



Gene Advocate

Issue 51

2008

The fight for a life-saving drug: a personal perspective

Medical practitioners often face the difficult challenge of delivering unpleasant news to patients. When my doctor used the words “brain tumour”, like most people who have to deal with that diagnosis, I found it difficult to comprehend anything else for a few moments. However, the word “benign” did bring me some comfort. I had had no pain and just a little hearing loss in my right ear so was stunned by the finding.

Over the next few months, I saw specialists for opinions on treatment options for meningioma. It was important for me to gain a better understanding of what I had to deal with and my treatment options and their associated risks.

I didn't let family or friends know for some time and needed more information to be equipped to deal with those who might react emotionally, particularly my elderly mother who was convinced my hearing loss was probably caused by ear wax.

It soon became apparent to me that, owing to the tumour's location at the skull base, adjacent to the brainstem (Box), and its involvement with three facial nerves and the carotid artery, removal or treatment was not going to be without considerable risk. While doing some research on the subject, I came across references indicating that a high percentage of meningiomas contained progesterone receptors, and there was mention of a drug that could halt the growth of the tumour. The drug was RU486 (mifepristone), the most effective progesterone antagonist available. In overseas clinical studies, it had been successful in some meningioma patients. In my view, a trial of the drug was a better option than the 50% risk of irreparable damage to my vision through surgery.

The uncertainty of the long-term prognosis after stereotactic radiotherapy was also unappealing.

After doing more research on the drug itself, I found that it had extensive medical uses, such as treatment of meningioma, some breast and ovarian cancers, endometriosis and fibroid tumours and, in higher doses, its action as a glucocorticoid antagonist in Cushing's syndrome. Research on the drug's myriad medical uses had been plagued by controversy. Why? Well, apparently because progesterone is the hormone necessary to sustain a pregnancy, and not interfering with it is considered to be sacrosanct by the powerful antiabortion lobby groups. As a result, research into and clinical trials on the drug's other uses have been hampered and delayed.

I contacted the Feminist Majority Foundation and the Association of Reproductive Health Professionals in the United States and had several email conversations with their representative. The insights provided were invaluable, and we maintained regular contact for some time. I will always be grateful for the information and support she provided at that time.

When I looked into the drug's availability in Australia, I came across a story on the website of the Australian Broadcasting Corporation titled “No room at the inn for RU486”, posted only a few months earlier in November 2004. It included dialogue with representatives of the Minister for Health and Ageing. In closing, the message to those who were interested in the drug being made available in Australia was “don't hold your breath”.

Continued . . .

The fight for a life-saving drug: a personal perspective

I had a tumour growing in a confined space that threatened to compromise the functioning of vital nerves and life itself. I understand there is about a 1 : 50 000 chance of a diagnosis of meningioma and 20% of these are at the skull base, therefore a 1 : 250 000 chance of diagnosis of a skull-base meningioma. What are the chances of having a diagnosis of meningioma while working in the Department of Health and Ageing, as I was at the time?

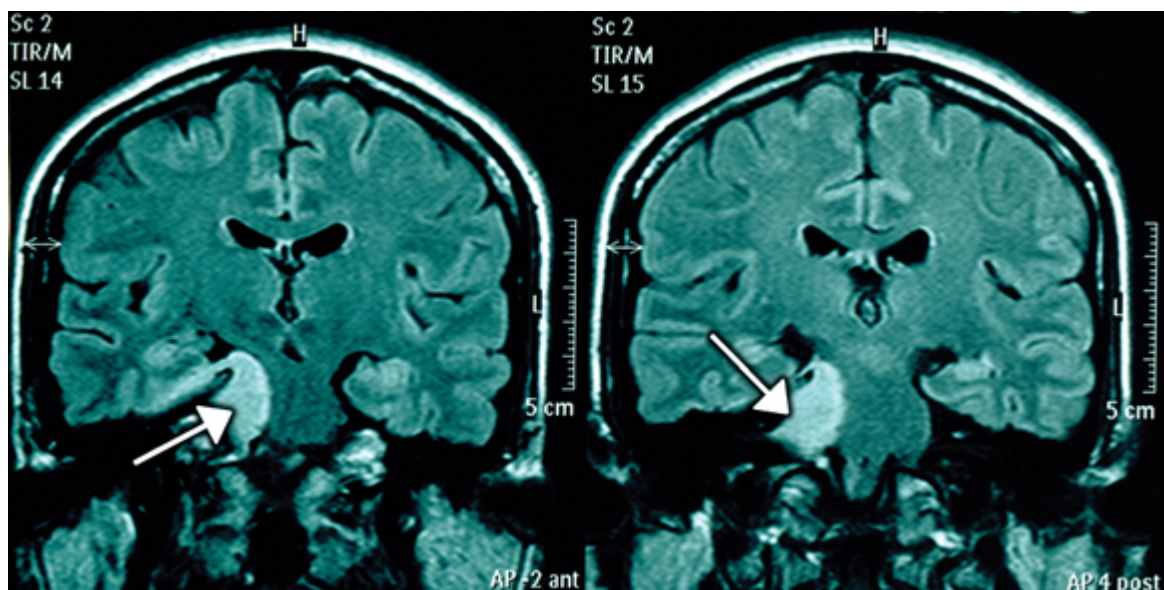
There was no point in raising the issue internally. I was acutely aware of the precarious position I was in, but, nonetheless, I had to do something about this issue. After giving the matter some thought, I contacted Senator Lyn Allison, the leader of the Australian Democrats, who made some enquiries in Parliament via Questions on Notice to the Minister for Health. I was later provided with a copy of the response. The government knew the drug could be used for a range of serious medical conditions and advised it could be obtained through the Special Access Scheme of the Therapeutic Goods Administration (TGA). I thought it peculiar that the government knew this, but did not make that information public to ensure patients and doctors were also informed.

I contacted my general practitioner with the details, and she lodged an application with the TGA. On 7 September 2005, Senator Allison gave a speech in Parliament titled “Matters of public

importance — mifepristone”. The campaign to amend the legal status of the drug was subsequently launched. Thankfully, Senator Allison had the courage to take on this enormous challenge and the breadth of vision to do so in the interests of public health.

The day after Senator Allison’s speech in Parliament, the TGA issued a permit to my GP to import the drug to treat my tumour. I was elated and spent the next month and a half trying to track down overseas suppliers, with the help of a local pharmacist. When I obtained those contact details, I then saw my GP again so we could get the importation under way. At that point she advised me that she had decided not to proceed, because of medical indemnity insurance issues. I offered to get a lawyer to draw up a personal indemnity. She refused the offer.

My GP gave me a copy of the letter which accompanied the permit. It was signed by a “delegate of the Secretary” and dated 8 September 2005. It stated “All parties involved need to recognise the practice may carry medico-legal risk, and there may be implications regarding indemnity”. Why did the TGA wait until they issued a permit before providing that advice? Clearly, no consideration was given to the impact on the patient who had the rug pulled out from under her feet in an instant. I contacted Senator Allison to inform her of this problem and she raised it at the



Coronal magnetic resonance images showing a meningioma (arrows) pressing and displacing the brainstem.

The fight for a life-saving drug: a personal perspective

public hearings in the Senate in December. Senator Allison asked the following question of the Secretary of the Department of Health and Ageing and the head of the TGA: "Could you outline the issues to do with medical indemnity, which I gather are a problem in some of these cases?". They both replied, "not that we are aware of". When asked whether the Department had done any studies of the drug, the Secretary advised that they had not. She also advised that the Department was responsible for administering the legislation and believed it did so with "due diligence". She claimed there were no barriers for anyone wanting to do research here into the drug's non-abortifacient uses, but the experiences of some have been to the contrary.

Unknown to most people is the fact that the supplier succumbed to pressures via threats of boycotts by the powerful antiabortion lobby groups some years ago and decided that "... the company would not sanction exports unless ranking government officials in the country urged them to do so ... there must be an actual wish for the licensing of mifepristone in a particular country ... the letter indicated such a wish could come in the form of a written request from a representative, competent body such as the government or health authorities".

Lobbying during the campaign to change the legislation to allow the TGA to regulate RU486 was intense, and to help raise awareness of the drug's use as a treatment for meningioma, I participated in some broadcasts, with the help of the Australian Broadcasting Corporation.

My contact in the US kindly did a submission for the Senate Inquiry, and I later found one from Professor Healy, who wrote the first clinical review of the drug in 1985. Because of the hard work of many, the parliamentary conscience vote to repeal ministerial responsibility for approval of RU486 in early 2006 was won by a resounding majority. The vote was an important milestone, but there is still a long way to go before the drug will be readily available. The amendment changed the legal status of the drug and allowed a drug company to lodge an application with the TGA for approval of mifepristone for use as an abortifacient. Easier access to the drug will facilitate research and

clinical trials into the drug's uses in Australia, depending on the necessary funding approvals by government. Access to the drug for individual patients and for non-abortifacient uses is, at this stage, only available via the TGA's Special Access Scheme.

It was over a year after I found out about mifepristone, and nine months after the TGA issued its first permit, before I was finally able to start my treatment, with the assistance of an oncologist who heard of my predicament. He was willing to import the drug and required only my written agreement to be treated with an unapproved drug.

I have now been taking mifepristone for just over a year at 200 mg per day and can say from personal experience that it has very little in the way of side effects, and I am happy to continue with my treatment. It will be another year or so before any meaningful responses can be measured via magnetic resonance imaging.

A few months ago, I was contacted by another patient with meningioma (diagnosed several years earlier and treated by monitoring of the progress of the tumour). She would have liked to have had a trial of mifepristone, but like most people, thought it was unavailable here. Unfortunately, her vision had deteriorated since her initial diagnosis. I provided her with information, and as a result, she has recently commenced treatment on the drug as well. Why don't GPs refer patients to oncologists when they refer them to specialists for opinions, especially when standard treatment options carry such substantial risks?

If the Australian Government is serious about "better health outcomes for all Australians", including those who would benefit from the drug's non-abortifacient uses, some thought should be given to the people who could be helped by this drug.

Interestingly, in addition to the medical uses mentioned earlier, recent developments in overseas research indicate that mifepristone has potential use in some gastric cancers as well, and it also has viability for use as a helper-dependent adenovirus vector in gene therapy for cancer treatments.

The fight for a life cont . . .

The more research I did, the more fascinated by this drug I became. The anti-glucocorticoid effects are dose-dependent, but on the basis of animal trials it has been shown to be neuroprotective and can minimise the adverse effects of ischaemic stroke. Mifepristone can prevent retrograde amnesia induced by electroconvulsive therapy and is currently being trialled for that purpose (ClinicalTrials.gov identifier NCT00285818). In animal studies the drug has been shown to help ameliorate the symptoms of diabetes. The drug's potential use in overcoming the adverse effects of elevated cortisol due to a dysfunctional hypothalamic-pituitary-adrenal axis means it is a potential treatment for Alzheimer's disease, in which higher cortisol levels are associated with a higher level of impairment.

The US Food and Drug Administration has just approved mifepristone for the purposes of reversing the side effects of corticosteroids and for use in patients with Cushing's disease. If only a drug sponsor in Australia would consider sponsoring the drug for the TGA's Orphan Drug Program. This would see it subsidised via a special appropriation until such time as it is made available on the Pharmaceutical Benefits Scheme, which may take up to 10 years for some non-abortifacient uses pending further clinical trials. It saddens me to think that those on low incomes or age or disability pensions would not be able to afford the drug via the TGA's Special Access Scheme, even if other treatment options are not suitable.

Although the Senate amendment was an important campaign to be part of, and I feel honoured to have contributed, given my personal circumstances, it was a challenge I really could have done without. The next is to be able to continue to pay the cost of this currently unsubsidised drug.

Mary Lander, Canberra, ACT.

Correspondence: mary.landerATozemail.com.au

Source: "Lander, Mary et al .The fight for a life saving drug: a personal perspective . MJA 2007; 187: (11/12): 706-708 8Copyright 2007. The Medical Journal of Australia - reproduced with permission".

Community Physiotherapy Services

Program/service

Community Physiotherapy Services (CPS) provides land and water based group interventions to prevent or manage chronic conditions and promote healthier ageing. All CPS programs focus on maintaining or improving mobility, function and physical activity with an aim to maximize independence of participants through exercise and self-management principles.

Description of program/service

CPS programs include 10-week programs for older adults that may not be able to access other physical activity opportunities. Specialised programs are also available for those patients with chronic respiratory, cardiac and/or orthopaedic conditions, as well as those patients with osteoporosis.

CPS programs:

- are supervised by a physiotherapist
- are suitable for individuals with multiple health problems
- provide education sessions and promote self management
- are delivered at minimal cost to the participants

Who can attend

A completed Community Physiotherapy Services Referral/Medical form is required to participate in the program. Please contact CPS for a referral package.

Cost

A nominal fee of \$1 per week is charged for classes. Participants will also incur a venue usage charge at most locations. This varies but is usually \$3-\$4 per week.

Contact

Phone: (08) 9224 1783

Fax: (08) 9224 1765

Address: Programs are located at recreation or seniors centres and public pools throughout the Perth metropolitan area.

Website: www.health.wa.gov.au/cps

Do you care for others?

- ⦿ Did the holiday season wear you down? Do you need some respite?
- ⦿ Are you caring for someone with a disability or illness?
- ⦿ Are you caring for someone with a mental illness?
- ⦿ Are you caring for a frail aged person?
- ⦿ Do you need in home help, domestic assistance, transport?
- ⦿ Are you a young carer, caring for a parent or relative? Would you like to attend hip hop classes, guitar lessons or holiday camps?

Commonwealth Carer Respite Centres provide information, support and advice on a full range of respite care services that are available to support people who provide voluntary care for a relative or friend.

The Centres help carers of people who have a disability, dementia, mental health issues, terminal illness or are frail aged, to take a break from their caring role. They can also assist in emergency or unexpected situations.

The respite services which offer carers a range of flexible options are available through the Centres and can include for example:

In home care: A qualified worker comes into the home to look after the person you care for while you go out or do tasks you are unable to do while caring for the person.

Out of home care: The person you care for can receive temporary residential respite care, centre-based respite services, recreational respite and attend camps, giving you a break from your caring role.

Assistance with home tasks: Someone to help you with meal preparation, cleaning and shopping.

Red Cross runs three Carer Respite Centres, which are an initiative of the Australian Government. Specific programs have been developed to address the growing needs for services for carers of people with a mental health issue or intellectual disability, and young carers.

Young carers, for example, can access after school activities such as cooking classes, musical and dance tuition and school holiday camps.

Australian Red Cross also have available school grants for young carers studying at high school to help cover the cost of books, school uniforms, after school tuition and extra classes.

The grant is available for young people who provide care and support for someone who has a disability, a mental illness, dementia, a terminal illness or is frail aged.

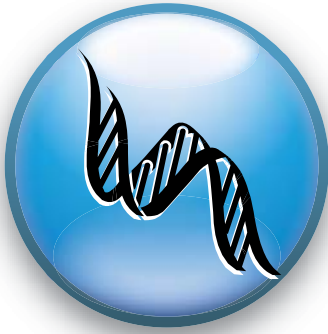
The Centres have a strong focus on linking people with services such as health specific organisations, support groups and other government funded programs in order to achieve longer-term support.

Commonwealth Carer Respite Centres can support you with the following -

- ⦿ Provision of information
- ⦿ Linking you to services that you might need now
- ⦿ Crisis management
- ⦿ Plan a regular break from your caring role
- ⦿ Plan for the future

Contact

Commonwealth Carer Respite Centres
Phone: 1800 059 059.



Member Profile

What is Tourette Syndrome?

Tourette Syndrome (TS) is a neurological disorder, which most often begins between the ages of 2 and 21, and lasts throughout life. TS is NOT degenerative and people with TS can expect to live a normal life span.

What causes the symptoms?

The cause has not been definitely established, although current research presents considerable evidence that the disorder stems from the abnormal metabolism of at least one brain chemical (neurotransmitter) called dopamine. Undoubtedly other neurotransmitters are also involved.

Is it inherited?

Studies suggest that TS is inherited as a dominant gene that may produce different symptoms in different family members. A person with TS has about a 50% chance of passing it on to his/her children, however it may not appear as a recognisable disorder to that extent. The gene may express itself as TS, as a milder tic disorder or as obsessive compulsive symptoms with no tics at all. It is now known that a higher than normal incidence of milder tic disorders and obsessive compulsive behaviours occur in the families of TS patients. In some cases, TS may not be inherited, and is identified as sporadic TS because the cause is unknown.

What are the symptoms?

TS is characterised by rapid, repetitive and involuntary muscle movements and vocalisations called "tics", and often involves behavioural difficulties. The term "involuntary", used to describe tics, is a source of confusion since it is known that most people with TS do have some control over their symptoms. What is often not recognised is that the control which can be exerted, from seconds to hours at a time, only delays more severe outbursts of symptoms. Tics are experienced as a build up of tension, are irresistible and eventually must be performed. Typically tics increase as a result of tension or stress and decrease with relaxation or concentration on an absorbing task. TS symptoms have long been misconstrued as a sign of behavioural abnormality or "nervous habits", which they are not.

How are tics classified?

The two categories of the tics of TS and some common examples are:

SIMPLE - Motor - Eye blinking, head jerking, shoulder shrugging, facial grimacing, nose twitching

Vocal - Throat clearing, barking noises, squealing, grunting, gulping, sniffing, tongue clicking

COMPLEX - Motor - Jumping, touching other people and things, twirling about, repetitive movements of the torso or limbs, pulling at clothing and self-injurious actions including hitting or biting oneself.

Vocal - Uttering words or phrases, coprolalia (the involuntary utterance of inappropriate or obscene words), echoalia (repeating a sound, word or phrase just heard) or palilalia (repeating one's own words)

The variety and complexity of tics or tic-like symptoms that can be seen in TS is enormous.

Do people with TS have all of these symptoms or just some of them??

People with TS rarely have all of these symptoms. Most people will exhibit some or many symptoms over a long period of time and in varying degrees: mild, moderate or severe. In milder cases a person may have just a few tics or twitches, which may be confined to the face, eye and shoulder areas. In more severe cases several areas of the body may be affected. The symptoms wax and wane, in some cases from day to day but more commonly over 3 to 4 month periods. The waxing and waning pattern can sometimes be frightening to people with TS who may find it difficult to understand the sudden intensification or waning of symptoms.

Are there behaviour problems which may occur frequently in addition to tics?

Yes, but not always. Additional problems may include:

Obsessive Compulsive Disorder (OCD), in which the person feels that something must be done over and over. Examples include touching an object with one hand after touching it with the other to "even things out" and repeatedly checking to see that the flame on the stove is turned out. Children sometimes beg their parents to repeat a sentence many times until it "sounds right". OCD can include counting rituals, obsessive preoccupations or thoughts which are unpleasant.

Attention Deficit &/or Hyperactivity Disorder (ADD/ADHD) may include difficulty in concentrating, being easily distracted, failing to finish tasks, acting on impulse, not seeming to listen, shifting constantly from one activity to another, needing a great deal of supervision, being unable to sit still, calling out and lack of self-control. Adults may have residual signs of ADD such as overly impulsive behaviour and concentration difficulties. Learning Difficulties such as dyslexia, arithmetic and perceptual difficulties, handwriting problems.

Behavioural Problems may include compulsive and repetitive behaviours, attention problems, sleep difficulties, depression, poor self-esteem, poor school performance, social isolation, school and social phobia. Some commonly observed problems include oppositional/defiant behaviour, aggressive and uncooperative behaviours.

What are the first symptoms?

The most common first symptom is a facial tic such as rapidly blinking eyes or twitching of the mouth. However, involuntary sounds such as throat clearing and sniffing, or tics of the limbs may be the initial sign. In some cases childhood behaviour difficulties precede tics. ADHD symptoms often precede development of tics in children with both conditions.

Information Source: Tourette Syndrome Association of Australia. Available: <http://www.tourette.org.au/whatis.php> Accessed: 5 December 2007.

Western Australia

Western Australian Tourette Syndrome Organisation (WATSO)

Contact: Irene Gray
Ph: 9448 4040
Email: mazzo48@bigpond.net.au
Web: www.tourette.org.au

Australia



Tourette Syndrome Association of Australia Inc.
Phone: (02) 9382 3726
Fax: (02) 9382 3764
Emails: info@tourette.org.au
Web: www.tourette.org.au



Coming Events



MDA WA Awareness Month

Date: 1 - 31 March 2008

Muscular Dystrophy Awareness Month promotes members, businesses and schools to get out and about representing MDA and holding fundraising days throughout the month for awareness.

Web: www.mdawa.asn.au

MDA WA Street Appeal

Date: Friday 7 March 2008

MDA WA's Street Appeal is held annually. There will be volunteers collecting from Albany to Perth and right through to Kalgoorlie. MDA are always on the look out for new volunteers as we try and make each year more successful than the last. Funds collected on the day directly benefit the MDAWA's aims and objectives.

Web: www.mdawa.asn.au

2008 MD Golf Classic

Date: Friday 28 March 2008

2008 Muscular Dystrophy Association Golf Classic. MDA have had two very successful years and the day is always a lot of fun with friendly competition! It will be the third year of holding the Golf Classic and the MDA are on the lookout for new sponsors. If you're interested in sponsoring opportunities and helping out a great cause please contact Fundraising and Events Manager Brooke Anthony on 9382 2700.

Involving People in Research

Advance Symposium notice

Date: 5 - 6 March 2008

Venue: University Club, Perth

A national symposium on consumer and community participation in health and medical research. The inaugural national meeting will bring together researchers, consumers, community members and students to showcase success stories and further explore the barriers to participation.

The program will include national and international speakers, showcase sessions, workshops and Posters displays.

There will be a limited number of special consumer and student scholarships.

Web: <http://www.sph.uwa.edu.au/go/sph/involvingpeopleinresearch>

National Consumer Congress

Date: 5 - 6 March 2008

Venue: Perth Convention Exhibition Centre

Tickets: Full Registration: \$180 Standard

Day Registration: Wed 5 March \$120

Thurs 6 March \$90

Consumer issues will be under the spotlight at the 2008 National Consumer Congress. NGO delegates will be eligible for heavily discounted registration fees, kindly subsidised by this year's host, the Department of Consumer and Employment Protection. Full registration fee also includes the Congress Gala Dinner on Wednesday 5 March at the stunning Government House Ballroom.

The theme for the Congress is 'Challenges and Responses - Current and Future Issues for Consumer Policy'

Issues to be discussed include:

The Confident Consumer – examining the current Federal review of the Australian consumer policy framework by the Productivity Commission;
The Complex Consumer – examining the impact of behavioural economics on understanding consumer decision-making;
The Virtual Consumer – examining ecommerce and the future of the Internet in Australia; and
The Sustainable Consumer – examining the interface between sustainability policies and consumer policy.

The program includes special presentations by international speakers from the European Union, University of Kent, United Kingdom Treasury, Consumers International as well as many of the leading lights of Australian consumer policy and protection.

Web: www.ncc2008.com



Date: Saturday 8 March 2008
Time: 7pm for a 7:30 start
Venue: Hyatt Regency Grand Ballroom
Tickets: \$160

PMH Intensive Care Unit and children's Cardiac Centre will benefit from the proceeds of this event.
Contact: Fran 0409 290 504



Do you have an event coming up?
Promote it here and on our website at no cost! Contact Kris on (08) 9389 6722 or e-mail info@geneticsupportcouncil.org.au

coles gluten free food & allergy expo

An event organised by The Coeliac Society of Western Australia, Inc.

Date: 15 - 16 March 2008
Venue: Perth Convention Exhibition Centre
Mounts Bay Road, Perth

Discover the key ingredients to gluten free and allergy aware lifestyles at the inaugural Gluten Free Food & Allergy Expo in Western Australia.

Taste - Australia's leading suppliers, retailers and distributors will showcase their latest product range.

Educate - Four seminars will be held daily featuring leading speakers on both gluten free and allergy aware living.

Cook - There will be eight different presentations over the two days showing how to cook with flair in your own home.

Inspire - Talk to the experts and find out more about safer, clearer food choices and a gluten free lifestyle.

Web: www.glutenfreeinwa.com.au

3rd International Congress on Women's Mental Health

Date: 16 - 20 March 2008
Venue: Melbourne Convention Centre

Building on the success of the previous Congresses held in Berlin and Washington this one in Melbourne will aim to attract over 1,000 psychiatrists, psychologists, mental health workers, carers, consumers, researchers, policy makers and bureaucrats from across the globe. Under the sponsorship of the International Association for Women's Mental Health and other Associations, and hosted by the Alfred Psychiatry Research Centre, this conference will focus on the psychosocial, biological and clinical sciences of women's mental health from individual, family, society, community and global perspectives.

Web: www.iawmhcongress2008.com.au



Resources

New depression fact sheets



MMHA and beyondblue fact sheets on depression available now in Arabic, Assyrian, Bosnian, Khmer, Simplified Chinese, Traditional Chinese, Croatian, Dari, Farsi/Persian, Greek, Italian, Japanese, Korean, Lao, Macedonian, Polish, Punjabi, Russian, Serbian, Somali, Spanish, Tamil, Thai, Turkish and Vietnamese.

Web: www.beyondblue.org.au/index.aspx?link_id=102

Multicultural Disability - seeking your help

The Multicultural Disability Advocacy Association (MDAA), Information and Cultural Exchange (ICE) and MHCS are working with people from the Afghani, Sudanese and Iraqi communities to produce an information kit and DVD about children living with a disability, their families and the services that are available to them.

They need you to help them contact children living with a disability and their families from these community groups.

Those behind this project are also keen to hear from anyone who can share their experiences of working with children with a disability and their families from these community groups.

Contact: Theresa Clark - (02) 9891 6400
Email: theresa.clark@mdaa.org.au

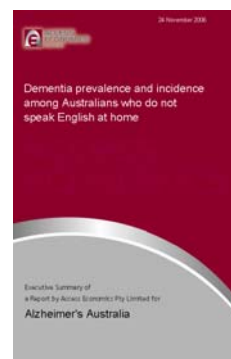
Help for Women

Gosnells Women's Health Service promotes the health and well being of all women regardless of age, religion, race or lifestyle with confidential and affordable services in a holistic environment.

Counselling and Self Esteem Courses are available. Counselling is offered to those having difficulty coping with a long term health condition. Topics covered in the Self Esteem Course include: Expectations, self-confidence, self-talk, self-praising, assertiveness, communication, problem solving, conflict resolution and goal setting.

Phone: (08) 9490 2258
Email: info@gwhs.com.au
Web: www.gwhs.com.au

Dementia Prevalence & Incidence Among Australians

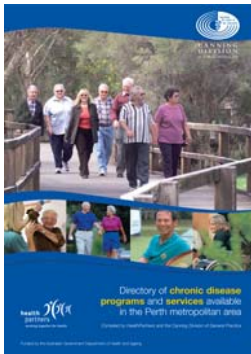


Dementia Prevalence & Incidence Among Australians Who Do not Speak English At Home by Access Economics for Alzheimer's Australia
A study into the prevalence and incident of dementia amongst Australians from CALD backgrounds. This study was designed to assist in

understanding the need for services capable of meeting the special requirements for people with dementia from this group. This study concludes that regional and local services need to be responsive to the particular profiles of their non-English speaking populations and must also acknowledge the various cultural customs, traditions and values of these groups.

Web: www.alzheimers.org.au/upload/NoEnglishAtHomeExecSummary1.pdf

Chronic Disease Directory



This Chronic Disease Directory has been developed by the Canning Division of General Practice with funding from the Australian Government Department of Health and Ageing. The Directory is a resource to assist GPs, practice staff, allied health

and other professionals in referring patients with chronic conditions to relevant health programs and services available in the Perth metropolitan area.

Web: <http://www.canningdivision.com.au/CDGP%20Documents/Chronic%20Disease%20Directory.pdf>

Assistive Technology Report

A new report exploring the potential for assistive technology to enhance the lives and independence of people with learning disability.

The report, "Gadgets, Gizmos and Gaining Independence", is the outcome of a two-year research project funded by the Department of Health and conducted by the Housing and Support Partnership on behalf of Advance.

Web: http://www.advanceuk.org/pages/process_content.asp?top=1097&sub=122&idno=642

Men's Health Australia

Men's Health Australia is Australia's primary source of information about the psychological and social wellbeing of men and boys. It has been developed in partnership with the Men's Health Information & Resource Centre (MHIRC) at the University of Western Sydney, the South Australian Men's Health Alliance (SAMHA) and the Australasian Men's Health Forum (AMHF).

Web: <http://www.menshealthaustralia.net>

About Genes, DNA, Cells and Genetic Inheritance

They are talked about so often, but not always well understood. Yet they have huge impacts on the person we are and our health status. This page provides links to explanations of these crucial aspects of our human condition, and to resources that explain how inherited genetic diseases are transmitted from one generation to the next. The sites range from information for readers with little science or medical knowledge, through to online medical textbooks.

Web: <http://www.nzord.org.nz/internal.asp?CategoryID=100005&SubCatID=100039>

StemGen

A web module of the HumGen website (www.humgen.umontreal.ca) which provides access to the ethical, legal, and social issues particular to stem cell research and related therapies.

The database includes a SEARCH PORTAL which provides comprehensive information regarding current laws, policies, regulations and guidelines adopted by national, regional or international organizations. A unique feature of StemGen is the 50 country compendium organized in the form of a STEM CELL WORLD MAP which compiles the laws and policies by region and country. StemGen also includes a search engine which lists SELECTIVE LITERATURE (ELSI) on the topic of stem cells and other therapies.

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

Need a meeting place?

Local Government halls to hire

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



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 or treatment.



Grants

Health & Wellbeing Research Grants

Funder: LotteryWest
Closing Date: Ongoing

Research Grants support research projects that investigate social issues impacting on the wellbeing of the Western Australian community.

Research Grants aim to:

- Provide an opportunity for community organisations to undertake social research
- Encourage collaboration between community organisations
- Promote a coordinated approach between researchers, service providers, policy makers and the local community.

Priority is given to proposals that:

- Have been developed in response to issues identified by the community
- Involve strong collaboration between community organisations
- Are based on sound research methodology
- Involve recognised and qualified researchers and
- Involve other funding support and resources

We encourage the findings of the research to be published or distributed to the community that identified the issue being researched. The research must be available to other interested community groups

Contact

Telephone: (08) 9340 5270
Fax: (08) 9340 5274
TTY: (08) 9340 5236
Web: <http://www.lotterywest.wa.gov.au/asp/index.asp?pgid=424>

Access to Major Research Facilities Programme

Funder: The Australian Nuclear Science
and Technology Organisation
Closing Date: Ongoing

Aim: To support access by Australian researchers from industry, private and public research organisations and universities to major international research facilities not available in Australia or to attend overseas strategic planning meetings to secure access to a major research facility.

The primary purpose of the programme is to support travel where time has been granted on an overseas major facility following a peer reviewed process.

Collaboration visits will not be supported unless time has already been granted at an eligible facility. Further information on the support available under the different elements of the Government's International Science Linkages Programme can be obtained at <https://sciencegrants.dest.gov.au/isl/Pages/Home.aspx>

Contact: Lauren Mackaway
Phone: (02) 9717 7276
Email: Lauren.Mackaway@ansto.gov.au
Web: <http://www.ansto.gov.au/AMRFP.html>

Disability Equipment Grants

Funder: Lotterywest
Closing Date: Ongoing

The Lotterywest Disability Equipment Grants program is managed by the Independent Living Centre (ILC) <http://www.ilc.com.au>

The ILC web site provides you with all the information to enable you find out more about Disability Equipment Grants, including who is eligible for a grant, what type of equipment may be supported and the assessment process.

Contact

For Disability Equipment Grants information and application form, link directly to the Lotterywest Disability Equipment Grants in the Programs and Services section of the ILC web site: <http://www.ilc.com.au/index.php?c=6>

Strengthening Community Service Delivery

Funder: Community Health Services
Closing Date: Ongoing

Strengthening Community Service Delivery grants have been developed to add value to the various not-for-profit community services available to the Western Australian Community. They recognise the critical role played by community services in helping to improve the quality of life for our citizens.

Priority for these grants is given to:

- ⦿ Organisations that provide support to disadvantaged people or groups
- ⦿ Proposals that will provide a broad community benefit

Lotterywest may support health-related services which are an initiative of the community, rather than a core government service.

Contact

Web: <http://www.lotterywest.wa.gov.au/asp/index.asp?pgid=431>

Active Participation Grant

Funder: LotteryWest
Closing Date: Ongoing

Lotterywest will consider Active Participation proposals that respond to the needs of people who are not fully participating in community life and that engage and involve the target group in recreation as a way of building their community involvement.

Particular encouragement is given to projects that aim to increase community participation by people with a disability.

This grant area aims to respond to a wide variety of needs and circumstances by supporting:

- ⦿ Initiatives such as weekend or holiday projects, workshops, 'come and try' and small group activities designed to build skills and confidence to encourage and facilitate future recreation participation within the broader community.
- ⦿ Projects that aim to facilitate long-term change that will benefit people facing barriers to participation as well as their communities. Projects must be time limited - that is having a beginning and end date. Support may be provided over a period of time up to a maximum of three years, depending on the nature of the project.

Contact

Web: <http://www.lotterywest.wa.gov.au/asp/index.asp?pgid=397>



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



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.

Progressive Supranuclear Palsy

A family from Western Australia who are living with Progressive Supranuclear Palsy would like to make contact with other families in a similar situation.

Contact: Advocate, Disability First Stop
Email: christina@pwdwa.org

Elhers Danlos Syndrome Type VIII (8) (periodontal friability)

A family from Western Australia who are living with Elhers Danlos Syndrome Type VIII (8), which presents with periodontal friability would like to make contact with other families in a similar situation.

Contact: Alison, Genetic Support Council
Phone: (08) 9389 6722
Email: Alison@geneticsupportcouncil.org.au

New Support Group for Diabetes and Heart Conditions

Heart Tempo Support Group is a Heart and Diabetes support group that meets on the third Friday of each month at Bayswater Waves. This group is made up of people affected by a heart condition or diabetes.

Contact: Ken Waters
Phone: (08) 9276 5940
Email: Ken.h20@bigpond.net.au

New Suicide Helpline Call Back Service

The Suicide Helpline Call Back Service (SHL CBS) is a nationwide outbound telephone counselling service provided by Crisis Support Services. The service offers specialised support to people who are at risk of suicide, people caring for someone who is suicidal or people bereaved by suicide. SHL CBS offers six sessions of telephone counselling, which run for approximately 50 minutes each, over a period of up to six months. The service gives people the opportunity to receive supportive counselling, information and referrals to specialist services for on-going support.

The service also caters for people from CALD backgrounds through its links with the Translating and Interpreting Service (TIS). SHL CBS is completely confidential and non-judgemental.

Contact
Phone: 1300 659 467.



GSC Members

Full Members

Acoustic Neuroma Association of Australia
Alzheimer's Association of WA
Angelman Syndrome Association
Arthrogryposis 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>

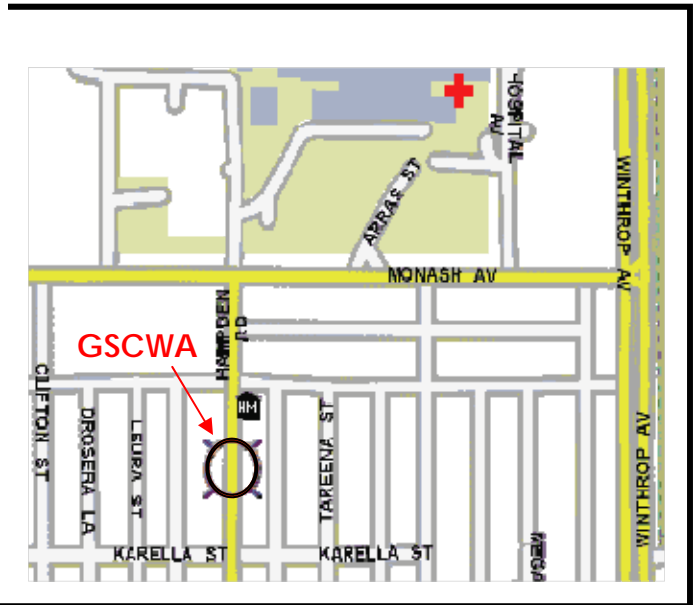


Our Location and Mailing Address:
 Oasis Lotteries House
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 Nedlands WA 6009

Attach mailing
 address label here

Contact Us

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 Nedlands WA 6009
 Phone: (08) 9389 6722
 Email: info@geneticsupportcouncil.org.au
 Web: www.geneticsupportcouncil.org.au
 Office hours: 9am to 4pm Monday to Friday.
 Staff: Sharon Van der Laan, Executive Director
 Kristina Johns, Resource Officer
 Alison Morse, Promotions & Admin Officer
 Joan Ryder, Book Keeper



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