

SELF HELP QUEENSLAND

June Newsletter

Issue 2. 2004



Self Help Queensland is a network of self help organisations and groups in Queensland. The network was formed by self help organisations to share resources, support each other, assist in the development of new groups, raise community awareness of the importance of self help and provide a strong united voice on issues which affect our members.

From the President

Sue Smyllie

Like many of our member organizations, SHQ has been working towards meeting the new reporting requirements for that part of our funding received from Queensland Health. Our Coordinator, Trish Fallon and most of our management committee attended the training program provided by QH. Considerable time and effort has been expended understanding and then applying the reporting process. As I have been on leave during most of this time the burden of all this has been carried by others and I'd like to thank Trish, Kim, Thea and Kathleen for all their hard work.

My first sight of the reporting framework was quite daunting and had I been consulted during the design phase of this instrument I would have had lots of suggestions to make. However, having been on the other side of the fence as well, I can also imagine the hard work which went into developing something to meet competing and what seem at times, incompatible requirements.

As with all accountability systems there will no doubt be an adjustment phase. I hope the door is open for frank and respectful exchange of knowledge between the coal face at the community level and the coal face at the funder level.

I always get a feeling of disappointment tinged with fear when confronted with accountability systems. Disappointment that the system never quite captures what 'really' happens, never seems to leave enough room or flexibility for change, innovation and unexpected outcomes and never adequately conveys an understanding of the complex inter-relationship of all the differ-

bits from a community capacity development approach.

The fear bit is also tied up with the unexpected. Detailing targets the organization may not meet, trying to share the excitement of unintended outcomes without having them co-opted into unattainable requirements for next time, spending so much time reporting that the doing gets left undone!

What is often left out of accountability systems is a little bit of faith and trust. Trustworthiness is earned of course but can also be assumed. A perceived break in trustworthiness may simply be a lack of communication or skill and is not a reason to change values as the foundation for the system, even if ill was intended.

I know we must be accountable for public funding but I think that the big picture is often over looked. We are accountable for meeting the values of our society not only in intent but also in the way we do our work. If this big picture is understood the detail should be less important.

Until next time

Sue

Volunteer Required

A small, proactive community based charitable organization is in urgent need of administrative assistance.

Enquiries to Darrin Larney at Survivors of Suicide Bereavement Support Association Inc Ph: 0412 787 302

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Self Help Old Management Committee Members

President Sue Smyllie
Treasurer Kathleen Zarubin
Secretary Kim Summers
Member Thea Biesheuvel

Committee Meetings

If you would like to attend our meetings, please contact the office for dates and times. Everyone is welcome to attend and we look forward to seeing some of you at our meetings. We are always on the lookout for new committee members!

Project Officer

Trish Fallon

Office

The office is attended (unless our staff are at meetings) from Monday to Friday from 9am to 4.00pm each week.

If you wish to call in to use the facilities at the office or talk to our project officer please phone first and check that there will be someone in the office.

Office Location:

Sunnybank Community Centre
121 Lister Street (Cnr Gager Street)
Sunnybank 4109

Postal Address

P.O. Box 353
Sunnybank QLD 4109

Phone/Fax: 07 3344 6919

Email: selfhelp@gil.com.au

The views expressed in this publication are those of the individual authors and not necessarily those of Self Help Queensland.

The material supplied is for information purposes only, and is not to be used for diagnosis/treatment, or as legal, tax, accounting or any other type of advice.

Thanks to Queensland Health for providing funding to Self Help Queensland for publication of the Self Help Queensland quarterly Newsletter.

Link Line



Through this newsletter column, Link Line is a mutually respectful, sensitive and confidential means of connecting individuals and families for whom no known support group exists.

Self Help Queensland will endeavour to facilitate contact wherever possible but is unable to determine the suitability or compatibility of linked individuals and families.

Currently no entries in Link Line

To make confidential contact regarding the above or to place a notice in Link Line, please call Trish at the Self Help Qld Office Phone/Fax (07) 3344 6919
Email: selfhelp@gil.com.au

Tell us about Your Group

If you belong to a self help or support group we would love to hear about it so we can let others know.

Please contact Self Help Queensland
Ph/Fax : 07 3344 6919
Email: selfhelp@gil.com.au

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Our New Email!

selfhelp@gil.com.au

Genetic Matters

with Kim Summers PhD

Treatment for Genetic Diseases

Technical developments of the last twenty-five years have allowed us to manipulate and understand our genetic material in ways we couldn't envisage in 1953, when Watson and Crick first worked out the structure of that genetic material, the DNA. For people with genetic conditions in the family, these new techniques held out the promise of treatments which corrected a genetic defect by inserting a fully functioning copy of the gene to replace or supplement the abnormal one. Twenty years on, we seem to be no closer to this kind of gene therapy and families might think that there has been no progress in finding treatments.

Why is gene therapy proving so difficult to use? There are a number of reasons.

- Firstly, not all genetic conditions are suitable. The greatest hopes are for conditions where we know a small increase in the product of the normal gene can compensate for the abnormal gene. Conditions like cystic fibrosis, severe combined immunodeficiency syndrome (SCID) and adenosine deaminase deficiency have been the focus of some gene therapy trials and there is evidence they could be successful. However for many conditions, like Duchenne muscular dystrophy, Marfan syndrome, osteogenesis imperfecta and many others, a small increase in the normal gene product will not be sufficient and more complicated gene therapy protocols would be needed.
- Secondly, some people make an immune response when the replacement gene is introduced. This was probably responsible for the death of one person in a gene therapy trial and might also prevent gene therapy being repeated in any individual.
- Thirdly there have been many technical problems in developing systems to target the replacement gene to the correct cell type, get it into the cells and make it work appropriately and at a high enough level. In one trial, the replacement gene became incorporated into the patient's DNA in a site which predisposed to development of leuk-

aemia. Problems like this need to be overcome.

- Finally many common conditions are caused by a number of faulty genes acting together and it would be difficult to discover and correct each of these genes. These conditions include Alzheimer disease and diabetes, which are unlikely to be cured by gene therapy.

If gene therapy does not provide the hope of a cure, there are other approaches which have come from the understanding of how genes work and how they can be manipulated to overcome problems caused by genetic defects. For example, two recent strategies, involving cystic fibrosis and Duchenne muscular dystrophy, look promising.

In many cases of cystic fibrosis, the gene product (a protein) works quite well if it can get to the right place in the cell. However the genetic defect prevents it from getting there. Now researchers have found a compound which helps the protein get to where it needs to be, at least in mice with the equivalent genetic defect. Discovery of this compound came about because of the knowledge of how the gene product works in unaffected people and in those with cystic fibrosis. The compound itself is one which is frequently used in food and is well tolerated by people, so the procedure for getting approval may be shortened. The researchers have not yet tried the treatment in humans and it will be some years before it will be clear that it works, but it is encouraging to see that lateral thinking coupled with information about the normal and abnormal functions of genes and gene products may lead to treatments.

Duchenne muscular dystrophy is caused by failure of a protein which is found in muscle. In many cases parts of the very large gene are deleted or rearranged so that the protein is abnormal or even missing altogether. Now researchers have come up with a method which skips over the abnormal part of the gene. This results in a protein which is still abnormal, but none-the-less can perform its function reasonably well. The researchers think that people on this treatment will have a very much milder condition than they would otherwise. The treatment would involve administering short pieces of DNA without the problems of current systems (Contd Page 4)

(Contd from Page 3)

which try to insert whole genes.

These are just a couple of examples of possible new treatments for genetic disease. Although gene therapy has not really lived up to the promise of the first trials in the early 1990s, discoveries about genes have allowed development of alternative therapies which may prove less problematic. It may seem that progress has been slow but it is encouraging to see that researchers are continually coming up with new ideas and possibilities for treatment.

For a good discussion of gene therapy go to: www.ornl.gov/sci/techresources/Human_Genome/medicine/genetherapy.shtml.

To contact support groups for cystic fibrosis and Duchenne muscular dystrophy:

Cystic Fibrosis Qld
PO Box 2245
Chermside Centre 4032
Freecall: 1800 670 990
Ph: 07 3359 8000
Fax: 07 3359 3380
Email: admin@cysticfibrosislqld.org.au
URL: cysticfibrosislqld.org.au

Qld Muscular Dystrophy Assoc
Locked Bag 3000
Spring Hill 4004
Freecall: 1800 676 364
Ph: 07 3016 1800
Fax: 07 3831 2666
Email: qmda@optusnet.com.au
URL: mda.org.au

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Endometriosis Assoc Qld Inc

Charity Dinner Auction

*Featuring the talents of Internationally
acclaimed singer*

Vanetta Fields

&

Mo-Award winning impressionist

Liz Taylor

Friday 27th August 2004
Marriott Hotel Brisbane

Tickets \$140 per person

Phone Kim 0403 136 608

Annual Family Meeting of

The Chromosome 18 Registry & Research Society (Aust) Inc

The Chromosome 18 Registry & Research Society (Aust) invites families affected directly with Chromosome 18 disorders to attend the annual social day for the Australasian Region. **The Registry is a contact point for families and individuals affected by 18q deletion, 18p deletion, Tetrasomy 18p, Ring 18, Trisomy 18, Partial Trisomy 18 or other unique rearrangements of chromosome 18.** More information about the Registry, its aims and goals can be accessed through the website at www.chromosome18.org

The upcoming social day will be an ideal opportunity, especially for those Western Australian families, to meet up. Interstate and overseas families will also find many things to see and do in and around picturesque Perth. Dinner arrangements will be made nearer to the date. We hope many families will be able to join us on the day. (The Chromosome 18 website also contains information about the Inaugural World Congress on Chromosome Abnormalities, San Antonio, USA, 27 - 30 June 2004).

**Saturday 28 August 2004
Meerilinga Community Hall
30 Chichester Drive
Woodvale, Perth WA
Time: 10am**

The Meerilinga Community hall is situated 15 kilometers north from the centre of Perth and 7 minutes from the beach area. The Hall is equipped with indoor/outdoor play activities for the children. Respite carers for children can be organized through your local area co-ordinator. Discuss your requirements with them. For enquiries and further information please contact:

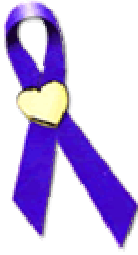
Veronika Ph: 08 9409 9854

Mob: 0416 240 066

Marlene Ph: 02 9580 5707

Mob: 0400 809 366

The Chromosome 18 Registry & Research Soc (Aust)
61 Kuroki Street, PENSHURST, NSW 2222



Australian's Celebrate International Herpes Week with a National Gathering and the Launch of a New Support Group Resource Website

There are many individual Herpes support groups throughout Australia delivering a wide range of services, including: support meetings, social activities, educational resources, online group forums, print and email newsletters.

The role of support groups in coming to terms with having an incurable STI like Herpes is very often underestimated. Doctors can test, diagnose, provide information and prescribe medications. However, learning to accept and manage your condition often requires more support than can be provided by the medical profession.

One major hurdle in coming to terms with Herpes is dealing with the negative social stigma attached to the virus. Unfortunately many people are ignorant of the facts regarding Herpes and make the assumption that only promiscuous people and sex workers catch STI's. This, of course, is not the case. Every sexually active person is at risk of contracting an STI.

Another aspect which causes many people a great deal of stress is resuming dating after having contracted the virus. When, where and how to tell someone your STI status can be a very real concern. Some people are so afraid of receiving a negative reaction that they refrain from dating or attending social functions.

Social/support groups can play a very important role in helping people come to terms with having the virus for life, encouraging people to get on with their lives by sharing their own experiences - from medication and alternative therapy experiences, to dating tips and "how to tell" stories.

Most groups are run entirely by volunteers who devote endless hours to keeping the groups going and growing. It can sometimes be a struggle to keep a group 'alive' when faced with the ongoing difficulties of promoting something as sensitive as Herpes.

To enable these groups to work together, share resources, ideas and tips and to expand the range of support services currently being provided, a new 'umbrella' organisation has been formed - The Australian Herpes Support Network. The AHSN's aim is to develop a comprehensive range of resources to assist existing support groups to promote and expand their groups, and to aid with the formation of new groups.

A new website is currently being developed which will incorporate: detailed listings for Herpes support groups Australia wide; independent reviews of Herpes information websites; 'H-Mates' volunteers providing one-on-one chat, email and phone support; alternative therapies and healthy lifestyle tips; discussion of related issues such as the negative social stigma and dating / relationship issues; and an in-depth Herpes Survey.

The team behind the AHSN includes original members of the Hevent 2003 team - an initiative to organise Australia's First National Herpes Gathering which took place in Adelaide last year. Primarily a social event, it focused on 'Celebrating Herpes!' or to be more precise, celebrating the fact that despite having Herpes, life is still worth celebrating.

This year's event will be held on the Gold Coast from 15-17 October to coincide with International Herpes Week (10-15 October). It will again be a weekend social event with a variety of functions and opportunities to make new friends and to share experiences in a casual, non-judgemental environment.

For further information, to volunteer your services, join the email list or enquire about sponsorship opportunities, please email the team at hevent2004@yahoo.com.au

Postal Address:

AHSN
PO Box 674
HELENSVALE QLD 4212

Hevent 2004 Website:

http://au.geocities.com/australian_hevent

Gold Coast H Friends

<http://au.geocities.com/gchfriends/>

Herpes Hangout

http://au.groups.yahoo.com/group/herpes_hangout/ -oOo-

Invitation to Support Groups
to
Participate in Health Research
with
The Queensland Institute
of Medical Research (QIMR)

Is your group interested in health and medical research? The Consumers' Health Forum of Australia is contacting consumer and community groups in and around Brisbane to find people who would like to learn more about and contribute to research work at the Queensland Institute of Medical Research. Consumers could get involved by:

- Learning more about research through information sharing sessions where researchers discuss their work with consumers.
- Helping researchers learn about consumers' experiences through information sharing sessions where consumers discuss their work and values with researchers.
- Joining a Consumer and Community Reference Group to provide consumer perspectives into decision-making about research.
- Communicating information about research processes or the results of relevant research to other consumers (for example, a researcher could write an article in plain English for a consumer newsletter).
- Working on specific projects with researchers to ensure that consumers' needs are met.

The Queensland Institute of Medical Research (QIMR) and the Consumers' Health Forum of Australia (CHF) are working together to improve consumer participation in QIMR's research. This is based on the *Statement on Consumer and Community Participation in Health and Medical Research*, which CHF developed in partnership with the National Health and Medical Research Council (NHMRC), who are funding this project. This envisages consumers and researchers working together in all stages of the research process. You can ask CHF for a copy

of this *Statement* if you would like to read it. (see contact details included in this article)

It is also available on the internet at:

<http://www.nhmrc.gov.au/publications/synopses/r22syn.htm>

CHF (www.chf.org.au) is Australia's leading non-government organisation representing consumers on health care issues. CHF establishes policy in consultation with its members, approximately 100 health consumer organisations across a wide range of health interests. It provides a balance to the views of government, industry, service providers and health professionals.

QIMR (www.qimr.edu.au) was originally formed to further the study of tropical diseases in North Queensland, but over its nearly 60 years' history has broadened its scope to include a wide range of infectious diseases, cancers and other disorders. It also studies the environmental, lifestyle and genetic factors that contribute to diseases in different populations.

Ever wondered what scientists at QIMR research? Here's a brief explanation of QIMR's research work:

- *Infectious diseases and immunology*
Scientists are examining diseases such as malaria (the biggest killer in the world), glandular fever, Ross River virus, dengue fever, Barmah Forest, influenza, giardia, trichomonas, HIV / AIDS, schistosomiasis and other infectious diseases. Scientists are also studying the human immune system and how it is activated when these diseases are present and are developing vaccines against many of these major diseases which kill millions of people world-wide each year.
- *Cancer and cell biology*
Scientists in this division study many forms of cancer, including breast, ovarian, prostate, lung, skin, bowel, brain, and liver cancer and lymphoma, leukaemia, and multiple myeloma. Through understanding the functioning of normal cells and how they differ from cancer cells, scientists hope to understand how mutations occur and to develop more effective screening tests and preventative methods for many of these life-threatening cancers. (Contd. Page 7)

(Contd. From Page 6)

- *Population studies and human genetics*
Scientists are researching many diseases that affect our population and populations world-wide - diseases include Schizophrenia, asthma, diabetes, alcoholism, anxiety and depression, liver diseases and cancer. Scientists are working to understand how environmental and genetic factors interact to cause many of these diseases.
- *Therapeutic development and clinical research*
Scientists in this division are developing new therapies for diseases such as cancer - QIMR has a number of clinical trials underway to test "immunotherapy" as a new treatment for cancer. People in the community are involved in clinical trials, which are undertaken under the strictest ethical protocols. QIMR also adheres to Therapeutic Goods Administration (TGA) guidelines in the development of experimental treatments and/or diagnostics.
- *Indigenous health research*
Indigenous Australians have significant health problems including much higher mortality and morbidity rates than non-Indigenous Australians. Through working with Indigenous communities, QIMR scientists are developing vaccines against diseases such as Rheumatic Heart Disease and trying to understand why diseases such as diabetes are rife in these communities.

If you would like to contribute a consumer perspective to QIMR's research, please contact Beth Micklethwaite, Research Project Officer at the Consumers' Health Forum of Australia by calling 02 6273 5444 x 205 or by email to b.micklethwaite@chf.org.au. If you use the Internet, you can complete the QIMR consumer interest form which is available on CHF's website at www.chf.org.au.

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Garage Sale

In support of the Lymphoedema Assoc Qld

Saturday 31 July at Brackenridge
Donations of goods welcome from 10th July
Contact Nerida after July 1 to arrange for
pick up of goods. Ph 3269 1498

Findings of Australian Youth Health Care Study

An Australian study, consisting of 81 focus groups, found that most adolescents define health as physical wellbeing but could identify a broad range of environmental and behavioural factors that they believed could influence their health.

One third of females and two thirds of male participants reported that they would not seek help for their health concerns, and if they did, help would be sought from family members, friends and others they trusted. When it came to health professionals, participants preferred someone they knew and trusted.

Barriers that affected adolescent's access to health care included concerns about confidentiality, knowledge of services, discomfort about disclosing health concerns, accessibility of services, and the characteristics of health services.

Journal of Adolescent Health , Vol 34, No 1, pp 97 - 103.

(Above article sourced from Health Issues Centre Journal Autumn 2004 No 78 p4)

Volunteer Small Equipment Grants 2004 (Round 2)

Due to an overwhelming response to the first round of Volunteer Small Equipment Grants in 2004 the Federal Government has decided to offer a second round for 2004.

This round of funding will provide grants of up to \$5000 each for community organisations to help them buy equipment items that will make the work of their volunteers easier, safer and/or more enjoyable.

This round has a simple application form that can be completed and submitted online. The guidelines also provide information on acceptable types of equipment that can be funded by these grants.

Information on the Volunteer Small Equipments Grants 2004 (Round 2) can be found on the Department of Family and Community Services' website:

www.facs.gov.au/vseg2004

Hotline: 1800 050 199

Closing Date !!!!! Friday 18 June

Why Do Our Public Policies Continue to Undermine the Mental Health of Asylum Seekers?

by Vanita Chopra

Health as defined by the WHO constitution (1948) is a “**state of complete physical, social and mental wellbeing and not merely the absence of disease or infirmity**”. Yet, there is evidence suggesting widespread prevalence of mental distress in asylum seekers who are held in detention in Australia. Many detained asylum seekers have already suffered extensive trauma, abuse, violence and torture, but despite these known facts, they are held in detention for reasons that are not understood and seem unjust. Instead of providing a safe and secure environment to recover from the impact of their experiences, policies are followed that undermine any effort to rebuild lives. Asylum seekers are placed in “re-traumatising” environments that add or contribute to their varying degrees of mental distress.

In maintaining the notion of health as a basic human right, there are several indisputable prerequisites for health. These include peace, food and shelter, adequate economic resources, stable ecosystems, and sustainable resource usage. These highlight the common links between the physical environment, individual lifestyles, and social and economic conditions that should exist for individual and collective health and wellbeing. However, there is much discrepancy between the health needs of asylum seekers held in detention centres and the fragmented foundation of health provided by the Australian government. Do not asylum seekers deserve basic human rights if not more?

In an attempt to rationalise society's core reality and the open animosity towards them, asylum seekers are seen as less human and consequently demonised. Detention centres versus concentration camps? Does history teach us nothing?

Grave concerns have been voiced particularly about the health and well being of children held in detention. These children are at high risk of emotional and psychological trauma as their parents are unable to provide adequately for their children or shield

them from dehumanizing acts of abuse and violence in the hostile, degrading and hopeless environment of a detention centre. Where is our compassion? Depriving children of formal education or opportunities for physical and mental growth shows a blatant disregard for their rights. Such experiences can only permanently affect the psychological and emotional health of children.

There are alternatives to detention, however imperfect, that allow asylum seekers to live with a degree of dignity and freedom within a community. Several countries have these systems in place whereby asylum seekers (both individuals and families) are integrated back into a community setting and have access to housing, employment, education and health services. While being monitored, financial bonds can be lodged by families, friends or humanitarian agencies ensuring compliance with immigration procedures and temporary forms of asylum. To date, no country that uses such alternative forms to detention have indicated a violation of social order as a consequence.

There is a conflict between Australia's image of being a country where people are entitled to a “fair go” and public policies that directly undermine the notion of human rights and health of an already vulnerable group of people seeking help. It is a shame that Australia no longer welcomes or embraces cultural diversity and humanitarianism given such widespread global instability. Instead, we fear strangers on our shores. With time, one can only hope for the collapse of this unjust system built upon the foundation of human rights abuse. The ramifications for mental health are serious. This is a breach of public health at its worst on an individual, community, population and global level.

It is pertinent to ask whether the Australian government's policy is able to provide asylum seekers with the basic elements for health. Is the notion of health as a basic human right being practiced? Have the very foundations of human rights and health ethics been breached?

(Source: Health Issues Centre Journal Autumn 2004)

Vanita Chopra has a background in nursing, is an Education Advisor at the Royal Children's Hospital, Melbourne, and is currently undertaking her Masters of Public Health specializing in International Child Health.

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Problems with Online Pharmacies

Like many items, prescription medicines can now be ordered through the internet. Concerns have been raised about this alternative source of drugs for those abusing prescription drugs.

Online pharmacies are subject to the laws of the country they are based in, however, those in Mexico and Asia can legally dispense drugs without a prescription allowing people to source quantities of prescription drugs without having to "buy on the street" or go "doctor shopping".

Other sites require a prescription before drugs can be dispensed, but there is little to stop people sending the same prescription to a number of sites. A three month supply of medication for personal use can be brought into Australia, but the selling-on of medicines is hard to police and some sites boast of having proven methods for getting packages through customs.

Medical Journal of Australia , Vol 180, pp118 - 119

(Above article sourced from Health Issues Centre Journal Autumn 2004 No 78 p5)

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Tell us about Your Group

If you belong to a self help or support group we would love to hear about it so we can let others know.

Please contact Self Help Queensland
Ph/Fax : 07 3344 6919
Email: selfhelp@gil.com.au

Free Meeting Room

A small meeting room is available free of charge for self help and support groups. The room is located at Sunnybank and seats about 10 people comfortably.

A kitchen with stove, microwave, wall urn and fridge is available for use. Toilet facilities and wheelchair accessible. Plenty of parking.

Phone Self Help Qld - 07 3344 6919

Queensland Young People in Alcoholics Anonymous (QYPAA)



2004 Convention

QYPAA stands for Queensland Young People in Alcoholics Anonymous. We are a committee of young AA members enthusiastic about our recovery. We aspire to host an annual convention in Queensland as a celebration of recovery, unity, and service.

Our primary purpose is to stay sober, and help other alcoholics to achieve sobriety.

QYPAA is all-inclusive, never exclusive or forbidding. The QYPAA convention is hosted by young people, for the fellowship as a whole. **Attendance is open to all persons concerned with a drinking problem, irrespective of age.** The theme of the 2004 convention is "A Vision for You" and includes participation by Al Anon and Alateen groups.

The convention will be opened by the Governor of Queensland, Ms Quentin Bryce AC, and addressed by Dr N O'Connor who has specialised in the treatment of alcoholism. Members of Alcoholics Anonymous will also comment on their past problems and tell of their recovery through the Alcoholics Anonymous program; and members of the Al Anon family groups will share their experience.

QYPAA 2004 Convention
The Chifley at Lennons Hotel
66 Queen Street Mall
Brisbane

Friday 23 July 2004
7.30pm

For more information please phone Richard on 07 3818 0180 or write to:

Convention Committee
PO Box 2232
MILTON BC QLD 4064

URL: www.qypaa.org
Email: mail@qypaa.org

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Crohn's Disease & Ulcerative Colitis

Brisbane Educational Meeting

- Information on inflammatory bowel disease (IBD)
- Latest clinical trials/investigating new drugs
- Genetics/Law/Research

Speaker: Dr Tim Florin, Director of Gastroenterology & Associate Professor, Medicine, Mater Adult Public Hospital

Date: Tuesday 22 June 2004

Time: 6.40pm - open for refreshments
7pm - meeting to commence
9pm close

Venue: Evan & Mary Thomson Auditorium
The Wesley Hospital
Chasley Street
AUCHENFLOWER

Parking & Directions

Parking is available in the multilevel carpark - enter from the corner of Chasley St & Lang Pde. A connecting walkway is available to the main hospital from a higher level of the carpark or alternatively walk along the path in Chasley Street to the main hospital entrance. Take the lift (near coffee shop) down to level 1 and exit the building to your right - across the courtyard is the auditorium.

**No Bookings Required!
Free Entry & Open to All!**

For further information contact:
Australian Crohn's & Colitis Assoc (Qld) Inc
Phone: 07 5437 7662
Fax: 07 5437 7103
Email: help@accaq.org.au
Url: www.accaq.org.au



Diet for Crohn's & Colitis

Free talk - by Lisa Farlow, Dietitian

Wednesday 16 June 2004, 1pm - 1.30pm

Wesley Healthwise Centre, Auchenflower
Bookings/Information 07 3232 7666

Drug Trials for Crohn's & Colitis

People diagnosed with Crohn's disease or ulcerative colitis are being sought to participate in new drug trials. Two of the trials involve the use of antibody treatments (similar to infliximab) for Crohn's disease. The drugs are Adalimumab and CDP870 and are given as an injection under the skin. The other trials are for ulcerative colitis and include testing a new formulation of mesalazine (SPD476) and a new type of therapy called OPC - 6535. All are given in tablet form. The centres conducting the trials in Qld are in Brisbane, however there are also two other locations for the OPC - 6535 trial, the Redcliffe area and Townsville.

For further information about the trials please contact ACCAQ freecall helpline: 1800 071 072 or register your interest on the website www.accaq.org.au



Crohn's & Colitis Educational Meetings

Mackay

Date: Tuesday 13 July 2004

Time: 7pm - 9pm

Venue: Emerald Room, Windmill Motel/
Reception Centre, 5 Highway Plaza,
MACKAY

Speakers: Dr Ric Reiner, Gastroenterologist
Monique Dunkley, Dietitian

Topic: Information on IBD & new treatments
Diet/Nutrition & IBD

Townsville

Date: Thursday 15 July 2004

Time: 7pm - 9pm

Venue: Robert Douglas Auditorium, Education Block, Ground Flr, Townsville Hospital, Angus Smith Drive
DOUGLAS

Speakers: Dr John Mason, Gastroenterologist
(Additional speaker not yet confirmed)

Topic: Information on IBD & a clinical trial which is to investigate a new drug treatment for ulcerative colitis.

**No Bookings Required!
Free Entry & Open to All!**

For further information contact ACCAQ:
Ph: 07 5437 7662 Email: help@accaq.org.au
Fax: 07 5437 7103 URL: www.accaq.org.au

“Breaking the Silence”

- a **new** non therapeutic self help support group for women who have experienced rape/sexual assault

Group Aims & Goals

The group will be set up on a self-help model and members will be women who have experienced rape and sexual assault.

- Confidentiality is an important aspect of the group so it can become a safe and trusting environment to share
- Reduce the feelings of isolation that survivors feel
- It will be an opportunity for members to give and receive support
- The group will be open allowing new members to join at any time
- Group members will have input and share responsibilities for what the group is doing
- The group will be ongoing and ever changing depending on the needs of the members
- Mary will be a contact person and assist with facilitating until the group evolves
- The group is not responsible for medical or legal issues

When: Once a month first Friday

Where: Womenspace
12/14 Homebush Road
KEDRON

Time: 11am - 12.30pm

**No bookings required
just turn up!**

For more information please contact Trish at Self Help Qld Ph: 07 3344 6919

Gold coin donation for use of the room
at Womenspace

Australian Ecto-
dermal Dysplasia
Support Group Inc
(ozED)



ozED is a not for profit organization founded in April 2004 and developed to provide support for persons and families affected by Ectodermal Dysplasia, a genetic disorder.

Ectodermal Dysplasia or ED as it is known, has over 150 different types to the ED group. The effects of ED include abnormalities to the affected persons hair, teeth, nails, sweating ability, skin disorders such as dermatitis and other ear, nose and throat issues.

Like other genetic disorders, ED affected people can have very similar physical appearances. Thin sparse blonde hair, darkened eyes, possibly recessed lower jaws, missing and/or deformed teeth are very common amongst different forms of ED. Reduced or absent sweat control causes associated issues regarding body temperature regulation.

ozED has a purpose to provide support to people and families affected by ED. We also have a plan to develop information and advice for professionals in both Health and Community Care. With over 150 different types of ED, ozED is committed to ensuring that each type is individual and equal.

ozED is committed to assisting families through the provision of support, information and education. ozED is also planning to produce education packages for health and other community professionals who interact with ED people and their families.

ozED would like to extend an invitation to any people affected by ED, their families, friends or any professionals that deal with ED to contact us and consider joining our organization. We are also very keen to seek any corporate supporters. For further information please contact:

Australian Ectodermal Dysplasia Support Group Inc
8 Dalmatia Court
ROWVILLE VIC 3178
Ph: 03 9755 5626 (after 7pm)
Email: info@ozed.org.au
URL: www.ozed.org.au

Free Self Management Courses for Chronic Disease

The **Chronic Disease Self Management (CDSM)** program, is a six week course (2-2 ½ hours per week), targeting people of any age with chronic condition/s. It aims to enhance participants confidence in their ability to manage their health and maintain active and fulfilling lives. CDSM is not designed to replace existing programs but rather enhances regular treatment and disease specific education such as Breathe Easy, cardiac rehabilitation or diabetes education. The course is not disease specific and covers the following topics:

- Techniques to deal with life issues
- Appropriate exercise
- Medication
- Communication
- Nutrition
- Use of community resources

The CDSM course was developed by the Division of Family and Community Medicine in the Department of Medicine at Stanford University. Extensive evaluation of the course demonstrated significant improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress, fatigue, disability and social/role limitations. Participants spent fewer days in hospitals with a trend toward decreased outpatients visits. The data demonstrated a cost savings ratio of approximately 1:10 with many of these results persisting for as long as three years.

The **Arthritis Self Help Course (ASH)** is a six-week education program, (2 ½ hours per week) targeting people with arthritis. The course aims to enhance participants ability to better manage their arthritis. The program was originally developed by Dr Kate Lorig at the Stanford Arthritis Centre, Stanford University, California, in 1979. Evaluation of the course indicated that:

- There were increases in knowledge about arthritis
- Practice of self help behaviours (exercise, relaxation, walking) increased
- There was a decrease in pain
- There was a decrease in depression
- Disability did not increase over the period, as would normally be expected

The Osteoporosis Prevention & Self Management Course is a four week education program designed to teach participants how to be active managers of their health in relation to preventing or living with osteoporosis.

The educational method and format are based on the highly successful Arthritis Self Help Course developed at Stanford University, California, in 1979. Research has shown the Osteoporosis Course is clearly effective in enabling participants to adopt behaviours that promote protection against or management of osteoporosis.

Dates & Course Localities

1/6/04 – 22/6/04 Tuesdays

Time: 10.30am -12.30pm

Course: Osteoporosis Prevention Self Management Mt Gravatt Area

Venue: Coopers Plains BCC Library

9/6/04 – 14/7/04 Wednesdays

Time: 10.30am -12.30pm

Course: Arthritis Self Help Course

Venue: Inala Community Health Centre

5/8/04 – 26/8/04 Thursdays

Time: 10.30am -12.30pm

Course: Osteoporosis Prevention Self Management

Venue: Carindale Library

31/8/04 – 5/10/04 Tuesdays

Time: 10.30am -12.30pm

Course: Arthritis Self Help Course

Venue: QEII 4A Resource Room

14/10/04 – 4/11/04 Thursdays

Time: 10.30am -12.30pm

Course: Osteoporosis Prevention Self Management

Venue: Inala Community Health Centre

2/11/04 – 7/12/04 Thursdays

Time: 10.30am -12.30pm

Course: Chronic Disease Self Management Coorparoo Area

A multi-disciplinary team from Community Health, together with trained lay leaders facilitate the course.

To register please contact Kathleen at Corinda Community Health Services Ph: 07 3710 2222

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Womensense

'Women Making Sense of their Lives'

Womensense is a self help support group for women going through separation and divorce. It is a community based initiative offering support to women as they overcome the emotional pain that accompanies the end of a love relationship.

Womensense brings women together, encouraging friendships, empathy and healing. The group offers information and referrals to women and their families about available community services which may help relieve financial hardship and social exclusion as they rebuild their lives.

Making the journey with other women may be a safety net during the highs and lows of separation and divorce.

Womensense offers:

Weekly support group meetings are held 7pm - 9pm Fridays with alternating social activities and a self help program.

Skills Workshops:

Effectiveness Training for women, goal setting, building self esteem.

Referrals to community organisations and specialist services.

Womensense officially started on 1st March 2004 in the Redlands district. The group has been involved in meditation and personal recovery, (discussions on dating, values, feelings, identity, boundaries), drinking coffee in cafes, dining out.

Future plans include more personal development, making new friends, learning to nurture self and value others, parenting through divorce and rebuilding etc. Scrapbooking, karaoke, movies, dancing, more coffee nights, a country drive, walking along the Wynnum/Manly Esplanade and much more.

For further information contact:

Womensense

Ph: 07 3245 4615

Fax: 07 3245 4615

Email: womensenseoz@yahoo.com.au

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Cancer Clinical Trials

- Better Outcomes for Australians

It has long been known that the best way of improving cancer treatment outcomes is by more patients participating in clinical trials. Clinical trials are being conducted in Australia, but progress is being hampered by low participation rates. Less than 3% of adults with cancer participate in clinical trials. Surveys show that the major barriers to better participation are lack of awareness of the existence and potential benefits of trials combined with insufficient funding of trials. The development of an accurate, accessible guide to available cancer trials is in the interest of everyone.

To help us all become more **AWARE** of cancer trials, the Cancer Council NSW is developing an Accessible Website and Register of Australian cancer trials. Through **AWARE** we hope to:

- Promote awareness of cancer trials being conducted in Australia
- Ensure that people find suitable trials in their region, state or elsewhere
- Bring together patients, clinicians and researchers

A draft proposal for the development of **AWARE** has been produced with input from many individuals and organisations including the Cancer Councils Australia and NSW, Cancer Trials NSW and the NHMRC Clinical Trials Centre. However, it still needs more work and input from key stakeholders, especially consumers.

If you'd like to help out, visit the website www.cancercouncil.com.au and fill in our online survey. This will provide valuable information about the proposed **AWARE** navigation system, as well as a little background information about your ideas and reactions.

A high quality resource that is useful to all Australian consumers and health professionals alike isn't going to come cheaply. We need the government and other potential funders to really get behind this initiative.

For further information please contact:

Marie Malica, Project Manager, Cancer Trials NSW, The Cancer Council NSW

Ph: 02 9334 1909

Email: mmalica@nswcc.org.au

(Source: Prostate News, Issue 18 - May 2004 Page 9)



Diary Dates

14 - 19 June 2004: Crohn's & Colitis Awareness Week For information about Crohn's disease and ulcerative colitis (inflammatory bowel disease), or for details of meetings:

Phone: 07 5437 7662

Email: help@accaq.org.au

URL: www.accaq.org.au

14 - 18 June 2004: Gems of Country - Country Music Festival

Contact: Vanessa Behrendt

Phone: 07 4982 8361

URL: www.gemsofcountry.com

22 - 23 June 2004: Australia's Health: Vital Statistics, Vital Signs - Weighing up our health and health system. Presented by the Australian Institute of Health and Welfare. Speakers include Hon Tony Abbott MP, Edward J Sondik PhD, Dr Rosemary Stanton OAM, Prof Kerin O'Dea, Prof Tony McMichael, Prof Gavin Andrews, Dr Richard Madden.

Phone: 02 6244 1011

Fax: 02 6244 1045

Email: conference2004@aihw.gov.au

URL: www.aihw.gov.au

Venue: Canberra, ACT

5 July 2004 10am - 12pm: Complementary Therapies: Aromatherapy & Meditation Would you like to feel calmer in yourself? Have more energy? Be healthier? More self assured?

Speaker: Anna Hall, Lecturer, Australian College of Natural Medicine

Phone: 07 3636 4285

(24 hr automated booking line)

Venue: Central City Library Theatre, Central City Plaza, Adelaide Street, Brisbane

28 - 30 July 2004: National Medicines Symposium. For consumers, health professionals, policy makers, researchers and academics, health organisations, community organisations and the pharmaceutical industry. Consumer organisations are most welcome to send representatives.

Email: ehuthnance@nps.org.au

URL: www.nps.org.au/nms2004

Venue: Brisbane, QLD

2 August 2004 10am - 12pm: Inner Relaxation Workshop Learn quick, simple easy methods to achieve relaxation, and how to create a more peaceful life by simply changing your thoughts.

Workshop Presenter: Helen King, Qualified Personal Empowerment Facilitator

Phone: 07 3636 4285

(24 hr automated booking line)

Venue: Central City Library Theatre, Central City Plaza, Adelaide Street, Brisbane

2 - 3 August 2004: Perspectives on Recovery Conference.

Contact: Leanne Craze

Phone: 02 6285 0111

Email: secretariat@amhcn.com.au

URL: www.amhcn.com.au

Venue: Brisbane, QLD

20 August 2004: Daffodil Day

The Cancer Council Australia

URL: www.daffodilday.com.au

26 - 28 August 2004: Walking Together: Side by Side. The National Services for Australian Rural and Remote Allied Health (SARRAH) Conference

Phone: 02 6285 4660

Email: conference@ruralhealth.org.au

URL: www.sarrah.org.au/SARRAH/conference.asp

Venue: Alice Springs, NT

15 - 17 October 2004: Hevent 2004. 2nd National Herpes Gathering A variety of functions and opportunities to make new friends and to share experiences in a casual, non-judgemental environment.

Contact: PO Box 674, Helensvale Q 4212

Email: hevent2004@yahoo.com.au

Hevent 2004 Website:

http://au.geocities.com/australian_hevent

Venue: Gold Coast

Tell us about Your Group

If you belong to a self help or support group we would love to hear about it so we can let others know.

Please contact Self Help Queensland

Ph/Fax : 07 3344 6919

Email: selfhelp@gil.com.au