



Top row from top left: Toowoomba's Victoria Street Bridge, lanterns at Lighting the Way 2018 forum, Tressa & RJ
Middle row from left: Ted & Joseph, Jeff & Liam, fun at lunchtime, the Colley family, Brisbane's Victoria Bridge
Bottom from left: Toowoomba City Hall, Treasury Brisbane, Brisbane's Story Bridge

May 2018 Huntington's disease awareness month

May is the internationally recognised Huntington's Disease Awareness Month, and Huntingtons Queensland was proud to participate in this international initiative.

One highlight was the global #LightItUp4HD campaign, which saw buildings and bridges lit up in blue and purple in 123 locations around the world to support people impacted by HD.

Here in Queensland, we saw blue and purple lights on Brisbane's Story Bridge and Victoria Bridge, Treasury Brisbane, Toowoomba's City Hall and Victoria Street Bridge, Maryborough City Hall and in various locations in Townsville.

We are pleased and grateful for the support of Brisbane City Council, Treasury Brisbane, Toowoomba Regional Council, Fraser Coast Council and Townsville Regional Council.

These councils and businesses all jumped at the opportunity to support #LightItUp4HD, flooding Queensland in blue and purple at different times during the month of May.

In addition to lighting awareness campaigns, Huntingtons Queensland also hosted the *Lighting The Way 2018 Forum*, an information and networking conference that you can read about on pages 4 - 5 of this newsletter.

Changes to the team

Huntingtons Queensland is very pleased to welcome Jason de Bakker to the board.

Jason has an extensive background in corporate services, compliance and organisational development, gained over more than 20 years in the NFP and community sectors.

He was previously a senior executive at Alzheimers Australia (Qld) and is a former Chair and Director of 3rd Space (previously 139 Club), a Brisbane-based drop-in centre for the homeless.

In turn, Jeff Buchanan has stepped down from the board (temporarily we hope) to work with our team on developing our fundraising capacity and future sustainability.



Board director Jason de Bakker with CEO Jan Samuels

We're excited to formally introduce our two new additions to the team: Elena in an HD advisor role, and Cathy in the Service Support Officer role.



Elena (left) & Cathy (right)

Elena and Cathy joined the team within three days of one another and have quickly made themselves invaluable in our small team.

Elena works with Lauren & Tressa providing support and services to families impacted by HD, and Cathy keeps our busy office running, so if you ever give us a call or pop in to say hello, Cathy is likely to be the one welcoming you.

Family Fun Day - Currumbin

More than 40 adults and children got together at Currumbin Wildlife Sanctuary in March, as part of our Family Fun Day series.

Families spent the morning taking in the beautiful animals and the lush green surrounds of the sanctuary, before escaping the heat for a sit-down catered lunch with everyone in the air conditioned cafeteria.

During the afternoon, families relaxed with train rides, family photos, and a quick ice-cream break before heading home.



Left - Right: Breie & her daughter; some of the locals

We would like to acknowledge our gratitude to Alecca McKinless, whose bequest has made these days possible free of charge for attendees, and Alecca's husband, Alan, who has generously supported these much-loved outings.

Support group calendar

Visit huntingtonsqld.org.au/support/whats-on for a list of all upcoming events and support groups.

July

- | | |
|---------------------|------------------------|
| 3 - Gympie | 20 - Townsville |
| 4 - Bundaberg (TBC) | 23 - Mackay |
| 11 - Brisbane | 25 - Rockhampton (TBC) |

August

- | | |
|----------------|-----------------|
| 8 - Brisbane | 17 - Townsville |
| 14 - Toowoomba | |

September

- | | |
|-----------------|-------------------------|
| 3 - Redlands | 14 - Sunshine Coast |
| 11 - Gold Coast | 21 - Logan & Townsville |
| 12 - Brisbane | 25 - Ipswich |

October

- | | |
|---------------|-----------------|
| 2 - Gympie | 10 - Brisbane |
| 3 - Bundaberg | 19 - Townsville |

Play for purpose!

Have you been looking for another way to support Huntingtons Queensland? Do you like throwing your hat in the ring? Perhaps you're just feeling lucky.

Huntingtons Queensland is very excited to participate in the first lottery round of *Play for Purpose*, a charity lottery that gives a whopping 60% of all proceeds to the participating charities without charging us to participate.

And as a lottery participant, you're in the chance to win any of the thousands of prizes on offer, with at least a 1 in 19 chance of winning a prize

Visit www.playforpurpose.com.au!

Thanks for supporting our fundraising efforts - we hope you win something fabulous!



Ticket sales are limited, and once they are sold out, you will have to wait until the next lottery opens to be in with a shot.

To buy tickets, visit the website below and make sure you select Huntingtons Queensland as your charity of choice when asked.

Save the date!

Kelly Stamnas's fantastic annual event *Running for Nan's HD* is back!

Get your running shoes out for **Saturday 9 September** – location to be announced – for the third running awareness event and barbeque.

Running for Nan's HD is a major awareness and fundraising event held in the community each year. The extraordinary event is organised by community member Kelly Stamnas and all funds raised are donated to Huntingtons Queensland.

For more information, search Facebook for **Running For Nan's HD** or visit <https://give.everydayhero.com/au/kel-6/wizard/share> to find out more!



Can you volunteer? We desperately need **more help** as this event gets larger every year! Contact our office if you can help!

The Huntington's Marathons

We are so proud of Steven Blaine – he is STILL running!

Steven has been doing a marathon or half-marathon every month this year – by the time Christmas rolls around, he will have done 12 – and all of them are raising funds and awareness for people impacted by HD in Queensland.

Steve's target is \$10,000 and he has already raised nearly \$7,000.



Please support Steven by sharing his fundraising page, making a donation, or even just sending a message of support – we can pass them on to him!

Find him through our Facebook page, visit <https://give.everydayhero.com/au/the-huntington-s-marathons> or follow **@the_wa_beer_runner** on Instagram to support him.

Lighting the way

As part of our commitment to Huntington's Disease Awareness Month, Huntingtons Queensland hosted a special event: *Lighting the Way 2018 forum*.

The forum, held on Friday 11 May at Treasury Brisbane, welcomed more than 80 people for an afternoon of diverse presentations about the future of, and living with, Huntington's disease.



Top left to right: Jeffrey Edwards, Natasha Reed, Julie Morrow, Gwen Pratten

Bottom left to right: Paul Mulhern, Tracey Mulhern, Shauna Mulhern, Amy Martin, Professor Julie Stout

Funded through the generosity of the Alecca McKinless bequest, and with support from Alecca's husband, Alan, we were pleased to offer the event free of charge to all attendees, including a delicious afternoon tea and post-forum social hour.

The forum, Huntingtons Queensland's official awareness month event, was an opportunity for people to learn more about HD, local services, and how to light the way for the HD community.

We were delighted to welcome a wide range of speakers, who spoke about everything from the science of HD to self-care to personal stories of living well with HD.



From left to right: President Gerry Doyle, Professor Julie Stout, Cathy Dart, Linda Wornham, Dr Trent Woodruff, CEO Jan Samuels, Kerrie Morgan, Kelly Stamnas, Alan McKinless, Janelle Rawlinson, Breie Starkey



Left to right: Tony Bird, Dianne Carroll, Fran Brennan, Chantelle Youngberg

Key note speaker Professor Julie Stout flew from Melbourne to present a fascinating 30-minute research update, with an important insight into the current clinical trials for the Ionis HTRx drug. Prof Stout has spoken in Queensland before – she presented and answered questions at the January HDYO Youth Camp on the Sunshine Coast.

Local researcher Dr Trent Woodruff also spoke about his work and the role of the immune system on brain diseases. Dr Woodruff is developing a treatment for Motor Neurone Disease through his position at University of Queensland. Huntingtons Queensland is supporting Dr Woodruff's research through a \$30,000 grant over three years.



Left to right: Michael Zeremes, Jill Kriedeman, Angelika Straker

Other local presenters included senior genetic counsellor Linda Wornham, who spoke about considerations for genetic testing, Spark NeuroCare's Kerrie Morgan who spoke about the NDIS, and clinical psychologist and former Huntingtons Queensland staff Cathy Dart, who spoke about the importance of self-care.

We were also thrilled to share a message from the founder of Huntingtons Queensland, Cliff Farmer, and a presentation from Executive Director of Huntington's Disease Youth Organisation (HDYO) Catherine Martin, who spoke about the role of HDYO around the world. They 'appeared' by video.



Left to right: Lily Tang, Professor Julie Stout, Dr John O'Sullivan, Dr Susana Mantovani

The second session of the afternoon had a different pace. Janelle Rawlinson, a Townsville resident and person with lived experience of caring for someone with HD, spoke about some of the challenges and successes of caring for her husband, Gerard, and her experience navigating the NDIS in its first rollout area in Queensland.



Left to right: Deputy Chairperson Cate Barrett, Cathy Dart, Angela Hall, Dion Hall

Kelly Stamnas, AKA *Running for Nan's HD*, spoke about why she runs... and runs... and runs... Kelly's Nan lives with HD, and Kelly has worked passionately for years to raise awareness and support for Queenslanders impacted by HD.

Finally, Gold Coast local Breie Starkey spoke about growing up, having a family, and living with HD. As a young woman living a full life, Breie's story resonated strongly and inspired many in the room.



Left to right: Kelly Stamnas, Jenny Williams, Michael Wickham, Cassandra Wickham

There were formal question-and-answer sessions, and a chance to chat with speakers, ask questions, share stories and network during the breaks.

Feedback from the event has been overwhelmingly positive, and we plan to run a similar (but maybe even bigger) forum next year – with **Friday 17 May** tentatively booked.

For those who could not attend in person, we were able to record each presentation and they will soon be available via our website. We'll let you know when they are there.

Feedback from *Lighting the way*

Immediately following the event, we asked attendees to tell us their thoughts on the forum. We've compiled the feedback - have a look at what was said:

Why did you attend?

- "HD is part of our lives now. We want to be informed."
- "To hear about research."
- "To learn to support my partner with HD, and still care for myself."

What would you like to hear more about?

- "Available services - especially housing"
- "The NDIS"
- "How to better support someone with HD as a friend or carer"

What was most valuable to you?

- "I realised I am not alone."
- "Research and clinical trial information."
- "Stories of lived experience."
- "The sense of community."



of respondents said they would love to attend another forum.

On the road with Client Services

The Client Services team have had a very busy quarter, covering more than 4,150km travelling around the state to appointments, meetings and education sessions.

Between them Lauren, Tressa and Elena have ranged across south east Queensland, including the Gold Coast, Logan, Ipswich, Toowoomba and Caboolture, and have headed further north to the Sunshine Coast, Gympie, Gladstone, Bundaberg and Mackay.

During these visits, our team also facilitate support group meetings to encourage locals to come together for group support, information, and to meet others.

Some recent support groups have also welcomed guest speakers, including local physiotherapists, and the team from Novacorr who specialise in furniture designed for people with HD.

The team have also attended the regular HD clinics at Royal Brisbane and Women's Hospital, visited individuals and families for one-on-one support, and delivered education sessions for staff at aged care facilities and other agencies.

These education sessions are highly sought after as they are often the only training opportunity staff have for caring for people with HD. Here is just a selection of feedback we have received for education services:

"I thought the presentation was extremely informative and gave me a better understanding of Huntington's disease. I especially found the information about behaviours, especially in relation to hunger and more importantly breakfast, really fascinating."

"I found it very informative, particularly working with a residential care service, and seeing what is part of the disease process vs what is a resident reaction to service care provision."

"I found it extremely relevant and helpful in the work that we have been doing recently with our cases involving residents with HD."

Huntingtons Queensland is very pleased to be partnering with Novacorr to raise awareness of their excellent HD beds and chairs.

If you are considering an NDIS application, you may be able to claim the cost of this excellent equipment as part of your package.



Sally and Marcus from Novacorr came along to a recent Brisbane support group meeting to demonstrate some of their Huntington's disease-specific furniture. Some of the attendees were very happy to test them out!

New contact details

We've had a few changes in contact details! Here's the full list of email addresses for our team:

Jan (CEO): **CEO@huntingtonsqld.org.au**

Lauren (client services): **Lauren@huntingtonsqld.org.au**

Tressa (client services): **Tressa@huntingtonsqld.org.au**

Elena (client services): **Elena@huntingtonsqld.org.au**

Caitlin (communications): **Caitlin@huntingtonsqld.org.au**

Cathy (service support): **Cathy@huntingtonsqld.org.au**

Jennifer (finance): **Finance@huntingtonsqld.org.au**

Support groups: **SupportGroups@huntingtonsqld.org.au**

Fundraising: **Fundraising@huntingtonsqld.org.au**

And of course, if in doubt, you can always email **admin@huntingtonsqld.org.au!**



Our whole team, left to right: Jennifer, Tressa, Caitlin, Elena, Jan, Lauren & Cathy

Membership renewals are on their way!

It's reached the time of year when we need to renew memberships with the association. We will be mailing these out to coincide with the new financial year.

This year, we will be only be sending out renewal letters and forms to those who were members throughout this past financial year.

If you have previously been a member, but did not renew your membership for the 2017/18 financial year, you will not automatically receive a membership renewal form. However, we'd still love to welcome you back.

Why membership?

Members provide a vital backbone to our work. Members also guide how the organisation is managed and shape our focus as a not-for-profit organisation.

Membership fees provide a major source of income, enabling the organisation to continue to meet demand for services.

If you do not receive a renewal form, but you are interested in being a member of the association, please call our team on 07 3435 4300 and we can help you with the details.

Life and honorary members will automatically have their membership details renewed, but as usual, we will send a form out with the opportunity to update contact details.

If you believe your contact details may be out of date, now is also a great time to let us know. Call our office or send us an email to confirm how we can get in touch.

We are also able to utilise our membership numbers and engagement to support our lobbying to government and funding bodies, providing better funding and financial security to help families living with HD.

Fees remain unchanged at \$22 for individual membership and \$33 for a family membership. 7

The tax clock is ticking!

The end of the financial year is almost upon us, so if you were considering making a donation this financial year, **now is the time.**

We are raising funds for our emergency response fund, which provides one-off emergency support to people impacted by HD that is not available from any other source.

It's a practical way you can help to make a difference at times of crisis in a person's life.

You can now donate straight through our website (huntingtonsqld.org.au), where you will receive an automatic tax receipt just in time for the tax man.

If you prefer you can call our office on 07 3435 4300 to make your gift.

Donations over \$2 are tax deductible and **every cent is very, very welcome.**

ABN: 45 130 081 598



Thank you for supporting our work

Donation form - Winter 2018

Name: _____

Postal address: _____

Email: _____ Phone: _____

Donation amount: _____

Visa or MasterCard?: _____

Card Number: _____ Card expiry date: _____

Name on card: _____

Signature: _____