



Newsletter

June Quarter Issue 2. 2006

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

At SHQ we try to build trustworthy relationships. Trustworthy relationships have elements of ethics, participation and accountability.

The ethics bit is about a sense of public good and of social responsibility. Sometimes this requires the courage not to conform. I am not necessarily talking about the grand gesture but also about the little ways we do as we say we will do everyday.. 'I will get back to you', etc.

Participation is about being inclusive, being open to and encouraging a widely diverse input into the organisation. This also means trying as much as possible, to move the decision making as close to those affected by the decisions as possible. If you have ever wondered how to 'empower' people this is what it means...getting to make the decisions about the why, the what and the how...it is not about just getting to make the decisions about how to implement others decisions about why, what and how.

Accountability has a number of bits in it. Each organisation and the individuals in it have to think about who they are accountable to. At SHQ we are accountable to the law, our clients and members, our funders, and the community – quite a list.

In common with all incorporated associations we have to meet the requirements of the laws that affect them. Practically this means we need to be aware of the need for elected committee members, their roles and responsibilities, quorums, minutes, reports,

auditing, AGM procedures etc. As a workplace we are responsible for the provision of a safe and healthy working environment. We owe our clients and members transparency – making sure how and why we make decisions is not only open to scrutiny but is accessible and inclusive. We need to make sure the services and activities we provide are of high quality. The community needs to know if SHQ is making a difference, if the community is a healthier one because we are doing our job.

Much of this information is similar to that which we provide for our funding organisation but often the funder requires different information, in different ways. Within the current system SHQ provides 10 reports to Queensland Health each year. We estimate that of our \$72,000 in funding each year, about \$11,000 is spent on wages and other administrative costs just to meet our funding accountability processes. That is about 25% of our project officer's time is taken up in collecting the necessary data and providing it in the format required. For a one person organisation currently working a nine day fortnight, this is a considerable cost, both in terms of what it takes to do and what we aren't doing when we are doing this.

In essence this is the age old dilemma of power and action – we act to appease power – doing what is funded rather than what is needed. I think this is very important information for any groups considering applying for funding from any source. Think carefully about how much it will cost to comply with your accountability requirements and budget accordingly.

Till next time
Sue

Self Help Queensland Inc Management Committee Members

President Sue Smyllie
Secretary Thea Biesheuvel
Treasurer Kathleen Zarubin
Members Jill Metcalfe
Ann Sprought
Kim Summers
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:

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

Postal Address

P.O. Box 353
Sunnybank QLD 4109
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Email: selfhelp@gil.com.au

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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.



Is your Support Group Applying for Funding Grants?

Self Help Queensland is happy to provide letters of support for member groups applying for funding grants. If you would like to talk over your ideas with someone, feel free to call Trish at the office on Ph 07 3344 6919.

SHQ Confidentiality and Privacy Policy

Self Help Queensland continues to review and update its Policies and Procedures Manual. Openness and accountability are valued by Management and Staff, and anyone is welcome to contact the office to view the Confidentiality and Privacy Policy.

Tell us what you think!

We would appreciate feedback about any aspect of our service. Please tell us what you think so we can try to do things better.

SHQ Website

Up at last! Many thanks to all who have assisted over time. The website is an ongoing project which will continue to grow and improve with the help of your feedback. Check it out at www.selfhelpqld.org.au

Have you changed your contact details?

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

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Genetic Matters

by Kim Summers PhD

The Science of Love

Why do we fall in and out of love and what is the difference between that initial euphoria of falling in love and the steady satisfaction of a long term loving relationship? And why do some people react so badly when love dies? The popular science magazine *New Scientist* devoted its issue of 29 April 2006 to the biology of love. This is a summary of the points made in the *New Scientist* articles.

The love of a mother for her child is a good starting place to look at the chemical changes brought about by a love relationship. Newborn infants are special to their mothers, and animals will change their behaviour dramatically once they have given birth. By a complicated physiological process involving the hormone oxytocin which is produced during the birth, rat mothers become "addicted" to their babies by the same reward system that is triggered by drugs like cocaine and heroin. A new rat mother has a heightened sense of smell as well as activation of this addiction process. So when she smells her babies she associates that with the impending reward, which bonds her very specifically to her own pups.

Unfortunately it looks like the same system does not operate between the parents. More than 95% of mammal species have multiple partners at the one time. But there are a few species where the mates are strongly bonded. Experiments with voles have shown that the prairie vole, which is monogamous, has a high density of the reward system molecules which are strongly activated during mating, associating the reward with the mate. Its promiscuous cousin, the meadow vole, has a much lower density of reward molecules and moves between partners throughout the mating season. What's more, monogamous prairie voles could be made promiscuous by injecting the meadow vole version of the molecules into their brain cells, and vice versa.

Bonding between prairie voles can't really be described as love, but it seems humans have a lot of variation of the molecules in the reward region as well. Studies of molecular

changes in the brains of long term couples when they look at a picture of their partner show strong activity in that part of the brain. Oxytocin is involved in developing trust. As shown by experiments with people performing a task which required them to trust a stranger, those who sniffed oxytocin before making the decision were much more likely to trust than those who did not. The hormone seemed to reduce fear of strangers, allowing the people to warm to the anonymous person more easily. And trust is an important part of long term love, so oxytocin production in couples should enhance bonding.

How do we discriminate between potential partners? *New Scientist* describes research showing that people tend to fall for those of similar attractiveness, intelligence and social status. But underneath those obvious characteristics is a hidden paradox: we choose people who are genetically dissimilar for many factors, including the genes responsible for proteins of the immune system. This may help to produce offspring who can fight off a wide range of infections. We seem to know who to focus on from their smell, since the research showed that people are attracted to the smell of someone with different immune system proteins – we sniff out the appropriate mate. And some mathematical studies showed that we will find such a mate by testing out only 10% of the available partners. There are lots of special someones around, so you don't need to look for too long – just trust your sense of smell!

Having settled on someone, in the early stages of romantic love, the activity in the reward system part of the brain goes into overdrive, similar to the response to a strongly addictive drug. At the same time, other parts of the brain involved in negative reactions seem to go dormant. This is why love is blind: the reward system is overwhelming the skeptical part of the brain and creating a powerful need to be with the source of the reward, the beloved. Of course this can't continue, and the intense feelings eventually fade. Sometimes what is left is a long term satisfaction with the partner, a strong pair bond. Other times the love is not maintained and we move on to someone new.

Fortunately most of us grieve for our failed relationships and

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gradually withdraw from the addiction. Maybe antisocial behaviours like stalking happen when one partner fails to shut down the biochemical response to love and maintains the heightened activity of the reward centres, which results in that partner seeking out the lost love at any cost, the same way a gambler will seek opportunities to bet. The symptoms are similar to obsessive compulsive disorder (OCD) and the outcome of this jealous obsession can be tragic. Given the relationship to the reward system in the brain it is no surprise that stalkers behave like addicts or people with OCD. But although possessiveness towards a romantic partner seems to occur in all human cultures, violence in the face of jealousy is not. This suggests that there are both genetic and cultural influences in the way we react to rejection and jealousy. Unravelling these factors might give us the chance to reduce the number of tragedies.

So science tells us what we might have guessed: mother love, falling in love and pair bonding share chemistry relating to the reward centres of the brain. Love can be biologically addictive and that is good for the family and our species as long as it is directed at maintaining the bond between partners and each other and their offspring. Understanding the biology of love may help us to assist those for whom love goes wrong, without reducing the satisfaction that a long-term relationship can bring.

If you have a problem with addiction there may be a support group that can help. You can contact Self Help Queensland on Ph 07 3344 6919 to see if there is a relevant group in your area.

New Scientist magazine can be accessed at most Council libraries.

Editors note: Kim wrote about one of the consequences of love gone wrong, "Broken Heart Syndrome - The Science of Tragedy and Grief" in the Sept 2005 issue of the Self Help Queensland Newsletter. For copies of that article contact Self Help Queensland or go to the website: www.selfhelpqld.org.au

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

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Feedback Invited

on

Consumer Complaints Management in Queensland Health

Queensland Health is seeking feedback about the consumer complaints management process. Queensland Health has drafted a number of policies and have published these on their website:

www.health.qld.gov.au/complaints/review.asp

The review project has tried to reflect the recommendations from the Queensland Health Systems Review and the Queensland Public Hospitals Commission of Inquiry.

Queensland Health is asking consumers and consumer groups to have their say about the ease of access, understandability and usefulness of the proposed changes and invites us all to use the feedback process on the internet or to make an appointment to meet with the Project Officer. Enquiries should be made to Noela Zuk, Data Reporting and Analysis Centre, Reform and Development Division Ph: 3636 9888.

Multicultural Assistance Program Grants 2006 - 2007

Grants are provided by the Queensland Government under the Multicultural Queensland - making a world of difference policy.

Guidelines and an application form at:
www.premiers.qld.gov.au/multicultural

For help to complete the grant application form or for more information about other sources of funding please contact the Grants Co-ordinator:

Ph: 07 3224 5690 or 1800 053 739

Email: maq@premiers.qld.gov.au

Closing Date: Friday 28 July 2006

Give Away

Canon Fax B120 with User Manual Excellent Condition

"to a needy not for profit home"

Please contact Trish at SHQ. Pick up from Sunnybank office. Phone 3344 6919

When The Cow Pat Hits The Windmill



Health professionals are known for being notoriously bad at looking after themselves. Add to this the extra stresses of working in an isolated environment and being away from your familiar support networks and you've got what has traditionally been a recipe for disaster.

The National Rural Health Network (NRHN) includes over five thousand students around Australia studying a variety of health disciplines and interested in working in rural and remote Australia.

The National Rural Health network is working with beyond blue: the national depression initiative to produce a handbook and web-based resources designed to equip students with the mental health awareness and self-care skills they will need on rural clinical placements and in their future careers.

As it is developed by NHRN members for their peers, the guide, "When the Cow Pat Hits the Windmill" will act as a relevant and non-threatening source of information and link to resources.

The guide includes specific self-care strategies, information about sources of help available in rural and remote areas, promotion of resources currently available (such as the CRNNA Bush Crisis Line), suggestions for how to make the most of their placements, and a variety of stories contributed by students - on how they survived and thrived, on clinical placements.

When the "Cow Pat Hits the Windmill" is due to be released soon and will be distributed to students in all health disciplines throughout Australia.

For further information contact:
Executive Support Officer, Lisa Kane
Phone: 03 9639 1742
Mob: 0417 696 280
Email: LitsaKane@arrwag.com.au

(Source: Written by Lydia Scott for "Party Line" Special joint edition newsletter of National Rural Health Alliance and beyond blue: the national depression initiative No 25 April 2006.)

Crows

By Thea Biesheuvel

Between the houses the afternoon
has stooped into a purple swoon
the moon looks down from velvet night
to where our street is bathed in light
and waving trees are there to greet
a possum braving busy street
and there I saw a black crow made
another black crow with his shade
there, beak to beak in fluctuation
shadow play of my imagination
they waited for the wind's wild surge
to lift and answer nature's urge.

(Among her many talents Thea is also a published poet and a member of the Self help Queensland Management Committee)

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About the SHQ Newsletter

- 1700 newsletters are posted or emailed each quarter to support groups, health professionals, hospitals, community health centres, neighbourhood centres, divisions of general practice, social workers, psychologist, politicians and other interested individuals and organisations.
- Copies of past quarterly newsletters commencing 2005 are available on the website www.selfhelpqld.org.au
- For the benefit of those who have purchased the Directory, inserts will be included with each newsletter, commencing this edition, updating any changes we have become aware of.
- As circulation has grown, so too has the length of the newsletter. This is in an attempt to provide a wider range of information to a very diverse readership.
- Please help us provide a better newsletter by contributing articles of interest, or letting us know what you think.

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Mensheds Australia

- saving an endangered species

There are growing problems with men's health. Isolation, loneliness and depression are now looming as major men's health issues, especially in rural areas. Men's sheds is a uniquely Australian movement dedicated to promoting the health and wellbeing of men and to supporting their communities. A men's shed is a place for social interaction, for gaining information on health and well being, and for making things together. They are locally based and structured to service the particular needs of their local community.

The men's shed movement is supported by Mensheds Australia which supports the planning, development and operation of men's sheds. They provide advice on "getting going", on-going operations and becoming sustainable in terms of management structure, programs and funding through commercial activities and partnerships. Guidance is provided on building the links to the community, developing leadership and a culture of learning and innovation and communication with both members and the community.

For information see :

URL: www.mensheds.com.au

(Source: "Party Line" Newsletter of the National Rural Health Alliance Inc. No 26 April 2006)

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Do you Belong to a Self Help or Support Group?

If your group is new or you think we may not know about it please email/call/leave a message and we will get back to you.

There are probably many groups we are still unaware of throughout Queensland, particularly in rural and regional areas. We would like to be able to help someone find yours.

Please call Self Help Queensland
Ph: 07 3344 6919
Email: selfhelp@gil.com.au

New Bowel Cancer Support Group Starting in Brisbane

"As a survivor of bowel cancer I am aware that the symptoms, diagnostic tests, surgical procedures, and chemotherapy and radiation treatment can be scary, arduous, anxiety provoking, embarrassing and isolating. Life post-treatment can continue to be very stressful as many survivors have to cope daily with permanent stomas and changed bowel function for the rest of their lives. It can be difficult and embarrassing to talk about such sensitive and intimate matters, even with doctors, family and friends and one can feel very alone.

When I looked for a support group specific to bowel cancer where I could feel more comfortable discussing my experiences and anxieties with others who would understand, I found there were none in Brisbane - in fact, there are no bowel cancer support groups in Australia at present as far as I am aware. I feel so passionate about this lack of ongoing peer support for bowel cancer survivors that I am starting the first bowel cancer support group in Brisbane - a place where survivors can meet regularly in a warm, welcoming, comfortable environment based on trust and confidentiality.

I see the support group as providing the social and emotional support so essential to well being and healing.

If your life has been affected by bowel cancer and you are interested in finding out more about this new support group, I would love to talk to you. Initial contact is made by phoning 07 3344 6919 (Self Help Queensland) and Trish will arrange for Pamela to contact you.

Living with the Herpes Virus?

Need some advice, help or support?

Herpes Hangout Online Support Group

Providing support and encouragement for over five years. Contact:

Mail: PO Box 674, HELENSVALE QLD 4212

Phone: 0414 074 874

Email: hsv_help@yahoo.com.au

URL: [http://au.group\[s.yahoo.com/group/herpeshangout/](http://au.group[s.yahoo.com/group/herpeshangout/)

Hoarding

Is hoarding a normal part of dementia? - a question commonly asked of the Alzheimer's Association Queensland

The answer is yes it can be. People with dementia may often appear to be passionately searching for an item which they are convinced is missing, but also hoard items, for example money for 'safe-keeping'.

Possible causes:

- Some possible causes of why people with dementia may be hoarding include a sense of isolation. As part of the progression of dementia, a person may become suspicious and distrusting of others, particularly when they are left alone. A common response is to be more self-focused and hoarding may be a result of this.
- The past memories come flooding back for a person with dementia even to the extent of previous memories of brothers and sisters taking their possessions, or having to scrape through the depression where nothing was wasted or perhaps during the hard times of war with a family to feed.
- Many people with dementia also become fearful and suspicious of belongings being stolen. The person may hide a possession they value but then later forget where they put it. The paranoia associated with dementia can create thoughts that someone must have stolen it. This process also contributes to hoarding.
- People with dementia continually lose memories and consequently parts of their lives and even a sense of themselves. This sense of loss extends to people such as family and friends and can increase the person's need to hoard.

What can help?

After a while you may start to come across the person's usual hiding places and regularly checking there for hoarded or misplaced items can be successful. Also providing the person with items they like to sort through may decrease the feeling to hoard other items. For example if a person with

dementia loved to 'tinker' and fix things around the house, allow them to continue to do so but with the risk managed - such as an old toaster but with the electrical cord removed or any other unfinished projects that may satisfy their need to use their skilled hands. It is important not to set the person up for failure, so the project would have to be in keeping with their skill level. If they are able to complete the project, perhaps with some assistance, it will increase their sense of purpose and self-esteem.

What can Alzheimer's Association Queensland staff do to help?

Staff members from the AAQ have come across all sorts of stories of hoarding from goods like lamb chops in the hand bag, to cutlery, to a years supply of newspapers and the list goes on.

Hoarding can be a daily occurrence for some people who did not start hoarding until other symptoms associated with dementia began. Extreme frustration can arise for both the person who does the hoarding, as well as their carer. Dementia Support Officers are available to offer support and assistance through face to face meetings with family carers.

Home visits allow a person with dementia or a carer to get as much information and support as is needed and in the privacy of their own home. This dissipates the inconvenience of having to 'drop in' to an office. If your home is not an appropriate place to meet, the Dementia Support Officer can meet you in a coffee shop, library or any other suitable and convenient location.

For more information on hoarding, to arrange a home visit, or to locate a carer support group please call:

Dementia Help Line on 1800 639 331.

URL: www.alzheimeronline.org

(Source: "Dementia Matters" Autumn 2006 Page 3. Publication of Alzheimer's Association Queensland)

Have you got your copy of the Self Help Queensland Directory of Self Help and Support Groups yet?



Phone 07 3344 6919 for more information

Time for Grandparents Program

Free school holiday, weekend and after school activities are now available in Queensland for children who are being raised by their grandparents.

In recognition of the importance of supporting families where children are being raised by their grandparents, Seniors Enquiry line in partnership with the Queensland Government and key service providers are trialling the "Time for Grandparents Program". This program funded by the Department of Communities is designed to provide the children of these families with fun and interesting activities and give grandparents the opportunity to have some well earned time out. Alternatively, grandparents may also enjoy attending these activities with their children. There may also be the opportunity for grandparents to attend a camp with their grandchildren.

Grandparents who are the primary carers and who are not receiving the fostering allowance and approved relative or kinship carers are eligible for the program. If you are uncertain about your eligibility please call Seniors Enquiry Line.

For all bookings and enquiries please contact Seniors Enquiry Line 1300 135 500 Monday to Friday between 9am and 5pm.

Sarcoidosis Support Group Would Like to Hear From You

The Sarcoidosis Support Group is the only one in existence in Australia for people with Sarcoidosis. The group is based in Victoria, and is interested in building up the network of support for people living anywhere in Australia.

The group would love to hear from new people who are seeking support, as well as those who have previously been in contact.

The focus of the group will be telephone support rather than group meetings. There is a list of people with Sarcoidosis in all States, and people can be linked with others in the same area for mutual support.

Contact: June Ph 03 9802 1219

In the Eyes of a Child

By Natalie aged 15 years

In the eyes of a child
Every day is worth living
Every sin worth forgiving

In the eyes of a child
Nothing can go wrong
And even harsh words can seem like a song

I wish I saw everything through the eyes of a child

If I saw everything so black and white
Then maybe happiness would not seem so out of sight

(Natalie is a published poet, who also has Tourette's Syndrome)

Volunteer Small Equipment Grants for 2006 Now Open!

Not for profit community organisations can apply for up to \$3000 (GST inclusive) to help them buy small equipment items that make the work of their volunteers easier, safer and/or more enjoyable. The Federal Government initiative is in recognition of the valuable work carried out by volunteers.

While organisations which have not received VSEG funding previously will be assessed strongly, groups which have received funding in previous years may still apply.

Applications can be submitted either online or by post. Application forms and guidelines can be accessed on www.facsia.gov.au

A paper based application kit can be obtained by phoning 1800 152 259.

For further information contact: VESG hotline 1800 197 760

Self Help and Support Groups receive little or no funding. Paying a membership fee helps them to keep going.

Rare Opportunity Presented to Families, Doctors, Professionals,
Friends, Extended Family and Interested Persons

Phelan-McDermid Syndrome - 22q13 Deletion Syndrome - Ring22

Dr Katy Phelan (as in the syndrome name) & Dr Curtis Rodgers from the United States are coming to Australia on July 29th & 30th 2006 to attend the first Australian Conference, and to meet with families and professionals.

They will discuss Phelan-McDermid Syndrome in depth, and offer individual assessments of each child along with blood tests to be studied in the USA.

Other presenters include a Psychologist and a teacher of the hearing impaired. All speakers will be available to ask questions or discuss concerns or particular problems families may be experiencing.

About Phelan-McDermid Syndrome

Phelan-McDermid Syndrome is a rare chromosomal disorder in which a portion of the long arm (q) of chromosome 22 is missing (deleted or monosomic). The syndrome is characterized by low muscle tone, normal to accelerated growth, absent to severely delayed speech, moderate to profound intellectual disability, and minor dysmorphic features.

It is thought that there are 200 to 300 families of affected children worldwide, with 17 **known** families in Australia. Range and degree of severity of symptoms varies.

Topics Covered

There will be a range of topics covered by Dr Phelan and Dr Rodgers - all in relation to 22q13. These include:

- Understanding the genetic diagnosis and role of chromosomes
- Typical characteristics of the syndrome ie physical features
- Developmental features - a guide to what to expect and common developmental side effects
- What to look for medically, and common problems

Other Speakers

Gaye McDermott, an experienced Psychologist who works with an autistic centre in Melbourne and also works with the hearing impaired community, will cover parenting as a team and adjusting to having a child with a disability. Gaye will discuss autism, behavior strategies, how to curb unwanted behavior, encourage wanted behavior etc.

Liz Levesque, a teacher of hearing impaired people for over 10 years will also be a guest speaker at the Conference. Liz signs fluently using auslan, is a mother herself and is very understanding and compassionate.

Liz will focus on communication, since one of the main features of the syndrome is that children are either non verbal, or develop a very limited vocabulary. An important part of day to day life is knowing different types of communication and the different devices available. Not every child will respond to the same device or type of communication, so being informed is very important.

Family get - together

There will also be a family get-together with all of the families, their children and siblings. This will be an opportunity to get to know each other, establish relationships and hopefully form a support network.

Australian Conference convenor, Penny, said "life is hard enough when you are faced with a disabled child. Knowing there is support out there means so much. I have a 6.5yr old child with 22q13, and have been to the USA twice. I can't explain how amazing it was and how much I have benefited from the experience. For the first time since the birth of my child I finally felt like I was home. I was surrounded by people who know and understand what it is like to raise a child with 22q13. There is an unspoken understanding. I think we would be lying if we said we have never compared our child to another. The first time I met another child with 22q13 was my first trip (Continued Page 10)

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to the USA. I have now met over 60 families and seen over 60 children. On my last trip my son wasn't able to walk. I saw older children and how they functioned, I spoke to their parents and asked many questions to know what life is like for them and some of the hurdles they have encountered.

We can't open a book like 'Toddler Taming' or a general development book. All we have is each other and the specialists - Dr Katy Phelan & Dr Curtis Rodgers.

I cannot stress enough the importance of this Australian Conference to all family members (not just parents but grandparents, aunts, uncles etc). I will be going to the 2006 US Conference in July, just prior to the Australian Conference and am hoping to bring back some video footage of the USA Conference to show to families."

Saturday 29 July 2006 (Professionals & Families)

Sunday 30 July 2006 (Families only)

Time: 10am to 5pm

Conference Venue: Dandenong Club, 1579 Heatherton Road, DANDENONG VIC

Accommodation: Sandown Regency (special rate \$110 per night)
Ph 03 9548 3444

Babysitting: Available Saturday

Registration: Essential

For further Conference information, registration, costs, meals etc please contact Penny, the Conference convenor:

Ph: 0421 354 988

Email: cwalker1@optusnet.com.au

(From 7th July to 26th July Penny will be attending the USA Conference, so you can contact another mother, Janelle, at jgdale@koeee.com.au or phone Trish at Self Help Queensland 07 3344 6919.

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Self Help Groups exist because ordinary people start them.

Together Through Talk

- a new Parent Support Group in the Springfield Lakes area

Do you have a child or children with a chronic, severe or rare illness/disorder - from asthma or severe allergies through to very serious illness - whether it be physical or mental?

After dealing with the stresses of severe illness in her own family, Trish recently set up "Together Through Talk", a support network for parents of children with rare or chronic illnesses.

"When you have a kid with a serious or rare illness it takes a toll on the family" Trish said. She has two daughters - her youngest suffering from severe asthma since birth, and her oldest diagnosed with a rare condition called *Achalasia*. The disorder affects the oesophagus, the tube carrying food from the mouth into the stomach. In *Achalasia*, food is not pushed down into the stomach and becomes lodged in the oesophagus. It is a very rare disorder, with lifelong effects.

It was her daughter's optimism that pushed Trish to launch the parent support group. "Her bravery and courage really inspired us. Often she'd be comforting her dad and she'd be able to smile and show a lot of maturity and strength."

The purpose of the group is to provide an opportunity for parents in the Springfield Lakes area to meet and offer support to each other - helping each other through similarly difficult times.

Enjoy a cuppa in a relaxed and friendly atmosphere with other parents at the Lakeside Café, Springfield Lakes every Wednesday from 10am to 12 midday.

For further information contact Trish.
Phone: 0431 924 972.

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Please let Self Help Queensland know:

- **If your group is no longer running**
- **If the contact details have changed**

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

2006/07 Inaugural Edition

Directory News



As a Way of Thanks

As a way of saying thank you to those who have supported us by purchasing the Directory we will be adding an insert to each quarterly newsletter which will list any changes/closures/additions we learn about. The first update is included with this edition.

We hope this will help keep the Directory as up to date as possible until we undertake the second edition in 2008.

Sales

Approximately 500 copies have been sold to date, which means we are well on the way to sustaining a future edition. If you are happy with what we have done so far, please help us by spreading the word, especially to your colleagues in northern, rural and regional Queensland.



Directory Feedback Needed

We would really like to know what you think about the Directory.

We are particularly interested to know:

- If you are happy with the Directory format or not.
- If you find it easy or hard to find what you are looking for in the Directory.
- If being listed in the Directory has had any consequences for your group, more members or enquiries for example.
- If the Directory has made it easier to do your work or to help people.
- If you would like the next Directory to have more or different information included.

We will be collecting this information all the time so feel free to phone, fax or email your feedback to us at SHQ.

Order Form

Self Help Queensland Directory of Self Help and Support Groups

The inaugural edition is a hard copy Directory which contains contact details and information for approximately 600 self help and support groups throughout Queensland - across a very broad range of health conditions and well being issues eg chronic illness, genetic conditions, mental health, grief and loss, disability, sexual health and others.

For further information, order forms or future entry in the Directory please contact the SHQ office. Alternatively, please feel free to complete/copy the form below.

Organisation.....

Contact name.....

Mailing address.....

Town/suburb.....

State.....Postcode.....

Phone.....Fax.....

Email.....

Please send (No of copies).....@ \$38.50 ea
(Includes \$5.00 Postage/Handling and \$3.50 GST)

Payment details

Please make cheques/money orders payable to "Self Help Qld Directory". (Sorry no credit card facility.) Purchase orders and EFT accepted. Post to:

Self Help Queensland Inc
PO Box 353 SUNNYBANK QLD 4109
Ph/Fax: 07 3344 6919
Email: selfhelp@gil.com.au
URL: selfhelpqld.org.au

Yes I would also like to receive the Free
SHQ newsletter by Post or Email

What Doctors and Pharmacists Mean - when describing the risk of particular side effects of medicines.

The terms used by doctors and pharmacists to describe the risk (likelihood) of particular side effects of medicines have quite specific meanings, and these meanings may be quite different to our personal interpretations.

The table below gives the official meaning of each term used to describe the risk of getting a particular side effect. Thus, if your doctor says a particular side effect is rare, they mean that the side effect is likely to be experienced by 1 - 10 people in every 10,000 people or about 0.01% - 0.1% of people.

<u>Term</u>	<u>Estimated no of people affected</u>	<u>Estimated % of people affected</u>
Very common	More than 1 in 10 people	More than 10% of people
Common	Between 1 and 10 people in every 100	Between 1% and 10% of people
Uncommon	Between 1 and 10 people in every 1,000	Between 0.1% and 1% of people
Rare	Between 1 and 10 people in every 10,000	Between 0.01% and 0.1% of people
Very rare	Less than 1 in 10,000 people	Less than 0.01% of people

(Source: Medicines Talk Newsletter No 17 Autumn 2006)

Open Invitation to First Ever Australian Albinism Conference

If you have Albinism, are a parent of a child with Albinism, are interested in learning more about Albinism or even sharing your experiences and getting to meet people, then you are welcome to attend this Conference.

The Conference will be friendly for all ages. Children are encouraged to attend age specific discussion groups and a child care service will be available to allow parents to attend the formal lecture program.

There will be plenty of "people time" so everyone can interact and share ideas and experiences in a family environment. Presentations include "School Bullying", "Vision Impaired Learning" and "Genetics." For further information:

Queensland Contact: Helene
(Albinism Friends & Family Support Group)
PO Box 6357
ST LUCIA QLD 4067 Ph: 07 3716 0363
Email: albinismqld@yahoo.com.au
Date: 25, 26, 27 August 2006
Venue: The Y Hotel (Hyde Park) SYDNEY

Link Line



The purpose of this column is to connect individuals and families for whom no known support group exists.

Self Help Qld will endeavour to facilitate contact wherever possible - *in a mutually respectful, sensitive and confidential manner* - though we are unable to determine the suitability or compatibility of linked individuals and families.

Do you or anyone you know have one of the following conditions?

Cauda Equina Syndrome
Incontinentia Pigmenti
Vitiligo
Hypotonia
Hypospadia
Tic Syndrome

If you would like to be in touch with someone in the same situation please call Trish at the Self Help Qld Office Ph: 07 3344 6919 to facilitate contact.

All information collected by Self Help Queensland is treated confidentially and no details are released without permission.



Flexible support for Queensland families with a child suffering a life threatening illness

There is no greater tragedy than a parent outliving their child. Unfortunately, this is an all too common reality for some families.

Zoe's Place understands the physical, psychological and emotional strains placed on a family when one or more of their children is suffering from a life threatening illness.

Opened in 2006, Zoe's Place is dedicated to assisting these families by providing a support network for families in Queensland with children suffering life threatening illnesses. It is Queensland's first purpose built Respite and Hospice Centre, exclusively catering to children and their families/carers.

With Stage One of the development already complete, Zoe's Place is a comfortable, friendly and serene environment surrounded by gardens and parkland. The Centre has a play room, plenty of activities and with Stage Two, a games area, a multi-sensory room, a purpose built playground and an area for a Zoe's Place pet to live on the property (children will also be able to bring their own pets).

Much more than just a place; we offer families who have a child with a life threatening illness living in Queensland, or receiving treatment in Queensland, a support network, including counseling, bereavement support, respite and hospice. Services that can now be offered include:

- Respite and hospice care for 4 children overnight at a time, as well as 6 day respite children.
- Outreach support services (both in-home and in-hospital) delivered by professional staff and properly trained volunteers.
- Specialist support services such as counselling, bereavement support, peer support and resource information.

As resources become available, support services will expand to include a sibling program and other specialised services.

The completion of Stage Two will allow us to expand the number of families we can support, increase our respite and hospice beds from 4 to 8 and will include a specialised end-of-life care facility.

Tragically, it is estimated that there are more than 3,000 families in Queensland who have a child with a life threatening illness. There is a substantial and increasing need for hospice services for children in Queensland and in fact, all over Australia. These families are in desperate need of support that stretches well beyond what any public hospital can provide. Zoe's Place is able to provide the kind of support that cannot be given anywhere else.

We currently (May 2006) have 64 families on our books and we are receiving an average of 5 referrals a week. Due to the complex care needs of these children the kind of support that Zoe's Place delivers cannot be achieved anywhere else in Queensland.

How do I become a Zoe's Place Family?

Any family who has a child with a life threatening illness are eligible to register with Zoe's Place to utilise their services. Once you have decided that our services may benefit you and your family all that is required at that point is that you make a call and arrange an appointment.

Once you have made the appointment a Family Support Service worker will arrange a meeting with you either at the Zoe's Place Centre or in your own home if this is more suitable to your needs.

Once registered, you are then able to use the centre for respite for up to 14 nights per year however this is flexible to your needs. There is also the opportunity for unlimited day respite days dependent on bookings.

You may also wish to consider having a volunteer come to your home to assist you on a regular basis though this is subject to available volunteers in your area. Your Family Support worker will provide you with all the details on our services at your request.

Zoe's Place
PO Box 739, Mt. Ommaney, Qld. 4074
Phone: 07 3376 6655 **Fax:** 07 3376 6466
Email: ann@zoespplace.com.au
URL: www.zoesplace.com.au



Buddy Network Under Way

Friends of Brain Injured Children, (FOBIC) is currently in the process of setting up a "Buddy Network". Families who are interested in networking for the purpose of exchanging information, emotional support, Riverwalk collaboration etc will be introduced to each other through the new "Buddy Network".

FOBIC, a not for profit Queensland organisation led by and built by families of brain injured people, has always promoted self support, though families also help each other emotionally as much as possible. It has become increasingly difficult to get together regularly due to the unique demands of disability, and as the organisation grows, it is a challenge to meet each other.

The Buddy Network is being implemented by Vick-Lee, a volunteer who can be contacted on Ph 07 3871 0530 (Mondays or Thursdays) or email info@fobic.com.au

Families and supporters are invited to take part in Riverwalk 2006 on Sunday 30 July, leaving Orleigh Park, West End at 10am. The walk to Southbank and return is about 10klms, and to date has proved to be a very enjoyable and worthwhile fundraising exercise for families. \$5 cost to participate includes sausage sizzle after the walk.

For general information, to join FOBIC, or to take part in Riverwalk contact Pam at FOBIC
Phone: 07 3871 0530
www.fobic.com.au
www.braininjury.com.au

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"To me, one of the great benefits of the group is finding out you're not alone.

Whatever you're thinking/deciding/experiencing, you're not the only person who's been there"

Brisbane VCFS Clinic First of its Kind in Southern Hemisphere

The Velo Cardio Facial Syndrome Foundation Qld (VCFS) in partnership with the Mater hospital has opened the first VCFS Clinic in Australia. Also the first of its kind in the southern hemisphere, the clinic has been developed to support families, children and young people living with VCFS.

Clinic innovations include partial funding from the VCFS Foundation (Qld) Inc, improved access to psychological services and an integrated research program.

VCFS Qld Inc Phone: 07 3857 1073
Email: mail@vcfs.com.au
URL: www.vcfs.com.au

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Invitation to all Families & Genetic Support Groups/ Organisations

11th International Congress of Human Genetics

Brisbane, 6th August 2006

It is important to raise awareness about genetic conditions and the needs of families and individuals. You can do this by attending and supporting this first International Genetic Alliance meeting in Australia. Come along and have your say.

This is an opportunity to hear from many international speakers. Bronwyn Gray will talk from the point of view of a mother whose daughter has been given a shock diagnosis of a rare and fatal lung disease Lymphangioleiomyomatosis. Bronwyn will present her successes in forming the LAM Foundation and her experiences with fundraising, research and setting up support and international links for patient support, information and scientific research.

Ysbrand Poortman, Founder of the Dutch Genetic Alliance and the International Genetic Alliance will give an overview on international genetic organisations.

Venue: Brisbane Convention Centre
Enquiries: AGSA Ph 02 9211 1462
URL: www.ichg2006.com

Report Finds One in Five Not for Profit Organisations Suffered Fraud

Recent research by BDO, in conjunction with the Not for Profit Network and QUT found:

A total of 19% of not-for-profit organisations responding to a recent survey had experienced fraud in the past two years, although the losses suffered were less than those experienced in the commercial sector, new research has revealed.

Most instances of fraud in the not-for-profit sector resulted in losses of less than \$50,000, well below the average fraud of \$337,734 in large organisations in the public and private sector, according to the research by chartered accountant and advisory firm BDO.

Other major findings included:

- The largest number of frauds reported occurred in organisations in the \$1 million - \$10 million turnover bracket.
- Cash theft and expense account fraud were reported as the most common types of fraud perpetrated.
- In not-for-profit organisations the typical fraudster is female, in her forties and a paid non-accounting employee.
- Only 15% of fraud was committed by unpaid volunteers.
- Financial problems and pressures (26%), maintaining a lifestyle (19%) and revenge (17%) were the three key motivations behind why a person committed fraud.
- 85% of survey participants considered fraud prevention to be important, very important or extremely important to the organisation.
- 34% of frauds were uncovered by internal controls, 37% by tips from employees, volunteers or others.
- Strong internal controls (42%) and an ethical culture (31%) within the organisation were considered important in reducing the risk of fraud along with internal audit (28%).

The research, which involved analysis of 547 responses from Australian and New Zealand

not-for-profit organisations, was carried out in conjunction with the Not-For-Profit Network and Queensland University of Technology.

Report author Lisa Bundensen said 58% of the reported fraud was discovered within a year of it commencing, which helped account for the fact that 89% of frauds resulted in losses of less than \$50,000.

“While the results have been positive overall for the not-for-profit sector, organisations must not let their guard down in their fight against fraud – vigilance is imperative,” she said.

Our Community recommends a range of basic risk management procedures to minimise the likelihood of fraud occurring in your organisation:

1. All cheques should contain two signatures – three to four people in the organisation should be authorised signatories, but no two related people should be included in that list – i.e. no husband/wife, mother/daughter, girlfriend/boyfriend, aunt/nephew etc. combinations.
2. For organisations that use internet banking, ensure at least two “keys” are needed to access the account – this is the electronic equivalent of requiring two signatures on a cheque.
3. Cheques should never be signed in advance. If a signatory is taking extended leave, formally transfer their authority to another group member.
4. Receipting and banking should be undertaken by two people – i.e. the person that receives money should not be the person that banks it.
5. Put in place clear guidelines on authorisation of spending – who can spend, how much they can spend, what they can spend on, what means they can use to spend.
6. Where credit cards are in use, ensure there is a clear credit card policy in place and followed.
7. Ensure your annual auditing is meaningful – make sure you know and spell out exactly what you want the auditor to look at.

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8. Ask questions – don't take any information provided on face value; don't withhold questions so as not to offend the treasurer.
9. Ensure a Treasurer's Report is tabled at every Board/Committee meeting. This should include an explanation of how the organisation is performing against the budget, the bank reconciliation, and importantly, up-to-the-minute bank statements.

For more detailed information about fraud risk management, refer to the Community Treasurer's Guide – available online at www.ourcommunity.com.au/treasurer.

(Source: "Our Community Matters" Newsletter May 2006)

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Committee's Lament

Oh, give me your pity, I'm on a Committee,
Which means from morning till night,
We attend and amend and contend and defend,
Without a conclusion in sight.

We confer and concur, we defer and demur,
And reiterate all of our thoughts,
We revise the agenda with frequent addenda,
And consider a lot of reports.

We compose and propose, we suppose and oppose,
And the points of procedure are fun!
Although various notions are brought up as motions,
There's terribly little gets done.

We resolve and absolve, but we never dissolve,
Since it's out of the question for us,
What a shattering pity to end our Committee,
Where else could we make such a fuss!

Anonymous

(Editor's Note: It is not to be construed that this in any way reflects the workings of the SHQ Committee!)

Active, participant directed communities are healthier places to live in than insular ones.

Developing Your Organisation

- a free resource manual for Queensland Incorporated Associations

A copy of the manual "Developing Your Organisation" was forwarded to Self Help Queensland recently, and we thought it was such a useful resource that we would let our members know about it.

Through participation in the Non Government Organisations strategy, it has been possible for Queensland Health to source and distribute copies of the Developing Your Organisation manual, a resource developed by the Queensland University of Technology with initial funding by the Department of Communities.

The manual addresses a range of topics and issues of interest such as starting a community organisation, management committee responsibilities, meetings, staff employment, volunteers, organisational performance, when things go wrong, risk management, consumer participation and accountability and legal obligations.

Developing Your Organisation is available in digital form at:
<https://olt.qut.edu.au/bus/dyo>

For further information, or to obtain a hard copy of the manual, please contact Beverly Sander at Queensland Health on 3131 6924.

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Health Quality and Complaints Commission Bill 2006

The Health Quality and Complaints Commission Bill 2006 was passed by the Legislative Assembly on 25 May 2006.

The Bill was passed without amendment, and can be viewed on the Office of Queensland Parliamentary Counsel internet site at: www.legislation.qld.gov.au/Bill_Pages/Bill_51_06.htm (Act is in right hand column)

The Bill was assented to on 29 May 2006. This will enable appointment of a Commissioner and Assistant Commissioners in advance of commencement of the Act on 1 July 2006.

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About PFLAG

PFLAG is a 100% voluntary peer support group, organised by parents for parents with lesbian, gay, bisexual and transgender (LGBT) sons and daughters.

We are non political, non religious, receive no government funding and operate under the auspices of the Qld AIDS Council.

Our information is of a generalist nature because we understand all families have their own values, morals and beliefs that have been established and operate within each family.

PFLAG aims to provide a support system for families and friends of LGBT to understand and accept their children with love and pride. By doing this we believe we are strengthening the family unit within the community.

How PFLAG assists Parents and family members

- Anonymous telephone information
- Written information and resources and referrals when necessary
- Individual support for those in crisis and bi-monthly group meetings

How PFLAG assists LGBT youth

- We assist youth by providing them with written information about what to expect when "coming out" to parents. Plus, information and phone numbers to give parents so they can access immediate support.
- We will also meet individually, or speak anonymously with LGBT youth, to discuss their fears and concerns about revealing their sexual orientation to family members.

PFLAG is friendly, accepting and informal. Our motto is "keeping the family united"

Current and past PFLAG newsletters in PDF form can be accessed on the website,

along with an excellent booklet by Shelley Argent, convenor of PFLAG Brisbane, called "Sexuality is Not a Choice".

If you would like support or resources please call or email.

Phone: 07 3017 1739
Mob: 0409-363-335
Helpline: mob. 0400-832-767
Email: pflagbris@hotmail.com
URL: www.pflagbrisbane.org.au
Location: 30 Helen Street
NEWSTEAD QLD 4006

PFLAG welcomes public support in the form of Individual or Family Membership (\$25 pa) or Corporate Membership (\$100 pa).

Rural Project 2006

PFLAG has embarked on a huge project for 2006 - to get information packs to all Queensland State High Schools, General Practitioners, Libraries, Community Health Workers and Police Service by the end of the year.

The pack is to include a handbook for professionals to give them extra understanding of LGBT issues especially when dealing with young people and their families, a booklet for parents, brochures a CD with parent's stories, a booklet for youth and a booklet especially for regional and rural parents which will hopefully hasten their understanding and acceptance.

There are PFLAG groups in regional Queensland which offer advice and support.

Babinda: Pam Ph: 07 4067 1634

Ballina: Kim
Email: kmscmb@yahoo.com.au

Gold Coast:
Margaret & Roy Ph: 07 5594 9890

or

Sue Ph: 0402 868 434
Email: suemb@ozemail.com.au

Gympie: Ricki Ph: 07 5484 3221

Rockhampton:
Neville & Rosemary Ph: 07 4928 7275
Email: rockypflag@itxtreme.com

Sarina: Patricia Ph: 07 4956 2509

Sunshine Coast: Tania Ph: 0412 132 289

Toowoomba: Shane Ph: 07 4659 9961

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Diary Dates

20th June 2006: Epilepsy Seminar 2006: "Hope for the Future". Presented by Epilepsy Queensland Inc. The seminar, which will focus on epilepsy and related issues, is aimed at parents, teachers, childcare workers, disability support staff, allied health and education workers and anybody with an interest in epilepsy.

Phone: 07 3435 5000 or 1300 852 853

Email: admin@epilepsyqueensland.com.au

Venue: Wesley Hospital, Auchenflower

3rd - 5th July 2006: 19th Australian Winter School. Annual inter-sectoral conference on alcohol, tobacco and other drugs and addictions. Presented by the Alcohol and Drug Foundation, Queensland.

Email: winterschool@adf.org

URL: www.winterschool.info

Venue: Brisbane

16th - 22nd July 2006: Disability Action Week "Changing Queensland" Visit the Disability Action Week website to see what events are happening in your area.

Phone: 07 3224 735

Freecall: 1800 010 120

Email: actionweek@disability.qld.gov.au

URL: www.disability.qld.gov.au/actionweek

25th - 27th July 2006: International "Growing Regions Conference." Hosted by DOTARS on behalf of the Australian Government. Eminent speakers in the field of regional development will discuss how different approaches to similar problems across the world are working.

Phone: 02 6274 7358

Email: growingregions@dotars.gov.au

Venue: Hilton, Brisbane

29th 30th July 2006: 1st National Phelan-McDermid Syndrome (Deletion 22q13) Ring 22 Conference:

Phone: 0421 354 988

Email: Penny cwalker1@optusnet.com.au
Janelle jgdale@koeee.com.au

Venue: Dandenong, VIC

6th - 10th August 2006: 11th International Conference of Human Genetics.

URL: <http://www.ichg2006.com/>

Venue: Brisbane Convention & Exhibit Centre

25th - 27th August 2006: 1st National Albinism Conference. Presentations include "School Bullying", "Vision Impaired Learning" and "Genetics."

Phone: 07 3716 0363

Email: albinismqld@yahoo.com.au

Venue: The Y Hotel (Hyde Park) SYDNEY

7th September 2006: Annual Prostate Cancer Phone In. Talk to an expert from the Cancer Council Team - urologist, radiation oncologist, urology nurse, specialist educator about Prostate Cancer.

Phone: 13 11 20

21st - 22nd September 2006: Shared Visions Disability Conference 2006. Bringing together people with a disability, families and carers, disability service providers, the government and corporate sectors.

Phone: 1800 302 510

URL: www.disability.qld.gov.au

Venue: Conrad Jupiters, Gold Coast

29th September - 1st October 2006: 11th National MPS Conference "Strengthening Partnerships". Presented by Mucopolysaccharide & Related Diseases Soc Aust. Key speaker Dr Ed Wraith, Consult Paediatrician Royal Manchester Chldn's Hospital.

Phone: 02 9476 8411

URL: www.mpsociety.org.au

Venue: Brisbane

2nd - 4th November 2006: Velo Cardio Facial Syndrome International Conference 2006. Hosted by VCFS Foundation (Qld) Inc. World professionals will present papers, tutorials and give clinics.

Phone: 07 3857 1073

Email: mail@vcfs.com.au

URL: www.vcfs.com.au

Venue: Carlton Crest Hotel, Brisbane

11th - 12th November 2006: MDDA Conference "Rising to the Challenge" Metabolic Dietary Disorders Assoc

Phone: 1800 288 460

Venue: Melbourne

7th - 10th March 2007: 9th National Rural Health Conference. "Standing up for Rural Health: Learning from the Past, Action for the Future."

Phone: 02 6285 4660

Email: conference@ruralhealthorg.au

URL: www.ruralhealth.org.au

Venue: Albury