

# SELF HELP QUEENSLAND

September Newsletter

Issue 3. 2003



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

Dear all

Every group, every now and then has a participation 'crisis'. That is, despite all our hard work people stop turning up or don't carry out the tasks they have promised to do or even if they turn up, never offer to do more. Often this is about time, priorities and how well people feel. Sometimes though it is a symptom of the way the group is operating.

In our enthusiasm and sometimes when we've all been working together for a long time, we can stop being aware of and consciously using a process which helps the group to operate well and supports the development of individuals. I thought I'd share one of my favourite tools (the participation checklist) with you in this newsletter. It is adapted from work by Jeremy McArdle and may help diagnose or evaluate what is happening in a group and give you some insight into changes which may build a stronger and more effective group in the future.

Try not only to answer yes or no to the questions, but also to think about what happened, that is, the evidence you have to support your answer. You may also like other people, within and without the group to give their opinion as well. Remember, this is not a 'blaming' exercise, it is a 'working together to make it better' exercise.

It is timely for us at SHQ to be thinking about these issues. 2003 marks the 20<sup>th</sup> anniversary of SHQ and I am proud to be associated with this caring, and dynamic community organisation. SHQ was formerly known as the 'Queensland Network of Self Help Organisations' and even further back as the 'Australian Association of Self Helping



Health Care'. Over the years SHQ has had the benefit of a number of highly skilled, motivated and dedicated friends, committee members and project officers. The present committee would like to thank them for their contributions and to invite you all to a celebratory morning tea to be held after our AGM on Friday the 17<sup>th</sup> of October. We would also be delighted to hear about any stories or history about your experience of SHQ you may like to share with us, either on the day or through the newsletter.

Following on from my story in the last newsletter I received a reply concerning my community cabinet submission soon after the newsletter was published. Finding out 'what happened next' just required patience!

Regards  
Sue Smyllie

### \* "Participation Checklist" Page 3 \*



Self Help Queensland  
Annual General Meeting  
&  
20th Anniversary  
Get Together

Friday 17 October 2003 at 9.30 am

A warm welcome is extended to all members and interested friends to come along and meet other members of your network, management and staff. A good opportunity to put a face to the names!

A delicious brunch will be served after the meeting.

Venue: Self Help Qld  
121 Lister Street (Cnr Gager Street)  
Sunnybank Community Centre Complex

RSVP Trish  
Ph/Fax 07 3344 6919  
Email: qnosho@gil.com.au



**Self Help Qld 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:** qnosho@gil.com.au

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.

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

**Self Help Qld says “Thank You”  
to Jupiters Casino Community  
Benefit Fund**

Since our last newsletter Self Help Qld was very fortunate to receive a grant of \$9,603 from Jupiters Casino Community Benefit Fund for much needed office equipment. We purchased two wonderful new **\*\*fast\*\*** computers, combined printer/ scanner/fax, excellent software including virus protectors and much valued “extended warranties.”

Self Help Qld is very thankful to the Trustees for their approval of our application, and acknowledges the valuable contribution the Fund makes in financially assisting not for profit community groups and organisations in Southern Queensland to carry out their projects and activities.

**Thank You Jupiters Casino  
Community Benefit Fund!**



**Do you belong to a Self Help/  
Support Group?**

We would love to hear from you! Please call/ email/leave a message and we will get back to you. There are many groups we don't know about in Queensland and someone may be desperately looking to join yours.

Contact: Trish Phone 07 3344 6919  
Email qnosho@gil.com.au

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## Participation Checklist:



### Reflective Questions:

- Were as many people as possible involved in management and/or policy decision making?
- Were people involved in day to day decisions?
- Were their decisions implemented?
- Who implemented the decisions?
- **Did the decision-makers see their decisions put into action?**
- Did people get feedback on their involvement?
- Did the activity involve working in large groups?
- What opportunities were there for people to meet their own or their families' needs?
- Were there opportunities to learn new skills and develop existing skills?

### Interpretive questions:

- Was the activity useful in other ways?
- Was it easy for people to be involved?
- Was the entry into the activity non-threatening?
- Was their contribution welcomed, accepted, sought after? How was this communicated?
- **Did people feel free to come and go?**
- How were barriers of time, language, culture, distance, child care, finance etc overcome?
- **Was each person's level of responsibility flexible?**
- Did people feel they were in groups of equals?
- Were they doing things they were interested in?
- Were they doing things they felt they were competent in?
- Were their existing skills utilised?
- Was there an opportunity to go beyond their comfort zone a bit?
- Was there an opportunity to achieve success?
- Was there opportunity to form relationships?

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## Facilitation Skills Workshop

- Repeated By Popular Demand!

Following a very successful "Facilitation Skills Workshop" held in March 2003, presented by Thea Biesheuvel, Self Help Qld has been inundated with requests for a repeat performance.

We, at Self Help Qld interact with groups of adults who need the support of others, who need to learn how to manage their own "condition", who need to remember the needs of others and relate to each other. This means that the person chosen to lead the group needs to know the importance of participative methods.

A good facilitator builds on experiences, connects a number of major needs for the participants and for the group as a whole and uses a variety of techniques to encourage growth. A good facilitator therefore needs to elicit responses from the group to determine experiences and needs. A good facilitator needs to know a variety of techniques. A good facilitator encourages growth, not obedience or conformity. They therefore have to be people who can "think on their feet", while keeping the major objective in mind.

### Facilitation Skills Workshop

**Date:** Friday 10 October 2003

**Time:** 9am (for 9.30am start) to 3.30 pm

**Venue:** Self Help Qld  
Sunnybank Community Centre  
121 Lister Street  
SUNNYBANK

**\*\*Morning & Afternoon Tea Provided\*\***  
**\*\*BYO Lunch\*\***

**Cost:** \$50 Professional, Salaried and Government Employees  
\$10 Bona fide support groups and disadvantaged individuals  
(negotiable in special cases)

**Pre-payment to SHQ will confirm booking**

Further information & programme details please contact Thea Ph: 3300 3368  
Bookings: Trish Ph: 3344 6919

**Limited to 24 places**

**-so book early!**



## *Genetic Matters*

- with

*Kim Summers PhD*

### Preimplantation Genetic Diagnosis

Some couples know they are at risk of having a child with a severe genetic condition, because the condition runs in the family, because the mother is in the older age group or for other reasons. Until recently, their only option was to conceive a child and then have the child's cells tested for the condition when the pregnancy had reached 11 weeks (cells obtained by chorionic villus sampling) or 16 weeks (cells obtained by amniocentesis). These procedures put the pregnancy at a slight risk of miscarriage. For many couples, testing in this way is stressful and decisions must be made too late in the pregnancy for comfort. Now, with *in vitro* fertilization (IVF) there is another possibility.

When a sperm fertilises an oocyte, a single cell results. Within a few days this cell has divided several times to result in eight identical cells. If one or two cells are removed from the embryo at this stage, the remaining cells will go on to develop into a healthy baby. This has led to the development of a new form of genetic testing for couples at risk of having a child affected with a severe condition, called preimplantation genetic diagnosis (PGD).

Couples who want to take advantage of this procedure are required to go through all the steps for IVF. Eggs (oocytes) are harvested from the mother and sperm from the father. The eggs are fertilised in the laboratory and the embryos are allowed to develop to the eight cell stage. One or two cells are removed from each healthy embryo and tested the same day for the genetic condition. Only embryos which are free of the condition are implanted in the mother's uterus, so that the couple can be sure that the baby will not have the condition.

This process has a number of disadvantages. It is used primarily where there is a DNA based test for the genetic condition, so the family must know what DNA change is

associated with the condition in their case, before the couple enrolls for IVF. The couple must go through the IVF procedure, with the associated emotional, physical and financial stresses. The likelihood of a healthy pregnancy is enhanced by the fact that the couple are not infertile, but reduced by the fact that many embryos will not be suitable for implantation (25% on average for a recessive genetic condition, 50% for a dominant condition). There are issues about what should be done with the unsuitable embryos. Couples must balance these disadvantages against the need for testing an existing pregnancy and possibly terminating it if the more conventional process is used.

It is also possible to test embryos at the eight cell stage for some other characteristics. For example, the chromosome complement of the embryo can be examined. This is being used by some IVF clinics to check the embryos of older mothers who are at risk of chromosome abnormalities. Analysing the chromosomes also shows the sex of the embryo. In cases where a genetic condition is sex linked, the process can be used to choose female embryos, so that there is no risk of a condition which occurs in males of the family. Following from that, it is also possible to select among embryos to implant only those of the sex desired by the parents, even where there is no genetic condition, for example to "balance the family". This is banned in some countries but available in others. PGD has also already been used in some countries to create "saviour siblings" who will be able to donate bone marrow or cord blood cells to a sibling with a terminal condition.

As we know more about the function of different genes, we will begin to understand the genetic influences on many human characteristics, some good (like musical, intellectual or sporting ability) and some bad (like criminal behaviour and tendency to psychiatric illness). The idea of the "designer baby" has arisen from the possibility that embryos could be screened to implant only those with combinations of genetic variants chosen by the parents to ensure the child is close to their ideal. The movie *GATTACA* exploits this idea and shows a society which has taken genetic discrimination to extremes. At present this is still far from possible. (Continued page 5)

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We don't know enough about the different genes and their functions, and we don't understand all the interactions with the environment (including other people) which determine the final characteristics of any human being. Even if we could choose embryos with specific genetic variants for the appropriate genes there would be no guarantee that the child would have the planned characteristics if the environment wasn't right.

PGD offers an alternative to couples in a difficult situation. It is a technology which can be exploited for purposes other than avoiding severe genetic conditions. Each individual and society must make the decision about where to draw the line in the use of this new technology.

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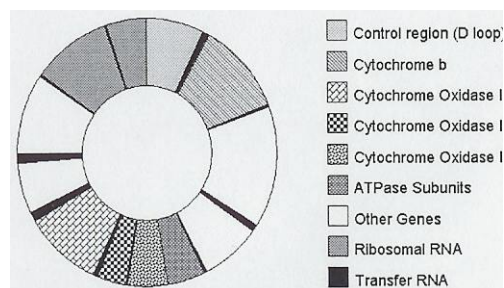
## Mitochondrial DNA and genetic conditions.

Mitochondria (singular: mitochondrion) are small organelles found in all human cells. They are responsible for energy production in the cell. They probably evolved from primitive single cell organisms which established a symbiotic relationship within the cells of other organisms. We now realize that mitochondria can hold the key to a wide range of diseases. This is because each mitochondrion contains its own circular DNA molecule and mitochondrial activities are controlled by a partnership between this DNA and the main DNA in the nucleus.

Human eggs provide all the mitochondria for the new baby after fertilisation. This means that we all get our mitochondria from our mothers and there is no contribution of our fathers to the mitochondrial DNA. So genetic conditions related to abnormal mitochondrial DNA always pass from the mother to her offspring, never from the father. Clinical geneticists look for this inheritance pattern when they suspect the condition might be mitochondrial.

Mitochondrial conditions can be very variable, because each cell contains many mitochondria and each mitochondrion contains many DNA molecules. So one person might have mitochondria with normal DNA mole-

cules as well as mitochondria in which some or all of the DNA molecules are abnormal. Usually, a person only experiences symptoms when the load of abnormal DNA is higher than a threshold level. The severity of the disease will depend on the proportion of abnormal DNA molecules and which tissue they are in. The proportion of abnormal mitochondrial DNA molecules will be determined in part by the proportion in the mitochondria of the egg.



Human Mitochondrial DNA

Since mitochondria are responsible for the cell's energy supplies, mitochondrial diseases typically affect tissues which have high energy requirements, like muscles. Common signs and symptoms include poor growth, loss of motor control and muscle weakness, visual and/or hearing problems, heart disease, disorders of the digestive tract, lung disorders, diabetes, liver disease, susceptibility to infection, developmental delays or learning disabilities, neurological problems and seizures. This covers a wide range, but specific mitochondrial conditions are known which involve a subset of these signs and symptoms. These include Leigh syndrome (the most common mitochondrial condition) MERRF, MELAS and a number of conditions involving vision or hearing. Diagnosis of a mitochondrial condition is made based on the inheritance pattern, clinical signs and symptoms and laboratory analysis of mitochondrial activities and DNA. If you suspect there might be a mitochondrial condition in your family, you can consult the Queensland Clinical Genetics Service on 07 36361686.

**To join a support group or talk to others with experience of mitochondrial disorders you can contact Tara at Aussiemito (UMDF)**

**Email: [tarac@powerup.com.au](mailto:tarac@powerup.com.au)  
URL: [www.umdf.org](http://www.umdf.org)**

## “Good Etiquette” will help you gather support for your Funding Submission.

“Letters of Support” are a very important component of every funding submission. Many groups miss out on grants because they are unable to satisfy the funding body that they are well known in the community and that other groups support them. We have picked up a few tips along the way that might help with your next application.

- Network your community so other groups get to know your work and are happy to recommend you.
- When asking someone to write a letter of support give them as much information as possible to assist them - name and address of fund, details of what you are applying for and the budget; other pertinent information about your group.
- Do not bulk email prospective referees with vague requests for letters of support - make a personal approach.
- When someone takes the time and effort to write your group a letter of support, pay them the courtesy of a thank you note or phone call. They are busy people too. If they feel appreciated they will be more likely to write another one in the future!
- Give your referees enough time to write a support letter, and give them a deadline.
- Reciprocate the gesture and offer to write a support letter in future if needed.
- Let your referees know the result of your application - successful or not. They will be very happy to hear from you.
- Introduce your group to your Local, State and Federal Members of Parliament - their support carries weight. Ask to be included on their mailing list (they often advise of upcoming grant opportunities) and send them your newsletters, brochures etc.



## Alternatives to Violence Project

AVPQ (Alternatives to Violence Project Queensland Inc) is an independent, non-profit association of trained volunteers who offer a community workshop program aimed at helping people find new, non-violent approaches to conflict resolution.

Everyone experiences some sort of conflict in their lives – at work or school, in neighbourhoods and within families. AVPQ programs help people to deal with those situations in creative, constructive and cooperative ways.

AVPQ is part of a world wide movement (AVP) that has a presence in all Australian States and Territories and had its origin in the US prison system in 1975. AVP works towards the creation of a non-violent society through affirmation, respect for all, learnt skills, community building, cooperation and trust.

Workshops are provided in community settings, in prisons and for groups and organizations to help promote team building, develop cooperative attitudes and build trust. AVPQ also provides ‘Help Increase the Peace’ (HIP) programs for young people in schools. These programs have been particularly successful in helping young people deal with bullying and other violent behaviour in their lives.

AVPQ depends entirely on membership subscriptions and donations to do its work. Workshops are low cost and are available on request for organizations, groups and school communities. AVPQ facilitators are highly skilled, required to undergo extensive training, mentored through an ‘apprenticeship’ period and supported by quality resources and a learning network.

You are invited to reserve your place in the next community workshop on the 27<sup>th</sup> and 28<sup>th</sup> of September, 2003 at the Esther Centre, cnr of Peel and Merivale Streets, South Brisbane. The cost is \$100 per person, \$40 concessions available.

Contact: Terry Pinnell (President)  
Ph: (07) 3278 2279  
Email: [dei@dei.com.au](mailto:dei@dei.com.au)  
Write: PO Box 78  
Sherwood QLD 4075  
URL: [www.avpq.org.au](http://www.avpq.org.au)

# Food Allergy - and Anaphylaxis

*Is there a connection between your chronic medical condition and allergy, food intolerance or chemical sensitivity?*

Allergic disorders such as asthma, hayfever and eczema have been increasing over the last 20 years. Food allergy is also on the increase and reactions are becoming more serious. Along with insect stings and patient administered medications, food allergy is the most common cause of fatal allergic reactions (anaphylaxis). Between 10 to 20 people in Australia die each year from anaphylaxis.

## **Food allergy symptoms**

These may be mild (causing mild skin rash or runny nose), severe involving any of the body systems (skin, gastrointestinal tract, respiratory tract), or potentially fatal (anaphylaxis) in a small number of cases.

The symptoms of food allergy depend on the severity of the allergy, the amount of allergen eaten, whether the food is solid or liquid (liquid is absorbed faster), whether it is eaten on its own or with other foods and whether the food is cooked or raw.

Early warning signs of allergic reactions to food include abdominal and oral symptoms such as sensation itching or tingling in the mouth, tightness in the throat. They can also include nausea; abdominal cramping and vomiting; acute urticaria (hives); angioedema (swelling of soft tissues); redness, itching and tearing of eyes as well as headache; blocked nose, runny nose, itching and sneezing (Rhinitis/Sinusitis). Symptoms may begin within minutes to hours after ingesting the offending food and become severe within 30 minutes to 2-3 hours.

## **What foods are involved in food allergy?**

A limited number of foods are responsible for the vast majority of food-induced allergic reactions. In children the main foods are cows milk, egg, peanut, fish, tree nuts, wheat and fish. In adults the main foods that result in allergic reactions are peanuts, tree nuts, fish and shellfish.

## **What is anaphylaxis?**

Anaphylaxis is the most severe of allergic reactions, it involves many organs of the body. The most dangerous symptoms are

breathing difficulties or a drop in blood pressure (shock), either of which can be potentially fatal. Anaphylaxis symptoms may be mild and require little to no treatment, or they can be life threatening. Anaphylaxis can occur from ingesting only minute amounts of allergen and in some cases, simply from being near someone who has eaten or handled the offending substance. The main food culprits in anaphylaxis in both children and adults are peanuts followed by tree nuts, milk and shellfish. Although anaphylactic reactions are rare they can be fatal.

## **Factors that contribute to the development of allergy**

- **Family history** of atopy (allergy)
- **Early exposure** to food allergens, including those introduced via the uterus and breast milk from the mothers diet, and foods introduced early in a child's life (1 to 5 years of age).
- **Frequent exposure.** Peanut and peanut products are found in a wide range of processed foods. When children develop food allergies it is usually in response to foods common in their diet.
- **Hidden ingredients in food.** Unknown ingestion of foods containing allergens. An American study tested 70 packaged food products including cereals, candies, snack foods and bakery products, peanut was found in 17% of products.
- **Lack of information and a need for better education.** The only treatment for food allergy is avoidance. Pregnant and breast-feeding women need to be aware that what they eat can affect the development of allergy in their child. When shopping and eating out, consumers need to be aware of which foods contain peanuts or other food allergens.

## **Food Allergens**

**1. Peanuts and other legumes.** Peanuts are not really nuts but belong to the legume group along with soybeans, green beans, peas, garbanzo & lima beans. Peanut is a strong allergen that persists over a long period and is a hidden allergen in many processed foods. Peanut allergy can cause hives (urticaria), eczema, swelling (angioedema), wheezing, choking, vomiting, runny nose, itching, difficulty breathing, nausea, asthma, tearing of eyes and in severe cases anaphylaxis.

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## **Australasian Genetic Alliance - Founded Sydney, 2003**

Self Help Qld is very pleased to announce the formation of the Australasian Genetic Alliance (AGA).

AGA is a newly formed network of peak organisations that represent genetic support groups, individuals and their families in the Australasian region who are affected by a genetic condition or a genetic predisposition. Inaugural members of AGA met in Sydney in May 2004 to establish this network.

AGA's mission is to work collectively to support people living with a genetic condition and to increase community awareness by networking, sharing resources and by representing common interests.

In practical terms, this means that the States, along with New Zealand (and hopefully other countries in the region in future) will work collaboratively to help promote, develop and sustain genetic support groups and engage in activities that support people with genetic conditions. A website is being developed which will provide information about genetic support groups in Australasia and thereby provide opportunities for people "in the same boat" to connect with each other.

Other members of AGA are:

### **Association of Genetic Support Australasia (AGSA)**

Ph: 02 9211 1462  
Fax: 02 9211 8077  
Email: [agsa@ozemail.com.au](mailto:agsa@ozemail.com.au)  
URL: [www.agsa-geneticsupport.org.au](http://www.agsa-geneticsupport.org.au)

### **Genetic Support Council Western Australia (GSCWA)**

Ph: 08 9389 6722  
Fax: 08 9389 9377  
Email: [info@geneticsupportcouncil.org.au](mailto:info@geneticsupportcouncil.org.au)  
URL: [www.geneticsupportcouncil.org.au](http://www.geneticsupportcouncil.org.au)

### **Genetic Support Network Victoria (GSNV)**

Ph: 03 8341 6315  
Fax: 03 83416390  
Email: [info@gsnv.org.au](mailto:info@gsnv.org.au)  
URL: [www.gsnv.org.au](http://www.gsnv.org.au)

### **New Zealand Organisation for Rare Disorders (NZORD)**

Ph: 64 4 566 7707  
Fax: 64 4 566 7717  
Email: [exec.director@nzord.org.nz](mailto:exec.director@nzord.org.nz)  
URL: [www.nzord.org.nz](http://www.nzord.org.nz)

### **Self-Help Organisations United Together ACT (SHOUT)**

Ph: 02 6290 1984  
Fax: 02 6286 4475  
Email: [shout@cybermac.com.au](mailto:shout@cybermac.com.au)  
URL: [www.shout.org.au](http://www.shout.org.au)

## **Contact AGA**

2003/2004 AGA Secretariat

C/- GSCWA

Level 1, Oasis Lotteries House

37 Hampden Road

NEDLANDS WA 6009

Ph: 08 9389 6722

Fax: 08 9389 9377

Email: [info@geneticsupportcouncil.org.au](mailto:info@geneticsupportcouncil.org.au)

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## **Reclaim the Night**

It's that time of the year again when community women come together to form a Collective to organise the annual Reclaim the Night march, rally and festival. Reclaim the Night events are held across the world on the last Friday in October, women coming together in solidarity to demand an end to sexual violence against women throughout the world.

The Brisbane Reclaim the Night Collective meet at 6pm every Tuesday night at Women's House to organise events for Brisbane. The Collective is open to all women who are interested in being involved in organising this year's event. Participation from services and community groups is welcomed.

Part of the RTN activities is the making of the RTN zine which includes a calendar of RTN events around Qld. If you are holding events in your local area please let us know so we can include you in our zine.

If you are interested in getting involved with RTN or would like more information about the collective or what you could do to support RTN please email Heidi at [info@brissc.com.au](mailto:info@brissc.com.au) or Ph. 3391 2573.



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The majority of reactions are mild but in some individuals, serious respiratory problems and anaphylaxis can occur.

### **2. Tree Nuts and Seeds:**

Some contain allergens and can produce clinical symptoms of allergy. Examples of nuts and seeds that can produce allergy symptoms are pine nut (anaphylaxis & urticaria), sesame seed, cottonseed protein, almonds, brazil nuts, cashews, chestnuts, hazelnuts, macadamia nuts, pecans, pistachios, walnuts.

### **3. Fish and Shellfish:**

Seafood allergy includes allergy to fish such as cod, salmon, tuna or dory; crustaceans such as crab, prawns or lobster and molluscs such as shellfish - oysters, clams. Seafood allergy is more common in adults than children and is usually a life-long problem. Allergy symptoms most often experienced are nasal allergy symptoms and anaphylaxis.

### **Diagnosis of food allergy**

Diagnosis of food allergy requires specialised medical knowledge and investigations such as a thorough medical history, skin prick tests, food challenge tests and RAST blood tests for specific foods. Because there are so many causes of adverse reactions to food, it is important that these investigations are carried out under experienced medical supervision.

### **Treatment and Management of Anaphylactic Reactions**

Epinephrine is the drug of choice to slow a potentially deadly anaphylactic reaction. Anaphylactic patients who are exposed to an allergic trigger may begin suffering from respiratory distress, which can quickly intensify, making breathing difficult or impossible. Severe symptoms include obvious respiratory distress, wheezing, cyanosis or loss of consciousness and the patient may require intubation (assistance with breathing).

### **Immediate Management of anaphylaxis includes**

1. Removal of the offending substance and minimisation of other co-factors – i.e. spit out food, stop exercise
2. Ensure patient does not choke or inhale vomit

3. Promptly call for medical emergency assistance
4. Inject epinephrine
5. Observe for relapse under medical supervision for a minimum of 12 hours. Severe symptoms (rebound) recur in up to 20% of severe food allergic patients when additional allergen is absorbed.

### **Reduce anaphylaxis risk**

When children are involved it is essential to educate the child itself, school personnel, day care providers and restaurant personnel about food induced anaphylaxis. The most common early warning symptoms are itchy mouth, hands or feet. Seek medical advice on the need to have an emergency kit containing epinephrine. Obtain and wear a medic alert bracelet.

Adapted from writings by Dr Sharyn Martin, PhD

for:

*ASEHA Qld Inc*  
*Allergy, Sensitivity & Environmental Health*  
*Association Qld Inc*  
*PO Box 96*  
*MARGATE QLD 4019*  
*Email: [asehaqld@powerup.com.au](mailto:asehaqld@powerup.com.au)*  
*Website: [www.asehaqld.org.au](http://www.asehaqld.org.au)*

ASEHA Inc is a volunteer community organisation promoting awareness in the community

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### **Two new clinical trials set to begin for Spinal Muscular Atrophy (SMA)**

Audrey Lewis, Executive Director, Families of SMA (United States) this week announced an important step forward in efforts to find a treatment for SMA. Two clinical trials are set to begin using 2 different drugs that have been shown to increase SMN protein levels.

Project Cure SMA team member, Dr. Kathryn Swoboda, and her team at the University of Utah and Primary Children's Medical Center will conduct these studies in tandem. Both studies are drug safety studies that will examine the tolerability by SMA patients of medications currently available for treatment of other diseases and conditions.

For more information about these clinical trials: <http://www.fsma.org/uresma.shtml>  
Families of SMA : Audrey Lewis,  
[audrey@fsma.org](mailto:audrey@fsma.org)



The Australian Pituitary Foundation Ltd  
in association with the  
Princess Alexandra Hospital &  
Mater Children's Hospital  
present



## Endocrine Disorders

Combined Adult & Paediatric Seminar

Located at the base of the brain, the pituitary is commonly referred to as the master gland because of the role it plays in controlling the function of all aspects of the body's vital endocrine glands.

These glands produce our hormones, complex secretions which define the differences between men and women; control our fertility, our emotions, our sex drive, and virtually make life worth living. Any disturbance of pituitary function is potentially devastating.

You are invited to a public education seminar, which will address the function of the pituitary gland, involve discussion of Cushings' Syndrome, Acromegaly, and puberty, growth and associated disorders.

Patients, families, carers and health professionals are all welcome to attend.

### How to get to the Seminar

"PA" bus stop on Ipswich Road  
BCC Hotline 13 12 30  
Street parking is available.

A car parking station is located opposite PA Hospital.

Accommodation is available at Tottenham Court

Free Public Seminar - All welcome

**Saturday 18<sup>th</sup> October, 2003**

**9.00am – 1.30pm**

**Russell Strong Auditorium (New Hospital, follow directions from main foyer)  
Princess Alexandra Hospital  
Ipswich Road, WOOLLOONGABBA**



### Public Seminar Program

9.00 am	<b>Registration</b>
9.45 am	<b>Welcome</b> Mr. Kel Childs - Australian Pituitary Foundation
10.00 am	<b>Overview of the Endocrine System</b> Ms Sally Skuthorpe, Nurse Educator, P.A. Hospital
10.30 am	<b>Cushings' Syndrome &amp; Acromegaly</b> Dr Ross Cuneo – Consultant Endocrinologist, P.A. Hospital
11.00 am	<b>Puberty, Growth, &amp; Associated Disorders</b> Dr Andrew Cotterill, Paediatric Endocrinologist, Mater Children's Hospital
11.30 am	<b>Question Time</b>
12.30 pm	<b>Close followed by lunch &amp; refreshments</b>



*For the convenience of attendees  
Food and refreshments will be available from 12.30 pm  
provided through the kind sponsorship of*



Call Sally Skuthorpe now to reserve your place on  
3240 2834.

**Please RSVP by the 10th October 2003.**



## Australian Pituitary Foundation Ltd

Patron – Hazel Hawke (AO)

Qld. Chapter : President;; Kel Childs Ph: 3273 3780  
Secretary; Sue Kozij Ph: 3376 2083

The Australian Pituitary Foundation Ltd was established in Sydney in 1994, and has since become a national organization. In 1999 the APF was registered as an Australian company with benevolent status, limited by guarantee. Our central committee is located in Sydney NSW, and state branches operate in Queensland, South Australia, Victoria and Western Australia. Other states are covered by these main state branches; The ACT is linked with NSW, Tasmania is serviced by the Victorian branch, and Northern Territory is covered by South Australia. All branches are run by voluntary committees of pituitary patients, or family members and friends, from home offices. We have recently joined forces with the Children's Growth Foundation of Australia, and intend to carry on their support of families who have children with growth hormone deficiency. The CGF was initially founded in the early 1990's to lobby for PBS funding of Growth Hormone medication for children, by a group of concerned parents. That goal was achieved several years ago.

In the past we have successfully lobbied to increase the availability of pituitary medications. As a result of our efforts, Sandostatin became funded by the Pharmaceutical Benefits Scheme (PBS) in 1998. We continue to maintain communication with the peak bodies and companies involved in the approval process for medications. Currently we are campaigning for PBS funding of Growth Hormone for severely GH-deficient adults. This is because many of our members are GH deficient and will remain so all their lives, with significant consequences for their health. GH is presently only funded for GH deficient children until they reach puberty. Naturally, we are concerned that GH should be available for all people of all ages who are genuinely deficient, including children who will go on to require growth hormone in adulthood, to maintain their ongoing quality of life and well-being.

We are assisted by the involvement by our members in writing letters and signing petitions in support of our goals.

We enjoy the support of Australia's leading endocrinologists, neurosurgeons, radiologists and endocrine nurses. They provide articles for our newsletters which are released throughout the year, and contribute to our patient information seminars. In turn we attempt to support medical education and research by encouraging patient participation in their projects. In all our patient support activities we avoid giving specific medical advice to patients, or acting as 'lay clinicians'. We will refer patients to the appropriate medical professionals when necessary.

We have social support get togethers approximately every three months (in Brisbane) and offer telephone contact between consenting members. We also offer educational seminars and informal talks with the assistance of health professionals. Annually The Princess Alexandra Hospital hosts a pituitary seminar for the APF in Queensland and this year the Mater Children's Hospital has included a paediatric section. The seminar is open to the public.

The APF is very keen to establish a child and parent support group and to welcome new members. Any queries please contact Sue Kozij Ph 07 3376 2083

Email: [eskozij@ozemail.com.au](mailto:eskozij@ozemail.com.au)

Email: [pituitary@bigpond.com](mailto:pituitary@bigpond.com)

URL: <http://www.pituitary.asn.au>



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You can call the Complaints Resolution and Referral Service for help with complaints about disability employment and advocacy services.

Free call: 1800 88 00 52

TTY free call: 1800 30 11 30

Fax: 02 9318 1372

URL: [www.disabilityhotline.org](http://www.disabilityhotline.org)

## *A Project of Hope....*

### 2nd Batten Disease International Conference in Australia

The Project aims to provide families and their friends, teachers and medical staff, affected or involved by this Disease with information, education and social interaction in various aspects of Batten Disease. Together with our BDSRA USA group, we have organised for many worldwide researchers to come here to share their knowledge, updating us on research and hope of trial treatments. A number of excellent speakers will travel from USA, Europe, NZ and Australia to give each of us a greater understanding of this disease.

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

This Conference welcomes the public with an interest in Batten Disease.

### **What is Batten Disease?**

(Neuronal Ceroid Lipofuscinoses)

Batten disease is an inherited disorder of the nervous system that usually manifests itself in childhood.

Batten disease is named after the British paediatrician who first described it in 1903. It is one of a group of disorders called neuronal ceroid lipofuscinoses (or NCLs). Although Batten disease is the *juvenile* form of NCL, most doctors use the same term to describe all forms of NCL.

Early symptoms of Batten disease (or NCL) usually appear in childhood when parents or doctors may notice a child begin to develop vision problems or seizures. In some cases the early signs are subtle, taking the form of personality and behaviour changes, slow learning, clumsiness or stumbling.

Over time, affected children suffer mental impairment, worsening seizures, and progressive loss of sight and motor skills. Children become totally disabled and eventually die.

Batten disease is not contagious nor, at this

time, preventable. To date it has always been fatal.

There are four main types of NCL, including a very rare form that affects adults. The symptoms of all types are similar but they become apparent at different ages and progress at different rates.

**Infantile NCL:** (Santavuori-Haltia type) begins between about 6 months and 2 years of age and progresses rapidly. Affected children fail to thrive and have abnormally small heads (microcephaly). Also typical are short, sharp muscle contractions called myoclonic jerks. Patients usually die before age 5, although some have survived a few years longer.

**Late infantile NCL:** (Jansky-Bielschowsky type) begins between ages 2 and 4. The typical early signs are loss of muscle coordination (ataxia) and seizures that do not respond to anticonvulsant drugs. This form progresses fairly rapidly and children live to between the ages 6 and 12.

**Juvenile NCL:** (Spielmeyer-Vogt-Sjogren Batten type) begins between the ages of 5 to 10. The most frequent beginning symptom is visual failure, less common are seizures. Motor disturbances occur late in the disease. After a slowly progressive course patients usually live to late teens, early 20's or more rarely, into their 30's.

**Adult NCL:** (Kufs or Parry's type) generally begins before the age of 40, causes milder symptoms that progress slowly, and does not cause blindness. Although age of death is variable among affected individuals, this form does shorten life expectancy.

**Other Types:** Some children who definitely have Batten disease don't fall into any of the patterns described above. About 1 in 10 cases are not typical of any of these groups of children. In some the disease progresses more quickly and in some slower.

### **How many people have these disorders?**

Batten disease and other forms of NCL are relatively rare, occurring in an estimated 4 of every 100,000 births in the United States. These disorders appear to be more common in Finland, Sweden, other parts of northern Europe, and Newfoundland, Canada. The incidence in Australia is not known precisely. Although NCLs are relatively rare,

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they can often strike more than one person in families that carry the defective gene. A family can be affected by one type of NCL only.

### How are NCLs inherited?

The cause of Batten disease lies in the chromosomes, which carry the hereditary characteristics and are found in the nuclei of somatic cells. The nucleus of every cell in the body contains twenty-three pairs of chromosomes. Each gene represents the 'code' for a particular characteristic. In the case of Batten disease, there is an aberration in one of the genes in one pair of chromosomes.

#### Recessive Mode of Inheritance

	Parents		
	B b	B b	
	Siblings		
BB	B b	B b	b b
Normal	Carriers	Affected	

Childhood NCLs are autosomal recessive disorders; that is, they occur when a child inherits two copies of the defective gene, one from each parent. When this occurs, each of their children has a one in four chance of developing NCL or a one in two chance of inheriting just one copy of the defective gene. Individuals who have only one defective gene are known as carriers, meaning they do not develop the disease, but they can pass the gene onto their own children.

Although there is no conclusive test yet available to identify carriers of the affected gene, recent breakthroughs in identification of the infantile and juvenile types have brought this one step closer.

Adult NCL may be inherited as an autosomal recessive or, less often, as an autosomal dominant disorder. In autosomal dominant inheritance, all people who inherit a single copy of the disease gene develop the disease. As a result, there are no unaffected carriers of the gene.

### Clinical course of Batten disease

Symptoms vary with each child. Early symptoms of Batten disease are confusing and not easily recognised even by medical personnel. The following is an outline of the most typical symptomatology:

- Visual impairment often progressing to complete blindness;
- Seizures, which may be frequent and difficult to control;
- Decline in cognitive function;
- Personality and behavioural changes;
- Loss of communication skills;
- Loss of fine and gross motor skills;
- Abnormal body movements;
- A general progressive deterioration.

(Source: [www.battens.org.au](http://www.battens.org.au))

### Guest Speakers:

**Genetics:** Dr. J. McGill, Brisbane, Qld  
**Paediatric Neurology:** Dr. B. Appleton, Qld  
**Diagnostic Testing:** Dr. M. Fietz, Adelaide  
**Lysosomal Storage Disorders Group:** Prof. J. Hopwood, Adelaide, SA

**Scientists:** M. Sands, Missouri, US; J. Cooper, UK; D. Palmer, NZ; I. Tammen, Sydney  
**Medical/Daily Care (Neurology Clinical Nurse):** K. Driver, Sydney

**Ophthalmology:** Dr. G. Gole, Brisbane, Qld  
**Family Support:** J. Johnson, Brisbane, Qld  
**Natural Therapies:** E. Jewell, Qld

**When:** Saturday 18th and Sunday 19th October 2003 (9am- 5pm)

**Where:** Sea World Nara Resort, Gold Coast, Queensland. (The Resort holds a group accommodation booking for attendees - view venue at [www.seaworldnara.com.au](http://www.seaworldnara.com.au))

**Cost:** \$70-00 per person (2 days) includes morning, afternoon teas and lunches.

#### For all bookings and enquiries:

Mrs Bronwyn Ward: Event Co-ordinator  
Email: [chookclub@bigpond.com.au](mailto:chookclub@bigpond.com.au)  
Ph: 07 3882 2862

Vanessa Anderson: Secretary  
Email: [gvjcando@ozemail.com.au](mailto:gvjcando@ozemail.com.au)  
Ph: 02 4334 5785



You can call the National Disability Abuse and Neglect Hotline for help about abuse and neglect.

Free call: 1800 88 00 52  
TTY free call: 1800 30 11 30  
Fax: 02 9318 1372  
URL: [www.disabilityhotline.org](http://www.disabilityhotline.org)



## Diary Dates

**26 - 28 September: Women in Prison Conference - State, National & International - presented by Sisters Inside Inc**  
Contact: Rebecca Baird  
PO Box 3407, South Brisbane, Qld, 4101  
Fax: 07 3844 2788  
Email: admin@sistersinside.com.au

**8 October: Prostate Cancer Awareness Evening** - presented by the Brisbane Prostate Cancer Support Network  
Contact: Davina 07 3258 2255  
**Venue: Qld Cancer Fund, 553 Gregory Terrace, Fortitude Valley**

**10 October: "Facilitation Skills Workshop" presented by Self Help Queensland**  
Contact: Thea 07 3300 3368 or Trish 07 3344 6919  
**Venue: Sunnybank Community Centre**

**17 October: Self Help Qld AGM**  
Contact: Trish Ph 07 3344 6919  
**Venue: Sunnybank Community Centre**

**18 October: Endocrine Disorders-Combined Adult and Pediatric Seminar**  
Contact: Sally Skuthorpe Ph 07 3240 2834  
**Venue: PA Hospital, Brisbane**

**18 - 19 October: 2nd International Batten Disease Conference**  
Contact: Bronwyn Ward Ph 07 3882 2862  
Email: chookclub@bigpond.com.au  
**Venue: Sea World Nara, Gold Coast**

**22 - 25 October: "Global Crisis: Local Action" 15th Annual conference for the Australasian Society for HIV Medicine**  
Contact: 02 9368 2700  
Email: nadine@ashm.org.au

**5 - 7 November: 5th International Aged Care Housing Summit.**  
Contact: 03 9529 4314  
Email: nnew@bigpond.net.au  
**Venue: Grand Hyatt, Melbourne**

**12 - 14 November: National Chronic Disease Self-Management Workshop**  
www.chronicdisease.health.gov.au  
**Venue: Melbourne**

**24 - 27 November: "Many Voices 9th Australasian Conference on Child Abuse & Neglect"**

Contact: Email only.  
childabuseconference@augment.com.au  
URL: www.community.nsw.gov.au/accan  
**Venue: Darling Harbour, Sydney**

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## Link Line



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

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

If there is no support group for you or someone you know, then perhaps you might like to connect with someone in a similar situation via Link Line. Please call Trish at the Self Help Qld Office Ph: 07 3344 6919

## Babysitter Safety Course for 13 - 16 year olds

The Wesley Hospital's Healthwise Centre is again offering the 2 day Babysitter Safety Course for 13 - 16 year olds during the school holidays!

Many teenagers don't think about what an important responsibility it is to be a babysitter. Apart from making sure the children are happy, it is even more important to keep them safe and make sure their needs are taken care of. During this course we focus on prevention as well as basic first aid for common injuries around the home.

When: Thursday 2nd & Friday 3rd October  
8.00am to 1.00pm

Where: Wesley Healthwise Centre  
Chasely Street, AUCHENFLOWER

Cost: \$88 (includes morning tea, First Aid Manual and Information Kit)

Bookings essential: Ph 3232 7666  
Email: healthwise@wesley.com.au