

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 5
September
2016



Self Help Queensland Office
Located at Sunnybank, Brisbane

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Thank You FSG

A special shout out to thank our newsletter sponsor FSG, for providing valuable practical support in the form of a bus and 2 staff, Julie and Chris Marsh, who volunteered their time to safely transport a group of Somali farmers, builders and others to visit a small goat and sheep farm in NSW. A successful and enjoyable exercise in community engagement by 3 great organisations!



Standing for Freedom, Social Justice & Growth.

The SHQ Newsletter is kindly sponsored by FSG Australia

From the President

Joseph Soda



I am pleased to say that we have received positive feedback to date regarding our Newsletter. A lot of effort goes into putting it together and we need your input to make it interesting and informative.

Our website now has a section for Personal stories, if you have a story you would like to share contact Trish by email.

The SHQ Facebook page has reached 1060 people in the past Month.

We have received an offer of sponsorship from the proprietor of the Caltex Service Station at Sunnybank Hills, Tommy Ho. On a selected day in September he will offer customers some good old fashioned service ie. Tyre checks, water, windscreen wash etc. For a gold coin donation. I encourage you all to support him on the day, which will be advertised locally.

Again I am calling for volunteers to assist on our committee. I am sure there is someone out there who has some time available each Month. SHQ is undergoing a transitional period and there is a need to have people on board with expertise in developing relationships with business, other organisations, marketing and building a strong support base.

Regards
Joe Soda

SHQ Annual General Meeting

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 office 33446919 or info@selfhelpqld.org.au by 22/11/2016
Further information to be sent prior to AGM

Refreshments Provided

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.



Queensland Government

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 Prah Elizabeth Carrigan
Co-ordinator	Trish Fallon
Bookkeeper	Janette Evans
Volunteer IT Assistant	Roy Hanfling

How to Contact Us

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Office Hours

Tuesday to Friday	9am - 4.30pm
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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.



It's Not Life Threatening But it's Definitely Life Changing

Alopecia Areata is an autoimmune disease causing hair loss. It is the loss of hair in single or multiple patches. Alopecia Areata is a highly unpredictable and cyclical condition.

A diagnosis of Alopecia Areata, or similar disorders that result in hair loss can, of course, be devastating news. Some people are fortunate enough to be able to quickly adapt to the unpredictable (and often extreme) changes to their appearance with little or no impact on their lives. However, for the majority of people a diagnosis of Alopecia Areata often results in a negative psychological impact. Men, women and children alike are at high risk of experiencing various emotional problems that can occur regardless of whether the hair loss can be easily masked, or whether the loss is a much larger patch impossible to hide.

In the initial stages of hair loss, it is common to experience an associated grieving process. This is considered a normal reaction that is a necessary part of learning to cope with the changes to appearance. After all, a person's hair is more than "just hair"; it also makes up a great portion of the identity of that person.

Those experiencing the grieving process may go through the following stages:

1. Shock and denial
2. Pain and guilt
3. Anger and bargaining
4. Depression, reflection and loneliness and finally
5. Reconstruction, Acceptance and hope

Support throughout this process is paramount, from family and friends but also from groups offering supportive networks which allow you to have a voice and to connect with others who are experiencing the same issues.

The AAAF (Australia Alopecia Areata Foundation) has a website with information necessary to help people deal with the disease. www.aaaf.org.au Inquiries can be directed to AAAF at info@aaaf.org.au anytime.

You can contact the Queensland Branch Manager (Judy Watson) on 0411 091 233 after 5pm weekdays and on weekends between 9am – 6pm or ask to join the Brisbane Support group on Facebook: <https://www.facebook.com/groups/360044287470628/>

Today there is no cure! Today the treatments vary! Today we have hope!

Alopecia — A Personal Story

.....I really missed my eyebrows and eyelashes much more than I missed my hair, it's easy to put a wig on but it was much harder for me to do my eyebrows and lashes. I felt like one of those faceless dolls you see hiding in the corner of the room..... Read Judy's inspiring story on the Self Help Queensland website at <http://www.selfhelpqld.org.au/content/stories-0>

Free Offer to People with Alopecia



<http://thebeautyspot.net.au/>
Ph: (07) 5593 5359.

Debbie LaBes, founder, and head Cosmetic Technician at The Beauty Spot in Burleigh Waters is generously offering cosmetic eyebrow tattooing valued at **\$550.00 free of charge** to people with Alopecia. Debbie told SHQ she enjoys being able to contribute her skills to help others feel better about themselves. "They have been through enough" said Debbie.

Debbie has 25 years' experience in Aesthetics and is an advanced specialist in cosmetic tattoo. She has been tattooing cosmetically since 2005, regularly updating her skills with advanced training with international Masters. If you have Alopecia and are interested in having your eyebrows tattooed, feel free to contact Debbie on (07) 5593 5359. For the full range of services Debbie provides, please check out The Beauty Spot at <http://thebeautyspot.net.au/>

I Could Have Been A Street Kid

Congratulations Constantin Mukendi

“I Could Have Been a Street Kid”

The amazing story of Constantin Mukendi (Costa). From life as an orphan in the Congo, fleeing a bloody civil war, surviving a corrupt Zambian bush refugee camp for eleven years, arriving as a refugee in Australia, beginning a new life in Brisbane and becoming an Australian citizen, Costa tells an inspiring story of courage, perseverance and unquestionable faith.

Costa is a proud Australian Citizen



SHQ congratulates Costa on his book

Self Help Queensland first met Costa in 2011. He is undoubtedly a leader who has an immediate impact on those fortunate enough to meet him. Gentle, charismatic and optimistic, Costa has the ability to move you in such a way that you can't help but hear his plea for those left behind - still living in fear, dying of poverty and ill-health in the Congo.

Quite quickly after his arrival here, Costa realized there was an expectation that refugees who settled in countries like Australia would have the funds to send back to desperate relatives and friends still living in poverty. Many refugees send money back home, sometimes even with feelings of guilt for their own good fortune. This in turn breeds poverty amongst refugees here in Australia, as they have little left to survive on themselves.

This situation prompted Costa to establish the AusCongo Network, (ACN) a not for profit community organisation in Queensland which Self Help Queensland has collaborated with on community capacity building projects. Costa could not forget those left behind in the Congo, but he also wanted to ensure that his people here would not fall into poverty also.

The work of AusCongo is framed by Community Development principles, an important one of which is 'self help'. This is not only our mantra at Self Help Queensland, but the World Health Organisation also recognises that "Self Help is the Best Help".

AusCongo worked hard to fundraise enough money to establish a small office and community meeting space in the Congo, provided community development training, employed a manager to oversee projects, and formed various groups such as microfinance, agriculture, business, internet etc to build the capacity of the Congolese people to help themselves. eg Small loans of \$100 are given for a period of 5 months, with the proviso that the money be repaid at \$20 per month. Low interest is paid to keep the project afloat, and loan repayments have a very high success rate. 14 acres of land have been bought for agriculture. Beans have been harvested ready for sale, and a cassava crop is still in its growth period.

How you can learn more and/or offer your help

Purchase Costa's book (SHQ does not usually promote books, but we think an exception is warranted here) Directly via AusCongo or online at http://www.inhousebookstore.com.au/index.php?route=product/manufacturer/info&manufacturer_id=11&page=7 It will soon be released through good Bookstores.

Volunteer Your Skills in any of the following areas by contacting: support@auscongo.org

Business Development Officer	Community Development Officer	Fundraising Co-ordinator
Public Relations Officer	Human Resources Officer	Legal Officer
Stakeholder Management Officer	Accounts and Finance Co-ordinator	

Make a Donation: Donate to AusCongo Capacity Building Project on especially designated webpage via World Relief Australia for AusCongo. Donations are tax deductible. <https://www.wra.org.au/1306capacitybuilding>

Invite Costa to Speak: media@auscongo.org
Make contact with AusCongo: support@auscongo.org
Website: <http://www.auscongo.org/>



ACN is a valued member of Self Help Queensland's network of Self Help and Support Groups

Genetic Matters

by Professor Kim Summers PhD FRSB

Highs and Lows of Genetic Testing

There has been an explosion in the number of genetic tests available for many different purposes: for people with serious medical conditions; for pregnancy screening; for those who want an estimate of their risk of heart disease, cancer or diabetes; as an aid to family tree research; as part of various research projects.

Two stories about genetic testing for serious conditions have made the news recently. Both highlight the importance of the relationship between the pathology laboratory, the doctors and genetic counsellors and the person having the testing. One of these cases is about a false positive test (where a fetus was wrongly diagnosed with a genetic condition) and the other is about a false negative test (where a child was incorrectly said not to have the genetic change associated with a condition), and both illustrate the power and the problems of modern genetic testing.

In the first case a pregnant woman was told her baby had Down syndrome (also known as trisomy 21). This was based on a screening test using a small sample of the mother's blood. During pregnancy, cells from the fetus (and its DNA) appear in the mother's blood. These new non-invasive prenatal tests look at the fetal cells and DNA for a variety of conditions. The test is said to be a screening test because it is offered to all women as an initial scan for potential problems. In a screening test the false positive rate (saying there is a problem when there isn't one) can be quite high. This is to make sure no cases are missed. Because of this high false positive rate, all women with a positive test are encouraged to have a second, more conventional test (for example sampling the fetal cells by chorionic villus biopsy at 12 weeks or by amniocentesis at 16 weeks) to confirm the result. Since these invasive procedures carry a risk of miscarriage, many women with a positive result of the screening test decide not to have the follow up test, and go through their pregnancies thinking that their child will be born with a genetic abnormality, or choose to abort the fetus without confirming the result.

In the recent case the couple did not have the follow up examination. The baby was born with no signs of Down syndrome and now at two years old has had a chromosome test that confirms that she does not have trisomy 21. The couple felt that the pregnancy was spoiled by thinking that their baby would have the condition, which was encouraged by their genetic counsellor and doctor, who claimed that he had never known the screening test to be wrong.

Clearly there is a lack of information here. Couples should be told that this is a screening test, potentially with a high false positive rate. So a negative result should be good news but a positive result is not necessarily bad news. What someone with a positive result needs to know is how often the positive screening test result is confirmed by a positive result from follow up tests. This is called the positive predictive rate and can be as low as 50% (that is, half of the positive screening tests are negative on follow up) depending on factors such as the mother's age. No-one should terminate a pregnancy on the basis of a screening test alone. Although the invasive options are associated with a small increased risk of miscarriage, they also give a much greater degree of certainty about the diagnosis. As more and more screening tests (using DNA, ultrasound and other procedures) are introduced, there must be clarity about the meaning of the results and greater understanding of the need for follow up and the limitations of the test.

The second case is an example of a false negative result, where a genetic test showed a DNA change that was not considered to cause the condition. A two year old child had been having seizures all his life. A genetic test was ordered to screen for known DNA changes that have been associated with epilepsy. A change was found in the gene for a protein that allows sodium to get in and out of cells.

The doctors were told it was a "variant of unknown significance", so the result was ignored and never even reported to the mother. The child was given medication that blocks these sodium channels in an attempt to control the seizures. Unfortunately, this may have been the wrong thing to do as the child already had a sodium channel problem because of the DNA change. Sadly he died at two years old.

(Continued on Page 6)

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The mother has now seen the test results and found that the head of the testing laboratory had previously published papers where the same DNA change as found in her son was given as a cause of a severe epilepsy condition called Dravet syndrome. She questions why the DNA change in her son was reported to be of unknown importance when in other cases the same DNA variant had been said to cause the condition. She was particularly concerned because the person reporting her result had been involved in detecting and writing about those previous cases. She is claiming that if the doctors had known about the significance of the mutation, they would not have given the sodium channel blocking drugs and her son might still be alive.

This story raises many issues. We all carry many DNA variants, some associated with the differences that make the fascinating variety of humans: hair colour, body shape, height, ability and so on. Looking at the whole human DNA (the genome) or even all of a single gene will reveal many places where two people are different. The challenge for the testing laboratories is to decide whether a difference in the DNA is likely to be what is causing a health problem. They have a number of strategies for this. There are computer programs that predict the impact of a DNA change on the protein. They can also now look at across animal species to see whether that variant is common – if it isn't found in nature, then it is likely to be harmful. There are also many databases of DNA variants which list publications relating to particular genes and the diseases they are associated with, in humans, mice and other animals. Sometimes a second test to confirm the result, testing of other family members, or testing members of the general public may be useful.

This leads to another issue. Pathology laboratories doing DNA tests have very different ways of reporting the results. Some simply send the DNA result to the genetic counsellor or doctor and let them do the analysis of the significance. Others provide a detailed explanation of what has been found, the significance it might have, the literature around the DNA change, even the risks to other family members. Most are somewhere in between – they provide some information but expect the doctor or counsellor to fill in the gaps and answer the patient's questions. In the case discussed here, the pathology lab said the variant was of unknown significance and the doctor did not take this further, assuming it was one of the many normal variants with no effect on function.

So what can patients do to ensure these cases are not repeated? Question everything! Ask for copies of the test results. Find out whether it is a screening test and if so ask what is the false positive rate and the positive predictive rate. If a DNA test shows a variant, ask what it does to the protein, whether it has been seen before, how they have determined that it is harmless or harmful. If you use one of the "self-service" genetic testing organisations (23andMe and others), make sure you understand exactly what the test will be telling you and how they come to the result.

Genetic testing is a powerful tool to ensure a healthy happy life for our families, but we need to be confident in the results, and these cases highlight the importance of good links between patient, counsellor, doctor and testing laboratory.

(Kim is Professor of Comparative Genetics, The Roslin 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)



Deakin University

NEW STUDY

Help us understand your experience of parenting a child with a rare disease

With little existing research in this field and no known research on this topic in Australia, this is an important opportunity to be a part of developing an understanding of the unique experience of parenting a child with a rare disease.

Participation simply involves completion of a short online survey. For further information, or to complete the survey go to: <http://psych.hosted-sites.deakin.edu.au/rare-diseases/>



Take a Walk in Paul's Shoes

Paul's real shoes

“They say that when you are doing what you love, you’ll never work a day in your life... so I haven’t worked for 9 years!”

Paul Sclater has been a part of the FSG Australia family for 9 years, in multiple positions. Paul explains why he feels FSG has become his home, “I know that everybody’s door is always open, I can walk straight into our CEO, Vicki Batten’s office and have a conversation, have questions answered... this is my home.”

Part of his FSG journey has been as a DSE (Direct Service Employee). As a carer of five people aging from 20-40 years, Paul’s time as a DSE has been full of rich, challenging and memorable moments. FSG DSE’s work on the ground, directly with the individuals FSG walks alongside, not just caring for but as their friend and mentor too.

“Being a DSE means walking in different shoes every moment of every shift. One second I am a carer, another an event planner, a cleaner, a friend or a driver... it is the most rewarding job.”

“My life has been and is enriched in every way, being able to live a principle centered life and act on those principles while walking alongside people is spiritually uplifting, at the end of every shift I feel fulfilled.”



Paul says there are also times that are challenging and you are pushed out of your comfort zone. “I was put to the test when I watched one of the participants I support in a lot of pain, whether that pain was emotional or medication induced or influenced by both...the total disregard of self for a prolonged period of time left me frustrated that I couldn’t do more. He now lives a fulfilling and meaningful life today. These challenging experiences also make for the most rewarding.”

He reflects on a time he walked alongside a young man who moved out of home for the first time. “Watching him move forward in his life, living in the home of his choice and being engaged in activities and friendships he enjoys... that is what it’s all about.”

Our 500+ FSG DSE’s are celebrated and valued as the faces of our organisation, all doing such great work and each with their own inspiring story. They are providing our community with opportunities to be connected, to have choice and self determination.

Our multi-talented DSE’s are ready to walk alongside you!

Embrace NDIS with one of our DSE’s.

Contact us on 07 5564 0655

or visit fsg.org.au



THE KEUNE
FOUNDATION

Foundation Provides Financial Support for Families with a Child with a Life Threatening Illness

The Keune Foundation provides financial support to Australian families (citizens/ permanent residents) who have a child under the age of 18 who has been diagnosed with a life threatening illness.

The Foundation does not means test any of its applicants and does not dictate what the financial support should be spent on as the needs of each family differ greatly.

The Foundation's role is to provide support to Australia's families without question, cost or prejudice.

To apply for financial assistance go to www.keune.com.au

You will be required to provide:

Application form completed signed & witnessed

Supporting Letter

Any other supporting letters or documents which may assist the application

Bank Details (Account Name, BSB, Account Number, Banking Institution)

Fax 02 9831 7550 or email tkf@keune.com.au all documents to commence the application process, then mail all original documentation to: The KEUNE Foundation PO Box 787 Kings Langley NSW 2147

What's the difference between a life-limiting and a life-threatening condition?

A Diagnosis of any illness, no matter how mild or severe, can feel as though a person's life is threatened. The difference between life-threatening and life-limiting illness are as follows –

Life-Threatening Illness are those that actively and continually threaten the person's life; for which there may be considerable and effective treatment, yet cure is either unlikely or not necessarily guaranteed and/or death is inevitable.

This means diseases or conditions where the likelihood of death is high. For example: cancer, motor neurone disease and AIDS.

Children in long-term remission or following successful curative treatment are not included.

Life-Limiting Illness limits the person's day-to-day life experience and limits them in achieving their potential had they not had the illness, whether this is through the restrictions arising from the impact of the illness on their body or through the constant reminders of medication, diets and use of appliances to aid their continued health and mobility.

Life-limiting conditions/illnesses progress quickly and others cause slow deterioration over time rendering the child increasingly dependent on parents and carers, such as Duchenne muscular dystrophy.

Life Limiting also includes life-shortening from complications that are secondary to the condition for example cystic fibrosis, multiple sclerosis and rheumatoid arthritis.

(Source: The Keune Foundation www.keune.com.au)

Wanted! - Unwanted Hearing Aids

Princess Alexandra Hospital runs a hearing aid bank for people who can't afford to buy their own. So, if you have any aids (behind-the-ear only) which are not being used or just are not wanted, please let Better Hearing Australia have them so they can pass them onto the hospital and give someone a chance of hearing better.

Contact Better Hearing Australia

Phone: (07) 3844 5065

Email: info@bhabrisbane.org.au

Website: www.bhabrisbane.org.au

Or post to Better Hearing Australia, 21 Vulture St, West End. Q. 4101

(Source BHA Newsletter July 2016)

PO Box 353 SUNNYBANK, QLD 4109

Ph: 07 3344 6919

Email: info@selfhelpqld.org.au

URL: www.selfhelpqld.org.au



Chromosome Structure XY & Variations (CSVXY)

CSVXY is A Not for Profit Incorporated Queensland Organisation which Supports Individuals and Families Diagnosed with a Sex Chromosome Variation

Chromosomes and Variations

What are chromosomes and variations? As Andrology Australia explains, chromosomes are found in each cell in the human body. The genetic material within these chromosomes determine all human characteristics, including hair colour, eye colour, height and sex. Each cell in the human body has 23 pairs of chromosomes (a total of 46).

Of these 23 pairs, one pair is called the sex chromosome because they determine a person's sex. The sex chromosomes in a female are called XX and in a male, XY. One sex chromosome is inherited from the mother and one from the father. Mothers always pass on an X chromosome, but fathers can pass on an X or a Y chromosome to their children.

Variations occur for a variety of reasons, and there are a number of other X and/or Y conditions including up to 49 chromosomes. These include 48, XXXX, 48XXXXY, 48XXYY and 48XYYY; and although rare, 49XXXXX, 49XXXXXY, 49XXXYY, 49XXYYY and 49XYYY.

Klinefelter syndrome

Rarely diagnosed, but far from a rare condition, there is 47, XXY, also known as Klinefelter syndrome. XXY is the most common of sex chromosome variations, with statistics to date showing approximately 1 in 400 males are affected. With no known cause or cure, Klinefelter syndrome affects social, physical and language skills in a person diagnosed with this syndrome. Effects include but are not limited to, weaker muscles, infertility, and testosterone deficiency, as well as processing deficits found in the domains of speech, reading, language, and motor development.

History/Background of CSVXY

Launched during Men's health week in June 2016, Chromosome Structure XY & Variations (CSVXY) became a Not for Profit Incorporated association in Queensland, Australia that supports individuals and families diagnosed with a sex chromosome variation.

CSVXY was founded due to a perceived gap within our Australian community, the gap showing there was minimal support and limited knowledge on not only Klinefelter syndrome, but all other chromosome variations. This became evident to the founder, Emily Wadsworth, following an opportunity to attend the 2nd international Klinefelters conference in Munster, Germany, where 120 participants from across the world came together to comprehensively discuss different aspects of this syndrome. She was astonished to find no other Australian representation at the conference. Emily's son Ayden was diagnosed with Klinefelter syndrome in 2015, and the journey to diagnosis was difficult. Following countless tests, the family GP suggested a genetic test, the diagnosis was finally given. Emily turned her initial feelings into quiet determination, establishing the organisation to raise awareness, raise funds for research, and support others living with a diagnosis of a chromosome variation.

Functions of CSVXY

Once founded, CSVXY established a campaign to:

- Increase awareness, as raising awareness is a responsibility to do something about what we are aware of.
- Provide individuals and families living with a chromosome variation with a foundation to start sending a message, to get attention.
- Get people talking about syndromes that aren't widely understood.

The campaign is a petition to ask the House of Representatives for an annual **Chromosome Variation Awareness day**, which will provide the foundation with a collective voice.

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Mission and Vision

The long-term strategic goal of this organisation is to:

- Provide one central location for patients with a chromosomal variation to have all required services in one integrated clinic where their medical information can be shared more efficiently as compared to the current approach, of different hospitals with a siloed approach in treating each symptom independently of one another.
- Implement a multi-disciplinary approach which will primarily benefit the next generation of patients with chromosomal variations due to having support services upfront and centrally located.
- Influence a unified approach within the community, from the GP, to how children are educated, as well as Universities and Hospitals having a collaborative relationship with support groups in these fields.
- Influence policy and processes to:
 - ◆ Fundamentally change the way Individuals with chromosome variations are supported in Australia
 - ◆ Fundamentally changing the way children with chromosome variations are educated and supported in Australia

This entails a significant expense, but the long-term economic savings will be visible. To provide an example, as infants, children and adolescents transition to adulthood, the economic benefit within the mental health system is expected to become evident, as they naturally mature, to adulthood confident and self-aware of their syndrome. The ongoing need for support services might show a decrease in some areas, as services are better integrated which will improve patient outcomes.

For further information please contact Emily at Chromosome Structure XY & Variations (CSVXY)

Phone: 0423 050 277. Email: info@csvxy.com.au Website: www.csvxy.org

Reading references:

http://www.genetic.org/Portals/0/Articles/47,XXY/Nieschlag_et_al-2016-Andrology.pdf

<http://onlinelibrary.wiley.com/doi/10.1111/gbb.12203/>

Managing Affairs After a Death - Checklist

The Queensland Government has created a very helpful checklist of tasks that need to be done after a funeral. There is a comprehensive list which allows you to delete any tasks that do not relate to your particular circumstance, and which can also be deleted once the task has been completed. You can also personalise the list.

The list includes a wide range of tasks such as applying for a death certificate, managing a will, finalising income tax, redirecting mail, dealing with banks, vehicle registration, pets, closing accounts, who to notify, what to cancel etc.

For each item on the checklist, there is also an easy link to very useful information to help you carry out the task - the who, how, when, where of it all etc.

The full checklist is available at:

<https://services.qld.gov.au/manage-affairs-after-death/>

If you need help with the checklist you can also phone 13 74 68

Congratulations to the Queensland Government for this excellent resource

(Source: Qld Gov Website. SHQ thanks Qld Women's Health Network for alerting us to this site through their "Network News" Issue 2, 2016)

"We generally admire the wisdom of those who come to us for advice."

Anonymous

Do You Still Feel Upset by the Past? How can you Forgive and Let Go?

- By Doctor Harmony, Psychiatrist (www.doctorharmony.com)

When we still harbour grief, resentment, anger, guilt or indignation about our past, it holds us back from moving on with our lives. Small triggers or reminders in life may then stir the old feelings, which could cause us to over-react to current events or people. It can make us feel angry, sad or hurt as it may feel as if the past is recurring, even though we may not make that conscious connection. I often see this in people with a past history of being bullied at school or at work. This also happens with reliving of sibling rivalry from childhood through other situations later in life. For example, have you ever felt jealous when others are being acknowledged or rewarded and you feel you have unfairly missed out or been overlooked?

Holding onto past pain can hurt our relationships and people round us. In some cases, many years have passed without having seen family or friends who have hurt us. Avoiding people who have hurt us may help our pain initially but longer-term there is a very high chance that we will encounter similar situations or people. There will also be reminders of the pain, such as Christmas, birthdays and Mother's and Father's Day. Ultimately we will need to face the issues or types of people again.

What can help us to resolve past pain?

Accept the Past has occurred and cannot be changed. What we can change is the effect it has on us. The choice is yours. Holding onto emotional pain only hurts yourself and others who you love.

Remember that we all make mistakes. If we reflect on the mistakes we have made in our lives and even how we may have contributed to a conflict or situation, our hurt and anger is more likely to dissipate. We are more likely to forgive. It takes a lowering of ego to admit we are human and are as fallible as others.

Empathise. Try seeing the situation from other people's perspectives. Often when we feel hurt and angry it is because we see it from our viewpoint only. We may feel wrongly treated or neglected. Often others are not aware that their actions or inactions have hurt us, as they may have been only thinking about their situation. Also we all have different backgrounds, cultures, personalities and coping styles. If we also take this into account, it may help to understand the situation from other perspectives, which we may have initially overlooked.

Emotional Pain is a Chance to Learn and Grow. If we are trapped in a state of emotional pain and find it hard to forgive, it can feel we are imprisoned by it. It is difficult to move on. When we can use our pain constructively, it turns our hopelessness, helplessness, anger, despair and sadness into a hopeful, empowering and uplifting feeling. We are then more likely to forgive and let go of emotional pain. Ask, "What can I learn from this?" "Is there anything I could have done differently?"

To summarise:

1. Accept the past has happened. It is difficult to move forward until you do.
2. Forgive yourself and others. We are all human. Mistakes are inevitable. Many times, people do not mean to intentionally hurt us.
3. Empathise. Put yourself in others' positions and you may see the situation different. This may change the way you feel about the past.
4. Use the past to learn and grow from. Past pain can make you a better person or break you. It is your choice.

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 www.doctorharmony.com. Although it is marketed as children's picture books, it has great tips for children and adults alike.



Last year I joined a support group for procrastinators.
We haven't met yet.

Anonymous



QAPS GROUP

Queensland's Asperger Partners Support Group

Supporting Each Other

The QAPS Group warmly welcome partners of people with Asperger Syndrome (AS). The group supports and informs the Neuro Typical Partner (NT) in their relationships with AS partners.

The group started at the end of 2007 with Professor Tony Attwood's endorsement. We are here to offer continued support and we encourage you to regularly attend the support group meetings which are held on the second Saturday of each month at different Library venues throughout Brisbane.

All of the members of our group have had, or have, relationships with someone who has Asperger Syndrome (diagnosed or undiagnosed,) and have different experiences to share. Some of us have been involved in long term relationships and have just discovered that our partners have AS whilst others have known for some time. Some however, are in new partnerships and are coming to terms with the dynamics of an NT/ASD relationship. All of us are on our own unique journey of self discovery and acceptance and are able to offer empathy and understanding in our own special way.

Our group members are not professionals and therefore are unable to offer professional advice, but can direct you should you wish, to some very understanding professionals. From time to time we call on these professionals to come and share with us at our meetings.

The benefits of attending the support group meetings regularly and listening to members sharing their experiences in dealing with issues/coping strategies, helps relieve the pressures of life and lifts our spirits. Over time you may find that you may form great new friendships. Coffee catch ups are wonderful ways of getting to know members more personally and for building up meaningful and trusting friendships with people who 'get you.' The co-ordinating team are people who have a genuine interest in Asperger Syndrome and are very supportive and willing to help you in your journey. Please feel free to contact us if you have questions or need assistance in any way.

QAPS Groups

- QAPS (Queensland Asperger Partners' Support) Group, meet every second Saturday of the month unless otherwise advised) at various Library venues throughout Brisbane.
- QAPS South Support Meeting is an added meeting to be held on the third Saturday's of some of the months at Logan City North Library.
- The QAPS Group, hosts 3 Tony Attwood Workshops throughout the year thanks to the Professor's generosity towards us, with his time and knowledge.
- APS (Toowoomba Asperger Partners' Support) Group meets as per diary of events
- WASPS (Wide-Bay Asperger Syndrome Partners' Support) Group would love to see you if ever you are in the area on meeting dates.

We invite you to register with us by email. You will be kept up to date with meetings & venues, upcoming events, relating groups & coffee mornings, educational information, the latest research, editorials, Centerlink Carers information etc. To register, or receive further information please contact:

Helen Boardman (QAPS Co-Ordinator) Phone: 0418 761 652 Email: gaps.group@gmail.com

A Bit of Aspie - Helen's Personal Story

.....I couldn't quite put my finger on it, but I realized early on, soon after our honeymoon ended, that he was eccentric, programmed differently, and out of the box, besides being very handsome of course and brilliantly funny. He was given to 'fits of rage' when stressed. It was my fault of course or the post-man's, or the governments, but never his..... Read Helen's story in full at:

<http://www.selfhelpqld.org.au/content/stories-0>

-oOo-

New!

Bipolar Bears Support Group - Fraser Coast

A support & discussion group for those who experience bipolar, or care for someone that does, led & facilitated by people with a lived experience of bipolar condition.

- Personal experiences & journeys
- Community Services & supports
- Strategies explored & shared for optimal health & well being
- Embracing the positives One2One discussion with FLOURISH AUSTRALIA Peer Workers available
- Tea, coffee & water supplied

Commences Monday 29th August 2016 ongoing

Meets: Weekly on Mondays

Time: 11.00 am

Venue: 46 Alice St Pinalba

Age: 18 years & over

For further information please call 1300 779 270

This is Your Special Invitation

To attend the 12 Step Program



Open Day

Wednesday 12th October 2016

10.30am—12 noon

\$2 donation appreciated for sausage sizzle

At the Hall 60 Thrush Street Inala

Behind the New Life Church

All you need to join is a desire to become emotionally healthy

-oOo-

Emotions Anonymous (EA) is a fellowship of people of all ages and backgrounds who come together to share personal experiences and hope as we work towards recovery from various emotional difficulties. We learn how to live a new way of life using the Twelve Steps of the program to help us find serenity and peace of mind.

The Inala EA group meets every Wednesday from 10am to 11.30am. Anyone is welcome to join. For further information phone 0403 821 152.



Chronic Anxiety Seminar

Open Invitation

Presented by

Queensland Obsessive Compulsive Disorder Support Group

Saturday 5th November 2016

10am - 12noon

Community Room, Brisbane Square Library
266 George Street Brisbane

Speakers

Dr Cynthia Turner (PhD, 2000)

Dr Turner holds an honorary lecturer position in the Department of Psychology at the University of Queensland. Her research interest spans areas such as anxiety disorders and body dysmorphic disorders in children and adolescents.

Rosa Prahll (MPhil, 2016)

Rosa has a long experience working in the field of Neuroscience and has been using her knowledge to support people who suffer from OCD and their relatives by explaining how the brain works and the mechanisms of actions of therapeutic drugs.

Time has been set aside for questions and a break.

RSVP to qldocdinfo@gmail.com

Limited seats - so only RSVP if sure of coming

Free Community Event Celebrating Refugee Communities



WELCOMEfest Sunday 2nd October, 2016 from 10am – 6pm

Music, Food, Dance, Markets, Arts

A free community event, WELCOMEfest brings Brisbane’s diverse cultural communities together to create welcome, discover cultures and celebrate everyone’s contribution to multicultural Australia.

Experience world culture through: international cuisine; music and dance performances; Ritual of Welcome: Bare Foot Fashion; Cirque Shara – Street Style Circus; Drumming Circle; DJs; busking; workshops and displays; eclectic stalls; lantern making; engaging children’s activities and so much more.

With over 15,000 people attending each year, WELCOMEfest has become one of Australia’s largest multicultural festivals and is one of Queensland’s signature community events.

Annerley Soccer Club Fields

Self Help Queensland Supports Refugee Support Groups

SHQ has enjoyed meeting and building relationships with leaders and members of several Refugee Support Groups. We have engaged in activities to help build the capacity of the groups to improve the health and wellbeing of their communities. We are always available to talk over how we might be able to assist. Below is a snapshot of some activities carried out over the past 12 months, a few in collaboration with other community organisations.



Sewing Graduation Class



Qld Fire & Emergency Services Distribute Fire Alarms



Mock Election for first time voters



**Young men chat easily with Qld Police - unlike in their country of origin.
A young girl learns how the sirens work.**



Traditional food of Sambusas, Goat’s meat, rice, vegetables



Finding a common language over lunch at the farm



Visiting a Goat Farm



Whirled Foundation – Support for Chronic Imbalance Sufferers

“Staring at the bottom of a bucket, trying to stop the room from spinning around me. These attacks... the vomiting hurts my stomach, I can’t control my bowels, my ears feel so full I’m sure they’re going to explode and this damn buzzing in my head is so loud, will it ever stop!? I just want to feel “normal” again.”

It is estimated that 5% of the population will experience vestibular vertigo episodes. That’s ONE Million Australians.

Vestibular disorders can affect people of all ages but is predominant in adults of working age and older persons with more females than males affected.

A Vestibular Disorder is one where temporary or permanent damage to the vestibular system, which controls balance, results in dysfunction. This damage can be caused by many things. A blow to the head or ear; excess fluid in the inner ear; the displacement of inner ear crystals; malformation of the inner ear structure; disease or infection; toxic chemicals; or even a tumorous growth.

Due to the complexity of the Vestibular System there are a great number of causes of dizziness and loss of balance, which require expert diagnosis and treatment. The major vestibular disorders are:

- Meniere’s disease
- Benign Paroxysmal Positional Vertigo (BPPV)
- Secondary Endolymphatic Hydrops
- Labyrinthitis and Vestibular Neuritis
- Vestibular Migraine
- Perilymph Fistula (PLF)

Inner ear Vestibular symptoms are distressing for individuals, life changing and often chronic in nature. People talk of experiencing sensations such as spinning, light headedness, dizzy spells, unsteadiness and loss of balance, tinnitus (buzzing or ringing in the ear), hearing loss, fullness or pressure in the ear and blurry or jumpy vision.

Vertigo is a special type of dizziness – where you feel the world is spinning around you, much like getting off a merry-go-round and trying to stand upright.

Individuals experiencing any of the above symptoms should consult their medical practitioner as soon as possible. Key treating medical specialists for vestibular disorders include Neurologists, Ear Nose and Throat Specialists, Neuro-otologists, Vestibular Physiotherapists and Audiologists.

Depending on the type of vestibular disorder, treatments may include medication, head repositioning manoeuvres, surgery, Vestibular Rehabilitation Therapy, dietary changes especially low salt diets, and other lifestyle changes such as reduction of stress etc.

Whirled Foundation is a national not for profit organisation providing information and support to those living with vestibular disorders. Whirled Foundation can:

- Put you in touch with medical professionals who can help
- Show you how to manage your symptoms
- Offer resources to help you live day to day with your vestibular condition
- Put you in touch with others living with and managing the same condition

Visit www.whirledfoundation.org or phone 1300 368 818 for more information.

“A government that robs Peter to pay Paul can always depend upon the support of Paul.”

George Bernard Shaw
Irish playwright, critic and polemicist
1856 to 1950

One More Simple, Free Thing You Can Do to Boost Staff Engagement and Make Your Team Healthier, Happier and More Productive.....Eat Together!



Almost half of all Australians work through their lunch break. And more than a quarter of us, 3.8 million Australians, don't take a lunch break at all, according to the Australia Institute.

While that's not as bad as in America where according to New York Times Magazine, 62% of professionals say they typically eat lunch at their desks, it does seem like the traditional lunch break is on the decline.

But while it might outwardly appear that your lunch-break-skipping staff are admirably committed to their work – and that's good for your team and your organisation – the real impact is more insidious.

Not taking a lunch break is bad for your team's health – studies show that people who don't eat lunch are more likely to "graze" throughout the day – which leads to an overall increase in the volume of food consumed.

But potentially more important for your organisation, when staff eat lunch at their desks they miss out on opportunities to interact with colleagues, share ideas, and build communities and networks of support with those around them.

In fact, the Australia Institute's Richard Denniss says that staff working through their lunch breaks is potentially an indicator of a bigger problem that must be addressed to avoid losing your best workers. "It's quite clear that people working in that way are not at their most productive. They're not at their most creative. They're not at their most communicative, And in the long run, the best staff will leave. It's a very short-term indicator of a productive workplace, to confuse not taking lunch with everything going well." Denniss told the SmartCompany website.

On the other hand, when staff prepare and/or eat food together, the impact on their wellbeing and their work performance is significant.

A recent Cornell University study on fire stations in a major US city found that the ones in which firefighters regularly cooked and ate together reported better team cohesion and cooperation, and workers were consequently better at their jobs.

That's because there's a special kind of intimacy involved in the simple act of sharing a meal. It strengthens bonds between staff, which in turn makes them feel happier at work – and, ultimately, happy staff equal productive staff.

The study, published in the journal "Human Performance" found that:

Cooperative activities among co-workers can provide valuable group-level benefits; however, previous research has often focused on artificial activities that require extraordinary efforts away from the worksite. We investigate organizational benefits that firms might obtain through various supports for co-workers to engage in commensality (i.e., eating together).

We conducted field research within firehouses in a large city to explore the role that interacting over food might have for work-group performance. Using a mix of qualitative and quantitative methods, our field research shows . . . that firms can enhance team performance by leveraging the mundane and powerful activity of eating.

So why not give it a go: organise a regular team lunch – it doesn't need to be fancy, and you don't even need to provide the food – just get your people to come together with their own meals on a regular basis. Or, go one further and cater your team's lunches. Providing a communal lunch even just once a week or month could have far-reaching team-building benefits that will greatly outweigh the cost of lunch itself.

(Source: 4/7/2016 Health & Wellbeing, Managing People Well. Image People Eating in Tunisia by Touzrimounir 15/11/2014)

"Cyberchondria"

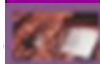
An increased anxiety caused by reviewing medical content online.



AAIC Australian
Anti Ice
Campaign
Putting the Freeze on Ice

*in
association
with*

Facebook Group
ICE – Affecting Families Capricorn Coast



Interested in attending a Support
Group? Register on Facebook

If you are unsure about joining this group
please email icesupcapcoast@gmail.com

INVITES MEMBERS OF THE COMMUNITY TO ATTEND

A COMMUNITY FORUM ON ICE AND OTHER DRUGS

WEDNESDAY — 5 OCTOBER 2016 AT 7.00-9.00PM

AT: YEPPON TOWN HALL

25 Normanby Street, Yeppoon Qld 4703

RSVP: 21 September, 2016 on 07 5665 6063 / admin@australiananticecampaign.org.au

This is a free event, however, a gold coin donation would be appreciated on the night.

TOPICS PRESENTED

- AAIC IN-SCHOOL & COMMUNITY EDUCATION & AWARENESS OF THE DRUG ICE AND ITS EFFECTS ON OUR COMMUNITY
- OPTIMAL HEALTH GROUP—DUAL DIAGNOSIS TRAINING
- PROVIDING COMMUNITY TRAINING FOR EARLY INTERVENTION AND FAMILY SUPPORT GROUPS
- DETOX, COUNSELLING AND TREATMENT
- RESIDENTIAL REHABILITATION

GUEST SPEAKERS MAY INCLUDE POLICE, LOCAL & FEDERAL GOVERNMENT LEADERS, SUPPORT SERVICE PROVIDERS, MEDICAL STAFF & COMMUNITY MEMBERS

**EDUCATION IS PREVENTION... KNOW WHAT ICE IS, WHAT IT LOOKS LIKE,
HOW IT AFFECTS THE BRAIN... HOW TO HELP A LOVED ONE.
WITH THE INCREASING EFFECTS OF ICE IN OUR COMMUNITY, KNOW THE FACTS AND HELP
EDUCATE YOUR LOVED ONES BEFORE IT'S TOO LATE.**



**TOGETHER, WE CAN
"PUT THE FREEZE ON ICE"**
www.australiananticecampaign.org.au



Ice - Affecting Families Capricorn Coast Support Group icesupcapcoast@gmail.com

PO Box 353 SUNNYBANK, QLD 4109 Ph: 07 3344 6919 Email: info@selfhelpqld.org.au URL: www.selfhelpqld.org.au

Interstate Organisations with a Role Similar to Self Help Queensland

There are no similar organisations that we know of in SA, TAS or NT

SHQ considers the organisations listed below to be our 'Sister Organisations' in the other States. While there are differences in what we do, we all have comprehensive databases of self help and support groups, and provide information, advice, assistance and resources to groups. Some of the organisations are exclusively dedicated to genetic conditions, while others cover all health conditions and related wellbeing issues, including genetic conditions. We are all the only organisations of our kind.

ACT

Self Help Organisations United Together (SHOUT)

Phone: (02) 6290 1984
 Email: Via Website
 Website: <http://www.shout.org.au/>

VIC

Genetic Support Network Victoria (GSNV)

Phone: (03) 8341 6315
 Email: info@gsnv.org.au
 Website: <http://www.gsnv.org.au/>

NSW

Genetic Alliance Australia

Phone: (02) 9295 8359
 Email: info@geneticalliance.org.au
 Website: <http://www.geneticalliance.org.au/>

WA

Connect Groups

Phone: (08) 9364 6909
 Email: info@connectgroups.org.au
 Website: <http://www.connectgroups.org.au/>

VIC

Collective of Self Help Groups (COSHG)

Phone: (03) 9650 2005
 Email: info@coshg.org.au
 Website: <http://www.coshg.org.au/>

WA

Genetic and Rare Disease Network (GaRDN)

Phone: (08) 9485 8999
 Email: hello@gardn.org.au
 Website: <http://www.geneticandrarediseasenetwrok.org.au/>



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@selfhelpqld.org.au

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

"Each man is good in His sight. It is not necessary for eagles to be crows."

Sitting Bull
 Religion: Lakotan
 Tribe: Hunkpapa
 Born: 1831 Died: 1890



Standing for Freedom, Social Justice & Growth.

The SHQ Newsletter is kindly sponsored by FSG