



Newsletter March Quarter Issue 1. 2010



Self Help Queensland Inc, Sunnybank Community Hall, 121 Lister Street

(PO Box 353) SUNNYBANK 4109

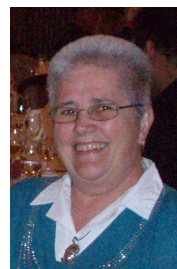
Ph/Fax 07 3344 6919 Email: selfhelp@gil.com.au www.selfhelpqld.org.au

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 readers,

All the best wishes for a great new year for you, your nearest and dearest and, of course, for your work. January is traditionally the time of year when we hide from the weather and take some time to think about the coming year, isn't it? Or is it a time where we take a deep breath and hope for the best? Whichever of those applies, we'd love to hear from you.



Thea Biesheuvel

Unfortunately some things force us to a reactive response rather than plan a proactive one. Illness, natural disasters, even small domestic disasters can be part of our climate and social sphere which propel us to just manage rather than operate at peak level.

Someone once said that 'a disaster shared is a disaster halved, whereas a joy shared is a joy doubled.' The operative words are 'shared'. No keeping your cards close to your chest about either joys or disasters. We need to share them.

Well, we at SHQ have had our share for the year, we reckon. Our roof was to be renewed but in the process lots of rain got in over Christmas, resulting in at least 20 cms of water over the floor and down our walls, lots of wet (and subsequently mouldy) papers and books and lots of sorting the good from the bad.

But, like all disasters, it could have been a timely reminder that we may have to deal more and more with data-bases and e-mail correspondence rather than pieces of paper.

Our web-site is still under development and the on-line Directory being perfected as you read this. Our Newsletter will soon 'morph' into more of a Journal, with some research findings and references.

Our work with mental health support groups has grown into regional visits and networking by 2 project workers who work from their own locations.

(Continued on Page 3)

Self Help Queensland Management Committee Members

President	Thea Biesheuvel
Vice President	Alan Noller
Secretary	Casey Barber
Treasurer	Chris Spriggs
Members	Joe Soda Zoe Farris Safia Raza

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
Noela McKinnon

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.

Office Location:

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

Postal Address

P.O. Box 353, Sunnybank QLD 4109

Phone/Fax: (07) 3344 6919

Email: selfhelp@gil.com.au

URL: www.selfhelpqld.org.au

Self Help Leaders Online Social Network: 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.



Regional Representation Sought for SHQ Committee

SHQ extends a warm invitation to regional and rural areas to fill a position on the SHQ Management Committee.

Ideally, the representative would come from a self help or support group, but not necessarily. Any person committed to the Sector would be welcome.

Meetings are held monthly, usually from 9.30am to 11am. The day/date is flexible to suit members. SHQ would arrange for the regional rep to engage by phone, and perhaps attend the AGM in Brisbane.

Please indicate your interest to the President, Thea, at selfhelp@gil.com.au

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 Inc reserves the right to edit contributed articles.

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There is an increasing focus on 'evidence-based' evaluations of services. The evidence we have is that self-help groups continue to operate and provide much needed support for individuals. So much so that the next few years will see an explosion of these into a 'self-help sector', where we can collaborate, support each other and advocate with a much stronger voice than has been the case.

So, as this year starts on its way, let's pick up the phone, get on the Internet, meet with each other and build this sector up.

Contact us, come to talk with us and let us know your needs. You can reach us by email at selfhelp@gil.com.au or phone 07 3344 6919. If you would like to meet us in person just call the office first to make sure there will be someone here to greet you.

Regards
Thea

Can You Help Pink in the Tropics?

Self Help Queensland recently received the following letter and has printed it in the hope that other groups in the self help network will feel strongly enough to support their colleagues in the far north.

Pink in the Tropics is a breast cancer support group offering support, information and resources to women from Port Douglas, Mossman, Cape Tribulation and Daintree.

One of the issues we have found that affect cancer patients in the Far North of Queensland is the Patient Accommodation Subsidy. Many cancer and other patients must travel from their homes to receive treatment as the treatment is not available locally. As you can imagine having to travel for treatment creates many problems for these patients, not the least is that the Patient Accommodation Subsidy sits at \$30.00 a day which includes all meals, accommodation and transport. This subsidy has not been increased in 22 years. A public servant who must travel for their employment receives an allowance of \$307.80 a day.

Pink in the Tropics' goal is to raise this subsidy and to that end has gone into partnership with Jason O'Brien MP to present the Queensland Parliament with a petition to raise this subsidy.

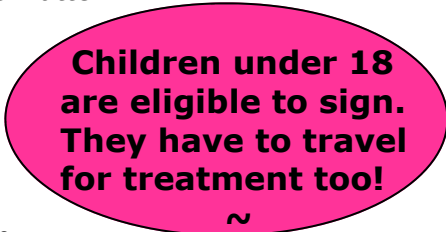
The goal is to achieve at least 10,000 signatures by March 31, 2010 to impress upon the Assembly the hardships being suffered by the State's rural and remote patients and the concern this causes to Queenslanders everywhere.

We are hoping that you can bring this petition to the notice of your members and to invite them to either sign the e petition at www.pinkinthetropics.org or to print out the hard copy of the petition and circulate it for signatures.

Thank you for your assistance with this important matter.

Yours sincerely

Natalie Halse
President
Pink In The Tropics



**Children under 18
are eligible to sign.
They have to travel
for treatment too!**



New!

Logan Bipolar Support Group Welcomes People with Bipolar and their Carers

The Logan Bipolar Support Group is a group that is for people who have been diagnosed with bipolar and/or their carers. It is a self run group and is facilitated by people who have first hand knowledge of bipolar.

The Group aims to:

- Provide support for anyone who has been diagnosed with bipolar and/or their carers.
- Provide an environment where each person feels understood.
- Provide a place they can express themselves freely without judgement.
- Talk honestly about experiences and behaviours.
- Find ways to manage the difficult times through use of group discussion and forum.
- To create a support network.

People diagnosed with bipolar disorder can live healthy normal lives!

Meetings

Meetings will be held on the 3rd Monday of each month

Time: 7.00pm - 9.00pm

Logan West community Centre 2 Wineglass Drive Hillcrest

For more information please contact Karlee Ph: 0401868994



**mental health
association qld**
connect learn participate

**Gold Coast OCD
Support Group is Back!**

The Obsessive Compulsive Disorder support group will bring together sufferers who share a common desire to find a supportive environment to assist with their recovery process.

The group will provide a space for participants to share their story, talk about strategies for coping, reveal experiences and knowledge and work together to improve their quality of life.

When: Wednesday 3 March 2010
Groups will run on the 1st Wednesday of each month

Time: 6:30 – 8:30pm **Cost:** Free

Where: Mental Health Association Qld
Unit 30, The Southport Trade Centre
3 -15 Jackman Street, Southport

For more information contact the mhConnect team 1300 729 686

“Pragmatism is what we settle for when idealism gets too difficult”

Author unknown



SELF HELP QUEENSLAND NEWS 1

and then it rained some more... and then the ceiling fell in... and then it rained some more!

The cartoon tells it's own story. This was what happened to SHQ over Christmas.

Unfortunately, what was to be a simple re-roofing of the Sunnybank Hall where our office is located, ended up being a disaster for Self Help Queensland. Due to a few sheets of iron too little, a tarpaulin was placed over our office and left to its own devices for five days over Christmas. Remember the rainfall during this time? Well, the tarp filled with water, collapsed and subsequently caused part of the ceiling to fall in. By the time it was discovered the damage had well and truly been done.

Small community organisations always suffer when these things happen. Many of you would have experienced similar sorts of events. We know of groups who have had to literally 'rise from the ashes', and it takes a lot of energy and resources to start again. Worst of all though, is the blow to the spirit. All those years of scrimping, saving and 'making do' draw you into a protective role when it comes to the group and its meagre possessions.

After two months we are finally starting to see the light again. Our resources are being replaced as best possible, and projects that were put on hold will shortly take on life.

SHQ would like to take this opportunity to apologise to anyone whom these delays have affected - either directly or indirectly. We have attempted to keep providing our services as best we could under the circumstances.

What's Happening with the Online Searchable Directory?

We are adding groups to the Directory each week, but still have many outstanding forms that are yet to be returned. We will probably be contacting your group again shortly for permission to add you into the Directory. Once there are sufficient entries to make it worthwhile, it will then go on-line.

This on-line Directory Project, (quite understandably when you speak with others who have done a similar project) is turning out to be a very long work in progress! While technology presents wonderful opportunities to do things better, there are still some things that require the old fashioned human approach - like picking up the phone and talking to people.

No matter how much you try to design a user friendly data collection form, even on-line forms, they seem to have a way of excluding the information that some people would like to give, and on the other hand, asking so much that people get fed up.

We would love it if you could contact us if you have lost your form, didn't receive one in the first place, or would like to talk to us about any aspect of the Directory. The hard copy version we compiled previously was a great success. It is the only directory in Queensland dedicated solely to self help and support groups. Housing them all under the one roof is a very convenient way for people to find a group. To contact the SHQ office please Ph 07 3344 6919 Email selfhelp@gil.com.au

Please tell us what you think! We welcome your feedback at any time, about any aspect of our service. Feedback is reported, discussed and acted upon at the SHQ monthly Management Committee Meetings.

SELF HELP QUEENSLAND NEWS 2

Farewell & Thank you Bob

Bob Wyborn SHQ Management Committee Member

It's always a sad time when a Committee Member moves on, and this time is no different. Bob Wyborn has been a member of the Committee for several years now, and has been a particularly valuable contributor in the areas of rare diseases, grief and loss. A clear and practical thinker, with vast business experience, Bob was always able to 'cut to the chase' and provide a balance when it was needed. He is moving on to concentrate on his tertiary studies, and we wish him well in these endeavours. Thankfully, Bob has agreed to be available to SHQ when his knowledge and expertise in rare diseases is required.

Hello & Welcome Noela

SHQ newest staff member - Community Capacity Building Project Officer

Noela was born and bred in Brisbane completing her Honours degree at University of Queensland before moving to Canberra where she met her husband Frank and raised their two children Simone (28) and Danny (26). Since 1991 Noela has taken an active interest in health and social welfare issues in rural and regional areas presenting a number of papers on rural aged care, rural mental health, rural GP issues, rural poverty and women's issues at various conferences. She has nearly 20 years experience working in the Australian Public Service in the portfolios of Health and Ageing and Primary Industries and Energy during which time she was seconded to the National Rural Health Alliance to undertake policy development work and to the Department of General Practice at the University of Newcastle to undertake research for the National Rural Female GP Project. In 2005 Noela moved with her husband to Maryborough taking on positions as the aged care advocate, the General Practice Manager for the Division of GPs, the Interim Manager for Headspace Fraser Coast and the Sector Development Worker for the Queensland Alliance. In December 2009, Noela moved to Brisbane and recently commenced work as the Community Capacity Building project officer with Self Help Qld. Noela's particular areas of interest are community mental health issues, rural health and community access, rural women's issues and the development of social firms/enterprises.

SHQ Seeks Funding

Thanks to the talents of our newest member of staff, Noela, applications were recently submitted to the Brisbane City Council Community Grants Program and to the Gambling Community Benefit Fund (GCBF). If successful, they will go a long way towards fulfilling some of our dreams for 2010.

An application was made to the BCC to undertake a range of community capacity building activities with self help and support groups in Brisbane - facilitator training, development of resources, networking of groups etc. Training would be based on adult learning principles with components on group development/ dynamics, fostering effective communication, building relationships/ understanding, advocacy skills, group roles and responsibilities, learning tools, strategies and activities.

New computer equipment for the SHQ office to replace very slow, outdated computers was top of the GCBF list. Some chairs for the meeting room, which is used frequently for support group and management committee meetings, interviews etc. was next. We would be over the moon if we were fortunate enough to be successful.

SELF HELP QUEENSLAND NEWS 3

National Self Help and Support Groups Awareness Day
- helping each other to help ourselves



Wednesday 8th September 2010

For the first time ever, self help and support groups throughout Australia are being invited to take part in a national week of recognition and celebration of the important role they play in Australian society. **The week extends from 6th - 12th Sept.**

On Wednesday 8th September 2010, in as many towns and cities as possible around Australia, SHQ and our sister organisations in the other States will be undertaking a range of activities aimed at raising an awareness of self help and support groups.

Of course we can't do it alone! We need all sorts of groups, small or large, to join us in our efforts to let the wider community, health professionals and government know about the existence of the broad range of groups and their value to the health, social, and economic fabric of Australian society.

In Queensland we are inviting groups from anywhere in the State to:

- 1 Join the Awareness Day reference group (SHQ can set up a teleconference or group email - regional reps very welcome! You can just be a keen supporter of self help and support groups to take part!)
- 2 Advertise the Awareness Day/Week in your group's newsletters, websites etc
- 3 Think of any awareness raising activities you could undertake in your town on the day, or any day during Awareness Week 6th to 12th September
- 4 Consider harnessing the support of any high profile personalities you think might lend a hand to raising awareness of the value of self help
- 5 Investigate the use of public space for a promotional activity - ask your local council for permission/support for an event
- 6 Think about what media outlets you could contact for publicity
- 7 Register your plans with SHQ so we can keep track of what's happening in our State (and gain helpful suggestions at the same time)
- 8 Please contact SHQ if there is any way at all you think we could help you

Please try to encourage your group to be part of this day, or week, even in a modest way. Any participation would be welcome - even a telephone call to a radio talk back station just letting people know about your group, and the value of self help.

Everyone is invited to join in

You may not even belong to a self help or support group, but you may be an avid supporter of the idea of people helping themselves to achieve better health and well being. **You may be a professional who facilitates a group.** If so, please consider joining the effort to raise the public profile of self help and support groups.

We will be keeping you up to date through our newsletter and website. **Please share your ideas and plans with us too.** We are all hoping that this will become a registered national event. It can only be of benefit to groups - we would hope that increased membership, better funding opportunities and a well informed community would be just some of the desired outcomes - **3344 6919 or selfhelp@gil.com.au**

Self Help Queensland News 4

What's Happening with the SHQ Website?

Anyone who has checked out our website would know it has been under construction for some time. Because of the slow progress of the on-line Directory, and the delay caused by the flooded office, we have decided to get the website uploaded ASAP. We were waiting for the on-line Directory to be completed so we could launch them both together. However, even the best plans go astray sometimes.

We are keen to help groups promote themselves and their important events. We shall have a special page dedicated to this purpose, so please send any ads for conferences, special events, fundraisers etc and we will advertise them in our on-line events calendar. This service is limited to self help and support groups and organisations, and does not include 'for profit' enterprises or professional services. Email ads to Trish at selfhelp@gil.com.au or Ph 3344 6919 if you'd like to chat further about it.

Have You Returned Your Directory Registration Form Yet?

SHQ is working hard to help develop, maintain and promote the Self Help Sector in Queensland. Part of the process is to provide information to the wider community about what self help and support groups do, who they are and where to find them. In order to do this we need you to send us your contact details and other relevant information.

If the data collection form we sent your group has gone astray - or you can't remember if you have filled one out - don't worry! We are happy to post you another one with a reply paid envelope, email a form or give you instructions for an on-line registration form.

The information you provide will form part of an on-line searchable directory that will be a special feature dedicated only to self help and support groups. It will be the only Directory of its kind for Queensland groups - a genuine one stop shop for the Self Help Sector - not mixed in with professional services etc

The first time collection is a bit laborious, but after the template is set up any future updates will be a much simpler exercise.

Please contact Trish at the SHQ office for further information, or to receive a data collection form. Your co-operation is very much appreciated, as we know groups are approached to fill out forms on a regular basis.

We hope that being part of the Directory will have positive outcomes for individual groups, as well as strengthening the profile of the entire Sector. Please Ph 07 3344 6919 or email selfhelp@gil.com.au

Stop Press!!!

Just as this newsletter was about to go to print SHQ learned that 2 more very talented people have agreed to come on board the Management Committee. We would like to welcome Chris Spriggs, our new Treasurer, and Safia Raza, general member.

We will bring you a short bio on Chris and Safia in the next newsletter. We are still looking forward to hearing from someone from a regional area who would be interested in joining us too. 2010 is going to be a busy but exciting year at SHQ.

Genetic Matters

by Kim Summers PhD

A moment on the lips, many lifetimes on the hips

Multicellular organisms like us have a problem. We start from a single cell which carries DNA from both parents. As this cell divides repeatedly, each daughter cell has the identical DNA (with a few exceptions). Surely all cells should then be identical? But we need a range of different cell types: red and white blood cells, skin cells, liver cells, neurones to make nerves, bone cells and so on. If they all have the same DNA, how do we get such a wide range of different cells?

The answer lies in the way that DNA is used to create proteins. Although all cells have the same DNA and so the same genes, the proteins encoded by those genes are only made if a working copy of the gene, called messenger RNA (mRNA), is made. Think of an office with a locked filing cabinet containing blueprints for everything needed to make a car. Different factories make different items, so separate factories make seats, tyres, chassis, paint, carpet and so on. Each factory needs lots of copies of the blueprints for its own item down on the factory floor, but might also keep a mastercopy of the full set of blueprints locked up in the manager's office. The only items that are actually made are those for which copies of the blueprints are available to the factory workers; instructions for the other items are available when needed, but they are not routinely made. Similarly, only 10% of the genes are actually being used to make proteins in most cell types. Proteins which are needed by liver cells are made in the liver cells but not in bone cells. Proteins involved in the immune response are made by white blood cells but their synthesis is switched off in nerve cells.

There are a number of mechanisms which control whether the genetic code of a specific gene is actively being read or not. A gene which is actively being copied to RNA and then protein is said to be expressed. Processes which control gene expression without changing the genetic code of the gene are called epigenetic; they influence the genome without altering it. The DNA remains the same in all cells but the segments of the DNA which are active change.

Epigenetics is a way for cells and organisms to respond to changes in the environment. By switching genes on and off, the organisms can adjust when the main source of nutrition alters, when the weather gets warmer or colder, when infection occurs. One mechanism to respond to environmental change involves modifying the DNA without changing its fundamental sequence. This process is called methylation and results in a slight chemical change to part of the DNA. DNA with this chemical mark is less likely to be copied into mRNA, so methylation of DNA is a way of deactivating a gene. There is now some evidence that patterns of methylation (and hence the activity or inactivity of specific genes) can be passed from parent to offspring. This has been called "the ghost in the genes".

Changes which have been shown to trigger inheritable epigenetic modification of DNA include living through a famine at a critical time of life, parental nurturing and exposure to toxic chemicals including smoking. In one interesting study, researchers found that mice who were groomed extensively by their mothers were more adventurous and resilient to stress than those groomed less. The chemicals in cigarette smoke have been known for some time to damage the DNA itself. There is now evidence that they also alter the epigenetic status of the DNA, even if it is undamaged. In one study overweight mice mothers had even more overweight offspring.

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Environmental factors affecting a mother during pregnancy (such as the level of folic acid in her diet or exposure to German measles) have been known for some time to affect development of her fetus. These factors might affect the offspring indirectly as well as directly if they trigger an epigenetic modification: a mother who is overweight may cause epigenetic changes in the fetus to adapt to high availability of food, leading to diabetes and obesity in later life.

Epigenetic status may also have effects on more distant descendants. One study showed that Swedish men who had lived through significant food deprivation in childhood had grandsons who were less likely to die of cardiovascular disease than those who had not experienced famine at a critical age. The grandsons of the better fed boys had higher incidence of diabetes. Results for women were different: paternal granddaughters of women who had suffered famine had shorter lives. Studies with animals have looked at exposure to toxic chemicals and drugs. In one experiment, pregnant rats were exposed to a pesticide, and their male descendants had reduced fertility for at least four generations. In another experiment, guinea pigs were given a steroid drug. Their offspring were hyperactive, and their grandchildren also showed behavioural abnormalities.

These epigenetic effects have been described as a second genetic code, and there is now an international collaborative effort to develop a map of the human "epigenome": all the epigenetic marks of human DNA at different stages of development, under different environmental influences and in different disease conditions. This map should help us to unravel the inheritance of epigenetic modifications of DNA and understand the impact that the environment of ancestors can have on their descendants.

But there are other explanations for the associations between parents and their descendants, and the jury is still out on the contribution of epigenetic modifications to these associations. We have to be careful not to move from "genetic determinism" (where everything about the individual is attributed to the genes and therefore can't be changed) to "epigenetic determinism" (where everything about the individual is attributed to epigenetic modifications brought about by the environment and therefore the outcome is determined by the environment). Most geneticists have always recognised the subtle interplay between environment and genes; the discoveries of epigenetic mechanisms show just one way that this can happen.

<http://news.bbc.co.uk/1/hi/health/5117752.stm>

http://www.timesonline.co.uk/tol/life_and_style/health/article4364054.ece

http://www.bionews.org.uk/page_46259.asp?iruid=2939

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.

Australian Gorlin Syndrome Mutual Support Group

A self help group for Gorlin Syndrome patients and friends is being set up. If you would like to be involved or know someone who may be interested in this group please contact the Collective of Self Help Groups (COSHG), VIC for more information.

COSHG
03 9349 2301
info@coshg.org.au
www.coshg.org.au



New Faecal Incontinence Support Group Proposed

Would You, Your Family, Friends, Clients, Patients or Anyone you Know be Interested in Joining?

Do you suffer from Faecal Incontinence? After being faced with this socially embarrassing problem for more than 20 years and secretly trying to deal with it I have come to realise that there are many people like me. We suffer in silence. It's just not something you can talk to people about to get advice or a sympathetic ear.

- If faecal incontinence has an impact on your quality of life and stops you from doing the activities you previously enjoyed every day such as shopping, working, participating in social activities, sexual intimacy, playing sport etc;
- If you find faecal incontinence difficult to discuss with friends and family or you would like to talk to others suffering from faecal incontinence to learn from them about what they have found that works;
- If you would like to hear how others are successfully living with this problem or to simply be a source of information to others experiencing incontinence;

- then join our faecal incontinence support group and find ways to help you deal with your incontinence. Come and share your story with others. Incontinence is a problem faced by all types of people and can occur at any age. Faecal incontinence has a massive impact on our quality of life.

This is my story....While having my first children overseas more than 20 years ago the doctor gave me a full episiotomy. I had more children with no complications but as the years went on I began to experience faecal incontinence. I knew that at some point I would need to have it fixed. I suffered in silence with the problem and tried to manage it as best I could. I avoided certain foods and wore pads. I didn't share my problem with my husband and family as I was embarrassed. I did pretty well at managing it. Some years after I finished having my children I decided it was time to see about getting it fixed. I gained the courage to talk to my doctor about it. She was really sympathetic and referred me on to a specialist. He conducted some tests and advised me that they had made a lot of advancements over the years in this area and that I would experience a marked improvement and probably full continence. I went ahead with the surgery having more confidence that I would have more normality in my day to day living and a sense of wholeness but that wasn't to be.

The outcome of the operation was not as successful as I hoped. I was left to wonder things like have I lost my quality of life altogether, how can I manage, do I attempt another operation? What else out there is available to me? Who else has experienced what I am experiencing, am I alone? What are my alternatives now? My hope is that by sharing my story you will share yours and together we will be able to support and help each other.

There is no need for anyone with faecal incontinence to suffer in silence. If you are interested in joining our support group please email me at in-con@live.com.au or contact Jane on 0433 134 527.

(Enquiries are welcome from anywhere in the State. Meetings will most likely take place in an area easily accessible to Brisbane and the Gold Coast. A website with practical information, frequently asked questions etc is also under consideration.)



Office Space Required for Quiet & Friendly Not-For-Profit

The Australian Pain Management Association Inc (APMA) established in 2009 supports those with persistent debilitating and disabling pain & their support people.

APMA has outgrown the kitchen table (& in fact my home). We don't receive any on-going funding so can't pay rent.

- We are quiet workers so are good neighbours
- Do outreach work & education so could **share office space**
- Have **printer/fax** which we can share

We are applying for office funding so may be able to pay rent at end of 2010

If you can help, please contact Lil on (07) 33916629

Volunteer Grants Program Now Open

Funding of between \$1000 and \$5000 is available to eligible non profit organisations to assist volunteers and encourage volunteering.

Volunteer Grants 2010 are available to help non-profit organisations to:

- contribute towards the costs of training courses for volunteers and/or undertaking background screening checks for volunteers; and/or
- purchase portable, tangible, small equipment items to help volunteers; and/or
- contribute towards fuel reimbursement for their volunteers, including those who use their cars to transport others to activities, deliver food and assist people in need.

Further Information: Website: <http://bit.ly/dhsRyr>

Guidelines: <http://bit.ly/9cjxqo> Appl. Form: <http://bit.ly/cgoHpB>

Dept of Families, Housing, Community Services and Indigenous Affairs

Email: vg2010@fahcsia.gov.au Freecall: 1800 183 374 TTY: 1800 555 677

Closes 2 pm AEST on Friday 16 April 2010

Proposed New Standards for Disability Access to Public Buildings ReleasedBut!!!

The proposed new standards were released on 15th March 2010, and are due to come into force in May 2011. However, some known disabilities such as environmental sensitivities were left out of the process and will not be included for at least another five years – if they are included then.

ASEHA Qld inc is a support group for individuals with environmental sensitivities that has been advocating for their recognition and inclusion in buildings and services for around thirty years now. ASEHA hopes that the Attorney General will change his mind about including environmental sensitivities in the access to building standards and the Australian Building Code. Some with severe chemical sensitivities are unable to access premises for necessary care.

For more information go to ASEHAs website a www.asehaqld.org.au

“It’s not what you look at that matters, it’s what you see.”

**Henry David Thoreau
US Recluse, Naturalist, Writer
1817 - 1862**

Some Official Recognition of Self Help Groups

By Thea Biesheuvel

The website of the Queensland Department of Communities has, in its 'community sector' section, some forward plans, where it says that unfunded peer (consumer) operated services have existed in Australia since approximately the 1950s, when peers first came together to support each other and developed new self-help organisations and groups. Currently there are few consumer operated services throughout Australia apart from the self-help group model, which has grown significantly over time. This limitation in models is in marked contrast to the experiences of overseas countries, including the United States, United Kingdom and New Zealand.

The United States has supported the development of funded consumer operated services, primarily for those with mental health issues, with the President's New Freedom Commission on Mental Health stating, "studies show that consumer-run services and consumer providers can broaden access to peer support, engage more individuals in traditional mental health services, and serve as a resource in the recovery of people with a psychiatric diagnosis."¹ Consumer-run services in the United States currently include several hundred programs encompassing self-help, drop-in facilities, peer support, accommodation, employment, social support, crisis prevention and respite care, education and training, and research.

New Zealand is also developing an array of consumer-run programs, with over 30 such organisations identified by the New Zealand Mental Health Commission.²

Consumer operated services have been defined³ as services:

- that are consumer controlled – i.e. have a minimum of 51% consumer participation on management structures and are independent, autonomous and accountable within the consumer-operated program.
- that are staffed and managed by peer workers – i.e. individuals who have received mental health services. In the United Kingdom, peer workers are often described as having the lived experience of mental illness, this being mandatory criteria for employment, and being a mental health service user as preferable criteria.⁴

The Evidence Base

There is an emerging evidence base of the effectiveness of peer-run support programs that has been articulated through the Consumer Operated Services Program (COSP) project in the United States,⁵ and by a major international literature review by the Mental Health Commission of New Zealand.⁶ (Continued on Page 14)

¹ New Freedom Commission on Mental Health, (2003) Achieving the Promise: Transforming Mental Health Care in America. Final Report. DHHS Pub. No. SMA-03-3832. Rockville, MD.

² Doughty, C. & Tse, S. (2005) The Effectiveness of Service-User Run or Service-User Led Mental Health Services for People with a mental Illness: A systemic literature review, Mental Health Commission of New Zealand, Wellington.

³ Substance Abuse and Mental Health Services Administration; Consumer Operated Services and Programs (COSP) (2007) Evidence Based Practices Kit – Building COSPs (Draft) Rockville MD.

⁴ VOIP discussion, Leeds Survivor Led Crisis Services.

⁵ Campbell, Jean (2005) the Emerging Research Base of Peer-run Support Programs www.power2u.org/emerging-research_base.html Downloaded 16th April 2008.

⁶ Doughty C. & Tse, S. (2005) Op Cit.

(Continued from Page 13)

The COSP projects identified, through a multi-site randomised control research program, that participants, utilizing consumer-led programs as an adjunct to traditional services, showed greater improvement in well-being than participants using traditional services only. The New Zealand review indicates that consumer-run services produce highly positive outcomes for services users, at the very least on a par with equivalent clinical services. No instances of harmful outcomes have been recorded. The authors caution interpretations of the findings, indicating that some services operate closely with clinical teams and are not necessarily completely autonomous consumer organisations, but that overall the findings are positive.

Other studies⁷ have found that people who use consumer-operated services experience improved quality of life, and reduced hospitalisation rates and use of crisis services. It is acknowledged generally that many studies of consumer-operated services are descriptive rather than comparative, and that the evidence base for such services is only just developing.

This means that when we have consumer/client groups running their own services, we should specify what it is we intend to improve, compare that with other 'like' services and so 'prove' that we achieve the drop in hospitalisation, or use of other crisis services. This means actively seeking the views of our participants and documenting their experiencing.

If you need help and support in that endeavour, you'd better let us know. Please contact the SHQ office on 07 3344 6919 or email selfhelp@gil.com.au

(Thea is the President of SHQ, published author and poet, support group co-ordinator.....)

⁷ See Klein et al, (1998) Chinman et al (2001)

Federal MP Expresses Concern for People with Rare Diseases and their Families

Graham Perrett, Federal Member for Moreton in Brisbane, commented in his recent enews newsletter of 15th February 2010 that families of people with rare diseases are often forced to carry the burden alone. He went on to say that there was no specific government support body to assist, and that maybe we can start to do something about it.

So Let's Do Something About It!

Graham is SHQ's local FEDERAL member of Parliament. When we received his enews we were thrilled that someone in the Federal field was talking about the lack of support for people with rare diseases. SHQ is following him up to see what can be done, but we would like to encourage others to contact him too - politicians take notice of numbers, particularly in election years!

Graham wrote: "Sunday 28 February is Rare Disease Day. Observed world wide, this day is an important time to consider the needs of people and their families affected by rare diseases and disorders. Like a young girl in our electorate who suffers from the rare neurological disorder, Angelman Syndrome. Parents and families do it tough and are often forced to carry the burden alone - including advocacy, support and promoting research. Australia does not yet have a specific government support body to assist but maybe from this 28 February we can start to do something about it."

So, the invitation is out there. Graham is a **FEDERAL MP** so contact him, no matter where you live - he may just take up the cause. If we don't tell him, he won't know we care. Email Graham Perrett, (MP) Graham.Perrett.MP@aph.gov.au

Resilience: An Ordinary Magic that Help Us Rise and Thrive

Very recently I attended a workshop on Resilience organised by the Sydney-based Happiness Institute. It was a really inspiring event and the speakers were excellent, particularly Ingrid Poulson who found happiness after an extremely traumatic event and now uses her own tragedy as a catalyst to help others. Instead of allowing herself to feel the victim of a cruel god or indifferent universe, Ingrid moved on from the past with something very positive, having the resilience that allows you to go down into the negative emotions, accepting the full palette of our emotional landscape, and bouncing back.

In 2003, Ingrid's estranged husband killed their two young children and her father. After time, she chose to start with survival and build from there. She recognised her resilience and chose to rise to the challenge of overcoming this terrible tragedy. Her focus is not on the story itself but on her recovery from the story.

While few of us have to suffer events such as those that Ingrid experienced we all have to deal with challenges, hardships and grief in everyday life. Our ability to be resilient in the face of these can help us get through troubled times and not only survive but live life to the fullest. 'It is better to be wire than steel', says Ingrid. Survivors are flexible and adaptable, allowing themselves to feel and allowing themselves to go there, knowing that they can come back.

According to Ingrid resilience is an 'ordinary magic'. It is natural, learnable, and normal; it is something we 'do' rather than 'are'. She described 4 main components of a RISE model of resilience: Resolve, Identity, Support and an Everyday plan.

Resolve includes giving ourselves permission to survive, a commitment to take responsibility for how we respond and react to experiences. Identity involves exploring and expanding those parts of our character that make us more resilient, acknowledging our wins and embracing flexibility. Support acknowledges that we can't do it alone so make use of support networks such as family and friends – and self help support groups - giving support to others as well as asking for ourselves. And an Everyday plan is the nuts and bolts of building resilience on a daily basis, including eating well, getting some exercise, not watching too much TV and (quoting the Dalai Lama when asked about his secret to happiness) getting a good night's sleep.

Ingrid has developed this further into the 6R model of resilience (see www.steadfasttraining.com.au/model) which is applicable to both individuals and organisations, helping to equip them with the necessary tools for coping with stress, change and adversity. She notes that resilient organisations are made up of resilient individuals: those who can handle ongoing, everyday stressors with ease and strive to find enjoyment and satisfaction in their work. These valued team members can help organisations thrive.

At the workshop I also gained some tips about the connection of our bodies to resilience and happiness (very thought provoking) and now keep reminding myself to sit up straight at my desk instead of slumping and it really does make a difference to how I feel! And I really appreciated Professor Tim Sharp's (Director of The Happiness Institute aka Dr Happy) newly-coined concept of 'pronoia' (ie everyone is out to make me happy) as opposed to paranoia. I'm all for being pronoid!

Diana East, Mental Health Project Worker, Self Help Queensland

"Blessed is the person who can laugh at himself – he'll never cease to be amused."

Author unknown

Play for Pain: New Tunes for Creative Brains

Consumer Forum

The International Association for the Study of Pain has designated 2010 as the Global Year Against Musculoskeletal Pain.

Chronic Pain Australia, the Australian Pain Society, the New Zealand Pain Society, the Australian Pain Management Association, the School of Physiotherapy, Curtin University & the Pain Medicine Unit of Fremantle Hospital present an educational program for all sufferers of chronic pain.

This educational program will also be of high interest to families and carers, health professionals and anyone with an interest in pain management health care. The Forum allows time for audience questions and for people to engage the speakers informally.

Join us for a unique seminar featuring:

'Steps: delivering services to people in pain' Presented by Dr Stephanie Davies (Pain Medicine Physician), Mr Carl Graham (Clinical Psychologist) & Mr Luke Parkitny (Physiotherapist), Pain Medicine Unit, Fremantle Hospital.

'Fine tuning that can fulfil your dreams: the role of a Lifestyle facilitator.' Presented by Jenny Faulkner, (Lifestyle Facilitator, South Australia)

When: Sunday 28 March 2010

Where: Gold Coast Convention and Exhibition Centre

Time: 09.30 am - 12.00 noon

Cost: Gold Coin Donation

To register your interest in attending please contact:

Amanda Nielsen

Email: a.nielsen@uq.edu.au

Phone: 0416 672 854



Disabled Surfers Association of Australia

'Surfers Helping Surfers'

The disabled Surfers Association of Australia (DSA) offers participants and volunteers an opportunity to get in the ocean together, have fun and socialise. Lasting friendships are made between people from all walks of life. Everyone from asthmatics to people with joint injuries and paraplegics are welcome.

Many members find friendship and support and have their interest in surfing renewed. DSA has about 100 volunteers at each event on the Gold Coast. They run the committee, they help to take people surfing, monitor surf conditions, help with the sign-in table, cook the barbecue, set up equipment, ferry wheelchairs across the sand, organise beach activities and make people feel welcome and at ease.

All people involved with the DSA do it on a voluntary basis. The Disabled Surfers Association of Australia operates in many locations across Australia and New Zealand. For more information, visit www.disabledsurfers.org

"Sometimes it is better to ask forgiveness than permission"

Tony Abbott

Federal Leader of the Opposition, Australia (March 2010)

1957.....

DSM-V Draft Promises Big Changes in Some Psychiatric Diagnoses

By John Gever, Senior Editor, MedPage Today

Published: February 10, 2010

Substantial changes are in the offing for the "psychiatrist's bible," the Diagnostic and Statistical Manual of Mental Disorders, according to a draft of the forthcoming fifth edition.

The American Psychiatric Association (APA) has posted the draft of DSM-V on a special Web site, www.dsm5.org, to obtain comments from its members, other members of the mental health community, and the public.

At a press briefing before the draft's release, members of the APA team leading the DSM revision highlighted several substantial innovations they are proposing:

- Recategorizing learning disorders, including creation of a single diagnostic category for autism and other socialization disorders, and replacing the controversial term "mental retardation" with "intellectual disability"
- Eliminating "substance abuse" and "substance dependence" as disorders, to be replaced with a single "addiction and related disorders" category
- Creating a "behavioral addictions" category that will include addictions to gambling but not to the Internet or sex
- Offering a new assessment tool for suicide risk
- Including a category of "risk syndromes" for psychosis and cognitive impairment, intended to capture mild versions of these conditions that do not always progress to full-blown psychotic disorders or dementia, but often do
- Adding a new disorder in children, "temper dysregulation with dysphoria," for persistent negative mood with bursts of rage
- Revising criteria for some eating disorders, including creation of a separate "binge eating disorder" distinct from bulimia
- Using "dimensional assessments" to account for severity of symptoms, especially those that appear in multiple diagnostic categories

The APA will accept comments through April 20. The work groups managing the revision will consider them and make further changes as needed to the draft, said David Kupfer, MD, of the University of Pittsburgh, chairman of the DSM-V task force.

The draft diagnostic criteria will then undergo two years of field testing. The final DSM-V is scheduled for release in May 2013, a year later than originally planned.

New Categories for Dyslexia, Autism

In the area of neurodevelopmental disorders, DSM-V will put dyslexia and dyscalculia -- reflecting disabilities of reading and mathematics, respectively -- into a new category of learning disabilities.

Autism, Asperger's syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified will make up the new "autism and related disorders" category.

The head of the APA's work group on substance-related disorders Charles O'Brien, MD, PhD, of the University of Pennsylvania, told reporters on the press call that substance dependence and abuse had no basis in the research on addictions.

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"We unanimously agreed that . . . there really isn't evidence for an intermediate stage [short of addiction] that is now known as abuse," he said. Instead, there will be substance use disorders for each of the major types of drugs that cause problems, such as alcohol.

He added that the term "dependence" was problematic as a psychiatric diagnosis because some types of physical dependence are "completely normal" for some medications, such as opioid painkillers.

In fact, under the draft, DSM-V will include "discontinuation syndromes" to allow physicians to properly assess symptoms of withdrawal from psychoactive substances, including caffeine, O'Brien said.

He also said his work group had considered including sex and Internet addictions as disorders, but decided there was insufficient evidence to allow development of reliable diagnostic criteria for them.

Consequently, gambling addiction is slated to be the only disorder formally listed in the behavioral addictions category.

But O'Brien added that, under current plans, sex and Internet addictions would be included in an appendix to DSM-V, intended to encourage additional research that could lead to their inclusion in future editions.

Carole Lieberman, MD, a Beverly Hills, Calif., psychiatrist who appears frequently on television, regretted the omission of Internet addiction.

Contacted for comment by MedPage and ABC News, Lieberman said in an e-mail that behavioral addictions are a worthy category. "But why would it not include 'Internet addiction,'" she wrote. "Could it be that the psychiatrists involved do not want to acknowledge that their own Internet usage could meet the criteria for addiction?"

Lieberman added that compulsive shopping was another form of behavioral addiction that deserves recognition.

Dimensional and Risk Assessments

APA leaders also emphasized the two new suicide risk assessment scales planned for DSM-V, one for adolescents and one for adults.

David Shaffer, MD, of Columbia University, told reporters on the press call that suicide nearly always occurs in the context of some psychiatric disorder, but not always depression.

The new risk assessment tools focus on risk factors such as impulsive behavior, heavy drinking, and chronic severe pain and illness.

In DSM-IV, suicidal ideation is treated as a symptom of major depression and certain other disorders.

Shaffer also explained the genesis of the proposed new childhood disorder, temper dysregulation with dysphoria (TDD).

"About 40% to 60% of the cases [seen by child psychiatrists] will be children who are doing things that other people don't want them to do," he said. Many of these are children who are "stubborn and resistant and disobedient and moody."

There is currently a recognized syndrome known as oppositional defiant disorder, but some children also display severe aggression and negative moods that go beyond mere stubbornness, according to Shaffer.

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Such children are often tagged as having juvenile bipolar disorder, but research has shown that the label is often inappropriate, since they usually do not qualify for a bipolar disorder diagnosis when they reach adulthood, although they remain dysfunctional. More often, these children are diagnosed as depressed when they become adults.

He said the addition of TDD would better describe the severity and frequency of irritable behavior while also recognizing the mood disorder that goes with it.

Another innovation in DSM-V will be the extensive use of so-called dimensional assessments. Whereas DSM-IV relied heavily on present-absent symptom checklists, the new edition will include severity scales for symptoms, such as anxiety or insomnia, that may appear to larger or smaller degrees in many different mental illnesses.

Darrel Regier, MD, MPH, the APA's research director, said such checklists "don't always fit the reality that someone with a mental disorder experiences." Often, a symptom like insomnia isn't on the checklist for a particular disorder, he said, "but they can still affect patients' lives and affect the treatment planning."

Incorporating quantitative dimensional assessments should allow clinicians to develop treatment and response-monitoring plans better tailored to individual patients' needs, Regier said.

But Lieberman foresaw problems with the dimensional assessments. "I don't think [they] will add anything but confusion," she said in an e-mail. "As it is now, people don't really make use of the subcategories that there are to describe severity of symptoms. Instead, I see this as a tool that insurance companies could well co-opt to try to deny benefits."

Gender Identity Disorder Stays

A closely watched issue in the DSM-V revision has been whether to change or do away with gender identity disorder, now listed in DSM-IV. At this point, the draft retains the designation but with some changes, officials said.

People who consider themselves "transgendered" have long criticized DSM-IV and previous editions for labelling them with a mental disease when their problems, they believe, are purely somatic; ie. they have the wrong genitalia and hormonal balance.

At the APA's annual meeting last May, members of the transgender community made a case for dropping gender identity disorder from DSM-V, but keeping some kind of "gender variance" diagnosis as a medical condition. Such an approach would eliminate the stigma of a psychiatric diagnosis while leaving a pathway for third-party payment for gender transition treatments, they said.

William Narrow, MD, the APA's research director for DSM-V, told reporters that the draft does remove the term "disorder" from the condition when applied to children, renaming it as "gender incongruence." For adults, gender identity disorder will remain in DSM-V but with substantially altered diagnostic criteria, Narrow said.

But APA officials said the organization planned more discussions with members of the transgender community.

Kupfer, the DSM-V task force chairman, stressed that further changes in many diagnostic categories are likely following the comment period and field trials. Final revisions will be submitted in 2012 for approval by the APA's two governing bodies, the Assembly and the board of trustees.

(This article was developed in collaboration with ABC News)

Celtic Curse?

Genetic Haemochromatosis (GH) is a genetic (autosomal recessive) disorder found in people with European ancestors. Those affected with GH absorb more iron from food and this leads to a build up of iron in their body. Too much iron in the body can cause several significant health problems including arthritis, diabetes and cirrhosis of the liver.

However, if GH patients are diagnosed in the pre-cirrhotic stage and regularly treated by phlebotomy (blood letting) to remove the excess iron, life expectancy is normal.

Haemochromatosis is a very treatable genetic disorder

However, once cirrhosis has developed, patients have a shortened life expectancy, with a significant risk of liver cancer, even when lower iron levels have been achieved.

In Western countries approximately 1 in 500 Caucasians are affected by the GH.

In 1980 it was proposed that the haemochromatosis gene mutation had originated in a Celtic population in central Europe and had spread across Europe through population movement. Further, subsequent migrations had confined the Celts to the western fringes of Europe, resulting in a particularly high gene frequency in the so-called Celtic regions. Viking conquests and migrations may also have played a significant role in the spread of the gene.

For further information contact:

Margaret Rankin
Haemochromatosis Society Australia Inc
07 3345 8051
www.haemochromatosis.org.au



Haemochromatosis is the most common inherited disorder in Australia today!

Spencer Brennan Coming to Melbourne in July

Expert, writer and renowned presenter in the self help sector, Spencer Brennan from the Self Help Resource Centre in Ontario Canada is coming to COSHG, Melbourne to share his knowledge

Thursday 15 July 2010

The Collective of Self Help Groups (COSHG) is delighted to announce 2 workshop sessions with Spencer Brennan. Spencer previously presented two workshops for COSHG when he visited Australia in July 2007. COSHG is already hearing expressions of eager anticipation for Spencer's return visit. His previous presentations were received with great enthusiasm.

(Editor's note: COSHG is SHQ'S sister organisation in VIC. We think they would be happy to field enquiries from QLD self help groups interested in attending www.coshg.org.au)

"Some people think that doctors and nurses can put scrambled eggs back into the shell. "

**Dorothy Canfield Fisher
US Author named by Eleanor Roosevelt as one of the ten most influential women in the United States.
1879 - 1958**

New Privacy Guidelines for Doctors

- on disclosing genetic information to genetic relatives

On 16th December 2009 the National Health and Medical Research Council (NHMRC), in cooperation with the Office of the Privacy Commissioner (OPC), released new guidelines to assist health practitioners in making decisions about disclosing genetic information to their patient's genetic relatives.

Dr Sandra Hacker AO, chair of the NHMRC's Guidelines Working Party, said the guidelines specify the strict requirements that must be met by health practitioners if they are faced with the difficult decision of having to disclose genetic information without patient consent.

"These new guidelines permit doctors to disclose information to a genetic relative of the patient without the patient's consent, but only in situations where they reasonably believe that disclosure is necessary to lessen or prevent a serious threat to the life, health or safety of the patient's relative," Dr Hacker said.

"It is important to emphasise that doctors can not disclose information to non-genetic relatives, for example husbands or wives, or when there is no threat to the genetic relative."

The Australian Privacy Commissioner, Karen Curtis, has issued a Temporary Public Interest Determination (TPID) which will allow medical practitioners to collect or use the contact details of a patient's genetic relatives in situations where the guidelines permit the disclosure of information.

"It is important to note that the guidelines and TPID do not require disclosure of information, but rather provide the framework for this to occur under the appropriate circumstances," Ms Curtis said.

"Disclosure of genetic information without consent is only permissible under the Privacy Act if it is in accordance with the guidelines."

The use and disclosure of genetic information to a patient's genetic relative under Section 95AA of the Privacy Act 1988 (Cth) – Guidelines for health practitioners in the private sector' are available for download at <http://www.nhmrc.gov.au/publications/synopses/e96syn.htm>

Further information is available from the Office of the Privacy Commissioner:
www.privacy.gov.au/law/act/genetic Ben Apple 0407 663 968
NHMRC: Simon Tidy 0422 008 512

National Hepatitis Awareness Week Grants Available

The Hepatitis Council of Queensland has received funding from Queensland Health to support community organisations to coordinate an activity during **National Hepatitis Awareness Week (NHAW) 17 - 23 May 2010. World Hepatitis Day is Wednesday 19 May 2010.** This year the Council is again offering small NHAW grants ranging from \$100 - \$500 to organisations that would like to run an activity.

As with the 2008 and 2009 campaigns, this year we are working to increase awareness among the general public of the alarming fact that one in twelve people worldwide are living with hepatitis B or C.

Applications close 5pm Friday 9th April, 2010. healthpromotion@hepqld.asn.au

Health Community Councils

- the Eyes and Ears of the Queensland Public Health System

Why not introduce yourself?

There are 36 Community Health Councils in Queensland. They are made up of local community representatives who help to ensure that public health services are highly responsive within their local district.

Members come from a wide range of community and cultural backgrounds. They focus on the safety and quality of public health services and consumer and community engagement. Members listen to feedback from the local community and provide a real community perspective to health services. The 36 HCC locations are:

Southern Health Service Area	Central Health Service Area	Northern Health Service Area
QEII Hospital	Prince Charles Hospital	Cairns
Bayside	Redcliffe-Caboolture	Tablelands
Logan Beaudesert	Rockhampton	Innisfail
Gold Coast	Gladstone	Cape York
Princess Alexandra Hospital	Banana	Mackay
Roma	Central Highlands	Mt Isa
Charleville	Central West, Fraser Coast	Torres Strait
Toowoomba	Royal Brisbane and Women's Hospital	Townsville
Northern Downs	Sunshine Coast	Bowen Charters
Southern Downs	Gympie, Bundaberg	
West Moreton South Burnett	North Burnett	

Councils have up to 8 members including a chairperson and usually meet on a monthly basis. Council members are remunerated for meetings, travel and special assignments. The Health Quality and Complaints Commission advertises and nominates to the Minister for Health, persons it considers suitable for appointment as members of councils.

For information about applying for council membership phone toll free:

1800 077 308 or email info@hqcc.qld.gov.au

Turn off the Lights - Earth Hour - 4th Year in Australia

Saturday 27th March 2010 at 8.30 pm

Earth Hour is the biggest mass participation event in the world.

Nearly 100 iconic landmarks in 1,000 cities and towns around the world will switch off their lights for Earth Hour 2010, joining hundreds of millions of people showing their commitment to the environment.

The world's 3 tallest buildings - the new Burj Khalifa in Dubai, CN Tower in Toronto and Taipei 101 in Taiwan - are going dark for the global event. By turning the lights off, cities are reflecting the aspirations of their citizens.

To register, or for more information, go to www.earthhour.org.au

Think Before You Print!

1 ream of paper = 6% of a tree and 5.4kg CO2 in the atmosphere

3 sheets of A4 paper = 1 litre of water

(Message appearing on emails from Department of Environment and Resource Management)



The **Mucopolysaccharidoses** (MPSs) are rare genetic disorders in children and adults. They involve an abnormal storage of mucopolysaccharides, caused by the absence of a specific enzyme. Without the enzyme, the breakdown process of mucopolysaccharides is incomplete. Partially broken down mucopolysaccharides accumulate in the body's cells causing progressive damage. The storage process can affect appearance, development and the function of various organs of the body. Each MPS disease is caused by the deficiency of a specific enzyme.

**11th International Symposium on Mucopolysaccharide and Related Diseases
23rd - 27th June 2010, Adelaide**

Mucopolysaccharide & Related Diseases Society Aust. Ltd, Lysosomal Diseases Australia and Lysosomal Diseases New Zealand are hosting the 11th International Symposium on Mucopolysaccharide and Related Diseases. The organising committee warmly invites you to join us at the Adelaide Convention Centre for this event.

The theme for the symposium is "Translating Research into Clinical Reality" Our scientific and family programmes will be exciting, and relevant with a focus on the areas of newborn screening, prognostics, understanding pathology and therapeutic options. Genuine opportunities for thorough discussion and debate will be a feature of the program - not only for the academics but also the families.

The organising committee hope you will be able to join us for 5 exciting days of cutting edge science, exciting family experiences and an enjoyable cultural experience. For more information and registration details please visit www.mps2010.com.au or email wendy@mpssociety.org.au



**3rd Annual Creutzfeldt-Jacob Disease
(CJD) Conference**

Invitation to Members and Health Care Professionals

Melbourne Saturday 15th May 2010

We are honoured and pleased that several of the world's most prominent experts have accepted our invitation to speak at the conference and the information afternoon, and are all funding their own travel to Australia to share their experience and knowledge. They are:

Professor Pierluigi Gambetti (USA), Nueropathologist, Director, National Prion Disease Pathology Surveillance Center USA

Professor Richard Knight (UK), Neurologist, Deputy Director National Surveillance Unit UK

Professor Neil Cashman (Canada), Neurologist, Scientific Director PioNet Canada CEO Amorfix – This Company is working on a blood test for variant CJD

Dr Brian Appleby (USA), Director of CJD Program, John Hopkins Hospital

These speakers will be joining our own experts, Professor Colin Masters and Associate Professor Steven Collins, in Sydney Professor Simon Hawke.

Please direct enquiries to contactus@cjdupport.org.au or call 1800 052466.



Invitation to Mitochondrial Information Day Brisbane, Saturday 10th April, 9am to 1pm

**Auditorium, Level 5, Woolworths Building
The Royal Children's Hospital, Herston Road, Herston 4029**

The information day is an opportunity to learn more about Mitochondrial Disease - a genetic condition which robs the body of energy.

Presentations

- Dr David Coman – Metabolic Physician/Clinical Geneticist, The Royal Children's Hospital, Brisbane
- Treatment & Healthy Living for Adults with Mitochondrial Disease - A/Prof Carolyn Sue – Director, Department of Neurogenetics Royal North Shore Hospital
- Treatment of Mitochondrial Disease in Children - Prof John Christodoulou, Director Genetics Program, Children's Hospital at Westmead
- Difficulties posed by Mitochondrial Diseases in the clinic. - Dr Jim McGill, Director of Metabolic Medicine, The Royal Children's Hospital, Brisbane
- Dr Doug Lingard, President AMDF
- Dr David Coman – Metabolic Physician/Clinical Geneticist, The Royal Children's Hospital, Brisbane

For further information, or to find out how to register contact AMDF:

Phone/Fax: (02) 9488 8058

Mobile: 0466 491 757

Email: public.officer@amdf.org.au

Website: www.amdf.org.au



Invitation to Pituitary in the Tropics Cairns, Saturday 8th May 2010, 8.20am to 2.30pm

Auditorium, A Block, 2nd Floor, 161 - 175 The Esplanade

The Australian Pituitary Foundation and the Cairns Base Hospital would welcome your attendance. Panel discussion and Q & A opportunities included.

Presentations

- Why it is referred to as the Master Gland: What can go Wrong – General Overview - Associate Professor Ashim Sinha, Director of Endocrinology
- Acromegaly - Dr Emershia Suthihran, Advance Trainee In Endocrinology
- Cushing's Disease - Dr Yogesh Raje, Advance Trainee in Endocrinology
- Prolactinoma - Dr Anna McLean, Staff Endocrinologist
- Hypopituitarism & Hormone Replacement - Dr Jenny Yarker, VMO Physician
- Surgical Interventions - Mr. Eric Guazzo, Senior Visiting Neurosurgeon/Acting Director of Neurosurgery, Townsville Hospital
- The Role of Radiation Therapy - Dr. Michael Collins, Senior Radiation Oncology Consultant, Townsville Hospital
- Growth Disorders and It's Management in Children - Dr Dyanne Wilson, Paediatric Endocrinologist
- Newer/ Novel Agents in the Treatment of Pituitary Tumours - Associate Professor Ashim Sinha, Director of Endocrinology

To register: Email qld@pituitary.asn.au or visit www.pituitary.asn.au



Invitation
to
5th Australian Batten Disease
Family Conference

**This Conference welcomes the public with an interest in Batten Disease
8th to 10th October 2010**

A Project of Hope.... The BDSRA Australian Chapter hopes that families, friends, doctors and researchers will come together in a wonderful and extraordinary way.

The Project aims to provide families and their friends, teachers and medical staff, affected or involved by this Disease with information about various aspects of Batten Disease, education and social interaction.

Together with the BDSRA USA group, we organise for worldwide researchers to come here to share their knowledge, update us on research and possibilities and hopes of trial treatments. A number of excellent speakers will give us a greater understanding of the disease. Families will travel from all states of Australia, NZ & USA.

Families and carers have a need for knowledge, hope and practical ways of managing. Our second aim is to have guest speakers form a panel group on the appropriate methods to provide the best care for these special children.

Included in the conference days are workshops for specific forms of Batten Disease and most importantly, a 'Ladies Art therapy' workshop (maybe a little champagne involved) and a 'Mens Outing' (which also probably involves a beer !)

The Children's Program (Saturday and Sunday) is packed with fun activities so affected children and siblings can interact safely while in the care of Commonwealth Respite Centre and volunteer carers.

When: Friday 8th October to Sunday 10th October 2010

Where: Sea World Resort & Water Park, Gold Coast, Queensland

For further information please email Vanessa at vanessa@battens.org.au



ASCA (Adults Surviving Child Abuse) in collaboration with SECASA, is pleased to announce the Mike Lew 2010 Tour Downunder. Mike Lew is a world authority in men's recovery from childhood abuse.

In April 2010 Mike will be running several one-day workshops around the country as well as a three-day residential retreat for male survivors of child abuse in Melbourne.

Mike will also conduct a series of one-day workshops for health professionals working with male survivors of child abuse.

For more information and/or to register please visit www.asca.org.au/mikelew

Mike Lew Workshops now have full APS and ACA accreditation

"Children seldom misquote you. In fact, they usually repeat word for word what you shouldn't have said."

Author unknown



Diary Dates

29th April - 1 May 2010: Health in Difference 2010: Doing Diversity

Presented by the National LGBT Alliance
URL: www.lgbthealth.org.au/Health-in-Difference-2010

Venue: Sydney

3rd - 6th May 2010: International Federation on Ageing 10th Global Conference

"Climate for Change. Ageing into the Future"

Phone: 02 9265 0700

Email: ifa2010@arinex.com.au

URL: www.ifa2010.org

Venue: Melbourne

18th - 21st May 2010: 6th National Australian Women's Health Conference

Women's economic, mental, sexual & reproductive health etc.

URL: www.awhn.org.au

Venue: Hobart

21st - 22nd May 2010: Palliative Care Queensland Biennial Conference 2010 "Looking in Looking Out"

URL: www.palliativecareqld.org.au

Venue: Ipswich

31st May - 2nd June 2010: Annual Communities in Control Conference

"Power Up! Who has it, how to get it & how communities can use it."

www.ourcommunity.com.au/cic2010

Venue: Melbourne

2nd - 4th June 2010: National Community Care Conference "Next Generation: Community Care: Rethinking, Reshaping, Rewarding"

URL: www.acqi.org.au/acsa2010/index.html

Venue: Gold Coast

21st - 23rd June 2010: Australian Winter School Conference 2010

"Back to Basics: A Commonsense Approach"

www.winterschool.info/index.php

2010 — 'Year of the Lung'

Neighbour Day 28th March 2010

Neighbour day is Australia's annual celebration of community. It's the perfect day to meet new neighbours and thank long term neighbours for being there when you needed them.

Say G'day to your Neighbour!

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

Old Software? Can't Read Email Attachments? Are you a Not for Profit?

Check out DonorTec to see if your organisation is eligible for their very low cost range of computer products.

www.donortec.org

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

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