

Summer 2017/18 news flash



Celebrating 40 years with families

Through the generosity of the Sunnybank Community & Sports Club grant, we were fortunate to offer a family fun day for all families across Queensland.

We put the call out for interest for a free family day pass to Australia Zoo (including travel for those not within driving distance), and we got a huge response!

Interest and applications to attend were far greater than any other event we have hosted at Huntingtons Queensland!

Once we confirmed the date, we were very excited to welcome 48 adults and 20 children to join us at Australia Zoo on 14 October.

Families were given a free wildlife studio photo with a koala or python or for the more adventurous, a snake, and everyone came together for a delicious catered BBQ and some celebratory cupcakes!

Feedback from families was very positive, and we are hopeful that, with proper funding, we can continue these family fun days in 2018.

Make sure you are on our email list to find out about family fun days in 2018!

Annual general meeting

The annual general meeting was held on Thursday 16 November.

Long-serving director and volunteer Gwen Pratten took the opportunity to step down from the Board. Huntingtons Queensland thanks Gwen wholeheartedly for her service, guidance and generosity during her time as director.



All other board directors have been re-elected and will continue in their roles.

Gwen also took the opportunity to acknowledge and celebrate the life and generosity of Alecca McKinless, whose bequest to Huntingtons Queensland will fund a number of direct services for the foreseeable future.

Calendar of events

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

January

- | | |
|-----------------------|-------------------------|
| 10 - Brisbane support | 17 - Bundaberg support |
| 12 - 15 - HYDO camp | 19 - Townsville support |
| 16 - Gympie support | |

February

- | | |
|------------------------|-------------------------|
| 13 - Toowoomba support | 16 - Townsville support |
| 14 - Brisbane support | 20 - Logan support |

March

- | | |
|----------------------------|-------------------------|
| 6 - Redlands support | 14 - Brisbane support |
| 9 - Sunshine Coast support | 16 - Townsville support |
| 9 - Caboolture support | 27 - Ipswich support |
| 13 - Gold Coast support | |

Thank you!

The team at Huntingtons Queensland would like to say a heartfelt thank you to the many donors who supported our winter appeal.

Homelessness is a very real risk for some people living with Huntington's disease, and your generosity helps reduce this risk.

Our Christmas appeal may have just reached you, in which case we hope you enjoy reading Ryan's story, highlighting the impact of our youth program.

Thank you again for your generosity. You are helping to change lives!

Office closure

The Huntingtons Queensland office will be closed from **23 December to 1 January**.

You can get in touch with the team until the close of business on Friday 22 December.

Staff will be back at work on Tuesday 2 January.

If you wish to leave a message on the phone or via email, staff will contact you as soon as they are back in the office.

Upcoming NDIS rollouts

1 January: Rockhampton, Gladstone & West

1 July: Cairns to Torres Strait region

1 July: Brisbane, Logan, Redlands, Gold Coast and Hinterland, Fraser Coast, North and South Burnett regions

1 January 2019: Sunshine Coast, Gympie and Moreton Bay region



Is NDIS funding for you?

Lauren and Tressa, our Client Services team, have been working closely with clients throughout their transition to the National Disability Insurance Scheme (NDIS).

In addition to liaising between our clients and service providers, our team has supported clients by attending NDIS meetings with them in an advocacy role, and educating clients about how the scheme operates and how they may be affected.

If the NDIS is soon to roll out in your region, get in touch with Lauren and Tressa to see how they can support you during the meetings and transition process.

Running for Nan's HD a great success!

Kelly Stamnas has successfully completed her second annual *Running for Nan's HD* event.

Running for Nan's HD is a signature fun run held in September and organised by tireless volunteer fundraiser Kelly Stamnas.

The event, in its second year, raises funds for Huntingtons Queensland, and raises awareness of Huntington's disease at a grassroots level.

Spark NeuroCare launches in Toowoomba

As part of our commitment to supporting families impacted by HD, we are thrilled to promote this new service in Toowoomba through our involvement in Spark NeuroCare.

Spark NeuroCare is now available in Toowoomba, at the newly established PND Wellbeing Centre at 10 Russell Street in the CBD.

Huntingtons Queensland is a founding partner and financial contributor of Spark NeuroCare.

If you have questions about these services, you can call Spark NeuroCare directly on 1800 875 244 or contact our team.

The second annual event was a wonderful success, with nearly 100 registered runners participating in Kangaroo Point and other parts of Queensland.

Despite the rain, there were plenty of smiling faces as people crossed the finish line, picked up their free BBQ sausage, and high-fived Kelly's Nan, who lives with HD.

The whole Huntingtons Queensland team would like to say a heartfelt thank you to Kelly.

Kelly has raised thousands of dollars to support our services, and is actively raising awareness of HD in the community. Congratulations for your incredible efforts and successes, Kel!



Research updates

We highly recommend accessing the online HD Buzz site for reliable, up-to-date information on research and information. This site is run and operated by scientists and is focussed entirely on Huntington's disease research updates. You can find it at: **hdbuzz.net**

The biggest topic of focus this past year has been the ground-breaking gene-editing technology being developed overseas.

The technology, known as CRISPR, is being developed to edit genes with the hope that one day this technology may be able to stop HD symptoms completely, essentially stopping the disease from developing.

This technique would likely not stop the inheritance of the gene, but is an exciting focus of study.

HD Buzz has written a lot about this subject, and is well worth the read.

In a bid to better understand how Huntington's disease works, scientists have also removed the Huntingtin protein from cells to study its role in the body.

Every person has the Huntingtin protein, and it is only in people with Huntington's disease that the protein is expanded.

By removing the protein and seeing the subsequent effects, it helps scientists understand what the protein does in the cell.

This research is helping scientists better understand the disease and possible treatments.

HDYO camp

Huntingtons Queensland is very excited to support the second annual HDYO camp for young people impacted by HD.



Last year's camp welcomed 42 young people from across Australia, with outstanding results.

100% of respondents thought the camp was 'great' or 'excellent', and 60% felt they could cope better with the impact of HD after camp.

The upcoming camp will welcome four young Queenslanders from across the state, and Client Services Coordinator Lauren will be there in a support role.

News around the world

The Huntington's Disease Society of America (HDSA) has commemorated its 50th anniversary.

HD communities around the world also commemorated 50 years since the passing of Woody Guthrie, the famous American folk singer who inherited Huntington's disease.

Film and reading enthusiasts will be very excited to hear that Lisa Genova's best-selling novel about Huntington's disease, *Inside the O'Briens*, is going to be made into a film! No more information is available yet, but we will update you when we know more.

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A message from the family of Jennifer Berrier

R.I.P Jennifer Berrier (nee Organ) - 15.3.17

She was an extraordinary woman, a wonderful mother who left behind five children. Her life was taken too short by HD.

We raised \$253 in Jen's memory. Thank you to all her family, friends and staff who donated to honour her.