



December 2014

# NEWSLETTER

## HUNTINGTONS QUEENSLAND



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### FROM THE PRESIDENT

Twelve months ago I reported Queensland Health advised they would be continuing to support Huntingtons Queensland financially up to June 30 2014. As required by Queensland Health we prepared and submitted a Transition Plan in September 2014 covering plans and actions needed to show how our Association would operate post 2015 without funding support from Queensland Health.

I am pleased to advise that our Transition Plan was accepted which means Queensland Health will continue to provide the current funding level until the end of 2015.

Next year will present us with many challenges as the Committee and our Executive Officer, Bernard Wilson, begins the roll out on a number of operational and administrative reviews and initiatives. Ahead we will need to prepare for the NDIS and look to new areas of fundraising and activities to support our evolving services, communications and relationships with Huntingtons' families throughout the state.

Although we face a great deal of uncertainty as to our future I am sure with the hard work and dedication of our staff and your Committee we will evolve to be a more successful Association. The needs of our family members are most important to us, so we will endeavour to do all in our power to continue to provide the level of support you so very much deserve.

I would like to thank Anne Stanfield and Jan Mealy for their work and support of Huntingtons Queensland as they move on to new endeavours. Anne will be attending University next year and I wish her well with her future studies.

I advised last year I would be stepping down as President but this has not yet happened and I have decided to stay on at least a little longer in support of my extended family and the team here.

Lastly, I wish all of you a very Merry Christmas and a joyous and prosperous New Year.

**Gerry Doyle, President**



**Huntingtons Qld will close from Mon 22 Dec & re-open Mon 5 Jan 2015**

**YOU MAY LIKE TO KEEP THESE IMPORTANT PHONE NUMBERS HANDY.....**

13 Health	1343 2584	Energex (power supply/outages)	131 962
Beyond Blue (depression, anxiety etc)	1300 224 636	GP Helpline (after hours)	1800 022 222
C'wealth Respite & Carelink Centres	1800 052 222	Lifeline Counselling & Support	131 144
Carers Qld (closed public holidays)	1800 242 636	Poisons Information	131 126
Disability Information Service	1800 177 120	SES (flood & storm assistance)	132 500
<b>Emergency (ambulance, fire, police)</b>	<b>000</b>	Weather warnings	<a href="http://www.bom.gov.au">www.bom.gov.au</a>
Emergency Management Qld	<a href="http://www.disaster.qld.gov.au/">www.disaster.qld.gov.au/</a>		

## FROM THE EXECUTIVE OFFICER

Greetings all, not quite three months into my role I am touched and challenged by the many personal stories and circumstances of Huntington's families. Each different, each challenging and sometimes painful to be sure, yet each filled with courage and compassion.

Days ago I visited Townsville where I was privileged to observe and meet a generous and supportive local Huntington's community. Each around the lunch table had the other's back and the mutual cooperation and respect was plain to see. For many, living with HD has been a way of life, for others the difficult journey just commencing. As Executive Officer, I am greatly challenged to lead and support our small team to provide the best possible support to Townsville and indeed all of the State. My sense is that you can't beat resources on the ground in the local area, but just how best to achieve that remains our challenge and focus. Thank you Townsville: Sue, Bill, Jean and all.



In reflection of the recent weeks, a highlight was the successful conduct of the HD Forum at QUT in collaboration with Dementia Training Study Centres (DTSC) and Ozcare on 6 November. Well done to all involved and additionally a wonderful opportunity for my own learning and understanding.

Many would be aware the Tuesday Day Centre Program at Annerley will not be offered in 2015. We appreciate participants have enjoyed and benefited from the program, however we recognise the program is available only to those with locality to Annerley. With funding reductions and uncertainties ahead the Committee considers we may better prioritise our resources and services to reach as many of our clients, carers and families as we can. Thank you to all those involved with the Day Centre over the years!

Plans for the annual Hervey Bay family holiday are in full swing for late December and we hope and trust those in attendance enjoy a wonderful break and family time with each other. Thank you to Sunnybank Community & Sports Club for their continued financial support for this event.

We also say thank you to Jan Mealy, Bookkeeper and Anne Stanfield, Administration Manager both moving on from the organisation with our appreciation and best wishes for their years of service. In Jan's case her service follows a long association with the organisation and at Committee level and Anne is scheduled to undertake full time study next year. Again, best wishes!

We welcome Jen Lysiuk in the newly titled Finance Officer role, currently working three days a week and assuming selected responsibilities both from the previous Bookkeeper and Administration roles. Jen is a degree qualified accountant and a CPA member and we look forward to her contribution. We are working on a newly titled Fundraising and Communications Officer role and will report further in the New Year.

On behalf of the Chair, Gerry Doyle, the Board and the management team, I am pleased also to welcome Iris Broadhurst to the Board/Committee and who will bring many years of service experience with HD to our efforts. I am delighted!



We thank very much the Salvos Stores for their September awareness and fundraising promotion which raised \$14,860 for Queensland and a near similar amount for NSW, a total of just over \$24,000! Well done Salvos Stores and customers!





Cam Wilson smashing the 2014 Guinness World Record!

We have established our EveryDayHero registration and immediately linked in Cam Wilson's next Karting Guinness World Record (GWR) attempt, a fundraising and positive awareness event to be celebrated and promoted throughout the state. Well done Cam!

We also acknowledge a number of generous donations received including several of \$500 and one major donor's regular gift of \$15,000. I was subsequently delighted to meet personally the major donor, an older lady with an earlier career in nursing who had professionally experienced the impact of HD on families. For all donation amounts, thank you for your generosity and compassion for the families of HD and the trust and confidence shown in our team.

May I ask if you or someone you know who has a successful business or career or is a successful investor and would like to make a social investment for a better deal and support for HD families, please contact me personally. We could meet for coffee and talk about where best we might work together and put your investment to work!

There are many others who help out quietly in the background. Firstly may I make mention and thank Mary Stunden who has helped out for many years in the office with newsletters, birthday and Christmas cards to mention just a couple of savers. Not so well at the moment, we wish Mary a speedy recovery and return to good health!



Diane Allan & her beautiful granddaughter Rosie

May I make mention also of Diane Allan who has been updating and hosting our website voluntarily for over ten years. When I enquired of her recently, Diane explained she had no connection to Huntington's Disease, but living on the Sunshine Coast was happy to help out as long as needed! Amazing! Thanks Diane!

The team was delighted to mix it up with the young crowd from HDYO recently, and connect up with Tonia and Breie as Qld Reps for HDYO who are ready to assist with HQ (that's us) as called upon. So if you're sub 30 and you would like to talk to someone who gets you, we're happy to

connect you up, no fuss. If you are post 30, well, we'll have to do!

May I finish with an apt lyric from Leonard Cohen:

*"Ring the bells that still can ring  
Forget your perfect offering  
There is a crack in everything  
That's how the light gets in"*

Thanks and best wishes for a happy Christmas for you and your families, from the team at Annerley!

A handwritten signature in black ink, appearing to be 'Bernard Wilson'.

**Bernard Wilson, Executive Officer**



Bernard Wilson, Matt Ellison (HDYO Founder), Tonia Bootle (HDYO Qld Rep) and guest speakers Lysle Turner and Kris King at the recent HDYO event



## FROM THE WELFARE DESK...

Hello Families and friends,

From July to November this year Emma Zheng from the Queensland University of Technology completed a four month work placement with Huntingtons Qld. Emma is currently studying a Masters in Social Work, and is on an exchange program from China. Not having any experience or prior knowledge of Huntington's Disease, many of our amazing families shared their stories and experiences with Emma at the Day Centre, one of the family support groups, and on home visits. Along with Emma, we would like to sincerely thank everyone for helping broaden her knowledge and understanding of Huntington's Disease. Emma is so very motivated now to spread the word and help families with HD. I am sure we will be keeping in touch.



Tressa, Emma & Christine



Forum speakers - Julie Morrow (Ozcare), Julie White (Genetic Health Qld), Dr John O'Sullivan (HD Clinic), Janet Wagland (OT) & Christine Fox (Huntingtons Queensland)

## Huntington's Disease – A Continuum of Care Forum

On Thursday November 6<sup>th</sup> 2014 a special event was coordinated by Ozcare with the Dementia Training Study Centre (QUT) and Huntingtons Qld to provide professional development for health care professionals to learn more about Huntington's Disease and strategies for caring for people with HD, ranging from the predictive testing stages and family planning through to full time care requirements.

Over 90 professionals from all over Queensland attended the free event, including allied health professionals, genetic counsellors, nursing home

staff and managers, community support workers, Queensland Health and Disability Services staff, psychologists, doctors, and so many more. The day was scheduled with three key sessions.

Dr John O'Sullivan – whom many of you will recognise as the head neurologist from the HD Clinic at the Royal Brisbane and Women's Hospital – spoke first about the onset and symptoms of HD throughout its progression, including medications and other strategies for minimising the challenges presented by symptoms.

Julie White, the Senior Genetic Counsellor from Genetic Health Qld – again many of you might have met with her at some time – spoke in the next session about the HD testing process. It was great to hear Julie speak, as she explained to the Forum the complexities and the 'not so simple' decision to have the test for HD. Hopefully Julie's talk has given people a different perspective on a person's decision whether or not to have 'the test'.

Finally, Janet Wagland gave an amazing presentation to finish the day off. Janet came along to our national HD conference here in Qld back in 2010 and it was great to hear how she continues to do ground-breaking work with families affected by HD in WA. Janet is a qualified Occupational Therapist and much of Janet's work over recent years has been in developing and refining accommodation and service models for younger people with complex support needs related to neurological disability. Working with the Brightwater Group, they were able to obtain the funding to build and service a unique community home for people with mid stage Huntington's Disease preventing them from being inappropriately accommodated in a high care environment and supporting them in regaining and maintaining both functionality and quality of life. The care model that the Brightwater Group provides for people with HD is inspirational, and I think the room



was certainly motivated by Janet’s presentation. Huntingtons Qld is very appreciative of Ozcare for providing significant funding to make this event happen –and to the Dementia Training Study Centre for hosting the venue. Ozcare also made it possible for the event to be filmed, and copies of the presentations will be available for service providers and health professionals in the New Year.

Over the years, a number of people with HD have participated in the Nerang Community Respite Care Assn Inc (NRCA) program. Recently, two of our clients were featured at the Gold Coast City Art Gallery for Disability Action Week. The following information has been extracted from the ‘Hands of Hope’ exhibition program.

We wish you all a wonderful Christmas and peaceful New Year!

**Christine Fox & Tressa Byrne - the Welfare Team**

## HANDS OF HOPE



Alissa Brown (right) and her artist helpers.

Daily a group of people, who live with a range of disabilities, join a social program at NCRCA. For many clients, this is the only opportunity in the week for much needed socialising and friendships. The programs offer choice and opportunities to be engaged in outings, computers, cooking, social activities, health and wellness and art. The 2014 Disability Action Week ‘Hands of Hope’ exhibition is a result of the creative pursuits of this group. ‘Hands of Hope’ is a project showcasing the deeply personal stories and challenges that the artists face. The exhibits aim to raise awareness and acceptance of people with disabilities within the community. Providing services throughout the Gold Coast, NCRCA supports the independence of people who have a disability, people who are older and frail, their carers and their families, by assisting them to remain living in their home, in the community.



## THE PRAYER

Hi, I’m Alissa. I am 30 years old and I have Huntington’s Disease. I love life and have worked and learned along the way until this disease made it more and more difficult. My family have raised \$3,000 so far to support Huntingtons Qld. I love to use my hands to do arts and craft. **‘The Prayer’** (my prayer) is that Huntington’s would no longer be in our DNA. I have two children, Blake and Ella. This year I lost my beautiful six year old Ella to this disease. The highlight of my week is my day at Nerang Community Respite Care. The welcoming joy is on everyone’s face, including the staff and volunteers.

*Sadly since starring in this Exhibition, Alissa passed in September this year. Her family and friends continue to raise awareness and funds for those affected by HD.*

## A STITCH IN TIME



Hello, I’m Alma. My passion is cross stitch and it takes patience and steady skill to complete a beautiful piece of work. I suffer from genetic Huntington’s Disease and over time this has left me with involuntary movements that stop me from holding my needle and creating something beautiful. When I came to Nerang Community Respite, I was supported to learn a new way to create, to do a ceramic piece of art. I had my actual hand moulded and it was as if I was stitching once again. I never thought I would do this again, but look at my piece! **‘A stitch in Time’** – it means in time (and with help) I could create again.



Alma Lee



## RECIPE BOOK REVIEW

# “SIMPLE SENSATIONAL SOFT” – SAFE & EASY TO SWALLOW

*From the foreword by Dr Patricia Kailis, AM, OBE, MBBS.....*

This is an inspiring cookbook. Not just because of its recipes – carefully tested and beautifully presented – but because of the love and care that triggered its creation.

Its roots are in Brightwater Kailis House (Belmont WA) home to six people living with Huntington’s Disease. Uncontrolled movements and difficulties chewing and swallowing associated with the disease require foods and drinks to be modified. It’s a challenge to make softened and pureed foods look appetising and taste appealing.

Respect and joy and a spirit of loving family are the foundations of this wonderful cookbook.

If someone you love can only eat softened, modified food, you will find lots of tempting delights to give them pleasure.

*Following is a sample recipe that you may like to try when friends pop in at Christmas time – get the kids to help!*



## PORK SWEET & SOUR SNACK BALLS



Serves 6

### Ingredients

- 1 teaspoon oil
- 1 kg pork mince
- 3 cloves garlic
- 1 large onion
- 1 teaspoon mixed herbs
- 1 egg, lightly beaten
- 1 cup of bread crumbs

### Method

Dice onion and garlic finely and place in bowl with lightly beaten egg.

Use a stick blender to mince together.

Add mince, mixed herbs and bread crumbs to the bowl, mix well.

Shape mixture into small bite size balls.

Heat oil in a frypan and lightly fry the meatballs until cooked through, but still soft.

Place meatballs in a bowl and serve with sweet and sour sauce.

### Hint

This dish blends well for people who are recommended a smooth puree diet; simply add extra sweet and sour sauce for moisture.

**This great cookbook is priced at \$30 (postage inc). To purchase online go to...**

[https://www.brightwatergroup.com/index.php?option=com\\_platform&view=crm&layout=productdetails&productId=2&Itemid=618](https://www.brightwatergroup.com/index.php?option=com_platform&view=crm&layout=productdetails&productId=2&Itemid=618)



## INTRODUCING OUR NEW FINANCE OFFICER – JENNIFER LYSIUK

Hello

I am Jennifer Lysiuk married to Stan. I am a qualified accountant/CPA having completed my degree part-time through QIT during the 80s, whilst working full time as an undergraduate accountant in the corporate manufacturing sector.

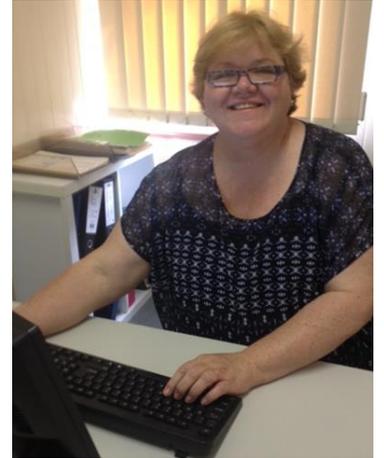
The 90s saw the birth of our two children and during their younger years I moved to part-time work in the service sector.

Post 2000 saw me back to full time work as a financial accountant when the children went to high school.

The 2010s saw me moving back to part-time work also trying my hand at tax consulting.

I have recently joined Huntingtons Queensland as Finance Officer and I wish to thank Bernard and our staff for making me feel very welcome.

PS My children are Louis 25 years and Irena 22 years.



Jennifer Lysiuk

## CHRISTMAS DONATIONS TO HUNTINGTONS QUEENSLAND

If you or a friend would like to make a Christmas donation to Huntingtons Queensland, please return the slip below to our office with your payment. Alternatively you can donate online – go to [www.huntingtonsqld.com](http://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 bottom of next page for payment options...***



# INTRODUCING TONIA BOOTLE FROM HDYO



**Kids** **Teens** **Young adults** **Parents** **JHD** **Professionals**

Hi! I'm Tonia Bootle. I'm the Queensland Representative for HDYO (Huntington's Disease Youth Organization).

After losing my mum to HD in 2009, and myself and my siblings going through the testing process, I realised that more work needed to be done for youth affected by HD, in a positive and engaging way. I grew increasingly more frustrated as no-one I spoke to had heard of it.

I am very excited to be working with Huntingtons Queensland in community awareness and much needed fundraising events.

We'd love you to visit our website [www.hdyo.org](http://www.hdyo.org)

Warm regards  
Tonia.



Bernard Wilson & Tonia Bootle at recent HDYO event



### Christmas Donations - 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 \_\_ / \_\_ 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 Email: [admin@huntingtonsqld.com](mailto:admin@huntingtonsqld.com)





## Huntington's Disease clinical trial announcement: huntingtin-lowering drug to enter Phase I trial in 2015

**A clinical trial for an exciting therapy against HD is planned for 2015. The first step is to make sure it is safe.**

By Leora Fox on November 4<sup>th</sup> 2014. Edited by Dr Tamara Maiuri. <http://en.hdbuzz.net/182>

*A new clinical trial just announced for 2015 aims to test a “huntingtin lowering” therapy, called an antisense oligonucleotide (ASO), that attacks mutant huntingtin directly. We’re extremely excited—it’s the first-ever human HD trial to fight HD at the root of the problem, and has shown great promise in animal models. What’s the scoop?*

### A potential drug targeting the HD gene

The announced clinical trial represents collaboration between California-based Isis Pharmaceuticals, and the Swiss pharmaceutical giant Roche. The drug, called ASO-HTT-Rx, is a therapy that aims to treat HD by targeting the gene itself.

The core of the problem in HD lies in a faulty stretch of DNA—an extra-long stretch of CAG building blocks within the huntingtin gene. The instructions contained in the mutant gene are first copied into an intermediate ‘messenger’ copy, from which the harmful protein is made. So, the mutant gene is the root of the problem, but it’s only bad because cells use the information in the gene to make a harmful protein.

The strategy behind ASO-HTT-Rx is to “shoot the messenger,” attacking the intermediate step between gene and protein by causing the destruction of the messenger copy.

These types of drugs are called ‘antisense oligonucleotides’, or ASOs. They’re a synthetic DNA-like molecule that can enter cells, stick to the mutant huntingtin RNA message, and cause its degradation. If it works as predicted, this therapy will stop huntingtin protein from being made—a “huntingtin lowering” strategy that, in the long term, has the potential to slow or to halt disease progression.

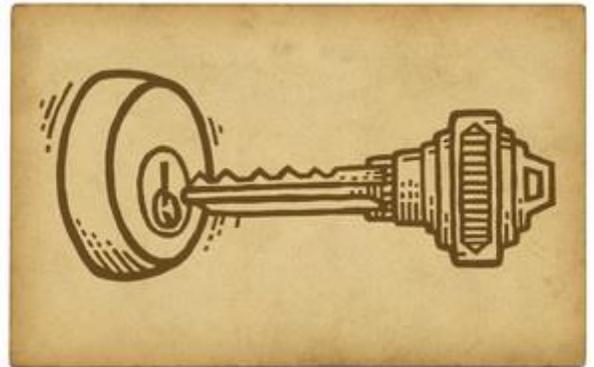
Every ASO has a basic structure that can be tweaked to help it stick to the right target message, ignoring the thousands of other messages in the cell. It’s a bit like when you go to the hardware store to have a key copied—the clerk selects the matching blank key and then etches the correct sequence of grooves to fit your lock, but none of your neighbours’ locks. In the case of ASOs, scientists at Isis use one of their established ‘backbone’ molecules and customize it, causing the drug to attack only the Huntingtin message.

This all sounds like cutting-edge technology, but the great news is that Isis has tested ASO-based drugs in human brains before, in experimental treatments for ALS (Lou Gehrig’s, or motor neuron, disease) and SMA (spinal muscular atrophy), and there have been no reported issues with safety.

### Drug delivery

One major way that ASOs differ from conventional drug treatments is that they cannot be taken orally as a pill, but must be delivered directly to the nervous system.

To get into the brain, ASO-HTT-Rx will be administered via a needle inserted into the fluid-filled space below the lower spinal cord. If that sounds extreme, rest assured that this method is routinely used in many areas of medicine. A similar



Much like a blank key is etched with a specific sequence of grooves; every ASO has a basic structure that can be tweaked to help it stick to the right target message, ignoring the thousands of other messages in the cell.



strategy is used by cancer doctors to deliver chemotherapy drugs to patients with brain tumours. More commonly still, many women receive similar ‘epidural’ delivery of pain drugs during child birth.

A major advantage of drugs like ASO-HTT-Rx is that researchers believe it can be administered intermittently and still be effective. Scientists have dubbed this approach to intermittent treatment in HD a ‘huntingtin holiday’; aiming to give the brain a healing break from the damage caused by the mutant Huntingtin protein.

Once injected into the spinal fluid, it takes about 4 to 6 weeks for ASO-HTT-Rx to have its effect, and from animal studies we think that the silencing will then last for about 4 months. At the moment, the study is designed to have patients receive the drug treatment once a month.

### Safety first

The decision to push forward with a clinical trial starting in 2015 is the result of more than ten years of work involving many researchers in both academia and industry. When treated with ASO-Htt-Rx, lab mice that model HD show robust benefits—even treating them with ASOs after they show symptoms leads to improvements in their brains and behaviour.

Isis researchers and Prof Sarah Tabrizi, University College London and global head of the ASO-HTT-Rx study, emphasize this first clinical trial is designed purely to evaluate its safety.

This is a critical point. As exciting as this science is, the first planned trial is strictly designed to understand whether the drug is safe. Directly injecting any drug into the nervous system cannot be done lightly—all the potential risks and side effects have to be exhaustively examined in a small number of volunteer patients.

“Drugs similar to ASO-Htt-Rx have safely restored healthy behaviors in animal models of HD, and moving the treatment into humans is an exciting step for the whole HD community. As exciting as this science is, the first planned trial is strictly designed to understand whether the drug is safe.”

### Anatomy of a clinical trial

All Phase I clinical trials aim first and foremost to evaluate safety and tolerability of new drugs. This means that a small group of patients (probably around 36) will be treated with differing amounts of ASO-Htt-Rx, in order to determine whether the drug has adverse side effects, and to help find the optimal dose.

About 25% of the patients involved will receive a placebo injection (one that does not contain any drug) to serve as a comparison group. Doctors will be monitoring the patients’ symptoms in response to the treatment, but the main focus of this trial is about whether the new drug is safe.

Once a drug has been deemed safe in Phase I, it can progress to Phase II. It’s at this second step that physicians can recruit larger numbers of patients and begin to examine how effective the drug is in treating disease symptoms. Having established safety and dose in the first trial, researchers can now ask the question, ‘does this treatment make people’s HD symptoms better (or worse!)’?

If the results of the Phase II trial are positive, a Phase III trial involves even greater numbers of patients, carefully examining the drug’s side effects, effectiveness, and safety. A successful Phase III trial is the kind of result that drug companies need to get a drug approved by national regulatory agencies.

### What does this mean for HD patients?

The entire process of bringing a drug to market takes years, even if everything goes perfectly. If ASO-Htt-Rx turns out to be safe in the just-announced Phase I study, this first result is just the beginning of a long road in the clinic. Each trial along that path, Phases I, II and III, will involve a relatively small number of treated patients. Furthermore, within each of these trials, some of the volunteers will receive placebo treatment to serve as a comparison for patients receiving HTT-ASO-Rx.

Patients in the Phase I trial of HTT-ASO-Rx will be recruited from just a few medical centres in



This first clinical trial is designed purely to evaluate its safety. Image credit: [Shutterstock](#)



Europe and Canada. A small set of designated HD research centres, to be announced in early 2015, will seek to recruit trial participants. The recruits will be people in the early stages of HD, but the specific enrolment criteria, locations and timing are not yet public information. We know for sure that a lot of detailed planning is happening behind the scenes, and that everyone is working really hard to advance this trial as quickly as possible.

### Safety, uncertainty, hope

In summary, we're excited that the first human trial of a drug that targets the root cause of HD will start as early as next year. This excitement is tempered by the realization that this first trial is all about safety, involves only a very small number of HD patients, and that many details of the study are still uncertain.

Drugs similar to ASO-Htt-Rx have safely restored healthy behaviours in animal models of HD, and moving the treatment into humans is an exciting step for the whole HD community. We'll be following the trial's progress with a keen eye, so that hopefully we can provide intermittent doses of cautious optimism.

*HDBuzz editors in chief Drs Ed Wild and Jeff Carroll have both conducted research in collaboration with Isis Pharmaceuticals, who have provided them with non-financial research resources. Dr Wild works under the supervision of Prof Sarah Tabrizi, global head of the ASO-Htt-Rx trial. Dr Carroll is a named inventor on a patent involving antisense oligonucleotide targeting of the mutant huntingtin gene – the technology for this patent is not being used for the ASO-HTT-Rx study, in which he has no personal financial interest. This article was commissioned from an external writer and the editor Dr Maiuri has no competing interest.*

## FUNDRAISING



*Our thanks to Megan Evans of Just Teezing Hair Studio for recently hosting a very successful fund-raising event in Gulliver (Townsville region)...a few words from Megan...*



“We decided to do this event for Huntington's Disease as it is so close to Layla's heart. The event was a fashion parade with live music and LOTS of raffles. We contacted all the local businesses and asked them

to help either by donating prizes or participating in the fashion parade. We picked a local venue



and they were so generous in donating so much (drinks and food) and the venue hire - all for nothing. If it wasn't for the generosity of the local businesses it would never have been as successful as it was. We had a ball and so did our guests.”

Regards  
Megan Evans, Just Teezing Hair Studio



## FUNDRAISING CONT'D

# CAM WILSON ANNOUNCES... 2<sup>nd</sup> GUINNESS WORLD RECORD ATTEMPT



Owner of Slideways Go Karting Australia and V8 Ute driver Cam Wilson has announced a second Guinness World Record attempt to raise money for Huntingtons Queensland.

Cam will drive a go kart non-stop for 24 hours, alongside five teammates in February to set a new record, while raising awareness and funds for the association.

Long-standing Slideways staff members and Cam's close mates, Dan Tuite, Tim Harris, Daniel Goddard, Chris Hinton and Nathan Roach will join the mission.



Cam Wilson (left) and his dedicated GWR team

Cam tragically lost his father, Murray, to Huntington's earlier this year and like many other family members of those with the disease, he lives with the 50% prospect of having inherited the defective gene. Extremely grateful for the support Huntington's Queensland provided to the Wilson family over the ten years following Murray's diagnosis, Cam is determined to give back as much as he can.

At his first overnight marathon record attempt earlier this year, Cam set a new record of 604km for "Karting – Greatest distance travelled in 24 hours indoors (individual)", and raised over \$20,000 for Huntington's Queensland.

The new world record attempt will take place at Slideways Go Karting Gold Coast at Nerang from noon on Tuesday 17 February.

The Slideways team aims to raise \$48,000.

We invite you to get behind Cam and the team. Please spread the word among your family and friends!

Donations can be made via <https://give.everydayhero.com/au/slideways-go-karting-gold-coast>.



## FUNDRAISING CONT'D

### GENEROUS DONORS & SUPPORTERS OF HUNTINGTONS QUEENSLAND

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

*The Salvos  
Miss A Harding-Smith  
Despa Sendra  
Norma Roberston  
AN Longland*

*Glen Sexton Pty Ltd Townsville  
Peter & Ellen Noonan  
Betty Stabler  
Maida White  
Megan Evans Just Teezing Hair Studio Townsville*

*Mrs M Turner  
Ken Horton  
Jack Flitcroft  
June Long*

### *Grill'd healthy burgers*

Great news! Huntingtons Qld has been nominated to participate in the Grill'd Local Matters donation program at Grill'd South Bank this month. Every month, Grill'd donates \$500 to local groups and asks their customers to decide who the money goes to.

When customers buy a burger, they will receive a token to put into one of 3 jars representing different groups. Whoever has the most tokens at the end of the month receives \$300. The other two groups receive \$100 each.

To do your bit to help our cause, spread the word and head on down to Grill'd South Bank.

*Grill'd healthy burgers*

Shop 3 / 167 Grey Street  
Southbank



### Continued Support from BEECHAM HOLDEN Caboolture

In 2010 Chris Beecham of Beecham Holden at Caboolture initiated a program for QBE Insurance to make a charitable donation to Huntingtons Queensland by way of CTP on first time registered vehicles sold through Beecham Holden. Since 2010 the Association has received over \$12,000 in donations from QBE.

We offer our ongoing thanks and gratitude to Chris, his son Lockie and all the team at Beecham Holden.

**Sales:** 1800 619 787    **Service:** (07) 5322 4015  
**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](http://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.

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



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 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 2014/2015:

- |                      |                 |
|----------------------|-----------------|
| ➤ President          | Gerry Doyle     |
| ➤ Vice President     | Jeff Allen      |
| ➤ Secretary          | Jan Szlapak     |
| ➤ Treasurer          | Heather Whye    |
| ➤ Committee Members: | Alan McKinless  |
|                      | Cate Barrett    |
|                      | Iris Broadhurst |

#### Staff Members:

- |                              |                 |
|------------------------------|-----------------|
| ➤ Executive Officer          | Bernard Wilson  |
| ➤ Senior Welfare Officer     | Christine Fox   |
| ➤ Welfare Officer            | Theressa Byrne  |
| ➤ Administration Manager     | Anne Stanfield  |
| ➤ Telemktg / Admin Assistant | Helen Johnston  |
| ➤ Finance Officer            | Jennifer Lysiuk |

### CONTRIBUTIONS & DISTRIBUTION

Please feel free to submit articles or photographs for selection for publication in this Newsletter. The deadline for the next issue is 7<sup>th</sup> March 2015. Please email or post articles, details above. Please be aware that the Newsletter is published on [www.huntingtonsqld.com](http://www.huntingtonsqld.com) in addition to postal and email distribution.

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