

November 2002
EDITION 7

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 November 2002 edition of the Genetic Support Council Western Australia (Inc) newsletter.

Current Issues and matters of interest

High prevalence of COELIAC DISEASE in a population- based study from WA: A case for screening?

Coeliac disease (CD) can be defined as a condition of malabsorption in a genetically prone individual. It is precipitated by antigens found in gluten and prolamines of other cereal grains namely barley and rye, and results in immunologically mediated inflammatory damage to the mucosa of the small intestine. Untreated it can result in severe steatorrhoea, malnutrition and increased risk of developing other diseases including lymphoma and osteoporosis, even, death (Lancet-8/01).

In 1994-95, a team of Gastroenterologists, primarily of Fremantle Hospital (Hovell, Olynke, Cullen, and Collett and Vautier

UK), undertook a study to determine the prevalence of CD in an Australian community.

An analysis of stored serum samples, from 3011 random subjects from the Busselton Health Study, resulted in those testing positive to IgA antiendomysial antibodies (AEA) being contacted and offered endoscopy and small bowel biopsy. The outcome was to 'determine the prevalence of AEA positivity and biopsy-proven CD in the community with reference to the proportion of symptomatic to asymptomatic patients'.

Conclusions: The prevalence of CD is high in a rural Australian community, 1: 250. Most patients are undiagnosed and asymptomatic. (MJA Vol1175)

This study compares extremely well with various international clinical studies, for example; Northern European studies based on serological screening report disease prevalence ranges between 1:50 and 1:200. A recent study in NZ reported, 1:82. It was believed the incidence of CD was 1:10,000 in the USA until last year when a New York clinical study reported the incidence is more likely to be 1:250. Dr Robert Anderson, a fellow at Oxford University, recently discovered the causative peptide in CD and now continues his research in Melbourne with the view to developing a cure. As a result of his studies, it would appear that the incidence of CD in the Caucasian and western Asian countries is very likely to be higher than previously thought, maybe as high as 1:100.

Symptoms of CD may occur singularly or in combination both adults and children.

These may include: unexplained anaemia, fatigue, gastrointestinal disturbances including: abdominal pain/ bloating, diarrhoea and or, constipation, flatulence, dyspepsia, anorexia, vomiting.

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*

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Department of Health

Varied symptoms of malabsorption include: easy bruising, bony and muscle pain, impaired fertility, premature menopause, anxiety, depression, neuropathy, ataxia.

Weight loss or gain and in more commonly in children, dental abnormalities, delayed puberty, severe irritability and short stature. It is also worthy to consider CD with early onset of osteoporosis or osteopenia.

Genetic factors.

CD is a heritable condition with more than 50% of patients with CD are likely to have 10-15% of first degree relatives with undiagnosed CD.

Princess Margaret Hospital, WA, has recommenced screening insulin dependant diabetics for CD, as the incident within this group is as high as 4%.

Thyroid dysfunction is a common associated disorder.

CD is not gender specific, even though many studies indicate there is a higher female prevalence.

1:3 patients who have dermatitis herpetiformis will also have CD.

Permanent removal of gluten from the diet, usually resolve the pathological changes of the small bowel.

The Coeliac Society of WA, a community support organisation makes available literature and resources to assist those medically referred to follow a gluten free diet. It provides the education to make the necessary life style changes, ongoing support and information. Dietary education and counselling is offered to patients free of charge.

The Coeliac Society conducts its services from Anzac Cottage in Mt Hawthorn. Further details on the Society and services can be obtained from the web site www.wa.coeliac.org.au or phone: 08) 9444 9200

Bev Ramsay RN
Executive Officer

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.

Coming Events

The Centre for Law & Genetics invites you to,

Symposium 2002, 'BREAKING THE CODE'.

**28-29 November 2002 Melbourne
Australia.**

The theme of this year's annual symposium targets the ethical and legal implications of an increasingly accessible set of genetic technologies. Contributors will seek to address the question 'in breaking the gene code what other codes have been broken'?

Sub Themes

- The merger of genetics/law/ethics
- Use of Genetic Information
- Genetic Testing
- Property Rights & Law
- Research Ethics
- Licensing
- Ownership
- Setting new ethical boundaries

for more information see the [programme](#) and [abstracts](#).

Contributors

Speakers will be drawn from the Centre for Law & Genetics, the Murdoch Children's Research Institute, the Walter and Eliza Hall Institute, the Australian Law Reform Commission and Oxford University.

More information about contributors will be added soon. In the interim you can try searching the [whitepages](#) for individual info.

Your Contribution

Given our prior experience with public symposia, we have found that participants value a more interactive and user focused discussion. Thus we have broken talks into topic area and shortened individual talk time. This will allow for 30-40 minute open panel discussions at the end of each session in which participants will be invited to discuss various themes raised by the talks with the speakers.

These are not simply 'question times' but interactive sessions which recognize that the technology, law and ethics are still in a state of development. Therefore *all* participants, both speakers and audience are recognised as having valuable input in the ongoing debate. The chairs will construct each session accordingly.

Location

The symposium will be held at the *Murdoch Children's Research Institute* and *Walter and Eliza Hall Institute* in Melbourne Australia on the 28th and 29th of November. Directions to these centres can be found in the '[venues](#)' page. If you need accommodation whilst you are in Melbourne we have put together some links to a range of hotels on our '[recommended accommodation](#)' page.

Source:

<http://www.lawgenecentre.org/symposium2002>

**Monday December 2nd
until Wednesday December 3rd**

NEUROLOGICAL EXPO – PUBLIC LECTURES – LIMITED PLACES

CHAIR: Sarah Dunlop & Giles Plant, WAIMR, University of Western Australia, AUSTRALIA
Conference Room, Centre for Neurological Support,
Niche house, QE II medical centre
11 Aberdare Road, Nedlands, WA 6009

**Tuesday December 3rd
until Friday December 6th**

3RD ASIA PACIFIC SYMPOSIUM ON NEURAL REGENERATION SHERATON PERTH HOTEL

Tuesday December 3rd

WELCOME RECEPTION
The Perth Mint

Wednesday December 3rd

Stem Cells

Thursday December 5th

Spinal Cord Injury & Repair I
In Association with The Neurotrauma Research
Program,
Road Safety Council, WA

Friday December 6th

Spinal Cord Injury DISCUSSION workshop –
Limited Places

Source:

<http://neuro.zoology.uwa.edu.au/sympprogram.htm> - please check this website also for detailed program

About our members

THE LUPUS GROUP OF W.A. (Inc.)

A Support and Education Resource-Contact for information sheets and coming educational and support events.

MISSION:

Act as the principle resource for lupus patients, their families, doctors and the community to provide educational awareness, support and facilitation of research activities.

PRIORITIES:

Education and Community Awareness:

To provide community displays, education seminars, media updates, newsletters and information kits to the general public, medical and political community to raise awareness, early detection and understanding of lupus.

Support Services:

To act as a source of support and information to people with lupus, their families and friends.

Research:

To actively fund and participate in research to enhance management practices and discover the potential cause and cure for lupus.

AN OVERVIEW OF LUPUS

WHAT IS LUPUS

Lupus is an autoimmune disease.

When you have lupus you produce an excess of proteins - called antibodies - which instead of protecting the body, react against substances normally present in the body to cause many symptoms. Lupus is not infectious or contagious.

WHO DOES LUPUS AFFECT

Lupus is not a rare disease. It affects over 20, 000 Australians, at least 1 in 2000 West Australians and is increasingly significantly in incidence due to improved detection by medical tests.

90% of those affected will be women and develop lupus between the ages of 15 and 45 years. Lupus is at least twice as prevalent in Aboriginal Australians.

International Studies have reported lupus as a leading cause of morbidity among women, with women five times more likely to die from complications of lupus than men.

Lupus is more common in Western Australia than leukaemia, multiple sclerosis, muscular dystrophy and AIDS.

WHAT CAUSES LUPUS

Medical researchers do not know the cause of lupus. It is known that the body's immune system attacks its own tissues instead of protecting them, as is the case normally.

Also, recent studies have shown that there is a link between lupus and certain hormones, together with environmental and genetic factors.

MAIN TYPES OF LUPUS AND SYMPTOMS

SLE has a wide range of symptoms.

It can remain undiagnosed or misdiagnosed for years.

Discoid Lupus: Is generally a milder disease than SLE, and affects the skin, with skin rashes and sun sensitivity being the main symptoms.

Systemic Lupus Erythematosus (SLE): Can affect almost any organ or system of the body.

- Fatigue
- Muscular pain/inflammation - tendons/ joints
- Skin rash - face, neck or arms

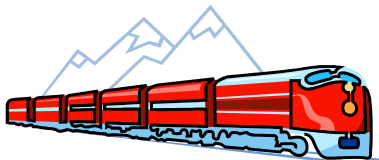
- Fever and weakness. feeling of poor health
- Sensitivity to sunlight
- Hair loss
- Unexplained headache, depression or anxiety
- Chest pain including pleurisy
- Mouth ulcers
- Kidney problems
- Miscarriages (lupus flares during pregnancy)

HOW CAN LUPUS BE TREATED

The treatment of lupus varies widely according to the severity of the condition and whether there is organ involvement. Some people will not need any treatment, whilst others need strong drugs. Regular monitoring to detect disease changes will be undertaken.

Medications aim to suppress the over active immune system and reduce the inflammation and associated symptoms. Medications include aspirin, steroids, immunosuppressants (severe cases) and broad-spectrum and high-grade blockout sunscreen. Antimalarials have also proven useful in the treatment of lupus.

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.

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.

Interesting Websites

The National Psoriasis Foundation (NPF)

<http://www.psoriasis.org/messageboards.htm>

The National Psoriasis Foundation (NPF) is proud to offer members the opportunity to connect and share with others. The message boards serve as a meeting place and online community for members of the NPF. Offer five different boards: General, Parents and Others Who Don't Have Psoriasis, Teens, Youth and Kids. They offer members the opportunity to grow, learn and take control of their psoriasis and psoriatic arthritis.

Gluten-free Dining Out Guide Australia/NZ

<http://members.ozemail.com.au/~coeliac/dine.html>

Gluten-free Dining Out Guide Australia / NZ

Would you like to recommend an eating place in Australia or New Zealand which understands what "gluten-free" means? With your help, we can make this page useful for coeliacs all around Australia and New Zealand.

Fundraising Institute Australia Ltd.:

<http://www.fia.org.au/>

The Fundraising Institute is committed to developing this website to provide Members and volunteers with information about the issues which impact on fundraising and opportunities to learn through training programs and conferences.

Australia Wide Fundraising:

<http://www.awf.net.au/>

Contact the AWF national call centre on any of the following numbers:
Nestlé Fundraising: 1800 880 456
Smiths Fundraising: 1800 001 432
Kellogg's Fundraising: 1800 00 22 32

Community Wise Western Australia:

<http://www.communitywise.wa.gov.au/sitemap.htm>

Government of Western Australia - CommunityWise is the Department of Local Government and Regional Development's package of community economic development programs designed to help communities find opportunities and funding to achieve their goals.

NICAN: <http://www.nican.com.au/>

NICAN is information on recreation, tourism, sport and the arts for people with disabilities. Contains information/activities for: International Day of People with a DisAbility – 3rd of December 2002. Community groups and organisations are encouraged to organise their own events to celebrate this important day. NICAN is available to assist organisations and groups in putting together their individual events.

GSCWA Members

FULL MEMBERS

Acoustic Neuroma Association of Australia
Alzheimer's Association of WA
Angelman Syndrome Association
Arthrogryposis Support Group
Australian Huntington's Disease Association
Australian Pituitary Foundation WA Branch
Australian Tuberos Sclerosis Society Inc.
Coeliac Society of WA
Cushings Disease Support Group
Cystic Fibrosis WA
Dyslexia SPELD Foundation WA Inc
Epilepsy Association of WA
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
Sjögren's Syndrome Support Group
SIDS and Kids Western Australia
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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Genomics Branch, Dept. of Health
The Kalparrin Centre
The Neurological Council of WA Inc
Western Australian Deaf Society Inc.

INDIVIDUAL ASSOCIATE MEMBERS

Professor Charles Watson, Curtin University
Terry Keating, GSCWA

