

Gene Advocate

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GENETIC SUPPORT COUNCIL OF WA (INC)

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GENETIC SUPPORT COUNCIL WA

Special points of interest:

- Angelman Syndrome p 6
- Psychosocial effects of Epilepsy p 7

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In December 2006 the Australian Parliament lifted the ban on therapeutic cloning; allowing embryos to be harvested for the purpose of producing stem cells. The most frequently asked and most intriguing questions about therapeutic cloning were presented to a panel of experts. These are their answers.



Q1: I'm confused about what cells are actually used in this procedure. Is it only fertilised ova? If every cell has DNA in it, why can't any cell be used?

A: We only use unfertilised eggs for therapeutic cloning from which we remove the nuclear DNA and replace it with a nucleus from a skin cell from a person with a disease that we're trying to fix. An unfertilised egg is not a embryo, but when you put the DNA in it, it starts to divide and forms a blastocyst and that's what you make the embryonic stem cell from. It's not really an embryo (in the traditional sense) but that was the name it was give early on by scientists. Dolly the sheep was formed in this way. Less than 1% of cloned embryos can turn into a viable creature while 70% of fertilised eggs can turn into one.

- Professor Alan Trounson, Professor of Stem Cell Sciences and Director, Monash Immunology and Stem Cells Laboratory, Monash University.

A: The unfertilised human ova in a cloning procedure, acts like an

incubator. It is unfertilised ova that are used in this procedure not a fertilised ova. No sperm is involved in therapeutic cloning. The ova's nucleus is removed, which therefore removes its genetic material. In its place a genome from a mature cell, let's say a skin cell (Somatic Cell) from a patient with cystic fibrosis, is inserted into the ova. Factors in the cytoplasm of the ova effectively reprogram the genome of the somatic, or mature cell, and in turn, a blastocyst, otherwise known as an early stage embryo, develops. It is from this nuclear transfer embryo that scientists can harvest stem cells that would be a genetic match of the patient, and would exhibit the genetic characteristics of that individual's cystic fibrosis. These cells could then be studied in vitro to investigate possible treatments or cures for the disease.

Only ova are capable of creating an embryo. Theoretically any mature cell from our body could be used to create a nuclear transfer embryo. Every living cell in our body certainly contributes toward life, but ova are unique cells that have the singular capability of programming cells to create an embryo.

A viable normal embryo derived from fertilisation of an ova with a sperm has a potential for life that far outweighs the potential of a nuclear transfer embryo. Animal studies have confirmed that the potential for life of a nuclear transfer embryo is significantly less.

- Professor Stephen Livesey, CEO, Australian Stem Cell Centre

"We are more than the sum of our genes!"

Therapeutic cloning cont . . .



Q2: What are the advantages of treatments devised from therapeutic cloning over conventional treatments for the same disease? And what kind of time frame are we looking at for the development of therapeutic cloning treatments?

A: In the case of making stem cells from a patient with Alzheimer's or cancer we're trying to understand the cause of the disease and we're hoping to develop new strategies or new drugs to prevent the development. Any new drugs or new therapies are probably 5-10 years (the earliest being 5 years) as just developing a new drug takes generally 5 years.

The other process is making cells completely compatible for transplantation - developing new liver stem cells, which can be transplanted and replace damaged liver cells. These stem cells don't need to be made for individuals, but they do need to be created in reasonably compatible groups otherwise they'll be rejected by their recipient. This process has been demonstrated in animals but not in humans. This is definitely 5 years plus away from happening.

- Professor Alan Trounson, Professor of Stem Cell Sciences and Director, Monash Immunology and Stem Cells Laboratory, Monash University.

A: Therapeutic cloning allows for the development of patient and or disease specific stem cell lines which can't currently be developed by conventional stem cell research. This is valuable because it allows not only the generation of cells for cell-based therapies that won't be rejected by the patient, but it can also allow for the generation of cells with a particular disease genotype so we can try to understand complex diseases, eg, motor neurone disease. Also, it allows us to test drugs more specifically, which could result in new drugs or possible new uses of existing drugs, which may be able to cure or halt the progress of diseases.

- Dr Megan Munsie, Scientific Development Manager, Stem Cell Sciences Ltd.



Q3: Aren't some stem cells available in the embryonic waters surrounding a full term baby? And are stem cells available in the cord blood and placenta?

A: Yes, there are primitive stem cells there, and lots of people are studying them. They look very, very interesting, and at this stage it's part of the research repertoire. But it's not possible to use these for therapeutic cloning. It's just another stem cell population that we're exploring.

- Professor Alan Trounson, Professor of Stem Cell Sciences and Director, Monash Immunology and Stem Cells Laboratory, Monash University.

A: There is a rich supply of stem cells in cord blood and in the umbilical cord. Some cells in the amniotic fluid are thought to have similar characteristics. The cord is routinely discarded after a baby is delivered, but these days many couples are opting to save the cord blood for their own use, just in case their child or sibling becomes ill at a later stage, or to donate the cord blood to a public bank.

Cord blood stem cells are successfully used in the treatment of small children with various forms of blood cancer. The cord blood stem cells are very immature and therefore don't need to be perfectly immunologically matched to the patient. Their job is to repopulate the child's blood cells following chemotherapy treatment.

Cord blood cells are considered adult cells as they are reasonably mature and committed to their specific role. Cord blood cells are not an acknowledged alternative to embryonic cells, they have significantly different properties and challenges. However, there is some evidence that under specific conditions cord stem cells can be coaxed to form other non-blood cell types. This research is relatively new and needs to be further validated.

- Professor Stephen Livesey, CEO, Australian Stem Cell Centre.

Therapeutic cloning cont . . .



Q4: I was interested to see that an embryo doesn't become an embryo until week 3. Prior to this it is a zygote, then a morula and then a blastocyst. From this it would be my understanding that "we" are not talking about "embryonic" stem cells but rather "blastocystic" stem cells at most. Could you please clarify this?



Image: Advanced Cell Technology

A: Yes, it is semantics, but scientists used the words to start with so we're responsible.

- Professor Alan Trounson, Professor of Stem Cell Sciences and Director, Monash Immunology and Stem Cells Laboratory, Monash University.

A: The point at which scientists can harvest stem cells is at the blastocyst stage, well before the cells would normally implant into the womb. At this stage the cells are not committed to certain cell types, no organs are developed, it is a donut-like structure of 100 or so cells. The normal pre-implantation development following fertilisation goes through zygote, two cell stage, four cell stage, eight cell stage, then a morula, to a blastocysts (5-7 days post fertilisation) and then it implants into the endometrium/lining of the uterus. The embryonic phase extends from the 3rd week through to the 8th or 9th week. It is at this point that the embryo becomes a foetus. Some scientists actually prefer the term pre-embryo to refer to the development prior to implantation. However, due to the community's understanding of what is an embryo from IVF the use of this term may diminish the significance of this early stage of development.

- Professor Stephen Livesey, CEO, Australian Stem Cell Centre.



Q5: Can scientists be sure or not, that the genetic material they insert into a nucleus to replace the unhealthy "template" doesn't carry other unwanted stuff?

A: It's a good question. We're still exploring this in animals. At this stage we haven't seen any untoward problems and this includes using cells from aged animals. But a situation with a human might be different and this is why we need to progress carefully, and we need to show that there are no alterations that would be concerning.

- Professor Alan Trounson, Professor of Stem Cell Sciences and Director, Monash Immunology and Stem Cells Laboratory, Monash University.

A: There is some controversy as to whether the egg, or ova, contains maternal mitochondrial DNA which is involved in the development of the somatic cell nucleus that is inserted into the enucleated egg during therapeutic cloning procedures.

Research will most likely reveal the answer to this question in time as laboratories in the UK and the US undertake cloning work.

The purpose of therapeutic cloning is to create a colony of stem cells that are a genetic match to a patient with a specific disease. So, we want to see the disease characteristics evident in the stem cells so we can test drugs on them and investigate the origins of the disease.

In terms of using healthy embryonic stem cells to replace or repair damaged ones, scientists only use donated excess IVF embryos that show no signs of disease.

In terms of adult stem cell treatments, scientists are able to identify signs of disease in these cells. But there is a question of these stem cells, both adult and embryonic, holding the basic blueprint of a number of diseases. It is an ongoing challenge that scientists are working on to be able to identify diseases within the cells before they are used in treatments in the future.

- Professor Stephen Livesey, CEO, Australian Stem Cell Centre.

Therapeutic cloning cont . . .



Q6: Why is there not more emphasis on adult stem cell research, which is far more advanced than embryonic stem cell research?

A: There is a lot of research into adult stem cells and it's perfectly reasonable that it is this way - about 80 or 90% of funding into stem cell research goes towards adult stem cell research. So there is a balance there, and quite correctly. We're using bone marrow stem cells for treating a wide range of blood disorders and immune problems. It's just that we generally think that we should not be inhibited from learning from different cell types.

- Professor Alan Trounson, Professor of Stem Cell Sciences and Director, Monash Immunology and Stem Cells Laboratory, Monash University.

A: There is considerable emphasis on adult stem cell research in Australia and overseas. In fact, the Australian Stem Cell Centre, which funds adult, embryonic and cord blood research, has committed more resources to date to its adult stem cell program than any other.

Adult stem cell research has been investigated for more than 45 years with significant advances emerging around the world in that time but restricted to blood disease or cancer based treatments. Embryonic stem cell research has been investigated for only seven years. So it is not reasonable to compare what has been achieved in 45 years with what has been achieved in seven.

Adult and embryonic stem cell research should be done in parallel. For they are both stem cells and what we learn in one area will be of benefit to the other. They have very different characteristics, scientific challenges, potential application and therapeutic and research uses. One should not be excluded in preference for the other.

- Professor Stephen Livesey, CEO, Australian Stem Cell Centre.



Q7: Is it possible to implant our chromosomal material in another species cell (such as a primate)? Would it be the same but with different proteins, cell components (such as mitochondria) etc, or would it be unable to carry out the basic functions that a cell does so well?

A: That's one of the recommendations from the Lockhart Committee, but the answer is we don't know, but it is certainly possible. It may be possible that rabbit eggs may be an alternative to using human eggs. We don't know the answer yet, but the few scientific publications about this kind of research are quite positive.

- Professor Alan Trounson, Professor of Stem Cell Sciences and Director, Monash Immunology and Stem Cells Laboratory, Monash University.

A: It is possible to use ova from another species, combined with a human somatic cell to develop to develop a blastocyst or nuclear transfer embryo. This is one of the recommendations of the Lockhart Review and in response to the concern that there may be insufficient human ova to use in research. This is a fairly contentious issue amongst scientists as some claim there is a transfer of mitochondria DNA to the developing blastocyst. Others claim there is not.

I believe there are a number of women, with children who have serious genetic diseases, that would be prepared to donate human eggs to develop a disease specific cell line, therefore reducing the need to use animal eggs. Opponents claim cloning research would require vast quantities of human eggs. It is unclear exactly how many eggs would be required to establish a cell line using therapeutic cloning technology.

Groups undertaking this work in the UK and the US will soon be able to tell us, but it is likely to be in the vicinity of around 10-30 eggs. An IVF cycle in which a woman's ovaries are hyperstimulated often results in a harvest of between 8-10 eggs. There is no doubt that human eggs are extremely valuable and ovarian hyperstimulation is not a procedure without risk. There is some argument for the use of animal eggs, but ultimately it is reasonable to assume that no human therapy could be developed with animal material for the concern that animal viruses and DNA may be transferred to a patient.

- Professor Stephen Livesey, CEO, Australian Stem Cell Centre.

The impact of genetic discrimination

Genetic testing has grown dramatically in the past decade, and is increasingly becoming an integral part of health care. Currently, genetic tests for about 1000 diseases are clinically available, and several hundred more are under development. These tests can help diagnose genetic conditions and guide treatment decisions, help predict risk of future disease, inform reproductive decision making, and assist medication choices or dosing.

The advent of genetic testing raises a number of questions about how an individual's genetic information can be used. In particular, can employers use genetic information to make hiring and firing decisions? Can insurance companies deny people coverage based on their genetic test results?

Source: Shawna Williams. (2006) The Genetics and Public Policy Center. Washington, DC, USA [Online]
Available: http://www.dnapolicy.org/policy.issue.php?action=detail&issuebrief_id=34

In a workplace setting, the Human Rights and Equal Opportunity Commission investigates alleged infringements of human rights under the Human Rights and Equal Opportunity Commission Act 1986 and breaches of anti-discrimination law under the Age Discrimination Act 2004, Disability Discrimination Act 1992, Racial Discrimination Act 1975 and Sex Discrimination Act 1984.

Complaints are handled on a confidential basis with an emphasis on conciliation.

For more information or to make a complaint call the complaints hotline in 1300 656 419 or email complaintsinfo@humanrights.gov.au or visit their website <http://www.hreoc.gov.au/>

Insurance coverage is a big issue for anyone with a genetic condition. The potential for discrimination when applying for insurance can be of concern to individuals and families with a history of a genetic condition.

A special guest speaker at the Genetic Support Council Annual General Meeting can help to answer some of these questions. Please see AGM information panel to the right of this article.



Genetic Support Council of WA Inc

All members and interested parties
welcome

2007 Annual General Meeting

**Tuesday 25th September
12.00 -1.00pm**

Lecture Theatre
Grace Vaughan House
227 Stubbs Terrace
Shenton Park
(parking onsite)

Special Guest Speaker

Michael Fitzgerald
Investor Logic

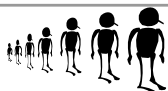
'Insurance and Genetics'

The potential for discrimination when applying for insurance can be of concern to individuals and families with a history of a genetic condition.

Information on life, total and permanent disability, trauma and income protection insurances as well as superannuation issues will be covered in this informative presentation.

A delicious light luncheon and refreshments will be served after the meeting.

RSVP by 18th September 2007
by phoning 9389 6722 or email
admin@geneticsupportcouncil.org.au



The Australian Angelman Syndrome Association



What is Angelman Syndrome?

Angelman Syndrome (AS) is a rare neuro-genetic disorder named after an English paediatrician, Dr. Harry Angelman, who first described the syndrome in 1965. (A syndrome is a number of features which occur together as a group and indicate a particular condition). AS is characterised by severe intellectual disability, speech impediment, sleep disturbance, unstable jerky gait, seizures and usually a happy demeanour.

Is it difficult to diagnose?

Yes, but with increasing public awareness of the condition and more accurate diagnostic tests, more children are being diagnosed. It is estimated that Angelman Syndrome occurs about one in 20,000 births. Assessing the physical and behavioural features of AS helps in a more accurate diagnosis.

Always Seen/Consistent (100%)

- Severe intellectual disability and developmental delay (failure to match developmental milestones of other children), eg. delays in sitting and walking, delay in fine motor skills development and delay in toilet training;
- Profound speech impairment: no speech or minimal use of words; receptive and non-verbal communication skills higher than verbal ones;
- Movement for balance disorder (tremulous movement of limbs, stiffness and jerkiness in limbs) and ataxia of gait (lack of muscular co-ordination when walking);
- Behavioural uniqueness: any combination of frequent laughter/smiling; Happy demeanour; easily excitable personality, often with hand flapping movements; short attention span and hyperactivity.

Usually Seen/Frequent (More than 80%)

- Small head size - often by age two years;
- *Seizures - onset usually before three years of age;
- *Abnormal EEG (brain wave pattern irregularity).

Sometimes Seen/Associated (20% to 80%)

- Flat occiput (flattened back of head);
- Protruding tongue;
- Tongue thrusting; suck/swallowing disorders;
- Feeding problems during infancy;
- Wide mouth, widely spaced teeth;
- Frequent drooling;
- Excessive chewing/mouthing behaviours;
- Scoliosis (curvature of the spine);
- Strabismus (crossed eye);
- Hypo pigmented skin, light hair and eye colour (compared to family), a feature in deletion cases;
- Wide based gait (feet far apart with flat, out turned feet);
- Tendency to hold arms up and flexed while walking;
- Increased sensitivity to heat;
- Sleep disturbance;
- Attraction to/fascination with water.
- Not all features may be present. A diagnosis of Angelman Syndrome is based on a combination of the clinical features as above, together with genetic diagnostic tests.

Latest Research

Information Source: <http://www.angelmansyndrome.org/whatis.html>

[Reviewed by Liz Stanley, National Vice President Australian Angelman Syndrome Association WA]

The WA contact for Australian Angelman Syndrome Association is Liz call her on 9447 8606.

Psychosocial Effects of Epilepsy in children

Many people report that the most frightening thing about seizures is their unpredictability.

Children with epilepsy must learn to live with epilepsy.

Epilepsy is a chronic disorder and may have the same types of effects on children as would a chronic disease.

Epilepsy is episodic; in other words, no one can predict when a seizure will occur. Therefore, it may be even more difficult to adapt to epilepsy than to other more predictable chronic conditions.

Even a child whose epilepsy is well controlled with medication may still be fearful about having another seizure, especially in the presence of peers.

Quality of Life

It is not enough to treat only the medical aspects of the child's seizure disorder. The psychosocial, emotional and physical components of the child's life must all be considered as well. Research shows that parents may interfere with their child's healthy psychosocial adjustment by being overprotective, rejecting, or having low expectations of him/her. Children with epilepsy can attain a high quality of life. Parents who know when to let their children have their own freedom, who accept and support their children as they are, and who encourage their children to have new experiences can greatly assist their children in attaining the skills which will help them to have fulfilling lives.

Stigma of Epilepsy

Research shows that the attitudes of others about epilepsy has more impact on people than does epilepsy itself. Attitudes toward people with an invisible impairment, such as epilepsy, are generally less positive than towards those with a visible impairment. The social stigmas associated with epilepsy can be very detrimental to children with epilepsy. Children are often very self-conscious about

their appearance and it may be very difficult for them to deal with having even brief seizures in public. Children fear being viewed as "different."

A newly diagnosed child's perceptions of the disorder largely depend on the parents' reactions to it. How the child's parents deal with the disorder, rather than the severity or frequency of the child's seizures, determines how well the child adapts to the disorder. Instill confidence in the child by praising what s/he can do. Allow your child to make choices to foster independence. Do not isolate the child, saying "It's for your own good." All children deserve the same opportunities. All children need to learn how to take reasonable risks. Facing fear and failure is a valuable learning experience necessary for a child to grow and mature.

Disclosure

The social stigma of epilepsy is experienced sooner or later by both children and adults. Many people feel anxious about the prospect of having to deal with a person who has epilepsy.

To help build your child's self esteem, you should encourage openness. Secrecy reinforces the idea that epilepsy may be something shameful. Secrecy interferes with acceptance and can erode a child's feelings of self-worth. A straightforward approach to dealing with epilepsy may appear to be difficult initially but will be more helpful in the long run.

Coping with uncertainty is part of having seizures. Taking an active role in understanding your child's seizures and how to deal with them can help make the uncertainty more manageable.

The decision whether or not to tell others about a child's epilepsy depends on many factors. Before you tell anyone outside of the family about your child's condition, you should discuss it with your child. Ensure that your child understands why it is necessary to disclose his/her condition. It is probably not

Continued over page . . .

Psychosocial Effects of Epilepsy in children continued . . .

necessary to tell everyone about your child's condition, so discuss with your child who you are going to give this information to. Allow your child to play a role in deciding who to tell about his/her condition.

As a general guideline, you should consider informing people of your child's epilepsy once s/he has had more than one seizure. This is especially important when the seizures are frequent and when the child's medication causes side effects. Informing others of your child's epilepsy will allow them to be prepared in the event of a seizure. If the child's friends seem understanding, the decision to tell them about the child's epilepsy may be easier. However, it is never easy to predict how others will react. While you may be fearful that other people will dwell on the disorder and blow it out of proportion, it is important for your child's safety that other people are informed. Use your own judgement in deciding what to tell others, remembering that openness is preferable.

Advantages of Disclosure

Helps others understand your child's condition.

Enables others to learn how to help your child during and after a seizure.

Disadvantages of Disclosure

Focuses the attention of others on just one component of the child's life: epilepsy.

Perceptions of the child as a whole may be diminished, with epilepsy assuming a disproportionate share of the child's identity.

Source: Epilepsy Association of Western Australia (Inc) 2007. Available: <http://www.epilepsywa.org.au/psychosocial.htm>

Epilepsy Association of Western Australia
Phone: 9346 7699
Helpline: 1300 852 853

Coming Events



AD/HD Awareness Week 2007

15 - 22 September

Annual Learning and Attentional Disorders Society of WA (Inc) Awareness Week highlighting research, education and developments in learning, attention and hyperactivity disorders.



Learning & Attentional Disorders Society of WA (Inc) - LADS

Contact: (08) 93467544

Website: www.ladswa.com.au

Genetic Support Council of WA 2007 Annual General Meeting

Tuesday 25th September 12.00 -1.00pm

Special Guest Speaker
Michael Fitzgerald, Investor Logic
'Insurance and Genetics'



See page 5 for more information

'Ask the Expert' - Professor Ralph Martins on Latest Dementia Research

28 September, 2pm

A 2hr presentation on the latest Dementia research. To be held at 9 Bedbrook Place, Shenton Park. Call to book as places are limited.



Alzheimer's WA

Contact: (08) 9388 2800

Website: www.alzheimers.asn.au

International Lupus Awareness Month

1 - 31 October

This month will raise the awareness of lupus across the community with corporate displays, educational seminars, literature and support services.



The Lupus Group of WA

Phone: 9224 3144

Website: www.lupuswa.com.au

Coming Events



The 8th Biennial National Angelman Syndrome Conference

5th, 6th and 7th October in Brisbane



This is a family conference with a theme of "supporting families". The latest research into the genetics of Angelman Syndrome will be reported. Angelman Syndrome is a 15th Chromosome deletion but there is a gene UBE38 which has been identified.

Contact: Liz on 9343 4430
Email: liz@allaboutbread.com.au

Advances in Tuberous Sclerosis from Pathway to therapy

Meeting for Health Professionals

Saturday, 3rd November in Sydney



The scientific meeting is aimed at health care professionals managing individuals and families with Tuberous Sclerosis. This meeting will highlight new developments in Tuberous Sclerosis.

Advances in Tuberous Sclerosis from Pathway to therapy

Meeting for Families

Saturday and Sunday 3rd and 4th November, 2007 in Sydney



This 2-day conference is intended for parents, carers, TSC affected adults and other interested parties. The program will cover topics such as the emotional impact of living with a chronic illness, TSC and Autism Spectrum Disorder (ASD) and planning for the future.

Sunday's program will give families a unique opportunity to hear about latest developments in TSC research and treatments from medical specialists across the dermatological, neurological, renal and genetic aspects of TSC.

Registration forms and more information are available online: <http://www.atss.org.au/>
Phone: 1300 733 435
Email: info@atss.org.au

Link Line



Genetic support groups are an important resource for families or people in a similar situation.

The Link Line provides a supportive and confidential means of connecting individuals and families for whom no known genetic support group exists.

If any individual is seeking contact with others in these circumstances, *The Link Line* is available to you for this purpose.

To date, there appears to be no specific support group for the following conditions/syndromes.

① A mother with twins is seeking support. One son has just been diagnosed with **Leigh's disease** and his twin brother also has a **Mitochondrial genetic chain disorder**. She would like to get in contact with other families around Australia with the same condition/s.



Directory of Genetic Support Groups and Community Organisations

2007 is now available!

The Online version is continually updated! To download your copy visit www.geneticsupportcouncil.org.au click on "Publications" menu item and Directory of Genetic Support Groups & Community Support Organisations 2007.pdf.

To order a FREE hard copy phone (08) 9389 6722 or email

Please contact Alison at the Genetic Support Council if seeking contact with these families.
Phone 08 9389 6722 or email to info@geneticsupportcouncil.org.au

Interesting Websites

Epilepsy information and support

The Epilepsy Association of WA Inc educates and supports individuals with epilepsy, their family, friends and the community and assist individuals with epilepsy to integrate successfully into the community, allowing them to enjoy a full and productive lifestyle. There is also a Teenage webpage designed and maintained by Teenagers.

Web: www.epilepsywa.org.au

US Discrimination Bill

A Bill to Prohibit Discrimination on the Basis of Genetic Information with Respect to Health Insurance and Employment (H.R. 493)

United States/House of Representatives, Washington
January 16, 2007, Web:

http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=110_cong_bills&docid=f:h493ih.txt.pdf

Halls for hire - need a place to meet?

Contact your Local Government for information about meeting rooms and halls to hire.

Web: <http://www.dlgrd.wa.gov.au/LocalGovt/LocalGovtContacts/LocalGovtList.asp>

Centre for Genetics Education New Website

The Centre for Genetics Education is dedicated to providing current and relevant genetics information to individuals and family members affected by genetic conditions and the professionals who work with them. This site contains research, info on genetic conditions, human genetics and patterns of inheritance, testing, screening and prevention.

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



Information accessed through the World Wide Web

is of varying levels of quality and accuracy.

The material supplied is for information purposes only & is not to be used for diagnosis



Global Health Watch

A broad collaboration of public health experts, non-governmental organisations, civil society activists, community groups, health workers and academics. This site was initiated by the People's Health Movement, Global Equity Gauge Alliance and Medact.

Web: <http://www.ghwatch.org>

Taking Reasonable Steps To Make Individuals Aware That Personal Information About Them Is Being Collected

An information sheets from the Office of the Federal Privacy Commissioner. (June 2003) Information sheets are advisory only and are not legally binding

Web: www.privacy.gov.au/publications/IS18_03.pdf

Jazz up your next newsletter or meeting, visit the Quote Garden

This free, searchable website is a personal collection of favorite quotes and sayings - inspirational, funny, thought-provoking, motivational, famous, and literary.

Web: <http://www.quotegarden.com/index.html>

Genetic testing and counselling in Europe

Recommendations for genetic counselling related to genetic testing available from EuroGentest Network of Excellence. June 1, 2007

Web: <http://www.eurogentest.org/web/info/public/unit3/guidelineswp31.xhtml>

Looking for a Government Service or Department?

Search the Australian Government
Web: <http://www.australia.gov.au/>

Promote your coming events in the 'Gene Advocate' or on our website at no cost!

Contact Alison via phone (08) 9389 6722 or e-mail info@geneticsupportcouncil.org.au



A resource for GPs - How can GPs help, Adjusting to illness and other major life events



General practitioners often see patients who are struggling with a change in their life circumstances. When this change involves illness, the GP is well placed to provide support and practical assistance.

However, research in this area has tended to concentrate on the patient who is overwhelmed and unable to cope, focusing on the negative consequences of anxiety and depression.

This article is designed to demonstrate the process of coping, and successful strategies that can be encouraged in the primary care setting.

The process of coping involves thoughts and behaviours. A patient with a new diagnosis, or a threatening change in their health, will assess the situation and determine how much it threatens them (primary appraisal) and how well they feel they are able to cope (secondary appraisal). They will then begin their preferred coping strategies. The GP can provide support and encouragement throughout this process.

Australian Family Physician

5 April 2007. Vol 36, (4) 193-288

Available: <http://www.racgp.org.au/Content/NavigationMenu/Publications/AustralianFamilyPhys/2007issues/afp200704/200704clarke.pdf>

Carers Recognition Act and Carers Advisory Council

Many people in our state 'care' for someone else. This means they do extra-ordinary tasks, assisting and supporting someone who can't do those things for themselves or who find it difficult to manage daily life, such as people who have a disability or chronic or mental illness, or are frail.

Many people don't recognise themselves as carers, or that what they do for another is special. Some think that it is just 'what you do' for a loved one, or is the 'thing to do' for a family member or significant person in their lives.

In Western Australia it is estimated that there are 246,800 people who 'care' for another person who has a disability or chronic or mental illness, or are frail.

The Carers Advisory Council was established after the creation of the Carers Recognition Act 2004 (CRA) which came into effect on 1 January 2005.

The Carers Recognition Act 2004 (CRA):

- defines who is a carer (see Appendix 1);
- sets out the objects of the legislation as (a) to recognise the role of carers in the community; and (b) to provide a mechanism for the involvement of carers in the provision of services that impact on carers and the role of carers;
- establishes the Western Australian Carers Charter which directs that carers must be treated with respect and dignity, included in service delivery decision making processes and have their needs, views and complaints considered (see Appendix 2); &
- establishes the Carers Advisory Council.

On the Carers Advisory Council website there are links to government agencies, including the Disability Services Commission and the Department of Health, plus non-government community agencies.

Contact: Helen on (08) 6217 8518 or visit www.carersadvisorycouncil.wa.gov.au

Grants & Fundraising

GrantsLINK
YOUR GOVERNMENT COMMUNITY GRANTS SITE



Government Grants Website

GrantsLINK is a web site that helps you find government grants by using a simple keyword search to pinpoint the grant or funding program you require. GrantsLINK searches all state, local and Australian government grants registered with the site, to save you time and effort. Web: www.grantslink.gov.au



Prefer a hard copy? Download the Grants Directory

The Grants Directory is a compilation of grants and other assistance programs available to communities and local governments in regional and metropolitan Western Australia. The Directory contains programs provided by the Western Australian and Australian Governments as well as private sector organisations.

Download and print:
www.grantsdirectory.dlgrd.wa.gov.au

Lotterywest Research Grants

Lotterywest has broadened the opportunity for research grants. In keeping with Lotterywest's overall grants approach which supports organisations to do what they do best – enhance the lives of West Australians – applications can now be considered for research projects that will inform policy or practice and address quality of life issues in a range of areas including social, cultural, economic, geographic and environmental. Applications can be made at any time. However applicants are encouraged to discuss projects with Lotterywest prior to preparing applications. For more information email

grants@lotterywest.wa.gov.au, call 9340 5270 or visit the website at www.lotterywest.wa.gov.au/grants

Autism Research Funds

The Apex Foundation Trust for Autism is offering grants of up to \$10,000 for research projects related to Autism. For details and application forms contact Amanda Golding at Autism Victoria (03) 9885 0533 or visit www.autismvictoria.org.au/research



GSCWA can assist with grant applications and resources for your group!

Does your organisation need to police check all volunteers?

Police checks are one form of background check but are not needed for all volunteers.

Consider only when the volunteer will be: **1.** working with children or other vulnerable people (aged, disabled etc.), **2.** working with money transporting people, or **3.** Working with drugs or medicines.

National Police Checks for Volunteers Program

This program run by the Volunteering Secretariat and the WA Police as a non mandatory risk management service to the volunteering sector provides a reduced fee police check for volunteers at a cost of \$9.50 per volunteer checked. Volunteer organisations must register with the Volunteering Secretariat. Checks are done through an email connection between the volunteer organisation registered and WA Police and not through local police stations. For an info pack or to register visit http://www.community.wa.gov.au/DFC/Resources/Volunteering/Police_Checks_for_Volunteers.htm

The checks indicate to the volunteer organisation whether the volunteer has a conviction and whether it is serious, minor or traffic. It does not tell the organisation the nature of the conviction. 89% of volunteers have no convictions and through this rapid process, can be immediately taken on as volunteers.

New Parent Support Group

Parent Support Groups WA

Are you feeling lonely and isolated? Do you feel no-one else understands what it's like for you?

Would you like to meet with other parents with children with disabilities for social interaction and learning opportunities?

Therapy Focus is running Parent Support Groups for parents of children with disabilities.

For more information please contact Anne Battista on 9478 9500, or visit www.mytime.net.au

Support for parents with learning difficulties

Healthy Start is an Australia-wide strategy to support parents with learning difficulties and promote a healthy start to life for their young children.

Healthy Start helps all families with a parent with a learning difficulty, including parents with a diagnosed intellectual impairment.

For more information visit: <http://www.healthystart.net.au> or contact Gabrielle Hindmarsh

University of Sydney, Australian Family & Disability Studies Research Collaboration
Tel: +61 2 9351 9510

Email: fhs.healthystart@usyd.edu.au

Members of the GSCWA

FULL MEMBERS

Acoustic Neuroma Association of Australia
Alzheimer's Association of WA
Angelman Syndrome Association
Arthrogyposis Support Group
Australian Cystinosis Support group
Australian Huntington Disease Association
Australian Pituitary Foundation WA Branch
Australian Tuberous Sclerosis Society Inc.
Australasian CHARGE Syndrome Association
CleftPALS Inc
Coeliac Society of WA
Cornelia De Lange Syndrome Support Group
Cushing's Disease Support Group
Cystic Fibrosis WA
Diabetes Australia - Western Australia
Down Syndrome Association of WA
Dyslexia SPELD Foundation WA Inc
Epilepsy Association of WA
Even-Keel Bi-Polar Support Association (Inc)
Fragile X Support Group WA (Inc)
Haemophilia Foundation WA Inc.
Heart Kids WA
Klinefelters Support Group
Learning and Attention Disorders Society of WA (LADS)

LQTS Support Group WA
Lupus Group of WA
Lymphoedema Association of WA
Mental Illness Fellowship WA
Motor Neurone Disease Association of WA
Mucopolysaccharide & Related Diseases Society (MPS)
Muscular Dystrophy Association of WA
Neurofibromatosis Association of WA.
Parents of Children with Disabilities
Periodic Paralysis Society of Australia
PXE Support WA
Raynaud's Syndrome Support Group
Rett Syndrome Association of WA
Senses Foundation Inc.
Short Statured People's Association WA Branch
SIDS and Kids Western Australia
Sjögren's Syndrome Support Group
Spina Bifida Association of WA
Thalassaemia Association of WA
Turner Syndrome Association of Australia (WA Branch)
Support Organisation for Trisomy and Related Disorders of WA (SOFTWA)
Western Australian Retinitis Pigmentosa Foundation

WA Tourette Syndrome Organisation (WATSO)

CORPORATE ASSOCIATE MEMBERS

ARAFMI Western Australia
Association of Genetic Support of Australasia
Australian Kidney Foundation
Carers Association of WA Inc
Ectodermal Dysplasia Support Group - OzED
Health Consumers Council WA
Lone Parent Family Support Service (LPFSS)
Office of Population Health Genomics
The Chromosome18 Registry & Research Society
The Kalparrin Centre
The Neurological Council of WA Inc
Western Australian Deaf Society Inc.

INDIVIDUAL ASSOCIATE MEMBERS

Anja Hermann
Darren Webb
Kristina Johns
Linda Bovill
Mark Bovill
Professor Charles Watson
Terry Keating



Membership Forms are available on the Web!

<http://geneticsupportcouncil.org.au>

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▶▶ The views and opinions expressed in this newsletter are those of the individual authors and not necessarily those of the GSCWA. The material supplied is for information purposes only, and is not to be used for diagnosis or treatment.

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