



Newsletter June Quarter Issue 2. 2009



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

From the President

Sue Smyllie

Hello Everyone

I attended a lecture recently by Mr Tom Calma, the Aboriginal and Torres Strait Islander Social Justice Commissioner. Mr Calma has been in this role for 5 years so during this time he has experienced a lot of different policy and attitudinal shifts. I was heartened to hear his 'glass half full' approach and the hope he has that as Australia has signed the United Nations Declaration on the Rights of Indigenous Peoples we now have a framework to support the serious efforts underway to 'close the gap' between the life experience of Aboriginal and non-Aboriginal Australians. We at SHQ will be at the 46 articles of the Declaration to inform our work with the Indigenous community.

Reflecting on Tom Calma's experience of changing attitudes I thought of the changes that SHQ has seen during the 12 years I have been involved. We have gone from 'the Fish Book' - where 33 groups and the contact details were recorded - to the over 700 included in our data base today. We are currently jumping into the 21st century by commissioning an updated website and online searchable version of the data

base. SHQ has gone from a relatively unknown organisation to recognition as a peak body for the sector and invited to participate in many policy processes. From having to cancel AGMs because we couldn't get the numbers to a meeting consistently supported by many in the sector and a venue for meeting new faces (and an overwhelming number of polities when an election is in the wind!)

In the last few years we have also been successful in attracting grant money. The Mental Health Project is something we have wanted to do for some time and I am delighted at the progress that has been made in this important area. The one thing that hasn't changed is our core funding. Yes the dollars are more but the value is not. Our achievements are due to the talents and dedication of Trish Fallon and the members of the management committee. In the last 12 years we have probably had over 20 different committee members all of whom have contributed generously to the organisation and brought their unique perspectives and skills to the task.

The point of all this nostalgic rambling is that I am announcing my intention to stand down as President at the next AGM and will not be standing for election as a committee member. This has

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Self Help Queensland Management Committee Members

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

Committee Meetings

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

Project Officer

Trish Fallon

Mental Health Project Officer

Diana East

Administration Officer

Janice Nankivell

Office

The office is attended Monday to Friday, 9am to 4.30pm. However, staff are sometimes required to liaise with groups or attend meetings away from the office.

If you wish to call in to use the office facilities or talk to the project officer, please phone first to ensure that someone will be available to meet with you.

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121 Lister Street (Cnr Gager Street)
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Self Help Leaders Online Social Network

URL: www.selfhelpleaders.ning.com

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



Queensland Government
Queensland Health

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not been an easy decision as SHQ feels more like home and family than an organisation. I have been privileged to learn so much from my involvement and have enjoyed every minute. However I strongly feel that all organisations thrive on diversity. New ideas, new ways of working and new passions and enthusiasms are important to sustainability. I am sure there is someone in the sector who will take on this role and who will bring their own perspectives to the future. It is not an onerous task, meetings are once every 4-6 weeks and any extra work is really at your discretion. Not to mention the lovely people you get to work with! I urge you all to consider serving on the committee, it is a very rewarding experience.

I will of course maintain my interest in and support for SHQ and continue to serve as a mentor for the Mental Health Project and serve on its evaluation committee.

There is still some time to go before the AGM and another one or two newsletters to write so until next time...take care.

Sue

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Genetic Matters

by Kim Summers PhD

It's a dog's life

Dogs were probably the first domesticated animal. At some point a relatively courageous, docile or sociable wolf may have sought the protection of a fire around which early humans were eating their meal. The wolf might have made itself useful by eating scraps and protecting the people. Perhaps this wolf produced a litter of puppies which became even more used to living with humans. The people might have encouraged the least aggressive of the puppies to stay with them and chosen amongst their offspring those which were most suited to sharing the camp. Thus the process of domesticating and selecting canines to be useful to humans would have begun.

The success of dog domestication was probably followed quickly by the recruitment of other mammals for human purposes: for food, transport, protection, clothing. Today a wide range of animals show evidence that they were selected and manipulated for use by humans: dogs and cats as domestic pets, cattle, pigs, sheep, goats to produce food and clothing, horses, camels and oxen for transport. These animals show some characteristics of their wild ancestors but their history is inextricably linked with human history, and they have been selected specifically for those characteristics which are useful to humans.

To enhance the characteristics which were most appropriate for co-existence with humans, people would have deliberately bred from those animals which most resembled what they wanted: the cow with the most milk was bred to a bull whose mother was a good milker; dogs which were easy to train were mated together. This process of artificial selection has been going on for thousands of years in almost all societies, resulting in the domestic animal strains we now have on our farms and in our houses.

The problem with selecting the desirable characteristics this way, is that sometimes they bring undesirable features with them. For some years pigs were selected for their low fat meat. Unfortunately, the meat turned out to be commercially undesirable: pale and textureless when uncooked, dry when cooked. And pigs with this kind of meat reacted badly to stress. It seems that in selecting for low fat meat, breeders also selected for a version of a gene which causes other problems. In humans, mutations in this gene are associated with a condition called malignant hyperthermia, where sufferers are at risk of dying when exposed to an anaesthetic. Studies of pigs with this problem helped untangle the human story, but pigs are now bred to avoid the mutation which makes their meat so undesirable.

Since the advent of artificial insemination, a small number of bulls are responsible for a large number of dairy cattle. One bull in particular is thought to have sired at least 30,000 calves between 1985 and 2008. Another has been a major contributor to the gene pool of US dairy cows. Unfortunately this bull was carrying a faulty copy of a particular gene involved in the immune system. Because his daughters were such good milkers, he was often the father and grandfather of calves and this inbreeding allowed two copies of the mutation to be passed on to some offspring, resulting in an immunodeficiency disease of cattle. Now we are able to perform a simple DNA test to check for the presence of the mutation, and only bulls who have two normal copies of the gene are used for breeding. The problem has been largely eliminated in cattle, and recognising it has given insight into the equivalent disease in humans.

Domestic pets, too, have genetic problems. The welfare issues involved in deliberately breeding from animals with debilitating genetic conditions are only now being assessed. Some of the breed characteristics, such as the flattened face of the pug or the ridge on the back of the Rhodesian (Continued on Page 4)

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ridgeback, are similar to genetic conditions in humans. Inbreeding to enhance these breed characteristics has also resulted in selection of other undesirable conditions. Some breeds of dog have a high incidence of mitral valve insufficiency, a problem which is increasingly diagnosed in humans as we live longer. Cats have a high frequency of hypertrophic cardiomyopathy, another cardiovascular problem found in humans. These are unlikely to be simple single gene conditions in humans or animals, but perhaps by understanding the disease in animals we will be able to develop treatments for humans as well.

Researchers have used animal models for many years to try to understand human diseases. In the past this has usually involved taking a healthy animal, making it sick by some surgical or pharmaceutical treatment, and then trying to cure it. That animal has often been a small rodent, from a species which is quite distant from humans on the evolutionary and physiological tree. As we discover more about animal diseases we are working to develop models using animals which are already sick. In examining and treating these animals we are coming closer to understanding the equivalent human condition, without causing additional suffering to any creature. At the University of Edinburgh, this philosophy is called "One Medicine" and unites veterinarians, doctors and research scientists in an effort to improve the lives of humans and their animal companions.

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

"Pain is real when you get other people to believe in it. If no one believes in it but you, they believe your pain to be madness or hysteria"

**Naomi Wolf
Author, Political Consultant
1962.....**



Can you Help The Pyjama Foundation?

The Pyjama Foundation would greatly value donations of Office Furniture eg:

- 2 x bookshelves no wider than 25cm and no longer than 100cm.
- 1 x table – rectangular – somewhere between 150cm – 180cm in length and 90cm wide
- 3 office chairs – gas lift

The Pyjama Foundation provides extra reading experiences for children in care to increase the number of books read to them. 'Pyjama Angels' read to children in foster care on a weekly basis, thereby giving foster carers support and a well deserved respite.

(The Pyjama Foundation is a not for profit community organisation and a valuable part of the Self Help Sector in Queensland)

If you can help please contact Diane Hawke on Ph: 07 3262 5569 or email diane@thepyjamafoundation.com www.thepyjamafoundation.org.au

Stroke Association of Queensland (SAQ) Celebrates New 'Online Community'

In its March 2009 newsletter, SAQ delivered the good news that it has developed an online stroke support group which will enable stroke survivors to talk to each other via their keyboards.

It was primarily designed for those who do not have access to a stroke support group. Several experienced support group members will be on the site at set times to assist new 'strokies'.

There is a 'contact us' feature for stroke survivors, carers or members of the public to ask peer support volunteers private questions about living with stroke - and get a prompt answer. Ph: 1300 753 787

Email: strokeaq@iinet.net.au

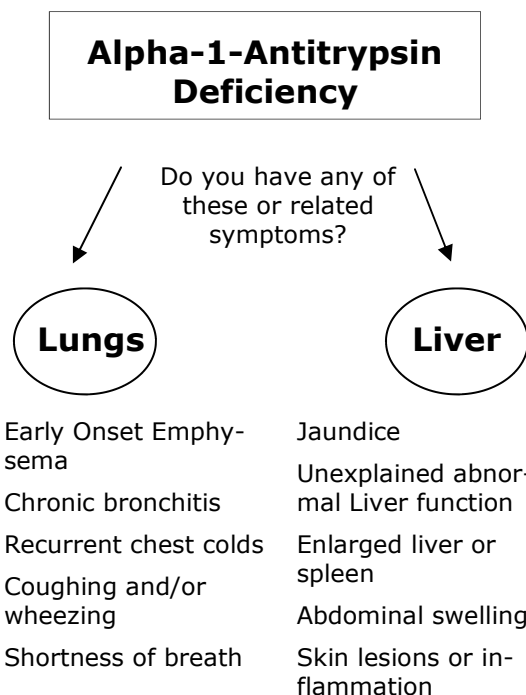
www.strokeqld.org.au

Not Responding to Treatment for Asthma?

Are you being treated for asthma but not responding to your medications and treatment? There is a chance that you may be suffering from Alpha-1 Antitrypsin Deficiency.

A rare type of emphysema, known as A1AD-related emphysema, is a genetic condition in which there is a lack of a protein called alpha1 antitrypsin (AAT). This protein normally helps protect the lungs from other harmful enzymes that can destroy lung tissue. In people with alpha-1 antitrypsin deficiency, smoking is especially dangerous because it hastens the speed at which emphysema develops.

A1AD can also predispose an individual to other illnesses which can affect the liver, such as liver cirrhosis, or more rarely, panniculitis (a skin condition) or vasculitis (inflammation of blood vessels).



The symptoms of A1AD

A1AD affects people in different ways and symptoms can vary between individuals. Some of the common early symptoms, associated with lung or liver dysfunction, are shown above.

With some symptoms similar to asthma it is not unusual for A1AD not to be detected and for the patient to be treated for asthma in error.

Who is affected by A1AD?

As a genetic condition, A1AD is passed from parents to children through genes. Everyone has two copies of the AAT gene; most people have two normal copies. A1AD sufferers may have either one normal and one disease-associated copy, or two disease-associated copies of the gene.

Approximately 1 in 50 people worldwide have at least one affected gene. The severity of the disease varies between individuals, as AAT levels in the bloodstream may range between 10-80% of normal levels, depending on the number and type of affected genes an individual has.

Medical tests and diagnosis of A1AD

A1AD is one of the most common hereditary disorders in the world, but it often remains undiagnosed. If you suffer from any symptoms listed above or if you are not responding to treatment for asthma, you can ask your doctor for a simple and inexpensive test to measure the level of AAT in your bloodstream. Low AAT levels may indicate a need for DNA testing to confirm A1AD and an individual's AAT genetic make-up.

If you have a relative who has been diagnosed with A1AD or a family history of early emphysema or liver disease, DNA testing is also recommended, even if your AAT levels are not especially low. ***Some people with A1AD may present without obvious symptoms and lead relatively healthy lives, especially if they avoid smoking.*** However, they still risk passing the affected gene on to their (Continued on Page 6)

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children. These people should also seek medical attention if early symptoms of A1AD become apparent.

Can A1AD be treated?

Currently there is no specific treatment for A1AD in Australia aside from standard procedures to relieve the symptoms of associated illnesses. However, with early diagnosis and by making particular lifestyle adjustments, affected individuals can minimise its effects.

Such measures include:

- avoiding tobacco smoke, noxious fumes, dust and pollution
- receiving early treatment for lung infections and colds
- receiving immunisations against influenza and pneumonia
- staying fit with regular exercise
- moderating alcohol consumption
- maintaining a healthy and balanced diet, ensuring the liver is supplied with essential nutrients.

What help is available?

For those who have been diagnosed and/or their family and carers, help is available via the Alpha-1 Association of Australia (AAA). The Association provides information on the illness which is updated from time to time with appropriate medical news. An online discussion group enables members to exchange information, tips and personal advice which can be of particular benefit to the newly diagnosed.

As with other forms of Chronic Obstructive Pulmonary Disease, it is important that A1AD be identified ASAP - for early management and better outcomes.

Alpha-1 Association of Australia

Web site, online discussion group or to purchase AAA t-shirt:
www.alpha1.org.au

Contacts: Steven Knowles
steven.knowles@alpha1.org.au
Skype: steven-knowles

Julie Moore julie.moore@alpha1.org.au
Tel: 0403 143 360 or (07) 4982 5594



SurveyMonkey

A free resource that could be helpful to your small group

SurveyMonkey is a free online survey tool that your group could easily use to survey its members.

Started in 1999, SurveyMonkey enables people of all experience levels to create their own surveys quickly and easily, and to receive the feedback needed to make more informed decisions.

SurveyMonkey gives you the tools you need to create your own surveys quickly and easily. There is a free version for the basic subscriber which allows for 100 responses per survey. This would be ideal for some small groups.

There is also a professional version for \$19.95 a month which allows for unlimited pages and questions, and 1000 responses.

SurveyMonkey says 'We've sweated the details to enable you to create a survey and start collecting responses with a minimum of fuss. There is no software to install, and no complicated manual to spill coffee on. Our software is designed with one goal in mind: allowing people of all experience levels to easily create professional surveys. There are no long-term commitments or hidden charges.'

SurveyMonkey.com is a licensee of the TRUSTe Privacy Program - an independent, non-profit organization whose mission is to build user's trust and confidence in the Internet by promoting the use of fair information practices. It is located in Portland, OREGON, USA.

If you know of any free or low cost resources that would be helpful to other members of the Self Help Network, we would love to hear about them.

Please contact SHQ on 07 3344 6919 or email selfhelp@gil.com.au

Thank you



NEW!



YOUNG ADULT CARER SUPPORT GROUP

Are you aged between 18 – 26 years and care for a family member or spouse with a mental illness?

Arafmi Qld and Carers Queensland recognise that it can be difficult to access the right sort of support once you turn 18 years old. You can no longer go to the Koping Program but don't really feel like you fit with adult groups or services.

We are starting a support group for people in this age group and would like to talk to you about this. For further information or to register your interest please contact:

Sharon at Arafmi Qld
Ph: 3254 1881
Email: supportgroups@arafmiqld.org
Lelia-Maree at Carers Queensland on 3900 8135 or email her on ldoherty@carersqld.asn.au.

"I don't know. People always think that there has got to be a dark side to everyone, a closet with skeletons, demons under the bed. People think all kinds of things about one another. They feel compelled to make up fears and false assumptions about their closest friends.

Truth is, I'll never know all there is to know about you just as you will never know all there is to know about me. Humans are by nature too complicated to be understood fully.

So, we can choose either to approach our fellow human beings with suspicion or to approach them with an open mind, a dash of optimism and a great deal of candour."

**Tom Hanks
Actor, Producer, Director, Writer
1956.....**

Jelly Beans

Social Support Group



Are you a guy with a girl's body?
Are you a girl with a guy's body?
Don't feel like a guy or a girl?
Feel like you're a bit of both?
Or maybe you're not sure...?
You're not the only one!!!

Come meet other people like you at Jelly Beans.

A free supportive social group for young people 23 or younger who are:

- Trans (eg transsexual, transgender, two spirit, sister girl, crossdresser, brother boy)
- Gender-Diverse
- GenderQueer
- Or who are not sure about their gender

Meetings takes place on the 2nd and 4th Saturday of the Month from 3pm to 5pm

Nibblies provided. Family members welcome!

There's no set way to dress (you don't have to dress up) – just wear whatever feels right for you.

Open Doors Youth Service
3 Julia St, FORTITUDE VALLEY
Ph: (07) 3257 7660 and ask for Lisa or Rocky
Email: opendoors@opendoors.net.au
URL: www.opendoors.net.au

Go Green - Read the Screen!

Are you willing to receive this newsletter by email rather than post? It would be a big cost saving to SHQ as well as the environment.

We are still happy to send it by post to small groups or individuals who do not have their own computer. Please let us know at 07 3344 6919 or email self-help@gil.com.au If you no longer wish to receive the newsletter we would appreciate hearing from you also.

Thank you



Are you Looking for a Support Group that focuses on a Particular Infertility Issue?

ACCESS AUSTRALIA is Australia's National Infertility Network. It is a consumer based, independent, non profit organisation which provides infertility information, support and advocacy.

Access offers support groups called 'Options Groups' that relate to different infertility issues.

Options Groups provide relaxed contact between people going through similar experiences. You are able to talk to another member via email (or letter), over the phone or catching up over a coffee. It can be anonymous if you prefer. Access to these groups is through membership.

The following Options Groups are available:

- Options when you're on IVF treatment
- Options for donor conception
- Options for those undergoing ART treatment with a genetic issue
- Options after IVF Miscarriage
- Options for Men Only
- Options for Single Women
- Options for Approaching Life without Children
- IVF Parents' Options

For further information contact:
ACCESS Australia Infertility Network
Box 3605, Rhodes Waterside
RHODES NSW 2138

Ph: 02 9737 0158
Fax: 02 9737 0245
Email: info@access.org.au
URL: www.access.org.au

Most self help support groups do not receive any funding.

Payment of a small membership fee assists with postage, phone costs and general expenses, and is often the only way a group can survive. If a group has helped you, please consider joining.

Aarskog Syndrome

- support network available for affected families in Australia

Aarskog syndrome (AAS) is an inherited disease characterized by short stature, facial abnormalities, skeletal and genital anomalies.

It is an extremely rare genetic disorder affecting mainly males, but females may have a milder form. The condition is caused by changes (mutations) in a gene called 'faciogenital dysplasia'.

Synonyms of Aarskog Syndrome:

Aarskog disease, Aarskog-Scott Syndrome, AAS, Faciodigitogenital Syndrome, Faciogenital Dysplasia, FGDY, Scott Aarskog Syndrome, Shawl scrotum Syndrome

Tests

Genetic testing for mutations in the FGDY1 gene and X-rays.

It is not known how many families in Australia are affected by AAS.

Pauline is a member of a family of four generations affected by Aarskog Syndrome. She invites anyone affected by Aarskog (and their families) to contact her for information and peer support on 03 5941 9073.

(Source: www.nlm.nih.gov/medlineplus)

Help for Menstrual Migraines

Learn about the latest treatments for menstrual migraine by viewing a video-streamed presentation by Dr Caroline Harvey of Family Planning Queensland. Visit the Women's Health Queensland Wide website to view the videostream at a time that suits you.

www.womhealth.org.au

For more support with your period concerns you can call the WHQW Health Information Line on 3839 9988 or 1800 017 676

Self Help Groups extend people's access to helping networks.



Creutzfeldt-Jakob Disease (CJD) in Australia and the Role of the CJD Support Group Network

by Suzanne Solvyns

I read with interest the article 'Genetic Matters' in the March newsletter written by Kim Summers about BSE in cattle (mad cow disease) and variant CJD in the UK.

It was opportune that I was invited to write about the Australian experience of CJD and the work of the CJD Support Group Network (CJDSGN) in Australia as this is a very appropriate follow up to Kim's article.

Kim mentions the deferral, as blood donors in Australia, of people who have lived for six months (cumulative) in the UK between 1980 and 1996. This of course had a dramatic impact on blood supplies in Australia. Deferral of donors relating to prion disease is not new and I, like other recipients of human pituitary hormones and people, who had received dura mater transplants, were deferred as donors in the early 1990's when we were recognised as being at an increased risk of developing CJD.

First and second degree relatives of a CJD patient are also unable to donate blood and given that we average about 30 cases of CJD each year in Australia, this could mean the permanent deferral of potentially 600 family members each and every year.

So what is CJD?

CJD is a rare and fatal degenerative brain disease in humans. CJD is one of a group of diseases that affects humans and animals known as transmissible spongiform encephalopathies (TSE) or prion disease. In animals the best known TSE is BSE (bovine spongiform encephalopathy) commonly referred to by the media as 'mad-cow' disease.

Classical CJD (cCJD)

For simplicity, the term 'Classical CJD' is used in the National Infection Control Guidelines to describe all forms of human CJD except Variant CJD (vCJD). Variant CJD, also commonly known as 'Mad Cow' Disease is related to the consumption of BSE contaminated beef and to date we have had no reported cases of vCJD in Australia.

In Australia we average about 25 - 35 cases of classical CJD a year. Symptoms of CJD include loss of memory, dementia, confusion, patients often become clumsy and lack coordination which is known as ataxia and can develop jerking movements known as myoclonus. The rapid decline, particularly with sporadic CJD, is very characteristic.

Classical CJD includes

- Sporadic CJD (sCJD)
- Genetic or inherited CJD (gCJD)
- Iatrogenic or medically acquired CJD (iCJD)

Sporadic CJD is a rapidly progressive disease that has no known cause. It occurs at random in about one person per million of population per year and accounts for 85% - 90% of all cases of prion disease. sCJD mainly affects people in the 50 - 70 year age group. The length of illness can vary but sporadic CJD is often recognised for the rapid progression with survival usually only 3 - 6 months.

CJD is unique in that it can be genetic and is transmissible.

Genetic CJD accounts for only between 5% and 15% of cases of classical CJD. Genetic CJD includes the following:

- Familial CJD (fCJD)
- Gerstmann-Straussler Scheinker Syndrome (GSS)
- Fatal Familial Insomnia (FFI)

Genetic CJD is usually recognised from a family history of the illness in two or more blood relatives or can be diagnosed from a positive prion protein gene (PRNP) on the patient. In genetic CJD there is a defect in the gene encoding of the prion protein and it is inherited in families in an

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autosomal dominant fashion from generation to generation at a rate of 50%. Each person carrying the genetic mutation has a 50% chance of passing it on to each of their children. For someone carrying the gene they will eventually develop the disease, but there is no test to know if, or how long, they will live.

Most forms of familial CJD are impossible to differentiate from sporadic CJD and it is not until a gene test is done that a genetic cause can be established. Patients with GSS often survive for several years and patients with FFI suffer from a progressive and untreatable form of insomnia.

CJD is transmissible and it was in the 1960's that it was realised that Kuru, a prion disease affecting the Fore people of Papua New Guinea, was transmitted through cannibalism.

Iatrogenic CJD is the form associated with medical treatments. Although rare, iatrogenic CJD has occurred due to the use of human derived pituitary hormones for fertility and short stature, dura mater grafts and corneal transplants. There is also a recognised risk of transmission from the use of contaminated instruments used in procedures involving high infectivity tissues such as brain, spinal cord and posterior of the eye.

Variant CJD was first recognised in 1996 following the first death in 1994 in the UK. There have been over 200 cases, mainly in the UK, as a result of the consumption of BSE contaminated products and it is now known that vCJD can be transmitted through blood and blood products. Variant CJD is clinically quite different to classical CJD and looks more like Kuru, has a longer duration of illness, presents often with psychiatric symptoms and affects a much younger age group (average age 27 years). Abnormal forms of the prion protein are often found in peripheral tissues such as the spleen, lymph nodes and tonsils which pose a risk of transmission that does not occur in classical CJD.

From the Kuru experience in Papua New Guinea we have also learnt that incubation periods can be as long as 50 years and this may be dependant on our genetic makeup. There are two different types of amino acid – methionine (M) or valine (V). As everyone has two copies of the gene, they can be MM, MV or VV, with 47% of the population being MV. Almost all of the patients with vCJD have been MM which researchers indicate may influence the incubation period. The incidence of vCJD is declining but there is fear that there may be another wave of vCJD amongst VV and MV genetic type people.

Why does this disease have such an impact on the blood supplies in Australia and attract screening questionnaires on admission forms in many hospitals in Australia?

Although there is no proof that classical CJD can be transmitted by blood there is also no proof that it cannot and for those who are at increased risk of developing CJD in Australia, for example over 2000 people who were on the human pituitary program up until 1985 and people who have received dura mater grafts during neuro-surgery until 1989, there is no way of knowing if they are incubating CJD. As the years pass we are more confident that there will not be any further cases relating to these medical procedures but with the research available and the lessons we have learnt from Kuru it is impossible to say and people who have been identified as having an increased risk of developing CJD, myself included, will continue to be deferred from donating blood and face screening questionnaires on CJD on admission forms in hospitals and other facilities.

For family members, where genetic CJD has not been ruled out by predictive testing on the individual, they are assumed to be at risk by the Australian Blood Bank as a precaution only, but if genetic CJD in the family has been ruled out by genetic testing on the patient then family members, although still deferred from donating blood, do not

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require any special precautions for any medical procedures.

Disclosure of risk is a moral obligation and not a legal obligation so it is important when people disclose their 'at risk of CJD' status that they are not discriminated against as this causes a real reluctance to disclose in the future.

CJD Support Group Network

The CJD Support Group Network (CJDSGN) was established in 1994 and funded by a 10 million dollar package provided by Dr Carmen Lawrence as a result of recommendations made by the Allars Inquiry into the Australian Human Pituitary Hormone Program (AHPHP). The recommendations included the establishment and funding of the CJD support group network to provide recipients of human Pituitary hormones (hPH) with information and support.

Over the course of the past 15 years the role of the CJDSGN has developed significantly. In 2005, I received a phone call from an upset young woman who had lost her father to genetic CJD and wanted to know why there was no support offered for families dealing with this horrific disease. We had been supporting families in a default manner for many years but recognised that a more formal structure needed to be in place. Assisted by the Australian National CJD Registry we negotiated an agreement with the Department of Health and Ageing to extend our contract and funding to provide an expanded range of services to people affected by all forms of prion disease in Australia.

For Families dealing with a loved one with CJD support and information can be vital. Families often feel isolated and frustrated as diagnosing CJD is difficult with an autopsy being the only way to obtain a definitive diagnosis. There is no effective treatment and no cure and families are left dealing with coming to terms with the fact that their loved one is going to die from this devastating disease. Families are also faced with the fear that there may be a genetic cause

which will in addition affect other members of their family.

The CJDSGN provides a helpline, information packs for families, a website and actively advocates for timely and non discriminatory access to health care for those at risk. We have established a network of state health department representatives and infection control experts to assist with any issues that arise for family members and people at risk of CJD.

In an attempt to resolve many of the issues facing individuals suffering with suspected CJD and their families, and those with an at risk, and to create more awareness we have produced an educational DVD 'Understanding CJD' with the assistance of notable Australian experts on prion disease as well as infection control experts in Australia. This is being used as a tool in a national education awareness program in hospital and at conferences. Since February 2008 when we launched this program we have presented on 50 occasions to over 1200 health care professionals.

More recently has seen the implementation of our family ACCESS project the has enabled the CJDSGN to extensively improve the experience of families caring for, or who have lost a loved one to CJD through the ongoing provision of information and contact with health and community services. The upset your woman who rang me in 2004 seeking support for her family become involved in the expansion and establishment of a family harm of our network and is now project manager of ACCESS (Access for carers to Education and Support Services).

2008 saw the first of our national annual conferences in Melbourne and this year it was held in Sydney. We hope to continue this event in different states each year.

The CJDSGN was a founding member of the CJD International Support Alliance (CJDISA) which brings together like organisations from around the world who share a commitment (Continued on Page 12)

(Continued from Page 11)

to all affected by prion disease and fills the gap that exists on an international level to assure excellence in the service to all individuals and families affected by prion disease. When CJDISA was formed in 2006 it attracted the attention of NeuroPrion, which consists of the leading research groups in Europe. For the past three years representatives of CJDISA have been invited to present to researchers and experts as the voice of those affected around the world.

Suzanne Solvyns, Director
CJD Support Group Network
Ph 02 98998905 Toll Free 1800 052466
Email: s.solvyns@cjdsupport.org.au
Website: www.cjdsupport.org.au

-oOo-

Community Engagement Needs Sound Principles to Guide the Process

An effective community engagement process needs to be guided by sound and equitable community engagement principles. These are fundamental to any effective consultative, participatory or consensus process. The principles below can be used to establish or assess any community engagement process:

Shared commitment to the process: Participants recognise that the agreed process offers the best opportunity to address the common identified issues.

Accountability: Participants effectively represent the interests of their constituents and have the support of the wider community. Participants are obliged to identify any conflict of interest, real or perceived.

Clarity of roles and responsibilities: Participation in the process is voluntary, with the roles and responsibility of all participants clearly defined.

Openness, procedural fairness and equity: All participants have equal opportunity to contribute to the process and its design. The degree of influence participants have on the outcome is clearly stated. Rationales for all decisions are comprehensively explained.

Timeliness of decision-making and information delivery: To maximise full and effective participation, decisions are made and information delivered in a timely manner. All participants agree to clear and reasonable timeframes.

Access to information, expertise and personnel: All participants have equal access to available information and resources to ensure their effective and informed participation throughout the process.

Easily-comprehended information and flexible processes: Technical information is communicated in a manner that allows informed participation. Flexibility is a feature of the process design, so that change can be adequately handled.

Continuity: The process is designed to ensure participants are able to be involved throughout. This means that emerging issues or new participants will not be disadvantaged.

Commitment to consensus: Participants are committed to reaching agreement, despite differences in values, interests and knowledge.

Feedback mechanisms: The process includes a mechanism through which frequent and open feedback on emerging issues, outcomes of consultations, and any recommendations arising from the process are brought to the attention of relevant stakeholders.

(Source: <http://ntn.org.au/index.php?option=content&task=view&id=50>) National Toxics Network)

New! Coming Soon!

SHQ Online Directory

Free to join! Free to Search!

A Singular Place Dedicated to Queensland & National Support Groups of All Kinds.

"I try to use the Australian idiom to its maximum advantage"

**Paul Keating
24th Prime Minister of Australia
1944.....**

Check out the Facts

from **Graham Perrett MP, Moreton**

'I want to set the record straight on a number of hoax emails on the airwaves about government assistance for refugees. I receive regular inquiries about these emails.

They are part of a coordinated campaign of misinformation designed to upset Australian pensioners. The text and figures mentioned do not originate from Australia; instead they compare Canada's payments to refugees and pensioners.

Refugees granted permanent protection visas are permanent residents of Australia and can access Centrelink benefits on the same basis and at the same rates as any other Australian permanent resident.

If you receive emails with other information I encourage you to check out the facts before forwarding it on. **www.newsroom.immi.gov.au/media_releases/269?page=2&** We all have a part to play to make sure divisive and racist claims such as these are refuted.'

(Graham Perrett's Email Update 23rd April 2009)

Resources Available to Address Myths and Stereotypes

The Australian Human Rights Commission has updated the online Face the Facts education resources, which aim to provide students with a stronger understanding of issues concerning Aboriginal and Torres Strait Islander peoples, migrants and multiculturalism, asylum seekers and refugees.

Race Discrimination Commissioner Tom Calma said there was a clear need for information that addressed prevailing myths and stereotypes about refugees, migrants and Indigenous peoples.

The resources are designed to introduce Australian students to human rights concepts in an engaging, relevant way. <http://humanrights.gov.au/education/facts/>

Bullying and Autism

Many parents worry if their ASD child will be bullied at school or elsewhere in life. Sadly this can happen, in the same way that other children can also be bullied. It is important to teach them early how to recognise a bully and to have the strategies in place to deal with them. The ASD child can also be the bully, so instruction needs to be given here as well. Bullies are not only in the playground or classroom. You can find them anywhere, and they are the type of person everyone needs to learn to handle - not only those with ASD.

Bullying is serious, not to be tolerated, and needs to be stamped out. If your child is bullied in any sense of the word, contact your child's school teacher, administration, regional office or sporting club etc immediately. A couple of websites you may find useful are:

<http://autism.about.com/od/theautismcommunity/a/bullies.htm>

<http://www.brighthub.com/education/special/articles/28002.aspx>

<http://www.bullyingnoway.com.au/who/default.shtml>

<http://education.qld.gov.au/curriculum/advocacy/access/equity/students/inclusion/supportive/cgp-bullying.html#who>

(Mackay Autism SG Newsletter No 4 April 2009)

How to deal with a boyfriend with Asperger's Syndrome

<http://www.wikihow.com/Deal-With-a-Boyfriend-Who-Has-Asperger%27s-Syndrome>

There's so much negative imagery of black fatherhood. I've got tons of friends that are doing the right thing by their kids, and doing the right thing as a father - and how come that's not as newsworthy?

**Will Smith
USA Actor, Film Producer, Rapper
1968.....**

Understanding the Meaning Behind the Stories Told by People with Dementia

On occasion the Alzheimer's Association Dementia Helpline receives calls from carers wanting to know the reason why their loved one with dementia is engaging in telling stories about the past which mix fact with fiction. Carers often report feeling a sense of frustration and distress especially if storytelling is repetitive. The literature on dementia states that the act of combining fact with fiction in storytelling is a process called "confabulation" or "pseudo-remembrance" (Crisp, 2000).

In her book "Keeping in touch with someone who has dementia", Jane Crisp describes from personal experience, the many issues, including confabulation, she faced when caring for her mother with Alzheimer's.

Below is a list of suggestions for learning to cope with storytelling:

- However fantastic the story may seem, the person with dementia is not lying to you. Rather, the person believes what they are saying to be true. Remember, people with Dementia can lose the ability to distinguish between past experiences in their own lives, what they may have imagined and what they may have watched in a movie or on television
- Listen to the person with dementia's story sympathetically. Instead of being distressed by the fact these stories may be untrue, ask yourself what is the meaning behind the story and what purpose does storytelling serve?
- Storytelling can be a means of social interaction for the person with dementia, it can be an act of needing to be heard and valued.
- A person with Dementia can experience a loss of social identity and self, it is important that we do not ignore their stories because they do not present the full facts.

Listen sympathetically to the person telling the story and ask what is the person trying to tell me?

Ref: Crisp, J. (2000) Keeping in Touch with someone who has Alzheimer's, Ausmed Publications, Melbourne, pp.85-94.

(Source: 'Dementia Matters' Autumn 2009)



Learn the Facts About Hepatitis

- In Australia 278,000 people have been exposed to hepatitis C and 160,000 people to hepatitis B
- Approximately 1 person is diagnosed with hepatitis C every hour
- Up to 39,000 people may be unaware they have hepatitis C
- In Queensland around 40,000 people have hepatitis C
- Hepatitis C is found in blood and spread by blood to blood contact
- Hepatitis B is found in all body fluids and is spread through blood to blood contact and unprotected sex
- A vaccine is available for hepatitis B, not for hepatitis C
- Both hepatitis B and C can be managed through healthy eating, exercise and alcohol management
- There is medical treatment available for both hepatitis B and hepatitis C

For news, information and support groups for people with hepatitis in Queensland please contact:

Infoline: 1800 648 491
Receptionist Phone: (07) 3236 0610
30 Herschel St, North Quay, Brisbane
Email: reception@hepqld.asn.au
Website: www.hepqld.asn.au

*** 1 in 12 people worldwide have viral hepatitis B or C. The message from recent World Hepatitis Day events is to encourage people to question themselves (not others) and to get tested.**

(Source: Hepatitis C Virus Projections Working Group; Estimates and Projections of the Hepatitis C Virus Epidemic in Australia 2006.)

Sharing Photographic Memories

By Bob Wyborn

"Line by line, moment by moment, special times are etched into our memories in the permanent ink of everlasting love"

Gloria Gaither

It really is a most precious and special occasion to share the memories of our loved ones who have died and are recorded in prized photos. The power of this shared love further cements our bond to each other and venerates our loved ones. This is not something we can do with those who do not know our journey. They do not have our experience nor would we wish that they did.

The memories recorded in the past only have power in the present. In the early days of our grief they can produce intense pain and love – and an ambivalent mixture of many other emotions. As we progress along the mountainous road of mourning that we desperately hope leads to the place called Understanding; our memories have signposted the way. They have many names and destinations. Some are marked as such - Sorrow, Tears, Pain, Confusion, Despair, Anger, Ambivalence, Love, Loss, Helplessness, Hope, Courage, Persistence, Honesty, Acceptance, Patience, Perspective, Forgiveness, Compassion, Awareness and Happiness.

All of these lead us to that place called Understanding.

There are some that have names such as – Revenge, Self Pity, Hatred, Morbidity, Hopelessness, Fear and Defeat.

These all lead to cul de sacs and can turn our experiences into a maze of extra pain and slow down our journey. Sometimes we just get lost and never get there. What a tragedy that is!

The power of our sharing emphasises the unique gifts our loved ones have given us through their lives and we always need to keep that as a key focus

in our memories. Whilst the past is where we draw our memories from it is only the present where they have meaning and exert the power to encourage us and return joy to our lives. They will always have a background of tinged sorrow but this is overshadowed by the illumination of supreme Joy that their memories bring to our lives and the sense of purpose that has now moulded our forever changed life.

I heartily endorse Corrie ten Boom's comments that – **"Memories are the key not to the past, but to the future"**

Bob is a member of SHQ Management and is always available to anyone who wants to contact him and chat about their personal growth or problems.) To contact Bob: Ph: 07 3283 7224 Mob: 0419 683 195 Email: bobwyborn@bigpond.com

*Corrie ten Boom was a watch and clockmaker, author and Holocaust survivor 1892 - 1983

*Gloria Gaither is a singer/songwriter of Gospel music 1942.....

Heard of The Wonderful Wonder Factory?

Did you know there is a fantastic place for children to visit while at the Royal Children's Hospital? Have you ever had a morning appointment and then had to wait around for hours till the next one? Make the time pass super fast and join the fun at the Wonder Factory!

The Wonder Factory is located on Level 1, Coles Building, RCH and is jam packed with things to entertain children of all ages - interactive games, arts and crafts, playstation, Nintendo, and Xbox, board games, karaoke and face painting. The centre is for the use of RCH patients, families and visitors. Whether you are just visiting for the day or staying a little longer, check out the Wonder Factory. You'll have a great time!

Weekdays: 7:00am – 7:45pm
Weekends: 9:45am – 5:00pm
<http://www.workingwonders.com.au/go/help-sick-kids/volunteer/wonder-factory/>

(Source: Thanks to the Cleft Pals Qld Newsletter Edition No. 56 Autumn 2009)

New!
Freedom
Transgender
Support Group



Located on the Gold Coast

Freedom is a social support group for transgender people, their family and friends to meet in a safe and friendly environment.

Freedom was started recently by a group of transgender women (MTF) who recognized the need for a support group on the Gold Coast for those who identify as transgender or gender variant. They received the support of the region's medical professionals as well as transgender support groups in Brisbane.

As with any group that is different or challenges societies' norms we face special issues and challenges that go with being and living as transgender people. Not the least of which is the social stigma associated with changing one gender or living outside the gender binary of society or the misguided association of gender and sexuality being the same issue. This, combined with the stigma of having to accept the diagnosis of a mental disorder to obtain treatment, would be one of the most contentious issues for not only transgender people but a lot of professionals as well.

The group held a very successful first meeting in April. 19 people represented a wide cross section of age groups and genders - demonstrating the need for such a group on the Gold Coast!

Information we would like professionals to know about working with their transgender clients

"When sociologists use the term sex they are referring to biologically determined features which make people male or female - and how precise even these are is debateable.

Gender on the other hand, refers to how these biological differences are interpreted and translated into social expectations in every day life".¹

Working with transgender people comes with special challenges and rewards. It calls for an open mind and requires the worker to first consider their own reaction to the issues. Are they comfortable with their own gender identity and sexuality, as working in this field will challenge their own perceptions of **sex and gender roles?** Workers also need to take into account the reactions of other workers and clients to their working with transgender clients.

Terms and Definitions

It is important to understand a few basic terms when working with gender variant people and address them with the correct pronouns and title. For instance a male to female transgender person as she or her, or a female to male transgender person as he or him.

Transgender is the politically correct term for gender variant people whether they be transsexual, intersex or androgenous in their gender presentation.

Transsexual is a person, ether male or female, who identifies as and has a desire to live and be accepted as a member of the gender opposite to the gender they were assigned at birth. Many transsexuals want to, and do, change their bodies to realign them with the gender they identify with. A transsexual is said to be suffering Gender Identity Disorder GID.

Gender identity is the gender that a person identifies as. Gender identity can be below the surface as is the case with many transgender people who remain in the closet or hide their gender identity for various reasons. In the case of transgender, the gender identity is the opposite of their birth gender.

Gender Identity Disorder (GID) is a recognised medical condition listed in the Diagnostic Statistical Manual of Mental Disorders 4 (DSM4) that describes the diagnostic criteria for transsexualism. This disorder is identity based not sexually or sexuality based.

Transgender or transsexual people find it extremely (Continued on Page 17)

(Continued from Page 16)

offensive to be referred to as Cross dressers or Drag Queens.

(Prosecutable under the vilification clause of the anti discrimination act)

Issues for those early in transition

Extra consideration needs to be taken of those transgender people early in their transition due to several issues.

Those early in their transition can be highly sensitive to the in correct use of titles and pronouns. At this stage of the person's transition they are looking for validation of their gender identity and may be socially isolated due to their transition. It is not unusual for the transgender person to lose the support of family and friends when they come out and need this support the most. If unsure it is better to ask how the person would like to be addressed and use that.

For those just starting out on their transition body language, speech and presentation may not be congruent with the gender identity they present. This may lead to misunderstandings or conflict, which can be avoided by carefully making sure both the worker and the client understand each other. This can also be caused by the expectation of the worker that a person of a certain gender should act in a certain way.

Most transsexual people are taking high levels of cross sex hormones to effect their transition. Thus, in the first few years, they can experience a sense of gender euphoria with intense highs and lows. This can affect judgement and interactions with others.

For those who have transitioned recently they may not have had the time or money to up date the documentation needed to represent the new gender. This can cause confusion for the worker when dealing with reporting and record keeping. The process and extent to which the person can change records varies from state to state.

Ongoing Issues

Even when transition is complete there are still issues worth considering for

transgender clients. Overall, there is a lack of general knowledge in both the community and the welfare industry of Gender Identity issues.

There is a lot of social stigma associated with gender issues and the classification of Gender Identity Disorder (GID) as a mental illness (See DSM4).

Gender identity forms part of the Anti Discrimination Act of 2003, but discrimination is still a fact of life for many transgender people in Queensland. Unemployment rates for transgender people average 60% in the western world.

Social isolation is a problem for many. When they transition genders, people often lose their friends and family at the time they need them most for support.

For information, meeting times, venue:
Freedom Transgender Support Group
Rochelle 0417 557 130
Linda 0415 410 385
Email: freedom.support@hotmail.com
Freedomqld@yahoo.com.au
Web: www.yourgender.com

¹ (Lupton, Short and Whip (1993)

Resources and Help

Gold Coast Sexual Health Clinic
Ph: 07 55769033

Australian Transgender Support Association
Queensland (ATSAQ) Ph:07 3843 5024
Email: info@atsaq.com.au URL: www.atsaq.com

Brisbane Gender Clinic. Ph: 617 3238 4081

Dr Lyn Conway: (Computer Scientist, Electrical Engineer, Inventor, Research Manager, Engineering Educator) home page <http://ai.eecs.umich.edu/people/conway/conway.html>

Same Service - New Name!

The Australian Crohn's & Colitis Association (Queensland) Inc (ACCAQ), recently merged with Crohns and Colitis Australia™ (CCA)

The service provided by the Queensland group will remain the same, only the name and some details are new:

Crohn's & Colitis Australia™ (QLD)
PO Box 497, Buddina Qld 4575
Tel: 07 5437 7662 Fax: 07 5437 7103
E: info.qld@crohnsandcolitis.com.au
www.crohnsandcolitis.com.au

Queensland Police Service Research Needs Volunteers



Seniors and Online Fraud

Have you ever received an email...

- asking you to invest money in an overseas company or scheme?
- telling you about a lottery win when you didn't buy a ticket?
- advising you of an inheritance of someone you have never met?
- requesting permission to use your bank account to deposit a sum of money?
- requesting you to confirm your account (bank, share trading, eBay etc.) details and passwords online?
- from an unknown person asking you for money, personal details or any of your personal passwords?

Have you ever sent money overseas to a person you have never physically met via a cash remittance agency such as Western Union?

If you answered **yes** to any of these questions and you are aged 50 years or older, we would like to talk to you about these online experiences.

The Queensland Police Service is currently seeking volunteers to participate in an important research project examining seniors and online fraud.

Have you ever replied to one of these emails, by sending money, your personal details or any of your passwords?

If you answered **yes** your participation is even more important!

We are seeking volunteers who have responded to these types of email requests as well as those who have not.

If you have responded to an email request for money, personal details or passwords, your experiences are vital to the research project. There is no need to feel ashamed or embarrassed about

this; the experience is shared by many people in Queensland and beyond.

By participating in this research project, you can help the Queensland Police Service to more effectively develop strategies to protect the community from fraudulent online schemes.

For further information about this project or to register your interest, please contact Dr Cassandra Cross:

Community Safety and Crime Prevention Branch, Queensland Police Service
Telephone (07) 3234 2111

Email fraud.research@bigpond.com

SHQ spoke with Dr Cross who advised:

- Meetings will be held face to face and will take about an hour
- There are no geographical limits - volunteers just need to be Queenslanders
- Where geographically possible, the researchers will come to you
- In more remote areas, if there are several participants, the researchers will try to arrange a suitable meeting place for interviews.
- The study will be conducted over a span of several months

FINANCIAL OMBUDSMAN SERVICE

Do you know what the Financial Services Ombudsman does?

If you have a problem with a financial product or service talk to your financial services provider first. (eg bank, financial advisor, mortgage broker, insurance, stockbroker, superannuation etc)

If you are unable to resolve the problem with your provider, the Financial Ombudsman Service provides accessible, fair and independent dispute resolution services as an alternative to taking your dispute to court. The service is free to consumers.

Hotline: 1300 78 08 08

(Ask for the free translation service if English is not your first language)

Information: info@fos.org.au

Website: www.fos.org.au



Do you have Klinefelter Syndrome?

Do you know someone who does?

You're not the only one... **Klinefelter Syndrome (47XXY) is a very common genetic condition**, yet most individuals go undiagnosed and untreated.

There have been many studies on the medical aspects of KS, but almost nothing is known about how a diagnosis of KS affects someone personally; the psychosocial impact. **We want to change this**, and we invite you to find out more about a study we are conducting.

Our Study

Andrology Australia, the national men's health organisation, together with the Murdoch Children's Research Institute, Prince Henry's Institute of Medical Research and Monash University, want to understand more about KS. Participation in this project is an opportunity to help. We want to ask people how their lives have been affected by being diagnosed, and living with, various aspects of KS.

We are seeking individuals with KS aged 18 years and older to participate in our study and share their views, opinions, experiences and stories of what it is like to be diagnosed with KS and to live with KS, including the good and the bad. Because the features of KS can vary greatly, we are keen to involve as many people as possible - of all ages, stages, and walks of life. This includes individuals that may have been diagnosed when their mothers were pregnant with them (prenatal diagnosis).

What does the study involve?

Participating in this study involves completing a written questionnaire (telephone assistance is available if required) of about 30-40 minutes. This asks questions about when and how you were diagnosed, what medical treatments you have received, family life, yourself and your body.

Participants will also be asked to provide

a saliva sample and will be invited to participate in an optional interview (in person or over the phone). You will receive a gift card as a thank you for your time. For further information contact: Amy Herlihy (Project Coordinator), Public Health Genetics, MCRI Royal Childrens Hospital, Flemington Road, Parkville VIC 3052 Ph:(03) 8341 6370 Fax:(03) 83416212 Email:klinefeltersyndrome@gmail.com

The study is Nationwide, and recruiting continues to August 2009.



Children & Natural Disasters

Free Resources to Help Children Cope

The Australian Child and Adolescent Trauma, Loss and Grief Network recognises the impact of floods and bushfires on the health and well being of Australian children.

To this end, the Network has provided an online list of Australian and International resources aimed at assisting children to cope with disasters. The resources are designed to provide useful and accurate information on the emotional impact of floods and bushfires and how children can be supported.

The resources are relevant to Teachers, Health and Allied Professionals, families and community members.

The Australian Child and Adolescent Trauma, Loss and Grief Network, ANU CANBERRA ACT. Ph: 02 6125 8412 http://www.earlytraumagrief.anu.edu.au/child_adolescent_disaster/

New SHQ Directory To Go Online in 2009

for self help/support groups

We will be contacting you soon for permission to include your group in the new online directory. It will be a free, one stop showcase for all support groups in Queensland.

Niemann-Pick Disease Group Being Formed in Australia

Niemann-Pick Disease is one of a group of lysosome storage diseases that affect metabolism and that are caused by genetic mutations. The three most commonly recognized forms are Niemann-Pick Types A, B and C. (NPA,NPB,NPC)

The clinical prognosis for NPA and NPB patients is very different. NPA is a severe neurologic disease that leads to death by 2 to 4 years of age. In contrast, patients with NPB generally have little or no neurologic involvement and may survive into late childhood or adulthood.

Niemann-Pick Type C (NPC) is very different than Type A or B. Type C Niemann-Pick Disease has about 500 cases diagnosed worldwide. It is believed, however, that the number of people affected by NPC is higher, but diagnostic difficulties do not allow an accurate assessment of the occurrence rate.

NPC has been initially diagnosed as a learning disability, mild retardation, "clumsiness," and delayed development of fine motor skills. It is not uncommon for families to spend several years seeking a diagnosis before NPC is identified.

An Australian group for people affected by Niemann - Pick Disease and their families is being formed. The founder, Mandy, has two adult sons who are both affected by Niemann - Pick Type C and she is keen to speak with others. Individuals or families affected by Niemann Pick Disease are welcome to contact: Mandy Ph: 0409 573 740 or email: mandy@jacobsfertandgrain.com.au

(Source: National Niemann-Pick Disease Foundation www.nnpdf.org)

Advertise your Group's 2009 Conference or Special Event in SHQ's 'Diary Dates'

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

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

Ever Heard of CDG?

The Bailee Ada Foundation is a research, awareness and support network for families affected by Congenital Disorders of Glycosylation (CDG)

CDG is a group of rare disorders. Most people have never heard of CDG and it can be difficult to understand. It is a genetic condition which occurs when one of the many steps involved in glycosylation goes wrong. There are many types of glycosylation error, and so there are many different types of CDG, and great variability in severity.

Glycoproteins perform important functions in virtually all parts of the body ie CDG can affect any part of the body. The brain is the most complex part of the human body and is the most common organ affected. CDG can also affect the liver, intestines, heart, bones, eyes, kidneys and immune system.

Around the world, hundreds of children (and some adults) have been diagnosed with CDG, but it is expected that there are many thousands more who have CDG but have never been diagnosed.

There is currently no specific treatment for CDG and certainly no cure. This means that once a diagnosis has been made, current treatment is to focus on managing the individual symptoms of CDG as they arise.

Bailee Ada Foundation

Ph: Melissa on 0414846603

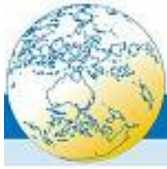
www.baf.org.au

(Source www.baf.org.au)

"The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not knowing not healing, not curing.... that is a friend who cares"

Henri Nouwen

**Psychologist, Author, Theologian
1932 - 1996**



National Toxics Network Inc

- working for pollution reduction, protection of environmental health and environmental justice for all.

The **National Toxics Network (NTN)** is a community based organisation formed in 1993 and since then has grown as a national network to support community and environmental organisations across Australia, New Zealand and the South Pacific. NTN provides non-government organisations (NGOs) with a national and international voice on chemical and toxics issues.

For news and up to date information on environmental health issues eg the shipping spill off Brisbane, two-headed fish in the Noosa River, Orica's plans to dump waste toxic waste from it's Botany Bay plant to Denmark, where they want to burn it, check out the NTN website.

If you want to know what's in your cosmetics, or how to detox your home it's there too.

NTN also has campaigns relating to children's health, sustainable food, persistent pollutants etc.

A spray drift kit has been developed along with an incident report form which can be downloaded from:
<http://www.ntn.org.au/index.php>

NTN is now calling on the Australian government to ban the toxic insecticide endosulfan.

The New Zealand government has joined 55 other countries in banning endosulfan. This followed the international finding that endosulfan fulfils the criteria of a persistent organic pollutant under the Stockholm Convention.

For further information contact:
National Toxics Network
PO Box 173, BANGALOW, NSW, 2479
Ph: 02 6687 1900
Email: info@ntn.org.au
URL: www.ntn.org.au

Thermoregulatory Dysfunction?

Do you rely on air-conditioning or heating to maintain a safe body temperature?

Are your power bills costing you a fortune?

A petition to subsidise power in Queensland for people with severe thermoregulatory dysfunction is to be brought before the Queensland Parliament.

A number of Queenslanders with severe disabilities are unable to control their body temperature. They rely on either air-conditioning or heating to maintain a safe body temperature. This requires extensive power usage of above average power consumption. The great majority of people in this situation are on pensions and incur financial hardship.

Thermoregulatory Dysfunction is suffered by people with a variety of medical conditions and disabilities including: stroke, head injury, neuro-degenerative conditions, skin conditions (severe burns and inflammatory diseases), vascular disease and multiple amputations.

You can e-petition or send a paper petition by going to the website below:

http://www.parliament.qld.gov.au/view/EPetitions_QLD/CurrentEPetition.aspx?PetNum=1191&Index=-1

Sponsoring Member of Parliament:
Jason O'Brien MP, Member for Cook (Cairns) Petition No: 1191-09

Closes 2nd August 2009

Australasian Genetic Alliance (AGA) Launches First Newsletter

AGA, the national body for genetic support groups in Australia, has produced its first newsletter - introducing State and NZ members. SHQ is the Queensland representative to AGA. To read the newsletter go to the AGA site:

www.australasiangeneticalliance.org.au



Top 10 Queensland Consumer Complaints in 2008

The Queensland Office of Fair Trading received more than 108,000 consumer queries during 2008, resulting in more than 11,000 consumer complaints statewide.

Top 10 most complained about products in 2008:

1. Residential property management 493
2. Faulty motor vehicles 332
3. Residential property sales 325
4. Motor vehicle sales 318
5. Gift and discount vouchers 287
6. Deposit and investment services 260
7. Maintenance and repair of motor vehicles 249
8. Unlicensed lotteries 236
9. Rainwater tanks 225
10. Personal computers and laptops 174

Top 10 most complained about industries in 2008:

1. Personal and household goods 2763
2. Gambling schemes and scams 1245
3. Real estate agents 1023
4. Personal and household services 925
5. Motor vehicle sales 690
6. Motor vehicle service, repairs and parts 409
7. Business services 354
8. Accommodation, hotels and motels 316
9. Telecommunications 314
10. Travel agents 285

Anyone who thinks they may have been ripped off or treated unfairly while making a purchase should raise the issue with the trader and if this is unsuccessful, the Office of Fair Trading and its investigators are there to help.

Consumers can contact the Officer of Fair Trading:

Phone: 131304

Download a complaint form from:

www.fairtrading.qld.gov.au



New! Free! Consumerwise Booklet

– a guide for Queensland consumers

The Queensland Government, through the Office of Fair Trading, has recently published a new booklet 'How to be Consumerwise'

It covers just about every contingency - far too many to describe here. The information is quite detailed and very broad ranged.

Consumerwise is a comprehensive 88 page booklet designed to help you with everyday transactions, show you how to avoid scams and take the stress out of being a consumer.

A few examples of some of the topics covered in the booklet:

- P4 - Your consumer rights under the Fair Trading Act
- P12 - Signing a contract
- P14 - Telemarketing
- P22 - Motor vehicles
- P24 - Real Estate
- P36 - Household repairs and itinerant traders
- P43 - Wills
- P49 - Miracle cures
- P53 - Computerised betting/stock market schemes
- P57 - Banking
- P72 - Retirement Villages
- P75 - Power of Attorney
- P79 - Sample complaint letter
- P80 to 85 - List of complaint services and other relevant consumer organisations

You can get more information on the booklet by calling the Office of Fair Trading:

Phone 13 13 04 or view it on their website:

www.fairtrading.qld.gov.au



Mercury Rising: Strengthening Mental Health Support Groups

Project Update No.2 – April 2009

With the Mercury Rising project starting 'where people and groups are at' it has taken some considerable time to complete the first stage of building the base. I believe that the groups involved understand that developing capacity is the key to their present and future successes so they are happy, indeed enthusiastic, to participate and help implement the priority actions. Thus the mercury is rising and the project has now moved to a 2nd stage' with quite a lot of progress to report.

Small grants: Letters regarding the 1st round of small grants have been sent to 56 groups and, to date, over 40 requests have been received and payments made. A process for implementing the agreed 2nd round of grants of up to \$2000 (on the understanding that there are insufficient funds to allow every group to receive the full amount) has yet to be discussed and agreed upon. However, the intended timeframe for implementation is that:

- Criteria and an application pro forma has been discussed and accepted by groups state-wide by the end of June with information about the application process and criteria then sent to all groups by the end of July.
- Applications close mid-September, are then assessed by the Project Advisory Group (PAG) and decisions made by the end of October with all payments made by the end of November.

The aim is to have the full amount of project funding currently allocated for grants (\$120,000) paid to groups by the end of the year.

Training: Training events held to date have gone well with participants saying it has all the components that make for an interesting, extremely informative, well-structured, fun learning experience.

If you are interested in taking part in an event near you please contact me ASAP.

Evaluation: SHQ is employing an independent evaluator (Jenny Ostini from the Healthy Communities Research Centre, Ipswich campus, University of Queensland) to provide feedback on the Mercury Rising Project. The goal of this evaluation is to reflect on the real issues surrounding capacity-building with mental health support groups in order to learn for the future.

As part of the process, Jenny will be interviewing a selection of network meeting attendees and also members of the PAG. Some of the interviews will be done in person and some by telephone. Jenny will be asking about your participation in, and experiences of, the project. Of particular interest is how you feel the project has affected the groups in which you are involved. Have things changed for the group and how? Have you learnt things that have helped build the group? What are the positive and negative impacts of your group being involved in the project? Does your group feel more stable, supported and connected? This information will be made available to participants through network meetings, a flexible process of learning together.

Jenny invites anyone who would like to participate in the interviews, to email her directly (jostini@gmail.com). She will then set up a time to do either a telephone or in-person interview.

Next Round of Network meetings:

Brisbane/Toowoomba: 20th May
Gold Coast: 29th May
Townsville: 18th June (to be confirmed)

A range of verbal feedback responses has been received regarding the most important understandings that have come out of these meetings but a typical comment is that 'this network meeting is really very valuable, offering (as it does) support and learning for facilitators. It is high time that facilitators of local mental health support groups network together as we are the key force of each individual group'. (Continued Page 24)

(Continued from Page 23)

Helping to build stronger groups: So many of you are contributing your time and effort, not just to your individual groups but also to achieving the goals of this project. Thanks to all of you for your contributions to making mental health support groups a supportive environment that increases the wellbeing of members and assists their recovery process. Thanks for:

- Coming along to meetings – your presence gives others encouragement to keep going;
- Contributing to discussions and activities – your efforts are helping to get things done;
- Speaking your mind – your ideas about what we should and shouldn't do help us make decisions;
- Being courageous – being willing to be part of creating change;
- Being patient – continuing to hang in there when things take longer than we all want.
- We have all worked well together thus far to develop a shared picture for the future of mental health self help support groups so let's keep 'living our vision'.

Diana East, Mental Health Project Worker, Ph: 3 8 8 0 3 5 0 1
Email: dianaeast@primus.com.au

Help Available to Manage Challenging Dementia Behaviours

Self Help Queensland members are being reminded about a **free service**, the Dementia Behaviour Management Advisory Service (DBMAS), administered in Queensland by Alzheimer's Australia (Qld), available to help people caring for someone with dementia whose behaviour is impacting on their care.

The program helps people to cope by having non judgemental, professionally trained staff assess the situation and make suggestions to support both the carer and the care recipient. Each

person's situation is different and needs to be assessed so the most appropriate support is given.

Examples include reviewing the physical environment, introducing more familiar surroundings or setting up new ways of managing the activities of daily living to help everyone involved feel more comfortable and confident. The program can also fund access to specialist services that might not otherwise be available.

Carers can contact the service on 1800 699 799 at any time of the day or night.

About Dementia

- Dementia describes a large group of illnesses that cause a progressive decline in functioning.
- Common symptoms include confusion, personality changes, apathy, withdrawal, loss of ability to perform everyday tasks, emotional changes.
- Dementia is more common over 65, but can occur in the 40s and 50s.
- The most common form is Alzheimer's disease (50-70% of cases).
- There is no prevention or cure though some medications can relieve symptoms in some people.
- There are currently 40,000 people living with dementia in Queensland and that number is set to grow to 171,000 by 2050.

For further more information contact:

Email: info@alzqld.asn.au

URL: www.alzheimers.org.au

Changes to Make-a-Wish®

Effective Monday 1st June 2009 Make-A-Wish® Australia will lower its minimum Wish-granting age to **3 years**.

Patients aged **3 to 18 years** with life-threatening medical conditions are encouraged to apply for a Wish. Patients **under 3** are encouraged to apply for a Wish Hamper. Wish Hamper recipients are welcome to apply for a Wish on or after their 3rd birthday. Contact:

Phone: 1800 032 260

URL: www.makeawish.org.au

Australian Charter of Rights?

A charter of rights, once set into the Constitution, is a strong legislative document that protects the rights of all people, cannot be infringed by government, and in particular can only be changed by a vote of the people.

The United Nations Convention on the Rights of Persons with Disabilities was ratified by the Australian government on 18 July 2008. Subsequently it was learned that the Rights protected by the Convention, on their own, had no value, and could only be effective if they could actually be used – that is, the Convention had no worth unless it was recognised under Australian law. Furthermore, Australia is the only democratic country in the world that does not have a Bill or Charter of Rights, and as long as this situation continues, the government cannot extend the Rights in the Convention to persons with disabilities.

A National Human Rights Consultation Committee has been consulting across the nation, hearing stories from those who have experienced human rights abuses including people with disabilities.

Submissions can be made as part of the consultation. Queensland Advocacy Inc. (QAI), has met with other like organisations and retained a human rights lawyer to formulate a submission articulating a strong policy position on the need for an **Australian Charter of Rights**.

Organisations, people with disabilities and friends are called upon to support the submission by communicating evidence of human rights abuse of people with disabilities.

Please send your submission to:
National Human Rights Consultation Secretariat, Attorney-General's Department Central Office, Robert Garran Offices, National Circuit, BARTON ACT 2600 or submit on line: <http://www.humanrightsconsultation.gov.au/www/nhrcc/nhrcc.nsf>

Closes 15th June 2009

(Source: Thanks to Marion Webb, Information Officer, Spinal Injuries Assoc & to QDIN Network)

Invitation to Have Your Say!

An invitation is extended to attend one of two health consumer forums that Health Consumers Queensland will be hosting in June 2009 to listen to the views of health consumers and their carers and family members.

Townsville: 4 June 2009 from 10 am to 3.30 pm - Metropole Hotel

Brisbane: 23 June 2009 from 10 am to 3.30 pm - Royal on the Park Hotel

Some sponsorship (accommodation and travel) is available to those consumers who would otherwise be unable to attend. Contact HCQ (07) 3234 0611
Registration Essential: For forms go to:

www.health.qld.gov.au/hcq

'News for Seniors'

News for Seniors Magazine, previously known as 'Age Pension News' is a free, quarterly publication containing helpful information not only for Age Pension pensioners, Service Pension pensioners, holders of the Commonwealth Seniors Health Card and members of the Pension Bonus Scheme but also for people approaching pension age.

It contains current pension rates and thresholds, concessions, allowances and services, along with Centrelink news, key phone numbers, websites etc.

Examples of information included in the latest edition are; claiming a pension from another country, Broadband for seniors, Centrelink's Financial Information Service, Updating Superannuation, Reverse Mortgages and more.

If you would like to receive a copy of News for Seniors call the Retirement Line on 13 2300.

For 16 languages version Ph: 13 1202
For audio version Ph: 13 2300.

View in English or other languages at:
www.centrelink.gov.au

Volunteer Treasurers

From Villain to Superhero in a Few Short Steps

Thanks to Our Community Matters Newsletter March 2009 for the following article.

At Our Community, we run a Board Matching Service, which helps to put community groups in need of new board members in touch with people with skills to offer.

One of the most frequent requests we get is for treasurers, and yet these are often the hardest vacancies to fill.

Nerida Gill from Admin Bandit takes a look at why people are so reluctant to take on the role of treasurer, and how you can overcome your own fear of doing the books.

Most people run in the opposite direction when asked to take on the role of treasurer. In fact, it's probably the least understood role in an organisation but, with a bit of know how, it's not difficult.

And it is actually very rewarding - managing your organisation's finances effectively is one of the best ways you can add real value to your local community.

You don't need to be an accountant, a book keeper or a financial magician to be a treasurer, you just need to start with the right attitude and some insight into what's required.

By using the right tool for the job and taking some time to understand what's required to be a treasurer, it can be a simple and straight forward task.

The following checklist has been designed by Admin Bandit to help new volunteer treasurers settle into the role and build confidence.

Arrange a Handover

1. Schedule a coffee or catch up with the outgoing treasurer to swap important documents. This includes handing over the accounts, cheque books, receipt books, invoices/receipts for purch-

ases, bank statements, budgets, reports and any other relevant documents.

2. If your organisation uses accounting software such as Admin Bandit, get a tutorial on how to use it, including passwords.

3. Hand over the treasurer's or financial procedures manual, if your organisation has one. If not, you can create one when you're more familiar with your role — this will add value to your organisation and future treasurers will breathe a sigh of relief!

4. Discuss any unfinished business, such as due bills or income, and any spending commitments or expected income that isn't in the latest budget.

5. Ask questions! This is your chance to discuss any worries, have accounting concepts explained or get troubleshooting advice. Grab the outgoing treasurer's contact details for future reference.

Change Bank Signatories

6. Your organisation probably has a rule that two or three committee members, including yourself as treasurer, must sign, and thus authorise, cheques and bank withdrawal slips. You need to update your bank's records of who these people are, which is as simple as picking up a form from any branch and then filling it in. All new signatories will probably need to go to the bank and show 100 points of identification, unless they are existing customers.

Get Organised

7. Start as you plan to continue — getting organised now will give you a clear picture of what you're doing and set the tone for your tenure as treasurer. It will also save many hours of late night hair-tearing and rummaging through a mess of paperwork.

8. Hopefully your predecessor was just as diligent as you're going to be, which means you can leisurely go through the accounts, checking everything is filed correctly and familiarising yourself with what's required. (Continued on Page 27)

(Continued from Page 26)

If not ... well, you may have a bit of work to do! But rest assured your organisation will thank you for it.

With a bit of planning, organisation and insight, you can take the role of volunteer treasurer from Villain to Superhero.

Find the right tool for the job, set up good processes for your committee and turn up to every committee meeting with your head held high knowing your organisation is in good shape.

(Nerida Gill is the creator of Admin Bandit accounting software for volunteer treasurers, designed from her experience as a volunteer treasurer so as to turn the task of managing books from a dreaded job into a simple weekly task.)

www.adminbandit.com.au

Changes for Tenants and Boarders in Queensland



Starting 1st July 2009

The Residential Tenancies and Rooming Accommodation Act 2008 is a new act that changes some of the rules for renting houses, units, townhouses, caravans and other moveable dwellings. It becomes effective on 1 July 2009.

Some key changes relate to before tenancy, tenancy agreements, rent and rent increases, entry to the property eg.

- Tenants must be given 2 months notice to leave without grounds
- Rent increases limited to 2 per year
- Rental properties must be advertised at a fixed rate - no rent ranges or auction-style bidding allowed.
- New Tenancy Agreement Forms

For all the new changes go to RTA at: www.rta.qld.gov.au or Ph:1300 366 311

"All I ask is the chance to prove that money can't make me happy."

Spike Milligan

1918....2002

Comedian, Playwright, Author, Poet

Showcase your Group?

Centenary Rocks! - an award winning annual festival which attracts around 10,000 people. You can promote your community group at a very low cost.

**Information Booth only - \$20
Stall - \$40 promote & fund raise**

This year the festival will include a community health area to highlight health and well being issues. SHQ will have a stall, so if you need us to help distribute your literature please contact us.

**Saturday 25 July 2.00 pm - 7.30pm
Sunday 26 July 10.00 am - 4.00 pm**

Venue: Rocks Riverside Park, Seventeen Mile Rocks, Brisbane
Organisations should complete the application form at www.ccconnect.asn.au

Queenslanders with Chronic Disease Face Ongoing Patient Transport Problems

Queenslanders for Patient Transport is an alliance of groups/organizations which have identified a major issue in Patient Transport in Queensland.

Many Queenslanders with chronic disease and needing transport to medical treatment do not have access to transport that is:

- Delivered in a timely manner
- Affordable
- Appropriate to the person in need
- Of a satisfactory Standard

Dialysis patients can wait up to 5 hours for the ambulance service to take them home after a 5 hour dialysis session.

Chemotherapy patients most commonly require 2 - 6 hours one day per week in hospital. Their repressed immune systems put them at risk in group settings.

For a comprehensive account of Patient Transport issues, or to find out how to take action, go to www.tdsa.org.au and follow the link to Queenslanders for Patient Transport or contact:

Jennifer Leigh Ph: 07 3849 4193

Email jenny.leigh@aapt.net.au

5 Independent Complaint Agencies Re-locate

The agencies listed below are now all together under the one roof at:

Level 17, 53 Albert Street,
Brisbane

The co-location will make it easier for people to access the right complaint agency and enable the 5 agencies to work more closely together. Reception, training and meeting facilities are shared for greater efficiency.

Health Quality and Complaints Commission (HQCC)

Ph: 07 3120 5999 Fax 07 3120 5998
Toll Free 1800 077 308
TTY 07 3120 5997
URL: www.hqcc.qld.gov.au

Anti-Discrimination Commission Queensland (ADCQ)

Ph: 1300 130 670
TTY: 1300 130 680
Email: info@adcq.qld.gov.au
URL: www.adcq.qld.gov.au

Queensland Office of the Commonwealth Ombudsman

Ph: 1300 362 072 Fax: 07 3228 9999
ombudsman@ombudsman.gov.au
URL: www.ombudsman.gov.au

Queensland Ombudsman

Ph: 07 3005 7000 Fax: 07 3005 7067
Toll Free: 1800 068 908
TTY: 07 3006 8174
ombuman@ombudsman.qld.gov.au
URL: www.ombudsman.qld.gov.au
(Please phone first for appointment)

Commission for Children and Young People and Child Guardian (CCYPCG)

Ph: 07 3211 6700 Fax: 07 3035 5900
1800 688 275 (Free call)
Email: wmasterccypcg.qld.gov.au
URL: www.ccypcg.qld.gov.au

Self Help Groups exist because ordinary people start them.

Invitation to Make a Difference

TOUGHLOVE® Basics Workshop "Helping You Help Your Kids"

Saturday 20th June 2009
9.00am – 4.30pm

This workshop introduces the basics of the TOUGHLOVE Program for Parents of Teens and Young Adults. It is aimed at:

- Parents who are struggling with their children's unacceptable behaviour
- Professionals who may wish to refer parents to the TOUGHLOVE Support Program
- Communities wanting to establish a TOUGHLOVE Parent Support Group of their own

The Program helps parents find new and effective ways of dealing with unacceptable behaviour like verbal/physical abuse, truanting, drug/alcohol abuse, stealing, refusing to look for employment, not cooperating at home etc.

Register: TOUGHLOVE Qld Ph 3856 3211
Website: www.qld.toughlove.org.au
Venue: Scout Association Headquarters, 32 Dixon Street, Auchenflower

Does Your Group Offer Learning Opportunities?

(eg. courses, workshops, seminars, conferences, discussion groups etc.)

Want to Let Others Know?

Self Help Queensland is a member of the Lifelong Learning Council Queensland (LLCQ) www.LLCQ.org

LLCQ is establishing a **Directory of Adult and Community Learning** <http://www.llcq.org/eddb/>

You are welcome to set up a **FREE** online account to let people know about the learning opportunities you have to offer. Once your account has been established, you can use your username and password to make changes at your convenience. Please contact LLCQ for further information: directory@LLCQ.org

**The Chromosome 18
Registry & Research Society
(Aust) Inc**

**2009 Annual Family Meeting
26th to 28th September**

The 2009 Chromosome 18 Registry & Research Society's Australasian Regional Annual Family Meeting will be held from Saturday 26th to Monday 28th September in Christchurch, New Zealand.

A wide range of topics will be covered. Our guest speaker will be Dr Jannine Cody from The Chromosome 18 Clinical Research Center, Texas, USA. This is an opportunity to network with affected Chromosome 18 families and individuals.

For enquiries please contact Marlene:
Ph: 02 9580 5707
Email: chromosome18@optusnet.com.au
Website: www.chromosome18.org

**Managing Pituitary and
Hormones in Adults Seminar**

Seminar for adults and adolescents affected by pituitary disease or disorders, their families and health professionals.

**Saturday 30 May 2009
8.45 am - 4.15 pm**

You are invited to a public education seminar, which will address the function of the pituitary gland, consequences of pituitary disease and the latest treatments and research.

For enquiries and registration please contact Sue Kozij
Ph: 07 3376 2083
Email: qld@pituitary.asn.au
URL: www.pituitary.asn.au

Venue: Mater Medical Centre, Conference Room, Level 1, 293 Vulture Street, South Brisbane.

Presented by the Australian Pituitary Foundation Ltd in association with Mater Private Hospital Brisbane, funded by a grant from NOVARTIS.

**Working with Adults
Surviving Child Abuse**

- A Workshop for Health Professionals
Friday 26 June 2009 9am to 4.30pm

**Presented by Adult Survivors of
Child Abuse (ASCA)**

Working with adults surviving child abuse is challenging and requires specialised training. Knowledge of the biological and interpersonal consequences of childhood trauma has exploded over the past two decades. This workshop integrates this new information and provides best practice guidelines for working with adults surviving child abuse.

The workshop has been designed for:

- social workers
- health professionals
- counsellors
- psychologists
- psychiatrists
- mental health nurses

Venue: Urban Brisbane, 345 Wickham Terrace, Brisbane, QLD. For workshop information and registration visit ASCA:

www.asca.org.au

**Healthy Male Forum 2009
Gold Coast 19th - 21st June**

The theme of the forum is 'an holistic approach to men's health', - an overview of latest developments and understanding in men's health that cross over social aspects and health behaviours, research and medical interventions.

An exciting program of speakers - Prof Rob Moodie, (Vic), International guest speaker Dr Steve Robertson (UK), Prof Alex Barratt (NSW), A/Prof Ian Davis (Vic), Dr Mark Wenitong (Qld), Prof Phil Mitchell (NSW),

Presentations include the health of incarcerated men, behaviour modification in men & lessons learnt from smoking cessation programs, engaging men in maternal and child health services, and associations between chronic disease and reproductive health.

More information can be found at:
www.asnevents.com.au/andrology/

Presented by Andrology Australia



Diary Dates

15th & 16th June 2009: Communities in Control Conference: 'Crisis, Catastrophe, Community: Rebuild, Renew, Recharge' (Performance by Original Members of Choir of Hard Knocks)

URL: www.ourcommunity.com.au/cic2009

Venue: Melbourne

17th - 20th June 2009: International Association for Community Development Conference: 'Building Community Centered Economies' Presenters from around the world.

URL: www.CDconference.com.au

Venue: Brisbane

25th & 26th June 2009: Queensland Alliance 2009 Conference: "Altering States - Reforming the System".

The 2007 Conference created a vision for how the Mental Health System should look in 2020. The 2009 Conference will discuss how to achieve it.

URL: www.qldalliance.conorg.com.au

Venue: Sofitel Hotel, Brisbane

20th to 22nd August 2009: Asian Pacific Autism Conference 2009

<http://www.apac09.org/general-information.php>

Venue: Sydney

27th to 29th August 2009: Australia and New Zealand Academy of Eating Disorders (ANZAED) Conference

URL: www.anzaed.org.au

Venue: Brisbane

31st August - 1st Sept 2009: QCOSS 50th Anniversary Conference

URL: www.qcoss.org.au

Venue: Brisbane

18th - 20th November 2009: 2nd National Siblings Australia Conference "Creating Connections"

Ph: 08 83571214

Mob: 0408 720 558

Email: kate@siblingsaustralia.org.au

URL: www.siblingsaustralia.org.au

Venue: Adelaide

Invitation

The Myositis Association Australia

The 'Keeping in Touch Queensland Group' welcomes members, family and friends to get together at the Gold Coast - lunch and meeting - 11am start.

Wednesday 17th June 2009

RSVP by 14 June to Marilyn Waters

Phone: 07 3823 1419 or

Email: waters-1@bigpond.net.au

Venue: Italo-Australian Club, 18 Fairway Dve, Clear Waters Island G.C.

Narcolepsy Community Conference 2009

For people with narcolepsy, families, interested professionals and community

Saturday 10th October 2009

Contact: Narcolepsy and Overwhelming Daytime Sleep Society of Australia (NODSS) Ph: 03 9432 9669

Email: info@nodss.org.au

URL: www.nodss.org.au

Key Centrelink Phone Numbers

- Retirement Line 13 2300
- International Services 13 1673 (Pensions outside Australia)
- Centrelink Multilingual 13 1202 (Languages other than English)
- Disability, Illness or Injury and Carers 13 2717
- TTY Customer Rel 1800 000 567
- Customer Relations 1800 050 004 (Comment, complain or compliment)

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

The material supplied is for information purposes only, and is not to be used for diagnosis/treatment, or as legal, tax, accounting or any other type of advice. Self Help Qld reserves the right to edit contributed articles.

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