

**December 2002**  
**EDITION 8**

## ***Our Mission***

To promote and develop awareness of genetic conditions within the community, provide information and advocacy to individuals and families, foster research, encourage and support service delivery by genetic support groups.

Welcome to the December 2002 edition of the Genetic Support Council Western Australia (Inc) newsletter.



## **A Christmas Message**

As 2002 draws to a close and we look back on world events, one cannot help but feel that there are some irreversible things that have changed our lives forever.

The world seems to be spiralling into ever increasing conflict. Australians have been thrust onto the world's stage following the terrible tragedy in Bali. Our thoughts are with those families whose lives have been so effected by this senseless act.

More than ever it would seem that the Christmas message of "Good will and Peace on earth" could never be more relevant.

To each and every one of you, we at the Genetic Support Council WA would like to wish you a safe Christmas that is full of joy and may 2003 be gentle and kind to you all.

Terry Keating  
Executive Director

## ***Current Issues and matters of interest***

### **CANCER FEES**

#### **US company to charge for vital checks**

By **Kristen Watts**

WEST Australians at risk of hereditary cancers could soon be charged thousands of dollars for early warning tests because of an international row over ownership of genetic information. People with a family history of breast and ovarian cancers are currently able to have free screening for the presence of gene mutations through a service run out of King Edward Memorial Hospital.

Patients found to be carrying the gene then have the chance to detect and treat the disease before it develops, leading to greatly improved long-term prognoses.

Health Minister Bob Kucera will this week call on the Federal Government to impose national regulations on gene testing to ensure that patients can retain access to the screening technology.

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The views expressed in this newsletter are those of the individual authors and not necessarily those of the GSCWA. The material supplied is for information purposes only, and is not to be used for diagnosis/treatment.

He said yesterday that access to the free screening was at risk because American company Myriad had claimed to own patents on the genes which predispose people to breast, ovarian and bowel cancer. It also claims to own genes associated with hypertension and melanoma.

The company has claimed exclusive worldwide rights to diagnostic testing of these genes and has closed testing in all public US laboratories.

"Myriad has indicated that it will prevent Australian publicly funded genetic services from offering testing to individuals and families at risk of hereditary breast, ovarian and other cancers," Mr Kucera said.

"Last month, Myriad signed an exclusive licensing agreement with Melbourne-based Genetic Technologies Limited to provide (breast and ovarian cancer) gene testing in Australia.

He said the company proposed to operate by mid-next year as a monopoly, providing tests to patients at a cost of about \$4.450.

The Federal Government can either negotiate with Myriad to secure broad-based licensing or it can introduce legislation to prevent one company from having exclusive access to the technology.

WA Cancer Foundation president D'Arcy Holman said gene knowledge should not become a commodity.

The Myriad example was a test case for genetic testing patents.

Mr Kucera will raise the issue of genetic information regulation at this week's Australian health ministers' conference.

It would be unethical if only women who could afford to pay a private operator could use such a service, he said.

**Source: The West Australian, Wednesday 27/11/2002**

**Letter to Editor**  
**West Australian Newspaper**  
**from GSCWA**

**Cancer tests must be free**

THE Genetic Support Council of W A is concerned about the implications of last month's agreement between US-based biotechnology company Myriad Genetics and Melbourne-based Genetic Technologies.

Myriad, which holds patents over tests for certain cancer predisposing genes, has entered into an exclusive licensing agreement with GTG to provide testing in selected private laboratories only - effectively monopolising the provision of genetic testing services for breast cancer in Australia.

The serious threat that gene patents and exclusive licensing agreements pose to public genetic testing services has been highlighted in recent newspaper articles. Privatisation and monopolies over genetic testing have the potential to restrict public access to what could be life-saving technology by shifting the cost from government to the consumer. In other countries Myriad charges approximately US\$2500 to test for breast cancer susceptibility genes.

Currently in Australia, people with a family history of breast cancer can be tested free of charge.

Exclusive private sector testing can also hinder research, innovation and may compromise the laboratory expertise we have developed in Australia.

While countries such as Canada, France and Britain have strongly opposed Myriad's exclusive patent and a challenge to the patent is pending in the European High Court, Australia is yet to take affirmative action.

We welcome the leadership shown by Health Minister Bob Kucera on this issue at the Australian Health Ministers' conference.

To ensure continued public access to high quality genetic testing in Australia, we urge the Federal Government to protect the existing clinical services in each State.

**TERRY KEATING,**  
**Executive Director,**  
**Genetic Support Council WA (Inc).**

**Source: The West Australian,**  
**Wednesday 10/10/2002**

**Coming Events**

**Carers WA Family Night Fundraiser**

Spiderman - 'It's Cool to Care'

Sunset Cinemas - Kings Park  
**Monday, January 20th 2003**  
Doors open 6.00pm  
Film commencing 8.00pm

Ticket price: \$12.00  
Carers / Concession / Children 5 - 15:  
\$9.00  
Family Ticket for 2 adults and 2  
children: \$32.00  
Children under 5 are free

Simply call 9202 8611 to make a credit  
card booking over the phone.

**ARAFMI Fundraiser**  
**Quiz Night**

Come along and enjoy a fun night out!

**Friday 7<sup>th</sup> March 2003**  
7pm START - Questions commence  
promptly at 7.30pm - 11.30pm

Subiaco Football Club  
201 Subiaco Road, Subiaco

Tables of 6 - 8  
Tickets: \$8.80 per person (GST incl.)

Thousands of dollars worth of great prices to be won!

Food and drinks available for purchase.

Book your tickets now as tables are sure to go EXTRA FAST!

For more information call ARAFMI Fremantle office on 9319 8799.

All proceeds to be development of a Carer Resource Centre.

## ***Interesting articles***

### **DNA raises sticky questions**

#### **Legislators will be urged to tackle the issue of DNA ownership**

##### **Richard Yallop**

WHEN Monica Lewinsky did not dry-clean her semen-stained dress after her White House encounter with Bill Clinton, she was unwittingly drawing attention to a key issue of modern genetics, according to Melbourne law professor Loane Skene.

Who exactly did the bodily substances - and the associated DNA material - belong to? President Clinton or White House intern Lewinsky? And what if she had subsequently used the DNA material to blackmail the most powerful man in the US?

At a Melbourne symposium on DNA and genetics beginning today, Professor Skene will urge legislators to tackle the issue of DNA ownership - be it human tissue removed for medical research or when a woman removes semen from a condom to inseminate herself without the man's consent.

It is not an offence to collect genetic material a person has discarded and to analyse it without that person's consent.

"If I am in a pub and a person walks away from a glass from which he or she has been drinking, I commit no

offence if I swipe the rim and analyse the DNA from it," Professor Skene, a specialist in medical law at the University of Melbourne said. "Similarly, if I collect the hair on the barber's floor after a client has left, or pick up a stray hair left in my room from a visitor."

Take the case of US film producer Steve Bing, who was forced by a DNA test to acknowledge he was the father of British actor Liz Hurley's child.

Another woman claiming Bing was the father of her child hired a private investigator who took dental floss from a bin outside his house to obtain DNA from his saliva. Concerns over DNA ownership, particularly in relation to human tissue obtained by hospitals, recently led Britain's Human Genetics Commission to recommend the creation of the criminal offence of stealing an individual's DNA, if obtained without consent or by deception.

The issue of DNA ownership originally arose in the US where a patient had his spleen surgically removed and a researcher then used its cells to develop a profitable product without the patient's approval.

The patient unsuccessfully sued for a share of the profits.

Professor Skene will tell the symposium that she does not support ownership rights of DNA material for the people from whom it was taken.

She believes that with hospitals, patient tissue should be treated like records and regarded as belonging to the hospital.

But she believes laws should be introduced to protect people whose DNA is used in a criminal way against them. "In the case of Lewinsky, it should be an offence if she says 'I have your DNA on my dress, now pay'."

**Source: *The West Australian*, Thursday 28/11/2002**

## **The Link Line**



*The Link Line* provides a supportive and confidential means of connecting individuals and families for whom no known genetic support group exists.

If any individual is seeking contact with others in these circumstances, *The Link Line* is available to you for this purpose.

*Genetic support groups are an important resource for families or people in a similar situation. To date, there appears to be no specific support group for the condition Ehler Danlos (connective tissue disorders) in Western Australia. A family living in the southwest region of Western Australia is seeking linkage with other people and families living with this condition.*

To make confidential contact with anyone using *The Link Line*, or for further information regarding this service, please call Terry Keating at GSCWA.

## **Interesting Websites**

### **Fundraising Ideas – Girl Guides Qld**

[http://www.guidesqld.org/sg/fr\\_howto.htm](http://www.guidesqld.org/sg/fr_howto.htm)

### **A to Z Guide to Fundraising Ideas**

The A-Z of ideas is a selection of fundraising ideas from the UK which might also be adapted to suit your locality and situation.

<http://members.aol.com/moggycat/fundraise.htm>

## **Listing of Program Ideas**

Contains ideas about Indoor & Outdoor Activities, Games, Fundraising Activities, Social / Recruitment Activities. This is an UK site

<http://www.everestvsu.co.uk/progweb/complete.htm>

### **A Guide to Organising a Fete – PDF Document link**

[www.fetesandfestivals.com.au/pdf/howto.pdf](http://www.fetesandfestivals.com.au/pdf/howto.pdf)

Page contains pointers to criteria for evaluating information resources, particularly those on the Internet. This is part of the Information Quality WWW Virtual Library (<http://www.vlib.org/>) <http://www.vuw.ac.nz/~agsmith/evaln/evaln.htm>

## **Other Addresses**

### **What is the Gene Technology Information Service?**

A free-call Gene Technology Information Service has been established to meet a growing community need for balanced information on gene technology. It provides reliable information on gene technology, ranging from a basic explanation of genetic modification to issues involving the regulation of products derived from gene technology and testing for food safety.

The GTIS participates in public events and conferences where an information stand is set up with fact sheets, and staff are available to respond to enquiries from visitors.

Resource material, fact sheets and brochures are provided to the service by a wide range of Commonwealth departments and agencies with responsibility for biotechnology. A list of current resources can be provided.

You can contact the GTIS by the Australia-wide free call number 1800 631 276,  
by email at [gtis-australia@unimelb.edu.au](mailto:gtis-australia@unimelb.edu.au) or by fax on (03) 8344 3905.



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Have you got anything you want to be published? Either our newsletter or our website can be the place to display your information. So contact us via e-mail or phone and we can arrange it for you.

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SIDS and Kids Western Australia  
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Spina Bifida Association of WA  
Thalassaemia Association of WA  
Trisomy and Related Disorders  
Western Australian Retinitis Pigmentosa Foundation  
WA Tourette Syndrome Organisation (WATSO)

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