



April 2015



# NEWSLETTER

## HUNTINGTONS QUEENSLAND

### CAM WILSON SETS WORLD RECORD

### & RAISES \$20,000 FOR HUNTINGTONS!

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As if once wasn't enough, the amazing Cam Wilson has set a second world record while raising awareness and funds for Huntingtons Queensland! **Cam and his incredible team now hold the world record for "Karting – Greatest distance travelled in 24 hours indoors (Team)."** Congratulations to the team: Cam Wilson, Dan Tuite, Tim Harris, Daniel Goddard, Chris Hinton and Nathan Roach!!

The team made setting a world record look easy, but we're pretty sure they were glad to see the clock tick over that 24 hour mark. The team drove a total of 774 kilometres in 24 hours! That's a whopping 4,868 laps at 17.72 seconds per lap. Even more incredible – there was an average of three seconds for the driver changeover. These men certainly were moving!

This incredible effort has raised more than \$20,000 so far for Huntingtons Queensland! This is an incredible achievement from the entire team for what is a very punishing, exhausting event.

*Huntingtons Queensland would like to congratulate Cam and the team on an absolutely phenomenal effort, and thank them for their generous support of our organisation. We are thrilled to use this support to improve the lives of Queenslanders impacted by Huntington's disease.*



#### Peta Paces It Out For HQ

**Peta Banks** is walking up a storm in support of Huntingtons Queensland! By the end of 2015, Peta will walk 1000km for HQ.

She is hoping to raise \$1 for each kilometre, and is already over half-way there. You can support her efforts by donating on her Every Day Hero page:

[give.everydayhero.com/au/peta-4](http://give.everydayhero.com/au/peta-4)



Phone (07) 3868 2225 or visit [www.gokartingbrisbane.com.au](http://www.gokartingbrisbane.com.au)



#### Leisa Sweats It Out for HQ

**Leisa Tuite** (wife of **Dan Tuite**, one of our amazing world record holders above) is currently training for a triathlon. Every dollar raised will go to Huntingtons Queensland.

The triathlon is currently scheduled for 19<sup>th</sup> of April, so there's not long to go! Follow her activities and donate at Every Day Hero:

[give.everydayhero.com/au/leisa-tuite-triathlon](http://give.everydayhero.com/au/leisa-tuite-triathlon)

**Make sure you leave a message for both these inspirational ladies, and share it on social media to get your friends involved!**

## EO Speak! .....

With Easter behind us and the official centenary of ANZAC approaching our key issues are how best we support and represent the Huntingtons community effectively and sustainably amidst the challenges and changes of the fast approaching National Disability Insurance Scheme (NDIS) competitive market environment.

As members and families may know, the former government discontinued Queensland Health funding post 2015 which augers a very significant impact on our services and operations. We have opened discussions with the current government to make our case anew, and we hope and trust our work will be fairly valued.

I was delighted and am most appreciative of those who supported and donated monies for both our Christmas Appeal and more recently Cam Wilson’s successful Guinness World Record fundraiser. Thank you so much for your important generosity. And thank you Cam and team!

I would also like to acknowledge the life and memory of the late Mrs Patricia Parrikka, who passed last year and who generously left Huntingtons Queensland a gift in her will.

Since last newsletter I report the family holiday at Hervey Bay in Christmas went well, and the team will start planning this year’s event soon enough. Please let me know if you would like any input and thanks also to the Client Services

**Bernard Wilson**  
*Executive Officer*

staff; Christine and Theresa for their work and attendance throughout.

I am very pleased to have welcomed Elicia Wright to the role of Executive Assistant and Fundraising Coordinator role in Caitlin Scarr. Both are part time roles and both are making an immediate positive impact for the team and our work and with Fundraising being such an important part of our future.

Within the changes of recent months, including the wind down of the Day Service, we said farewell to Helen Johnston who had for many years been a valuable and popular support for the organisation both behind the scenes and with families and programs directly. Thank you Helen, and best wishes for your plans ahead.

Softly, softly we have launched our facebook and invite all our digital friends out there to come on board, and like and share! Caitlin has the wheel!

You may notice also the otherwise seamless transfer from our former .com address to the current huntingtons.org.au address, which we feel is more in keeping with the non profit nature of the organisation.



## Quarterly Outreach

We are proud to have provided the following Service Performance Outputs!

<b>500</b>	<b>739</b>
Provisions of Information Non-Clinical Counselling Support Groups	Client & Community Contacts

### FUNDRAISING OPPORTUNITIES



As mentioned earlier, we have a few amazing independent fundraisers (**Peta Banks** and **Leisa Tuite**) doing their bit to support HQ in the next few months. **Rowena Goodair** is planning a fundraising and awareness fun run (or walk) in the second half of the year (we’ll give you more info further down the track).

The great news? It doesn’t have to stop with them. Contact us for any fundraising ideas you may have, and we will do everything we can to support your efforts. We’ve even included some suggestions later in this newsletter!



## What Happened Since Christmas?

Helen Johnston has left the organisation after nearly two decades of service. We are very sad to see Helen go, but are grateful for her incredible contribution. We wish you all the best in your future endeavours, Helen!



We have been very busy since the last newsletter went to the post. With holidays, fundraising opportunities, new staff, and new prospects, we have plenty to fill you in on. Our most exciting event was the Cam Wilson World Record Attempt we mentioned on our front page. Congratulations again to Cam and team!

### DO YOU HAVE EMAIL?

Help us reduce printing costs by providing us with your email address, and we can send you future newsletter editions by email! Just email us on [admin@huntingtonsqld.org.au](mailto:admin@huntingtonsqld.org.au).



### SOCIAL MEDIA FOR HQ

It was only a matter of time – Huntingtons Queensland has a social media account! We have just launched ourselves on Facebook as “**Huntingtons Queensland**” and we are there to share information, resources, and provide a lighter touch for our social-media-savvy cohort. If you have Facebook, visit to our page, or better yet, like and share it.

P.S. keep an eye out on Twitter, LinkedIn and Instagram – we may be popping up there shortly too!

### A NEW WEBPAGE

We also want to take this opportunity to say an enormous, heartfelt and public THANK YOU to Diane Allan. Diane, a wonderful supporter of Queenslanders impacted by HD, has generously and consistently offered her time and her finances to support this organisation. In her own time, and as a volunteer, Diane created, established and maintained our current website for over a decade. This is an absolutely phenomenal effort, and we are grateful for her outstanding commitment and support.

Diane, from all the team at HQ, thank you!

### Updated Contact Details

We have made some minor changes to our office contact details, and here is the full list for you:



Updated Website:	<a href="http://www.huntingtonsqld.org.au">www.huntingtonsqld.org.au</a>	 “Huntingtons Queensland”
Updated General Contact Details:	07 3435 4300	<a href="mailto:admin@huntingtonsqld.org.au">admin@huntingtonsqld.org.au</a>
Bernard (EO):	07 3435 4301	<a href="mailto:bwilson@huntingtonsqld.org.au">bwilson@huntingtonsqld.org.au</a>
Caitlin (Fundraising):	07 3435 4302	<a href="mailto:frc@huntingtonsqld.org.au">frc@huntingtonsqld.org.au</a>
Elicia (EA):	07 3435 4303	<a href="mailto:ea@huntingtonsqld.org.au">ea@huntingtonsqld.org.au</a>
Jen (Finance):	07 3435 4304	<a href="mailto:finance@huntingtonsqld.org.au">finance@huntingtonsqld.org.au</a>
Christine (Welfare):	07 3435 4305	<a href="mailto:christine@huntingtonsqld.org.au">christine@huntingtonsqld.org.au</a>
Theresa (Welfare):	07 3435 4306	<a href="mailto:theressa@huntingtonsqld.org.au">theressa@huntingtonsqld.org.au</a>

**\*\*We each have a personal voicemail now, so if you call or are directed to our direct lines and we don't answer, you can leave a voicemail that will only be heard by the person you tried to call!\*\***



## FROM THE WELFARE DESK...

2015 is under way, and after a nice holiday over the Christmas break (once you read what the welfare team have been up to, you'll understand why!) both Theresa and I are well and truly back into the swing of things. As you will have read by now, the New Year has brought with it some changes to staff here at Huntingtons Qld. Our amazing administration duo of Anne and Helen left Huntingtons Qld at Christmas time – they worked here, combined, for more than 20 years. We miss them both and wish them all the best in their new endeavours. Their departures made way for Elicia and Caitlin to join not only our team, but the HD community. They have been very interested and keen to not only learn about HD, but also to learn who all of you are – our families, carers, service providers and supporters. Be sure to say hello and introduce yourself if you're popping in sometime, or find yourself speaking to them on the phone.

### Family Support Groups

To take you back to last year for a moment, December was an incredibly busy month for HQ. Theresa and I made our way around south-east Queensland catching up with families and friends at Christmas family support group gatherings. That time of year sees a lot of people coming along to say hello and catch up with one another, as well as finding out about latest news, research, support and services. Family members provide wonderful peer support and first-hand experiences to one another, including: how they have accessed supports and services in their local area; experiences on the services they receive; advice for dealing with particular issues; benefits and services available to people in their town; and reflections on things they have tried that has worked well and maybe not so well. Support groups also provide that social opportunity for people to get out for a little while and enjoy some friendly company without having to explain HD or make any excuses. How frustrating is THAT when you find yourself having to tell people over and over again, and even then you know they probably haven't really "understood" what it is like to be in your shoes?! Support groups provide that safe, friendly environment where people can come along as themselves.

**Support groups** are held around the state in the following regions:

Ipswich	Gold Coast	Toowoomba
Sunshine Coast	North Brisbane	Logan
Hervey Bay	Bundaberg	Gladstone

Mackay                      Townsville                      Cairns

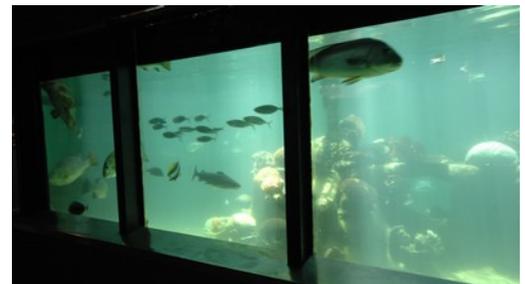
Each group runs with different frequencies, and some are run by family members. We'd love to have more family members facilitating support groups the way you'd like to see them run, and when groups are run by family members it opens up avenues for fundraising and donations specifically to that group to be able to subsidise the cost of things from your coffee or lunch at the gatherings, through to respite and holidays for families and carers, or even specific equipment to help care for someone with HD. Having a local person run a local group empowers the group and provides that locally-based contact, which is what is often looked for when applying for grants. If you attend one of our support groups and think you might like to learn more about facilitating the group for us, please give Theresa or Christine a call and we would be more than happy to give some information and help on how this is done. Similarly, if you would like to start a support group in your area, or a specific type of support group – say a group for gene positive but not yet symptomatic people – we'd love to hear from you and are happy to help. We won't leave you to your own devices, we promise!

### HYPE – Huntingtons Youth Program etc.: Eight Families for our Eighth Year!

Along with all the support group activities that occurred in December, we also held our 8<sup>th</sup> Annual HYPE Family Holiday. This holiday is only possible due to the amazing support from the **Sunnybank Community and Sports Club Community**

### Grants Program

who provide HQ with an amazing \$10,000 grant each year, of which some is used to help our families



participate in this holiday activity. Eight families (consisting of 19 children and 12 adults) from around Queensland came to the **Emeraldene Inn and EcoLodge** at Hervey Bay to enjoy 5 days and 4 nights of fun, sun and relaxation. With two new families along for the holiday, we had some great times together going out to some fun and exciting places, and of course lots of swimming in the pool – which is still, hands down, THE favourite activity the kids enjoy.



This year we visited the **Reefworld Aquarium** where we walked around the large tanks trying to beat one another to find specific types of fish, sharks, and other sea creatures. We got to see some shark eggs – which look more like mango seeds than eggs! – and if you watched them long enough you could actually see the little sharks moving



inside the eggs. That was incredibly cool for the kids to see. We found Nemo and his friends in one fish tank, we saw a grouper

that was bigger than some of the children, and other reef fish, octopus, and sharks. One of the funniest things the kids enjoyed watching was the crazy fish swimming non-stop laps around the large aquarium like it was training for the Olympics!

After all this, our families went outside and got to feed lettuce to the large Green Sea Turtles. At first, some of the kids were a little frightened (in case their fingers were nibbled on) but once they started watching the others, they all got in and had a go. What an amazing experience!



Always a highlight of the holiday is the chance to dress up and go out for dinner at the

**Hervey Bay RSL**, and this year was no different. The Hervey Bay RSL is a major supporter of this event, donating a \$250 voucher towards the cost of dinner for the families. For the third year in a row, this generous donation goes an incredibly long way towards a wonderful evening for our families. The kids feel important and special having their own table and activity packs to colour-in whilst they choose their dinner themselves, whilst the Mums, Dads and carers get to sit back and relax over a lovely meal and socialise with one another. Making the night even more special was one of our families celebrating their wedding anniversary and another person celebrating their birthday.

**Subway** at Pialba came to the party again – literally – with three amazing HUGE platters of a variety of Subs! Such a delicious and healthy lunch, we all enjoyed tucking in to Subway in the picnic area by the pool, followed by and

afternoon swim. To top that off, after our swim we were all treated to a waffle ice cream cone thanks to **McDonald's** Pialba – what more could a child want on a hot summer's afternoon than a swim and an ice-cream? YUM! Thanks also to **Woolworths** at Eli Waters and **Coles** at Pialba who

continue to support the HYPE holiday with grocery gift vouchers.

#### Coffee Catch-Up - CCU

Our Coffee Catch-Up Program has been going for almost 5 years now and this year we have welcomed some new members to the group along with **Nicole**, our volunteer. The CCU is funded by **IOOF** and provides an opportunity for people who



are no longer working and are experiencing the earlier stages and symptoms of HD. This group comes together twice a month to enjoy one another's company over lunch – catching up on the latest goings on in their families, but more importantly providing peer support to one another. And although it is called the "Coffee Catch-Up", funnily enough we don't sit around drinking coffee. As the years have gone on, we can't quite remember why we came up with that name, but the people who come along like it and so do we.

On Thursday, March 26<sup>th</sup>, we went along to **Grill'd** at Southbank and were treated like royalty! As you would have read by now, **Huntingtons Qld** received the highest number of votes at the Southbank Grill'd store and we were awarded a \$300 donation. Our CCU group went along to collect the donation and the Grill'd team at Southbank treated us to an amazing lunch on the house! What a wonderful treat that was! We tried some amazing burgers – including the Chilli Addict, The Big Queenslander, and the Moroccan Lamb – and we can highly recommend their seasoned chips, especially the zucchini chips and sweet potato chips. *Thank you so much to Kim, Zoe, and the team at Grill'd Southbank!*



### Day Centre Closure

Unfortunately in December, significant changes in our funding over the past few years meant that we are no longer able to offer the day centre program so we wrapped it up with a big bang of a Christmas Party. Some of our old friends came along for our final day to say hello again and join in the festivities, as we enjoyed the beautiful voices of Christmas carollers and challenged one another with some Christmas trivia. All the team from Huntingtons Qld, including our amazing volunteers, were invited to join in for a sumptuous Christmas lunch with all the trimmings, followed by trifle, plum pudding, and fruit mince pies. The day centre program has run in many different formats with support from many different staff members and volunteers over the years – over 20 years now to be precise, but one of the main stayers throughout that entire time was our amazing Welfare Officer Theresa Byrne, who started as a respite assistant and worked with Iris Simpson to grow the program to what it had become. When Iris left, Theresa took over the reins and facilitated an active program which included concerts at Brisbane City Hall, picnics, and sailing adventure on the Brisbane River to name but a few. In fact, did you know that we came to meet Theresa through the day centre program first, recognising the amazing contribution



she made to supporting families with HD that we then brought her in to our welfare team in 2009?

A very big thank you to all the volunteers, staff, and supporters of the day centre program over the years who have made it the very special –and one of a kind – program that it was. Even more than this, thank you to all our families and clients who came along week after week, month after month, to participate in the program and to brighten our days. Rest assured we are working hard to find another way to have a program running like this in the very near future.

### Direct Phone Lines

Did you know that we each have our own direct phone number now? You can still contact us on the old number for now, or the new main phone number, which is: 3435 4300 and we would recommend you store this number. But to call us direct, where you can leave a message, you can ring us on:

Christine: 3435 4305 & Theresa: 3435 4306

Your call will go to voicemail and we will return your call as soon as we can. If a little time has gone by and we haven't returned your call, well that usually means we are out of the office or on leave, in which case you should call the main line.

If you would like to know anything more about anything you have read here, or have any questions or concerns that you would like to discuss with us, please feel free to give us a call and we'll be only too happy to help.

Take care

*Christine and Theresa*

## ARE YOU A CAREGIVER?



There are new apps available (and FREE!) that are perfect for caregivers.



The first is called **CareZone** and it's available free of charge through iTunes and Google Play. It helps you track appointment times, sets medication reminders, and record notes at appointments.

The second is called **Standwith**, and is a support app for carers. It provides carers with a digital support community, where you can reach out for advice, favours, and simply to connect. It's also available through iTunes and Google Play.

### CONTRIBUTIONS & DISTRIBUTION

This isn't about us – **it's about you!** We'd love to publish your articles, photos and other news. Please feel free to submit these for consideration for publication in this Newsletter. The deadline for the next issue is 15<sup>th</sup> June 2015. The Newsletter is published and freely available to view online in addition to postal and email distribution.



## RESEARCH UPDATE

### Novel research technique suggests an antioxidant gene protects vulnerable neurons

Researchers have developed a new technique that allows them to screen for genes that could contribute to the progression of Huntington's disease and other neurodegenerative disorders. This is the first time this is possible in the mammalian central nervous system. They used the technique in an HD mouse to uncover an antioxidant gene, *Gpx6*, which is protective to neurons.

#### Elegant models for eminent questions

HD researchers are constantly looking for clues to explain the big questions behind their work. Why does a single genetic mutation cause a complex and progressive neurological disorder? On which molecular pathways should we focus in order to work towards successful treatments?

Simple model systems, like yeast, or cells in a dish, are often used to "screen" large numbers of genes that could be key to damage or protection in the course of a disease. But the findings don't always translate to the nervous system of mammals - this is a major obstacle to research progress.

Recently, a team of researchers developed a novel method

to test for genes that are protective in the **central nervous system** of mouse models of disease. They decided to employ their new technique for the first time in a Huntington's disease mouse, and were able to uncover a gene that is important for keeping vulnerable cells alive and promoting improved behaviour. But how did they know which genes to look at?



Findings from simple model systems, like yeast, or cells in a dish, don't always translate to the nervous system of mammals.

#### First things first: the search for changes in aging neurons

The research team is led by Dr. Miriam Heiman, at the Broad Institute of MIT and Harvard University. They focused on neurons in the striatum, an area of the brain that controls functions like movement, mood, and motivation. Striatal cells are the most vulnerable to degeneration in the early stages of HD.

Neurons naturally change with age, with different sets of genes being turned on, or off, over time. The team first examined normal mice to track the 'gene expression' changes that occur in the striatum during aging, comparing 6-week-old with 2-year-old mice. (Normal lab mice live to around 2 ½ years). These changes can tell us how each gene's role changes during aging, and provide clues to which ones are involved in disease progression.

When they looked for changes in gene expression among cells in the striatum of a healthy mouse, the biggest changes they saw between 6-week-old and 2-year-old mice were in genes that work to counter oxidative stress, including a gene called *Gpx6*.

#### An antioxidant important during aging

*Gpx6* is part of a family of antioxidant proteins. Regular HDBuzz readers may remember that another member of the *Gpx* family, *Gpx1*, was identified to be important in a yeast model of Huntington's disease (<http://en.hdbuzz.net/156>). What is the role of these proteins that keep popping up in HD research?

Antioxidants work to counter oxidative stress, which is caused by reactive oxygen species (ROS), a byproduct of normal metabolism. Oxidative stress increases during aging – and even more so in disease. (For a review of oxidative stress and how it's being targeted to treat Huntington's disease, check out this previous HDBuzz article: <http://en.hdbuzz.net/107>).

Having uncovered some important age-related gene expression changes in the most vulnerable brain region in Huntington's disease, the striatum, the researchers were ready to try their new technique in a mouse model of HD.

#### Introducing SLIC

The method is called SLIC, for 'synthetic lethal in the central nervous system'. The idea behind "synthetic lethality" is that sometimes a combination of two genetic changes is more damaging than either of the changes alone. Much like a playground seesaw with kids balancing on each side, there



is a balance of gene expression that keeps a cell healthy. One mutation alone might not bear enough weight to unbalance the seesaw. But if there are mutations in two different genes in the same cell, it's like taking two extra kids off one end: the balance is disrupted and that cell is much more likely to die than if either one of those mutations was made alone.

We can think of the Huntington's disease mutation as a big kid on the seesaw: each HD neuron has already been shifted in the balance towards degeneration. Using the SLIC technique in a common HD mouse model called the R6/2, which contains human huntingtin with the repeating CAG



**We can think of the Huntington's disease mutation as a big kid on the seesaw: each HD neuron has already been shifted in the balance towards degeneration.**

Here's their cool new technique, broken down into three steps.

1) Select a group of genes to knock down with short hairpin RNAs (shRNAs).

shRNAs are small sequences of RNA that can 'silence' a gene by binding to the RNA message so it never gets translated into protein, effectively short-circuiting the gene. The authors selected a group of shRNAs that would knock down genes important for Huntington's disease and the aging striatum. They picked about 100 different genes to silence, based on the gene expression changes they found in the

striatum, such as Gpx6, and some identified previously by other scientists.

2) Inject the chosen group of shRNAs into the HD mouse striatum.

To get into neurons, the shRNAs are packaged into special viruses. These aren't the kind of viruses that would give the mouse a cold – they are specifically used in research to deliver molecules that cause genetic changes. When the viruses are injected into the HD mouse's striatum, each neuron receives a single shRNA that knocks down one gene in that cell. This happens in many, many neurons – around 250,000 per injection! Divide that by the 100 different genes they chose, and they can test what happens to 2,500 cells with the HD mutation that have a single other gene silenced.

3) Check which genes caused HD neurons to die.

If silencing a certain gene were particularly bad for a cell in the striatum that already had the HD mutation, that cell would not survive. The injected shRNA would disappear if the cell died, but stick around in a cell that was living. By doing a genetic sequencing test to detect each shRNA, the authors could tell which ones were the most damaging – one month after the injection, there would be much less of them left. This would indicate which genes were the most important for survival of vulnerable neurons in the striatum in HD.

### So, which genes were most important?

Gpx6 was at the top of the list of genes that, when knocked off the seesaw, caused the death of neurons in the striatum of HD mice. What's more, knocking down Gpx6 in normal mice wasn't as bad for neurons as it was in HD mice. This is the root of 'synthetic lethality' – the HD gene mutation plus knockdown of the protective Gpx6 is a one-two punch that's really bad for neurons in the striatum. So if Gpx6 is truly important for protection, could adding more of it improve symptoms in the HD mice?

To test this, the researchers overexpressed Gpx6 in the HD mouse striatum – this means they genetically added extra Gpx6. The mice showed improvements in behavior on two movement tasks – not total recovery, but better than HD mice that didn't have extra Gpx6. HD mice given extra Gpx6 also had less degeneration in the striatum.



## A confirmed research path and a new method

Overall, this study's findings agree with other research that identifies Gpx6 as important for protection of cells in the progression of Huntington's disease. There are existing drugs that can mimic the action of Gpx proteins, which is an important consideration when moving forward in the study of a molecular disease pathway. Improvements to the behavior of the mice in this study were modest but still suggest that oxidative stress pathways make a critical avenue of research.

Most importantly, this study introduces a novel methodology, SLIC, which can be used to test for relevant molecular pathways in many different types of disease models in the mammalian central nervous system. That the authors chose to test it first in a model of Huntington's disease is a testament to the strength of the HD community's research tools and collaborative effort.

*This article was published on the HD Buzz website (URL: <http://en.hdbuzz.net/194>) on April 6<sup>th</sup>. It was written by Leora Fox and edited by Dr Tamara Maiuri.*

## Our Amazing Donors

### DONOR ROLE

Since late 2014, the following people and organisations have made contributions of more than \$200:

**Alethea Harding-Smith**

Beta Sigma Phi (Epsilon Chapter)

**Carly Snodgrass**

Coles (Pialba)

D. Walton

**Dan Tuite**

Danielle Walton

**Dr Joan Lawrence A.M.**

Emeraldene Inn and EcoLodge

**Graham Aston**

Hervey Bay RSL

Jody Williams

Joyce Bennett

**Jen & Forde Williams**

**John Zamofing**

Karen & Bedford Astley

Kay Ward

**Ken & Diane Allan**

Leisa Tuite\*

**Lion's Club, Townsville**

LV & JM Hartkopf

MacDonalds (Pialba)

Michael Tuite

**Mel Deacon**

Pamela Webb

**Paul Schokker**

Peta Banks\*

**Peter & Shirabdi Gordon**

Rob Turissi

Rebecca Johnson

**Slideways Go Carting Brisbane**

Subway (Pialba)

**Sunnybank Community and**

**Sports Club Community**

**Grants Program**

The Order of the Eastern Star

**Townsville Family Support Group**

William Norris

Woolworths (Eli Waters)

Names in **bold** have made significant financial contributions, and we recognise and thank these people for their generous gifts.

Names with \* still have fundraising efforts underway that you can choose to support.

### A GIFT OF A LIFETIME

On behalf of the Huntington's community in Queensland, the Board and the organisation are privileged to honour the life and memory of **Mrs Patricia Ellen Parikka** who passed late last year, and who lived with Huntington's disease. Mrs Parikka, her family and estate generously provided for a bequest for \$30,000 for Huntingtons Queensland to be used for palliative care and support for stroke and heart victims. Thank you for this very substantial and generous consideration.

It is never too late to make a difference.

If you would like to leave a gift to Huntingtons Queensland in your will, we would be happy to help you better understand the simple process. Speak with Bernard or Caitlin today.



## HOW CAN YOU HELP?

**Promote Us** by following, engaging with and sharing our new Facebook page. It's a great page for accessing resources and seeing what the global community are up to (and trust us, there is a LOT going on!). We will also post fundraising updates & opportunities there!



**Hosting** an event can be a fun and simple way of raising awareness and a few funds for the organisation. And you don't need to plan on the scale of the Sydney Olympics. Host a simple movie night or barbeque with friends, a dress up day, or an upmarket high tea, wine and cheese tasting, or dinner party and pass around the donation tin while discussing HD with your friends. It all counts!



**In lieu of gifts** for your birthday, special event or even wedding, you can request donations be made to HQ.

**Volunteering** is an invaluable resource, and we can always use a hand around our office. Or perhaps you would like to be involved some other way! If you have the time, give us a call and see how you can become a proud HQ Volunteer.

**VOLUNTEER  
POWER!**

**Donating** to Huntingtons Queensland has a significant and direct impact upon the Queensland HD community. If you know a person or business who may be interested in supporting us, reach out to them, or put them in contact with Caitlin. We cannot overstate how important every donation is – every dollar counts.



**Leaving a gift** to Huntingtons Queensland through a bequest in your will means that you choose how your life's earnings are distributed. This decision is incredibly personal, and imprints a lasting memory of yourself to those you support. A gift in your will to Huntingtons Queensland will go directly to supporting the day-to-day lives of Queenslanders impacted by Huntington's disease. If you choose to do so, make sure you discuss your decision with your family.



And please don't forget to let us know. We would like to make sure we thank you properly.

## Other Business

### OUR NEW EXECUTIVE ASSISTANT – Elicia Wright

Hi! I joined HQ in January as EA and I look forward to speaking with you when you call! I have really enjoyed my return to work with Huntingtons Queensland after eight years of family leave raising two boys. I am married to Simon and we are lucky to live in Brisbane – a sunny change from living, working and studying overseas in the US, NZ, Europe and most recently the United Kingdom. Thank you Bernard and the team at HQ for such a warm and friendly welcome and I hope to meet many of you and your families soon!

MY FAVOURITE WEEKEND ACTIVITY – National Park camping with my family

MY FAVOURITE FOOD – Japanese teppanyaki...and dark chocolate

MY NEXT HOLIDAY – skiing (hopefully!! Fingers crossed for a good snowfall)

MY PETS – Two long haired guinea pigs (Spike and Milo)



Elicia (L) and Caitlin (R)

### OUR NEW FUNDRAISING COORDINATOR – Caitlin Scarr

Hi! I've had the pleasure of meeting a few of you in the five weeks since I started, and I couldn't be more excited to be part of such a dedicated, focussed and passionate group of people. Thank you all for making me feel welcome! I will be increasing public awareness, securing funding for the organisation, and promoting us wherever, whenever and however I can. I am even kicking off the dreaded social media accounts! So look for us on Facebook, connect with us, and help us make a roaring leap in to the digital age.

MY FAVOURITE WEEKEND ACTIVITY – Saturday mornings at the local farmer's market, and going to the theatre

MY PET – a 6 month old black Labrador puppy named Delilah

MY SECRET SKILL – I can speak French (I was lucky enough to live there for 5 months with a French family)



## Grill'd healthy burgers

We are thrilled to thank **Grill'd South Bank** for allowing us to again participate in their Local Matters fundraiser – we won! So we say a huge thank you to Grill'd South Bank – we couldn't do it without you!

If you're out for a meal in South Bank Brisbane, pop into Grill'd to have a healthy burger, and thank them for their ongoing community support!



### Beta Sigma Phi International – Epsilon Chapter

We would like to thank the ladies of Beta Sigma Phi who kindly invited a representative from Huntingtons Queensland to their Eighth Annual Change-Over Dinner, where we were presented with a cheque for a donation they had raised. We are deeply grateful for their commitment to HQ, and are appreciative of the support they have shown to our Queensland community.

Thanks, Beta Sigma Phi!



### Shop To Make A Difference

Did you know that you can indulge in online shopping and donate to Huntingtons Queensland at the same time? **Shopnate** allows you to do just that, and even better, you aren't charged anything extra for shopping through them. Simply nominate us as your favourite charity, buy your online items (at the same price as anywhere else online) and that shop will donate a portion of its profits to us! No need to feel guilty about your online spending anymore!

### The Order of the Eastern Star



This fantastic group of Mackay locals, through the activities of Karen & Bedford Astley, are supporting our organisation throughout this year. We are so appreciative! Thank you all!

### Hervey Bay RSL

Each year, this fantastic RSL donates a voucher towards our HYPE family holiday. We are so appreciative, as it is often the most treasured of the holiday events. Thank you, Hervey Bay RSL!

## HUNTINGTONS QUEENSLAND

### Location:

Florence Dannell House  
385 Ipswich Rd cnr Ponsonby St  
Annerley Brisbane

### Postal Address:

PO Box 635  
Annerley Q 4103

**Phone:** (07) 3435 4300

**Website:** [huntingtonsqld.org.au](http://huntingtonsqld.org.au)

**Email:** [admin@huntingtonsqld.org.au](mailto:admin@huntingtonsqld.org.au)



**Our Mission is:** *To provide professional advice and support to clients, their families and carers in the management and care of people at risk and affected by Huntington's Disease*

### 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
- Coordinating the annual HD Awareness activities
- Fundraising activities

### Management Committee 2014/2015:

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

### Staff Members:

- |                           |                 |
|---------------------------|-----------------|
| ➤ Executive Officer       | Bernard Wilson  |
| ➤ Executive Assistant     | Elicia Wright   |
| ➤ Senior Welfare Officer  | Christine Fox   |
| ➤ Welfare Officer         | Theressa Byrne  |
| ➤ Finance Officer         | Jennifer Lysiuk |
| ➤ Fundraising Coordinator | Caitlin Scarr   |



## PLEASE SUPPORT OUR WORK BY MAKING A DONATION!

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.*

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

Name on Card ..... Signature ..... Date.....

Your Name.....

Address.....

Phone #:..... Email (please print clearly) .....

You can donate easily online – go to [www.everydayhero.com.au](http://www.everydayhero.com.au) and search in the charities for “Australian Huntington’s Disease” – we will come up under the name: “**Australian Huntington’s Disease Association (Qld) Inc**”. Alternatively, call us on **07 3435 4300** to donate over the phone, or to discuss other payment options. **All donations over \$2 are tax deductible and will receive a tax receipt.**

*Please don't email credit card details – only fax or mail them, or call to pay by credit card over the phone.*

