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CAN YOU HELP?
to improve the
care we offer
mesothelioma
sufferers



Research report

Our Vision: Cancer Defeated

cancercouncil.com.au

Spring 2010 | Issue 13

Research conducted at Cancer Council NSW will help all Australians

With a population of seven million, a third of Australia's Aboriginal population and one-quarter of its residents born overseas, NSW's large and culturally diverse population represents a microcosm of both Australia and the world.



This diverse population base allows CCNSW to conduct and fund research into the underlying causes of various cancers and how best to prevent them at the population level. Results from this research allow us to dispel myths, support positive behavioural change and inform public policy and practices.

We explore new and improved ways of diagnosing and treating different cancers and undertake studies into enhancing the quality of life of those affected by the disease.

An update on the Aboriginal Patterns of Cancer Care Project

Barriers to health care have resulted in Aboriginal people being up to three times more likely to die from some cancers than non-Aboriginal people living in NSW.

"Lack of transport to treatment centres, limited child care facilities and feelings of isolation while undergoing treatments are some of the barriers that we believe may prevent Aboriginal people from accessing health care," said Dr Andrew Penman, CEO of Cancer Council NSW.

"These issues are putting lives at risk, with NSW's Aboriginal population being up to three times more likely to die from some types of cancer, and 60 per cent more likely to die from all cancer types combined than non-Aboriginal people."

Lung cancer is the most common cause of cancer death in Aboriginal men and they are 50 per cent more likely to die from the disease than non-Aboriginal men. Meanwhile, for women the risk is double.

Studies from other states have shown that Aboriginal people in remote communities often had their cancer diagnosed later — and received less treatment — than non-Aboriginal people with the same types of disease.

The Aboriginal Patterns of Cancer Care (APOCC) project is the first to focus on the cancer death rate gap that

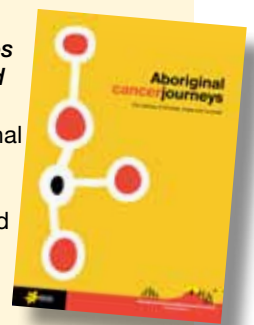


exists for Aboriginal people in NSW and in particular people living in urban NSW. **We need Aboriginal people to join our study.**

This will help us to identify any barriers to treatment and improve the unacceptable survival rate from cancer.

The APOCC team needs Aboriginal people to join a new study investigating why this gap exists in cancer death rates and what measures are needed to close it across the state. The study is open to Aboriginal cancer survivors over 18 years of age, people who have cared for Aboriginal people who have had cancer, and Aboriginal Health Workers.

Aboriginal Cancer Journeys: our stories of kinship, hope and survival is a book of stories from Aboriginal people affected by cancer. It includes personal insights and words of wisdom so Aboriginal people can get an insight into other people's experience of cancer.



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We need your help to find out what causes cancer

In order to assess cancer risk factors, we still need more people who have been diagnosed with cancer for the first time within the past 18 months to participate in the CLEAR study.

We now have over 4,300 participants,



with a goal of 10,000. The major cancer types are breast, colorectal and prostate.

We urgently need more study participants so that we can reach our goal. Participation in the CLEAR study involves completing a questionnaire and providing a small blood sample (optional). Both are a one time only activity, and there are no further

obligations. It's that simple to help us find the answer.

Do you know someone who might be interested in participating?

Partners are strongly encouraged to join too, provided they have not

You can participate online in the CLEAR study

previously had cancer themselves. Email them a link to: www.clearstudy.org.au.

We have study documentation in multiple languages, if English is not their preferred language.

**LIFESTYLE?
GENES?**


WHAT REALLY CAUSES CANCER?

Cancer Council NSW is undertaking a landmark research initiative to assess the influences that may cause cancer.

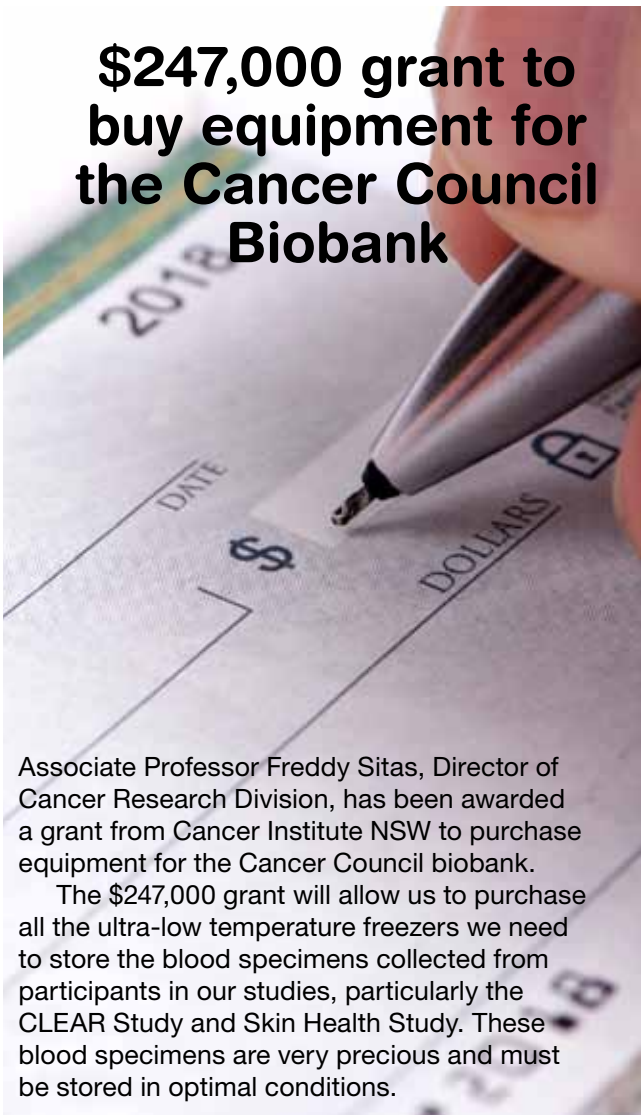
You can participate if you have been diagnosed with cancer for the first time within the past 18 months.

For more information, call us on 1800 500 894 (free call in NSW).

THE CLEAR STUDY.
www.clearstudy.org.au



\$247,000 grant to buy equipment for the Cancer Council Biobank



Associate Professor Freddy Sitas, Director of Cancer Research Division, has been awarded a grant from Cancer Institute NSW to purchase equipment for the Cancer Council biobank.

The \$247,000 grant will allow us to purchase all the ultra-low temperature freezers we need to store the blood specimens collected from participants in our studies, particularly the CLEAR Study and Skin Health Study. These blood specimens are very precious and must be stored in optimal conditions.

A new guide to managing advanced prostate cancer

When you are told that you have advanced prostate cancer, many thoughts flash through your mind. One is that I need to find out more about what is happening to my body and what can I do about it.

There are 100's of books available that offer a wide variety of views, some soundly based, some offering cures without any evidence to support their theories. For the first time consumers now have a reliable source of information, written and reviewed by some of the nation's leading practitioners in all forms of treatment.

This book aims to explain the advanced stages of prostate cancer, its treatments and how men can manage their health while dealing with this condition.

Dr David Smith, Suzanne Hughes, Dr Louisa Jones, Hayley Griffin, Amy Nolen, Dr Annette Moxey, and Professor Dianne O'Connell identified



Call 1300 303 878 to obtain a free copy

and summarised the evidence on which recommendations are based with funding from Australian Cancer Network (TCCA), Andrology Australia and Prostate Cancer Foundation of Australia.

The consumer version of the guidelines is available on the Cancer Council Australia website www.cancer.org.au.

‘Tackling Tobacco’

— finding out how to reduce smoking rates among the socially disadvantaged

While smoking rates in Australia have been steadily declining over the past 30 years, this decline has not been equal among all groups of the population. Aboriginal people and severely disadvantaged and marginalised groups, such as the homeless, prisoners, individuals with a low income, and individuals with a mental illness are consistently found to have significantly higher rates of tobacco use.

‘Tackling Tobacco’ is a research partnership between the Cancer Council NSW’s Centre for Health Research & Psycho-oncology and Tackling Tobacco teams to gain insights into how smoking rates can be reduced among socially disadvantaged groups. They are investigating the acceptability and effectiveness of engaging community organisations to deliver ‘quit smoking’ support to their disadvantaged clients. These organisations have ongoing contact with a large number of highly disadvantaged members of the community and are in a position to provide personalised and tailored quit support. However, little is currently being done within community service organisations to help their clients quit smoking.

The results have overwhelmingly suggested that the non-government community social service setting is a promising access point for targeting socially disadvantaged smokers. Managers and staff reported that



smoking was a significant issue for their clients, contributing not only to poor health but also financial strain. They believed that the provision of quit smoking care was compatible with their role as care providers, and they were keen to access quit smoking programs and resources. Many clients reported a desire to quit smoking and thought that personalised support from the community service organisation would be helpful.

To build on these promising findings, in 2010 a pilot study funded by the

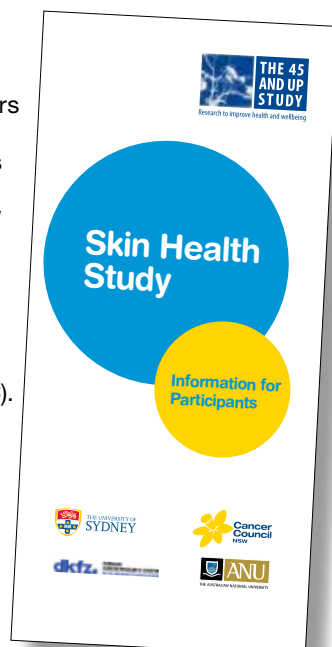
Cancer Council NSW, University of Newcastle and Cancer Institute NSW is being conducted in a Sydney based community service organisation. Support workers within Anglicare’s Personal Helpers and Mentors program will receive smoking cessation training and will be asked to provide quit smoking advice to their clients. Outcomes including smoking status, number of quit attempts, intention to quit and the acceptability of receiving and providing this type of support will be measured over six months.

Study investigates causes of skin cancer beyond the sun

Cancer Council NSW has launched a pioneering study investigating how lifestyle factors beyond sun exposure cause Australia’s most common types of skin cancer.

Launched in 2009, the NSW Skin Health Study will provide the first substantial evidence on the roles smoking, alcohol and HPV infections have on basal cell carcinoma (BCC) and squamous cell carcinoma (SCC).

“It is well documented and universally accepted that the sun plays a major role in causing skin cancer,” said Associate Professor Freddy Sitas, Director of Cancer Council NSW’s Cancer



Research Division.

“However, other risk factors may play a role in these common cancers, including tobacco and alcohol, along with viruses such as HPV. This study seeks to discover if and how these factors link together to cause the most



common skin cancers.”

Up to 3,300 participants from the 45 and Up Study will be involved in the three year study. Participants will complete a questionnaire that asks about their lifestyle habits, provide a blood sample and take a skin swab. Researchers will then compare their lifestyle information to the blood and skin samples, to build a holistic picture on the causes of BCC and SCC skin cancers.

Funded by a NHMRC project grant, the study is a collaboration between Cancer Council NSW, The University of Sydney, the Australian National University, the German Cancer Research Centre, and the 45 and Up Study. Researchers at Cancer Council NSW are coordinating the study.

Can you help us improve the care we offer mesothelioma sufferers and their caregivers?

The incidence of mesothelioma in Australia is one of the highest in the world, and continues to rise. While patients can experience a considerable physical burden — pain, breathlessness and fatigue — patients and their caregivers often experience significant psychosocial burden — anxiety, depression, anger and social isolation.

The Cancer Council's Centre for Health Research & Psycho-oncology (CHERP) will be undertaking a qualitative study to explore not only the perceived needs of people with mesothelioma (as well as current or recently bereaved caregivers), but also how people with mesothelioma and their caregivers cope with these needs, and their perceptions about the types of interventions that

would be beneficial to meet these needs.

The information gathered by this research will help us find ways to assist people with mesothelioma and their caregivers, as well as to improve their supportive care and other needs.

We would like to hear from anyone who has been diagnosed with mesothelioma, or who is currently caring for, or has recently cared for, someone with mesothelioma. If you are interested in participating in a focus group or



a telephone interview to tell us your experiences, please contact Afaf Girgis by email on afaf.girgis@newcastle.edu.au or by phone on 02-49138600.

Cancer researcher awarded Australia's highest honour



"Professor Dame Valerie Beral, Oxford, Britain. For eminent service to medicine and women's health through significant advances in cancer research and epidemiology, through seminal contributions to public health policy and as a mentor to young scientists."

Scientists at CERU are proud to collaborate with Australian-born Professor Dame Valerie Beral, who was awarded Australia's highest honour, Companion of Australia, in the 2010 Queen's birthday honours list. She was also created a Dame in England earlier this year.

Professor Valerie Beral and her team at Oxford University made headlines around the world when they found a link between hormone replacement therapy and breast cancer in 2003. The suggestion of a link had been fiercely debated until the researchers mined data from 1.3 million British women to show the risk of breast cancer doubled for women using hormone replacement therapy.


It was hard to argue with the findings, which effectively collected data on one-quarter of British women in a 15-year age group yet the suggested link has been an inflammatory topic.

Dr Karen Canfell from CERU has been closely with Professor Beral in ongoing work on this



Professor Dame Valerie Beral

topic. Professor Beral has been a valued adviser on the CLEAR Study and is also a long-term collaborator of Associate Professor Sitas.



Help us Defeat Cancer:

Join a Research Study NOW.

yes, please include me on the mailing list

From time to time Cancer Council conducts research studies on people drawn from the New South Wales population. These studies range in type from questionnaire based surveys, focus groups and interviews to other types of research.

We need your help in undertaking our research to defeat cancer. Register your interest to be included on our mailing list and fill in your contact details below. Please note that study participants will not necessarily be cancer patients.

By helping us NOW, you can help us defeat cancer in the future.

Return by post: Study Mailing List
Reply Paid 79819, Potts Point NSW 1335

Or: Register online
www.cancercouncil.com.au/joinastudy

Mr/Ms/ _____

Name: _____

Address: _____

Town: _____ Postcode: _____

Email: _____

Telephone: _____

At Cancer Council we recognise the importance of your privacy and the safeguarding of your personal information. Please refer to our Privacy Management Plan at www.nswcc.org.au which addresses our compliance with all legislative requirements.

Please be assured that your health information will be stored for the Study Mailing List in a password protected electronic database accessible only by appropriate Cancer Research Division staff.

www.cancercouncil.com.au