



## June Quarter Issue 2. 2008



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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

### From the President

**Sue Smyllie**

Hello all

There is a lot of news to tell so I'll just dive right in. SHQ has recently been involved in a consultative workshop initiated by Queensland Health, that is working to establish Health Consumers Queensland's (HCQ) Ministerial Consumer Advisory Committee, by the middle of 2008.

HCQ's Secretariat is located in the Director-General's Office and comprises a Director, Paige Armstrong; two Senior Policy Officers, Russell Flynn and Carolyn McDiarmid; and an Executive Support Officer, Sue Finn.

The establishment of this body is an attempt to deliver the recommendations for a Queensland health consumer body made by Mr Peter Forster in his *Queensland Health System Review Report*.

QH envisages that HCQ will provide high level strategic advice to the Minister for Health as well as building the capacity of health consumers state-wide to engage with government on health related matters.

A two stage implementation process was put forward. Stage One is due to be completed by mid 2008 with the appointment of Ministerial Advisory Com-

mittee members following the development of terms of reference and a public call for expressions of interest for committee membership. At Stage Two the Ministerial Consumer Advisory Committee is to develop its strategic plan and priorities, focussing upon the areas of consumer engagement, capacity building as well as developing a framework to guide advocacy support.

The consultative workshop, designed to develop a set of terms of reference for the HCQ, was held on 15<sup>th</sup>. I attended on SHQ's behalf. There were about 40 people there with some from Queensland Health, some from health and disability consumer groups and some from other stakeholder organisations such as the Public Advocate, the Office of the Adult Guardian and Health Community Councils. The outcome of that meeting was the development of some draft terms of reference (see below).

As I understand it, expressions of interest to become a member of HCQ will be advertised in the near future. With membership limited, the effort of submitting an expression of interest must be weighed with the unlikelihood of success. We at SHQ are still discussing our response to this process and would be very interested to hear from our constituents as to the stance you would like us to take.

Our concern with the 'Health Consumers  
(Continued on Page 3)

## Self Help Queensland Management Committee Members

President	Sue Smyllie
Secretary	Thea Biesheuvell
Treasurer	Kathleen Zarubin
Members	Diana East Sharon Neill 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

### 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

**URL:** www.selfhelpqld.org.au

### Self Help Leaders Online Social Network

**URL:** www.selfhelpleaders.ning.com

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

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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### You're Never too old to Register!

#### Organ Donation Australia

It's easy - you can save a life!  
Don't forget to talk with your family!

[www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au)

The only national register for Organ/  
Tissue Donation in Australia

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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.

(Continued from Page 1)

Queensland' model proposed by QH is the ensuing difficulties and limitations that will accrue to this organisation as it sits within a public sector. The committee felt that it is important that Queensland has a truly grass roots consumer organisation that is actively supported across the board, transparently accountable to the consumers of Queensland, inclusive in its design and participation and independent of government. While lots of discussion ensued about the best way forward with the limitations with which we were presented, we should not forget that as it stands, HCQ cannot be an independent consumer organisation within this model. That is not to say that it won't serve a useful and valuable function.

I believe that if the consumer movement in Queensland really wants an independent advocacy and capacity building organisation it should be formed from the clamour at ground level. Rather than just picking holes in the work of the Public Sector...if we want it we should build it. SHQ would be very happy to host a meeting to discuss such a possibility so if you are interested please contact me and I'll get the ball rolling. For further information about Health Consumers Qld, please contact the Secretariat on 32340611 or [www.health.qld.gov.au/consumerhlth/](http://www.health.qld.gov.au/consumerhlth/)

Other important news is that SHQ is to receive \$300,000 from the Department of Communities, Directorate of Mental Health for use in the 2008-10 financial years. The funds are to be used to support Mental Health Self Help Groups in Queensland. At present the service agreement is yet to be finalised although we have had a very encouraging discussion with directorate staff on the principles which will guide the use of the funds. SHQ's view is that these principles should include:

- 'Do no harm' to guide all decisions
- The aim of the program will be to build the capacity of the Mental Health Self Help Sector in Qld - capacity includes knowledge and skill

transfer, leadership, networking, problem solving and infrastructure.

- Transparency to be non-negotiable
- The Mental Health Self Help Sector will be directly and equitably involved in decision making for the program from the beginning
- SHQ will be resourced to mentor the program

Other principles will be developed by the Mental Health Self Help Sector and the funder. SHQ is well aware that all self help groups deliver mental health outcomes. However due to the funding source there will be some limitation as to which groups will be eligible for this funding. It is our hope at SHQ that if we do this well and evaluate comprehensively, we will be in a position to make a strong argument to other funding bodies to support a similar program across the self help sector.

When we have signed on the bottom line, SHQ will be issuing invitations across the sector for involvement in program development and implementation. Please let us know if you wish to be included.

I also wanted to say a big thank you to all those who contributed and participated so enthusiastically in our recent leadership workshop facilitated by Liz Mellish. We had a great day and the feedback indicated an impressive amount of learning and 'ahah' moments. Thanks also to Jeannie, Bernadette and Mike who have offered to take the lead in developing a website, learning to set up on-line support groups and strategic planning respectively. The next one is in November and is not limited to only those who came this time. We had over 50 indicate their interest this time. I think about 45 turned up...so reserve your place!

Please feel free to email me at any time if you have an opinion on sector development, the mental Health program or anything else. [ssmylie@bigpond.net.au](mailto:ssmylie@bigpond.net.au)

Till next time  
Sue

## New Self Help Leaders Online Social Network Up and Running!

Facilitating a self help or support group? Feeling a bit alone or isolated in the role? Want to share knowledge, or just sound out other leaders?

As a consequence of a Leadership Day held by Self Help Queensland on 8th May 2008, participants expressed a desire for an online support network. Thanks to the talents of Jeannie May from the "Living Sphere" support group, we now have a wonderful site so it's all systems go for anyone who would like to participate.

Here's the link to the site: <http://www.selfhelpleaders.ning.com> To join and start participating, click on the link above or copy and paste it into your browser.

Click on the 'Sign Up' link on the right and complete the form. Note: If you do not wish your full name to appear online, just use your first name (or even a nickname of you prefer).

You may complete as much or as little of your Profile questions as you wish - your answers will appear online on your profile page. You may change your profile answers at any time by clicking on the 'My Settings' link.

### Features of the site

**My Page** - This is the page where your profile questions are displayed. You can change the look of your page by clicking on the 'Theme' link beneath your profile image. Note: Your profile image may be a photo of yourself, your support group logo, or simply any image you like.

**Members** - This page lists all the group members with links to their profile pages.

**Events** - You can add meetings, workshops, social functions, etc to the Event calendar. You can even choose to accept online RSVPs if you wish. Note: Events require an image be uploaded to repre-

sent them - this could be your logo, or any other image your wish to use (as long as it is not copyright).

**Forum** - You can post (write and submit) questions on the forum and discuss any topic you wish. Note: This is a public forum - if you have any topic to discuss which is confidential or sensitive in any way, please use the 'Private' group section.

**Groups** - Subgroups can be added to the site for specific purposes - currently the only subgroup is a 'Private' group for confidential discussions.

**Invite** - From this page you can enter colleagues and friends email addresses and invite them to join the network direct from the site.

**Photos** - You can upload photos if you wish and view other members uploaded photos.

**Videos** - You can add video to the site here and view other members videos.

**Communicating with other members**  
You can 'Comment' directly on other members pages by simply entering a message. Note: Comments are publicly visible to everyone. Note: Comments are publicly visible to everyone.

You can send 'Private Messages' via the site (like email) but only to your 'friends' on the site. So, you need to request that a member accept you as a friend before you can send them a private message - to do this, click on the 'Add as friend' link beneath their profile image. To view private messages, click on the small envelope icon at the top left of the page.

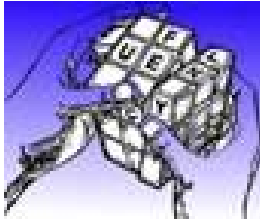
### Questions

Please post your queries directly on the site, or email [jeanniemay@gmail.com](mailto:jeanniemay@gmail.com)

**"Don't tell people how to do things, tell them what to do and let them surprise you with their ingenuity."**

**- George S. Patton (1885 - 1945)**





## Queensland Speak Easy Association

### Do you Stutter or Do you Know Somebody Who Does?

The Queensland Speak Easy Association is a self help group of stutterers and ex-stutterers who assist each other to stay fluent. This assistance is especially important after some form of treatment. Treatment is usually a speech intensive course that teaches the stutterer to speak fluently. Once these skills are learnt and practiced they must be maintained after the course. This is where the Speak Easy Association comes in to help to maintain these new skills. The Association offers an avenue of support and experience for all, whether they are children or adults.

The two elements of self-help and mutual caring are interwoven into the activities of our Association; comprising social activities, live theatre, debates, weekend camps, workshops and conventions, as well as the normal weekly meetings for speech maintenance in regional groups throughout Australia.

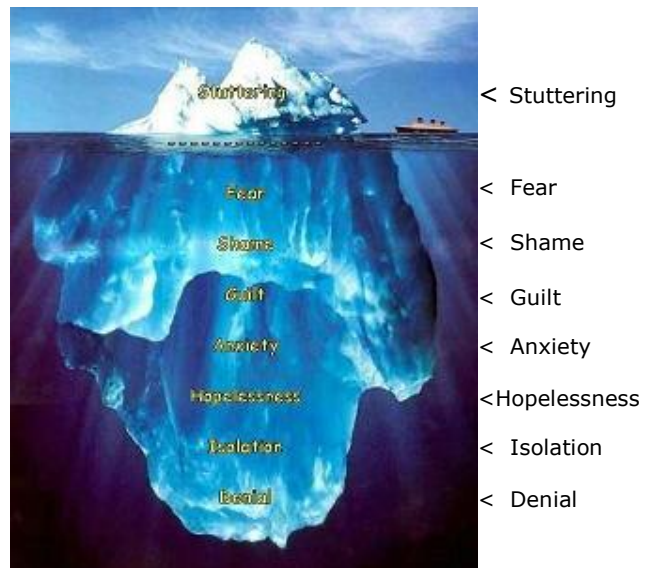
Through these means, stutterers are encouraged to develop not only the ability, but also the confidence in that ability, to cope with all of life's speaking situations. This assistance is especially important after treatment. Once these new speaking skills are learnt and practiced they must be maintained. The Speak Easy Association offers help to maintain these new skills on an ongoing basis.

Group meetings afford members an opportunity to practice fluency techniques and develop self confidence through role playing exercises. In Queensland groups meet weekly at:

- Brisbane City
- Gold Coast
- Darling Downs area

In their organisational brochure, Queensland Speak Easy Association features an excellent 'Iceberg Analogy of Stuttering' developed by Russ Hicks. Hicks says that "while no analogy is perfect, the iceberg analogy of stuttering is quite useful for visualizing a lot of aspects of stuttering".

### The Iceberg Analogy of Stuttering



[www.russhicks.com/iceberg](http://www.russhicks.com/iceberg)

Photograph©Ralph A. Clevenger

### Smooth Speech - What is it?

Any Speech Pathologists in Australia use Smooth Speech treatment for teenagers and adults. The Speech Pathologist teaches you how to:

- Change the way you speak
- Start words gently and connect them smoothly
- Pause at the right places
- Practise your new techniques in treatment sessions
- Practise your new techniques between sessions and gain confidence

For further information please contact:  
Queensland Speak Easy Association Inc  
PO Box 5342  
WEST END QLD 4101  
Phone: 07 3876 9915  
[www.qld.speakeasy.org.au](http://www.qld.speakeasy.org.au)

## 'Breaking Free'

- Adult Survivors of Child Abuse

We are several groups of people in Queensland who are helping each other to survive abuse meted out to us as children. There are many of us, but few of us receive the help and support we need and deserve.

Included is any type of abuse which effects a child either physically or emotionally, e.g. neglect, harsh or unjust punishment, repeated criticisms, constant ridicule, verbal abuse, physical abuse, sexual or ritual abuse.

All of the above constitutes an abuse of power over essentially powerless children and is a total denial of trust. The resulting harm can include trauma, emotional deprivation, as well as serious impairment of a child's cognitive, intellectual and social development.

To reclaim our lives we have a long hard road to travel, and to have support from other survivors, we can progress a little faster and easier.

The journey, ideally, begins with the help of trained professionals who are experienced in this field. Along with that help, to be able to talk with other survivors, and realize the many things we have in common, is amazing and very liberating.

We don't and can't give professional advice. We can talk, listen and learn from each other. We are all survivors.

Feel free to join us in our journeys with safety, confidentiality, and respect. Groups are open to anyone who has suffered any form of childhood abuse.

Breaking Free (Bardon) meets fortnightly from 10am to 12noon at "The Meeting Place", Communify Community Centre, 180 Jubilee Terrace, Bardon. Ph: (07) 3510 2700 Men and women welcome. To attend a group, or for further information please contact the convenor, Amie on: Mob: 0406 164 840 Email: amie8@live.com.au

## Support Group for Guys - to 'Getaway'

There is a Men's Recreational Group in the Brisbane North and Pine Rivers area which provides an opportunity for male carers to come together and enjoy a range of activities on a regular basis.

The group is directed by the participants based on what the group collectively decides. There is a worker who organises the activities and meetings and is there to support carers and provide assistance in an any capacity.

A carer is a family or community member who provides care to someone in their own home who may be frail aged or have dementia, have a disability, a mental health condition, a chronic illness or who have palliative care needs.

Having "timeout" from caring provides the opportunity to socialise, relax, have fun and talk to other men in a similar position. Home based respite can be arranged to allow men to attend the monthly meetings.

For further information, or to join the group, please contact the Commonwealth Respite and Carelink Centre on Freecall™ 1800 059 059

**\*Editor's Note:** We were going to list the suburbs within the Brisbane North and Pine Rivers area but there are 60 of them! They cover a broad spread - including Albany Creek, Petrie, Dayboro, Pinkenba, Spring Hill, New Farm, Toowong, Brookfield, and places in between.



**Can you guess what this is?**

(Answer on Page 20)

# Genetic Matters

by Kim Summers PhD

## The stem cell debate: dreams and realities

One of the most heated areas for discussion these days is stem cells and how they could be used to save or improve lives. Adult or embryonic? Specialised or multi-purpose? From cultured cells or early stage embryos? Even in the scientific community opinions are divided, with dedicated groups of researchers attempting to find the optimal solution which solves the health problems without breaching ethical guidelines.

Stem cells can be defined as cells which have the capacity to develop into a range of different cell types. In contrast, most cells in the body have very specialised functions and probably can't change their role. These include muscle cells, red and white blood cells, nerves and so on. But in an adult, for every cell type there is a stem cell capable of becoming that cell type under the right stimulus, or a related type if the trigger is slightly different. This is how we replace cells that die, are damaged, or lost.

When an egg and a sperm come together at fertilisation, the resulting single cell has genetic material from both parents. It is a simple cell type, capable of becoming any cell necessary to create and sustain the pregnancy and the developing organism. Very soon after fertilisation, this single cell begins to divide, and then divides again and again. Within a few days (in humans) there are 8 identical cells, each one thought to be capable of creating a pregnancy.

Identical twins are proof of this: they arise when the early embryo splits and the resulting groups of cells both develop into separate individuals. These cells are called totipotent stem cells, because they are totally potent and can

make any cell needed to produce an individual, including all the cells of the placenta and amniotic fluid which are not part of the baby.

After a few days, however, something happens to the cells and they begin to specialise. At around 100 cells, the developing offspring becomes a hollow ball of cells called a blastocyst. Most of the sphere will go on to produce the tissues that sustain the pregnancy; a small cluster of cells called the inner cell mass will develop into the baby.

The cells of the inner cell mass are pluripotent stem cells: they can develop into any cell type from fetus to adult, but they can't make placenta and the other extraembryonic tissues. The pluripotent stem cells of the inner cell mass are the embryonic stem cells which many researchers believe could be used to create new tissues and organs, or replace dead cells in people with a range of diseases.

As the pregnancy progresses, the inner cell mass begins to take on the shape and structure of the early fetus. Cells specialise into different functions. The baby has blood, muscle, nerves, all developing from the stem cells. As this differentiation takes place, some stem cells also become specialised, so that they can only generate cells of a particular type. All blood cells arise from a single stem cell type which can only give rise to blood cells. These semi-specialised multipotent stem cells are called adult stem cells (even though they are first present in the fetus) and there are a number of different lineages in the body, each giving rise to cells of related functions.

During development of the fetus, a small cluster of cells remains pluripotent. These are the embryonic germ cells, cells destined to form the germ line: eggs and sperm. These cells have the same capacity as the inner cell mass cells to develop into any adult tissue type.

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So the stem cell debate has two parts. The first one is whether it is going to be necessary to use pluripotent stem cells as the source of differentiated cells for therapy, and the second is whether there are ethical sources of these cells.

First to the adult vs embryonic stem cell question. Although it is likely that embryonic stem cells will be more versatile in creating a range of cell types, it is possible that there are adult stem cells for every adult cell type. For example, for many years it was thought that nerve cells could not be replaced because there were no nerve stem cells. Recent research has shown that this is not true: adults do carry a limited number of nerve stem cells. If methods of activating these stem cells and encouraging them to divide and differentiate can be developed, this holds great hope for people with neurological damage from disease or accident.

Another controversial area is whether stem cells are in fact as limited in their range as previously thought. Some studies suggest that stem cells can transdifferentiate into related cell types which they would not normally produce, or dedifferentiate back into a less specialised form. If reliable techniques can be used to cause stem cells to cross their preset cell type barriers, it may not be necessary to isolate stem cells for every tissue type.

In adults, stem cells make up a very small proportion of the total cells, and a lot of research is concentrating on finding ways to identify and purify adult stem cells of different families, so that they can be grown and specialised in a test tube or transplanted into a diseased individual. So there is a strong focus on developing technologies which will allow the use of adult stem cells, preferably the sick individual's own, to treat the disease.

Using embryonic stem cells (or embryonic germ cells) avoids most of these problems. It is thought that they can be

pushed into any of the specialisations (although techniques for doing this are not perfected yet), so there is no need to isolate the semi-specialised precursor cells. They can be grown in a test tube for many generations. There are currently a number of cell lines of human embryonic stem cells which are maintained in laboratories all over the world.

The problem, of course, is that these cells are genetically unique. They were taken from embryos or fetuses which arose from a fertilisation process which merged the genetic material from egg and sperm. So any specialised cells developed from existing embryonic stem cell lines are likely to be rejected when used to replace damaged cells in a recipient, just as transplanted organs are rejected. And that is the cause of the second heated debate: the source of the embryonic stem cells.

Current cell lines were created from donated embryos which were not used for implantation after in vitro fertilisation. Since many embryos are created in this process, most are not required and some couples are happy to donate their unneeded embryos to further research in this area. But to get embryonic stem cells from the inner cell mass, the embryo must be destroyed. Clearly this is controversial, and the debate is whether the embryo at this stage is "alive", "a person". If not used for research or to develop treatment, these embryos are usually destroyed by the IVF laboratory, so the outcome is the same.

Embryonic germ cells have been derived from aborted fetuses. This is also controversial, both because of individual ethical issues with abortion, and from the use of material gained in this way for research and potential treatment.

But the biggest disadvantage of working with these existing embryonic stem cell lines is that they are genetically unique. With the development of mammalian cloning and the recent disclosure that the first human clones had been created, one option is to create embryos

(Continued on Page 9)



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cloned from the adult cells of the person who needs treatment. The clones would be allowed to develop to the stage when the inner cell mass had formed, and then the cells would be removed, allowed to divide in a test tube, and then differentiated into cells of the type needed for treatment. These cells would be genetically identical to the donor (the sick person) and so would not be rejected when introduced back into the body. This is the dream of stem cell biology: to have a source of compatible material which can replace diseased cells, tissues or organs as needed.

Of course the ethical issues raised by this possibility are extensive. Is it ethical to create an embryo just to destroy it? Is creating embryos by cloning for this purpose leading the way to cloning of the whole individual? If adult stem cells could be identified, purified and differentiated to do the same job, the use of embryos would be avoided. So the debate rages on, between those who believe the only solution is embryonic stem cells and those who think they can work with adult stem cells. Many laboratories around the world are trying to solve these problems and allow the dream of stem cell treatment to become the reality.

**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. She is a past member of the SHQ management committee.**

**\*Editor's note: Kim has kindly agreed to continue writing articles for the SHQ Newsletter - we feel quite important now having our own foreign correspondent!**



**Would you like to catch up on past SHQ newsletters?**

Quarterly Newsletters dating back to March 2005 can be viewed or downloaded free from the Self Help Queensland website at [www.selfhelpqld.org.au](http://www.selfhelpqld.org.au)

## A Big Thank You!

Thank you to everyone who responded to the request in our last newsletter to receive future editions by email.

As we explained, the cost to SHQ, and very importantly to the environment, had become too great.



We may not know your current email address, so please contact us to receive the newsletter electronically in future.

Of course there will be some people who need to receive the newsletter by post for a variety of reasons, and we are still happy to accommodate you if you please just let us know this is what you would like. Otherwise, unfortunately, you will probably disappear from the list.

Also, if you no longer wish to receive the newsletter we would appreciate hearing from you on 3344 6919 or [self-help@gil.com.au](mailto:self-help@gil.com.au)

## Tried Wheelchair Dancing Yet?



### Check it Out and Join in the Fun!

The Scenic Rim Rollers hold regular wheelchair dance mornings on 1st and 3rd Fridays of each month at All Saints Hall, John Street, Boonah from 10am-12noon. There is a small charge of \$2.00 to help with morning tea.

Everyone is very welcome to come and have a look at what wheelchair dance is all about and join in the fun.

Need more information???? Contact Natalie on 5463 8285 or Mavis 5463 8191

**"Washington is a place where good ideas go to die."**

**Barack Obama 1961.....**

**- US presidential hopeful**



## Newsletter Feedback

**Self Help Queensland regularly asks for, and occasionally receives, feedback about our newsletter. The following is one such response. Please help by sending us your views about particular articles, or perhaps some constructive criticism about the newsletter in general.**

Kristina kindly responded to our request, sending us a guide for the formatting of newsletters to assist people who have learning difficulties or who may have a visual impairment. We are thankful for Kristina's guide, and you may notice we have made changes to our newsletter as a result.

We have also published the guide below for the benefit of others who may want to make their newsletter accessible.

### Appropriate Formatting Guide

#### Design

- Keep your colour scheme simple and well balanced – keep tables and graphs simple
- Aim to keep the appearance consistent
- Avoid over use of fancy borders, it detracts from the focus of your article/newsletter/power point contents
- Clear large headings – borders/frames are good (frames around article/text contents should be lighter than font colour so not to distract)
- Do not cramp story/article together, rule of thumb 4-5 sentences per paragraph
- Use dot points to list information – 4-6 bullets
- Don't underline

#### Font Size

- Use fonts without the bits on the end of the letters. They are easier to read in hard copies, on-screen, online and from distances

- Font size should never be smaller than 11, and 12 and 14 font sizes are best.

#### Easier to read fonts:

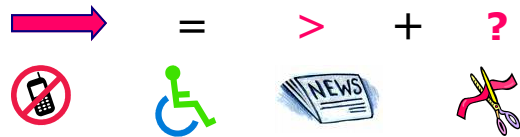
Veranda, Arial, Mangal, Tunga

#### Difficult to read fonts:

Times New Roman, Century Gothic, Garamond, Comic Sans

#### Images

Pictures and symbols are important i.e



#### Content

- Keep abbreviations and acronyms to a minimum. Always write the full name out the first time you use them.
- Include information source details clearly at end of document/story etc.

#### Source:

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

<http://www.speldvic.org.au/AboutLD.html>

[http://www.ncddr.org/products/researchexchange/v08n03/2\\_materials.html](http://www.ncddr.org/products/researchexchange/v08n03/2_materials.html)

[http://www.ncddr.org/products/researchexchange/v08n03/2\\_materials.html](http://www.ncddr.org/products/researchexchange/v08n03/2_materials.html)

-oOo-

#### "You print good stuff"

**Elga Kenins**  
**Australian Baltic Friendship Society**  
**- about the Self Help Queensland newsletter. April 2008**

#### Does your group still exist?

Please let us know so we can change our records. Referrals to groups that have closed can have destructive effects, causing frustration and disappointment for callers. If you no longer require the newsletter we would also appreciate knowing - on Ph: 07 3344 6919 or email: selfhelp@gil.com.au



## Have you heard of Tuberous Sclerosis?

**Thank you to the Australasian Tuberous Sclerosis Society (ATSS) for providing the following information for our readers, and for their support of others in the community who are affected by this condition.**

Tuberous Sclerosis Complex (TSC) is a genetic disorder that affects people in different ways. It is a complex disorder, affecting individuals with different degrees of severity. Some people with the disorder are totally unaffected and may go through life without the diagnosis ever having been made; others may be affected quite severely.

Tuberous Sclerosis Complex (often referred to simply as Tuberous Sclerosis) derives its name from the tuber-like growths on the brain, which calcify with age and become hard or 'sclerotic'. Abnormal TSC growths can affect almost any organ of the body, including the skin, eyes, heart, kidneys and lungs.

### **Symptoms of Tuberous Sclerosis**

There are a number of different signs of TSC, although not all are present in an affected individual. Some of the main signs are:

#### **Skin**

The earliest sign may be white skin patches, especially on the limbs and body, which can sometimes be seen from birth. They do not cause any problems and often disappear later in life. As a child grows older other skin signs may develop, including a characteristic facial rash across the nose and cheeks.

#### **Developmental delay**

Approximately 50% of people with TSC show signs of learning difficulty, although the degree varies markedly.

#### **Epilepsy**

Because the brain may have some ab-

normal TSC cells, there is a tendency for children with TSC to develop various forms of epileptic seizures.

#### **Behaviour**

Sometimes people with TSC may show autistic and hyperactive tendencies or attention problems.

#### **How common is Tuberous Sclerosis?**

Tuberous Sclerosis is more common than generally realised. It is thought to affect approximately 1 in 6,000 people.

#### **What is the Outlook?**

The effects of TSC vary greatly. Over 50% of people with TSC are intellectually normal and lead perfectly normal lives, but others have a range of symptoms. The life expectancy for the great majority of people with TSC is normal, even for those with severe learning difficulties and epilepsy.

#### **What is the treatment? Is there a cure?**

Unfortunately there is no cure for TSC, but there is treatment available for a number of symptoms.

#### **Could other family members or future children be at risk?**

In about 70% of cases TSC has come as a 'bolt from the blue', the result of a new genetic mutation, and no-one else in the family is affected. Genetic counselling is recommended for all families affected by TSC.

#### **About ATSS**

ATSS is run entirely by volunteers, many of whom deal with TSC on a daily basis.

The aims of The Australasian Tuberous Sclerosis Society are:

- Supporting people with TSC and their families or carers.
- Providing education, publicity and information to promote an understanding and awareness of the problems encountered by the condition.
- Support research into the treatment and management of TSC.

(Continued on Page 12)

(Continued from Page 11)

### **Information and Support**

ATSS provides accurate and current information about Tuberous Sclerosis. A 1300 telephone service is available, as well as various brochures regarding aspects of TSC.

### **Journal**

*Reach Out* is published twice a year and offers an opportunity for members to share news, information, experiences and opinions. It contains updates on research, treatment and management of TSC.

### **Website**

The ATSS website provides information about Tuberous Sclerosis and the Australasian Tuberous Sclerosis Society. Links to other organisations which offer support and information are provided.

### **Regional Representatives**

Much of Australia is covered by a network of regional representatives: members with personal experience of TSC who offer local support.

### **Family Conference**

The annual Family Conference allows families to meet and share their experiences of TSC. Members, friends and professionals are invited to hear specialists talk about TSC and related topics.

### **Genetic Testing**

A genetic testing laboratory for Tuberous Sclerosis Complex, funded by ATSS, is currently being established in Sydney. This will make genetic testing available for all Australian TSC families.

### **DVD**

A DVD about Tuberous Sclerosis Complex was recently produced by ATSS, and is available from the society. An excerpt may be viewed on the ATSS website.

### **Queensland Representatives**

ATSS has three regional reps in Queensland. However, initial contact with ATSS is made via the 1300 number or email.

A one day conference will be held in Aug 2008

### **Australasian Tuberous Sclerosis Conference 2008**

#### **Sunday 10th August**

- Time: 9:00 a.m. – 3:30 p.m.
- Venue: Doreen Dew Lecture Theatre  
Westmead Hospital  
Cnr Darcy & Hawkesbury Rds,  
WESTMEAD NSW
- Cost: \$25 per person contribution  
towards lunch, morning &  
afternoon tea.
- Guest Speaker(s) to be advised on the ATSS website.
- For further information contact:  
Australasian Tuberous Sclerosis Society  
17 Linksvie Rd, Springwood NSW 2777  
Phone: 1300 73 435  
Email: nfo@atss.org.au  
URL: www.atss.org.au

### **Epilepsy Queensland Seminar**

#### **Wednesday 18 June 2008**

For those who work with people with epilepsy in the health, education and disability sectors.

- Are you sure this is epilepsy?
- "Dis-Enabled - Perceptions of Ability" - Considerations in Supporting Clients with Autism and Epilepsy
- Managing Difficult Epilepsy
- Practical Administration of Midazolam

Bookings essential

**Ph:** 3435 5000 or 1300 852 853 or  
Email [rsvp@epilepsyqueensland.com.au](mailto:rsvp@epilepsyqueensland.com.au)

**Venue:** Lifetec Qld Conference Room,  
Level 1, Reading Newmarket  
Cnr Newmarket & Enoggera Rds  
NEWMARKET

**Time:** 9am to 1pm

**Cost:** \$30 members \$40 non-members

**"I think it would be a good idea."**

**Mahatma Gandhi (1869 - 1948)**

**- when asked what he thought of  
Western civilization**

## Interested in finding out about the "Forgotten Australians"?

As a health professional, service provider or member of the general community, would you like to better understand who the Forgotten Australians are, what they endured back when...., and what they continue to deal with now?

A free information booklet for service providers titled "Forgotten Australians: Supporting Survivors of Childhood Institutional Care in Australia" is now available.

With the assistance of Families Australia, the Alliance for Forgotten Australians (AFA) has produced a booklet, designed to inform and assist doctors, nurses, mental health professionals, dentists, social workers, counsellors and welfare workers. It will also be an essential resource for service delivery organisations.

It aims to give health and other professionals the background information they need to recognise, relate to and assist people who are experiencing long term trauma because of a childhood spent in orphanages or homes - the Forgotten Australians.

The people who identify as Forgotten Australians are generally now aged from around 40 up. They are the survivors of the roughly 500,000 children who found themselves in orphanages or Homes in the 20th century, between 1930 and 1970.

AFA details some of what the survivors experienced:

- Abandonment and Loss of Family
- Neglect and Exploitation
- Brutality
- Sexual Assault
- Poor Health Care
- Poor Education
- Loss of Identity

In 2004 The Inquiry of the Senate Community Affairs References Committee developed a report titled "Forgotten Australians: A report on Australians who experienced institutional or out-of-home care as children."

The Senate reported that they had "received hundreds of graphic and disturbing accounts about the treatment and care experienced by children in out-of-home care.... Their stories outlined a litany of emotional, physical and sexual abuse, and often criminal physical and sexual assault....neglect, humiliation and deprivation of food, education and healthcare." (Forgotten Australians, xv)

If you or your organisation would like copies of the free booklet, please call Eris Harrison on 02 6273 4885  
[www.forgottenaustralians.org.au](http://www.forgottenaustralians.org.au)  
[www.familiesaustralia.org.au](http://www.familiesaustralia.org.au)

(Source: Alliance for Forgotten Australians  
[www.forgottenaustralians.org.au](http://www.forgottenaustralians.org.au))

**\*Editor's note: Thank you to Rosemary, a Forgotten Australian, who never forgets to ring and remind us to spread the message about the Forgotten Australians. We thank Rosemary for continuing to inform and educate us, and especially for teaching us how important our language is when communicating with those people who have suffered such terrible abuse at the hands of State, Church and an ambivalent community.**

-oOo-

### Tenants Wanted!

We are looking for a community group for an office in our building.

Office for rent - 6m x 7m, New Farm location, street parking available.

Friendly environment. For further information please direct enquires to Liz Davis at SANDS on Ph: 07 3254 3422  
[sandsqld@powerup.com.au](mailto:sandsqld@powerup.com.au)

**"A poet is someone who can pour light into a spoon"**

**David Ladinsky**

**- From "I heard God Laughing: Ponderings of Hafiz"**





# Matrix Tool for Comparing Self Help Groups to Professionally-led Support Groups

## Background

This matrix is based on the work of Professor Thomasina Borkman, a leading researcher on the characteristics of self-help/mutual aid. It has been adapted into a clear language tool by the Ontario Self Help Network (OSHNET). This matrix includes a scale, since with growing recognition of the many benefits of self help/mutual aid approaches, many professionals now integrate self help/mutual aid strategies into the groups they lead. Borkman calls these "hybrid" groups.

## You can use this matrix tool:

1. To highlight the unique characteristics of self help/mutual aid groups in contrast to professionally led support groups; and
2. To explore how your hybrid (or transitioning) group already incorporates aspects of a self help/mutual aid approach - choose a number that illustrates where your group's structures fall along the spectrum, list benefits and drawbacks and decide if/how your group wants to change. Discuss ways that the group could build capacity to move towards increased member leadership in groups.

	<b>Self Help/ Mutual Aid</b>	 1 2 3 4 5 	<b>Professionally- Led</b>
<b>Knowledge Emphasised</b>	Personal Experience		Training/Education
<b>Type of Leader (s)</b>	"One of Us"		"Outsider"
<b>Focus of Meetings</b>	Mutual Support		Guidance
<b>Structure</b>	Informal		Formal
<b>Decision Making</b>	Everyone		Led by Facilitator
<b>Resources Used</b>	Volunteer and "In-Kind"		Paid Staff, Fees or Funding
<b>Duration</b>	Ongoing		Time-Limited
<b>Evaluation</b>	Decided by Members		Often Required by Funder

Source: Courtesy of March E-newsletter of the Ontario Self Help Network, (OSHNET) CANADA  
To access the Matrix Tool online go to: <http://www.selfhelp.on.ca/resource/matrix.pdf>

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

## Struggling with Hyperemesis Gravidarum (HG)

*by Rose*

I had always expected pregnancy to be a positive and joyful experience (especially since I was very health-conscious). So I was shocked and unprepared when my first pregnancy became the most painful and difficult challenge of my life.

The first five months were marked by excessive vomiting. I was bedridden and unable to perform basic daily tasks (like showering, cooking, cleaning and driving). Some days I even struggled to walk. I was devastated when I was forced to give up full-time work.

During this time I was hospitalised with a kidney infection and dehydration due to excessive vomiting. Put on an IV drip, I was diagnosed with Hyperemesis Gravidarum (HG). I left hospital still vomiting and not even knowing what HG even was. No one I knew had ever heard of this illness before.

The HER Foundation (Hyperemesis Gravidarum Education and Research) quotes:

*"Hyperemesis Gravidarum (HG) is a severe form of nausea and vomiting in pregnancy. HG is a debilitating and potentially life-threatening pregnancy disease marked by weight loss, malnutrition, and dehydration due to unrelenting and excessive nausea and/or vomiting with potential adverse consequences for the mother and unborn child."*

By six months I had tried everything to feel better – small frequent meals, ginger, sea bands, anti-nausea medication .... but nothing worked. Then I tried acupuncture, which helped to relieve some of the symptoms. My husband was very supportive, but many people failed to understand what I was going through and comments like "get over it, you're only pregnant, not dying," really didn't help. Some days I did feel like dying.

At 7mths I just couldn't cope anymore. I was exhausted from the nausea, vomiting and dry reaching which caused numerous health issues (malnutrition, throat and stomach irritation, insomnia, fatigue, anxiety etc). I also had motion sickness and a heightened sense of smell. I constantly worried about the health of our unborn child.

By 8mths I had plunged into a deep depression. Everyday was a struggle. I was angry and confused why the 'joy' and 'glow' of pregnancy had been ripped away from me. I desperately counted down each day. Our baby was 10 days overdue; I was induced and we had a beautiful (and thankfully healthy) baby boy by emergency caesarean-section.

I absolutely adore my gorgeous son and I love motherhood. However due to the physical and emotional trauma of suffering from HG, I have battled with Post Natal Depression and Post Traumatic Stress Disorder. Our son is now 16mths old and although we would love to expand our family I am scared, because it is very likely that I will endure HG again, and I don't know how I could cope with being so ill AND caring for an active toddler.

**This is why I would like to establish a Support Group – to provide comfort and understanding to women (and their family and friends), who have, or have had HG - so we can share our stories, experiences, courage and strength. Please contact by email: [hq-forum@live.com](mailto:hq-forum@live.com)**

For information, research and on-line forums about HG refer to:

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

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

[www.beyondmorningsickness.com](http://www.beyondmorningsickness.com)

If you don't have an email address and would like to speak with Rose about joining a group, please phone Self Help Queensland on 3344 6919 and we will arrange to put you in touch.

**"A leader is a dealer in hope"  
Napoleon Bonaparte (1769 - 1821)**

## Please Join Us!

### Muslim Women and Friends

- a group of women from various backgrounds, religions, cultures and histories

Muslim Women and Friends is a group emanating from the Logan Women's Health and Wellbeing Centre.

The group extends an open invitation to other women to join them on a regular basis for a range of interesting and varied learning activities.

#### Have fun! Meet new People!

Since its initial formation the group has evolved into two divisions:

1. Sharing Circles Sessions tackling internal issues of a more personal nature such as building confidence and stress management.
2. Skills Building Workshops which endeavour to provide a series of talks from a panel of experts. It is hoped that topics will allow for live demonstrations and be interactive in effect.

#### 2008 Sharing Circles Sessions

- How to become Assertive Part 3
- Relaxation Techniques
- Visualization & Laws of Attraction
- Childbirth Education & Stories
- Positive Parenting
- Emotional Intelligence
- Sharing Stories

#### 2008 Skills Building Workshops

- Global Responsibility
- Becoming handy
- Career & Business
- Sports Workshop
- Arts & Crafts
- Preloved Charity Fundraiser
- Certified First Aid Course

For more information please contact:

Farina 0405 448 045

Farina.mwaf@gmail.com

Michelle 0424 470 266

Michelle\_beck@hotmail.com

1 Mary Street, KINGSTON

Ph: 3808 9233

**Kindly bring a plate of Halal food to share**  
(Ask Farina if you're not sure!)

## Carers!



Want to get back into the workforce and don't know where to start?

### You may need a little...Momentum

Whether you just need help writing a resume, or you need training and support to help you gain employment, momentum can help.

Momentum offers:

- individual career support and advice
- counselling
- job ready training through tafe
- vocation specific training
- placement and post-placement support

All carers are multi-skilled and can offer employers a lot. Through Momentum we can help you realise your potential.

\*To be eligible you must be over 45 years of age, and have been unemployed for the past 12 months.

Contact:

Carers Queensland

07 3843 1401

(Source: Carers flyer [www.carersqld.asn.au](http://www.carersqld.asn.au))

## Families Connect Expo

**18th & 19th September 2008**

**9am to 4.30pm**

Stalls, Information display workshops, talks on what's to offer, Fengshui, crafts, art and beading. Indigenous dancers, entertainment, raffles, face painting.

All proceeds to Holistic Connected Awareness Association - to open a program centre for special needs children and their families.

Venue: Redcliffe Library  
Cnr Oxley Ave & Irene St  
REDCLIFFE

For further information please contact Cheryl on 3880 4594



## We've Had a Make Over

Yes, it happens to organisations as well.

### "Survivors of Family Abuse"

#### - getting better, not bitter

We still support women who are survivors of family abuse and their children. We'd like to heighten community awareness of the prevalence of abuse within families and advocate on behalf of women. This invariably means contacting government at all levels and seeking to influence legislation and the Court system.

We will be training our group facilitators so that these discussion groups can be delivered locally.

We will also be holding 'preparation for Family Court' workshops as the number of women asking for such preparation increases as it has over the past year.

We are getting together an advisory board of professionals able to view the big picture.

We welcome men who are supportive and sympathetic to our aims but are unable to provide services for them.

Currently we are lucky to have been auspiced by Self Help Queensland Inc., as it relieves us of the necessity to co-opt certain members to a Management Committee, do Annual Returns, have Auditors and all that jazz.

This enables us to concentrate on the 'hands-on' work. Exciting developments, aren't they?

We're looking forward to lots of interest in the groups, the workshops and the Advisory Board.

Thea Biesheuvel, CEO  
Survivors of Family Abuse  
PO Box 5790, WEST END QLD 4101  
Mob 0403 920 204  
Email: thea@gil.com.au

## High Level Health Consumer Body Wants You!

Are you interested in being part of a Health Consumer Ministerial Advisory Committee to the Queensland Health Minister, Stephen Robertson?

Currently there is a public call for Expressions of Interest (EOI) to be appointed as a member of Health Consumers Queensland's Ministerial Consumer Advisory Committee (HCQ's MCAC)

### Applications close 13 June 2008

Applications will be considered by an expert selection panel, comprised of a Senior Qld Health Staff Member, a representative of the Health Quality and Complaints Commission, Consumer Advisory Committee, an expert Academic and a respected professional in the community sector, referred by Queensland Council of Social Service. The panel shall sit and make recommendations to the Minister regarding MCAC membership and appointment of the Chair.

An Expression of Interest Information Pack (EOI) contains the finalised Terms of Reference (TOR) key functions of the committee, which incorporates overall feedback received by the Secretariate on the draft TOR.

The Expression of Interest Information Pack and Forms Pack are available at [www.health.qld.gov.au/hcq](http://www.health.qld.gov.au/hcq)

### We'd Love to Hear from any type of Self Help and Support Groups in Regional and Rural Queensland!

Please let us know what is happening in the Sector in these areas so we can tell others. Tell us about the good things you are doing, or just advertise your group' activities, conferences, fundraisers etc Contact [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)

**"I don't make jokes. I just watch the government and report the facts."**

**Will Rogers (1879 - 1935)**

## New, Informative Consumer Medicine Newsletter

- and it's Free!

Medicine Update is a quality use of medicines (QUM) newsletter that provides independent information about medicines that are newly available on the Pharmaceutical Benefits Scheme (PBS) in Australia or have a change in listing.

**The latest edition of Medicine Update reviews strontium ranelate (Prontos) for osteoporosis in post-menopausal women.**

**The next edition of Medicine Update is scheduled for release on 1 August 2008.**

It is a consumer-focused version of the newsletter for health professionals, NPS RADAR (Rational Assessment of Drugs And Research), provided by National Prescribing Service Limited (NPS).

### What is it about?

Medicine Update helps answer some of questions that are commonly asked about medicines when they first become available through the PBS. It:

- Informs consumers of the PBS listing, any restrictions in use and the reasons for those restrictions
- Provides independent information about new medicines, that will assist consumers in making a decision about using a new medicine (in partnership with their doctor)
- Informs consumers of specific quality use of medicines issues in the use of selected medicines. These might include:
  1. who is most likely to benefit from using the medicine
  2. important side-effects, dosing and administration issues
  3. what is known about its place in therapy compared to other medicines and nondrug measures (as relevant)

- Improves consumer awareness of lifestyle and non-drug interventions to treat the condition for which the drug is prescribed
- Improves consumer awareness of CMI

### Who should use it?

Medicine Update is designed to be used when a new medicine is being considered, or has recently been started, to help inform consumers who are making decisions about new medicines. It will be available as soon as possible after the PBS listing.

It can be used by health professionals in tandem with the "Information for patients" section of NPS RADAR which aims to highlight specific issues for health professionals to discuss with patients who are prescribed the medicine.

### Is Medicine Update available for all medicines?

Like NPS RADAR, Medicine Update will only review some of the medicines that are newly listed on the PBS, or which have had their listings updated. Medicine Update is developed when information about drugs that are newly available on the PBS is of particular relevance for consumers. Medicines for review are chosen according to specific criteria, by an expert Working Group. An equivalent NPS RADAR review for health professionals will be available, however not all NPS RADAR reviews will have a corresponding Medicine Update.

### Does it replace CMI?

Consumers should also refer to the Consumer Medicine Information (CMI) for medicines they have been prescribed. Medicine Update will encourage consumers to use CMI; it does not replace CMI.

### How do I get a copy?

Medicine Update is available in electronic format from the NPS website. Visit [www.nps.org.au/consumers](http://www.nps.org.au/consumers).



National Prescribing Service Limited



## Imagine a Woman

(Anonymous)

Imagine a woman who believes it is right and good she is a woman.

A woman who honours her experience and tells her stories.

Who refuses to carry the sins of others within her body and life.

Imagine a woman who believes she is good.

A woman who trusts and respects herself

Who listens to her needs and desires  
And meets them with tenderness and grace.

Imagine a woman who has acknowledged

The past's influence on the present.

A woman who has walked through her past

And who has healed into the present.

Imagine a woman who authors her own life.

A woman who exerts, initiates, and moves on her own behalf

Who refuses to surrender

Except to her truest self and to her wisest voice.

Imagine a woman who names her own gods.

A woman who imagines the divine in her image and likeness

Who designs her own spirituality

And allows it to inform her daily life.

Imagine a woman in love with her own body.

A woman who believes her body is enough, just as it is

Who celebrates her body

And its rhythms and cycles as an exquisite resource.

Imagine a woman who honours

The face of the Goddess in her changing face.

A woman who celebrates the accumulation

Of her years and her wisdom.

Who refuses to use precious energy

In disguising the changes in her body and life.

Imagine a woman who values the women in her life.

A woman who sits in circles of women

Who is reminded of the truth about herself when she forgets.

Imagine yourself as this woman.

(Source: Courtesy of **ISIS News, Volume 8, Issue 1, March 2008**)

## What is ISIS?

ISIS – Centre for Women's Action on Eating Issues is a community based feminist organisation funded through the Queensland Government to provide group work and individual counselling to women with eating issues such as bulimia, anorexia, and compulsive eating.

ISIS has been operating for 11 years and continues to provide a safe and supportive environment for women to explore their eating issues and what it means to them.

ISIS is the first project of its kind to be funded in Australia. We use the term eating issues rather than eating disorders and we do not require medical diagnosis of an Eating Disorder for women to access our services.

Our understanding is that women develop eating issues as a way of coping with some greater conflict or underlying issues or experiences such as trauma, loss or grief. Rather than focusing only on the eating behaviours, ISIS works with women to explore these issues. ISIS assists women to find other ways of expressing their emotional needs or issues while respecting that eating issues may have served important functions in the woman's life but since may have become problematic/ 'out of control'.

For further information please contact:

**ISIS – Centre For Women's Action on Eating Issues Inc.**

625 Fairfield Rd

(Cnr Fairfield Rd & Paragon St)

YERONGA QLD 4104

Ph: 07 3848 3377 Fax: 07 3848 9382

Email: [info@isis.org.au](mailto:info@isis.org.au) URL: [www.isis.org.au](http://www.isis.org.au)

## A 'Hidden Carer' could be someone you know.

### - Or is it you?

Many people in a caring role, do not identify with the term 'Carer'. There is often a misconception that Carers are paid workers, however this is not true.

There are currently 2.7 million Carers in Australia and an increasing population of Hidden Carers within our community.

A Carer can be a wife, husband, partner, parent, son, daughter, relative, neighbour or friend who may provide significant care for someone who may be: frail aged, has dementia, a disability, chronic or terminal illness, mental health or palliative care needs.

Anyone in our community can become a Carer at any time. Most Carers live with the person whom they provide care for, however some live separately. A Carer becomes a life line for someone. This may start with a gradual process and increase as time goes on depending on the needs of the person they care for. Many people find themselves becoming involved as someone's Carer, due to a family or friendship connection, or for reasons pertaining to a cultural, ethical or moral responsibility towards a family member, friend or neighbour.

A typical caring role may include providing assistance with daily living supports such as; shopping, cooking, showering, medication reminders, appointments, cleaning and household affairs, paying bills, general social and emotional supports. This support can often require 24 hour round the clock caring.

Are you providing significant advocacy, emotional and personal supports as well as physical or financial supports to someone to aid them in their every day life, who could not manage to stay at home without your help?

Commonwealth Respite & Carelink Centre is interested in building partnerships

with 'Hidden Carers'. Our aim is to enhance support networks and respite options for Carers by assisting them to maintain optimum 'Health & Wellbeing' throughout their caring journey.

## You don't have to do it alone

Commonwealth Respite & Carelink Centre supports Carers with vital life lines to access:

- Information, advice and guidance on respite care options
- Practical and Emotional supports for Carers
- Carer Education and Referrals to Counselling services
- Referrals to appropriate Health and Community Care Professionals
- Respite Care: Emergency & Planned Respite options
- Assistance with In Home Respite and Residential Respite bookings
- Access to a 24 hour a day Emergency Respite service

### Commonwealth Respite & Carelink Centre

**"Reaching & Identifying the Hidden Carer"**


**FREECALL™: 1800 059 059**

*\*Except from mobiles*

A typical caring role may include providing assistance with daily living supports such as; shopping, cooking, showering, medication reminders, appointments, cleaning and household affairs, paying bills, general social and emotional supports. This support can often require 24 hour round the clock caring.

Are you providing significant advocacy, emotional and personal supports as well as physical or financial supports to someone to aid them in their every day life, who could not manage to stay at home without your help?

Commonwealth Respite & Carelink Centre is interested in building partnerships



**This is Molly's most recent prosthesis.**

**The picture on Page 6 shows the bottom of the prosthesis has a smiley face embossed in it.**

**Wherever Molly goes, she leaves a smiley hoof print behind!**

**Molly**

## Sunshine Coast Support Group for ABI Children and their Families???

There is a good prospect that a support group for children with Acquired Brain Injury (ABI) and their families and friends may soon get underway on the Sunshine Coast. It is hoped that the group would provide support and friendship both to the children and to their families.

Once a group is established the members will decide its direction. However, to begin with, it is anticipated that people will come together informally to get to know each other and take it from there. Even if only three families get together it will be a good place to start.

If you or anyone you know would like to make contact with a family on the Sunshine Coast with a view to getting a group up and running, please contact Self Help Queensland and we will put you in touch.

Please phone Trish on 07 3344 6919 or email [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)

## Beaudesert Community Expo 10th July 2008

The Beaudesert Region Interagency is hosting a Community Expo on Thursday 10th July, from 10am at The Centre, Brisbane Street, Beaudesert.

There is no cost for services to participate, with over 50 of the region's services having already registered. Services can opt for any style of stall or activity they would prefer.

Please contact Ally Kenrick if you'd like to participate or for more information.

beaucare

Ph: 07 5541 3762

Mob: 0408 413 762

Fax: 07 5541 3654

Email: [cdo@beaucare.org.au](mailto:cdo@beaucare.org.au)



ToughLove  
Basics  
Workshop

## "Helping You Help Your Kids"

**Saturday 14th June 2008**

### Is your child's behaviour causing you...?

- Concern, worry or fear
- Conflict, or arguments within your family
- Conflict or arguments with others
- Sleepless nights
- Withdrawal from, or by your partner
- Loss of time from work, or other activities
- Physical illness, or emotional stress
- To feel isolated and ashamed
- To feel guilty, or like a failure as a parent

### Are you feeling...?

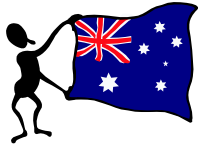
- Confused
- Angry
- Sad
- Overwhelmed
- Helpless
- Frustrated

### A one day workshop for:

- Parents in crisis with their kids
- Parents who want to start a TOUGHLOVE Support Group in their own area
- Professionals, working with families and kids, who want a better understanding of the TOUGHLOVE Program and to utilise the support network for clients.

### Learn about:

- The beliefs which underpin the program
- The process of change
- How to get started on dealing with problems
- How to keep moving in a positive direction
- How to overcome obstacles to change
- How a TOUGHLOVE support group operates.



# A Copy of the Self Help Queensland Inc Submission to 2020 Summit

The following submission was made by Self Help Queensland Inc to the Australia 2020 Summit held in Canberra in April 2008.

## About Self Help

Self help groups are voluntary associations of individuals with activity centred on health issues, environment issues, social justice issues, economic issues among many others.

The self help process on an individual, group and community level has a role in building a civil society by facilitating the means by which citizens actively participate in their communities, develop and use their talents and balance the dependence on governments, service organisations and professional care.

Self Help groups have been shown to increase physical and mental health, reduce depression, increase self-esteem and to encourage a more selective use of the formal systems while addressing unmet needs.

Outcomes in community capacity include infrastructure development, knowledge, skill and problem solving ability, increased networking and communication and increased leadership capabilities.

## Self Help Queensland Inc (SHQ)

Self Help Queensland (SHQ) is an NGO working to increase the capacity of the self help sector in Queensland. Membership currently exceeds 2000 from across Queensland. SHQ has sister organisations in NSW, WA, Vic and SA and global networks.

## People involved?

SHQ membership includes 700 self help groups. For every self help group known

the ABS estimates three actually exist . A conservative estimate would be over 2000 groups in Queensland alone with over 40,000 members.

Each group participant has social and economic networks. Potentially, up to 10% of the Queensland population may be positively affected by the existence of self help groups. Nationally the figure would be highly significant. Self help groups and their impacts represent savings to the health and community public service sector alone of many millions of dollars.

## Approach to the 20/ 20 topics

SHQ submits that:

These topics are massively entangled requiring a complex, interrelated approach.

A common intervention across the community based on a capacity building approach would fundamentally change the system.

Government efforts which develop community capacity to solve problems at the grass roots level will have exponential impacts.

Decision making should be moved as close as possible to those affected by the decisions. Importantly this must include responsibility for the distribution of funding.

A commitment to a transparent knowledge sharing infrastructure is required. Practical Suggestion.

Develop a community funding model which:

1. Is based on inclusive, community wide processes and collaborative problem solving at the community level.

(Continued on Page 23)

(Continued from Page 22)

**2.** Assumes that each community will be given funding (level to be based on numbers of people in the community with a loading for indigenous members and rurality).

**3.** Has an accountability process which is flexible, not burdensome, based on TRUST.

**4.** Is targeted at very small local level groups , which may or may not be incorporated

**5.** Is allocated by locally based community members – each community to determine its own model.

**6.** Is supported by government infrastructure such as:

a. knowledge and skill - all Public Servants act as portals to the wider support system.

b. Network development – funding of learning exchange opportunities

c. Policy which supports funds to be spent as needed rather than within a time frame

**\*Editor's note: We did have a lot more to say, but the computer program wouldn't accept the submission till it was pared back to 500 words!**



**Australian  
Pituitary  
Foundation**

**Queensland Seminar**

**Saturday 19th July 2008**

The seminar will address the management of pituitary illness, from diagnosis and beyond.

Parents, families, carers and health professionals are all welcome to attend.

For further information please contact Sue:  
Ph: 07 3376 2083  
Email: sue.pituitary@ozemail.com.au

## By Anonymous

Tax his land, Tax his wage  
Tax his bed in which he lays

Tax his tractor  
Tax his mule  
Teach him taxes is the rule

Tax his cow  
Tax his goat  
Tax his pants  
Tax his coat

Tax his ties  
Tax his shirts  
Tax his work  
Tax his dirt

Tax his tobacco  
Tax his drink  
Tax him if he tries to think

Tax his booze  
Tax his beers  
If he cries  
Tax his tears

Tax his bills  
Tax his gas  
Tax his notes  
Tax his cash

Tax him good and let him know  
That after taxes, he has no dough

If he hollers, Tax him more  
Tax him until he's good and sore

Tax his coffin, Tax his grave  
Tax the sod in which he lays

Put these words upon his tomb  
'Taxes drove me to my doom!'

-oOo-

**"The sun shines and warms and lights us and we have no curiosity to know why this is so; but we ask the reason of all evil, of pain, and hunger, and mosquitoes and silly people."**

**- Ralph Waldo Emerson  
(1803 - 1882)**





## Diary Dates

**16th & 17th June 2008: Communities in Control Conference** - The Community Challenge: Building Political, environmental, social & economic pathways towards true social inclusion. (Annual gathering of community sector workers, volunteers and supporters)

**URL:** [www.ourcommunity.com.au/cic](http://www.ourcommunity.com.au/cic)

**Venue:** Melbourne

**24 June 2008: 4<sup>th</sup> National Motor Neurone Disease Conference** 'Living Better for Longer, Pathways for the Future'

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

**Venue:** Melbourne

**6th - 8th July 2008: Inaugural Rural and Remote Health Scientific Symposium** Presented by the National Rural Health Alliance

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

**Venue:** Brisbane

**15 - 18 July 2008: 8th International Conference on Grief and Bereavement in Contemporary Society** Consequence of Loss: Resilience and Complications in the Grief Experience

**Ph:** 03 9265 2100

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

**Url:** [www.icgb08.com](http://www.icgb08.com)

**Venue:** Melbourne

**27th - 30th August 2008: 2008 SARRAH Conference:** (Services for Australian Rural and Remote Allied Health) Presented by the National Rural Health Alliance

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

**Venue:** Yeppoon

**20th - 23rd November 2008:** The 1<sup>st</sup> Asia-Pacific Lysosomal Diseases Conference incorporating the 12<sup>th</sup> Australian MPS Society Conference. Nanny agency to care for the children. Disabled children will be one on one. Siblings will be four to one nanny.

**Contact:** Jenny Noble

**Email:** [jenny.noble@xtrata.co.nz](mailto:jenny.noble@xtrata.co.nz)

**Venue:** Christchurch NZ



**Siblings of Children with Special Needs**

### A workshop for Parents Wednesday 18th June 2008

The workshop will assist parents to:

- Understand the concerns of siblings of children with special needs
- Identify behaviours that might indicate stress
- Explore factors affecting the adjustment of siblings
- Identify what they can do to support siblings
- Identify other sources of support for siblings

Presented by Kate Strohm, Director, Siblings Australia Inc. & Author of Siblings: Brothers and Sisters of Children with Special Needs (Wakefield Press)

RSVP Helen Hunter 33598000 or email [service@cfqld.org.au](mailto:service@cfqld.org.au) by Wed 11th June 2008 to secure your place Cost \$10 at the door \* Places are limited and workshop CANNOT accommodate children.

Time: 9.30am - 11.30am

Venue: Cystic Fibrosis Queensland  
31 Kate St, KEDRON, BRISBANE

### A workshop for Service Providers

Tuesday 17th June 2008

- Issues for siblings of children with special needs
- How concerns present themselves
- Factors affecting adjustment
- What siblings need
- Role of parents, service providers, others
- Introduction to running sibling groups
- Networking/Where to from here?

If you would like to advertise your event in Diary Dates or contribute an article about your group, please contact Trish at SHQ on Ph 07 3344 6919 or [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)