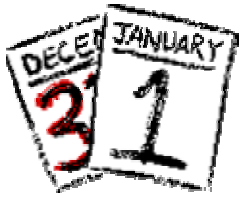


Gene Advocate

GENETIC SUPPORT COUNCIL OF WA (INC)

EDITION 42



Special points of interest:

- Free Computers!
- Coeliac Society WA.
- The Genographic Project

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How do genes influence behavior?

No single gene determines a particular behaviour. Behaviours are complex traits involving multiple genes that are affected by a variety of other factors. This fact often gets overlooked in media reports hyping scientific breakthroughs on gene function, and, unfortunately, this can be very misleading to the public.

For example, a study published in 1999 claimed that over expression of a particular gene in mice led to enhanced learning capacity. The popular press referred to this gene as "the learning gene" or the "smart gene." What the press didn't mention was that the learning enhancements observed in this study were short-term, lasting only a few hours to a few days in some cases.

Dubbing a gene as a "smart gene" gives the public a false impression of how much scientists really know about the genetics of a complex trait like intelligence. Once news of the "smart gene" reaches the public, suddenly there is talk about designer babies and the potential of genetically engineering embryos to have intelligence and other desirable traits, when in reality the path from genes to proteins to development of a particular trait is still a mystery.

With disorders, behaviours, or any physical trait, genes are just a part of the story, because a variety of genetic and environmental factors are involved in the development of any trait. Having a genetic variant doesn't necessarily mean that a particular trait will develop. The presence of certain genetic factors can enhance or repress other genetic factors. Genes are turned on and off, and other factors may be keeping a gene from being turned "on." In addition, the protein encoded by a

gene can be modified in ways that can affect its ability to carry out its normal cellular function.

Genetic factors also can influence the role of certain environmental factors in the development of a particular trait. For example, a person may have a genetic variant that is known to increase his or her risk for developing emphysema from smoking, an environmental factor. If that person never smokes, then emphysema will not develop.

Where can I learn more about the genetics of different behavioural traits?

Online *Mendelian Inheritance in Man* (OMIM™) is a continuously updated catalogue of human genes and genetic disorders. "Mendelian inheritance" refers to the transmission of inherited characters from generation to generation through the transmission of genes. It is named after Gregor Mendel, an Austrian monk who determined the basic principles of inheritance in the latter half of the 19th century, and who is considered the "Father of Genetics."

OMIM focuses primarily on inherited, or heritable, genetic diseases. Considered to be a phenotypic companion to the human genome project, OMIM is authored and edited by Dr. Victor A. McKusick and a team of science writers and editors at [Johns Hopkins University](http://www.hopkins.edu) and elsewhere.

The online database is updated daily and also provides links to a variety of related resources.

Cont 2...

“ We are more than just the sum of our genes! ”

The OMIM provides a large, searchable, up-to-date database of human genes, genetic traits, and disorders. Each OMIM record contains bibliographic references and a summary of the scientific literature describing what is known about a particular gene, trait, or disorder. The following behavioural traits are included in OMIM. The six-digit number MIM number is used to uniquely identify each record.

- Hand skill, relative (handedness): ([139900](#))
- Hand clasping pattern: ([139800](#))
- Arm folding preference: ([107850](#))
- Ears, ability to move: ([129100](#))
- Tongue curling, folding, or rolling: ([189300](#))
- Musical perfect pitch: ([159300](#))
- Novelty seeking personality trait: ([601696](#))
- Stuttering: ([184450](#))
- Tobacco addiction: ([188890](#))
- Alcoholism: ([103780](#))
- Homosexuality: ([306995](#))

You also may want to search OMIM for behavioural traits not included in the list above.

Ref:

Online Mendelian Inheritance in Man, OMIM (TM). McKusick-Nathans Institute for Genetic Medicine, Johns Hopkins University (Baltimore, MD) and National Center for Biotechnology Information, National Library of Medicine (Bethesda, MD), 2000. WWW URL: <http://www.ncbi.nlm.nih.gov/omim/>

Genetic Support Groups

Does your support group need a computer?



The Genetic Support Council WA has three (3) Pentium III computers which can be donated to member genetic support groups.

The computers include a PC, monitor, keyboard, mouse, and an internal modem and are loaded with Windows XP and MS Works.

Call Kristina or Sharon to register your interest.

9389 6722

How big is the human genome?

It is estimated that it would take "about 9.5 years to read out loud (without stopping) the more than three billion pairs of bases in one person's genome sequence".



[Source: Human Genome Projects Information: http://www.ornl.gov/TechResources/Human_Genome/faq/faqs1.htm].



About Our Members



Coeliac Society of
Western Australia Inc.

Coeliac disease is a permanent intolerance to dietary gluten — a protein found in cereal grains such as wheat, rye, barley and oats.

Gluten causes inflammation of the small intestine, which may affect absorption of important nutrients such as iron, folic acid, calcium and vitamins.

The Coeliac Society of Western Australia aims to ensure that those with Coeliac disease and Dermatitis Herpetiformis are educated about the gluten free diet and provides ongoing support to members, their families and carers.

Through this support and education, members will hopefully maintain an optimum state of good health and therefore minimise their reliance on the services of the health care system.

The management plan and treatment of Coeliac disease includes the permanent withdrawal of gluten from the diet, which must be strictly adhered to.

The cause of the disease is not known, however susceptible individuals experience gluten as a toxic substance. Often considered to be an inherited disorder, the development of coeliac disease cannot be explained through genetic factors alone.

People with Coeliac disease have a higher incidence of other autoimmune diseases such as diabetes and thyroid diseases.

Coeliac disease is now recognised as an under diagnosed life long disease affecting over 250,000 Australians, with a prevalence estimated as high as 1:70 individuals. Given the estimated population data of Western Australia this translates to 28,300 individuals with Coeliac disease in this state.

The symptoms of Coeliac disease can be highly varied. People may experience the following symptoms either singularly or in combinations.

- ◆ Unexplained anaemia; iron and folic acid deficiency are the most common
- ◆ Fatigue, weakness and lethargy
- ◆ Diarrhoea or constipation
- ◆ Flatulence, bloating and pain
- ◆ Nausea and vomiting
- ◆ Weight loss or gain
- ◆ Early menopause, infertility
- ◆ Altered mental state including depression and anxiety

In children this may also show as delayed growth or delayed puberty.

Coeliac disease can be screened for in individuals using a screening blood test. Diagnosis is then confirmed by showing an abnormality in the lining of the small intestine. This is done by taking pinch biopsies of the intestine during a gastroscopy.

Screening can be undertaken by a GP however a gastroenterologist referral is required for gastroscopy.

There are some long-term risks of undiagnosed Coeliac disease such as chronic poor health, osteoporosis, infertility, recurrent miscarriages, neurological disorders, dental enamel defects and, very rarely, an increased risk of gastro intestinal and oesophageal cancer.

In children undiagnosed Coeliac disease can cause lack of proper development, short stature and behavioural problems.

The Coeliac Society can be contacted on:

PO Box 1344,
East Victoria Park, 6981

Ph: (08) 9470-4122
Fax: (08) 9470-4166

Email: info@wa.coeliac.org.au
Website: <http://www.wa.coeliac.org.au>

(This article has been reviewed by the Coeliac Society of WA)



The Genographic Project hopes to trace ancient human migration using DNA from more than 100,000 people worldwide, including samples from indigenous populations such as Australian Aborigines. But there are implications in undertaking the task that have raised culturally sensitive concerns.

Funded by National Geographic magazine, IBM and the Watt Family charity foundation, the five-year study involves population geneticists, and experts in ancient DNA, linguistic and archaeology.

However, the project faces a number of issues to do with privacy, Aboriginal cultural beliefs and scientific history.

Roots of the genetic tree

When the project was launched in April, National Geographic explorer-in-residence and project leader, Dr Spencer Wells said "the greatest history book ever written is the one hidden in our DNA."

Wells said different populations had distinct markers that could be traced back through generations to reveal a genetic tree and possibly a common African ancestor.

Wary of getting burnt

Yet while scientists talk about the vast knowledge to be gained from the project and its altruistic goals, some privacy and indigenous advocacy groups are wary.

Aboriginal researcher and visiting fellow at the Australian National University Centre for Aboriginal Economic Policy and Research, Dr Dennis Foley, said indigenous communities could benefit through such studies but had been "burnt" in the past.

Foley said the collection of any indigenous tissue or blood products would also raise concerns as many communities held strong beliefs about the connection between the body and spirit.

Associate Professor John Mitchell, from La Trobe University in Melbourne, Australia, is responsible for collecting DNA from indigenous people in Australia and the Pacific and is aware of Aboriginal concerns about the project.

"We can really only go into these communities with the permission of the elders," Mitchell said. "And only after we have explained the purposes of the project and addressed their concerns."

Following early discussions with some Aboriginal elders, Mitchell had informed project leaders he would be asking Aboriginal volunteers to spit into a bottle rather than collect blood or cheek tissue scrapings. "We won't get as much DNA as we would from blood but we can get the same quality of data from a saliva sample," said Mitchell.



Privacy concerns

An Office of the Federal Privacy Commissioner spokeswoman said its staff had not looked at the Genographic Project specifically but any research in Australia would have to follow national, state and territory privacy laws relating to genetic information - even if that information was being sent overseas.

Participants should also ensure the project had the approval of relevant research ethics committees both in Australia and overseas as such a body would also require privacy protections were in place, she said.

Anyone can get involved

Members of the public can buy kits to have their DNA tested so they can trace their genetic origins as part of the [Genographic Project](#).

Extract from an article written by Catriona Purcell

Information Source:

<http://www.abc.net.au/science/features/globaldna/default.htm>

An introduction to Risk Management

What is risk?

Every non-profit organisation faces a certain amount of risk, whether it's ensuring the health and well-being of their volunteers or protecting their premises.

Risk is virtually anything that threatens or limits the ability of a community or non-profit organisation to achieve its mission.

It can be unexpected and unpredictable events such as destruction of a building, the wiping of all your computer files, loss of funds through theft or an injury to a member or visitor who trips on a slippery floor and decides to sue. Any of these or a million other things can happen, and if they do they have the potential to damage your organisation, cost you money, or in a worst case scenario, cause your organisation to close.

What is risk management?

Risk management is a process of thinking systematically about all possible risks, problems or disasters before they happen and setting up procedures that will avoid the risk, or minimise its impact, or cope with its impact. It is basically setting up a process where you can identify the risk and set up a strategy to control or deal with it.

It is also about making a realistic evaluation of the true level of risk. The chance of a tidal wave taking out your annual beach picnic is fairly slim. The chance of your group's bus being involved in a road accident is a bit more pressing.

Risk management begins with three basic questions:

- What can go wrong?
- What will we do to prevent it?
- What will we do if it happens?

Why should we bother with risk management?

There are a number of reasons why a community or non-profit group should put some time into considering risk management and it does go beyond the recent issue of rising insurance premiums.

For your own safety

You want an atmosphere where everyone in your group feels safe and secure and knows their safety

and security is one of the paramount considerations in every activity your group undertakes. A group that does this is normally a group that boasts a happy, loyal and effective membership or volunteer force.

For the safety of the people you are trying to help

The mission of most community groups is to help people, not harm them. If you are providing services for outside clients/groups the aim is to enhance their lives not do something that causes them pain, either physical or mental.

The threat of possible litigation

In the current circumstances this is a very real threat. Litigation is increasing according to the Insurance Council of Australia as are the size of the payouts for people who successfully sue. Not every group has faced legal action and not everyone who gets hurt then sues over it but by setting up a risk management strategy you can reduce the chance of people taking costly legal action against that will financially hurt your organisation.

Risk management systems

Setting up risk management systems is about preparing some written procedures to be put in place to ensure you know what, how, and when action has been undertaken or is to be undertaken - and by whom.

While it is important that your risk management plan takes in as many possibilities as possible, it is also important that your system be easily understood by your management team.

To be effective, it has to be workable.

Step 1: Make somebody responsible for risk management

If you're a very small organisation, appoint a risk manager. If you're slightly larger, set up a risk management committee with representatives from all the people involved - the board, staff, volunteers, clients - to review the risks you face.

Step 2: Review your group and identify the risks

Have the person or the committee review your premises, your financial procedures, your equipment, your human relations practices, and your client operations to identify any risks, risky behaviour or practices. Ask what could go wrong and what

An introduction to Risk Management Cont.

protections you have in place against them going wrong. It's important to get everyone involved to discuss any possible flaws in your practices and procedures.

Identifying risk

Risks come in two kinds; risks that apply to every workplace or organisation, and risks that come from doing the particular work you do. In other words there are unique risks that are faced by a welfare agency with volunteers working at night in high-risk areas or a football club training on a poor surface that are not shared by a bridge club meeting in the home of a committee member. The possible risks facing community groups might include:

Standard risks: Check

- Occupational health and safety risks: your physical surroundings (eg. dangerous machinery, kitchen, blind corners, electrical equipment, car parks, asbestos, passive smoking, playing surface, slippery floors, safety rails, etc)
- Transport (eg. bus license, car maintenance)

Financial and administrative risks: Check

- Your financial controls (eg. cheque handling, expenditure authorisation, financial reporting, insurance, petty cash box, bank accounts)
- Your record maintenance (eg. computer backup, file integrity, privacy protection, meeting minutes, member database, accounts database.)
- Your legal status (incorporation status, Corporate/Government returns etc)

What could go wrong?

Get everyone together for a brainstorming session where you can go through a range of hypothetical possibilities or "what ifs" - what if all your records disappeared in a fire? What if a key staff member left suddenly? What if you were sued for ten million dollars? - and ask how well you'd function if that happened. And - importantly - what you can do to ensure it doesn't.

Professional liability

Non-profit groups are set up to service, to assist, to

support communities but with any special service that your group provides, there is the margin for things to go wrong. It could be advice, treatment, placing someone in a position you knew was dangerous. What are the possible downsides if it does go wrong or you have a bad episode? Have a look at the potential for harm and look at how bad it could be.

General liability

Your employees, or your volunteers, may be dangerous in themselves - child abusers, or prone to hit people, or abusive. Have you set up a screening service or taken measures to guard against these possibilities?

Step Three: Fix what you can fix

Change your systems, your procedures, your physical plant, or your attitudes to address the hazards. Have the risk manager or the risk management committee, check that the changes have been made. Evaluate the effect of the changes. Review them regularly and modify them when needed

You can't foresee all possible risks, and you're still going to be faced with the unexpected. Even so, it helps to have procedures. If you've planned for a flood, for example, and you get a fire, at least you have an evacuation plan in place. Remember, too, that your liability for whatever happens is going to be affected by whether or not people think that you've done all you reasonably could have to avoid it.

If someone's car is hit by a meteorite in the parking lot, people will cut you some slack for not putting up a sign warning of the possibility. If the one hundred and forty-fifth person to trip over the rug breaks their leg, you can expect less indulgence. You had 144 chances to fix the problem and didn't.

Managing risk

Look at the risks and see which ones you can avoid altogether or eliminate, which ones can't be eliminated but can be reduced or modified to bring the risk within acceptable limits, which ones you can share with or give away to someone else (for example, you can get outside contractors to carry out dangerous operations after making sure they have the requisite insurance) and which ones you can insure against. Come up with concrete plans for each of these.

An introduction to Risk Management Cont.

You also have to look at:

- the balance between risk and benefit - you may be able to avoid the risk of abuse, for example, by dropping your services dealing with children, but that might remove the purpose for your organisation existing in the first place. The implementation of requiring a police check for all staff or requiring and checking references may diminish risk substantially.
- the balance between risk and cost or convenience - you may be able to reduce the risk of falling down stairs by moving to a new building, but that could divert all your funds to a secondary purpose. Putting up handrails, warning signs and non-slip strips may lessen the risk.

You will also need to have a strategy in place for what to do when the disaster happens - who is going to be assigned to deal with it, how you are going to handle the public relations, and how you are going to keep the loyalty of your clients and donors and volunteers. Remember, public relations is one area where insurance isn't going to help you at all. If you run a swimming program you may be fully covered for the financial impact of a child suffering a serious injury while under your care, but you may need to be able to manage media and public concern that everything that could have been done was done and that there is one person to act as a spokesperson

Avoiding risk

Develop risk-minimising procedures - staff screening, for example, or financial controls. Ensuring that any contractors that come onto your premises are covered by their own insurance policy (eg. the merry go round operator has public liability insurance and has provided you with proof of its validity) will also help you avoid risk.

Minimising risk

One possible way of minimising the risk of litigation is by having your clients sign waivers before entering your service. It is important to realise that waivers do not constitute an excuse or protection for people or organisations that act in a negligent manner. And a waiver does not relieve the organisation from its duty of care to the person signing the waiver.

A waiver is valid only if all the possible foreseeable risks have been fully explained and that everything has been reasonably done to either eliminate or minimise or control the risk. A waiver works only to cover inherent risks, and does not cover negligence or excuse an organisation's failure to act when it could or should have. This area is a legal minefield in itself and waivers tend not to hold much credence in courts, however, they do tend to make people think twice about suing when they have signed something saying that they are aware that they are participating in an activity and have been made aware of all the possible risks that that activity could possibly entail.

Disclaimers - statements about what you're accepting responsibility for or not accepting responsibility for - also does not excuse you from your duty of care. Putting up a sign saying that you're not liable for people slipping on the rug is not a protection if you have acknowledged that the rug is dangerous, have had numerous complaints and still not done anything to remove the danger.

Insuring against risk

Insurance is not a substitute for risk management. Getting insurance only comes into the picture when you've done all you can to minimise risk. You can't foresee everything, though, and you can't avoid quite a lot of what you can foresee, and so you want to spread the risks across the sector; which means you need insurance.

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No responsibility can be accepted by the author(s) for any known or unknown consequences that may result from reliance on any information provided in this publication.

Australian Porphyria Association

The Australian Porphyria Association is a voluntary non-profit organisation, supporting people with porphyria and raising awareness of the disorder.

The Porphyrias are a collection of disorders of haem synthesis, each resulting from a separate enzyme deficiency in the pathway.

- ♦ Broadly, the build up of haem precursors cause neuro-visceral problems and/or skin reactivity to light.
- ♦ Active Porphyria is extremely painful and can be very debilitating.
- ♦ The Porphyrias can become progressive degenerative disorders.
- ♦ Currently the main aim is prevention strategies to keep them latent.
- ♦ Once triggered an episode can escalate into a biofeedback loop causing toxic build up of

porphyrins.

- ♦ Porphyria has been mistaken for: somatisation disorders, Guillain Barre, growing pains, eczema, epilepsy, MS, dermatology, depression, acute appendicitis, chronic fatigue, Parkinson's, Irritable Bowel syndrome and many, many more.

For more ideas or information on Porphyria contact:

The Australian Porphyria Association.

Ph (03) 9845 2737 Fax: (03) 9845 2777

Email: porphyria@mssociety.com.au

Website: <http://www.porphyria-australia.org>



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.

- A mother with an eight year old son living with **Hereditary Multiple Exostosis** in the Canberra region would like contact with other families around Australia with a child with the same condition.
- The mother of an eight year old son living with **CAPOS syndrome** in Victoria would like contact with other families around Australia with a child with a similar condition.
- A mother with a 16 month old child living with **Bilateral periventricular nodular heterotopia** in Victoria would

like contact with other families in any part of Australia with a child with a similar condition

- A Perth family would like contact with other families living with **XXX Syndrome** in the expectation of forming a support group, online and or in person.
- Health professionals with an interest or knowledge are welcome to contact us
- A family from Western Australia who have a child severely affected with **Lissencephaly** would like to make contact with other families in a similar situation.

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



Interesting Websites



Guide for Community Treasurers

This handbook on financial management for community organisations includes pointers on keeping the books, asset registers, cash flow and tax, to help you run a more successful operation.

Also included is a section to help you understand how to better manage your accounts and special offers on educational and other resources that are available exclusively for community organisations.

The Guide can be posted to you — call Westpac on 1300 660 953 and a copy will be posted in 24 hours — or copies can be downloaded from:

http://www.ourcommunity.com.au/files/community_treasurers_guide.pdf

The Centre for Genetics Education

The centre 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.

The site offers:

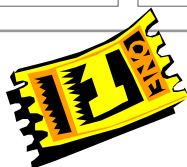
- Fact Sheets covering genetic inheritance, counselling, testing and ethical issues
- contact details of support groups
- services for genetic counselling, familial cancers and prenatal diagnosis
- multicultural resources & web site links

<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, and is not to be used for diagnosis

Coming Events



2006 GP & Primary Health Care Research and Information Service Conference is to be held in the beautiful city of Perth!

Wednesday 5th - Friday 7th, July 2006.

Please stay tuned for updates regarding venue, theme and the line up of Invited Speakers.

Go to our website www.phcris.org.au for updated information as the conference planning unfolds.

Primary Health Care Research & Information Service, Flinders University
GPO Box 2100
ADELAIDE SA 5001

Phone: (08) 8204 3188

Fax: (08) 8204 4690

Website: <http://www.phcris.org.au>

Communication Disorders In Childhood Organisation: Children's Hospital Education Research Institute (CHERI)

Friday, February 17, 2006

Venue: John Loewenthal Auditorium, Education Block, Westmead Hospital
Westmead, NSW

Communication disorders represent a major challenge for many health professionals, families and schools. This conference will focus on communication difficulties that are present in two common developmental disorders: specific language impairment and autism.

Keynote speaker is Professor Dorothy Bishop, Professor of Developmental Neuropsychology and Wellcome Principal Research Fellow, Department of Experimental Psychology, Oxford UK.

Professor Bishop is internationally recognised for



Coming Events

her research on communication disorders and is author of the 'Test for Reception of Grammar' and 'Children's Communication Checklist'. Presenters will also explore the risk factors for language impairments and the overlap between autism and other developmental disorders.

This is an excellent opportunity to hear well-known international and national researchers in this field. This conference will be of great value to speech pathologists, psychologists, special educators, school counsellors, teachers, paediatricians, medical professionals, psychiatrists and other specialists in this field.

Phone: 02 9845 0418

Email: gerrym3@chw.edu.au

Web: <http://www.cheri.com.au/conferences.html>

For more information:

<http://www.aushealthcare.com.au/documents/events/945/CHERI%20261005.pdf>

Asia Pacific Interventional Advances Conference - First annual cardiovascular interventional symposium. APIA (Asia Pacific International Advances)

Tuesday, November 29, 2005 to
Friday, December 02, 2005

Venue: Newcastle Civic Precinct,
Newcastle, NSW

More than 1000 cardiologists are expected to attend the inaugural APIA. This cardiovascular interventional symposium will bring together cardiologists from around the world to discuss the latest developments in interventions and interventional cardiology, the latest treatments for stroke and migraine, devices and heart failure management and risk factor management. Leading experts will present live cases and symposia on the latest technology and research.

For further information contact the APIA Conference Secretariat on:

Phone: + 61 2 4973 6573

Fax: + 61 2 4973 6609

Email: apia@willorganise.com.au

Website: <http://www.apia.org.au>

The 2nd Australasian Redesigning Health Care Summit. Stamford Grand Hotel, Adelaide, SA

March 28 -29 2006

Improving the flow of patients is the biggest challenge facing health care today. Meeting this challenge is the responsibility of clinicians, administrators and managers of all kinds and at all levels.

Contact: Denise Bolch

Email : redesigningcare@fmc.sa.gov.au

Web: <http://www.flinders.sa.gov.au/redesigningcare>

The International Society for Equity in Health 4th International Conference in Adelaide

September 11-13, 2006.

The theme for the conference is Creating Healthy Societies through Inclusion and Equity, and this reflects the central role of social, political, and economic determinants in creating health. The organisers are *now calling for abstracts*, which are due by March 1 2006. Early registration is available until July 11 2006.

Further information, including forms, is available from the Conference website at:

<http://www.iseqh.org/>



Promote your coming events in the 'Gene Advocate' or on our website!!!

Contact Kristina via e-mail or phone and we can arrange it for you.

Email: info@geneticsupportcouncil.org.au OR Telephone: (08) 9389 6722

Grants

Macquarie Bank

Closes: Ongoing

Aim: To provide financial assistance to community organisations in areas including education, arts, welfare, health care

Ph: (02) 8232 9673

Email: julie.white@macquarie.com.au

Guidelines: http://www.macquarie.com.au/au/about_macquarie/macquarie_in_the_community/application_process.htm

Tye Estate Fund

Deaf Children Australia

Closes: Ongoing

Aim: To provide financial assistance towards the costs of holidays, rest and recreation and/or convalescence for deaf people.

Contact Details: Chief Executive Officer

VSDC Services for Deaf Children

Freecall: 1800 645 916

Ph: (03) 9510 9961 or TTY: (03) 9510 7143

Web: <http://www.deafchildrenaustralia.org.au>

ING Foundation

Closes: Ongoing

Aim: To fund organisations dealing with acute needs in the community. Special consideration is given to services that:

- ♦ directly benefit individuals in need
- ♦ deal with welfare and the disadvantaged
- ♦ help children

Ph: (02) 9234 7411

Application form: http://www.ing.com.au/public/pdfs/INGFoundation_applform.pdf



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

Members of the GSCWA

FULL MEMBERS

Acoustic Neuroma Association of Australia

Alzheimer's Association of WA

Angelman Syndrome Association

Arthrogryposis Support Group

Australian Huntington Disease Association

Australian Pituitary Foundation WA Branch

Australian Tuberculous Sclerosis Society Inc.

Australasian CHARGE Syndrome Association

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

Mental Illness Fellowship WA (Formerly:

Schizophrenia Fellowship of Western Australia)

Motor Neurone Disease Association of WA Inc.

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

Genomics Directorate, Dept. of Health

Health Consumers Council WA

Lone Parent Family Support Service (LPFSS)

The Chromosome18 Registry & Research Society

The Kalparrin Centre

The Neurological Council of WA Inc

Western Australian Deaf Society Inc.

INDIVIDUAL ASSOCIATE MEMBERS

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Darren Webb

Kristina Johns

Linda Bovill

Mark Bovill

Professor Charles Watson

Terry Keating



GSCWA 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/treatment.**

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