

NEWSLETTER HUNTINGTONS QUEENSLAND

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FROM THE PRESIDENT

Dear Friends

The 37th Annual General Meeting of Huntingtons Queensland was held on 25th of September. I'd like to welcome Jaime and Tim Colley as new members to the Management Committee.

Over the past 37 years the Association has experienced many challenges and successes in its development and evolution. Unfortunately the attendance at the AGM was rather poor and we are still looking for members to fill two positions on the Committee – they are Secretary and Vice President. Please give these roles some consideration as we cannot continue to reply on the same few members year on year to manage the Association and I will be stepping down as President after this year.

In the 2012-13 Annual Report I advised that the Queensland Department of Health had rolled over our funding for another six months from the 1st of July to 31st December 2013 at the same level as the previous tri-annual funding but without the usual CPI increase. We have just received the documentation for contesting our funding and we will be completing this with great diligence. Funding past 31st of December is however not at all guaranteed. The ongoing sustainable funding for the Association is our number one priority so I would ask you all to assist in our fund raising activities either directly, by organising functions or by assisting with selling raffle tickets. Please let us know if you are able to help.

Later in this Newsletter you will see an article on our HQ Assist Equipment Loan Program – this is certainly one of our successes. We'd like to thank the Queensland Department of Communities, Child Safety and Disability Services for their great contribution to the welfare of our clients and their carers in funding this program.

Gerry Doyle, President

FROM THE EXECUTIVE OFFICER

Oh!!! What a Year!

I believe the expression goes "How time flies when you are having fun". I am not sure that fun is the apt word for the past twelve months although there has been a peppering of it since I took on the Executive Officer role.

On a personal journey it has been a year of learning, compassion, understanding and valuing. Valuing being the greatest of them all. Valuing of the staff of Huntingtons who give their all for all. Valuing the volunteers who are forever there be it for outings, Management Committee meetings, transportation, support groups, gardening, newsletter assistance and of course the "handyman" whom we can never go without for a myriad of reasons.

Learning is a daily occurrence of this job: learning of the many facets of Huntington's Disease, about the families and the inherent idiosyncrasies of the disease; learning of "what more can we do" for our members and the community of people with Huntington's, their families and carers; and feeling compassion for the health workers, carers, medical practitioners and every person who is associated with Huntington's Disease.

I do believe that through the heightened awareness of the learning, compassion and understanding I am not quite the same person I was twelve months ago and I do hope, albeit different, a better person. Thank you to all who I have had the pleasure of associating with during this year.



We hosted the HDYA (HD Youth Alliance) forum here in August and what a great day that was with Sally McKay travelling from NSW and Tonia Bootle doing amazing presentations on the day and Tony Mimms providing a great video and insight into his life and his family. Dr John McMillan who was in New Zealand for a Geneticists Conference also provided a great video for everyone. We are planning another get to together in mid-November for this 18 – 40 year old group but this time on a more informal basis with maybe a BBQ on a Saturday or Sunday afternoon – so watch this space.

As this year has progressed there is now uncertainty as to our funding through Queensland Health. We have been granted interim funding until 31st December 2013 but at this point we still have not received the documents for the contestability process which means that many plans are "hanging in the balance".

One plan however which has been successfully accomplished was the wonderful fundraising initiatives which Jaime Colley has undertaken in Toowoomba in the past few months and thanks go to all who have supported Jaime with these enterprises. One of Jaime's fundraisers was a High Tea for HD held during Huntington's Awareness week which this year was high-jacked due to our Federal election, but that did not phase Jaime "the show must go on" and on it did with a great day. Two other High Teas for HD were held by Irene Golby and Merrilyn Brown which were also great successes and thanks goes also to Irena and Merrilyn and all who supported their High Teas for HD.

What a great way to get our message out and to fundraise for Huntington's. Can you host a High Tea for HD? Jaime, Irene and Merrilyn obviously have a great model to work from.

One plan not "hanging in the air" is Cam Wilson's attempt at the Guinness World Record on 5&6 November at his indoor Go Karting track at Eagle Farm Brisbane. The event details and how you can participate by fundraising and supporting Cam are on our website www.huntingtonsqld.com. I urge all who can get involved with Cam to do so not only to support Cam with his attempt but also to help in raising the profile of Huntingtons and in his fundraising attempts.

Our family holiday is in planning and this year will be slightly different with the holiday being in January rather than the usual December but, remaining at Hervey Bay which appears to be such a favourite with everyone.

Cheryl Miller, Executive Officer

*

FROM THE WELFARE DESK...

Kenneth Serbin is HD gene positive. He is an academic and writer who blogs under the pseudonym, Gene Veritas. Gene's blog is a great affirmation of life and the ways he has chosen to live positively with his risk. It discusses his HD advocacy, his participation and relationship with the HD research community, his work, the way he has responded to the challenges of living with Huntington's Disease and some of the choices he's made.

Gene's blog is a thoughtful and sensitive response to the challenges encountered by him personally and by the HD community at large. Many people living within the HD community will recognise many of the same issues and dilemmas that he explores. For those people who have an interest in Huntington's it is a recommended read, as Gene's personal and proactive approach to living with HD makes it slightly different to other literary offerings.

He has written some great notes on the recent 6th World Congress on HD held September 15-18 in Rio de Janeiro.

If you are interesting in reading about the Congress and following his blog, here's the link http://curehd.blogspot.com.au/

Christine Fox (Senior Welfare Officer) and Theressa Byrne (Welfare Officer)

UQ HD Study – Volunteers Needed!

A message from the 6th World Congress on HD

"HD is the most curable of incurable diseases because we exactly know the cause. But to fight against this terrible disease we do need each others' help. Scientists and HD families should work together and connect, to reach the goal of treating HD faster.

The UQ HD Study

In our lab we are studying in depth the relationship between HD and the immune system. Our goal is to understand the role the immune system plays in driving the progression of disease in HD. We hope to pave the way for a possible future therapeutic treatment for HD.

We would like to ask for your help to continue with our studies.

We need a small donation of blood (20mls – a tablespoon) from both HD patients and healthy volunteers. We would really appreciate you participating in our study – together we can do much more to fight against HD!

What is required?

- ➤ A single 20ml blood sample
- Signed consent
- > Brief questionnaire & examination for HD patients

How can participate?

- Males & females over 18 years of age
- > HD patients and healthy volunteers

For more information please contact: Dr Susanna Mantovani Mb 0468 753 805 Em: s.mantovani@uq.edu.au

We look forward to hearing from you.

Regards

Dr Trent Woodruff School of Biomedical Sciences The University of Queensland



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TOWNSVILL SUPPORT GROUP

The following members have been elected for another year to manage the HD Townsville Family Support Group. The Huntingtons Queensland Committee of Management recognises and appreciates the great work they carry out in the Townsville region.

Chairperson	Sue Bourne	4778 2495
Secretary	Bill Klaassen	4773 1816
Treasurer	Janelle Mains	4779 4047
Contact Person	Jean Paterson	4775 2787



Suggested Buzz Reading....

Following are some recent articles published on the HDBuzz website (http://en.hdbuzz.net/) which you may find interesting. Just type the first few words of the title of the article in the search bar at the top right corner of the HDBuzz website to access the article.

If you do not have internet access and would like a copy of any of these articles, please call Anne on 3391 8833 for a paper copy to be mailed to you.

- A DNA repair protein modifies the stability of long CAG tracts in the Huntington's disease gene Carly Desmond 3 June 2013
- Gene silencing drug safe in ALS patients... bring on Huntington's disease trials
 Joseph Ochaba 29 June 2013
- Can sad mice help treat Huntington's disease?
 Dr Jeff Carroll 17 July 2013
- How long is too long? Rethinking the Huntington's disease 'gray area'
 Dr Peter McColgan 16 August 2013
- Does a 'rusty hinge' cause Huntington's disease?
 Dr Ed Wild 27 August 2013
- The 2013 HDBuzz Prize for Young Science Writers Dr Ed Wild 2 September 2013
- Could muscle problems help explain movements in Huntington's Disease patients?
 Dr Kurt Jensen 6 September 2013
- 'Buzzilia' from the Huntington's Disease World Congress: day 4
 Dr Jeff Carroll 18 September 2013
- And look out for other HDBuzz reports from the 6th World HD Congress 2013 on http://en.hdbuzz.net/



September 2013

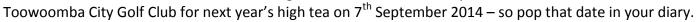
THREE VERY SUCCESSFUL HUNTINGTON HIGH TEAS

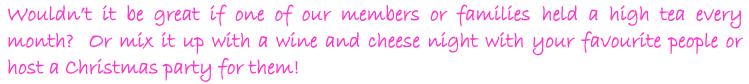
A very special thanks to three generous supporters of the Association for conducting high teas to raise much needed funds.

Irene Golby held a 'bring and buy' morning tea in July at the Victoria Point Adventist Retirement Village with 39 guests attending and raised \$600 through sales and donations.

Merrilyn Brown from Flowers by the Bay at Gumdale held her second annual September afternoon tea at her home in Wakerley and raised \$590 with just a number of close friends. See page 9 for Merrilyn's next fund raising activity.

Jaime Colley from Toowoomba enlisted the help of the Toowoomba Family Support Group and together with Yvette O'Brien and Appelein Stride raised \$1800 through auctions, raffles and donations at their high tea. Jaime has already booked the





Every dollor raised helps to make a difference to someone affected by HD.

Please call Anne on 3391 8833 or email <u>anne@huntingtonsqld.com</u> if you'd like some details. We'd be happy to run an advertisement for you in our Newsletter – the next one comes out in December.

DONATIONS TO HUNTINGTONS QUEENSLAND

If you or a friend would like to donate to Huntingtons Queensland, please return the slip below to our office with your payment. Alternatively you can donate online – go to www.huntingtonsqld.com. All donations over \$2 are tax deductible. We will send you a receipt for taxation purposes.

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Please see next page for payment options...



THE TEN COMMANDMENTS FOR REDUCING STRESS FOR CARERS

Extract from Carer's Chronicle August 2013



- 1 Thou shalt not be perfect...or even try to be!
- 2 Thou shalt not try to be all things to all people
- 3 Thou shalt allow thyself to leave some things undone

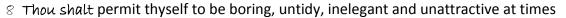


- 4 Thou shalt not spread thyself too thin
- 5 Thou shalt learn to say NO...it really is OK to say no
- © Thou shalt schedule time for thyself to be with friends and to do the things thou likest

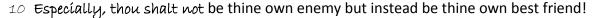




₹ Thou shalt switch off regularly and do nothing



9 Thou shalt not feel guilty for not meeting the expectations of others





Easier said than done, but certainly worth trying!

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Payment Options:	_
☐ Cheque ☐ Money Order ☐ Visa ☐ MasterCard ☐ Electronic Funds Transfer (EFT) ☐ Cash	
Bank: Westpac BSB: 734-002 Account No: 07-5025 Please include your name in your EFT transaction.	
Credit Card No / / Expiry Date / _ CVC: AMOUNT \$	
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Thank you so much for your very kind donation to Huntingtons Queensland! We will post you a tax receipt. Please retain a copy of your completed slip for your records and mail, fax or scan & email a copy to:	
Huntingtons Queensland PO Box 635 Annerley Qld 4103 Tel: (07) 3301 8833 Fax: (07) 3301 0443 Fmail: admin@huntingtonsqld.com	

*

POEM

Extract from Relaxation Centre Newsletter (Aug-Oct 2013) – written by Lionel Fifield who is one of the founders of the Relaxation Centre. You may remember his address at the 2010 HD Conference at The University of Queensland.

Good Question!

I wonder the rush Follow your feelings To follow the herd The wise man said

Do they know the outcomes? It will cause you less pain These haven't been heard. With your knowing instead.

Today it's the 'in' Why follow others?

Tomorrow it's the 'out' Is it for sameness or greed?
We rush to the next thing Being your uniqueness
And still don't doubt. Puts you in the lead.



Relaxation Centre QLD

You may like to investigate the Relaxation Centre QLD. They offer an extensive selection of short courses for all ages including Managing Stress/Relaxation, Building Self-Esteem, Building Confidence, Communication/Relationships, Creativity and Personal Discovery, Overcoming Anxiety, Depression and Fears, Encouragement/Motivation, Improving Health, Movement/Yoga and Meditation/Inner Exploration....phew what a great list!

Their contact details: Phone: 07 3856 3733

Email: relaxcentreofqld@powerup.com.au
Web: www.relaxationcentreqld.org

Have your say – an invitation to participate in the Chronic Illness Project!

This Griffith University project (funded by the Australian Government Department of Health & Ageing) is currently seeking participants for a phone survey. The information you provide will help to better understand how people manage their ongoing health conditions and what health care providers such as pharmacists can do to assist them. Participate in the project and have your say to improve health and pharmacy services in Australia.

The study involves completing a 30 minute phone survey with participants reimbursed with a \$50 supermarket voucher.

Do you:

- ✓ Have one or more ongoing health conditions?
- ✓ Care or support others who have an ongoing health condition?

Do you live in:

- ✓ Logan / Beaudesert area Qld
- ✓ Mt Isa and North West Qld
- ✓ Northern Rivers NSW

Griffith University is recruiting now, so please register your interest on:

www.chronicillnessproject.com.au or phone 1800 600 687.



Prana Updates Progress on PBT2 Trials in Huntington's Disease

See more at: http://www.newshd.net/articles/4265/prana-updates-progress-on-pbt2-trials-in-alzheimers-and-huntingtonsdiseases/#sthash.FkJD4SFG.dpuf

MELBOURNE, September 13, 2013: Prana Biotechnology (ASX:PBT / NASDAQ:PRAN), a leading global developer of first-inclass treatments for neurodegenerative disease, has today provided an update on three clinical trials testing its proprietary drug, PBT2, in Alzheimer's and Huntington's Diseases.

Huntington REACH 2HD Trial

The Reach 2HD trial is a six month double-blind placebo controlled Phase 2 trial on 109 early-to-mid stage Huntington's disease patients. The trial was successfully completed at the end of July 2013 with 95% of participants completing the entire six months of treatment. There has

been a delay in finalising the database to achieve 'database lock', required before statistical analysis of the data may begin. The results, originally anticipated in the last quarter of 2013, are now expected to be reported early in 2014.

"Apart from the timing delay, which is disappointing, nothing has changed. The trial was conducted and completed to protocol, and will provide the robust data needed to meet with the FDA in 2014 as we prepare for the next PBT2 trial," said Geoffrey Kempler, Chairman and Chief Executive Officer.

Huntingtons Queensland's HQ Assist Equipment Loan Program

In mid-2011 the Association received a one-off grant from the Queensland Department of Communities, Child Safety and Disability Services for \$300,000 to provide loan equipment to clients with HD. This has been a very successful project in terms of practical everyday assistance and direct benefit to our clients. It means that clients can be more comfortable in their beds and safer and more secure in their chairs. We have shipped gear to many parts of the state including Gold Coast, Sunshine Coast, Cairns, Charters Towers, Toowoomba, Rockhampton, Caboolture, Flinders View, Deception Bay as well as the Brisbane metro area.

Most of the funds have been spent on providing major items such as adjustable tilt recliner chairs, padded beds that tilt, rise, drop and bend in all the right places and wheelchairs. We've also provided all manner of other useful items such as shower chairs, lifting slings, and adaptive cutlery and cups.

All equipment is provided on a loan basis which means that Huntingtons Queensland retains ownership of all items. We have already been able to re-allocate quite a number of items such as recliner chairs and beds to other clients in need. We have retained a small pool of funds to maintain and transport items once they become available again.

Equipment has been shipped to both private homes and residential care facilities. In addition to making clients' lives a little better the equipment also makes carers' and nursing staffs' daily tasks just that bit easier and safer.

Here are some of the comments from happy clients and carers.....

- © Carer said over the phone "Everything is just fantastic, I couldn't thank you enough. My son slept through the night for 1st time in ages and didn't cry out for me once. Driver was wonderful." Carer also wrote "Thank you for your lovely gesture I can only repay you with my gratitude. Thank you."
- "My husband had a big stretch and the best night's sleep for ages. He loves his new bed."
- © From residential care facility "As you know, the bed has been specially adapted for our client's needs and will greatly enhance her comfort and quality of life. It will also make it easier and safer for our staff to deliver the specialised care that she requires in a safe and appropriate manner."
- "Thank you so much for all your assistance, it was greatly appreciated. The equipment has met everyone's expectations. You should hear the nursing staff call out through the corridor look at this sling, it's fantastic!"

\$

September 2013

FUND RAISING

THANKS TO THE QUEENSLAND COMMUNITY FOUNDATION



Huntington's Recently Queensland received \$3,000 from the Qld Community Foundation to assist with support group meetings on the Gold Coast. Executive Officer,

Cheryl Miller, is photographed receiving the cheque from Chair of Gold Coast Community Foundation, Richard Attwood, accompanied by Gemma Glover and her mother Jenny Laws. Huntingtons Queensland is grateful for the support of GCCF.

MERRILYN BROWN FROM FLOWERS BY THE BAY (GUMDALE) IS FUND RAISING AGAIN

Merrilyn is holding a lingerie party at her home in Wakerley on Sunday 26th October 2013. From 2:00 till 4:00pm you will be able to try and buy beautiful lingerie by Intimo. They offer a lovely range of everyday and glamourous underwear, casual and active sportswear and even a range of underwear for men.

Proceeds to Huntington's Queensland.

For more information please call Merrilyn on 0421 643 057 or email merrilyn@flowersbythebay.com.au



ROTARY CLUB OF BRISBANE INNER WEST – XMAS RAFFLE



The Rotarians of Brisbane Inner West have opened their 2013 Christmas raffle valued at approximately \$5,000. It's a registered 1800x1200mm (6'x4') trailer filled with toys, gardening, electrical and hardware items.

Half the proceeds of tickets our members and staff sell on behalf of Rotary will be donated back to us.

Please call Anne or Helen on 3391 8833 if you would to buy some tickets or better still take a book or two and help us boost our sales.

SUNNYBANK COMMUNITY & SPORTS CLUB

For the fourth consecutive year the kind members of the Sunnybank Community & Sports Club have donated funds to support HYPe (Huntingtons Youth Program etc).

To date the Club has donated a total of \$40,000 to

Huntingtons Queensland. Their support and generosity enabled our Welfare Officers to establish and grow this wonderful kids' program. A particular favourite activity is the annual family holiday at Hervey Bay.



GENEROUS DONORS SUPPORTING HUNTINGTONS QUEENSLAND

A big thank you! We have received and gratefully acknowledge major financial assistance from the following kind donors:

Ron & Sue James Joyce Bennett Fiona Price Margaret Buchanan Peter Gordon Good Shepherd Home T'ville William Van Heel Dr Geoffrey Cheyne Despa Sendra Mrs Long Betty Stabler

Miss Alethea Harding-Smith Mrs C Gordon Maree Norris Delmae Clark Lynette Lane Fay & Ian Linley Peter & Ellen Noonan Christine & Andrew Taylor Redlands Horticultural Society

Cliff & Jenny Farmer Mrs J O'Connell Coleen Andrews Tim Doyle, Mt Sheridan Amanda Corney Pamela Webb Sally Stevenson Val Polzin

Bob & Rhonda Goodair Alan & Alecca McKinless Margaret Bruce John Gauci Meralyn Saunders Dr Joan Lawrence WG & MM Abraham John Stride

Jean Farmer Catherine Fitzpatrick

Irene Golby & Victoria Point Adventist Retirement Village

Merrilyn Brown Flowers by the Bay Gumdale

Jaime Colley Toowoomba

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HIGH TEAS:

AND MORE FUND RAISING



The **eftpos** Giveback tradition is all about giving back to Australia each Christmas. The program demonstrates the power of Australians banding together to give back to our community.

In 2011, \$1 million was raised for The Salvation Army and in 2012 the same amount was raised for Vision Australia. Wouldn't it be great to raise \$1 million for Huntingtons Queensland?

Please Facebook this request and ask all your friends and family to vote for Huntingtons Queensland by visiting this website http://www.eftposgiveback.com.au/vote then nominate us as your charity and select the box "People with Disabilities".

UPDATE - CAM WILSON'S GUINNESS WORLD RECORD ATTEMPT

If you are planning on supporting Cam in his GWR attempt – PLEASE NOTE:

Date change

Now starting at midday on Melbourne Cup Day 5th November 2013 Finishing midday 6th November

Venue change

Now at Go Karting Brisbane 870 Kingsford Smith Drive Eagle Farm

Cam's Fund Raising Goal

Cam is aiming to raise a minimum \$24,000 (his target is for over \$48k) All proceeds to Huntingtons Queensland

For more info

Phone 3868 2225

Website www.gokartingbrisbane.com.au



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On the 8th September 2013, I held an HD High Tea Fundraiser in conjunction with National Huntington's Disease Awareness Week 2-9 September. The High Tea was a joyful and exciting afternoon with auctions, multi-draw raffles and lucky door prizes with all proceeds to aid Huntington's Queensland. Paul Reedy our great MC/Auctioneer for the afternoon was amazing and got us all up for games, we all had so much fun. I hope I will see you at our Annual HD High Tea Fundraiser next year.

My sister Kelly and I made a video together about HD

and our Mum, which we debuted at the High Tea. Since my Mother passed away on the 13th of August this year, I wanted to honour her memory and raise money for Huntingtons Queensland, who helped her and her loved ones out each year with so many things. The Toowoomba Chronicle Newspaper did a story about our Fundraiser. The article above appeared in the Weekend Edition - September 14-15. I was so excited when the photographer from The Chronicle turned up to take photos. I couldn't have done it without everyone who helped out in anyway, so a huge thank-you to you all. I hope you all will continue supporting Huntingtons Queensland. Thank you to everyone who attended. I was really happy when I realised we raised \$1800.



\$

HUNTINGTONS QUEENSLAND

Florence Dannell House 385 Ipswich Rd cnr Ponsonby St Annerley Brisbane

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Website: www.huntingtonsqld.com



Huntingtons Queensland is a not-for-profit service organisation. Established in 1976.

Our Mission is:

To provide professional support and advocacy for all persons affected by Huntington's Disease in Queensland.

Our Services Include:

- Providing individual and family support
- Facilitating the HD Day Centre Program
- Facilitating support group meetings
- Recreational activities for families with young children
- Organising respite holidays
- Providing information to families and health professionals
- Distributing a regular Newsletter
- Co-ordinating the annual HD Awareness activities
- Fundraising activities

Management Committee 2013/2014:

President Gerry Doyle
 Vice President Vacant
 Secretary Vacant

Treasurer Robert Hannaford

Committee Members: Jan Szlapak

Alan McKinless Gwen Pratten Heather Whye Pam Cummings Jaime Colley Tim Colley

Staff Members:

Executive officer
 Senior Welfare Officer
 Welfare Officer
 Administration Manager
 Telemktg / Admin Assistant
 Bookkeeper
 Christine Fox
 Theressa Byrne
 Anne Stanfield
 Helen Johnston
 Jan Mealy

CONTRIBUTIONS & DISTRIBUTION

Please feel free to submit articles or photographs for selection for publication in this Newsletter. The deadline for the next issue is 26th November 2013. Please email or post articles, details above. Please be aware that the Newsletter is published on *www.huntingtonsqld.com* in addition to postal and email distribution.

This Newsletter has been printed free of charge by the office of Graham Perrett, Federal Member for Moreton. Our kind thanks to Graham & Staff.

