

SELF HELP QUEENSLAND

March Newsletter

Issue 1. 2004



Self Help Queensland 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

Over the years I have used the President's Letter as an opportunity to participate with you some in the development of philosophies, plans and strategies not only for SHQ but also for the sector as a whole. I have also found this letter a great opportunity to develop and refine my thinking on a number of issues and to share whatever I have been involved in at the time.... I hope you don't mind!

This newsletter finds SHQ walking slowly down the path to discovering the possibilities of a co-operative insurance system. SHQ is also busily getting an application together to find funds for a much requested Queensland Self Help Directory.

More than 50% of our phone and email communication these days is from health and other professionals looking for information about groups. If the hard copy of the directory becomes a reality, SHQ expects to have much more time to devote to our group support and community development work. SHQ intends to charge for the Directory to support its on-going maintenance, enabling it to become and remain a reliable, accurate and user friendly resource. We should know the outcome of our application by the time the next newsletter is distributed, so will keep you posted.

At the moment I am thinking and reading about "participatory governance". Governance is a fancy term for the strategic and administration structures and the decision making and accountability processes of organizations, groups, governments etc. Participatory governance is about including the individual citizen in these processes. So the

next time you are "consulted...collaborated with ... surveyed ... focus grouped...networked...engaged...etc" you may be being included in a participatory governance objective (or just a tick in someone's 'to do' box!)

Participatory governance aims to combine citizen's rights, government political vision, good corporate governance and social justice (thanks to Diane Guthrie for this summary). In short it is about building the strength and inclusiveness of our community at whatever level it is practiced. The stronger, more knowledgeable and more involved we all are in our lives and that of our community, the better our representatives will need to be. From this point of view ultimate power lies in the hands of the citizen and isn't this what self help (and democracy) is all about?

Happy participating until next time.

Sue

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**Self Help Old Management
Committee Members**

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

Committee Meetings

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

Project Officer

Trish Fallon

Office

The office is attended (unless our staff are at meetings) from Monday to Friday from 9am to 4.00pm each week.

If you wish to call in to use the facilities at the office or talk to our project officer please phone first and check that there will be someone in the office.

Office Location:

Sunnybank Community Centre
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

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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.

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

**Link
Line**



A mutually respectful, sensitive and confidential means of connecting individuals and families for whom no known support group exists.

Self Help Queensland will endeavour to facilitate contact wherever possible but is unable to determine the suitability or compatibility of linked individuals and families.

A Gold Coast family with a 21 year old son with a very rare condition, Kabuki Syndrome, would like to make contact with any other families who may have a member with this condition.

Another family also living on the Gold Coast would like to speak with someone who has knowledge or experience of Cauda Equina Syndrome.

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

Competition Winners

Congratulations to the following winners of the Computer and "Grapple" competitions which were announced in the December edition of the Self Help Queensland newsletter.

The Computer System, which was kindly donated by Green PC, was won by "The Ipswich Support Group."

3 Grapple CD-Roms, kindly donated by the Royal Flying Doctor Service, were awarded to:

Clermont Support Group, Clermont
West End Community House, Brisbane
The Ipswich Support Group, Ipswich

Many thanks to all who took the trouble to enter the competitions, and especially to the generous sponsors, Green PC and the Royal Flying Doctor Service.

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Genetic Matters

with Kim Summers PhD

“Just that much more chocolate”

My mother used to tell us a joke about the little girl who was offered a chocolate baby to eat. She said yes please, and could she please have a boy baby. “Why?” asked her mother. “Well,” said the little girl, “I’d like a boy baby because there’s just that much more chocolate!” We now know there’s more to determining sex than the mould you’re poured into.

Humans have 46 chromosomes, arranged into 23 pairs. In females both members of each pair look identical under the microscope. Males have 22 pairs where both members look identical but the 23rd pair consists of one middle sized chromosome, similar to those in one of the pairs in females, and one tiny chromosome only the size of the smallest of the other chromosomes. Because this was the only visible difference between male and female chromosome sets, the two chromosomes making up this 23rd pair were called the sex chromosomes. All the other pairs were numbered in order of size, from 1 to 22, but the members of this odd pair were called X and Y to distinguish the sex chromosomes from all the others, called autosomes. So the chromosome constitution of a female is usually 46 XX and for a male it’s 46 XY. It’s the tiny Y chromosome which is responsible for that little extra chocolate and all the other characteristics which go with maleness.

When eggs in women and sperm in men are formed, the chromosome number gets reduced by half. Eggs and sperm have just 23 chromosomes, one member of each pair. In females, all the eggs have 22 autosomes and an X chromosome. In males, about half the sperm have 22 autosomes and an X chromosome while the other half have 22 autosomes and a Y chromosome. If an egg (23 X) is fertilized by an X-bearing sperm (also 23 X) a baby girl will result (46 XX). If an egg is fertilized by a Y-bearing sperm (23 Y), a baby boy will result (46 XY).

This simple system ensures that about half of new born babies are boys and half are girls, and every time a baby is conceived there is a 50:50 chance of boy or girl. A similar system of sex determination is found in most

vertebrates, though in birds and reptiles the female may have the “Y” chromosome.

Since most chromosomes are present in pairs, most genes, which are found in the DNA which is part of the chromosomes, are also in pairs. If something goes wrong with one copy of the gene, its partner on the other chromosome can often compensate, so that we are unaware that there is a problem. This is difficult for males who have only one X chromosome. If something goes wrong with a gene on the X, males have no paired gene to compensate and they are likely to have problems related to the abnormal functioning of the altered gene. Females may only have these problems if both copies of the gene (one on each X chromosome) are altered. This is the basis of X-linked (or sex linked) inheritance. Some X-linked conditions are colour blindness, haemophilia, Duchenne muscular dystrophy and fragile X syndrome.

Some people have extra or missing sex chromosomes. Klinefelter syndrome results when a male has extra X chromosomes (47 XXY, 48 XXXY etc). Women with a missing sex chromosome (45 X) have Turner syndrome. The presence of a Y chromosome almost always results in development as a male and the absence of a Y results in a female. There are a few conditions where a Y is present but there is a problem with a critical gene. Since the activity of this gene switches on a whole developmental sequence which ultimately gives all the male characteristics, these people may have predominantly female characteristics. But since they have only one X chromosome and the rest of the Y is functional they are not fully female. Similarly, occasionally a small critical part of the Y gets moved on to the X, and these people may develop as males with two X chromosomes and no obvious Y.

So whether you have “that much more chocolate” depends on whether you have a functional Y chromosome or not, and each conception has a 50:50 chance. The rest of how you develop depends on genes on many chromosomes including the X and autosomes, as well as factors in your environment as you are growing up. For a great discussion on the Y chromosome and its interactions with its partner X, read “Y: The Descent of Men”, by Steve Jones (Abacus, London; 2002) -oOo-

Thinking of Getting a Speaker for Your Group?



Is your group looking for meeting speakers? If so, why not invite someone to talk about medicines. More than 200 million prescriptions are dispensed in Australia each year, and, at any one time, over 70% of Australians are taking at least one medicine. All that adds up to the fact that medicines are a significant part of life for most Australians, and a good reason why we should all learn more about medicines and their wise use.

Topics

What could you ask someone to talk about? Obviously, it depends on your group's needs/interests, but some possibilities are:

- Common mistakes people make when using medicines
- Things you should know about medicines
- Getting information about medicines
- Using Medimate to get the most out of your medicines
- Consumer Medicine Information (CMI) leaflets
- Getting the most out of Pharmacists
- Home Medicines Reviews
- Information about the medicines most commonly used by your members

Speakers

Who could you ask to speak? Again, that depends on your group's needs and interests as well as the topic you want to cover. Three possibilities are discussed below.

Local Pharmacists or GPs

You could approach a local Pharmacist or GP, and invite them to speak. Contact them in person, by telephone or by letter at their Pharmacy or rooms.

Divisions of General Practice

Each local area has its own Division of General Practice, which is a professional organisation that provides support, training and professional development for GPs in the area. Your local division may be able to recommend a GP who can talk to your group about medicines and their wise use. Each State also has a body that co-ordinates and represents the State's local Divisions of General Practice. The state body may be able to recommend a good speaker.

Many Divisions of General Practice employ people who teach GPs about medicines and good prescribing. Some also employ people who promote home medicine reviews. One of these people may be available to talk to your group about quality use of medicines or home medicines reviews.

The Queensland Divisions of General Practice

website lists contact details of the State's 19 local divisions of general practice. 467 Enoggera Road ALDERLEY QLD 4051
Ph: 07 3552 5444
Fax: 07 3856 5833
Email: qdgp@qdgp.org.au
URL: www.qdgp.org.au

Peer Educators

If your group is an older persons group, you may like to invite a peer educator to talk to your group. Peer educators have been trained to support and teach their peers about a particular topic. Australia has several peer education projects that focus on quality use of medicines for older people.

In 2004 - 2005, COTA - National Seniors is running a peer education program on medicines issues. The program's peer educators are available to talk to seniors groups in every state and territory.

Contact: Gwen Gilbert Ph 03 9820 2655
gbgilbert@cota.org.au

Hints

It often pays to do a bit of research before approaching your speaker to make sure they are a good public speaker who can explain medical terms and ideas in plain language. If approaching a Division of General Practice or other professional body, try to talk to someone about the type of person you would like, and ask them if they can recommend someone who fulfils those requirements. If possible, seek the advice of other community groups who may have had the person as a guest speaker.

Some speakers may charge a fee or want their travel costs reimbursed, so check this out when you discuss arrangements with them. Allow plenty of time for questions, and make sure the speaker realises there will be a question time afterwards. It often pays to end the meeting with light refreshments, allowing the speaker to mingle with the audience and talk to people individually.

(Source: Medicines Talk No 9 Autumn 2004)

Small Gympie Support Group Assists Sufferers Australia Wide In Battle With Little Known, Rare Neuro - degenerative Disease.

A handful of extraordinarily remarkable people from a community located in the Cooloola Coast Region of Queensland has been working tirelessly to improve the health and well being of Australians with **Progressive Supranuclear Palsy (PSP)**.

In 2001 the small group rallied around a friend who was finally diagnosed with PSP, after years of searching for answers to explain a range of very disturbing symptoms. It seemed that every doctor had a different opinion of what was wrong.

PSP Support Australia Inc supports people with PSP and their carers through the provision of up to date information and international research, telephone and email support, linking PSP families with other families in a similar situation (as nearby as possible), fundraising for research, liaison and encouragement of the Medical Profession to study and acknowledge the condition in order to ensure speedy and certain diagnosis and management.

Following are some frequently asked questions about PSP:

What is PSP?

Progressive Supranuclear Palsy is a comparatively rare and progressive brain disorder, little known until Dudley Moore's revelation that he had the disease himself. In PSP there is a selective and progressive loss of nerve cells (neurones) in certain regions of the brain. The population of neurones concerned are particularly involved with the control of eye movement and balance.

Why is it called PSP?

This term refers to the progressive nature of the illness and the fact that a particular pattern of eye movement disorder often characterises the condition. This comprises an inability of the patients to voluntarily move their eyes.

"P" stands for Progressive because, over a period of time, some symptoms of the disease do get worse.

"S" stands for Supranuclear. Many patients with the disease have a characteristic difficulty with eye movement and it is, in fact, this eye movement disorder that gives the disease its name. Eye movements are controlled in the brain by nuclei. PSP is caused, not as one might expect, by a problem in this part of the brain, but by a complex region above these nuclei, hence "supranuclear".

"P" simply stands for Palsy, or weakness.

What causes PSP?

The cause of PSP, like many other neuro-degenerative diseases, is not known, but there may be a genetic component. Recent research has suggested that some people may inherit genes which make them more prone to developing neuro-degenerative diseases (a so called genetic predisposition), but this is a complex area not yet fully understood. It is currently the subject of intense research at both national and international levels.

A plausible theory is that an environmental trigger factor (or there may be several triggers) may be needed to bring on the illness, and that the size of the trigger(s) required depends upon the individual's genetic predisposition. However, despite current research, there is as yet no proven explanation of how PSP is "triggered".

Is PSP inherited?

The vast majority of patients with PSP do not have relatives with this disorder. There are believed to be no more than a handful of families in the world where a patient with PSP has a sibling also with PSP.

Treatment

There is no effective treatment at present to halt the progression of PSP. Although there have been several trials of various therapies, they have not shown significant benefit. There is thus an urgent need for large-scale trials of potential treatments.

What are the main symptoms of PSP?

Early symptoms usually include loss of balance and unexpected falls, usually backwards; stiffness or rigidity in the muscles in the back of the neck and problems with vision. These problems include inability in looking up or more particularly, down - "the supranuclear palsy". (Continued on Page 6)

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other early symptoms are often vague and may include depression, apathy and loss of judgment.

As the disease progresses, there is normally increasing difficulty in speech and in swallowing. Movement can become increasingly difficult with possibly the need for a zimmer frame to help balance and, later, a wheelchair. Despite the increasing disability, memory is usually well preserved, although patients are distressed by their failure to communicate effectively because of their physical difficulties. There can be mild incontinence. There may also be other behavioural effects, including emotional lability (laughing and/or crying with minimal or no provocation), depression and inability to handle complex issues.

Following is a "GP ALERT" compiled by PSP Support Australia to assist General Practitioner's and Allied Health Professionals in recognising indicators of PSP.

- If I walk into your room with staring eyes and a shuffling gait, ***I do not necessarily have Parkinson's Disease!***
- If I have any or several of the following symptoms : slurred speech, slow responses, low cognition levels, perhaps even a little confusion with responses, some rigidity, staring gaze and an anxious demeanour, ***I do not necessarily have Motor Neurone Disease, Multiple Sclerosis, Alzheimers Disease or Diffuse Cerebrovascular Disease***

I may have ***Progressive Supranuclear Palsy***

- Check out my eye movements. They are slow. I may have difficulty looking up, but definitely cannot look down - an eyeball palsy - a very definite clinical clue to my condition. I can be between 40 and 80 years old, but usually in my sixties.
- Early recognition and referral to a competent Neurologist is most important for me and my family - Why? Because we need to make plans and appropriate decisions for our collective future, because there is no future for me. Wrong decisions will cause huge problems for my family!

To date, PSP Australia has offered support to sixty three families throughout Australia, as well as to health professionals and service providers.

PSP Australia is currently attempting to acquire DGR status to enable the group to receive tax deductible donations and have access to grant funding for research into the disease. Any offers of expertise or support in this area would be greatly appreciated.

For further information or to offer assistance please contact:

PSP Australia Inc
114 North Deep Creek Road
GYMPIE QLD 4570

Ph: 07 5482 5819
Email: pspsupport@ozwide.net.au

Useful sites:

www.psp.org
www.pspeur.org
www.pspinformation.com

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Six Disabilities to Gain Automatic Access to Carer Allowance

Six disabilities are to be added to or modified on the Lists of Recognised Disabilities that give automatic access to the Carers Allowance.

The disabilities are: **Down Syndrome, Cystic Fibrosis, Epilepsy (Uncontrolled), Haemophilia (moderate), Phenylketonuria, and Fragile X Syndrome.**

Anyone with one of these conditions will now be eligible for the Carer Allowance without the need for further medical assessment prior to their 16th birthday.

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Give Away

Fold up table and 10 stackable chairs

Contact: Trish at Self Help Queensland

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

Lifelong Learning - and helping yourself and others

The Lifelong Learning Council Queensland promotes the idea that lifelong learning is about:

- Learning to know
- Learning to do
- Learning to be
- Learning to live and work together (Delors'(1998)1), and underpinning this is the need to "Learn how to Learn".

Our organisation focuses on supporting community-based organisations and individual adult and community educators, trainers, teachers, tutors and mentors, who are involved in helping to make learning opportunities available, principally to adults in the community. Self Help Queensland, its member organisations and the people involved in your movement, are excellent examples of Lifelong Learning and Adult and Community Learning in action.

We are an unfunded organisation that works as a peak body (amongst other roles) in this field. To help us support our members we offer a range of developmental activities and services. These include:

- A group insurance scheme for not-for-profit community groups involved in some aspect of lifelong learning / adult education. This scheme offers 4 different insurances: Public/Product Liability; Professional Indemnity/ Directors & Officers; Voluntary Worker Personal Accident; and, Industrial Special Risks (ie. Property insurances). This scheme works in the sense of a "bulk-buying" process. The renewal date for the policies is the 31st May each year. We are hoping to extend its availability to individual adult and community educators.
- An Online "Directory of Adult and Community Learning" which is available to any organisation involved in the field. Visit www.LLCQ.org/ald and add your group to the directory.
- Professional development opportunities that are offered through our Networking

meetings and other public activities as well as courses we offer from time to time.

- Advocacy, lobbying and promotion of the field through such activities as representation on various organisations, newsletters, and Adult Learner's Week.

If you would like further information please visit our website: www.LLCQ.org or phone 3844 8400. The office is guaranteed to be staffed for five hours per week.

1. DELORS, Jacques (1998) Learning: The Treasure Within. Report to UNESCO of the International Commission on Education for the Twenty-first Century. UNESCO Publishing: The Australian National Commission for UNESCO.

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Independent Living Centre

Preliminary Schedule - to June 2004

Long Distance

Torres Strait Islands and North Peninsula Area: 28 March - 2 April 2004

Central West Queensland: 10 - 14 May 2004

Mackay: 7 - 11 June 2004

This schedule is subject to change. Please contact ILC Mobile on 1300 885 886 to confirm details.

Staff Development - On Road

We will be touring Coastal Queensland from April 15 to 23, 2004 to deliver Professional Development Sessions on Pressure Care to allied health staff.

Staff Development - Video Conference

"Equipment for Children in Vehicles"
- 3 March, 2004

"Barrier Free Design" - 31 March, 2004

"Gait Trainers" - 26 May, 2004

"Standers for Children" - 30 June, 2004

ILC Mobile is a request based service.

Bookings are essential

Please contact ILC Mobile on 1300 885 886
Email: mail@ilcql.org.au to request a visit.

Alternatives to Violence Project Qld Inc (AVPQ)

Want to boost your confidence, communication and conflict resolution skills? AVPQ offers practical, skills-based, creative workshops on resolving conflict within ourselves and in the community.

In AVP workshops participants are encouraged to participate in various exercises and activities in which they can explore feelings and ideas at their own level of comfort. The aim of the workshops is to give participants the tools they need to defuse violent situations.

The Basic Workshop (Level 1)

Everyone starts by taking the level 1 course, which provides a structured introduction to the ideas of AVP. In the Basic Workshop, participants consider *what is violence* and the nonviolence tools that they can use to transform violence. The workshop encourages self esteem and a sense of community through **affirmation, respect for all, community-building, co-operation and trust.**

Advanced Workshop (Level 2)

At Level 2, the group moves forward from the Basic Workshop with a theme being identified by the group for deeper exploration. This workshop looks at consensus and how it can be used to assist non violence. Within this workshop, the participants focus on an issue that can pre-empt a violent situation. **eg fear, stereotyping, anger, forgiveness, gender issues.**

Upcoming workshops:

Level 1

Date: 24th and 25th April, 9am to 5.30pm

Venue: Rockhampton

Contact: Margaret von Breeman

Taster Evening (Introduction)

Date: 16th April, 7pm to 9pm

Venue: Relaxation Centre

Level 2

Date: 1st and 2nd of May, 9am to 5pm

Venue: Esther Centre South Brisbane

For further information:

Ph: 07 3286 2593

URL: www.avpq.org.au

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Arthritis Week Public Seminars

April 2004

Arthritis is Australia's major cause of pain and disability. National Arthritis Week is an awareness program to encourage people to become more informed about advances in the management of Arthritis.

The theme for this year's campaign, presented by the Arthritis Foundation of Queensland, is "Living well with Arthritis."

Topics discussed in the Public Seminars:

What is Arthritis?

Latest Trends in Medication and Treatments

Exercise and Diet

Pain Management

Alternative Treatments

Public Seminars

Date: Tuesday 20 April, 10am to 12 noon

Venue: Brothers Leagues Club

Cnr Wildey St & Robertson Rd

Raceview, Ipswich

RSVP: 07 3857 4200

Cost: \$10

Guest speakers:

Dr Joe O'Callaghan - Rheumatologist

Dr M Treffene - Orthopaedic Surgeon

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Date: Wednesday 28 April, 10am to 12 noon

Venue: Community Centre

196 Robina Town Centre

Robina, Gold Coast

RSVP: 07 3857 4200

Cost: \$10

Guest speakers:

Dr Shunil Sharma - Rheumatologist

Dr C Vertullo - Orthopaedic Surgeon

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Date: Thursday 29 April, 10am to 12 noon

Venue: Russell Strong Auditorium

Building 1

Princess Alexandra Hospital

Ipswich Rd

Woolloongabba, Brisbane

RSVP: 07 3857 4200

Cost: \$10

Guest speakers:

Dr Phillip Vecchio - Rheumatologist

Dr M Dekkers - Orthopaedic Surgeon

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Albinism Support Group a First for Queensland

The Albinism Friends and Family Support Group (QLD) was formed in 2003. The group consists of interested professionals and affected families and individuals. Several successful group meetings have been held to date, with member numbers steadily increasing. The group distributes information about Albinism, produces a newsletter, maintains telephone/email contact with members and seeks to inform the wider community about Albinism.

Albinism is a condition which results in absence of colour in the eyes and sometimes in skin and hair. Dark colour and tanning of the skin, brown colour in the eyes and red or dark colour of the hair are due to the pigment melanin. Some people have a genetic abnormality which means that melanin is not synthesised or is reduced in amount so that their skin, eyes and hair are very pale or even white. These people may have a kind of albinism. About 1 in 20,000 babies is born with albinism in our population.

The best studied form of albinism is oculocutaneous albinism type 1 (OCA1). OCA1 results from a deficiency of the first step in the pathway within cells for making melanin. In OCA1A there is no colour at all in skin, eyes and hair while in OCA1B these tissues can darken with age. People with either form of OCA1 usually have nystagmus, which is an involuntary movement of the eyeballs. Because the melanin deficiency also affects development of the eye, OCA1 sufferers tend to have poor vision. They may also have strabismus (lazy eye or crossed eyes).

There are other forms of albinism, resulting from alterations at different steps in the melanin synthesis pathway. In OCA2, the hair has some colour at birth. The skin does not tan during life but the irises of the eye may develop some pigment over time. OCA3 has primarily been reported in people of African descent and is usually accompanied by some pigmentation. OCA4 is a very rare form, similar to OCA2 but caused by a different abnormality.

There are a number of abnormalities associated with Hermansky-Pudlak syndrome.

These patients have pigment abnormalities similar to those with the OCAs, but also have bleeding disorders and are susceptible to lung problems.

In ocular albinism (OA) the eyes are affected but the skin and hair are generally not. In some forms of albinism there is also hearing loss.

Melanin is made from tyrosine, which is an amino acid found in proteins in the diet. In the various forms of albinism, there are problems with the process which converts tyrosine to melanin and deposits the melanin in pigment granules in the cells. OCA1 is caused by a defect in the gene responsible for the first step in this conversion, called tyrosinase. OCA2 is caused by a defect in a gene which seems to be involved in production of pigment granules while the defect in OCA3 is not fully understood although we know the protein which is defective, called tyrosinase related protein. The rare OCA4 involves a defect in a membrane protein called MATP. The roles of other genes which cause different forms of albinism when abnormal are not yet understood.

Most forms of albinism are inherited in autosomal recessive fashion. That means that each parent carries one copy of the gene with a change associated with albinism and one normal copy. Children inherit one copy of the gene from each parent, so they can inherit two normal copies or one normal and one abnormal copy (carriers) or two abnormal copies (affected with albinism). Parents who already have a child with albinism have a one in four chance that another child will also have albinism. People with albinism will usually have unaffected carrier children, unless their partner is also affected or a carrier. About 1 in 100 people is a carrier for albinism.

The most common form of ocular albinism is inherited in a sex linked manner. That means that the gene is found on the X chromosome. Boys only have one X, so if they inherit an abnormal copy of the gene they will have the condition. Females have two Xs, so they need to inherit an abnormal copy on both to have the condition and most females are carriers (one normal and one abnormal copy of the gene).

Albinism is common in (Continued page 10)

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other animals. Understanding the genetic abnormalities involved in producing white mice, rats, rabbits, cats and other creatures has helped us to understand the different forms of human albinism. White cats tend to be deaf, similar to some forms of human albinism. A range of mouse pigment abnormalities has been matched with different types of human albinism. In some species lack of pigment is useful, for example allowing them to escape predators in snowy landscapes. The pigment pattern in Siamese cats is due to a genetic alteration which makes the production of melanin temperature sensitive. Pigment is only made in the colder parts of the cat's fur, such as on the ears, muzzle, lower legs and tail.

Humans have a range of skin, eye and hair colours, due to the amount and type of melanin formed. People with albinism represent one end of this range, where little or no melanin can be made. As yet we do not have drug or other therapy which could turn on the process of making melanin or replace the missing pigment, but advances in genetic technologies and studies of animals with similar problems may bring such treatment to patients at some time in the future.

(Albinism information courtesy of Kim Summers PhD)

Useful website: www.albinism.org

For further information about Albinism, or the support group, please contact coordinator, Helene Johanson:

Albinism Friends & Family Support Group
PO Box 6357, St Lucia, QLD 4067
Email: albinismqld@yahoo.com.au

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Searching for Families with Children with Food Allergies

Efforts are being made to start regular morning information meetings in the Logan area. Families with children with food allergies that cause either severe asthma or Anaphylaxis are welcome.

For more information please contact Michelle Forster 07 3803 2065.

"Grandparents Talking"

- a group for grandparents who have the responsibility of raising children.

The aim of "Grandparents Talking" is to meet others in the same situation, to come together to share and access information, provide support, socialize and to promote awareness of grandparents raising children.

If you are interested, you are invited to attend our first get-together - an informal morning tea hosted by the HUB and Family Support Programs at Kingston East Community Centre.

Date: Tuesday 20 April 2004
Time: 10am to 12 noon
Phone: 3808 1684
Venue: Kingston East Community Centre
177 Meakin Road
Slacks Creek

Free child-minding is provided by qualified staff at our Occasional Childcare @ Kingston East.

Support Groups for Workplace Bullying

Queensland Working Women's Service (QWWS) has started free support groups for women and men who have experienced workplace bullying. The groups run for 6 weeks with a structured program. Participants say that they have found the groups beneficial, the most useful aspect being the opportunity to talk with others who have had the same experience.

QWWS have had a long involvement with the issue of workplace bullying for nearly 10 years, and it accounts for about 27% of their client calls.

QWWS hope that their experience in running the support groups will be useful to other organisations who would like to start such groups in their own areas.

Contact: Barbara Wilson
Ph: 3211 1440
Email: Barbara@ywas.org
URL: www.qwws.org.au

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Hearing Impaired Support Group Active and Growing in Redlands

The Redlands Hearing Impaired Support Group had its third birthday celebration at its February meeting. During formation of the group, great support was received from Better Hearing Australia, Brisbane Inc. (at West End), the Redlands Shire Council and the Donald Simpson Over 50's Leisure Centre. It is an active and growing group with members receiving the benefits that come from information sharing and mutual support. Importantly, they come to a better understanding of their disability and some of the common myths surrounding it.

Some of the common myths are – *"He/she can hear when they want to"*. This ignores the complexity of impaired hearing. Often one family member can be heard and understood, but not another – a very common scenario. More correctly – they hear when they can, depending on a variety of factors in the situation..

"Hearing loss is a sign of old age". Not so. It can occur at any age. We are familiar with 'industrial deafness' (or noise induced hearing loss). Unfortunately, not so familiar with the fact that childrens' hearing is being placed at risk due to recreational noise – such as frequent attendance at discos or playing Walkmans/personal CD's at a high level. Hearing loss can also be caused by illness, disease, accident, or it can run in the family.

"Hearing loss only affects the person with the problem". Wrong. Hearing loss can impact not only on the person with the loss, but on family and friends and workplace relationships. Its effect on communication can lead to relationship breakdowns and ultimately to withdrawal and isolation of the hearing impaired individual.

"Hearing loss is something you just have to live with". Wrong again! A person who suspects that they have impaired hearing should have a thorough medical review and audiological assessment. Depending on the cause, medical treatment may be needed. Hearing aids may be an option. Special assistive listening devices may help specific situations such as TV and telephone.

The aims of the Support Group are to:

- provide support and understanding for those persons and their families who experience the difficulties associated with hearing loss.
- provide information about the range of services available.
- advocate the provision of greater access to technology and facilities to assist people
- provide information to the general community regarding the implications of living with hearing loss.

Meetings are held on the 2nd Saturday of each month (except Dec/Jan) at the Donald Simpson Over 50's Leisure Centre, 172 Bloomfield St. Cleveland.

Further information can be obtained by contacting Dawn on 38224868

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Tell us about Your Group

If you belong to a self help or support group we would love to hear about it so we can let others know.

Please contact Self Help Queensland
Ph/Fax : 07 3344 6919
Email: selfhelp@gil.com.au

White Wreath Association Inc Action Against Suicide Support Group

White Wreath Association Inc is an organisation supporting victims of suicide. It is a non-denominational, non-political and anti-discriminatory group which has several aims. We will support those people seeking help who have been directly affected by suicide and those affected by mental illness.

Support group meetings are held every Tuesday from 6pm to 9pm.

Venue:
Sunnybank Community Centre
121 Lister Street
Sunnybank QLD

Phone: 07 3219 7279
Email: white.wreath@bigpond.com

Australian Arachnoiditis Sufferers Queensland Association Inc

Call for Senate Inquiry

In January 2004 The Australian Arachnoiditis Sufferers Queensland Association (AASQA) called for an Independent Senate Inquiry into the use and abuse of Myodil/Pantopaque oil based, water based dyes; Metrizamid, Dimer X, Omipaque, Amipaque, still in use today. Side effects can cause death or life long pain with no cure. Adhesive Arachnoiditis can come from oil based dyes that remain in the central nervous system as a thin film or encapsulated mostly in the lumbosacral region or the base of the skull. Chemical Contents: Iodine, Benzene, Hydrochloric Acid, Sulphuric Acid, Sodium Permannanganate (This chemical cocktail can melt rubber). The majority of sufferers - 80% to 90%, are forced on to invalid pensions; financially damaging, even bankrupting, some Australian businesses.

The Myelographic Dyes can take up to 20 years to show some of the following side effects: Syringomyelia, Multiple Sclerosis, Cancers of the Liver & Bowel, Kidney problems, Epilepsy, Meningitis, Immune system breakdown, Blindness, unexplained heart attack, slow healing wounds, Tinnitus, Joint pain, a purple rash that appears and disappears, burning feet, muscle spasms, twitching and cramps.

Arachnoiditis can also be caused by other medical procedures such as Epidurals and Cortisone Injections, Disco-grams and Spinal Taps. Multinational Pharmaceutical Companies have known of disastrous side effects since 1945. Sufferers sometimes undergo multiple surgeries, and have nerves removed with no subsequent relief. They can be forced to pay their own medical expenses, the greatest of which can be medication.

Some may become paraplegic, then quadriplegic. They may be diagnosed with Multiple Sclerosis and then later have an MRI

prove that no Multiple Sclerosis is present. Research has shown that a sufferer's life can be shortened by up to 12 years. Little wonder after having been hit by a lethal injection of toxic chemicals.

The Queensland group has links with US and UK sufferers. New members/interested persons are invited to visit our website, read our newsletter (so we can keep you up to date with what is happening), complete the Health Survey and forward it to our email address.

AASQA believes that a Medical Research Compensation Foundation, along with an Arachnoiditis Registry needs to be created. It should be funded by the responsible Multinational Pharmaceutical Companies and Medical Profession, thereby allowing present and future Medically Acquired Arachnoiditis sufferers access to free medical diagnosis and treatment. AASQA believes the Foundation and Registry should be independent, and set up by the Government of the day.

Meetings

Meetings: Every second Wednesday each month
Time: 10.30am to 12 noon
Venue: Lake Laguna
Laguna Avenue
PALM BEACH, GOLD COAST

Contact Information

Contact: Peter Groves, Chairman
Ph: 07 5535 6655
Email: petergroves@asqa.info
URL: www.asqa.info
Post: The Secretary
Suite 294/80
The Pines
ELANORA GOLD COAST 4221

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Free Meeting Room

A small meeting room is available free of charge for self help and support groups. The room is located at Sunnybank and seats about 10 - 12 people comfortably. A kitchen with stove, microwave, wall urn and fridge is available for use. Toilet facilities and wheelchair accessible.

Phone Trish at Self Help Qld - 3344 6919

Addison's Disease Association Holds June Awareness Seminar for Queenslanders.

Addison's Disease is a rare endocrine disorder that affects approximately 1 person in 100,000. It occurs in all age groups, males and females equally. Addison's disease is a severe or total deficiency of the hormones made in the adrenal cortex, caused by the destruction of the adrenal cortex. The outer portion of the adrenal, the cortex, is the more important. It is this part of the adrenals that makes the two important steroid hormones, cortisol and aldosterone. Cortisol mobilizes nutrients, modifies the body's response to inflammation, stimulates the liver to raise the blood sugar, and helps to control the amount of water in the body. Aldosterone regulates salt and water levels, which affects blood volume and blood pressure.

Addison's Disease was described by Dr. Thomas Addison in London in 1855, where the most common cause was TB. This remained the leading cause until antibiotics reduced the incidence of TB. Since then, the leading cause is an over reaction of the body's auto-immune system, which attacks and slowly destroys the adrenals.

The slowly progressive loss of cortisol and aldosterone secretion usually produces a chronic, steadily worsening fatigue, loss of appetite and weight loss. Blood pressure is low, and falls further on standing. Nausea, sometimes with vomiting, and diarrhoea are common. The muscles are weak and often go into spasm. There are often emotional changes, particularly irritability and depression. Because of salt loss, a strong craving for salty food is common.

Finally, the increase in ACTH due to the loss of cortisol will usually produce a darkening of the skin. Unfortunately, the slowly progressive chronic symptoms are usually missed or ignored until a sudden event like the 'flu, an accident, or the need for surgery, triggers a medical emergency – an "Addisonian crisis".

Diagnosis and Treatment :

Once the possibility of Addison's Disease is raised, diagnosis is made definitive by

blood tests. The treatment for Addison's Disease is to replace the lacking hormones with similar steroids.

Cortisol is usually replaced orally by cortisone acetate or hydrocortisone tablets. Aldosterone is replaced by a similar synthetic steroid, fludrocortisone (flurinef) tablets. Since Addison's Disease is a chronic condition, daily replacement medication can never be stopped.

An "Addisonian" will never return to "normal". However, with vigilance by the patient, a great deal of "fine tuning" by both patient and Doctor, most "Addisonians" return to near normal lifestyles. This initial adjustment period may take anything up to twelve months or more, so be patient.

For further information, the Australian Addison's Disease Association (AADA) maintains an excellent website : www.addisons.org.au

Queensland will be hosting an information seminar on "Addison's Disease and Living with a Chronic Condition." The program is aimed at helping the medical profession recognize Addison's Disease, as well as helping both the medical profession and patients understand what can be done to minimize the "life" impact of Addison's, and having a positive approach.

Information Seminar

Date: Saturday 12 June 2004

Time: 9am to 3pm

Cost: Free

Venue: Chermshire Library
375 Hamilton Road
CHERMSSIDE

Guest Speakers: Addison's experienced Endocrinologist, Psychologist, Allied Health Professionals.

Contact the Queensland State representatives of AADA:

Michael and Diane Joblin

Email: joblin@cust.caloundra.net

Phone : 07 5492 6110

Bookings Essential!

We Have a New Email Address!
Self Help Queensland has a new, easy to remember email address.

Contact us at:
selfhelp@gil.com.au



Diary Dates

30 March - 2 April Wills Week Help with making a will is available over four days from members of Brisbane's legal fraternity in the main hall at Red Cross headquarters. \$40 donation per will. Appointments are essential.

Ph: 3835 1345

Ph: 0403 251 212

Time: 10am to 3pm each day

Venue: Red Cross

397 Adelaide Street, Brisbane

1 April 2004 Forum on the PBS: The US - Australian Free Trade Agreement and the Trans - Tasman Agreement "Ensuring that the needs of health consumers are recognized in these policy changes."

Enquiries: Christine Walker

Ph: 03 9805 9126

Venue: La Trobe University City Campus, 215 Franklin Street, Melbourne

2 April 2004 Women Speak Series - Patience Vormawor Patience is from Ghana where she is the head Trauma Counsellor of released female Trokosi slaves.

Ph: 07 3357 7444

Venue: Womenspace, Brisbane

20 April 2004 Workplace Awareness Course - Free course funded by Qld Dept of Employment and Training.

Contact: Trish Farrell

Ph: 3289 1262

Venue: Brisbane

26 - 30 April 2004 18th World Conference on Health Promotion and Health Education

Email: 2004wcphe@vichealth.vic.gov.au

URL: www.health2004.com.au

Venue: Melbourne

28 - 30 July 2004 National Medicines Symposium: For consumers, health professionals, policy makers, researchers and academics, health organisations, community organisations and the pharmaceutical industry. Consumer organisations are most welcome to send representatives.

www.nps.org.au/nms2004

Give Away

Fold up table and 10 stackable chairs

Loan

Overhead Projector and Tripod Screen

Contact: Trish at Self Help Queensland
Ph 3344 6919 Email: selfhelp@gil.com.au

Interstate Self Help Centres

Act

Self Help Organisations United Together (SHOUT)

Ph: 02 6290 1984

Email: shout@cybermac.com.au

New South Wales

The Association of Genetic Support of Australasia (AGSA)

Ph: 02 9211 1462

Email: agsa@ozemail.com.au

URL: www.agsa-geneticsupport.org.au

Victoria

Collective of Self Help Groups (COSHG)

Ph: 03 9349 2301

Email: coshgmelb@yahoo.com.au

URL: www.vicnet.net.au/~coshg

Genetic Support Network of Victoria (GSNV)

Ph: 03 8341 6315

URL: www.gsnv.org.au

Western Australia

Western Institute of Self Help (WISH)

Ph: 08 9228 4488

Email: info@wish.org.au

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