

## Autumn 2018 news flash



*Clockwise from top left: the Ipswich Christmas catch-up, Kat & Tressa at the Huntingtons Queensland Christmas party, the welcome pack for HDYO campers provided by Huntingtons Queensland, a few happy HDYO campers with Lauren, the Townsville support group celebrating Christmas in style, and the Colley family raising funds for Huntingtons Queensland through their school's crazy hair day.*

## 25 years since HD gene identified

The month of March this year marks a significant historical event for Huntington's disease – it has been 25 years since news broke that the disease-causing gene had finally been discovered.

The news was first published in as a journal article in the scientific journal *Cell*, on 26 March 1993.

The article identified the discovery of the CAG expansion, after studying 75 different families with the disease.

This discovery provided researchers with a new, targeted focus, and offered a breakthrough that would lead to many new discoveries for a range of diseases.

It has also led to the new clinical trials underway overseas that may provide a form of treatment.

So it's with great excitement that we acknowledge this 25 year anniversary! Jump onto our Facebook page towards the end of March for some flashbacks to the game-changing announcement.

***Make sure you are on our email list to get the latest news and event invitations!***

## Family Fun Day coming up at the Gold Coast

We have a Family Fun Day coming up at the Currumbin Wildlife Sanctuary on the Gold Coast.

Families are invited to join us for a free day on **Sunday 18 March**, where you will tour the sanctuary, see the wildlife, come together for a catered lunch, and maybe even cuddle a koala.

This wonderful day has been made possible through the generosity of the Alecca McKinless fund. Alecca was greatly involved with Huntingtons Queensland, and left a generous bequest to our organisation.

Alecca's husband Alan still actively volunteers for us, and we are proud and humbled that we can use Alecca's gift to bring joy to HD families.

This will be the first of three Family Fun Days for 2018. The other two will be held later in the year in different parts of Queensland.

To reserve your free ticket, go to our website and complete the form online. Expenses covered are entry and lunch.

You can find out when the next Family Fun Days are coming up (one is mentioned in this newsletter) through our newsletters, email notifications, website and Facebook page.

## Family Fun Day in Cairns – save the date!

As part of our Queensland-wide Family Fun Days for 2018, we are hosting a sponsored family day in Cairns on **Sunday 17 June**.

This event is available to all Huntingtons Queensland clients and their families.

Please note, however, we are unable to cover transport and accommodation costs. Costs that will be covered will be entry to the event and lunch.

Information about the event will be sent out in the next few months via email, and will ask for expressions of interest.

If you would like more information and to express interest in attending, make sure we have your email address.

You can call or email our office (07 3435 4300 or [admin@huntingtonsqld.org.au](mailto:admin@huntingtonsqld.org.au)) to confirm we have your correct details.



## Calendar of support groups

Visit [huntingtonsqld.org.au/support/whats-on](http://huntingtonsqld.org.au/support/whats-on) for a list of all upcoming events and support groups.

### March

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

### April

3 - Gympie support    11 - Brisbane support  
4 - Bundaberg support    20 - Townsville support

### May

8 - Toowoomba support  
9 - Brisbane support  
18 - Townsville support

### June

5 - Redlands support    15 - Townsville support  
8 - Sunshine Coast support    20 - Logan support  
12 - Gold Coast support    26 - Ipswich support  
13 - Brisbane support



# The drug trial that broke headlines around the world

The biggest HD news in recent months was the announcement that a drug targeting Huntington's disease was confirmed to be safe for human use, and would be moving on to a second phase of trials to test its effectiveness against HD.

The trial for the drug, named IONIS-HTTRx, is a huntingtin-lowering therapy (sometimes called 'gene silencing') delivered directly into the spinal fluid via lumbar puncture.

It is hoped the drug can reduce the harmful number of CAG repeats in the faulty HD gene.

The first trial to test the drug's safety was announced a success, meaning it can move towards trialling the drug's effectiveness in lowering the huntingtin protein.

However, researchers were excited to announce that they did identify a lowering of the protein in recipients during the initial trial, which was the cause of great excitement throughout the international community.

To answer some more of your questions, we've included the excellent articles from HD Buzz, explaining what the trial means, and answering some of the most common questions.

You can view the articles online here: [hdbuzz.net/249](https://hdbuzz.net/249) and [hdbuzz.net/250](https://hdbuzz.net/250).

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## The headlines kept on coming...

**Huntington's disease: 'Ground-breaking' new drug gives hope for patients**

**New experimental drug for Huntington's disease could be groundbreaking, local doctor says**

**Ionis Pharmaceuticals Licenses IONIS-HTT Rx to Partner Following Successful Phase 1/2a Study in Patients with Huntington's Disease**

The science behind the stories: drug treatment to slow progress of Huntington's disease.

**New drug could offer first treatment for irreversible Huntington's disease**

**Huntington's breakthrough may stop disease**

**Success! ASO drug reduces levels of mutant protein in Huntington's disease patients**

**Excitement as trial shows Huntington's drug could slow progress of disease**

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## A few important notes about the drug and the initial human trial:

- The completed trial was only to test the drug's safety for people, and was not testing if the drug actually worked. That will come with the next trials, which are not yet scheduled, so we cannot currently say if the drug will work or not.
- The trial is not currently available to people in Australia. The next series of trials will likely take place in Europe and possibly North America, but this is yet to be confirmed.
- If a trial does eventually occur in Australia, most applicants will likely be selected from those involved in Enroll HD. You can participate in Enroll HD now - visit [www.enroll-HD.org](https://www.enroll-HD.org) for information. (However, participation in Enroll HD does not guarantee selection for any forthcoming clinical trial.)
- The drug is intended to reduce the harmful levels of huntingtin protein. However, even if it can do this, researchers cannot yet say if that will have any effect on symptoms. They are hopeful that this reduction may slow down or stop the progression of HD symptoms, but they cannot know this until they complete further trials.
- If the drug is successful, it will not stop the genetic factor of HD – this means that HD can still be passed from parent to child.

# May: HD awareness month

Awareness is one of the greatest challenges facing any rare disease, and Huntington's disease is no different.

A key focus of Huntingtons Queensland is to increase awareness of HD, which in turn leads to greater support in the wider community and of research projects.

This year, Huntingtons Queensland is joining an international awareness movement called *#LightItUp4HD*.

This campaign is part of the internationally recognised Huntington's Disease Awareness Month, and will be acknowledged and celebrated throughout the world during the month of May.

We are excited to announce that we have a number of city and regional councils and private businesses on board to support this campaign, lighting up buildings and bridges throughout Queensland.

**Save the date:** On Friday 11 May, Huntingtons Queensland will be hosting a special forum for awareness month. Save the date, and keep your ear to the ground for more information! We are also planning some special events during the month of May, so keep an eye on our Facebook page and help us spread the word.

## You can see the lights here:

- Brisbane Victoria Bridge: 9 and 10 May
- Brisbane Story Bridge: 9 and 10 May
- Brisbane Treasury Casino: 11 May
- Maryborough City Hall: 11 May
- Toowoomba City Hall: 7 – 13 May
- Toowoomba Victoria Street Bridge: 7 – 13 May

If you think you can get somewhere lit up in blue and purple, let us know! The more we can achieve, the greater the impact.

We'd also love to see you light it up at home – pop some blue or purple cellophane over a lamp, snap a photo, and flood our social media with blue and purple. Let's *#LightItUp4HD*!



## Office closure

Easter is just around the corner, and with Easter comes public holidays. Our office will be closed Friday 30 March – Monday 2 April.

During this time, you may leave voice or email messages for our team, who will respond upon their return from Tuesday 3 April.

Our office will also be closed for the Anzac Day public holiday on Wednesday 25 April, and the Labour Day public holiday on Monday 7 May.

In an emergency, you should always call 000 first. If you need crisis support while our office is closed, you can call Lifeline 24 hours a day on 13 11 14.

# Huntingtons Queensland supporting local PND research

Huntingtons Queensland is proud to be supporting the acceleration of a research project being undertaken by University of Queensland Associate Professor Dr Trent Woodruff.

Through the generosity of supporters, we have committed \$30,000 over three years, with the majority of this year's contribution coming from a generous gift from the late Susan Arnison.

Dr Woodruff's research relates to an inflammation-inhibiting drug that has the potential to slow progression of MND and help manage the symptoms of people living with the condition, which like HD, is a progressive neurological disease.

This research could have significant impact for a range of progressive neurological disease, and the organisation is proud to support important PND research.

You can read the full article here:

**<https://shorthand.uq.edu.au/medicine/mnd-drug-nears-clinical-trials/>**

Donations toward HD research are always welcome. To make a donation, please call our office or donate through our website at [www.huntingtonsqld.org.au](http://www.huntingtonsqld.org.au).

## A marathon a month!

Steven Blaine doesn't have time for much socialising this year – if he's not working, he's training for a marathon.

Well, more specifically, 12 marathons.

Steven, a Perth resident and accomplished runner with family in Queensland, has set himself a challenge to run a marathon every month throughout 2018, for an amazing reason.

Steven is raising awareness and funds for people impacted by Huntington's disease, and all his fundraising is being donated to Huntingtons Queensland.

Funds will go towards our range of services and support options, directly helping local families.

Steven is hoping to raise \$10,000 this year, but cannot do this without your support.

You can follow his journey and donate to his efforts by visiting: **[everydayhero.com.au/the-huntington-s-marathons](http://everydayhero.com.au/the-huntington-s-marathons)**.

You can also find the link through our Facebook page.



*Steven is running a marathon a month in 2018!*

Steven is also looking for sponsors to help cover the cost of entry to the marathons. If you have a business and would be able to support Steven's efforts through sponsorship, please contact our office and we can help get things organised.

Thank you Steven! We're right behind you!

# HDYO camp 2018

A huge congratulations and thank you is in order for the team from Huntington's Disease Youth Organisation (HDYO), who travelled from the USA and England to facilitate the 2nd ever HDYO Australasian camp.

Huntingtons Queensland was very proud to support this great event, which saw nearly 50 young people from across the country come together for a few special days of networking, fun and information.

Our special thanks to Kat and Chandler from HDYO and Monica from Huntingtons WA for their integral role in making the camp a reality, and for making their way to Queensland to run the camp. We can't wait for next year!

For information about future HDYO camps, follow our Facebook page and HDYO's website ([hdyo.org](http://hdyo.org)).



*Top (from left): Kat (HDYO), Lauren (Huntingtons Queensland), Chandler (HDYO), Monica (Huntingtons WA), Jan (Huntingtons Queensland)*

*Bottom: 2018 campers working up a sweat while indoor climbing*

## Membership renewals

Membership renewal invitations will be sent out before the end of the financial year. Invitations to renew membership will only be sent to those who renewed membership for the current financial year.

If you believe you are a current member and have not received a membership renewal pack in the mail or by email by 1 June, please contact our office on 07 3435 4300.

If you would like to become a new member, or would like to renew a membership you held before this financial year, please call our office and we will be happy to assist.

**Your membership fee helps to fund our services and ensure families impacted by HD can access the information and support they need.**

Members can also stand as and vote for board directors and influence changes to the organisation's constitution, and other governance issues.

Membership is not related to services, and you do not need to be a member to access client services support.

## Contact us

**Phone:** 07 3435 4300

**Website:** [huntingtonsqld.org.au](http://huntingtonsqld.org.au)

**Email us:** [ADMIN@huntingtonsqld.org.au](mailto:ADMIN@huntingtonsqld.org.au)

**Post:** PO Box 635, ANNERLEY QLD 4103

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

**Support Groups:**  
[SUPPORTGROUPS@huntingtonsqld.org.au](mailto:SUPPORTGROUPS@huntingtonsqld.org.au)

**ABN:** 45 130 081 598