

## Newsletter

December Quarter

Issue 4. 2007

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

#### From the President

Sue Smyllie

Hello Everyone

SHQ was recently invited with a number of other groups to attend a consultation process on Adult and Community Education, initiated by the community sector and facilitated and supported by the Department of Education, Training and the Arts. I was extremely pleased SHQ was included. While we do not consider SHQ to be a community education service provider, our strong community development practice principles lay the foundation for SHQ's role as a co-learner with our community participants.

I was therefore also very interested in the presentation by Peter Kearns (Research Fellow, Adult Learning Australia) who outlined the international shift in thinking from community education to community learning and the emphasis on learning communities as the way forward in developing and understanding the community sector.

This was supported by the presentations made by Departmental staff as they outlined the drivers of the consultation. These drivers also included a significant concern about the skill shortage and the role community education could play in re-engaging the disengaged and making of them, productive workers. There is a connection here with many of SHQ's constituents as the impact of living with a chronic and challenging life issue on the ability of individuals and carers to work is profound. I think this issue may be a 'revelation too far' though as other participants described the lack of support and

services for well people who's life's journey had dis-engaged them from learning opportunities.

The process for the consultation had been founded on wider and more in-depth processes that had taken place in the months before the meeting. The day was firmly structured and bells invariably interrupted discussions just warming to their theme. Due to a prior commitment I was unable to stay for the whole day so I can't report the conclusions that were reached...There is a report in the plan I believe.

After I finished my work for that day, while taking the dog for her much loved walk, I was ruminating on the event and the questions that were asked of the participants. One of the questions concerned the way in which community members could be engaged in ongoing policy/ program design. The answers that were given have been given in similar forums many times before...time, two-way feedback, etc.

I am discouraged that that was all that emerged....I think the issue of long term stakeholder participation in policy and

The Management and Staff of SHQ thank you for your support during 2007

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wish all our readers a safe and relaxing holiday season & a very happy 2008

## Self Help Queensland Inc Management Committee Members

President Sue Smyllie
Secretary Thea Biesheuvel
Treasurer Kathleen Zarubin

Members Diana East

Sharon Neill Opal Ocean Cossette Urbani Bob Wyborn

#### **Committee Meetings**

If you would like to attend our meetings, please contact the office 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:

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(Continued from Page 1)

program decisions is vital and terribly complex...We need a better way, an understanding that this is not a side issue, a consultation tick in the box but the fundamental principle by which system wide change will occur. We need a commitment to short, action - based time frames, of inclusive processes which devolve authority and are based on trust, not suspicion, a bureaucracy that is brave enough to take a back seat, to guide, coach, mentor and debrief, one that funds (flexibly and easily) the spaces in which whole of community learning can occur and one that knows that sometimes, another department has already engaged a community and enters via the same door.

I would just like to add a welcome to our new committee members Sharon Neill, Cossette Urbani and Opal Ocean. Our first meeting clearly showed the value of new faces and different voices in decision making groups.

Have a happy and safe holiday season

Sue Smyllie

Precident's Message

\* A copy of Sue's "President's Report to the 2007 AGM" is featured on Page 19

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

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#### Genetic Matters

by Kim Summers PhD

#### Milking the human genome

Humans have about 25,000 different genes in their DNA. Most genes consist of the instructions for making a particular protein. When that protein is needed, the gene sends out copies of the instructions and the cellular protein synthesis machinery makes the protein molecules. Each protein is responsible for a different function in the cell or organism. Some proteins form the structure of the cells and tissues, others (such as hormones like insulin) carry information from one cell to another.

One large class of proteins is the enzymes. These proteins act as catalysts, to carry out essential reactions within the cell. Enzymes in the gut break down the nutrients in food into small molecules needed by the cells. Lactose (milk sugar) is broken down by the enzyme lactase into two components, glucose and galactose, which are simple sugars that cells can use to generate energy.

In general mammals only need to break down lactose when they are being fed on mother's milk. Once weaned, they no longer get lactose in the diet and the enzyme is redundant. At that stage, the lactase gene is inactivated so that it no longer sends out the instructions for making the protein lactase. Most mammals have no lactase protein after weaning. This is an example of a gene which is only active for a limited time in the life of the organism (in this case from birth to weaning).

Humans, too, use lactase in the gut to digest lactose. Almost all human populations are like the rest of the mammals: they shut down the lactase gene after weaning because they no longer drink milk. However, a few human groups traditionally use dairy products as a major part of the diet into adulthood. These include Europeans and some Arabic groups, where cow, sheep, goat or camel milk forms the basis for a number of foods. In these groups, lactase activity can be found in the gut of the majority of people into adulthood.

Unfortunately, there is considerable variability in the extent to which the lactase gene is active in adults in these population

groups. Some of us find that we can no longer tolerate milk products after a certain age. Tests of cells from the lining of the stomach may show that there is no activity of the lactase enzyme, and if we drink milk we suffer from bloating, cramps, diarrhoea and other symptoms. Remember Meg Ryan in the movie "French Kiss"? It is not much comfort to know that we are like most humans and those who can digest lactose are the minority amongst humans, since our society is one which has a focus on dairy products as a source of nutrients.

For most people, lactose intolerance isn't an allergy because it doesn't involve an abnormal immune response to lactose. Rather, people with lactose intolerance simply lack the enzyme needed to break down lactose in the gut. They suffer the uncomfortable digestive consequences of this failure to digest lactose. But they are not at risk of anaphylactic shock as can happen to those with allergies such as peanut intolerance.

The lactase gene contains instructions not only for making the enzyme, but also for determining when during the life of the individual the instructions are sent out so that the enzyme is made. Those fortunate people who are able to digest lactose into old age have a variant of the gene which allows it to stay active after weaning. Recent studies of the gene have shown exactly how this is done in lactose-tolerant Europeans. Part of the gene which is essential for inactivation has been changed so that it can continue to send its message throughout life. This genetic difference can be used as a test for probable lactose tolerance (or intolerance) in people of European origin. However, this is not the reason that people of Arabic background can continue to digest lactose - that change or changes in their gene has not yet been discovered.

The story of lactose tolerance probably shows evolution in action in humans. As human societies developed, some groups domesticated animals and found that their milk could provide a nutritious food for all ages.

Those people who were able to digest lactose into adulthood would have had an advantage: they could drink milk to obtain calcium, proteins and carbohydrates while their neighbours relied on other sources of these nutrients. (Continued on Page 4)

(Continued from Page 3)

Dairy products might have been a major source of nutrients in difficult times and those people who were able to use milk-based products as food would have had a greater chance of surviving and producing more offspring. The genetic variant which allowed them to retain activity of lactase would have been favoured in populations which had access to dairy products, so that eventually almost all population members had this variant.

Now that we have a greater variety of sources of nutrition, lactose intolerance isn't such a major disadvantage, so the number of people who don't have the desirable variant is probably increasing again, and more and more of us are becoming aware of the problems associated with being lactose intolerant. So much cheese and cream used in cooking! How difficult it is to find a dessert which is free of dairy products! And latte made with soy milk just isn't the same.

(Kim Summers is a member of the School of Molecular and Microbial Sciences of The University of Queensland and an immediate past member of the SHQ Management Committee.)

Editor's Note: For information about allergies, including lactose intolerance, The Allergy, Sensitivity and Environmental Health Assoc Qld Inc (ASEHA Qld Inc) has an excellent new website with up to date, well researched information.

To contact ASEHA Qld Inc: PO Box 96 Margate Qld 4019 E-mail: asehaqld@bigpond.com Website: www.asehaqld.org.au

Self Help and Support Groups generally receive little or no funding. Please help them to keep going by paying a modest membership fee in return for their service.

#### Please Tell Us What You Think!

We value feedback about any aspect of the services we provide. Please assist us by letting us know how you think we may be able to do things better. Ph 07 3344 6919 or email selfhelp@gil.com.au



#### Please call us if you need us!

The Amputees and Families Support Group Qld Inc is a Statewide, not for profit organisation which has been providing support to amputees and their families for over 23 years.

We are committed to the care of amputees from pre-surgery to final rehabilitation and beyond by offering:

- Companionship through hospital and home visits
- Individual and family support and socialising.
- Practical support by way of loan equipment, quarterly newsletters, Information on technical aids and equipment; and
- We liaise with like support groups and with professionals both government and non-Government organisations to get the best possible outcomes for amputees and their families.

Apart from monthly meetings held in Brisbane, there are sub branches which also conduct meetings in Toowoomba, Mackay and Cairns. People living outside of these areas can be linked with support people across the State who have made themselves available for contact.

We are very excited about our website. It is almost ready for viewing and will provide lots of FREE information and links to other helpful sites. Even people without an amputation may find some of the information and articles inspirational and helpful.

For further information contact:

Amputees and Families Support Group Qld Cnr. Cinderella Drive and Vanessa Blvde (PO Box 848) SPRINGWOOD QLD 4127

Ph: 07 3290 4293

Email: admin@afsg.org.au URL: www.afsg.org.au

"Those are my principles, and if you don't like them.....well, I have others."

- "Groucho" Marx (1890 - 1977)



### Hello, Goodbye and Thank-you to People on the Go at Self Help Queensland

## Farewell Kim, Jill and Penny - and a very big thank you!

It's always sad saying goodbye to Committee Members whom we have grown to know and love during their time at SHQ. Yes, you are reading correctly, there really are some Management Committees and staff who not only work together productively, but actually grow very fond of each other and enjoy being together.

This time, we are saying a sad farewell to Kim Summers who is taking off to the other side of the world after 8 years with SHQ. Our love and good wishes go with her, along with our thanks not only for all the great things she has done for SHQ, but because she's special!

Kim is held in very high esteem by the many genetic support groups who have benefited from her professional help over the years, along with the fans of her "Genetic Matters" column in this newsletter. Kim assures us she will still write for the newsletter from foreign fields, so we look forward to seeing what comes our way.

We also thank Jill Metcalfe and Penny Threlfall for giving us their precious time, wisdom and mad sense of humour. Though their stay was shorter, we will miss them at our monthly meetings - especially since they both turned up to almost every one!



Have you or your group changed contact details?

#### 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

## Welcome Sharon, Opal and Cossette

Thank you Sharon Neill, Opal Ocean and Cossette Urbani for joining us and providing a short personal profile outlined below.

#### **Sharon Neill**

Sharon is the mother of Riley 18 and Carter 16. She is currently working at the Qld Cancer Council and has worked within the health industry for 18 years. She enjoys being involved in all aspects of community life, including P&C, tuckshop, QCPCA, Just Rights Qld, Amnesty, Democrats, Toastmasters. She has recently taken up ballroom dance lessons and her challenge for 2008 is to learn the word "no".

#### **Opal Ocean**

Opal is the founder of the newly formed self help group EISHA (Electrical Injury Self Help Australia). She has a broad range of interests - from quantam physics to the creative arts. She has a thirst for research, and believes that you can find valuable information anywhere.

#### Cossette Urbani

Cossette is the State Co-ordinator of the Amputees & Families Support Group Qld Inc. Her background is in frail aged and disability care and welfare. She has a passion for pushing the boundaries and encouraging people to be the best they can.

#### SHQ Holiday Office Closure

The SHQ office will close for the annual holiday break on Thursday 20th December 2007.

The office will re-open on Monday 21st January 2008.

"My grandfather once told me that there are two kinds of people: those who work and those who take the credit. He told me to try to be in the first group; there was less competition there."

- Shrimati Indira Gandhi (1917 - 1984)

## Does your group want to set up its own FREE website?

A blog is your easy-to-use web site, where you can quickly post thoughts, interact with people, and more. All for FREE.

Just go to **www.blogger.com/start** and follow the 3 easy steps.

- 1. Create an account
- 2. Name your blog
- 3. Choose a template

Thanks to Ken Aitken of the Brain Injury Survivors Network for providing this information to us. Ken wrote: "You or the members of Self Help Qld can make up free websites (blogs) and send photographs etc to other people around the world if you wish to.

It is like setting up a free book (very small and compact) which you can send to someone on the Internet. In this book you can add chapters of writing called posts and with photographs inserted (as many as you like). You come back at a later date and edit your posts, delete and add more photographs or add another post if you so desire.

Other people who receive your blog can add comments to your blog site at the area indicated at the bottom, and other people who read what they have said can add more comments and so on. It becomes possible to have a long term world wide discussion on your blog site.

When you have created a blog with a name, you then go through a section of preset templates for colour and layout. Then you can add chapters of writing called posts and with photographs inserted in the post. I have nearly 80 blogs now which I keep coming and editing or adding fresh posts.

When you have set your first blog, you can edit your blog (or later blogs) through what is called a Dashboard. This a central control panel is which only entered by you through e-mail address and password. Then you access to functions such as: View blog, Create a blog, manage posts (ie. The chapters you have written in your blog), settings (where can edit the name of your blog or delete your blog altogether).

Blogs or blog sites can be very useful for self help group communication ..... It's free which is wonderful. You can come back anytime and add photos and a message .....whenever you want.

If people need more information, they can either phone me on 07 3297 0069 or e-mail me on aitkken@gmail.com."

## Does your group want a FREE, new kind of email?

Just go to <a href="https://www.google.com/">https://www.google.com/</a>
<a href="https://www.google.com/">accounts/ServiceLogin?service=mail</a>

Gmail (a product of Google) is an experiment in a new kind of email, built on the idea that you should never have to delete mail and you should always be able to find the message you want. Key features are:

**Search, don't sort.** Use Google search to find the exact message you want, no matter when it was sent or received.

**Don't throw anything away.** Over 2911.259541 megabytes (and counting) of free storage so you'll never need to delete another message.

**Keep it all in context.** Each message is grouped with all its replies and displayed as a conversation.

No pop-up ads. No untargeted banners. You see only <u>relevant text ads</u> and links to related web pages of interest.

(Source: <a href="https://www.google.com/accounts/ServiceLogin?service=mail">https://www.google.com/accounts/ServiceLogin?service=mail</a>)

#### WISH Has a New Name!

WISH (Western Institute of Self Help), located in Western Australia, is an organisation which carries out similar work to SHQ.

After much community consultation the organisation has rebranded itself to become

"ConnectGroups - Support Groups Association of WA".

New email: admin@connectgroups.org.au

"If computers get too powerful, we can organize them into a committee - that will do them in."

- Author Unknown

## Does Your Group Suffer From "Founder's Syndrome"?

Self Help Queensland first saw the term "Founder's Syndrome" used in a recent copy of the COSHG newsletter. (SHQ affectionately views COSHG as our sister organisation in Victoria.) We contacted Christine and Gary at COSHG, and they kindly provided the following introductory article for us.

"At the end of July, the Collective of Self Help Groups (COSHG) had the great pleasure of presenting Spencer Brennan from the Ontario Self Help Network (OSHNET) as our quest speaker at our Working Together for Successful Self Help Groups Forum in Melbourne.

Spencer was a delightful and very well received speaker who shared his extensive experience in Canada both as a participant in self help groups and his consequent work with OSHNET.

One of the topics that Spencer included in his discussion was one that is very familiar to those of us who have been involved as members of self help groups and also for those whose role as workers for self help organisations like COSHG and Self Help Queensland can readily identify.

This is the issue that OSHNET has so succinctly named as 'Founders Syndrome' in describing what so often occurs for those who begin or instigate groups. As Spencer commented, 'because they have the vision and energy, they frequently then become the prime mover and shaker, the one who leads the group and takes care of all the other details. Soon the group is seen as theirs, and more and more responsibility is placed on their shoulders, until at some point, they crash and burn'.

As Spencer went on to describe, it is at this point that groups then approach OSHNET with their dilemma. A dilemma that obviously has no geographical boundaries as it is one that over the years we continue to encounter at COSHG. That is the dilemma of stressed and 'burnt out' members who have initially taken on a leadership role in forming or establishing a group and have subsequently found themselves continuing that role far beyond what is reasonable and comfortable in the giving of time and energy. So

often, continuing on because of perceived difficulties in finding another group member who will step up and take on the leadership role and feeling concerned that if they do not continue, then the group will cease to exist.

With new groups that are evolving there are ways to prevent Founders Syndrome occurring by building in strategies from the beginning so that no one person is 'responsible'. For example:

- Exploring how the group itself will operate and not just focussing on the activities it will participate in.
- Looking at consensus decision making to make sure all members have a voice and provide opportunity to hear everyone's opinion.
- Planning for workloads to be shared eg co-facilitation of meetings and skills sharing.
- Considering how new members will be welcomed, informed and are encouraged to be active in the group.
- Incorporating time to review how the group is going every so often to make sure members feel it is on track or maybe recognise it is time to change direction.

These strategies can also benefit existing groups who because of 'burnout' may feel in danger of the group folding.

In April COSHG will be holding the Self Help Groups – The Path to Health and Well being Conference in Melbourne. Founders Syndrome will be one of the topics explored amongst others that help to keep 'groups on track'. This information will also contribute to the new update of our resource kit "In the Same Boat" to be published in late 2008."

#### COSHG

Ph: 03 9349 2301 Email: info@coshg.org.au Web: www.coshg.org.au

Spencer Brennan

Ontario Self-Help Network
Email: oshnet@selfhelp.on.ca

Web: selfhelp.on.ca

"A consensus means that everyone agrees to say collectively what no one believes individually."

- Abba Eban (1915-2002)



#### Free Couples-Based Treatment for Problem Gamblers

#### "Winning Together"

Psychologists at Griffith University are calling for volunteers for a therapy program designed to examine the benefits of a couples-based treatment program for problem gamblers. Winning Together is a couples-based treatment program that has been developed to assist problem gamblers to either control or abstain from gambling.

Couples-based interventions have been shown to be useful in the management of many problems such as depression, anxiety and substance abuse. Many people with gambling problems are reluctant to seek help with their problems in part because they do not feel confident that they will be able to overcome their problem on their own. And, many partners of people with gambling problems would like to help their partner overcome their gambling problem but are not sure of the best ways to help them or to encourage them to start treatment.

Psychologists at Griffith University are offering a free couples-based treatment program for problem gambling. The Winning Together program offers advice on helping gamblers to enter treatment and provides either individual or couple-based treatment for problem gambling. Participation in the Winning Together program is free and those involved can withdraw at any time.

Winning Together involves initially helping partners of individuals with gambling problems to 'recruit' the individual to participate in treatment. Once recruited, the individual with a gambling problem will participate in a 6-week cognitive-behavioural treatment program, either individually or with their partner. Couples will be provided with regular feedback on their progress throughout the treatment.

Couples will be asked to complete confidential questionnaires during the program, and again 6 months after the program's completion. Couples will need to complete confid-

ential questionnaires during the assessment and treatment sessions and 6 months after the program has finished.

Recruitment for the project will continue until the end of October 2008.

Participants will be required to travel to the Psychology Clinic, Griffith University, Mt Gravatt for all treatment sessions (initial screening is conducted over the phone).

For more information, please contact the Winning Together Project team on:

Ph: 07 3735 3386

Email: winningtogether@griffith.edu.au



The Cancer Council Queensland has recently launched a new manual for cancer support groups throughout Queensland. "Cancer support groups: A guide to setting up and maintaining a group" is a comprehensive handbook that offers practical ideas and advice about the role of support groups, starting a new group, facilitating a group, maintaining a group and dealing with challenging situations.

The Cancer Council Queensland is committed to the ongoing development of cancer support groups. The independence of all support groups is respected, and group leaders are encouraged to use the services offered by The Cancer Council Queensland to help make things that little bit easier.

Other services available include annual cancer support group facilitator training, the support group newsletter, support group leader forums, financial assistance, mentoring and guidance, and self-help resources. An online cancer support group network is also currently in development.

If you would like to access any of these services or would like a **FREE** copy of "Cancer support groups: A guide to setting up and maintaining a group" call the Cancer Helpline on 13 11 20.

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The National Organisation of Vascular Anomalies (NOVA)

## Vascular Anomalies ..... More than a birthmark

NOVA Australia is a not for profit community organisation dedicated to assisting those affected by haemangioma and vascular malformation.

Like many organisations of its kind, NOVA came about because a mother was unable to find support for her child. Melissa Downes didn't just identify an unmet need, she proceeded to do something about it. Unable to find support for her daughter who suffered from a subglottic hemangioma, Melissa set about founding NOVA Australia in 2006.

NOVA provides assistance to those affected by haemangioma, vascular malformation, PHACES, PWS, SWS, KT, KHE, Tufted Angioma and other benign vascular tumours.

#### **About Haemangioma**

Haemangioma is the most common benign tumour of infancy in children.

Most are not evident at birth but develop in the first weeks of life. Haemangiomas occur in 5 - 10% of all children and are 3 - 5 times more common in females than males. Haemangiomas can occur anywhere on the body however most occur in the head and neck region. Haemangiomas occur more often in Caucasian infants.

A haemangioma may grow for the first 8 - 12 months of life. The growth phase can be prolific and may appear to change daily. A haemangioma may begin to regress spontaneously at around one year of age. This involution phase may take several years and may leave residual scaring.

#### **Complications**

During the growth phase of a haemangioma, the tumour can cause complications including bleeding, pain, ulceration and infection. Haemangiomas can interfere with major organ structure and therefore be life threatening. They can interfere with breathing, feeding and vision. Haemangiomas can occur externally or internally.

#### **About Vascular Malformations**

Vascular Malformations are abnormally developed vessels.

Vascular Malformations can exist in the veins, arteries, capillaries or lymphatic vessels. Vascular Malformations are always present at birth but may not become evident until later in life. Vascular Malformations do not spontaneously regress. Vascular Malformations grow throughout an individual's life.

#### **Complications**

Vascular Malformations can be localised or diffuse. They can affect veins, capillaries, arteries and lymphatic vessels. The mass they form can cause significant pain and disfigurement. They can interfere with major organ structures, breathing, limb function and vision. Vascular Malformations are often first diagnosed as a haemangioma. This leads to frustration for the patient and family of those affected. Often individuals learn as adults they have a vascular malformation.

NOVA provides the following services

- Educational Materials and Resources
- Medical Conference (in the US)
- Patient Advocacy
- Patient Support
- Webpage and Messageboard
- Physician Networking
- Networks with other Charities
- Medical Research
- Charitable Grants/Assistance

NOVA will also attempt to connect families of children with like conditions where possible. For more information please contact:

Melissa Downes NOVA Australia

c/- Lucima Pty Ltd, Suite 804, Level 8

26 Ridge Street

NORTH SYDNEY NSW 2060

Ph: (02) 9922 4778 Fax: (02) 9922 4779

Email: nova@lucima.com.au

URL:www.novanews.org/NOVAaustralia.htm

"I will not let anyone walk through my mind with dirty feet"

- Mahatma Gandhi (1869 - 1948)



#### Newsletter Feedback

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

"I read with interest the article about transgender people in the September 2007 Self Help Queensland Newsletter. As the president of the largest group for people affected by intersex conditions in Australia, I would like to clarify a definition provided in the article.

The ATSAQ definition of "transgender" is "an ordinary person with a medical condition". I think it is quite obvious that there are flaws with this definition. My dad, for example, has diabetes. Despite his medical condition and being apparently "ordinary", his is not transgender. Under this definition anyone with a wide variety of conditions erroneously qualify as transgender.

Transgender specifically relates to a person who is born one sex and, for various reasons, identifies as a member of the opposite sex. In other words, a person who has Gender Identity Disorder (also known as Gender Dysphoria). Regardless of whether the condition is psychologically or physically based, it is clear transgender people deserve respect, legal rights and medical assistance to affirm their true gender identity.

Nonetheless, as the definition of transgender was so broad, I would like to clarify what intersex conditions are because they are quite different.

Intersex conditions are those where, for genetic reasons, a baby is born with sexual reproductive organs and/or chromosomes that are not exclusively male or female.

Intersex conditions include Androgen Insensitivity Syndrome, Congenital Adrenal Hypoplasia, Gonadal Dysgenesis and Klinefelters Syndrome. Although medical technology is improving, the vast majority of people with intersex conditions have hormonal problems and are sterile. Many have an

unhealthy body image due to the sense of shame and stigma attached to not being physically "normal sexually". Osteoporosis is very common among people with intersex conditions. Significantly, people born with ambiguous genitalia (about 25% of people with intersex conditions) also undergo inappropriate treatment as children which can include unwanted surgeries, repeated medical examinations and medical photography.

I invite your readers to visit our website if they would like any further information about intersex conditions."

Sincerely

Tony Briffa JP

President, AIS Support Group Australia Inc.

Ph: 03 9315 8809

Email: aissg@iprimus.com.au Website: www.vicnet.net.au/~aissg





As many of you are aware, The Global Institute of Learning and Development (GILD) recently asked SHQ if we would like to distribute a large quantity of very good office furniture to members of our network.

We sent the word out, and there was an overwhelming response - so much so that it took over a week to deal with all the phone calls and emails. The exercise certainly identified the need in the not for profit sector!

Unfortunately, many worthwhile organisations missed out on receiving any of the furniture. However, we kept all the emails and notes of phone calls, so if anything becomes available (which it since has) we can contact you to see if you are still interested.

We are happy to provide this service for our network, and will act as the "go between" should anyone care to pass on equipment (in good condition) they no longer need.

Please contact the SHQ office if we can assist. Ph: 3344 6919 or selfhelp@qil.com.au

"I would have made a good Pope."
- Richard M. Nixon (1913-1994)

#### Thalidomide Survivors to Reunite in Australia in 2008

Distaval, Costergan, better known as Thalidomide. Call it what you like, but this "new" medical marvel was the most published medical blunder in history.

Fifty years ago Thalidomide was introduced into the market as a sedative to help people sleep. Doctors unwittingly prescribed it to pregnant women who had been sleep deprived due to severe morning sickness, with diabolical ramifications which didn't become apparent until the arrival of their newborn babies. Birth defects!

These defects were nothing like what doctors, or indeed the medical profession, had ever seen before, but the sale of Thalidomide went on regardless, until Dr William McBride of Australia discovered the relationship between mothers who had taken Thalidomide and the subsequent defects to their newborn babies.

Compared with other countries Australia had a very small number of babies affected by Thalidomide, around fifty proven cases. Lance Fletcher, one of the last known cases to be born with Thalidomide defects prior to its reintroduction to the market ten years ago, has set out to find all the Australian survivors with a view to building a support base for these people. The prime objective of the group is to share the skills and knowledge they have gained through their life journeys and experiences.

Fifty years on, and the children previously known as 'Thalidomide Victims' now want to be recognised as 'Thalidomide Survivors.'

On the 29th of March 2008 Lance has organised a re-union for these survivors and others with Thalidomide-like disabilities at the Rydges Camperdown in Sydney with a view to meeting up with fellow survivors and their families, some of whom haven't seen each other for thirty years. Guests will also meet a host of international survivors from England, Germany, Sweden and Spain who will be making the trip to Australia especially for the event.

Several guest speakers have generously offered their time. They include Dr Janet McCredie who has done extensive research

and written several books on the subject of Thalidomide, and Dr Mark Chorlton, a lecturer at the School of Psychology, University of Newcastle. Mark is a Thalidomide survivor who suffers chronic pain on a daily basis, as most survivors do. He will outline how he has coped, along with others who will share their life's experiences.

The main aim of this event is to meet the survivors and families who have travelled the same journey, and to build up the network.

It is envisaged that an Australasian web site will be built soon with links to other international website already available. The web site will also have links to many organisations and product suppliers that may be able to assist Thalidomide survivors as well as people with Thalidomide like disabilities. An email network has been operating for some time now, thanks to the wonderful work of Kali Wilde, a British survivor who has made a life for herself and her son David here in Australia.

If you are a survivor or you have Thalido-mide-like disabilities and would like to attend the reunion, or if you can't make the event in Sydney but would like to be a part of the support network please contact Lance at <a href="mailto:thalidomide@people.net.au">thalidomide@people.net.au</a>

"Onwards and upwards and may your skies always be blue".

Lance Fletcher

## 2008 Performing Arts Workshops for Children with Special Needs

The Holistic Connected Awareness Association Inc (HCAA) is a not for profit community organisation supporting children with special needs and their families.

Commencing on 26th January 2008, HCAA is offering Performing Arts Workshops in dance ranging from tap and ballet to ballroom and belly dancing, as well as singing and instruments.

Cost:\$10 per workshop. Venue: Red Cross, Redcliffe. For Insurance purposes, access to HCAA Services is by membership only. For further information phone Cheryl 3880 4594

"Copy from one, it's plagiarism; copy from two, it's research."

- Wilson Mizner (1876-1933)

#### More Power to You

#### by David Hulme

Remember when you were small, and just bursting with curiosity about everything from milk to matches? Remember the adult response?

"Ask no questions and be told no lies," they said.

"Children are to be seen and not heard," they sniffed.

"Curiosity killed the cat," they cautioned.

"What you don't know won't hurt you."

Or perhaps, less kindly: "Everybody knows that, Dummy!"

Small wonder that so many of us, as adults, prefer not to show our ignorance. To be fair, though, our parents and grandparents did not invent the question killer. If we look back into history, we find our roots sunk deep into cultures that allowed little or no reward for curiosity.

Place yourself in, say, thirteenth century Europe. Odds are you will live out your life without even seeing a book, let alone reading one. Childish questions – Why do we get sick? Why should we be hungry? Why must I become a loyal soldier for the overlord who oppresses us? – are dismissed, even if you can get them off your tongue. "God made it so," is likely the best answer you ever get.

If there is information to be had, it is kept from you. Information is power, and so is held in monopoly by ruling elites. Almost any question can be taken as perverse, or subversive to state, church or social order.

#### **Continuing change**

This situation had to change. Individuals of extraordinary talent, good fortune and courage did arise to blaze new trails in the sciences and philosophy, religion and politics. Successive technological advances kept making curiosity potentially more rewarding.

Around 1440, Johannes Guttenberg's printing press opened the door to a radically different world. Ordinary citizens could readily receive the printed word, and literacy would be perceived as a basic right. Without the printing press we would have no

freedom of belief, no concept of universal education, probably no democracy and certainly no equal opportunity.

The information revolution was multiplied and accelerated by such inventions as the electric telegraph, the typewriter, the telephone, various recording systems for both sound and images, commercial radio, television, computers, satellite communications, IC chips, PCs, the Internet, e-mail and the mobile phone.

No longer must a question lie entombed by ignorance and isolation. Today, a mind of ordinary agility can project a question on any topic, almost instantly and at virtually no cost, to any part of the world. It may be for fun, for profit or to solve an acute problem. The reward for curiosity has never been greater.

Suppose you have an unusual medical condition. You have common interest with a small community spread across the globe. The best current information may be developing in another country, in a different culture and in a language that is foreign to you. To overcome those hurdles today, all you need is a blazing curiosity.

Not only do we have new tools, we also have a new culture of information sharing. The best medical specialists are those most open to your questions. The most effective institutions and organizations have already abandoned the guild mentality of old. Information monopolies, reinvented for the one-way mass-communications of the twentieth century, are rapidly dissolving. Our world is increasingly one of individual responsibility, the second opinion, public scrutiny and freedom of access. Information is still power. The difference is that we can have as much as we want!

#### Who do you trust?

We are constantly hearing that predators use the Internet to spread lies and lay snares. This is true. Still, if you are going to ask questions, the rules regarding trust are still the same. If a "miracle cure" seems too good to be true, it probably is. The purpose is not to supplant the experts, but to learn more from them. Our responsibility is to check, double-check cross-reference and strengthen our own personal grasp of the key concepts. (Continued on Page 13)

(Continued from Page 12)

The only bad question is the one we fail to ask. With care, we can now gather reliable information with relative ease.

On top of that, curiosity is tons of fun. Nailing answers is immensely satisfying. Learning is adventure. In exercising our curiosity, within the scope of our own interests, we can experience the same awe and excitement of discovery as the renowned inventors and explorers.

#### **Elements of the question**

We don't all come fully loaded with potent queries. There are three parts to a question that we can strengthen: conception, articulation and application.

Conception is the bit where curiosity gets active. It is a realization that the information to hand might be flawed or insufficient. "Why is it so? Who says I can't? Can we look at this from another angle? How can I understand this better?"

Articulation is the basic framing of the question, and the more work this part gets the better. As a young reporter, I was astonished at the penetrative questions of my senior colleagues, but I soon learned that it had little to do with talent. The best questions were the result of meticulous research and careful thought.

Then comes application. Friends, experts, books and the Internet are all part of the toolkit for digging up answers. A crucial part of this process is to check the validity of new information, and services are naturally evolving to meet this demand.

For example, an e-mail circulated recently warning urgently that eating shrimp and vitamin C together may be lethal. Just one of the many easy ways of checking such a claim is the Truth or Fiction site previously recommended in this newsletter, www.truthorfiction.com. Truth or Fiction determined that the shrimp alarm was bogus.

So, go ahead. Remember when you were a child and questions tumbled out naturally. This time nobody can tell you to stop, slow down, keep quiet, curb your curiosity or be satisfied with what you already know. When it comes to our own quality of life, our questions can have no boundaries.

Keep in mind, also, that there is practically no limit to the power of the question. Better questions mean better information. The better your information, the more powerful your next question will be.

#### About the author:

As a reporter, freelance writer and editor in Japan and other parts of Asia, Caboolture resident David C. Hulme built a career on practical curiosity. He is currently active in the field of smoking cessation.

#### **Editors Note:**

David's welcome article is a reminder of how asking questions paid dividends for several self help groups.

By asking questions of each other, members of some groups have contributed to the determination of secondary factors in their own conditions, thereby leading to further medical research. Questions and self help groups go well together!

#### Have Your Say!

The Health Quality and Complaints Commission (HQCC) has released a consultation draft of a Code of Health Rights and Responsibilities.

The draft is now available for public comment, and consultation closes on Friday 29 February 2008. The HQCC is keen to hear your views, in particular:

- 1. Do you support the need for a Code of Health Rights and Responsibilities?
- 2. How should the Code be used?
- 3. What should be included or deleted from this draft?
- 4. What do you think should be considered when implementing the Code?
- 5. Other comments.

To have your say contact HQCC:

Ph: 07 3120 5999 Fax: 07 3120 5998

Qld Toll Free 1800 077 308

Email: standards@hqcc.qld.gov.au

URL: www.hqcc.qld.gov.au.

Code Consultation, HQCC, Reply Paid PO Box 3089, BRISBANE QLD 4001

"The most successful people in life are generally those who have the best information."

- Benjamin Disraeli (1804 - 1881)



#### "Trudy's Story"

I had been widowed for four years when I came to Solace and I was in a mess! I was angry, confused, bitter, resentful and totally lost when I made a desperate visit to a Solace meeting. I was greeted by caring Support Workers and taken to a private room to talk through my problems.

The first thing I began to understand is that I was not the only one! My grief was very real as is the grief of every other widowed person. I was not alone with my feelings and I was not going made. As time went on my feelings of desperation and resentment and hollowness began to abate to an ever present dull ache in my heart and I began to emerge from the fog.

When I looked up and really saw this organisation Solace, I realized I had arrived in a safe place with new friends and new experiences. We all have our own story to tell and learn that other members have been there and they do understand. The dedicated Support Workers are on hand at all meetings to talk to all members old and new and to conduct small workshops where we can all participate and discuss a relevant topic if we wish to do so.

I was invited to join the Committee and became the Social Secretary. This has been a most enjoyable role as I have been able to get to know all the members on a social basis and it has provided me with useful involvement in the operations of the organisation.

I realized I wanted to give back to this organisation and its members some of the support they have given me and I have undertaken some Support Worker courses to enable me to be better equipped to assist new members and learn myself.

I recently attended the Human Systems Dynamics Workshop co-ordinated by Self Help Queensland and was astounded by the number of dedicated Self Help and Support Groups in Queensland. The Directory of

Self Help and Support Groups will prove invaluable in our efforts to network with other organisations either by phone or email, sharing knowledge, techniques and information to all groups encouraging people to contribute to their own well being and to support others. The Workshop was most interesting and beneficial to all those working in the complex field of self-organising organisations.

#### **About Solace**

Solace is a voluntary and nondenominational support group for those grieving the death of their partner.

Solace is a support group for widowed people run by widowed people.

It is important for grief to be acknowledged and worked through. The details may need to be repeated over and over again before we can come to terms with our loss.

#### The Solace objectives are:

- To help normalise the grieving process and reassure those who grieve that their feelings are normal
- To provide a safe environment in which grief can be freely expressed
- To assist bereaved people in adjusting to their loss
- To provide referral information to professional services when requested
- To provide social activities for members

For further information please contact:

Gold Coast Betty Mounser 07 5580 7034

Brisbane - Garden City Kathy Thomas 07 3341 4643

Email: solace@nqvemail.com

URL: www.solace.org.au/queensld.htm

\* The next SHQ newsletter will pass on details of a new support group to be formed on the north side of Brisbane in 2008.

"Every time that we try to lift a problem from our own shoulders, and shift that problem to the hands of the government, to the same extent we are sacrificing the liberties of our people."

- John Fitzgerald Kennedy (1917 - 1963)

# Coping With Stress A lecturer, when explaining stress manage-

A lecturer, when explaining stress management to an audience, raised a glass of water and asked, "How heavy is this glass of water?"

Answers called out ranged from 20g to  $500\sigma$ .

The lecturer replied, "The absolute weight doesn't matter. It depends on how long you try to hold it. If I hold it for a minute, that's not a problem. If I hold it for an hour, I'll have an ache in my right arm. If I hold it for a day, you'll have to call an ambulance.

In each case, it's the same weight, but the longer I hold it, the heavier it becomes." He continued, "And that's the way it is with stress management. If we carry our burdens all the time, sooner or later, as the burden becomes increasingly heavy, we won't be able to carry on."

"As with the glass of water, you have to put it down for a while and rest before holding it again. When we're refreshed, we can carry on with the burden."

"So, before you return home tonight, put the burden of work down. Don't carry it home. You can pick it up tomorrow. Whatever burdens you're carrying now, let them down for a moment if you can."

So, my friend put down anything that may be a burden to you right now. Don't pick it up again until after you've rested a while. Here are some great ways of dealing with the burdens of life:

- Accept that some days you're the pigeon, and some days you're the statue.
- Always keep your words soft and sweet, just in case you have to eat them.
- Always read stuff that will make you look good if you die in the middle of it.
- Drive carefully. It's not only cars that can be recalled by their maker.
- If you can't be kind, at least have the decency to be vague.

- If you lend someone \$20 and never see that person again, it was probably worth it.
- It may be that your sole purpose in life is simply being kind to others.
- Never put both feet in your mouth at the same time, because then you won't have a leg to stand on.
- Nobody cares if you can't dance well. Just get up and dance.
- Since it's the early worm that gets eaten by the bird, sleep late.
- The second mouse gets the cheese.
- When everything's coming your way, you're in the wrong lane.
- Birthdays are good for you. The more you have, the longer you live.
- You may be only one person in the world, but you may also be the world to one person.
- Some mistakes are too much fun to only make once.
- We could learn a lot from crayons...
   Some are sharp, some are pretty and some are dull. Some have weird names, and all are different colours, but they all have to live in the same box.
- A truly happy person is one who can enjoy the scenery on a detour.

#### **Editors Note:**

Unfortunately, the author of the above article is unknown, but we thank him/her anyway for their sound advice and sense of humour. The piece was kindly contributed by Ken Aitken, founder of the Brain Injury Survivor Network and creator of many inspiring blogs - "created for people with a brain injury by brain injury survivors".

http:braininjurysurvivornetwork.blogspo t.com/2007 04 01 archive.html

#### Please Tell Us What You Think!

We value feedback about any aspect of the services we provide. Please assist us by letting us know how you think we may be able to do things better. Ph 07 3344 6919 or email selfhelp@gil.com.au

"Don't refuse to go on an occasional wild goose chase. That's what wild geese are for."

- Author Unknown

## Seniors Peer Education Program Reaches Major Milestone!

COTAQ (Council on the Ageing Qld) is about to pass a milestone with its Seniors Peer Education Program. Just on 400 health information sessions on a range of topics will have been presented since January 2007. This means more than one session is being presented to a seniors group for every day of the year!

Topics include Seniors Quality use of Medicines, Falls Prevention, and beyond maturityblues – depression and older people. COTAQ Peer Educators are volunteers over 50 who have been trained by COTAQ to talk with groups about good health. The sessions are presented free of charge to seniors groups and clubs (see number below if you wish to make a booking).

COTAQ is currently recruiting Peer Educators for their beyond maturityblues project. This is a national project that assists older people to learn about depression, ways to identify and prevent it and what can be done to enjoy better health. Peer Educators come from different backgrounds with a broad range of skills and knowledge. They are trained to develop the knowledge , skills and attitudes necessary for them to run interactive sessions with groups of older people.

Initial training is strongly based on adult learning principles. It is held over 2.5 days and has a focus of building an understanding of depression in seniors. There are ongoing opportunities for Peer Educators to meet together regularly for support, sharing of experiences and identification of further training needs.

So, if you are fifty-ish or older and have a genuine interest in health and wellbeing, enjoy talking with older people and are keen to be involved as a volunteer in this program, we encourage you to apply!!

If you are interested or have any questions about the program please call COTAQ on 3316 2999 (if you are in the Brisbane area) or 1300 738 348 (if you live elsewhere in Queensland). Please call this number also if you would like to book a session for your organization or group. We would love to hear from you!



## Have you recently stopped driving? Are you 65 or over?

## The UQDRIVE transport and lifestyle groups for retired drivers may help.

People retiring from driving may feel loss and isolation, and can experience a change in lifestyle, as can their family members "I still mourn for my car...I miss my independence...I miss being able to please myself"

If you have recently retired from driving, and you are aged over 65, the **UQDRIVE** group program may help you to stay independent and active in your community. The groups are free, and are being run in the Brisbane North and Ipswich areas as part of a research project.

The groups run one morning a week for six weeks. There are no costs to you. The groups include:

- Talking with other retired drivers
- Finding out ways to stay active and involved
- Activities and outings.
- Light refreshments.

Groups will be run in the Ipswich and Brisbane North areas, commencing with Ipswich in February and Chermside in March 2008.

The groups are run by an occupational therapist. Your needs will be assessed and help provided. Help with travel to and from is available if needed.

The groups are part of a research project. This means that we would check if you meet the guidelines for the project and then put you into a group. We would also ask you to answer some questions about your health and lifestyle before and after the groups.

If you would like to find out more about the groups, please contact Melody Webb.
Division of Occupational Therapy
School of Health and Rehabilitation Sciences
Phone: 3346 7487

Email: m.webb3@uq.edu.au

## Paying Attention and Being Hyperactive

by Thea Biesheuvel

Have you sat at meetings and 'drifted off'? Have you come away from meetings or events and wondered what 'they' were 'on about'? Of course you have. We all have.

At its simplest, an 'attention deficit' is like a deficit of cash, or property. We'd like more, or know that there is more, but we haven't got 'it'.

Have you ever been 'hyper' active? That is, you've raced around, often in a panic, mistaking lots of 'racing' as being necessary to achieve something. We do it before we go on holidays, or getting kids off to school while at the same time doing a million other minor chores.

At its simplest, 'hyperactivity' is going over the fence and thinking 'more' is 'better'.

If we can all recognise having had an attention deficit and having been hyperactive why is it that identifying kids with these problems is so prevalent? Why is it a 'disorder'?

The Dictionary of Psychology defines attention deficit disorder (ADD) and attention deficit hyperactivity disorder (ADHD) as:'a disorder characterised by hyperactivity, attentional deficits and impulsivity. Although it is first manifested in childhood, it may not be diagnosed until later in life. It is a fairly common disorder and over the years various terms have been used for it and for disorders occasionally thought to be related. Some that are thought to be related are hyperkinesis, minimal brain damage, and other 'organic' dysfunctions.'

The term 'disorder' is also interesting. It is generally and literally, a lack of order, or disruption of order that was once present. In this sense the term has become one of the favoured 'labels' in contemporary psychiatry.

In the Diagnostic and Statistical Manual essentially all psychiatric syndromes are listed as various kinds of disorders. It is also gradually taking over the role that the term neurosis previously played in the psychologists' lexicon. These days we even have an

obesity disorder and a stress disorder. It seems that there must have been a great disruption of order once present in people who are prone to obesity or stress.

It makes sense, however, this labelling. IF one accepts that there is a disorder THEN one can also accept that there is a cure of some sorts. One could even accept that there would be medication to effect that cure. The most often prescribed medication is Ritalin. Its long-term use can damage the muscles of the heart, however.

Neuroscientists have known for a while that kids' brains are programmed to eliminate some of the neural connections they no longer need as they mature. The outer layer of grey matter, the cortex, thickens during childhood and thins out during adolescence as unused neural connections are discarded. Kids with diagnosed ADDHD (3-5% of kids), hit on this process some three years later than other kids, but most of them catch up with their peers.

Let me tell you the story of Jimmy. He's one of the typical kids in a class of 8 and 9 year olds. His parents separated a year ago. He spends alternative weekends with his Mum and Dad and half his holidays with either of them. He has one younger sister in Kindergarten. Both children are taken to school by the relevant parent on Monday morning but it is generally a bit early, before school starts.

The kids are usually a bit sleepy when they arrive but soon start running around. Their behaviour is difficult to control during the first three periods of the day (up until lunchtime). Jimmy is particularly frenetic just before lunch-time. He often does not want to eat his lunch either preferring to run around, push kids over, climb onto the roof of the shed, etc. He often falls asleep late in the afternoon. His sister often has to be woken from her nap to go home with a parent.

The teachers have sought advice and the school has sent a note home that Jimmy probably has ADHD and the parents should seek advice. Mother took him to the GP who said he could prescribe Ritalin. The parents are a bit worried about giving him pills.

Father looked at the note advising him that Jimmy probably has an attention deficit.

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'Well,' Dad said to his mates, 'I've got to take him fishing and that.' He not only took the boy fishing, he took him to the football. When he met with his mates the boy came along for some of that. They embarked on a fairly busy schedule.

'Jimmy just falls into bed. He's dead to world in no time,' his Dad told his Mum. 'He's eating like a horse as well.'

The school teachers noticed the change after about a fortnight. 'Well,' explained his Dad, when they commented on the change, 'I'm paying him a lot more attention, aren't I? That's what you said.'

It has now been documented in a handful of studies that children get less sleep each night than you and I did some years ago. The reasons are varied but some for Jimmy and his sister were that they both go to art and music during the week. The children attend after school care most days. Both parents are strict about 'homework' even for the little sister. Both parents work and are determined to spend 'quality time' with their children but they get home after dark. They all get to bed totally overloaded. The children have trouble getting to sleep. (To tell the truth, so do the parents, but they can have a nightcap, can't they?) There's never enough time in the morning to think about breakfast. Everyone is lucky if they have a full bowl of cereal. They certainly don't chop up fruit or cook porridge. After a full week of this, the 'weekend parent' fills up the days with more running around and even later bed times. Can you see what's happening?

Tired children can't remember what they've just learned, because neurons lose their elasticity; they don't form new connections between them. Sleep repairs our brain functions. Loss of sleep stops our body from extracting glucose from the bloodstream. Without these connections (synapses) and glucose a part of the brain suffers. This part is the pre-frontal cortex. It does all sorts of thinking, goal-setting, predicting outcomes and understanding consequences of actions. So, tired people don't control their impulses and can't study. The brain repeats the same pattern over and over; it gets stuck on the wrong answers.

Tired people have problems with their metabolism. If we don't sleep enough, we increase the hormone ghrelin which tells us we're hungry and decreases leptin which usually suppresses appetite.

People who get less than eight hours sleep have about a 300 per cent higher rate of obesity, no matter what activities they engage in. (Japanese, Canadian and Australian childhood studies).

I've been a mother and a grandmother long enough to know that getting kids off to sleep is not easy, especially when you're tired yourself. I worked and studied and brought kids up in a 'broken' home. I did have the great, good luck to be raised by strict, Dutch parents. Routine was the secret to everything, so my parents believed.

And you know what? At about the same time each night we'd get tired. If we were not we'd read in bed. At about the same meal times we'd be hungry. If we weren't we'd sit up at the table and wait until everyone was finished.

There was no thought of us helping ourselves to breakfast or waiting until we got tired enough to go to bed.

Come to think of it, there weren't any attention deficit or hyperactivity disorders either.

Thea Biesheuvel, BA., ScSoc., MBA, Dip. HRD, Justice of the Peace (Qual).



#### Still Available!

Inaugural Queensland Directory of Self Help and Support Groups

Copies of our 2006/07 Self Help Queensland Directory of Self Help and Support Groups are still available for sale through the office, at a reduced price of \$20 plus postage & GST. Updates are sent quarterly to all who purchase the Directory. Enquiries please phone 07 3344 6919 or email: selfhelp@gil.com.au

"It depends upon what the meaning of the word 'is' is."

- William Jefferson Clinton (1946-), August 17, 1998

## SHQ President's Report to the AGM October 2007

Hello again

One of the nicest things I have to do each year is to report to the members and constituents of SHQ about our activities and achievements during the year. Without this opportunity many of our successes would go unheralded and many learning opportunities missed. So I am happy to provide the following report but must begin by acknowledging that some of its content is drawn from our regular reports to Queensland Health, very ably put together by Trish Fallon.

Following the last AGM, the planning session delivered 2 proposed projects for 2006-2007 - the Mental Health Project and the Deep Democracy project.

The Deep Democracy Project is aimed at providing the opportunity for the community sector to take some positive steps towards strengthening our relationships, links and networks through conversation, show some leadership and explore highly communicative relationships, getting to know each other, sharing our issues, challenges and disappointments – not just once but regularly and sustainably.

This year the project took the form of providing the opportunity for some free training for the sector. The funds were provided by Queensland Health as part of a once-of amount in 2005. The training was founded on *Human Systems Dynamics (HSD)* which is a way of working which looks at developing innovative and successful organisations in times of rapid and complex change.

**Kristine Quade**, an accredited HSD consultant was sponsored by the Global Institute for Learning and Development and as I know this was not a break-even exercise for them, I would like to thank them for their support.

42 people attended and feedback has been extremely positive. Participants particularly enjoyed meeting representatives of other groups and a general call for more networking opportunities and training was made.

#### Self Help Queensland

#### Self Help Queensland

#### Self Help Queensland

#### **Values**

Social Justice – everyone's fundamental right to equal well being regardless of race, culture, gender, age, income or geographic location.

**Empowerment** – each individual's ability to have control over and participate in the decisions which affect their lives.

**Grace and dignity** – behaving ethically and non-competitively, working for the common good, earning and providing trust, respect and compassion, supporting everyone's ability to behave in the same way.

#### **Principles of Practice**

- Do no harm /social responsibility
- Transparency/participative decision making
- Collaboration/listening
  - Learning/continuous improvement of organisation

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Symposium on community building convened by the Centre for Civil Society. It was a great opportunity to talk to like minded people about the government policy and program issues that face the community sector and to start discussions about taking control and leading from this sector.

The Mental Health Project has had a slow start, quite often the way in this sector. A few interested people came together with Dianna East (thanks for leading this Dianna) to discuss options early in the year, but since then enthusiasm has been hard to pin down! However, SHQ after consultation with and in partnership with the Loganlea Indigenous community (through Jenny Shale) submitted an application for funding through

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the Mental Health Community Based Program at the Department of Families, Community Services and Indigenous Affairs. A project to place an Indigenous community development worker, recruited from the local Indigenous community, at the Loganlea High School campus was put forward.

The Directory has continued to sell, but slowly, and is updated regularly. SHQ is currently discussing the wisdom of a new edition, due to some unexpected developments with Queensland Health putting an electronic version of something similar together. We would appreciate your thoughts on this.

As always our day to day work continues in and around project activity. SHQ has responded to 2023 requests for assistance, with 631 referrals being made to self help/support groups and 238 referrals to various other community and government services. 82 face to face meetings have taken place with groups.

Letters of support, advice relating to grants and submission writing and assistance with administrative issues have been provided along with information and support to people seeking to establish new support groups. As an ongoing piece of work, groups previously unknown to Self Help Queensland are constantly being sourced, introduced to SHQ services, and added to the database which currently holds 2121 entries. 27 new groups have either been identified or formed during this period. 4 newsletters have been produced with circulation increasing to a current total of 1650.

We have continued to meet our quality management and accountability processes, with special attention to policy reviews and the continued monitoring of the safe storage and use of consumer records.

I would like to acknowledge the commitment and support provided by our committee in 2007 - Bob Wyborn, Thea Biesheuvel, Jill Metcalfe, Penny Threlfall, Diana East and Kathleen Zarubin. Many thanks.

I would like to single out Kim Summers for special mention as sadly she is leaving us this year after being a much valued member of our committee for the last 8 years. For most of that time Kim has been SHQ Secretary and has done a fabulous job. Kim has also written a very popular column in each newsletter and was very active in the Directory Project and data base development. Kim often represented SHQ at Australian Genetic Alliance meetings and wrote a number of successful submissions for conferences papers/ posters on SHQ's behalf. Kim has been a thoughtful, insightful, compassionate and supportive presence on the committee and will be much missed. We wish her well in that cold and snowy land and hope to see her again soon.

At last year's AGM we also welcomed our new administration assistant, Cristina Zomer. Unfortunately Christina left at Christmas owing to personal reasons, and we would like to thank her for her contribution to Self Help Queensland's activities during her time with us, particularly her computer/website skills. In light of the organisation's capacity to meet increased costs a decision was reluctantly taken not to appoint a replacement.

The committee at SHQ would like to thank all those who have supported us during the year and provided assistance to those we refer to them, Queensland Health for continued funding support, website designers "Glass Obelisk", DOTARS, for Directory Project assistance and Brisbane City Council for ensuring our office is affordable!

As always a big thank you to Trish Fallon who has delivered superb outcomes all year, often through difficult personal and professional circumstances.

May I wish you all a happy and safe holiday period.

Self Help Queensland Inc

Sue Smyllie 11.10.2007

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

"Put 'eat chocolate' at the top of your list of things to do today. That way, at least you'll get one thing done."

- Author Unknown



# 2008 Dementia Care Competency Course by distance education

- available for a short time for the unbelievable price of \$100.00

The Alzheimer's Association of Queensland provides dementia specific education for aged care staff. As a provider of community, respite and residential care services, we understand the unique challenges and rewards of providing care that is responsive to the needs of people with dementia, both from a clinical and management perspective.

#### **Dementia Care Competency**

CHCAC15A Provide care support which is responsive to the specific nature of dementia. This nationally recognised competency is designed for individuals who provide care for persons with dementia in a variety of settings including family homes, community day settings and residential care. Successful completion of these modules entitles the participant to a Statement of Attainment for competency CHCAC15A

Students will receive a comprehensive workbook, support from leaders in the area of dementia education and access to an extensive library.

#### Why choose Distance Education?

- Learning can happen anywhere at anytime - at your convenience
- You can learn at a pace that is comfortable and reasonable for you.
- You do not have to wait until the beginning of a quarter or semester to begin your studies - start your program on your timetable.
- Course materials are tailored to meet the needs of the distance student.
- Modules are fully self-contained. It's as simple as working through the material, completing the activities /assessment and contacting the Association for support along the way.

 All professional development programs are endorsed by APEC No 04112246 as authorised by the Royal College of Nursing, Australia. Nurses can earn CNE points as part of the RCNA 3LP program.

Book before 1st January 2008 to receive this educational program at the reduced cost of \$100.00 (a saving of \$120.00).

#### New courses on offer in 2008.

- "Mandatory Reporting of Elder Abuse in Residential Care"
- "Together We Achieve More Team Building in Aged Care"
- "Communication Skills in Aged Care"
- "Successful and Appropriate Activities for Dementia Care"
- "Advanced Dementia Care for Respite Services"
- "Advanced Dementia care for Residential Services"

For further information please contact the Alzheimer's Assoc of Qld Inc Education Department Hotline on:

Ph: 1800 1800 23 Fax: (07) 3422 1488 2/43 Tryon Street, Upper Mt Gravatt Q 4122

#### "Time For Grandparents"

In recognition of the important role of grandparents in raising their grandchildren, a "Time For Grandparents Program" has been developed to provide children with fun and interesting activities and to give grandparents the opportunity to have some well earned time out. Alternatively, grandparents may also enjoy attending activities with their children. Combined grandparent/grandchildren camps are also available.

Grandparents who are the primary carers of grandchildren and who are not receiving the fostering allowance and not approved relative/kinship carers with the Department of Child Safety are eligible for the program.

All enquires are welcome and confidential. Ph: 1300 135 500

URL: www.grandparentsqld.com.au

(A Seniors Enquiry Line/Qld Govt partnership)

"I think 'no comment' is a splendid expression. I am using it again and again."

- Winston Churchill (1874 - 1965)



# Diary Dates

11th - 14th March 2008: National Nutrition Networks Conference. Presented by the

National Rural Health Alliance **URL:** www.ruralhealth.org.au

Venue: Alice Springs

29th March 2008: Thalidomide Network Re-union. For Australian and International survivors and their families. Visitors from England, Germany, Sweden and Spain, expert guest speakers - Dr Janet McCredie, Dr Mark Chorlton

Contact: Lance Fletcher

Email: <a href="mailto:thalidomide@people.net.au">thalidomide@people.net.au</a>
Venue: Rydges Camperdown, Sydney

12 - 13 May 2008: Connecting Up 08 Conference: "Online and Off to the Future". Presented by Community Information Strategies Australia (CISA) Inc. (Australia's only national conference focused on the use of information and communications technologies in charity and non-profit settings). Emphasis will be on practical and hands-on workshops, and opportunities to network.

URL: www.communit.info

Venue: Brisbane

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

URL: www.ruralhealth.org.au

Venue: Brisbane

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

Venue: Yepoon

#### Please Tell Us What You Think!

We value feedback about any aspect of the services we provide. Please assist us by letting us know how you think we may be able to do things better. Ph 07 3344 6919 or email selfhelp@gil.com.au

"I have not failed. I've just found 10,000 ways that won't work."

- Thomas Alva Edison (1847-1931)

## New Carer Business Discount Card to be introduced in 2008

In 2008, a Carer Business Discount Card will provide eligible carers with the opportunity to obtain discounts from participating businesses. The card, an initiative of Disability Services Qld, will provide cardholders with some genuine financial benefits in recognition of their contribution to the people they care for and the community.

To be eligible, a carer will need to show:

- They are a resident of Queensland and
- Receive the Centrelink Carer Payment and/or the Centrelink Carer Allowance.

For further information contact Kerry Wilson at Disability Services Queensland by phoning 07 3896 3167.

http://www.disability.qld.gov.au/community/carer-recognition/carer-card.html

#### Lifeline Professional Development Courses on offer in 2008

Lifeline is offering an expanding range of short courses and seminars to frontline carers, professional staff, and interested individuals.

- Counselling and Communication skills
- Working Effectively
- Moving on
- Applied Suicide Intervention Skills Training
- Tailored Courses

For more information about course dates, costs etc please contact Paul Norton:

Professional Development, Lifeline Brisbane

Ph: 07 3250 1837

Email: paul.norton@lccq.org.au

#### **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

sandsqld@powerup.com.au

Ph: 07 3254 3422.