



# Newsletter

## September Quarter

### Issue 3. 2010



Self Help Queensland Inc, Sunnybank Community Hall, 121 Lister Street  
(PO Box 353) SUNNYBANK 4109

Ph/Fax 07 3344 6919 Email: [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au) [www.selfhelpqld.org.au](http://www.selfhelpqld.org.au)

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

### From the President

Hello everyone

Last time you read all about my exposure to 'third sector' thinking, that is, the sector in which the not-for-profit organisations play a central role in our nation and community. There were 8 factors for which government would like our combined ideas, as I listed in our Newsletter. And then the Government fell on hard times, just as happens in groups, where **forming** a group is perhaps the easiest thing. It then becomes necessary to do some **norming**, that is, for everyone to 'get on the same page', (as they call it these days). After that there's usually some **storming**, meaning that not everyone agrees and some people storm out. Generally, though, once those hurdles are jumped we get a group **performing**, getting their outcomes and fostering good processes. I guess the government had reached the storming stage.



*Thea Biesheuvel*

So what do groups need, to progress from **storming** to **performing**? We know that group members need to feel part of a good team, with everyone in the team doing the things that they do best. They need to have an open approach to their leadership or leader. They need to **combine** their efforts.

We, at Self Help Queensland, have been part of a National network of self help organisations, liaising with our 'sister' organisations in other States. These organisations exist in other countries as well, where they are called 'clearing houses'. I guess we clear information coming our way and distribute it **to** those of you who need to know, while clearing information **from** you we would like others to know about. For example, someone suffering from Bardet-Biedl syndrome might like to hear from others similarly affected. There might only be a hundred or so people in Australia. There would be more overseas. How would they all get to know each other? They contact a 'clearing house'.

From the 6<sup>th</sup> – 12<sup>th</sup> September, each of our 'sister' organisations and ourselves focussed on the benefits of self help and support groups for people who share some illness, syndrome, social or health concerns. That week, **National Self Help and Support Groups Awareness Week** led to a number of activities.

(Continued on Page 3)

## Self Help Queensland Management Committee Members

President               Thea Biesheuvel  
Vice President       Alan Noller  
Secretary             Casey Barber  
Treasurer            Chris Spriggs  
Members              Joe Soda

### Committee Meetings

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

### Co-ordinator

Trish Fallon

### Mental Health Project Officer

Gina Jacobsen

### Administration Officer

Janette Evans

### Office

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

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

### Office Location:

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

### Postal Address

P.O. Box 353, Sunnybank QLD 4109

**Phone/Fax:** (07) 3344 6919

**Email:** selfhelp@gil.com.au

**URL:** www.selfhelpqld.org.au

**Self Help Leaders Online Social Network:** www.selfhelpleaders.ning.com

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



**Queensland Government**



## Regional Representation Sought for SHQ Committee

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

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

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

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

### Disclaimer

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

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

### Contents

President's Message	1
SHQ Management & Contact Details	2
NPS Review	3
Springfield Mental Health Support Group	4
Self Help Queensland News 1	5
Self Help Queensland News 2	6
Vista Print, DonorTec, Survey Monkey	7
Genetic Matters	8
Headache Australia	10
Nevus Support Australia	11
Benefits of Owning a Dog	13
What's New in the New Scientist?	14
Marfan Syndrome: A Tall Story	15
United Brain Tumour Support	17
Bardet Biedl Australia	17
My Time	18
Cookery Nook	19
Vitamins and Minerals are Medicines Too	20
Self Injury - Voice and Movement Therapy	21
Sjogren's Syndrome	22
For Lexophiles	23
Dress Spotty Day	24
Alopecia Aereata Support Group	24
Got a Cold and Feeling Lousy	25
Zonta Club Grant Nth Brisbane	25
Diary Dates	26

(Continued from Page 1)

We were fortunate to attract funding from **Queensland Health** to organise an inaugural **Awareness Day**, thank goodness. They approved our outline and sent us a solid grant, for which we are very grateful. Due to time constraints and other events, we could only secure **Thursday, 9<sup>th</sup> September** in Brisbane to bring our member groups to the attention of the general community. Due to the election and its aftermath we could get very little Media coverage. All this is, by now, ancient history. **We had a great day.** So did **56 other groups.** We believe in the 'cascade' principle, however, and will radiate out from Brisbane next year for what will be an Annual event. Exciting, isn't it?

You know and I know that 'a squeaky wheel gets the oil'. A combination of our efforts is crucial to getting our voices heard at government, at business and at local council levels and, more importantly, will ensure vulnerable people find out that there are others who will help and support them to recover and get some quality into their lives.

We would like to have you combine with us at our **Annual Party** as well. Yes, you read that right! It's our **Annual General Meeting**, of course, but the business end will only take a short time, the rest of that time will be set aside to celebrate our combined efforts. Please set aside **Wednesday, 6<sup>th</sup> October** for us to meet and talk. Networking over a delicious lunch is always a feature enjoyed by everyone who attends our AGM. Remember that we need **your** support to keep **us** going, just as you need our support from time to time. Let's combine our efforts

Thea



## Type 2 Diabetes?

People with type 2 diabetes can find independent reviews of two new blood glucose lowering medicines in the latest edition of [\*Medicine Update\*](#), a newsletter published by NPS – better choices, better health. NPS (formerly known as the National Prescribing Service) is an independent organisation that enables people to be medicinewise.

The reviews of Januvia (sitagliptin) and Galvus (vildagliptin) outline who the medicines are suitable for, how they work and ways in which they differ from existing medicines for type 2 diabetes. Both articles also discuss possible side effects of these and other medicines for diabetes.

[\*Medicine Update\*](#) is an online publication produced by [NPS](#), designed to be used by consumers who are considering new medicines. It aims to highlight important information about how the medicine is used in therapy, how it compares with other therapies, provides important safety information and explains the conditions of its listing on the PBS.

For more information, see the full articles at <http://www.nps.org.au/medicineupdate>



Cancer Council Queensland are looking for people to participate in a weekly active cancer support program in Redcliffe.

**Redcliffe Qi-Gong Group**  
**8am Saturday from 16<sup>th</sup> October – 4<sup>th</sup> December**

Qi-Gong is a quiet meditative activity that strengthens your posture, muscles and improves your balance, flexibility and mobility.

To register for the program on visit [www.c-vivor.org](http://www.c-vivor.org) or call the Helpline on 13 11 20.

## New Area, New Service

The fight against community mental illness

### Springfield Mental Health Support Group

The international award winning urban area of Springfield just south of Brisbane, is rapidly growing weekly with people moving from interstate and overseas to settle in this new style community and all its benefits. Springfield is also housing quite a number of new military service families from the greatly expanded Amberly RAAF base, often used as a final staging point for service personnel who are being deployed to combat destinations overseas.

However, as with any new area where new homes are bought and families have to settle into a new environment; where vital infrastructure is not always available and often creating a feeling of isolation, it is only natural that there is going to be associated mental health issues within the community.

In order to try and alleviate some of the issues of emerging mental health problems in the community, the Springfield Mental Health Support Group has just been launched to provide non-clinical, educational and supportive services to people who experience, or are living with someone who is experiencing a mental illness.

The group will conduct meetings where people can speak to others who are experiencing a similar illness, where information and literature can be accessed for individuals to better understand the issues they are faced with and where simple strategies can be offered to help steer them in a positive direction; all this within a non-clinical, supportive and understanding environment.

Services that will be provided include, a list of local professional services that can be accessed, emergency contacts, a local support network of people willing to assist others in need, guest speakers for workshops from a wide range of mental health services, associations and professionals, workshops in art, visual imagery, relaxation and communication skills and much more.

The group is run totally with volunteers who have all experienced some form of mental illness in the past and can provide a good ear for listening, and understanding of what the other person is going through and a willingness to support them through the process of recovering their health.

Already we have gained invaluable support from the Psychology Department at the University of Southern Queensland, local GPs and clinics, Queensland Police, local inter-agency groups in Goodna and Ipswich, Delfin, Ipswich City Council, local psychologists, agencies such as SIDS, the QLD Stroke Association, Self Help QLD, local mental health agencies and a special mention of the Goodna RSL Sub-Branch who will be covering our administration needs.

The group will be meeting at the Community board room at Delfin's offices, Springfield Lakes and the Community room next to Councilor David Morrison's office at Commercial Drive, Springfield. There is both a day and an evening session so that people who work get the opportunity to come along.

Any inquiries are to be directed to the facilitator, Richard McLaren on 0429 485 921 or, email; [richard@integratedimages.org.au](mailto:richard@integratedimages.org.au)

# SELF HELP QUEENSLAND NEWS 1



## Self Help Queensland Thanks and Congratulates all the Groups that Participated in Self Help and Support Groups Awareness Week September 2010

It was an inaugural NATIONAL event in recognition of the valuable contribution that self help and support groups make to the Australian community. The aim was to raise awareness of the existence of self help and support groups; the broad range of conditions and issues, and the large numbers of volunteers who contribute greatly to the health, social and fiscal well being of the country.

Queensland groups generously and willingly came together with very little lead up time to present a strong, united presence at Reddacliffe Place, Brisbane on 9th September 2010. Because it was such a great day, many groups have indicated they are keen to participate again next year. SHQ is dedicated to making it a Statewide event, with opportunities for hundreds of groups to participate in a variety of ways.

Over the next few months or so we will be inviting feedback, welcoming new ideas and consulting widely as to how we can do things better next year. A main point of focus will be the inclusion of more groups and attempting to interest the media!

### Thank you to the following groups for your participation in the National Awareness Week in Qld

Albinism Fellowship of Australia (Queensland)  
Alopecia Areata Support Association (Queensland)  
Amputees and Families Support Group Queensland  
ARAFMI Queensland  
Asperger Services Australia  
Australian Leukodystrophy Support Group  
Australian Pain Management Association  
Australian Pituitary Foundation Support Queensland  
Australian Tinnitus Association  
Bardet-Biedl Australia  
Bayside Diabetes Support Group  
Bereaved by Suicide Support Group  
Better Hearing Australia (Brisbane)  
Bipolar Disorder and Depression Support Group  
Brisbane Bowel Cancer Support Group  
Brisbane Obsessive Compulsive Disorder SG  
Cardiomyopathy Association of Australia  
Crohn's and Colitis Australia (Queensland)  
Down Syndrome Association Queensland  
Eczema Association of Australasia  
Fibromyalgia/ME Support Group  
Haemochromatosis Society Australia  
Hearing Voices Support Group  
Heart Support Australia  
Hepatitis Council of Queensland  
Irritable Bowel Information & Support Assoc of Aust

Lymphoedema Association Queensland  
Myasthenia Gravis Association of Queensland  
Nevus Australia  
Parkinson's Queensland  
People Surviving Psychiatry  
PFLAG Brisbane  
Qld Asbestos Related Disease Support Society  
Qld Homicide Victims' Support Group  
Queensland Positive People  
Queensland Positive Speakers Bureau  
Respect  
Retina Australia (Queensland)  
Self Help Queensland  
Sleep Disorders Australia  
SOLACE Queensland  
Southside Anxiety Disorders Support Group  
Springfield Mental Health Support Group  
Stroke Association of Queensland  
Survivors of Suicide Bereavement Support Association  
The Brook Red Centre  
The Compassionate Friends Queensland  
The Panic Anxiety Disorder Association Queensland  
The Scleroderma Association of Queensland  
Thyroid Australia (Brisbane)  
Tourette Syndrome Association of Australia (Brisbane)  
United Brain Tumour Support



## Thank You to the Gambling Community Benefit Fund

Self Help Queensland is very thankful to the Queensland Gambling Community Fund for approving a submission for a grant to purchase 2 much needed computers to replace our very old and outdated ones. We are also thrilled to finally own 10 decent chairs for the meeting room and a coffee table that has four intact legs.

We would also like to publicly thank our 3 referees; The Australian Pain Management Association, the Brisbane Obsessive Compulsive Disorder Support Group and the Motor Neurone Disease Association of Queensland. The great letters of support we received played an important role in the success of the grant application.



## SELF HELP QUEENSLAND NEWS 2

Thank you Queensland Health!

for your support of



## Self Help and Support Groups Awareness Week 2010

All credit to Queensland Health on 2 counts! Firstly, for recognising the work carried out by Self Help and Support Groups in Queensland, and secondly for taking the decision to fund the first ever National Self Help and Support Groups Awareness Week in the State. It would not have been possible otherwise!

SHQ and 57 other groups took a big plunge. It was exciting and invigorating! We look forward to making a bigger and better splash in 2011, and hope that Queensland Health will not only pay the pool fee but jump right in and swim with us!



# SELF HELP QUEENSLAND NEWS 3

**Please Join Us! We Would Appreciate Your Support!**

**Self Help Queensland AGM 2010**

**9.30am 6th October 2010**

All friends of SHQ are invited to join us, as always, at our usual friendly AGM and networking lunch at our Sunnybank home. RSVP Trish 3344 6919 or email [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au) for catering purposes by Monday 4th Oct.

Venue: Sunnybank Community Hall, 121 Lister Street, Sunnybank

---

**Please Put This Date in Your Diary Now!**

**Self Help and Support Groups Awareness Day**

**Thursday 8th September 2011**

All the States are keen to grow National Awareness Day into a bigger, more celebrated and better recognised day next year. We are hereby sending an invitation to Queensland self help and support groups to come on board again next year, or join us for the first time. It may be 12 months away, but we need to start planning now! All offers of assistance will be very welcome. Any planning, marketing, publicity, creative or other expertise particularly welcome!

If you need any information or have any ideas please call Trish for a chat on 3344 6919 or email [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au). We are particularly eager to include regional and rural groups in 2011, as well as those who were unable to participate in 2010.

---



## **Thank you Councillor Graham Quirk**

Thanks to Councillor Graham Quirk, Deputy Lord Mayor and Self Help Queensland's local councillor, we have been very fortunate to receive a grant through the Lord Mayor's Suburban Initiative Fund to purchase a Data Projector and Portable Screen for our training initiatives. We are very thankful for Councillor Quirk's continued support, and that of his great staff!

---

## **Welcome Gina Jacobsen!**

Self Help Queensland welcomes and congratulates Gina Jacobsen on her appointment to the position of Project Worker, Mental Health.

Gina holds a Social Work degree from the University of Queensland. She has worked in various roles for both the government and non-government sector since 2002 including Queensland Health, Department of Communities and Save the Children. Gina also volunteered at the Capalaba Community Centre while studying. Gina has a broad range of experience from working with children to reduce chronic addictions to working with adults who have experienced mental illness. Gina spent considerable time as a Family Health Counsellor which led to her role as the Coordinator of the Bayside Sexual Assault Service. During that time, Gina developed and facilitated numerous anti-violence health promotion activities and workshops for schools, community organisations, hospital units and police campaigns. Gina's broad background and experience in the community and Mental Health has given her a great introduction to her new role as Project Worker-Mental Health.



## Looking for Free or Very Low Cost Business Cards?

SHQ is always on the lookout for free or low cost resources for self help and support groups. Some groups have already taken advantage of the free offer of 250 business cards, though there isn't much choice in design or colour. However, you may still find something suitable. The next range has a small cost, with many more choices. You only pay for postage.

**Free**  
**250 full colour business**  
**cards**  
**42 designs to choose from**  
**Pay only for postage**

Visit

[www.vistaprint.com.au](http://www.vistaprint.com.au)

**\$9.49**  
**250 Premium Business Cards**  
**Thousands of designs to choose**  
**from**  
**Plus postage**



**We got our software through DonorTec**  
[WWW.DONORTEC.COM.AU](http://WWW.DONORTEC.COM.AU) | BRINGING TECHNOLOGY DONATIONS TO NON PROFITS

## Needing Low Cost Software? Checked out DonorTec Lately?

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

**In May 2010, thanks to DonorTec, Self Help Queensland applied for, and received, 5 x 2007 Microsoft Office Professional Plus licences with upgrades to 2010 for a total cost of \$121.00. To pay full price for all this software would have been prohibitive.**

There may have been a slight increase since then, but it is almost negligible compared to what you would have to pay in a retail store. It's well worth checking out to see if your group is eligible.

[www.donortec.org](http://www.donortec.org)

## Want to Create a Professional Survey of Your Members?

### Like to do it for Free?

SurveyMonkey allows you to create a basic, online survey for free. There is no software to install and no complicated instruction manuals.

- 10 questions per survey
- 100 responses per survey
- intuitive web based survey tool
- 15 pre-designed question types
- 24x7 customer support

The basic survey should be sufficient for most groups.

Advanced surveys provide more features, but come at a monthly cost.

[www.surveymonkey.com](http://www.surveymonkey.com)

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



# Genetic Matters

by Kim Summers PhD

## The answer lies in the genes: new genetic technologies and disease

Three years ago I wrote about the possibility that we could all have the whole of our DNA sequenced for just \$1,000.\* It's still not possible for everyone, and it costs closer to \$50,000, but two recent studies show the value of doing it, at least for genetic disorders where the inheritance pattern is obvious and there are family members for comparison.

In the first study, siblings were both suffering from two genetic diseases. The parents were healthy and it seemed that the children had been very unlucky in the genetic lottery, because they had inherited disease variants for two different genes from each parent. In the past, one approach would have been to look for candidate genes, genes which are likely to have a role in the development of the conditions if they carry mutations. That approach depends on how much is known about the condition and the normal process that seems to be going wrong in the affected people.

In this family, one condition affected limb and facial development and the other caused increased risk of lung infection. Logical candidate genes for the first condition (affecting development) would be genes responsible for a product known to be necessary for normal development. There are many such genes which are active at different times in development, and the task of deciding which ones to test would be quite daunting.

The lung condition occurs because the small hairs lining the lungs do not form properly and hence there is a build up of mucus which makes infection more likely. We know of a number of genes whose normal function is necessary for the correct movement of these hairs, but this is a relatively new area of research and there are probably many more. So it would be easy to miss a key candidate.

Instead of using this hit-or-miss candidate gene approach, the researchers sequenced the whole genome (all the DNA including genes and other stretches of DNA) from the two children and both parents. They were looking for any gene where the parents carried two forms in their DNA and both children had inherited the identical abnormal (dysfunctional) form from both parents. There were four possible genes and two of these were identified as causing the two conditions. A study of people affected with one of the conditions identified more than 30 genes which were considered candidates. Sections of DNA sequence from the two affected children were compared with DNA from these unrelated patients. The advantage of the family sequencing was that it immediately eliminated 30 of these candidate genes and allowed the researchers to focus on the most likely candidates.

In the second study, the lead researcher was also a research subject. There is a precedent for this: Craig Venter used his own DNA as part of the first human genome sequence and Nobel Prize winner James Watson, one of the discoverers of the structure of DNA, has also had his DNA sequenced. In this case several members of the researcher's family had a neuromuscular condition, Charcot-Marie-Tooth (CMT) disease, but had been tested negative for mutations in known CMT genes.<sup>†</sup> The affected researcher's DNA was fully sequenced and then the sequence was scanned for genetic variants in genes suspected to be involved in neuropathies like CMT. All four affected siblings were found to have the same genetic variants for one gene.

---

\* *The thousand dollar DNA sequence*, March 2007.

<sup>†</sup> CMT was discussed in the SHQ Newsletter of June 2005

(Continued on Page 10)

(Continued from Page 9)

One of the variants came from the mother and one from the father, as expected for a recessive condition. Interestingly, several people with only one of the variants had mild neuromuscular symptoms, including carpal tunnel syndrome.

The power of sequencing all the DNA (the whole genome) is that it highlights regions where a patient is different from a healthy person. In the first study, the use of both parental genomes allowed the researchers to eliminate some candidates suggested by looking at unrelated patients. In the second study, sequencing of the genome of a single affected family member highlighted candidate genes which were then tested by smaller scale sequencing of family members. The candidate genes in both studies were not unknown, but could easily have been ignored within the large number of candidates, if the sequence hadn't indicated their importance.

So sequencing the whole of your DNA isn't the ultimate test: it still requires an understanding of the biology of the condition and the ability to check your genome against your family members'. And for \$50,000 we are a long way from being able to offer this approach to most people. But the technology is getting cheaper and our understanding of the genome is now greater, so the era of whole genome diagnosis can't be far away.

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

---

## Do You, or Does Anyone You Know, Suffer from Headaches or Migraine?



More than 5 million Australians are affected by headache or migraine.

**Headache Australia** is inviting Australians to join a national register if you suffer chronic headaches or migraine.

The register will become a very important resource to help **Headache Australia** provide more research to bring more efficient and effective treatments and take further steps on the road to a full recovery.

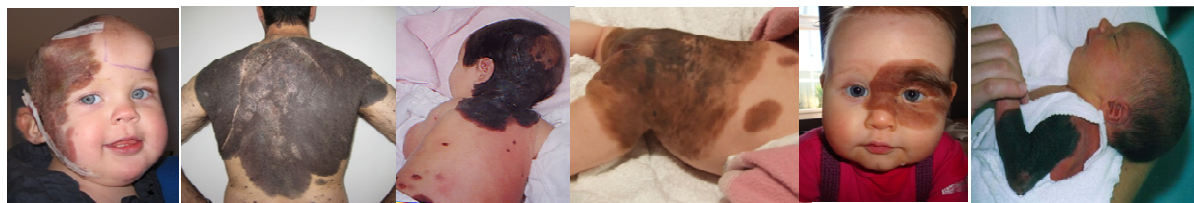
'As new treatments become available we will be able to inform those on the register. We can let everyone know when research projects are being planned so that those who wish to volunteer, and fit the requirements specified such as women and/or men in a particular age group, can be advised about who to contact to become involved. Contact details will never be given out.'

There are also occasions when pharmaceutical companies ask **Headache Australia** to find some who would like to try a new, approved treatment and report their experience with it in the media. Once again, we let everyone on the register know about the opportunity and those who fit the criteria can make contact with the person nominated by the company.

Large numbers on the register lend considerable weight to our requests for research funding from pharmaceutical companies and the government.

Once **Headache Australia** has sufficient numbers on the register, then loyalty programmes can be established free of charge under the **Brain Foundation** Banner so that discounts are available.'

**[www.headacheaustralia.org.au](http://www.headacheaustralia.org.au)**



## Nevus Support Australia Inc

**Who are we?** Nevus Support Australia is a self-help support group for individuals and families affected by a birthmark condition known as Congenital Melanocytic Naevus. We provide on line and telephone support to our members, run regular camps/conferences, work to raise public awareness about the condition and encourage research into it and its associated conditions such as Melanoma and Neurocutaneous Melanosis.

We focus on the Australasian region but also have members from many other parts of the globe. We have a national register to aid research and are working towards a national birth register. We work corroboratively with other organisation across the globe to pursue better understanding, treatment options and ultimately a cure.

**So what is a nevus?** A Congenital Melanocytic Naevus (spelt Nevus or Naevus) is a skin growth present at birth. A rare disorder, it affects around 1 in 20,000 newborns in some form and as few as 1 in 500,000 in its most severe form. It is composed of special pigment producing cells called nevomelanocytes, which are related to the normal pigment producing cells normally found in skin, called melanocytes. They can exist on any part of the body, and grow in proportion to body growth. There are several definitions used to refer to the size of a congenital nevus, from small, medium, large or giant. A giant nevus is one which covers a large portion of an anatomical site, for example scalp, face, arm, leg or back. Another definition is if it covers more than 2% of a patients total body area or will measure over about twenty centimetres when the patient is fully grown. Many large or giant nevi are far more extensive than this. Many patients also have multiple other nevi called satellite nevi on other parts of their body, and some will continue to develop these over their lifespan.

**What does a Nevus look like?** Most Nevi are brown or black in colour, and have an increased tendency for hair growth. The skin texture can be smooth or leathery and because oil and sweat glands do not form properly within the nevus, overheating can be a problem. The skin is often dry and fragile. Many nevi have tumours just below the skin that give the nevus a lumpy or folded appearance. Every CMN is unique. There is no specific pattern of distribution or skin texture within the nevus itself and no way to be certain just how having a CMN will affect a person's lifestyle. Below are some of the most common questions answered, however each case is individual and will have its own particular areas of concern.

**How many people have a CMN?** About 1 in 500 of us are born with a small (mole sized) CMN somewhere on our skin. Around 1 in 20,000 will be born with a bigger one, up to about the size of an adult's palm. This can be a problem if it involves the face, scalp or some other highly visible area and can cause psychosocial problems although health problems with these are rare. As few as 1 in 500,000 will be born with a giant CMN and these have the potential to cause both health and psychosocial challenges.

### **What are some of these challenges?**

**NCM.** The biggest risks faced by people with CMN are the possibility of these same lesions forming within the central nervous system,

(Continued on Page 12)

(Continued from Page 11)

the brain and/or the spinal cord. This can cause neurological symptoms including hydrocephalus and seizures, if present the prognosis is uncertain but often poor. This is known as Neurocutaneous Melanosis. Thankfully this is a relatively rare occurrence.

**Melanoma.** People with giant CMN have a greater risk of developing melanoma and other rarer forms of skin cancers than the general population. These skin cancers will often occur during childhood and even occur in babies. The exact risk of this is uncertain but it is now thought to be around 4% - 10% of patients. We recommend vigilant sun safety practices as promoted by the various State Cancer Councils/associations. It is not necessary to exclude outdoor activities but recommended to approach these with a view to avoiding harmful exposure.

**Overheating.** The skin of a CMN is often lacking in subcutaneous fat. It also generally has no sweat glands or oil glands within the pigmented areas plus will often have increased hair growth. This makes it very difficult for the body to lose heat through the pigmented areas of skin or equally through any scar tissues that may be present due to surgical intervention. Overheating can be a major problem in patients with CMN. Modern climate controls make this easier to manage however be aware if you are planning sports sessions or are in a non air conditioned environment that this is taken into consideration. It is not necessary to exclude children from sports sessions nor does this help their psychosocial outcomes. Planning outdoor activities for the mornings or evenings during warmer months helps. **Heat stress and heat exhaustion can occur very quickly and are potentially life threatening.** Some ways to manage overheating include the use of cooling vests, cold face washers, cool foot baths, splashing face and head with cool water, quiet time in a cool spot.

**Itching** The lack of oil glands and increased hair growth along with the CMN's naturally volatile nature also has the potential to lead to a problem with itching. It is also thought that this may be a result of abnormalities in the nerve fibres in the nevus skin. This is the same extreme itching usually associated with eczema. Steroid and non steroid creams can help as can moisturisers and emollients particularly oils. Heat or cold can aggravate this condition. Ice packs can sometimes help. This extreme itching can also occur in scar tissue.

**Psychosocial issues.** Obviously with a visible physical difference the potential for psychosocial problems arise. Different children manage questions and stares in different ways. A very effective response is that it's a birthmark, it doesn't hurt and you can't catch it. Bullying is an issue and can often be quite subtle but hurtful in nature. The impact of this will also vary from child to child. This can also be affected by the gender of the child and the location of the pigmented skin and/or scar tissue. Sometimes areas where nevus tissue has been removed can look like burns scarring. It is thought that over 30% of patients with CMN will suffer from depression and/or anxiety specifically related to the psychosocial pressures related to their CMN.

**Will they grow out of it?** No. This is a lifelong condition. The nevus may change over time, it may fade slightly (not disappear), get darker, get hairier, but it will not go away.

**So what is the general prognosis?** Honestly we don't really know. CMN patients have only been really followed for about the last 10 years or so in the UK and USA to see what happens. Nevus Support Australia has been around for less than 8 years. We have no national birth register so have no way of tracking outcomes for patients. Thankfully this is slowly changing. We do know that there are older CMN patients out there, some of them have married and had children of their own.

(Continued on Page 13)



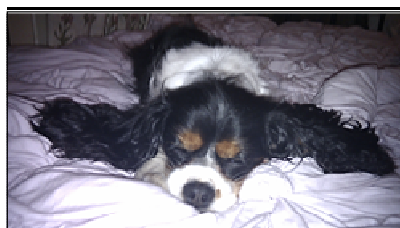
(Continued from Page 12 )

**So is it hereditary?** We don't think so. There are a few cases where there is more than one member of a family with a large nevus but not with a giant CMN as far as we know at the moment. As far as we are aware no one with a CMN has had a child with a CMN nor have any siblings. There are cases where twins and triplets have been born with one affected by CMN and the others not. So our best guess at the moment is that no it is not hereditary, it is just one of those things we can't explain.

**What about medical intervention?** Sometimes medical intervention can help cosmetically, sometimes not. It depends on where the nevus is, the size, skin type (nevus can be thin and fragile or thick and bumpy) and the patient. There are various medical possibilities including shaving the upper layers of skin (curettage or dermabrasion) to reduce the visible pigment or to de bulk a thick CMN, excision by either serial excision, expanded full thickness skin flaps, or split skin grafting, and laser for both pigment and hair reduction (not removal). Most children with a CMN will have a paediatrician, dermatologist and plastic surgeon as part of their regular care team, others may also have a neurologist, psychologist, GP, ophthalmologist, ear nose and throat specialist, dental specialist, scar management specialist, physiotherapist, oncologist, or social worker. Regular medical appointments are usual, particularly in the early years. There is no way to medically reduce the risks associated with CMN. We just don't know enough about it yet.

**What about all those other spots?** Many but not all patients with CMN will have other spots as well as the primary nevus. These are generally referred to as satellite nevi. The skin structure is the same as in the primary nevus. These 'spots' can continue to develop after birth and in fact can continue to appear over the lifespan.

Nevus Support Australia Inc, the Australasian support group for people affected by CMN and their families. [www.nevussupport.com](http://www.nevussupport.com)



**Lotty**

## **The Benefits of Owning a Dog**

The Delta Society [www.deltasociety.org](http://www.deltasociety.org) was founded 30 years ago. Its first president, a veterinarian, pioneered human-animal bond theory and application. Research proved the beneficial effect of having contact with a responsive animal. By the 1990s, dogs screened by the society were placed in hospital and nursing home pet visitation programs.

- Owning a dog gives isolated people a routine, a sense of purpose, and a sense of fulfillment that helps prevent depression and loneliness.
- Elderly people with dogs are better able than non-pet-owning elderly people to cope with daily activities.
- Children who have dogs tend to be more self-reliant, sociable, and less selfish than children without pets.
- Stroking and patting a dog can be relaxing, which is measured by a slower heart rate and a drop in blood pressure.
- Dog owners are more likely to survive heart attacks than non-pet owners are.
- The presence of a dog can ease the effects of Alzheimer's.
- People with dogs have been found to have lower cholesterol and triglyceride levels when compared to people who do not.

**\*Lotty is a loving companion to a young double transplant recipient**

## What's New from the New Scientist?

### Autism Brain Scan

Ten minutes in a brain scanner could be all it takes to diagnose autism. So says Christine Ecker at the Institute of Psychiatry, UK, who has developed software that identifies the anatomical signatures of the condition.

Ecker's team carried out MRI scans on the brains of 20 adult males with autism, 20 with attention-deficit disorder and 20 healthy controls. They used a machine-learning tool called a support vector machine (SVM) which analyses data and identifies patterns – to identify key differences between the groups, such as in the cortical folding and curvature of the brain. The SVM was then used to build a model to predict whether brain scans fall into the autistic or control group. When the original scans were fed into this model, it diagnosed autism with a 90% success rate (*Journal of Neuroscience*, DOI:10.1523/jneurosci.5413-09.2010)

Current diagnostic tools are based on time-consuming and potentially stressful behavioural tests and interviews. Ecker now plans to test her model on children for whom she predicts more accurate results, 'because the differences in anatomy between health and autistic brains are more prominent in childhood.'

**From :- New Scientist, 14 August, 2010, page7**

### Autism and Guilt

Those familiar with the scientific method may be puzzled why many parents of autistic children seek interventions and therapies with no evidence base. However, it is not so surprising when you consider the context of autism and parenting.

For decades parents have been told that they are the cause of their child's autism. The idea promoted by psychologist Bruno Bettelheim in the 1960s and 70s that autistic behaviours are triggered by a mother's emotional frigidity is still widely believed. More recently autism has been attributed to parental genes. Thus a diagnosis of autism can trigger feelings of parental guilt. Many parents seek to counter the notion that their child's autism is their fault by doing whatever they can to alleviate the effects, even trying medications and interventions that have not been scientifically verified.

Increasing scientific literacy in the general population would help, as well as more government funded health and education support services for autism. The best-practice guidelines published by the New Zealand ministries of health and education are a good example of how a government can help. (*to be found at* [www.bit.ly/9uSYUU](http://www.bit.ly/9uSYUU)).

**From: New Scientist, 14 August, 2010 Author Hilary Stace**

---

## Migraine Breakthrough Brings New Hope - Blame A Gene Called "TRESK"

A genetic defect that is a key cause of migraines has been identified by scientists at the University of Oxford's Medical Research Centre. The new study found a specific gene called TRESK was directly attributable, and gave researchers hope for finding better treatments for the common form of migraine. For the latest information go to:

**[www.mrc.ac.uk](http://www.mrc.ac.uk)**

---

## Major Breakthrough in Alzheimer's Research

Researchers from the University of Sydney's Brain and Mind Research Institute (Alzheimer's and Parkinson's Disease Laboratory) have achieved a major breakthrough by finding the causes of Alzheimer's disease at a cellular level and thereby identifying a potential therapy as a result. The study is published in the prestigious international scientific journal "Cell" on 23rd July 2010. Go to: **[www.sydney.edu.au/bmri/](http://www.sydney.edu.au/bmri/)**



## MARFAN SYNDROME: A Tall Story

What could the famous Abraham Lincoln and infamous Osama Bin Laden possibly have in common? Not a lot one would assume except that both have been speculated in the media as being affected by Marfan Syndrome. While there may be wide and wild speculation about some famous and infamous people of history having MFS, the condition can still be unfamiliar within the general community and medical professions, allowing some people to remain undiagnosed and vulnerable to possible life threatening events.

### **What is Marfan Syndrome?**

Marfan Syndrome is a heritable disorder of the connective tissue that affects many organ systems, including the skeleton, heart and blood vessels, eyes and lungs. The condition affects both men and women of all races and ethnic groups. It may be diagnosed in children, teenagers or adults. In appearance, people with MFS often have very long arms and legs, usually resulting in tall stature. They may have a hollow or pigeon chest, long fingers and toes, flat feet and curvature of the spine (scoliosis) and be short sighted. Often they are loose-jointed and have a high palate and crowded teeth. As many of these appearance traits are shared with the general community, a combination of these traits may only be an indicator for the need for further investigation of the more vital internal systems.

### **How is Marfan Syndrome diagnosed?**

MFS is difficult to diagnose because there is no specific laboratory test for the condition. In addition, characteristics of the disorder vary greatly among affected individuals. Affected people may not have all the possible signs and complications of the syndrome. To make a diagnosis of MFS, a complete physical examination which focuses on the systems affected by the disorder is needed and includes: An echocardiogram of the heart and aorta assessed by a cardiologist; a slit lamp examination of the eye by an ophthalmologist; a skeletal examination; and a discussion of family history. A combination of specific symptoms must be present for a person to be diagnosed with MFS.

In 1991, the gene which is abnormal (mutated) in MFS was discovered. It carries the recipe for a component of connective tissue called fibrillin, which is involved in giving tissues elasticity. Once a diagnosis has been established for an individual it may be possible to look at this gene and identify the change which causes the condition, and compare it to other members of that individual's family. However, this test is only available through one private laboratory in Australia, and the family must bear the cost. Genetic counselling is available to assist families in making decisions about testing and the inheritance of the gene in future generations.

### **What Medical Problems are associated with Marfan Syndrome?**

#### **The Cardiovascular System**

The most serious problems associated with MFS involve the heart and blood vessels. The aorta is generally wider and more fragile in patients with MFS. This widening is progressive and can cause leakage of the aortic valve and or dissection in the aorta wall. When the aorta becomes greatly widened or dissects, then surgical repair may be necessary. In addition, mitral valve prolapse can lead to inefficient operation of the valve or irregular heart rhythm.

#### **The Eyes**

The most significant problem with the eyes is the subluxation of the lens, when the lens moves or becomes detached. People with MFS are also often myopic and may have a flat cornea.

(Continued on Page 16)

(Continued from Page 15)

### **The Skeleton**

As described above, the tall, loose limbed structure of the skeleton and the hypermobility of joints can lead to a variety of difficulties associated with lifestyle activities while possibly exacerbating other medical issues.

### **Other Clinical Problems**

People with MFS are prone to pneumothorax (collapsed lung) and hernias and dural ectasia. They may have a congenital abnormality of the spine diagnosed using MRI or CT scan.

### **What causes Marfan Syndrome?**

MFS is a dominant genetic condition. Most affected people have an affected parent although up to one third are thought to have a new or spontaneous mutation. A person with MFS has a 50:50 risk of passing it on to each offspring. The gene which is mutated in Marfan Syndrome is located on human chromosome 15.

### **How is Marfan Syndrome Treated?**

People affected by MFS need to be treated by a physician familiar with the ways in which it affects all body systems. There is no cure for the disorder, but careful medical management can greatly improve the prognosis and lengthen the life span. In general, treatment may include: an annual echocardiogram to monitor the size the function of the heart and aorta; periodic examinations of the eyes by an ophthalmologist; and careful monitoring of the skeletal system, especially during childhood and adolescence.

Beta-blocker medication may be prescribed to lower blood pressure and reduce the stress on the aorta; antibiotics may be prescribed prior to dental procedures to reduce the risk of infection; and lifestyle adaptations, such as avoidance of strenuous exercise and contact sport may be necessary to reduce impacts on aorta, lungs and eyes.

As any symptom arises or deteriorates, a person affected by MFS will need to consult a variety of medical specialists across their lifetime, and may need to seek genetic counselling and psychological support to assist them to cope with any changes to their health or lifestyle.

### **What to do if I think I or a family member might be affected?**

**The Marfan Clinic at Prince Charles Hospital, Brisbane** has been established for diagnosis and management of Marfan Syndrome. It is held every three months. For appointments and information Email [j.west@uq.edu.au](mailto:j.west@uq.edu.au) or phone 0417 194 162. The **Marfan Association Queensland Inc.** which works closely with clinic staff to ensure that affected families have connections to each other for support.

Marfan Association Queensland also encourages wider general public and medical profession knowledge of MFS and as a deductible charity recipient, raises funds for MFS specific research by the Dept. of Medicine University Qld. We welcome contact by Email: [maq@qld.chariot.net.au](mailto:maq@qld.chariot.net.au) or post to PO Box 294, Sumner Park, Qld. 4074.

Ps: People affected by MFS can be as intelligent, intellectual and creative as the rest of the community and have been known to tell some very funny tall stories on occasions!

### **Contact:**

**Marfan Association Queensland Inc**  
**PO Box 294**  
**SUMNER PARK, QLD 4074**  
**Email [maq@qld.chariot.net.au](mailto:maq@qld.chariot.net.au)**

(The majority of this article is reprinted with permission from the Marfan Syndrome Fact Sheet of the Marfan Association Qld Inc)



## UNITED BRAIN TUMOUR SUPPORT



### Group Aim:

To connect all brain tumour sufferers and their families, offering them help and support, as well as helping them to obtain the knowledge in order to give them a better understanding of brain tumours and how they affect everyone's lives.

### How Do We Achieve This?

By regular monthly meetings held in a relaxed atmosphere (overlooking the beach), which allows our members to talk and listen to each other, as well as to be updated on the latest medical information available. We also attend bi-monthly meetings held at the Cancer Council in Brisbane, where there is regular presentations by Neurosurgeons, Neuropsychologist, Psychologist and as well as representatives from the Brain Injury Association of Queensland. There is also a *Question* and *Answer* time which allows you to ask those questions which are relevant to your situation.

### When and Where are the United Brain Tumour Support Meetings Held?

**When:** 3<sup>rd</sup> Wednesday of each month

**Where:** Tugun Surf Lifesaving Club  
29 O'Connor Street, Tugun

**Time:** Commences at 10.30 am

### Social Events:

Barefoot Bowls, Restaurant Dinner Parties & Christmas BBQ

### Fund Raising Activities:

Dianne Moore Memorial Walk (Burleigh to Miami & back) Bunning's (Burleigh)  
Sausage Sizzle



## Bardet-Biedl Australia You're Not Alone

Bardet\_Biedl Australia is a contact base to support those affected by Bardet-Biedl Syndrome (BBS) in Australia.

Bardet-Biedl Australia is proud to announce that it now has a website:

**[www.bardetbiedlaustralia.org](http://www.bardetbiedlaustralia.org)**

Please contact the website if you are affected by Bardet-Biedl Syndrome. Also register your interest on the website for a Conference in 2013.

Please note our new email address:

**[info@bardetbiedlaustralia.org](mailto:info@bardetbiedlaustralia.org)**

**"Knowledge is knowing a tomato is a fruit; Wisdom is not putting it in a fruit salad."**

**Peter Kaye**

**UK Comedian, Writer, Producer, Director, Actor**

**1973.....**



## What is MyTime?

If you are a parent, grandparent or anyone caring for a child with a disability, developmental delay or chronic medical condition, then MyTime is a wonderful program designed to help and support you. It provides the opportunity to socialise, share ideas and information with others who understand the rewards and intensity of caring for a child with special needs.

In Queensland, Playgroup Association of Queensland is a major provider of MyTime and has established 31 groups throughout the state for parents of school age and preschool children.

The MyTime program is designed to increase community connectivity and promote positive childhood development for families with children. Parents and carers can participate in MyTime while their children are cared for in a stimulating environment nearby. Parents choose topics and activities to discuss and explore with their group facilitator, while their children are kept busy and happy.

MyTime is unique because it is focused on the carer. It gives them time to look after their own needs, build confidence and is a place for both giving and receiving. As one parent stated "there is something compelling about sharing the ups and downs of our lives with others who are walking a similar path. It builds bonds that are very strong".

Parents either meet fortnightly or weekly for a couple of hours and they decide on the group activities which provide not only information and skills development but also lots of laughter and fun. These include guest speakers who provide information and link carers to services and resources; excursions, coffee & conversation mornings; movie outings; relaxation and massage sessions; parenting strategies

### Who can join?

Parents and carers – including mums, dads, grandparents and the principal carer – who are eligible for the Carer Allowance (Child) for a child with a disability or chronic medical condition.



*"I feel quite sure that you can never have enough supportive friends in this life and I think the MyTime philosophy actively encourages us to connect and be enriched by the experience."*

*(Quote from a Parent at the MyTime group at Mitchelton Special School)*

**For more information, contact Anne Gooley, State Coordinator**

**Ph: 3855 9600 Email: [agooley@playgroupqld.com.au](mailto:agooley@playgroupqld.com.au)**

**[www.playgroupaustralia.com.au](http://www.playgroupaustralia.com.au)**



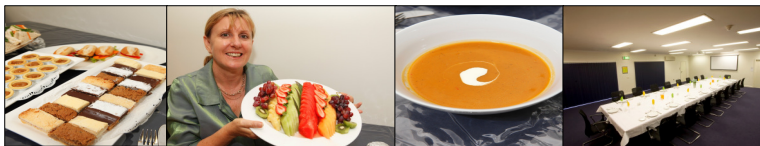
## **Need Quality Home Style Delivered Catering for Your Group?**

## **Happy to Assist a Not for Profit at the Same Time?**

## **How About Extremely Competitively Priced Conference Rooms?**

A not-for-profit organisation in Brisbane, the Cookery Nook, is producing fabulous home-style catering and all for the great cause of supporting people with an intellectual disability obtain employment and services.

Yes, unbelievable that this can all be rolled into one business – but very true! The Cookery Nook is a business unit on the north side of the city, operating from premises at Woolloowin (near the Lutwyche shopping centre) conveniently situated near the Woolloowin Train Station and on the bus route. It is a thriving home-style catering service, supplying local cafes, private functions, many corporate businesses and more recently negotiating with hospitals and community groups for their food demand on a larger scale.



The Cookery Nook's Traditional Mud Cake has been enjoyed by locals for more than a decade and enjoys the same fame as the gourmet sandwiches!

The Cookery Nook operates under the auspices of the Sisters of Mercy, the Catholic organisation which has ministries in various fields of society. All profits from sales from the Cookery Nook have a social impact as they go towards funding services for people with an intellectual disability.

Products made by the Cookery Nook include a variety of the most scrumptious slices, cakes, sandwiches.. The list is extensive – offers include corporate catering for workshops, business meetings – eg wraps including fresh and crunchy salads. But then in addition we cater to sit down meals, either on our premises making use of our fabulous Conference facilities, and providing waitressing if necessary.

The service incorporates assisting you to arrive at the best catering option for your specific needs. Deliveries are made anywhere in the city. The Cookery Nook is the proud owner of a 4-star rating from the Brisbane City Council for their food hygiene and safety procedures! In addition they have achieved a BSI accreditation.

Please feel free to contact the Cookery Nook to obtain a current price list. The Cookery Nook is able to tailor-make your menu choices to suit your specific tastes.

**Contact: The Cookery Nook**

**Email: [cookerynook@mds.org.au](mailto:cookerynook@mds.org.au)**

**Phone: 07 3866 4200**

**(We thank Self Help Queensland for this forum and congratulate them on their newsletter!)**

**Editor's Note:** We don't normally make recommendations, but Self Help Queensland people have had the pleasure of sampling a selection of delicious mixed slices from Cookery Nook's kitchen. Not only do they taste unbelievably good, but are very reasonably priced as well! Cookery Nook people are great to deal with, and it's good to know that the profits are directed towards services for people with intellectual disabilities.

**How about giving them a go?**

## Vitamins and Minerals are Medicines Too

Most of us don't think of vitamin and mineral supplements as being medicines, but they are. Vitamins and minerals occur naturally in food, and are used by our bodies to maintain good health and prevent a range of diseases.

However, if vitamins or minerals are being taken in the form of supplements (tablets, capsules, powders, etc) they should be regarded as medicines and treated as such.

### Who might need supplements?

While vitamins and minerals are essential for good health, our bodies need only tiny amounts of them. Therefore, most people don't need supplements, as they obtain enough of each vitamin and mineral by eating a good and varied diet.

Nevertheless, some people may need supplements to correct specific deficiencies in their diet, or because their circumstances mean they need more of a particular vitamin or mineral than their diet can provide. Such people include:

- Women who are pregnant or breastfeeding
- People who drink large amounts of alcohol
- People with some chronic health conditions
- Some vegetarians
- People who use illicit drugs
- Older people

### Use wisely

When using vitamin and mineral supplements, always read the label and take only as recommended. Taking more than the recommended dose of some vitamins and minerals can cause problems. For example, vitamins A, D, E and K are stored in the body. If too much of one of these vitamins accumulates in your body, it can become toxic. With others, if you take in more than you need, the excess is simply wasted.

Like other medicines, supplements can cause side effects and can interact with other medicines, especially when taken in large doses. So, when telling a doctor or pharmacist about the medicines you are taking, don't forget to tell them about any vitamin and mineral supplements.

### Further information

Your doctor, pharmacist or dietitian can give you advice about vitamin and mineral supplements.

**A reliable website for detailed information about vitamin and mineral supplements is the Drugs and Supplements section of the United States MedicinePlus website ([www.nlm.nih.gov/medlineplus](http://www.nlm.nih.gov/medlineplus))**

(Source: NPS Newsletter "Medicines Talk" Autumn 2010 No 33)

---

## Are you Looking for Free, Up to Date, Reliable Information about Genetic Conditions and Rare Diseases?

The Genetic and Rare Diseases Information Center (GARD), is a collaborative effort of two agencies of the US National Institutes of Health; The Offices of Rare Diseases Research (ORDR) and the National Human Genome Research Institute (HGRI) to help people find useful information about genetic conditions and rare diseases.

GARD is a user friendly website which gives people the ability to search extensive lists of rare diseases and genetic conditions, provides up to date information, allows contact with GARD information specialists, gives tips for dealing with undiagnosed conditions and much more.

**[www.rarediseases.info.nih.gov/GARD/](http://www.rarediseases.info.nih.gov/GARD/)**





THE UNIVERSITY  
OF QUEENSLAND  
AUSTRALIA

## **Do you Know Someone Who Self Injures and Really Wants to Change?**

Voice and Movement Therapy May be the Chance to Reduce  
Non Suicidal Self Injury in Young Women.

### **Voice and Movement Therapy**

Group participants will be encouraged to write and create songs, dance, and sing, using the full range of voice in a way that is psychologically uplifting and physically invigorating.

Participants will learn new ways to express their emotions using the singing and speaking voice as a psychological and physiological tool.

### **We are looking for:**

- Young women aged 18-25 years.
- Women with ongoing self-injuring behaviours without suicidal ideation, and occurring in the past 6 weeks.

### **What is required for this research?**

- Participants will be required to complete a questionnaire before and after therapy.
- Participation in 10 group sessions, weekly for 10 weeks, each session lasting 2.5 hours with a 20-minute break.

## **The group will commence in November 2010**

### **Additional information:**

- Therapy sessions will be held in Brisbane in a central location, time and day to be advised.
- Participants will be reimbursed \$10.00 per hour for their time and energy to take part in this therapy, and to cover any incidental expenses (i.e. \$250.00 for the whole therapy).

**Please register your interest by phone or text to Anna on 0459-227-455  
or by email to [vmtuq@hotmail.com](mailto:vmtuq@hotmail.com).**

**Note: Participation is strictly confidential and privacy and anonymity will be respected outside the therapy. The therapy involves group work as interaction and sharing is intended to be therapeutic by building self-awareness, confidence and resilience; therefore confidentiality cannot be maintained during group work. You have the right to withdraw at any time during the course of the therapy.**

Professor Graham Martin  
Professor, Adolescent Psychiatry  
Discipline of Psychiatry

Anna Follent  
Research Assistant

Assistance from Sarah Swannell  
Senior Research Technician  
Discipline of Psychiatry



## Sjogren's Syndrome

(pronounced show-grins)

**Dry Eyes? Dry Mouth?  
Dry Nose? Rheumatic Disease?**

**Sjögren's syndrome is an autoimmune disease in which the body's immune system mistakenly attacks its own moisture producing glands.**

Sjögren's is one of the most prevalent autoimmune disorders, striking as many as 0.5% of Australians (according to the Arthritis Foundation). Nine out of ten patients are women. The average age of onset is late 40's although Sjögren's occurs in all age groups in both women and men.

About 50% of the time Sjögren's syndrome occurs alone, and 50% of the time it occurs in the presence of another connective tissue disease. The four most common diagnoses that co-exist with Sjögren's syndrome are Rheumatoid Arthritis, Systemic Lupus, Systemic Sclerosis (scleroderma) and Polymyositis/Dermatomyositis. Sometimes researchers refer to the first type as "Primary Sjögren's" and the second as "Secondary Sjögren's." All instances of Sjögren's syndrome are systemic, affecting the entire body.

The hallmark symptoms are dry eyes and dry mouth. Sjögren's may also cause dryness of other organs, affecting the kidneys, GI tract, blood vessels, lung, liver, pancreas, and the central nervous system. Many patients experience debilitating fatigue and joint pain. Symptoms can plateau, worsen, or go into remission. While some people experience mild symptoms, others suffer debilitating symptoms that greatly impair their quality of life.

**Early diagnosis and treatment are important for preventing complications.**

The symptoms of Sjögren's syndrome may overlap with or "mimic" those of other diseases including lupus, rheumatoid arthritis, fibromyalgia, chronic fatigue syndrome, and multiple sclerosis. Furthermore, dryness can occur for other reasons, such as a side effect of medication like anti-depressants or high blood pressure medication.

Additionally, because all symptoms are not always present at the same time and because Sjögren's can involve several body systems, physicians and dentists sometimes treat each symptom individually and do not recognize that a systemic disease is present. The average time from onset of symptoms to diagnosis is over six years. Rheumatologists have primary responsibility for diagnosing and managing Sjögren's syndrome.

Once Sjögren's is suspected, a physician will order a series of blood tests.

**Contact:**

TASSA,

39 Main Arm Road, Mullumbimby, NSW 2482

Ph: 02 6684 3704 Email: [bevnorton@sjogrens.org.au](mailto:bevnorton@sjogrens.org.au) URL: [www.sjogrens.org.au](http://www.sjogrens.org.au)

### 2011 Declared International Year of Forests

**Think Before You Print!**

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

**3 sheets of A4 paper = 1 litre water**

(Source: Department of Environment and Resource Management)

## For Lexophiles (Lover of Words)

1. A bicycle can't stand alone; it is two tired.
2. A will is a dead giveaway.
3. Time flies like an arrow; fruit flies like a banana.
4. A backward poet writes inverse.
5. A chicken crossing the road: poultry in motion.
6. When a clock is hungry it goes back four seconds.
7. The guy who fell onto an upholstery machine was fully recovered.
8. You are stuck with your debt if you can't budge it.
9. He broke into song because he couldn't find the key.
10. A calendar's days are numbered.
11. A boiled egg is hard to beat.
12. He had a photographic memory which was never developed.
13. The short fortune-teller who escaped from prison: a small medium at large.
14. Those who get too big for their britches will be exposed in the end.
15. When you've seen one shopping centre you've seen a mall.
16. If you jump off a Paris bridge, you are in Seine .
17. When she saw her first strands of grey hair, she thought she'd dye.
18. Santa's helpers are subordinate clauses.
19. Acupuncture: a jab well done.
20. Marathon runners with bad shoes suffer the agony of de feet.
21. The roundest knight at king Arthur's round table was Sir Cumference. He acquired his size from too much pi.
22. I thought I saw an eye doctor on an Alaskan island, but it turned out to be an optical Aleutian.
23. She was only a whisky maker, but he loved her still.
24. A rubber band pistol was confiscated from algebra class because it was a weapon of math disruption.
25. No matter how much you push the envelope, it'll still be stationery.
26. A dog gave birth to puppies near the road and was cited for littering.
27. Two silk worms had a race. They ended up in a tie.
28. A hole has been found in the nudist camp wall.. The police are looking into it.
29. Atheism is a non-prophet organization.
30. I wondered why the baseball kept getting bigger. Then it hit me.
31. A sign on the lawn at a drug rehab centre said: 'Keep off the Grass.'
32. A small boy swallowed some coins and was taken to a hospital. When his grandmother telephoned to ask how he was, a nurse said, 'No change yet.'

---

(From Page 4)

**Answer: 'Twice the length from the middle to each end'**



**Sunday 21 November 2010**

**Come join members of the Brisbane Bowel Cancer Support Group  
and wear something spotty for fun.**

**Dress spotty and save lives from bowel cancer**

**Spot the symptoms of bowel cancer  
Raise community awareness**

**Venue: Orleigh Park, West End  
Time: From 11am  
Look for 'Dress Spotty Day' sign**

**Buy a cute spotty dog badge  
Musical entertainment and raffles  
Bowel cancer information  
Meet Support Group members**

**For more information about the Brisbane Bowel Cancer Support  
Group or 'Dress Spotty Day' please contact Pamela:  
Ph: 07 3856 5546 Email: peatea2@uqconnect.net**

---

## **Invitation**

**Meet Fellow Alopecia Sufferers and Make Some New Friends!**

**Saturday 6th November 2010**

### **Alopecia Areata Support Association Annual Meeting**

Redland Bay Uniting Church Hall, 228 Gordon Road REDLAND BAY  
(Nearest Streets are Main Street and Blair Street - Ample parking)

A friendly welcome awaits you

Cost \$10 per person includes afternoon tea and much more

**Please RSVP to Angela Jackman Ph: 3829 0684 or  
Email: angelajackman\_1@hotmail.com**

## Got a Cold and Feeling Lousy?

### Antibiotics Have no Effect on Common Colds

Common colds are caused by viruses. Antibiotics fight only bacterial infections, so taking them for a cold will have no effect.

There are many things you can do to relieve the symptoms of colds without taking medicine.

- Take it easy or rest, so your immune system can fight the infection
- Loosen and clear you blocked nose by
  - using saline (salt water) nose spray or drops
  - having a hot shower and inhaling the steam
  - filling a bowl with hot water and inhaling the steam. Do not use for children as the steam may burn the lining of their nose and they may spill the hot water
- Drink soothing liquids
- Use an ointment to soothe dry and chapped skin around the nose
- Gargle warm salty water
- Suck an iceblock or throat lozenge

Many 'cough and cold' medicines are sold to relieve the symptoms of colds. However, good quality research indicates that very few are effective, particularly in children, and they may not be suitable for children under two years. In addition, some of the active ingredients can interact with commonly used prescription medicines.

Similarly, decongestants are not usually effective in children under 12, and are not safe for adults if they have certain health conditions, or take certain medicines.

Before using a cough and cold medicine or decongestant, check the label, and ask your doctor or pharmacist for advice about whether the medicine is safe for you.

See your doctor if your symptoms come on suddenly, are severe, last longer than usual, or aggravate any other ongoing medical conditions.

For more information, talk to your doctor or pharmacist, or visit the NPS common colds website ([www.nps.org.au/commoncolds](http://www.nps.org.au/commoncolds)).



**Zonta International**  
*Advancing the Status of Women Worldwide*

**ZONTA Club of Brisbane North  
Invites Applications**

**Zonta Advancement Grant of \$1000 to improve status of women  
Up to 3 Awards offered each year. Closing date 8th Oct 2010  
For women working or living in Brisbane**

The grant has been awarded in the past to assist with the cost of: educational courses, child minding to allow attendance at courses, books for study and/or research, transport assistance to allow access to development opportunities.

Please forward a letter setting out your name, address, phone number/s, email address (if applicable), personal situation, aims, and describing how this grant could assist you. Also include the names of two referees and, if possible, copies of references and any other supporting material such as school/TAFE/ University results to:

Zonta Advancement Grant, c/- Ms Gina Brosnan  
PO Box 368, SPRING HILL, QLD 4004

For help in completing the letter of application, please feel free to contact Gina at home, on 3378 9645/33772311 or email [brosnang@brigidine.qld.edu.au](mailto:brosnang@brigidine.qld.edu.au).





## Diary Dates

**2010 — 'Year of the Lung'**

**7th - 9th October 2010: 3rd Australian Lung Cancer Conference**

**Email:** [info@alcc.net.au](mailto:info@alcc.net.au)

**URL:** [www.alcc.net.au](http://www.alcc.net.au)

**Venue:** Melbourne

**8th - 10th October 2010: 22nd Annual Batten Disease Support and Research Association Family Conference "Fields of Dreams and Hope"**

[www.battens.org.au/family\\_conferences](http://www.battens.org.au/family_conferences)

**Venue:** Sea World, Gold Coast

**10th - 16th October 2010: Mental Health Week**

**11th - 12th October 2010: Older Women's Network National Conference**

**11th - 13th October 2010: National Centre for Farmer Health Inaugural Conference** Opening the Gates on Farmer Health.

**Phone:** 03 5551 8587

**Email:** [sally.stevenson@wdhs.net](mailto:sally.stevenson@wdhs.net)

**Website:** [www.farmerhealth.org.au](http://www.farmerhealth.org.au)

**Venue:** Hamilton VIC

**13th - 15th October 2010: Community Centres and Family Support Network Assoc Qld Conference** "Creating Possibilities - Strengthening Community"

**Ph:** 07 4776 1822

**Email:** [linda@hcsc.rg.au](mailto:linda@hcsc.rg.au)

**URL:** [ccfsnaq.org](http://ccfsnaq.org)

**Venue:** Jupiters Casino, Townsville

**17th - 23rd October 2010: Carers Week**

**18th - 19th October 2010: Communities of Practice Conference**

**Phone:** 07 3357 4188

**URL:** [www.ndsqlldprojects.net](http://www.ndsqlldprojects.net)

**Venue:** Sofitel Hotel, Brisbane

**13th - 16th March 2011 11th National Rural Health Conference**

## Important

**Please Put This Date in Your Diary Now!**

**Self Help and Support Groups Awareness Day**

**Thursday 8th September 2011**

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

Please contact Trish at the SHQ Office:

**Ph:** 3344 6919

**Email:** [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)

## Go Green - Read the Screen!

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

We are still happy to send it by post to small groups or individuals who do not have their own computer. Please let us know at 07 3344 6919 or email [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)

If you no longer wish to receive the newsletter we would appreciate hearing from you also. Thank you

## Disclaimer

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

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

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