



Newsletter March Quarter Issue 1. 2011



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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

Hello everyone

It seems like years since our last Newsletter to you. What a year it has been so far! We sincerely hope that you and your group are on dry ground with minimal losses. As a former 1974 'victim' I can feel for those of you who weren't so lucky. If there are group resources missing, or some talking needed, you must let us know how you would like us to help. It is just as well Australians are generally credited with having a good resilience. What does that mean?



Thea Biesheuvel

In my Dictionary it says that this is the capacity to spring back to the original shape or form after having been bent, stretched or compressed. It is also the capacity to rebound quickly from misfortune or illness. All that is good and well, but how soon is meant by 'quickly'? Certainly not overnight and probably not within a week. Some of us resume our 'original shape' or 'form' and resume our normal routine only to find that we are shorter of temper, or suddenly need a lot more sleep, or can't relax at all. Everyone congratulates us on getting 'over' things so well and so we carry on ignoring the changes in our life's rhythm.

Of course some of us are really resilient. We are too busy to dwell on misfortunes. Sometimes another misfortune befalls us or illness resurfaces. Life gets difficult.

This is when we need to have someone to talk to. A group of people who have all suffered the same misfortunes or illnesses is like a 'homecoming' then. We can talk without having to censor ourselves. That, my friends, is how I became 'hooked' on self-help groups for mutual support.

Even today, the 2011 flood brings back memories for me and my children (now adults) of all we had to manage in 1974 and afterwards. It still tests our resilience. There are other misfortunes that we all share. In fact, the biggest revelation for participants of our Self Help networking workshops is to find that there are so many of us sharing similar conditions.

There will be two opportunities for us all to come together in 2011 (Continued on Page 3)

Self Help Queensland Management Committee Members

President	Thea Biesheuvel
Secretary	Joe Soda
Treasurer	Chris Spriggs
Members	Casey Barber Cathy Wu Clemencia Naranjo

Committee Meetings

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

SHQ Staff

Co-ordinator

Trish Fallon

Project Officer - Mental Health

Gina Jacobsen

Project Officer - General

Mosmin Marediya

Administration Officer

Janette Evans

BOCDSG Co-ordinator

Pat Minnaar

Office

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

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

Office Location:

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



Disclaimer

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.

"My years as a medical practitioner, as well as my own first-hand experience, have taught me how important self-help groups are in assisting their members in dealing with problems, stress, hardship and pain..."

the benefits of mutual aid are experienced by millions of people who turn to others with a similar problem to attempt to deal with their isolation, powerlessness, alienation, and the awful feeling that nobody understands...

Health and human service providers are learning that they can indeed provide a superior service when they help their patients and clients find appropriate peer support."

- former U.S. Surgeon General C. Everett Koop, MD

Contents

President's Message	1
SHQ Management & Contact Details	2
The Digital Divide	3
Impact of Floods on Mental Health Groups	4
Genetic Matters - It's only a game	5
Lonliness - As bad for health as smoking	6
Self Help Qld News	7,8,9
Assorted Resource Information	10
Kleinfelter Study Update	11
I Can't Take It!	14
Diabetes - What Now?	15
Disability Lifestyles	15
What Makes a Great Constitution?	16
Journey Through Road Trauma	17
Diary Dates	18

Thank you to all our current funding bodies - Qld Health, Dept Communities (Mental Health Branch), Brisbane City Council.

(Continued from Page 1)

to share our joint experiences in mutual support. We will also re-convene our Self Help and Support Group Awareness day in the city, so successful in introducing some of you to each other while making the public aware of our existence.

We've all been bent, stretched and pressured, I'm sure. Let's rebound together.

Thea

The Digital Divide!

New Perspectives on Barriers to Accessing Health Information

(The following extract comes from the "Genetic Alliance Monograph Series #5" - a publication produced by the Genetic Alliance, Washington DC, based on the September 22, 2009, Meeting "Trust it or Trash It". (Page 26) The meeting and subsequent publication were the result of a co-operative agreement funded by the National Centre on Birth Defects and Developmental Disabilities Centres for Disease Control and Prevention - aimed at examining issues relating to the creation and assessment of health information.)

Patients, parents, healthcare providers, and the public are inundated by a constant flow of health information from myriad sources, both reliable and unreliable. This bounty of information is ever-expanding, along with opportunities to disseminate it online further and more quickly.

"There are many types of literacy at play in understanding health information. General literacy is an important factor, but one audience member noted the difference between general literacy and health literacy, and digital literacy is yet another factor.

Speakers described health-illiterate patients with low general literacy or a lack of computer skills. The participant countered that his father is highly literate, but nonetheless has trouble understanding genetics articles.

Similarly, participants commented that hyperlinks are useful for people who are highly computer literate, but useless for people who read on the Web as if they were reading a brochure. For these users, printable versions should be available in a way that preserves the hyperlinked information.

The need to communicate with all members of a community affected by a genetic disorder requires using a variety of tactics. We cannot "leave behind a subset of the population." In general, Gepp concluded, when "designing educational materials or in communicating information, I suggest using a combination of print and Web-based formats."

To read the entire Monograph Series#5 go to:

http://www.geneticalliance.org/sites/default/files/ksc_assets/publications/atcg_monograph.pdf

***Editor's Note:** *Most of us would probably suppose that web-based formats of accessing health information are the "modern way". The above information gives us reason to think again. Those of us charged with providing health information need to take a more considered approach - looking beyond those in cities and towns with speedy internet connection; beyond those who are computer literate and those who are health literate. Queensland's rural and remote areas are already suffering from a classic case of "Digital Divide" - with internet access that is slow, unreliable, black-spotted or non-existent. SHQ will continue to send the quarterly newsletter by post to those on the other side of the "Digital Divide" who require it that way.*

Impact of Recent Floods on Mental Health Support Groups

The recent floods have no doubt affected many of us in some way. We are aware that some support group facilities were completely inundated and our thoughts are with you. Our hearts also go out to those who have lost their loved ones, homes, businesses, possessions, family pets and precious personal items, not to mention all of those intangible losses where lives were so disrupted. We hope that support has found those many people who suffered.

Amidst the recent disasters of floods and cyclones, we have also witnessed the amazing generosity of volunteers pulling together in the initial Brisbane clean up with the reaching out to complete strangers in need. This reminds me of the relentless voluntary work that self help support group facilitators and members do every day to help and support one another. So we thank you for being there for our community.

Queensland self help support groups that cater for grief and loss and vulnerable mental health may see a slight increase in membership in the coming months as the impact of stress, loss and trauma challenges the mental health of our community. There may be an increase in anxiety and depression for some people and added complexity to existing vulnerable mental ill-health for others. The overall predicted increase in mental ill-health in the community as a result of the floods sits at around 10 -20%, and some of these people will select self help support groups as their preferred method of support. A Springfield self help support group facilitator for those experiencing PTSD has already linked in with some of the Valley flood victims.

It would appear that for much of the community, the impact of the floods and cyclones have disappeared, but for some people.. the danger still feels imminent! Acute trauma symptoms may be evident in some people by nightmares, avoidance, reliving the experience, a high startled effect, numbing or panic attacks. If these symptoms persist long term they may be symptomatic of PTSD. Trauma symptoms may also play out differently for children causing unusual behaviour. These trauma symptoms can have serious long term consequences if left unrecognised or unsupported.

Other consequences of the impact of the floods and cyclones may be grief and loss. Symptoms of grief and loss can sometimes be mistaken as symptoms of depression and can be misdiagnosed. Grief and loss can also become very complicated by other symptoms of mental ill-health and life situations. For others directly impacted by the floods, the grief and loss may be unleashed at a slower pace. Some people may be very busy at the moment replacing lost items, reorganising their lives, but in a few months when things slow down, they may start to grieve and that is very normal. They may appear very active and productive one day and struggle to get out of bed the next day, which is also normal when grieving a loss. With support and some internal work, most people will move through their grief successfully in their own time. Everybody grieves their losses differently and there is no right or wrong way to grieve.

If you recognise any group members with new long lasting trauma symptoms or complicated grief and loss please ensure they are encouraged to seek all avenues of support to ensure these new symptoms are not left unrecognised or unsupported. Everyone has individual strengths they take on their journey of loss and these strengths can be used to promote healing as they do in recovering from mental ill-health. Many Queensland self help and mutual support groups are well placed to recognise individual strengths and to support people who are on their journey of recovery from both tangible and intangible losses, trauma and mental ill-health. Thank you again Queensland self help support groups for just being there.

Gina Jacobsen - Mental Health Project Worker

Genetic Matters

by Kim Summers PhD

It's only a game

In 2006, a young American college student collapsed and died following an intense football training session. It was subsequently found that he carried a genetic variant in a gene for haemoglobin, the protein that carries oxygen around the blood. Now the US National Collegiate Athletic Association is forcing testing of all incoming college sportspeople (about 170,000 in one year) to be tested for sickle cell trait.

Most people make normal haemoglobin, called haemoglobin A, which binds oxygen in the lungs and delivers it to the extremities. But some people have one copy of the sickle cell variant of haemoglobin. This is called sickle cell trait. They make some haemoglobin A but also sickle cell haemoglobin, haemoglobin S. There is enough normal haemoglobin to provide oxygen to the tissues under most circumstances, so these people generally have no symptoms. Most problems occur in people who have two copies of the sickle cell variant and so make no normal haemoglobin A. These people have clinical symptoms related to the fact that their haemoglobin doesn't function properly. Without treatment they tend to die in childhood.

It is now clear that people with sickle cell trait (one copy of the normal haemoglobin gene and one of the sickle cell version) may also get some symptoms, especially under extreme conditions. Since 2000, 10 high level USA college athletes, who didn't know they carried the sickle cell trait, have died following intensive training sessions. This is why college athletes are now being tested, in an attempt to reduce the incidence of deaths related to sickle cell trait.

This might seem like a beneficial and helpful strategy. However, there are many arguments against forced genetic testing, particularly in a country like the USA where health insurance premiums are based on health status. Most of those who test positive for sickle cell trait will be African American, since the sickle cell variant is at high frequency in equatorial Africa where malaria has been rife for generations. Some carriers have no symptoms and no increased risk from extreme exercise. It is feared that discovery of sickle cell status could result in discrimination. At present the aim of the testing would be to ensure that sickle cell carriers receive appropriate training schedules which take into account the risks, but the possibility that colleges might select against carriers or that there could be other consequences of the screening has been discussed.

There are many other genetic conditions that can result in sudden death during intense exercise. Should there be genetic testing and screening for every variant known to be associated with risk to elite athletes?

In 1986, American volley ball player Flo Hyman collapsed and died during a match in Japan. She was later diagnosed with Marfan syndrome, a condition in which the aorta, the major blood vessel from the heart, can split (dissect), frequently with fatal results. Hyman's brother, a basketball player, was subsequently also diagnosed with Marfan syndrome and had his aorta repaired by surgery. In 2008 a 14-year-old boy from rural New South Wales was recruited to the Sydney Swans. During a routine medical examination, the club doctor was struck by the boy's great height, chest shape and flat feet. Marfan syndrome was diagnosed, and the boy is now unable to play any strenuous contact sport because of the risks to his aorta. There is no genetic screening test for Marfan syndrome, and yet there are many athletes who have been diagnosed and several who have died from the condition.

(Continued on Page 6)

(Continued from Page 5)

An 8-year-old boy scores a goal at soccer, races around the field in his excitement and then suddenly collapses. Another swims a length of the pool before losing consciousness. These young athletes may have long QT syndrome. Although we know of a number of gene changes which can lead to abnormal heart rhythms and possible cardiac death, it would not be possible to screen all those at risk from relatively mild and common levels of exertion. But if the cardiac abnormality is detected by a doctor, should the individual be banned from playing sport? That is the current recommendation of the American Heart Association and the European Society of Cardiology.

There is no doubt that involvement in sports is beneficial for most people. But there are some whose genetic makeup predisposes them to fatal consequences of exercise and activity. Genetic testing, moderating training, and discouraging participation in certain sports for people with these genetic predispositions will reduce the incidence of sports-related deaths. However, it is important to ensure that all people are able to take part in a healthy level of exercise, regardless of their genes. Finding the right game or activity and the appropriate level of training for young people is a central part of helping them to adjust to the diagnosis of a genetic condition so that they can make the transition to adulthood without unnecessary trepidation or concern.

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.

Loneliness Can be Just as Bad for Your Health as Smoking

A recent study published in the Public Library of Science Medicine indicates that having a poor social network is just as bad for a person's health as heavy smoking and drinking, and twice as bad for one's health as being obese.¹

The study, which involved analysis of more than a century's worth of papers (1900 to 2007) on social relationships and mortality, showed that people with adequate social relationships had a "50 per cent greater likelihood of survival compared to those with poor or insufficient social relationships".

According to the authors, this effect was comparable with quitting smoking and outstripped many well-known risk factors for mortality such as obesity and physical inactivity.

The researchers behind this study said there were two ways a social network of friends and family could contribute to good health – the support of others might help reduce the harmful effects of stress, and the influence of others could also encourage behaviour that contributed to good health.

Australia's recently released National Male Health Policy recognises the impact of social isolation on health. The Policy encourages a move towards social connectedness with the support of Men's Sheds, an initiative which is in line with the recommendations proposed by the authors.

They suggested health care policies and public health initiatives could benefit from considering social factors in efforts to reduce mortality, because "social relationship-based interventions represent a major opportunity to enhance not only the quality of life but also survival".

¹ Holt-Lunstad J, Smith TB, Layton JB, 2010 Social Relationships and Mortality Risk: A Meta-analytic Review PLoS Med 7(7): e1000316. doi:10.1371/journal.pmed.1000316

(Source: Andrology Australia Newsletter Issue 37 Summer 2010)

SELF HELP QUEENSLAND NEWS 1

Farewell Kevin Robins...we will miss you

Just after Christmas last year Brisbane lost one of its long standing support group facilitators, Kevin Robins of the Southside Anxiety Disorders (SAD) Group to a stroke. Kevin left behind his beloved wife Julia, many friends and colleagues and a dedicated support group. Kevin was also an active member of the Project Advisory Group for the Mercury Rising Project and a highly involved member of Parkinson's Queensland.

Thank you Kevin for the time you were here with us, the lessons you shared with us, and the lives you touched every day.

You will be missed but not forgotten.



Thank you Councillor Graham Quirk

Self Help Queensland has been very fortunate to receive a grant through the Lord Mayor's Suburban Initiative Fund (LMSIF) to purchase a desktop computer with wide screen monitor, wireless mouse and key board, along with a desk with mobile pedestal.

We are very thankful to our local Councillor and Deputy Mayor, Councillor Graham Quirk, for his support of our grant application, and for the ongoing support we receive from Graham and his staff.

We were lucky to receive the grant just in time! Only a few days later we were notified by BCC that the LMSIF program has now been diverted to Brisbane's flood recovery effort for the 2011-12 financial year. The future of this and other programs now depends on the level of financial commitment from the Federal Government.

Let's hope the program will be re-instated as soon as possible so more community organisations in Brisbane can continue to benefit from this generous program.

A Message to Brisbane Self Help and Support Groups!

It is great being able to introduce myself to self-help/support groups across Brisbane. My name is Mosmin Marediya. I have been employed by Self Help Queensland as a project officer for a Community Capacity Building Project funded by the Brisbane City Council. The purpose of the project is to help build the capacity of self help and support groups across the wider Brisbane area.

Firstly, I am aiming to connect with established groups, locate any newly formed groups, promote networking amongst groups, and seek to identify the current needs of groups. If common needs are readily identified, I will be endeavouring to work with groups to address some of these needs wherever possible.

I would like to invite members of self help groups within Brisbane to discuss any needs or issues. Feel free to contact me at:

Mosmin Marediya (Project Officer SHQ) Mon, Wed Thurs 9am to 4.30pm
Mob: 0447 152 516 Ph: 07 3344 6919 Email: selfhelpccb@gil.com.au

Mental Health Support Groups can contact our Mental Health Project Officer, Gina Jacobsen Mon to Friday 9.30am - 2pm on 0487 304 873 or selfhelpmh@gil.com.au

SELF HELP QUEENSLAND NEWS 2

News update February 2011:

Self Help Support Group Mental Health Project: Mercury Rising

It's been a great start to the year with the Mercury Rising project in full swing now. The project plan has been revised and contains slightly broader group criteria than the previous project in 2009. This means that the project will have a stronger focus on groups from CALD backgrounds and will accommodate a slightly broader range of groups. More information about group criteria and the small grants program will soon be available on a new Mercury Rising link on the Self Help Queensland website: www.selfhelpqld.org.au

To all the groups and facilitators who I have had the pleasure of meeting so far....thank you for the lovely warm reception! If I haven't spoken to or visited your group representative so far, don't worry, I'm not too far away!

Gina Jacobsen - Mental Health Project Worker -Self Help Queensland

Welcome Nicole!

Self Help Queensland extends a warm welcome to Nicole Mitchell who has joined the staff of SHQ for 3 months.

"As a third year Social Work student I am very much looking forward to the opportunity to explore and build my understanding of the role of Self Help Groups in supporting Queenslanders' Mental Health. I feel very privileged to be contributing to the Mercury Rising project, working alongside Gina Jacobsen, a Social Worker with a wealth of experience for me to observe and draw upon. I bring with me seven years experience in a variety of roles in Community Services and what I'm hoping this chance of reclaiming my (nearly full-time) 'student status' brings is space to reconnect and strengthen my optimism and conviction in people's ability to support each other well, with compassion and respect. I look forward to meeting and speaking with some of you in coming months."

Give Away

Self Help Queensland will give to a self help or support group:

1 x 4 drawer Namco filing cabinet, Lockable, Beige, Metal, Very good condition

Must be picked up from SHQ office. Contact Trish - Phone only - 3344 6919



Important! Please Put This Date in Your Diary Now!

National Self Help & Support Groups Awareness Day

Thursday 8th September 2011

Contact Trish at SHQ to register interest or for more information

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 selfhelp@gil.com.au If you no longer wish to receive the newsletter we would appreciate hearing from you also. Thank you

SELF HELP QUEENSLAND NEWS 3



Another Big Thank You to the Brisbane City Council!

The staff at Self Help Queensland are very thankful to those at BCC who made the recent brilliant renovations to our office possible.

We now have a modern kitchen area with new sink, under bench fridge and shelves galore to stack all the things that used to find their way onto the floor and under desks!

Our particular thanks go to Jason Woodhouse, Senior Project Manager - Land and Buildings City Assets Branch, who sought approval for the work to be done, designed the renovations, supervised their construction/installation and saw to it that SHQ did not have to pay!

We would also like to thank Jason's team, and all who gave approval for this project.



Those of you familiar with the SHQ office would understand why the staff are smiling so broadly!

Janette

Mosmin



2 Training Workshops in the Offing for Interested Self Help and Support Groups in 2011

Self Help Queensland would like to offer 2 training workshops to self help and support group members this year. However, we need YOU to tell us what you would like us to provide. We envisage one day in each half year dedicated to providing what the majority preferences would be.

Each of the two days could be broken into separate topics, or a whole day dedicated to one topic if that is what groups prefer. At this stage, workshops will be in Brisbane.

Topics could include such things as telephone listening skills - dealing with anger, grief, threats of self harm etc. Group facilitation, leadership, governance, conflict resolution, funding submissions, communication, group sustainability, public speaking etc

Please contact Trish at SHQ on 3344 6919 or selfhelp@gil.com.au with your preferred choices. We would like to hear from you so we can get the planning underway ASAP.

Don't Forget Self Help & Support Groups Awareness Day Thursday 8th September 2011

Those groups who took part in the National Self Help and Support Groups Awareness Day in the Brisbane City Mall last year, along with other groups who were unable to take part at that time, are again invited to join with us in 2011 to help promote awareness of the benefits of self help and at the same time promote your own particular group. We will be sending out information in due course, but it would help us a great deal if you could indicate your desire to participate so we can begin planning for the number of stalls required. There will be a limit of about 50 again this year, so we may not be able to accommodate everyone. Contact Trish 33446919 or selfhelp@gil.com.au



Looking for a Speaker at Your Next Function?

Officers representing the Public Trustee's Office are available to give free talks to your group about Wills, Enduring Powers of Attorney and Executor Services.

**To book a speaker phone 1800 014 536
or submit your request online by visiting www.pt.qld.gov.au**

(Source: Serving Queensland, the eNewsletter to keep The Public Trustee's NGO, Not-for-Profit, Government and Community stakeholders up to date.)

Free Enduring Powers of Attorney for flood and Cyclone Yasi affected Queenslanders

The Public Trustee (Qld) can supply you with a new copy of your Will and check that it's up to date at no cost to you.



We are also preparing Enduring Powers of Attorney at no cost to people affected by flooding and Cyclone Yasi, phone 1300 360 044 to make an appointment.

(Source: **Serving Queensland eNewsletter of Public Trustee 1st edition Summer 2011**)

Tap Into Help for Abused Seniors

Free practical support is available for Queensland seniors concerned about being abused, mistreated or financially exploited.

The Elder Abuse Prevention helpline provides free information and counselling to seniors. The helpline assisted 1153 callers in 2009-10

Where to turn for help

Elder Abuse Prevention Unit Helpline – 1300 651 192

Seniors Legal and Support Service – Brisbane 3214 633; Toowoomba 4616 9700; Hervey Bay 4124 6863; Townsville 4721 5511; Cairns 4031 7179

Australian Productivity Commission calculates the non-government, non-business groups' contribution to national economy.

The PC says there are around 600,000 organisations in this sector. 4.6 million Volunteers work in this sector and it is contributing \$43 billion to Australia's economy.

Find more at <http://www.pc.gov.au/projects/study/not-for-profit/report/key-points>

How to Change Your Name

While in the past the Public Trustee has provided a service by which the public could change their name by Deed Poll the introduction of the Births Deaths and Marriages Registration Act 2003 means that the Public Trustee can no longer provide this service.

People wishing to change their name should contact the Registrar, Births, Deaths and Marriages. Please go to the Department of Justice and Attorney-General(<http://www.justice.qld.gov.au/justice-services/births-deaths-and-marriages>).

Serving Queensland – Free Public Trustee eNewsletter for the non government, not-for-profit and community sector. To subscribe email: clientenq@pt.qld.gov.au

2011 Religious Calendar Now Available

A religious calendar developed by QH Multicultural Services to help health workers identify various religious holidays and festivals which may affect the treatment of patients is available at: www.health.qld.gov.au/multicultural/support_tools/mcsr.asp.

Klinefelter Syndrome (KS) Australian Study Update

(Or 47XXY or XXY syndrome, a condition in which males have an extra X chromosome)

The first part of this Australian study tried to answer a question that many have asked..."How common is Klinefelter Syndrome?"

KS was first discovered in the 1940s and it was thought to be a very rare condition. In 2003, Danish researchers found about 1 in every 650 males would be born with KS. However, they also found that only a small proportion of those with KS were ever diagnosed – in fact, most people with KS were never diagnosed and didn't know they had the condition.

In 2008, researchers in the United Kingdom found, through prenatal testing, that KS was increasing from previously estimated rates. We decided that as part of this study, it was important to try and determine how common KS was in Australia, and how many people with KS were being diagnosed in this country.

What are the results from the Australian study?

The findings from this study agreed with previous research that KS is increasing.

We found that in Australia, 1 in 450 males are born with KS.

We also found that in Australia, about 50% of those born with KS are diagnosed with the condition during their lifetime. This is a far greater number than those who are diagnosed overseas, but there are still more than 12,000 males in Australia who have not been diagnosed and do not realise they have KS.

In this study, we found that 70% of those diagnosed with KS, are diagnosed as adults (20 years or older). Testosterone treatment is thought to be beneficial from puberty onwards, but cannot be started if the condition hasn't been diagnosed. This might seem like a good thing or a bad thing, depending on your own experiences, but it is something that needs further attention so we can work out what is best for the majority of people.

How can we use this information?

This information is helpful because it allows us to show that in Australia, KS is a common but under-diagnosed condition. We can use these results to show that KS is an important condition requiring more public health attention, advocate for the development of more medical and other support programs, and to apply for money to conduct more research.

The next update will contain results from the questionnaire, and how we can use this information to develop more resources and supports for those diagnosed with KS, their families and their partners. It will also discuss some of the ways we can help increase the rate of KS diagnosis and the best age for various treatments.

The interviews are still continuing! Thirty-two interviews have taken place now. It has been a wonderful experience to meet and interview participants from Melbourne, Adelaide, Sydney and Canberra.

I am still hoping to come to Brisbane, Perth and Hobart over the next couple of months, but if not, there is still the opportunity to take part in the interview over the phone.

This is the last stage of the research project. Results from the interviews will not be ready until the end of 2011. For information, comments or feedback about the study please contact: Amy Herlihy – on (03) 8341 6279 or klinefeltersyndrome@gmail.com

Involuntary Electroconvulsive Therapy (ECT) Debate Welcome

Letter to the Courier Mail (Unpublished) in response to Des Houghton's column on 11th December 2010

By Malcolm Campbell

I am pleased to see that Des Houghton and the Mental Health Review Tribunal have started a debate about the use of involuntary ECT in Queensland. Over the last few years there has been a significant increase, albeit from a low base, in the use of ECT (both voluntary and involuntary) and no one seems to know why.

When I was completing my undergraduate social work degree in the early seventies, ECT was a treatment of last resort for severe depression. It subsequently fell out of favour as new and allegedly more effective antidepressant medications were developed. ECT also changed over the years. The amount of current run through the brain was reduced and applied to one hemisphere of the brain. It is not clear to me if one ECT method is used across Queensland or if it varies from hospital to hospital and psychiatrist to psychiatrist.

Recently, it appears ECT is not only used for treating severe depression but also catatonic schizophrenia and also, say reputable websites, any psychotic illness that appears resistant to other treatments. My belief about this is that patients are now given less time to show remission of symptoms because of the pressure for beds.

Administering ECT requires the patient to be anaesthetised. There is general agreement among medical experts that ECT, which approximates a controlled (?) epileptic fit, causes short term memory loss (forget how to find your way home, your phone number, the names of friends or workmates) for around 4 weeks. A sizeable minority of psychiatrists, believe that repeated use of ECT treatments on a patient can lead to permanent memory loss and decline in cognitive ability. I believe that in the USA there have been two court cases concerning the harm or otherwise of repeated ECT treatments. In one state the court found that it did risk permanent damage in another state the court held it wasn't dangerous.

I have no difficulty in a person voluntarily having ECT if they are apprised of all the facts. Two of my friends voluntarily opted for ECT at various times when their depression was deepening. However, there need to be strict protections in place to ensure the rights of patients are protected when involuntary treatments are being sought. Presently, in the tribunal a patient is usually supported by an "allied" person who can only tell the tribunal "what the patient has told them". These allied persons are usually family or friends.

Presenting the case for involuntary treatment are the registrars and residents with the authority of medical degrees behind them. Yet it must be admitted that there are instances of psychiatrists making errors of judgement eg patients who commit suicide after discharge or having been refused admission and on occasion dangerous people have been returned to the community and have committed violent crimes. I do not attribute these mistakes to lack of skill or ill will but rather to the pressure under which they are forced to work. My point is only that in the present system psychiatrists may not know all the facts about the individual, rely on second-hand information or don't have time for a thorough assessment. I would therefore advise all patients appearing before the tribunal to have a lawyer with them and if possible to get a second opinion from an independent psychiatrist.

(Continued on page 13)

(Continued from Page 12)

A Mental Health Legal Service now operates under the umbrella of Queensland Advocacy Inc. Patients in hospital, due to appear before the tribunal should at least consult with this organisation. If a patient has an order for involuntary ECT made against them, they can appeal to the Mental Health Court and legal aid can be available for this appeal. The involuntary treatment of mental health should be seen as a legitimate human rights issue. Sometimes a more welfare less legalistic approach may inadvertently lead to an injustice being allowed to happen.

Finally, I would take this opportunity to suggest that the Mental Health Review Tribunal differentiate out in their annual report the number of patients under involuntary orders who are receiving "maintenance" ECT. That is patients receiving ECT weekly, fortnightly etc. forever. I believe there may be quite a number of them but it is not easy to get a breakdown of the figures.

Malcolm Campbell
CARINA
Phone 3844 1301

(Malcolm is a member of the support group "People Surviving Psychiatry")

Calling on all Patients, Family Members and Health Providers...

Australian Pituitary Foundation (APF) supports children and adults with pituitary disorders and their families. APF now needs strong public support for a very urgent and important submission to the Australian Government.

Currently the Foundation is involved with consumer advocacy in relation to an application for Growth Hormone for adults to be available on the Pharmaceutical Benefits Scheme. Growth hormone currently is subsidized for children, is only indicated for growth and our children are "knocked off the system" at an early age – round about the age of 14 years.

Recent studies have shown that Growth Hormone replacement is beneficial to adults throughout life, particularly in the late teen and early adult years. Presently use for adults is not subsidised by the PBS. Please go to our website www.pituitary.asn.au for more information.

Looking for a Support Group Meeting Place?

Elorac Place Community Centre would welcome enquires from support groups in the local area who are looking for a place to meet.

Located in what is now called Ellen Grove, previously Carole Park, the centre is about to undergo extensive building renovations, and there will be plenty of meeting spaces, though unfortunately no storage or permanent home.

Any developing or existing groups located in areas such as Forest lake, Richlands, Durack, Carole Park, Doolandella, Inala are invited to contact the co-ordinator.

Phone Cheryl for further information. Ph: 07 3271 3592



Free Walking Groups Throughout Queensland

Heart Foundation Walking is Australia's largest network of free community-based walking groups, led by volunteer Walk Organisers.

Due to the Qld floods some walking groups have been temporarily suspended, though new groups are starting up each week. Go to www.heartfoundation.org.au or Phone 1300 36 27 87 for more information.

I Can't Take It!

By an anonymous support group member

I'll never lose weight,
I'll never be thin,
I'm always being picked on,
For not going to the gym!
I'll never be perfect,
Now I don't even try,
Forever screamed and yelled at,
I always seem to cry.
Others harsh words,
Are making me ill,
Go see the doctor,
And take some more pills!
The doctor's advice is little use,
Against all the families,
Verbal abuse!
I can't take it,
Or hear it anymore,
From those I once adored!
I'm always told I'm not any good,
If I could change,
I'm sure that I would!
I'm in trouble for speaking my mind,
Told in words that is rather unkind,
This makes me want to harm myself,
Or hang myself up by a belt,
I'd rather be jugged or kissed,
But wonder if I'll be sadly missed!

-oOo-



New Name New Address Same Service

Synapse, formerly the Brain Injury Association of Queensland Inc (BIAQ), has moved from Milton to its brand new head office in West End on the corner of Montague Road and Jane Street.

Level 1 - 262 Montague Road, West End,
Brisbane Q 4101
(Please note we have moved from our Petrie Terrace office.)
PO Box 3356
South Brisbane QLD 4101

P: +61 7 3137 7400
P: 1800 673 074 (outside Brisbane)
F: +61 7 3137 7452
E: info@synapse.org.au
W: www.synapse.org.au



**New Name New Address
Same Service**

Hepatitis Queensland

Unit 2, 12 Cordelia Street
South Brisbane QLD 4101

You can send mail to:
PO Box 3490
SOUTH BRISBANE QLD 4101

1800 648 491 Free call number remains unchanged

BUT other phone numbers must change.
New numbers will be advised ASAP.

Temporary Office Number: 0428 477 373

DonorTec Waives Fees - for Queensland Flood Affected Organisations

Donortec is giving Queensland community groups with flood-damaged IT infrastructure a hand to get systems back up and running by waiving administration fees associated with Microsoft-donated products. DonorTec is waiving admin fees until August 2011.

DonorTec provides donated and discounted technology products and services from companies such as Microsoft, Symantec, Sophos, Kaspersky and Cisco to eligible income tax exempt (ITE) Australian nonprofit groups. Via this program nonprofits can access the latest technology via donations or generous discounts. Go to www.donortec.org

Diabetes – What Now?



A Diabetes Australia – Queensland program for people with type 2 diabetes

Diabetes Australia Queensland is preparing to roll out the second part of a pilot program to support peoples with type 2 diabetes; in particular those who have been newly diagnosed. The Diabetes –What Now? program aims to provide initial self management education. There will be an emphasis on participants developing an understanding of a team care approach in diabetes management and will encourage links to local health care networks .

The first part of the pilot concluded in the Darling Downs and West Moreton Health Service district in November 2010. The second part of the pilot will be delivered in the Brisbane North region from March to June 2011 in various community locations around the Brisbane North Region.



The program is delivered over two consecutive weeks by a Credentialed Diabetes Educator and Accredited Practising Dietician and will provide an overview of:

- What is diabetes
- Diabetes medications and insulin
- Your diabetes health care team
- Physical activity
- Blood glucose monitoring
- Setting your own health goals

The program is free to participants and registrations are by self referral.

People with type 2 diabetes and a support person can register to attend by calling Diabetes Australia – Queensland on 1300 136 588, email health@diabetesqld.org.au or register online at www.diabetesqld.org.au.

Brisbane North session 9.30am to 11.30am

Northgate	30 March & 6 April	Bracken Ridge	12 & 19 May
Hamilton	14 & 21 April	Caboolture	26 May & 2 June

DISABILITY LIFESTYLES

Do You Have a Personal Story to Share?

www.disabilitylifestyles.org.au

Check out the Website Today!

Disability Lifestyles is a website that was created in 2004 with the support of the Centre of National Research on Disability and Rehabilitation Medicine (CONROD). The vision for the website was to provide lifestyle information on a range of topics (such as learning new skills, working, having fun, relationships, personal support, ways of coping, transport and housing) to people living with a physical disability. At the time of its creation the website was one of very few websites that aimed to assist people with spinal cord injuries in Qld.

One of the novel aspects of the website is that its content has been written by people with a range of physical disabilities (mostly wheelchair-users) and includes a range of different personal stories from people who are living with a spinal injury. While the website is mostly aimed at people who have left rehabilitation and who are looking for information on how to create a new life for themselves, the website is appropriate for anyone who has a physical disability. The website's writers believe that it's never too early or too late to start seeking out ideas and information to create a better or different life for oneself.

One of the most popular sections of the website has been the **Personal Stories** section. The current stories describe the life experiences of five people who had accidents resulting in a spinal cord injury or an acquired brain injury. (Continued on Page 16)

(Continued from Page 15)

They speak about topics such as their rehabilitation, relationships, work, leisure, where they live... and their hopes for the future. The aim of having the Personal Stories section is so other people with physical disabilities, their families and friends can hopefully learn more about their own experiences by reading about those of others.

For members on the Gold Coast, a workshop entitled "Creating Change in your Community" will be held this month. There will be a demonstration of the Disability Lifestyles website and its online toolkit for creating change in your community. Come along to discuss and get ideas for increasing accessibility to physical facilities that you know need to be more accessible! Please come along on 28th March between 10 am and 1.00 pm at the Broadbeach Branch Library, 61 Sunshine Boulevard, Mermaid Waters. Morning tea and lunch is provided. For catering purposes, please register with Gunela Astbrink by 25th March - email g.astbrink@gsa.com.au.

The Disability Lifestyles website is a community service by the Centre of National Research on Disability and Rehabilitation Medicine.



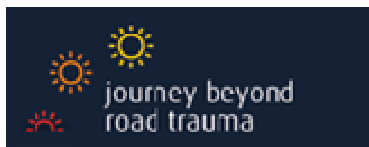
What Makes a Great Constitution?

If yours is like many organisations, you probably never think to pull out your Constitution unless there's some sort of trouble – a dispute about the rules, perhaps. Our Community has spent a lot of time looking at Constitutions and their governing legislation.

A great Constitution is:

1. **Intelligible:** Take special care to ensure that the language you use is plain English (avoid legalese) and absolutely clear and free from misunderstanding.
2. **Tailored:** There are some laws that say what you have to include in your Constitution, but there is still quite a bit of scope for you to write a Constitution that's tailored to your organisation's specific needs.
3. **Inspiring:** Include the objects that you've used to draw up your mission statement.
4. **Forgiving:** Avoid including provisions that have sweeping permanent effects.
5. **Informational:** Don't force your members to read between the lines for meaning. Say what you mean.
6. **Trusting:** A Constitution can't cover every problem that might conceivably arise, and shouldn't try to. Stick to broad allocations of powers and functions.
7. **Incomplete:** A Constitution doesn't have to cover everything that needs to be covered. You can spin off whole areas to other instruments – By-laws, regulations, codes, standing orders, policies – that are easier to amend and less trouble to apply. The only things that have to go into the Constitution are the bits that allow the Board to make By-laws.
8. **Legal:** You can't put anything in your Constitution that's incompatible with the law, or legal principles like natural justice. If you're thinking of putting in anything strikingly innovative, it's a good idea to find a lawyer to check it.
9. **Invisible:** A smoothly functioning organisation should tick along without the kind of crisis that would make someone pull out the Constitution; and a smoothly functioning League is one that, among many other things, has a suitable Constitution.
10. **Updated:** That said, even a good Constitution can go rotten if it's thrown into the back of the cupboard and not brought out for 20 years. Without being obsessive, have a formal look over it regularly (we recommend every three years at a maximum), along with the By-laws and standing orders and policies, and see whether they need any adjustments in the light of changed circumstances and new experience.

(Source: "Our Community Matters" Edition 1, 2011)



Journey Beyond Road Trauma

Journey Beyond Road Trauma is an online social network for people affected by road trauma.

In Australia there are more than 1600 deaths on our roads each year. Alarmingly, another 60 people are seriously injured each day. Not only is this site aimed at those affected by road fatalities, but also the thousands of people who have, or are caring for someone who has, a serious injury.

Whether the crash was yesterday or 15 years ago, the free site can be used to connect with family and friends, or to engage with a broader online community.

Producer/director Sandra Cook and producer/writer Kerry Sunderland believe that people affected by road trauma – either by a serious injury or a fatality, often feel voiceless and need to be heard, and that they could benefit by connecting with others who have experienced a similar trauma.

Journey Beyond Road Trauma is also a resource for the wider community, particularly those with an interest in road safety education as well as those who are affected by road trauma in their workplace (emergency services, lawyers, health workers etc)

When you first join the community, you will be able to set up your profile, mark the scene of the collision (a virtual roadside memorial mark) on a Google Map, connect with others affected by road trauma, tell your story with blogs and video and watch short documentaries.

The site provides comprehensive contact details and information on counseling services, legal services, victims of crime support, road safety education programs and disability carers.

Community member Peter Longland is holding a games night in Brisbane to raise money for the much needed community. On a games night you will play between 12 to 16 different games which include miming and debating games through to more active games. The emphasis is on the fun of playing and not winning. The night is open to anyone including those with disabilities, families are also welcome. Details on the games night are below:

Date: 26 March 2011
Time: 7:30pm start 10:30pm finish
Location: Albion Peace Hall 102 McDonald Road Windsor Q4030
Costs: \$15 Adults, \$40 families

For more information about the games night please call Peter on 0422 367 757

To find out more about the site visit: www.journeybeyondroadtrauma.org

Behind every fatality and serious injury statistic there are thousands of stories. Tell your story to educate and help others.

For more information please contact Sandra Cook:
mob: 0413 146 013
email: sandracook@onlinestoryexchange.com

This year we're going to experience four unusual dates. 1/1/11, 1/11/11, 11/1/11, 11/11/11 and that's not all...Take the last two digits of the year in which you were born - now add the age you will be this year, and the result will be 111 for everyone...!! This is the year of Money..!!! This year October will have 5 Sundays, 5 Mondays and 5 Saturdays.

This happens only every 823 years... These particular years are known as 'Moneybags'



Diary Dates

17th - 20th April 2011: Rare Diseases Symposium
"Awakening Australia to Rare Diseases"

URL: www.raredisease.com.au

Venue: Fremantle WA

13th - 19th June 2011:
International Men's Week

16th - 17th June 2011:
Happiness and its Causes 6th Annual Conference:

www.happinessanditscauses.com.au

Venue: Brisbane Convention and Exhibition Centre



Invitation

Australian Pituitary Foundation would like to invite you to an educational seminar to be held at Princess Alexandra Hospital on Saturday, 21st May. Topics include information on hormones and mood, cortisol and thyroxin, growth hormone and androgens.

After morning tea there is a session on tumours and surgery. Patients, general public and health professionals are welcome to attend.

For more information please contact Sue on gld@pituitary.asn.au or Phone 1300 331 807.

Please let us know about your Conferences, Information Days, Seminars, Workshops, Celebrations etc and we'll do our best to let others know about them too!

**Please contact Trish at SHQ
Ph: 3344 6919
Email: selfhelp@gil.com.au**

2011 - International Year of Forests

RentConnect - helps Queenslanders to find and secure a tenancy in the private rental market.

The Dept of Communities RentConnect scheme provides information on how to apply for a rental property and, if needed, one-on-one help to find a property. RentConnect officers help people identify what type of assistance they may need. They can:

- advise how to find a rental home
- help people to understand the rental application process
- help prepare a rental application.

They may also put people in contact with local real estate agents and providers of community services. For more information contact your nearest Dept of Communities housing service centre, (approximately 28 Centres throughout Qld)

Phone 1300 880 882 or visit RentConnect: <http://www.housing.qld.gov.au/renting/info/rentconnect.htm>

DRESS SPOTTY DAY

for Bowel Cancer Awareness

When: Saturday
4th June 2011
10am to 2pm

Where: Queen Street Mall Stage

Look Cool! Wear spotty like me

Enjoy live music!

Brisbane Bowel Cancer Support Group
www.bowelcancerupport.com.au