

## Newsletter

#### December Quarter

Issue 4. 2006

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

#### Self Help Queensland Inc **President's Report to the AGM October 2006**

Hello again,

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

Following the last AGM, the planning session delivered 2 proposed projects for 2005-2006. The Directory Project and the Deep Democracy project.

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

Interest in a conversation café was invited and contact with Jim Rough, (a USA based dynamic facilitation trainer) was made. Jane Gregg from the University of the Sunshine Coast agreed to partner the project and the Health Promotion Association of Queensland was also invited to participate. (Continued on Page 4)

#### **Values**

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

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

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

#### **Principles of Practice**

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



The Management and Staff of Self Help Queensland Thank you for your support during 2006

Wish all our Readers

#### Self Help Queensland Inc Management Committee Members

President Sue Smyllie
Secretary Thea Biesheuvel
Treasurer Kathleen Zarubin

Members Diana East

Jill Metcalfe Kim Summers Penny Threlfall Bob Wyborn

#### **Committee Meetings**

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

#### **Project Officer**

Trish Fallon

#### **Administrative Assistant**

Christina Zomer

#### 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**

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URL: www.selfhelpqld.org.au

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



#### Facilitator Training Offered to Cancer Support Groups in North Qld in 2007



After a very successful pilot training program launched in Brisbane in May 2006, the Queensland Cancer Fund is now offering Support Group training to facilitators of cancer and cancer related support groups who reside in north Queensland. Topics included in training are:

- Cancer and Cancer Treatments
- Privacy and Confidentiality
- Grief and Loss
- Group Facilitation
- Practical considerations when setting up a Support Group

The Cancer Fund is now taking applications from Support Group Facilitators in northern Queensland (from Rockhampton to Cairns).

Training will take place in Townsville, at a date to be announced. To enquire about the application process, please contact Tracey Ward at the Oueensland Cancer Fund.

Phone: 07 3258 2257

Email traceyward@gldcancer.com.au

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#### Genetic Matters

by Kim Summers PhD

### New Treatments for Old Diseases

Twenty-five years ago, people working in the area of genetic conditions were sure that cures based on adding back normal genes to affected people or changing their abnormal ones were only a short way off. Unfortunately these "gene therapies" have never lived up to those early hopes, because of technical difficulties which caused bad outcomes, ranging from cancer to death. Recently gene therapy has been promoted as a way of treating cancers, but researchers have looked at other ways of treating genetic conditions. Two years ago I summarized the problems with current approaches and talked about some alternative strategies which were in development.

In August Brisbane hosted the 11<sup>th</sup> International Congress of Human Genetics and two possible gene-based treatments for one genetic disease were revealed. The disease is Duchenne muscular dystrophy, a muscle wasting condition affecting boys who are usually in a wheel-chair in their teens and die before they reach 20. A milder form, Becker muscular dystrophy, results in later onset of muscle problems and many affected men live into their sixties and beyond.

Both conditions result from changes in the gene responsible for a protein called dystrophin. Dystrophin has been likened to a "molecular shock absorber", functioning to cushion the muscle cells from the forces of muscle contraction. The absence of dystrophin in the muscles of boys with Duchenne muscular dystrophy means that the cells take the full stress of muscle action, resulting in their destruction. These boys often have a chunk of the dystrophin gene missing, leading to the abnormal protein.

Surprisingly, people with Becker muscular dystrophy can have more dramatic changes in their DNA than those with Duchenne muscular dystrophy and yet have milder disease. By looking at the difference between the two conditions, researchers now have some idea of the kinds of treatments which might help.

In one approach, a group at the University of Oxford in England discovered that there is a very similar protein called utrophin which can substitute for dystrophin in muscle cells and absorb the force of muscle contraction. Unfortunately, utrophin protein is not normally found in muscle cells because its gene is switched off. So the researchers reasoned that if they could switch it on, the cells might be able to function normally. They have made a detailed study of the factors which influence when and where the proteins are made and have been able to switch on utrophin in mice with a version of Duchenne muscular dystrophy. The researchers are screening molecules to find those which activate the utrophin gene. This work has not yet resulted in a treatment for humans, but the molecules they have identified are being prepared for clinical trials. If all goes well it might be possible to develop a drug which could be injected into affected muscle tissue, or even taken orally, to slow down or stop the degeneration caused by the abnormality of dystrophin.

A different approach has been taken by researchers at the University of Western Australia. They have developed a strategy which may "convert" the more serious Duchenne muscular dystrophy into the milder Becker form. Although the treatment won't change the damaged gene, it will trick the cell into removing the segment which carries the mutation. This will result in a protein which has the characteristics of dystrophin in Becker patients, and could allow boys with the Duchenne form to maintain healthy muscles for much longer. The first clinical trials of this approach are planned for later this year.

So perhaps gene therapy will take a different form from that envisaged twenty five years ago. We will not be trying to correct or supplement the damaged gene; we will look at ways of substituting it or tricking the cell into repairing the gene product. Modern developments in molecular genetics are taking these approaches from dream to reality.

(A copy of Kim's previous article on Gene Therapy in the September 2004 SHQ newsletter can be obtained by calling Trish at SHQ on 07 3344 6919.

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

(Continued from Page 1)

At this stage, despite a couple of interested people contacting us, no widespread community interest or activity has occurred. We hope to revisit this project during the post AGM planning meeting.

The Directory Project has come along in leaps and bounds. The Directory was launched in February at a morning tea collaboratively hosted by SHQ and the Greater Brisbane Area Consultative Committee. Our thanks go to the more than 60 people who turned up to wish us well, the Honourable Gary Hardgrave, Member for Moreton, who launched the Directory, Bob Wyborn for kindly sharing once again his personal story and Nick Xynias, Deputy Chair of the Greater Brisbane Area Consultative Committee for his support and kind words.

Since the launch over 500 copies of the Directory have been sold, generating almost \$16,000 for use in the development of the next edition planned for 2008. The Directory Project was always about more than sales. Monitoring of our received calls over time had shown that a significant proportion of them were from health and other service professionals seeking information. We hoped the production of the Directory would:

- Decrease the numbers of calls to the office freeing up Trish's time to provide more hands on help to groups and faster turn around for the more complex inquiries.
- Update and extend our data base.
- Promote SHQ more widely through the community.

#### To date:

- Calls to the office have decreased by almost 50% compared to the same time last year.
- Calls are more complex in nature and are now resolved in shorter time frames.
- Our data base now has over 2096 entries, up from 1300 before the Directory project began. 700 of these entries are self help groups, an increase of 400.
- The geographical diversity of known groups has increased and now includes communities as far west as Mt Isa, north

to Cairns and south to the Gold Coast in Queensland and a much broader selection of interstate and international groups. 10 interstate groups, previously unknown to us, have contacted SHQ as a direct result of the directory.

The staff time generated has been used to review and modify systems, train new staff, archive important documentation, build the foundation for the next Directory update and provide intensive assistance to complex enquiries. Feedback about the Directory has been extremely positive. A few people have requested an electronic version. At this stage we are keeping the Directory information as current as possible by sending out updates, additions and changes in our newsletter.

As always our day to day work continues in and around project activity. SHQ has responded to over 2000 requests for assistance, attended over 60 networking, and support meetings including representing Queensland at and hosting the National Conference of the Australasian Genetic Alliance, developed our new website, met our quality management and accountability processes and produced 5 newsletters.

SHQ has gradually increased its community profile over the last few years, with a reputation for helping people who "fall through the cracks". As a result, the number of people contacting SHQ to find support for very rare conditions, particularly genetic disorders has increased. Most requests were successful. However, the most difficulty in finding support groups was encountered in the Mental Health Sector. They are next to non-existent, since people are generally too unwell to facilitate a group themselves.

In order to meet this work load SHQ has employed and would like to welcome our new administration trainee, Christina Zomer to the team. Christina has been with us since August and has already made a difference to the work place.

I would also like to acknowledge the commitment and support provided by our committee members – Bob Wyborn, Kim Summers, Thea Biesheuvel, Jill Metcalfe, Ann Sprought and Kathleen Zarubin – in 2006. Many thanks. We would all like to wish Ann

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well as she is leaving the committee to meet her increasing commitments at Zoe's Place.

As we look towards 2006-2007 SHQ has been exploring options for funding to provide a suitable resource for Queensland; one containing practical information gathered through interaction with groups over a period of many years. At present SHQ relies on the knowledge and experience of the Project Officer to impart practical advice to people wanting to start groups. The obvious problem is that much of the knowledge goes when the Project Officer goes.

There have been 27 requests to SHQ for such a resource since the last year, 19 having come from professionals eg community health workers, social workers, disability service workers, mental health workers and clinical nurses.

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

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

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

Sue Smyllie President

### Need medical help? Not sure about what to do?

Queensland Health operates a 24 hour, seven-day-a-week State wide service providing access to health information, triage and referral.

If you are not sure about the seriousness of your symptoms, or where you should go for help, there are qualified nurses at the end of the phone to listen and assist. They will direct you to the most appropriate service.

Phone 13 43 25 84

### Thank you for all your newsletters!

The call went out in our last edition for groups to send us their newsletters. The response was just marvellous, so thank you everyone who kindly took the trouble to include us on your mailing list!

All of the newsletters, whether coming to us by post or email, are thoroughly read. The information is extremely valuable in gaining knowledge about the Sector, so please keep them coming.

If you have any ideas to improve our own newsletter they would be most welcome. It's been getting a bit longer lately because we receive great support with the articles people contribute. If you would prefer a smaller, bi-monthly newsletter, or have other suggestions for improvement please let us know. (The cost factor is what has always determined the frequency!)

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

#### Can You Help?

The Allergy Sensitivity and Environmental Health Association (ASEHA) is currently compiling a list of **unfragranced** cosmetics and personal care products that are easily available from supermarkets, pharmacies, health food stores or other retail outlets.

If you know of any **unfragranced** products could you please let Dorothy at ASEHA know about them. Your contribution to the research will benefit people with Multiple Chemical Sensitivity.

Contact:

ASEHA Old Inc

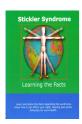
PO Box 96, MARGATE QLD 4019

Phone: 07 3284 8742

Email: asehaqld@powerup.com.au URL: www.asehaqld.org.au

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



### The First DVD on Stickler Syndrome

#### "Stickler Syndrome: Learning the Facts"

"Stickler Syndrome: Learning the Facts" is the first in a series of 3 DVDs that will provide practical information to those living with Stickler Syndrome and healthcare professionals.

Stickler Syndrome is a progressive disorder due to a genetic malfunction of the connective tissue found in bones, eyes, ears and the face. Stickler Syndrome is believed to be the most common autosomal dominant inherited syndrome in the UK, Europe and the United States. It is often under-diagnosed because the collection of symptoms is frequently not linked together. This film brings together the experiences and knowledge of healthcare professionals and people living with the syndrome from the UK, Canada, and the US.

This film was made possible through the assistance of the Tides Canada Foundation, Sage Centre, over 100 private donors, the participants, Stickler Syndrome Support Group (SSSG) and Stickler Involved People (SIP).

Orders are now being taken - the charge is a request for a donation to cover costs and will not exceed \$10 per copy including P&H.

Stickler Syndrome Australia Support Service

Email: ssass@hotkey.net.au

Phone: 07 3886 0665

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#### New Web Site Advises on Support Services for women with Advanced Breast Cancer and their Partners

Advice on support services available for women with advanced breast cancer and their partners is available on a new web site offered by the Group for Women with Advanced Breast Cancer. The site is www.advancedbreastcancergroup.org

(Source: "Health Matters" News and Information from Queensland Health. Vol 11 No 10 November 2006)

#### VOICE!

### It's free, and worth checking out for your organisation!

One of our member groups recently drew our attention to VOICE, an excellent collection of free management resources and information designed to help with the day-today running of a community organisation.

VOICE contains user-friendly information about office administration and management, along with 'how-to' guides, policies and procedures, templates and samples on topics such as:

- managing human resources
- running meetings
- strengthening governance
- strategic planning
- risk management.

For assisting with office administration the group found the templates and samples particularly helpful. (There are about 22 in all.)

Structured around the draft Standards for Community Services, VOICE includes resources relating to the three categories of standards:

- people who use services
- people working in services
- governance and accountability.

VOICE (Valuing Organisational Improvement and Community Excellence) can be found on the Queensland Government's Department of Communities website www.qld.gov.au/qcoor/

Just click on the VOICE icon to the right of screen.

Resources are available online, or you can phone Smart Service Queensland on 131 304 for your free copy of the VOICE CD-ROM.

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#### Queensland Health Provides Online Information Directory

The Health Information Directory provides access to online health and well-being information. The fact sheets and other resources on this site are constantly expanded and regularly reviewed.http://access.health.qld.gov.au/hid/index.asp

#### LAM Australia

#### Lymphangioleiomyomatosis

#### "takes your breath away"

Lymphangioleiomyomatosis (LAM) It's a tricky word to pronounce. The name reflects the different parts of the body that are affected by this extremely rare condition that affects only women in their prime; usually manifesting between early 20's to late 30's. Lymph and angio refer to the lymph and blood vessels, leiomyo refers to the smooth muscle.

In LAM abnormal smooth muscle-like cells proliferate in the lungs, lymphatics and blood vessels. As the smooth muscle cell proliferates the smallest airways in the lungs are overgrown, destroyed and replaced by thin walled cysts. New research indicates that there is more variety in the actual cell line with differing results to the destroyed aiveioli – some women exhibit cysts (blebs) and nodules in others.

Diagnosis is a truly devastating experience. Women are told that LAM is incredibly rare, with no cure, no treatment and very poor life span prognosis. Incidence is now lifting; probably as a result of increased medical awareness and higher profile for the condition. Leading scientists refer to LAM as the "Cinderella Story" of the orphan lung disease group.

Traditionally the incident rate was supposed to stand at 1: 1 million. However New Zealand has 14 patients on the national register, Australia has 50 and American researchers now estimate that there could be up to 250,000-300,000 LAM patients worldwide.

Perhaps the higher than normal incident rate in Australia and New Zealand is because of our generally better national health system and generally better standard of living and education. However; this thought is pure conjecture by the writer.

It is thought that there is a heritage of common misdiagnosis due to the vagueness of symptoms and overlap of these to other respiratory conditions like emphysema and asthma. LAM is interesting to Asthma researchers as the two conditions are the only respiratory ailments that share a similar smooth muscle cell appearing in the lungs.

Generally: women present with unexplained sustained (chronic) shortness of breath (dyspnea), a persistent cough, coughing up blood (hemoptysis), recurrent lung collapses (pheumothorax), chest pain, abdominal and side pain.

Other inclusions to the condition include renal angiolymphomas and LAM may manifest in the abdomen, and there may also be problems with chyle – the milky white thin fluid that is distributed and transferred around the body via the lymph system.

Diagnosis is obtained by a variety of diagnostic tools including: lung biopsy, CT Scans, PFT's (Pulmonary Function Testing), x-rays and close consultation with the relevant physicians." The LAM cell line shares a mutation in the TSC1 and TSC2 gene common to Tuberous Sclerosis sufferers. It is now recognized that up to 40% of female TS patients will exhibit LAM. Interestingly researchers are currently of mind that TS LAM patients are generally "milder".

This new line of thinking also considers that there may be a couple of types of LAM. Sporadic LAM for women who do not have TS and who have LAM, an "unbranded" TS LAM and within these groupings, at least two versions: extremely aggressive and a much more mild variant. The team at the NIH LAM protocol under Dr Joel Moss discuss the different shapes of LAM cells having distinct behavioural differences.

There is a tremendous amount of optimism amongst the international scientific community in their efforts to find a treatment and cure for LAM. The first trial site for Rapymcyin is currently under way in Cincinnati, Ohio and Dr Deborah Yates of St. Vincent's Hospital, Sydney has secured funding towards trials on Doxycycline in LAM treatment.

LAM Australia is a patient support organisation for Australian LAM women, their family, carers and friends. The organisation endeavours to provide information, foster increased awareness, education and research activities. The organisation has a growing website where resources are constantly updated to provide visitors to the site with as much information as possible.

There are 2 LAM clinics in Australia – at St. Vincent's Hospital, (Continued on Page 8)

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Sydney and The Alfred Hospital, Melbourne with hopes for a 3<sup>rd</sup> to be established in Queensland. All LAM women are encouraged to attend clinics – there are isolated travel subsidies available and the clinics are fully funded by Medicare. To find out more information regarding these, please visit the website on <a href="https://www.lam.org.au">www.lam.org.au</a>

I have LAM and I am now 48. I was diagnosed whilst living in Ireland at the age of 39 after a series of major pneumothoraces over a number of years. Fortunately for me, my "new" consultant suspected LAM having come across it once, whilst doing post graduate training in Canada. My two other options were far less exciting: particularly aggressive cancers with expected demise within 6 months. Not many people get excited about a LAM diagnosis, but considering the alternatives, I nearly popped the champagne.

At the time of diagnosis I was the only living LAM patient in Ireland and I have the report from my consultant to GP indelibly imprinted in my memory....."extremely poor prognosis of perhaps 18 months to 2 years". He talked to me about "assessment" (for lung transplant). I asked when that process was started. He said when it was thought the patient had about 2 years left to live. I then asked how long was the waiting list. He said about 2 years. I did the math (and I'm a blonde) and came up with an interesting result.

Common to many people diagnosed with a rare condition the overwhelming reaction and sensation is utter isolation, desolation and shock. I was initially patronised by the medical profession – but not for long.

Time and time again we hear that it is so important for people to become informed and educated so that they can participate equally with their health care professionals in deciding what treatments and what approach is right for them. I can not underestimate this importance – and I hope that our organisation is able to assist LAM women in their efforts to become educated and therefore empowered – helplessness is a terribly destructive emotion and opens the way for patient vulnerability and error.

My lifeline was Sue Byrnes, Founder of The

LAM Foundation in the US and mother to Andrea who has LAM. Sue is the most remarkable person. She single handedly is responsible for the current focus, "sexiness" and breakthroughs in LAM research and understanding. Without her, we would be still waiting for anyone, someone and anything ......at all to help.

With Sue's assistance and wonderful introductions to some amazing physicians in the States I set about becoming educated and empowered.

I recommend to patients to develop a list of questions, then fax it through to their consultant's office a couple of days prior to their next visit. Take someone with you – it is estimated that patients absorb approximately 15% of the information being presented to them. Stick to that list. Get your answers.

Another hugely important issue that is shared by many people who struggle with chronic illness is the unspoken black bear of depression. Of course a person who has a chronic disease is likely to be depressed. She/he may be young, with a family, a future, ambitions, hopes. We need to ensure that people with chronic illness receive adequate levels of professional and specific counselling support.

And the final comment I would like to make about developing proper resources for people is the absolute and urgent need for a national platform that can move priority issues forward to advocacy, policy makers and influencers. I can think of nothing more urgent that the need to radically overhaul the current state by state ad hoc assessment and subsidization of supplemental oxygen.

Summing up: I know I've wandered off the "LAM track" – it seems there are just so many aspects which compete for urgent priority – however the single most important aspect and objective of LAM Australia is to "be there" so that LAM women and their families know they are not alone and that there is a strong spirit of kinship and hope in the LAM community.

Thank you
Tamar Nissen
Acting President, LAM Australia
PO Box 168, ROZELLE NSW 2039
Email: admin@lam.org.au
URL: www.lam.org.au

## Spinocerebellar Ataxia (SCA) Support Group a First for Australia

It can be very daunting to live with a condition that others cannot see; a condition so rare your GP may not be conversant with it. You look okay, though your speech and balance may already be affected. You can be mistaken for being under the influence of alcohol. Going to the supermarket can be a major and very daunting event. The simple things of life are not so simple anymore.

You can feel very isolated even around many people. You are often misunderstood; with even your loved ones unable to relate.

You may be a carer of someone who has been diagnosed with SCA. You need support and understanding in order to provide appropriate care and support.

SCA is a genetically inherited disorder characterized by abnormal brain function. It represents a varied group of disorders. It is most commonly inherited as a dominant trait, which means that any individual who is a carrier of one of the many different gene mutations is affected.

Individuals affected with Spinocerebellar ataxia develop a degenerative condition that affects a region in the base of the brain called the cerebellum, which is located behind the brainstem. The primary function of the cerebellum is to coordinate the body's ability to move. Loss of this quintessential function leads to a progressive atrophy, or wasting away of muscles. The spine also atrophies and this can lead to spasticity.

The condition can be physically devastating and the progressive loss of the ability to coordinate movements can be emotionally challenging and bring significant lifestyle changes. Adverse effects involve the legs, hands, and speech.

SCA is diagnosed through genetic testing, though it is not normally tested in children who may be at risk in later life - except in extreme circumstances. There is no known cure for SCA, though a breakthrough in adult stem cell research is very promising.

Most of the Ataxias have only been identi-

fied in recent years. There are over 20 types, as there are many different gene mutations that cause this disease. There are different names for each type of ataxia, with each different type having a numerical assignment. For example, Spinocerebellar ataxia type 1 is also known as SCA1 and so on. Some people do not know what type they have.

The newly formed Spinocerebellar Ataxia Support Group is in place and aims to:

- Provide a positive and comfortable environment to share concerns
- Support each other and our carers
- Provide a mutual understanding of the condition and its management

People with SCA have a strong message to impart to health care givers:

- Listen to your patients
- We know our bodies; please help us by learning about this little known condition
- We can teach each other, and together make a difference

Spinocerebellar ataxia can be managed, with a positive attitude and learning to live the most positive and complete life you can. Though these life management choices will not slow the progression of the condition, they certainly help with quality of life.

Of course there will be changes in lifestyle. You may have to change some life expectancies, but life's a journey and not always as we plan, so let's make the best of it, regardless of circumstances thrown at us.

The group will meet bi-monthly in Brisbane and is the only known group in Australia. For those who do not live in the Brisbane area or are interstate, support by phone or email is also available.

For venue, dates and meeting times contact Vicki at:

Spinocerebellar Ataxia Support Group Phone: 07 3807 2426 Mobile: 0410530157 Email: vjpedler@bigpond.net.au

Please let Self Help Queensland know:

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

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

### Brisbane City Council Community Grants

#### Closing Date 8th January 2007

Does your community group need funding? The Community Grants Program provides funding to local non-profit community groups to improve and develop services in Brisbane. Council is looking to fund projects that achieve one or more of the following:

- Develop and improve facilities for community use
- Encourage physical activity
- Respond to local and city-wide community issues
- Foster an understanding of Brisbane's history and cultural heritage
- Promote creativity, culture or arts
- Develop the capacity of local community groups to deliver services

For details or copies of grant guidelines and application form for this program:

Phone: 07 3403 8888

URL: www.brisbane.qld.gov.au go to "Communities" and click "Grants and funding" or visit your local Ward Office.

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#### New Alcohol and Drug Support Group (ADS) in Beenleigh

ADS is a support group which arose out of a need in the Beenleigh community for a safe place where people with alcohol and drug dependence could manage their lives and develop self worth.

#### **ADS** is about:

Alcohol problems
Drug problems
Being honest with yourself
Being respected and supported
Making changes you want
Setting your own limits
Talking and listening
Not being pressured or judged
Confidentiality
Relief

People who still use drugs or alcohol

ADS meets at Beenleigh each Thursday from 7pm to 8pm. For further information phone Michael: 07 3287 2561 or 0418 878 413

# 10 Ways to Drive Hard of Hearing People Crazy!!!!!!!



- 1 Yell at them from another room
- 2 Cover your mouth while talking
- 3 Turn or walk away while talking
- 4 Talk with food in your mouth
- 5 Mutter under your breath
- 6 If they ask you to repeat what you said, say "Never mind"
- If they ask you to repeat what you said, exaggerate the response, as if they weren't hard of hearing, but hard of understanding
- 8 Tell them they are just ignoring you
- 9 Ignore them
- 10 Tell them "You hear when you want to"

(Source: "Let's Hear It" Newsletter of Better Hearing Australia Brisbane Inc November 2006)

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#### A Speaker for Your Group?

Would your group like someone to come to one of your meetings, and talk about the quality use of medicines for older people? The sessions are interesting and informative with plenty of time for discussion. They usually last about 1 - 2 hours.

You could be a group of older people who belong to a self help or support group, service club, social club or hobby group, or just a group of friends, retirement village residents or people who attend a local health service or whatever.

All participants at sessions will receive a Medimate booklet, fridge magnet and a plastic 'wallet' for their Medicines List.

Trained peer educators are available to come to meetings in most parts of Australia. To contact the Seniors Peer Educator Coordinator in Queensland:

Diana

Phone: 07 3316 2999

Email: dianaeast@cotaq.org.au

(Source: "Medicines Talk" Newsletter of the National Prescribing Service. Information for Consumers and Consumer Groups. No 19, Spring 2006)



#### **Treatment Hope for Rare Disease**

Self Help Queensland only recently became aware of the rare disease, Pompe's, when sent a very informative DVD about the condition by The Australian Pompe's Association (APA). APA is a Support Group for patients who have been diagnosed with Pompe's Disease, their families and friends especially those who have just recently been diagnosed. There are 22 diagnosed people in Australia; 21 adults and 1 child, with 4 people residing in Queensland. It is not known how many undiagnosed people may also have Pompe's.

#### What is Pompe's Disease?

Pompe's Disease was first described in 1932, by Dutch pathologist J.C.Pompe. The disease is caused by a deficiency or total lack of the enzyme 'acid alpha glucosidase', This enzyme is responsible for breaking down excess glycogen which accumulates in the lysosomes of the muscles. Because the Pompe's patient is deficient in this enzyme, the excess glycogen is not broken down and continues to accumulate in the muscle-cells. This results in progressive muscle damage and severe muscle weakness, so that normal muscle function is increasingly impaired. Respiratory muscles are also involved, severely affecting pulmonary function and, in time, most - if not all - patients will need ventilatory support.

Pompe's Disease can present itself at any age from birth to older adults, its severity often depending on the age of onset, and level of enzyme activity. Babies have the most severe 'infantile' form of Pompe's Disease, and can develop symptoms in the first few months of life. These can include muscle weakness, feeding problems, enlarged liver and heart, and respiratory problems, due to a total lack, or a severe deficiency of the enzyme 'acid alpha glucosidase'.

The 'infantile' form of Pompe's Disease will progress very quickly and, without treatment, these babies may not live longer than twelve months. However, Pompe's Disease can now be treated! The recently approved

treatment, Myozyme, is an Enzyme Replacement Therapy which will allow Pompe's patients to look at a much brighter future.

#### **Symptoms**

Symptoms of adult onset Pompe's Disease will vary from patient to patient. They are disabling, frustrating, often painful and unrelenting. Respiratory muscles will also be affected and a ventilator needed to assist with breathing. Many patients need other aids, such as wheelchairs, walkers, special beds and lifters to cope with everyday life.

#### **Diagnosis**

Diagnosing Pompe Disease has become much simpler than it used to be. Professor John J Hopwood and his team, from the Lysosomal Diseases Research Unit, at the Women's and Children's Hospital, in Adelaide, Australia, have developed a diagnostic test that uses a dried blood spot rather than a muscle biopsy. The new method uses a drop of blood - collected from a finger prick - and dried on a paper card. This card can then be posted to the diagnostic laboratory. Thankfully, painful muscle biopsies will no longer be necessary for diagnosing most new patients.

#### **Treatment**

Treatment comes in the form of an Enzyme Replacement Therapy, where Myozyme is administered by infusion into the patient's blood stream. It has taken many years and many millions of dollars for research, developing and manufacturing to reach this point.

Clinical trials are presently still underway and are scheduled for completion in 2007. Already the European Union and the American FDA have approved Myozyme treatment for all Pompe's patients' age groups. Some Australian patients are already receiving treatment under Special Access Programs. We are now waiting for the marketing approval of our Australian Therapeutic Goods Administration (TGA), so that all Australian patients may have access to Enzyme Replacement Therapy.

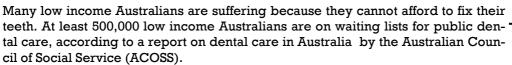
For further information contact: Helen Walker, President Australian Pompe's Association

Phone: 03 5975 9114

Email: brelmar@surf.net.au

**URL:http://users.tpg.com.au/cookie22/**(Source: Helen Walker, President, and APA website)

### Do you want dental care made more affordable and accessible for low income Australians?





ACOSS is calling on the Federal Government to take action to make dental care more affordable and accessible for low income Australians - by funding a free course of basic dental services every two years for low income Australians.

Please go to **www.acoss.org.au** and send a letter to your local Member of Parliament expressing your support for urgent action to improve access to dental care.

### Logan Autism Spectrum Disorder Support Group Under Way

The purpose of this group is to provide support and friendship to any family or individual affected by, diagnosed or associated with Autistic Spectrum Disorder or Pervasive Development Disorder. The group is run by parents who have involvement with Autism. This varies from Aspergers through to Autism and includes all degrees in between.

Come along for tea/coffee and biscuits and a good chat. We have limited facilities for children i.e. there is space for them to play, we provide some toys and there are toilets next door. You would be responsible for your own child/ren.

The group is facilitated by Penny Threlfall, Wendy McFazdean and Karan Smith, and meets on the Third Tuesday of each month at 9.30 to 11.30am at:

18 Blackwood Road, LOGAN CENTRAL (Upstairs in the blue and brick building - next door to Yellow Cabs)

For further information:

Phone: 07 3219 9601 Mob: 0403 695 116

Email: peneth6@yahoo.com.au

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#### **Interstate Self Help Organisations**

There are organisations in most States which provide information, resources and referral to self help and support groups. Each works independently and may have a different focus from State to State. Some relate specifically to genetic conditions and others to more broad based health conditions. For details please contact Self Help Queensland.

### Mackay Parents Initiate Disability Enhancement Fund

 for families residing in Mackay, Sarina, Nebo, Whitsunday, Bowen, Mirani, Belyando, and Broadsound Shires.

Under the auspices of the Mackay Regional Council for Social Development (MRCSD), a group of parents of children with a disability in the Mackay region got together and formed the Disability Enhancement Fund. The purpose of the group is to assist individuals and families who support people with a disability (aged 0 to 65 years), to enhance their quality of life.

The Fund will offer practical help to people who are caring for, or have a disability, to purchase equipment such as house and vehicle modifications, communication devices, wheelchairs, etc. These items can be very expensive, and often out of reach for a large number of people.

Access to the Fund (which holds DGR status) is through an application process. It is hoped that, as it grows and donations increase, so will the geographic area. Meetings are held on the 2nd Thursday of each month from 9.30am to 11.30am for anyone with an interest. If people are unable to attend in person, help is offered to join in via teleconference. Assistance with fuel costs is also offered to people who live regionally.

For further information contact MRCSD:

62 Wellington Street

PO Box 984, MACKAY 4740

Phone: 07 49573088
Fax: 07 49511701
Email: admin@mrcsd.com

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### Australians nominate 10 essentials needed for a fair Australia

The Australian Council of Social Service (ACOSS) conducted a consultation from June to Sept 2006 asking people across Australia to nominate 10 essentials they felt were needed to make Australia fair. 1600 people participated in community meetings and online.

The 10 essentials Australians came up with to make Australia fair are:

- Fair Education
- Fair Health
- Fair Community
- Fair Services
- Fair Welfare
- Fair Reconciliation
- Fair Environment
- Fair Housing
- Fair Work
- Fair Rights and responsibilities

The report collating results from all States and Territories is now available online at www.acoss.org.au. Go to the 'Have Your Say' link to download the report. The site also details the ACOSS Nov 2006 Congress, which further examined whether Australia is a fairer place.

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## Free Community Computer Facilities and Training available at Townsville "Drop In" Centres

Townsville City Council has installed computers at each of its 6 Community Centres for (free) use by the general public during "Community Drop In" times. All Centres have a Community Computer Space comprising of 4 x computer stations and printer. The computers are all online to the internet.

Free computer training is also available for holders of a current pensioner concession/health care card issued by Centrelink or the Department of Veterans Affairs. Courses end on 16th Dec 2006 and re-commence on 15th Jan 2007. "Drop In" Centres and Times will remain the same in 2007.

For bookings and application form please contact Townsville City Council Community and Cultural Services 07 4727 9680.



#### **Survey Participants Welcomed!**

Whatever its cause, chronic pain is regarded as the most widespread physical disorder that people have, worldwide. Chronic pain is often linked to specific physical injury(ies) or illness(es) which have arisen in people's lives.

However, in many cases there are no clearly identifiable reasons as to why pain occurs, and no traditional medical treatment than can completely take away people's experience of their pain. Over the years, many investigators have followed a number of hunches to better sort out the issues, but much remains to be learned.

To advance existing knowledge, Michele Chalmers, a PhD (Psychology) candidate at the University of Southern Queensland, is conducting a study of (non-malignant) chronic pain among Australian residents. The confidential questionnaire survey can be completed either electronically on the web, or, as a paper copy using a pen. So, if you meet the following criteria, your completion of the Chronic Pain Survey would be much appreciated.

If you do not meet the criteria, perhaps you know someone living with chronic pain (family member, friend, neighbour, or acquaintance) who may be interested in participating. It is hoped that as many people as possible who experience chronic pain will agree to participate in the study.

### Criteria for inclusion in 'Chronic Pain' study:

Any person over the age of 18 years, experiencing any (non-malignant) persistent, ongoing, or recurrent pain, for more than 3 months. This pain can be of any type and level of severity, and may be due to injury, illness, disease, or unknown causes.

#### Access the research questionnaire at:

http://www.psych.sci.usq.edu.au/ChronicPa in.asp If preferred, a reply-paid hard copy survey package is available. Contact Michele on 0408 727 249, or email request to chalmemi@usq.edu.au

#### The use of Homeopathy in rebalancing the effects of Trauma

(The following article was sent in by Sacha Petersen who, as a practitioner of Homeopathy, thought it may be of interest to some groups.)

"Trauma, alongside the lack of ability or awareness to process it at the time, is an important aspect to consider when looking at "dis-ease". Trauma can easily be transformed into physical or mental symptoms if feelings are not expressed and processed readily. Dysfunctions can start as early as the time of conception and during the pregnancy (where life statements and beliefs can be developed, especially after the 6<sup>th</sup> month when sounds can be heard).

Trauma may be experienced in certain specific events or as repeated traumatic experiences, where the basis of feelings is a lack of love. When there is lack of love, fear holds us and we therefore become "stuck."

When we are feeling hurt or fearful we stop processing and responding appropriately and this is where disease can begin. Therefore the core suffering needs to be dissolved and processed to create health. Each time we come into a similar situation we become 'stuck' and fall into the old malfunctioning pattern. This 'stuckness' becomes part of our posture, our cells, our attitudes, our responses, our being in the world.

Homeopathy allows an 'out' of this cycle. The effects of trauma to look for in day to day living may be:

- Over/under reactions
- Being out of the present moment ie. responding as if in past situations
- Repetition i.e. finding ourselves in similar situations which bring about the feelings of our primary trauma, allowing to resolves these feelings allows for resolution and no need for repetition

Homeopathy guides the body to a path of healing by stimulating the immune system and energy in the body to achieve healing. Homeopathy is excellent for bringing about healing on a cellular level, where effects of trauma is held as it aims to deal with the cause of the illness and sees the symptoms as simply the body telling us there is an imbalance."

If you have ever wondered about homeopathy and would like to have someone speak at a meeting about the benefits of homeopathy you are welcome to call:

Sacha Petersen (Adv. Dip Hom., Dip Nut.) Indigo House

860 Brunswick St NEW FARM QLD Phone: 07 3358 1311 or 0416 260 849

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#### New Redcliffe group formed to assist families of children with special needs.

Its new, not for profit, and enthusiastically going about setting up a centre which will provide a very broad range of services to assist families of children with special needs.

The Holistic Connected Awareness Association Inc (HCAA) is a not for profit community organisation which aims to serve families in the Sandgate, Redcliffe, Clontarf, Woody Point, Margate, Brighton, Scarborough, Deception Bay, Kippa-Ring, Kallangur and Caboolture areas.

A call is going out for interested persons to join the group to help find a suitable premises and get the centre under way. Along with families, volunteers with blue cards who would like to work with children with special needs are very welcome, along with professionals who are interested in having their services employed.

It is envisaged that the centre will need the services of Holistic Therapists, Occupational and Speech Therapists, Physiotherapists, Tutors, Counsellors, Homeopaths, Kinesiologists, Dieticians, Nutritionists, Chiropractors etc.

Volunteers with administrative, computer, secretarial, bookkeeping, fundraising and network marketing skills would be welcomed, along with those with first aid and experience working with children with special needs.

For further information about HCAA and to obtain details and venue of support group meetings please contact:

Cheryl Brealey HCAA

Phone: 07 3880 4594



Metabolic Dietary
Disorders
Association

#### About Inborn Errors of Metabolism

#### The food we eat

The food we eat contains fat, carbohydrate and protein, which need to undergo a series of chemical reactions to change them into a form which the body can use for growth or energy. This process is called metabolism. Each chemical reaction is controlled by an individual special protein called an enzyme. Inborn errors of metabolism, abbreviated to IEM (or metabolic disorders) result when a particular enzyme does not work properly. Left untreated, failure or deficiency of the particular enzyme can lead to symptoms ranging from feeling vaguely unwell to being so acutely ill that admission to an intensive care unit may be necessary. With time, mild to severe brain damage, physical disablement or death can occur.

#### Metabolic Disorders and their diagnosis

Metabolic Disorders are usually grouped according to the type of food that cannot be broken down properly. Hence you may have heard your/your child's condition described as an Inborn Error of Protein/Fat/Carbohydrate Metabolism.

Inborn Errors of **Protein** Metabolism include: (these lists are not complete)

- PKU the most common diagnosis
- the Urea Cycle Disorders (0TC, Argininosuccinicaciduria, Citrullinaemia)
- other Amino Acid disorders (Homocystinuria, Lysinic Protein Intolerance (LPI), Maple Syrup Urine Disease (MSUD), Non-ketonic Hyperglycinaemia, Orthinine amino-transferase deficiency, Tyrosinaemia)
- the Organic Acidaemia's (3-methylcrotonyl-CoA carboxylase deficiency (3MCC), Glutaric aciduria, Methylmalonic acidaemia (MMA), Proprionic acidaemia)

Inborn Errors of **Carbohydrate** Metabolism include:

- Glycogen Storage disorders
- Fructose metabolism disorders
- Galactosaemia

#### Inborn Errors of Fat Metabolism include:

- Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)
- Very Long Chain Acyl-CoA Dehydrogenase Deficiency (VLCHAD)
- Long Chain Acyl-CoA Dehydrogenase Deficiency (LCHAD)
- Carnitine Palmitoyltransferase Deficiencies (CPT 1 and CPT 2)

Metabolic disorders are genetic conditions, usually inherited as a recessive trait from both parents (meaning both parents carry the gene and all their children will have a one in four or 25% chance of inheriting the metabolic disorder). Most parents do not know they are carriers and the diagnosis of a baby or child with an IEM usually comes as a huge shock to the family. Diagnosis usually occurs because the newborn has been identified through the "heel prick test", taken within 72 hours of birth.

\*\*It is important to remember that, in areas where Tandem Mass Spectroscopy newborn screening has only recently been introduced in some Australian states (2000), diagnosis for many disorders only takes place after clinical symptoms occur. In many of these cases, some physical and/or brain damage has already been done by the time symptoms have developed. It is widely believed that a small number of "cot death" or Sudden Infant Death Syndrome cases, are in fact, undiagnosed metabolic disorders. This is not a concern for those who are living in States that use TMS newborn screening\*\*

#### **Treatment**

Early detection and better treatment has meant that many people with IEM's are able to live normal, healthy lives so long as they maintain diet and treatment. Most properly treated children or adults will progress normally both physically and intellectually and be indistinguishable from their peers apart from their "strange" diet. Some affected individuals may need assistance with feeding including tube feeding. (Continued on Page 16)

(Continued from Page 15)

There are a few metabolic disorders or forms of metabolic disorders that are less likely to respond well despite early intervention and treatment.

An individual's dietary treatment (usually) severely restricts the intake of the particular food that cannot be broken down properly and can be complex to manage. Typically it involves weighing all food to calculate exact protein/carbohydrate/fat content and includes the use of highly specialised, manufactured, expensive and "difficult to cook with" foods such as flours, pastas, breads, milks, "fake" eggs and oils. Supplements and/or medication to help remove the build up toxic by-products may also be necessary to maintain normal growth and development.

Failure to adhere to diet or treatment can trigger immediate (within the hour) to slow (over months or years) consequences, in most cases causing neurological or intellectual disability and death.

Treatment is quite specific as each disorder has its own unique variations and may have secondary symptoms that need careful monitoring. A common problem for parents/carers is access to "Metabolic Physicians" and good dieticians which can be difficult in some areas. This field of medicine is highly specialised and extremely complex, typically there are only 1 - 2 fully-qualified metabolic physicians in each state. The Northern Territory and Tasmania rely on interstate physicians. Despite best intentions from other Doctors or Paediatricians, parents of children with rarer metabolic disorders are often reluctant to follow guidelines outside the express advice of their metabolic physician, based on prior experi-

### Understanding more about Metabolic Disorders

Given their rarity, Metabolic Disorders are not well understood or seen very often, even in large teaching hospitals, which has sometimes resulted in late detection for those areas where TMS newborn screening has only recently been implemented.

Every three years an International Congress of Inborn Errors of Metabolism is held for health professionals to share their knowledge and expertise. The MDDA works in partnership with these health professionals to keep you up to date with the latest developments in research and treatment. There are other International Congresses such as the International Human Genetics Congress which includes all human genetic disorders and is not as specific for the needs of our members as the ICIEM.

At the 2006 MDDA National Conference, "Rising to the Challenge" held in Melbourne in November, those present were very fortunate to hear several speakers report on the ICIEM held in Japan in September this year.

#### **Sharing Experiences**

Self help groups, such as the MDDA exist to share the day to day living issues of living with a metabolic disorder, an area of expertise itself. The MDDA recognises and celebrates the achievements of individuals and groups that make a difference in people's lives affected by a metabolic disorder. The MDDA is recognised by the Federal Government as the key organisation to support individuals and groups with metabolic diagnoses through a co-operative volunteer network.

The vast majority of MDDA members have an inborn error of protein metabolism. As PKU is the most common disorder there are MDDA PKU representatives in each state. For the rarer disorders there are national disorder representatives. The MDDA welcomes other people and groups of IEM to become members. The newsletter and website currently reflects the state of the knowledge base of most members, and we welcome input and suggestions from others so we can continue to grow and represent equitably those with other IEM's.

#### For further information contact: MDDA

PO Box 33, MONTROSE, VIC 3765

Phone: 1800 288 460

Email: mddaaustralia@iprimus.com.au

URL: www.mdda-australia.org

(The basis of this information comes from the MDDA website <a href="www.mdda-australia.org">www.mdda-australia.org</a> Collated and cowritten by Rachael Sharman, parent and National Organic Aciduria Representative MDDA. Co-written and edited by Dr Jim McGill, Director Metabolic Medicine, Royal Children's Hospital, Brisbane, QLD, Australia 2002. This presentation has been updated and revised by Kerri Carboon, PKU Parent and MDDA Executive Director.)



# Australian Participants Needed for Neurofibromatosis Type 2 (NF2) Survey

The Children's Tumor Foundation (CTF), is currently conducting an NF2 survey to determine the level of interest in clinical trials that exists for the NF2 community. Located in New York, CTF is a not for profit medical foundation, dedicated to improving the health and well being of individuals and families affected by neurofibromatosis. "Ending Neurofibromatosis through Research" is their logo's message.

Survey forms have been sent by the Medical/Research Department to their NF2 contacts throughout the world, including Queensland contact person, Brian Cross. (The Children's Tumor Foundation is also for adults, so don't be confused by its name.)

Kim Hunter-Shaedle from CTF is the scientific officer behind the survey initiative. The aim is to gather data from all international groups, clinics, and individuals.

This is the very first preliminary NF2 survey. The Q and A form was put together to see if there were enough NF2 people interested in participating in drug trials before proceeding with the long process of setting up trial/s.

People generally may not be aware that it is very hard to get a clinical trial happening for any rare genetic disorder/disease. The world NF2 population is very small compared to other genetic disorders/disease populations. However, the CTF is confident that trials will be happening sooner, rather than later.

There is no guarantee Australia would be included in the first trial. It most likely won't. However, if no interest is shown from Australia it would ensure that any future trials or trial plans would not involve Australia. Therefore, it is in the best interests of Australian NF2 patients to show interest in being included, even at this very early stage. NF2 medical records are not being requested at this time; that will come later.

The NF2 Clinical Trials Survey Form indicates that the closing date is 30th October 2006. Please disregard this, as the date has been extended for those living outside the USA.

The survey form indicates that name and email address are optional. However, Brian is urging people to fill them in so that CTF can make future contact. If you don't have an email address, you can put your full postal address in its place.

Australia does not have a central NF2 database due to our fragmented health systems. (Federal, State, Individual hospitals within the States and Territories). Brian suggests this survey is a golden opportunity for Australians to be registered on the first NF2 data-base.

He also recommends that people photocopy all documents, and pass on a complete set to their treating specialists/doctor/s in the hope they will contact their other NF2 patients.

The survey form and supporting documents are available by contacting Self Help Queensland. If further information about the survey is required, please email Min Wong <a href="mailto:mwong@ctf.org">mwong@ctf.org</a> who is the contact person at CTF for the Project.

Children's Tumour Foundation URL: http://www.ctf.org/

Brian Cross NF2 Queensland Representative 15 Threadfin Street PO Box 60, TIN CAN BAY QLD 4580 Phone: 07 5486 4034

Email: ba.cross@bigpond.net.au

(Brian will be unavailable for contact in the New Year

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Have you got your copy of the Inaugural 2006/2007 Self Help Queensland Directory of Self Help and Support Groups yet?



(Approximately 600 groups covering a broad range of health conditions and well being issues eg chronic illness, mental health, genetic conditions, disability, sexual health, grief and loss etc.)

Quarterly updates are posted/emailed free of charge with our newsletter to keep the Directory as current as possible until we undertake the second Edition in 2008.

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



## Diary Dates

26 - 28 February 2007: Community Resource Unit Conference: "Myth Busting and Momentum Building: a community conference about truths in the lives of people with disabilities." The CRU Conference will feature international, national and local presenters.

**Phone:** Debbie on 3870 1022

Email: cru@cru.org.au.

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

**Phone:** 02 6285 4660

Email: conference@ruralhealthorg.au

**URL:** www.ruralhealth.org.au

Venue: Albury

14th - 16th March 2007: Biennial Australian National Autism Conference: "Creative Futures". The research presented will have relevance to people living on the spectrum, their families and to those who work in health, education, therapy, accommodation, support and lifestyle services.

#### Email:

angie.walker@astmanagement.com.au

URL:www.astmanagement.com.au/autism7/

Venue: Royal Pines Resort, Gold Coast

1st - 4th May 2007: Australian Health Promotion Association 17th National Conference "Grass Roots to Global Action: Health Promotion in Challenging Environments." Also incorporates annual Indigenous Health Promotion Network Forum on 1st May.

**Phone:** 08 8274 6059

URL: http://www.sapmea.asn.au/

conventions/ahpa2007/index.html

Venue: Adelaide Convention Centre, SA

4th July - 7th July 2007: 18th Annual Australian Winter School on Alcohol and Other Drugs "Drugs, Lifestyles and Culture - Innovation and Evidence".

**Phone:** 07 3834 0211 **Fax:** 07 3832 5625

Email: winterschool@adfq.org
URL: www.winterschool.info/
Venue: Carlton Crest Hotel, Brisbane

2nd - 5th October 2007: 7th National Men's Health Conference & 5th National Aboriginal and Torres Strait Islander Male Health Convention

For further information contact Greg Millan, Conference Development Officer, Australasian Men's Health Forum

**Phone:** 0417 772 390

Email: gmillan@bigpond.net.au

Venue: Adelaide Convention Centre, SA

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#### Improving the Odds!

 a free, six week online treatment program for people with gambling problems



The Improving the Odds treatment program is a joint initiative between Griffith University and the University of Queensland. It is designed to increase treatment options for problem gambling.

An internet-based intervention, it has the potential to help people who are unable or otherwise unwilling to attend face-to-face treatment for their gambling problems. Participants will log on to weekly sessions and work through the program materials which include both psychoeducational material and interactive quizzes. They are assigned to a therapist online and are able to contact the research team if necessary. All treatment is offered under the supervision of a qualified clinical psychologist.

#### The program will be run throughout 2007.

If you are interested in the treatment program or have any questions, please contact: Griffith University, School of Psychology Mount Gravatt Campus, BRISBANE QLD

Phone: 07 3735 3383

Email: info@improvingtheodds.com.au URL: www.improvingtheodds.com.au

#### Self Help Queensland Holiday Office Closure

The SHQ office will close on Wednesday 20th December 2006 for the holiday break and re-open on Monday 15th January 2007. The answering machine will be available for messages and calls will be returned as soon as the office re-opens.

Thank you.