

Cancer Council Update 2010

Would you like to hear more about
Cancer Council Western Australia's events and news?
Please register your details at the desk outside



Get Behind Bowel Screening

- Bowel cancer - most common cancer affecting both men and women
- Incidence increasing as population ages and because of poor lifestyle habits
- Early detection is the key
- National Bowel Cancer Screening Program beneficial



Get Behind Bowel Screening



Get Behind Bowel Screening

- National Bowel Cancer Screening Program only invites those turning 50, 55 or 65
- Extending the Program to invite everyone over 50 should be an election priority
- How you can help:
 - Attend Cancer Council WA's **Bowel Cancer Forum, Thursday 12 August 2010**
 - Visit or call your local MP
 - Share your story with local media




Cancer Council Update 2010

Towards improving outcomes for
adolescents and young adults living
with cancer

Shaun Mays
CanTeen, WA




Shaun Mays
CanTeen WA Manager

CanTeen Overview 

- Who we are and what we do?
- Advocacy – Youth Cancer Networks Group (new treatment & support model for AYA cancer patients)
- Now What resources
- Questions

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CanTeen What is CanTeen 

What is CanTeen?

- The Australian Organisation for Young People Living with Cancer
- A national peer support network for 12-25 year olds living with cancer



CanTeen Our Mission & Vision 

CanTeen's Mission is...
To support, develop and empower young people living with cancer

CanTeen's Vision is...
To bring together young people living with cancer

Our Philosophy
No young person should go through a cancer journey alone

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CanTeen Who do we support 


CanTeen's Members are young people aged between 12 and 25 and include

- Patients
- Siblings & Offspring
- Bereaved Siblings & Offspring



CanTeen has over 4000 Members Australia-wide

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CanTeen Our History 

In 1985: CanTeen was founded by 6 young cancer patients and a number of health professionals from the Children's Hospital in Randwick, Sydney

Why: The health system was NOT meeting the unique support needs of adolescents with cancer – and their siblings

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CanTeen Our Governance 

CanTeen is a youth driven organisation with young people involved at all levels.

It is governed by

- Board Of Directors (5 Member Directors & 4 Associate Directors)
- MAC- The Member Advisory Council (8 Members)
- Each Division has its own Committee

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Our Locations

CanTeen supports young people throughout Australia from nine offices

And provides programs and activities in a huge variety of locations



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Our Services

CanTeen programs provide a mixture of psychological support and development, and recreational based activities.

- Camps
- Recreation days
- Group work counselling
- Workshops
- TeenLink
- Online information
- Leadership
- Advocacy



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Our Services

All programs are facilitated by CanTeen staff that have qualifications in:

- Psychology
- Social Work
- Youth Work
- Teaching
- Sport and Recreation

Qualified Medical and Psychosocial Volunteers work alongside CanTeen staff

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Why we do what we do in the way we do it – research

Psycho-oncology research highlights the importance of peer support for young people living with cancer.

Adolescents with higher levels of perceived support report:

- Fewer health complaints
- Lower levels of depression and anxiety
- Higher optimism and self-esteem
- Fewer behavioural problems and
- Better adjustment to illness

(Decker 2007; Barrera et al., 2004; Kristjanson et al., 2004)

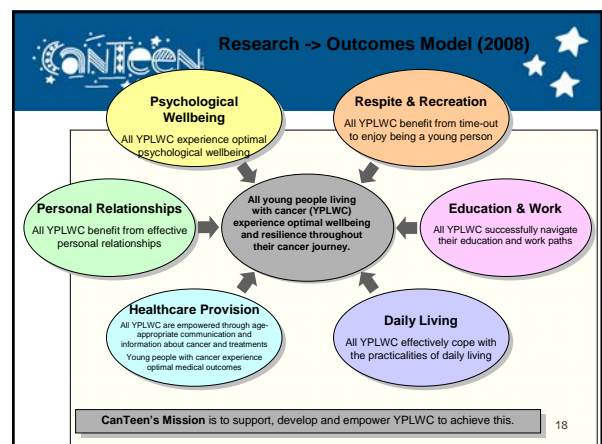
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Our Research

CanTeen's own needs-based research with 390 young people (offspring, patients, siblings, and bereaved offspring/siblings) identified the importance of peer support needs. The need for support from friends and from other young people who have had similar experiences with cancer, strongly emerged in the qualitative research (focus groups and telephone interviews), and was also consistently prominent in the quantitative needs study.

Higher unmet peer support needs were also correlated with poorer psychological functioning scores (using the DASS-21 and SDQ questionnaires).


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CanTeen Funding \$\$\$

CanTeen is a not-for-profit-organisation and receives its financial support from

- National Bandanna Day (NBD)
- General fundraising events
- Sponsorships
- Donations
- Direct Marketing



Because of this, membership (including programs and travel) is **FREE** to all young people who are CanTeen Members

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CanTeen joining

Q. How can you join?

A. Simple.

Contact CanTeen and speak to the Member Liaison Officer (MLO) (Amanda, Emma or Bianca)

We will:


- Send a membership application form and information pack.
 - Organise a hospital or home visit or a phone call
 - Connect the young person with an existing CanTeen Member
 - Give you feedback on the young people you refer

www.canteen.org.au
08 9287 5111

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CanTeen

- Show movie Shaun!



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CanTeen Part two

- Advocacy – Youth Cancer Networks Group (new treatment & support model for AYA cancer patients)

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CanTeen Our Advocacy Position

CanTeen is the only national Australian organisation specifically for adolescents and young adults (AYA) living with cancer.

CanTeen is advocating for the development of AYA Specialist Cancer Centres in each mainland capital city.



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CanTeen Why now? Story of 3

1. The Organisation
 - In January 2005, CanTeen had 20+ years history providing support programs for young people living with cancer
 - No advocacy experience
 - No history of big donations or major gift appeals
 - No government income
 - \$4.5m turnover in the last year

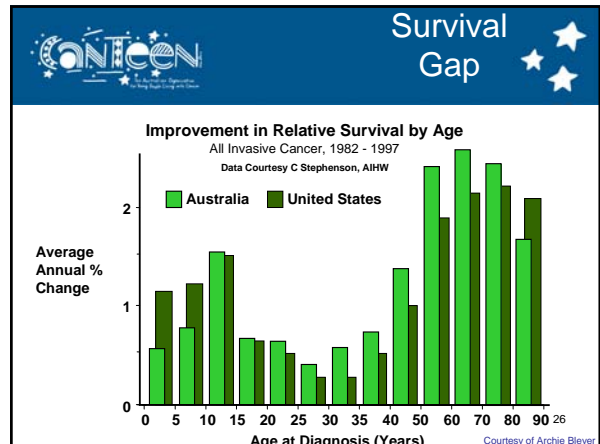
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Our Advocacy Position

2. The Need

- AYAs have the lowest improvement in survival over the past 20-30 years of any age group.
- There is little research devoted to improving cancer outcomes for AYAs. Clinical trials are generally not available or participation rates in trials are very low.
- AYAs have unique and critical psychosocial needs, but we provide little or no support for these needs.
- In summary - care is divided into adult and paediatric by age. This isn't working for adolescents and young adults with cancer.

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Timely Senate Inquiry

3.And a handy Senate Inquiry

2005 Senate Committee Inquiry "The Cancer Journey: Informing Choice"

Recommendation #31:
"The Committee recommends . . . consider the development of appropriate referral pathways that take account of the particular difficulties confronted by adolescents with cancer."

Recommendation #32:
"The Committee recommends that State & Territory governments recognise the difficulties experienced by adolescent cancer patients being placed with inappropriate age groups and examine the feasibility of establishing specialised adolescent cancer care units in public hospitals."

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Why?

	Simon	Rebecca
Age	15 years, 11 months	16 years, 1 month
Referral 1	Referred to cancer specialist by a GP that sees one AYA cancer every ten years	Referred to cancer specialist by a GP that sees one AYA cancer every ten years
Diagnosis	Acute Lymphoblastic Leukaemia (ALL)	Acute Lymphoblastic Leukaemia (ALL)
Referral 2	Specialist paediatric hospital	Local adult hospital
Treatment	Paediatric protocol	Adult protocol
Clinical Trials	80% participation (all cancers)	3% participation (all cancers)
Environment	<i>Bananas in Pyjamas</i>	Stark, grey, clinical

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Why?

	Simon	Rebecca
Age	15 years, 11 months	16 years, 1 month
Shared with	An eight year old and a six year old	Three over-eighty-year-old men
Impact of treatment	Paediatric treatments are more intensive, with more side-effects. Likely to be inpatient more	Adult treatments are less intensive, with fewer side-effects. Likely to be outpatient more
Support	Psych, SW, Music, Education	Very limited access
Followup	Care coordinator visited local community, integrated care with local providers	Limited discharge planning (fewer resources than in paediatric system)
Prognosis¹	67% chance of survival	34% chance of survival

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1. ERALLE vs LALA, France (Boissel et al., ICO, 2003)

From idea to action

Plan of Action

- Developing the solution: collaboration with Cancer Australia (May 2007)
 - Development of the *National Service Delivery Framework*
 - Funding a project officer to facilitate faster outcome
- Media support
 - *The Australian* health feature "The Lost Generation"
 - 60 Minutes story "The Forgotten Generation"

From idea to action

Letter of support from six national charities working with children and young people living with cancer.
Yours sincerely


 Simon Rountree
Chief Executive Officer, Camp Quality


 Camp Quality


 Jenni Seton
Chief Executive Officer, Redkite


 Redkite


 Malcolm Couits
Chief Executive Officer, Ronald McDonald House Charities


 Ronald McDonald House Charities


 Jill Weekes
Chief Executive Officer, Starlight Children's Foundation


 Starlight Children's Foundation Australia


 Jenny David
Director, Variety, The Children's Charity


 Variety


 Andrew Young
Chief Executive Officer, CanTeen Australia


 CanTeen Australia

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From idea to action

A Leveraged "Pitch"

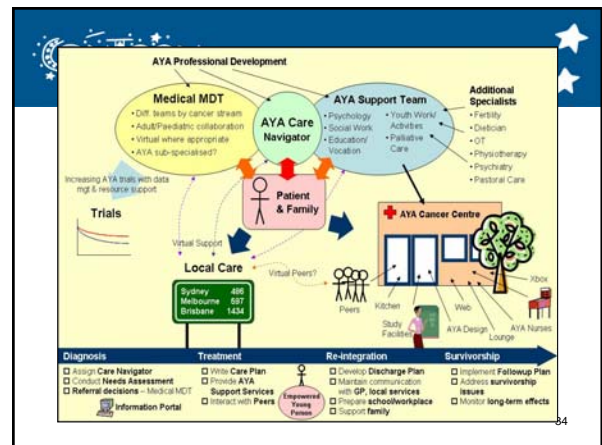
- Lead-up to the Federal election in 2007
 - Opportunity?
 - Health services a state responsibility
- Our proposal
 - \$30m needed to build an AYA cancer centre in six locations; services to be based around these centres but support AYAs across state/territory regions
 - Federal government commitment \$15m
 - CanTeen fundraising commitment \$15m
 - States to commit service delivery costs

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Our aims (the small print)

- Consistent with the NSDF, CanTeen's aims include:
 - Increase access to AYA (psychosocial) support services
 - Increase access to and enrolment in relevant clinical trials
 - Access to care navigation throughout the cancer journey which will involve AYAs in decision making about treatment and support options
 - Provide the opportunity for every AYA to be assessed at diagnosis by medical and psychosocial clinicians skilled in AYA care
 - Ensure expertise in the management of AYA cancers through expert medical MDTs skilled in AYA cancer – with adult & paediatric participation
 - Include age appropriate facilities to treat and support 15-25 year-olds preferably incorporating the needs of inpatients and outpatients.
- Tier-2 objectives include a national network, professional development for AYA professionals, AYA cancer data and more.

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From idea to action

Outcome

- Incoming Labour government committed \$15m for this purpose
- Confirmed in May 2008 budget

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Overview of Funding

Australian Government Youth Cancer Networks Program funds (\$15m) split into:

- Jurisdiction Funding \$12m – allocated on proportionate basis for five Jurisdiction proposals
- National Projects, Evaluation & Administration \$3m

CanTeen is the manager of this program and has executed contracts with all project partners (nearly)

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WA (10% of AYA Aus Populationbut the best looking)

- WA to build a **\$3m outpatient AYA facility** at the Sir Charles Gairdner Hospital – part of a larger cancer centre project
 - Outpatient AYA Centre include recreation room, meeting, counselling, consult/exam room, treatment bays; base for psycho-support team
 - Project complete by end of calendar year 2011 (approx)
 - \$1.2m federal and **\$1.8m CanTeen funds**
- Jurisdiction commitment** to ongoing service delivery (care navigators, social work, psychology, admin/reception, medical lead)
 - Existing PMH Johanna Sewell Adolescent Oncology Unit to be relocated to SCGH site – 2018?

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National Projects Summary

Project	Description	Budget	Lead Agency
AYA Network	Establishment of a national adolescent and young adult cancer (AYA) network of health professionals	\$470k	COSA (Protocols also CINSW)
Guidelines/Protocols	Development of web-based, evidence-based guidance on particular issues related to the care of AYA cancer patients		
Research/Trials	Clinical research: increase participation in clinical trials for AYAs with cancer (includes \$100k investment in trials)		
Professional Education	AYA specific health education for professionals working with AYAs with cancer – accredited (postgraduate certificate) course and free-access version (EdCan) Course development + 20 scholarships	\$520k	The Centre for Adolescent Health/ University of Melbourne

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National Projects Summary

Project	Description	Budget	Lead Agency
Minimum Dataset	Development of a dataset specification for AYAs with cancer to facilitate monitoring of diagnosis, stage, intervention & late effects for AYAs with cancer, pilot test and implement an agreed dataset specification in at least two sites.	\$320k	Cancer Australia
AYA Web Portal	Development of an AYA cancer services portal incorporating medical (AYA lead sites/ services), support (NGOs etc) & other for AYAs, families & clinicians	\$460k	Tender
Needs Assessment (Evaluation)	Development of an AYA with cancer psychosocial assessment tool	\$40k	CanTeen
	Evaluate the implementation of National and Jurisdiction Projects, to monitor & evaluate interim outcomes of the Youth Cancer Network Program projects	\$460k	Tender

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timeframes

2005 – 2008/09

2009/10 – 2010/11

2011/12 ...

Senate Inquiry

NSDF

YCN Program development

Projects finalised

YCN Projects implementation & reporting

Network sustainability

CanTeen and Partner Fundraising

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youcan.org.au



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How can I help?

- You can support the improvement of cancer treatment for young people in Australia by giving us your old mobile phones at no cost to you.

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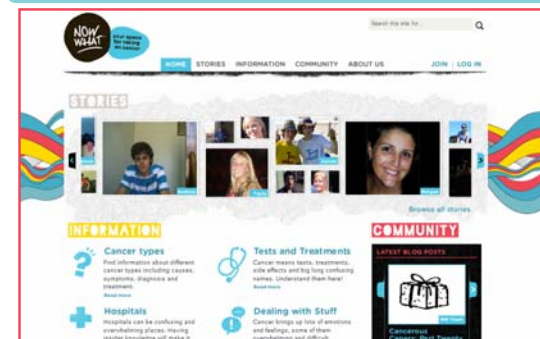
Part 3
'Now what' resources

www.nowwhat.org.au

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Our new online service : A new and unique service for all young people living with cancer




www.nowwhat.org.au

ONTEON

Features

- Information (age-appropriate and filterable)
- Stories and experiences
- Connection with others



IN THE FUTURE: Access to help from qualified professionals.

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ONTEON

Information

PERSONALISE NOW WHAT
Choose your group

Because different people have different experiences of cancer, you can personalise Now What. In choosing your group, you'll be shown things like information fact sheets and other people's stories that are relevant to your situation.

- Cancer types**: Find information about different cancer types including causes, symptoms, diagnosis and treatment. [Read more](#)
- Hospitals**: Hospitals can be confusing and overwhelming places. Having insider knowledge will make it easier. [Read more](#)
- Day-to-day Stuff**: School, work, uni, TAFE, Life still goes on even if someone has cancer. [Read more](#)
- Grief and Loss**: Cancer often means there is grief and loss to deal with. People show emotions in different ways. [Read more](#)
- Tests and Treatments**: Cancer means tests, treatments, side effects and big long confusing names. Understand them here! [Read more](#)
- Dealing with Stuff**: Cancer brings up lots of emotions and feelings, some of them overwhelming and difficult. [Read more](#)
- Relationships**: Relationships can be tough, three cancer into the mix and it can change everything. [Read more](#)
- Beyond Cancer**: Your life and outlook will have changed a lot due to your cancer experience. [Read more](#)

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ONTEON

Information

Please choose a group

You can personalise Now What so that you can find information that is relevant to your group easily and quickly.

By selecting a group below that best describes your situation or interests, you will see related content like information fact sheets and other people's stories that are relevant to your situation.

I would like to see info most relevant to:

- All groups
- A young person with cancer
- A young person whose sibling has cancer
- A young person whose parent has cancer
- A young person whose sibling has died from cancer
- A young person whose parent has died from cancer
- A friend of a young person living with cancer

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ONTEON

Factsheets

TESTS AND TREATMENTS

Choose your group

Bone marrow biopsy and aspiration

A bone marrow biopsy is an extremely important test which can accurately diagnose some types of cancer, and help track the progress of your treatment.

The bone marrow is a type of soft tissue inside some of your larger bones, which produce red and white blood cells and platelets. By examining a small amount of your bone marrow, usually taken from your hip bone, your doctors can make important decisions about your care.

How does it all work?

First of all, you'll probably receive some medication to sedate you. Drugs commonly used include Fentanyl and Propofol. These will be administered by an anaesthetist.

Then, you'll have to lay face-down on an examining table. A small blanket or towel may be placed under your hips to raise them. If you receive sedation medicine, you'll soon be off to sleep and you won't feel any of the procedure. Some people really like the feeling they get from Propofol, as it makes all things very dreamy and relaxing... (and if you want, you can bring an iPod with you to help you stay calm).

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CanTeen Stories

HOME STORIES INFORMATION COMMUNITY ABOUT US JOIN LOG IN

STORIES

Recent Stories

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CanTeen Stories

Home > Stories > Looking Forward To the Future

Featured stories

STORIES

Browse stories

Looking forward to the future

Angela's Story
30 May 2010

Tagged breast cancer, chemo

My cancer journey began when I was diagnosed with breast cancer at 22.

I was diagnosed with breast cancer in July 2009. I was aged 22 years old. I had just got full time employment and had just graduated from University. My first few months were hell as I did not come to the realisation that I actually had breast cancer at my age. I thought it was an old women's disease. How wrong I was! I had my lumpectomy and had one lymph node removed which came back clean. A week after my op I was told by my surgeon that he and the surgeon board at the hospital had all agreed that I should have a mastectomy for a better chance of long term survival and I would not have to have radiation most likely.

It took me ages to come to terms with having to lose a breast... I had lots of negative thoughts going around my head. My breast care nurse was very supportive with phone calls and chats over the phone. I was really glad about it. I had a really good chance and

Choose your group

Share this page Follow
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RELATED STORIES

Nothing's stopping me
13 March 2010

Hey, I'm James and even though I have cancer I'm doing loads with my life.
Read more

CanTeen Community

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Blog

Forums

Commenting and Posting Guidelines

Story Guidelines

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BLOG

Cancerous Capers: Part Twenty
01 June 2010. By NW Team

4 months ago Jamie thought he had the 'win on bad cancer'... until he realised. He does not though...
Read more

FEATURED BLOG POSTS

Cancerous Capers: Part Sixteen
03 May 2010

Jamie talks about the effect chemo has on the hair, the things and what might just happen if he...
Read more

POPULAR FORUM TOPICS

1 Comment

What would you like to see on Now What??
11 replies for readability?

CanTeen Order Resources

It's like this...

Maybe Later Baby:
A guide to fertility for young people with cancer

CanTeen Order Resources

Books > Now What...? Dealing with your parent's cancer

ABOUT US

Now What...? Dealing with your parent's cancer

This book provides information, practical tips, support and advice across a whole range of areas that impact on young people who have a parent with cancer.

Now What...? Dealing with your parent's cancer is divided into 5 sections:

- Head Stuff
- Heart Stuff
- Practical Stuff
- Medical Stuff
- Handy Stuff

ORDER A FREE RESOURCE

We have several resources that you can order for free.

Order resource

CanTeen Volunteers

CanTeen would not be able to run the activities that we do for our Members without the support and contribution of:

- Psychosocial Volunteers
- Medical Volunteers
- General Volunteers

CanTeen always needs Volunteers.

Volunteers provide an invaluable expertise and are a major asset to CanTeen.

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How to support us

Selling bandanna's is a great way to help CanTeen. This year National Bandanna Day is on Friday 29th October 2010. Ask me how to become a CanTeen Champion!



Thank you
www.canteen.org.au

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Questions?



Audio of this lecture will be available thanks to 720 ABC Perth at:
www.cancerwa.asn.au/resources/cancer-update



Next week's lecture

Who owns your genes?

Dr Graeme Suthers
South Australian Clinical Genetics Service, SA

