

Gene Advocate

EDITION 13

May 2003

Special points of interest:

- * DNA 50th Birthday
- * Links Line: Tegra Collins Facio Cranial syndrome.

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About Our Members

DNA 50th Birthday Genomics Branch Department of Health

April 2003 marks the 50th year since the discovery of the double helical shape of deoxyribonucleic acid more commonly known as DNA. James Watson and Francis Crick developed previous work by Rosalind Franklin to later claim a Nobel Prize with another colleague Maurice Wilkins. As with many scientific discoveries, at the time Watson and Crick first published their work in Lancet on April 25,

1953 the true value lead to great advancements in many fields of science and yet to be realised. DNA is used in forensic science, botany, biology and most relevant to human health in the area of genetic diseases. DNA is a chemical code and is stored in every cell of the human body.

This chemical code gives the instruction to the cell to perform its unique function. When DNA is damaged or changed (called a mutation) in some way the function of the cell is also changed. These changes can lead to hereditary diseases and/or genetic conditions.

The DNA code for some conditions is already known and has lead to the development of predictive and presymptomatic testing. Other conditions are yet to be identified through the changes to their DNA,

so testing may not be available. In a time of great discoveries the developments of these are still forthcoming.

In recognition of this the 50th year since the discovery of the structure of DNA interpretive signage has been placed at the DNA Tower at one of Perth's highest points in King's Park (see pictures below)

The story behind the original reason for constructing the tower has its own twist and is worth a visit to the tower to find out. Why not taken in some of the view whilst you are there and check if it is still 101 steps to the top?



DNA tower at Kings Park WA

Source: Genomics Branch Department of Health Western Australia
189 Royal Street
East Perth, WA 6004

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.

The GSCWA Board of Management

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Carmel Wright
Client Services Coordinator
Spina Bifida Association of WA Inc.

Our Location and contact details:

Level 1, Oasis Lotteries House
37 Hampden Road
Nedlands WA 6009
Telephone: 08 9389 6722
Mobile: 0411 585 113
Email: admin@geneticsupportcouncil.org.au
Web: <http://geneticsupportcouncil.org.au>

Office hours:

9.00am to 12.00pm and 1.00pm to 5.00pm.
Monday to Friday.
12.00pm to 1.00pm by appt.
Monday to Friday.

Staff:

Terry Keating, *Executive Director*
Anja Hermann, *Administrative Officer*
Kristina Johns, *Resource Officer*

Current Issues and Matters of Interest

Do you know anyone with type 1 diabetes??

Helping Individuals with Type 1 Diabetes to Exercise Safely. The biggest challenge that people with type 1 diabetes are faced with is maintaining their blood sugar levels within a "normal" range. This is done by daily insulin injections, careful control of diet and regular checking of blood sugar levels.

While regular participation in exercise is recommended for everyone, exercise can make management of blood sugar levels even more difficult for people with diabetes. Unfortunately, due to a lack of research on the effects of different types of exercise on blood sugar levels in people with diabetes, doctors cannot provide detailed advice on how to manage blood sugar levels during and after exercise.

Exercise Physiologists at the University of Western Australia in association with a team of Medical Doctors from Princess Margaret Hospital (with funding from the National Health and Medical Research Council and the Juvenile Diabetes Foundation) are breaking new ground with research in this area. The primary aim of this research is to develop guidelines for people with type 1 diabetes to safely participate in all types of activities by maintaining their blood sugar levels within the "normal" range. If you are interested in learning more or possibly participating in this research please call Kym or Vanessa on 9380 1383, e-mail vbussau@cyllene.uwa.edu.au, or alternatively contact Dr Luis Ferreira on 9380 3181. [Notice approved by UWA Human Research Ethics Committee]

Source: University of Western Australia: UWA Events

Study participants needed - 18-60 years, without PKU

Neuropsychological and Neurophysiological Effects of Dietary Modification in Adults with Phenylketonuria. Phenylketonuria (PKU) is a genetic disorder which results in severe mental retardation and structural brain damage if left untreated.

Treatment involves placing the patient on a protein-restricted diet within one-two weeks of birth. At present, PKU sufferers are recommended to stay on the diet for life. In the past, however, individuals were recommended to stay on the diet only until the age of about twelve years.

This research, conducted under the supervision of Dr Allison Fox, from the UWA School of Psychology, and Dr John Burnett, from the Adult Phenylketonuria Clinic at Royal Perth Hospital, concerns the effects of dietary modification in adults with PKU. Part of the research involves the voluntary participation of adults aged 18-60 without PKU.

Participation requires completion of a set of tasks assessing general knowledge, problem solving and memory abilities. It also involves completion of a computerised task requiring you to respond to particular letters presented on a computer screen, and to withhold your response to other letters. During this task a measure of your brain's electrical activity will be recorded using electrodes placed on the surface of your scalp. Participation is completely voluntary. You will be reimbursed \$15 to cover travel expenses and time spent.

For further information

Email: jonson@psy.uwa.edu.au

Ph: 9380 1420

Jonson Moyle MPsych (Clinical Neuropsychology) / PhD Candidate - School of Psychology
University of Western Australia

Hackett Dve Crawley 6009

[Notice approved by UWA Human Research Ethics Committee]

Source: Jonson Moyle

MPsych (Clinical Neuropsychology) / PhD Candidate - School of Psychology



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 *Tegra Collins Facio Cranial syndrome*.

A Greek mother with an 18 month old child with Tegra Collins Facio Cranial syndrome in the Northern metropolitan region would like contact with another mother with a child with a similar condition.

Please contact Kristina at the Genetic Support Council if seeking contact with this family, telephone: 08 9389 6722 (see page 2 for GSCWA contact details and location).

Coming Events

Carers Participation Forum -Carers of people with Mental Illness. Carers WA

Date: 12th June 2003

Time: 10.00am—12.30pm Followed by lunch

Where: The Niche Conference Room, Cnr of Aberdare Rd & Hospital Ave Nedlands WA

Contact: Josephine Majnoon at Carers WA

Ph: 9202 8620

Website: www.carerswa.asn.au

RSVP: 6th of June

Youth Health Forum

The forum has been developed by Young People's Health Australia (WA Branch) to provide young people and youth service providers the opportunity to develop contemporary policy regarding youth health and well being in Western Australia. The forum will consist of:

- A panel of speakers exploring key themes in youth health
- Focus group discussions
- Morning tea & networking opportunities

Recommendations developed at the forum will be used by YACWA & YPHA to guide their future lobbying and policy development work. A report and recommendations will be forwarded to key government ministers and departments.

When: 8.30am—12.00pm

Date: Thursday 29 May 2003

Where: Alexander Library Theatre, Perth Cultural Centre, Francis Street, Perth. Please

RSVP by 23 May 2003

Contact: Midge Turnbull Executive Officer
Youth Affairs Council of WA
PO Box 1001, West Leederville WA 6007
Ph: 08 9388 0640
Fax: 08 9388 0650
Email: midge@yacwa.org.au

ASMR Medical Research

Date: Week 2-6 June
Email: Events@central.murdoch.edu.au
When replying, please edit your Subject line so it is more specific than "Re: Contents of Events digest..."

Find out more about the various medical research being conducted in WA.
<https://www.murdoch.edu.au/cgi-bin/newsitem?2740>

Free Vision WA Public Seminar:

Health for all - are community expectations outgrowing our health system?

Guest Speaker: Mike Daube, Director-General, Department of Health, Western Australia
Panel: Professor Linda Kristjanson, Associate Professor, Edith Cowan University and 2002 Telstra Australian Businesswoman of the Year
Dr Penny Flett, CEO, Brightwater Care Group and 1998 Telstra Australian Businesswoman of the Year
Chair: Professor Alan Robson, Deputy Vice-Chancellor, UWA
Date: Tuesday, 29 April, 2003 at 5.30-7.00pm
Venue: Western Australian Museum, James St foyer, Cultural Precinct, Perth
RSVP: No charge but bookings required
Ext 7977 or visionwa@uwa.edu.au

Multiple Sclerosis Awareness Week

Multiple Sclerosis Society of WA
Dates: 2 - 8 June
This week aims to raise the profile of multiple sclerosis in WA.
Contact: 9365 4888
Website: www.multiple-wa.asn.au

International Men's Health Week

Men's Advisory Network
Dates: 9 - 15 June
A national and international program aimed at raising awareness of men's health and related issues.
Contact: 0414 950 902
Website: www.menshealthweekaustralia.org

Annual Epilepsy Seminar

Epilepsy Association of WA (Inc.)
Date: 21 June
The day provides an opportunity to discuss and listen to epilepsy issues with professional presentations by neurologists and epileptologists.
Contact: (08) 9346 7699

Global Day

Motor Neurone Disease Association
Date: 21 June
An international day dedicated to raising awareness of Motor Neurone disease by providing an internet chat room to council people living with Motor Neurone disease all over the world.
Contact: (08) 9346 7355
E-Mail: www.mndawa@cns.wa.com

Deafblind Awareness Week

Senses Foundation (Inc.)
Dates: 23 - 29 June
Deafblind Awareness Week is held to raise awareness of the condition.
Contact: (08) 9272 1122

Red Nose Day

SIDS and Kids Western Australia
Date: 27 June
Red Nose Day is SIDS and Kids' major fundraising event. Funds raised are applied to bereavement counselling for anyone who has been affected by the sudden and unexpected death of a young child; health promotions to reduce infant death; and funds for research into infant mortality.
Contact: (08) 9474 3544
Website: www.sidswa.org.au

National Blood Donor Week

Australian Red Cross Blood Service
Dates: 30 - 6 June
National Blood Donor Week salutes those anonymous donors who save the lives of thousands each year.
Contact: 131 495
Website: www.giveblood.redcross.org.au

Drug Action Week

Alcohol & other Drugs Council of Australia
Dates: 23 - 28 June 2003
Drug Action Week is an initiative of the Alcohol & other Drugs Council of Australia (ADCA)
Website:
http://www.adca.org.au/policy/drug_action_week.htm (see also state & territory contacts)



Grants

The GSCWA maintains a list of grants that can be applied for by community organisations such as genetic support groups. Members can contact our office for further information.

Several relevant grants this month are:

Vacation Camp Grants

The Lotteries Commission of *Western Australia*.
Purpose: To assist children with special needs to participate in group holidays.

Further information can be obtained at:
www.lottery.wa.gov.au/corporate/grantsguide/guid_014.html

Health and Wellbeing Grant

ANZ Charitable Trusts
Purpose: To charitable organisations and for charitable purposes *throughout Australia*.
Categories: Older and frail people, children and young people, disadvantaged, cancer and sight impairment.

Further information can be obtained at:
www.anz.com.au/australia/charitabletrusts/guidelines.asp

* GSCWA can assist members with grant applications.

GSCWA SPECIAL PROJECT FUND GRANT

The Genetic Support Council WA has a limited one off fund that is available to 'full' members (located in WA) for grants of up to \$1000 to assist with special projects such as:

- Assisting with publications
- Conducting seminars and forums
- Compilation of information base for consumers
- Attendance at conferences
- Assistance in engaging expert speakers at conferences, seminars and forums.
- Other projects that have a direct benefit to Genetic Support Groups and their members may be considered.

* Contact GSCWA for further information and criteria

Interesting Websites

Fairer Medicare Package - 28 April 2003. Australian Department of Health and Ageing

<http://www.health.gov.au/>

The Prime Minister announced significant reforms to Medicare, as part of the Federal Government's: 'Fairer Medicare Package'.

The Wellcome Trust

www.wellcome.ac.uk/genome

The Human Genome: your genes, your health, your future An accessible, up-to-date and interactive guide to the human genome and its medical, ethical, social and legal implications. News, views and reviews on the human genome and modern genetics.

The full human genome sequence has opened up myriad new possibilities for research - to provide a better understanding of human health and disease, and to create new opportunities for medical advances. With these opportunities come fears about how genetic knowledge may be used or misused.

The Human Genome: Science, Medicine and Society provides an authoritative, balanced and accessible guide to these issues. With a blend of News, Feature and Background articles, plus interactive guides to the science and biology of the genome this site will be an indispensable source of information for everyone interested in this key area of biomedical science.

HIC

<http://www.hic.gov.au/corp>

HIC is Australia's primary health information management and payment agency. This site provides information about the services offered as well as access to online forms. For example, Medicare Services
http://www.hic.gov.au/yourhealth/our_services/m_sfy.htm

Eureka Science

<http://www.eurekascience.com>

Designed to provide the information fun and engaging look at DNA basics for people of all ages.

GSCWA Members

FULL MEMBERS

Acoustic Neuroma Association of Australia
 Alzheimer's Association of WA
 Angelman Syndrome Association
 Arthrogryposis Support Group
 Australian Huntington Disease Association
 Australian Pituitary Foundation WA Branch
 Australian Tuberous Sclerosis Society Inc.
 Coeliac Society of WA
 Cushings Disease Support Group
 Cystic Fibrosis WA
 Diabetes Australia -Western Australia
 Down Syndrome Association of WA
 Dyslexia SPELD Foundation WA Inc
 Epilepsy Association of WA
 Even-Keel Bi-Polar Support Association (Inc)
 Haemophilia Foundation WA Inc.
 Heart Kids WA
 Klinefelters Support Group
 Learning and Attention Disorders Society of WA (LADS)
 Lupus Group of WA
 Motor Neurone Disease Association of WA Inc.
 Mucopolysaccharide & Related Diseases Society (MPS)
 Muscular Dystrophy Association of WA
 Neurofibromatosis Association of WA.
 Parents of Children with Disabilities
 Periodic Paralysis Society of Australia
 Raynaud's Syndrome Support Group
 Rett Syndrome Association of WA
 Schizophrenia Fellowship of Western Australia Inc.
 Short Statured People's Association WA Branch
 SIDS and Kids Western Australia
 Sjögren's Syndrome Support Group
 Spina Bifida Association of WA
 Thalassaemia Association of WA
 Trisomy and Related Disorders
 Western Australian Retinitis Pigmentosa Foundation
 WA Tourette Syndrome Organisation (WATSO)

CORPORATE ASSOCIATE MEMBERS

ARAFMI Western Australia
 Association of Genetic Support of Australasia
 Australian Kidney Foundation
 Carers Association of WA Inc
 Genomics Branch, Dept. of Health
 Health Consumers Council WA
 Lone Parent Family Support Service (LPFSS)
 The Kalparrin Centre
 The Neurological Council of WA Inc
 Western Australian Deaf Society Inc.

INDIVIDUAL ASSOCIATE MEMBERS

Anja Hermann, GSCWA
 Bonita Anne Eaton, LPFSS
 Professor Charles Watson, Curtin University
 Terry Keating, GSCWA

GSCWA News Corner

The GSCWA would like to thank the Muscular Dystrophy Association for sharing their display with us at the Muscular Dystrophy conference held in Perth on the 9th and 10th of May 2003.



Advertise in 'Gene Advocate' or on our website!!!

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.

(see page 2 for GSCWA contact details).