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ISSUE 6
SPRING 2011



care & connect

For our patients, staff and community

The Sydney West Cancer Network newsletter

Boost for research and care

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A groundbreaking new cancer research centre has been established in western Sydney to drive improvements in patient care.

The NSW Cancer Institute recently announced a five-year grant of \$6.5 million for the establishment of the Sydney-West Translational Cancer Research Centre.

The Centre is expected to make western Sydney a hub for world-class cancer research, and to improve the links between research and clinical care.

It will link multidisciplinary teams from the Sydney West Cancer Network, cancer research groups of the Westmead Millennium Institute for Medical Research, the Westmead node of the Melanoma Institute Australia, and other affiliated clinical and research groups involved in cancer care in the area.

"This is a hugely exciting development for western Sydney," said the Centre's director, Professor Paul Harnett. "It will create a connected professional community of cancer researchers and clinicians who are committed to the common goals of excellence in collaborative translational cancer research and evidence-based practice.

"It recognises our pioneering work in embedding research as a core element of our multidisciplinary teams."

The Centre's associate director, Dr Rosemary Balleine, a researcher who has been active in improving the connections between research and patient care, says it "recognises the contributions of a broad professional community in improving cancer care".

"Our vision is to create a dynamic professional community across multiple sites and disciplines that is connected in real time through an interactive information technology network," she said.

"The success of our grant application is an endorsement of the powerhouse of academic medicine that has been built up in this area over the last 20 years."



Dr Rosemary Balleine:
The new Centre will connect cancer researchers and clinicians in a "dynamic professional community"

The Sydney West Cancer Network is a collaboration between cancer services in western Sydney, which aims to improve the range and quality of services available. It includes the Blacktown Oncology Centre, Mt Druitt Palliative Care Unit, Nepean Cancer Care Centre, Westmead Cancer Care Centre and the Westmead Institute for Cancer Research.

from the director

Putting patients first

By Professor Paul Harnett

Sometimes it is worth taking a moment to stop and consider what is really meant by the terms we use every day, such as "patient-centred care".

Patient-centred care means that all members of the team are focused on providing care that is in the best interests of the patient.

We often speak as though this refers only to what occurs at the bedside, where the care is delivered.

But patient-centred care also means putting the needs of patients first when we are planning research projects and writing grant applications.

One of the reasons I am so delighted by the establishment of the new Sydney-West Translational Cancer Research Centre is that it will help cement a patient-focused approach to using research to improve clinical care.

The Sydney West Cancer Network has been a leader in embedding research in our multidisciplinary team meetings. As reported on page one of this publication, the new Centre will allow us to be much more proactive in promoting a two-way exchange between research and clinical practice.

I feel confident in predicting that the Sydney-West Translational Cancer Research Centre will bring real benefits for patients in our area.

• Professor Harnett is director of the Sydney West Cancer Network and a medical oncologist at Westmead Hospital.



Professor Paul Harnett

network news

Academic appointment for Westmead doctor

Dr Sandra Turner, a radiation oncologist at Westmead Cancer Care Centre, has been appointed clinical associate professor in the Sydney Medical School at the University of Sydney.

Dr Turner has led the way in developing multidisciplinary care for patients with genito-urinary cancers and sarcomas, and is also the chief censor of the Faculty of Radiation Oncology for the Royal Australian and New Zealand College of Radiologists.

Dr Turner says radiation oncology is an intellectually challenging and exciting specialty that incorporates the best aspects of direct clinical care with a highly effective and technologically interesting treatment.

Dry July a huge success

More than \$239,000 was raised for the Nepean Cancer Care Centre as part of the Dry July event, in which people raise funds for cancer care by giving up alcohol for the month.

Jenny O'Baugh, the nurse manager of medical specialties at Nepean Hospital, was one of 11 Nepean staff who took the Dry July pledge. They raised almost \$12,000. Ms O'Baugh says the funds will find many uses across the Centre, including buying a digital music library for patients in the day ward.

She says the month of abstinence was "good for the soul", and encourages others to consider going dry next year. "I would absolutely recommend it," she says.

a patient's journey

It helps to be informed and connected

If Michael Corti were a superstitious person, he might well try to avoid the number four.

At the age of four, he had open-heart surgery; at 14 he fell off a four-storey building; and at 24, he was diagnosed with stage four testicular cancer.

He may have an unlucky number, but one thing is more certain: Michael is a survivor.

When Michael, now 26, was diagnosed with testicular cancer in February last year, it had already spread to his lung and kidney. He had visited a medical centre twice, and was told he had pneumonia. When he became so sick he ended up in emergency, he was referred to a chest specialist, who spotted the lung cancer on an earlier X-ray.

Within days, Michael was admitted to Westmead Hospital and began treatment for advanced testicular cancer, under the care of Professor Howard Gurney.

“I ended up reconnecting with my friends and that helped a lot.”

The treatment began so quickly Michael didn't have a chance to catch his breath. He had seven cycles of aggressive chemotherapy over seven months and spent many weeks in hospital during that time. Last September, he had surgery to remove a testicle and a kidney.

Professor Gurney has told Michael he is in remission and there is a good chance the cancer won't return.

Michael, who has returned to work full time as a security guard, says the early days after the diagnosis were a blur.

“Because I went straight into chemotherapy and I was admitted to hospital, I didn't have time to register what was happening to me,” he says.

At first he only had a basic understanding of his condition, but he used his time in hospital to search the web and find out more.

Michael says he found this research helpful because he discovered the outlook was good. “I learnt the survival rate was very high.”



Michael Corti with sisters, Stephanie (left) and Laura

Meanwhile, he was struggling to come to terms with the cancer that had turned his life upside down overnight. In the early days in hospital, he barred his friends from visiting him because he didn't want them to see him at his lowest, a stark contrast to his usual “bubbly and happy” self.

“If I they came to visit, it felt as if I would be seeing them for the last time. I didn't want to deal with that,” he says. “I didn't want their sympathy.”

He found it helped to talk to clinical psychologist Dr Jemma Gilchrist and psychiatrist Dr Cathy Mason at Westmead, but he also realised the need to keep his friends close.

“Shutting them out was one of the worst things I did,” he says. “I ended up reconnecting with my friends and that helped a lot.”

Michael says the main gem of advice he wants to share with people is the importance of not delaying if you're worried about symptoms.

When the medical centre doctor told him he had pneumonia, Michael says he suspected it may have been more serious, as he had been unwell for some time – he had lost a lot of weight and had been coughing up blood for three days.

“I knew something was wrong,” Michael says. “I should have pushed harder for a blood test, but I didn't because I didn't want bad news. I wanted it to just be pneumonia.”

“Everyone's obviously scared of the worst, but if you're worried, see the doctor. If cancer is found early, you won't have to go through as much pain and treatment.”

team focus: Nepean Cancer Care Centre

Fundraising efforts pay off

When patients walk into the new day ward at the Nepean Cancer Care Centre, the first thing they notice is the bright, spacious and welcoming environment.

"It's really important for the psyche of the staff and the patients," says Jenny O'Baugh, the nurse manager of medical specialties at Nepean Hospital.

"If you're sitting or working in a place that is bright and airy, it's a much better environment."

The new ward began operations earlier this year, after a long-term fundraising effort by staff, patients and supporters.

It has four beds and 11 treatment chairs, with about 35 to 45 patients receiving chemotherapy there every day, avoiding the need for hospital admission.

Patients can watch TV while having treatment, and there are plans to also provide some iPads so they can listen to music or play games.

Dr Colin Bull, clinical director of the Radiation Oncology Network, says the \$1.353 million cost of the day ward was funded through bequests and fundraisers, including one organised by P&O.

"The funds raised via the Radiation Oncology Network Trust Fund were due to the efforts of our dedicated network team of radiation therapists, medical physicists, nurses, supporting administration staff, and the senior and junior medical staff," he said.



Nepean Cancer Care Centre



Jenny O'Baugh: Having a supportive and caring team is important for patients and staff alike

Patient feedback

Patients are generally very pleased with the quality of service provided by the Nepean Cancer Care Centre, according to patient feedback surveys.

Surveys conducted over the past three years show most patients rate most aspects of their care as very good.

Waiting times for appointments and treatments are issues of concern for a small proportion of patients.

Jenny O'Baugh, the nurse manager of medical specialties at Nepean Hospital, says that having a supportive and caring team is important for patients and staff alike.

"Working in cancer care can be difficult and overwhelming at times," she says.

"You cannot survive without the respect and support of your colleagues.

"That's a real strength of the team we have here – the way they treat and feel about each other, and the way they treat and feel about patients."

staff profile

A specialist author explains his story

After caring for women with breast cancer for more than 30 years, Associate Professor Phillip Yuile has learnt a thing or two about what women need to know.

One issue he has heard from many breast cancer patients over the years is the need for practical and comprehensive information.

"There are a lot of pamphlets and brochures out there, but women found they weren't answering their questions," Dr Yuile says.

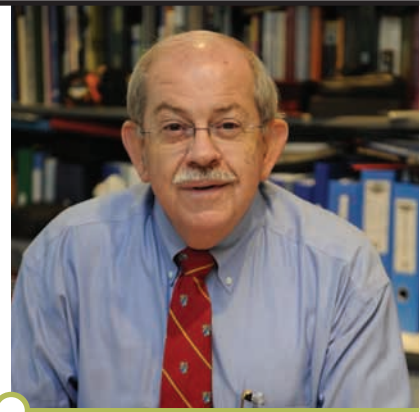
These questions prompted him to write a guide to breast cancer and its treatment, called *The Little Pink Book*, which was published in June. The book is an easy-to-read and comprehensive guide that is designed for women to read in stages in line with their breast cancer journey.

Dr Yuile says the book aims to explain to women why they need – or don't need – various tests and treatment. "If we explain why things are done – or conversely why other things aren't done – you cope a lot better and you tend to have a better outlook because you're more empowered or more in control of your fate," he says.

Dr Yuile has been at Westmead for 18 months after many years at the Mater, Concord and North Shore hospitals. As director of the Radiation Oncology Network, Dr Yuile oversees the radiation oncology centres at Westmead and Nepean hospitals, which combine to form the biggest centre in the state in terms of equipment and facilities.

While much of his time is spent on administration and supervision, he still has time to see patients. "I'd be lost without that – that's what keeps your sanity," Dr Yuile says. "One of the good things with oncology is that you have a long-term relationship with patients, so you get to know them and their families and that's very rewarding."

- ***The Little Pink Book is published by Finch. For more information, see Resources, Page 8.***



Associate Professor Phillip Yuile

question corner

Q My teenage daughter has had the HPV vaccine in the school vaccination program. Should I consider having it as well, to protect against cervical cancer?

A Cervical cancer is caused by certain strains of the human papilloma virus (HPV), which is transmitted during sexual activity.

Dr Gerry Wain, director of gynaecological oncology at Westmead Hospital, says HPV vaccines are very effective at preventing new HPV infections in women of all ages, but have no effect on past infections. He says women who have been sexually active and are unvaccinated have probably already been exposed to HPV.

"The concern for older women is their risk of new HPV infections, and that will depend on their future sexual activity and their partner's future sexual activity, which is very difficult to predict in an individual woman's case," he says.

"The key thing to remember is that women who have been sexually active before having the vaccine still need to have regular cervical screening."

He says HPV vaccines are about preventing future infections and Pap tests are about picking up past infections.

news & views

Social media boosts health

The negative aspects of social media often hit the headlines, but a recent Canadian project suggests that Twitter, Facebook and the like can be used to help improve the quality and safety of health care.

The two-year project, which investigated how social media is used in hospitals and other health services in North America, resulted in a two-part report, *Using Social Media to Improve Healthcare Quality*.

It recommends that health services should proactively engage with social media for community and patient education, to help with the translation of research into practice and policy, and to gain feedback.

The report says social media holds great promise in health care, through information sharing, providing a network for patients to support each other, and the opportunity for patients and health care providers to collaborate in all aspects of care.

- **The report is available at:**
<http://www.changefoundation.ca>

Understanding end-of-life care

The importance of communication and support networks has been highlighted in a recent study of the experiences of those involved in providing end-of-life care at home.

The research project, *Bringing Our Dying Home: Creating Community at End of Life*, was funded by the University of Western Sydney and Cancer Council NSW.

Researchers collected 96 visual and oral stories of caring and support around end-of-life care at home.

The researchers said that while the focus is generally on the burden and stress of providing such care, they wanted to look at the potential for it to contribute to social capital and community capacity.

Their investigations found that being involved in caring for a person who is dying can extend people's knowledge, skills and personal resources.

"People resisted the potential isolation and social exclusion often associated with caring by working hard to stay connected with each other," the researchers reported.

"Central to staying connected was clear and controllable communication, often using technology to good effect. Additionally we found that humour and remaining light-hearted enabled people to stay engaged in the process of caring."

Texting helps quitters stay strong

Text messaging is an effective strategy for helping smokers to quit, suggests a large UK trial.

The study, published in *The Lancet*, was carried out by researchers from the London School of Hygiene and Tropical Medicine, the University of Auckland, and the George Institute at the University of Sydney.

Almost 6000 smokers were randomly assigned to receive either a stop-smoking text message or a text message unrelated to quitting.

By texting the word "crave", quitters could receive instant messages to distract and support them, and they could also text each other for support.

At six months, 10.7% of those receiving the quit-smoking texts had stopped smoking, compared with 4.9% of those in the control group, with results verified by saliva tests.

The intervention had similar results in both younger and older smokers and in all socioeconomic groups.

An independent analysis of the study, by the National Health Service, said it was well designed, and that text messaging is "a relatively cheap intervention that could reach large numbers of people".

Time 2 quit - Gr8!

guest appearances

Meet your new Medicare Local

By Professor Di O'Halloran

Western Sydney has been chosen as one of the first 19 communities in which to establish a Medicare Local aimed at improving primary health care services for our diverse communities.

The Medicare Local will be working collaboratively with communities and other organisations – particularly our local health district (previously the area health service), to make it easier for patients to find their way through the often-complex health care system. Top priorities will include better integration between hospital, specialist and community-based services, and improving relationships within the health care system so that health services are more focused on meeting the needs of patients, families and carers.

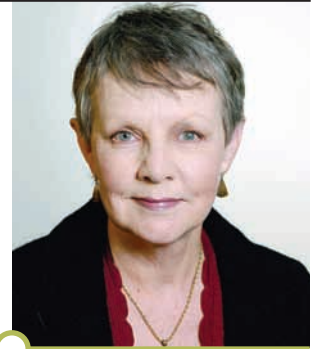
WentWest Limited, which is the local Division of General Practice and general practice training provider for western Sydney, has been chosen to establish the Medicare Local. As the Western Sydney Medicare Local, WentWest will continue and increase its current work with GPs, nurses, allied health professionals, Indigenous health organisations and the local health districts to identify and respond to gaps in local health services.

Many services that are routinely provided in a hospital or specialist setting could be equally

provided in a community health setting, so we will also look for ways to shift some hospital-based services into the community, making them easier to access. In cancer care, for example, some chemotherapy treatments could be provided in a community health centre or in a patient's home. We will also work to improve co-ordination between a hospital and community health services to ensure cancer patients have appropriate care when they go home.

Patients, their carers and families will play a key role in planning how the Medicare Locals can improve services. To achieve this, WentWest is establishing a district-wide Community and Consumer Forum. These groups will each engage consumers and communities in planning health services to meet identified community needs using the best information available.

- **To register interest in being a member of the forum, or to find out more about the Western Sydney Medicare Local, please visit our website: www.wentwest.com.au.**
- **Di O'Halloran is chair of WentWest and conjoint professor, Department of General Practice, University of Western Sydney.**



Professor Di O'Halloran

connections

Help in the Blue Mountains

Blue Mountains Cancer Help (BMCH) offers a wide range of services and support for people diagnosed with cancer and their families in the Blue Mountains community.

Director Robyn Yates says BMCH has assessed more than 300 clients since its inception in 2005, and now supports more than 150 clients and their families.

"Our aim is to work with GPs and specialists and to complement services such as community health, palliative care and other support organisations in the Blue Mountains."

A registered nurse assesses each new member, after which they may choose from a wide range of subsidised complementary therapies provided by trained and insured therapists.

"In 2010, we provided 1525 therapies, including counselling, to clients," Robyn says. "These therapies promote relaxation during a very challenging and often life-changing experience."

BMCH also runs support groups, a buddy system and a library, and offers help with transport costs.

The organisation is a registered charity, which raises money through events and donations, and also through its op shops in Katoomba and Blaxland, which provide a focal point for the community and volunteers.

- **For more information, please call our office on 4782 4866 (10am to 1pm Monday to Friday), visit our op shops at Unit 2, 27 Whitton Street, Katoomba, and 148 GWH, Blaxland, or go to our website: www.cancerhelp.net.au**

useful resources

A practical guide to breast cancer

Westmead radiation oncologist Dr Phillip Yuile (see profile page 5) has written *The Little Pink Book*, a comprehensive guide that aims to answer the common questions that women ask about breast cancer.

www.finch.com.au/books/little-pink-book

Working with cancer

Cancer Council NSW has produced a new free book, called *Cancer, Work and You*. The book is a practical guide for employees and self-employed people who have cancer, and working carers. It includes tips about working during treatment and recovery and information about rights. Call the Cancer Council Helpline on 13 11 20 to ask for a copy, or download it from www.cancercouncil.com.au/editorial.asp?pageid=2792

Help with expenses

Cancer can be expensive for patients – both through loss of income and treatment bills. The Medicare Safety Net is a government program that subsidises costs once your out-of-hospital expenses exceed a certain amount. For more information, call Medicare on 132 011, or visit your local Medicare office.

www.medicareaustralia.gov.au

help support our work

Please help us continue to treat and support cancer patients in our community. Your donation, made out to Westmead Medical Research Foundation, will go directly to the Sydney West Cancer Network, and will benefit patients across western Sydney.

To donate you can:

- **Donate online:** www.wmrf.org.au/donate (option 'Westmead Cancer Care')
- **Donate by phone:** 1800 639 037
- **Donate by post:**

C/ Westmead Cancer Care Centre
Westmead Medical Research Foundation
PO Box 74 Westmead NSW 2145

contact details



Blacktown Cancer Care Centre	02 9881 8047
Mt Druitt Palliative Care	02 9881 1695
Nepean Cancer Care Centre	02 4734 3500
Westmead Cancer Care Centre	02 9845 5200

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We welcome your comments on the newsletter and suggestions for stories.

This newsletter is produced by Melissa Sweet and Marge Overs and designed by Rock Lily Design & Consulting. ISSN 1838-1529