



What is a Clinical Trial?

A clinical trial is a scientific study, or an organised test of medicines and new treatment options involving patient and non-patient human volunteers. Clinical trials confirm whether medicines are safe and effective to introduce as new treatments for a particular disease or condition.



Clinical trials may also be used to determine whether an existing medicine can be safely and effectively used for other diseases and/or conditions.

Why are clinical trials so important?

While medicines are extensively tested in laboratories, these tests can only predict how a medicine will act. To thoroughly understand how a new medicine actually works in humans, it needs to be tested on people affected by the disease the medicine is designed to help. These human tests (clinical trials) help doctors to assess if the new medicine is more effective or safer than old medicines or treatments, and to determine the correct dosage of the medicine.

Clinical trials are needed to collect data required by the Australia government to demonstrate that the medicine is safe and effective. It is not until this data has been assessed by the Australian government's Therapeutic Goods Administration (TGA) that new medicines are approved for prescribing by your doctor or hospital and made available for sale at the pharmacist.

Results from clinical trials can lead to the development of medicines that can prevent thousands of deaths each year and also improve the lives of thousands more people suffering from various medical conditions. How are clinical trials approved?

In Australia, clinical trials must conform to the Ethical Principles of the Declaration of Helsinki and to international Good Clinical Practice guidelines. Before a trial can go ahead it needs to be approved by independent ethics committees that operate according the guidelines issued by the National Health and Medical Research Council (NHMRC Guidelines).

Who runs a clinical trial?

Each clinical trial is led by a doctor. The clinical trial team includes doctors and nurses as well as pharmacists and other health care professionals. The clinical trial team is responsible for checking the health of the participants at the beginning of the trial, monitoring them during the trial, and staying in touch with them for a period of time after the clinical trial has been completed.

Are all clinical trials the same?

There are four different types of clinical trials, each one associated with a different phase in the development of a new medicine or treatment:

- Phase I clinical trials involve the first administration of the medicine to humans, usually to small numbers of healthy volunteers. Phase I clinical trials determine the safety of the medicine, how it works and how well it is tolerated. These clinical trials also identify preferred routes of administration (eg. tablet, liquid or injection) and help determine the appropriate doses for later studies. Phase I clinical trials are usually undertaken in centres appropriately equipped for the specialised monitoring and the high degree of surveillance needed.
- Phase II clinical trials are normally the first trials of the medicine in patients suffering from the condition for which the medicine is intended. The principal aim of these clinical trials is to determine effectiveness and safety. These clinical trials are undertaken in a small number of closely supervised patients and conducted by researchers regarded as specialists in the particular disease or condition and its treatment.
- Phase III clinical trials involve greater numbers of patients and are undertaken for the purpose of determining whether the medicine confers clinical benefit in the disease/s for which effectiveness was demonstrated in Phase II clinical trials. They also determine the nature and likelihood of any side effects. Phase III clinical trials are undertaken if the Phase II clinical trials indicate the medicine has potential benefit that outweighs the hazards.
- Phase IV clinical trials are those clinical trials undertaken after the medicine has been approved for the treatment of a particular disease. Phase IV clinical trials are undertaken to compare a new medicines to a wider range of existing medicines/therapies. Such clinical trials are used to establish

where, in the range of treatment options, the new medicine is best used.

Phase IV clinical trials are also undertaken to further investigate the use of the medicine in the normal clinical setting of the disease, as this may differ quite markedly from the conditions under which the other clinical trials were conducted. This includes post marketing surveillance studies.



Do all participants receive the new trial medicine?

In order to objectively determine the benefits of a new medicine it is necessary to remove any subjective bias. This is particularly the case in Phase III and IV clinical trials where participants are normally divided into two or more groups.

One group (the test group) is given the trial medicine while the other group (the control or reference group) is given the standard treatment for the disease or condition. Where there is no pre-existing standard treatment a placebo – a look-alike or dummy medicine containing no active ingredient – may be given to the control group instead. Participants are randomly assigned to either group.

Ideally, neither researchers nor participants should know which group a particular patient is in. Clinical trials where this occurs are referred to as double blind trials. However, safety does come first. Should a participant develop an unexpected or serious side effect the blinding of the trial can be broken so that appropriate action can be taken.

Why participate in a clinical trial?

There are a number of possible advantages of

participating in clinical trials. These can include:

- Gaining early access to new medicines not otherwise available;
- Obtaining the clinical trial medicine at no cost, at least during the trial;
- Receiving extensive medical care associated with the clinical trial; and
- Contributing to the development of future life-saving or life-enhancing treatments.

Participation in clinical trials is not, however, without its downsides. For example:

- There may be side effects from the trial medicine;
- The trial medicine may not work;
- You may be placed in the control or reference group and not receiving the trial medicine until after the clinical trial has finished; and
- You may need to visit the hospital or doctor's room more frequently or stay there longer.



Becoming a clinical trial participant

Eligibility

Depending on the type of clinical trial (Phase I, II, III or IV) and the medicine being trialled it may be necessary for participants to have been previously diagnosed as having the disease or condition for which the trial medicine is intended to treat.

Enrolling

Before making this important decision a person must be given a full written plain-language explanation of the clinical trial by a doctor. Only after carefully considering this document

should a person provide their written consent to participate.

The explanation of the study will include things such as the eligibility criteria; possible risks and benefits of the new medicine; the risks of any side-effects; the type, frequency and risks of any medical tests or procedures that may be undertaken as part of the trial; and the person's rights and responsibilities.

Potential participants will be made aware that they can withdraw from a study at any time, without any effect on ongoing medical care and that their involvement is entirely voluntary.

Commencement

The clinical trial will commence when a sufficient number of people have been enrolled to participate in the clinical trial. This may take some time.

Important considerations

Who pays for clinical trials?

Clinical trials are conducted, or 'sponsored', by a wide range of organisations. They include:

- Pharmaceutical companies, either solely or jointly with other research institutions such as universities and hospitals;
- Private research organisations under a grant from the government's National Health & Medical Research Council or from public donations;
- Publicly funded research organisations such as universities and teaching hospitals.

Regardless of the type of organisation sponsoring the clinical trial, the clinical trial must be approved and monitored under the ethical and good clinical practice guidelines set down by the Australia government.

What happens if there are side effects from participating in a clinical trial?

By the time a medicine reaches the clinical trial stage it has already been extensively tested in laboratories for likely side effects. However, part of the purpose of the clinical trials is to see what unexpected side effects emerge, and how severe

or common they are. So as well as experiencing the benefits of a new medicine, there may also be side effects for some people. The doctor or study nurse will carefully record any problems or side effects you have, and these are relayed to the principal researcher to ensure that you are kept as safe as possible.

In company sponsored clinical trials, compensation is available for participants who suffer personal injury (including death) caused by participation in clinical trials. Copies of the Guidelines for Compensation for Injury Resulting from Participation in a Company-Sponsored Clinical Trials are available from Medicines Australia.

What happens with the results?

As well as being reviewed by the government authorities such as the Therapeutic Goods Administration, the results of the clinical trials may be reported in the medical press and are made available for doctors. The publication of results is done so that doctors can make scientifically valid assessments of the benefits and risks of a new medicine for their patients.

Although the results of the study may be published, nothing that identifies individual patients will be released. All details of a clinical trial participant's treatment are kept confidential and patient anonymity is assured.

In addition, your doctor will be notified of the results of the study as soon as they are made available. Your doctor should be able to inform you of the outcomes of the clinical trial. If you participate in a study, it is recommended that you keep in touch with your doctor so that you can find out the results of the study when they become available.

Questions and Answers

If you decide you would like to participate in a clinical trial you should discuss it with your doctor and other healthcare professionals to make an informed decision. You should also seek to understand the credentials and experience of the people and the company

involved in the study. Discuss with them the trial and the implications it may have for you.

Below is a list of questions you might like to ask the clinical trial doctor before agreeing to participate in a clinical trial.

- What is the clinical trial about?
- Why are you doing the clinical trial?
- What do you expect to get out of the clinical trial?
- What will you do with the results?
- Have you or others done this type of clinical trial before?
- What did you learn?
- Who put this clinical trial together?
- Who are the researchers? Who do they work for?
- Have they done a clinical trial like this before?
- Is the government part of this clinical trial? Who else is part of this clinical trial?
- Who is paying for the clinical trial?
- Who will make money from the results of this clinical trial?
- Who can I go to with questions or complaints?
- Who is going to be in this clinical trial?
- What kinds of people are you looking for? Why?
- How are you finding people for this clinical trial?
- Can I quit the study after signing a consent form?
- What will I get out of the clinical trial?
- What are the benefits? What are the risks?
- Will I get treated the same as everyone else?
- What kinds of different treatments are offered in this clinical trial?
- Is there a trial and a control treatment?
- Is payment involved?
- Do I get reimbursed for my fares to and from the clinical trial centre?

- What do I have to do in this clinical trial?
- How much of my time will be needed
- Will I need to take extra time off work?
- What extra tests or procedures will I be subjected to?
- How will I be protected from harm?
- Do I stand a chance of being harmed in the clinical trial? In the future?
- Does the clinical trial protect me from all types of harm?
- If I get harmed in any way, will I get all needed treatment and compensation?
- Who pays for the treatment?
- How will my privacy be protected?
- Who is going to see the information I give?
- Will my name be used with the information?
- What happens to the information I give if I quit the clinical trial?
- Is there a written guarantee of privacy?
- What progress has already been made?
- When did you start this clinical trial? How long will it last?
- How much of the clinical trial have you already done?
- Have there been any problems so far?
- What will be left behind after the clinical trial is over?
- What are you going to do with the results of the clinical trial?
- Will results be in places where the public can see them?
- Are you going to send me a copy of the results?
- Will I continue to get the clinical trial medicine after the study is complete?

Additional information on clinical trials can be obtained from [Therapeutic Goods Administration](http://www.tga.gov.au/industry/clinical-trials.htm) <http://www.tga.gov.au/industry/clinical-trials.htm>

Acknowledgements

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[Department of Health and Ageing Therapeutic Goods Administration](http://www.tga.health.gov.au/) <http://www.tga.health.gov.au/>

[National Health & Medical Research Council](http://www.nhmrc.gov.au) <http://www.nhmrc.gov.au>

[Medicines Australia](http://medicinesaustralia.com.au) <http://medicinesaustralia.com.au>

[Research Australia](http://www.researchaustralia.org) <http://www.researchaustralia.org>

[The Cancer Council of NSW](http://www.cancercouncil.com.au) <http://www.cancercouncil.com.au>

The Weight of Genetic Information

A recent article in the Sydney Morning Herald revealed that 15 Australian pharmacies are offering weight loss programs that test customers' carbohydrate and lipid metabolizing genes to produce "a personally-optimised eating plan and weight loss program."

MyGene, the "all Australian" company responsible for this product, says it wants to help Australians lead "healthier, happier and more productive lives by knowing their individual genetic profile and having the information and tools to make the best health and lifestyle choices for their unique needs." Consider me a skeptic.

The weight loss program's \$1600 price tag buys an analysis of metabolic genes followed by nine sessions with a pharmacy dietician. Its rhetoric comes close to promising something like a magic bullet, one that will allow you to eat more calories than we burn off – say, "your carbohydrate metabolism is fantastic so mountains of hot toast with jam is fine, but given your sluggish lipid metabolism, steer clear of margarine."

On the other hand, any consultations with a qualified dietician are likely to benefit those seeking to lose weight, so perhaps these genetic weight loss programs are not so bad. Additionally, placebo effects stemming from the genetic mystique could improve results even further. After all, far more harmful weight loss products with a lower likelihood of success have been on the market in the past and likely will be again in the future.

So what continues to rankle? Here are some concerns:

- The TGA (for you Americans, roughly the Australian equivalent to the FDA) has taken a hands-off approach, and decided that MyGene's program does

not need to be registered as a therapeutic product, leaving it outside the regulatory system for weight loss devices.

- The involvement of pharmacists, who enjoy high levels of public trust (see, for example, the 2011 Roy Morgan Image of Professions Survey: <http://www.roymorgan.com/news/polls/2011/4655/>), is troubling. Most have little to no genetic education, suggesting that they are doing more work for the weight loss companies than for patients. This is risky in an area as complex as weight retention.
- Using genetic gimmicks preys upon overweight people's vulnerability in a society in which attractiveness (common translation: slenderness) is so important that some jurisdictions have legislated against discriminatory treatment based on looks.

Some may claim that the whole controversy is overblown and that market forces are the right tool to determine MyGene's success or failure. But it seems to me that anyone seeking weight loss or a healthier lifestyle would be better off putting their \$1,600 towards a membership at Jenny Craig.



Information Source: Center for Genetics and Society.
Biopolitical Times:

<http://www.biopoliticaltimes.org/article.php?id=5916>

Article in the Sydney Morning Herald Available: <http://www.smh.com.au/national/health/pharmacies-cop-flak-over-genetic-testing-for-weight-loss-20111026-1mk90.html>

Groundbreaking Cystic Fibrosis study brings researchers closer to finding a cure

03/11/2011. Spokesperson: Queensland Children's Medical Research Institute (QCMRI)

A revolutionary new treatment for Cystic Fibrosis (CF) has been uncovered during a groundbreaking study involving two leading Brisbane researchers bringing them one step closer to finding a cure for the disease.

Queensland Children's Medical Research Institute (QCMRI) Associate Professor Scott Bell and Professor Claire Wainwright have both contributed to a paper on the study which has today been published in the prestigious New England Journal of Medicine.

The study sponsored by Vertex Pharmaceuticals involved researchers from across the globe and explored the effectiveness of a new drug called ivacaftor which was developed to target a defective gene that causes CF.

Associate Professor Bell said after 12 months of testing it was discovered that patients treated with ivacaftor had significant and sustained improvement in lung function, quality of life and increased weight amongst other measures.

Until now the management of CF has focussed on treating and minimising the infections that patients acquire as a result of their disease, Associate Professor Bell said.

While this has helped to minimise the rate of lung damage in CF patients and extend their life expectancy, the results of this study mean we are now one step closer to developing a cure for CF itself.

Associate Professor Bell said while ivacaftor was only being used to treat CF patients with a particular gene mutation, it also provides hope for patients with more common mutations.

This drug may improve the health of only about one in 12 patients with CF but it has opened the door to an entirely new way of treating this disease, he said.

QCMRI Director Professor Keith Grimwood said the results of Associate Professor Bell and Professor Wainwright's work had been eagerly awaited by the CF community world-wide and would have far reaching implications.

I'm delighted that researchers from QCMRI have been able to contribute to such an important international study, Professor Grimwood said.

CF is the most common life threatening, recessively inherited condition affecting Australian children and adults today and there are many people throughout Queensland who have to cope with this disease on a daily basis.

I'm pleased to think this study will help provide them with further hope for their future wellbeing.

The randomised controlled study involved 161 cystic fibrosis patients from around the world, including 19 from Australia.

Patients who took part in the study are now involved in an open label study and will continue receiving the drug so that its ongoing effectiveness and long term safety can be monitored.

The next step is for the drug to undergo regulatory approval, and to be trialled by younger patients.

In addition, the effect of Ivacaftor on other more common disease-bearing CF genes will be conducted in order to determine if it will also provide benefit to a larger proportion of the CF population.

The Queensland Children's Medical Research Institute is supported by the Royal Children's Hospital Foundation. Associate Professor Bell's work is also supported by The Prince Charles Hospital Foundation.

Information Source: AHHA e-healthcare brief - 4 November 2011. <http://ahha.asn.au/news/groundbreaking-cystic-fibrosis-study-brings-researchers-closer-finding-cure>

Medicare rebate for expensive IVF treatment PGD sought by clinics

CASH-STRAPPED families carrying faulty genes may soon be able to more easily access specialist IVF procedures in their bid to have healthy babies.

An application has been made to the federal government to provide a rebate for the expensive treatment.

At present, pre-implantation genetic diagnosis, or PGD, does not attract any Medicare rebate - and can add as much as \$5000 to the cost of a regular IVF cycle.

The procedure, which involves analysing embryos before implanting them into the would-be mother, is the only way couples carrying a genetic condition such as cystic fibrosis or Huntington's disease can guarantee a healthy baby.

Sydney IVF has submitted the application for PGD to be given a Medicare item number in a move that has been welcomed by other IVF clinics across the country. The clinic is also offering a financial assistance scheme to help couples who cannot afford treatment.

Sydney IVF CEO Kylie de Boer said that the clinic submitted the application and launched the PGD assistance scheme after watching the heartache suffered by clients desperate for a baby.

Information Source & Full Article Available: <http://www.news.com.au/national/medicare-rebate-for-ivf-treatment-pgd-sought-by-clinics/story-e6frfkw0-1226100132291#ixzz1dBU5GpAG>



Is the patent system broken?

Does the patent system in Australia need major reform?

According to Professor Luigi Palombi from the Australian National University, the current system does not take into account the complexities of genetic breakthroughs and new biotechnologies.

Intellectual Property Australia, the statutory authority that grants patents, disagrees. Its director general Philip Noonan says the law needs amendments to ensure research is not stifled but the system protects inventor's rights and drives innovation.

Australia is part of a worldwide patent system known as the TRIPS convention under the World Trade Organisation. All signatories to the convention must agree to protect patent holder rights and there are severe penalties if countries fail to do so.

Mr Noonan says we wouldn't have new drugs to fight disease without patents, while Professor Palombi says the system is run and managed by "vested interests".

This is a video debate between two adversaries - Professor Luigi Palombi from the Australian National University and Philip Noonan, the head of IP Australia.

Information Source: ABC News. Video Duration: 3min 55sec. Available: <http://www.abc.net.au/news/2011-05-03/is-the-patent-system-broken/1219672>

Additional Information

IP Australia

Website: <http://www.ipaustralia.gov.au>

Heartbreak for parents with rare genetic condition

Sydney Morning Herald
Julie Robotham, 8/11/2011

AN OMINOUS silence followed the brief first cry of Abby Baines, and then the controlled chaos of a hospital emergency response. Doctors were "basically walking up the corridor while they did CPR at the same time on our little daughter," says her father, Scott, of the first minutes of Abby's life in October 2006.

Abby's heart was destined never to support her. She had inherited myotonic dystrophy - a genetic condition that prevents normal function of muscle cells - from her mother, Naomi, who has a mild and previously undiagnosed form, and she died five weeks later in her parents' arms.

But the Thirroul couple's hope for another unaffected child using combined in vitro fertilisation and genetic technologies, to join Jonathan born 18 months ago, has been crushed by the surprise rejection of a bid to extend Medicare funding to the procedure.

Full Article & Video Available: <http://www.smh.com.au/national/health/heartbreak-for-parents-with-rare-genetic-condition-20111107-1n3yp.html#ixzz1d5idNJiV>

Additional Information

Support Group: Muscular Dystrophy Association of WA
Website: <http://www.mdwa.org.au>

Genea

Genea (previously Sydney IVF) has been driving and financially supporting a project to obtain funding for PGD for single gene disorders and translocations via the Medical Benefits Schedule (MBS) to ensure equity of access to PGD for the Australian population.
Website: <http://www.genea.com.au>

ADHDgene: a genetic database for attention deficit hyperactivity disorder.

Zhang L, Chang S, Li Z, Zhang K, Du Y, Ott J, Wang J. 2011 Nov 10

Abstract

With a worldwide prevalence of ~5%, attention deficit hyperactivity disorder (ADHD) has become one of the most common psychiatric disorders. The polygenetic nature of ADHD indicates that multiple genes jointly contribute to the development of this complex disease. Studies aiming to explore genetic susceptibility of ADHD have been increasing in recent years. There is a growing need to integrate the genetic data from various genetic studies to provide a comprehensive data set and uniform access for convenience of in-depth data mining. So far, there has been no such effort for ADHD.

To address the genetic complexity of ADHD, we developed the ADHDgene database by integrating ADHD-related genetic factors by profound literature reading. Based on the data from the literature, extended functional analysis, including linkage disequilibrium analysis, pathway-based analysis and gene mapping were performed to provide new insights into genetic causes of ADHD. Moreover, powerful search tools and a graphical browser were developed to facilitate the navigation of the data and data connections. As the first genetic database for ADHD, ADHDgene aims to provide researchers with a central genetic resource and analysis platform for ADHD and is freely available at <http://adhd.psych.ac.cn/>.

Information Source: [PubMed - as supplied by publisher] Free full text. Available: <http://www.ncbi.nlm.nih.gov/pubmed/22080511?dopt=Abstract>

Australian National Rare Diseases Working Group

Rare Disease Symposium

A report and the preliminary outcomes from the symposium 'Awakening Australia to Rare Diseases: Global perspectives on establishing a coordinated approach to a national plan' have been published have been published in Orphanet Journal of Rare diseases, available at <http://www.ojrd.com/content/6/1/57/abstract>.

The two symposium organising committees are currently re-structuring to undertake the roles of a national coordinating committee and a working group. These committees will work together to progress the outcomes of the symposium. The OPHG have been undertaking a thematic analysis of all the issues and recommendations airing from the 6 Symposium workshops and will circulate these for further comment in due course. Based on the analysis to date, the National Rare Diseases Working Group met for a half day to discuss the key issues arising from the symposium, which issues the working group should focus on, and allocated short and longer term priorities as appropriate.

In addition to this, WA Health sponsored an item to the Australian Health Ministers' Advisory Council to develop a National Plan on Rare Diseases. The Clinical, Technical and Ethical Principal Committee have requested the OPHG to develop a scoping paper.

Community consultation on rare diseases
In order to better understand the attitudes, beliefs and knowledge of the general public about rare diseases, OPHG recently undertook a community consultation. A comprehensive questionnaire was completed online by more than 1000 randomly selected Western Australian members of a consumer panel who were recruited and managed by an Australian research unit. The data is now being analysed to determine how well people understand rare diseases and to what extent that understanding influences their attitudes towards rare diseases and government expenditure in this area.

Information Source:
Office of Population Health Genomics e newsletter.
20/10/2011

Rare Friends

The Symposium saw the launch of Rare Friends, a non-partisan network of state politicians, formed to raise awareness of rare disorders, support solutions that improve life outcomes, and to extend the network amongst state and federal parliamentary colleagues. Seven politicians attended the launch, including: Peter Tinley MLA, Peter Abetz MLA, Brian Ellis MLC, Sue Ellery MLC and Linda Savage MLC. Approximately thirteen politicians have signed up to be Rare Friends.

National Rare Diseases Working Group

On 2nd September, the National Rare Diseases Working Group met face-to-face to decide on the priority actions for the next twelve months. Four priority actions were identified from amongst the many issues you raised during the Symposium. They are:

1. To progress the establishment of a peak umbrella association;
2. To develop a clearer picture of the common unmet needs;
3. To establish new registries and develop a map of current registries in Australia; and
4. To create a "one stop shop" web page.

Rare Disease Plan Discussed at the Australian Health Ministers Council (AHMAC)

Western Australia's Director General of Health, Mr Kim Snowball, sponsored an Agenda Item on the development of a National Rare Diseases Plan for Australia for discussion at the recent Australian Health Ministers' Council (AHMAC) meeting. AHMAC is the national health executive, the membership comprising all Director General's and Chief Executive Officers of State, Territory and Commonwealth Health. This is terrific news to have rare diseases as part of the national health discussion, and the community should welcome this important step.

Information Source:
Rare Gems newsletter.
October Issue 2011.

Google strikes deal to preserve DNA data online

27/10/2011 By Peter Delevett

Concerned that the federal government might not keep funding the world's largest free database of genetic data, Google Inc. has forged a deal with a Mountain View, Calif., startup to keep the information online - and free for researchers.



The Internet giant began talks with DNAnexus last spring, when the National Institutes of Health announced it might have to drop support of the Sequence Read Archive due to funding cuts.

The database is a vast repository for short snippets of genetic data decoded by sequencing machines, which spell out the unique combinations that make up a specific person's DNA. Researchers can compare data in the archive to look for similarities and differences between people and better unravel how genetics affects health.

While NIH officials recently announced they'd keep funding the database, "We wanted to make sure we had a Plan B," said DNAnexus Chief Executive Andreas Sundquist. Using the Google Cloud Storage service, DNAnexus will maintain a "mirror" of the public archive, together with tools Sundquist's company has developed to make it easier for scientists to search the database and share their findings.

Google officials said the Sequence Read Archive is one of the largest datasets ever deposited in Google Storage, but Sundquist predicts there will be thousands of similar databases in the future. That's due both to

the growing speed and power of gene sequencers and to the decreasing cost of storing and sharing information in the remote network of web servers known as the cloud.

"DNA sequencing becomes 10 times cheaper every 18 months thanks to hardware improvements," said Sundquist. "It's sort of like Moore's Law on steroids."

A year ago, he says, it cost about \$30,000 to sequence a person's entire DNA. Today, that number's down to \$4,000. Sundquist believes researchers eventually will sequence everyone on earth and make that data part of each person's medical record.

But given that each genome is about 3 billion letters long, improvements in gene sequencing are creating a massive data management challenge, said Krishna Yeshwant, a partner at Google Ventures who's joining Sundquist's board as part of a separate \$15 million investment in DNAnexus.

The SRA database alone, he said, is hundreds of terabits in size, referring to the unit of measure for a trillion bits of computer data.

The decreased cost of gene sequencing is making it possible for genomics to move out of the research lab and into clinical settings, added Yeshwant, a Harvard-educated physician who also practices at Brigham and Women's Hospital in Boston.

"It feels like we're on the cusp of a revolution in genomics and how we think about health care," he said.

Information Source & Full Article Available:

PHYSorg. <http://www.physorg.com/news/2011-10-google-dna-online.html>

Direct-to-consumer genetic testing in children

Are the kids really all right? Direct-to-consumer genetic testing in children: are company policies clashing with professional norms?

Abstract

The genetic testing of minors within the direct-to-consumer (DTC) genetic testing (GT) context has been given relatively little attention. The issue of testing healthy children for diseases that would only develop in adulthood raises many important ethical, legal and social issues.

As genetic testing is now available outside of the traditional health care system, often without even the intermediate of a health care professional, we surveyed 37 DTC GT companies regarding their policies for testing in children. Although the response rate is relatively low (35%, 13/37), our findings reveal that a clear majority of companies do perform genetic testing in minors. As such, companies testing for adult onset diseases are acting in contradiction of established professional guidelines, which state, among others, that, for predictive genetic testing, the availability of therapeutic or preventive measures is necessary for testing to be performed in asymptomatic minors.

The community of stakeholders in children's health care and genetic testing should, therefore, decide which standards need to be upheld by DTC GT companies and ensure that these are met.

Information Source:

Howard HC, et al. Eur J Hum Genet 2011 Nov;19(11):1122-6

Available: <http://www.nature.com/ejhg/journal/v19/n11/full/ejhg201194a.html>

Promising New Approach to Treating Spinocerebellar ataxia type 1 (SCA1)

ScienceDaily (Oct. 16, 2011) — A groundbreaking study in the journal Nature Medicine suggests what could become the first effective treatment for a debilitating and fatal disease of the central nervous system called SCA1.

In the first part of their study, researchers conducted several tests that demonstrated that mice with SCA1 had low levels of VEGF (vascular endothelial growth factor). In the brain, VEGF stimulates the growth of blood vessels and works in other ways to keep brain cells healthy.

Researchers then tested whether boosting VEGF levels would benefit mice that had SCA1. They boosted VEGF two ways: By genetically engineering mice to produce more of the protein and by delivering VEGF directly to the brain.

Mice that had SCA1 were given a performance test called Rotarod, which measures balance and coordination. The test, which is somewhat like a log-rolling competition, measures how long a mouse can stay atop a rolling cylinder.

Researchers compared diseased mice that had been treated with VEGF to diseased mice that received no treatment. The VEGF group performed significantly better than the untreated mice -- and in some cases nearly as well as healthy mice that did not have SCA1. In addition, microscopic examinations found significant improvements in the brains of diseased mice that had been treated with VEGF.

The findings suggest that reversing low VEGF levels "may be a potentially useful treatment in patients with SCA1," researchers wrote.

The results also could prove relevant to other ataxia disorders "and possibly even other neurodegenerative syndromes," researchers wrote.

Full Article Available: www.sciencedaily.com/releases/2011/10/111016132040.htm

Genuine partnership essential for Aboriginal and Torres Strait Islander health

03/11/2011. Spokesperson: Australians for Native Title and Reconciliation

ANTaR today welcomes the Government's commitment to work in partnership with Aboriginal and Torres Strait Islander peoples and organisations to develop a national plan to improve health equality.

Minister for Indigenous Health, Warren Snowdon and Minister for Health and Ageing, Nicola Roxon announced this morning that the National Health Leadership Forum (NHLF) is to become the national representative voice to Governments on Aboriginal and Torres Strait Islander health.

"This partnership provides a significant and promising opportunity for real change," said ANTaR National Director, Jacqueline Phillips. "For the first time at a national level, Aboriginal and Torres Strait Islander people will play a central role in developing the policies and programs that affect them."

"Aboriginal centred policy and genuine partnership is fundamental to achieving health equality and overcoming entrenched disadvantage. It has been a core aspiration of ANTaR's campaigns for many years" Ms Phillips said.

The NHLF is made up of peak Aboriginal and Torres Strait Islander health organisations from across Australia and the National Congress of Australia's First People.

"ANTaR congratulates this new representative body, which will be an important mechanism through which Aboriginal and Torres Strait Islander people can engage with Government to improve health outcomes" said Ms Phillips.

"It is now up to Government to ensure the partnership is respected and used effectively. Aboriginal organisations must play a lead role in the development and implementation of the national health plan, not merely a consultative one."

Media contact: ANTaR National Director, Jacqueline Phillips – 0423 773 395

Equal Pay agreement an historic next step towards fair pay for community sector

Australia's peak community and social services body has welcomed the agreement between the ASU and the Australian Government in the Equal Pay Case as an historic moment for people who work with some of the most vulnerable members in the community.

The Australian Council of Social Service has hailed the announcement that the Federal Government and unions have agreed to make a joint submission in the case which would see community sector workers get pay rises of between 19 and 42 per cent, a key part of ensuring the long-term sustainability of this historically underpaid sector.

"We congratulate the Prime Minister and Government on this important announcement as a welcome step towards securing equal pay for the workforce that is so vital to providing effective community services across Australia," said Dr Cassandra Goldie, CEO of ACOSS. "Millions of people in this country living with mental illness, drug and alcohol problems, insecure housing or homelessness and domestic violence seek the support of community services every day. ACOSS has long advocated for adequate funding to ensure effective, sustainable services with experienced workers to meet these needs.

Information Source: AHHA e-healthcare brief
- 11 November 2011

Further Information Available: http://www.acoss.org.au/media/release/equal_pay_agreement_an_historic_next_step_towards_fair_pay_for_community_se

Nurse practitioners a success in community pharmacies

Spokesperson: Curtin University and Griffith University

Date: 02/11/2011

Nurse practitioners based in community pharmacies have great potential to ease the burden in primary care, research by Curtin University and Griffith University has found.

The independently funded research, undertaken by Associate Professor Lynne Emmerton, of Curtin's School of Pharmacy, and Sara McMillan, of Griffith's School of Pharmacy, explored the roles of nurse practitioners who are based in community pharmacies in Western Australia.

Community pharmacies are a relatively new site for nurse practitioner clinics, which have traditionally operated in hospitals and, more recently, local general practitioner (GP) clinics.

Nurse practitioners have at least three years' post-university nursing experience and a Masters (Nurse Practitioner) degree. They can perform some roles of a GP, including ordering blood tests and x-rays and writing prescriptions for a wide range of medicines. They can also manage immunisations, wound dressings and suture and staple removals.

The services are covered by Medicare and many are bulk billed.

The researchers interviewed nurse practitioners, pharmacists, pharmacy staff operating as a Revive Clinic, and users of the service, involving city and rural clinics. Revive Clinics are currently the only pharmacy-based clinics supplying nurse practitioner services in Australia.

Associate Professor Emmerton said interviews with people who had consulted an 'in-store' nurse practitioner revealed they appreciated the convenience of a 'walk-in' service located at their local pharmacy.

"This is likely to be particularly welcomed by parents of sick children, people working long hours and those who need repeats of prescriptions for medicines such as the contraceptive pill," Associate Professor Emmerton said.

The study identified roles performed by pharmacists, such as giving advice about medicines, recommending medicines for conditions such as coughs and colds and taking blood pressure, were not impacted by the nurse practitioner.

In fact, having another health professional in the pharmacy for a second opinion worked both ways. Pharmacists were able to ask the nurse practitioner to perform some tests and observations, while the nurse practitioner could ask the pharmacist for specific medicine-related information and to check a person's prescription record in the dispensary computer.

Lecturer Sara McMillan explained that nurse practitioners offered another convenient healthcare option to people.

"People now have a choice whether they consult their regular doctor or a pharmacy-based nurse practitioner," Ms McMillan said.

"Importantly, the nurse practitioners are trained to recognise when they are outside their limits of expertise, and when necessary, can easily refer people to their regular doctor or write a referral to a specialist."

The research centred on the WA-based Revive Clinic franchise, which supplies nurse practitioners to 10 pharmacies in Western Australia and one pharmacy in NSW.

Founder and director of Revive Clinic, Louise Stewart, said the clinics had been established in collaboration with general practitioners, pharmacists and allied health services to alleviate the pressure on general practice and hospital emergency rooms.

"Many regional areas and even some metropolitan areas do not have access to a GP, so there is a real need to increase access to timely and affordable healthcare in these communities. This is what Revive Clinic hopes to achieve," Ms Stewart said.

Notes to editor:

- The Revive Group supply trained nurse practitioners to pharmacies who have bought a Revive Clinic franchise. The nurse practitioner provides an independent service from a private consultation room within the pharmacy.
- The nurse practitioners, by law, use Revive Clinic clinical guidelines or protocols approved at State level to guide their clinical decision making. Clinical governance is maintained by the Revive Group's medical committee.

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Web: <http://curtin.edu.au>

Information Source: Australian Healthcare & Hospitals Association. <http://ahha.asn.au/news/nurse-practitioners-success-community-pharmacies>

Access controls and decision support for genetic information in electronic medical records

Practical considerations to guide development of access controls and decision support for genetic information in electronic medical records.

Darcy DC, Lewis ET, Ormond KE, Clark DJ, Trafton JA. Nov 2, 2011.

ABSTRACT

BACKGROUND: Genetic testing is increasingly used as a tool throughout the health care system. In 2011 the number of clinically available genetic tests is approaching 2,000, and wide variation exists between these tests in their sensitivity, specificity, and clinical implications, as well as the potential for discrimination based on their results.

DISCUSSION: As health care systems increasingly implement electronic medical record systems (EMRs) they must carefully consider how to use information from this wide spectrum of genetic tests, with whom to share information, and how to provide decision support for clinicians to properly interpret the information. Although some characteristics of genetic tests overlap with other medical test results, there are reasons to make genetic test results widely available to health care providers and counterbalancing reasons to restrict access to these test results to honor patient preferences, and avoid distracting or confusing clinicians with irrelevant but complex information. Electronic medical records can facilitate and provide reasonable restrictions on access to genetic test results and deliver education and decision support tools to guide appropriate interpretation and use.

SUMMARY: This paper will review some of the key characteristics of genetic tests as they relate to the design of access controls and decision support for genetic test information in an EMR, emphasizing the clear need for health information technology (HIT) to be part of optimal implementation of genetic medicine, and the importance of understanding key characteristics of genetic tests when designing HIT applications.

Source: PMID: 22047175 [PubMed - as supplied by publisher] Free full text. <http://www.ncbi.nlm.nih.gov/pubmed/22047175?dopt=Abstract>



Member Profile

Coeliac Western Australia, Inc

Profile

Coeliac Western Australia was founded in 1979 with fifty-six members. Today there are over two-thousand members with this number expected to increase. 1 in 100 individuals are known to have coeliac disease but 75% remain undiagnosed.

What is Coeliac Disease

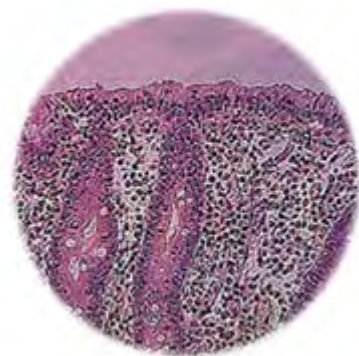
Coeliac disease (*pronounced seel-ee-ak*) is an auto-immune disease. Auto-immune means the body mistakenly produces antibodies that damage its own tissues. It is a permanent intestinal intolerance to dietary gluten. A number of serious health consequences can result if the condition is not diagnosed and treated properly.

In those with untreated coeliac disease the mucosa (lining) of the small bowel (intestine) is damaged: The tiny, finger-like projections which line the bowel (villi) become inflamed and flattened. The function of the cells on villi is to break down and absorb nutrients in food. Through a microscope, the lining of the small bowel normally looks rather like shag-pile carpet, the villi making up the "pile". The entire surface area of a healthy small bowel is comparable in size to that of a tennis court.

In those with untreated coeliac disease, the villi become inflamed and the bowel has a characteristic flat appearance (like a threadbare carpet). This is referred to as villous atrophy. The surface area of the bowel available for nutrient absorption is markedly reduced (to the size of a table or less) which can lead to nutrient deficiencies.



Healthy normal villi of the small intestine (as seen under the microscope).



Damaged villi of a person with undiagnosed coeliac disease.

Who gets Coeliac Disease?

People are born with a genetic predisposition to develop coeliac disease. They inherit a particular genetic make-up (HLA type) with the genes DQ2 and DQ8 being identified as the "coeliac genes". Gene testing is presently available through pathology laboratories (by blood test or buccal swab). The gene test is useful for excluding coeliac disease.

The presence of HLA DQ2 and HLA DQ8 is not helpful as a positive predictor of coeliac disease, as only 1 in 30 people (approximately) with these genes will have coeliac disease. The gene test cannot diagnose coeliac disease – only exclude it.

Environmental factors also play an important role in the development of coeliac disease.

A first-degree relative (parent, brother, sister, child) of someone with coeliac disease has about a 10% chance of also having the disease. If one identical twin has coeliac disease, there is an approximate 70% chance that the other twin will also be affected (but not necessarily diagnosed at the same time). This highlights the role of both genetic and environmental factors in the development of coeliac disease.

Coeliac disease can also be associated with other autoimmune conditions such as type 1 diabetes, autoimmune thyroid disease, pernicious anaemia, rheumatoid arthritis, inflammatory bowel disease and lupus. It has not been shown that there is a causative link, but having one genetic autoimmune disease increases your risk of having another.

I feel much better on a gluten free diet so does this mean I have coeliac disease?

There are a number of reasons why you may feel better on a gluten free diet but this does not necessarily mean you have coeliac disease. If a gluten free diet is commenced before medical investigations are made coeliac disease cannot be diagnosed. Gluten must still be being eaten to diagnose coeliac disease. It is therefore strongly recommended that if you suspect you have coeliac disease, see your GP now.

Is there a cure for coeliac disease?

There is currently no cure for coeliac disease. Coeliac disease and its symptoms are managed by adhering to a lifelong gluten free diet.

For information on research into coeliac disease see www.coeliac.org.au

Information Source:

www.coeliac.org.au

[Article Reviewed By Don Huggins,
Executive Officer Coeliac WA]



Contact Details

Telephone: 08 9451 9255

Country Callers: 1300 GLUTEN (1300 458 836)

E-mail: wa@coeliac.org.au

Website: www.coeliac.org.au



Coming Events

2012 International Data Linkage Conference (IDLC)

The conference will bring together a wide range of exciting leading international speakers, researchers, data linkers, practitioners, policymakers and consumers to discuss and exchange ideas relating to the full spectrum of utilising data linkage to advance knowledge for better health and social outcomes.

Date: May 02 2012 - May 04 2012

Location: Perth WA

Convenor: Telethon Institute for Child Health Research, University of WA, Curtin University & the Department of Health WA

Phone: +61 (0)8 9389 1488

Fax: +61 (0)8 9389 1499

Email: eecw@eecw.com.au

Website: <http://www.datalinkage2012.com.au>

Asia-Pacific Prader-Willi Syndrome (PWS) Conference



The 2nd PWS Asia-Pacific Conference will be held in Sydney, Australia March 10-11, 2012.

The two day conference provides an opportunity for scientists, professionals, parents and caregivers to join together and share expertise.

The speakers come from around the wider Asia

Pacific region and are recognised as leaders in their fields. Each has a particular interest in Prader-Willi Syndrome and in depth experience in this area. A wide range of topics will be covered at the conference, for all age groups and the programme will include both scientific presentations and interactive workshops.

Website: <http://www.pws.org.au/conf12.html>

How Does Our Health System Measure Up?



Australian Healthcare and Hospitals Association (AHHA)

Start Date: Mon, 24/09/2012

End Date: Thu, 27/09/2012

Venue: Sofitel Sydney Wentworth, 61-101 Phillip Street, Sydney NSW 2000

Following the success of The Great Healthcare Challenge in 2011, the Australian Council on Healthcare Standards (ACHS) and the Australian Healthcare and Hospitals Association (AHHA) will again join forces in 2012 to bring you - How does our health system measure up? Reporting on performance: the views of consumers, providers and regulators.

Whether you are a clinician, a manager or

finance officer, you are required to measure and assess your outcomes. The National Health Reform will put this part of your job under the microscope.

Register your interest at: admin@ahha.asn.au

Website: <http://ahha.asn.au/event/how-does-our-health-system-measure>



Rare Disease Day 2012

Rare Disease Day is an annual, awareness-raising event co-ordinated by EURORDIS at the international level and the National Alliances of Patient Organisations at the national level.

February 29, 2012 marks the fifth international Rare Disease Day coordinated by EURORDIS and organised with rare disease national alliances in 25 European countries. On this day hundreds of patient organisations from more than 40 countries worldwide are organising awareness-raising activities converging around the slogan "Rare but strong together".

Activities will take place across Europe, all the way to Russia, continuing to China and Japan, in the US and Canada, and as far as Australia and New Zealand! Get involved!

The Info Pack on the downloads page gives you background information on Rare Disease Day and will help you understand the choices made and how they will help us achieve our awareness raising goal.

Visit: <http://www.rarediseaseday.org>

Australia

Email: info@raredisease.com.au

Visit: <http://www.raredisease.com.au>

Everylife Art Contest

Artists are invited to participate in the Third Annual EveryLife Art Contest. The competition is open to all artists affected by a rare disease ages five and older, as well as close friends, family members or care-takers of those with a rare or undiagnosed disease.

International entries are accepted. Prizes will be awarded, including an iPod touch.

Entries must be received by Friday January 31, 2012

Website: http://www.rareartist.org/main/about_contest

Last Years Winner - Adult (age 18+)



"I am a 22 year old from Puerto Rico. I suffer from Ehlers-Danlos Syndrome and so does my cousin Ileana. This is a representation of EDS with the marbles from my physical therapies, the flexible finger, the "EDS" block, and the famous zebra toy. The zebra is a national symbol for EDS sufferers like me. I can barely paint anymore because of the horrible pain caused by dislocations or subluxations, but I don't give up on making an awareness of this painful condition. The painting took me about 12 hours because I had to take many breaks to rest my hands, back, and neck. I hope you can all enjoy my hard work. I hope we can find a cure or a treatment soon. Spread the word of its existence!"



Promote your event here and on our website at no cost! Contact us on

(08) 9389 6722 or e-mail

info@geneticsupportcouncil.org.au



Resources

Podcast – Professor Georgia Chenevix-Trench: Genetic pre-disposition to breast cancer

Professor Chenevix-Trench, Laboratory Head of Cancer Genetics at the Queensland Institute of Medical Research, talks about her goal of identifying the genes that underlie predisposition to breast cancer to support better treatments and screening.

The podcast and transcript is now available on the NHMRC website: <http://www.nhmrc.gov.au/media/podcasts/2011/genetic-pre-disposition-breast-cancer?>

New Indigenous fact sheet for Mental Health Week

Kurungkurl Katitjin, Centre for Indigenous Australian Education and Research
Kurungkurl Katitjin has developed a specific Indigenous timeline fact sheet. The fact sheet has been compiled to provide an overview of significant events, policies and reports that have shaped Aboriginal and Torres Strait Islander mental health and wellbeing in Australia.

See: <http://www.ecu.edu.au/schools/kurungkurl-katitjin/news-and-events/kk/2011/10/new-indigenous-fact-sheet-for-mental-health-week>

Conflict of interest guidelines for clinical guidelines

Williams MJ, Kevat DAS, Loff B. (2011). MJA, 195: 442-445

While clinical guidelines are routinely produced with the aim of improving the quality of health care, they are vulnerable to bias. It was found that only 15% of guidelines of the National Health and Medical Research Council portal from the most prolific developers have published conflict of interest statements and even fewer have details about the process of managing conflicts.

It is recommended that peak bodies and clinicians should promote an improvement to current practice. [Abstract précis by PHC RIS] See: http://www.mja.com.au/public/issues/195_08_171011/wil11130_fm.html

New report on Disability Pension reform.

The Centre for Independent Studies has published a new report on Disability Pension reform. The report, Working towards self-reliance: three Lessons for Disability Pension reform (PDF 731kb) examines "how [Disability Support Pension] DSP can be redesigned to ensure that all those people who have disabilities but can join the workforce are given the opportunities to do so." Review of Student Income Support Reforms report released <http://servicedelivery.govspace.gov.au/2011/10/18/review-of-student-income-support-reforms-report-released/>

Australian Department of Health and Ageing (DoHA) releases draft Personally Controlled Electronic Health Records Bill 2011

<http://servicedelivery.govspace.gov.au/2011/10/18/australiajn-department-of-health-and-ageing-doha-releases-draft-personally-controlled-electronic-health-records-bill-2011/>

Talking Glossary of Genetics

The Talking Glossary of Genetics Terms features more than 250 common genetic terms pronounced and explained in an easy-to-understand way by leading scientists and professionals at the National Human Genome Research Institute.

<http://www.genome.gov/glossary/index.cfm>

The Australian Charities and Not-for-profits Commission (ACNC) Taskforce

The ACNC has launched its website to keep you up-to-date on their activities.

Visit: <http://acnctaskforce.treasury.gov.au>

Heart Foundation Heartmoves

Heartmoves is a gentle physical activity program suitable for anyone who hasn't done any exercise in a while. You can exercise at your own pace in a friendly atmosphere. Heartmoves is open to everyone and is designed to be safe for people with stable long term health conditions such as heart disease, diabetes or obesity. Heartmoves is run by accredited exercise professionals specifically trained in

managing safe, low to moderate intensity physical activity programs.

Contact: the Heart Foundation (08) 9382 5905

www.heartfoundation.org.au/heartmoves

FOODcents Education Workshops

Cancer Council WA conducts adult community FOODcents education workshops. These are available free of charge to all community groups, workplaces and schools.

Each workshop is flexible to the time, needs and interests of the group. FOODcents workshops provide take home information and will cover health eating and smart budgeting. Supermarket tours and cooking workshops are also available to follow the workshop on the same day or a later date.

- Workshops are also available some Western Australian regional areas and cover healthy eating, food budgeting, cooking and a supermarket tour.

If you have a group of 8 or more people who would like a free FOODcents workshop in Perth or regional WA please contact us.

Source: www.foodcentsprogram.com.au/workshops/



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



Top 10 Fundraising Ideas

In the eternal pursuit for funding, it is tempting for community groups to fall back on tried and true methods, relying on just one or two fundraising ideas to bring in all or most of their funds. In doing so, however, such groups are ignoring one of the most important keys to sustainability - the need to diversify your funding base. Ensuring that you obtain funds from several sources means that you reduce the damage done if one of these sources falls though or dries up.

Below we've listed the top 10 methods you can go about raising funds. Think about these methods and how they fit in with your own group's fundraising strategy. Are you doing all of these things? Could you be doing them better?

Tip 2 - The Raising Funds Newsletter and fundraising books

Raising Funds is Australia's most practical and best value fundraising newsletter, bringing you an endless supply of fundraising ideas (including everything on this list), as well as interviews with grantmakers and successful grantseekers. How to Find Money Fast is a fun book that lists 50 ways that you can raise up to \$5,000, and the Complete Community Fundraising Handbook will help show you how to put in place a sustainable, diverse fundraising program.

✓ You can read more about these books by www.ourcommunity.com.au/books.

Tip 3 - Rotary

Rotary clubs are an excellent source for a quick cash injection - provided you know a Rotarian. Rotary clubs will often have several thousand dollars that can be put to quick use for a worthy cause nominated by a member. There are thousands of Rotary members across Australia and most of them are heavily involved in community life so there's a good chance one of them is a member of your community group - or knows someone who is. Lions groups often provide a similar service and so they may be worth approaching as well.

Tip 4 - Donations

You don't necessarily have to have Deductible Gift Recipient (DGR) status to receive donations (although it is a handy incentive for donors). If you haven't investigated your options why not have a look at Our Community's free Online Donations Facility and see what options are available to you. Alternatively you can email to: donations@ourcommunity.com.au or call us on (03) 9320 6800.

Tip 5 - Membership

Do you charge for membership to your community group? Should you? Membership is perhaps the best regular source of income your community group can obtain - in fact, for many groups membership fees ensure their

very survival. Members also form a great group of people who you know support your organisation and can press for a donation or to attend your next event. You should be looking to increase your membership base by around 33 per cent a year. If you think that's too high then you're probably not trying hard enough.

Tip 6 - Sponsorship

Sponsorship is a great win-win opportunity for both your community group and the sponsoring organisation - they provide you with a little bit of money to help put on your event and you provide them with a great advertising opportunity. There are many different varieties of sponsorship deals but basically they involve a business giving you a bit of money and you providing them with a good plug. To secure a sponsorship deal it is usually best to look for a local business you already have a good relationship with.

Tip 7 - Community-Business Partnerships

Our Community has compiled dozens of free help sheets on all aspects of finding, keeping, expanding and ending community-business partnerships. While partnerships do not necessarily involve cash donations (although some do), they do often involve in-kind donations of goods or pro bono services. Visit www.ourcommunity.com.au/partnerships to find out more.

Tip 8 - Wills and Bequests

People don't like talking about money and they don't like talking about death, so they really don't like talking about wills and bequests. That's a shame because but they really are a constructive way for someone to leave a legacy to an organisation they were involved in during their life. It's a relatively simple thing to do - just ask people if they would like to remember your group in their will and tell them how to do it. We recommend that the donation of anyone's estate should be organised in consultation with a lawyer. See our help sheets on this topic for more.

Tip 9 - Tenders

In the current climate of increasing privatisation of government assets and services it is increasingly common for governments at all levels to contract out community services. This has created a great opportunity for community groups to get some extra funding for things they were already doing, or to take on some extra roles. Because they are the people on the ground community groups are often the best people for these sorts of jobs. But beware: this can come at the cost of your independence, and it may divert you from your mission.

Tip 10 - Sale of Goods and Services

Finally, just because you're a community group doesn't mean that you can't sell your goods and services. In fact countless community organisations have one thing or another that they sell, from advice in the form of books and newsletters to food at the cooperative to in-home care. As long as any "profit" is put back into the organisation, you are still non-profit. Remember to constantly review your fundraising plan. You can always be doing something better and have more money at your disposal that will help you to make an even greater difference.

Information Source:

Our Community Pty Ltd.

http://www.ourcommunity.com.au/funding/funding_article.jsp?articleId=1026 [Accessed 15/11/2011].



GSCWA can assist members 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. For further details ph or 08 9485 8999 or email: info@geneticsupportcouncil.org.au

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

Monomelic Amyotrophy

A person from Western Australia who is living with monomelic amyotrophy would like to make contact with others living with this condition.

Synonyms: of Monomelic

Amyotrophy: Benign Focal Amyotrophy, Hirayama syndrome, O'Sullivan-McLeod syndrome, Sobue disease and Single limb atrophy.

If you would like to contact with one of these families or individuals, please call Kristina at the Genetic Support Council for further details on 08 9485 8999 or email: info@geneticsupportcouncil.org.au

Dandy Walker Syndrome Support Group

Available: <http://www.facebook.com/group.php?gid=2357002701&v=info>

Basic Group Info

For people who have Dandy Walker Syndrome, or know someone who has it.

Privacy Type: Open: All content is public.

Contact Info

Website: <http://www.dandy-walker.org>

Online Tetrasomy/Pentasomy X Support Group

Online Tetrasomy/Pentasomy X Support Group and this website to provide support, friendship and information for all of them throughout the world and raise awareness of 48XXXX & 49XXXX, amongst the medical profession and the public. We have achieved our goal of creating a non-profit status within this group and we hope to be able to help our girls and their families.

Group Information

- Members: 129
- Category: Health Care
- Founded: Jan 28, 2000
- Language: English
- Membership requires approval

Visit: <http://groups.yahoo.com/group/tetra-x-list/>



Genetic Support Council WA

The Genetic Support Council WA Inc (GSCWA) is a not for profit organisation that acts as a peak body for genetic support groups in Western Australia. The Council provides information to individuals and families about genetic conditions including information on the services provided by Genetic Support Groups.

Genetic support groups can be a useful resource for individuals and families affected by a genetic condition. Support Groups can provide information about the condition and community resources, as well as an understanding and empathetic ear.

In Australasia, there are hundreds of such groups each focussing on a specific genetic condition. We can help put you in contact with these groups or provide the support and guidance to help you establish a new support group.

The Council may also be able to provide information and support for conditions so rare that there is no specific local support group.

The GSCWA maintains a database of Genetic Support Groups throughout Australia and with international links can provide up to date information on genetic conditions – including the latest information on research developments.

Information is also readily available on a range of associated topics - online resources, living with a family member with a genetic condition, parenting, and education in association with a genetic condition are some of these.

The Council conducts forums for members on issues of interest or concern to enable member's views to be represented to the wider community and State and Federal Governments. We also provide written and verbal submissions to Government and others in the field of genetics and participate with like bodies nationally to further represent Genetic Support Groups and their members.

We conduct forums and awareness events to enable participants to increase their skills and knowledge and access up to date information about resources for people affected by genetic conditions and their families. The Council maintains an up-to-date website and publishes a bi-monthly newsletter and information sheets for consumers.

The GSCWA actively supports the ongoing development of Genetic Support Groups. We are able to assist with the development of resources such as information packages, pamphlets and the printing of promotional material. Groups can also publish articles and advertise and promote awareness of their Support Group's activities on the GSC website and in our bi-monthly newsletter the "Gene Advocate".

Staff can assist groups and individuals in researching information regarding particular genetic conditions or predispositions and help keep members aware of matters of interest such as changes of legislation etc.

All GSCWA services are free to member groups and individuals. Please call us for further information or to access any of these services.

What causes genetic conditions?

There are three types of genetic conditions:

- Heritable conditions: Due to a mutation in a single gene
- Chromosomal conditions: Occurs when an individual is affected by a change in the number, size or structure of his or her chromosomes
- Multifactorial conditions: Due to the interaction of the genetic information and environmental factors such as diet, chemical exposure and lifestyle.

What can be done about Genetic Conditions?

Prevention

Some people are more at risk than others for developing a condition that is due to the interaction of environmental factors with their inherited genetic information. They are "genetically predisposed" to develop these conditions. However, the presence of an environmental "trigger" is necessary for the person to be affected with the condition. In some cases, prevention of the condition can be achieved by the person avoiding being exposed to the particular environmental factor that will trigger the condition.

For example, it is possible to prevent about 70% of the cases of spina bifida (a neural tube defect) in babies if women who are more likely to have a baby affected with spina bifida, because they are genetically "predisposed", take the vitamin folic acid before, and continue it during early pregnancy.

Early Diagnosis and Treatment

In some genetic conditions, early diagnosis, sometimes even before the symptoms appear, can lead to specific treatment. For example, all newborn babies in Australasia are screened for phenylketonuria (PKU) by a simple blood test.

Diagnosis and treatment within the first month of life are crucial to avoid intellectual disability.

Also, some cancers which have a genetic component, e.g. breast cancer, bowel cancer and melanoma, can be detected early enough to enable treatment to take place.

Checking the family health history may determine if a person or another blood relative are at risk for developing a genetic condition or for passing it on to their children.

Genetic Counselling

Genetic counselling is available to families and individuals that have concerns about a condition in their family which may have a genetic basis. A team of health professionals which may include clinical geneticists, genetic counsellors and social workers, work together to provide information and supportive counselling so that families may be better able to understand, and adjust to, the diagnosis of a genetic condition.

Genetic testing, if it is available and appropriate, can also be organised on the basis of informed consent. Genetics Services are available throughout Australasia and provide genetic counselling to assist in informed decision making regarding genetic testing.

Support Groups

Support groups provide affected individuals and families with information about the condition and community resources, as well as an understanding and empathic ear. There are over 200 genetic conditions for which there are over support groups/branches in Australasia.

Some points to remember when contacting a group

Many of the support groups contact numbers are home numbers, so please be considerate of the hours at which you call.

Many support groups do not receive funding and rely on their group members for income. Offering to pay for postage, photocopying and/or materials provided will be appreciated by many groups.



GSC Members

Full Members

Acoustic Neuroma Association of Australia, WA Branch
Alzheimer's Association of WA
Angelman Syndrome Association
Arthritis Foundation of WA
Arthrogyrosis Support Group
Australian Cystinosis Support group
Australian Dyspraxia Association
Australian Leukodystrophy Support Group
Australian Mitochondrial Disorder Foundation
Australian Pituitary Foundation WA Branch
Australian Tuberous Sclerosis Society Inc.
Cardio Facio-Cutaneous Syndrome Support
Charcot-Marie-Tooth Association Australia
CHARGE Syndrome Association of Australasia
Chiari & Syringomyelia Australia
CleftPALS WA
Coeliac Society of WA, Inc
Cornelia De Lange Syndrome Support Group
Cushing's Disease Support Group
Cystic Fibrosis WA
Diabetes Western Australia
Down Syndrome Association of WA Inc
Dyslexia SPELD Foundation WA Inc
Epilepsy Association of WA
Even-Keel Bi-Polar Support Association (Inc)
Fabry Support Group of Australia
Familial Hypercholesterolaemia Support Group WA
Fragile X Support Group WA Inc
Haemophilia Foundation WA Inc.
Heart Kids WA
Huntington's WA Inc
Klinefelters Support Group
Learning and Attention Disorders Society of WA (LADS)
LQTS Support Group WA
Lupus Group of WA
Lymphoedema Association of WA
Menieres Support Group WA
Mental Illness Fellowship WA
Mitochondrial Disease Foundation
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 Group of WA
Retina Australia (WA)

Rett Syndrome Association of WA
Senses Foundation Inc.
Short Statured People's Association WA Branch
SIDS and Kids Western Australia
Spina Bifida Association of WA
Thalassaemia Association of WA
Tourette Syndrome Support Group, Perth
Thyroid WA Support Group Inc
Turner Syndrome Association of Australia (WA Branch)
Support Organisation for Trisomy and Related Disorders of WA (SOFTWA)
Usher Syndrome Support Group

Corporate Associate Members

ARAFMI Western Australia
Androgen Insensitivity Syndrome Support Group Australia
Association of Genetic Support of Australasia
Australian Kidney Foundation
Carers Association of WA Inc
ConnectGroups
Ectodermal Dysplasia Support Group - OzED
Genetic Support Network of Victoria
Health Consumers Council WA
Kidney Health Australia
Learning Centre Link—Linkwest
Myasthenia Gravis WA Friends and Support Group
NZ Organisation for Rare Disorders
Office of Population Health Genomics
People with Disabilities WA
Self Help Organisations United Together (SHOUT)
Speak Easy Association Western Australia
The Chromosome18 Registry & Research Society
The Kalparrin Centre
The Neurological Council of WA Inc
Unique in Australia Chromosome Disorder Support Group
Western Australian Deaf Society Inc.

Individual Associate Members

Linda Bovill	Robyn Hendriks
Anja Hermann	Terry Keating
Sindhu Kurup	Amanda Samanek
Kristina Sengotta	Abdulla Sheikhi
Darren Webb	
Professor Charles Watson	

Membership Forms are available on the Web.
<http://geneticsupportcouncil.org.au>



At the close of another year, we gratefully pause to wish you and your family a warm and happy Holiday Season and a peaceful and prosperous New Year.

We value our relationship with you and look forward to working with you in the year to come.

Kind Regards,
Genetic Support Council Staff and Board

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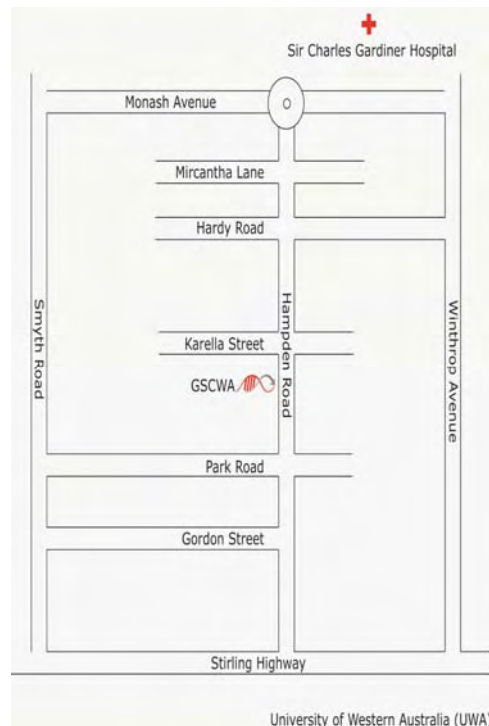
Contact Us

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Nedlands WA 6009

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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.