



# Newsletter December Quarter Issue 4. 2008



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

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

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

## From the President

Sue Smyllie

### President's Report to the AGM, November 2008

Hello all

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

Our committee lost 4 members this year – Cossette Urbani, Opal Ocean, Sharon Neill and Diana East. Diana has served on the committee for 2 years and we are very grateful for the expertise, interest, commitment and humour she has shared with us.

Following the last AGM, the planning session reconfirmed the 2 current projects for 2007-08 - the Mental Health Project and the Deep Democracy project.

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### Values

**Social Justice** – everyone's fundamental right to equal well being regardless of race, culture, gender, age, income or geographic location.

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

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

### Principles of Practice

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



**The Management and Staff of Self Help Queensland  
Thank You for Your Support During 2008**

**We Wish You All a Safe Holiday Season  
and a Very Happy 2009**

**(The SHQ office will close on Friday 19th December 2008  
and re-open on Monday 19th January 2009 )**

**HAPPY  
2  
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9**

## Self Help Queensland Management Committee Members

President	Sue Smyllie
Secretary	Thea Biesheuvel
Treasurer	Kathleen Zarubin
Members	Alan Noller Joe Soda Bob Wyborn

## Committee Meetings

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

## Project Officer

Trish Fallon

## Mental Health Project Officer

Diana East

## Administration Officer

Janice Nankivell

## Office

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

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

## Office Location:

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

## Postal Address

P.O. Box 353, Sunnybank QLD 4109

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

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

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

## Self Help Leaders Online Social Network

**URL:** [www.selfhelpleaders.ning.com](http://www.selfhelpleaders.ning.com)

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



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## Advertise your Group's 2009 Conference or Special Event in this newsletter's "Diary Dates" P 26

Closing dates are first day of February, May, August & November

**Ph.07 3344 6919**  
**or [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)**

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

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.

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**The Deep Democracy Project** is aimed at providing the opportunity for the community sector to take some positive steps towards strengthening our relationships, links and networks through conversation, show some leadership and explore highly communicative relationships, getting to know each other, sharing our issues, challenges and disappointments – not just once but regularly and sustainably.

This year the project again took the form of providing the opportunity for some free training for the sector. The funds were provided by the Brisbane City Council. As the sector had requested some leadership development, Dr Liz Mellish a Certified Management Consultant ([www.mellish.com.au](http://www.mellish.com.au)) and consultant to government, was engaged. Liz has developed *Appreciative Inquiry* learning modules available at [www.aileadership.com](http://www.aileadership.com).

Over 30 people attended Session 1 and feedback has been extremely positive. Participants particularly enjoyed meeting representatives of other groups and a website has since been developed by Jeannie May to help the sector share information and learning around this topic ([www.selfhelpleaders.ning.com](http://www.selfhelpleaders.ning.com)) Session 2 will be held in the 2008-09 financial year.

**The Mental Health Project** had an unexpected boost with some \$300,000 in funding being supplied by Disability Services Queensland. Diana East was appointed as the Project Coordinator and has done a great job in getting the project off to a flying start. SHQ will evaluate this project rigorously to determine if there are any learnings which could help to inform policy for small grants and capacity building programs for the sector. Please take the time to read Diana's project updates in the SHQ newsletter as they continue to be very exciting.

**The Directory** is due to be updated and SHQ is in the process on engaging some

assistance for this activity to be completed in 2009.

As always our day to day work continues in and around project activity. SHQ has responded to over 1600 requests for assistance, attended 94 networking, and support meetings met our quality management and accountability processes and produced 4 newsletters. The number of requests for information about groups has dropped a little due to the production of the Directory. However, as genetic testing has increased the discovery of new diseases, the nature of many of the requests has become more complicated. Longer and more circuitous routes are often undertaken in order to come up with the desired result.

I would like to welcome a new member of staff, Janice Nankivell who will be assisting in the office for two days per week commencing today. Janice's presence will make a big difference in handling the increased administrative requirements of our growing organisation.

I would like to acknowledge the commitment and support provided by our committee members – Bob Wyborn, Thea Biesheuvel, Dianna East, Kathleen Zarubin, Cossette Urbani, Opal Ocean and Sharon Neill in 2008. Many thanks particularly to Bob, Thea and Diana for their extra efforts during trying times and to Trish for ensuring our task would be as easy as possible and to Jill Metcalf who stepped in to help when it wasn't easy. We would be lost without the expertise of our treasurer, Kathleen, who comes to the fore each year working with the auditor to produce end of year financial accounts according to the various requirements of the funding bodies.

A special thank you to Dr Kim Summers, Scotland, for her continued support of SHQ through the quality articles she provides for the newsletter each quarter, and to all the other contributors who help make the newsletter such a success.

The committee at SHQ(Continued on Page 4)

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would like to thank all those who have supported us during the year and provided assistance to those we refer to them - Queensland Health for continued funding support, website designers "Glass Obelisk", DOTARS, for Directory Project assistance, Hartmann Wilson Accountants for the audit, Ros Beveridge of Handlyn Financial Services for Bookkeeping, Brisbane City Council for a funding grant and low cost rent, and Disability Services Queensland for the Mental Health funding grant.

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

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

**Sue Smyllie**

**President 11.11.2008**

### Heard of the SAD Group?

The Southside Anxiety Disorders Group (SAD Group) hold their support group meetings on the 2nd and 4th Thursdays in each month, from 10:00AM - 12:00 Noon at the Mt Gravatt Community Centre, 1693 Logan Rd, Mt Gravatt.

The group is for people who are suffering with anxiety disorders, and their support persons.

For further information, please phone Kevin on 0407574739, a/h 38070228 or email: [kevinrobins@iinet.net.au](mailto:kevinrobins@iinet.net.au)

### Please Help Us

Please help us save valuable resources by receiving the newsletter by email.

Don't worry if you have already contacted us about keeping up with the posted version - that's fine.

We would just like anyone who is happy to receive it by email to contact us at:  
Ph: 07 3344 6919  
Email: [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)

## Health information for women and health professionals



No matter how simple or complex call the Health Information Line at Women's Health Queensland Wide Inc (Women's Health) or 'Ask a Health Question' via [www.womhealth.org.au](http://www.womhealth.org.au)

### Our nurses/midwives can answer your health questions on:

- periods
- endometriosis
- menopause
- depression
- sexual health
- incontinence
- fertility
- pap smears
- pregnancy and much more

### Reasons to contact us:

- assist health professionals with information provision to female clients
- qualified nurse/midwives
- confidential free service
- unlimited call time
- ask a Health Question via website
- holistic and non judgmental service philosophy
- comprehensive statewide referral database
- understanding of women's health needs

Women's Health Queensland Wide (Women's Health) is a not for profit, health promotion, information and education service for women and health professionals throughout Queensland.

For more information visit:  
[www.womhealth.org.au](http://www.womhealth.org.au)

# Genetic Matters

by Kim Summers PhD

## Just Cloning Around

February 2008 was the 10th anniversary of the introduction of Dolly the cloned sheep to the world. Dolly, who died a few years ago, is preserved in the Museum of Scotland in Edinburgh and has become the number 1 attraction of the museum. Dolly was significant because she was the first mammal created from the genetic material of an adult animal and hence almost identical to her donor.

The word "clone" comes from the Greek "klon" meaning twig or slip. It was originally used in biology more than 100 years ago to describe a plant created from a cutting ("slip"), which would be identical to the parent plant. It was adopted to describe cells in a test tube which are derived from a single parent cell (so are identical to it – cellular clones). More recently the term has been applied to stretches of DNA which have been copied to a high number in the laboratory (molecular clones). But the clones which are raising issues today are reproductive clones: identical copies of a whole individual.

Reproductive clones are produced by taking the nucleus of one of the individual's cell and inserting it into an ovum which has had its own nucleus removed. The nucleus contains almost all of the genetic material of the individual, the DNA. In theory the nucleus has the capacity to create an identical copy of the donor. The ovum with the inserted nucleus is then allowed to develop. If implanted into a surrogate mother, it can result in a pregnancy and delivery of an infant whose DNA comes from the donor.

Since the breakthrough production of the most famous clone, Dolly the sheep, reproductive clones have been made for a wide range of mammals including mice, pigs, cattle and cats. The success rate is very low – in producing the first cloned cat over 200 embryos were crea-

ted for one liveborn kitten. The cloned creatures often do not survive, are born with abnormalities or live shortened lives. This may be related to irreversible aging processes affecting the donor nucleus which often comes from an adult.

The cloned animals are not identical to the donor, for a number of reasons. There is a small amount of genetic material which is not in the nucleus, and in a clone this material comes from the ovum. Other processes which affect one of the two DNA copies can change the characteristics of the clone. The nucleus donor of the cloned cat was tortoiseshell (patches of tabby and orange) but the clone is all tabby. Some characteristics are not due solely to genes and how the offspring develops depends on external factors such as the environment pre- and post-birth.

Clones of humans might offer the promise of replacement parts, cells or organs which could be created from cloned cells in the laboratory (*in vitro*) and transplanted to replace diseased cells without the risk of rejection. This would also overcome the shortage of organs for transplantation.

Currently the technology to grow cells and make them convert into particular types is being developed. These cells might be used to replace damaged spinal nerves in paraplegic patients, to reseed the heart with healthy cells after a heart attack, to populate the liver in an individual with advanced cirrhosis, or to replace damaged brain cells in Parkinson or Alzheimer disease. Unfortunately, to create these replacement cells, an early stage embryo must be created and then destroyed to extract the critical cells.

The ethical issue involved in creating a potential life to destroy it make many in the scientific as well as general community uncomfortable. But the promise of safe, healthy replacement cells holds out hope for people suffering incurable diseases, and research will continue on how to cause the (Continued on Page 6)



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cells to develop into the specific type, or even to form a whole tissue or organ.

If we can clone humans (and it hasn't been done yet in the laboratory), it raises even more ethical issues. Why would anyone want to clone a human? The organs in the clone would take years to develop to a size which could be used for transplants, so it would not be a short term solution to kidney or liver failure. Removal of the heart and many other organs would result in death of the clone, and the clone could not legally be a source of spare parts.

Some people might want a clone to replace a dying relative. But the clone would not be physically or behaviourally identical to the donor, for the reasons outlined above, both social and biological. Identical twins are natural clones who are genetically more alike than artificial clones would be, and yet they are not the same as each other. Because of the low success rate of cloning, it is likely that many embryos would be created to result in a single full term pregnancy, which is unacceptable to many people.

The company that cloned the cat tried to make a profit by creating clones of treasured pets but was unable to sustain a viable business. They created two cat clones for \$US50,000 but were never able to clone dogs and went out of business at the end of 2006.

Clones of agricultural animals, made by splitting early stage embryos (similar to identical twins) have had some success and nuclear transfer clones have now also been produced commercially. These clones cost about 8 times as much to produce as normal breeding (about \$US15,000 per animal), so they are created from highly desirable parent animals, to be used as sperm and ovum donors. Herds of cloned cattle won't be roaming the fields at those prices. But our own backyards contain hundreds of clones: every time you snip a piece off a neighbour's plant and get it to grow in your own garden you are cloning.

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

## Office Equipment to Give Away!

Better Hearing Australia have generously offered some no longer needed office equipment to support groups.

**1 Projector Screen ( for wall mounting) in Metal Case.**

**1 Microphone Stand**

Please contact Better Hearing Australia  
Brisbane, WEST END Ph: 07 3844 5065

## More Office Equipment to Give Away!

Self Help Queensland has some office equipment to give away to member self help support groups.

- Very heavy duty, commercial guillotine \*Heavy to lift!
- Heavy duty, commercial thermal binder
- Very heavy duty commercial laminator \*Heavy to lift!
- Very heavy duty stapler
- OHP Older type, used
- Smaller document binder
- 4 hole punch

**(None of the above come with any instructions!)**

- OHP - brand new - still in box
- Breville Espresso/Capuccino Maker - new - still in box
- Computer & Printer oldy but goody
- Computer desk/chair Good condition

**If you are interested in any of these items please contact Trish at SHQ by phone on 07 3344 6919.**

(SHQ closes for the holiday break on 19th December and we would appreciate if all items could be picked up before then if possible. Thank you.)



# Rett Syndrome

## - a Queenslander's Story

My name is Heather Jennings and my 13 year old daughter has Rett Syndrome.

Rett Syndrome, a debilitating genetic disorder, is the second most common form of severe mental retardation in females. It affects one in 8,500 births by the age of 15 across Australia. Girls that are less affected are often diagnosed initially with Autism, while those more severe are often diagnosed with Cerebral Palsy.

Affected girls, known as 'Silent Angels', develop normally for the first six to twelve months of life. Then, development stops and even reverses. The disorder results in severe disability and for most, impairs speech and mobility.

The diverse and multiple nature of the disabilities suffered by the girls includes:

- Mobility problems
- Osteoporosis
- Spinal curvature
- Digestive disorders
- Epilepsy

These girls often require major surgical interventions, in particular corrective spinal surgery. In fact the care required for a young woman with Rett Syndrome has been compared to that required for a person with high-level quadriplegia.

- Most girls need assistance for all activities of daily living such as feeding, dressing & toileting.
- 25% of all girls may never walk at all, and about half of those who do walk will lose the ability at some time.

- 80% have epileptic seizures, which can be mild to severe.
- 100% are at risk of some degree of curvature of the spine.

Our Scientists here in Australia are working together with other scientists around the world in order to find a cure.

## Rett Syndrome Australia Research Fund

### "Your Help is our Hope"

The establishment of the Rett Syndrome Australian Research Fund 13 years ago has enabled this research in Australia to go from strength to strength and your help in raising funds today will help us to maintain that momentum.

Since our formation, our Australian Research Team led by Professor John Christodoulou, has established the capacity to identify mutations in the Rett gene, which allows an earlier diagnosis, and to reassure family members with regards to their genetic risks. This is now offered as a nationwide diagnostic service.

In addition, eight years ago the clinical team also established the first multidisciplinary clinic in Australia specifically designed for girls and women with Rett syndrome. The clinic is staffed by doctors, genetic counsellors, dieticians, physiotherapists, occupational therapists, play therapists, dentists, and orthotists, and offers a comprehensive service to anyone with Rett syndrome who lives in Australia.

In 2004 our research team had a major breakthrough when they discovered the second gene responsible for Rett syndrome. It was like winning lotto as medical breakthroughs don't come often and we were proud to have witnessed one here in Australia and to have provided the funding that made it possible. (Mutations in this gene have also been found in at least one individual with autism.)

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Since the discovery of the main gene responsible for Rett Syndrome there has been intense research interest around the world. Until recently it was felt that the brain defects in Rett syndrome were permanent.

However, in 2007 stunning research from the UK showed that in a mouse model for Rett syndrome, the changes in brain function may be reversible.

"The successful restoration of normal function demonstrated in the mouse models suggests that we may be able to reverse neurological damage in children and adults with Rett, autism and related neuropsychiatric disorders" Huda Y Zoghbi M.D. Baylor College of Medicine.

This has led to hope that it may be possible to develop specific treatments for Rett syndrome that will one day lead to a cure for this devastating disorder. The research efforts of our Australian Research team for Rett Syndrome Research are focused on understanding the biological function of the genes associated with Rett syndrome; with the primary goal being to one day develop a cure.

Gene chip studies performed on tissues from patients with Rett syndrome and in a mouse model of Rett syndrome by our Australian team have been able to identify several genes which could potentially regulate essential brain function. To confirm these findings, our researchers are currently investigating whether there is a direct interaction between the main Rett gene and these other genes. Once confirmed, Professor Christodoulou will go on to study the functional consequences of the interaction using a combination of sophisticated techniques on cultured cells both from patients and mice, and perform behavioural activity studies on our Rett Syndrome mouse model.

If any of these therapies are proven to be safe and effective in the mouse model, then their plan would be to quickly move into carefully designed

clinical trials in patients with Rett syndrome here in Australia. Our research team's ultimate goal is to implement effective treatments that can reverse, slow or even prevent the development of the devastating neurological abnormalities associated with Rett syndrome.

Our long-term dream is that some day we may be able to have newborn screening for Rett syndrome, and then be able to start preventative treatments even before the girls show any signs of the disease. This is still a number of years off, but with the support, both financial and moral, provided by functions such as this brings us closer to our objectives.

Kate is non verbal; she is still mobile but is slowing down now. She needs to use a wheelchair for outings and moving around school. She has digestive disorders that require her to be on a gluten and dairy free diet. She needs to be bathed, dressed and fed and needs full-time supervision and care 24/7.

However she is as bright as anyone her age. She communicates with a communication device, is in a mainstream class in our local College with a full time teacher aide provided by our family and is doing the same curriculum as her peers. She has often typed that she hates her body and that it lets her down.

I am proud to be associated with the Rett Syndrome Research Fund as the Queensland Representative.

November the 24 - 28 is Angel Week and we will be selling our merchandise at Ed Harry and Mr Minit Stores as well as selected Curves Women's Gyms. The merchandise is available from early November through to the 31 December and all proceeds go directly to Research so please consider purchasing one of our Angels. Most Mr Minit stores will engrave the Christmas Decorations for free during Angel Week.

Also I run an ongoing fundraising activity where I collect old and dead mobile

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phones for recycling with all money going to research so if you have any old phones please contact me and I would be happy to arrange for them to be collected.

To find out more information about Rett Syndrome, the research work and Angel Week please go to:

[www.rettsyndromeaustralia.org.au](http://www.rettsyndromeaustralia.org.au)

or contact Heather direct at:

[cure4rett@yahoo.com.au](mailto:cure4rett@yahoo.com.au)

or phone 0403 99 31 81 and leave a message and I will return your call.



## The Meditation Society of Australia

Free Meditation Online

The Meditation Society of Australia offers a free online meditation course with guided exercises, music and podcasts. You can take your own time learning to put the lessons into practice. The site also offers online forums, meditation support groups and resources.

It is a non-denominational community organisation with no religious, political or financial affiliations. It exists to help people to learn to mediate.

The free, online course features a written step by step guide for people learning to meditate. There are 33 classes available at present, with more to come. eg Class 1 covers the following:

- Learn how to meditate
- Establish a regular, daily meditation practice
- Practice the basics of concentration and meditative breathing techniques

Each class includes a free radio quality audio recording of the discussion topic and a guided meditation exercise that you can download and play (these are also available as podcasts). Everyone can access the written classes. To access the downloads you need to be a member. (Membership is free) Go to: [www.meditation.org.au](http://www.meditation.org.au)



## Care Leavers Australia Network

*A network for people who grew up in Australia's orphanages, Children's Homes & in foster care.*

2009

**United Nations**

### **International Year of Reconciliation**

CLAN holds the hope that the Australian Federal Government will issue an apology in 2009 as was the \*No 1 recommendation of the 2004 Senate Enquiry Report. Forgotten Australians: A report on Australians who experienced institutional or out-of-home care as children.

#### **\*Recommendation 1**

**7.110 That the Commonwealth Government issue a formal statement acknowledging, on behalf of the nation, the hurt and distress suffered by many children in institutional care, particularly the children who were victims of abuse and assault; and apologising for the harm caused to these children.**

If you were a state ward, home child or foster child, grew up in an orphanage, a children's home or institution, or if your parents grew up in a home, then CLAN can offer you the following support:

- telephone support
- socials in all states
- reunion support
- bi-monthly newsletter
- help to obtain your Ward/Home file
- help to write your personal story
- free advertising in the CLAN newsletter to locate lost family members or Home friends.
- advocacy and lobbying on issues relating to care leaver services in all states so that we do not remain Forgotten Australians.

Ph:02 9709 4520 Mob: 0425 204 747

Email: [support@clan.org.au](mailto:support@clan.org.au)

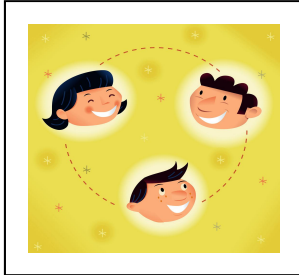
Website: [www.clan.org.au](http://www.clan.org.au)

Contact CLAN free on: 1800 008 774

## Self Help Queensland and Mental Illness Fellowship NQ

### TOWNSVILLE MENTAL HEALTH SELF HELP SUPPORT GROUP CONSULTATION

MONDAY 8TH DECEMBER 2-4PM



Community-based mental health self help support groups can play a major part in aiding individual recovery and in developing resilience in the community. The 'Mercury Rising' project (Funded by M H Branch DSQ) is looking at how development of these groups can be encouraged and supported with the ultimate aim of developing a sustainable network of community-based support groups that meet the needs of people in North Queensland.

*Mental health self help support groups bring together groups of people who share a common desire to find a mutually supportive environment to increase their wellbeing and assist their recovery process.*

Key features are that:

- Members give each other emotional support
- Experiential knowledge is highly valued
- Groups are flexible and relevant
- Members may also be involved in information, education and social advocacy
- Number of members varies widely between groups

For this project self help groups are those with a strong community focus both in terms of their initiation, facilitation and management. They are not professionally-led therapy groups.

Self Help Queensland and the Mental Illness Fellowship of North Queensland want YOUR views on how we can:

- Better support the development of such groups
- Support those groups currently in existence
- Provide supports that ensure that groups can develop in a sustainable manner

You are cordially invited to meet with us to look at how we can assist the further development of such groups in North Queensland.

Date: Monday 8th December

Time: 2pm (to finish by 4 pm)

Venue: TBC

RSVP: Andy Froggatt at [andyfroggatt@mac.com](mailto:andyfroggatt@mac.com) or on 0423 053057



## Australian Online Parenting Forum a Winner

Essential Baby is an Australian website which hosts the largest and most active parenting forum in Australia with an average of 1500 members online in peak times.

The traffic on the site is an indicator of its popularity, and the experience has been described by participants as "like being with a group of friends".

Forums are supported by a team of 35 moderators who help to oversee more than 10,000 posts per day.

### Forums and Sub-forums

Forums and sub-forums include categories such as:

- Housekeeping
- Hotspot
- Meet other members
- Conception
- Pregnancy
- Miscarriage, Stillbirth and the Loss of a Child
- Your Birth Experiences
- Tips and Questions
- Parents Room
- Parent's Groups
- Babies
- Toddlers & Kids
- Daycare, Pre-school & School
- Parties and Special Occasions
- Hobbies and Crafts
- Health
- General
- Shopping
- Lifestyle & Entertainment
- Essential Work

Essential Baby joined the Fairfax Digital network in January 2007 to ensure the the longevity of the site in the future.

Web: <http://www.essentialbaby.com.au>

## Essential Baby Includes Rare Syndromes/Diseases Online Support Group

For mothers of children suffering from rare genetic disorders, rare syndromes and rare diseases, it is often very difficult to find others in a similar situation.

Essential Baby offers a forum for mothers to make contact with other mothers whose children have similar conditions.

Mothers are able to provide emotional support to each other and share practical ideas and information about day to day issues - often helping break down feelings of being alone or isolated.

### Some of the more recently discussed conditions have been:

- Sacrococcygeal teratoma
- Wolf-Hirschhorn Syndrome
- Late Infantile Batten Disease
- N-B CIE Ichthyosis or non bullous Ichtyosiform erythroderma
- Juvenile Xantho Granuloma
- Mastocytoma
- Dandy Walker Malformation
- Cerebellar hypoplasia
- Acrodermatitis enteropathica (AE)
- Persistent Hyperplastic Primary Vitreous (PHPV)
- Haemophilia b
- Haemophilia c

<http://members.essentialbaby.com.au/index.php?showtopic=96193>

**"Mutual help groups are a powerful and constructive means for people to help themselves and each other.**

**The basic dignity of each human being is expressed in his or her capacity to be involved in a reciprocal helping exchange. Out of this compassion comes cooperation. From this cooperation comes community."**

**Phyllis Silverman, PhD  
Dept of Psychiatry  
Harvard Medical School  
(From Introduction to the "Self-Help Sourcebook," 1995, p. 24.)**

**A tribute to all the Grandmas and Grandpas who have been fearless and .....have learned to use the Computer.**



Author unknown

The computer swallowed grandma.  
Yes, honestly its true!  
She pressed 'control and 'enter'  
And disappeared from view.

It devoured her completely,  
The thought just makes me squirm.  
She must have caught a virus  
Or been eaten by a worm.

I've searched through the recycle bin  
And files of every kind;  
I've even used the Internet,  
But nothing did I find.

In desperation, I asked Mum  
My searches to refine.  
The reply from her was negative,  
Not a thing was found 'online.'

So, if inside your 'Inbox,'  
My Grandma you should see,  
Please 'Copy, Scan' and 'Paste' her  
And send her back to me.

## 2 Australian Families with Rare Genetic Condition linked via USA Association

As far as Self Help Queensland is aware, there is no national support group in Australia for a rare genetic condition called Lowe Syndrome.

Thanks to the Lowe Syndrome Association in Dallas, TEXAS, two Australian families with Lowe Syndrome were connected with each other this year.

If other families in Australia are looking for similar assistance just go to the LSA website and there is page where you can direct an email enquiry.

Debbie Jacobs, President  
Lowe Syndrome Association  
Web: [www.lowesyndrome.org](http://www.lowesyndrome.org)

## Carers of People with Dementia needed

### - for Sleep Research Project

The purpose of this project is to trial an information package designed to help carers of people with dementia, who live in the community, to prevent sleep loss and manage sleep problems.

The project is funded by the Queensland Nursing Council. The funding body will not have access to personally identifying information about you.

The research team is looking for people who live with and care for people with dementia at home, who also have noticed changes in their normal sleep patterns since commencing caregiving. You must also have been the primary caregiver for longer than six months. If you routinely take sleep medication or have been diagnosed with certain sleep disorders such as sleep apnoea, you may not be able to participate and will need to discuss this with the researchers.

Your participation will involve completing a questionnaire which asks questions about your sleep and lifestyle patterns and those of the person you care for. There are also questions about your sleep, fatigue and stress levels and some of your thoughts and feelings about sleep in particular. You can complete the questionnaire in your own home, with a researcher assisting you over the phone, when it is convenient for you to do so.

Your participation will also involve you receiving a package of information about sleep. A researcher will call you three or four times during the trial period to answer any questions that may arise, and to ensure the package is understandable and usable. For further information or registration contact:

Dr Sandy Sacre, Senior Research Fellow  
Phone: 07 3138 3022  
Email: [s.sacre@qut.edu.au](mailto:s.sacre@qut.edu.au)

Please contact us by the 31st of January



**The Myositis Association-Australia Incorporated was formed to:**

1. Provide an association where people suffering from the same condition can come together, exchange ideas and gain help and assistance from other members.
2. Promote Myositis awareness to the general public
3. Work towards establishing Research Grants

In this regard the Myositis Association has established groups in NSW, Vic., ACT, Qld, and W.A. which hold functions during different times of the year. The Association also has a newsletter which is mailed to all members. It contains details of functions, members' stories, network contacts and other useful information to assist those with Myositis. The cost of membership of the Association is \$5.00.

The main objective for next year is to hold a National Myositis Awareness Week commencing 21<sup>st</sup> September to co-incide with National Days being held in America and the U.K. Functions will be planned for most of the States of Australia to help raise the awareness of Myositis both in the community and the medical profession.

**What actually is Myositis?**

Myositis is the general term used to describe inflammation of the muscles. Dermatomyositis (DM), Polymyositis (PM), Inclusion-Body Myositis (IBM), and juvenile forms of myositis are all considered inflammatory myopathies. Inflammatory myopathies are diseases where there is swelling and loss of muscle. Inflammatory myopathies are thought to be autoimmune diseases, where the body's immune system attacks normal, healthy tissue. Inflammatory myopathies are considered rare and in Australia the Association knows of approximately 500 people, but there are probably a lot more.

**There are 4 main types of Myositis**

**Inclusion-body Myositis (IBM)**

Inclusion-body myositis is found in more men than women. Signs of IBM usually start after age 50. IBM progresses more slowly than the other types of myositis as weakness happens over months or years. Most muscles are affected, including neck, hip, back, shoulder, wrist and finger muscles. Many IBM patients notice shrinking, or atrophy, in the arms and thighs as the muscles become weaker. Dysphagia is a common problem for IBM patients. Weakness of face muscles is sometimes seen.

**Juvenile Myositis (JM)**

Juvenile forms of myositis are found in children younger than 18. Juvenile dermatomyositis (JDM) is the most common and affects 3,000 to 5,000 children in the United States. Polymyositis in children is very rare. Signs of JM may include the [DM] rash, falling, weak voice, or problems swallowing. About half of the children with JM have pain in their muscles. Some children may have calcinosis or contractures. Contractures happen when the muscle shortens and causes the joint to stay bent.

**Dermatomyositis (DM)**

Dermatomyositis affects people of any age or sex, but is found in more women than men. DM is the easiest type of myositis to diagnose because of its visible skin rash. The DM rash looks patchy, and reddish or purple. It is found on the eyelids, cheeks, nose, back, upper chest, elbows, knees and knuckles. Some people also have hardened bumps under the skin, called calcinosis. The rash is often seen before muscle weakness is felt.

**Polymyositis (PM)**

Polymyositis is found mostly in people over the age of 20. More women than men have PM. PM does not cause a rash. Muscle

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weakness usually happens over days, weeks or months. The weakness begins with muscles closest to and within the trunk of the body – neck, hip, back and shoulder muscles. Some patients also have weakness in muscles farther from the trunk, like hands and fingers. Many PM patients have trouble swallowing (dysphagia). Some have trouble breathing and experience muscle pain.

### **Some of the symptoms, which can also mirror other conditions**

- Muscle disease patients may mention “heaviness” of limbs or inability to perform tasks eg getting out of a chair or up stairs.

### **What Doctors look for:**

- Appearance of patient - syndromes like Cushings, myxoedema, rashes
- Muscle bulk - is there wasting?
- Strength - esp. practical things - stand up, stand on toes, get on bed
- Symmetry
- Reflexes and sensation

### **How is it diagnosed?**

A muscle biopsy to determine the type of Myositis that you could have.

### **What is the treatment?**

- “Standard” treatment - high doses of steroids until CK (blood test to determine muscle activity) is normal and strength improved then reduce (many side-effects)
- Patients with poorer prognosis, or at special risk of side-effects or have failed steroids receive methotrexate or Imuran with prednisolone
- Others- IVIG, cyclosporine

There are other drugs being trialed, but as they were for other conditions like rheumatoid arthritis eg Enbrel, cannot be used for Myositis due to the cost.

For Polymyositis and Dermatomyositis the above drugs can bring it under control. Currently there is no cure for any form of Myositis. There is no known treatment or drugs for Inclusion Body Myositis.

If you would like any further information on the Myositis Association in Australia please contact the Secretary:

Anita Chalmers,  
14/10 Albany Lane, BERRY NSW 2535  
Phone 02 4464 2043,  
Email: [geoffandanita@ihug.com.au](mailto:geoffandanita@ihug.com.au)  
Website: [www.myositis.org.au](http://www.myositis.org.au)

### **Disclaimer**

**This article is only a “layman’s” guide to Myositis and if anyone has any concerns regarding their health they should contact their medical practitioner.**



## **Autism Research Study**

### **2 ways Parents can be Involved**

My name is Karen O’Brien and I am a PhD student at the University of Queensland undertaking autism research. I would be very thankful for parents’ participation.

For my PhD I would like parents of Queensland children aged 4 - 12 to participate in an online survey asking about their child's play behaviour. Please go to <https://surveys.psy.uq.edu.au/asdplaybehaviour.survey>

I would also like to test children aged 4-12 who have a diagnosis of an autism spectrum disorder. The testing session is a fun one on one interaction and includes testing your child’s verbal and cognitive skills as well as using the Autism Diagnostic Observation Schedule (ADOS) the gold standard tool for autism diagnosis.

### **Parents will receive a written report of the results of the study.**

This study aims to understand autism and the role families play in the development of cognitive and social skills in children with autism.

To participate or receive further information please contact Karen at UQ:  
Email: [k.obrien@psy.uq.edu.au](mailto:k.obrien@psy.uq.edu.au)  
Ph: 07 3346 7326  
Call/text: 043 0063 355

## Mental Health Support Groups: Building Relationships that Assist Learning and Recovery

by Diana East

*"It is within these groups, whose members share common concerns, that (people) are offered an important aid to recovery, the understanding and help of others who have gone through similar experiences". (C. Everett Koop, Surgeon General U.S. Public Health Service, 1988)*

*"Without dialogue, without a truly sensitive and truly human relationship, there can be no inspiration, no teaching, no learning, no communion." (Sulak Sivaraksa: A Buddhist Vision For Renewing Society)*

Numerous studies clearly reveal that having access to a safe, high-quality mental health support group means that a person living with a mental health condition, who chooses support from others with a direct experience of the condition, can achieve sustainable improvements in their social and emotional wellbeing and their whole recovery journey.

While no two mental health support groups are exactly alike they mostly fit within one of the following models:

- groups where the participants all have the lived experience of mental illness and run the group on their own
- groups that are led by an empathetic professional or community volunteer
- groups that are co-led by a professional or community volunteer and by a self-helper

Clearly, in the latter two instances, some very successful mental health support groups work in close cooperation with a professional or community volunteer who can 'blend in' by relating as an equal with the members. They may fill the role of facilitator/co-facilitator and/or fulfill some admin-

istrative tasks whilst ensuring that, at all times, the ultimate responsibility for group management lies with the participants.

I have had the personal experience of being such an 'external' facilitator for many years of Myriad, a support group for women with MPD/DID, and have had numerous discussions with members about what works/does not work for this group. The following comments are distilled from these discussions and I thank those Myriad members who have shared their insights about the group and thus contributed to the writing of this article.

Members agree that Myriad demonstrates how a support group can play a very effective role in promoting healing and recovery with the key to success being the quality of the relationships which develop between each member of the group. For Myriad members, the sharing of experiences and expertise, the gaining of hope and motivation, learning and developing more effective coping mechanisms greatly assists their recovery journey.

Myriad is a mental health support group that promotes learning and recovery by focusing on:

- The establishment of a safe, non-traumatic, nurturing environment
- Forming positive, accepting relationships and working together as a team
- Identifying and discussing individual and collective strengths
- Increasing the range of coping and problem solving skills and the capacity to tolerate a variety of feelings, memories and experiences
- Developing positive self-esteem and self-acceptance
- Building social connectedness and helping members to fulfil their familial and social interpersonal relationships
- Developing links to appropriate community resources

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- Raising awareness and providing education about DID.

It is based on principles of personal empowerment, self-help, equitable access to information, networking and self-responsibility and emphasises the value of using the diversity of perspectives and richness of knowledge within the group.

The facilitator's role is to:

- Ensure the environment is safe, non-traumatic, non-judgmental, nurturing. This is a must.
- Assist the group to work through issues such as safety, crisis procedure, etc.
- Assist the group to establish and adhere to a set of "guidelines"
- Help members to feel comfortable in the group and assist everyone in having the opportunity to be heard
- Have an empathic attitude, a sound knowledge base about DID and creativity
- Provide some level of structure around the meeting process by keeping a watchful eye on group dynamics and maintaining healthy group processes while surrendering control to group members
- Work towards self-empowerment of all members
- Act as advocate for individual members
- Provide some out-of-hours support to individual members, particularly around issues which have arisen in the group
- Process new referrals and form a positive, accepting alliance with new members before they are introduced to the group
- Promote the group and maintain networks with other allied organisations

Members participate in the group at their own pace and their own chosen

level. They are encouraged to take responsibility for their own actions and feelings, to be non-judgmental and respect confidentiality, to share and learn from each other. Each person's feelings, thoughts, needs and life journey are appreciated, responded to, respected and cared about. Advice is not offered but members share their experiences, thoughts and learnings about the issue under discussion. It is not about coming to the group asking to be made well but coming to listen and speak and be a mutual support to each other.

In the words of one group member, "I found people who spoke my language, who totally accepted me. I felt that I had come home at last... We meet on a regular basis and share our experiences...and we learn to trust and feel safe again. Most importantly we learn to nurture and love ourselves through the support, the acceptance and the understanding offered."

Another member states, "They care about my needs, my pain, my happiness and my well-being. I have never before been able to trust at the level I do in this group. Because I have been so loved and respected I have learned to love and respect myself and my self-esteem is higher now than it has ever been. I have learned that I am worth caring for. I have learned to value my feelings, perceptions, needs and judgments. Thus I now take much better care of myself than I ever have. What I have learned generalizes to other parts of my life, freeing me more and more."

The key to the group's success, then, is the quality of the relationships which develop between each member, all of whom are accepted, affirmed and respected. Thus they feel cherished and learn to love themselves. When they love themselves they are then able to extend themselves and grow, emotionally and spiritually. They become learning, growing people.

If people are enabled to feel good about themselves and the group they are in then learning and (Continued on Page 17)

(Continued from Page 16)

personal development will take place. The dynamic factor in learning is not so much knowledge but the quality of the relationships which develop between the group members, the experience of participation in a group where members are affirmed as valuable persons, both as learners and as potential learning resources.

Group members agree that Myriad plays an essential part in their journey to recovery, allowing them to work on healing from childhood abuse and to eventually reclaim their lives. The achievement of Myriad members conveys a very important message to other survivors about recovery, the value of each individual's experiences and the importance of sharing such experiences. They are proving that experience of a severe mental health problem such as DID does not necessarily prevent a person from being a productive and valued member of their community.

Being part of a group such as Myriad, sharing and learning from each other and working collectively on issues, presents a different way of looking at the world. This is the experience of community. When people share experiences (good and bad), pain and hope and dreams, they are part of a community. Community is often seen only in terms of location or culture. For Myriad members, however, the experience of community is much more pervasive as they share experiences and expertise, gain hope and motivation, develop more effective coping mechanisms and become thrivers, rather than mere survivors.

**Diana East**  
**Self Help Queensland**  
**MH Project Worker**  
**18/11/08**

"What really counts in Mental Health Support Groups is focusing on developing right relationships rather than solving problems. Everything else flows from there."

Support Group Facilitator



**Australian  
Human Rights  
Commission**

*everyone, everywhere, everyday*

## **Human Rights Commissioner concerned with discrimination against gender diverse people in Australia.**

On the 10th international transgender day of action (20/11/08) the Human Rights Commissioner, Graeme Innes encouraged Australians to take time to consider the horrors and difficulties that discrimination can inflict upon people who are gender diverse.

Over the last 12 months, the Australian Human Rights Commission has been conducting consultations and research that look at issues faced by the gender diverse communities. This research has focussed particularly on the problems caused when identity documents do not reflect the gender in which a person lives.

**Gender diverse people face difficulties in relation to using and completing identity and other documentation, accessing health services, general discrimination in day-to-day life and a lack of public education and awareness.**

Commissioner Innes said he will soon be releasing a report which will include recommendations for the achievement of greater consistency in tackling discrimination in this area.

"I call on federal, state and territory governments to implement these recommendations and work to minimise discrimination against people who are gender diverse," Commissioner Innes said.

You can receive the latest news and updates on human right issues by subscribing to the free, online Australian Human Right Commission mailing lists.  
**[www.humanrights.gov.au](http://www.humanrights.gov.au)**

## - QHCC say that's a good thing!

The Health Quality and Complaints Commission (HQCC), say their data shows that Queenslanders are driving improvements in their own healthcare.

In the HQCC 2006-07 annual report tabled in Queensland Parliament on 18 November 08, QHCC reported managing over 4500 complaints and enquiries.

CEO Cheryl Herbert said the number of complaints was increasing every year. "This shows that Queenslanders are no longer passive about the standard of care they receive – instead they are aware of their rights, prepared to question and willing to speak out."

The HQCC received almost 1900 enquiries from people with healthcare concerns and managed 2675 complaints. Mrs Herbert said inadequate treatment and communication continue to be the most common sources of complaint.

"Patients or their friends and family can complain about any aspect of healthcare provision, be it at a major hospital, their local GP or an alternative healthcare provider," she said. "We do see common complaints about inadequate treatment, where a patient is not happy with how they have been treated or may have had an adverse outcome.

"Communication is also a big problem, where a patient feels they weren't adequately informed about their care."

To make it easier to complain and improve response times, an easy to use online complaints form is being developed. A member of the complaint team will then follow up.

Established in July 2006, the HQCC is an independent body which has three key functions – managing complaints, monitoring and promoting quality improvement in health services and sharing information.

The HQCC Annual Report 2007–08 is available at [www.hqcc.qld.gov.au](http://www.hqcc.qld.gov.au)

## All complaints closed (by category)

Inadequate treatment 269  
 Communication 216  
 Diagnosis 157  
 Treatment – others 125  
 Unexpected complication 86  
 Coordination of treatment 74  
 Fees/costs/rebates 69  
 Delayed treatment 48  
 Incorrect treatment 48  
 Medication 43  
 Professional conduct 42  
 Discharge/transfer 30  
 Facility Management 29  
 Privacy/confidentiality 24  
 Medical records 22  
 Reports/certificates 20  
 Complaint handling 17  
 Consent 9

## Complaints received (by provider)

Medical Practitioner 401  
 Public hospital 374  
 Private hospital 77  
 Dental 72  
 Public health service 51  
 Allied health 30  
 Other health service 24  
 Aged care 17  
 Pharmacist 17  
 Diagnostic radiology 15  
 Psychologist 11  
 Correctional facility 8  
 Alternative health 7

(Source: HQCC Media Release 19/12/08)

### The Silent Generation

People born before 1946

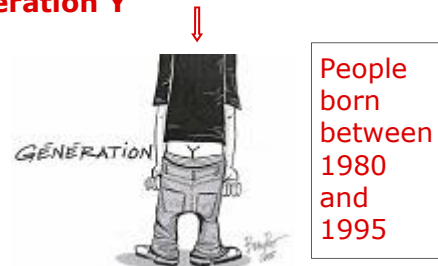
### The Baby Boomers

People born between 1946 and 1959

### Generation X

People born between 1960 and 1979

### Generation Y



Journal de Quebec Mardi 22 Janvier 2008





## Build your own website it's free and it's easy!

ComfyPage was designed by two brothers in Perth, WA. Their office is a cell in an old prison.

Cameron and Andrew wanted to design an easy way to create and operate websites, putting website owners back in control.

ComfyPage is being used by community groups, businesses, clubs and individuals. You are able to select from a range of templates and make changes to the site look and feel as often as you like.

The process is quite simple. First you register (FREE), and then you get taken through an easy setup wizard. You can create your own website in a day.

You get everything you need to build a website and have it live to the world. The basic ComfyPage is free. You can:

- Choose from a wide range of templates
- Customise your own template
- Add as many pages as you like
- List products and services
- Upload files and images.

You can view some websites people have created with ComfyPage eg.

### **West Australian Council of Social Service**

[www.wacoss.comfypage.com](http://www.wacoss.comfypage.com)

### **YSMS Cairns**

[www.ysms.comfypage.com](http://www.ysms.comfypage.com)

### **The Apex Club of Rowville**

[www.apexrowville.comfypage.com](http://www.apexrowville.comfypage.com)

### **Laugh Resort Comdy Club**

[www.laughresort.comfypage.com](http://www.laughresort.comfypage.com)

ComfyPage makes its money by charging for more advanced features called add-ons. There are also some options for including advertising. Some add-ons are free, while others can be unlocked for seven Australian dollars. The following are just a few examples of some of the \$7 ones.

**Accept Donations** - your visitors can donate with a credit card or PayPal account

**Flickr Photo Gallery** - Display a Flickr photo gallery on your ComfyPage

**Thermometer** - If you want to display the progress of a campaign you're running to collect money, signatures, sales or anything else a thermometer style progress meter may be helpful. (See the wacoss ComfyPage for an example of a useful thermometer)

**Run ads** - Run Google ads to make money from your site

**Contact us form** - Include a contact us form so visitors can email you without you having to give out your email address

If you want to try building your own website go to [www.comfypage.org](http://www.comfypage.org)

### **\*Note from the editor**

Self Help Queensland does not recommend private businesses, and does not have any financial arrangements with ComfyPage. We just try to find useful, low cost resources for our members. We heard about the site, and thought it might be helpful for unfunded community groups.

Good luck if you try it. We would love to hear how it goes if you do!

-oOo-

**"If only God would give me some clear sign. Like making a large deposit in my name at a Swiss bank."**

**Woody Allen**

**1935 - ....**

**Actor, Writer, Director**



## Grass Roots Support for Australians with Wegener's Granulomatosis

The Wegener's Granulomatosis Support Group of Australia is a non profit community organisation committed to providing a range of support and information to people with GW, their families and interested health professionals. Education and raising awareness of WG in the general and medical community, as well as supporting research into the cause and finding a cure for GW are also priorities of the group.

Wegener's Granulomatosis (WG) is a rare form of vasculitis which affects approximately one in 30,000 people. The disease characterized by inflammation of the walls of the small blood vessels. This inflammation results in a reduction of oxygen in the blood and damages vital organs of the body by restricting blood flow to those organs and destroying normal tissue. WG primarily affects the respiratory tract (sinuses, nose, trachea [windpipe] and lungs) and the kidneys. This disorder can occur at any age, usually during middle age, strikes men and women equally, and is extremely rare in people of Negroid origin. The cause of Wegener's Granulomatosis is unknown but much research is being done. As of this time no single genetic marker, environmental agent, micro-organism, or other factor can be identified as initiating this syndrome. WG is not contagious and there is no evidence that it is hereditary.

Before the 1960's, Wegener's granulomatosis was almost uniformly fatal (generally between 6 and 12 months), and renal failure was the main cause of death. Corticosteroids (prednisolone) therapy resulted in improvement in some cases, but the overall mortality rate was not altered appreciably. With the use of cytotoxic drugs for the treatment of WG, the course of the disease has been altered favourably.

## History of WG

In 1931, Heinz Klinger at the University of Berlin first reported two patients who died having prolonged sepsis with inflammation of the blood vessels scattered throughout the body. Five years later, Friederic Wegener in Breslau described a distinct syndrome in three patients. These patients were found to have necrotizing (gradually degenerating) granulomas involving the upper and lower respiratory tract. In 1954 seven more patients were described. This resulted in the establishment of a definite criteria for the diagnosis of the disease by Friederic Wegener. Dr Friederic Wegener died in July of 1990 at the age of 83.

## Symptoms

WG can be difficult to diagnose as its symptoms are similar to various other medical conditions. However, a tissue biopsy together with a blood test for ANCA (a specific form of antibodies) can give strong indications of the presence of this illness. Wegener's Granulomatosis is a "multi systemic" condition in that it may appear in different bodily systems in different people at different times. The initial symptoms of Wegener's Granulomatosis are often vague or non specific and frequently include upper respiratory tract symptoms, joint pains, weakness and fatigue.

Each individual will have different combinations of any of the following symptoms:

- pain in the sinuses or ears
- nasal discharge and nosebleeds
- fever and fatigue
- pain in the joints and muscles
- loss of appetite and weight
- skin rash or ulcers
- redness and swelling in the eyes
- chronic cough
- breathing difficulties
- numbness in the limbs
- kidney or liver involvement

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## Treatment

With the appropriate treatment, the outlook is good for patients with Wegener's Granulomatosis.

In most cases, standard therapy consists of a combination of corticosteroids (such as Prednisone) that reduces inflammation and an immunosuppressive drug (cyclophosphamide) that interferes with the abnormal growth of cells.

Prednisone is the most common corticosteroid that is used. It is chemically different from the anabolic steroids that have been used by athletes and is given in doses much higher than the body normally produces. Prednisone is usually administered as a single morning dose in an attempt to imitate how the body normally secretes hydrocortisone.

When the person's illness improves, the prednisone dose is gradually decreased, usually over a period of 3 to 4 months. With further improvement in the disease, the prednisone is very gradually decreased and discontinued completely after approximately 6 to 12 months. When prednisone is taken by mouth, the body stops making its own natural hydrocortisone. As the prednisone dose is gradually reduced the body will resume making hydrocortisone again. Prolonged usage of prednisone may affect bone density, which can lead to osteopenia and osteoporosis. Patients taking Prednisone should have a bone scan done initially and annually thereafter to check for possible osteopenia or osteoporosis.

It is extremely important that prednisone never be stopped or changed suddenly without the knowledge and concurrence of your physician. The body requires prednisone (or hydrocortisone) for its function and may not be able to immediately make what it needs.

Cyclophosphamide (Cytoxan O) is the most commonly used cytotoxic (immunosuppressant) drug. Cyclophosphamide acts principally by destroying the cells that produce antibodies.

Cyclophosphamide may be, but is not always, continued for a full year beyond that point at which the disease is in remission. Current therapy, if possible, is to use cyclophosphamide for shorter and shorter periods so that it is still effective but will not have the side effects that it is capable of. The dose of cyclophosphamide is then decreased gradually and eventually discontinued.

Cyclophosphamide and prednisone are both powerful drugs that suppress the immune system. Although these medications are beneficial in treating Wegener's granulomatosis, patients and their doctors should be aware that the drugs potentially have serious side effects. Careful monitoring by the doctor is very important. Because these drugs suppress the immune system, they can affect the body's ability to fight off infection. Patients should report immediately any symptoms of infection and, specifically, any fever to their doctors. Prolonged use of prednisone can cause weight gain, cataracts, brittle bones, diabetes, and alterations in mood and personality. Cyclophosphamide can cause bone marrow suppression (lowering of blood counts), sterility, hemorrhagic cystitis (bleeding from bladder) as well as other serious side effects.

Other immunosuppressant drugs such as Azathioprine, cyclosporine, methotrexate and Mycophenolate Mofetil (Cellcept) are used, if required, in patients to retain remission after treatment with cyclophosphamide or as an alternative treatment for those who are unable to tolerate cyclophosphamide.

Although certain reports have indicated that trimethoprim-sulfamethoxazole (Bactrim) may be of benefit in the treatment of Wegener's granulomatosis there are no firm data to substantiate this, particularly in patients with serious renal and pulmonary disease.

Bactrim is frequently used to prevent opportunistic bacterial infections. It may also have anti-inflammatory properties that may help control inflammation.

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Bactrim or other formulations are often prescribed beyond remission of the WG to help maintain the disease in remission.

Approximately half of people with Wegener's Granulomatosis may experience relapse of their disease. This occurs most frequently within two years of stopping medication, but potentially can occur at any point, both during treatment or after stopping treatment. Thus, it is extremely important that patients continue to see their physicians regularly, both while they are on these medications, as well as after the medications have been stopped. Even while on medication, many patients are able to lead relatively normal lives and will remain in remission after therapy has been stopped completely.

The Wegener's Granulomatosis Support Group of Australia was established to assist the healing and management of WG by recognizing each person's unique experience, minimizing isolation and maximizing quality of life.

The group has well over a hundred members Australia wide and publishes a quarterly newsletter. The group's committee is based in Melbourne which meets five times a year. Anyone is welcome to attend these meetings.

There are contact people available in most states who are willing to talk with others living with WG. The group also maintains a website.

For further information please contact:  
Wegener's Granulomatosis Support  
Group of Australia  
10 Chessy Park Drive  
NEW GISBORNE VIC 3438

President: Wally Van Dort  
Ph: 03 54281849  
Secretary: Cheryl Van Dort  
Website: [www.wegenersaustralia.com](http://www.wegenersaustralia.com)

\*Disclaimer. This article was contributed for information purposes only. It is not intended as medical or pharmaceutical advice. If anyone has concerns about their health they should consult a medical practitioner.



## Young Widows & Widowers Support Group of Brisbane

The Young Widows & Widowers Support Group of Brisbane is a non denominational self-help group open to those who have been widowed. The Group believes that sharing in a caring environment by people with similar life experience helps ease the pain of grief. The group is open to anyone who is widowed and wishes to become a member however as a guideline 'young' usually means under 55 years of age at the time widowhood commenced.

The objectives of the group are:

- To conduct regular support meetings.
- To provide outreach support by way of a newsletter.
- To provide a network of telephone numbers for members and non-members.
- To facilitate social interaction for members.

For enquiries contact Ellen or Robin on 3376 9545 or 0414 871 461

### Support Group Meetings

Support Group meetings are held on the second Wednesday of each month (except January) at 7.30 p.m. at Rainworth State School, 185 Boundary Rd, Bardon - 1st room on the left at the top of the concrete stairs at the very front of the school.

We have a web site which has just been revamped address is: <http://www.youngwidows.info/>

**"Though I am grateful for the blessings of my wealth, it hasn't changed who I am. My feet are still on the ground. I'm just wearing better shoes."**

**Oprah Winfrey  
1954 - ....  
O Magazine**

## Changing Organisations & Communities...

### One Meeting at a Time

A report on the "Don't Just Do Something, Stand There!" Workshop

By Sue Smyllie

I was very lucky to be the SHQ representative at this workshop. I was particularly interested in going as one of our major challenges at SHQ is how to support system wide development on a very limited budget. Each time we manage to gather groups together we must do all we can to provide opportunities that are not only enjoyable and informative at the time, but also have application **and are applied** -back in the real world—where the optimism and energy developed in workshops is severely challenged by the full on nature of our lives and work.

Sandra Janoff and Marvin Weisbord are internationally known and respected organisational consultants and have worked across sectors including community and fortune 500 companies. They developed and now direct an international non-profit organisation called the Future Search Network. This is a network of 500 practitioners worldwide who use the Futuresearch process across the world. Futuresearch is a 2 day meeting design, a philosophy and a theory of facilitation based on changing the world one meeting at a time. Futuresearch processes have delivered broad commitment to common goals, creative strategies and individual action across a range of communities including Sydney.

The workshop I attended was focused on the theory behind the facilitation principles and the philosophy of futuresearch. The premise was that you can only change the world one meeting at a time..the meeting you're in now may be the only chance you get to make a difference.

Over the next few newsletters I will share some on the ideas and practices

and keep you up to date about how they are or are not contributing to my own practice as a facilitator. I hope you enjoy it and as always I am eager to discuss or run stories of others experiences and practices that they have found helpful.

For this time I thought you might be interested in a practical guide to running meetings that matter....given we all go to so many....wouldn't it be good if they all delivered great outcomes! Next time I'll explain more about the meaning of each point.

#### **Structural Tips for Successful Meetings (Weisbord and Janoff 2007)**

Get the right people in the room for each task. Help groups differentiate functionally, e.g. based on the task. If your goal is fast action, have people with authority, information, resources, skills, and responsibility together.

Be aware that meetings can help or hinder differentiation and integration. How you use subgroups matters. Know your intent when you ask for pairs, trios, groups of six, or whatever.

Use groups based on similarities (expertise, job, department, region, etc.) when it's important to clarify or investigate different perspectives.

- Use mixed groups to integrate where common ground is desired.
- In mixed groups people may find similarities amidst differences.
- In affinity groups people often find differences amidst similarities.
- One skill in getting things done is the ability to differentiate and integrate as needed--to keep doing it, and help others do likewise.

(From the workshop presented by Sandra Janoff & Marvin Weisbord, Co-Directors, Future Search Network In Collaboration with The Australian Future Search Network [www.futuresearch.net.au](http://www.futuresearch.net.au) Macquarie University, Sydney 22-24 October 2008

International Future Search Network 4700 Wissahickon Ave. Suite 126, Phila., PA 19144, +1-215-951-0328 [www.futuresearch.net](http://www.futuresearch.net) / email: [fsn@futuresearch.net](mailto:fsn@futuresearch.net))





## What to do with Unwanted Medicines

How many out-of-date or unwanted medicines are lying in the cupboards in your house? Where are the left over tablets you stopped taking last year?

### Dangers

We all understand the dangers that unwanted medicines in the house pose to children because of the risk of accidental poisoning. However, few of us think about the dangers they can pose to the community as a whole. Medicines past their use-by date may slowly deteriorate and become less effective. Medicines used by someone other than the person for whom they were intended may be unsuitable for that person, or they may interact with their other medicines and cause a harmful reaction.

### Return Unwanted Medicines Project

So, what should we do with our unwanted medicines?

Simply putting them down the toilet or sink or in the rubbish bin is not the answer. Medicines disposed of via the toilet or sink may go through the sewage treatment process unchanged, which can pollute our waterways. Medicines disposed of via the rubbish bin usually end up in landfills, which can pollute our soils and air.

To dispose of your unwanted medicines, simply take them to any pharmacy (it doesn't have to be the one you got them from). The service is free.

The pharmacy will place the medicines in a special yellow container. When the container is full, the pharmacy will arrange for it to be transported to a disposal depot where it will be destroyed in a high temperature incinerator.

### Further information

To obtain a brochure about the RUM project, ring Simon Appel, the Project Manager, on 03 9583 8699 or 1300 650 835, or visit the RUM Project website [www.returnmed.com.au](http://www.returnmed.com.au)

("Medicines Talk" Newsletter Spring 2008 P5)

## Now... a Wiki for Non-profits!

Like its famous forerunner, Wikipedia, there is now a Wiki designed especially for non-profit organisations.

The Queensland University of Technology's (QUT) Australian Centre for Philanthropy and Non-profit Studies (CPNS) has launched the CPNS Wiki. Within the CPNS WIKI are the Developing Your Organisation (DYO) and Developing Your Board (DYB) Wiki pages.

A Wiki is a technology for creating collaborative websites - it allows users to create, edit, and link web pages easily, making it ideal for community websites.

The purpose of the Wiki is to:

- Provide ready access to useful knowledge, resources, and information generated by CPNS
- Provide free access to surveys and diagnostic tools developed as part of the DYB and DYO projects
- Stream audio and video presentations and training aids
- Encourage feedback and foster communication about corporate governance issues in the non-profit community
- Provide links to useful resources and noteworthy seminars, references, developments and news items
- Archive free newsletters from professional firms

By definition, the Wiki is a work in progress; it will build and grow with more input from members of the non-profit community and consultants who work with them. CPNS encourages all those interested in non-profit organisations to access and contribute to the Wiki by visiting: <https://wiki.qut.edu.au/display/CPNS/CPNS+Wiki+Home>

(Source: Philanthropy + Nonprofit matters Page 2 Edition 35 October 2008)

**Mentally healthy people know when to say YES when to say No and when to say YIPEE!**

**Author unknown**

## Report on Review of Organ and Tissue Donation in Queensland Completed

In previous newsletters we have reported on the progress of the Committee looking into Organ and Tissue donation in Queensland.

As promised, we are now letting our readers know that the report has been completed and was tabled in Parliament in October 2008.

The upshot of the report is that the Committee did not identify any convincing evidence that organ and tissue donation rates would improve significantly under a system of presumed consent.

Taking into account federal government policy and funding support to improve rates of organ and tissue donation, along with Queensland based action, the Committee is confident that the number of organ donors in Queensland can be doubled over the next 5 years.

Karen Struthers MP, Committee Chair, wrote "This increase in organ donation should result from better co-ordination of organ donation services and improved clinical practices across the State: improved community awareness of organ and tissue donation; and as a result of family discussion and agreement to organ donation".

The Committee proposes that 80 donors per annum for Queensland is achievable by 2013. In 2007, organs from 39 deceased donors were transplanted to 122 recipients. Given that in 2007 there was an average of 3.3 organs transplanted from each deceased donor, the number of recipients would indeed double by year 2013. This does not include live donor organs eg kidneys. While organ donation rates are low by international standards, Australia's success rates with organ transplantation are among the highest in the world.

**The final report is available on the Queensland Parliament website at: [www.parliament.qld.gov.au/organ](http://www.parliament.qld.gov.au/organ)**

## Advertise Your Group Free!

- or just share your thoughts on Sector issues.

**We'd Love to Hear from Self Help and Support Groups - anywhere - especially those in Regional and Rural Queensland!**

Please let us know what is happening in the Sector in these areas so we can tell others.

Tell us about the good things you are doing, or just advertise your group's activities, conferences, fundraisers etc Contact Trish at SHQ on 07 3344 6919 or [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)

## Invitation to Sporting Wheelies Gym Open Day



Wednesday 3rd December 2008

9am to 12 noon

- Meet Paralympic Athletes
- Morning tea and sausage sizzle
- Try out specialised equipment
- 10am Topic " Physical activity measurement in children with a disability"

Places are limited so please RSVP to:  
Shane Gilligan, Gym Co-ordinator  
Sporting Wheelies and Disabled Sport and Recreation Association Queensland  
60 Edmondstone Road  
Bowen Hills 4006  
Ph: 07 3253 3333  
Email: [mail@sportingwheelies.org.au](mailto:mail@sportingwheelies.org.au)  
Website: [www.sportingwheelies.org.au](http://www.sportingwheelies.org.au)



## Would you like to catch up on past SHQ newsletters?

Quarterly Newsletters dating back to March 2005 can be viewed or downloaded free from the Self Help Queensland website at [www.selfhelpqld.org.au](http://www.selfhelpqld.org.au)



## Diary Dates

**11th to 13th May 2009: Connecting Up 2009 Conference—The Online Future of Nonprofits....Are we There Yet?** For nonprofit organisations to learn to be in control of how technology is used and take them to the leading edge of the nonprofit sector.

**Email:** [CU09@connectingup.org](mailto:CU09@connectingup.org)

**Web:** [www.connectingup.org](http://www.connectingup.org)

**Venue:** Brighton Novotel, SYDNEY NSW

**17th to 20th May 2009: 10th National Rural Health Conference**

**Phone:** 02 6285 4660

**Email:** [conference@ruralhealth.org.au](mailto:conference@ruralhealth.org.au)

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

**Venue:** Cairns

### Notice of Group Closure

#### Survivors of Child Abuse Group Bardon

Unfortunately, interest in this group did not meet expectations, and I have had to disband same. I understand that people sometimes just hurt too much, and can't face other people and other people's hurts.

Survivors of any kind of child abuse - ritual, sexual, physical, mental, institutional, (including men and women) need to talk of their experiences but often are unable. To talk to like minded people is so much easier.

If there are people (and I know there are many survivors) who would prefer to talk on line, I would like to try to organise a safe e-mail address, with members only to have access. I have no idea how to do this, so I am asking for help from like minded people, men or women, to get this up and running.

Expressions of interest would be appreciated. Then down the track, perhaps a meeting at the Self Help Queensland Office could be arranged.

Regards

Amie Cartwright (Survivor)

Email: [amie8@live.com.au](mailto:amie8@live.com.au)

## Wanted - Dead or Alive!!

### Old Mobile Phones



All profits to the Rett Syndrome  
Australian Research Fund

[www.rettsyndromeaustralia.org.au](http://www.rettsyndromeaustralia.org.au)

**"Your Help is our Hope"**

Rett Syndrome is a rare neurological disorder that affects mainly girls. Girls with Rett Syndrome lose communication skills and purposeful use of their hands along with the ability to walk. The majority of girls develop epilepsy, scoliosis and breathing issues. They will always require full time care, 24 hours a day, seven days a week which places enormous strain upon their family. Professor John Christodoulou who is head of the Australian Rett Syndrome Research Team is currently working on a project with the hope of starting human trials in the near future.

RSARF, a voluntary run charity, raises much needed funds to support this ongoing research to find a cure.

As an ongoing fundraiser RSARF are collecting old mobile phones for recycling. The phones do not have to be working and do not have to have chargers. Thank you for your kind support. Your help is our hope!

For further information please contact:  
Heather Jennings - 0403 99 31 81 & [cure4rett@yahoo.com.au](mailto:cure4rett@yahoo.com.au)

**Most self help support groups do not receive any funding.**

**Payment of a small membership fee assists with postage, phone costs and general expenses, and is often the only way a group can survive.**