

Huntingtons QUEENSLAND

Newsletter

Contact Us!

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Gerry's Farewell Lunch

Left, from L – R: Theresa, Elicia, Bernard, Caitlin, Alan

Right, from L – R, Jeff, Gerry, Jenny & Cliff

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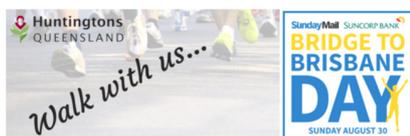
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Walk with Team Huntingtons at the largest community event in Queensland!
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Research Update - HD Buzz

HD Buzz

Get the latest on research from HD Buzz

Insert

Announcing a Queensland film premiere!

INTRODUCING THE QUEENSLAND PREMIERE OF

twitch

KRISTEN POWERS' STRIKING DOCUMENTARY ABOUT LIFE, HOPE & HUNTINGTON'S DISEASE

DATE
Wed 9th September

TIME
6:15pm start

VENUE
REIQ, 21 Turbo Drive

TICKETS
Free but bookings essential.
RSVP to Caitlin at frc@huntingtonsqld.org.au or 07 3435 4302



 **MONASH University**
Medicine, Nursing and Health Sciences

 **PRANA BIOTECHNOLOGY**

Board & Governance

with Jeff Allen, Chair

At the last meeting of the Board, I was delighted to be nominated Chair and President of the Australian Huntington's Disease Association of Queensland (HQ). For me, my time with HQ has been a journey of learning from my first meeting with the then Executive Officer Cheryl Miller and President Gerry Doyle in late 2013, to the time I visited Carmel Mohr and family at her house. It didn't take me long to work out that Huntington's disease is a cruel progressive neurological disease which affects families in a devastating way. What I also learnt was that for the person affected by the disease, their carer and family gaining access to the appropriate level of care and specialised support services was difficult.

My key priorities as Chair of HQ are to improve access to care and specialised support services for clients irrespective of where they live in Queensland. The key strategies to achieve this:

- Securing continued government funding for the Association
- A more open and constructive approach to partnerships with

Neurological organisations and service providers

- A more tangible approach to referral pathways, including the establishment of preferred contractors and suppliers of professionals services
- A case management approach to client support
- Development of a strategy to actively seek to re-engage with any dis-engaged clients and families, and improved connection with the Regional Areas

Recently, the Executors of the estate of Thea Harding-Smith contacted HQ to indicate that Ms Harding-Smith had given instruction to provide a substantial bequest to the Association. This bequest will allow HQ to resume the two person model of welfare and provide financial certainty at a time when speciality not for profit organisations are under a level of pressure not seen before in Queensland. More will be said about the bequest of Thea Harding-Smith once the details have been finalised and HQ decides how best to acknowledge the importance and significance of this bequest to the association.



I wish to acknowledge the incredible work of the past President Gerry Doyle, who has dedicated the last 30 years of his life to improving the lives of clients, cares and families of the association. Gerry, who has taught me much in the time since I met him, is a great example of what clients and families expect from a President – humble, driven and personable. I look forward to working with Bernard and his staff to work towards offering the care and services which clients and families deserve.



As you may know, September is Australian Huntington's disease awareness month. So to kick the month off as big as we can, **we have entered a team in the Bridge To Brisbane 5km walk, and we want you with us!**

Join "Team Huntingtons" from gam on August 30th at the Hamilton Recreational Reserve, and help us kick off September Awareness Month a few days early.

Bridge To Brisbane is the largest community event in the state, and is a great opportunity for us to gather as a local community, raise funds and awareness, and enjoy the sunshine on a Brisbane Sunday morning. We will be walking 5km, but you are welcome to run, skip or jump the distance! You can also invite as many people to join as you like.

Registration is \$35 per person (children in strollers are free), and will cover your entry in the event, free public transport to and from the walk, and a shirt that you can proudly wear. **To register, visit bridgetobrisbane.com.au and follow the registration prompts. Choose to register as part of a team, and enter team #83854 – that will sign you up to Team Huntingtons!**

Participants can also set up a fundraising page on Everyday Hero (you can link it to Team Huntingtons), and help us raise some funds for awareness month. If you aren't able to participate, you can still make a donation to the team – just donate online through Everyday Hero.

We also want to use the opportunity to raise some much-needed awareness through local media. If you would be happy to share your story, contact Caitlin!

For more information, or for help signing up, please contact Caitlin on 07 3435 4302 or frc@huntingtonsqld.org.au and she will be happy to help you. Otherwise, you can visit bridgetobrisbane.com.au for more information about this exciting community event!

EO Speak...

with Bernard Wilson



I am pleased to acknowledge Jeff Allen has been appointed Chair and Cate Barrett, Deputy Chair. Jeff and Cate both bring very significant human services and governance experience to their roles and the staff team and I look forward to working with them. We are delighted also Gerry Doyle, having stood down as Chair will continue in a Director capacity.

Thank you to all who renewed their membership with the organisation and additionally to those who so generously made a donation over and above their membership fee. Once again those closest to the organisation have taken it upon themselves to help share the load. For those members yet to renew, we will have reminder letters in the mail shortly where

we look forward to your continuing support.

The organisation was privileged to receive advice recently from the executors of the Alethea (Thea) Harding-Smith estate of a substantial gift left in her will for Huntingtons Queensland. This is indeed welcome and opportune financial support. Together with news also of the pending support from the Alecca McKinless Foundation, the organisation's financial pressures for the present time have been relieved.

The immediate impact of these very generous gifts is twofold:

1. Without delay the organisation will proceed with the recruitment of a Client Services Coordinator; to boost and support program and service delivery and work alongside the Client Services Officer; Theresa Byrne.

2. Secondly, our plans to consider selling or borrowing funds against the value of Florence Dannell House have been deferred indefinitely.

Bequests of this kind are genuinely transformational for the organisation and are testimony to the life, generosity and memory of the donor and their commitment and belief in the support for the Huntington's community. For such gifts to provide optimum value however, the organisation remains challenged to create a sustainable business model; one which includes a reasonable contribution from state and federal governments and a business model efficient and competitive in the human services marketplace.

Finally, may I note the change of date and format to the AGM this year where the formal meeting will take place on Thursday 8th October at 11am for members, followed by an informal lunch from midday for the wider community of clients, carers and friends.

What's Coming Up

September Awareness Month, of course! The team at Huntingtons Queensland, and others around the state, are busily preparing for awareness month activities, and we'd love you to get involved where you can.

To kick off the month, we are entering a team in the annual Bridge To Brisbane day – read more on page 2, or contact Caitlin for more information!

On Wednesday 9th September at the Real Estate Institute of Queensland, we are proud to present a free screening of **Twitch**, a documentary about the decision to be tested for Huntington's disease. The subject of the documentary, Kristen Powers, will



The largest community event in Queensland, and a great opportunity to raise funds and awareness for Queenslanders living with Huntington's disease

be travelling to Australia to present the film, and will be there on the night for a special Q&A.

Tickets are free, but seating is limited, so bookings are essential. RSVP to Caitlin at frc@huntingtonsqld.org.au or 07 3435 4302 to make sure you don't miss out!

Any donations made either before or at the event will help to cover the cost of this free community event, and to support Queenslanders impacted by HD.

Some of the key figures in local research and treatment will be meeting in mid-September for a professional forum and update, so we look forward to bringing you news from that meeting.

Within our community, we have some eager individuals hosting their own events. Rowena Goodair is organising a walk for Brisbane families in September to raise awareness of HD, and Natasha Stanton is organising a fundraising morning tea in Kilcoy. Stay tuned



An inspiring documentary about one young woman's decision to be tested for Huntington's disease.

through Facebook for more information and how to get involved!

If you would like to host an event for Awareness Month, or need more information about planned events, please contact Caitlin on frc@huntingtonsqld.org.au or 07 3435 4302.

Family Support Groups Coming Soon: Dates are yet to be confirmed, and the list is not exhaustive. Please contact us for further information, or if you would like to facilitate a support group in your region.

Brisbane region	Logan
Ipswich	Gold Coast
Toowoomba	Bundaberg
Townsville	Mackay

AGM 2015 & Clients, Carers & Friends Lunch

This year's Annual General Meeting for members will be held at 11am on Thursday 8th of October.

Meet The Board

From midday, we are pleased to invite our clients, carers and friends to an informal lunch.

During this time, you will have the opportunity to catch up with one another and meet the new Chair, Jeff Allen, and other members of the Board.

More information to follow



Some of our wonderful community catching up recently for a coffee and a chat.

FOND FAREWELLS



Gerry's farewell Lunch

Thank you, Gerry!

Following many years of commitment, hard work and service as Chair of the Board at Huntingtons Queensland, Gerry Doyle has stepped down. We are so grateful for his contributions, and wish him all the best for this next period of his life.

CLIENT SERVICES FACTS

955

personal & community supports in
April, May and June!

636

contacts through information,
counselling and support groups in
April, May and June!

Client Services & Support

by Theresa Byrne

Contact Client Services on:

**07 3435 4305 or
theressa@huntingtonsqld.org.au**

Well, it's already more than half-way through the year, and things are, as usual, full steam ahead! Following a few big months, there is no sign of slowing down, as we continue to bring services to regional and metropolitan areas around the state.

I've been kept busy as the sole welfare officer since Christine Fox's departure from the role of Senior Welfare Worker, so thank you to everyone for being so helpful, and thank you to Christine for all her guidance and help in preparing me for this time – she has been a terrific mentor and a wonderful advocate for our community. We are pleased to now be looking for a Client Services Coordinator to help bring our services to as many Queenslanders as possible. Please feel welcome to share the job far and wide and help us find someone great to fill the role!

Throughout the past few months we have continued to bring families together through scheduled Family Support Groups in various locations across the state. We've had some wonderful members and supporters step up to help facilitate their local support groups when our staff hasn't been able to attend, ensuring family members

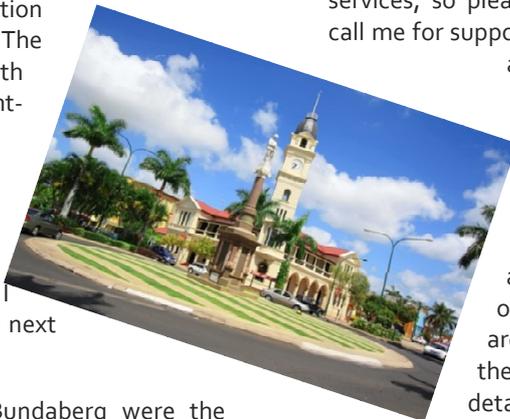
have felt supported and that morning teas and lunches have continued to take place. A big thank you to you all!

If you would like to see more regular family support groups in your area, you might be the right person to help facilitate! Facilitating these events can be a great way to make contact with your local community, so if you would like to help by being that contact person for your local group, please don't hesitate to get in touch with us here at the office, where we can help to schedule and organise them with you. We'd love to hear from you!

I was pleased to attend some of the support groups in Brisbane and surrounds, including Logan, Gold Coast and Redlands, and as far away as Bundaberg, Rockhampton and Townsville.

I visited Rockhampton and Gladstone region in March (a few months ago now), and helped facilitate a new Family Support Group. Families in the area felt that regular support group meetings may help reduce their isolation from the community, and I encourage any families in the area to reach and get involved! I look forward to joining you again in the coming months.

I visited Townsville in May for a few days to meet with clients, members, supporters and service providers. It was great to meet a few new faces, and to catch up with some familiar faces too. Much of my time was spent visiting people at home, finding the best referrals for individual situations, and seeing what else we can do as an organisation to assist. The community in North Queensland is tight-knit and provides exceptional support to one another through their family support groups. I look forward to my next visit up north!



Hervey Bay and Bundaberg were the latest destinations for regional travel, and I took the opportunity to meet with a number of clients, as well as having a session with the local Carers Queensland and other health providers. There are some great resources in this region for our clients, so I was delighted to take the opportunity to liaise with these workers.

It was also a great opportunity to bring together some of the young local families in the region and hopefully establish some local support networks. It's particularly great to be able to link up families with children, as it provides the young ones with great opportunities for social interaction with others in the region.

I have at least one more regional trip scheduled for the near future. This time, I will be coming to Mackay, so please get in touch with me if you're in that area and would like to catch up, even if it's just about putting a name to a face. It would be lovely to see you! I will also be planning for a few more regional trips in the coming months, so keep your ear to

the ground (or your eye on Facebook) for up to date information.

Throughout this busy period, and in between support group meetings, regional trips and individual client meetings, I have been fortunate to have greater availability for phone consults. I'm so pleased to be able to assist so many Queenslanders through phone services, so please feel welcome to call me for support and advice, or for a chat.

If I am out visiting someone, there will usually be someone available in the office to attend to your calls or queries, and if they aren't able to help, they will pass on your details to me and I will get back to you as soon as I can. Don't forget, too, that family members are always welcome to drop in to the office for a face-to-face catch up with me. Just make sure you call ahead to make sure I am in the office. And, of course, I am available on email if that is easier for you: theressa@huntingtonsqld.org.au.

As many of you may know, a free clinic is available to Queenslanders impacted by HD. The clinic is run in the Royal Brisbane & Women's Hospital on the first Friday of each month (although very occasionally is postponed). You can often see a neuropsychologist, psychiatrist, speech pathologist or neurologist, all of whom operate as part of the clinic team.

There can be a bit of a wait throughout



the day due to demand, so make sure you bring along some activities for the waiting room. We often provide some light refreshments, just to make sure you aren't too hungry while waiting!

Research opportunities are also available through this program, so if you were interested in participating in research, the clinic is a great place to reach out. You will need a referral from your GP to attend, and you can contact the Clinical Nurse Coordinator, Anna Nolan, on 3646 1481 for more information about the clinic.

In the next few months, we have some big events planned in south-east Queensland that we would love to see you attend if you're in the region. We are gearing up to this year's September Awareness Month, and I know that the team has some exciting things planned. I'd encourage you to get involved where you can, and really raise awareness throughout the month. It's a great opportunity to come together as a community.

We are entering a large walking team into the Bridge To Brisbane, so if you think you can cover 5km (don't worry, we're walking), register and join us for a fun morning of awareness-raising. If you can't join us, you can donate online to those who are participating.

We're also really excited to bring you a beautiful documentary called *Twitch* by Kristen Powers. Kristen is touring her film through Australia, and has chosen to screen it for one night only in Brisbane on Wednesday 9th September. Come along if you can, but make sure you book, as tickets are strictly limited!

If you have any events that you would like to hold during this month, either to raise funds or awareness, we encourage you to do so. For suggestions, you can always chat with Caitlin in the office. Feel free to contact me any time if you have any questions, queries or concerns. I hope you've been able to stay warm throughout winter, and we'll chat soon!

Theressa

What have you been up to?

We are thrilled to share updates from our amazing supporters. Here are a few quick updates on what our community has been doing:

Running the Distance

July 5th was a big day for Hannah, Lech and Steve Blaine. The Gold Coast Airport Marathon kicked off before the sun was up, and Team Blaine Train were in the thick of it, all to help Queenslanders living with Huntington's disease!

Hannah and her awesome team (Team Blaine Train) prepared for months, and raised more than \$1,500.



Thank you so much Hannah, Lech, Steve and Team Blaine Train! We are so proud to have amazing supporters like you out representing our community!

Peta's almost half-way!

Peta Banks has been walking for about

eight months now! Peta is aiming to walk 1000km over 12 months to raise awareness and funds for Queenslanders impacted by HD.

We are so grateful for her dedication, and are thrilled to announce that she is nearly half-way towards her goal, and has raised over \$700 in the process!

You can make a donation here: <https://give.everydayhero.com/au/peta-4>.

Triathlon Success!

In case you missed the update, we are so excited to announce that Leisa Tuite completed her recent triathlon with great success, and all in support of Queenslanders living with Huntington's disease!

Leisa came 16th in her age group (the pro series) and clocked her time at 1hr, 4minutes and 49 seconds!! This is an absolutely amazing effort, and she still

managed to crack a smile in every photo!

As if competing in a triathlon wasn't enough, Leisa raised a whopping \$1,258.06 for Huntingtons Queensland! Thank you so much, Leisa, and congratulations on your very impressive result!



Thank you, Christine!

In May, we farewelled Christine after more than eight years of service. We and our community are so grateful for her hard work, and wish her all the best!



If you would like to share what you've been up to, drop us a line in the office, and don't forget to send in some pictures!

NDIS Update

With Bernard Wilson

The NDIS rollout commences in July 2016 and will be a very significant change for how disability and community support funding is determined and distributed. Huntingtons Queensland (HQ) supports strongly the principle of people living with disability, accident or illness including those living with Huntington's

disease being in receipt and control of the funds needed for them to live a full and rewarding life of their choosing. As we approach the introduction of the NDIS, HQ will monitor and feedback to clients and carers how the rollout will impact and we hope benefit the Huntington's community. As EO, I will be the information contact point for you, and assist you with queries or dealings

National
disabilityinsurance
Scheme

with government. For now, I encourage clients, carers and family members to visit the NDIS website and take a look at the information being provided. Please let us know where we can assist.

Bernard.

HD In The Media

If you're looking for mentions of HD in the global media, here are a few sources we are keeping an eye on:

The Inheritance (a documentary from New Zealand)

The Lion's Mouth Opens (a documentary from the United States)

Inside The O'Briens (a novel written by award-winning author Lisa Genova)

The Prayer of a Lifetime (a memoir by James D'Ambola Jr)

Appreciation

With your support!

Individual Donors

Major Donors and Fundraisers (more than \$500)

Lech Blaine
Hannah Blaine
Steve Blaine

Tim Doyle (Cairns)
Cliff & Jenny Farmer
Peter & Shirabdi Gordon

Richard Sivell
Betty Stabler

Leisa Tuite
Margaret Turner

Generous Donors (Donations of \$200 or greater)

Patricia Barnes
June Barrett
Joyce Bennett
Delmae Clark
John Clark

Eric Denham
Gerry Doyle
Samantha Dunn
S & J Gauci
Ken & Christine Gordon

PD & JA Le Feuvre
Nicole Lofting
Mrs Lupton
Malcolm Scarr

Graham Scott-Hunter
Bill Van Heel
Jenny & Forde Williams
Jody Williams

Regular Donors

David Crabb

Nicola Duncombe

Mr Keune

Heather Whye

Corporates, Foundations and Organisations

We extend our sincere gratitude to the following organisations, foundations and businesses who have kindly supported us in the past few months:



The Wine Emporium



RE/MAX
Caloundra



Special thanks goes to Chris Beecham and the team at Beecham Holden for their ongoing support and generosity. Thank you so much, team!



We would like to sincerely thank the office of Graham Perrett MP for kindly printing this newsletter free of charge!

A Gift of a Lifetime

On behalf of the Huntington's community in Queensland, the Board and organisation are privileged to honour the life and memory of **Ms Alethea (Thea) Harding-Smith** who passed in May this year.

Thea was a generous and strong supporter of families living with Huntington's disease and through her estate and with the support of her family, left a gift in her will to Huntingtons Queensland. We are truly grateful for her generosity, and are honoured to continue her legacy of kindness through our work.



We're listening!

We love feedback – we love to know what we're doing right, and we love to know how we can make our services even better.

Feel free to give us some feedback, anonymous or with your contact details, to help us deliver the best services we can to you, your loved ones, and the wider Queensland community!

You can write to us, email us, fax us, call us, or even drop in for a chat. All our details are at the bottom of this page.

Support Queenslanders Impacted by Huntington's disease

1. **My Gift Amount:** \$200 \$100 \$50 \$30 My choice of: \$ _____

2. **Payment Method:** Cheque/Money Order (to "Huntingtons QLD") Direct Deposit Card (Visa / MasterCard) (Please circle)
Name **AHDA (Qld)**, BSB **734-002**
Accnt: **075-025**, Ref: **YOUR NAME**

Card Number: _____ Expiry: _____ / _____ CCV: _____

Name on card: _____ Signature: _____

3. **My Details:**

name:		email:	
address:			
home ph:		mobile:	work ph:

4. **Huntingtons Queensland Torch Society**

I have left a gift in my Will or would like to know more about leaving a gift in my Will.

Please mail (using the pre-paid envelope), fax, email, call or donate online.
mail: Huntingtons Queensland, PO Box 635, Annerley, QLD 4103 | **fax:** 07 3391 0443
e: admin@huntingtonsqld.org.au | **ph:** 07 3435 4300 | **w:** huntingtonsqld.org.au