



Winter 2017 News Flash

Thank you

Thank you so much to everyone who generously donated to our winter tax appeal. The funds raised from this appeal will go towards our advocacy and support program, with the goal of reducing homelessness in the Huntington's disease population, and providing daily supports for those at risk of homelessness.

There is always more work to be done, and donations will help us lay the foundation to provide greater support throughout the state. Thank you for supporting people living with Huntington's disease.

Contact us

Phone: 07 3435 4300

Website: huntingtonsqld.org.au

Email us: ADMIN@huntingtonsqld.org.au

Post: PO Box 635, ANNERLEY QLD 4103

Visit us at Florence Dannell House,
385 Ipswich Road, ANNERLEY QLD 4103

For **Support Group information**, email
SUPPORTGROUPS@huntingtonsqld.org.au

ABN: 45 130 081 598

Membership renewals

The financial year has rolled by very quickly, and it is time once again to renew membership. Renewal letters and forms have been sent out, so if you have not received a membership form and would like one, please call our office on 07 3435 4300. You can also download a membership form from the website.

Membership gives you the opportunity to vote at the AGM, vote for board representatives, or nominate yourself to serve on the board. **You do not need to be a member to receive services or support.**

Calendar of events

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

August

8 - Toowoomba support

18 - Townsville support

9 - Brisbane support

22 - Ipswich support

September

5 - Redlands support

15 - Townsville support

8 - Sunshine Coast support

17 - *Running for Nan's HD* event

12 - Gold Coast support

20 - Logan support

13 - Brisbane support



We're pleased to introduce you to the full team at Huntington's Queensland (L - R): Lauren Ward (Client Services Coordinator), Caitlin Scarr (Communications Coordinator), Jan Samuels (Chief Executive Officer), Jennifer Lysiuk (Finance Officer), Despina Gomez (Service Support Officer), and Tressa Byrne (Client Services Officer).

NDIS on a roll

Townsville has recently marked the one-year anniversary of the National Disability Insurance Scheme (NDIS) rollout, and Huntingtons Queensland has observed significant positive outcomes for many of our community.

Although there are significant challenges that come with an overhaul of this scale, several Townsville-based clients have received substantial funding packages which have enabled them to have better access to health professionals, quality equipment and daily supports and services. This funding has resulted in improved quality of life for many, and our team is cautiously optimistic that many in our community will face improvements in their daily lives as a result of the NDIS.

NDIS participants have an opportunity after the first year of funding to review their package with the National Disability Insurance Agency (NDIA), who organise and operate the NDIS. This one-year review is a key opportunity for individuals to assess and amend their funding package. Lauren and Tressa are available to act as advocates and supports through this process if you wish. Give the team a call to discuss your options.

Mackay participants are also approaching their one-year anniversary, and Toowoomba and Ipswich rollouts are now well and truly underway. Our team is anticipating similar positive outcomes in these areas for our clients, and continue to work alongside and support clients through the rollout process.

There is also good news for current Queensland government disability funding recipients in Bundaberg and Rockhampton, who will be able to transition to NDIS funding earlier than anticipated. You can see the updated rollout dates to the right.

NDIS rollout dates

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|---|---|
| 1 September 2017 Bundaberg Current funding recipients only | 1 October 2017 Bundaberg region - All eligible participants |
| 1 November 2017 Rockhampton, Gladstone and West Current funding recipients only | 1 January 2018 Rockhampton, Gladstone and West All eligible participants |
| 1 July 2018 Cairns to Torres Straight region | 1 July 2018 Brisbane, Logan, Redlands Gold Coast and Hinterland, Fraser Coast, North and South Burnett regions |
| 1 January 2019 Sunshine Coast, Gympie and Moreton Bay region | |

Spark NeuroCare, of which Huntingtons Queensland is a founding partner, also celebrated its one year anniversary in Townsville, and is rolling out in Toowoomba as well. If you have questions about these services, you can contact us on 07 3435 4300 or call Spark NeuroCare directly on 1800 875 244.





Education sessions in nursing facilities provide better quality of life outcomes for people living with Huntington's disease

On the road

Our Client Services team have been working alongside families, healthcare providers and the community to improve education and support the care needs of people with Huntington's disease in Queensland.

As a complex disease, our team has found that education is a primary requirement for all involved in the care and support of our clients, and it has become a leading charter for the team to ensure our clients are receiving the best care and treatment possible.

Education sessions occur regularly in nursing homes, accommodation facilities, schools and in general community sessions, and are available upon request. If you would like information about our education sessions, contact Lauren on 07 3435 4305.

Support group meetings are quickly developing into well-attended and diverse occasions, with attendees discussing areas of concern in managing day-to-day issues, healthcare options and outcomes, research updates and general social chit-chat.

Lauren and Tressa are able to attend most meetings to facilitate general discussions and answer one-on-one and group enquiries. **One-on-one and crisis support** is a very important area for our team, and Lauren and Tressa have been working with individuals and families to provide advocacy and mediation.

Updated contacts

Lauren: CSC@huntingtonsqld.org.au, 07 3435 4305 or 0488 556 636

Tressa: CSO@huntingtonsqld.org.au, 07 3435 4306 or 0488 556 626

Please be aware that old mobile numbers are no longer monitored.

If you have questions, need support, or don't know who to talk to, give Lauren or Tressa a call to see how we can help.

NDIS support and advocacy for people with Huntington's disease has been a focus for Huntingtons Queensland since the rollout commenced, and the team has been working closely with families throughout Queensland to ensure positive outcomes through the funding packages.

We will also continue our involvement with Spark NeuroCare in Townsville and Toowoomba to ensure great outcomes for all involved.

HDYO Camp 2018

HDYO Camp is back, with support from Huntingtons Queensland! Early in 2017, the international Huntington's Disease Youth Organisation (HDYO) brought their highly successful youth camp to Australia for the first time, and luckily for us, they chose the beautiful Sunshine Coast.

HDYO will be returning in January 2018, and our staff will be there to assist. Registrations are now open for young people (15 - 25) living in Australia or New Zealand who are impacted by HD.

The camp will run from Friday 12 January – Monday 15 January 2018 in Currimundi. And the best thing? The camp is **COMPLETELY FREE**, including travel to and from the location! Registrations and more information are available at **HDYO.org**.



Running for Nan's HD 2017

Running for Nan's HD is returning in 2017, and **we want you!** Get out in the fresh air, raise awareness for Huntington's disease and support this great event.

The wonderful Kelly Stamnas is organising a huge community fun run in honour of her much-loved Nan, who lives with Huntington's disease. All funds raised will go to support Huntingtons Queensland's work in the community.

Last year, Kelly ran 2,200km and smashed her fundraising goal of \$10,000. This year, she wants to raise \$15,000, and she needs your help to make it happen by participating in another fabulous community fun run.

The details

Date: Sunday 17 September 2017

Time: 6am start

Location: Holman Street Park, Kangaroo Point, Brisbane

Distance: 5km or 10km (which you can stroll, walk, jog, run or sprint!)

Entry: \$25

Register your entry: stickytickets.com.au/55159

Participants will get a race bib, medal, and have the opportunity to revive themselves with a delicious free sausage sizzle at the end of the race.

Huntingtons Queensland is very proud to support Kelly in her extraordinary efforts. We hope you can lace up your jogging shoes and pound the pavement with Kelly, but if you're not able to walk or run, we'd love some volunteers on the morning.

Contact Caitlin on FRC@huntingtonsqld.org.au if you think you can help. If you can't be there on the day, you can support Kelly by making a donation and sharing the page with everyone you know.

Running not your thing?

Can you help us by volunteering?

Contact Caitlin at FRC@huntingtonsqld.org.au

Donate to Kelly's fundraising campaign! Visit: give.everydayhero.com/au/running-for-nan-s-hd

Please come along for free to cheer on those walking and running!

All funds raised go to Huntingtons Queensland