



June 2013

NEWSLETTER

HUNTINGTONS QUEENSLAND

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FROM THE PRESIDENT

Dear Friends

It was heartening to see that the Federal and State Governments have signed an agreement to implement the National Disability Insurance Scheme (NDIS) now known as DisabilityCare. Pilot schemes are due to commence July this year in South Australia, Tasmania, Victoria and New South Wales. We will be watching the Pilot schemes in the two latter States closely as these will be covering the age groups normally associated with Huntington's Disease. If you want to keep track of developments on DisabilityCare then the following website is available <http://www.ndis.gov.au/>. The Neurological Alliance Australia (NAA) has published a position paper on the NDIS as it relates to progressive neurological and neuromuscular diseases. This includes Huntington's Disease as the progressive nature of these diseases will require very flexible support packages under the NDIS.

It is nearly the end of the financial year and we are planning to hold the Annual General Meeting at the end of September. We are looking for new members for the management committee so I would ask you all to consider taking on this role. If you are interested please contact either Cheryl or me. You will find a Membership Form included with this Newsletter – please take the opportunity to renew your membership before the end of June. Memberships provide a vital contribution to our operating revenue.

Many of you will know that Queensland Health has abolished the position of the HD Clinic Coordinator which has been held by Iris Simpson for many many years. Iris has been a true friend of Huntington's families throughout Queensland and her support and advice have helped many families face the difficulties of dealing with HD. On behalf of the Association, and personally, I would like to express my appreciation of her work helping our families. Iris was awarded Honorary Membership of Huntingtons Queensland in 2001.

Gerry Doyle, President

Queensland Health Notice...

Clients with HD, their families and supporting health professionals who have any questions regarding the current monthly HD Clinic conducted at the Royal Brisbane and Women's Hospital can phone the Neurology Department on (07) 3646 4266.

HD Youth Alliance - Brisbane Youth Forum

For people aged 18-40yrs affected by Huntington's Disease
Saturday 10th August 2013 9am-4.30pm at Annerley Brisbane

Please tell your children and other young people you know about this great forum! Go to page 5 for all the info!



FROM THE EXECUTIVE OFFICER

At the outset I would like to acknowledge our wonderful volunteers. Volunteers week 2013 was 13th – 19th May. Huntingtons's Queensland is blessed with volunteers who help organise and transport people to and from our Support Groups, assist with Day Centre, transport clients to and from Day Centre outings, fold our newsletters and stuff the envelopes, maintain our gardens, carry out general maintenance, tirelessly fundraise and last but not least, the Committee of Management who keeps me in line. Our "THANK YOU" to each one of you who has in any way volunteered for Huntingtons. I am not going to "name names" as I can be assured that I will miss somebody and thereby offend, so again "THANK YOU" to all.

Whilst on the matter of the Committee of Management I would like to acknowledge the work of Heather Whye who has been our Treasurer but due to other commitments has had to retire from the role. Robert Hannaford, a new face for Huntingtons Queensland, has taken on the role of Treasurer and we welcome Robert and the experience he brings to our Committee.

We have had a number of people contact our office asking about National Huntingtons Awareness Week which is 2nd – 9th September 2013. If anyone is looking to do promotions and awareness events for Huntingtons please let me know. Merrilyn Brown is running another high tea after last years' great success – see page 4 for RSVP details or ideas to run your own high tea or perhaps a cocktail party.

I know Jaime Colley from Toowoomba is looking for "happy helpers" who would be available to sell raffle tickets, general fundraising and awareness projects and those with green thumbs who can help her raise *Amaryllis* bulbs (our logo is a stylised *Amaryllis*). Jaime can be contacted at hdac131@outlook.com or by mobile 0499 150 331.

There has been much publicity with regard to Queensland Health and its funding for the not-for-profit sector. We have in the past been greatly supported by the Queensland Government. We have just been advised that our three year recurrent funding has been extended until 31st December 2013. Here is an extract from Queensland Health's 'Blueprint for Better Healthcare in Queensland' - "In a review of 'grants' in the healthcare system, the former Auditor-General identified fundamental weaknesses in definitions, accountability and lack of clear links between funded ventures and health goals. With funding allocations from multiple levels, the grants program was open to waste and duplication."

Huntingtons Queensland will therefore, during the next few months, be subject to a 'contestability' process and documents for this process will be provided to us by the Queensland Government around August 2013 for completion by September 2013.

This means that we will need to be even more prudent than ever with our spending in the next six months or at least until we know if our funding request is granted and to what extent. We are in the process of planning our trips to regional Queensland to best utilise our time, resources and expenditure. Our welfare staff will be in contact with families in the regions in the near future as soon as we know the dates.

Cheryl Miller, Executive Officer

FROM THE WELFARE DESK...

Hello families and friends,

Over the past few months the highlight of our Day Centre outings has been a trip to the newly renovated Brisbane City Hall where we saw first-hand the huge scale of the renovations. Impressive as the renovations appeared, it was the lunch time concert that we were really there to see. The concert was themed along a journey through the hey-day of rock'n'roll, spanning the 50s right through to the 70s and what a journey it was! The energy and enthusiasm of the performers was palpable, and for an hour rock'n'roll was King.

The concert was also enhanced by some very spirited and enthusiastic dancing by



professional performers, but also by 'groupies' and concert goers themselves. One of our staff may even have had to rise to her feet and do a very poor imitation of rockabilly dancing with another concert goer. All in all, the outing was greatly enjoyed by all of us. Special commendation must also go to the City Hall attendants who went out of their way to assist us and make our trip fun and trouble free.

We also enjoyed an outing to the Mt Coot-tha Botanic Gardens last month on one of our beautiful Queensland days. While not everyone loved the amount of walking involved (one attendee said she hadn't walked so far in years!) the surroundings and weather made us appreciate how lucky we are to live in a place where the cooler weather makes enjoying the great outdoors such a pleasurable experience. Our plant knowledge also got a little bit of a work out, and there was lots of reminiscing about plants we all recognised, or had killed in our own gardens. This month we'll do another outdoor outing weather permitting, as being outside really seems to enhance the group's feelings of health and well-being. As outings have become an important feature of the Day Centre program, any ideas for interesting days out will be gratefully received.

eHealth Records

You might have already heard about eHealth (electronic health), but we thought we'd bring you some information about this initiative. The eHealth Record is essentially an electronic medical record created for people who register. When someone goes to see their GP, specialist or hospital, their doctor can see their medical history at glance. We think this is a great idea, especially for our clients with HD as we all know how tedious it can be when we have to explain our medical history each time we present to a health service. The following information has been taken from the eHealth website.

eHealth Records – Helping You Manage Your Health

An eHealth Record can help getting the right treatment better, faster and easier! You and healthcare organisations you authorise can quickly access information regarding your health.

Until now, health records have mostly been stored in different locations with little connection to each other, healthcare professionals or hospitals. This means doctors and nurses often spend valuable time double-checking your treatment history.

As the eHealth Record system expands important information such as your current medications, allergies or tests could be accessed quickly.

You Can Register for an eHealth Record in Four Ways

1. Online at www.ehealth.gov.au
2. Over the phone, call 1800 723 471 and select option 1
3. In person by visiting a Department of Human Services centre offering Medicare services
4. In writing, complete a registration form available from Medicare

You can also nominate a trusted person, such as a carer or family member, to view or manage information on your behalf.

Will my Health Information be Safe?

The eHealth Record system is protected by existing and new legislation. You and/or your trusted person will have a login and password to access your eHealth Record and you choose which organisation/s can view your information.

If you'd like to know more, or would like some help to set up an eHealth Record, please call the welfare team - we'd be more than happy to help. We can also send you a brochure and further information if you'd like.

Christine Fox (Senior Welfare Officer) along with Theresa Byrne and Fiona Kerr (Welfare Officers)



2nd ANNUAL HUNTINGTON'S HIGH TEA

Hosted by Merrilyn Brown – Florist, Flowers by the Bay
Shop 18 Eastside Village Shopping Centre
696 New Cleveland Road Gumdale

Merrilyn would love you to join her and her friends for a sumptuous afternoon tea, a great laugh and a lively chat!

- TIME:** 2:00-4:00pm
DATE: Sunday 8th September 2013
TICKETS: \$30 p/p
(includes \$20 Tax deductible donation)
RSVP: Thursday 5th September 2013
PHONE: Merrilyn on 0421 643 057
Or Anne at Huntington's office 3391 8833
ADDRESS: 29 Campbell Street Wakerley



All high tea donations/funds to aid Huntingtons Queensland and HYPE (Huntingtons Youth Program etc)

The 2012 | 2013 Entertainment™ Book has just expired

If you haven't already purchased the new 2013 | 2014 Entertainment™ Book, now is a great time to do so...before they sell out!

If you buy a book, with just a few of the hundreds of 50% off and 2-for-1 offers, you'll more than cover the cost of your Entertainment™ Book. Plus, you can take advantage of valuable Member-only benefits until 1 June 2014!

And...Huntingtons Queensland receives 20% on all book sales.

To buy either:

- go to <https://www.entertainmentbook.com.au/orderbooks/2295h33> and nominate Huntingtons Queensland as your charity
- or call our office (3391 8833) to pay by credit card over the phone



HD Youth Alliance Brisbane Youth Forum



3 good reasons to attend:

- 1) Get up-to-date on HD
- 2) Plenty of personal stories
- 3) A chance to meet people....like you!

This forum is for you if:

- You are 18 to 40 years of age
- You come from an HD family
- You're gene positive but not symptomatic
- You're not tested or you've tested negative
- You're a partner, friend, sister or brother

Workshop topics will include:

- ✓ An overview of gene testing with personal stories
- ✓ HD research update
- ✓ Having babies
- ✓ Living positively: nutrition, exercise & looking after YOU
- ✓ Resources for young people & taking action

DATE: Saturday 10th August 2013

TIME: 9am-4.30pm

PLACE: Florence Dannell House 385 Ipswich Road cnr Ponsonby Street Annerley Brisbane

PARKING: Off Ponsonby Street

MORE INFO: www.hdalliance.com.au

RSVP: By Friday 19th July 2013 on rsvp@hdalliance.com.au

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.



Personal Details:

Title..... Name.....

Address.....

.....Postcode.....

Telephone..... Mobile..... Fax.....

Email *(please print clearly)*.....

Please see next page for payment options...



POEM



Here's a little poem written by Californian children's author and funny poet, Kenn Nesbitt, that might appeal to your children and perhaps the kid in you too! It's taken from his book 'Revenge of the Lunch Ladies – The Hilarious Book of School Poetry'.

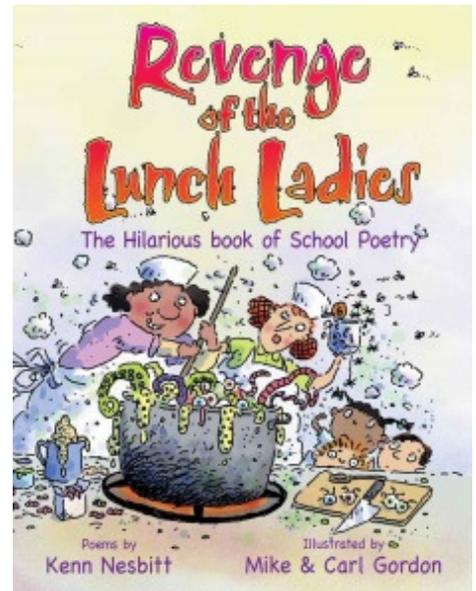
I'm Staying Home from School Today...

I'm staying home from school today.
I'd rather be in bed
pretending that I have a pain
that's pounding in my head.

I'll say I have a stomach ache.
I'll claim I've got the flu.
I'll shiver like I'm cold
and hold my breath until I'm blue.

I'll fake a cough. I'll fake a sneeze.
I'll say my throat is sore.
If necessary I can throw
a tantrum on the floor.

I'm sure I'll get away with it.
Of that, there's little doubt.
But, even so, I really hope
my students don't find out.



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 \$.....

Name on Card Signature Date.....

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) 3391 8833 Fax: (07) 3391 0443 Email: admin@huntingtonsqld.com

Your Story...



Following a number of requests over the past few months we're introducing a new section in our quarterly Newsletter - 'Your Story'. We would love this to become a regular feature in our Newsletters if we receive enough articles from our families and friends. We know that many of you out there have many interesting tales to tell...about your experiences, your trials and tribulations, your inspirations and your amazing achievements. If you or a family member or friend would like to feature in one of our future Newsletters please give one of our welfare officers a call for a chat about it. If you wish, we can assist you with writing your story.

To launch 'Your Story' we're featuring an article written by one of our family members, Jaime Colley. Her article was published on the Sunshine Coast Daily website (<http://www.sunshinecoastdaily.com.au/news/huntingtons-disease-awareness/1840019/>). We would like to congratulate Jaime on her great achievement in having her article published.

Jaime Colley's Story...

Hello, I'm Jaime Colley and I have Huntington's Disease.

I feel like it's my job to make people aware of Huntington's Disease and finding a cure.

I'm watching my Mother slowly wasting away and losing herself. She can't speak for herself and can't tell us what's wrong or if she is in pain. She can't eat solids and has trouble swallowing. If too much food gets into her lungs, she will catch pneumonia. One day she will need to be tube fed.

She has involuntary movements all day long and people are scared of her. She is losing her memory and soon won't know who we are. She can't go to the toilet by herself, so we can't take her out of the aged care facility anymore.

She is becoming a stranger and the worst part is Mum is only 50 years old. It's so hard to be with her but I don't have a choice. I'm watching my Mother become this stranger and can't do anything about it.

My children will never know who their Nanny was and what an amazing person she was. When I give my Mother a cuddle it doesn't feel the same anymore, it feels like there is no one left in the shell of her body. I miss my old Mum so much and every time I go to see her I cry afterwards.

It's hard being in a daughter/carer relationship and sometimes I feel like I fail her. It is hard being her carer because not many people know what Huntington's Disease is and what she needs. I had to fight for all the services that she has, with the help of Huntingtons Queensland. And even still I'm fighting to keep her guardianship because no one understands the needs of people with Huntington's Disease and how it affects them.

I don't want my children to have to go through what I'm going through with Mum and being her carer. I'm 28 years old and still don't understand the full effect of Huntington's until Mum goes through the stages and I see it with my own eyes.

I wouldn't have been able to get through caring for Mum without the support of Huntington Queensland. After I got the test results and saw that they were positive for HD, I had a very dark period in my life and thought what have I done to my children? Without the support of a very special lady at Huntingtons Queensland, I wouldn't have been able to get through it all. She made me see there is hope for my children's future. I wouldn't be where I am at in this part of my life and fighting for Huntington's awareness without her. She listened to me when I had no one else and pushed me when I needed it. Thank you C. Here's the link for Huntingtons Queensland, without them Queensland families with HD would be lost.

<http://huntingtonsqld.com>



This is my life and I'm trying to bring Huntington's Disease out of the darkness and into the light by using my voice to make the world aware of Huntington's Disease which is a terrible and painful disease for everyone involved. Huntington's Disease (HD) is an inherited neurological condition.

- This means that it is a disease of the brain which affects the nervous system and is passed down through a family line.
- Huntington's affects men and women as well as all races and ethnicities
- HD symptoms do not usually appear until a person is between 35 and 45 years of age and can include impaired movements, mood, speech and memory. As the disease progresses, symptoms worsen.
- There is no cure.

I inherited Huntington's Disease from my Mother and she inherited from her Mother and my children have a 50% chance of inheriting this horrible disease.

For me to spread the awareness about Huntington's Disease, I need you to help me and pass the message along. So please help me get/keep Huntington's out of the darkness by making the world aware of Huntington's Disease and help find a cure, so the next generation is HD free.

I have a Facebook page if you would like to join, Huntington's Dis AC. If you think you may have HD or would like to talk/meet other people with Huntington's send me an email HDAC131@outlook.com or my new blog Huntington's Disease Awareness (hdac131.blogspot.com)

Thank you for reading my story, kind regards Jaime Colley

Can I Mix Medicines and Alcohol?

Extract from NPS Medicinewise – Medicines Talk No 43 December 2012

A question that might run through your mind when you're given a new medicine is, "Can I still have a drink?"

Much of the time, the answer will be, "yes" but it's worth checking. Sometimes, you may have to avoid alcohol completely. While at other times, you may need to limit your alcohol intake in line with the advice of your doctor or pharmacist to avoid interactions between the two.

Interactions don't just occur if you consume alcohol and the medicine at the same time. Alcohol can take several hours to be removed from the body, so an interaction may occur at any time there is alcohol in your body.

Not Only Prescription Medicines

Interactions with alcohol can occur with many prescription and non-prescription medicines, for example:

- Sleeping, anti-anxiety and antidepressant medicines
- Cough, cold, allergy and travel sickness medicines
- Most opioid pain medicines, such as morphine (eg MS Contin) and oxycodone (eg OxyContin), patches like fentanyl (eg Durogesic) and even codeine which is found in some pain medicines such as Panadeine.

These medicines can interact with alcohol to cause increased drowsiness and dizziness, which can make it harder for you to think clearly and may diminish your physical coordination. This, in turn, may make you more prone to falling and impair your ability to do things like driving a car.

In addition, some common anti-inflammatory medicines, such as aspirin (eg Disprin), celecoxib (Celebrex), ibuprofen (eg Nurofen) and naproxen (eg Naprosyn) can interact with alcohol to cause stomach upsets, stomach bleeding and ulcers. In general, the occasional drink or two while taking these medicines is less likely to cause problems, but heavy drinking may increase your risk of problems.

Preventing Problems

- When starting a new medicine, find out about drinking alcohol while taking it. Ask your doctor or pharmacist or ring NPS Medicines Line (1300 633 424) for information about drinking alcohol while taking medicines.



- Read the medicine's consumer medicine information (CMI) leaflet available from your pharmacist or the NPS website www.nps.org.au/medicines
- Check the label or packaging. Prescription medicines that can interact with alcohol will usually have a warning sticker put on by the pharmacist. Non-prescription medicines will have a warning notice on the packaging.
- Take care if you're told your medicine may interact with alcohol to cause drowsiness or dizziness. Follow any advice about driving or using heavy machinery.

Is Access to Predictive Genetic Testing for HD a Problem?

By Deepti Babu April 23 2013. Edited by Dr Ed Wild. Article courtesy of HDBuzz – <http://en.hdbuzz.net/126>

Is access to 'predictive' genetic testing for Huntington's Disease a problem? Research from University of British Columbia researchers suggests that it is, at least in Canada. We explore the problem and possible solutions.

Predictive testing for the gene mutation that causes Huntington's Disease allows people who know they're at risk to find out if they will develop HD later on. People who want predictive testing usually need to come to a specialist clinic in person, for several counselling appointments. But this and other reasons could be barriers that stop some from pursuing predictive testing altogether. To help understand these barriers and explore ways they could be addressed, researchers at University of British Columbia conducted interviews with 33 people who accessed predictive testing through their Center for Huntington's disease in Vancouver, Canada.

Predictive testing is offered worldwide, typically through a process following international guidelines. These guidelines, for which updated recommendations were recently produced, are designed to make sure that people thinking about getting tested have enough information and time to make whatever decision is right for them - whether they choose to opt for the test or not - and enough support throughout the whole process and beyond. Three to four appointments are recommended before testing, but it's clear that individual needs vary.

The team in Vancouver follows this process, but may adjust it so only one appointment happens in Vancouver. The remainder can involve the individual's local general practitioner, including receiving results.

Distance and Inconvenience

Many of those interviewed said distance was a major barrier for them. Those in rural areas said it was difficult to take a variety of transportation (like an airplane, ferry or bus) to get to Vancouver for appointments.

Some study participants said that the long travel to Vancouver also meant missed work and family opportunities. Some study participants said they couldn't afford long travel for appointments, or couldn't take the time off work. Even though some rural participants were eligible for financial support and assistance in traveling to medical centers, some indicated that this didn't go far enough in covering overall costs.

Stressful Travel and Lack of Support

Some participants, both far from and near to Vancouver, indicated the commute to the testing center was stressful. Sometimes the city rush-hour traffic meant a long commute home, even if the distance was not great. Still others said they felt too far from their family and friends, particularly when making the trip to and from Vancouver to receive their test results.

An Inflexible and Lengthy Process?

Another major barrier study participants identified was the testing process itself. Specifically, many felt it was too rigid and not possible to tailor to an individual's specific circumstances and needs. Others commented they found the process was somewhat 'paternalistic', as if the testing center somehow knew what was best for them.



For people at risk of Huntington's Disease, deciding whether or not to have a genetic test is a difficult and very personal decision. There is no right or wrong decision.



Some felt there were too many appointments, and could not understand why so many were required. As well, some participants said the testing process took too long. Including a waiting period for the first appointment, the testing process can take several weeks or months to complete (the exact time varies at each testing center). Many described this as difficult.

“Barriers need to be addressed to help those who want to access predictive testing.”

Receiving Results and Bringing a Support Person

Most interviewed felt the way results are delivered is a very personal preference, and most preferred to receive them in person. Some indicated they would have preferred for their general practitioner to give them their results, while others preferred to hear them from the testing center. Some did not like having to bring a support person to their results appointment. This follows the international guidelines, but some participants thought it was too restrictive and would have preferred to hear their results alone.

What are the Take-home Points of the Study?

- In this Canadian population, there were two major barriers to those accessing predictive testing: distance and inflexibility of the current testing process. Of note, a large geographical distance is not always the cause - sometimes those living in the testing center's city can experience distance barriers.
- Barriers need to be addressed to help those who want to access predictive testing. Otherwise, people who want it may be put off predictive testing - or worse, they could access testing without proper assessment, genetic counseling and support. Addressing barriers promotes equity in healthcare, particularly in countries with socialized health care delivery. In an ideal world, predictive testing shouldn't be available only to those who can manage travel or taking time off work for their appointments.
- Many people do not understand the predictive testing process. Education about the process, and why it's structured how it is, can help people understand it, which in turn might make it more acceptable.

Does the Study Have Limitations?

Since they only come from one area and one health system, these results may not apply to all health care regions. Those interviewed may not be representative of the population at-risk for Huntington's disease. Importantly, they had all opted to go through genetic testing. Further studies may be needed to determine why those who decide **not** to test make that decision, and whether these barriers, or others, are part of the reason.



Final Thoughts

The recently updated predictive testing guidelines suggested two options to bridge distance if needed: telehealth (video-conferencing between two sites) and phone calls. The group in British Columbia is currently undertaking a study to evaluate telehealth for this use.

The testing process aims to provide as much information and support as people need to make the decision that's right for them.

Those of us who specialize in seeing people for predictive testing for Huntington's Disease meet regularly and are constantly evaluating our approach, as our colleagues in other countries do.

We do make adjustments to fit the needs of our population when needed. For example, we use a telephone call in place of some sessions. As well, we have used telehealth in situations where individuals were absolutely unable to travel to us with their support person. So far, this has worked well.

There is no “one size fits all” for every region that offers predictive testing for Huntington's Disease, but research studies like this are important to learn about ways the process can be improved, and new approaches to consider.



FUND RAISING

FINANCIAL ASSISTANCE TO HUNTINGTONS QUEENSLAND

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

<i>Beryl Gillespie</i>	<i>GR Phillips</i>
<i>Ken Horton</i>	<i>Norma Robertson</i>
<i>Angus Perkins</i>	<i>Betty Stabler</i>
<i>Dr Michael Gattas</i>	<i>Irene Golby</i>
<i>Jan Hall</i>	<i>Margaret Bruce</i>
<i>John Gauci</i>	<i>Paul & Meg Johnson</i>
<i>Pam Webb</i>	<i>Ingrid Gaida</i>
<i>P&J LeFeure</i>	<i>R Dredge</i>
<i>June Long</i>	<i>L&J Hartkoph</i>
<i>Marg Turner</i>	

HUNTINGTONS QUEENSLAND NOMINATED AS BENEFICIARY

Our sincere thanks continue to **Beecham Holden Caboolture** who has kindly nominated Huntingtons Queensland as the beneficiary for a charitable donation by way of CTP on first time registered vehicles sold through them.

You can contact them on:

Ph: 1300 661 958
29 Bribie Island Road
Caboolture



DONATIONS TO HUNTINGTONS QUEENSLAND



If you would like to donate to Huntingtons Queensland and have internet access, go to our website www.huntingtonsqld.com. Scroll down to the 'Please Make a Donation' section on the bottom left, click on the button <CLICK HERE> and follow the instructions.

Alternately you can return the slip on page 11 of this Newsletter and return to us with your donation – cheque, money order or credit card.

All donations over \$2 are tax deductible and we will send you a receipt for taxation purposes.

MEMBERSHIPS ARE DUE!

And so the end of the financial year rolls around once more.

Membership renewals are due July 1st 2013. We would greatly appreciate receiving your renewal as soon as possible.

New members are always very welcome too. If you have friends or neighbours looking for a worthy cause to support then please contact us on 3391 8833 or admin@huntingtonsqld.com for more information or a Membership Form.



THANKS TO MICK & HIS TEAM

We'd like to express our gratitude to Mick, Deb and the great team from Mick's Total Garden Maintenance for their generous contribution to our garden upkeep.

Someone from Mick's team calls by periodically to trim our numerous and vigorous hedges and take all the clippings away.

Thanks Mick & Deb – every dollar we save on our gardening costs is dollar toward our family services.



CAM WILSON IS SET TO BREAK GUINNESS WORLD RECORD

It's official! On the 12th of November 2013, Cam Wilson is going to attempt a Guinness World Record (GWR), in the name of Charity. Cam has chosen Hungtintons Queensland as the beneficiary of the world record attempt of Karting – Greatest Distance in 24 Hours Indoors (Individual). The Attempt will be held at Go Karting Gold Coast, on Spencer Road at Nerang.

Goal

Cam is aiming to raise a minimum \$24,000 (his target is for over \$48k) for the charity 'Huntingtons Queensland'. There are Huntingtons offices in all Australian state capitals.

The Record

The current record was set last December at just shy of 503kms at an indoor facility in America. It is Cam's aim to 'smash' this record to a fraction over 600kms.

Why Huntingtons?

Cam's father has Huntington's and it has been a shocking thing for him to see this take over his dad's body and mind. Unfortunately it is hereditary and the chances that Cam may get it in the coming years is 50/50. There is as yet no cure for the disease but specialists in genetic research are getting closer. Cam hopes that the money he raises can assist in speeding up the finding of a cure...hence this is why he has decided to take the plunge this year and fulfill his lifetime dream to race in the 2013 V8 Ute Racing Series as well as attempting the world karting record. Cam is almost 39 now!

Cam's Thoughts

Keeping awake for 24 hours is a massive challenge in itself, although anyone who really knows Cam, knows how hard he works at both of his indoor karting centres. Both are open from 10am till 10pm 7 days a week. Cam also regularly does a lot of the track maintenance and facility improvements after hours in the early hours of the morning when most people are sound asleep. Driving a race ute for 24 hours is a risky task as the chances of dozing off are huge on straight highways. But driving a go kart around the Go Karting Gold Coast track is just in another dimension. Cam will be busy the entire way around and there is literally only about four seconds per lap where he can 'relax' on the main straight which is across the bridge.

Like any successful motor racing, prior planning and preparation is vital for Cam to go the distance required to secure this world record. He knows it will certainly not be easy. Cam is assembling a strong team around him to ensure his body is able to cope. He is under no illusions about how massive this task will be. It's been a big year for Cam so far behind the scenes aside from racing and with this announcement he is sure to 'have a bit on' for the rest of the year in everything he does. Announcements of key sponsors for the GWR attempt will be formally announced in the coming weeks. Details of all charity benefits and how public and business alike can support Cam and his team in this world record attempt will also be announced shortly.

Dan Tuite GM Go Karting Brisbane & Gold Coast www.gokartingbrisbane.com.au or www.gokartinggoldcoast.com.au

Huntingtons Qld wishes Cam the very best in his record smashing kart attempt and ute race. Have fun Cam, we're right behind you!



Cam Wilson and his V8 race ute sporting the Huntington's logo



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

HUNTINGTONS QUEENSLAND

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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 Respite 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 2012/2013:

- | | |
|----------------------|------------------|
| ➤ President | Gerry Doyle |
| ➤ Vice President | Robert Westley |
| ➤ Secretary | Pam Cummings |
| ➤ Treasurer | Robert Hannaford |
| ➤ Committee Members: | Jan Szlapak |
| | Alan McKinless |
| | Marty Harmsworth |
| | Emma Kyle |
| | Gwen Pratten |

Staff Members:

- | | |
|------------------------------|----------------|
| ➤ Executive officer | Cheryl Miller |
| ➤ Senior Welfare Officer | Christine Fox |
| ➤ Welfare Officer | Theressa Byrne |
| ➤ Welfare Officer | Fiona Kerr |
| ➤ Administration Manager | Anne Stanfield |
| ➤ Telemktg / Admin Assistant | Helen Johnston |
| ➤ Bookkeeper | 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 6th September 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.

