



Newsletter

March Quarter Issue 1. 2005

Self Help Queensland Inc is a network of self help organisations and groups in Queensland. The network was formed by self help organisations to share resources, support each other, assist in the development of new groups, raise community awareness of the importance of self help and provide a strong united voice on issues which affect our members.

From the President

Sue Smyllie

Hello Everyone,

All of us at SHQ have been doing our planning for the year (somehow we seem to be on a calendar rather than a financial year). Our 2 major projects for the year are to review our policies and procedures and to see if we can set up a grant application training day. There is information about this in the newsletter, so please let us know your preferences.

The policy work can be viewed as really boring stuff. I think we have to remember that all policy is, is an agreement and an obligation that we take on in order to help our actions match up to our values. If we think people should be happy, productive and safe in our workplace then we need to have agreements (WHS, employment etc policy) that help us remember and do all the physical and mental things that will ensure it.

If we think our organization supports and nurtures others and helps them to live with dignity then we need privacy policy. And if we think what the organization does is important we need to make sure it can all go on if the plane taking us to our Vanuatu Christmas function falls out of the sky!

I have also included in the newsletter some information from Bruce Muirhead, Director of a new research centre in Queensland...prepare to engage!

Sue

Eidos (from Greek - idea, form of thinking, plan) is a consortium of Queensland universities, government and non-government agencies or statutory bodies (see below) committed to improving education and social change research, policy and practice. It seeks to ensure that Queensland and Australia further becomes recognized as a hub for high quality, innovative and engaged education and social change research that makes a significant contribution to improving social policy and practice. Initially set up as an institute for educational research, policy and evaluation by the Queensland universities and government, Eidos is a newly established mechanism for generating linkages between state and national governments, universities and communities, and ensuring that research contributes to improved education and social policy and practice.

Eidos has been established in a context in which there is a need for new ideas, reflection and debate on how to create the conditions necessary for sustainable development and social cohesion in a world of constant change. There is a need for "participatory, creative and empowering methods of educational, community and social research and practice"* and for the continuous monitoring and evaluation of the impact of public and private policy and practice on individuals and communities. There is also a need for a new generation of linkages between the public and private sectors, and between universities, governments and communities, to include the excluded and to build a common future.

(Continued Page 4)

Self Help Old Management Committee Members

President	Sue Smyllie
Treasurer	Kathleen Zarubin
Secretary	Cheryl Russell
Member	Kim Summers
Member	Thea Biesheuvel
Member	Glenis Charlton

Committee Meetings

If you would like to attend our meetings, please contact the office for dates and times. Everyone is welcome to attend and we look forward to seeing some of you at our meetings. We are always on the lookout for new committee members!

Project Officer

Trish Fallon

Office

The office is generally attended from Monday to Friday, 9am to 4.00pm. However, staff are sometimes required to liaise with groups or attend meetings away from the office.

If you wish to call in to use the facilities at the office or talk to our project officer, please phone first to ensure that someone will be in the office.

Office Location:

Sunnybank Community Hall
121 Lister Street (Cnr Gager Street)
Sunnybank 4109

Postal Address

P.O. Box 353
Sunnybank QLD 4109

Phone/Fax: (07) 3344 6919

Email: selfhelp@gil.com.au

The views expressed in this publication are those of the individual authors and not necessarily those of Self Help Queensland Inc.

The material supplied is for information purposes only, and is not to be used for diagnosis/treatment, or as legal, tax, accounting or any other type of advice.

Thanks to Queensland Health for providing funding to Self Help Queensland for publication of the Self Help Queensland quarterly Newsletter.

Self Help Queensland Inc Management Committee

Member Profile

Glenis Charlton

Glenis has worked in the area of administration, recruitment, training, project and policy development and coordination. Based on her community work she has been involved in projects to enhance knowledge and understanding of Aboriginal and Torres Strait Islander peoples. Her interest in the performing arts saw Glenis become the founding chairperson for Kooemba Jdarra Performing Arts Theatre and she continues in this role 11 years later.

Glenis joined SHQ as she is a survivor of cancer and will set up a support group for Indigenous women, their family and friends who have or who are going through this journey of healing.

She loves to relax by quilting, reading and spending time with family and friends.

-oOo-

Tell us About Your Group

If you belong to a self help or support group we would love to hear from you.

Please contact Trish at the Self Help Queensland office:

Ph: 3344 6919 Email: selfhelp@gil.com.au

Contents

President's Message	1
SHQ Committee & How to Contact Us	2
SHQ MC Profile - Glenis Charlton	2
Link Line	3
Australian Polio Association	3
Free Meeting Room for Support Groups	3
Dare to Life	3
Hello from Toowoomba - MS Support Group	4
Genetic Matters by Kim Summers PhD	5
Funding for Cancer Support Groups	6
Mistreatment of Older People	6
Mucopolysaccharide and Related Diseases	7
New Anxiety Support Group	8
Epilepsy - how to reduce your seizure risk	9
Consumer Scholarships	9
Tourette Syndrome Association	10
Thyroid Australia	11
GPs & Genetics	13
Multilink - outreach support	14
Diary Dates	14

Meeting Room Available for Self Help and Support Groups

- Central Location!

The Management of West End Community House is kindly offering a meeting room for the use of self help and support groups. The room seats about 20 people comfortably and is wheelchair accessible. There are tea making facilities, along with toilet and limited parking.

The room is available:

Monday: All day and evening

Tuesday: Morning and evening

Wednesday: All day every 2nd Wednesday

Thursday: All day

Friday: Afternoon and evening

West End Community House hosts drama, dancing, art and craft and storytelling groups, and has always been available to people who at some stage in life may have experienced mental illness.

The meeting room is located at:

West End Community House

4 Norfolk Road

SOUTH BRISBANE

For further information re the above please contact Malcolm on Ph (07) 3846 2114

-oOo-

Australian Polio Association Inc

The Australian Polio Assoc Inc is a support group which provides information and support to people who have had polio, and their carers. The Association holds support group meetings, with occasional guest speakers, and is currently lobbying Government for a clinic at Prince Charles Hospital for assessing people who could have Post Polio Syndrome. (It is estimated that approx 45,000 people in Qld and 5,000 people in Brisbane have been affected by Polio.)

The group meets bi-monthly - 3 times per year on each side of Brisbane, on a Saturday starting at 1pm. Meetings for 2005 are:

Yeronga RSL

19 March

16 July

19 November

Kedron Wavell RSL

21 May

17 September

For further information please phone Alan on (07) 3263 4598.

Link Line



Through Link Line, Self Help Queensland hopes to facilitate contact between people with rare conditions for whom no know support group exists.

Link Line endeavours to foster mutual support and information sharing in a respectful, sensitive and confidential way. However, we are unable to determine the suitability or compatibility of linked individuals and families.

- *A person in WA with an intersex condition, True Hermaphroditism, is very keen to make contact with another person with this exact condition.*
- *A Brisbane family would like to connect with someone who has Meniere's Disease.*
- *A family in Caboolture, QLD, would like to contact anyone who has the condition Cryptogenic Sensory Polyneuropathy(CSP).*
- *A lady in NSW would like to contact another person in Australia with the rare condition, Multiple Enchondromas.*

To make confidential contact regarding the above or to place a notice in Link Line, please call Trish at the Self Help Qld Office Phone/Fax (07) 3344 6919

Email: selfhelp@gil.com.au

-oOo-

Invitation to "Dare to Life"

Come to Queenie's traditional tea house for a lovely morning tea of tea/coffee and scones. Hear how to explore the difference between living day to day or having a real life force working for you.

"Dare to Life" is hosted by Life and Human Relations, a not for profit community group based at Red Hill.

Date: 8th April 2005

Time: 9.30am to 11.30am

Venue: Queenie's Nundah Village
1279 Sandgate Road, NUNDAH

Cost: \$16.50 includes morning tea & talk

Enquiries/ Bookings: Ph: 07 3369 2124

(Continued from Page 1)

Eidos supports and brokers a wide range of government and non-government research and evaluation programs. It is providing a more effective mechanism for encouraging collaborative and interdisciplinary research, and for ensuring the quality, relevance and effective utilization of research outcomes and products. Eidos seeks to nurture the development of young researchers and to strengthen the pool of research and evaluation expertise available to local communities and to state, national and international organizations.

In its first three months Eidos has been fortunate to have facilitated a Fulbright Senior Scholar Award for 2005 focusing on the school-university-community engagement and pedagogical partnership, partnered the Commonwealth Foundation and > 30 peak education bodies to propose large scale Asia Pacific research projects for the Commonwealth Consortium for Education, and will be formally named and launched following a one day public symposia 'Ideas for Social Change' on the river in Brisbane on May 18, 2005. The Eidos interim board is represented by all partners and is chaired by Professor Colin Power, past Deputy Director General, UNESCO.

If you would like to find out more about Eidos, participate in the launch, and/or begin to explore potential partnerships please feel free to call me on 38755774 or send your email address for listserv inclusion in future updates.

Bruce Muirhead
Director
Eidos
Phone: (00617) 07 3875 5774
Fax: (00617) 07 3875 5618
Email: b.muirhead@institute.edu.au

-oOo-

Tell Us What You Think

We would like to receive feedback about the newsletter and invite you to contact us about content, quality, format, or any issues you would like addressed in future editions. Please contact Trish at the SHQ Office:

Ph/Fax 07 3344 6919
Email: selfhelp@gil.com.au



Self Help Queensland Newsletter Now Available by Email

At last we are able to offer our readers a choice of receiving our newsletter by either post or email. This offer will be available commencing the June edition. Please contact Trish at the office on Ph/Fax 07 3344 6919 or by email on selfhelp@gil.com.au if you would like to change from post to email.

If you would like to switch to email, it is important that you identify the name and address to which the newsletter is currently being posted.

The newsletter will be a document in PDF format and you will need Adobe Acrobat Reader to read it.

-oOo-

Hello from Toowoomba!

The Toowoomba and District Multiple Sclerosis Support Group covers a large area of South Western Qld.

We have a newsletter that comes out every month with research information, local news, doctors reports etc.

We have a meeting or social once a month held in the MS Hall, Middle Ridge. We have a Regional Services Co-ordinator, who helps people in this region to services available, and who is employed by MS Qld in Brisbane.

Contacts are:
Linda (07) 4633 4175
Trish (07) 4693 7232

Judy, newsletter
Email: judyjames1@optusnet.com.au

Janice, Service co-ordinator (07) 4638 9327,
Email: janicewheeler@msqld.org.au

-oOo-

Genetic Matters

by Kim Summers PhD

Patterns of Inheritance

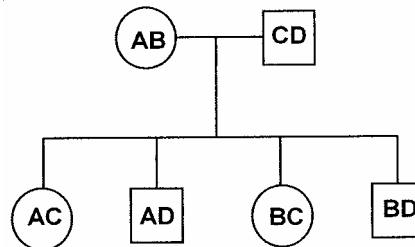
Genes are carried on chromosomes, and humans have two sets of 23 chromosomes, because the chromosomes, and the genes, occur in pairs. For some conditions we can identify a characteristic pattern of inheritance and a characteristic collection of symptoms. Other conditions appear to occur more often in some families than others but it is more difficult to identify a specific gene which might be involved. Often there are a number of genes and these conditions are called polygenic conditions.

In this article I will look at what we mean when we say a condition is dominant, recessive or X-linked. These are called the Mendelian conditions after Gregor Mendel who first explained how characteristics are inherited from his studies of peas. Mendel worked out that the **factors** which were involved in inherited variation come in pairs and that the two partners can be the same (homozygous) or different (heterozygous). When they were heterozygous, the peas looked like one of the parents and Mendel said that form was **dominant** over the other. The other form was **recessive**.

In peas he found that round seed shape was dominant over wrinkled. The plants only had wrinkled seeds if they inherited a factor for being wrinkled from each parent. That meant the two copies of the factor were identical in the wrinkled plants. Plants which had two different types were round and couldn't be distinguished from plants which had two copies of the round variant. Some years after Mendel's work, it was proposed that human diseases could behave in the same way.

We now call Mendel's factors **genes** and the different forms or variants of the same gene are called its **alleles**. A gene has a particular function in the cell. It may be responsible for pea shape for example. Different versions of that gene (alleles) can cause the pea to be round or wrinkled. Mendel found that the round allele is dominant over the wrinkled allele.

Another gene is responsible for flower colour and different forms can cause the flower to be purple or white. The purple allele is dominant over the white allele. Strictly we shouldn't really say the gene for purple flowers, since it is the specific variant of that gene (one of its alleles) which results in the purple flowers.



Inheritance of genetic "factors". Squares represent males and circles females. The four lower people are the children of the two upper people. Each individual has a pair of factors for any characteristic, one inherited from the mother and one from the father.

In human genetics we now know that many diseases behave in exactly the same way as flower colour or pea shape. When a human genetic disease is said to be dominant, that means that you only need one copy of the disease allele to get the disease. In these cases the condition tends to appear in every generation, apparently passed from affected parent to affected offspring. These dominant conditions include Marfan syndrome, Huntington disease and the common forms of Charcot-Marie-Tooth syndrome. In the diagram, the A form of the factor might result in the disease, so the mother (AB) and the first two children (AC and AD) would have the condition while the father (CD) and the other children (BC and BD) would not.

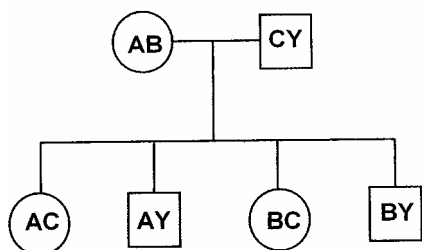
If a human disease is recessive, you need two copies to get the disease. People with only one copy will not have the condition but they risk passing that copy on to their offspring and are said to be carriers of the condition. People who have the condition have two copies of the factor for that condition while their parents have one copy for the disease version and one for the normal version. In the diagram, the B and D forms might be associated with the condition.

(Continued Page 6)

(Continued from Page 5)

Both parents (**AB** and **CD**) would be carriers, as would the second and third children (**AD** and **BC**). Only the fourth child (**BD**) would be affected. These recessive diseases include cystic fibrosis, haemochromatosis, one form of Charcot-Marie-Tooth syndrome and many other conditions.

An additional complication in animals is the presence of the X and Y chromosomes which are involved in determining the sex of the offspring. In humans, males have one X and one Y chromosome, while females have two Xs. So for genes on the X chromosome, males only have one copy. If a female passes a recessive disease factor to her son, he will show symptoms of the disease, because he doesn't have another copy of the factor to mask it.



X-linked inheritance.

If a factor is carried on the X chromosome, males only have one copy since they only have one X.

In the diagram, A, B and C are forms of a factor on the X chromosome. The father and sons have only one copy on their single X chromosome. If B is associated with the condition, the fourth child (a son, **B**) will be affected and the third child (a daughter, **BC**) will be a carrier like the mother. X-linked inheritance is a special case but the patterns of inheritance can still be predicted by the rules discovered by Mendel 150 years ago.

-oOo-



Funding Available for Cancer Support Groups

- through Australian Govt
"Strengthening Cancer Care" package

As part of its Strengthening Cancer Care package, the Australian Government (Dept of Health and Ageing) has committed \$500,000 each year over four years (from 2004/2005) to support the development of cancer support groups.

Grants of up to \$90,000 will be made available as seed funding for cancer support groups. Preference will be given to those proposals which have a focus on lung, bowel, ovarian and other cancers. This funding will contribute to salary and administration expenses of the organisations.

This is the first round of funding under the Cancer Support Groups Grants Program. Further funding rounds may be undertaken in future years to support the development of cancer support groups.

The total package is \$137 million over four years - to ensure better co-ordination of the national cancer effort, more research funding for cancer care, enhanced cancer prevention and screening programs, better support and treatment for those living with cancer, and better support for the professionals who care for them.

Self Help Queensland is delighted that cancer support groups have been recognised in the grants package, and strongly encourage Queensland groups to apply.

For information and assistance contact:
Cancer Support Groups Grants Program
Officer Ph 1800 020 103
Email: cancer@health.gov.au

What is regarded as Mistreatment of Older People?

- Financial - illegal or improper use of ones money or possessions.
- Psychological - causing fear or shame, intimidating, humiliating or threatening.
- Physical - inflicting pain or injury, eg hitting, slapping, restraining or over-medicating.
- Sexual - sexually harassing, assaulting or embarrassing.
- Social - preventing a person from having social contact with family members or friends.
- Neglect - the intentional or unintentional failure to provide necessities of life and care.

Elder Abuse Prevention Unit

Helpline 1300 651 192



Support Available for People with Mucopolysaccharide Diseases

The Australian Mucopolysaccharide & Related Diseases Society Aust Ltd (MPS Society) is a non profit organisation formed by parents, relatives and friends of those suffering from a range of rare genetic disorders known collectively as the mucopolysaccharide (or MPS) diseases. The MPS Society supports individuals affected with MPS, parents of affected children, other relatives and friends of affected children as well as those affected by related disorders. Professionals working in the MPS and related fields are welcome to join.

Mucopolysaccharidoses (MPS) are rare genetic disorders in children and adults. They involve an abnormal storage of mucopolysaccharides, caused by the absence of a specific enzyme. Without the enzyme, the breakdown process of mucopolysaccharides is incomplete. Partially broken down mucopolysaccharides accumulate in the body's cells causing progressive damage. The storage process can affect appearance, development and the function of various organs of the body. Each MPS disease is caused by the deficiency of a specific enzyme.

The MPS diseases are part of a larger group of disorders known as Lysosomal Storage Disorders (LSD). The combined incidence of LSDs in the population is 1 in 5,000 live births. Each of the more than 40 individual LSDs result in a deficiency in the activity of a specific protein (enzyme) which is normally present in each of the billions of cells that make up our bodies. This missing enzyme causes the body to fail in the chemical breakdown of complex sugars and leads to an excess of MPS in the cells. This affects each person differently. Each MPS disorder has its own set of characteristics and children with the same disorder can look similar to each other, like "peas in a pod". However, each person diagnosed with MPS will have their own particular gene change or variation of the disorder. It is important to realise that no one can really predict a child's life expectancy.

All major hospitals offer medical support for

families affected with MPS through their genetic units. Genetic counselling is available to discuss options for future pregnancies. Ongoing education for children with MPS is important. Early intervention services which focus on developing skills in pre-school children often have the expertise of physiotherapists, occupational therapists, speech pathologists and specialist teachers. A range of options is available for children starting school either in integrated regular school settings or specialist classes and schools, depending on the needs of the child.

The recognised forms of MPS are:

Hurler Syndrome	MPSI
Hurler – Scheie Syndrome	MPSIHS
Scheie Syndrome	MPSIS
Hunter Syndrome	MPSII
Sanfilippo Syndrome	MPSIII
Morquio Syndrome	MPSIV
Maroteaux-Lamy Syndrome	MPSVI
Sly Syndrome	MPSVII

Associated Diseases

Mucopolipidoses	ML
Fucosidoses, Mannosidosis	
Sialic Acid Diseases	

Support from other families

There are other people who have experience of MPS. Through membership of the MPS Society you can be put in touch with other families, attend conferences and social gatherings and receive a quarterly newsletter. The MPS Society is a support group run entirely by volunteers whose own families are affected with MPS.

At present there is no cure for MPS. However, currently there are a number of clinical trials being conducted around the world. Scientists in Adelaide are leading the way in finding medical treatments for MPS. Enzyme Replacement Therapy (ERT) - the infusion of the missing enzyme into patients is the greatest hope for the future treatment of MPS.

To contact the Mucopolysaccharide & Related Diseases Society Aust Ltd:

(Continued Page 8)

(Continued from Page 7)

Contact details for the Mucopolysaccharide & Related Diseases Society Aust Ltd:

MPS Australia
PO Box 623
HORNSBY NSW 1630
Ph: (02) 9476 8411
Fax: (02) 9476 8422
URL: www.mpsociety.org.au

For Genetic Counselling in Queensland contact:

Queensland Clinical Genetics Service
c/- Royal Children's Hospital & Health Service District
Herston Road, BRISBANE 4029
Ph: (07) 3636 1686 Fax: (07) 3636 1987
Email: gqgs@health.qld.gov.au
URL: www.health.qld.gov.au

-oOo-

New Anxiety Support Group

- with an emphasis on Recovery

A new Anxiety Support Group will be getting under way in Brisbane commencing in April, 2005. The group has an educational emphasis and takes the form of a structured Anxiety Recovery Program. It will be facilitated by Peter Elliott, who himself experienced debilitating levels of anxiety for over a decade. As such the support group and program are designed and informed from first hand experience. In addition, Peter has been successfully facilitating a social anxiety support group in inner city Brisbane for the past four years and is a Psychotherapist in training at the University of Queensland's School of Medicine.

What is the objective of the support group? The objective of the support group is to provide people who experience anxiety with the guidance, methods and techniques that will allow them to significantly reduce and eventually overcome debilitating anxiety.

The group is also a forum in which people can share their experiences and gain support from others who have had similar experiences.

How is the support group conducted? The group covers, in a step-by-step fashion, a

number of anxiety alleviating methods and techniques. An Anxiety Recovery manual written by the facilitator will be supplied to each participant and it is estimated it will take 6-8 meetings to cover the manual's contents.

The program operates in a revolving fashion throughout the year which means that topics are repeated every 6-8 meetings. This means that if a meeting is missed it can be picked up at a future date. The program structure also allows people to enter the program at any stage.

It is important to emphasize that there are no formal introductions in this support group (although we do wear a name tag) and there is no obligation to contribute verbally to the discussion. People are quite welcome to simply come along and listen in.

What type of people attend the support group? It is expected that a variety of different people will attend the group, people from diverse backgrounds and life experiences, and ranging in age from 20yrs and upwards. But age and background are not important - all people are welcome to attend.

The one essential commonality between people attending the support group is that they all experience anxiety and have a desire to overcome it.

How many people will attend the support group? The support group will initially be limited to 10 people per program cycle, but as few as 5 participants will satisfy the commencement and continuation of the support group.

When is the support group conducted? We meet every 2nd and 4th Monday of each month at 7pm till around 9pm.

Where do we meet?
Cnr Ann and Church Streets
FORTITUDE VALLEY
(Entry via Church Street - sign outside reads "Senior Citizens Respite Centre")

Cost: \$3 per meeting for venue hire
\$2 one off fee for admin costs

For further information re program or bookings please contact Peter Elliott:

Ph: (07) **3201 1740**
Email: pseljw@eis.net.au

Epilepsy - how to reduce your seizure risk

With regular medication and a sensible lifestyle most people with epilepsy lead full and active lives. In fact, over 70% of people become seizure free with treatment. Epilepsy is a disorder of the brain and affects approximately 2% of Australians. Epilepsy causes seizures, which occur as a result of an abnormal discharge of electrochemical activity in the brain. Seizures can affect the person's consciousness, movement, perception, sensation, memory and/or behaviour. There are many different types of seizures that can all affect the person in different ways. Epilepsy is not a mental illness nor is it contagious. Between seizures, people with epilepsy are no different to anyone else.

10 tips for better control:

Taking responsibility for your epilepsy is the key to good control. Consulting with a neurologist (preferably one who specialises in epilepsy is highly recommended)

1. Take your medication as prescribed and never stop taking it without talking to your doctor or neurologist. Side effects of the medication often subside over time.
2. Do not change brands of your regular epilepsy medication unless advised to do so by your doctor. Brand changing may lead to break through seizures.
3. Get enough sleep. Lack of sleep is an important trigger for seizures.
4. Identify stress and try to reduce it.
5. Be aware of your personal triggers ie coffee, flashing lights, recreational drugs, lack of sleep, stress etc and try to avoid them.
6. Consider safety first. Never swim alone. Avoid dangerous sports ie rock climbing, scuba diving etc. Take care with heavy machinery, climbing ladders, riding a bike etc.
7. Do not drive until advised by your doctor or neurologist.
8. Alcohol can make you more likely to have a seizure and can affect your medication. Ask your doctor or neurologist for advice.
9. Consider wearing a medical ID bracelet if your seizures are not fully controlled.
10. Learn lots about epilepsy and seizures. It will help you to reduce your fears and take control.

The Epilepsy Association has 2 offices in Queensland and offers guidance, support and information to people affected by epilepsy. For further information please ring Sue Edwards at the Cairns office or Claire Lisle at the Brisbane office on: 1300 EPILEPSY (1300 37 45 37) or visit our website www.epilepsy.org.au

-oOo-

Consumer Scholarships to Attend the 3rd Australasian Conference on Safety and Quality in Health Care

The Australian Council for Safety and Quality in Health Care invites consumers to participate in the 3rd Australasian Conference on Safety and Quality in Health Care in Adelaide from 11 – 13 July 2005. The Council is offering a limited number of consumer scholarships to cover the costs of travel, registration and accommodation.

Consumers who have an interest in issues related to the safety and quality of health care and who are prepared to take the knowledge gained from the conference back to their local communities and health services are invited to apply for these scholarships.

For further information about scholarships:
The Office of the Safety and Quality Council
MDP 46
GPO Box 9848
CANBERRA ACT 2601
(02) 6289 4244
<http://www.safetyandquality.org>

Applications for the scholarships close on Wednesday 20 April 2005.

Details of the Conference can be seen at:
<http://www.sapmea.asn.au/conventions/aaqhc2005/index.html>

-oOo-



Tourette Syndrome Assoc of Australia Inc

3rd National Conference on Tourette Syndrome and Related Disorders - to be hosted in QLD in May, 2005

Tourette Syndrome

Tourette Syndrome (TS) is a neurological disorder frequently mistakenly identified or undiagnosed. It is characterised by involuntary body movement and vocalisations called 'tics', and may also be accompanied by behavioural difficulties due to its 'complex nature. TS is often found with associated conditions, such as ADHD or Obsessive Compulsive Disorder and normally first appears in childhood.

If undiagnosed, it can lead to isolation, bullying and learning problems for children as they try to cope with the intense urges to tic that are part of the disorder. Early diagnosis and ongoing support can make a huge difference in the management of symptoms and living with this chronic, lifelong condition. Frequency in the population may be as high as 1 in 200 persons and there is a genetic component, as it often runs in families.

The Association

The Tourette Syndrome Association of Australia Inc is a Charity serving the needs of people with TS. The Association provides education, information, counseling and support. It is totally run by volunteers with experience in the condition and welcomes enquiries from anyone.

The Conference

This will be a one day Conference and will feature leading experts discussing clinical characteristics, medical and psychosocial perspectives of these disorders along with educational and management skills. This Conference will appeal to anyone wishing to know more about Tourette Syndrome, ADHD or OCD including doctors, health care workers, educators, and individuals and families with TS.

Date: 28th May 2005

Time: Registration 9.30am for 10am
Morning Session 10 am to 1pm
Afternoon Session 2pm to 4.30pm

Venue:

Princess Alexandra Hospital Auditorium
Building 1, Ipswich Road
Woolloongabba, BRISBANE

Keynote Speaker:

Professor Perminder Sachdev - President of the International Neuropsychiatric Assoc, Professor of Neuropsychiatry at University of NSW and Clinical Director of the Neuropsychiatric Institute at Prince of Wales Hospital, Randwick, Sydney, NSW. Prof Sachdev was a founding member of the TS Association of Australia in 1989 and has since continued to support its work. He is eminently qualified to present his paper "Clinical Characteristics, Aetiology and Medical Perspectives of Tourette Syndrome."

Other speakers:

Prof Paula Barrett, Griffith University, to speak on "Obsessive Compulsive Disorder and its relationship to Tourette Syndrome."

Dr Michael McDowell, Mater Hospital, Brisbane, on "Recent Developments in Diagnosis and Management of ADHD +/- Tourette Syndrome."

Elizabeth Burns, Vice President of TS Association of Australia Inc on "Psychosocial Perspectives, Educational and Management Strategies for Tourette Syndrome."

Support Group leaders from TS Association on "Self Help, Support and Advocacy."

For Conference bookings, or other information relating to Tourette Syndrome contact:

Tourette Syndrome Assoc of Australia Inc
PO Box 1173
MAROUBRA NSW 2035
Ph: (02) 9382 3726
Email: info@tourette.org.au
URL: www.tourette.org.au



**We'd like to hear
from you!**

- Would a grant application training day at SHQ be of use to your group?
- Are there any particular policies/procedures you would like to see adopted by SHQ?

We'd love to hear from you. Call Trish on
Ph: 3344 6919 Email: selfhelp@gil.com.au



THYROID AUSTRALIA LTD

SUPPORT FOR THOSE WITH THYROID CONDITIONS
THEIR FAMILIES AND FRIENDS

“It is extraordinary that more than 100 years since the first description of the treatment of hypothyroidism and the current availability of refined diagnostic tests, debate is continuing about its diagnosis and management.”..... Thyroid Australia

Thyroid Disease - The forgotten disease?

The thyroid gland is in the throat, just below the Adams apple. It helps regulate our energy levels and metabolic rate and we need Iodine in our bodies to keep it healthy.

Queensland is a state where **Iodine Deficiency** is common and in respect of this Thyroid Disease is more widespread than medical authorities are prepared to admit. Iodine's main purpose on earth is to maintain healthy Thyroid glands in people and animals. Attention has to be drawn to this health care problem in our community that to date has had very little public exposure or understanding yet has the potential of reaching epidemic proportions in Queensland.

Cellular Metabolism

Although a little thyroid hormone normally goes a long way, the body's needs are extensive. The thyroid is a vital link in the endocrine system. Even a small decline in the output of thyroid hormone, if sustained over an extended period of time, can have profound consequences for health and longevity. With no thyroid hormone, we would die within a short time.

Thyroid hormone helps regulate virtually every cell in the body, including those in the brain, heart, liver, kidney, skin and bone. Among its most important functions in our cells is to control the rate of metabolism, altering thermogenesis and oxygen consumption. If *cellular metabolism* drops too low, the result is widespread dysfunction that can manifest in a variety of ways, including depression, anxiety, cognition, learning, and/or memory impairment, loss of hair, hearing and muscle tone, weight gain, heart disease, hypoventilation, psychosis, and in extreme cases, death.

Thyroid deficiency syndrome most often affects women over 40, but men and teen-

agers can also have reduced thyroid function, especially if it runs in the family. According to some estimates, as many as 15 to 20% of women over age 60 may have subclinical hypothyroidism (meaning they would benefit from thyroid supplementation) even though most conventional doctors would insist, based on standard laboratory tests results, that they had no thyroid pathology requiring treatment. This opinion is now more widespread across the whole community. Each year, 5 to 15% of these women develop symptoms which may contribute to shortening their lives.

Some hypothyroidism, clinically diagnosed as thyroid deficiency syndrome, may be caused by a condition called Hashimoto's thyroiditis. This is an autoimmune disease in which the body's own immune defences turn on the thyroid gland, causing an inflammatory process that can eventually destroy it. Immunosenescence, immune decline with aging, is associated with increased autoimmune reactions. This progressive destructive process is a major reason why thyroid function commonly declines with age (Nine out of ten cases of Hashimoto's syndrome occur in women).

Hashimoto's thyroiditis is commonly seen in people who have other autoimmune diseases, including insulin-dependent diabetes mellitus, pernicious anaemia, or myasthenia gravis. It may also occur with greater frequency in people who are left-handed or who have prematurely grey hair.

Hypothyroidism can also be caused by certain drug treatments (e.g. alpha-interferon, used to treat hepatitis C) or destruction of thyroid tissue by radioactive iodine treatment or surgery for conditions such as Grave's disease or thyroid cancer. It can also have a genetic origin, in which case it may manifest shortly after birth.

Overt hypothyroidism is relatively simple to diagnose, if -- **(Continued Page 12)**

(Continued from Page 11)

-- and this is a big IF -- you and/or your doctor look for it. Hashimoto's thyroiditis may cause the gland to enlarge or swell, something an alert physician should be able to feel, even in its early stages. The diagnosis can then be confirmed by performing a series of blood test, especially measured of TSH, FT4, FT3 and antithyroid antibody. Elevated TSH is an indication that the thyroid is putting out insufficient thyroxine to maintain normal functioning; ergo hypothyroidism.

By age fifty, one in ten women have thyroid failure as evidenced by a simple blood test for Thyroid Stimulating Hormone (TSH). Your pituitary gland located at the base of your brain normally regulates thyroid function by producing Thyroid Stimulating Hormone. If your thyroid fails, your TSH levels rise. In contrast, the high blood levels of thyroid hormone in hyperthyroidism are associated with low TSH levels. It is also recommended that men over sixty have similar TSH screening tests done, for by that age nearly 9% of men are hypothyroid and need thyroid hormone treatment.

More recent research has confirmed an increased incidence of thyroid dysfunction in patients who are found to have high levels of cholesterol and other lipids. Since those with hypothyroidism will improve their lipid profile with thyroid treatment, if your lipids are high be sure that your doctor orders a TSH test."

However, the diagnosis of age-related thyroid slowdown is more problematic, largely because primary care doctors are not generally trained to look for it. Or it may be because age-related functional decline of any sort is considered "normal" and thus not a medical problem. On this basis, doctors may dismiss signs of hypothyroidism, like fatigue, chilliness, muscle cramps, hair loss, dry skin, and constipation as "just" part of the aging process. As a result, the disease can and probably does go undiagnosed in a large number of patients.

Thyroid function tests provide the primary tool for diagnosing thyroid disease and for managing doses for thyroid hormone replacement therapy. The interplay of the thyroid hormones (T4 and T3) and the regulatory hormone (TSH) provide a pattern which can be used to deduce the thyroid status of

the patient.

Thyroid Conditions

- Hypothyroidism (including Hashimoto's Disease)
- Hyperthyroidism (including Graves' Disease)
- Thyroid Cancer
- Congenital and Childhood Thyroid Conditions
- Post Partum Thyroiditis
- Thyroid Eye Disease
- Nodules and Goitres
- Iodine and Iodine Deficiency
- Thyroiditis
- As well as a range of related conditions.

Thyroid Australia (Brisbane)

The intention of Thyroid Australia (Brisbane) being an arm of Thyroid Australia is to be able to organise public awareness through functions, activities and meetings to get to know who we are and where we are in the community. With hundreds of people to our knowledge and thousands to be aware of in SE Queensland alone with Thyroid Conditions we now consider it time to bring the issue of Thyroid Disease into the public arena.

- Doctors and Health Care Professionals - supply them appropriate and up to date literature;
- Invite speakers to talk on pertinent issues;
- Releasing media statements; and family, friends and employers - through various activities pin pointing the disabilities related to Thyroid disease and the devastation it causes in all our lives.

Summary

In the early stages of therapy and at later stages following changes in dose, TSH alone is potentially unreliable as an indicator of the adequacy of therapy. Free T4 is more accurate in these periods. Free T4 levels should be at the upper end of the reference range. The international consensus opinion is that Free T4 levels should be in the upper third of the reference range. Some authorities believe that even higher levels may be necessary for some patients. They accept Free T4 levels at or slightly above the reference range provided that Free T3 levels are normal. Patients should be symptom free.

(Continued Page 13)

(Continued from Page 12)

TSH levels should be below 2 mIU/L. There is some debate about specific target points below 2mIU/L. A target of 1.0 mIU/L coincides with the most common level within the normal population. TSH readings at or below the bottom of the reference range are accepted by those authorities who accept Free T4 levels at or slightly above the reference range provided Free T3 levels are normal.

Personal range is important: The particular issue for thyroid patients is that an individual's thyroid hormone levels do not naturally move over the whole Reference Range. Individual thyroid hormone levels are confined to narrow personalized ranges around the so called Set Point. Based on new 2004 standards, the new normal TSH range was found to be between 0.4 mU/ml to 2.5 mU/ml.

We all have individual set points and need to be dosed to these points.

- **Under dosing** is a risk factor for coronary artery disease.
- **Over dosing** is a risk factor for heart disease and possibly osteoporosis.
- **Pregnant women** and those on Hormone Replacement Therapy require higher doses.

Information relating to Thyroid Australia (Brisbane) activities and support can be made by contacting
Thyroid Australia and your enquiries will be forwarded to the support coordinator that best suits you.

Thyroid Australia Limited
333 WAVERLEY RD ,
MOUNT WAVERLEY VIC 3149
Phone: (03) 9888 2588
URL: www.thyroid.org.au
Fax:(03) 9561 4798
E-Mail: support@thyroid.org.au

(This article is an overview and contains components of freely published documentation. The information in this article does not dictate an exclusive course of treatment or procedure to be followed and should not be construed as excluding other acceptable methods of practice.)



Invitation

What are your views on GPs & Genetics?

Self Help Queensland and the Genetic Support Council of WA, as participant States in the Australasian Genetic Alliance, are hosting a discussion morning for genetic support groups, people with genetic conditions, their families and carers.

This is an opportunity to have direct input into a national genetic education programme for general practitioners - how would you like Australian GPs to be educated about genetics?

Topics for discussion:

- **What makes the GPs role different?**
- **What do GPs do well?**
- **What could GPs do better?**

Facilitated by Gabrielle Reid, Genetic Counsellor, Genetic Support Council WA.

**Please join us for discussion,
morning tea and lunch!**

on

Thursday 7th April 2005

9.30am to 12.30pm

(Followed by lunch)

at

Self Help Queensland
Sunnybank Community Hall
121 Lister Street (Cnr Gager Street)
SUNNYBANK

RSVP: Trish by Friday 1 April (for catering)

Ph/Fax: (07) 3344 6919

Email: (07) 3344 6919

No cost

Wheelchair accessible

Plenty of free parking!

**Your feedback will help draft an
Australian resource for GPs.**



Diary Dates

16 April 2005: Healthy Living Seminar. This free seminar will provide healthy living information to people affected by cancer. Presenters will cover: Managing stress and relaxation, Physical activity during and after cancer treatment, Tai Chi.

Morning tea provided, free parking.

Contact: Judith Phone 07 3258 2267

Venue: Queensland Cancer Fund Auditorium
553 Gregory Terrace, Fortitude Valley
Brisbane

20 - 22 April 2005: 5th Women's Health 2005 Conference. A forum for individuals, organisations and services involved and concerned with women's health. This conference will examine the evidence from the perspective of gender as a determinant of women's health, in all its dimensions.

URL: www.awhn.org.au

Venue: Melbourne

12 - 13 May 2005: New Horizons in Health Philosophy. A conference of interest to those who treat or support severe trauma, dissociation and psychosis.

Contact: Judi Ph 0416 220 539

Email: shearerj@zygo.com.au

URL: www.wowconsultants.com.au

Venue: Greek Club, South Brisbane

4 - 7 July 2005: The 2005 Australian Winter School. Presented by the Alcohol and Drug Foundation Queensland, the Winter School will address Drugs, Lifestyles & Culture in the context of the practical application of research and policy for those working in service delivery agencies. International keynote speakers, practical workshops, posters and presentations.

Phone: (07) 3834 0211

URL: www.winterschool.info

Venue: Carlton Crest Hotel, Brisbane

18 August 2005: Partners in Pain: Patients, Clinicians and Pain Management. This is a satellite meeting immediately preceding the 11th World Congress on Pain. (21 - 26 August 2005).

Phone: (02) 9954 4400

Email: pinp2005@dcconferences.com.au

URL: www.dcconferences.com.au/pinp2005



Are you a Refugee or Migrant?

Do you know someone who is a Refugee or Migrant?

Did you come to Australia within the last 5 years?

Are you living in the Sunnybank, Runcorn, Kuraby area?

Are you living in the Browns Plains Area?

Would you like help with.....?

- Housing
- Health
- Education and schools
- English
- Finding a job
- Understanding how things are done in Australia

Sunnybank, Runcorn, Kuraby area:

Every Thursday 9am to 1pm
Self Help Qld Meeting Room
Sunnybank Community Hall
121 Lister Street (Cnr Gager Street)
SUNNYBANK

Browns Plains area:

Every Monday 9am to 12 midday
Estramina House,
10 - 14 Estramina Road
REGENTS PARK

For further information about any of the above please contact Elisabeth at:

Multilink Ph 3808 4463

Monday - Estramina House Ph: 3809 0196

Thursday - Self Help Qld Ph: 3345 1930