

Gene Advocate

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GENETIC SUPPORT COUNCIL OF WA (INC)

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Special points of interest:

- Incorporated Associations p 4
- New Resource. Safe Handover: Safe Patients p 4

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UNDERSTANDING DRIVERS OF COMMUNITY CONCERNS ABOUT GENE TECHNOLOGIES

Gene technology has been the focus of much public and political debate around the globe for the past 30 years, and has continually posed a communications challenge for both scientists and the community. Yet many policy decisions based on public attitudes towards gene technology, being made by industry researchers and government agencies, are based not so much on what the public think, but on what key people think the public think.

Common faulted assumptions used in communicating about gene technology include:

- the public is ignorant of scientific facts,
- the public believe GMOs are unnatural, and
- the public is a victim of distorting media.

Communications strategies that have been based on these premises have generally proved ineffective, both through not engaging in dialogue with the community to better understand their concerns, and through not understanding that the community have specific interests that they wish to be communicated with on. This has been shown clearly in cases of risk communication, where the public are generally not interested in the facts of the science when they have high concerns about a technology, but wish to know who is ensuring their safety.

Vincent Covello has described this as: The community don't care that you know, but want to know that you care.

While many surveys have been undertaken to find out what the public

thinks about gene technology, or to map public concerns, there has been less work concentrating on the underlying causes of community concern, which need to be fully understood in order to minimise public rejection of new technologies with broad benefits.

Also, many policy decisions by industry, researchers and government, referring to public attitudes towards gene technology use over-simplified or erroneous statements of public attitudes. A better understanding of community concerns and factors of acceptance enables for more effective education, consultation and community uptake of new technologies.

This article examines some key studies into drivers of attitudes towards gene technology, and looks at the five factors of influence that have been developed which can be applied to many other emerging technologies.

THE SCIENCE COMMUNICATION PROCESS

The problem with public concerns about biotechnology, from many biotechnologists' points of view, is that the public simply don't understand the science, and if they were only educated about it, the concerns would go away or diminish. This model, however, is an oversimplification and fails to take into account the opposing point of view, which is that the developers of biotechnology applications simply don't understand the public, and if only they were educated about the causes of public concerns they would engage better

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

with them and develop applications that better suited the public's needs.

Public debates on gene technology are too often characterised by scientists speaking a different language from the community, one factual-based and one emotive-based, so a process is clearly needed to bring the two closer together. Effective science communication and science education is part of this, but the other part is more effective understanding of the community.

Fostering a better two-way dialogue between developers of the technologies and society, and better understanding of drivers of social concerns needs to be undertaken, to minimise rejection of new gene technology applications.

This need has recently been highlighted by the British Association for the Advancement of Science's report *Connection Science: What we know and what we don't know about science in society*. It found three key areas requiring action:

- The need for a 'broker' to disseminate and discuss research developments, bringing together researchers from different fields and disciplines, and connecting researchers with stakeholders, policymakers and the public.
- Pragmatic research to fill factual gaps, for example, about where do people currently gain their knowledge about scientific matters, and about developments in education.
- Research which goes into greater depth about people's values, motivations and concerns. Survey results tell us much about what people believe; we need to understand more about why they hold these beliefs and how they manage their anxieties and concerns.

Biotechnology Australia has been conducting qualitative and quantitative attitudinal studies since 1999, looking at issues as diverse as genetically modified food and crops, cloning, and human health issues, including stem cells, and using this to position itself as a credible source of factual and balanced information that meets the community's information needs. Key findings from the research

includes the strong influence of ethics in decision making and the five key factors of influence.

Factors of Influence

Focus group studies, used to compliment quantitative studies, have been very useful in delving deeper into the way people form their attitudes and the influence these attitudes might have on behaviours. The three major studies undertaken for Biotechnology Australia by Yann Campbell Hoare Wheeler and Millward Brown included 40 focus groups

A key finding from the focus groups studies was the emergence of five key factors of influence in governing acceptance of gene technologies – which also apply to many other emerging technologies. These are:

1. **Information** - a level of understanding of the technology and what it can and cannot do, which has to be provided from a credible source. Misinformation campaigns, either demonizing the technology or over-promising its benefits tend to increase confusion and diminish trust in many people, leading to a lessening of the influence of information on attitude formation. And it is worth noting that pro and anti-gene technology information does not have equal weighting. A recent study of information mixes in the USA showed that negative information on GM foods had a larger impact on people than positive, and when people were shown both positive and negative, the net effect was still a slightly lower rating of GM foods.
2. **Regulation** - a level of confidence that effective regulation exists to protect humanity and the environment. In relation to gene technology regulation in Australia government regulation is much more highly preferred over industry regulation, and while knowledge of government regulators is low, confidence in them is relatively high (70%).
3. **Consultation** - a feeling that the public has had some input to the development of the technology. If the public believe that a technology has been foisted upon them they are more likely to reject it. Consultation must also address root concerns in the language of those concerned, and must be seen to be

having some effect. Hence scientific information is often not well received by members of the public who are seeking information that addresses their more emotive concerns. Consultation is also more effective if done before the development of an application, rather than after its development (as has occurred with GM foods).

4. **Consumer choice** - the ability for an individual to accept or reject each application of the technology. In relation to human health applications of gene technology there is high perceived choice, but in relation to GM foods most people want to see more labeling of GM foods.
5. **Consumer benefit** - a clear individual and societal benefit from each application. The current generation of GM foods, for instance, do not have many perceived consumer benefits, while most health applications do.

It should also be pointed out that perceptions are more important than realities in relation to these five factors of influence – so if there is a perception that there is no good regulation, than in mind of the public(s) there is no good regulation. Perception, in effect, becomes reality. Very few applications of biotechnology currently fulfill all five criteria well and contentious applications, like genetically modified foods and crops, fulfill none of them well.

Pro-gene technology advocates work very hard to push these factors towards higher acceptance, through key messages such as ‘this technology will feed the world’, while anti-gene technology advocates work hard to push them towards higher rejection, through such key messages as: ‘we don’t know enough about the technology’ or ‘regulation is not thorough enough’.

The high rejection of GM foods can be mapped out as having confusing information due to the high amount of conflicting information, or misinformation; a feeling that no public consultation was undertaken; a lack of consumer choice in countries without GM food labeling; and no direct consumer benefits as the technology was produced to benefit farmers and large agro-chemical companies. GM medicines, by

comparison, rate high against all five criteria and have high acceptance.

EVALUATION

So what does it all mean? To seek optimal adoption of a new technology it is necessary to best understand both the drivers of concerns and the factors of influence that govern adoption, so that it is possible to match technological development with community acceptance.

DISCUSSION

We are already witnessing nanotechnology being highlighted as a technology of global concern, not primarily because of the technology itself, but because of the lack of perceived regulation and community consultation undertaken in its development.

Science communication needs to best understand drivers of community concerns to most effectively meet them or many emerging technologies will meet strong community resistance that will hamper their introduction.

CONCLUSION

How a technology is introduced into society can be more important than the benefits of the technology. We live in a rapidly changing world and need to best understand the nature of social change to optimise the development of new technologies that are both beneficial economically and are acceptable to society.

Extract from:
C Cormick and S Ding
Biotechnology Australia, GPO Box 9839, Canberra,
ACT, 2601. Australia.



Full article can be viewed at:
<http://www.biotechnology.gov.au/assets/documents/bainternet/Beijing200520060209145752.pdf>

Safe Handover: Safe Patients.

The Australian Medical Association has launched a new publication, Safe Handover: Safe Patients, to assist hospitals, doctors, and other health professionals improve patient safety, particularly at times when there is a transfer of responsibility for patient care.

Based on a similar guide prepared by the British Medical Association, which is highly regarded and widely used in the UK, Safe Handover: Safe Patients is the first guide of its kind to be published in Australia.

Handover is 'the transfer of professional responsibility and accountability for some or all aspects of care for a patient, or group of patients, to another person or professional group on a temporary or permanent basis.'

The aim of any handover is to achieve the efficient communication of high-quality clinical information at any time when the responsibility for patient care is transferred. Good handover is at the heart of an effective health care system and stands alongside patient clinical documentation, letters of referral and transfer and discharge documentation.

Together, these make up the links in the chain of continuity of patient care. Handover requires systemic and individual attention and needs education, support, facilitation and sustained effort to ensure it maintains a position of importance in an already full working day.

In the face of the changing work patterns of the medical workforce, clinical handover is an increasingly essential practice. Health administrators, and medical and nursing professionals must work together to ensure good clinical handover practices are developed and maintained. Staff must be supported in their endeavours to achieve this – and this means having dedicated time and resources.

Safe Handover: Safe Patients is available in PDF format from the AMA website.
<http://www.ama.com.au/web.nsf/doc/WEEN-6XFDKN>

Department of
Consumer & Employment Protection

Incorporated Associations

You can change the laws affecting incorporated associations

The Incorporated Associations Act 1987 provides a framework for the regulation of not-for-profit organisations such as sporting and recreation clubs, societies and community groups.

The Associations Incorporation Bill 2006 was tabled in State Parliament on 30 November 2006 as a Green Bill – a proposed new Act. The Green Bill is not the Government's final policy position on changes to the law but presents an opportunity for members of associations and other interested people to see the details of the proposed changes and provide constructive comment.

For copies of the introductory brochure, Green Bill, Explanatory Memorandum or Consultation Guide please call Consumer Protection on 1300 30 40 54 or email a message, including your mailing address, to consumer@docep.wa.gov.au.

The documents can also be viewed at your local public library or be downloaded from www.docep.wa.gov.au/agb.

The closing date for submissions is Monday 30 April 2007.

Details on how to make a submission are available on the website and online submissions are welcome. Alternatively you may use the Consultation Guide to make a written submission by post or by email to agb@docep.wa.gov.au.

Enquiries about policy matters or submissions may be directed to the Project Manager, Stephany Durack, on (08) 9282 0909.

Employment: assisting young people with disabilities

EDGE Employment Solutions has a strong commitment assisting young people with disabilities to establish meaningful, productive and sustainable careers in open employment. In the coming years people with disabilities who have no vocational qualifications will have to compete with more job hunters for less entry-level (i.e. unskilled) positions.

These positions are also likely to become progressively less well-paid and offer less attractive conditions than semi-skilled and skilled positions. If people with disabilities do not begin to gain recognised vocational competencies and qualifications as they move through school and into employment, the very real danger exists they may become part of the future working poor in low paid jobs that offer little interest, opportunity or enjoyment.

School students with disabilities have a great opportunity to get their careers on the right track while they are still at school by entering into a School-Based Traineeship. Traineeships involve a minimum of 832 hours of paid employment (which can be organised through EDGE), which provides both valuable work experience and much appreciated income for the trainee. The training component of the traineeship is usually undertaken during school hours and can be delivered at the school, on the job or elsewhere.

Trainees who successfully complete their traineeships are awarded a nationally recognised Certificate II level qualification in their area of training. The traineeship is also an excellent bridge to a work-based traineeship

further vocational education or training after completing the School-Based Traineeship, they will already have developed valuable vocational skills, have a better insight into work, have a more impressive resume, have established a good relationship with EDGE and, for all the forgoing reasons, be far easier to place into a suitable job when they leave school.



“School students with disabilities have a great opportunity to get their careers on the right track while they are still at school ...”

EDGE has developed a generic web-site, <http://www.careertips.net.au>, that provides practical information and resources for school students with disabilities who are seeking to make a successful transition from school to work.

EDGE currently partners with a number of schools developing School-Based Traineeships for final year students with disabilities.

Schools wishing to learn more about School Based Traineeships can visit Edge’s apprenticeships training page on their website at: <http://apprenticeships.training.wa.gov.au>.

Any school that wishes to explore working more closely with EDGE to develop School-Based Traineeships can register their interest by phoning EDGE’s Manager Customer Relations, Matt Eaton, on 9286 6600.

Information Source and Further Info Available:
<http://www.edge.org.au/mm04/mm04.htm>

Cleft Palate and Lip Society of W.A.



ANNUAL GENERAL MEETING

**Sunday 27th May 2007
@ 1.00pm**

**Princess Margaret Hospital
Administration Building
Roberts Road, Subiaco**

**Guest speakers
& Crèche facilities**

Afternoon tea provided

**Please RSVP to Kelly by 22nd May
on 9418 3842 or 0416 216 350**

*Everyone is welcome.
We hope to see you there!*



FRAGILE X SYNDROME SUPPORT GROUP WA

The Fragile X Support Group of WA offer our support and services to families, carers, relatives or interested parties of individuals diagnosed with Fragile X Syndrome.

Our Aims

- To promote knowledge of Fragile X Syndrome within the community
- To provide access to, and distribute up-to-date information about Fragile X Syndrome
- To provide family contact and encourage social interaction between members and their families
- To liaise with, and exchange information with other interested groups
- To promote awareness of appropriate educational and social opportunities for individuals with Fragile X Syndrome
- To promote and support appropriate planning for the future lives of individuals with Fragile X Syndrome.

If you have any concerns about your child, know a family affected by Fragile X Syndrome, or would like further information about Fragile X Syndrome, please contact us.

Azma Hosken
08 9439 1828
hoskens@optusnet.com.au

Aaron and Sharon Sargent
08 9439 3184
shazazz2@bigpond.com.au

Or visit our website at:

www.fragilex-wa.websyte.com.au



Members Profile



Diabetes WA offers a range of diabetes management services designed to help you to understand your diabetes and how it affects your body, whilst identifying ways in which you can manage your lifestyle to keep your diabetes under control.

Shop Smart: A two-hour shopping tour conducted by one of our Diabetes Educators, Shop Smart is a hands-on way for you to learn how to decipher and analyse food labels in order to make healthy choices for every day meals while determining what foods are best chosen as the occasional treat.

Shop Smart is free to NDSS registrants and Diabetes WA members.

Cook Smart: After this 90-minute interactive food preparation session conducted by one of our Diabetes Educator Dieticians, you will leave equipped with a range of cooking techniques that will enable you to prepare tasty and healthy snacks and meals without compromising on taste. You will also be encouraged to taste test a variety of healthy products that you may not have tried before.

Cook Smart is free to NDSS registrants and Diabetes WA members.

Refresh: Designed specifically for people with Type 1 diabetes, Refresh provides a supportive and friendly forum for participants to discuss issues they may have on a range of topics such as nutrition, physical activity or stress management. Two three-hour sessions are held over consecutive weeks in order to allow participants the opportunity to explore issues that are important to them.

Refresh costs \$45 - Diabetes WA members receive a 20% discount.

Living with Diabetes: A must for people with Type 2 diabetes that are either newly-diagnosed or have never attended a diabetes program before. Full of practical and pragmatic information and advice, Living with Diabetes has

been designed to equip you with the necessary skills to manage and live well with your diabetes in six informative and interactive modules:

Getting Started: A great session that is all about getting you on the road to truly understanding and managing your diabetes, it includes everything you need to know about monitoring your blood glucose levels.

Balance in Your Eating: A must for learning about the essentials of healthy eating for diabetes which, you will find out, is about so much more than just watching your sugar in-take!

Shop Smart: A hands-on way for you to learn how to decipher and analyse food labels so you can make healthy food choices and decide what is best kept as an occasional treat.

Physical Activity & Stress Management: A motivating session to help you get active and avoid stress which, if left unchecked, can impact on your diabetes.

Risk Management & Medications: A practical session that will take you through which regular tests you should be performing to keep on top of your diabetes and what medications can help you to best manage it.

Foot Care & Self-Management: A great way to learn how to keep your feet healthy, decipher the plethora of information you may read about diabetes in the media, and generally live well with your diabetes.

You can choose to do all six modules as a set, or once you've completed module 1 – Getting Started – you can simply pick which of the other modules best suit your needs.

Modules 1 and 3 – Getting Started and Shop Smart - are free to NDSS registrants and Diabetes WA members. All other modules cost \$60 each, with a 20% discount for Diabetes WA members.

Discounts also apply if all six modules are booked at once. Plus HIF and Medibank Private members may be eligible for rebates.

Bookings are essential.
Call us on 1300 136 588 to find out more about any of our sessions or to secure your place and request a Diabetes WA Calendar!

Cont...

Members Profile cont.

Keeping on Track: Designed to inspire and motivate people with Type 2 diabetes, Keeping on Track is created for people that have attended some form of diabetes education in the past and aims to help them continue on the path of good self management by updating existing knowledge and providing additional support and encouragement.

Two three hour sessions are held over consecutive weeks, Keeping on Track costs \$45 -Diabetes WA members receive a 20% discount.

Eat Smart Seminar: Designed for people who want to avoid fad dieting but still need help with weight management, the Eat Smart seminar will show you just how healthy eating and weight management go hand in hand.

All Diabetes WA seminars cost \$15 – Diabetes WA members receive a 20% discount.

Tai Chi: We are all aware of the importance regular physical exercise plays in our health and wellbeing. However, finding the most suitable type of exercise is just as crucial. Let's face it, the idea of a one hour kick boxing class does not appeal to all! For those of us who prefer a more gentle form of exercise, Tai Chi may be the perfect choice.

Tai Chi is based on a system of slow flowing movements and shifts of balance. These movements strengthen the legs while conditioning the tendons and ligaments of the ankles, knees and hips - increasing their range of motion and making them less prone to injury.

Term 1: 31/1/07 – 4/4/07
Term 2: 2/5/07 – 4/7/07
Cost: \$5 per class / \$50 full term

Diabetes WA also offers a number of additional services including:

Diabetes Advice and Information Line:

DIAL is a free service, manned by a team of experienced Diabetes Educators who are able to answer any questions you may have about diabetes, provide support and recommend referrals to other health providers if required. No query or concern is too small or too large for our team to deal with – there are no silly questions! You can reach the DIAL team by phone, fax or e-mail from 8am to 8pm Monday to Friday.

Simply call 1300 136 588, fax (08) 9221 1183 or e-mail dial@diabeteswa.com.au.

One-on-One Education Sessions: Personal education and information sessions can be booked with any of our Diabetes Educators to discuss whatever questions or concerns you may have about your diabetes and how to best manage it. Our educators are able to assist with a broad range of issues such as dietary advice, preparing for an overseas holiday and insulin management.

Individual consultations cost \$60 – Diabetes WA members receive a 10% discount. Medicare and private health fund rebates may also be applicable in some cases.

Call us on 1300 136 588 for further information.

Advocacy Advice & Support: Our Advocacy Officer strives to ensure a fair deal for all people with diabetes and can help you if feel you are being discriminated against or treated unfairly because of your diabetes.

For confidential advice and support, contact us on 1300 136 588.

Detour Diabetes: A free self-paced program, Detour Diabetes is a step-by-step guide to helping prevent Type 2 diabetes. It combines a number of home-based activities with regular contact with an experienced Diabetes Educator to help participants find the motivation to meet the challenge of changing habits that may be putting them at risk of diabetes. You can learn more about Detour Diabetes by visiting www.diabeteswa.com.au/detour or by calling us on 1300 136 588.

Speak Out: With the help of a team of experienced and qualified volunteers, the Speak Out program raises awareness of Type 2 diabetes through community presentations on the risk factors that contribute towards its onset and how to reduce them.

To book a free Speak Out presentation for your group call the Health Promotion Team on 1300 136 588

For further information on Diabetes WA and our work call us on 1300 136 588 or check out our website.



<http://www.diabeteswa.com.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.

- 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.
- A person living with **Kleinfelters Syndrome** XXY in Canberra/NSW is starting a support group for guys with XXY in Canberra / NSW and would like to get in contact with any other guys that have KS.
- 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.

- A lady living with **multiple enchondromas** is seeking contact with others living with this condition in Australia.
- **Chromosome 6q27 deletion** Rita and Arthur have two sons with this rare deletion and would love to hear from other families with the same condition. They can be contacted through the *Genetic Support Network of Victoria*.

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

Senses Foundation: Usher Syndrome Support Group



A 12 month project is underway to promote information and support relevant to individuals who have Usher Syndrome and their families. Usher Syndrome is a genetic condition which causes **hearing loss** and progressive **vision impairment** due to Retinitis Pigmentosa.

Senses plans to meet with each person with Usher Syndrome to invite their ideas on what and how we could provide the best information and support. We will also be providing information to associated agencies so that people with Ushers can find out about support networks for people with similar needs and concerns.

We hope that more regular on-line and face to face contact will build on the friendships between people that have developed over many years and

provide a welcoming groups for people new to the services of Senses Foundation.

The World Deafblind International Conference in Perth in 2007 will provide a wonderful opportunity for us all in Australia to learn more about Usher Syndrome. We aim for the people in the Usher Syndrome Support Group to be in the next position to take advantage of the conference on our doorstep. In particular there is a two day Usher Study Group before the conference which will have Australian and international speakers, many well known in the Usher world.

For more information contact Robin Hamilton, Communication Specialist (Tues & Wed) at the Senses Foundation on 9473 5419 or by email at Robin.hamilton@senses.asn.au.

Information about the 2007 World Deafblind Conference can be found at:
Www.dbiconference2007.asn.au

Interesting Websites

For debate: Individual patient consent in research.

Waiver of individual patient consent in research: when do potential benefits to the community outweigh private rights?

Nikolajs Zeps, Barry J Iacopetta, Lyn Schofield, Jillian M George and Jack Goldblatt.

Med J Aust 2007; 186 (2): 88-90.

Read the full article at:

http://www.mja.com.au/public/issues/186_02_150107/zep10300_fm.html

[Last Reviewed: 17/01/2007]



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 or treatment.

Activ - Parent Portal

Information is important to the parents of children with developmental disabilities in making decisions about the best care for their child. However finding quality information easily and quickly can be difficult.

Activ Library's Parent Portal aims to provide a starting point for parents to quality resources about developmental disabilities and covers books, videos and websites.

This resource provides a guide for parents to resources appropriate to all stages of life from diagnosis to aging. about intellectual disabilities



<http://www.activ.asn.au/parentportal>

[Last Reviewed: 23/01/2007]

Understanding Genetic Conditions

Genetics Home Reference provides consumer-friendly information about the effects of genetic variations on human health.



Genetics Home Reference
Your Guide to Understanding Genetic Conditions

<http://ghr.nlm.nih.gov/>

[Last Reviewed: 05/07/2007]

Services and self-help groups

How do we ensure that everyone gets the help they need?

Do we set up our own services or try to work in partnership with local providers?

This article provides guidelines for establishing local services and introduces the two following articles by parents describing how they have set up early years intervention groups.

In the first article, Ann Haig in Ireland, describes the way in which she has set up a group with other parents. The group provides support and it aims to specifically promote the children's development through structured activities.

The second article is from the founders of the Bristol Branch of The Down Syndrome Educational Trust. Here parents have worked with the statutory services to provide speech and language therapy groups and they also offer a chance for parents to meet and talk over coffee. The speech and language therapist works for the local National Health Service Trust but the Bristol Branch pay for her time for one day per week.

Source - Buckley S. (2002). Services and self-help groups - how do we ensure that everyone gets the help that they need? Down Syndrome News and Update, 2(3), 103-103.

Available: <http://information.downsed.org/library/periodicals/dsnu/02/3/103/>

Coming Events



Muscular Dystrophy Street Appeal

Date: Friday 16 March 2007



This event raises funds for research into a cure for Muscular Dystrophy. This event raises funds for support services for our MD community and for research into a cure for muscular dystrophy". Contact: (08) 9382 2700

Website: <http://www.mdawa.asn.au>

Kidney Street Appeal — Kidney Health Australia

Date: 23 March 2007



The annual fundraising street collection day will be held in Perth. The regional dates may vary.

Contact: (08) 9381 9311

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

The Australian Stem Cell Summit 2007

Date: 29 - 30 March 2007

Location: Hilton on the Park, Melbourne, VIC
The Australian Stem Cell Summit will provide a forum for Australian researchers to meet and discuss the issues facing the industry, opportunities and the shape of things to come.

Website: <http://www.informa.com.au>

2007 GP & PHC Research Conference 2007

23-25 May, Sydney Convention & Exhibition Centre,

This conference is a must for anyone with an interest in primary health care research, evaluation and development. It will provide ample opportunities for PHC researchers, decision makers, practitioners and consumers, to get together to network, form collaborations, share ideas, and debate the many issues raised by speakers and delegates.

Website: <http://www.phcris.org.au/conference/2007>

Motor Neurone Awareness Week Motor Neurone Disease Association

Date: Sunday May 6 to Saturday May 12, 2007

This week aims to increase awareness in WA of Motor Neurone disease. Various awareness raising and fundraising events will be held across the week.

Contact: (08) 9346 7355

Website: <http://www.mndawa.iinet.net.au>



National Arthritis Week

Arthritis Foundation of WA Inc.

Date: 2 - 8 April 2007



Something can be done for people living with the pain of arthritis and other musculoskeletal conditions. 10 simple steps can help better manage arthritis and improve quality of life. Call 1800 011 041 for your free copy of 10 Steps to Living well with Arthritis.

Contact: (08) 9388 2999

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

Activ Awareness Week Activ Foundation

Date: 3 - 9 April 2007



An awareness week to educate the public about the services Activ Foundation provides to individuals with intellectual disability and their families in Western Australia.

Contact: (08) 9387 0555

Website: <http://www.activ.asn.au>

Violet Ribbon Day Continence Advisory Service

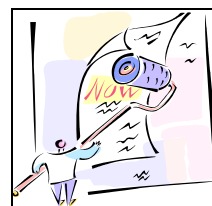
Date: 26 April 2007

Violet Ribbon Day aims to raise the awareness of bladder and bowel control problems in the community. Everyone needs a healthy bladder and bowel and by wearing a Violet Ribbon people are encouraged to talk about bladder and bowel problems and to seek help.



Contact: (08) 9386 9777

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



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

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

Grants

Respite and Family Support

Provider: Disability Services Commission (WA)

Closes: April 2, 2007

To provide respite opportunities to families who care for a family member with a disability who has complex and/or high support needs in the family home and who are in need of crucial support.

Respite opportunities may include a range of activities, services or supports that could have a 'respite effect', that is, results in a break for the carer from their carer role. The activities should ideally assist the family to manage the issues that precipitated the urgent need for respite.

The intended outcomes of Intensive Family Support Funding are:

1. support is provided for primary carers at times of critical need;
2. services provided are holistic, flexible and individually tailored to address the critical need and maximise the family's control;
3. services support and strengthen family well being and enhance family capacity to provide ongoing support; and
4. the services or supports provide enjoyable and positive developmental experiences for the person with the disability.

Typically, funding is provided for supports, such as personal assistants. Support is provided to enable the primary carer an opportunity to have a break from their carer role. (Note: Administration, coordination and direct care costs are funded according to relevant benchmarks.)

Priorities: Ageing Carers and families with an "immediate need" for assistance.

Who can apply: To be eligible to apply for funding, the person with a disability must qualify for level two or three services from the commission.

Further Information

Contact : Manager Community Support Program
Disability Services Commission

Email: cap@dsc.wa.gov.au

Freecall: 1800 998 214

Phone: (08) 9426 9200 **TTY:** (08) 9426 9315

Assistance for Day to Day Living in the Community Programmes

Provider: Dept of Health and Ageing

Closes: March 20, 2007 [Will re-occur]

To improve health outcomes for people with severe and persistent mental illness who experience social isolation through the provision of structured and socially based activity programs.

The overall objective of the D2DL program is to improve social and health outcomes for people with persistent and severe mental illness by funding experienced NGOs and Indigenous-specific primary health care organisations to provide structured social activity programs where individuals can participate in social rehabilitation activities and improve their independent living skills.

Specific objectives of the D2DL program are to:

- expand the capacity of the NGO and Indigenous sector to offer structured day programs for people experiencing social isolation through severe and persistent mental illness; and
- increase program participants' ability to live at an optimal level of independence in the community through:
- development of new skills or relearning old ones;
- strengthening social networks;

Limitations: Funding is not available for:

- Services outside of the identified geographical sites;
- projects or activities that duplicate existing resources or initiatives (applicants must demonstrate funding is for new places);
- one on one psychosocial rehabilitation;
- capital works;

Who can apply: Funding is being made available to experienced NGOs and Indigenous-specific primary health care organisations for the provision of structured programs for people with severe and persistent mental illness living in the community in the **pre-selected geographical sites**. involved in supporting both individuals affected by a mental illness as well as their families and carers.

How to apply: Mail

Further Information

Telephone: 1300 887 745

Working full-time and caring for a disabled or chronically ill child?

Are you working full-time and caring for a disabled or chronically ill child?

If so, your participation in a University of Western Sydney national survey would be appreciated. Its aim is to identify your needs and provide valuable information to plan better support services for you.

The information you provide will enhance the research team's understanding of the difficulties and support requirements of full-time workers who are also caring for a child who is chronically ill or has a disability.

Your participation will involve completing a questionnaire and returning it in a reply-paid envelope that will be provided.



This is a great opportunity for you to have your say about your needs and those of your child.

You can also complete the questionnaire on-line at <http://www.workingandcaring.org> (Link opens in new window).

It will take about 25-40 minutes of your time and your confidentiality and anonymity will be maintained.

✳ Copies of the questionnaire are kept at the University of Western Sydney.

Please contact Ajesh George on 02 9845 0422 who will send you one.

If you would like further information about this study, please call:

Professor Lesley Wilkes on 02 4734 3181 or
Email: mcmanua@wahs.nsw.gov.au

Members of the GSCWA

FULL MEMBERS

Acoustic Neuroma Association of Australia
Alzheimer's Association of WA
Angelman Syndrome Association
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Australian Cystinosis Support group
Australian Huntington Disease Association
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Australian Tuberous Sclerosis Society Inc.
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Coeliac Society of WA
Cornelia De Lange Syndrome Support Group
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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)

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

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