status not discernible by other means.

Patients in the standard group were more likely to be discharged to another care facility instead of home than those in the project group. In order to determine whether this outcome was a consequence of stage or severity of disease or of diagnosis, further examination of the demographics of the patients in the standard group revealed that the subjects were a representative sample of all patients normally admitted to the ward. The fact that patients assigned to the project group were more likely to be discharged home than those in the standard group was considered to be a positive outcome of the study. Anecdotal evidence suggests that there is an increasing trend towards patients and families wishing to care for loved ones in the home environment. Where possible, and due to shortages of beds in extended care facilities, the aim of discharge facilitation on the oncology ward is to discharge the patient home where possible, if the family and patient desire this outcome and are in a position to facilitate it.

The success of follow-up community physiotherapy among project group patients was affirmed by the fact that more patients in the project group were likely to die at home than those patients in the group that received standard care limited by lack of physiotherapist time, resources and community follow-up. When considering the place of death, it is important to remember that some patients elect to be admitted to a formal care facility in preference to dying at home. While there are many factors that influence a person’s ability to remain at home until death, the ability of the carer(s) to effectively manage is a primary concern. The ability of the patient to move or be moved is a major component of the ability to cope at home. The greater proportion of project group patients dying at home suggests that the contribution of physiotherapy to the maintenance of mobility and function enhanced the choice of place of death.

Functional level

On admission, the project group had a higher level of functional independence. This was not considered to be sampling bias but rather a reflection of referral practices on the ward. Patients were randomly recruited to the project group on the initiative of the project physiotherapist as sufficient time and resources became available through the discharge or death of other patients. Patients recruited to the project group were newly admitted patients whose medical notes identified an indication for physiotherapy intervention and who had not at that time been referred for physiotherapy. Conversely, patients in the standard group were those who may have had indications for physiotherapy intervention at admission but who were not referred to the ward physiotherapist by medical or nursing staff until some time after admission. Such referral was often based on the inability of the patient to manage functionally on the ward even though he or she had been managing earlier in the admission. The ward physiotherapist had 15 years of clinical experience and had been working in the field of chronic care and palliative care over a number of years leading up to this study. The increased human and material resources available to the project physiotherapist, and the palliative-specific focus of the project service increased the variety and effectiveness of the physiotherapy interventions undertaken.

While the difference in admission levels of functional independence between the two groups may be viewed as significant clinically, the difference reflects a crucial variable potentially affecting outcomes for physiotherapy intervention in palliative care. The ability to provide timely physiotherapy intervention is essential to maximise outcomes. The results from the standard group indicate that due to referral practices in existence at the time of this study, there was a population of patients passively being denied access to physiotherapy when they clearly had indicators for physiotherapy.

While the level of statistical significance is weak, there were distinct clinical differences between groups in patients’ functional abilities. Such differences could be considered to have greater clinical significance when attached to related factors such as quality of life and ability to function effectively in the home. The comparison of the functional independence measurement tool with the measurement component of the QLQ-C30 demonstrated a significant positive correlation, suggesting that the components assessed were representative of factors contributing to the quality of life of the patients.

At mid-survival follow-up, the patients in the standard group required light to moderate assistance of a carer with all tasks, while patients in the project group were independent with the use of a walking aid in all tasks. The level of independence alone strongly supports the benefits of optimising physiotherapy in outcomes for patients requiring palliative care. The deterioration noted in the standard care group of patients has an impact on the amount of carer support required, the costs of that support (financial, physical and psychological) and the potential need for re-admission to a formal care facility with the attendant costs of such care.

Quality of life

Patients in neither the standard nor the project group experienced significant changes in any of the function components over the study period. However, noticeable trends existed within the two groups. The trend within the standard group was toward a decline in function, whereas the trend within the project group was towards improvement in function. These trends are verified by the results acquired from the functional independence measurement tool.

While it is intuitively appealing to make sweeping claims from these results, it would be unwise to do so in the context of the lack of supporting data regarding pharmacological, dietary and other factors that may have influenced these results. It is interesting to note though, that the patients in the standard group experienced an improvement in symptoms during the inpatient period following by a decline in five of six function components assessed at follow-up to a point below the admission score. Conversely, the project group maintained or improved function in all but one component over the same period. The results for each group are similar in the scores for symptom impact over the same time course. The links between quality of life factors, well-being, follow-up and physical independence/activity have been noted by other authors10-12 and so it would seem reasonable to conclude that the maintenance of independence and physical activity, along with community follow-up, were likely to have been directly related to quality of life scores noted in the project group.

Patient satisfaction

While satisfaction with various aspects of physiotherapy services was high among patients of both groups, patients in the project group were significantly more satisfied with the advice
and instructions given to them by the treating physiotherapist.

As the project physiotherapist had more time and was able to adjust her workload to maintain adequate patient intervention time, it may be expected that the project group would be more satisfied with the amount of physiotherapy received. It is important to emphasise that the individual skills or approaches of the physiotherapists concerned were not the subject of this investigation but rather the way in which the service was delivered. Given the extensive knowledge base and skills of physiotherapists it is not surprising that the two groups were equally satisfied. Regardless of the communication skills of the individual physiotherapists, the increased time available to the project physiotherapist may have influenced the ability to ensure understanding of advice and instructions contributing to this result. Where general commentary was given in the QLQ-C30, it was found that no patients reported dissatisfaction with the service provided by any of the healthcare professionals involved in their care.

Physiotherapist workload data

The individual treatment episodes provided by the project physiotherapist were longer than those of the ward physiotherapist. One must note that while the project physiotherapist was employed solely for the study and the time was quantified for the provision of enhanced patient care, the ward physiotherapist providing the standard level of care was required to provide a service to three busy medical wards and a specialist outpatient clinic. Based on the results of the nation-wide survey (stage one), the latter situation is typical of physiotherapy service delivery and should have influenced the ability to assess and treat patients effectively. The provision of an adequately resourced physiotherapy service incorporating early intervention and community follow-up can contribute significantly to the maintenance of functional independence, patient satisfaction and quality of life among patients requiring palliative care. In turn, this may result in decreased demand for formal inpatient care and subsequent cost savings. A physiotherapist to inpatient ratio of 1:12 is recommended in order to produce such results.

Acknowledgements

To Ms Elaine Unkles for her sponsorship of the project and useful suggestions on the manuscript, Ms Pamela McNeill (social worker) for her support during the project, the staff of the Division of Oncology, Royal Brisbane and Royal Women’s Hospitals, Health Service District, for their professionalism and interest in the study, and most of all to the patients and carers who agreed to participate in the research.

References


Conclusion

In summary, in comparison to the standard treatment group, patients in the project group were significantly more likely to be discharged home and significantly more likely to die at home. The provision of a specialised physiotherapy service resulted in significantly higher functional levels on follow-up assessment. A trend towards the maintenance or improvement of the functional component of quality of life and significant improvements in fatigue, pain and appetite were noted in patients who received optimised levels of physiotherapy time and resources. The provision of an adequately resourced physiotherapy service incorporating early intervention and community follow-up can contribute significantly to the maintenance of functional independence, patient satisfaction and quality of life among patients requiring palliative care. In turn, this may result in decreased demand for formal inpatient care and subsequent cost savings. A physiotherapist to inpatient ratio of 1:12 is recommended in order to produce such results.

The state and territory cancer organisations, which comprise The Cancer Council Australia, are the major sponsors of cancer research and related activities in Australia. Grants are made following a competitive, peer-reviewed assessment from funds derived from donations and bequests. In 2003 the value of these grants is $20 million.

In addition, the grants for breast cancer research made by the National Breast Cancer Foundation are listed. The Foundation has been established by the Federal Government, with an independent Board of Trustees to encourage research in all aspects of breast cancer.

THE CANCER COUNCIL NSW

RESEARCH GRANTS

J Kirk  Westmead Hospital  kConfab: A national consortium for research into familial breast cancer $55,000
A Gruelich  National Centre in HPV Epidemiology and Clinical Research, University of NSW  Cancer in dialysis patients and kidney transplant recipients: incidence, risk factors and survival $36,200
P Hersey  Newcastle Mater Mittermbein Hospital  Sensitization of human melanoma to killing by the immune system $134,620
R Lord  Children’s Cancer Institute Australia for Medical Research  Targeting angiogenesis signalling pathways in childhood acute lymphoblastic leukaemia $80,000
S Ward  St Vincent’s Hospital  The significance of CpG island methylation in the pathogenesis of hyperplastic polyposis and colorectal cancer $135,000
A Delatycki  Children’s Hospital for New South Wales  Molecular epidemiology of ovarian cancer: WA, Tasmania and a national clinical follow-up care $69,500

Total research grants $5,103,200

CONTINUING RESEARCH PROJECT GRANTS

J Stevens  Collaborative Health Education Research Centre, St Vincent’s Hospital  Sentinel node vs axillary clearance trial $13,000
S Tangney  Centenary Institute of Cancer Medicine and Cell Biology  Lymphocyte activation and anti-tumour immunity mediated via SAP-associating surface receptors in health and disease $70,000
R Lock  Children’s Cancer Institute Australia for Medical Research  Molecular mechanisms of drug resistance in childhood acute lymphoblastic leukaemia $71,649
Q Dong  University of Sydney  The role of FHL1 and SPRK1 in androgen-independent prostate cancer $60,000
R Henderson  Westmead Institute for Cancer Research  Regulation of beta-catenin nuclear trafficking in cancer $80,000
M Mason  University of Sydney  Role of 1,25(OH)2D3 in photosprotection $70,000
C Mountford  Institute of Magnetic Resonance Research  MRI/MRS applied to breast cancer detection, diagnosis and prognosis $70,000
M Tattersall  When the treatment goal is not cure: a randomised trial of decision aids in patients with incurable metastatic cancer $141,800
J Wiggins  Hunter Centre for Health Advancement  A randomised controlled trial of a computerised smoking cessation intervention in a surgical pre-admission clinic $31,123
D Joshua  Centenary Institute of Cancer Medicine and Cell Biology  Identification of the specificity of potential myeloma specific clonal CD 13 cells using TCR transfectants $63,167
A Rice  Children’s Cancer Institute Australia for Medical Research  Development of targeted immunotherapy to treat relapsed leukaemia post stem cell transplantation $66,940
B Barendt  SEALS, Prince of Wales Hospital  (South Eastern Area Laboratory Service)  The autotogy of breast cancer and the involvement of diet, hormones and the human homologue of the mouse mammary tumour virus $75,548
A Feinberg  Children’s Cancer Institute Australia for Medical Research  Antidepressants and subjective well-being in advanced cancer: a double blind randomised clinical trial $15,705
P Hogg  University of NSW Centre for Tumour Angiogenesis  $211,000

Support for research 2003

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In 2003 the value of these grants is $20 million.

In addition, the grants for breast cancer research made by the National Breast Cancer Foundation are listed. The Foundation has been established by the Federal Government, with an independent Board of Trustees to encourage research in all aspects of breast cancer.
### RESEARCH FELLOWSHIP

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<td>Children’s Cancer Institute Australia for Medical Research</td>
<td>Defining the cause and improving the treatment of childhood neuroblastoma</td>
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<td>R Sutherland</td>
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<td>Steroid and growth factor signalling in the pathophysiology of breast and prostate cancer</td>
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<td>R Reddel</td>
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<td>Carcinogenesis</td>
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<td>G O’Neill</td>
<td>Children’s Hospital Westmead</td>
<td>Career Development Research Fellowship &amp; $150,000 proteins and breast cancer cell response to chemotherapy</td>
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### OTHER RESEARCH PROGRAMS

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### TOTAL RESEARCH FUNDED

- **Total Research Funds:** $5,749,958

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### THE CANCER COUNCIL SOUTH AUSTRALIA

#### RESEARCH GRANTS

- **J Ainslie, W McCarthy, B Burmeister, M Smithers, J Thompson, M Henderson**
  - Division of Radiation Oncology
  - Peter MacCallum Cancer Institute
  - A randomised clinical trial of surgery versus surgery plus adjuvant radiotherapy for regional control in patients with completely resected macroscopic nodal melanoma
  - **Amount:** $4,241

- **O Ben-Tovim, A Stapleton, C Pinnock**
  - Clinical Epidemiology and Health Outcomes Unit
  - Flinders Medical Centre
  - The influence of coping strategies on outcomes in prostate cancer: a longitudinal study
  - **Amount:** $60,000

- **D Bowtell, A deFazio, M Davy**
  - Dept of Research
  - Peter MacCallum Cancer Institute
  - Molecular epidemiology of ovarian cancer: Australian ovarian cancer study – Western Australia, Tasmania and a national clinical follow up core
  - **Amount:** $33,000

- **A De Angelis, D Findlay, B Coventry**
  - Child Health Research Institute
  - An expression clonal strategy for identification of a molecular lesion in polycythemia vera
  - **Amount:** $57,886

- **A Endo, D Fahy, L Bunting**
  - Dept of Haematology
  - St Vincent’s Hospital
  - A novel non-toxic approach to bone cancer therapy
  - **Amount:** $50,000

- **A Forse, F Macrae, P Bown, J Bown**
  - Dept of Gastroenterology and Hepatology
  - Flinders Medical Centre
  - A comparison of screening tests for colorectal neoplasia in average risk asymptomatic subjects
  - **Amount:** $41,897

- **B Goodall, J Collins, M Bochnor, D Walker**
  - Dept of Surgery
  - University of Adelaide
  - Sentinel lymph node biopsy versus axillary clearance in operable breast cancer
  - **Amount:** $53,376

- **G Goodall, J Collins, M Bochnor, D Walker**
  - Hanson Centre for Cancer Research
  - IMVS
  - Sentinel lymph node biopsy versus axillary clearance in operable breast cancer
  - **Amount:** $64,197

- **M Guthridge, A Lopez**
  - Hanson Centre for Cancer Research
  - IMVS
  - Regulation of HF-1a by PI3K signalling in breast cancer
  - **Amount:** $59,505

- **J Harrington, P Hewitt**
  - Haematology-Oncology Dept
  - The Queen Elizabeth Hospital
  - Detection of disseminated tumour cells in colorectal cancer using tumour-specific gene expression markers and immunohistochemical RT-PCR
  - **Amount:** $67,808

- **P Hewitt, J Moore, C Platen**
  - Dept of Gastroenterology
  - Flinders Medical Centre
  - Gender and anatomical site differences in the survival benefit from SFU chemotherapy for colorectal cancer patients
  - **Amount:** $51,340

- **D Horsfall**
  - Dame Roma Mitchell Cancer Research Laboratories
  - Hanson Institute
  - Modulation of prostate cancer cell attachment to stromal matrix by versican
  - **Amount:** $56,799

- **Y He, G Young, R Le Leu**
  - Flinders Centre for Digestive Health
  - Dept of Gastroenterology
  - Flinders Medical Centre
  - Do dietary interventions protect in a p53 deficient model of colorectal tumorigenesis?
  - **Amount:** $56,000

- **S Kumar**
  - Dept of Haematology
  - Hanson Centre for Cancer Research
  - Regulation of caspase-2 activation and its implications in acute promyelocytic leukaemia
  - **Amount:** $51,340
### Reports

#### THE CANCER COUNCIL TASMANIA

**Total Research Funded** $2,201,447

- **Centre for Cancer Control Research** $222,000

**Other Research Programs for 2003**

<table>
<thead>
<tr>
<th>Program Name</th>
<th>awardee</th>
<th>amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>RD’Andrea, Child Health Research Institute</td>
<td>G Buchanan, University of Adelaide</td>
<td>$62,200</td>
</tr>
<tr>
<td>OLF</td>
<td>M Whitehead, J Gorman, D Peet</td>
<td>$61,000</td>
</tr>
<tr>
<td>G Lindeman, D Amor, J Kirk, J Gathers, J Goldblatt</td>
<td>N Ahmed, M Quinn</td>
<td>$65,000</td>
</tr>
<tr>
<td>J McKay The molecular genetics of familial prostate cancer</td>
<td>N Ahmed, M Quinn</td>
<td>$20,000</td>
</tr>
<tr>
<td>S Ragg University of Tasmania</td>
<td>N Ahmed, M Quinn</td>
<td>$47,800</td>
</tr>
<tr>
<td>G Lindeman, D Amor, J Kirk, J Gathers, J Goldblatt</td>
<td>N Ahmed, M Quinn</td>
<td>$65,000</td>
</tr>
</tbody>
</table>

#### THE CANCER COUNCIL VICTORIA

**Total Research Funded** $308,860

- **Centre for Cancer Control Research**
  - **Total Jeanne Foster scholarships** $3,300
  - **Total fellowships** $124,400
  - **Total research grants** $235,000

**Other Research Programs**

- **Total other research programs** $70,560

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Reports

POSTGRADUATE RESEARCH SCHOLARSHIPS AND VACATION STUDENTSHIPS

J Becanovic, Dept of Biochemistry and Molecular Biology, Monash University $21,150
T Can, Baker Medical Research Institute $43,969
A Deans, Peter MacCallum Cancer Institute $5,288
J Dow, Peter MacCallum Cancer Institute $21,150

S Foo, Ludwig Institute for Cancer Research $2,263
H Gan, Ludwig Institute for Cancer Research $27,150
K Moran, Dept of Biochemistry and Molecular Biology, Monash University $21,150
R Redvers, Peter MacCallum Cancer Institute $21,150
W Shi, Dept of Microbiology and Immunology, University of Melbourne $27,150
J Stone, Dept of Public Health, University of Melbourne $21,150
S Yong, Dept of Medicine, University of Melbourne $6,788

Vacation Studentships $52,405
Total scholarships and studentships $199,763

FELLOWSHIPS

Carden Fellowship $200,000
D Metcalf, Walter and Eliza Hall Institute of Medical Research

Queensland Cancer Fund

QUEENSLAND CANCER FUND

RESEARCH GRANTS

C Baldick, Y De Deene, B Healy, A Whitaker, O Schiff Queensland University of Technology $70,000
Development of ultrasonic scanner for evaluation of radiotherapy polymer gel dosimetry changes

A Boyd, A Yap, G Burns Queensland University of Technology $72,590
The role of truncated transcripts of the Fat protocadherin in T lymphocyte tumours

B Gabrielli, J Hancock University of Queensland $72,590
Mitotic regulation of the Ras/RafMEK/ERK pathway

I Frazer, J Wellington University of Queensland $70,000
Evaluating therapeutic interventions to overcome tolerance to tumour antigens

S Burrows, T cell recognition of peptides derived from tumour antigens and bound to non-self MHC molecules

R Redvers, Peter MacCallum Cancer Institute $72,590
Characterisation of a novel human DNA damage response protein that interacts with the CHK2 and P53 tumour suppressors

G Lindeman, G Suthers, G Thorne, J Kirk, M Aitken, R Kefford, R Jass, J Aitken, K ConFab: A consortium for research into familial melanoma progression

A Jefferson, D McFarlane, I Colman, L Wu Walter and Eliza Hall Institute of Medical Research $412,000
Centre for Behavioural Research in Cancer

A Whittaker, D Schlect Queensland Institute of Medical Research $52,990
Centre for Clinical Research in Cancer

R Redvers, Peter MacCallum Cancer Institute $348,000
Walter and Eliza Hall Institute of Medical Research

Total fellowships $443,888

OTHER RESEARCH PROGRAMS

Medical and scientific activities $190,000
Total other research programs $109,000

CANCER CONTROL RESEARCH INSTITUTE PROGRAMS

Cancer Epidemiology Centre $596,000
Vic Cancer Registry

Centre for Clinical Research in Cancer $1,096,000
Walter and Eliza Hall Institute of Medical Research

Walter and Eliza Hall Institute of Medical Research $4,614,000
Total cancer control research institute programs

TOTAL RESEARCH FUNDED $7,047,151

26 Cancer Forum - Volume 27 Number 1 - March 2003

27 Cancer Forum - Volume 27 Number 1 - March 2003
QCF/School of Social Science UQ: The ethnic experience of cancer in Queensland – A case study of the Chinese and Vietnamese communities in Brisbane $14,937
QCF/Gift of Medicine: Cancer support centre (psychosocial oncology) $100,000
QCF/School of Population Health and Institute for Molecular Biosciences UQ: Genetic science, molecular biotechnology and the public’s perceptions of future prospects for the care and prevention of cancer $27,000
QCF/School of Public Health, QUT/School of Psychology UQ: Quality of life and unmet needs of colorectal cancer patients at the time of diagnosis and treatment $55,000
Total collaborative studies $233,000

EPIDEMIOLOGY AND BEHAVIOURAL RESEARCH PROGRAMS
QCF Cancer Epidemiology Unit
Total epidemiology and behavioural research programs

OTHER RESEARCH GRANTS
Familial adenomatous polyposis register $44,540
Australian paediatric cancer registry $43,679
Total other research grants $88,219

PHD SCHOLARSHIP PROGRAM
2001 – 2003
R Allard, Dept Physiology and Pharmacology, University of Queensland $19,500
S Duffy, Division of Cancer and Cell Biology, Queensland Institute of Medical Research $19,500
S Wright, George Roberts Scholar, QLD Dept Physiological and Pharmacology, James Cook University $19,500
2002 – 2004
M Rinaldi, 2002 John Earnshaw Scholar School of Psychology, University of Queensland $21,500
S Joseph, Institute for Molecular Bioscience, Queensland University $19,500
L Papp, Signal Transduction Lab, Queensland Institute of Medical Research $19,500
2003 – 2005
L Packer, 2003 John Earnshaw Scholar School of Psychology, University of Queensland $21,000
J Kiewiet, Division of Cancer Immunotherapy, Queensland Institute of Medical Research $19,500
H Hacken, Division of Cancer and Cell Biology, Queensland Institute of Medical Research $19,500
R Parrett, Mater Medical Research Institute $19,500
Total PhD scholarship program $198,500

TOTAL RESEARCH FUNDED $4,069,896

CANCER FOUNDATION OF WA

RESEARCH GRANTS
L Abraham, D Spagnolo YY 1 and AP 1 expression in anaplastic large cell lymphoma $55,000
B Dwyer, School of Pharmacy Curtin University of Technology An investigation of the specific targeting of cancer cells by adenosinomimetics $47,372
G Forbes, J Edwards, R Mendelson, L Fritschi A comparison of screening tests for colorectal neoplasia in average risk asymptomatic subjects $31,423
M Garlepp, S Fox School of Pharmacy Curtin University of Technology Induction of anti-tumour immunity by manipulation of endogenous antigens $55,000
G Lindenmayer, J Goldblatt Genomic Services of WA King Edward Memorial Hospital and Princess Margaret Hospital IcOnFab: The Kathleen Cunningham Consortium for research into familial aspects of breast cancer $27,500
A Lane, C Bresolin, X Xu, WU School of Public Health Curtin University of Technology Tea consumption and epithelial ovarian cancer survival: a prospective cohort study $54,800
R Minchin Enhancement of cancer gene therapy by combination of nitroreduction and phase II metabolism $55,000
G Fairbairn, J Edwards, R Mendelson, L Fritschi Department of Gastroenterology and Hepatology Royal Perth Hospital A comparison of screening tests for colorectal neoplasia in average risk asymptomatic subjects $31,423
R Nelson, D Robinson Department of Medicine University of Western Australia Evaluating the effects of intra-tumoural cytokine therapy on tumour-infiltrating T cells and tumour growth $55,000
J Olijnyk, J Hutchinson, G Yesh Department of Medicine University of Western Australia Determining the effects of arterial therapy of chronic hepatitis C on hepatic oval cells and risk for hepatocellular carcinoma $55,000
D Bowtell, N Zeps, I Hammond Peter MacCallum Cancer Institute Sir Charles Gardiner Hospital Molecular epidemiology of ovarian cancer: The Australian Ovarian Cancer Study - WA, TAS and a national clinical follow-up core $36,000

Cancer Forum - Volume 27 Number 1 - March 2003
COSA Annual Scientific Meeting 2002
The 29th annual scientific meeting of COSA was held at Darling Harbour in Sydney in November 2002. This meeting represented a departure from the previous Brisbane meeting, with a decrease in the number of concurrent group sessions and an emphasis on joint sessions and multidisciplinary presentations and symposia.

Delegates heard from a wide range of speakers, courtesy of a number of concurrent or preceding meetings. Joint sessions were held with the Second Sino Australian New Zealand Conference on Surgical Oncology, the Australian Society for Breast Diseases, the Australian Association of Cancer Registries and the Australian Society for Clinical Oncology.

The first day was devoted to individual group meetings. The most heavily attended – with standing room only – was the Second Sino Australian New Zealand Conference on Surgical Oncology, where presentations were made with equivalent contributions from Australian and Chinese surgeons in colorectal cancer, oesophageal, gastric and breast cancers. Major overseas speakers included a distinguished Chinese faculty and Professor Irving Taylor from the UK on colorectal cancer related liver metastases, and Dr Hans Bonnennkamp from the Netherlands on gastric surgery. This proved to be one of the largest surgical oncology sessions ever held at COSA, and we hope it will lead to an increased presence of surgeons at future meetings.

Concurrently, the Australian Society for Breast Diseases and the Breast Group of COSA held a day-long program. Filled to capacity, the presentations included minimally invasive surgery, diagnostic and adjuvant therapy and issues of survivorship. In addition to a stellar local cast, the overseas speakers included Professor Kathy Pritchard from Toronto who did a major review on minimally invasive surgery and mammography/ultrasound.

On the second day of the meeting was followed by a keynote address by Professor Rick Keeford on molecular horizons in treatment. His overview of the translation of molecular knowledge to the delivery of novel therapies in the clinic was forceful and educational, with an outstanding use of multimedia.

A further travel prize by Mayne Pharma was given to Dr Jenny Denholm for a presentation on “Metastatic cancers”, and book prizes to Dr Trevor Leong for “Radiation in gastric cancer” and Dr Michael Dooley for “Dosing in obese patients”. This session highlighted like no other the great importance of COSA to cancer care delivery in Australia. A session of the best research in the meeting included an epidemiologist, a professor of nursing, a pharmacist, a psychologist and a radiation oncologist, all sharing the podium. No other cancer society in the world successfully combines the talents of so many different health professionals involved in the care of cancer patients.

The MOG Pierre Fabre award lecture was by Professor Lester Peters, one of the most famous radiation oncologists Australia has produced, on the international study headed by him and Dr Danny Rischin on a novel approach to treatment of head and neck cancer with a new radiosensitiser tirapazamine.

Concurrent workshops on sexuality and cancer, clinical trials recruitment, an update on hereditary cancer and on dealing with cancer in the family meant attendees were never short of options and an emphasis on joint sessions and multidisciplinary presentations and symposia. A wine tasting highlighting the wares of the Mudgee region capped a busy day.

The meeting was able to provide a wide range of “meet the professor” sessions including “Good practice in surgical oncology” by Professor Irving Taylor (sponsored by the Surgical Society), “Breast cancer and HIV” by Kathy Pritchard, “Management of mucositis” by Dorothy Keefe, “Advances in radiation oncology” by Andrew Turrisi (sponsored by Aventis), “Assessing quality of life” by Darius Razavi (jointly sponsored by the National Breast Cancer Centre), and Dr Mark Tannock (sponsored with the Head and Neck Society) on “Critical interpretation of medical literature”.

The formal opening by Professor Marie Bashir, Governor of NSW, on the second day of the meeting was followed by a keynote address by Professor Rick Keeford on molecular horizons in treatment. His overview of the translation of molecular knowledge to the delivery of novel therapies in the clinic was forceful and educational, with an outstanding use of multimedia.

State of the art symposia were held in management of lung and breast cancer, with participation of all disciplines from basic science to palliative care.

A further travel prize by Minyane Pharma was given to Professor Deborah Czernichow for a presentation on “Management of mucositis” and book prizes to Dr Trevor Leong for “Radiation in gastric cancer” and Dr Michael Dooley for “Dosing in obese patients”. This session highlighted like no other the great importance of COSA to cancer care delivery in Australia. A session of the best research in the meeting included an epidemiologist, a professor of nursing, a pharmacist, a psychologist and a radiation oncologist, all sharing the podium. No other cancer society in the world successfully combines the talents of so many different health professionals involved in the care of cancer patients.

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State of the art symposia were held in management of lung and breast cancer, with participation of all disciplines from basic science to palliative care.

A highlight of the day was the “best of the best” abstracts session. Five presentations, originally nominated by each group and narrowed down by a larger panel, were presented. Our overseas guests judged the presentations of the three best. Our international travel prizes kindly donated by Pharmacia and Eli Lilly were Professor Patwy Yates for her paper on “Behavioural intervention for cancer pain” and Professor Graham Giles for his paper on the “Risk of colorectal cancer associated with food consumption”.

A further travel prize by Minyane Pharma was given to Dr Rebecca Hagerty for her paper on “Metastatic cancers”, and book prizes to Dr Trevor Leong for “Radiation in gastric cancer” and Dr Michael Dooley for “Dosing in obese patients”.

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Australian Behavioural Research in Cancer

This is a regular feature in Cancer Forum describing behavioural applications in cancer prevention. Australia has five behavioural research centres: the Cancer Prevention Centre, the Centre for Health Research and Psycho-oncology, the Cancer Control Research and Evaluation Centre, the Centre for Behavioural Research in Cancer and the Centre for Cancer Control Research (C3CR). The Cancer Council of South Australia. This report has been edited by Anne Gibbs (C3CR) from the reports received.

New results
- Centre for Behavioural Research in Cancer (CBRC), WA
- Evaluation of the Prostate Care Nurse Distance Education Program

Nurses working with men with prostate cancer require ongoing education and training in prostate care to meet the multiplicity of needs faced by these men. The 13-week Prostate Care Nurse Distance Education program developed by The Cancer Council Victoria and Latrobe School of Nursing and Midwifery is a tertiary-based education package for nurses, which can be undertaken full or part-time or as part of a graduate diploma in advanced nursing. The program aims to educate nurses in the specialty areas of prostate cancer and prostate disease so they have access to up-to-date information, current guidelines and education, as well as enabling students to develop the resources to establish a network of information and support across Australia and overseas for delivering and professional development purposes.

An evaluation of the course, designed and conducted by staff at CBRC, was undertaken by students enrolled in the first two intakes in June and September 2001. Forty-six students participated in one or more stages of the evaluation. The topics the respondents reported as most helpful were treatment options (55%) and understanding and managing side effects of treatment (23%). Other topics reported as helpful included the topic on prostate cancer in general (19%), psychosocial issues (19%), anatomy and physiology (14%), support services and resources (12%) and grief and loss (12%).

Thirty-six (78%) students reported planned changes to their support services and resources (12%) and grief and loss (12%). The topic on prostate cancer in general (19%), psychosocial options (55%) and understanding and managing side effects at CBRC, was undertaken by students enrolled in the first debriefing and professional development purposes.

Information and support across Australia and overseas for appropriate services, and ongoing education. It also enables prostate disease so they have access to up-to-date information, to educate nurses in the specialty areas of prostate cancer and of a graduate diploma in advanced nursing. The program aims which can be undertaken as a stand-alone certificate or as part of a course in years of age. The results were similar to those obtained from across the 20-69 year age span, with approximately 66% of the likely coverage of the population with cervical screening. In hysterectomy rates in South Australia and their effect on hysterectomy rates

Cervix screening coverage adjusting for important geographic differences. Fewer women, who are socio-economically disadvantaged and from the country, have an intact uterus than metropolitan women. While the effects on estimated screening coverage of adjusting for geographic differences in hysterectomy rates generally were small, there were some regions where the effect of adjusting for age and especially among older age groups. These findings will be relevant in the evaluation of screening coverage in South Australia and for setting priorities for health promotion.

Canberra Cancer Quality of Life Project

Further findings:
- A group of patients with advanced cancer and their caregivers' knowledge of treatment intent (117 pairs) identified high levels of congruence (75%) that the illness was life-threatening but pronounced disagreement in perception in all other relevant areas of treatment. One third of pairs were aware of the true nature of treatment goals, and one third were partially aware in that one respondent had the wrong perception. Among the final third classified as "non-aware", two distinct groups were identified those where both respondents considered the aim of treatment was to cure (15%) and those other defined as confused (22.2%) where both indicated they did not know the purpose of treatment intent, or one said they did not know, and the other party believed treatment was to cure. Significant predictions included gender and whether respondents lived in a metropolitan or non-metropolitan area for both patients and for caregivers, together with patient clinical characteristics marked by metastatic spread of disease and time to death.

- Centre for Health Research and Psycho-oncology (CHERP), NSW (previously the Cancer Education Research Program (CERP))

How might we improve adolescent use of sun protection measures?

Australia has one of the highest incidence rates of melanoma in the world. During the 1980s and 1990s Australia became a world leader in research in this area, with the aim of improving public health. The importance of further research into the causes of these cancers is highlighted. Progress is occurring in the treatment of these cancers, with gains in patient survival being most apparent for lymphomas and leukemias, particularly childhood leukemias. A reduction in mortality of approximately 40% from childhood leukemia over a 20-year period in South Australia is attributed to advances in chemotherapeutic and bone-marrow transplantation. The Cancer Council South Australia also has drafted a sixth report in this monograph series, with participation from the C3CR, on survivorship following a diagnosis of cancer. Both monographs are due for release in early 2003.

Cervix screening coverage adjusting for importance of further research into the causes of these cancers and in the health field, and the public with information on cancer trends in South Australia trends in health service provision and improvement in outcomes. Compared with cancers addressed in previous monographs, limited scope for primary and secondary prevention is apparent for these haematological tumours. Nonetheless, the monograph indicates the desirability of avoiding unnecessary exposures to ionising radiation, benzene and other solvents, chemicals, pesticides, herbicides, and to drugs and infections that suppress the immune system. The importance of further research into the causes of these cancers is highlighted. Progress is occurring in the treatment of these cancers, with gains in patient survival being most apparent for lymphomas and leukemias, particularly childhood leukemias. A reduction in mortality of approximately 40% from childhood leukemia over a 20-year period in South Australia is attributed to advances in chemotherapeutic and bone-marrow transplantation. The Cancer Council South Australia also has drafted a sixth report in this monograph series, with participation from the C3CR, on survivorship following a diagnosis of cancer. Both monographs are due for release in early 2003.

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schools adopted an ‘any hat is better than no hat’ policy with the approval of students wearing caps or ‘bucket’ hats. The main reasons cited for adopting the policy was to have sunshine protection available for student use on specific occasions such as physical education, sports days and excursions. The most common strategies for providing hats for student use outdoors between 10am and 3pm was the availability of indoor venues for students during lunchtimes and morning breaks.

Individual interviews and focus group discussions were also held with principals, teachers, students and parents from four schools across Sydney, investigating these interviews explored facilitators and inhibitors to the development and implementation of sun protection policies and ways of improving the sun protection knowledge, awareness and behaviours of secondary school communities. While sun protection was recognised as an important issue, its priority was relatively low compared to other competing health issues such as drug abuse, mental health and obesity. Schools were dealing with having a sun protection policy was not seen to be as relevant for secondary schools as it is for primary schools, particularly with the expectation that high school students should be taking personal responsibility for their health and well-being. A key issue for the staff interviewed was not so much the development of a policy but the implications in terms of its implementation. The major barriers were trying to ‘force’ or manage the policy and teenage compliance. Immediately was found to be an effective means of promoting sun protective behaviours, such as staff handing out sunscreen to students at sporting events. The use of reminder systems for staff was believed to be important in encouraging sun safe behaviour as well as having students have choice, particularly with being permitted to wear their own hats and sunglasses.

Research in the pipeline

n CBCC

Testing for the early detection of bowel cancer in rural Victoria

There is level 1 evidence that screening the population using the faecal occult blood test (FOBT) can reduce colorectal cancer mortality. A Centre for Cancer Control and Prevention (C3P) project will be investigating a program to implement screening in rural and metropolitan sites across Australia. Little is known about the extent to which people in a rural setting are likely to participate in screening if recommended by their general practitioner. A team led by Trish Livingstone is aiming to gain an understanding of the factors associated with participation in the early detection of bowel cancer using FOBT.

One hundred people aged 50-74 years who presented to a medical centre in a rural city, were approached to participate in this study. Written consent was obtained and a brief questionnaire completed prior to the consultation with the doctor, discussing the bowel cancer screening pilot program is being implemented in rural and metropolitan sites across Australia. While the optimal timing for referral to palliative care has not yet been identified, there is a growing body of evidence to suggest that the needs of advanced cancer patients may not be adequately met by later referral to palliative care.

A team of researchers comprising Associate Professor Alf Girgis, Dr Chris Paul and Claire Johnson from the Centre for Cancer Control and Prevention, University of NSW/University of Newcastle, is conducting research to develop a deeper understanding of current referral patterns, perceptions of palliative care and barriers to appropriate and timely referral of cancer patients to palliative care services.

Initially, a qualitative approach will be used to investigate the perceptions and ratio of potential influences on referral patterns and behaviour, attitudes to timely referral, and to investigate the use of predictors or triggers (eg patient circumstances or characteristics) to initiate referral to palliative care services. This will involve semi-structured telephone interviews across Australia with medical referrers to palliative care services, and focus groups of multidisciplinary health care professionals. Focus groups are to be conducted in New South Wales, Victoria and Western Australia. Outcomes from this phase of the research will include a list of potential factors that encourage or hinder the referral of perceptions and attitudes to palliative care services, and the identification of triggers used to initiate the referral process. This information will then be used to develop a quantitative instrument that will explore how extensively these particular issues influence the referral of cancer patients nationally.

As a result of this research interventions may be implemented to increase the utilisation of palliative care services in Australia, and to ensure equitable access for patients with cancer to palliative care, at an appropriate time in the disease trajectory. Key areas that require publicity and education will be identified.

n CBCC

“The No Fry” media campaign

Evaluation of the Cancer Foundation of Western Australia’s 2002-03 “No Me Fry” media campaign continues, and a report summarising the findings of the tracking of the National Tobacco Campaign has been completed for the third volume of Australia’s National Tobacco Campaign Evaluation Report.

n CBPC

The PLACE project

Physical inactivity has recently been identified as a behavioural risk factor for breast and colon cancer, both independently and through its influence on weight gain (see International Agency for Research on Cancer, IARC, Handbooks of Cancer Control). The project will review the 10 most frequently-read general, health or food related monthly or bi-monthly magazines over a 12 month period, to identify cancer-related articles, the mention of nutrition. It is intended that this study will be the first phase of a more detailed content analysis of nutrition and cancer coverage in popular magazines.

The aim of this project is to determine the extent to which nutrition and cancer is covered in popular magazines, and to describe the type and nature of articles. The results of the study will be used to inform the development of the PLACE project and data will also be collected regarding the experiences and needs of managers and day-to-day practitioners involved with nutrition and cancer education. The project will also investigate the current and perceived needs of stakeholders involved with nutrition and cancer education to guide the development of the PLACE project.

n CBCC

Testing for the early detection of bowel cancer in rural Victoria

“Identifying the role of genes and the environment in the development of smoking and drinking behaviours of adults” Melanie Wakefield will investigate “Possible harmful influences of advertising for nicotine gum and patch” during 2003.

n CBHR

After 14 years, the Cancer Education Research Program (CERP) has changed its name to better reflect its full range of research activities and future directions. The new title is the Centre for Health Research and Psycho-oncology (CHeRP).

Congratulations to Associate Professor Alf Girgis, Associate Professor D’Este and Mo Allen Boys who were awarded a National Health and Medical Research Council grant of $440,000 over three years from 2003 to 2005 for a population based longitudinal study of cancer survivors’ psychosocial and physical wellbeing.

In November 2002, CHeRP hosted a workshop on “Practical aspects of needs assessment in oncology” at the Sydney Convention Centre. This workshop was conducted as the first step in the development of user-friendly procedures for scoring, analysing, interpreting and reporting the collected data via the Supportive Care Needs Survey. Thirty-three participants representing consumer advocacy, health care professionals, researchers, and support service administrators attended. The workshop was facilitated by Associate Professor Alf Girgis and focused on the practical aspects of using the survey including: (i) practical and potential uses of the perceived needs surveys, (ii) barriers to using the survey and data and (iii) additional resources or support required to facilitate use of the survey. The outcomes of the workshop will be considered by a group of clinical and scientific advisors in March 2003 to consider ways of data the best meet the identified uses of the survey.

CHeRP has had a number of papers published and accepted for publication, including:

- “RA Walsh. “Nicotine lozenge trial: a ‘real-world’ perspective.” Archives of Internal Medicine, 162(2), 268-274.
- “RA Walsh, F Tzelepis, C Paul. “Environmental tobacco smoke in homes, motor vehicles and licensed premises: Community attitudes and practices.” Australian and New Zealand Journal of
Australian's Biggest Morning Tea – hosts set to raise their cups again in May

Now in its tenth year, Australia’s Biggest Morning Tea (ABMT) looks set to capture the attention of thousands of participants yet again this May with 40,000 Australians expected to host morning teas.

The Cancer Council Australia’s member organisations are already working hard to ensure the popular event – scheduled for 22 May – is a success, and the national target of $6 million is reached.

A new creative campaign will launch ABMT in April. Anyone interested can register as a host from March onwards via the new look website at www.biggestmorningtea.com.au or by calling 1300 65 65 85.

Hosts will receive a kit containing posters, Bushells tea bags, a donation box and other materials to ensure their morning tea is a huge success.
National conference to focus on investment in tobacco control

The case for greater long-term investment to reduce smoking rates will be the focus of a national conference to be hosted by The Cancer Council Victoria in April.

Delegates will hear from a group of outstanding international and Australian speakers at the 2nd Australian Tobacco Control Conference, to be held in Melbourne from 9-11 April 2003. Leading international tobacco control experts including Dr Michael Cummings and Dr Frank Chaloupka from the US, Dr Ann McNeil from the UK and New Zealand’s Professor Alastair Woodward will present keynote addresses.

A number of high profile Australian speakers will also be giving keynote addresses, including Australian Competition and Consumer Commissioner Chair Professor Allan Fels, and Professor Simon Chapman.

Lawyer Peter Gordon from Slater and Gordon will also give a keynote address about tobacco litigation and his firm’s representation of Rolah McCabe in her lawsuit against tobacco company British American Tobacco Australasia.

The conference aims to show that tobacco control measures – like helping smokers quit and reducing the health effects of passive smoking – are one of the best investments communities can make to enhance their health – and their economic wellbeing.

It will also focus on new marketing tactics of the tobacco industry.

Full details about the conference themes and program can be found at http://tobaccocontrol03.conference.net.au

In the news – prostate cancer testing

Debate about the pros and cons of testing for prostate cancer has been in the headlines in recent months.

The Cancer Council Australia’s position on this issue – that the decision to be tested is one to be made by individual men, on the basis of informed consent – is stated in a letter from CEO Alan Coates on its website (www.cancer.org.au). The Cancer Council Australia’s Parliamentary Cancer Information Network.

Further details about the testing debate can be found on the Cancer Council’s website, which has been in the headlines in recent months.

The Cancer Council Australia’s position on this issue – that the decision to be tested is one to be made by individual men, on the basis of informed consent – is stated in a letter from CEO Alan Coates on its website (www.cancer.org.au).

For a copy of the latest issue of Cancer Update – which summarises presentations given at the briefing – please email info@cancer.org.au.

New offices

The Cancer Council Australia, Clinical Oncological Society of Australia (COSA) and the Australian Cancer Network (ACN) have moved.

Level 5, Medical Foundation Building 92-94 Parramatta Road Camperdown NSW 2050

GPO Box 4708, Sydney NSW 2001

Telephone: (02) 9306 3100

Facsimile: (02) 9306 3101

Email: info@cancer.org.au

Website: www.cancer.org.au

The Australian Cancer Network

Phone: (02) 9306 3120

Fax: (02) 9306 3121

Email: acn@cancer.org.au

Website: www.cancer.org.au/acn

Staff changes at The Cancer Council Australia

A pivotal member of the COSA secretariat was farewelled in March.

Rozanne Gilbert helped organise five COSA annual scientific meetings during her time at The Cancer Council Australia, and her name and voice are familiar to many of COSA’s members. The Cancer Council and COSA thank Rozanne for her hard work and dedication, and wish her all the best with her move to country NSW.

The Cancer Council has new staff in the form of Kerrin Burgess, PA to CEO Alan Coates; Sonia Gibbons, PA to Finance and Business Manager Robert Frith; and Matthew Wood, who joins the accounts department.

CEO profiles

In each edition of Cancer Forum this year we will be profiling CEOs of The Cancer Council Australia’s member organisations.

Cancer Foundation of WA

Susan Rooney

The Cancer Foundation of WA appointed Ms Susan Rooney as its new Chief Executive Officer in April 2002, following the resignation of Mike Daube.

Ms Rooney has had extensive high-level experience in the leadership and management of non-government community organisations, having served as executive with the Fire and Emergency Services Authority, the Sydney Anglican Retirement Villages, Rehabilitation Tasmania and the Royal Blind Society of NSW. In each of these positions she has successfully implemented major change management programs.

Ms Rooney has a health background in physiotherapy, graduating from Curtin University. She has since completed a MBA from the University of WA and the Advanced Program in International Management at the Copenhagen Business School.

The Cancer Council Victoria

Professor David Hill AM

Before becoming Director of The Cancer Council Victoria, Professor David Hill - a behavioural scientist - was founding Director of Cancer Council Victoria’s Centre for Behavioural Research in Cancer.

Prof Hill is a Professorial Fellow at the University of Melbourne, an Adjunct Professor at Deakin University and an Honorary Professor at Monash University. In 2001, he was made a Member of the Order of Australia (AM) for "services to the promotion of communities health, particularly in the development of cancer awareness and prevention programs".

Prof Hill, who received his PhD in psychology from the University of Melbourne, has authored or co-authored over 200 scientific articles and reports in the medical, public health and psychological literature. His published work includes research on the prevalence of adolescent and adult smoking, strategies for smoking cessation, reduction of smoking uptake, smoking regulation, behavioural aspects of screening mammography, management of primary operable breast cancer, efficacy of breast self-examination, monitoring trends in skin cancer prevention, and exploring determinants of behaviours related to skin cancer prevention.

In 1990 he chaired the International Union Against Cancer project on behavioural sciences, and was Secretary to the 1996 World Conference for Cancer Organisations. He holds senior positions on major national committees, including the NHMRC Health Advisory Committee.

Prof Hill has been successful in winning research grant funds in the NHMRC’s national competition, including as a member of teams of Principal Investigators which have been awarded grants totalling over $10m in 2001 and 2002.

In 1996, the Federal Minister for Health invited him to chair the Ministerial Tobacco Advisory Group to establish the first comprehensive national anti-smoking campaign launched in Australia. He is now chairman of the National Expert Advisory Committee on Tobacco, which is responsible for the National Tobacco Strategy to which all states and territories committed in June 1999.

Prof Hill’s appointment followed the resignation of Professor Robert Burton, who had been Director of The Cancer Council Victoria from December 1995.

Queensland Cancer Fund

Dr Jeff Dunn

Dr Jeff Dunn took up the position of Executive Director at the Queensland Cancer Fund in May 2003, upon the retirement of Mr Graeme Brien. Dr Dunn is only the third person to hold this office in the 41-year history of the Queensland Cancer Fund, and brings to the role substantial experience.

Dr Dunn has been a staff member of the Queensland Cancer Fund since 1989, filling the role of Director of Community Epidemiology Centre, addressed federal MPs at the breakfast meeting at Parliament House in Canberra.

For a copy of the latest issue of Cancer Update – which summarises presentations given at the briefing – please email info@cancer.org.au.

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REACHING FOR THE STARS – a profile of Professor Lester Peters, winner of the 2002 MOG/ Pierre Fabre Cancer Achievement Award

One of Australia’s leading cancer specialists could have been lost to the cosmos.

As a young boy in country Queensland, Lester Peters wanted to be an astronomer when he grew up.

“I was all set to go into the science faculty – I’d planned to become an astronomer,” he says. “But a family friend told me I was mad, that I’d never have any job options – I should do medicine, and if I wanted I could use that background to become a physicist or engineer.”

But once Professor Peters, 60, started medical school, there was no going back – he soon became excited about a career in medicine. He decided on a technical specialty – radiation oncology – which in the late 60s was the only medical specialty related exclusively to cancer.

“I became fascinated with cancer as a disease – it was such a mystery at the time. Most of the treatments seemed empirical. I was strongly motivated to get involved in research,” he says.

After registrar training in Brisbane, Professor Peters won a scholarship to do research work at the Gray Laboratory in the UK, which at the time was the leading radiobiology lab in the world. Four years later, with no possibility to pursue radiobiology on his return to Australia, he joined the prestigious MD Anderson Center in Houston for a mix of clinical and lab work.

In 1982, the chair of the radiotherapy department at MD Anderson retired, and the position was offered to Professor Peters. He stayed in this role until 1995, during which time he became internationally recognised as a leader in academic radiation oncology. At age 53, he was lured back to Australia – with his Australian wife and two children – by the creation of the first professional post in radiation oncology at the University of Melbourne at the Peter MacCallum Cancer Institute.

A year after taking up this position, he started work on research which he considers the jewel in the crown of his career.

Professor Peters and Peter Mac colleague Dr Danny Rischin, a medical oncologist, Unveiled the potential for a new treatment approach to advanced head and neck cancer while going through some pre-clinical work. Their idea was to use the triple combination of trastuzumab, cisplatin and radiotherapy. Trastuzumab is a currently unlicensed prodrug that is selectively toxic to tumour cells starved of oxygen. In experimental tumour systems, it has been shown to enhance the effect of both radiotherapy and cisplatin. Drs Rischin and Peters persuaded the company that owned the patent on trastuzumab to let them conduct an exploratory study of the triple combination.

Although this Phase I trial was aimed at developing a suitable treatment protocol for further testing, the results were unexpectedly good – of the 16 patients who were near the end of the road with advanced disease, 14 had durable local eradication of their disease and 11 were long term survivors.

“This was an unheard of result in my experience and I’ve worked almost exclusively in head and neck cancer for the past 20 years, so I’ve treated a lot of patients. This was definitely worth pursuing further,” Prof. Peters says.

A Phase II trial involving 123 patients then went ahead under the banner of the Trans-Tasman Radiation Oncology Group (TRQG) comparing the combination therapy with a more standard form of chemo-radiotherapy.

Preliminary results of the Phase II trial confirmed the excellent results achieved in the Phase I study and showed that patients taking the experimental therapy fared substantially better than those receiving standard therapy. “The survival rates were very good compared with anything seen before.”

Professor Peters and Dr Rischin are now leading an international Phase III registration trial which will involve 550 patients in 83 centres worldwide, including 13 in Australia and New Zealand. Interim results of this trial should be available in about 2.1 years.

At the beginning of 2002, Professor Peters resigned his position as Director of Radiation Oncology at Peter Mac to take on the responsibility of setting up a new Foundation to support the strategic goals of the Institute. More recently, he was elected Dean of the Faculty of Radiation Oncology.

The MOG/Pierre Fabre Cancer Achievement Award recognises a lifetime of achievement in the field of cancer. Last year’s winner was Emeritus Professor Tom Reeve AC CBE, Executive Officer of the Australian Cancer Network.

Services, a department that incorporates the Prevention and Early Detection Unit, Cancer Support Services, the Cancer Helpline and more recently, the Cancer Advocacy Program. While developing and managing these areas, he has also fulfilled key roles nationally with The Cancer Council Australia and internationally with the International Union Against Cancer. In this regard, Dr Dunn has worked extensively in supporting the development of cancer support programs in South East Asia.

Dr Dunn holds a PhD in sociology and maintains academic appointments as Adjunct Professor, School of Social Science, and Associate Professor, School of Population Health both at the University of Queensland. In addition, he is the Chairman of the Board of Management of the Queensland Cancer Fund-Griffith University Collaborative Centre for Psychosocial Oncology – a project located in the Griffith University School of Applied Psychology.

Dr Dunn has a long commitment to volunteering, with a special interest in intellectual disability. As well as his cancer-related volunteer work, for the past 14 years he has worked as a volunteer in support of people with an intellectual disability.

The July edition of Cancer Forum will profile The Cancer Council South Australia’s CEO, Associate Professor Brenda Wilson, The

BOOK REVIEWS

Aspiring reviewers

Cancer Forum publishes reviews of up to 80 new publications every year.

Self-nomination is invited from Australian-based readers for reviewers in every field of cancer interest.

Email your area(s) of expertise and contact details (including phone, fax, mail and email addresses) to info@cancer.org.au if you would like to join our panel.

ADULT LEUKEMIAS

P Wemik

Published by BC Dekker (2001)


RRP: $346.72

This book, in the Atlas of Clinical Oncology Series, ambitiously sets out to cover diagnostic and management aspects of adult leukaemias. The first half of the book is about etiology and diagnostics. There are excellent chapters on epidemiology and genetics, pathogenesis, morphology, immunophenotyping, cytogentic and associated molecular changes. In general, these chapters are well written, comprehensive and referenced, and beautifully illustrated. There are inevitable omissions resulting from “not” new findings being published after publishing deadlines have closed, the major one being the discovery of prognostically important FRA-3 mutations in one quarter of cases of adult acute myeloid leukaemia.

My main criticism of the first half of the book is the frequent overlap and repetition of material between chapters. For example, overlapping sections on immunophenotyping appear in chapters (Diagnosis), four (Morphology), and five (Immunophenotyping). Similarly, there are lengthy sections on cytogenetic abnormalities in three different chapters, with much repetition of material. The editor could have avoided this unnecessary lengthening of the text.

The second half of the book covers clinical aspects of adult leukaemias, including treatment, its complications, extramedullary leukaemia, and a final brief section on supportive care. The largest of these chapters, written by Yousef Ali and Martin Tallman, is on management, and covers treatment of all acute and chronic leukaemias, a major undertaking that perhaps could have been divided up among a larger group of authors. Nevertheless, this is an excellent and comprehensive review of the various types of adult leukaemias.

The section on the use of Gleevec (STI-571) in chronic myeloid leukaemia is unfortunately brief and does not include important recent information on the use of this drug. In addition, while the section on chronic lymphocytic leukaemia omits mention of the highly promising results using the Fludarabine, Cyclophosphamide, and Rituximab combination. Inevitably, these sorts of issues could have been divided up among a larger group of authors.

The book will interest advanced trainees in haematology, and perhaps medical oncology, wanting a comprehensive coverage of this topic in the one volume. Haematologists and oncologists regularly dealing with adult leukaemias may be attracted by the extensive bibliographies in each chapter, and the excellent illustrations, which might serve as teaching aids.

The main drawback, as usual, is the high cost ($346). The book comes with a CD containing all chapters in PDF format.

K Bradstock

Dept of Haematology

Westmead Hospital

Westmead, NSW

BREAST CANCER SOURCEBOOK (1ST ED)

E Puchta et al

Published by Omnigraphics


RRP: US$169.95

First impressions of the Breast Cancer Sourcebook provide an enticing array of chapters and topics, which would interest health professionals and consumers alike. It was good to see an overall use of basic medical definitions and a glossary of cancer terms, which were concise and user-friendly. It was reassuring to read a contemporary overview around controversial issues, such as the role of antipsychotic deodorants, oral contraceptives, alcohol and fat intake in the development of breast cancer. There was an excellent overview of complementary and alternative medicines used in managing breast cancer, explaining the origin of each approach and a summary of research to date.

Upon closer examination of the book, it was disappointing to find a very clinical, disjointed, lengthy text that was repetitious and resulted in a disturbing overlap between chapters. The greatest deficiency, however, was the lack of regard for psychological and support issues along the continuum of breast cancer. In what appeared to have been an afterthought, less than 20 pages of this 580-page test were allocated to address psychological issues of breast cancer for the woman and her family or carers. Similarly, issues of sexuality, body image and intimacy were addressed in a two-line summary, and the consumer voice was almost nonexistent throughout the clinical text. Diagrams were minimal and of poor quality, and detail was lacking about specific chemotherapy options or treatment regimes for early breast cancer. Overall, this is not a user-friendly resource book.

A Hordern

Registered Nurse, VIC

There are many breast cancer books to be found in bookshops, and they vary in content and depth. The Breast Cancer Sourcebook is an extremely comprehensive and detailed text.
on the topic. From a consumer’s point of view a few words of caution before you embark on this text. Firstly, the book is American and therefore provides reputable references and is all American. If you required specific Australian statistics and data, you would have to look elsewhere. Secondly, not every woman who is diagnosed with breast cancer wants to read about it in great depth. This is a text for someone who wants to learn all they can about the topic.

The book begins with an explanation of breast changes and factors that may lead to a diagnosis of breast cancer. It examines the stage and provides reputable references to back up the content. Screening tools and possible treatments are explained in an easy-to-understand way. A clear explanation of the different stages of breast cancer is provided and many sections have glossaries of key terms, and in some sections there are suggested questions for consumers to ask health professionals. The Breast Cancer Sourcebook also provides detailed sections on clinical trials and genetic testing for people with a familial history of breast cancer.

The final section on coping with life after breast cancer is helpful although brief. It is pleasing to see that a section has been included to cover males with breast cancer and some complementary and alternative therapies.

As it is in hard cover form and from the US it may well be unaffordable to many consumers. It would be a useful reference book in a library or on loan to women in a support group.

D Wilson Consumer Representative Breast Cancer Network Australia Melbourne, Vic

ENCyclopedia of Cancer 2nd Edition

J Bertino Published by Elsevier Science (2002) ISBN: 0-12-2261-1 2,800 pages RRP: $1,568.60

The revised encyclopedia now contains four rather than three volumes to accommodate the advances in cancer research in 220 articles. Typically of less than 12 pages each, they cover a range of topics from molecular biology and genetics through to clinical trials and cancer treatment. The authorship is predominantly, but not exclusively, North American. The encyclopedia format, which arranges articles in alphabetical order by title, is somewhat artificial in determining how on the title is phrased. Although the results in succeeding articles often bear no relationship to each other, navigation through the volumes is made easier by the contents grouped by subject as well as listed in alphabetical order. It has an excellent index of over 7,500 entries and at the end of each article many of the entries are cross-referenced to other chapters. The format of each article, which contains a glossary, outline and referencing of techniques for cloning disease-associated DNA and carcinogenesis complete a comprehensive overview of basic cancer biology.

The chapters on treatments include biological therapies and immunotherapy, chemotherapy and radiotherapy with radiobiology and photodynamic therapy. Specific articles highlight the development and mechanisms of action of commonly used chemotherapeutic agents while a dozen articles form a useful review of the mechanisms of drug resistance. There is also a section on updates on chemoprevention.

The brevity of the chapters on specific tumours means that they are of limited use in discussing treatment options in any detail, which is clearly not the focus of this collection and is better reviewed in other oncological texts. But aetiology and risk factors, when supported by the information in the basic biology chapters, are well covered. A small section on tumour imaging covers the more recent techniques of MRI, MRS and PET scanning.

The editorial staff have minimised the amount of duplication despite the large number of authors, and when this does occur it examines the issue from a different viewpoint and tends to reinforce and clarify the concepts being presented.

This is an up-to-date reference that provides an excellent overview of multiple areas of the rapidly expanding field of tumour biology, while relating this to the astology, diagnosis and management of cancer. It will be a useful initial reference on a wide range of topics for cancer clinicians and researchers.

In Olver
Professor of Cancer Care University of Adelaide, SA

GENETIC DISORDERS OF ENDOCRINE NEOPLASIA


The main focus of the text is genetics of endocrine neoplasias. Editors, Patricia Dahia and Chars Eng, together with individual chapter authors are renowned for their research in this field since the identification of germline RET mutations responsible for Multiple Endocrine Neoplasia type 2 (MEN2) in 1993, there have been rapid advances in our understanding of the molecular basis for this group of conditions. In addition to expanding our understanding of the disease pathogenesis, the availability of molecular testing allows accurate information for family members, which influences screening and management. This text provides a state of the art review on the molecular basis of inherited endocrine neoplasia, including its relevance to clinical practice. In addition to the previously well-characterised disorders such as MEN1, MEN2, and Von Hippel-Lindau disease, the text provides a comprehensive review on other conditions of emerging clinical importance such as hamartoma and lentigines syndromes.

The introduction entices us into the body of the text by providing a brief, but interesting clinical and molecular overview of the inherited endocrine neoplasia syndromes, which are each covered in more depth in the following chapters.

The first chapter provides a succinct outline of fundamental concepts relating to cancer genetics in addition to more complex areas of important such as gene methylation, imprinting, single-nucleotide polymorphisms (SNP) analysis, CNDA microarrays and proteomics with comprehensive referencing. It is an introduction of basic background knowledge and referencing of techniques for cloning disease-associated genes, which although clearly written, is aimed at an audience with some basic background knowledge of molecular genetics.

The following chapters include the clinical and molecular aspects of MEN1, MEN2, Von Hippel-Lindau disease, Carney Complex, and Carney Syndrome. The syndromes of particular interest to individuals with a strong molecular background or research interest. For the more clinically orientated reader, the molecular sections would serve as excellent reference material.

However, the sections covering clinical presentations, diagnosis, management of family members, treatment, genotype/phenotype correlation and molecular testing in individuals with apparently sporadic endocrine neoplasia are well presented as potential knowledge for specialist endocrinologists or cancer geneticists working in this field. The text is well researched, referenced and indexed. The content detail makes this a specialist text, which would be of valuable addition to an endocrinology, oncology or clinical genetics department library.

T Dudding
Hunter Genetics
Waranah, NSW

HANDBOOK OF GYN Oncology

Santoso & Coleman

This handbook was designed for the use of medical students, residents and fellows. In the preface, the authors state their aim that “readers will use this Handbook of Gyn Oncology as a guide, an atlas and a basic tool for those caring for gynaecological oncology patients. As a portable resource it would enable residents to cram in the early hours of the morning prior to the arrival of senior medical staff for a ward round. Its size leads you to believe the book was designed for a white coat pocket. However, Australian residents and fellows no longer wear white coats and may find it difficult to know where to keep their book.

There are separate brief chapters for each tumour site with the management recommendations being sound, well referenced and up-to-date. Current concepts such as sentinel node biopsy for vulval and cervical malignancies for cervical cancer are covered. There is also a balanced coverage of controversial issues, for example, lymphadenectomy in endometrial cancer, though the recommendations for bowel resection are only surgical management and do not cover the modern medical and palliative care approaches.

A major criticism would be the disproportionately large amount of space dedicated to the diagnosis and management of...
of medical diseases, as many of these conditions are rarely encountered in gynaecological oncology practice. In reality these complex situations would be managed by referring a physician rather than consultation with a pocket handbook. The book also provides a description of surgical procedures, which seems to have been written to assist the surgical resident in dictating operative reports.

In all texts, differences in terminology and drug names are to be expected between the American and Australian systems. In a commercial practice guidebook, however, these differences appear frequently and therefore limit the usefulness of the book. While being too brief to be a sole reference source for gynaecological oncology, the portable format of the handbook offers quick access to information on cancer types, treatment options and follow-up care.

J Maiden
Dept of Gynaecologic Oncology Royal North Shore Hospital St Leonards, NSW

HANDBOOK OF STATISTICS IN CLINICAL ONCOLOGY
J Crowley

The intended audience for this book is statisticians working in cancer research. At more than 500 pages it catalogues and describes the statistical techniques associated with clinical cancer research. It concentrates on the design and analysis of clinical trials, including phase I, phase II and phase III trials. There are also chapters on health-related quality of life measurement, economic evaluation, prognostic factor studies and meta-analysis. The techniques covered have applications in other areas of clinical research.

It is not a book to be read from cover to cover. Instead it is a reference book to be consulted as the need arises. Statisticians will find it a useful resource, however, non-statisticians will probably find much of the material is presented at a more technical level than they require.

More than 40 researchers (described as leaders in their fields) contributed to the book. This has created the (probably unavoidable) problem that the chapters are uneven in the way they cover their topics. Admittedly, the focus of the book is clinical trials, and the chapters that deal directly with this area are comprehensive and up-to-date. However other topics, such as economic evaluation and meta-analyses, are dealt with in a more superficial way.

In short, a good reference book for statisticians who will be designing and analysing cancer trials.

M Coory
Health Information Centre Queensland Health Department Brisbane, QLD

MANUAL OF BREAST DISEASES
J Jatoi (Ed)

I would highly recommend this manual for any medical specialist working in the field of breast diseases. It is, as titled, a manual and therefore perfectly sized as a desktop book for quick and ready reference. It covers such a broad range within the field of breast cancer diseases that there will undoubtedly be areas of interest even in the super-specialised breast clinician, be they a surgeon, oncologist, pathologist or radiologist. For its size, it is surprisingly comprehensive. At the present time, it’s also current and evidence-based and hopefully it will remain so with subsequent editions.

The first few chapters deal with non-malignant disease, which is refreshing to see in a text like this. The anatomy and physiology is covered reasonably comprehensively as well as design considerations such as nipple discharge and mastalgia. There is even a chapter on management of common lctalional problems and breastfeeding. This is a useful chapter, which is omitted from many textbooks. There is excellent practical advice about the management and evaluation of breast masses and the supporting data for that rationale. There is also an excellent overview of the risk factors (HRT etc) and the epidemiology of breast cancer. While this is pre the National Women’s Health Study, it is, not unexpectedly, fairly close to the mark. There is a number of chapters dealing with the principles of breast cancer screening, diagnostic imaging and newer techniques, which is a useful read for the clinicians amongst us. Pathology is dealt with in chapter 11, though there is a slight North American bias and not much information on less common pathologies like phyllodes. Surgery for primary invasive breast cancer has an historical introduction, which as the chapter title suggests, deals only with surgery (no mention of Bravectin or McQuincinn). There are a few unsupported statements regarding the surgical management of breast cancer, but I am perhaps being a little more pedantic here, having a surgical background. Overall, the author of this chapter, who is also the editor, has a balanced approach, in particular with dealing with issues of the management of the axilla and sentinel node biopsy.

There are then two excellent chapters on adjuvant systemic therapy and the role of radiotherapy, which are evidence-based overviews and reasonably current. Metastatic cancer is also well dealt with in chapter 17 and if you have the strength for chapter 18, there is a critical review of hormone replacement therapy. Patty Dang has contributed with a chapter on psychosocial support. Whilst it can only skim the surface, it covers most areas of concern and the breadth of the chapter precludes in-depth information, but is a good starting point for a focus on areas that perhaps do not receive enough emphasis in clinical practice. Again, this is an important chapter, often omitted from medical textbooks.

Genetic testing and breast cancer predisposition also have a good overview chapter and finally chemoprevention of breast cancer is dealt with.

At AS150, I think it reflects fairly good value in terms of its content, though don’t expect too much in terms of presentation as it is a soft-cover manual I think that’s what makes it so accessible however, and I was able to read it from cover to cover.

O Ung
NSW Breast Cancer Institute Westmead, NSW

MANUAL OF CLINICAL ONCOLOGY
R Pollock

Pancreatic Cancer, which is part of the MD Anderson Solid Tumour Oncology Series, is an extremely worthwhile reference book for clinicians involved in the management of pancreatic cancer. The book introduces the reader to the current understanding of the molecular pathways thought to be important in the carcinogenesis of pancreatic cancer. The hope is that these molecular markers may one day be used to identify patients with ‘early’ pancreatic cancer amenable to curative surgery. Chapters dealing with the surgery of pancreatic cancer and the literature that supports current practices then follow this. The emerging role of endoscopic ultrasound in diagnosis and staging of pancreatic cancer is discussed, together with radiological and laparoscopic staging in comparison to the lesser role that ERCP is playing in diagnosis.

The factors responsible for the marked improvement in morbidity and mortality of the ‘Whipple’ procedure have led to discussion of patient selection and referral to centres of specialisation for this type of surgery. Some technical aspects of surgery are compared, pylorus preserving versus non-pylorus preserving pancreaticoduodenectomy and techniques of reconstruction. The role of more aggressive surgery including nodal and pancreatic resection for pancreatic head tumours is discussed as well as surgery for peripanulapy, body and tail of the pancreas tumours.

The next section discusses the results of adjuvant and neoadjuvant regimens in adjuvant therapy trials and their differing regimes and modes of delivery. The experience of various centres involved in the development of adjuvant therapies is presented and their results discussed with a view to the running of further randomised trials.

The final section on emerging therapies takes one on a journey beginning in the laboratory with experimental models of pancreatic cancer. They are used to test the potential of various novel therapies, which can then be identified as being important in the mitogenic pathways responsible for pancreatic cancer.

In summary, pancreatic cancer poses a difficult management problem for clinicians. An understanding of tumour biology by clinicians will assist with the introduction of these new therapies into clinical practice. This book will undoubtedly achieve its intended aim.

D Fenton-Lee

Pancreatic Cancer

R Pollock

Cancer Forum • Volume 27 Number 1 • March 2003

St Vincent’s Clinic Darlinghurst, NSW

PRINCIPLES OF PALLIATIVE CARE–AN INTRODUCTION
B Pollard (Ed) Privately published
Copies available from Dr B Pollard, 40 Chisholm St Greenwich NSW 2065

RRP: Single copy AS9.00, Ten or more AS8.00 each, plus AS1.00 postage

Brian Pollard was one of the founding fathers of the discipline of palliative care in Australia. Renowned as a clinician and teacher, he has for several years been delivering a well-regarded lecture with this title to medical students at the Northern Clinical School. Asked by the students for suitable background reading, he has responded by producing this short book as an overview of the area.

Covering such topics as the background and philosophy of palliative care, control of pain and other symptoms, communication and ethical issues, it provides an excellent summary of current practice. This will be of particular use to nursing and medical students new to the area.

For those interested in communication and psychosocial support, Pollard offers insights gathered from lengthy experience and keen observation. He highlights the role of the health professional in not only communicating honestly with patients about their illness and treatment choices, but in helping family members communicate amongst themselves on clinical issues and social concerns. In regard to hope, he argues that the role of the health care team is to help channel the patient’s hopes along realistic lines, not to destroy them.

This book fulfills an important niche in palliative care literature.

F Boyle
Dept of Medical Oncology Royal North Shore Hospital St Leonards, NSW

SOMETHING MORE WONDERFUL
Sonia Orchard

Something More Wonderful is the true story of two young women – best friends – whose worlds fall apart when one of them is diagnosed with advanced liver cancer. Author Sonia Orchard, who was one of her friend Emma’s carers, takes the reader through their journey together from Emma’s diagnosis to her death five months later. It’s also a story of their special friendship, and a tribute to a unique woman.

As well as covering the medical realities of Emma’s illness – from her treatment to dietary changes and palliative care arrangements – the book explores the emotional reactions of Emma and those close to her. It describes their transition from optimism that she would be cured (“We’ll write a book about it, teaching others with cancer how to get through it, how to...
conquer those odds”) to reluctant acceptance that she would not (“So – that’s it. She’s dying. As they all said. She can stop trying – and the anguish and mental demise following diagnosis – and the anguish that she and those who love her go through as the disease progresses and after her death. But as someone who works in the field but has been lucky enough not to have someone close to me die from cancer, I found it an enlightening and moving insight into the cancer journey.

J Denholm
The Cancer Council Australia
Sydney, NSW

Viruses, Cell Transformation & Cancer

A Zuckerman et al
RRP: US$143.00

Viruses are rather like some administrators: they take our best ideas, use them for their own nefarious purposes, and leave us either non-viable or else transformed and ready to kill those around us. Still, you have to admire them, since they do it very effectively.

Recent years have seen rapid advances in our knowledge about viruses and this in turn has led too much greater understanding about the biology of cancer. Everything from signaling molecules associated with various receptors through to nuclear transcription factors can be used by viruses for their own ends. As we understand these processes better we will be more able to devise appropriate therapies for cancers, even those that are not related directly to viruses.

This book is an impressive and heavy volume of 524 pages and contains some very complete reviews on various aspects of virology as it relates to cancer. I see clearly that my own ends. As we understand these processes better we will be more able to devise appropriate therapies for cancers, even those that are not related directly to viruses.
<table>
<thead>
<tr>
<th>Date</th>
<th>Name of Meeting</th>
<th>Place</th>
<th>Secretariat</th>
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</thead>
<tbody>
<tr>
<td>26-28 May</td>
<td>30th COSA Annual Scientific Meeting</td>
<td>Perth, WA</td>
<td>Ruth Lilian, Pharma Events, PO Box 265, Amandale NSW 2038. Tel: +61 2 9280 0577; Fax: +61 2 9280 0533. Email: <a href="mailto:conferences@pharmarevents.com.au">conferences@pharmarevents.com.au</a></td>
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<td>April 2003</td>
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<tr>
<td>25-29 April</td>
<td>18th World Conference on Health Promotion and Health Education</td>
<td>Melbourne VIC</td>
<td>Conference Manager, Tel: +61 3 9667 1133; Fax: +61 3 9667 1375. Email: <a href="mailto:2004wchph@vichealth.vic.gov.au">2004wchph@vichealth.vic.gov.au</a></td>
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<tr>
<td>August</td>
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<tr>
<td>4-8</td>
<td>International Society for Nurses in Cancer Care 13th International Conference on Cancer Nursing</td>
<td>Sydney NSW</td>
<td>MP Events, Tel: +61 3 9852 9941; Fax: +61 3 9852 9961. Email: <a href="mailto:enquiries@mpmeetings.com.au">enquiries@mpmeetings.com.au</a></td>
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<tr>
<td>November</td>
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<tr>
<td>24-26 May</td>
<td>31st COSA Annual Scientific Meeting</td>
<td>Canberra ACT</td>
<td>Clinical Oncological Society of Australia, GPO Box 4708, Sydney NSW 2001. Ph: +61 2 9036 3100; Fax: +61 2 9036 3101. Email: cosacancer.org.au</td>
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<td>November</td>
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<td>June</td>
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<tr>
<td>1-3</td>
<td>2nd ESTRO Workshop on Biology in Radiation Oncology</td>
<td>Berg en Dal / Nijmegen</td>
<td>ESTRO Office, avenue E. Meeuwenlaan 83/12, 1200 Brussels. Tel: +32 2 775 9340; Fax: +32 2 779 54 94. Email: <a href="mailto:info@estro.be">info@estro.be</a>. Website: <a href="http://www.estro.be">www.estro.be</a></td>
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<td>1-5</td>
<td>Imaging for Target Volume Determination in Radiotherapy</td>
<td>Nice, France</td>
<td>ESTRO Office, avenue E. Meeuwenlaan 83/12, 1200 Brussels. Tel: +32 2 775 9340; Fax: +32 2 779 54 94. Email: <a href="mailto:info@estro.be">info@estro.be</a>. Website: <a href="http://www.estro.be">www.estro.be</a></td>
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<tr>
<td>19-22</td>
<td>National Conference of Cancer Self Help Groups Annual Conference</td>
<td>Manchester, UK</td>
<td>Andrea OZ, National Conference of Self Help Groups, 107 Crowther Road, London SE25 9RE. Tel: +44 8656 7520. Fax: +42 8656 7910. Email: <a href="mailto:ncssg@aol.com">ncssg@aol.com</a></td>
</tr>
<tr>
<td>19-28</td>
<td>23rd Congress of the International Society of Chemotherapy</td>
<td>Durban, South Africa</td>
<td>International Society of Chemotherapy, University of Natal of Durban, Dept of Medical Microbiology, Congella, South Africa. Fax: +2731 206 4431. Email: <a href="mailto:starm@med.univ.ac.za">starm@med.univ.ac.za</a></td>
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<tr>
<td>22-26 May</td>
<td>IMRT and Other Conformal Techniques in Practice</td>
<td>Amsterdam, The Netherlands</td>
<td>ESTRO Office, avenue E. Meeuwenlaan 83/12, 1200 Brussels. Tel: +32 2 775 9340; Fax: +32 2 779 5494. Email: <a href="mailto:info@estro.be">info@estro.be</a>. Website: <a href="http://www.estro.be">www.estro.be</a></td>
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<td>August</td>
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<td>3-8</td>
<td>12th World Conference on Tobacco or Health: Global Action for a Tobacco Free Future</td>
<td>Helsinki, Finland</td>
<td>Dr Lisa Elavaino, MD, Secretary General, Cancer Society of Finland &amp; Pros Finnish Centre for Health Promotion, Helsinki, Finland. Fax: +358 9 135 1093. Email: Lisa.ela@<a href="mailto:elavaino@cancer.fi">elavaino@cancer.fi</a></td>
</tr>
<tr>
<td>10-14</td>
<td>10th World Conference on Lung Cancer</td>
<td>Copenhagen, Denmark</td>
<td>International Conference Services, Vancouver, Canada. Fax: +1 604 681 1049. Email: <a href="mailto:francis@meetccs.com">francis@meetccs.com</a>. Website: <a href="http://www.2003worldlungcancer.org">www.2003worldlungcancer.org</a></td>
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**CALENDAR OF MEETINGS – International**
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<th>Date</th>
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<tr>
<td>31 Aug - 2 Sept</td>
<td>Brachytherapy for Prostate Cancer</td>
<td>Kiel, Germany</td>
<td>ESTRO Office, avenue E. Mounierlaan 83/12, 1200 Brussels Tel: +32 2 775 9340 Fax: +32 2 779 54 94 Email: <a href="mailto:info@estro.be">info@estro.be</a> Website: <a href="http://www.estro.be">www.estro.be</a></td>
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<tr>
<td>31 Aug - 4 Sept</td>
<td>Physics for Clinical Radiotherapy</td>
<td>Leuven, Belgium</td>
<td>ESTRO Office, avenue E. Mounierlaan 83/12, 1200 Brussels Tel: +32 2 775 9340 Fax: +32 2 779 54 94 Email: <a href="mailto:info@estro.be">info@estro.be</a> Website: <a href="http://www.estro.be">www.estro.be</a></td>
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<tr>
<td>September</td>
<td>15-18 7th ESTRO Meeting on Physics and Radiation Technology for Clinical Radiotherapy</td>
<td>Geneva, Switzerland</td>
<td>ESTRO Office, avenue E. Mounierlaan 83/12, 1200 Brussels Tel: +32 2 775 9340 Fax: +32 2 779 54 94 Email: <a href="mailto:info@estro.be">info@estro.be</a> Website: <a href="http://www.estro.be">www.estro.be</a></td>
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<tr>
<td></td>
<td>21-25 ECOO 12 – the European Cancer Conference</td>
<td>Copenhagen, Denmark</td>
<td>FICS Conference Unit, Brussels, Belgium Fax: +32 2 775 0200 Email: <a href="mailto:ECOO12@fics.be">ECOO12@fics.be</a> Website: <a href="http://www.fics.be">www.fics.be</a></td>
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<tr>
<td></td>
<td>21-25 22nd Annual European Society for Therapeutic Radiology and Oncology (ESTRO 22)</td>
<td>Copenhagen, Denmark</td>
<td>ESTRO Office, Brussels, Belgium Fax: +32 2 779 5494 Email: <a href="mailto:info@estro.be">info@estro.be</a> Website: <a href="http://www.estro.be">www.estro.be</a></td>
</tr>
<tr>
<td>October</td>
<td>8-11 SIOP 2003: International Society of Paediatric Oncology</td>
<td>Cairo, Egypt</td>
<td>SIOP, Congrex Holland, Amsterdam, The Netherlands Fax: +31 020 540 225 Email: <a href="mailto:siop@congrex.nl">siop@congrex.nl</a> Website: <a href="http://www.congrex.nl">www.congrex.nl</a></td>
</tr>
<tr>
<td></td>
<td>12-16 Basic Clinical Radiobiology</td>
<td>Santorini, Greece</td>
<td>ESTRO Office, Brussels, Belgium Fax: +32 2 779 5494 Email: <a href="mailto:info@estro.be">info@estro.be</a> Website: <a href="http://www.estro.be">www.estro.be</a></td>
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<td>19-23 45th ASTRO Annual Meeting (American Society for Therapeutic Radiology and Oncology)</td>
<td>Salt Lake City, Utah, USA</td>
<td>ASTRO, Fairfax, Virginia, USA Fax: +1 703 502 782 Email: <a href="mailto:meetings@astro.org">meetings@astro.org</a> Website: <a href="http://www.astro.org">www.astro.org</a></td>
</tr>
<tr>
<td>November</td>
<td>2-7 XVI FIGO World Congress of Gynecology and Obstetrics</td>
<td>Santiago de Chile, Chile</td>
<td>International Federation of Gynaecological Oncologists, London, United Kingdom Fax: +44(0) 20 735 0736 Email: <a href="mailto:fgo@figo.org">fgo@figo.org</a> Website: <a href="http://www.figo.org/figo2003.asp">www.figo.org/figo2003.asp</a></td>
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<td></td>
<td>9-14 Evidence-Based Radiation Oncology Methodological Basis and Clinical Application</td>
<td>Lisbon, Portugal</td>
<td>ESTRO Office, Brussels, Belgium Fax: +32 2 779 5494 Email: <a href="mailto:info@estro.be">info@estro.be</a> Website: <a href="http://www.estro.be">www.estro.be</a></td>
</tr>
<tr>
<td></td>
<td>19-21 10th Hong Kong International Cancer Congress</td>
<td>Pokfulam, Hong Kong</td>
<td>10th HWCC Congress Secretariat, Department of Surgery, University of Hong Kong Medical Centre Queen Mary Hospital Hong Kong Tel: +852 2818 0232 Fax: +852 2818 1186 Email: <a href="mailto:medicalcon@hku.hk">medicalcon@hku.hk</a> Website: <a href="http://www.hwcc.org">www.hwcc.org</a></td>
</tr>
<tr>
<td>December</td>
<td>3-6 26th Annual San Antonio Breast Cancer Symposium</td>
<td>San Antonio, Texas, USA</td>
<td>Cancer Therapy &amp; Research Center, SACI, Rich Marlow San Antonio, Texas, USA Fax: +1 210 949 5009 Email: <a href="mailto:marlow@sacci.org">marlow@sacci.org</a> Website: <a href="http://www.sabcs.org">www.sabcs.org</a></td>
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</table>
THE CANCER COUNCIL AUSTRALIA

The Cancer Council Australia is the peak national cancer control organisation. Its members are the leading state and territory cancer councils, working together to undertake and fund cancer research, prevent and control cancer and provide information and support for people affected by cancer.

MEMBERS
The Cancer Council ACT
The Cancer Council New South Wales
The Cancer Council Northern Territory
The Cancer Council South Australia
The Cancer Council Tasmania
The Cancer Council Victoria
Cancer Foundation of Western Australia
Queensland Cancer Fund

AFFILIATED ORGANISATIONS
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Clinical Oncological Society of Australia Inc
Palliative Care Australia

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Professor J Ward MBBS, MHPed, FAHPHM, PhD
Dr K White PHD

THE CLINICAL ONCOLOGICAL SOCIETY OF AUSTRALIA INC

The Clinical Oncological Society of Australia (COSA) is a multidisciplinary society for health professionals working in cancer research or the treatment, rehabilitation or palliation of cancer patients.

It conducts an annual scientific meeting, seminars and educational activities related to current cancer issues. COSA is affiliated with The Cancer Council Australia.

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(ANZ Childhood Cancer Study Group)
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Surgical Oncology

MEMBERSHIP
Further information about COSA and membership applications are available from
GPO Box 4708, Sydney, NSW 2001.
Membership fees for 2003
Ordinary Members: $140
Associate Members: $80
(includes GST)