



# Newsletter

September Quarter Issue 3. 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

SHQ was recently invited to participate via submission in the health systems review undertaken by Mr Peter Forster. Finances and time lines did not allow for us to provide our members with the opportunity to actively participate in the development of our submission. We invite participation in decision making through our newsletter, our AGM and by open invitation to any and all of our committee meetings. Unfortunately we do not have the resources to generate special processes to meet timelines that do not coincide with these strategies.

With this in mind I wanted to share with you the essences of our submission and invite you to let us know if you agree or disagree with anything we said. We are more than happy to print any responses in our newsletter to support open discussion across the sector.

SHQ drew on the more than 4000 communications via phone, email and fax from self help groups, individuals and health and other professionals, requesting information, advice, support and referral we attend to each year.

Our impressions from this extensive communication suggested that some of the major concerns facing the Self Help Sector included:

- Overwhelming hardship experienced by groups struggling to meet liability

issues and ongoing infrastructure costs including wage increases, insurance costs and increasingly complex reporting requirements leading to long serving groups closing down and Staff and volunteers of overstretched organizations suffering 'burn out' in increasing numbers.

- Extensive 'self responsibility' and 'community valuing' rhetoric from government is not followed with either access to decision making or increased funding.

(Continued on Page 3)

## *Invitation*

**Self Help Queensland Inc**

**AGM**

*A warm welcome is extended to all members and interested friends to come along and meet other members of your network, management and staff. Enjoy Self Help Queensland's hospitality following the meeting.*

**Wednesday 26th October at 9.30am**

Venue: Self Help Queensland  
Sunnybank Community Hall  
121 Lister St (Cnr Gager St)  
SUNNYBANK

RSVP to Trish by 21st Oct  
Ph/Fax 07 3344 6919  
Email: [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)



**Self Help Queensland Inc  
Management Committee Members**

President Sue Smyllie  
Treasurer Kathleen Zarubin  
Secretary Kim Summers  
Member Thea Biesheuvel

**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

**Administration Officer**

Therese Kelly

**Directory Project Officer**

Anne Meehan

**Office**

The office is attended Monday to Friday, 9am to 4.30pm. 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 office facilities or talk to the project officer, please phone first to ensure that someone will be available to meet with you.

**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 Qld 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. Self Help Qld reserves the right to edit contributed articles.

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

## Can You Help?

National Prescribing Service Limited and the Consumers Health Forum are currently undertaking an evaluation of the **Rural Community Quality Use of Medicine Program** to assess the extent to which the program is meeting the needs of rural consumers. As part of this evaluation, we would like to get feedback from people who have received the **Get to Know Your Medicines kit**.

Your feedback is valuable to us whether you had the opportunity to use the kit already or not. All information you provide will be de-identified in reports. Should you have the opportunity to contribute to this evaluation, please contact Ms Linda Kehoe, at National Prescribing Service Ltd on Ph (02) 8217 8700 or Fax (02) 9211 7578

-oOo-

## Please Tell us About Your Group!

If you belong to a self help or support group, anywhere in Queensland, we would love to hear from you. As an information and referral service for the Self Help Sector, we greatly value knowing what groups are available where, so we can provide better information to those seeking our assistance.

Please contact Trish at the Self Help Queensland office: Ph/Fax: (07) 3344 6919  
Email: selfhelp@gil.com.au

## Contents

President's Message	1
SHQ Committee & How to Contact Us	2
Thank You from Self Help Qld	3
AAFCD and National Noticeboard	4
ACOSS and "Action Network"	4
Long QT Syndrome	5
Walk a Mile in My Shoes	6
Rett Syndrome	7
Disability Services Qld Grants	8
Older Women's Network	8
Bipolar Support Group	8
Aust Leukodystrophy Support Group	9
Have you heard of Myasthenia Gravis?	10
Autism Carer Support Group	11
Link Line	12
Broken Heart Syndrome	13
Diary Dates	14

(President's message continued from Page 1)

- Sector 'consultation' processes represent a significant drain on community capacity. Small organizations, those closest to community and the relatively 'uncoopted' are hard pressed to contribute without jeopardizing their core business processes, decreasing the diversity of voices able to be heard.
- Competitive funding processes are undermining sector cohesion.
- Significant reticence towards "making waves" exists across the sector due a perception of the possibility of funding reprisals.

In order to address these issues and to increase the community's capacity to improve well being SHQ made the following suggestions:

- Set up and provide financial support for an inclusive, democratic, participative, emergent, decision making infrastructure to provide strategic leadership for the QH non-government funding program.
- Contribute to the capacity of the community sector to contribute to policy decision making by financially supporting participation.
- Engage QH personnel and community participants in collaborative learning opportunities based on knowledge and power equity.
- Encourage 'big picture thinking' with respect to the understanding of democracy, citizenship and community well being in all QH personnel.

In short, it is time to really share the power. Health and wellbeing is built on more than service provision. Active communities, participating in decision making, nurture the efficacy and generate the frameworks necessary to improve wellbeing for every member of the community in the long term. As a sector we must realise that the time for partisan battles is over, and enact principles which disengage us from the competitive imperative subtly embedded in many current funding programs.

I think it is time for the non-government

health sector to come together of its own accord, to have some high quality, powerful conversations - to air as many diverse viewpoints as possible, over as long a time frame as we need - to generate some collective wisdom and action.

"We need ways to focus our full capabilities - heart, mind, soul and gut - on our collective situation. We need to be informed by big-picture sensibilities, aware of our potential for both catastrophe and evolution, for both co-stupidity and collective wisdom. We need methods that help us deepen and expand our thinking, feeling and dreaming and we need ways to weave it all together, collaboratively, into a shared future."

Tom Atlee, 2003. *The Tao of Democracy*. Using co-intelligence to create a world that works for all. Published by the Writers Collective.

Till next time

Sue

Thank You  
From Us



Self Help Queensland would like to thank everyone who kindly filled out forms and agreed to be included in the 2006 Queensland Directory of Self Help and Support Groups - *for health conditions and related issues*.

We are frantically trying to gather in the last pieces of information, and hopefully our inaugural Directory will prove to be a valuable resource, and a reflection of the marvellous work carried out by community support organisations in Queensland.

We have endeavoured to include as many regional groups as we could find, and if we have missed your group we would be very happy to hear about it and make sure it is included in the next edition.

It is hoped that the Directory will be launched some time in November. We will keep you all posted!

Thank you once again from all at SHQ.

**"Strength Together!"** Do you care for a child or young adult with a Disability?

### **AAFCD and National NoticeBoard**

The Australian Association for Families of Children with a Disability (AAFCD) is a national self-help organisation for families of children and young adults with any type of disability across Australia.

AAFCD is a non-profit organisation run by families, for families. All AAFCD members are parents/carers, siblings or extended family of children or young adults with a disability or young people with a disability themselves.

Their bi-monthly magazine National NoticeBoard includes parent stories and up-to-date news on national disability issues.

AAFCD is active in advocating for improvements to government policies, and raising community awareness of the realities of life for families of children and young adults with disability. AAFCD also encourages families to join other disability self-help groups and aims to work together on issues that reach across all disabilities.

For more information and to get on the FREE membership list to receive National NoticeBoard, contact AAFCD:

Phone: 1800 222 660

URL: [www.aafcd.org.au](http://www.aafcd.org.au)

-oOo-

Matzat's (cited in Jack, 1995) summary of the literature identified the following benefits of self help groups

- Reduced depression
- Increased self-esteem
- More personal contact
- Increased skills in conflict management
- A comparative perspective of one's own problems
- A more selective use of the formal care system

### **ACOSS & "Action Network"**

- have your say on proposed budget changes to welfare

The Australian Council of Social Service (ACOSS) has come up with a feature on their website called "Action Network" - just 3 quick and easy steps to contact your MP (and Senators if you wish) about the budget changes to welfare.

Action Network allows people to enter their postcode and this autogenerates an email to their local Member of Parliament.

ACOSS is concerned about legislation that will be introduced in Parliament this year to put many people with disabilities and single parents on unemployment payments.

This includes rules that mean after July 2006 up to 300,000 people could have less money to live on. Take action online now in three quick steps and tell your Member of Parliament and Senators that you care about jobless people.

**Just go to the ACOSS website:**  
[www.acoss.org.au](http://www.acoss.org.au)

On the left hand side there is a column saying "Take Action"

- 1 Enter your postcode
- 2 Read the letter and if you agree you can tick on Send to Senators (if you wish)
- 3 Click NEXT

You then type in your details including a password and confirm this password. Read the Terms & Conditions and you then click on REGISTER and SEND your email. It's as easy as that.

You then see the letter with your name and are advised which Ministers and Senators it has been sent to.

-oOo-

**Would you prefer to receive this newsletter by email?**

Please contact Trish at the office.

Ph/Fax: 07 3344 6919

Email: [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)

## Genetic Matters

by Kim Summers PhD

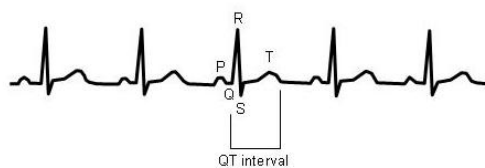
### Long QT Syndrome

- a genetic disease of the heart

We have all seen a medical movie or TV show where a patient is hooked up to a heart monitor. The line on the monitor wavers up and down in a steady repeating pattern and then suddenly .... it goes flat. The heart has stopped. People rush in and perform various procedures to try to get the heart started again. It makes a dramatic and often climactic scene.

The line is an electrocardiogram (or ECG) which represents the electrical pattern of the heart beat, as the heart muscle contracts to expel the blood and then expands to fill again. The beating of the heart (and in fact all muscle action) is controlled by the flow of electrically charged particles (chemical ions) in and out of cells. At each stage of the heart beat, the concentration of ions in the cells changes. If this flow of ions is disturbed, the muscle can't function properly. This is what happens in a genetic condition called long QT syndrome (LQTS).

The wavering line of the heart beat is divided into intervals with the transition points given a letter. The QT interval represents the time for the ventricles (lower chambers



of the heart) to contract and relax, sending a pulse of blood out of the heart through the arteries. In LQTS the time between Q and T in the heart beat is extended because there is a delay in the time it takes the heart muscle to adjust the levels of the charged particles inside and outside cells, so that another beat can occur. With this delay, the heart rhythm can become very fast and irregular so that not enough blood is pumped through the body. When the brain is starved of oxygen, because it is not getting enough blood, the patient may faint, suffer a seizure or die.

We now know that there are at least seven different proteins, called ion channels, involved in allowing different chemical ions to move in or out of cells. Changes (mutations) in any one of the genes which carry the recipes for these proteins can cause LQTS. LQTS occurs because the pattern of movement of these ions is disturbed by the abnormality of one of the ion channels so that the electrical state of the heart muscle doesn't follow the normal pattern. These specialist proteins are only found in heart muscle, so people with familial LQTS usually have no symptoms other than the problems with the heart beat, although in one form patients may also be deaf.

Tragically LQTS is frequently missed in a medical examination, because the electrical abnormality may only be seen in conditions of stress and emotional excitement, exercise, following administration of some medicines, during sleep or on sudden waking. Children with LQTS may die suddenly without pathological changes to the body which indicate there was an electrical problem with the heart. Some researchers believe LQTS is involved in at least some cases of sudden infant death syndrome (SIDS).

LQTS can be treated with drugs or surgery. Occasionally the problem doesn't respond to these treatments and the only solution is a heart transplant. A major problem for people with LQTS is the lack of information for medical professionals, which can result in inappropriate responses when a patient suffers a seizure.

Genetic testing is not yet available routinely for LQTS. Like many genetic conditions, there are a number of different mutations which can cause the problems, and there are at least seven genes to check. Our research group is currently studying one family with several cases of LQTS, to identify the genetic change and allow us to work out which family members are at risk of having a potentially lethal episode of heart rhythm abnormality.

If you have a family history which may suggest LQTS (seizures, sudden death of child or adolescent), talk to your doctor about your symptoms. Your doctor may recommend a consultation with a cardiologist and

(Continued on Page 6)



# Walk A Mile In My Shoes

A National Day of Action  
by  
Unpaid Family Carers

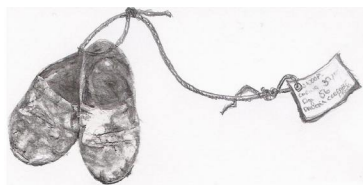
**Tuesday 13th September 2005**

Carer solidarity, strength of numbers, vocal-ity and visibility are the aims of the action day. The central focus of action will take place in Canberra.

Family carers and their supporters will gather on the lawns directly behind Old Parliament House by 10am. Speakers will address the rally and all Federal politicians will be issued with an invitation to listen to, meet and speak with carers at this rally. All Federal politicians will be presented with the symbol for this rally – a pair of old, worn out shoes – and asked to “walk a mile in my shoes” by carers.

## Tag Your Shoes

- With your name:
- Your age:
- With the number of years you have cared:
- With the age of the person/people for whom you care:
- With the disability of the person/people for whom you care:



Either bring them to Canberra on the day or Post them to your Federal Representative tagged and ask them as your Elected Representative to place them on the lawn with the shoes of other unpaid family carers on the 13th September.

The address is: Att:.....  
Parliament House,  
Canberra,  
A.C.T  
Australia, 2600

Family carers who cannot make it to Canberra, due to costs, distance or the logistical nightmare that carers face in organising substitute supports for family members, are

encouraged to take similar action at their State/ Territory Parliament House – on the same day at the same time. Carers living in rural/remote areas may also wish to take action via post, e-mail, telephone or fax. We do ask though that if you can, please post a tagged pair of your old shoes to your elected representative at Parliament House in Canberra with a request that they place your shoes in your absence.

We cannot underestimate the impact of vast amounts of shoes lined across the lawns of Parliament House. If we all send our shoes to Canberra the impact will be incredible.

URL: walkamile.net  
Qld Contact: Felicity Maddison  
Email: fmaddison@ozemail.com.au

-oOo-



The effectiveness of families and other micro-level support systems is heavily dependent on the adequacies of programs and policies at governmental levels ie housing, transport etc. and the depletion of such services disrupts natural helping networks.

( Pilisuk and Minkler, 1985).

(Continued from Page 5)

testing to check for abnormal heart rhythm, either at rest or during exercise or medication. Remember that the abnormality may not show up during routine testing and so testing should be done by a specialist cardiologist who is aware of the possibility of LQTS.

Support and advice is available for people with LQTS from:  
SADS Foundation (Australian Sudden Arrhythmia Death Syndrome )  
PO Box 19 Noble Park Vic 3174;  
URL: www.sads.org.au;  
Email: sadsau@optushome.com.au.

ABC website relevant article:  
<http://www.abc.net.au/science/k2moments/s1422463.htm>

-oOo-

# Rett Syndrome

## *- to know her is to love her*

Rett Syndrome (RTT) is a neurological disorder seen almost exclusively in females. First described by the late Dr. Andreas Rett, it wasn't until 1983 that the syndrome received worldwide recognition when a paper on the disorder was published by Dr. Bengt Hayberg and colleagues.

In general, the child with RTT shows an early period of apparently normal or near normal development until 6 – 18 months of age. A period of temporary stagnation or regression follows, during which there is a loss of communication skills and purposeful use of the hands. Stereotyped hand movements, gait disturbances, and slowing of the rate of head growth, soon become apparent. Other problems may include seizures and disorganized breathing patterns while awake.

Apraxia (dyspraxia), i.e., the inability to program the body to perform motor movements, is the most fundamental and severely handicapping aspect of RTT. It can interfere with every body movement, including eye gaze and speech, making it difficult for individuals with RTT to do what they want to do.

RTT is most often misdiagnosed as autism, cerebral palsy or non-specific developmental delay. While many health professionals may not be familiar with the disorder it is a relatively frequent cause of severe neurological dysfunction in females.

Most researchers now agree that RTT is a developmental disorder, rather than a degenerative one as was once thought, and barring illness or complications, survival into adulthood is expected.

In October 1999, mutations of the MECP2 (Mec- P-2) gene within band Xq28 on the X chromosome, were discovered as a cause of Rett syndrome. Other mutated gene(s), yet to be found, may also prove to be responsible for the disease.

Intensive research into communicative, genetic, neurochemical, neurophysiological and neuropathological mechanisms for RTT,

is being carried out at several research centres throughout the world including Australia.

The young girl with RTT is well known for her attractive features, and as she grows older, her especially penetrating eyes. Predicting the severity of RTT in an individual is difficult. Many girls begin independent walking within the normal age range, while others show significant delay or inability. Some begin walking and lose this skill while others continue to walk throughout life. Seizures can range from non-existent to severe, but do tend to lessen in their intensity in adulthood. Breathing abnormalities may occur but also tend to decrease with age. Scoliosis (spinal curvature) is prominent in RTT and can range from mild to severe.

Apraxia makes it difficult for her to perform motor movements when directed to do so. However when she is emotionally motivated, a movement can be automatic. Providing environments and situations that are strongly motivating will make it easier for her to show what she understands, resulting in greater success and satisfaction. Despite such difficulties, girls and women with RTT can continue to learn, and enjoy family and friends, well into middle age and beyond.

The Rett Syndrome Association of Australia (RSAA) was established in 1989 in response to the needs of RTT children and their families, in order to develop an understanding and awareness of the disorder, and further the advancement of research, therapy and care. The association provides phone support, information and brochures on the disorder.

Rett Syndrome Association of Australia Inc  
GPO Box 3497  
MELBOURNE VIC 3001  
Ph: 03 9615 7077 0418 561 796  
Email: [rettaust@bigpond.com.au](mailto:rettaust@bigpond.com.au)

Queensland families have regular get togethers; picnics etc where parents catch up with each other and exchange information and experiences. All are welcome.

The Queensland Contact person for RSAA is Heather, who can be contacted by phoning 0403 993181 (please leave a message and it will be returned asap).

## \$5,000 Grants Available for 2005/2006 through Disability Services Queensland

Under the Building Supportive Communities (BSC) grants program for 2005/2006, grants of up to \$5,000 are available for community based events and activities that welcome and include people with a disability.

Events that target a number of communities could attract funding of up to \$15,000. Small as well as large organisations are encouraged to apply, particularly those in regional and rural communities.

Guidelines and application forms for the Building Supportive Communities grants are available on the departmental website at [www.disability.qld.gov.au](http://www.disability.qld.gov.au), through the nearest DSQ office, or by contacting DSQ's disability information service on:

Phone: 07 3224 8444  
Toll Free: 1800 177 120  
TTY: 1800 010 222

**Application close on 30 September 2005**, with successful applications being announced on 3 December 2005.

-oOo-

### What issues would you like covered in this newsletter?



This newsletter is distributed throughout Queensland, and to a lesser degree, interstate. It goes to all our member groups (anyone who receives the newsletter is a member), hospitals, divisions of general practice, community health and neighbourhood centres, Qld politicians, health professionals, Centrelink personal advisers, Disability service workers, social workers, community workers, various organisations and interested individuals.

We sometimes don't quite get it right in terms of balancing the content so that there is "something for everyone", and so we invite you to provide us with constructive feedback, and even better, some articles!

We also invite any suggestions about how we could better improve the service. Please contact Trish, or the President, Sue Smyllie c/- the SHQ office.



## Older Women's Network Qld Inc

*"For women who have had quite a few yesterdays and want quality tomorrows"*

### Aims:

- Encourage life enrichment, mutual support & companionship amongst older women
- Promoted healthy ageing
- Promote discussion and action about ageism and sexism
- Lobby for a fairer deal on issues affecting older women such as income security, work opportunities, housing, health, home & community care & transport
- Provide information and education
- Enhance the positive image of older women

OWN has groups located in 15 different centres in Queensland.

### For further information contact OWN:

Ph: (07) 3236 1399 Fax (07) 3236 1105  
Email: [ownqld@bigpond.com](mailto:ownqld@bigpond.com)  
URL: [www.connectqld.org.au/ownqld](http://www.connectqld.org.au/ownqld)

### New Bipolar Support Group

West End Community House has started up a new bipolar support group which runs every 1st and 3rd Monday of the month. The meeting runs from 2p.m. to 4p.m. at the West End Community House located at 4 Norfolk Rd, South Brisbane. For any further enquiries please contact Malcolm Campbell on 3846 2114 or you can just drop in to the Community House.

### Difficulty in locating mental health support groups!

In the process of researching support groups throughout Queensland for the upcoming 2006 Directory of Self Help and Support Groups we seem to be confirming what we already suspected - that mental health support groups are very thin on the ground in Queensland. If you know of a group for any mental health issue, anywhere in Queensland, we would love you to let us know. Please contact Trish at the Self Help Qld Office. Ph/Fax (07) 3344 6919  
Email: [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)





## Australian Leukodystrophy Support Group Inc

The Leukodystrophies are a group of rare genetic disorders that progressively and degeneratively affect the nervous system. They are estimated to affect 1:20,000 people worldwide. Individuals afflicted by a Leukodystrophy have a genetic mutation causing an enzyme deficiency. This affects the nervous system as the protective covering (myelin sheath) around the nerve cells (neurons) of the brain, spinal cord or peripheral nerves is slowly destroyed. Leukodystrophy is no respecter of races or gender.

The word Leukodystrophy comes from the Greek Leuko = white and dys - trophy = ill - growth. Leukodystrophy describes a series of diseases that affect the growth or maintenance of the white matter (myelin). Myelin is a white fatty substance that acts as a protective sheath around the axons in our nerve cells. It allows for very fast transmission of signals to other nerve cells (neurons) along the axons. It acts in a very like fashion to the insulation on our electrical appliances. The destruction of this protection causes our Central Nervous System (CNS) and Peripheral Nervous System (PNS) to fail and death occurs as a result.

There are some 35 known Leukodystrophies, with the following being some of them;

- \* Adrenoleukodystrophy (ALD)
- \* Adrenomyeloneuropathy (AMN)
- \* Alexanders
- \* Canavans
- \* CADASIL
- \* Krabbe Disease
- \* Metachromatic Leukodystrophy (MLD)
- \* Pelizaeus Merzbacher (PMD)
- \* Refsum Disease
- \* Zellweger Syndrome
- \* Undiagnosed Leukodystrophies
- \* Vanishing White Matter Disease

Inheritance is either X linked (the mother carries the faulty gene) or both parents must

have the abnormal gene. We do not know the inheritance patterns for all the Leukodystrophies. Adrenoleukodystrophy is the most known and came to some prominence with release of the movie Lorenzo's Oil. Most of the Leukodystrophies bring about the premature death of our young children.

There is no known cure for any of them and the only glimmer of hope at this time for some cases is for a Bone Marrow Transplant. The answers for a cure would appear to lie in the area of Stem Cell Research.

The Australian Leukodystrophy Support Group Inc - ALDS- was established in Victoria in 1992 by Sister Julie Thomas CSB OAM to provide support to sufferers of Leukodystrophy, their families, and their friends. Sister Julie herself suffers from Adrenomyeloneuropathy (AMN) and is confined to a wheelchair which does not prevent her from actively guiding the ALDS in its future growth. Part of this strategic growth has seen the Eastern States develop their own contributing groups which has allowed for the families to network in a more personal way and share each others load.

The ALDS is a voluntary, non-profit organisation, which is dependent upon membership subscriptions and the generosity of those who make donations.

Activities of the ALDS also include raising awareness of the disease, disseminating information and raising funds for research. The ways in which the ALDS does this include:

- \* ALDS Website [www.alds.org.au](http://www.alds.org.au)
- \* Quarterly Newsletter
- \* ALDS Information Kit for Families
- \* Social Gatherings
- \* Fundraising Activities
- \* Medical Guest Speakers at the AGM
- \* ALDS Conferences

For further information in Queensland please contact:

Bob Wyborn  
Phone: 07 3283 7224  
Mobile: 0419 683 195  
Email: [mailto:bobwyborn@bigpond.com](mailto:mailto:bobwyborn@bigpond.com)  
URL: [www.alds.org.au](http://www.alds.org.au)

-oOo-



## Have you heard of Myasthenia Gravis?

The chances are that you have not, unless of course one of your family members has been diagnosed with this disease! The name sounds like that of some weird lizard, but it isn't. It means **grave muscle weakness**, and that just about sums it up. However when your GP tells you that all the tests he has run and your visits to specialists - neurologists, ophthalmologists, leave no doubt, you have won this lottery and your life will probably need some adjustments. As is usual with "strange" conditions, your age and general health will probably have a bearing on your immediate future.

Myasthenia Gravis (MG) can select its victims at any age, but it can strike 1:20,000 persons of any race, sex or colour. You cannot catch it from anyone, and you cannot pass it on. In rare situations it may zigzag down one's family tree, and then it has a slight name change - it may be diagnosed as Congenital Myasthenia.

OK. You've been informed you have MG. You will probably pause for breath and then ask your doctor what this means. If you are fortunate, your GP will have seen other patients with MG so he has some experience. Younger GPs will probably have studied the condition and are yet to meet one face to face. You might find a GP will pick it quickly and will refer you to specialists to confirm what he thinks you have.

If there is a general path along which the condition runs, it may be as follows. You may have aching muscles, either in one or more limbs, your shoulders, your face, lips, tongue and most obvious to family and friends, you may develop droopy eyelids and double vision. You may have one or more symptoms which commence by being a nuisance and your self diagnosis is that you have "caught" something. Further questions from your GP may reveal that you find trouble chewing on a good steak or have difficulty bringing your teeth together. Eating toast may be a problem, and swallowing is a real challenge. You may recognise a common thread in each of these problems. Your muscles are involved, and you

want to know why, and how do you fix the problem?

The interesting thing with those who have MG is that the sufferer may appear to be perfectly well so when he complains of his problems he can be thought to be "bunging it on a bit" or family will think "mum is going a bit odd!". Even health professionals can miss it, and can concentrate on some other condition which more readily springs to mind.

MG is an autoimmune disease which causes a fault in one's path which lets messages pass between the brain and muscle. If you drive a car, you don't give much thought to the process by which you start its engine. You simply insert the key, turn it to the right and the motor will (or should) fire up and you can go anywhere you choose. However, if the petrol tank is empty, you don't move. Those of us with MG find it impossible or very difficult to use our muscle of choice. Say you wish to walk or pick something off the table. You know what you want and you expect the task to be easy - but the message from the brain never reaches the muscle because like the car, the petrol tank is empty. Our petrol tank is called the receptor area which lies between the nerve endings and the muscles. A special chemical named acetylcholine is either totally absent, or there is a very low number of receptors. Your doctor (the mechanic) tracks this fault down and with his colleagues, will decide on an appropriate course of action.

At this stage you swallow some "patience" pills and sit back to discover how this condition called MG is going to change your lifestyle, if at all.

The Myasthenia Gravis Association's members meet often for what we call "coffee therapy" where people can listen and share. Some may think they are unique, while in reality they simply have one or more symptoms, just like me!

Early in my walk, I needed to travel to Dalby on business, and when about 30 miles out of Toowoomba, I realised I hadn't taken my medication with my breakfast. I realised this when one long cattle trailer loomed up in front of me and suddenly turned into TWO monsters. I realised it was double vision, but which of the two (Continued on page 12)

## Autism - and how a Carer Support Group in Brisbane approaches this “invisible disorder”

Self Help Queensland recently learned of a support group for carers of people with Autism that has been meeting in Brisbane for over a year. The Autism Spectrum Disorders Carers Support Group kindly provided the following article for our newsletter which gives a view from the carer perspective, information about the group, and what they are doing to support each other

“Autism affects people of all intellectual levels. People with Autism do not have any observable physical signs that indicate they have difficulty communicating, understanding or socially interacting.

Many of the very able people with Autism can often behave entirely appropriately at certain times. This tends to lead to their outbursts of inappropriate behaviour being labelled as “spoilt”, “naughty”, “selfish”, “bad” or “obnoxious”. What the onlookers are actually experiencing is that the autistic person is having great difficulty in making sense of what’s going on. Their outburst of inappropriate behaviour is a way of expressing confusion, fear and frustration.

Parenting these children can be a monumental task. It is both physically and mentally exhausting. In 2003 Autism Queensland ran a “Caring for the Carer” Workshop. As a result of the support and friendships that were developed during this course, two of the mums decided to form a new support group.

The Autism Spectrum Disorders Carers Support Group meets bi-monthly for a formal activity which will be geared towards our goal of information, education, empowerment and relaxation for Carers of Children with ASD followed by “bring a plate or your own lunch” and chat. This group meets mostly at the Relaxation Centre, Corner of Brookes & Wickham Streets in Fortitude Valley at 10.00 am. There will be an assortment of guest speakers and activities.

The charge at the Relaxation Centre is \$5.00 which includes tea or coffee and the activity.

It is a wonderful time to hear what others are doing and to be able to support a carer who needs a friend to talk to.

Carer is mum, dad, grandparents if available.

To this date we have planned for, or already had the following speakers or activities:

- a counsellor who is also the parent of an autistic child talking about how to take care of ourselves
- an associate professor from University of Queensland who is conducting tests on ADHD children to see if their medication is effective
- a motivational speaker
- reflexology
- feldenkreis
- deep breathing and relaxation
- a supermarket tour with a dietitian to discover what is good and bad on the food labels
- yoga and relaxation

During school holidays we meet at the Southbank Cinemas and go to a movie with our children.”

-oOo-

Welcome to  
all our new  
readers



Welcome to everyone who is receiving the SHQ newsletter for the first time!

As a result of our researching groups throughout Queensland for the Directory Project, we were fortunate in locating many and varied groups in all parts of the State - as well as some National groups for rarer conditions.

We invite all new readers to contribute information about their groups, or upcoming events they would like advertised.

If you would like to network with other like groups please let us know and we will try to assist.

(Continued from Page 10)

Was the real one and how much open space on that narrow road did I offer them? I took the best way out and went bush - well I went right off the road and on to the dirt shoulder thus avoiding the "two trucks". I stayed there while I dug out my medication and swallowed it down, on the spot. I then drove slowly to Dalby where I booked in at the motel and had a very good snooze. On my return home I visited my ophthalmologist who said not only did I suffer double vision, but my left eyelid was badly drooped. Off to the eye clinic and in day surgery I had the eyelid slit open a small slice removed. It was stitched up and once healed there was no trace of any wound. My eyelid has remained level with its mate on the right. Today, it may sag slightly if I become overtired.

Another symptom of MG was a large tumour attached to my Thymus. The specialist said it had to come out as it was pushing my thorax over to the right. Into hospital I went, and out it came, thankfully to be pronounce benign, which I later learned was normal for Myasthenics. The result was that my gravelly voice disappeared and I could swallow a good steak again. Life was looking good.

By chance, one day in 1998, I saw the entry for the Myasthenia Gravis Association in a country phone book, and on looking in all the others I found the same entry. I rang the 1800 802 568 number and a friendly male soon had me organised to join, aided by lots of very interesting literature, the best of which was "What is Myasthenia Gravis?" I was hooked, and since then I joined their committee and became President, and later Secretary, both very busy and worthwhile tasks. I travelled by train twice to Cairns and back, and spoke to public meetings along the way and distributed our good pamphlets to the public, chemists, doctors, hospitals and the ambulance centres. We are not medical professionals, but we have the condition and we know what it does to us. Being able to share this knowledge with others has always proved to be of assistance.

Do you wish to learn more? Call 1800 802 568 and a friendly voice will listen to your concerns. We won't even ask who you are, but we like it when you tell us. We are a not for profit incorporated community organ-

isation and a registered charity, whose sole role is to be a support organisation for those who need us.

by Gordon Jiear (Secretary)

Myasthenia Gravis Association of Qld Inc  
PO Box 16  
MT GRAVATT QLD 4122

Ph: 1800 802 568  
Email: mgqld@gil.com.au  
URL: www.mg-qld.gil.com.au

-oOo-

People with higher levels of emotional and pragmatic support, from family and friends, from the wider social networks of work or recreation, experience better health than people with diminished levels of such support

(Rosenfeld, 1997).

## Link Line



Through Link Line, Self Help Queensland hopes to facilitate contact between people with rare conditions for whom no 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 Brisbane family would like to connect with anyone with experience of the lung condition, Fibrosing Alveolitis.***
- ***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



# Broken Heart Syndrome

## - The Science of Tragedy and Grief

Most of us have suffered a tragedy in our lives, whether it was the death of a child, the breakdown of a relationship, a professional failure or some other event or circumstance. In clinical genetics families often discover that a close relative has an incurable disease and grieve for that person and for the other family members who are also at risk. Now scientists have presented research on a physical syndrome which accompanies the experience of tragedy and grief, which they have called broken heart syndrome.

Broken heart syndrome is also known as stress cardiomyopathy. It involves a range of cardiovascular symptoms which are similar to a heart attack, such as pain in the chest, difficulty breathing, abnormal heart rhythms and fluid in the lungs. It follows a sudden shock, such as hearing of the death of close relative, a car accident, discovery of infidelity in a partner, armed robbery, a fierce argument, or even a surprise party. The research on people admitted to emergency rooms with stress cardiomyopathy showed that the majority were post-menopausal women, although the youngest patient was 27. It is not yet clear whether a tendency to react to grief and tragedy with these physical symptoms is genetic, but it seems probable that these physical reactions are part of what makes up our personality and some of us are more likely to respond this way than others.

The researchers showed that the patients had a surge in stress hormones including adrenaline following the shocking event. They think that the high level of stress hormones, which persists for several days, temporarily stuns the heart, perhaps by closing the small blood vessels or by poisoning the cells of the heart muscle. Tests showed that there were no signs of a heart attack or coronary artery disease. The good news is that the symptoms resolved quickly and the patients recovered rapidly with no long term damage to the heart.

Adrenaline and other stress hormones can have several effects on the body. Because production of adrenaline is part of the "fight or flight" response, the body is readied to cope with increased physical demands to

the muscles. Blood supply is directed to systems which are important in the response to the "threat". There is an increase in the heart rate, blood pressure and rate of breathing. This produces the initial stress cardiomyopathy which often takes the sufferer to a hospital emergency room with a suspected heart attack.

There are other effects of the adrenaline surge which someone with broken heart syndrome may experience. The body's sugar stores are mobilized and the blood sugar level increases. Systems which are less important to the body's response to threat are given a lower priority. These include the digestive system and part of the brain. There may be a feeling of nausea and lack of appetite, and increased secretion of body wastes, which is associated with diarrhoea and the desire to urinate. So there can be relatively sudden loss of weight. Sleeplessness, dry mouth, tense muscles which interfere with fine motor control and increased sweating are also possible. Speech may be affected. And high levels of stress hormones can interfere with rational thinking and clear judgement, so at a time when many decisions are being made the person with broken heart syndrome is in no condition to make them. As the person progresses through cycles of the grieving process the stress hormones diminish and normal functioning is gradually restored, though when something triggers a memory of the tragedy, a surge of adrenaline can cause a temporary recurrence.

So next time a well-meaning person tells you that your grief is all in your mind, you can explain that your symptoms are real: you have broken heart syndrome and it will take time to recover.

Kim Summers PhD

(Kim is a member of the SHQ Management Committee)

Looking for a specific grief and loss support group?



We may already know of a group we can refer you to, or we can try to help you find one.

Contact the SHQ office PH/Fax 3344 6919





## Diary Dates

### 3rd Australian Batten Disease Family Conference

*"A Project of Hope"*

**1st & 2nd October 2005**

at

**Australis Noosa Lakes, Noosaville QLD**

The Batten Disease Support and Research Assoc Inc represents and supports children and families affected by the neurological degenerative terminal illness, Batten Disease.

The Conference aims to provide families and their friends, teachers and medical staff, affected or involved by this Disease with information, education and social interaction in various aspects of Batten Disease.

Worldwide researchers will be here to share their knowledge, updating us on research and possibilities and hopes of trial treatments. A number of excellent speakers will travel from USA and Australia-wide to give each of us a greater understanding of this disease. Members of the public with an interest in Batten Disease are most welcome.

For further information please contact:  
Vanessa Anderson Ph: 02 43345785  
Email: [gvjcando@ozemail.com.au](mailto:gvjcando@ozemail.com.au)

-oOo-

### The Chromosome 18 Registry & Research Society (Aust)

**Annual Family Meeting  
8 & 9 October 2005**

The Chromosome 18 Registry & Research Society (Aust) Inc is a voluntary based, non-profit organisation supporting families and individuals affected by a Chromosome 18 disorder - eg 18q deletion, Ring 18, Tetrasomy 18p, Translocations, partial trisomy 18, trisomy 18 and other unique rearrangements of chromosome 18.

For a registration form or further information please contact the Australian Co-ordinator, Marlene Brightwell. Ph: (02) 9580 5707  
Email: [chromosome18@optusnet.com.au](mailto:chromosome18@optusnet.com.au)  
URL: [www.chromosome18.org](http://www.chromosome18.org)



## Angelman Syndrome Association

### 7th National Conference

**30 September - 2 October 2005**

The 7th biennial National Conference of the Angelman Syndrome Association also celebrates the 40th anniversary of the discovery of the Angelman Syndrome by Dr Harry Angelman in 1965.

The Friday pre-conference drinks, Saturday Conference seminars and the Conference dinner are all to be held at the Stamford Grand, Moseley Square, Glenelg, South Australia. The Stamford Grand is a four and a half star hotel, situated on the beach front at Glenelg. Glenelg is a popular tourist destination and just a short tram ride to the city centre.

For further information regarding accommodation, child care, costs, program etc please stay tuned to the Angelman Syndrome Association website:  
[www.angelmansyndrome.org](http://www.angelmansyndrome.org)  
PO Box 554  
SUTHERLAND NSW 2232  
Phone: (02) 9520 5857

Would you prefer this newsletter by email?



If you would prefer to receive the newsletter by email rather than post, please let us know.

We would also like to receive feedback about our service. Please feel free to pass on any suggestions you may have that might help us to do better.

If you would like to contribute an article about your group for the newsletter, or suggest any issues you would like addressed in future editions, please contact Trish at [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au) or by Phone/Fax (07) 3344 6919 (The newsletter will be in PDF format. You will need Adobe Acrobat Reader to read it.)