



# Newsletter March Quarter Issue 1. 2009



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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

Welcome to 2009. If recent events are anything to judge by it will be a challenging, inspiring and emotional year.

I recently attended the launch of the Strategic Plan developed by Health Consumers Queensland. The document sets out goals for 2008-2010 and strategies for achieving them.

*'Health Consumers Queensland...your voice in health'* is the tag line for a program designed to capture and amplify consumer sentiment to impact government policy making and service delivery. The plan outlines strategies to gather community information and to identify appropriate policy slots for it. Sometimes the policy slot may be identified before the information is gathered. There are also some 'capacity building' initiatives (like network strengthening and skill and knowledge development) and communication, evaluation and reporting strategies.

On the day, I was impressed by the continued enthusiasm of the committee and the secretariat for the work in hand. I was also encouraged by the stated aim of becoming a non-government organis-

ation by 2010. During the speeches much was made of the importance and value to be placed on consumer involvement. As with all such documents it remains a collection of words until put into action. Cynicism will be quieted by transparency and value supported when community time is counted as equally important as government time.

Copies of the plan and a brochure outlining the roles and responsibilities of what is now widely referred to as HCQ, are available from Queensland Health.

The SHQ committee continues to monitor and support our projects for the year. These are the Mental Health Self Help Groups projects funded by DSQ (please refer to Diana's report for an update), 'Self Help House' and the updating of our Directory. Plans are underway to translate the Directory to an online searchable data base, concurrently updating and expanding our Website. I am hoping our website will also become an interactive space where groups can contact and support each other, share resources and knowledge and strengthen the sector. SHQ does not view this as the complete answer to providing our service in a timely, relevant and accessible way but we hope it becomes a useful tool for everyone. I

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## Self Help Queensland Management Committee Members

President	Sue Smyllie
Secretary	Thea Biesheuvel
Treasurer	Kathleen Zarubin
Members	Alan Noller
	Joe Soda
	Bob Wyborn

## Committee Meetings

If you would like to attend our meetings, please contact us for dates and times. Everyone is welcome to attend.

## Project Officer

Trish Fallon

## Mental Health Project Officer

Diana East

## Administration Officer

Janice Nankivell

## 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](mailto:selfhelp@gil.com.au)

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

## Self Help Leaders Online Social Network

**URL:** [www.selfhelpleaders.ning.com](http://www.selfhelpleaders.ning.com)

**Thanks to Queensland Health for providing funding to Self Help Queensland to help carry out its activities, and for supporting the publication of this quarterly Newsletter.**



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## Advertise your Group's 2009 Special Event in 'Diary Dates'

### Back page SHQ newsletter

Closing dates are first day of February, May, August & November

Ph:07 3344 6919 Email:[selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)

SHQ's Policies and Procedures Manual is reviewed annually, and may be seen at the office by contacting 07 3344 6919.

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

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.



**Coming  
Soon!**

**2009 Edition**

**SHQ Queensland Directory  
of Self Help and Support  
Groups**

**New, Free, User-friendly,  
Multi-function and Online**

SHQ will soon be contacting groups and inviting them to participate in the next Directory. The 2009 edition will replace the outdated 2006/2007 hardcopy version, which proved to be a very valuable resource.

The new, free, user-friendly, multi-function, online version will have the advantage of being able to be kept up to date more readily. Groups can advise changes to their information and the Directory will be updated immediately. This is essential if a Directory is to be of any real use.

While there are many directories around, this is the only one we are aware of dedicated solely to Queensland self help and support groups. They will be in a class of their own; all housed under the one roof!

Our thanks go to GO1 for awarding SHQ a 'GO Community Project', whereby the development cost has been discounted by 50%. GO is primarily provided to community based organisations who undertake sizeable development projects.

A registration form and explanatory letter will be emailed or posted to your group shortly. If you have any questions about the project please do not hesitate to contact Trish at the SHQ office. Ph: 07 3344 6919  
Email: selfhelp@gil.com.au

**Thank you for participating!**

## **Do You Hear Voices?**

### **Are you interested in joining a self help group?**

Hearing voices has traditionally been regarded by psychiatry as 'auditory hallucinations', and in many cases a symptom of schizophrenia. However not everyone who hears voices has a diagnosis of schizophrenia. There are conflicting theories from psychiatrists, psychologists and voice hearers about why people do hear voices with some people believing that they are similar to dreams, symbols of our unconscious minds.

Until recently, the usual treatment for voice hearing has been major tranquilisers, administered to reduce the delusions and hallucinations. However not everyone responds to this treatment. There is now a growing practice amongst some psychiatrists and psychologists of working with people who hear voices using talking therapies and exploring the meaning of the voices. As the improvement in individuals who are encouraged to talk about their voices becomes more apparent an increasing number of health professionals are beginning to understand that the key to understanding voices lies in the 'content' of the voices.

There are also now national and international Hearing Voices Networks which strongly advocate that:

- Hearing voices is not in itself a sign of mental illness
- Hearing voices is experienced by many people who do not have symptoms that would lead to diagnosis of mental illness
- Hearing voices is often related to problems in life history
- If hearing voices causes distress, the person who hears the voices can learn strategies to cope with the experience. This is often achieved by confronting the past problems that lie behind the experience.

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### **Hearing Voices Self-Help Groups**

Hearing Voices Groups provide peer support, encouragement and mutual learning opportunities to people (sometimes also including relatives and carers) who share the experience of hearing voices. Members share the same problems and may have similar life situations. Groups offer a safe haven where people feel accepted and comfortable and an opportunity to accept and 'live with their voices' in a way that gives some control and helps them to regain some power over their lives. Some of the above information has been adapted from the Hearing Voices Network Website: [www.hearing-voices.org](http://www.hearing-voices.org)

The Hearing Voices Network Australia (HVNA) has produced a comprehensive information booklet which can be downloaded from the Richmond Fellowship website at [www.rfwa.org.au](http://www.rfwa.org.au)

For other sources of background information about the voice hearers movement try:

Intervoice - The International Community for Hearing Voices  
[www.intervoiceonline.org](http://www.intervoiceonline.org)

### **New Hearing Voices Self Help Group in Brisbane**

A new self help group for voice hearers has recently commenced on the south side of Brisbane. There has been one meeting to date, and future meetings have been set down for Wednesdays of each week at 2.30pm. (These arrangements can be changed to suit the group).

If you would like further information about the group please contact Mary on Ph 0423 208 218

**"It is not the strongest of the species that survive, nor the most intelligent, but the one most responsive to change."**

**Charles Darwin  
British Naturalist  
1809 - 1882**

**A place for people who have suffered abuse while in the care of state, churches, foster homes or detention centres.**



### **A Place to Connect with Others**

Lotus Place aims to provide people with a safe place with reliable connections to others, where their shared experiences of childhood and these consequences can be respected.

Organisations and networks located at Lotus Place are:

### **The Historical Abuse Network (HAN)**

The Historical Abuse Network exists to connect people who were in the care of the church or state as children. Membership includes people who experienced abuse in church or state institutions, foster care, youth detention centres and those who as children were placed in adult mental health institutions.

The aims:

- To maintain a voice to continue dialogue with governments and churches
- To share and disseminate information
- To reconnect and provide opportunities
- To participate in reconciliation events and children's homes reunions
- To promote affirmative action and ensure recognition of the lifelong impact and disadvantage of being a former child in care

### **Aftercare Resource Centre (ARC)**

ARC provides counselling and support services, including assistance with educational opportunities, record searches, family reunions and support group activities, to former residents of state and church run institutions and foster care.

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# Genetic Matters

*by Kim Summers PhD*

## **Mad cows, itchy sheep and sleepless humans – what do they have in common?**

Those of us who lived in the UK in the early 1980s are not permitted to give blood in Australia. This is because of the very low risk that we might have been infected by a novel infection, from eating British beef in that era. The infectious particle isn't a virus or a bacterium, a fungus or an amoeba. It appears to be a short piece of protein. Proteins are linear polymers of amino acids. Depending on the type of amino acids and the order in which they are joined together, the proteins can have a number of functions. But until recently, no-one suspected that a protein could have the power to cause a devastating disease.

Even today, after more than 20 years of intensive study, researchers are still not sure how, or even if, this protein causes mad cow disease, scrapie of sheep, chronic wasting disease of deer and familial fatal insomnia in humans. One thing is clear: the abnormal protein is found in the brain of sufferers from all these conditions. And injecting an extract of those brains can transmit the same condition to healthy creatures. Unfortunately the condition develops over many years, more than half an average life time in some instances, so experimental and natural cases are difficult to create or discover.

The outbreak of mad cow disease in the UK started with a few cases of cattle which kept falling down. Those cattle were quickly sent to market where they were kept out of the human food chain and instead used for animal feed. Unfortunately, some of that feed went to other cattle, some of whom then eventually developed the same symptoms. By the time the British government had realised it had an epidemic on its hands, beef contaminated by the infectious protein had appeared on tables and in rest-

aurants and a large proportion of the British population had been exposed. Then a few humans, often said to be people who had a great liking for hamburgers, developed symptoms similar to the cattle, and to a genetic condition called Creutzfeldt-Jakob disease (CJD). But CJD was usually inherited, or appeared as a spontaneous mutation. Now there were people who apparently had an infectious form of CJD.

As the mad cow epidemic progressed, researchers noticed similarities to a disease of sheep which caused them to scratch their backs obsessively against fence posts. Called scrapie in the UK, it has a range of names in all countries where sheep are reared, and had exploded into a massive epidemic in the early 19th century. Could scrapie and mad cow be caused by the same thing? Then there was the curious case of kuru in the Foré people of Papua New Guinea. This neurological condition appeared to be caused by funeral rituals which involved eating the flesh of the departed relative. Women were more likely to be affected than men, and the women were often left to eat the brain after the men had eaten the more nourishing muscles.

Sporadic and familial CJD is caused by a DNA change in the gene encoding a brain protein called PrP. This protein apparently has a normal function in the brain (although it is not yet clear just how it does function). When the altered gene is inherited, all cells have half and half normal and abnormal protein. The mutation causes the protein to fold improperly and then change the folding of other copies of itself, both normal and abnormal. It now seems that introducing the abnormal protein, through eating beef from a mad cow or by treating laboratory animals, is enough to cause the normal protein to fold incorrectly. This is why the protein itself seems to be infectious, even though it is not living and does not resemble any known infectious organism. It is still not clear exactly how the infectious protein operates, or whether

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there is some other agent in addition to or instead of this protein which is the real cause of the disease.

For a small group of families, the mad cow outbreak and the subsequent intense research on the rogue protein holds out some hope of treatment of a devastating condition. These are the families with familial transmissible spongiform encephalopathes (TSEs), as this group of diseases of animals and humans is now called. Among the recognised human TSEs are CJD and familial fatal insomnia (FFI). These conditions are characterised by pathological abnormalities of the brain, giving it a spongy look similar to cattle with mad cow disease and sheep with scrapie. They are very rare conditions, where symptoms often develop in adults, who are likely to die within a few years.

In FFI, early symptoms in affected people include the inability to sleep, giving it its name. Cases of FFI have now been shown to have mutations in the same gene which produces the PrP protein. The mutation causes the renegade form of the protein which upsets the normal folding of all copies, both normal and abnormal. Eventually this leads to the deterioration of the brain tissue and death.

The focus on understanding TSE should give us confidence that our meat is not tainted with the fatal protein and that the world's population is not at risk of acquiring CJD from the Sunday roast. But it may also bring treatment or even cure to families with genetic TSEs, surely an unexpected outcome from the initial observation of cows who couldn't stand up.

**Kim Summers is a Senior Scientist at the Roslin Institute, University of Edinburgh and a member of the School of Molecular and Microbial Sciences of The University of Queensland. Kim is also a very valued past member of the SHQ management committee.**

**"Wit is educated insolence"  
Aristotle  
(384-322 B.C.)**

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approach this leap into advanced technology with some trepidation as I have seen these tools begin a life of their own, gobbling up time and money and distancing people from each other. As with all types of infrastructure I find it useful to remember these words of Lao Tzu: "Clay is shaped into a vessel; it is the empty space that makes it useful. Profit comes from what is there; Usefulness by what is not there."

Self Help House....a long held dream of SHQ and many others in the sector, is our long range project for the year. We are again gathering the energy for a further foray into possible funding and other support to make it a reality. Anyone interested is more than welcome to become involved.

Till next time  
Sue

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### **The Forde Foundation**

The Forde Foundation is an independent trust set up to make small monetary grants to former child residents of institutions and some foster care residents to help them overcome the disadvantage they now experience as a result of childhood disadvantage. The Foundation invites grant applications from people formerly in state care or who, as children, lived in institution examined by the Forde Inquiry. Grant Application dates are available through Lotus Place.

Contact Lotus Place:  
26 Merivale Street, SOUTH BRISBANE  
Ph: (07) 3844 0966 Fax: 07) 3846 5207  
Email: [esther.team@merivale.org.au](mailto:esther.team@merivale.org.au)

**"I am a firm believer in the people. If given the truth, they can be depended upon to meet any national crisis. The great point is to bring them the real facts."**

**Abraham Lincoln  
16th US President  
1809 - 1865**



## Drowning Prevention, Awareness and Support

**A not for profit community organisation dedicated to supporting bereaved families**

### About Hannah's Foundation

*By Andrew Plint*

On 4 October 2007 my wife Katherine and I lost our daughter Hannah Isabella Alyson Grace Plint at 34 months of age in a tragic drowning at our home in Laidley. Hannah had carried a plastic chair from our deck around and opened the pool gate whilst my wife was changing our son's nappy. Less than 2 minutes later my wife found her in the pool but it was too late.

***After the loss of Hannah we went searching for a support group of those who had also lost someone through a drowning. To our dismay we were unable to find one and as a result we decided to start Hannah's Foundation.***

Hannah's Foundation was started with the aims of providing support to the families of those who had lost loved ones through drowning and to prevent and to raise awareness of the risks of drowning around the Australia.

Some of the ways that we as the Foundation provide support for Families is to assist with the financial costs following a drowning accident. Hannah's Foundation contributes towards the funeral costs to help the family through the initial stages following such a traumatic loss. We are working with a number of corporations in order to provide assistance with basic needs in the period following the death and the funeral, these include basic necessities such as milk, coffee, sugar, bread and general foodstuffs, and also assistance with telephone bills is also provided.

After the funeral we provide ongoing 24 hour peer to peer support and provide assistance with obtaining counseling

services for the family and friends who are members of Hannah's Foundation. The Federal government only provides a limited number of professional counseling services through a Medicare mental health plan and we have found that many families have received some benefit from these services, however due to the financial cost of these services once the plan runs out they stop receiving counseling and support services. This of course has a detrimental effect in the short, medium and long term. We as the Foundation offer financial assistance to these families to be able to receive ongoing professional services.

Hannah's Foundation is a not for profit community organisation which receives no government funding. All our funding comes from personal donations and fundraising initiatives with the sale of pens, stickers and magnets as well as some limited corporate sponsorship.

Our principal source of fundraising is when businesses, schools or organisations undertake fundraising activities such as free dress or gold coin days. Our other source of income derives from Workplace Giving where employees indicate an amount generally \$2 per fortnight to be taken from their pay and deposited into the Foundation Account. We certainly would encourage this method of donation as it provides an easy method for the employee to make regular donations to a worthwhile charity without having to attempt to keep track of receipts over the year.

URL for the Workplace Giving Form:  
<http://www.hannahsfoundation.org/Forms/Workplace%20Giving.pdf>

These fundraisers are generally conducted as part of an overall campaign where we encourage participants to raise awareness of (Continued Page 8)

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drowning risks around the home. This includes checking pool fence safety (fence and gate condition, materials in close proximity to the fence), encouraging first aid training and general water safety awareness.

Willing organisations, schools, workplaces etc are invited to undertake an Awareness or fundraising activity, be it a gold coin donation for a non uniform day or something of a similar vein. If practical I would certainly endeavor to make myself available to speak with the group as a whole or to provide some materials for the day.

For further information please contact:

Hannah's Foundation  
PHONE/FAX: (07) 5465 2000  
Mobile: 0412 742 203 (Andrew)  
Families contact 1800HANNAH (426624)  
For general enquiries:  
Email: info@hannahsfoundation.org  
URL: www.hannahsfoundation.org

### Ovarian Cancer Support Group Formed in Brisbane

A very much needed, dedicated Ovarian Cancer Support Group has now been formed in Brisbane.

Run by Ovarian Cancer Australia, the group provides a wonderful opportunity for patients, family and support people to chat and spend time with people who are going through the same things when dealing with Ovarian Cancer.

The group meets on the 2nd Thursday of the month from 10.30am to 12 noon.

Guest speakers, meditation/relaxation, massage therapists, information to assist with diagnosis and treatment, friendship and emotional support etc.

Venue: Nursing Australia  
127 Creek Street, BRISBANE

For further information please contact Michelle Ph: 0458 437 440  
www.ovariancancer.net.au

## Did you Know?

**There are about 8000 rare diseases affecting an estimated 1.5 million Australians, including about 300,000 Australian children.**

Self Help and Support Groups provide opportunities for individuals and families to come together, support each other, share information and advocate on their own behalf. Groups help reduce feelings of isolation and assist people to take charge of their own well being.

Unfortunately, there are not always groups for every condition - particularly very rare ones.

If you have a rare disease for which no support groups exists, and you would like to be a contact to speak with and support others with the same condition, Self Help Queensland would love to hear from you. The following information is about such a support contact.

### Treacher Collins Syndrome Support Contact

Treacher Collins Syndrome (TCS) is one of those very rare syndromes. It is thought that there might only be about 30 people in Australia who have the condition.

**There is no known existing support group for TCS in Australia.**

A Treacher Collins Advisory Service has been set up to assist other families and professionals seeking information about the condition. The Consultant, Jade has a multi-faceted view of the condition, having TCS herself, and being a member of a family of three generations currently with the condition.

Jade, while living in Queensland, is very happy to be contacted by anyone in Australia seeking confidential, compassionate and comprehensive information about TCS. Please contact Jade:

Ph: 07 4638 8454

Email: tcsadvisory-service@live.com

**(TCS will feature in SHQ's June edition)**



## Meetings that Matter (Part 2)

By Sue Smyllie

In the last newsletter I started sharing some of the interesting concepts I learned about at a workshop facilitated by Martin Weisbord and Sandra Janoff. Their book is based on the premise that if you want to change anything you can only do so one effective meeting at a time. Their ten principles were summarised last letter. I intend to elaborate on a couple of principles in each newsletter so you should have a complete set by the end of the year. By necessity my summaries need to be kept short. I do not necessarily agree with all of their ways of looking at things but it is always interesting to think about another's way of doing things to inform your own practice. There is much more detail in their book. Happy meetings!  
Sue Smyllie

### Principle 1: Get the whole system in the room.

The 'Whole System' is a group made up of people concerned with the issue who either have authority to act, resources, expertise, information and/ or who need to be involved because the decisions taken will affect them. Once you have thought about all the possible invitees keep the following in mind:

Match the people to the task, when you decide to include someone make a note of the consequences of leaving them out.

- Be realistic about how much time the meeting will need to take and be honest about it.
- Give people time to participate so you can take advantage of the rich diversity in the room.
- Sometimes people will need to work together or alone during the meeting- make a plan for this.
- If you can't get the whole system try to get any 3 levels and any 3 functions on any issue of major concern.

### Principle 2: Control what you can, let go what you can't.

This principle is about 'leading' meetings in ways that support the development of responsibility in the group. This means controlling as much as you can before the meeting eg working out your role, who will participate, the agenda time etc and then during the meeting, control only those things that will keep the group working on the task. The following tips help with this principle:

- Know your role and make sure the group understands and agrees with you.
- Be clear about reaching your purpose in the time available
- Make sure the people who attend are up to the task
- Arrange seating for a purpose. Self responsibility doesn't often grow from formal rows...try a circle.

Next time we will look at Principles 3 & 4 - 'Exploring the whole elephant and Let People be responsible'.

Sue

<sup>1</sup>Weisbord, M., and Janoff, S., 2007. Don't just do something, stand there. Ten principles for leading meetings that matter. Berrett-Koehler Publishers Inc: San Francisco.

**Non Profit Advice Team  
Australian Taxation Office  
1300 130 248**

*There should be support groups for women who can't put their dishes in the dishwasher dirty.*



## Australians Invited to Participate in Research on Ehlers-Danos Syndrome

Do you have a form of Ehlers-Danos Syndrome? Help support EDS research by participating in an online research study aimed at evaluating your personal experience of having EDS and the impact it has on your daily life.

My name is Stacey Le Fevre and I am the primary investigator for this research project. I was diagnosed with Ehlers-Danos Syndrome, Hypermobility Type in 2003. I am currently working on my doctorate in clinical psychology at the University of Indianapolis and this research is being conducted in partial fulfilment of my doctoral requirements. Although research on the medical aspects of EDS has increased dramatically over the past decade, little attention has been given to how EDS affects those of us who deal with it on a daily basis.

The aim of this research is to gather your collective experiences and better understand what it is like to live with the different types of EDS. To participate you must be at least 18 years of age and have EDS. The questionnaire is 106 questions and will take approximately 30 minutes to complete. No identifying information will be asked.

Please go to the survey website. [www.surveymonkey.com/s.aspx?sm=5C\\_2fxpdbhjBgAlOyRewpoFg\\_3d\\_3d](http://www.surveymonkey.com/s.aspx?sm=5C_2fxpdbhjBgAlOyRewpoFg_3d_3d) You will be asked to enter a password to access the survey. (for test security)

### **The password is EDSResearch**

For any concerns please contact Stacey, Research Investigator, University of Indianapolis at: [lefevresr@uindy.edu](mailto:lefevresr@uindy.edu)

**Thank you for your participation!**

**"Just remember - if the world didn't suck, we would all fall off"**

**Larry the Cable Guy  
Stand up Comedian and Actor  
1963.....**



## Community Seminar

### Affecting Same-Sex Couples

#### **Changes to Centrelink Payments**

Queensland Association for Healthy Communities in association with Welfare Rights Centre (Qld) and Queensland Positive People is organising a community seminar in Brisbane and Cairns to discuss upcoming changes to Centrelink payments affecting same-sex couples.

From 1st July 2009, same-sex couples will be recognised by Centrelink for all payments, including the Age Pension and Disability Support Pension. People in a same-sex relationship, currently assessed as single, are being asked to declare their relationship to Centrelink and will then be assessed on their joint income. This may mean a reduction in payments for some people and possible loss of concession card.

Find out what's going to happen, how it might affect you and what you can do about it.

#### **Brisbane**

Thursday 12th March  
6:30pm to 8pm  
QAHc Brisbane  
30 Helen St, Newstead  
RSVP to 3017 1777

#### **Cairns**

Thursday 26th March  
6:30pm to 8pm  
QAHc Cairns  
290 Draper St, Cairns  
RSVP to 4041 5451

To read QAHc's summary or full document relating to changes to centrelink payments for same-sex couples go to: [www.qahc.org.au/petitions](http://www.qahc.org.au/petitions)

## 'Mercury Rising' Mental Health Support Groups Project Update

*By Diana East  
Mental Health Project Manager  
Self Help Queensland*

The definition of 'mercury rising', that things are improving, excitement is growing, etc, is proving to aptly describe Self Help Queensland's project to strengthen mental health support groups. In the first six months some of the achievements have included:

- Known groups have been contacted and new groups have been identified via vigorous community networking. All groups have been advised of the purpose and parameters of the project and invited to participate.
- The Scoping Report and Project Plan have been written and accepted by DSQ.
- The 1st round of regional network meetings has been held with high attendance rates and positive discussions about ways to progress project outcomes, particularly with reference to the distribution of small grants. Reports and recommendations from these initial network meetings have been circulated to all participating groups
- A survey of selected groups has been completed (with a 67% response rate) and results presented at network meetings.
- In partnership with Mental Illness Fellowship of North Qld Inc, a consultation meeting was held in Townsville in early December to discuss needs and actions for the possible formation of new support groups in that region.
- Meetings have also been held with various agencies supporting the development of new and emerging multicultural groups to discuss ways in which the project might support such groups to grow and become more sustainable.

- Initial planning for a 2-day training opportunity for support group facilitators and potential facilitators has commenced. This will aim to be responsive to some of the needs identified by group facilitators; to continue to build connections with each other; to share some thoughts, feelings and ideas about being a support group facilitator; to have fun and share some activities together in a way that is safe.

This project has 'started where people are at', a practice that is quite highly sophisticated and that takes time. The groups involved understand that developing capacity is the key to their present and future successes. So the mercury is rising with most groups happy, indeed enthusiastic, to participate in the project because they feel that they own the process. Much can be learned from a project such as this where participating groups have a large say in what happens. In the words of one participant, *"The way that the small grants will be distributed is very fair. And this is so important as it doesn't often happen that way. This is as good as it gets!"*

Groups also understand that the project's agreed processes will take time and so they do not have unreasonable expectations but they are also keen to see visible progress now that the first stage (ie building the base) is almost completed. This base will be used as a benchmark to measure progress over the next 12 months, eg in terms of feedback from groups regarding small grants expenditure and other knowledge and skills gained.

**If your support group has not appeared on our radar, and you would like to be part of this exciting project, or if you know of a group who may wish to participate, please contact SHQ's Mental Health Project Manager, Diana East.**

**Phone: 3880 3501**

**Email: [dianaeast@iprimus.com.au](mailto:dianaeast@iprimus.com.au)**

**Diana would be delighted to hear from you!**



## Dementia Specific Support Groups 2009

For family and friends who are carers of people with dementia; information, education, guest speakers & emotional support. Please call to register.

### **Queensland Wide Telephone Group**

(Telephone Support Group 10am to 11am on last Tuesday of each month)  
Contact: Elizabeth Howden  
Ph: 1800 639 331 or Ph: 3252 4622

### **Young Onset Dementia Support Group**

Information, education and support are offered to people 65 years and younger diagnosed with dementia along with family carers.  
Meets 10am to 12 noon on 2nd Saturday of each month  
Contact Lorrae Martin  
Ph: 1800 639 331 or Ph: 3252 4622

### **Brisbane North Region**

#### **Gaythorne Support Group**

Meets 10am to 12 noon on 1st Thursday of each month  
Contact: Lorrae Martin  
Ph: 1800 639 331 or Ph: 3252 4622

#### **Kedron Support Group**

Meets 7pm to 9pm on 2nd Wednesday of each month  
Contact: Lorrae martin  
Ph: 1800 639 331 or Ph: 3252 4622

### **Brisbane South Region**

#### **Mt Gravatt Support Group**

Meets 10am to 12 noon on 2nd Tuesday of each month  
Contact: Lorrae Martin  
Ph: 1800 639 331 or Ph: 3252 4622

### **Sunshine Coast Region**

#### **Redcliffe Support Group**

Meets 1.30pm to 3.30pm on 1st Thursday of each month  
Contact: Lorrae Martin  
Ph: 1800 639 331 or Ph: 3252 4622

### **Noosa Heads Support group**

Meets 10am to 12 noon on 1st Friday of each month  
Contact: Lorrae martin  
Ph: 1800 639 331 or Ph: 3252 4622

### **West Moreton Region**

#### **Ipswich Support Group**

Meets 10am to 12 noon on 3rd Wednesday of each month  
Contact: Lorrae Martin  
Ph: 1800 639 331 or Ph: 3252 4622

### **Darling Downs Region**

#### **Toowoomba Support Group**

Meets 12 noon to 2pm on 1st Monday of each month  
Contact: Lorrae Martin  
Ph: 1800 639 331 or Ph: 3252 4622

### **Wide Bay Region**

#### **Hervey Bay Support Group**

Meets 12pm to 2pm on last Thursday of each month  
Contact: Lorrae martin  
Ph: 1800 639 331 or Ph: 3252 4622

### **Central Region**

#### **Rockhampton Support Group**

Education and home visits conducted  
Contact: Lorrae Martin  
Ph: 1800 639 331 or Ph: 3252 4622

#### **Gladstone Support Group**

Meets 10am to 12 noon on 3rd Friday of each month  
Contact: Lorrae martin  
Ph: 1800 639 331 or Ph: 3252 4622

[www.alzheimersonline.org](http://www.alzheimersonline.org)

**"The relationships that develop through peer support are usually informal and characterised by the values of friendship, independence, empowerment, consciousness raising and mutual aid. It is suggested that it is the reciprocal nature of these relationships that enhances self-esteem, personal competence and strengthens support networks."**

(Source: Wilson, M., Flanagan, S & Rynders, C. (1999). The FRIENDS Program: A Peer Support Group Model for Individuals with a Psychiatric Disability. *Psychiatric Rehabilitation Journal*, 22 (3), 239 - 247)

# The Club

*by Bob Wyborn*

I want to tell you about one of the most exclusive clubs that I am aware of on this planet. It is so rare that very few people even know about it. It is not widely publicised nor do you receive invitations to join it, either in the mail or by any other form of solicitation.

It has global membership. You will find fellow members in all nooks and crannies of this universe. It has no age restrictions or colour barrier. Gender is not an issue nor your belief system. It is not a club that you are asked to join nor would you want others to enlist. The membership is the highest that can be paid. The cost.... the death of your child. The manner of death is not a prerequisite. It has an open exclusivity about its qualifications.

Its members are drawn from all the walks of life. There are the rich and there are those who are not. Some hold high office and some do not. Life has been kind to some whilst to others not so gentle. There are those whose life experiences have created great wisdom and those who are still on the learning trail. There are atheists and believers. For some these roles have reversed. They range from the very young to those who have lived for many years. Its members are Mums, Dads, Brothers, Sisters and Grandparents.

What is it that you get for the terrible price of your membership?

In the beginning your "dues" simply bring the most intense pain that is imaginable and one the rest of the world does not know or understand; and that is only the start. The mixture of all your emotions in turmoil and chaos produce in you a very bitter dish which is stewed daily by its own almost toxic ingredients. This club appears to have a strange policy in the way that it treats its members.

As the messages of time and experience are slowly shared by other members

you come to realise that this club has specific knowledge that is not known by non members. It is really quite like "secret members business." You come to understand that those who have not paid their "subs" quite simply do not understand some eternal truths.

The Club endows you with special knowledge and insight that really changes you forever and disallows a return to your former days. The reality is that whilst you have irrevocably changed; those changes are not all negative and you become privy to some very powerful "Secrets".

You come face to face with your eternal reality and thus an understanding of mortality. You can not have life without death. What is inordinately hard to accept is the order in which it visited your family. You learn from this premature act that you truly know the depth of your love where those outside of your club have not had this test. This knowledge empowers you in your relationships with other family members and society.

You can no longer listen or read a story relating to the death of a child and not feel deeply affected. You really know the profound meaning of John Donne's words that, "no Man is an Island." You are part of the same soil and have an insider's understanding.

Your awareness of the pain of Grief is heightened to a level that produces true cognisance and this will help you in time to be a true friend to other new members. You will come to understand the journey that is Grief and the power of healing that your pain brings you. This great enigma takes some time to resolve.

This self same enigma is what creates the unwanted hurt delivered by those who have no membership. Your pain is not understood and therefore it must be likened to some, oft times, minor experience that the speaker relates to your child. A pet canary is totally dissimilar to a human; (Continued on Page 14)

(Continued from Page 13)

however this does not stop the earnest comforter who feels a contribution to your healing is mandatory.

The word love is "sanctified" by the death your child and you are given your special and secret knowledge of this much misused word. You can truly find the depth of your love by the depth of your grief for they are directly related. However the length of your grief is not determined by the length of time with your child. Your attachments vary greatly by vastly different factors and expectations.

Another "Secret" is the law of Perspective. The blinding revelation of what is really important in this world is suddenly made known to you. You see what you did not know as an eternal truth and it is as if you always had this truth. The darkened glass is now your crystal ball from which you scry as you often cry. The importance of a broken finger nail or a lost football game resumes is rightful triviality. You "see" reality. The balance of what really is significant in life is placed in your understanding and frees you from the unnecessary distortion of self importance, self pity and blindsidedness.

This can also have the side effect of making you very impatient with those who have not experienced your enlightenment.

Your level of compassion is greatly enhanced and you come to a real understanding of the word "empathy" as opposed to the far less committed term "sympathy." The Club teaches you the significance and power of feeling with someone as distinct from feeling for someone.

As your membership lengthens your imagination will foster hope; this hope will lead to your healing and recovery. The hope that you do not have to feel that way forever and that grief is *not* a life sentence. It will become apparent from observation that other members are rediscovering happiness, a sense of

purpose, understanding, acceptance and even exhibiting a life full of joy.

The Club will teach you many more secrets; all of which will fashion you into a person of greater substance. Above all it will teach you the awesome power of the human spirit and you will come to realise that there is absolutely nothing on this earth that you can not overcome. The power of the human spirit is almost beyond comprehension and it is the most energising and uplifting piece of reality that the Club bestows.

The question that I ask of those members that have come to discover these secrets is this; "When will you release this information to those that need this knowledge?"

**(Bob is a bereaved Dad whose 11 year old Son Brendan died of Adrenoleukodystrophy in 1999. One of his brothers died four months after Brendan and his marriage finished during the very painful experience of his Son's illness. 1999 was a tough year and he discovered that the help he needed was not readily available.**

**He realised that he had a lot of work to do to resolve his grief and the personal growth that was required for him to be a functional and joyful person again. He undertook a journey that encompassed all those areas of his being that needed to be readdressed and he learnt that love and forgiveness are the most powerful forces involved in Healing.**

**His life long passions and commitments are the resolution of Grief, Paediatric Palliative Care, Dying Well (Holistically), World Indigenous People, Young People and an abiding passion for all to be able to feel the hand of support when life appears to have deserted them.**

**He is on various committees and holds positions that will help him achieve some of these aims. He is always available to anyone who wants to contact him and chat about their personal growth or problems.) To contact Bob:  
Ph: 07 3283 7224 Mob: 0419 683 195  
Email: bobwyborn@bigpond.com**

(Along with his many other roles, Bob is a valued member of the SHQ Management Committee!)

## Email Health Hoaxes and Internet Scams

When it comes to health matters, email hoaxes and internet scams are just as prolific, if not nearly as easy to spot as the Nigerian scams.

We like to think we are awake to these cons, but sometimes they are so well disguised they get by us without our antennae raising as much as a whimper.

We in the Self Help Sector are always looking to improve our health and that of those we care about - especially if it means less medication. We lovingly pass on our new found information to save and protect others.

However, there is a continuous flow of emails about health issues that if not deleted, should at least be authenticated before being forwarded on to perpetuate sometimes dangerous myths and recommendations.

Because they quote the source as being a renowned medical institution, journal etc we tend to take the information on trust - not challenging its authenticity.

For example, how many of us have received, and **believed!!** the one about **"How to survive a heart attack when alone"** or **"Cough CPR."** It recommends a procedure that involves vigorous coughing as a means of surviving a heart attack when alone.

### **Not True- Dangerous!**

Or how about the email **"Cancer Tips from Johns Hopkins Hospital?"** This email contains a long collection of supposed cancer prevention and treatment tips. It also claims that freezing plastic containers or using them in a microwave oven can release cancer-causing dioxins into the container's contents.

In response to the hoaxes, the Johns Hopkins Kimmel Cancer Centre released a statement in March 2007. "An email falsely attributed to Johns Hopkins describing properties of cancer cells and suggesting prevention strategies has begun circulating the Internet. Johns Hopkins did not publish the email, en-

titled 'Cancer Update from Johns Hopkins,' nor do we endorse its contents.

The Internet is flooded with messages warning against freezing water in plastic bottles or cooking with plastics in the microwave oven.

Freezing water does not cause the release of chemicals from plastic bottles. In general, it is best to follow the manufacturer's recommendations when using any plastic products. When cooking with plastics, only use those plastic containers, wraps, bags and utensils for their intended purposes."

### **Top 10 Health Hoaxes doing the rounds now (not in order)**

Antiperspirants cause breast cancer  
Aspartame causes serious disease  
Bananas spread flesh-eating disease  
Cough CPR can save your life  
Fish Contaminated With Deadly 'Zulican Virus " After Tsunami  
Freezing Water In Plastic Bottles Releases Cancer-Causing Dioxin  
Woman Catches Leptospirosis From Unwashed Coke Can  
Lead In Lipstick  
Tampons Contain Asbestos  
Shampoo Causes Cancer

### **Why do people create and send hoax messages?**

Hoaxbusters.com says only the original writer knows, but cites some possibilities:

- to see how far a message would go
- to damage a person's or organization's reputation
- or simply for the perverse pleasure of spreading misinformation.

Whatever the motivation may be behind hoax messages, maintain a healthy dose of skepticism when checking your inbox. When you receive an email that looks like a hoax, the most prudent course of action is to verify the information with a medical professional before acting on or sharing it. Or just hit the delete button. As hoaxbusters.com aptly puts it:

**"When in doubt, don't send it out "**

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## National Prescribing Service Limited

National Prescribing Service Limited (NPS) is an independent, non-profit organisation for Quality Use of Medicines. NPS provides accurate, balanced, evidence-based information and services to help people choose if, when and how to use medicines to improve their health and wellbeing.

[Medicines Update](#) is a quality use of medicines consumer newsletter that provides independent information about medicines that are newly available on the Pharmaceutical Benefits Scheme (PBS) in Australia or have a change in the listing. Medicine Update is designed to be used by consumers who are considering new medications. Medicines Update is published three times per year and consumer input is sought prior to the publication.

The April issue will review Exenatide (Byetta) for type 2 diabetes. NPS is seeking expressions of interest from consumer organisations who are interested in reviewing the April article from a consumer point of view, prior to publication. The review would need to be completed by the 6 March. If you are able to assist or would like to publish this publication on your website please contact Rosanne McMaster via email [rmcmaster@nps.org.au](mailto:rmcmaster@nps.org.au) or phone on 02 8217-8772.

Free consumer resources are available from the NPS website. You can sign up for free consumer publications including: [MedicineTalk](#), [Medicine Update](#), [Community Update](#) and order free consumer resources including fridge magnets for [Medicines Line](#) and the [Adverse Medicine Events Line](#). To find our more please visit [www.nps.org.au/consumers](http://www.nps.org.au/consumers) or call 02 8217 8700.

**"We all are worms, but I do believe I am a glowworm"**

**Winston Churchill  
1874 - 1965  
Prime Minister, United Kingdom**



**Seriously!  
Please Tell Us  
What you Think!**

### **How can the emergent SHQ Website serve your Group?**

As Sue mentioned in her President's address, SHQ is in the process of developing a new website which we hope "will also become an interactive space where groups can contact and support each other, share resources and knowledge and strengthen the sector."

While administered by SHQ, the site is ultimately for the benefit of the Sector.

Please, share your ideas with us - we promise to listen and take notice! This is the ideal time to pass on your ideas to the site developers - groups, organisations, individuals, professionals - all welcome to have a say about any aspect.

What features, functions, resources, etc would be helpful to your group, or to the Sector in general? Please contact Trish at SHQ on Ph: 07 3344 6919 or email [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)

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So you don't become an unknowing participant in the spread of misleading health information, we have listed some websites below that you can go to help verify their authenticity. You will be surprised how many emails are hoaxes!

Hoax Busters (long list of hoax emails)  
[www.hoaxbusters.org](http://www.hoaxbusters.org)

Hoax Slayer [www.hoaxslayer.com](http://www.hoaxslayer.com)

Break the Chain [www.breakthechain.org](http://www.breakthechain.org)

Snopes  
[www.snopes.com/medical/disease/disease.asp](http://www.snopes.com/medical/disease/disease.asp)

Buzzle.com  
[www.buzzle.com/articles/internet-scams/](http://www.buzzle.com/articles/internet-scams/)

There are many more websites devoted to exposing scams. If you know of any really good ones please let SHQ know and we will pass them on next time.



# Mental Health Self Help Support Groups and the Recovery Process

By Diana East

Research clearly confirms that people who experience mental illness can and do recover to live a satisfying, hopeful and contributing life in their community even with the limitations caused by the condition. Recovery is a journey as much as a destination and is different for everyone; it is a distinctly unique and personal journey. It happens when people can live well in the presence or absence of their mental illness and the many losses (eg isolation, poverty, unemployment, discrimination) that may occur as a result. Recovery does not always mean that people will return to full health or retrieve all their losses. But it does mean that people can live well in spite of them.

While no one but the individual consumer can walk the pathway to wellness, it is important that they do not have to walk this path alone. Support and understanding from those around them can be a powerful tool in recovery, especially as living with a mental illness can be so very isolating. Opening up and sharing the journey with other people who care and provide positive support helps the individual to break free from this isolation. Recovery, then, requires an environment where people are not isolated from their communities, where they have access to choices, where they are provided with hope of getting better.

Whilst historically mental health services have failed to use a recovery approach, mental health self-help groups have always provided, and will continue to provide, the type of environment essential for recovery to be assisted. They are very clear examples of the current evolution in thinking which has occurred in the mental health sector and which now emphasises a recovery approach in the design and delivery of a range of serv-

ices and service models. Indeed Queensland Health's policy document, - *"Sharing Responsibility for Recovery: Creating and sustaining recovery oriented systems of care for mental health"* (Queensland Government 2005), identifies peer support and self help as one of the essential components of a recovery-oriented service provision, an acknowledgement that greatly pleases those groups which have long awaited some formal recognition of their vital role.

Mental health support groups, then, bring together groups of people who share a common desire to find a supportive environment to assist their recovery process, ie to overcome or cope with their mental illness or otherwise increase their level of cognitive or emotional wellbeing. Members give each other emotional support and place high value on experiential knowledge in the belief that it provides a special understanding of a situation. In addition to providing support for their members, groups may also be involved in information, education, material aid and social advocacy in their communities.

No two groups are exactly alike. Their make-up and attitudes are influenced and shaped by the group ideology, the environment and the individual people who attend meetings. Their very nature means that they are often very fragile, constantly changing shape, sometimes having a short or very intermittent existence.

There may be a very small number of members who make up the core and who are not able to perform all the necessary operational tasks on their own. Or potential new members may feel a little overcome when they find that the group is self-facilitated and so do not come back any more. A member who is acutely unwell may disrupt group discussions or place extra stress on other group members who may feel powerless to help. Or a group that is driven by strong personalities may be unable to resolve their conflicts and the group implodes.

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For these and other reasons, the group may turn to an 'external' person, eg a related professional or community volunteer who has not had the lived experience of the particular condition, for assistance. Or a group may even be initiated by an external person who sees the need for it.

In addition to the model of mental health support groups outlined above there are also **support networks**. Sometimes a person with a lived experience of a mental illness may try to set up a support group but it never really fully gets going or it goes through a hiatus period due to issues such as the intermittent nature of their particular condition. However support may, to some extent, continue to be available through that individual for quite some time and so a bit of a support network continues to exist amongst a certain group of people. This was the history of attempts in Brisbane over a number of years to establish a Borderline Personality Disorder support group which then became a support network.

Then there are **online self-help groups**, a new trend that appeared during the 1990's. Going on-line has contributed to the self-help group movement in several ways. Firstly, the Internet has made it much easier for people to communicate with each other, especially those who are separated by great distances or have conditions such as Dissociative Identity Disorder for which there is still little understanding and support, and thus easily form groups, nationally and internationally. Secondly, by using search engines, people can easily find out if groups they would like to participate in exist (as long as they have web pages). Many groups use web pages to provide information and informal chat rooms, or facilitated discussion groups for opportunities for peer support.

Whatever the model of peer support, it is the reciprocal nature of the relationships that develop that enhances the

development of new meaning and purpose in the lives of the people involved, thereby encouraging and facilitating recovery and wellness.

Diana East  
Mental Health Project Worker  
Self Help Queensland Inc

## Invitation

# Charcot-Marie-Tooth Association

**Awareness Day Seminar**  
**Saturday 23rd May 2009**

The Charcot-Marie-Tooth Association (CMT) is holding an awareness day seminar in Brisbane for people with Charcot-Marie-Tooth Disease. One of the guest speakers is a researcher from Sydney, Dr Josh Burns, who has been investigating the effects of Vitamin C on children with CMT.

The CMT Assoc is keen to convey that:

**GP's, Health Professionals, Allied Health Workers & interested others are especially welcome.**

**Venue:** Kedron Wavell Services Club  
375 Hamilton Rd  
Chermside, QLD 4032  
Ph: Margaret 07 3886 2492

**Registration essential**



Creating solutions with the community sector

Community Sector Banking (CSB) is a specialist banking service exclusively for not for profits, with the major shareholders being not for profits. It is Australia's first and only such service.

Only available to non profit organisations, the Cash Management Trading Account has a full list of features including a minimum opening balance of \$1.

Ph: 1300 550 603  
URL: [www.csbanking.com.au](http://www.csbanking.com.au)

# Tips for the Helping Professional

## Exploring your role in the world of Self Help

**In self help initiatives, people with a common life challenge share experiences and emotional support. They also exchange practical strategies and information about other supports in the community. Self help is a recognized health promotion strategy that can be complementary to other forms of support. Following are some tips on how professionals can draw upon and contribute to the world of self help.**

### **1. Educate yourself through the experience of self help**

Many self help/mutual aid groups are happy to have visitors who want to find out what takes place during a self help/mutual aid group meeting. Attending a group related to your field of interest and/or relevant to your client/patients' needs, can be an excellent learning experience.

### **2. Make referrals to self help groups**

Self help/mutual aid groups may be an effective supplement or follow up to other forms of treatment and support. Assess whether your client/patient is ready for this experience. A person is not a good candidate for a self help/mutual aid group if they are in active crisis, suicidal, actively using drugs/alcohol or feeling unable to conform to the behavioural expectations of the group. A person may be a better candidate if they are ready and able to both give and receive support with others who share a common concern or issue.

### **3. Prepare your client/patient for the self help/mutual aid group**

You can contribute to the success of your client/patient's experience by making sure they are fully informed about what to expect when they attend a self help/mutual aid group: what will take place, and what will be expected of them. Make sure they understand the difference between a professionally led group and a member-led self help group.

### **4. Share your expertise with a self help/ mutual aid group**

Self help/mutual aid groups rely on outside resources to provide expert advice and/or professional assistance on special topics or concerns related to their group. You can offer your assistance as a guest speaker, consultant, or phone contact.

### **5. Offer practical support to a self help/mutual aid group**

Helping a group find meeting space, providing free use of meeting space, fax, phone or photocopying and/or donating supplies such as paper or coffee are all examples of in-kind help that can really contribute to the success of a group.

### **6. Promote referrals to a self help/ mutual aid group**

If you know the group and feel comfortable, allow members to put up flyers on your office notice board or advertise in your newsletter. Tell your colleagues about the group and how they can make referrals. If you have visited the group, share your experience with your colleagues. On a broader basis, you can find out what kind of referral and resources are available at your local self help centre and refer clients or colleagues there.

### **7. Spread the word about the value of self help/mutual aid**

Share your experiences with your colleagues. Invite representatives of a self help group to speak to your staff team. Have the group members participate in special events like fairs, forums, etc. Introduce your colleagues to members of the group.

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### **8. Help start a new self help/mutual aid group**

Introduce clients/patients who you know have a common concern and/or an interest in starting a new self-help/mutual aid group. Help them organize their first meeting and/or put them in touch with someone else who can support them.

### **9. Help a group make the transition from professionally led to a (member-led) self help/mutual aid group**

In professionally led groups, you can identify opportunities to make the transition to a self-help/mutual aid group and nurture the potential leaders. You can help members learn about selfhelp/mutual aid models and train them on the skills needed to carry out this process.

### **10. Stay connected with local self help centres, organizations and networks**

Local self-help centres and organizations can be an excellent resource to you and your clients/patients. They can: provide information about existing self-help/mutual aid groups, be a source for up to date research about self help/mutual aid, support a new or ongoing self help/mutual aid group with their development issues, or offer skill training opportunities for yourself, your clients/patients, your staff and/or your colleagues.

### **Your client is ready for self help/mutual aid IF...**

- You believe self help has benefits, and you have discussed this with your client
- Your client wants to explore self help
- Your client is not in crisis
- Your client is not too angry, does not exhibit behaviours that would make it difficult for them to "take care" of themselves in a group.
- The group is not actively dealing with issues that may trigger your client to their detriment

- Your client can respect group guidelines and norms about safety, confidentiality, air time, etc
- Your client is seeking other people to talk to about his/her situation

If you are not sure of your role within a group: in the spirit of self help, ask the group!

(Source: Fact Sheet Courtesy of the Ontario Self Help Network (OSHNET), Ontario, CANADA. <http://www.selfhelp.on.ca/oshnet.html>)

**Self Help Qld thanks OSHNET for allowing us to reproduce this excellent resource.**



**Support Group for Mental Health**

**Townsville**

**Hand Up** is a self help support group for anyone dealing with mental health issues such as depression and anxiety. We are a group of people in Townsville, who have experienced depression, anxiety and other mental illnesses who come together to share our experiences, by doing so we find and offer understanding, acceptance and friendship. We have two weekly support groups.

**The HAND UP day group** meets on Tuesdays from 9.30am to 11.30am at Saint Matthews Church Hall, Hermit Park 4812. For more information contact John on 07 4779 2203 or Carol on 07 4725 5755.

**The HAND UP Depression & Anxiety group** meets on Thursdays from 7.00pm to 9.00pm, at the Mental Illness Fellowship, 159 Kings Road, Pimlico. For more information contact Karen on 07 4 7 2 9 0 6 2 9 or email: [karen@handup.org.au](mailto:karen@handup.org.au). This is a new group which started on Jan 29th 2009.

For more information please visit our website [www.handup.org.au](http://www.handup.org.au)

Tea and coffee provided  
**Hand Up Support Groups are FREE!**



AUSTRALIAN  
MITOCHONDRIAL  
DISEASE FOUNDATION

### **Australian Mitochondrial Disease Foundation Launched in 2009!**

At an inaugural information day in Sydney on the 5th March 2009, the AMDF was launched in the presence of over 200 families, carers and world renown medical professionals.

The results of several recent studies were outlined along with other valuable medical and 'healthy life' information.

Dr Doug Lingard explained there were several reasons why Australia needed its own Foundation.

- Funds donated to offshore institutions do not qualify for tax exemption
- Funds donated in the USA benefit American patients instead of Aussie ones
- Australian donations will support Australian mitochondrial research which is as good as any in the world
- The United Mitochondrial Disease Foundation is expecting considerable support from the new Obama initiatives to fund American research

Dr Lingard was at pains to point out that the formation of the Australian Mitochondrial Disease Foundation is not to offer competition to the United Mitochondrial Disease Foundation but to complement it, to expand research into mitochondrial disease, and to keep building research and awareness in Australia. The objectives of the Australian Mitochondrial Disease Foundation are:

- to raise funds for research
- to provide information on diagnosis, treatment, and progress in treatment

- to connect those affected and build support
- to build connections between specialists
- to raise awareness among the general medical profession and the public
- to lobby governments for cheaper drugs and better support facilities
- to provide information on what ancillary services are available, such as Centrelink, social workers, pharmaceuticals, etc.

### **Join Now and go to Work!**

'Join Now and go to Work' is the enthusiastic call of long serving advocates of support for people with Mitochondrial Disease in Australia.

"We need activists: lobby your local member and Minister for Health. It is planned to post ideas and suggested letter templates on the web for people to use.

Link with the hospitals and work towards an information day this year in at least every main capital city. The Sydney team will provide all the support it can and the Foundation will organise a presence at any gathering.

Write letters to the media. Broadcast to all and sundry the existence of the Foundation and the web site (in particular those medical practitioners with whom you are in contact), and information about mitochondrial disease."

Membership forms are available on the website now. For further information:

Phone/Fax: (02) 9488 8058

Mobile: 0466 491 757

Email: [public.officer@amdf.org.au](mailto:public.officer@amdf.org.au)

[www.amdf.org.au](http://www.amdf.org.au)

**Most self help support groups do not receive any funding.**

**Payment of a small membership fee assists with postage, phone costs and general expenses, and is often the only way a group can survive.**

## Incorporated Association vs Company Ltd by Guarantee

There are a few differences between an incorporated association and a company limited by guarantee.

The first major difference is that an incorporated association is organised under state or territory legislation (various Associations Incorporation Acts) and companies fall under federal legislation (The Corporations Act 2001).

Choosing the former structure is ideal if a not-for-profit's activities are confined to one state and there is no trading or activities outside the boundaries of one state or territory. This is because the state or territory legislation governs only areas within state boundaries. This structure is the more common one chosen by not-for-profits.

The latter structure is more suitable for an organisation trading and raising funds for charitable purposes outside the boundaries of one state. If this is the case, it is preferable to register with the Australian Securities Commission as a company limited by guarantee to gain a national system of administration.

In addition, a company limited by guarantee limits the liability of its members to an amount agreed by them (usually a nominal amount) to contribute to the assets of the company in the event it is wound up.

A company limited by guarantee is incorporated as a public company under the Corporations Act. The company is owned by the members and has the legal capacity to sue and be sued.

An incorporated association is a legal body which is incorporated under the Associations Incorporations Act of the relevant state or territory. It is owned by the members and has the legal capacity to sue and be sued. The liability of the members is generally limited to unpaid subscriptions and other charges.

Two good summaries on not-for-profit structures and the law are at the Australian Securities and Investment Commission site: (<http://tinyurl.com/3zupmh>) and the National Employment Services Association website: (<http://tinyurl.com/52x5gn>).

(Source: The Board Builder Newsletter Edition 16 November 2008 A publication of Our Community [www.ourcommunity.com.au](http://www.ourcommunity.com.au))

\*The Board Builder newsletter is exclusively for members of not-for-profit Committees and Boards

### What should be included in the minutes of a board meeting?

The content of your group's board meeting minutes can vary depending on the needs of your individual organisation.

However the basic elements do feature some specific inclusions that most groups should look to incorporate:

- Your organisation's name
- Date and time of the meeting
- Board members in attendance, and apologies
- Existence (or otherwise) of a quorum
- Voting results (or at the minimum, whether a motion passed or failed)
- Names of abstainers and dissenters (if and when requested)
- Reports and documents introduced;
- Future actions or steps to be taken;
- The time the meeting ended;
- The signatures of the secretary and the chair.

Some boards also include details about the motions made and who made them, as well as brief details of any debate.

Try to strike a balance between having enough detail to make sense of the meeting, without having the document cluttered with irrelevant information.

(Source: The Board Builder Newsletter Edition 16 November 2008 A publication of Our Community [www.ourcommunity.com.au](http://www.ourcommunity.com.au))



Does your child, or a child that you know, suffer from a life-threatening medical condition?

The mission of Make-A-Wish® Australia is to grant the Wishes of children aged four to 18 with life-threatening medical conditions to enrich the human experience with hope, strength and joy. Eligible children aged under four are entitled to apply for a "Wish Box" full of age-appropriate toys.

Make-A-Wish® is supported by over 1,000 Volunteers in 56 Volunteer Branches Australia-wide, including 11 Volunteer Branches in Queensland.

To find out more about Make-A-Wish speak to your Social Worker, Medical Specialist, or call Make-A-Wish® directly on 1800 032 260.

[www.makeawish.org.au](http://www.makeawish.org.au)

In information sent to Self Help Queensland from the Make-A-Wish® people, they defined "life-threatening" as "a progressive, degenerative or malignant medical condition that has placed the child's life in jeopardy."

A child's illness does not have to be "terminal" to be considered by Make-A-Wish®. Many of our Wish recipients are fortunate enough to beat or manage their illness and go on to lead happy and healthy lives. The link below attests to the survival of many Wish recipients.

[www.makeawish.org.au/NetCommunity/Page.aspx?pid=310&chid=1](http://www.makeawish.org.au/NetCommunity/Page.aspx?pid=310&chid=1)

**"When people are free to do as they please, they usually imitate each other."**

**Eric Hoffer**  
**Writer and Philosopher**  
**1902 - 1983**



## Companion Card Here Soon for Queenslanders with a Disability

In order to participate in certain activities, some people with a disability are required to pay two admission fees – one for themselves and another for their companion.

Companion Cards will soon to be issued by Disability Services Queensland. People with a disability can register now.

### How it works

When purchasing a ticket to an event or an activity, people with a Companion Card will be issued a second card FREE for their companion.

### Criteria

The card will be issued to people with a disability who can demonstrate that:

- due to the impact of their disability, are unable to participate at most community venues or activities without attendant care support
- the level of support is lifelong or likely to be lifelong

The success of 'Companion Card' will rely on strong support from the QLD business sector. It already operates successfully in VIC, WA, SA and TAS.

To register your interest in a card:

Ph: 13 13 04 (Mon to Fri 8am – 6pm)

Email

[cardservices@smartservice.qld.gov.au](mailto:cardservices@smartservice.qld.gov.au)

Applicants who are deaf or have a hearing or speech impairment may contact the program through the National Relay Service:

TTY users Ph 133 677 - ask for 13 13 04  
Speak and Listen (speech-to-speech relay) users phone 1300 555 727 then ask for 13 13 04

Internet relay users connect to the National Relay Service for details and then ask for 13 13 04



## Brisbane to Host National Albinism Conference

**12th - 13th Sept 2009**

Albinism is a rare genetic condition. People with albinism have markedly lightened hair, skin & eyes when compared to others from the same familial ancestry. They often have vision impairment within the legally blind range and suffer from sunburn and glare.

The Albinism Fellowship of Australia (AFA) is one of the largest albinism support networks in this region of the world. It is holding its 3rd Australian Conference in Brisbane, focusing on encouraging more professionals to attend as well as individuals and families.

AFA wants to maximise the opportunity that this gathering provides for professionals (& students) to interact with people who have albinism and learn about it, hopefully to improve the services they will then go on to offer to the general community in the future.

There is no specific 'albinism' based conference that allows researchers to present their work and network with a view to collaboration. AFA is working towards encouraging these interactions.

### **Can your group possibly help?**

The AFA is a fledgling not for profit organisation, relying solely on membership fees and the good will of professionals to donate their time. The group would greatly appreciate being able to 'borrow' or hire the following equipment at a reasonable price.

- Two data projectors
- Cordless microphone radio handheld
- Display Boards/ Room Dividers (Free Standing).

For further information please contact:  
Helene Johanson Ph: (07) 3288 1511  
Email: [h.johanson@imb.uq.edu.au](mailto:h.johanson@imb.uq.edu.au)  
URL: [www.albinismaustralia.org](http://www.albinismaustralia.org)

## Two Invitations

from

## *friends* of the National Rural Health Alliance

### ***friends* Photo & Poetry Competition**

In conjunction with the 10th National Rural Health Conference, *friends* of the Alliance is holding an amateur photography and poetry competition to highlight life in rural and remote Australia.

*friends* are invited to enter by submitting entries about rural people at work or play; capturing the unique feel of life in rural/remote Australia; vibrant rural communities; the advantages of living outside a capital city; description of the beauty and reality of life in rural/remote Australia; healthy rural lifestyles; or any rural or remote theme. First prize in each category will be \$500.

To apply for a Photographic and Poetry Competition 2009 Entry Form:

Email: [friends@ruralhealth.org.au](mailto:friends@ruralhealth.org.au)

**Entries close Friday 3 April 2009**

-oOo-

### ***friends* Unsung Hero Award**

There are many people who work tirelessly for their rural or remote communities and contribute greatly on issues about which they are passionate. Rural and remote communities are much richer for their contribution, yet we often don't know who they are. They might be the quiet achiever, the volunteer, or the worker who constantly goes above and beyond their normal role to contribute to their community.

The purpose of the *friends* Unsung Hero Award is to recognise these grassroots people who have made a significant contribution to the health of their remote, Indigenous or rural community.

To apply for an Unsung Hero Award 2009 Entry Form:

Email: [friends@ruralhealth.org.au](mailto:friends@ruralhealth.org.au)

**Nominations close 17 April 2009**



# Silver Memories

**A radio service addressing issues of isolation, boredom and loneliness among older people through broadcasting music, serials and other programs relevant to the period when they grew up – the 1920s to the 1950s.**

In 2007, the Australasian Centre on Ageing at the University of Queensland, in collaboration with radio 4MBS, a Brisbane community radio station, was awarded a grant from the JO & JR Wicking trust to evaluate a unique 24 hour a day radio program – **Silver Memories**.

**Silver Memories** is a radio service designed to address the needs of socially and emotionally isolated older Australians living in the community as well as those living in Residential Care facilities. It is a dedicated radio service with the specific aim of addressing issues of isolation, boredom and loneliness among older people through broadcasting music, serials and other programs relevant to the period when they grew up – the 1920s to the 1950s. **Silver Memories** is available via a small, portable radio receiver tuned to the **Silver Memories** frequency.

**We are currently looking for people aged 60 years and older to participate in a 3 month evaluation of the program.**

Feedback from listeners has been very positive so far and listeners rate the quality and friendliness of **Silver Memories** highly and really enjoy the old-time music. We are in the process of conducting an evaluation of **Silver Memories** to ascertain listeners' opinions regarding the program with a view to improving its quality and appeal, prior to making the program more widely available.

We are currently looking for people aged 60 years and older to participate in a 3 month evaluation of the program. Participants will receive a **FREE** radio receiver for the duration of the trial and we ask that you listen to **Silver Memories** regularly and tell us what you think of the program.

**Please contact:**

**Linda Moran, Project Officer  
The Australasian Centre on Ageing,  
The University of Queensland  
Ph: 3346 7577  
l.moran1@uq.edu.au**

If you do not wish to participate in the evaluation but would like to receive **Silver Memories**, radio receivers can also be purchased for \$44 by contacting Peter McCahon, Promotions, Marketing and Sponsorship Manager, radio 4MBS; Ph: 3847 1717.

Alternatively, **Silver Memories** can also be accessed via the internet. The web address is:

<http://www.4mbsclassicfm.com.au/>

## Rockhampton ME/CFS/FM Self Help Group

The group meets from 11am - 12.30pm on the 3rd Thursday of each month at Maddy's on the Mall, East Street. Families and carers welcome.

For further information please contact:  
Ph: 0403 391 388

**(Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome/ Fibromyalgia)**



## Diary Dates

### **2nd & 3rd April 2009: Shared Visions Disability Conference 2009**

Open to anyone with a disability, people with a mental illness, their families and carers, service providers, government and corporate partners.

**Website:** [www.disability.qld.gov.au](http://www.disability.qld.gov.au)

**Venue:** Brisbane (BECC)

### **1st to 4th May 2009: Manshine 2009 Men's Gathering "Create Your Own Possibilities" to grow and develop as a man - presented by Men's Health and Wellbeing Assoc Qld**

**Phone:** 0403 880 665

**Email:** [manshine@mhwaq.org.au](mailto:manshine@mhwaq.org.au)

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

**Venue:** Ewen Maddock Dam, near Landsborough Qld

### **11th to 13th May 2009: Connecting Up 2009 Conference—The Online Future of Nonprofits....Are we There Yet?** For nonprofits to learn to be in control of how technology is used.

**Email:** [CU09@connectingup.org](mailto:CU09@connectingup.org)

**Web:** [www.connectingup.org](http://www.connectingup.org)

**Venue:** Brighton Novotel, SYDNEY NSW

### **13th to 15th May 2009: 15th UICC: International Breast Cancer Support Conference "Reach to Recovery"**

**URL:** [www.reachtorecover2009.org](http://www.reachtorecover2009.org)

**Venue:** Brisbane

### **17th to 20th May 2009: 10th Biennial National Rural Health Conference** - seeking to identify how people in rural and remote areas are coping with the threats and opportunities they face.

**Phone:** 02 6285 4660

**Email:** [conference@ruralhealth.org.au](mailto:conference@ruralhealth.org.au)

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

**Venue:** Cairns

**"Beer is living proof that God loves us and wants us to be happy"**

**Benjamin Franklin**  
**American Scientist, Inventor,**  
**Statesman, Printer, Philosopher**  
**1706 - 1790**

White  
Wreath  
Day



### **In Remembrance of all Victims of Suicide**

**Yearly 29 May**

Commemoration/Remembrance Day remembering loved ones, friends, work colleagues etc who have taken their lives by tragic means. Thousands of White Wreaths, Flowers, Photographs, Poems etc are laid on their behalf.

Suicide is shockingly common, affecting almost every Australian family directly or indirectly. It can strike a child, a brother, a grandparent or a co-worker. It can strike someone of any background. It can strike at any stage of life, from childhood to old age. No community is unaffected, no school or workplace untouched.

Main Service commencing at 12.30 - 1.30pm. Post Office Square Queen St Brisbane. All welcome to lay photos, flowers, white wreaths, poems etc

For More Details Contact:- Fanita Clark  
1300 766 177 Mobile 0410 526 562 or  
visit website [www.whitewreath.com](http://www.whitewreath.com)

### **25th to 27th May 2009: Australian Winter School "Integration: Research - Policy - Practice"**

**URL:** [www.winterschool.info](http://www.winterschool.info)

**Venue:** Brisbane

### **25th & 26th June 2009: Qld Alliance 2009 Conference: "Altering States - Reforming the System"**. Conference 2007 envisioned how the Mental Health System should look in 2020. Conference 2009 will discuss how to achieve it.

**URL:** [www.qldalliance.conorg.com.au](http://www.qldalliance.conorg.com.au)

**Venue:** Sofitel Hotel, Brisbane

**"You can discover what your enemy fears most by observing the means he uses to frighten you."**

**Eric Hoffer**  
**Writer and Philosopher**  
**1902 - 1983**