



Supporting people living with Huntington's disease.

From The Board...

Huntingtons Queensland has a busy time ahead this year with a full schedule of events planned for 2016. In January, the Board held a planning workshop held by Board Connect focusing on the key opportunities and challenges for the Association – the opportunities and challenges are equally important and we need to be prepared.

As the current Chair of Huntingtons Queensland (HQ), let me say that the working relationship between the Board, Bernard and his current team is highly active with the present and future in mind. HQ is very fortunate to have the mix of skills on the Board that we do; members whose families have experience the suffering, hurt and anguish due to HD, highly experienced clinicians, policy makers, financial managers, fundraisers and managers.



Jeffery Allen
Chair, Huntingtons Queensland

This mix places HQ in a unique position to remain grounded and retain our focus on delivering the mix of services needed to deliver the information, support and care needed for clients, families and carers to achieve or maintain a good quality of life.

One of the main challenges for HQ is delivering a state-wide service with a limited capacity (number of staff and resources). Since HQ moved back to a two person welfare model, strengthening linkages with families in regional Queensland has been a priority and the growing number of Support Groups, events and regional trips indicate that this approach is on track.

HQ also ensures that clients and families are kept up to date with the latest research being undertaken towards a cure for HD, and I am pleased to say that HQ will be supporting a grant application to be submitted by a research team from the University of



Supporters Gathering: Jenny Farmer, Cliff Farmer, Mary Grant and Gerry Doyle

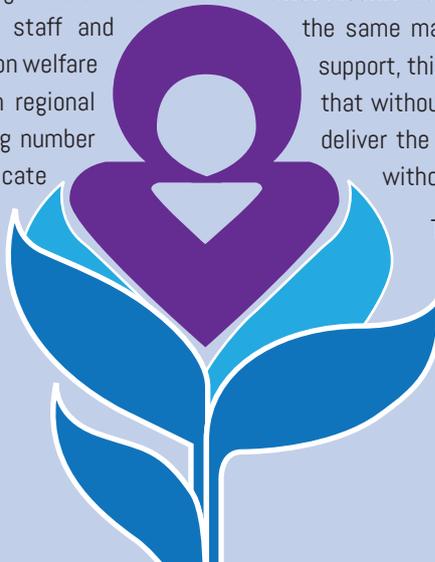
Queensland to the Advance Queensland Innovation Program (AQUIP) for a clinical trial relating to the use of a drug which had previously been shown to slow disease progression in rodents. HQ will keep you informed about whether this grant is successful.

Fundraising efforts by HQ will continue as governments place an increased emphasis on specialist not for profits such as Huntingtons Queensland being self-sustaining, particularly as we move towards the introduction of the National Disability Insurance Scheme in Queensland on 1 July 2016. On 11 February 2016, HQ held a function at the Sunnybank Community Sports Club to thank donors and supporters for their ongoing assistance in helping HQ to continue to deliver. While the attendance on the night was small, I was delighted to meet a range of people who had gone the 'extra step' needed to provide their support.

What I learnt was that not everyone is affected by HD in the same manner and for some people who provide support, this is their way of giving back and knowing that without this support HQ could not continue to deliver the information, support and understanding without it.

The opportunities for the future are based on HQ being seen as a value proposition to our stakeholders and exploring the possible avenues which the NDIS may provide to strengthen our existing core services.

Jeff Allen



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2016 Calendar

JANUARY

15 HYPe Gold Coast Trip

FEBRUARY

3 Ipswich Family Support Group
5 HD Clinic
16 Logan Family Support Group\
19 Townsville Family Support Group
26 Toowoomba Family Support Group

MARCH

4 HD Clinic
7 Gold Coast Family Support Group
16 Redlands Family Support Group
17 – 20 Regional Trip (North & Far North Qld)
18 Townsville Family Support Group
29 – 31 Family Holiday (Gold Coast)

APRIL

1 HD Clinic
12 – 17 Regional Trip (Cooloola Coast, Hervey Bay, Bundaberg & Gladstone)
13 Bundaberg Family Support Group
15 Townsville Family Support Group
16 Gladstone/Rocky Family Support Group
21 Sunshine Coast Family Support Group

MAY

4 Ipswich Family Support Group
6 HD Clinic
18 Logan Family Support Group
20 Townsville Family Support Group
27 Toowoomba Family Support Group

JUNE

3 HD Clinic
6 Gold Coast Family Support Group
15 Redlands Family Support Group
17 Townsville Family Support Group
Date unconfirmed: Regional Trip (TBC)

EO Speak

It was a great pleasure to hold the Supporters Gathering in February at Sunnybank Community and Sports Club, and a fitting opportunity to acknowledge and thank all our Supporters for their generosity and compassion for the Huntington's community over the past year and more.

As reported in the Annual Report late last year Huntington's Queensland (HDQ) was very pleased to receive notice of continued state government funding until June 2019. Taken together with the remarkable generosity of the late Ms Thea Harding-Smith in the gift from her estate and indeed with the support of members and generous donors the Board and staff team look forward to the future with increased confidence.

The Client Services team had a busy pre-Christmas period before taking a short break and bouncing back in January! Recent highlights include the HYPe (young families) event at Whitewater World and Dreamworld and the team is currently planning for a Gold Coast HYPe family holiday in March. Support Groups have largely resumed for the New Year and we look forward to attending and supporting where we can. The mainstay of the Client Services effort remains being available on phone, though the office and in person for information, advice, referrals and non-clinical counselling. We acknowledge and thank the team for their professionalism.

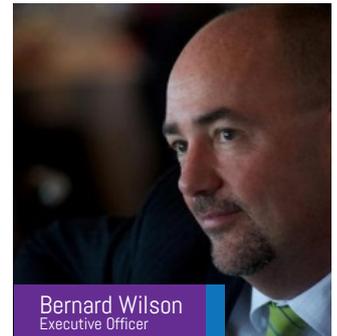
The HD Clinic also resumed in February and remains a very valuable specialist resource and support for the Huntingtons community and the Client Services team is very happy to support and be on hand at the Clinic on the first Friday of each month.

The Client Services calendar points to the growing number of Support Groups, Events, Regional Trips and other activities under planning.

Late last year the Executive Officer, Bernard and Community Services Officer, Tress made the trip to Townsville to meet with family members and the Townsville Support Group.

Additionally, we now see Townsville has been chosen as the launch site for the NDIS, albeit for the initial stages eligibility is mostly limited to persons under age 18. For further information about the NDIS in Queensland, see the NDIS.gov.au site and click on Queensland, www.ndis.gov.au/about-us/our-sites/qld

The Board and staff group participated in a strategic planning workshop in February to update and renew key planning priorities. Stakeholders can expect to see more as the plan continues to develop and is communicated through the community.
Bernard Wilson



Bernard Wilson
Executive Officer

CONNECT & IMPACT

NOVEMBER TO JANUARY 2016

383

Occasions of support, meaning a whopping 383 phone calls, emails, visits, education sessions, Family Support Groups, and a range of other contacts in three short months

524

Individuals helped, including Family Support Group and Education Session attendees, people who've called over the phone, families who have received a home visit (or came to visit us in the office), and the many other forms of support our team offers.

Client Services Updates

Welcome to 2016! The Client Services team is excited about plans for the year and are also pleased to share with you some of the things we have already been up to. At the end of last year a HYPe survey was sent out to families with children under 18yrs old to ask you what you wanted for future family orientated events and holidays. A BIG thank you to everyone who responded and those of you we have spoken to, we appreciate your feedback.

SURVEY RESULTS SNAPSHOT:

- Overall people were happy with being offered the opportunity to meet with other families and have fun together.
- Families indicated they enjoyed both the holidays and the one off events.
- They were able to contribute financially, but some had not been able to participate due to distance/travel expenses.

This was invaluable in helping to plan for 2016 and how we can fairly offer families around the state access to more family orientated events. Our goal in 2016 is to facilitate more one off activities in both South East QLD and the regional areas. Keep an eye on the website for more information or please call the team.

HYPe - Young Families

Our HYPe January event of day trip to White Water World & Dreamworld was a great day and an amazing opportunity to catch up with some of the wonderful families in our community. We need to acknowledge Allen McKinless too who volunteered on the day – the esky would still be in the car boot without him! The team received lovely feedback from some of the children who attended and their parents, and we are really looking forward to all the planned events around the state. Remember even if we are not able to attend, we would love to get photos and feedback from the day – you may be our star in the next newsletter!



Another part of the HYPe program has been the holiday Huntingtons Queensland has been able to secure a limited number of apartments at Turtle Beach Resort at the Gold Coast this year for the Easter holidays. As you can appreciate this is an expensive endeavor and in the future we may be focusing on more one-off events across the state, to ensure families are given opportunity to create those special memories with each other and most importantly; just have some FUN!

2016 CALENDAR

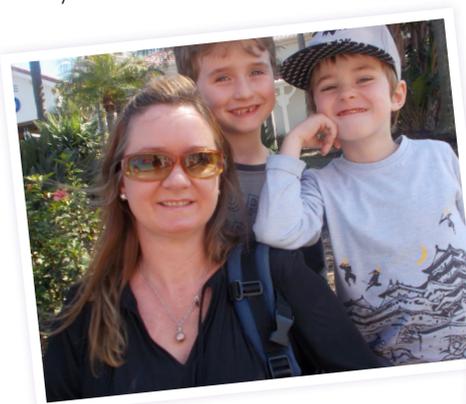
The Organisation has a full calendar for 2016 (on page 2), with several regional trips planned, numerous HYPe events across the state, 11 HD Clinics, monthly support groups and an education forum we are developing in conjunction with the HD Clinic. Although our calendar is full, our focus as always is with the individuals we have the privilege of supporting in our daily phone conversations and face to face meetings. I would encourage you to phone us if you feel we may be able to assist in anyway and look forward to meeting more of you as we travel around in 2016!

See you around the state,

The Client Services Team

Thank You & Farewell, Toya!

Thank you to Toya Lindstrom for her work and contribution to the Huntington's community and who has decided to move on and return to Ozcare. Thank you Toya, the team wishes you well!



Research UPDATE

At our recent Supporters Gathering, we were thrilled to welcome Dr Susanna Mantovani, a researcher at Wesley Medical Research at the University of Queensland.

Dr Mantovani presented her team's findings on a very recent model of HD in mice: mice displayed a number of behaviours and physicalities similar to humans with HD. For instance, affected mice had greater difficulty on rotating rods and balance beams, and researchers were even able to look at the difference in striatal sizes between HD and non-HD mouse brain scans (interestingly, there was no difference in size!). They even found that HD mice navigated and engaged with open spaces differently. All this research is helping scientists better understand how HD works.

Dr Mantovani, in collaboration with A/Prof Woodruff and his team, will be able to discover more using blood collected from volunteers since 2013. These blood samples, coming from both HD and healthy volunteers, make up the largest HD biobank in Queensland!

With all this research going on, the team at the research lab has applied for a grant to allow them to explore further, intending to establish a clinical trial for medical relief for people with HD. Huntingtons Queensland hopes to support this grant application by acting as a community partner and funding contributor.

Dr Mantovani and the team have also received ethical approval to start sleep studies for people with HD. Sleep alterations have been observed very early in HD, often before the start of



other symptoms, and Dr Mantovani explained her team hopes that targeting sleep could be a strategy to slow down HD's progression.

In future editions, Dr Mantovani will be answering your questions about science, research and Huntington's disease. *If you have a question for Susy, send them through to us and we will pass them on. We will keep all submissions anonymous, so feel free to ask whatever you like.*

Some Other Research:

The latest HD Buzz article explores research done on harmless viruses that can be used, like a carrier pigeon, to deliver 'gene silencing' messages throughout the brain. This article can be found on the HDBuzz website: <http://en.hdbuzz.net/>. You can also check out our Research page on our new website for a directory to other reputable sources: huntingtonsqld.org.au/resources/research/

Philanthropy & Communications

Presenting...

If you are yet to jump online and have a look at our new website, you should definitely take the time to do so. It is now up and running, with a plethora of information and resources for everyone in the community.

There are information fact sheets, links to other useful organisations, helpful suggestions for getting involved and making a difference, and even a monthly blog from our team giving brief updates on their area of the organisation.

The website will continue to grow and develop over the next few months, so make sure you keep checking in to see what's new. And if you have any feedback or suggestions, we'd love to hear them!

Stories of Hope and Love...

We believe that the stories of our community are important and deserve to be heard. So we will be collating submissions from

within our community, known as Stories of Hope and Love. If you would like to tell your story, please contact Caitlin (07 3435 4300 or FRC@huntingtonsqld.org.au). You can remain anonymous or share your name; tell snippets or share your whole story. Perhaps you'd rather record something and send us the video or audio. However you wish to do so, we encourage you to trust us with your stories – *they are precious.*

Our Champions...

Kelly Stannas will run three half-marathons this year, all to raise awareness and funds for Queenslanders living with Huntington's disease. For months now, Kelly has been tackling the summer heat as she trains, and has been posting her run updates through Everyday Hero. We are so proud to have Kelly running for us, and we ask the community to support her in turn by visiting her Everyday Hero fundraising page, sharing it with your family and

if you can, making a donation. You can find Kelly's page here: <https://give.everydayhero.com/au/running-for-nan-s-1>

In a few short months, *Chantelle* will challenge her body and mind in a test of stamina and sheer willpower. In early May, Chantelle will take her first steps along the famed Larapinta Trail, walking solo for up to 20 days through the taxing West MacDonnell Ranges until she reaches Alice Springs. Read her story below, visit her Everyday Hero page here: <https://give.everydayhero.com/au/chantelle-42> and leave a message for her on her Facebook page: <https://www.facebook.com/223forHD>

The Larapinta Trail

Hello! I'm Chantelle, a 22yr old Gold Coastian living at risk of HD. I've always wanted to do something significant for HD, but I've never been able to pull off my plan of jumping in a Kombi with my Great Dane, Odin, and travelling around Australia meeting those who have been impacted by HD. A couple of weeks ago, my beautiful Odin fell ill and passed away; this shattered my world and all I could think about was "this is what it feels like to lose everything..."

I decided that I needed to put this heartbreak to good use and raise awareness for HD and the struggle those affected by it go through. I decided that it needed to be something physically and mentally tough, something that people could see as the true challenge it really is; introducing the Larapinta Trail, located in Central Australia. This trail is a gruelling 223km, end to end, which I will be trekking completely solo. The hike will take me along the backbone of the West MacDonnell ranges and the plains below; it can take anywhere between 15-18 days. It is a hot, rocky, rugged and hard surfaced trail that is both flat and mountainous; scorching hot during the day and chillingly freezing at night; the perfect experience to reflect the impact of HD. My biggest challenge leading up to the trial will be training to walk 15-20km a day with 8-10kgs on my back. I'm looking forward to the pure experience of it, the beauty and untainted sights of Central Australia, as well as reconnecting with the bare essentials of life.

I'm hoping to really gain some traction with this hike regarding awareness for HD; that is what matters most to me. Getting the awareness out there, so there is more understanding and support for those impacted by or living with HD. I remember when

Jetty 2 Jetty

Calling all who stroll, amble, walk, jog and run in the Brisbane and Sunshine Coast area! The Jetty2Jetty fun run is on July 17, and we've had a few enquiries about teams. We'd love a team to represent Huntingtons Queensland, and it will be good practice before the Bridge To Brisbane the month afterwards. If you're interested in participating in Jetty2Jetty, please get in contact with Caitlin on frc@huntingtonsqld.org.au or 07 3435 4305. The distances are great for all participants: 3km, 5km, 10km or a half-marathon! Find out more here: <http://j2j.com.au/>



Chantelle in training

I found out that I am at risk, and I felt so isolated and alone, trying to understand what this meant, how it could change my life. I remember feeling like I had no body to turn to, even though I have family and friends, no one really understood because they don't understand the disease. I don't want others to go through the cold isolated struggle that I went through. This hike, for me, is to reflect that struggle and let others know that no matter what, you can get through it.

I honestly feel like it's something I will not be totally prepared for until I'm on the trail, both physically and emotionally. I'm not sure I've ever felt such a rollercoaster of emotions leading up to something! Will I have all my gear in time? What if I hurt myself? Can I befriend the dingos? What if they bite me!?! So many unanswered questions, but I do know one thing for sure. The Larapinta Trail is going to push me like I've never been pushed before, and the woman who walks off that trail is going to be wiser, stronger and ready to face HD.

General Updates

HD Clinic

The HD Clinic operates on the first Friday of most months, in the Neurology area of the Royal Brisbane and Women's Hospital. Attendees at the clinic can see a range of service providers, including a neurologist, psychiatrist, psychologist and speech therapist.

We are pleased to be working with the new Clinic Coordinator, Lily, who can book you in for an appointment if you wish to attend. You can contact Lily on (07) 3646 7103. You will need a referral from your treating GP to attend, and those travelling from outside Brisbane may be eligible for travel assistance.

Huntingtons Queensland will provide sandwiches during the Clinic, and our Client Services team will be there on the day to help out, but you may wish to bring some food and activities to keep you occupied while waiting for appointments

HD Pro-Forum

Towards the end of 2015, Huntingtons Queensland hosted a professional forum for members of the local professional community who assist families impacted by Huntington's disease. The forum was a great opportunity for these professionals to share relevant research and treatment updates, and to discuss the year ahead. We were very pleased to host the event, and look forward to another forum during 2016.



HD In The Media

Some suggestions for your media viewing/reading (links available on our website):

Rules for 50/50 Chances (a novel by Kate McGovern)

Breathless: An Inward Journey (a book about a family living with HD)

Huntington's Dance (a documentary from the United States)

Twitch (a documentary from the United States – now available to stream online)

did you know...

More than 1/3 of our funding comes from the generosity of donors

[DONATE TODAY](#)

Donations keep our team in contact with our widespread community. You can help us make a difference by donating online through our website, calling our office, or sending us a cheque. Thank you for your support!

Where are you @?

Increasingly, the team at Huntingtons Queensland is using digital and social correspondence to share news and updates. We don't want you to miss out on the latest research updates and activities with the team, so tell us your email address and we'll keep you in the loop!

Email or call the office (admin@huntingtonsqld.org.au or 07 3435 4300).

Vale

Huntingtons Queensland offers sincere condolences to the family and friends of members and supporters recently passed

Rhiannon Burow

Noeline Campbell

Gerry Sulzberger

In Memory

Thea Harding-Smith

Ms Alethea Harding-Smith, 'Thea', was a wonderful supporter of the Huntington's community over a very long period until her passing 20 May 2015. Thea had enjoyed a successful career as a Nursing Sister where she observed first-hand the often cruel and debilitating effects of Huntington's disease on individuals and their carers, families and friends.

Thea had said Huntington's was the most challenging medical condition she had witnessed and expressed her desire for support to be directed to families as a means of relief and respite from their day to day struggles.

Huntington's Queensland is honoured and privileged to have received a most generous gift and legacy from Thea's estate. We are pleased to honour her memory and her gift to the Huntington's community.



Bequests

Huntingtons Queensland proudly and humbly acknowledges the generosity of the following people, who chose to give a lasting contribution to our community through a Gift in their Will.

In memory:

Mr Raymond Burnip

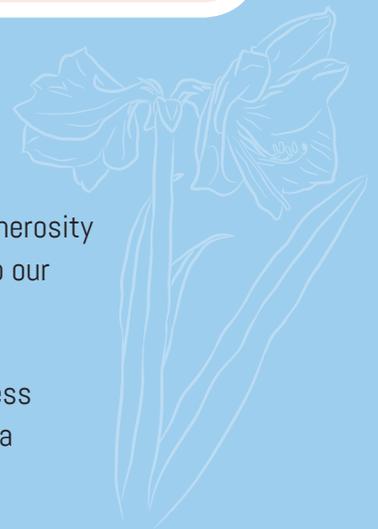
Ms Florence Dannell

Ms Alethea Harding-Smith

Mrs Alecca McKinless

Mrs Patricia Parikka

Mr Cornelius Rote



Individual Donors

MAJOR DONORS AND FUNDRAISERS OF \$500 AND MORE

Mr & Mrs Ken & Diane Allan
Mrs Grace Politch

Mrs Sue Nadollek
Ms Sue Woodland

Ms Kelly Stamnas
Ms Chantelle Y.

COMMUNITY DONORS OF \$200 AND MORE

Joyce Bennett
J & L Hartkopf
Ian & Glynis McGuckin

Lisa Milliner
Gwen Pratten
Alastair Scarr

Natasha & Trevor Weaver
Margaret Turner
Jenny & Forde Williams

REGULAR DONORS

Mr David Crabb
Nicola Duncombe

Mr D Keune
Ms Lisa McGuinness

Ms Heather Whye
Ms Cassandra Buckley

Businesses, Foundations & Organisations

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



Can you believe it has already been 12 months since Cam and team achieved their spectacular Guinness World Record!



We are proud to receive funding from IOOF Foundation towards our Coffee Catch Up program, and also the funding for our new website.



We are so grateful for the support ECN Communication Solutions provides through their ongoing free web hosting.

MinterEllison

We are grateful for the generous, ongoing support we receive from Minter Ellison Solicitors. They have advised us a number of times, and continue to support us. Thank you!



A big thank you to Sunnybank Community & Sports Club for allowing us to host our Supporters Gathering. Thank you for your ongoing support for our HYPe program, and for our various activities throughout the year.



Beecham Holden Caboolture provides generous donations every year. Their gifts make a significant difference to our fundraising efforts. Thank you.

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If you believe in a better life for those living with this most challenging disease, please make a donation today and consider Huntingtons Queensland for a gift in your will.

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