



Newsletter

June Quarter Issue 2. 2005

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

From the President

Sue Smyllie

Hello All

I was reading a very interesting article by Ruth Mc Cambridge recently. She asked 3 very important questions about how non-profit organizations are run. In essence the questions were:

1. Should nonprofit organizations do business in a way that is in the best interests of the community or the institutional interests of the organization?
2. How do we think about what *community* we are responsible to?
3. Why is it so hard to get creative in our approaches to governance?

At SHQ we have developed a set of principles which we use to help us make decisions about what we do and also to help us evaluate how well we are doing. We see a very clear responsibility to the community as a whole, both now and in the future. We want to make relevant decisions and take useful actions.

We think it is important to make our work, accounts and processes open and inclusive. This is why we are always asking for feedback, inviting comment and participation in our committee.

It won't be long now until another AGM rolls around. I hope to see lots of folk there. While the morning tea is always good, I would like to encourage you all to think about joining the committee. Diversity is great for organizations. We can't expect to have the same committee forever and re-

main relevant and progressive. Yes, even the President's position is always up for grabs!

I also wanted to say a warm welcome to Ann Meehan, our new Directory Project Officer. Many of you would have already been in contact with Ann concerning your entry in the Directory as I know she has hit the ground running. I know we'll have a great product at the end.

Cheers

Sue

Available Nov 2005!

First Ever!

**2006 Queensland Directory of
Self Help & Support Groups**

- for health conditions and related issues

As many of you are aware, we are currently compiling a Directory of Self Help and Support Groups for Queensland. A large number of groups have been contacted already, and some we are still trying to locate.

Many thanks to all who have kindly returned their Directory Forms, and a gentle reminder to those who haven't that we would still love to hear from you. (A replacement form is included with this newsletter.) Your group's inclusion in the 2006 Directory will be a very valuable Sector resource.

For further information call Anne (07) 3345 1930 or Trish (07) 3344 6919 at SHQ.

**Self Help Queensland Inc
Management Committee Members**

President Sue Smyllie
Treasurer Kathleen Zarubin
Secretary Cheryl Russell
Member Kim Summers
Member Thea Biesheuvel

Committee Meetings

If you would like to attend our meetings, please contact the office for dates and times. Everyone is welcome to attend and we look forward to seeing some of you at our meetings. We are always on the lookout for new committee members!

Project Officer

Trish Fallon

Administration Officer

Therese Kelly

Directory Project Officer

Anne Meehan

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

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Thanks to Queensland Health for providing funding to Self Help Queensland for publication of the Self Help Queensland quarterly Newsletter.



**Would you like
the SHQ news
letter by email?**

If you would like to receive the newsletter by email instead of post (a lot easier and cheaper for us!) please email Trish at the SHQ office at selfhelp@gil.com.au or call Ph/Fax 07 3344 6919

(The newsletter will be in PDF format. You will need Adobe Acrobat Reader to read it.)

Thank you Heidi!

We would like to say a very sincere thank you to Heidi Bone who has generously lent her creative talents and technical skills (not to mention her patience!) to the creation and development of a new SHQ website.

Coming very soon !

keep an eye out for

www.selfhelpqld.org.au

We look forward to sharing Sector news, providing information about SHQ, our work, networks, policies, etc. We hope to facilitate interaction and provide feedback on issues of interest to the Sector.

Tell us About Your Group

If you belong to a self help or support group we would love to hear from you. Please contact Trish at the Self Help Queensland office: Ph/Fax: (07) 3344 6919
Email: selfhelp@gil.com.au

Contents

President's Message	1
SHQ Committee & How to Contact Us	2
Link Line	3
Autoimmune Disease Support Group	3
Older Women's Network	3
Genetic Matters by Kim Summers PhD	4
Charcot-Marie-Tooth Association	5
The Australian Lung Foundation	6
Hype and Hope in the Media	7
Mitochondrial Disease	9
Southside Anxiety Disorders Group	10
Co-dependency	12
Role of Women in Prostate Cancer Groups	13
ADD/ADHD Parent Support Group	13
Batten Disease International Education Day	14
Chromosome 18 Annual Family Meeting	14
Diary Dates	14

Link Line



Through Link Line, Self Help Queensland hopes to facilitate contact between people with rare conditions for whom no support group exists.

Link Line endeavours to foster mutual support and information sharing in a respectful, sensitive and confidential way. However, we are unable to determine the suitability or compatibility of linked individuals and families.

- ***A Brisbane family would like to connect with anyone with experience of the lung condition, Fibrosing Alveolitis.***
- ***A family in Caboolture, QLD, would like to contact anyone who has the condition Cryptogenic Sensory Polyneuropathy (CSP).***
- ***A lady in NSW would like to contact another person in Australia with the rare condition, Multiple Enchondromas.***
- ***A Brisbane family would like to connect with someone who has Meniere's Disease.***
- ***A man in Atherton would appreciate talking to anyone diagnosed with Mitochondrial Disease.***

To make confidential contact regarding the above or to place a notice in Link Line, please call Trish at the Self Help Qld Office Phone/Fax (07) 3344 6919
Email: selfhelp@gil.com.au



**Tell Us What You
Think!**

We would like to receive feedback about our service. Please feel free to pass on any constructive criticism or suggestions you may have that might help us to do better.

We would also like to hear what you think of the newsletter and invite you to contact us about content, quality, format, or any issues you would like addressed in future editions. Please contact Trish at the SHQ Office:

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

Autoimmune Disease Support Group Newly Established in Beaudesert Shire

A support group has been established in the Beaudesert Shire (in SE Qld) for people in the region who have autoimmune disorders. (There are over 100 autoimmune disorders including Lupus, Scleroderma, Crohn's Disease, Graves Disease, Diabetes, Hashimoto's, Multiple Sclerosis to name just some).

Membership is open to anyone who has been diagnosed with an autoimmune disorder, their partner, family, or others affected by their illness. The aim of the group is to provide support, education and information of interest to members, to promote public awareness and to provide resources for referral to interested professionals.

For further information contact:

Elaine Ph: (07) 5543 2093 or Email:
autoimmunesupportgroup@hotmail.com

Meetings:

10am on second Thursday of every month at Blue Care Bldg, 7 Duckett Street, Beaudesert

Does Anyone in Your Family Have a Cranio Facial Condition or Facial Difference?

Would you like to meet other families in similar situations?

Our Faces Support Group is currently a small support group based in Brisbane hoping to expand and have more people join us. The group was founded in 2004 by Joe and Jenny. Jenny and their two children have Crouzon Syndrome. The group was formed to enable contact with other families in similar situations.

Anyone who has a craniofacial condition or facial difference is most welcome to join. It does not matter if the condition was from birth or acquired through illness, disease or accident. The aim of this group is to support, provide friendship and provide an avenue to share experiences.

Contact from anywhere in QLD is welcome.

Ph: Jenny (07) 3881 3073

Email: ourfacesinfo@yahoo.com.au

URL: <http://au.geocities.com/ourfacesinfo/>

Genetic Matters

by Kim Summers PhD

The Same Name, Different Gene, Different Risks

Sometimes the same symptoms can be caused by mutation at any one of a number of genes. Even more confusing, a very similar condition may be inherited in a dominant, recessive or X-linked fashion depending on which gene is mutated. And there may be cases of a very similar condition where there is no familial or genetic factor involved. This makes calculating the risks to family members very difficult and means that detailed genetic studies must be done to understand the inheritance pattern, prognosis and possible treatments. Charcot-Marie-Tooth hereditary neuropathy (CMT) is one of these complicated conditions.

CMT causes problems with the nerves extending to the feet and hands. Both the sensory nerves (which detect what's happening and send messages back to the brain) and the motor nerves (which receive instructions from the brain to move a muscle) can be affected. This means that a patient can have muscle weakness, particularly of the ends of the arms and legs, as well as reduced sensitivity to stimulation of the limbs. CMT is diagnosed based on whether the condition has been found in other family members, in addition to clinical examination and some specialized tests designed to check the function of the nerves. Other conditions which affect the peripheral nerves may need to be excluded by looking at the specific range of symptoms.

There are a number of genes associated with the symptoms of CMT. Genetic testing may be possible, to clarify the inheritance pattern by knowing which of these genes is responsible in a particular family. CMT can be classified on the basis of inheritance pattern and primary abnormality into CMT1, CMT2, CMT4 and CMTX. There is also a rare intermediate form with characteristics of CMT1 and CMT2. Each of these is further subdivided based on the known genes which are mutated in forms of CMT.

CMT1

About half of all cases of CMT are classified

as CMT1, which is an autosomal dominant form. This means that it is usually passed from one parent to offspring. The offspring of the affected person have a 50% risk of also having CMT1. It doesn't skip a generation and within a family, an unaffected person can't have affected children.

Some cases may result from a new mutation, which only appears in the first affected person. The offspring of that person has a 50% risk of having CMT but siblings are not at risk.

CMT1 results in very slow transmission of the message along the nerves from or to the brain (slow nerve conduction) and appears to result from abnormalities of myelin, the sheath which surrounds the nerves to insulate them and ensure that the electrical message is carried correctly between brain and tissues. At least four different genes can be responsible for CMT1 when they are mutated, the main one being CMT1A (70-80%), which maps to chromosome 17.

CMT2

CMT2 is also an autosomal dominant form which results in normal or mildly reduced nerve conduction speeds. At least eight different genes, when mutated, can cause CMT2. Several of these have unknown functions, although the chromosomal location of the gene is known. 20-40% of CMT cases can be classified as having CMT2, which is generally less severe than CMT1.

CMT4

This is a rare form of CMT, which is inherited in an autosomal recessive fashion. This means that there the parents and other relatives are unaffected but the siblings of an affected person have a 25% risk of being affected. More distant relatives have a low risk of having affected children. They may be carriers and if they marry another carrier their children are at 25% risk. CMT4 can be caused by alteration in one of at least seven genes, but affected people must have an abnormality of both copies (one inherited from each parent).

CMTX

This form of CMT accounts for 10 – 20% of CMT cases. The gene involved is carried on the X chromosome. Males generally show more severe symptoms. Males always inherit the condition from (Continued on Page 5)

(Continued from Page 4)

their mothers and it never passes from father to son. Daughters can inherit the milder form from their mothers and all daughters of an affected male will carry the abnormal gene and may have mild symptoms.

Clearly the situation with CMT is complex and a detailed evaluation is necessary before it is possible to determine the inheritance pattern, type of CMT or risks to other family members. A similar situation is found with other genetic conditions, such as familial cardiomyopathy for which any one of several genes may be involved. If you suspect there may be a condition like this in your family it is important to seek genetic counselling so that the precise variant and inheritance pattern can be determined. Genetic counselling is available through the Queensland Clinical Genetics Service, phone (07) 3636 1686.

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**“Help Us to Stay
on Our Feet”**



Charcot-Marie-Tooth(CMT) Association of Australia Inc

Coping with any medical condition for life is a daunting prospect. But it is made more difficult when there is little information about it and even the doctor find it hard to diagnose. This is the problem faced by many people who suffer from Charcot-Marie-Tooth Disease.

Charcot-Marie-Tooth Disorder of CMT is a group of genetic disorders of the peripheral nervous system that affect the sensory and muscle control nerves of the legs and arms. It is a common but frequently undiagnosed condition. It is not a contagious disease but it is an inherited neurological disorder with a 50% chance of passing it on to subsequent generations. CMT affects 1 in 2500 people.

CMT causes slow degeneration of the nerves in the extremities including feet, legs, arms and hands. Typically, muscles are weakened due to the loss of stimulation by the affected nerves. The severity of the disease can vary a great deal from person to person. Symptoms may also vary. There is

no known cure for CMT but research is continuing both in Australia and overseas.

The peroneal type of muscular atrophy was separated from other forms of progressive neuromuscular disorders in 1886, simultaneously by two French neurologists, Jean-Martin Charcot and Pierre Marie and an English neurologist Howard Henry Tooth hence the name CMT.

We need to be aware of the implications of this disability to both children and adults in regards to schooling, sports, socializing and in their daily living activities.

Weakness in the leg muscles affects one's co-ordination and balance with regards to walking up or down stairs, walking on uneven ground, standing still or standing for long periods of time.

Other systems which may affect CMT patients include: Tremors, fatigue and fine motor skills. For those with symptoms, foot abnormalities such as club foot, weak ankles and tendon tightening may pose problems. Sometimes patients may need to wear orthotics, braces or even undergo surgery.

Even the simplest things like unscrewing a bottle top, fastening buttons, turning a tap or opening a door pose problems. These are all things most people take for granted. Things like untidy hand writing due to not having control over the muscles and nerves in the hands and fingers can pose a big problem for children and adults alike.

The main idea is that people with CMT be treated and given the same chances as everyone else both socially and in the work force.

CMT Australia has a Head Office in Sydney (Ph: 02 9767 5105) and co-ordinators in most States. We have support groups in some areas and our co-ordinators distribute information related to the welfare of CMT people. We also hold Awareness Day Seminars. The Charcot-Marie-Tooth Association of Australia is entirely run by volunteers.

For further information please contact:
Queensland Co-ordinator
CMT Association of Aust Inc
13 Constance Court
MURRUMBA DOWNS QLD 4503
Ph: (07) 3886 2492

Resources, information and assistance available to help start Lung Support Groups in Queensland - you can bring the "LungNet" to your region

Self Help Queensland recently learned a great deal more about the excellent Sector support, LungNet, offered by the Australian Lung Foundation (ALF). A comprehensive Patient Support Group Start-up Manual is available by calling the ALF on 1800 654 301. The manual is available for patients and health professionals.

The LungNet is not a patient support group. It is a network of affiliated Patient Support Groups Australia wide. The services provided to patient support groups and their members include:

- Helping people find a suitable patient support group through toll free telephone assistance and referrals
- Assisting new groups to form where needed by providing guidance and set-up financial assistance
- A national clearing-house for producing and distributing patient education information
- A national LungNet newsletter informing patient support group members of national issues and the activities of groups in other states
- A communications link between patient support groups
- A point of contact for group members with other groups when they travel and require "away from home" support
- National initiatives from time to time for member enjoyment and participation
- A medium for patient support groups to participate in the promotion of lung health at a national level

Patient support groups or patients do not pay any fees to be affiliated with LungNet. The LungNet simply exists to ensure patients can access and enjoy the benefits of a continuity of patient support Australia wide.

Services provided by the LungNet directly to patients, such as the Toll Free 1800 654 301 information and referral assistance, and the national newsletter, are also free of charge to patient support group members.

Getting Started

The LungNet can provide information and advice on setting up a patient support group, having harnessed this advice from a number of established groups across Australia. There are several ways patient support groups "originate" including:

- through the motivation and enthusiasm of a patient or carer who sees a need
- from a community health setting, where health professionals have identified a need
- as an extension of hospital based pulmonary rehabilitation programs, to ensure that program participants receive ongoing support.

Guidelines for Starting a Lung Support Group

- Make contact with key health workers in the local area/community to investigate the level of support and the "need" to establish a support group.
- Hold a meeting to discuss interest in establishing a support group, resources available and level of co-operation which could be achieved between local health agencies.
- Make contact with LungNet State Coordinator and Australian Lung Foundation National Secretariat to advise them of your intention establish a patient support group, and discuss areas where the LungNet can offer support.
- Establish a venue for a pilot "interest" meeting for a new support group.
- Promote pilot meeting - formally & informally.
- Hold a pilot meeting to gauge level of interest. This should feature an interesting guest speaker to give attendees a taste of what a patient support group can offer. At the meeting, establish some guidelines for the group's future activities - frequency of meetings, possible guest speakers, objectives the group would like to pursue. (Continued Page 8)

Hype and Hope in the Media

We all want to be healthy and free of illness, so health stories tend to catch our attention easily, particularly if we have an illness or know someone who does. Health topics are some of the most commonly reported subjects in the media and a lot of people use them as a source of information about health.

Newspaper and magazine editors and radio and television producers are in the business of telling stories and they often sensationalise information to grab our attention and get bigger audiences. Journalists may also simplify complex and scientific health information to make it more readable and appealing, and fit it into a few sentences. In doing so, they may oversimplify, take information out of context or get it wrong.

It pays therefore to ask yourself a few key questions while ‘digesting’ and making sense of health stories in the media, to work out how much you can rely on them and whether you need to find out more.

This article highlights some questions you might like to consider, and gives suggestions about following up health stories that interest you, or worry you. The emphasis is on stories about medicines, but the comments apply equally to most health stories.

Where did the story appear?

As we all know, some newspapers and magazines are more inclined to be sensational than others. Similarly, some television programs are well known for exaggerating the facts. When you read or hear a story, thinking about the publication’s or program’s record for balanced or sensational coverage can help you decide on its likely credibility.

Be aware that most journalists, including most ‘health reporters’, do not have health training or a scientific background. Articles by health reporters who write regularly on health and medical topics, can probably be relied upon more than articles written by other reporters.

Where did the story come from?

Stories about medicines can come from many sources, including articles in medical

journals, talks at medical conferences and company or organisation promotion material. Knowing the source of a story can help you make judgments about its likely credibility.

Articles in medical journals are usually reliable, because their articles have to meet very high standards in order to be published. However, just because a story quotes a reputable medical journal doesn’t guarantee that the reporting of the story will be accurate or give the full picture.

When considering stories based on talks given at medical conferences, be aware that the researchers may be talking about the early stages of their research into a potential new medicine. At this stage the findings may look promising but it is still far too early to be certain. In the course of time, many potential medicines don’t meet their early expectations, and many never make it to commercial production.

Also look out for ‘advertorials’, advertisements dressed up as stories. Advertorials are designed to sell products, so they usually mention only the medicine’s benefits. They often include a testimonial, a personal success story about the medicine by a person, sometimes a celebrity, who is paid to tell their story. Sometimes the word ‘advertisement’ will appear in small letters at the top. Advertorials usually appear in magazines, but they are also increasingly appearing on television and radio talk shows. They should be taken with a large grain of salt.

Sometimes the source of a story is not revealed. However, you may be able to make an intelligent guess by ‘reading between the lines’.

What about the experts?

Stories about medicines often interview doctors or other experts to get their opinion of the treatment. Such comments are usually designed to give the story greater credibility. We can trust an expert speaker if they are an independent expert or speaking on behalf of a reputable organisation such as the Australian Medical Association (AMA).

(Continued on Page 8)

(Continued from Page 7)

However, sometimes the expert being interviewed has ties to the company selling the medicine. This is something to watch out for but it may not be always obvious from the way the story is reported.

When will it be available?

Many announcements about new medicines are made long before they have been approved, so they may still have to undergo 5 - 10 years of testing and approval before they become available, assuming they make it through both processes.

What's known about it?

We tend to believe that 'newer is better'. However, when it comes to medicines, this belief can be wrong. The testing process for medicines involves testing on relatively small numbers of people, so not all the medicine's benefits and risks are known when it is released for sale. Some problems only become clear when the medicine has been approved and used by large numbers of people for several years. An example of this situation is the arthritis medicine Vioxx, which was withdrawn from sale in October 2004, when it became apparent that long-term use may lead to heart attacks and strokes in some patients.

Does it give the full picture?

All medicines have benefits as well as risks (side effects). When deciding with your doctor or pharmacist to use a new medicine it is important to weigh up its benefits and risks.

Stories in the media that focus only on the benefits, or only the risks, are not giving you the full picture; similarly those that overstate the benefits or understate the risks. Take with another grain of salt reports that say, or imply, that a medicine has no side effects.

Stories about new medicines often overstate the importance of the medicine, and don't mention its limitations. For example, stories often announce 'a new cure for cancer', without specifying for whom the treatment is suitable and what the success rate is, making it sound like it will work for everyone with cancer. In reality, such 'cures' are usually suitable only for very small numbers of people, because they can be used for only one type of cancer and only under specific circumstances.

Many 'new medicines' are not really new. Many are duplicates or refinements of existing medicines. While small improvements in medicines may be useful, true medical 'breakthroughs' are, unfortunately, very rare.

Following up

Deciding whether a particular medicine is right for you, means weighing up many considerations to work out whether the benefits you can expect outweigh the possible risks. It is hard to get the full picture from a short story in the media. The media can alert you to new developments, but it is important to follow up the story with other reliable sources of information, such as:

- Your GP or specialist
- Pharmacist
- Naturopath (if alternative medicine)
- Medicines Line (staffed by pharmacists) 1300 888 763
- Internet (see Medicines Talk Spring 2004 for advice on finding good information on the internet)
- Manufacturer of the medicine
- Media Doctor website. This reviews current news items about medical treatments, assesses the quality of the reporting and presents reviews of good and bad examples of media stories. See www.mediadoctor.org.au

(Source: Medicines Talk Newsletter Autumn 2005)

(Continued from Page 6)

- Commence promotion to expand group membership. Distribute LungNet Quality of Life brochures, group promotional flyers etc.
- Use the community media to profile the group. Network with other community organisations, health agencies and health professionals to gain referrals to the group.
- Maintain contact with LungNet State Coordinator and The Australian Lung Foundation National Secretariat for on going assistance.

(Source: www.lungnet.com.au)

For further information contact:
The Australian Lung Foundation
PO Box 847, LUTWYCHE QLD 4030
Freecall 1800 654 301
Ph: (07) 3357 6388 Fax (07) 3357 6988
Email: enquiries@lungnet.com.au

Mitochondrial Disease

- more common than you think

Self Help Queensland received this letter from a reader.

"On January 4th, 2003 my wife had a seizure. Within three months she was dead. We were astounded to discover, then, that not only she but both our sons had been exhibiting symptoms of mitochondrial disorder with increasing severity and complexity for over thirty years. Despite that not one specialist, not one physician, not one GP that we had consulted during that time had made the correct diagnosis.

Since then I have embarked on a journey to try to discover why not, and it is apparent that, despite mitochondrial disorders having been first diagnosed some 40 years ago, the general practising medical profession seems to be almost totally unaware of their potential impact which, the research community now suspects, may be at the root of nearly all neurological ill-health. And time and again I have found a similar story of sufferers being unaware of the condition and of parents of seriously ill children searching, sometimes for years, before getting a proper diagnosis.

Our initial reaction was to publicise this story in the hope that the public would get the message, but I was advised by Australian researchers that that was not the way to go. Not all people who exhibit some of these symptoms necessarily have a mitochondrial disorder, so that many might be alarmed without cause. The better way is to alert the medical profession. Efforts to do this via the medical journals and the teaching profession are under way.

However, it is my belief that the main thrust must come from those who are affected, either personally or via someone in their family, and who cannot get satisfactory diagnoses from their doctors. By helping people to learn about mitochondrial disorder, it is hoped that they will then go to their medical consultants, and, armed with this knowledge, demand answers."

(Name and address supplied)

So "Think Mitochondria"

Mitochondria are little bodies that are found

in numbers in all cells. They convert the food we eat into the energy that drives the cells. If the mitochondria fail, the cells fail, and that part of the body malfunctions or ceases to work altogether. Any part of the body can be affected: ears, eyes, brain, intestines, muscles, heart, nerves, etc. Mitochondrial disorder is genetic. It can be inherited, via the mother, or can occur spontaneously in an individual. There are many mitochondria in each cell and not all may fail. In fact none may fail, so even those who have inherited the disorder may not ever be affected. The greater the percentage that fail, the more that person will be affected.

"One of the principal features of mitochondrial disorder that emerges from case histories is that the symptoms are atypical and hard to diagnose."

We should "think mitochondria" when:

- a "common disease" has atypical features that set it apart from the pack;
- three or more organs are involved;
- recurrent setbacks or flare-ups of a chronic disease occur with infections.

Where to go to find more

In Australia contact can be made with others via the Yahoo Group 'AussieMito'. The United Mitochondrial Disease Foundation in the USA has a newsletter, chapters all over the USA and elsewhere, and access to a range of experts who can answer specific questions from sufferers.

United Mitochondrial Disease Foundation
8085 Saltsburgh Road Ste 201
Pittsburgh PA 15239, USA
Phone: (412) 793 8077 Fax: (412) 793 6477
Email: info@umdf.org URL: www.umdf.org

For information in Queensland write to:

Rob Ryan, 19 Dalziel Avenue, Atherton 4883.
URL: www.puzzlingsicknesses.info

In its pamphlet 'Could it be Mitochondrial Disease?' the UMDF says:

"There are more than 200 inherited diseases of metabolism that are known to affect mitochondria. More than 1 in 4,000 children born in the United States each year will develop a mitochondrial disease by 10 years of age. Because mitochondrial diseases are currently under-recognised this figure may underestimate the real number by as much as 4 fold.

(Continued Page 10)

(Continued from Page 9)

Four million children are born in the US each year. This means that 1,000 to 4,000 children will be born each year with a mitochondrial disease. By comparison, about 8,000 new cases of childhood cancer are reported each year. Both mitochondrial disease and childhood cancers range in mortality from 10 to 50 percent per year, depending on the specific disease."

Australia has about 20 million people so these figures translate into about 70 to 275 children that may be born here each year with a mitochondrial disorder.

Other studies suggest that the incidence of mitochondrial diseases is in the range 1 in 2,000 to 1 in 5,000 live births, with 50 showing symptoms before age 5 and the remaining 50% between childhood and old age.

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Southside Anxiety Disorders Group

"a support group run by sufferers, for sufferers of anxiety disorders"

We see ourselves delivering a quality support care service according to individual needs. We do not endorse any particular type of treatment, and do not encourage or discourage the use of medications. We do recommend sufferers to seek diagnosis and treatment from a health professional.

The group is non judgemental, confidential, and there for the mutual support and release from isolation for us all. We offer education, group discussion, support & professional speakers. The group assists you in learning to cope with panic and anxiety using ongoing management techniques, including relaxation and meditation.

The group originated through the lack of anxiety disorders support groups. My wife had been stricken with major panic attacks. After diagnosis of anxiety disorder with agoraphobia and social anxiety disorder, we started with a group in Beenleigh. After 3 years we realised that there was a need for this group to expand. We relocated to the Mt Gravatt District 2 years ago, to encompass the greater southside areas of Brisbane.

There is a stigma that exists towards mental disorders within the community in general, but also within the individual. This stigma causes real difficulties for people with anxiety disorders, or those who think they may have anxiety disorders.

Anxiety disorders attack us at the most fundamental level of who we are. One of the most destructive aspects is the way in which anxiety reduces our self-esteem and self-confidence. This in turn makes it harder to reach out for the help and support we need.

The Southside Anxiety Disorders Group is about us - real people with a real illness - an insidious illness that strikes at the core of who we are. We are not medical professionals in any way. We are totally independent. We are there to help anyone whose lives are affected by anxiety disorders.

We are people who understand and care, providing an opportunity for people living with anxiety disorders to meet, communicate, give and receive understanding, care and support. We listen, hear and respond - from one human being who understands, to another. We work as a team to do the best we can for each person we come in contact with. There are so many people out there who used to struggle alone.

Our support group is about making a difference, letting isolated people know that they are not alone. They now have somewhere to go where they can talk openly about their particular problems. They both give, and receive, the support, hope and encouragement they need themselves. The people who best explain how our support group is different are those who visit our support group meetings - our members themselves. It is these people who give it life.

In addition to information we are available for anyone who just needs to know that there is another human being out there who will listen. The needs of people living with anxiety disorders is my number 1 priority.

Meetings are held on the 2nd Thursday and 4th Thursday of each month at Mt Gravatt Community Centre
1693 Logan Road, Mt Gravatt
(Bus stop 40 is outside the Centre)

Contact can be made by telephone with Kevin: 07 3807 0228 or mobile 0407 574 739

Co-dependency

- what is it ?
- a personal story
- where do I go for help?

Co-dependents Anonymous (CoDA) is a peer support group for people whose common purpose is to develop healthy relationships. Co-DA does not offer a definition or diagnostic criterion for co-dependence. However, they do provide a list of behaviours and characteristics that are common to people suffering from co-dependency. These patterns and characteristics are offered as a tool to aid in self-evaluation.

Patterns and Characteristics Of Co-dependency

Denial Patterns

- I have difficulty identifying what I am feeling.
- I minimize, alter or deny how I truly feel. I perceive myself as completely unselfish and dedicated to the well being of others.

Low Self Esteem Patterns

- I have difficulty making decisions.
- I judge everything I think, say or do harshly, as never "good enough."
- I am embarrassed to receive recognition and praise or gifts
- I do not ask others to meet my needs or desires
- I value others' approval of my thinking, feelings and behaviour over my own.
- I do not perceive myself as a lovable or worthwhile person.

Compliance Patterns

- I compromise my own values and integrity to avoid rejection or others' anger.
- I am very sensitive to how others are feeling and feel the same.
- I am extremely loyal, remaining in harmful situations too long.
- I value others' opinions and feelings more than my own and am afraid to express differing opinions and feelings of my own.

- I put aside my own interests and hobbies in order to do what others want.
- I accept sex when I want love.

Control Patterns

- I believe most other people are incapable of taking care of themselves.
- I attempt to convince others of what they "should" think and how they "truly" feel.
- I become resentful when others will not let me help them.
- I freely offer others advice and directions without being asked.
- I lavish gifts and favours on those I care about.
- I use sex to gain approval and acceptance.
- I have to be "needed" in order to have a relationship with others.

(Source: www.vicnet.net.au/~coda/home.htm)

Jane's Story

"My name is Jane and I am a recovering co-dependent.

I was laying on the floor which I had slept on for the last six nights, reaching for the knife, thinking if I cut my wrists this would stop the pain, and I would be free. All the rejection, abandonment, enmeshment and neglect would be gone, free of all worries of this physical life. This was my last emotional rock bottom, when I had no other choice but to hand my will and my life over to a Higher Power.

I had been abused and rejected by my family again - eight people. That's a lot of people. As I look back on my life this has been a theme throughout; rejected and abused by my family members who were supposed to love and nurture me and model healthy behaviour. They asked me to leave the family home. I promised myself this would be the very last time anyone would abuse me. I packed my things but I had no where to go.

I prayed to my God and was lead to respond to an advertisement for accommodation. The beautiful landlady said I could move in that day. I only had the things on me that I left with. I went to the welfare and was given food and furniture to get me through this time.

(Continued Page 12)

(Continued from Page 11)

For a few weeks I was in grief and denial and walking around in a daze. I couldn't do much. I prayed that resentment would not well in me. I promised myself that my life was going to be about me today, and that I no longer needed my family to affirm me, and that I needed to distance myself from them until I was well enough emotionally - even if it took years.

We had always looked like every body else's family. We lived on a farm quite isolated from society; an ideal set up for addiction and abuse. My caregivers repeatedly molested me, my other brothers and my sisters. It was a family secret, and my brother committed incest upon me when I reached puberty. My role in the family was that of counsellor. I was my mother's best friend; my father's sexual partner. As I grew into a young adult I experienced several instances of rape, which led to six abortions.

I had allowed others to treat me so badly that I treated myself badly. I used suppression, repression and disassociation to try to deal with the abuse. I also minimized, denied and was delusional about the level of abuse. This was my coping mechanism for dealing with the terrible feelings of anger, shame, guilt and fear. I used passive aggressive behaviour to express the rage I felt.

I have learned this set up is multi generational and do not pass blame on any of my family members. I am grateful I have Co-dependents Anonymous to go to, to share my history, my pain, my feelings and be in a safe place, which I call 'my home and my family'. I have been 4 years sober in AA, after a 24 year relationship with alcohol, and working my program in Adult Children of Alcoholics and Emotions Anonymous.

Co-dependency ruled my life, my career, my relationships, and my work situations. I kept attracting the same type of people to me over and over again. My inner child was looking for a nurturing relationship, trying to find a home to fit into and be a part of. I had worked in Kings Cross for eight years in the banking and hospitality industry. I also felt at home in this environment with the drug addicts and street workers. I then went into the field of support worker in the drug and alcohol field.

Today I am in therapy for the rape and incest and am gentle and nurturing with myself and the people I am around. It gets easier. It gets better the longer I am in Co-dependents Anonymous. When I came to Co-dependents Anonymous I felt like I had found my 'home'. I could share my pain and not be shamed. They would not leave me. They hugged me and gave me their telephone numbers.

At this point in my recovery I choose not to go into a relationship, because I would only be looking for the nurturing mother relationship I never had in my childhood. I have chosen a life of celibacy until I recover from the rape and incest abuse. Until I fully love myself I am not ready to have a relationship with another person. I am not perfect today and I am still working on myself. The joy and love is building in me one day at a time, and it is beautiful. This disease of co-dependency is progressive and requires daily mediation and prayer.

Today, if I am presented with a situation with another person and I feel uneasy, I now know to ask what is it about me that I need to learn from this experience and do something about? I know today that every thing I do, say, see, feel is interpreted from my childhood experiences. I love identifying this so much because it helps me to get to know who I really am today.

As a child I always did what others wanted and learned my caregivers' behaviour and carried their shame and guilt for them, and never knew who I was. Today I have freedom to be who I am, feel my body, love myself, and to be present for myself totally."

(Self Help Queensland would like to thank Jane sincerely for sharing her story so openly and courageously in the hope that it may assist others.)

Co-Dependents Anonymous relies on the Twelve Steps and Twelve Traditions for knowledge and wisdom. These are the principles of the program and guides to developing honest and fulfilling relationships.

Co-dependents Anonymous, Brisbane, conduct weekly meetings:

Mondays at 12:00 noon

Tuesdays at 7:00 pm

Venue: Level 3 "Biala", 270 Roma Street,
Brisbane Ph: Info Officer (07) 3321 0338 or
Secretary : 0422 482 796

The Role of Women in a Prostate Cancer Support Group

By Pat Trelor

It is possible for some of us to assume that having prostate cancer is solely a male affair. Clinically, it is, but as with any illness, whether it is gender specific or not, it involves not only the patient but those family members, close friends and carers associated with that person who has the illness. So may I stress that prostate cancer is not just 'men's business'. This is a meeting of the Prostate Cancer Support Group. This title tells us that we are here to support one another in the best possible way. This can be done so much better if wives, partners and carers become an interested and active part of the group in which all can begin to learn and have a better understanding of the problems prostate cancer can bring.

We experienced, in our group in Tamworth, that the women played a positive role in many aspects of the group. They were able to:

1. Support one another and their partners.
2. Have a better understanding of the issues of prostate cancer.
3. Share their worries in confidence with others.

By having a greater knowledge of the problems associated with prostate cancer the important roles of sharing, understanding and supporting can be achieved more fully. Women usually take on the caring role and so they too need support during anxious times. The prostate cancer support group gives them that opportunity to share with others facing similar problems and, on the other side of the coin, they can feel positive about reaching out to others. The roles played by the women in our group in Tamworth were very varied.

- They acted as a support network for one another.
- They became involved in the promotion of the group in shopping centres and at the annual men's health expo.
- They were involved in education and fellowship at our monthly meetings.

- They welcomed new comers. They helped organise BBQs and social events and were involved in fund raising and raffles, etc.
- They were part of small discussion groups - choosing their own topics.
- They took on executive positions.
- They managed the large volume of resource material and books the group had collected.
- When the group travelled to other communities for an information evening, our ladies were part of the team.

The husbands of our two most active members died last year but both of them have found strength in one another. They have been able to comfort each other due to a better understanding of the other's grief. For the men it can, at times, be a lonely journey. It can be difficult to share with others some of the more personal issues associated with prostate cancer. What better person can there be than an understanding partner who has an awareness of some of these issues? I would encourage women to become an active part of this group as it can lead to positive outcomes for the group, their partners and themselves.

Supporting, sharing, understanding and being involved are the key issues to the success of a group.

(Source: Prostate News June 2005 Issue 22)

ADD/ADHD Parent Support Group

Kingston East Neighborhood Group offer interested parents the chance to support each other, exchange information and listen to invited guest speakers.

The ADD/ADHD Parent Support Group meets at the centre on the 4th Wednesday of each month, beginning at 10 am to 11.30 am approx (except during school holidays).

Kingston East Neighborhood Group is located at 177 Meakin Road, Slacks Creek.

For further information please contact:
Kingston East Community Centre
Ph: (07) 3808 1684



Diary Dates

13 - 18 June 2005: Crohn's & Colitis Awareness Week. Free (& open to all) Educational meeting on Wednesday 22 June at Evan & Mary Thomson Auditorium, Wesley Hospital
Contact: Australian Crohn's & Colitis Assoc
Phone (07) 5437 7662 **Fax** (07) 5437 7103
Email: help@accaq.org.au
URL: www.accaq.org.au

17 June 2005: Prostate Cancer Foundation of Australia "Be a Man" Launch. Special guests include Wayne Swan, Federal Opposition Treasurer & Leigh Matthews, Brisbane Lions Coach & others.

Venue: Queen Street Mall stage, Brisbane
12.30 to 1pm

Contact: Phone: 1800 220 099

Email: prostate@prostate.org.au

4 - 7 July 2005: The 2005 Australian Winter School. Presented by the Alcohol and Drug Foundation Queensland, the Winter School will address Drugs, Lifestyles & Culture in the context of the practical application of research and policy for those working in service delivery agencies. International keynote speakers, practical workshops, posters and presentations.

Phone: (07) 3834 0211

URL: www.winterschool.info

Venue: Carlton Crest Hotel, Brisbane

17 - 23 July 2005: Disability Action Week

Contact: Disability Action Week State Planning Committee, Disability Services Qld, GPO Box 806, BRISBANE 4001

Phone: (07) 3224 7535

Freecall: 1800 177 120

TTY Freecall: 1800 010 222

Email: actionweek@disability.qld.gov.au

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

18 August 2005: Partners in Pain: Patients, Clinicians and Pain Management. This is a satellite meeting immediately preceding the 11th World Congress on Pain. (21 - 26 August 2005).

Phone: (02) 9954 4400

Email: pinp2005@dcconferences.com.au

URL: www.dcconferences.com.au/pinp2005

3rd Australian Batten Disease Family Conference

"A Project of Hope"

1st & 2nd October 2005

at

Australis Noosa Lakes, Noosaville QLD

The Batten Disease Support and Research Assoc Inc represents and supports children and families affected by the neurological degenerative terminal illness, Batten Disease.

People will travel from all states of Australia and New Zealand, and the Association 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, education and social interaction in various aspects of Batten Disease. Together with our BDSRA USA group, we have organised for worldwide researchers to come here to share their knowledge, updating us on research and possibilities and hopes of trial treatments. A number of excellent speakers will travel from USA and Australia-wide to give each of us a greater understanding of this disease.

The families' and carers from all fields, have a need for help in the form of knowledge, hope and practical ways of managing. Hence our second aim is having guest speakers who can form a panel group on the appropriate methods in which to provide the best care for these special children.

For further information please contact:

Vanessa Anderson Ph: 02 43345785

Email: gvjcando@ozemail.com.au

Members of the public with an interest in Batten Disease are most welcome.

The Chromosome 18 Registry & Research Society (Aust)

Annual Family Meeting

Sydney on 8/9 October 2005.

For further information please contact:
Marlene Brightwell Ph: (02) 9580 5707