

SELF HELP QUEENSLAND

September Newsletter

Issue 3. 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

Our regular readers will be aware that SHQ tries to involve and inform our constituents in and about the decisions that are made regarding our organization. After the last AGM we held a brief planning meeting and it was decided to focus on 2 major tasks for the year.

The first was to progress the development of a Queensland Directory of Self Help Groups. The second was to see what SHQ could do to ease the burden of insurance costs on the self help sector.

As the next AGM is just around the corner I am really delighted to tell you that SHQ has reached both of these goals. The Queensland Directory of Self Help Groups project has attracted funding from the Commonwealth Department of Transport and Regional Services and Queensland Health and should be completed by March of 2005.

We are currently in the process of employing a Project Officer. Once the PO is on board we will contact everyone to see if they wish to be included and to check on the accuracy of our information.

It is planned to develop a hard copy directory initially, with the prospect of web access in the future. The Directory will be sold to cover costs and updates and represents an important infrastructure support for the sector. We are very happy both Queensland Health and DOTARS have recognized the importance of this project.

The insurance issue was a much slipperier fish! Included in this newsletter is a draft

Insurance Auspicing Protocol as a starting point for discussion with interested groups. Exactly how the protocol works will be determined by those groups who wish to become members - within the framework of what is acceptable to our insurance underwriters and the capacity of SHQ to carry the admin burden.

It is expected that groups who join the Protocol will not pay any other insurance and will be unincorporated. This may mean that groups currently incorporated, who are struggling to pay insurance costs, may choose to become unincorporated to take advantage of the protocol.

Continued Page 2

Invitation

Self Help Queensland Inc AGM and 21st Anniversary Get Together

A warm welcome is extended to all members and interested friends to come along and meet other members of your network, management and staff. Enjoy Self Help Queensland's hospitality over a delicious brunch following the meeting.

Wednesday 6th October at 9.30am

Venue: Self Help Queensland
Sunnybank Community Centre
121 Lister St (Cnr Gager St)
SUNNYBANK

RSVP to Trish by 4th Oct
Ph/Fax 07 3344 6919
Email: selfhelp@gil.com.au



**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 Inc.

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.

**Continued from Page 1
(President's Message)**

It is also expected that while the general principles of the way the protocol will run will be decided by the members of the protocol collectively, each member group may wish to negotiate special reporting conditions with SHQ.

This Protocol is by no means set in concrete. Please let us know what you think, how we might change it to make it more helpful or indeed if you would like to participate! The Protocol planning session will be held following our AGM in September.

I am really proud of our efforts this year, congratulations to all the committee and Trish!

Till next time

Sue

*** Draft Insurance Auspicing
Protocol Pages 10 and 11**

Contents

President's Message	1
SHQ Committee & How to Contact Us	2
Genetic Matters	3
Link Line	4
Free Guide for Community Treasurers	4
Building Inclusive Communities - Grants	4
Limbkids Support Association	5
Stanthorpe Combined Health Support Group	5
Mt Gravatt Community Centre Groups	6
Medicines Without The Mix Ups	7
Myeloproliferative Disorders	8
Androgen Insensitivity Synd Support Group	9
Self Help Qld Draft Insurance Protocol	11
Healthy Women Healthy Communities	12
Nicotine Support Group	12
Did You Know?	12
Survivors of Family Abuse & Dom Violence	13
Living Large Group	13
Fibromyalgia Support Service	13
Diary Dates	14

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

Genetic Matters

by Kim Summers PhD

Genetic Testing

Genetic diseases result from changes to the DNA found in almost every cell in the body. DNA is a bit like a recipe which tells the cell how to make different proteins, required to carry out the functions of the body. The stretch of DNA carrying the recipe for a particular protein is called the gene for that protein.

So what is a protein? Proteins are long linear strands of amino acids arranged in a very precise order specified by the DNA in the nucleus. Each protein has a unique order and number of amino acids, and any change in its composition can change the way it works or shut down its activity altogether. That's how some genetic conditions can arise: a change in the DNA results in a change in the amino acids and the protein doesn't work properly.

Some proteins are enzymes, biological catalysts, that make chemical reactions happen faster without actually being changed by the reaction themselves. Since the advertising of certain laundry detergents, you may have an image of an enzyme as a Pac-Man character nibbling on the dirt in your clothes. But enzymes have a much wider range of activities. Enzymes in the digestive tract break down the food we eat and then enzymes in many tissues use the breakdown products to make other vital molecules like DNA and lipids. Enzymes detoxify compounds coming from the environment which could cause cancer and other diseases. Enzymes synthesise the pigments which give our hair, eyes and skin colour. Enzymes even break down other enzymes when their activity is no longer needed. Those are the enzymes which help to clean our clothes.

Other proteins are involved in regulating the entry of a wide range of molecules including glucose, chemical ions and hormones, into cells. Different proteins are structural proteins, which give cells and tissues strength, elasticity, flexibility, shape and structure. Different types of genetic disease result from abnormalities in proteins, depending on the role and function of the affected protein in the cell and body.

The language of the DNA recipe for protein involves only four letters, called adenosine (A), thymine (T), cytosine (C) and guanine (G). If the recipe is changed, for example when one of the letters gets swapped for another one or some letters are removed or added, the wrong wording may be read in the recipe causing one or more amino acids to be substituted, introduced or omitted. The incorrect protein doesn't function properly, and the symptoms associated with the syndrome result. DNA testing for a genetic condition involves looking at the full recipe for the protein (the sequence of the four letters) and checking whether there are changes in the DNA of a person who has the condition, that might cause malfunctioning of the protein.

DNA testing is available for some genetic conditions. In many cases the test is done in a research laboratory rather than an accredited pathology service and there is no Medicare rebate. There may not be a laboratory in Australia which has the expertise to check a particular gene, and it may be difficult to interest laboratories overseas in a local case. For some conditions there is no testing available while for others a test may be offered which does not guarantee to find the DNA change involved. There are a number of reasons for this.

The recipe may be very long with many interruptions (which are like having advertisements in the middle of the recipe). DNA testing mainly concentrates on the recipe and ignores the interruptions, but even so a long gene like those involved in breast cancer and Marfan syndrome will have many separate parts to be checked. There are also some parts at the beginning and end which are not part of the final recipe, but give instructions about how to read the recipe, where to start the protein and so on. Changes in these instructions could also affect the protein. So one reason why DNA testing isn't offered to everyone is that it is a huge task and it can take a year or more to find the critical change (perhaps one letter altered within more than 100,000 letters).

Another reason is that, for some conditions, just about every family has a different DNA change. For some other genetic conditions, like cystic fibrosis or haemochromatosis, most families have the same change and it is easy

Continued Page 4

Continued from Page 3
(Genetic Matters)

to check family members for that single alteration. However, in other conditions most families have to be screened individually to find the change in the DNA which is specific to that family. So it isn't possible to reduce the amount of work and time by looking for common DNA changes—for each family the laboratory has to start from scratch.

Finally, some people have some of the symptoms of the condition but not enough for a full diagnosis. This may indicate that there is more than one gene in which changes can give symptoms of the condition. Some affected individuals will have a change in the DNA of another, unknown gene and we can't yet test these other genes. For families with only a subset of the symptoms, the genetic analysis may be looking at the wrong gene.

DNA technology has changed dramatically over the last 15 years. Back then, it would have been impossible to check the whole of a large gene in less than 10 years; now it can be done in a matter of months. As new developments are incorporated into laboratories, it should be increasingly easy to screen genes and find the DNA changes. But at the moment genetic testing for many conditions remains a slow, tedious and expensive process which is only really useful in a limited number of families.

-oOo-

Free Guide for Community Treasurers

An excellent guide for treasurers of community organisations has been jointly produced by Our Community and Westpac.

The publication is free, and is called "Guide for Community Treasurers". This guide includes advice on keeping the books, asset registers, cash flow and tax all of which can help you run a more successful organisation. Also included is a section to help you understand how to better manage your accounts and a range of special offers that are available exclusively for community organisations.

For a free copy of the guide Ph 1300 660 953 or go to www.westpac.com.au to download.

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 for rare conditions.

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

The parents of a child in WA who has been diagnosed with Bilateral periventricular nodular heterotopia (BPNH) are very keen to make contact with other parents.

Contact would be welcomed from individuals or parents with children with Medium Chain Acyl CoA Dehydrogenase Deficiency (MCAD) to link with a family in WA.

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

-oOo-

Building Inclusive Communities - grants available!

Disability Services Queensland is now offering grants of up to \$5,000 to community organisations for local projects and events to be staged in 2005, which welcome and include people with a disability, and encourage participation in community life.

A small number of grants up to \$15,000 are being offered for projects of statewide significance.

For further information contact the Disability Information and Awareness Line.

Ph: 1800 177 120

TTY: 1800 010 222

URL: www.disability.qld.gov.au

Closing date: 24 September 2004

Medicines Without The Mix Ups

With more than 70% of Australians taking medicines at any one time and 140,000 hospital admissions per year possibly related to problems with medicines, it is important for all of us to be responsible for the medicines we are taking.

Medicines have an important role in maintaining health for all of us but unless we use them wisely and safely there is the potential for them to do more harm than good. So understanding medicines will help you avoid any mix-ups and allow you to enjoy better health.

Medicines come in many forms including tablets, liquids, inhalers, drops, patches, creams, suppositories and injections. Medicines include those that are prescribed by your doctor, those that are dispensed and purchased at a pharmacy, as well as herbal and natural therapies.

To help you better understand your medicines National Prescribing Service Ltd (NPS), Australia's peak independent, education and information provider about medicines, has developed an information brochure – Medimate. A sample copy of Medimate is included inside so that you too can actively manage your medicines.

As you will see Medimate encourages you to talk to your pharmacist or doctor about all your medicines – prescription, over-the-counter and herbal and natural therapies. On the back inside cover Medimate also provides space to record the information you wish to keep such as a list of the medicines you take.

To make sure you get the best medicine, it is really important to talk to your doctor or pharmacist and let them know about:

- The health problem you are having.
- Other health problems you may have.
- All other medicines you are using including herbal and natural therapies.

- Any allergies you have.
- Any problems you have had with any medicines in the past.
- Your preferences and choices - can you choose between tablets and capsules? Is the medicine available at a cheaper price?

You will also find a list of questions you should ask when you are either prescribed a medicine or when a medicine is recommended. These questions cover areas such as:

- What the medicine is for.
- How to use the medicine.
- When to stop using the medicine.
- Special instructions.
- Side effects.

If you would like more copies of Medimate ask your doctor or pharmacist for your free copy of Medimate or order online at www.medimate.org.au.

You may also like to contact Medicines Line on 1300 888 763. Medicines Line is a national telephone service for all Australians so that you can find out more about your medicines (for the cost of a local call).

National Prescribing Service :Ltd (NPS) is a non-profit organization funded by the Commonwealth Department of Health and Ageing. NPS is independent and works in partnership with GPs, pharmacists, specialists, other health professionals, Government, pharmaceutical industry, consumer organisations and the community to improve the health of all Australians.

For further information:
National Prescribing Service Ltd
PO Box 1147
STRAWBERRY HILLS NSW 2012
Ph: 02 8217 8700 Fax: 02 9211 7578
www.nps.org.au

Tell Us What You Think

We would like to receive feedback about the newsletter and invite you to contact us about content, quality, format, or any issues you would like addressed in future editions.

SHQ Office: Ph/Fax 07 3344 6919
Email: selfhelp@gil.com.au

Mt Gravatt Community Centre Supports its Local Community by Providing a Home for a Diverse Range of Self Help Groups

Currently there are six groups (listed below) that meet at the Mt Gravatt Community Centre:

For further information contact Rebecca on 07 3343 9833.

Mt Gravatt Community Centre, 1693 Logan Road, MT GRAVATT 4122

(If you are looking to join a self help or support group in your area a good place to start is by contacting your local Community Health Centre or Neighbourhood Centre.)

Co-Listening Network

Co-Listening Network is a community where:

- you can be listened to deeply and compassionately
- have the opportunity to find encouraging and empowering friendships
- find support in times of struggle through emotional trauma or disconnection from family or friendships
- learn skills in Compassionate Listening, Community Connection and Befriending
- begin to build better inclusive community in your locality

Meetings are on the 1st, 2nd, and 3rd Saturday of each month from 9:00am to 11:30am.

-oOo-

Diabetes Support Group

- this casual and informative group shares information on problems relating to diabetes in a friendly and supportive environment
- exchange information, experiences and treatments
- information, support and motivation for improving diet and exercise
- occasional guest speakers

Meets on the last Wednesday of each month from 10:00am to 12:00pm .

-oOo-

Menopause Support Group

The menopause support group has been developed with the aim of sharing:

- the roller coaster ride some women experience during their menopause
- information about alternative treatments and their effectiveness/ineffectiveness
- exchange of successful/unsuccessful approaches of dealing with menopausal symptoms
- interesting articles, books and videos relating to menopause

- information about Hormone Replacement Therapy (HRT) and the latest medical research
- guest speakers from various organisations are invited to present

Meets on the 2nd Tuesday of each month from 7:00pm to 8:30pm.

-oOo-

Queensland's Young People with Parkinson's (QYPP) Support Group

QYPP is a way of empowering people to help themselves, and others, cope with Parkinson's disease. The aim of the group is to provide active support, friendship, understanding and information for those whose lives have been, or are being affected by Parkinson's.

Meets on the 2nd Tuesday of each month from 10:30am to 1:00pm.

-oOo-

Southside Anxiety Disorders Group

The Southside Anxiety Disorders Group is a support group run by sufferers, for sufferers of anxiety disorders. The group is non judgemental, confidential, and there for the mutual support and release from isolation for all of us. We offer education, group discussion, support and professional speakers.

Meets on the 2nd Thursday of each month from 10:00am to 1:00pm.

-oOo-

Survivors of Suicide Bereavement Support Group

Empathy and support is provided to survivors of suicide and to those suffering the loss of a loved one.

Meets on the 1st and 3rd Friday of each month from 7:00pm to 9:00pm.

-oOo-

Limbkids Support Association Offers Wide-spread Support to Queensland Children with Limb Differences, and their Families.

Limbkids Support Association Inc is a Queensland based, non-profit organisation comprised of parents, professionals and interested people concerned with the care of children with limb differences.

We provide counselling, special needs musical instruments, a regular newsletter, brochures and information services to effected families and members, social outings, as well as boosting public awareness of the capabilities of children with limb differences. We recently competed in the Gold Coast Airport Marathon and were the 2nd largest group to enter. Our sponsor, Attwood Marshall Laywers, provided us with Limbkids logo t-shirts and next year we plan to be the largest entry.

It is our goal to grow our organisation to a point where we can also fund medical research, and the supply of prosthetics to children not in a position to afford them.

We have members throughout Australia, USA, Canada, United Kingdom and Switzerland.

Invitation

Limbkids Christmas Party

Bring friends, relatives, neighbours, hats, sunscreen, swimmers, picnic food, drinks, and plenty of smiles to greet new members. Santa will be there at 12.30, and please bring a wrapped gift for your child/ren. There will be a lucky door prize and much more! See you there. Just look for the yellow balloons.

Date: Sunday 28th November 2004

Time: 11am

Place: The Plantation
1204 New Cleveland Road
Gumdale, QUEENSLAND

Cost: To be advised. Keep a watch on the noticeboard at www.limbkids.asn.au

*Please note, for safety reason glass is not permitted in any form. If you wish to obtain more information, including a copy of the map to the venue, please contact Cindy on (07) 5533 97 54.

Invitation

Limbkids AGM

Sunday 12th September 2004 at 11 am - venue to be advised.

We welcome your visit to our website at www.limbkids.asn.au
For more information please telephone Cindy (07) 55339754 or email markmak@optusnet.com.au or post mail to:
Limbkids
244 West Burleigh QUEENSLAND 4219.

-oOo-

Stanthorpe Combined Health Support Group

- an inclusive solution

When some members of various support groups for particular health conditions in Stanthorpe noticed that their numbers were dwindling they decided to do something about it. As happens in many regional areas the people took a community approach, and opted to form an inclusive group which welcomed people with a wide range of health issues.

The Stanthorpe Combined Health Support Group now includes members who are affected by Arthritis, Rheumatoid Arthritis, Cancer, Heart Disease, Diabetes, Parkinson's Disease, Chronic Fatigue and Fibromyalgia.

Meetings are held at the Community Health Centre once a month, always on the last Tuesday. About 15 to 20 people attend and most months include a guest speaker. Lunch outings to local scenic spots (eg winery, lavender farm) have also become an enjoyable means of getting together to chat and support each other.

The group extends a warm welcome to anyone who would like to attend. For further information contact:

Marg Sims Ph 07 4681 4191
Marg Gimm Ph 07 4683 3262



Androgen Insensitivity Syndrome (AIS) Support Group Australia Inc

The AIS Support Group Australia Inc provides support and information for those affected by Androgen Insensitivity Syndrome and similar conditions.

What is AIS?

Androgen Insensitivity Syndrome (old name is Testicular Feminisation Syndrome) causes a variation in the development of the reproductive system as a result of a complete or partial inability to respond to androgens ("male" hormones) during foetal development. People with AIS have 46XY sex chromosomes and are born with testes. Physical characteristics (phenotype) and gender identity can vary from male to female and anywhere in between.

There are two basic types of AIS - Complete AIS (CAIS) and Partial AIS (PAIS).

CAIS

People with CAIS do not respond to androgens and have completely typical female external genitalia. The sex of rearing of people with CAIS is usually female.

PAIS

People with PAIS have a degree of responsiveness to androgens so that they are born with external genitalia that ranges in a spectrum from completely female, through mixed female/male, to almost completely male. Some people with PAIS are males, and are raised as boys and later identify as men.

What other similar conditions do the AISSG support?

- 5 alpha-reductase deficiency
- 17-beta hydroxysteroid dehydrogenase deficiency or 17-beta HSD
- XY gonadal dysgenesis (also known as Swyer Syndrome)
- Leydig cell hypoplasia
- Mayer Rokitansky Kustner Hauser (MRKH) Syndrome (also known as vaginal agenesis)
- Mullerian Dysgenesis

People with either one of the last two conditions are chromosomally 46XX.

What does 'intersex condition' mean?

Intersex conditions are one of the many long established biological conditions where a child is born with reproductive organs, genitalia and /or sex chromosomes that are not exclusively male or female.

Incidence

Conservative estimates suggest at least one in 4000 people have intersex conditions, which equates to a least 5,000 Australians. AIS occurs in about one in 13,000 births.

Diagnosis and effects of AIS

People with AIS do not have ovaries or a uterus, and if they are born with a vagina it will be blind ending and possibly short. Undescended testes can result in an inguinal (groin) hernia in infancy, which may be the reason the condition is diagnosed in an otherwise typical girl. Alternatively, CAIS may not be discovered until puberty as a result of a girl not menstruating.

It is vitally important that any diagnosis is accurate and excludes other conditions which may require different treatment.

Having a child with AIS or similar conditions

The birth of a child with AIS or a similar condition is not a medical emergency. Peer support and accurate information is vital at this time, and is only a phone call or email away. Please contact us to put you in touch with others who have been through what you are going through.

If the emotional needs and anxieties of the parents are addressed first it will be easier for them to provide effective support to their child. Everyone will feel better if there are no taboos about the subject. Talking, like grieving is therapeutic, enabling feelings to be confronted and resolved.

Pushing the matter under the carpet is just storing up psychological trouble for later.

(Continued Page 10)

Continued from Page 9

It is important that parents encourage discussion with their child and actively seek out information on their behalf. Unfortunately, keeping the condition a secret can become more important to some parents than acknowledging their child's needs for emotional support and appropriate clinical intervention. It wastes mental/emotional energy that is better spent helping the child come to terms with the truth.

Living with AIS or similar conditions

Truth, counselling, peer support and appropriate medical support are vital to living successfully with AIS and similar conditions. Many have said meeting others is the single most useful therapeutic measure.

Medical issues vary for different intersex conditions, but we always recommend seeking opinions from others who have been through similar experiences. Never be afraid to ask questions.

Aims of the AIS Support Group

- To put parents and people with AIS and similar conditions in touch with each other in a safe and confidential environment and encourage them to seek support and information.
- To reduce the secrecy, stigma and taboo surrounding AIS and similar conditions, by encouraging doctors, parents and society to be more open.
- To encourage the provision of psychological support within the medical system, for people affected by AIS and similar conditions, including their parents.
- To put people affected by AIS and similar conditions in touch with others and to encourage them to seek support and information.
- To increase the availability of information on AIS and similar conditions both verbal (from health professionals) and written (from the support group and other sources.)
- To encourage improvements in the treatment for men and women with AIS and similar conditions in both surgical and non-surgical means.

- To encourage research into Gender Identity and Sexual Identity issues.

Membership, Meetings, Publications

The AISSGA has members in many countries including Australia, New Zealand and Canada, the United Kingdom and the USA. Our membership includes people with AIS, similar conditions, their families and supportive medical professionals. Publications include our newsletter "dAISy" (2 per year). We have members and representatives all over Australia and encourage our State Representatives to organise local functions. Membership includes a yearly subscription of dAISy and access to information and support.

AIS Support Group Australia Inc
PO Box 1089
ALTONA MEADOWS VIC 3028
Phone: 03 9315 8809
Email: aissg@iprimus.com.au
URL: www.vicnet.net.au/~aissg

Editor's Footnote: Self Help Qld Inc thanks the AIS Support Group for allowing us to print the above information which is also available on their excellent website. We would like to encourage any Queenslanders who are affected by AIS or any similar conditions to make contact with the AIS Support Group. You will receive generous support from people who are the most equipped to provide it - people in the same situation who have vast knowledge and practical information. Where possible, you will be put in touch with a representative in your State for mutual support and sharing of useful local information.

-oOo-

Tell us about Your Group

If you belong to a self help or support group anywhere in Queensland - especially in rural or regional areas, we would love to hear about your particular group so we can let others know.

If you are searching for a group for a health or related condition then please contact the SHQ office and we will endeavour to locate the group you are looking for.

Ph/Fax : 07 3344 6919
Email: selfhelp@gil.com.au

Do you have a Myeloproliferative Disorder?

Would you be interested in forming a self help group for people who suffer from Myeloproliferative Disorders?

- * **Essential Thrombocythaemia** - too many platelets
- * **Polycythaemia Vera** - bone marrow produces too many red blood cells
- * **Myelofibrosis** - bone marrow produces fibrous scar tissue

(Sometimes Chronic Myeloid Leukaemia is included within this category but it is more usual to treat this as a separate disorder)

The Myeloproliferative disorders are a group of conditions closely related to Leukaemia and affecting blood forming stem-cells, in which there is an excess production of one or more type of blood cell in the bone marrow. There are three main types classified according to the cell type mainly affected.

Essential Thrombocythaemia

Essential thrombocythaemia is due to an abnormality of platelet producing cells (megakaryocytes) in the bone marrow, but the underlying cause is not known. Essential thrombocythaemia is only one of several possible causes of an increased number of platelets in the blood. For example, bleeding, inflammation or cancer can cause high platelet counts, but these are not essential thrombocythaemia.

The condition is most commonly diagnosed in patients between the ages of 50 and 70 years, though it has been reported (rarely) in children and may occur at any age. Men and women are equally at risk.

Polycythaemia Vera

Polycythaemia Vera or polycythaemia rubra (red) vera, is a myeloproliferative disorder in which the abnormal bone marrow produces too many red blood cells. As a result, the blood is thicker than normal and contains increased numbers of red cells. In some patients the numbers of white cells and platelets may also be increased.

The average age at diagnosis is about 60 years with about 95% of patients diagnosed at 40 years or older. The disease is virtually unknown under the age of 15 years, and

then becomes progressively more common up to about 80 years of age. It is more common in men. The causes of polycythaemia vera are unknown.

Myelofibrosis

Myelofibrosis (also called agnogenic myeloid metaplasia) is a myeloproliferative disorder in which the bone marrow is initially over-active but then develops scar tissue (fibrosis). Normal bone marrow had a very fine network of fibres supporting the blood forming tissues. In myelofibrosis this network is coarsened and thickened so that normal blood cells production is progressively produced. As a result blood cell production begins to take place in the liver and spleen which become enlarged. The production of blood cells in the liver and spleen is not as efficient and so patients frequently develop anaemia.

The average age at diagnosis is 50 to 70 years, although myelofibrosis may affect patients of any age. It is particularly rare, though not unknown in childhood. Men and women are equally at risk. Myelofibrosis may occur in patients who have had either essential thrombocythaemia or polycythaemia vera or it may develop in patients with no previous history, when it is known as primary myelofibrosis.

If you, or anyone you know with a myeloproliferative disorder would like to form a self help group, please contact Barbara:

Phone: 07 5464 6131.
Email: tbhines@gil.com.au

-oOo-

Ratification Date:**Review Due:****Protocol Background:**

Information gained from SHQ constituents has revealed the unprecedented burden the decrease in insurance availability and the high cost of the insurance available is placing on the capacity of small self help organisations.

Small self help organisations are usually either unfunded or funded from no-growth funding pools. Insurance costs are representing an increasing proportion of organisational income, leaving less with which to carry on the work of the organisation.

Some groups have decided to carry unacceptable risk by remaining uninsured. Some groups find meeting the Incorporations Act to be an unacceptable burden on organisational capacity and are considering disbanding.

As the peak body within the Queensland Self Help Sector, SHQ has developed the **Insurance Auspicing Protocol** to provide the infrastructure by which small self help groups can decrease the cost and risks related to insurance.

Protocol Articles:

The values and operating principles of the Insurance Auspicing Protocol will be decided by potential partner discussion and agreement and will be reviewed on a regular basis or at the instigation of any of the members.

Separately incorporated, individuals, businesses & sole traders:

Groups that are separately incorporated, individuals, businesses & sole traders should have their own covers.

If separately incorporated, individuals, businesses & sole traders use SHQ's venue, they need to provide a Certificate of Currency.

If separately incorporated, individuals, businesses & sole traders are regular users of SHQ venues it is advisable that their Public Liability policy should note SHQ as an 'interested party'.

Unincorporated Groups recognised as SHQ 'partners'.

'Partners' are unincorporated community groups and individual volunteers who propose projects, courses and other activities commensurate with SHQ values and principles of practice.

'Partners' cannot be involved in activities excluded under SHQ policies.

'Partners' covered under SHQ policies will be declared to the Lifelong Learning Council Queensland Inc.

'Partnering' Process:

Groups and individuals wishing to enter a partnering arrangement with SHQ in order to utilise the Insurance Auspicing Protocol will negotiate the terms of their partnering agreement with SHQ on an annual basis.

It is not SHQ's intention to co-opt partners' assets for SHQ's use. However, in order to comply with the underwriters conditions, SHQ is required to take some reporting responsibility for partner organisations.

As SHQ currently works to the maximum capacity of its funding, Partners will be required to contribute to the administrative cost of the Protocol via a membership fee. The membership fee will fluctuate depending on the number of partners utilising the Auspicing Protocol. The membership fee will be not less than \$50 / year. Any change in fees will be negotiated with the participating partners.

Continued Page 12

In Order to meet underwriters requirements Partners must agree to provide the following information to SHQ on an annual basis:

- Name of the group
- Type of activities undertaken
- Number of people normally involved
- How often the activities are normally undertaken

Partners agree that the assets, turnover and payroll (if any) of the group will be reported under SHQ's assets, turnover and payroll, and unambiguously identified.

Partners agree to inform SHQ of any change in circumstance that may compromise the Insurance Auspicing Protocol

-oOo-

Healthy Women Healthy Communities

The National Rural Women's Coalition is hosting a national forum which will address issues affecting the physical, mental and social health and wellbeing of rural women. The Coalition will bring together rural women, community representatives, government and non-government stakeholders from all over Australia to discuss the issue.

The NRWC wants your views on the major health and wellbeing issues facing women today in rural areas. This information will determine the focus areas in the Forum and guide NRWC research and advocacy efforts.

The NRWC will consult widely with rural women in their member organisations and in all communities to focus on the areas that are important to you.

Date: Mon 18 and Tues 19 October 2004
Contact: NRWC Executive Officer
Ph: 02 6162 0430
Email: admin@ruralwomen.org.au
Venue: Melbourne
(Source: QWHN News, August 2004)

Would a Nicotine Support Group be Helpful to You?

If you are interested in joining others (at any stage of the nicotine journey!) to form a group in Brisbane please contact Anne. Phone 07 3824 0531 After hours - or leave a message on the machine and Anne will call you back.

-oOo-

Did You Know?

- The liquid inside coconuts can be used as a substitute for blood plasma.
- No piece of paper can be folded in half more than seven times.
- Venus is the only planet that rotates clockwise.
- Apples, not caffeine, are more efficient at waking you up in the morning.
- Pearls melt in vinegar.
- Elephants are the only animals that can't jump.
- It 's physically impossible to lick your elbow.
- A snail can sleep for three years.
- No word in the English language rhymes with 'month'.
- The main library at Indiana University sinks over an inch every year because when it was built engineers failed to take into account the weight of all the books that would occupy the building.
- Our eyes are always the same size from birth, but our nose and ears never stop growing.
- Almost everyone who reads this will try to lick their elbow!

(Source: Inglewood 60 & Better Newsletter & Community Health Chat Aug-Sept 04)

-oOo-

Survivors of Family Abuse and Domestic Violence Inc.

Long Term Support

Long term support exists for Survivors of Family Abuse and Domestic Violence.

We meet every fortnight for 2 hours at:

Nundah - Tuesdays
Sunnybank - Tuesdays
Nerang - Fridays
Dutton Park - Fridays

For further information please phone:
Mob: 0403 920 204

-oOo-

Living Large Group

Living Large is a fun and supportive group for women who are overweight to obese, or have had a significant weight gain and whose weight restricts their daily living.

The aim of our group is to support, inform and engage women to participate fully in their communities while "living large".

The partnership between Logan Women's Health Centre Inc and local women envisages that the Living Large group will provide a dynamic, creative and supportive environment for the health and well being of all Logan and Beenleigh women living with a weight issue.

When: 1st and 3rd Monday of the month from 1pm to 3pm

**Where: Logan Women's Health Centre
25 Ewing Road
LOGAN CENTRAL**

A guest speaker will be available to address the group on the 1st Monday of the month.

The group is open to all women from the Logan and Beenleigh areas and surrounds.

For further information please contact:
Catherine or Kiernyn on 3808 9233

Valuable Support Available to People with Fibromyalgia

The Fibromyalgia Support Service is a voluntary service which provides Encouragement, Support and Information to people living with Fibromyalgia. It's long-serving co-ordinator, Johanna, provided the following information to Self help Queensland.

Fibromyalgia is a chronic condition of widespread musculoskeletal pain, fatigue and mindfog - the cause of which is still unknown although some theories are floating around. We do know that it is a dysfunction of the central nervous system and pain gate.

Most sufferers say they ache all over. Sometimes the muscles twitch and at other times they burn. It feels like you have a bad dose of the flu and someone has unplugged your power supply. The severity of symptoms vary from person to person, and in some people it can be so severe that it interferes with daily tasks.

Associated symptoms are sleep disorders, irritable bowel syndrome, chronic headaches, temporomandibular joint dysfunction syndrome. Other common symptoms are painful periods, chest pain, morning stiffness, cognitive or memory impairment, numbness and tingling sensations, irritable bladder, skin sensitivities, dry eyes and mouth etc etc.

Although Fibromyalgia is incurable, assistance is available that can help make your life easier. The main thing is to learn as much as possible about the disease and what you can do to help yourself. This is where I come in. Although I can no longer offer a support group I can offer information packs and a monthly newsletter to keep you up to date and give helpful tips. I will be most happy to talk to people on the phone.

If you suffer from Fibromyalgia or know of someone who does, then please ring me for further information. Alternatively, you can send a book of stamps to receive the information packs or the monthly newsletters, or one book of 20 stamps for both.

Contact: Johanna Ph: 07 3806 0552
Fibromyalgia Support Service
123 Pohon Drive
Tanah Merah QLD 4128



Diary Dates

10 September: National Gynaecological Day.

For more information: Gynaecological Awareness Information Network's (GAIN) website
URL: www.gynsupport.com
Email: mazzella@bigpond.com

22 - 23 September 2003: Senior & Retirement Expo. 80 exhibitors, hands-on activities, displays of new products and services, workshops and seminars.

Phone: 02 9452 7575
URL: www.seniorexpo.com.au
Venue: Brisbane Convention Centre

14 - 15 October 2004: 2nd National Conference on the Mental Health Aspects of Persons Affected by Family Separation. Presented by Origins Inc Qld and Mental Health Assoc Qld.

Venue: Brisbane

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

23 October 2004: Scleroderma Association Seminar. All welcome - Queensland wide. For information or bookings contact Assoc.

Phone: 07 3411 3558
Cost: \$20
Venue: Griffith University, Brisbane

24 - 27 October 2004: Australian Nursing Homes & Extended Care Assoc National Congress & Federal Education Forum

Phone: 08 8354 2285
Email: anheca@aomevents.com
Venue: Adelaide Convention Centre

1 - 4 November 2004: International Not For Profit Convention and Exhibition

Phone 1800 630 866
URL: www.ince.com.au
Venue: Surfers Paradise

Social Justice Conference 2004

"Effective Advocacy – Speaking and Listening"

8th October 2004 – Wesley Auditorium
Presented by

UnitingCare Centre for Social Justice

The UnitingCare Centre for Social Justice will again hold an informative and challenging conference. This time our theme is *advocacy* – how to do it, who should do it, and related topics, including practical workshops on how it works. We are welcoming community sector workers in UnitingCare and the whole welfare / community sector, church congregations, advocates in human rights, the environment, and the peace and refugee movements.

Register your interest now.
Email kkunzelmann@ucareqld.com.au.

If required by mail, please write to:
UnitingCare Centre for Social Justice
PO Box 2248 Milton BC
Phone: 07 3512 9421.

Ask about the Call for Posters – win a prize for your organisation!

-oOo-

Lunch with Germaine Greer

The Continuing Professional Education Unit, in partnership with the Australian Institute of Management, invites you to hear one of the world's most controversial figures, Germaine Greer, speak at the Sheraton Hotel, 249 Turbot Street, Brisbane on **Friday 17th September.**

Professor Sandra Harding, Deputy Vice-Chancellor (International and Development) has been invited to interview Germaine Greer after her lecture.

For further information contact Susy Trier at Continuing Professional Education Unit, Qld University of Technology.
Phone: 07 3864 2141
Email: s.trier@qut.edu.au
Bookings Ph: 13 16 48
URL: www.aimevents.com.au