Self Help Queensland

Support & Information Since 1983



'supporting people in finding their own solutions to improve well being' Queensland Self Help & Support Group Sector

News & Information
Bi-monthly

Issue 6 November 2016



Self Help Queensland Office Located at Sunnybank, Brisbane

Issue 6 Features

- 1 President's Message
- 1 Invitation to AGM
- 2 SHQ Contact details etc.
- 3 It's The Little Things
- 3 Volunteers Needed
- 3 Do you have a personal story to share?
- 4 Genetic Matters
- 5 This is a Scam!
- 6 FSG Dreamweaving
- 7 Can You See What I See?
- 8 Good & Bad Colour Combinations
- 9 Ice Support Central Queensland
- 10 Empathy: Keep it Alive
- 11 Munchausen by Internet
- 12 Myositis
- 13 How to Support Someone with a Mental Illness
- 13 Somali Youth Achievement
- 14 Autism Queensland
- 15 Autism Family Support Groups
- 16 Building Resilience in Children



Self Help Queensland wishes you a safe and happy holiday Season.

May 2017 be a rewarding and enjoyable one for all.



The SHQ Newsletter is kindly sponsored by FSG Australia https://www.fsg.org.au/

From the President

Joseph Soda

Special thanks to FSG for sponsoring our bimonthly Newsletter. Without this support we would not have been in a position to continue its publication. FSG also recently provided a bus and

drivers for a farm visit which Trish arranged for a group from the Somali Community. This was a real success story as most of the men were from the land as well as associated farming practices.

In line with our organisational programme, we are currently reviewing possible relationships with other organisations. This will be ongoing and we are hopeful of some successful outcomes.

Our AGM is fast approaching, and this is the time we get to let, people know what we have been doing over the year, talk about future plans and have an opportunity to meet new people and catch up with old friends. We would love as many people as possible to join us on the day.

As we approach the end of the calendar year I would like to wish everyone a safe and happy festive season; and thank in particular our Management Team, Trish for her dedication to the organisation, Janette - a stalwart who travels from the Gold Coast to do our bookkeeping and our valued volunteer Roy whom we now wonder how we ever managed without him.

Invitation

Members and Friends of Self Help Queensland are warmly invited to attend our AGM on

Thursday 24th November 2016 9.30am to 11am

Sunnybank Community Hall
121 Lister Street (Cnr Gager Street) Sunnybank

RSVP: Trish at SHQ on 3344 6919 or info@selfhelpqld.org.au by 22/11/2016

Refreshments & Networking After the Meeting

Best wishes, Joseph Soda

To receive This Newsletter in Hardcopy

Self Help Queensland can no longer afford to distribute a free hardcopy newsletter. The cost of paper, printing, postage and handling has forced us to charge a fee of \$20 per year for 6 issues.

We appreciate that some professionals like to leave them in their waiting rooms, or facilitators take them to group meetings, and we apologise that we are no longer in a financial position to provide this service free.

Please contact Trish if you would like to opt for a hardcopy by post. Ph 07 3344 6919 or Email info@selfhelpqld.org.au

Looking for a Self Help or Support Group in Queensland?

The Self Help Queensland Directory of Self Help and Support Groups is now online and free. To search for a self help or support group follow this link http://www.selfhelpqld.org.au/ On the Home Page click on 'Search the Directory' and follow the prompts.

Please Register Your Group in the Free SHQ Online Directory

We are aiming to feature all of the Self Help and Support Groups in Queensland under the one roof so they can be found more easily.

Please go to http://www.selfhelpqld.org.au/ and click on 'Register a Support Group' or call Trish at the SHQ office on 33446 919 or email info@selfhelpqld.org.au for a registration form.

Disclaimer

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

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. The SHQ newsletter editor reserves the right to edit contributed articles.



Thanks to Queensland Health for providing funding to Self Help Queensland to help carry out its activities.



Please Like Us! We're Just Getting Started on Facebook.

https://www.facebook.com/SelfHelpQueensland/

Who We Are

President Joseph Soda
Secretary Kathy Thomas
Treasurer Christopher Spriggs
Committee Members Val McNamara

Rosa Prahl

Elizabeth Carrigan

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121 Lister Street SUNNYBANK QLD 410

Office Hours: Tues - Friday 9am - 4.30pm

Please Help Us by Becoming a Member of SHQ

After 33 years, Self Help Queensland has been forced to introduce a membership fee to help sustain our work. There are three tiers of membership which we have kept to an absolute minimum cost.

Concession: Students, pensioners (\$10) Support groups and individuals: (\$20) Professionals and organisations: (\$30)

To become a member please click the link below http://www.selfhelpqld.org.au/membership

What We Do

Self Help Queensland (SHQ) supports self help and support groups in Queensland across a broad range of health conditions and related issues. We do this by:

Providing a free, online Directory of self help and support groups in Queensland.

Assisting people to start new self help and support groups where no groups exist.

Working individually with existing groups to build their capacity to improve the wellbeing of their members.

Providing Sector information to individuals, groups, organisations and professionals in Queensland.

Making referrals, providing low cost training, assisting groups with funding applications.

Promoting the benefits of self help and support groups. Bi-monthly newsletter, website, facebook.



From the Editor

I was hurrying to finish putting this newsletter together today (because I am running behind time) when I received a phone call from my daughter who is very sick in hospital. I have been extremely worried about her, so was quite surprised to hear excitement in her voice and the brightness of its tone.

"Mum, I have something wonderful to tell you that has just made me feel so good. I have been hearing these cute little chimes ringing through the ward now and again, but didn't know what they were. A nurse told me that every time a baby is born in the maternity ward the chimes ring throughout the other wards. If there are two chimes fairly close together it usually means twins. The chimes go crazy on caesarean days."

Jane now listens for the chimes to interrupt her long days and lift her spirits. "Mum it makes me feel so happy to hear a new life is being brought into the world, instead of the hushed tones you hear when someone leaves it."

Congratulations and thank you to the Wesley Hospital for cheering up patients and staff (and mothers of patients!) in this small way.

It Really is the Little Things!



Volunteers Needed

The Australian Pain Management Association is looking to expand its support services throughout Queensland. We are looking for at least two volunteers in each location who can facilitate a pain support group once a month for a minimum commitment of 1 year.

The facilitator of a pain support group (PSG) helps the group to: share their experiences of living with chronic pain, educates the group about self-management techniques and to effectively use healthcare settings. The PSG provides an avenue for people with pain to socialise with others and reduce the isolation of chronic pain. Locations include:

Caboolture Cairns Bundaberg Hervey Bay Rockhampton

Contact: tpobjie.APMA@gmail.com or 1300 340 357 to discuss the role further.

Do You Have a Personal Story to Share that Could Give Hope and Inspiration to Others?



If you have a personal story that could be an inspiration to others in the same situation we would love to hear from you.

Self Help Queensland has recently started featuring stories on our website. The objective is to inspire and empower others through hearing how you or your family may have learned to live with/overcome/survive a health or related crisis in your life.

The lessons you learned could help bypass unnecessary grief and pain for others. It may help them navigate a complex health system or find useful support in the community or elsewhere.

We would be particularly interested in hearing how you received support through attending or starting a support group. Please contact Trish at Self Help Queensland on 3344 6919 or info@selfhelpgld.org.au

If you would like to read our first 3 stories go to: http://selfhelp.sites.go1.com.au/content/stories-0

Genetic Matters

by Professor Kim Summers PhD FRSB

Sickle Cell Gene Therapy

Haemoglobin is the protein that carries oxygen in red blood cells from the lungs to all our tissues where it is used to provide energy so the different types of cells can carry out their tasks. There are many genetic defects in haemoglobin, and they are particularly common in countries where malaria has been present over the generations. This has led to the idea that the malarial parasite cannot grow in red blood cells that have abnormal haemoglobin. So there is a balance between the problems caused by the abnormal haemoglobin (including early death in severe cases and lifelong problems with joints in others) and the benefits of being resistant to malaria.

The sickle cell mutation is the best known haemoglobin mutation. A change in a single component of the protein means that the red blood cells change their shape when the amount of oxygen is low (in the tissues) and become sticky and clog the small capillaries that deliver oxygen to the cells.

This only happens when people have two copies of the abnormal haemoglobin beta gene. These people are said to have sickle cell disease or sickle cell anaemia and they are at lifetime risk of major complications such as stroke and organ damage through lack of blood flow. People who have only one copy of the sickle cell mutation rarely show any signs or symptoms and can lead normal lives. In fact, they are able to resist infection by the malaria parasite so in tropical regions they have an advantage over both those with two copies (who have sickle cell disease) and those with no copies (who are susceptible to malaria).

Because of this advantage to people with sickle cell trait, the sickle cell mutation has risen to high frequency in countries where malaria is prevalent, and cases of sickle cell disease can appear in the children of people from those countries, even when they move to a malaria free area. So the sickle cell mutation has been the target of research into gene therapy for many years.

Before birth, oxygen comes from the mother via the placenta and the kind of haemoglobin needed is different from the haemoglobin found after birth. There is a switching process that eventually stops the production of the foetal form of haemoglobin and replaces it with the adult form.

Sickle cell anaemia is caused by a problem in the adult form of haemoglobin, so affected people have normal foetal haemoglobin. It has been known for some time that some people who carry two copies of the sickle cell mutation don't have sickle cell disease. This is because haemoglobin production fails to switch from the foetal form to the adult form, so the red blood cells continue to produce foetal haemoglobin their whole lives. In spite of the fact that their red blood cells are filled with foetal haemoglobin, the cells look normal and do not undergo sickling. ? It has been shown that any increase in the foetal form of haemoglobin has benefits for sickle cell disease sufferers, including increasing the life span.

This suggested that a way to treat sickle cell disease would be to turn off the production of the adult form so that sufferers could survive with their foetal haemoglobin. There are a number of genetic changes that cause hereditary persistence of foetal haemoglobin (HPFH), a benign condition with apparently no bad effects. Could our knowledge of these genetic changes help to develop drugs or other therapies to prevent the switch to adult haemoglobin in sickle cell disease patients? A number of studies are currently looking into this approach by trying to understand fully the molecular basis of the switch, so that techniques to block it can be developed.

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(Kim is Professor of Comparative Genetics, The Rosllin Institute, University of Edinburgh and Honorary Professor, School of Medicine, The University of Queensland. Kim is also a valued past Committee Member of Self Help Queensland Inc)

For support in Australia:

Thalassaemia Australia Inc

Phone: (03) 9888 2211

Email: info@thalassaemia.org.au Website: www.thalassaemia.org.au

Sickle Cell Support Group

https://www.facebook.com/sicklecellsupportgroupaustralia/

This is a Scam!

A range of emails are currently targeting Support Groups and Organisations in the Health Sector in Australia. They are pretty much identical, are likely to emanate from the same source and have different contact names. Their Websites change rapidly.

Ignore any emails that resemble the following.

New Healthcare Industry Email List 2016 with emails, and complete Contact information

List Contains:

Name, Company's Name, Phone Number, Fax Number, Title, Email address, Complete Mailing Address, Web address etc.

Our Specialties:

Anesthesiologists, Cardiologist, Cardiovascular Disease, Registered Nurse Anesthetists Chiropractor, Dentist, Dermatology, Diagnostic Radiology, Doctor of Dental Surgery Doctor of Medicine, Emergency Medicine, Family Medicine, Gastroenterology, General Dentistry General Practice, General Surgery, Internal Medicine, Marriage & Family Therapist, Medical Director, Naturopathic Medicine, Nephrology, Neurology, Nurse, Nurse Practitioner Obstetrics & Gynaecologist, Occupational Therapist, Oncology, Ophthalmology Optometrist, Orthopaedic Surgery, Orthopedics, Otolaryngology, Pathology, Paediatrician Physical Medicine & Rehabilitation, Physical Therapist, Physician, Physician Assistant Podiatry, Psychiatry, Psychologist, Pulmonary Disease, Radiology, Registered Nurse Social Worker, Speech-Language Pathologist, Surgery, Urology, Veterinarian, Massage Therapist

If this sounds of any value, please specify your requirement in detail so that I can share a few **Healthcare professionals'** business contacts just for your review.

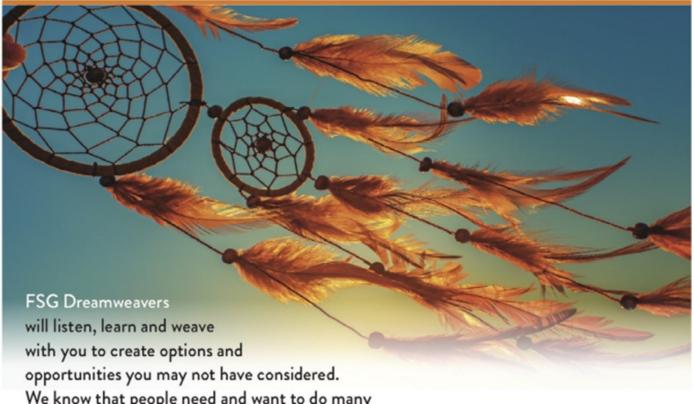


Sg Dreamweaving

Registered NDIS Provider.

'Creating connections and solutions with YOU, for now and the future.'

Your dreams can become reality.



We know that people need and want to do many things in their lives, so we are action and solution focused, allowing you to plan for both now and into the future. Truly reflecting what YOU want and meeting your personal needs, aspirations and goals.

GET IN TOUCH WITH A DREAMWEAVER TODAY:

Call (07) 5564 0655 to find out the closest FSG location to you, with 20+ locations from Ballina to Hervey Bay, and in between.

Together with you the FSG Dreamweavers create solutions that reflect what can be, rather than what has always been.

When a dream is turned into a plan and then into reality, we grow, and in growing we can make what we believed was impossible, possible.





Can you see what I see?

By Dennis R Overton Colour Blind Awareness and Support Group Australia

Colour blindness implies people can only see in black and white and not in colour! We may be colour blind but we are not blind to colour! The community fails to realise we see the world in our own colours, or perceived colours, which is not unlike normal people, except that some of our colours tend to merge. That is, certain colours like reds and greens, in my case, may look the same colour (what colour? – that depends on the light) but vary in intensity or shading. The same may be said for colours consisting of any red or green component such as violet and purple, which appear to me as blue. A bit like watching colour T.V. with the red and green tuning knobs broken. At least 1 in 10 males and 1 in 200 females almost 1 million Australians, have hereditary colour defective vision. The figures exclude colour defective vision caused by illness, injury, diabetes, some medicines and as when we get older our colour vision deteriorates.

Colour blindness is inconvenient; it does effect every day living, and does limit career opportunities. How would you like it not to be able to read of the blackboard or out of a book and not know why? Or not to able to distinguish ripe or unripe fruit or follow colour coded instructions; or for your clothes to be coordinated by some one else every day? Or your career path excluded from being a police, fire or ambulance officer, and marine or air pilot? (Can you think of a career that does not use colour?)

Some people may not even be aware of their colour perception problem. Did you know that a considerable number of children leave schools without knowing they are colour blind? (they are not tested) What would it feel like to be accepted by the defence academy on your academic achievement to find out later you are colour blind? It happens! How did you learn your colours? Does every person perceive the same colour or intensity of colour? Most people with colour blindness have a sufferer in silence syndrome? Why? Because non-colour blind people fail to understand colour blindness.

Today, at work and even leisure, with computers, maps, information, coding, timetables, weather maps, advertisement and games, colour is more prevalent than 30 years ago. As a matter of fact, you might say, we suffer from colour overload. Colour should be used to guide us through or to important information. The community, including teachers, employers and parents, fail to fully understand colour defective vision. Employees may get orders mixed up. Travellers may not be able to understand colour-coded train or bus timetables or routes. Unknown to advertisers, colour may turn over 5% of the population off their product. (We can't buy it if we can't see it? And some colours make us feel sick) Yet, up to 10% of males and 0.5% of females of the population are excluded or ignored.

Did you know there are eight types of colour defective vision? What can we do? Well, designing for people with different types of colour defective vision is not easy, as you are not going to please them all but at least by being aware there are colour deficiencies in the world, is a start, and keeping to **some basic rules of colour** then **colour compensating**, will result in a lot more people accessing the product and or information. By **basic colour rules**, I mean, use bright colours like yellow, black, blue and white. Keep away from low intensity colours on small bands. By **colour compensate** it means you can still use red and green but not together instead use red **or** green with different intensity of colour or line. Use shading instead of colour or use secondary navigation clues.

Less than 0.5% of women have colour defective vision, yet 18-20% of <u>all women</u> will carry the defective gene which causes the colour defective vision in males and they may not even be aware of it. Therefore with *C.D.V.* it is also a question of awareness for females.

If you would like to know more about Colour Defective Vision or if you need assistance or if you need a parent /teacher strategy kit please contact:

Colour Blind Awareness and Support Group Australia

E Mail: <u>colourblind@optusnet.com.au</u> Web Site: <u>www.members.optusnet.com.au/~doverton</u>

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Self Help Queensland is very thankful to the Colour Blind Awareness and Support Group Australia for helping us better understand the world of Colour Defective Vision, and the implications for people who manage their daily lives with very little thought from the rest of us. With the help of Dennis Overton we are going to endeavour to improve our newsletter and website, but it may take a little while.

To start off simply, below are a couple of Colour Combinations which illustrate what is good and what is bad for people with Colour Defective Vision.

Good Colour Combinations

- for text against a solid background

bright yellow against full blue

black against white

white against black

bright magenta against very dark green

dark blue against bright yellow or green

For colour coding multiple lines or bars in a graph choose colours that differ in 'blueness' and or 'brightness' from each other and against the background.

yellow, cyan, and bright magenta against dark blue

black, red, grey, and blue against white

Bad Colour Combinations.

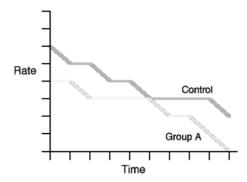
Avoid these combinations in text or figures

reddish-blues against greenish-blues

yellows, greens and oranges in combination

reddish-blues against blues

If dark orange and yellow lines had been chosen for the graph below, this is how it would be perceived by a red-green colour blind viewer.



Colours that differ greatly in luminance will be able to be readily distinguished from each other by colour blind as well as normal sighted viewers. It is important therefore to be aware of both (hue) differences and luminance differences when designing slides.

(Source: Colour Blind Awareness and Support Group Australia; Templates/Guidelines: Dr. Anya Hurlbert, Chairman, The Colour Group, and to the Audio Visual Centre, University of Newcastle)

The Fact That There's a

Highway to Hell

and only a

Stairway to Heaven

Says a lot about Anticipated
Traffic Numbers

"The opposite of poverty is not wealth. In too many places, the opposite of poverty is justice."

Bryan Stevenson American lawyer Social justice activist

Founder & executive director of the Equal Justice Initiative Clinical professor at New York University School of Law who spends most of his time in jails, prisons, on death row or in low-income communities. He has won relief for dozens of condemned prisoners, argued five times before the Supreme Court, and won national acclaim for his work challenging bias against the poor and people of colour.

Born: November 14, 1959



ICE Support Central Queensland

In our July 2016 newsletter Self Help Queensland wrote in depth about ICE, its effect on families, and where to get help. One of those resources was a support group called ICE Affecting Families Capricorn Coast.

In our September edition the facilitator of the group, Debbie, asked us to promote a Community Forum on ICE and other drugs in the Yeppoon Town Hall. Debbie reported that people are still talking about the Forum, which is a really good sign.

Not content with what she has already achieved, Debbie is ploughing ahead trying to help more families affected by ICE in the region. "I am trying to raise awareness west, south and north of us with a new face-book page and flyer, Debbie told Self Help Queensland.

"The main idea is to keep everyone talking and to try and remove the stigma away from addiction. I know there must be families in these other areas of Central Queensland who need the support. I'm hoping you can promote it for me." wrote Debbie.

"The aim of this page is to involve all Central Queensland families, their friends, GP's, Councils, local business people, schools etc. to educate themselves about the drug ICE which is devastating families across the country Top to Bottom, East to West and everywhere in between.

Our Central Queensland region is home to over 237,000 people (please correct me if I am wrong) and I'd like to know how many of you have been affected or touched in some way by this drug and what are you doing about it. What would you like to do about it?

My goal is to have a Detox / Rehabilitation in Central Queensland so families don't have to travel to Brisbane or as far North as Mackay and further. I'd like to see an improvement in the delivery of services by

bridging the gaps in the services we already have.

I can't do by myself, so I need the voices of others in Central Queensland to prove to the people who can help us, Government, that our need is genuine."

Our families need help. Our affected loved ones need help. When our loved ones come to us and say, 'Please help me I have had enough', we need to be able to get that help for them; and closer to home. At the moment there is no where to go."

To join with Debbie, or for help or information:

Email: icesupcapcoast@gmail.com

URL: https://www.facebook.com/groups/icesupcapcoast/

EMPATHY: Keep It Alive

-By Doctor Harmony, Psychiatrist

- Do you get easily impatient and intolerant?
- How tolerant are you to others having different opinions to you?
- Do you feel cranky when people do not do things to your standard or do it your way?
- What you argue, are you only seeing the issues from your own perspective?
- Do you feel easily hurt or rejected?
- Are you finding it difficult to forgive someone?
- Do you find it difficult to be generous to others?
- Do you feel easily angered?
- Have you got a tendency to act or speak before thinking?
- Are you self-destructive, such as excessive gambling, alcohol, recreational drugs or even self-harm?
- Do you tend to judge people?

When we only are able to see our own perspective and think about ourselves, it can lead to a multitude of issues. It can damage relationships, lead to anxiety and depression, affect our ability to parent, work or study. Failing to think about others can even lead to getting into trouble with the law or when we are younger, getting into recurrent trouble at school.

When we only think about ourselves, we are more likely to feel angry with the world, life and others. We are more likely to feel empty and directionless in life. We may repeatedly look for pleasures to satisfy ourselves, even if it's only short-lived gratification.

How can we feel more connected with others, less angry, more at peace? This is where empathy play as an important role. Empathy is the ability to see a situation from others' perspective. It is about "putting yourself in someone else's shoes."

The more we practise empathy on a daily basis, it will come naturally in the way we think, feel and behave. It will be easier to accept others for their differences and in the way they do things differently to us. We are more likely to accept uniqueness.

Empathy makes it easier to forgive ourselves and others. Instead of feeling wronged and hurt by others, we will be more likely to see that others may not have meant to hurt us and may have been unaware that they hurt us. With empathy, it helps us to see that others may have their own issues and past pain (which may have been unrelated to us) and that this affects their behaviour. Empathy will help us not to take others' behaviour as a personal insult or attack.

Empathy helps us to see how we may have hurt others with our actions. We are then more likely to ask for forgiveness and learn from our mistakes.

With empathy, we will be able to see that our perceptions may not actually be accurate or helpful to us. This will then have positive effects on our mood, self-consciousness and relationships.

If that's not enough, what's the other benefit of having empathy??? It is FREE and the effects is immediate! So, be sure to have a healthy dose of empathy every day and feel the benefits grow.

If you would like to find out more ways of dealing with anger, sadness and other uncomfortable feelings, check out series one of my Building Resilience books series <u>www.doctorharmony.com</u>. Although it is marketed as children's picture books, it has great tips for children and adults alike.



^{*}This column is general information only and is not intended to be taken as clinical advice. Please seek professional advice with your local doctor or counsellor for individual circumstances.

Munchausen by Internet More Common than Real Life

Munchausen by Internet is a term first coined in 2000 by Dr Marc Feldman, a clinical professor of psychiatry at the University of Alabama.

"Actually, Munchausen by internet has now become more common than real-life Munchausen syndrome because it's so easy to do. It used to be that real-life Munchausen patients would have to go to medical libraries, research the illnesses they would feign and go to doctors' offices to re-enact the symptoms," Now they don't need to do any of that — instead, they can go online and deceive hundreds or thousands of people." said Dr Feldman.

"Unlike malingerers, who play the sick role for monetary reward or to avoid something undesirable (e.g., work, school), people with Munchausen by internet crave only the emotional gratification that comes from eliciting care and concern. They go to extremes to tug on the heartstrings of internet strangers with sad status updates and photos: posting images of their shaved heads; stealing photos of real patients and posting them as their own; and using medical expertise to create believable lies about their supposed illness or injury."

Warning for Internet Support Groups

Self Help Queensland first spoke with David Pascoe around 1999 when we were trying to find a support group in Australia for people with Rosacea. David had started an email group called "Rosacea Support" which was the only one in the country. Not much was known about the condition then. David was wonderful. A sufferer himself, David was only too happy to share information with anyone who needed it. He was well informed, and had up to date information about credible treatments that were not even available in Australia yet. His group continued to grow and flourish. People from all around the world were learning from each other - and it all originated from a remote part of Australia. Then disaster struck!

David was prompted to tell the unfortunate story of what happened to the group to clear the air and serve as a warning to other groups. He has unselfishly written an amazing account of how an internet stranger endeared himself to the group and then proceeded to slowly build trust and credibility until he reached "Guru Status". The guru was a "researcher, author Doctor and Rosacea expert, handing out medical advice and recommending drug treatments"

When Your Internet Angel is a Dog

David's story is titled "When Your Internet Angel is a Dog" and we thank him for telling it. It begins:- "My internet support group for rosacea was a dream come true. We had thousands of members and a selfless guru to guide us. This was as good as the internet could get. Sadly the foundations were crumbling; our saviour was proffering blatant lies. Things were looking bleak. How did we miss the warning signs?" For the full story go to :https://rosacea-support.org/wp-content/uploads/2007/07/internetanddogs.pdf

What David Tells Us He Learned from the Experience

- 1. Expect high standards of behaviour from everyone. Don't allow anyone in your group to have special privileges where you let them behave poorly and without respect.
- 2. Don't rely on information solely from the internet. Google is good; so good that you can be tempted to think that if you can't find it there, it doesn't exist. In academia and indeed in real life, much is not visible on the internet.
- 4. Watch out for experts without peers. I'm sure that if Nase had had a single personal or professional peer that we could have talked to, this story would never have needed to be told. No one can exist without accountability in their lives. Make sure that you have some form of accountability for everyone in leadership in your internet group.
- 5. Your local doctor may just be your best friend. Don't ignore the wise counsel of doctors with real patients. The medical community may be staid and slow moving, but there is good reason for this.

The Rosacea Support Group website hosts a community forum, blog, resources, treatments, FAQ's, up to date information, Dermatologists and clinics in Australia etc. https://rosacea-support.org/australia



Peers Providing Support to Other Australians with Myositis

The Myositis Association Australia is a not for profit community organisation which provides support and assistance to people with Myositis and their families.

Myositis is a medical term that describes inflammation of muscle tissue. In every-day life, inflammation is most commonly experienced as the swelling around the site of wounds and around muscle and joint injuries. But, with the conditions known collectively as Myositis, the inflammation is within the muscle tissue as a chronic autoimmune response.

The most common defined forms of Myositis are:

- **Dermatomyositis**
- **Polymyositis**
- **Inclusion Body Myositis**
- Juvenile Myositis

In addition there are some rare and ill defined overlaps of the above, other versions that are even rarer still eg Interstitial Myositis, and yet other very rare, acute and aggressive versions requiring urgent hospitalisation eg Necrotising Myositis.

The seriousness of these diseases lies in the fact that the body's inflammatory response is turned against us causing our autoimmune system to attack and destroy our own muscle tissue. Once gone the muscle cannot be regenerated (although there are research studies working on this) and over time this can result in a progressive and cumulative loss of muscle that leads to a state of weakness and disability. In rare instances with some of the diseases remission can occur. In the case of Necrotising Myositis, urgent medical care is required due to the aggressive nature of the attack on the muscles putting limbs or even our life at

Myositis Association Australia is an organisation dedicated to:

- Providing a network of support for myositis patients and their families
- Assisting myositis patients to manage their condition
- Reducing isolation with newsletters, meetings and events where people can access information and share experiences
- Supporting research to help find a cure for myositis or improve the quality of life of myositis pa-
- Promoting awareness of myositis to the health profession and the general public

Thanks to the organizing capabilities of the Myositis Association, an extremely successful 3 day Conference was held recently in Wollongong, featuring outstanding key note speakers and other stakeholders.

'The conference also presented the opportunity for those who have never met anyone with Myositis to meet and share information.'

The Myositis Association would like to advise those people who have any of the forms of Myositis, that

we have established satellite groups in various Queensland towns/locations. They include the Gold Coast, Brisbane, Hervey Thanks to the Myositis Association Bay and Townsville.

For further information contact:

Myositis Association Australia Incorporated Phone: 0421 314 138 - Anita Chalmers

Email: mail@myositis.org.au Website: http://myositis.org.au/ for speaking with us, and giving permission to re-produce information.

Useful info sheets, along with news about current and up-coming Clinical Trials can be found at http://

myositis.org.au/

How To Support Someone with Mental Illness

Supporting someone with mental illness takes an understanding of what that person may be experiencing. Generally speaking, living with mental illness presents a host of challenges, not the least of which is a sense of isolation and separateness from the rest of the world. It's not uncommon for people who've been diagnosed with a mental illness to lose jobs, friendships, or marriages. Having a mental illness can mean extended loneliness.

However, this isn't always due to intentional abandonment. Sometimes, friends and partners want to remain connected and supportive. Knowing what do say and do, though, can be difficult for even the most well-meaning of people

5 Principles in Supporting Someone with a Mental Illness

These five principles can form the foundation of your plan to support someone with mental illness.

- 1. Reassure: "I'm here for you. I won't stop liking/loving you because you're struggling."
- 2. **Ask**: "What would be helpful to you right now?"
- 3. Offer: "Cleaning helps me deal with stress, and I'd like to come over there and clean."
- 4. Check in: "I'm going to touch base with you tomorrow."
- 5. **Encourage**: "This isn't who you are. You are your strengths and character."

When it comes to being supportive, simple is best. Often, the very best way to support someone with mental illness is to just be present. The goal isn't to solve someone's problems but rather to stand beside him while he works through them.

(Source: Healthy Place Mental Health Newsletter http://www.healthyplace.com/other-info/mental-health-newsletter/how-to-support-someone-with-mental-illness/)



Somali Youth Soccer Team Achievement a First in 20 Years of the Gorilla Sports Gold Coast Championship Cup

Only a short few years after arriving in Australia from a refugee camp in Eretria, a team of young Somali soc-

cer players became the first African team to ever enter the Gorilla Sports Gold Coast Championship in its 20 years history. Not only did they take on the best teams from all around Australia for two weeks, but also international teams from the UK, USA, Canada and New Zealand. And they finished a brilliant 4th!

The Gorilla Sports Gold Coast Championship is prestigious international youth football tournament and cultural exchange annually on the Gold Coast. It is the largest tournament of its kind in the Southern Hemisphere. Other teams to participate have come from Wales, Chinese Taipei, Cook Islands, Samoa, New Guinea and New Caledonia.

Congratulations also go to the Somali Community Association of Queensland, its elders and youth leaders who encourage their youth and work hard to help them achieve in all aspects of life in Australia. Self Help Queensland works very closely with the Somali community and joins in congratulating all the participants on a remarkable achievement. Well done!

www.somalicommunityofqueensland.com

"I contend that for a nation to try to tax itself into prosperity is like a man standing in a bucket and trying to lift himself up by the handle."

Sir Winston Churchill Prime Minister of Great Britain 1940-45, 1951-55 Born 1874, Died 1965



How Much Do You Really Know About Autism? Want to Know More? Need Help?

Autism Queensland has chalked up 50 years of experience, progress and innovation.

Autism Queensland has been helping individuals with autism and their families for the past 50 years. We are a not-for-profit organisation. Our vision is for a life of participation, opportunity and choice for people with Autism Spectrum Disorder (ASD). We provide specialised education, therapy and support services for people of all ages with ASD and their families.

The Autistic Children's Association of Queensland (Inc), as we were first known, was registered as a charity with the Queensland Government on 1 October, 1967. Its first funded program was employment of a part-time Occupational Therapist who worked with two children.

After several slight name changes, Autism Queensland Association Inc (1999), Autism Queensland Inc (2002), the organisation became a company limited by guarantee, Autism Queensland Limited, in 2013.

The modern day Autism Queensland is the lead agency in Queensland for the provision of targeted services and supports to people with autism.

Our highly skilled professionals with expertise in ASD deliver education, early childhood intervention, therapy and other specialised services. We are located in Brisbane at Sunnybank Hills and Brighton, and regionally in Gladstone, Rockhampton, Mackay and Cairns.

Our services include:

- Accredited, Independent School supporting school aged children from Prep to 18 years at campuses in Sunnybank Hills and Brighton
- Adult Services we provide support for people to live in the community across the Brisbane region and offer Community Access Programs.
- Allied Health Assessments and Therapy Services formal assessments to support the diagnosis and treatment of ASD including speech-language and communication, occupational therapy, cognitive and psychological assessments.
- Early Childhood Intervention flexible and individualised family-centred services for children under 7 years.
- Group programs and therapy for older children and adolescents focusing on key elements such as behaviour, development and social skills.
- Professional Learning and Development ASD specific workshops for parents and professionals supporting individuals with ASD.
- Respite and Holiday Programs Weekend and weekly respite in Brisbane and facilitated group programs during school holidays.
- School Advisory Visits our specialist teachers and therapists visit schools to provide information, advice, support and strategies to staff, other key professionals and parents of students with ASD.
- Studio G a group-based digital arts program for young people aged 16-24 years and available in Brisbane and Mackay.

Autism Queensland is also involved in a variety of research programs in collaboration with universities and the Autism CRC to better understand ASD and develop improved interventions for people with ASD in the future.

Demand for our services continues to grow every year and we rely on community, government and businesses to support our valuable programs. For more information:

Visit our website: www.autismqld.com.au Email us: outreachservices@autismqld.com.au

Autism Family Support Groups

Self Help Queensland takes every opportunity available to promote the benefits of self help and support groups. It is great to see that so many groups exist in Queensland to provide support to individuals and families with Autism. Below and overleaf is a list of Autism groups which are autonomous, run by volunteers and joined by the common thread of people giving and receiving support to each other.

Asperger Services Australia

Support for parents, carers, families, individuals, service providers and professionals. Includes a Youth Support Group & Adult Support Group.

www.asperger.asn.au

PO Box 159 Virginia QLD 4034

Ayr ASD Support Group

Anita Julyan P. 07 4782 1123 E. <u>anitaandduncs@westnet.com.au</u> PO Box 140 Home Hill QLD 4806

Bowen ASD Support Group

Meet 1st Saturday of every month @ Cooinda Family Centre, 20 Williams Street. Nadia Todd P. 07 4785 2812 or 0408 159 502 E. nadiatodd1@hotmail.com PO Box 469, Bowen QLD 4805.

Bundaberg Autism Support Group

Meet 2nd Wednesday of month @ Kenalwyn House Bundaberg Neighourhood Centre, 111 Targo Street Norelle Kasberger P. 0432 284 700 E. bundabergasd@hotmail.com
PO Box 5034 Bundaberg West QLD 4670

For any enquiries please leave a message, Norelle will respond to your call outside of business hours.

Central Highlands ASD Parent Support Group

Meet last Friday of the month 10.30 am @ Borilla Kindergarten, cnr Borilla & Loch Streets, Emerald. Jenny Finlay P. 07 4982 4734 E. director@borillakindy.com.au
PO Box 1564, Emerald QLD 4720

Gold Coast ASD Support Group

Meet 1st Wednesday of the month 10am–12pm and 3rd Wednesday of the month 7pm-9pm. Helen Steinhardt P. 07 5539 9903 (Please leave a message if phone is unattended.)

E. admin@autismgoldcoast.com.au
www.autismgoldcoast.com.au
PO Box 2272, Burleigh Heads QLD 4220

Ipswich ASD Support Group

Meet every 2nd Friday 9.30- 11.45am @ Cr Bruce Casos office (Ipswich City Council), Shop 2, 38 South Station Road Booval.

Jodie Kochman P. 0419 744 701 E. <u>ipswich.asd.carers@gmail.com</u> PO Box 39, Ipswich QLD 4305

Kids Outside the Box Gladstone

Messy Play Date & Parent Support Group.

Meets first Friday of the month (commencing 4 November 2016*) 9.30-10.15am @ Autism Queensland Gladstone, 2 Joyner St, Glen Eden 4680.

Hosted by Roseberry Communities & Autism Queensland Gladstone.

E. kidsoutsidetheboxgladstone@gmail.com

South Burnett Autism Support Group

Meet first Friday every month 7pm @ SB Care Building, Cnr Kingaroy & Avoca Sts, Kingaroy P. 07 4164 1107 E. <u>jlutz@bne.catholic.edu.au</u>

(Continued from Page 15)

Mackay Autism Support Group

Meet 3rd Tuesday every month (during school terms)

Debbie Brooker P. 07 4942 3458 E. autismmackay@gmail.com

Southern Downs ASD Support Group

Meet monthly @ Bush Children's Place, 47 Guy Place, Warwick.

Vicki P. 0419 945 791 Facebook

Sunshine Coast ASD Support Group

Meet @ North Shore Community Centre, Little Mudjimba Room.

Claire Gilmore P. 0448 965 779 E. sunshinecoastasdsupportgroup@live.com.au

Toowoomba - Pieces of the Puzzle (ASD Support Group)

Meet Mondays @ St Luke's Hall, 152 Herries Street Toowoomba, 10.30am-12.30am.

Teagan P. 07 4616 8000 E. TMcDonald@anglicaresq.org.au

Townsville & Surrounding Areas - North Queensland Autism Support Group

Meet 1st Saturday of the month 10am @ NQCES Community Hut, Hodges Street.

Gwenyth Cutler P. 07 4774 0637 E. gwenyth.cutler@bigpond.com or secretary@ngasg.org.au

PO Box 1659, Aitkenvale, 4814

Warwick ASD Support Group

Meet 4th Monday of every month10am-11.30am @ St Marks Anglican Church Meeting Rooms, Albion Street, Warwick.

Kellie Chapman P. 0478 600 115 E. warwickasd@gmail.com

FREE Presentation by Psychiatrist, Dr Harmony

Building Resilience in Children

22 November 2016 at The Relaxation Centre at 6pm-7.15pm

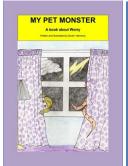
Dr Harmony is a Brisbane psychiatrist, mother and author of the "Building Resilience" books series, helping parents, children and educators alike to build a brighter future.

Dr Harmony writes articles of interest in each edition of the Self Help Queensland Newsletter. (See Page 8 of this edition "Empathy: Keep it Alive".

School teachers, parents, grandparents and childcare workers have found her books and presentations to be helpful, motivating, informative and interesting.

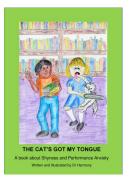
She will cover:

- What is resilience? When should we start to build resilience in children?
- Do you wonder why the hype about resilience?
- Do you want to prevent mental illness and behavioural issues in your children and reduce their chance of being bullied?
- How can you help your children to grow into confident, kind, caring, responsible, capable adults?











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