

Autumn 2022 news flash



Event organiser Kelly Connolly with her Nan, xx.

Running for Nan

It's back! If you have been keeping a low profile you may have missed the news – Running for Nan's HD is back after a hiatus. It is being held on Sunday, May 22 – an ideal time given May is Huntington's Disease Awareness Month.

Organised by HD advocate Kelly Connolly whose Nan, a great great grandmother aged 94, lives with HD, this wonderful event aims to raise money for Huntington's Queensland and will be held on the Wynnum Esplanade.

Participants can choose to walk or run 5km or 10km routes at their own pace and all participants receive a finisher's medal and free barbecue.

It has been just over two years since the last Running for Nan's HD due to COVID-19 restrictions so the excitement levels are high. For anyone not able to make it on the day, you can register and participate virtually and complete your 5km or 10km wherever you are.

Entry is \$25 with raffle tickets for some awesome prizes only \$2 each. Registration is from 5.30am with the event kicking off at 6.30am at the Wynnum Wading Pool on The Esplanade.

To register or purchase raffle tickets visit huntingtonsqld.org.au/run

We look forward to seeing you on the day. And thank you Kelly for your tireless work in supporting Huntington's Queensland and people impacted by HD.

Did you know?

Huntingtons Queensland has Facebook and Instagram to keep you connected with our latest news. Find out more about us, our events and services as well as the latest research news and information on other interesting topics. Check us out today!



www.facebook.com/huntingtonsqld



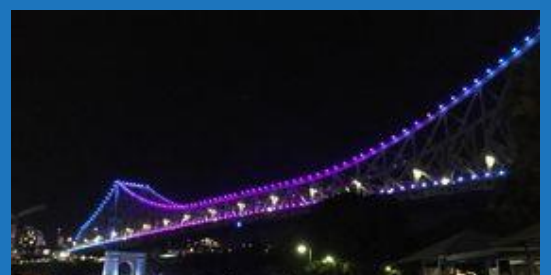
www.instagram.com/huntingtonsqld

Forum update

Time keeps running away from us! This year's Alecca McKinless Forum has been postponed until 21 October 2022. With the last forum held only seven months ago the decision was made to spend more time securing presenters you would like to hear. If you have any suggestions for speakers or topics of interest please let us know by emailing admin@huntingtonsqld.org.au

Light up for HD

May is Huntington's International Awareness Month – now a global campaign to increase awareness of the disease. In previous years iconic Brisbane structures such as the Story Bridge and Treasury Hotel have been lit with the Huntington's colours of blue and purple. And while Brisbane will miss out this year make sure you check out the efforts of our other states and our international partners in shedding light on such an important disease.



Give a warm welcome to Shaun

Hello! I am delighted and honoured to be writing to you as the Operations Manager with Huntingtons Queensland. I would like to thank the Huntingtons Queensland Board for my appointment, replacing CEO Jan Samuels who has retired to her native New Zealand.

I come to Huntingtons Queensland having worked within the not-for-profit sector for the past 20 years in residential and community aged care services. This includes the past 14 years as the Director of Jubilee Community Care, a community aged care service provider in Brisbane.

I enjoy working within service organisations alongside staff and volunteers in the development of support services that benefit clients and staff. I also respect the voluntary time, energy and commitment invested by Board Members of not-for-profit organisations and look forward to making a positive contribution and support to the Huntingtons Queensland Board.

During the three months of my employment to date, I have met with a number of people including former Board Members, staff, financial donors and CEOs from other Huntingtons state associations. Our meetings have been invaluable to me in learning of the history of Huntingtons Queensland, of projects that would not have happened without the funding by donors and of contemporary issues faced by people and families impacted by HD.

On a more personal note, I am married to Sarah who, like me, has spent her career working in service organisations. We have a daughter Kate who is studying at UQ. Our family is completed by Lilly the cat and the love of my life Molly the dog (my wife is accepting of the love Molly and I have for each other)! Sarah and I spend time bushwalking and I am an avid sports fan of any sport that involves a ball, particularly football (as in soccer).



*Shaun is enjoying meeting friends of HQ.
Above: Former staff and Board member Gwen
Below: Jackie from the Gold Coast social group*

As we have just acknowledged ANZAC Day, I am proud to inform of my service in the British Army with the Royal Electrical and Mechanical Engineers for five years in the 1980s, having served in West Germany (as it was then known), The Falklands and Northern Ireland.

My role at Huntingtons Queensland is on a fixed-term basis until August 2022. During this time I will be very much motivated in working alongside staff and my thanks go to staff members who have made me welcome and provided valuable knowledge and information to assist me in my role.

Lastly, can I please ask you to reach out to me at Huntingtons Queensland with your operational and fundraising thoughts and ideas, as we all have the common aim of supporting people and staff within the Huntingtons community.

Kind regards
Shaun

Join the Map-HD Registry

Do you want better access to future clinical trial opportunities and services to support you in your Huntington's Disease journey?

Join the Map-HD Registry - the first-ever Australia-wide registry which is an initiative of the Huntington's Disease Network of Australia (HDNA) led by Monash University Professor Julie Stout.

Responses for the Registry are beginning to trickle in, but more are needed to help facilitate the best quality of life for every person impacted by Huntington's Disease.

Australians affected by the disease, including family members and carers, are encouraged to register as soon as possible.

The Map-HD Registry aims:

- To map families, clinicians, and support services to create a complete picture of HD across Australia.
- To develop an Australia-specific HD model of care in 2022, to address the disparities and unmet needs of people impacted by the disease across Australia, and
- To enable rapid uptakes of treatments and interventions for HD when they become available.

Professor Stout said data collected by the Map-HD Registry would also be shared with State and Commonwealth governments to inform decisions about where resources should be located, and what resources are needed.

"The registry will show where HD support and clinical services are best placed, increase the efficiency of HD research, connect people with research and clinical trial opportunities and generate new knowledge to inform the development of new treatments," Professor Stout said late last year when promoting the program.

"We know that families affected by HD have so much to bring to the table. We want to work with them to create the tools they need to navigate the systems and support each other in their HD journey."



Learn more at [HDNA.com.au](https://hdna.com.au), email info@hdna.com.au or call 03 9902 0081.

2022 Tax Appeal

Keep an eye on your letterboxes - it is time for our annual tax appeal.

Here at Huntingtons Queensland we rely heavily on your generous donations which make up a significant proportion of our total annual income.



These donations are key to HQ being able to continue delivering services across the state, supporting individuals and families impacted by Huntington's Disease.

Money raised also helps us to provide education and assistance to health professionals and service providers also supporting our cherished community.

So, as we near the end of the financial year we ask for your support. Donations over \$2 are tax deductible. If you don't subscribe to receive our tax appeal via mail, donations can be made via the QR code above, our website huntingtonsqld.org.au or by calling our office 3364 3222. Thank you for your generosity.

New drug trial starting

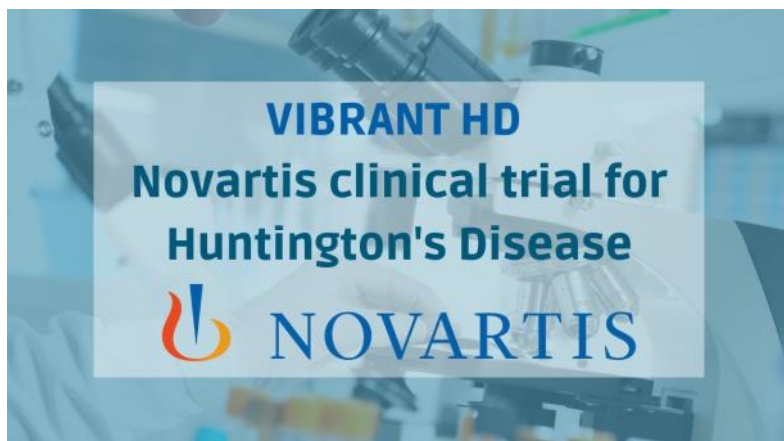
New research is showing how an existing drug could hold promise for treating Huntington's Disease. According to an article on the HD Buzz website, Novartis Pharmaceuticals scientists have detailed how the oral medication Branaplam, originally used to treat spinal muscular atrophy, can lower levels of the Huntingtin protein. The finding is now being tested in the phase IIb study VIBRANT-HD.

The effects and ways to lower the level of the Huntingtin protein in an individual is the focus of a few studies currently. Every person with HD has an expansion in their huntingtin gene which means they will make an expanded form of the huntingtin protein. This expanded form of the protein is thought to be toxic and to cause the signs and symptoms of HD. If scientists can reduce the amount of this toxic form of the protein, researchers hope to slow or stop the progression of HD.

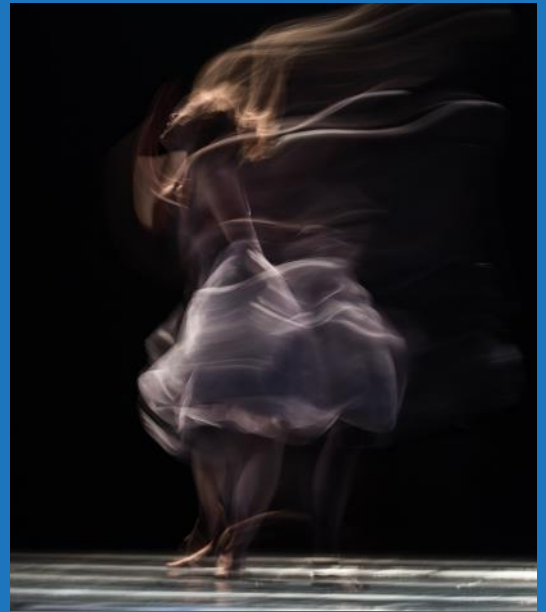
So far Branaplam's interactions have been studied in cells in a petri dish and also in mice. The next stage is to test its effectiveness in adults with HD to work out what dose of Branaplam is needed to lower huntingtin. This will be the focus of the VIBRANT-HD trial.

The trial will be conducted over approximately two years and will include participants showing early signs of HD. Each will be given varying amounts of the Branaplam oral solution or a placebo once a week with the aim to determine the correct dose required to lower mutant huntingtin protein levels in the cerebrospinal fluid (CSF) to a degree expected to be efficacious over longer periods of time.

While Australia is not one of the trial sites you can find more information on the trial and branaplam by visiting the HD Buzz website at <https://en.hdbuzz.net>



Education key to effective support



The provision of best-practice care and support underpins all we do at Huntingtons Queensland. While we are readily available, your day-to-day support may come from your local medical professional or service provider who might have little or no experience caring for and assisting someone with HD. But we can help with that too!

The Client Services team at Huntingtons Queensland can provide education and information sessions for service providers caring for individuals with Huntington's Disease. These may include residential care staff, medical professionals, and NDIS and other community service providers.

The presentation-style sessions include a thorough overview of Huntington's Disease in a practical and educational way. There also is the opportunity to seek further knowledge from our experienced staff about best practice and what to expect as the disease progresses during Q&A sessions afterwards.

Sessions are available upon request to any service provider in Queensland. To find out more or to book a session visit huntingtonsqld.org.au/education/ or email education@huntingtonsqld.org.au

Federal election postal vote



With the Federal Election being held on Saturday, May 21 there is help available if you are unable to get to a polling booth to cast your vote. You may be eligible to register for a postal vote.

You should apply for a postal vote as soon as possible, with the applications to the Australian Electoral Commission closing May 18. Once you register a voting pack including instructions and ballot papers will be sent to you.

To find out more information or to register visit www.aec.gov.au/election/pva.htm

Mark your calendar

Visit huntingtonsqld.org.au/support/whats-on/ for a full list of upcoming events and support groups. Please note that some events may be changed or cancelled, check our website for the most up-to-date information. RSVP is essential. If we receive no RSVPs the event will be cancelled.

May

- 20 – Toowoomba visit
- 22 – Running for Nan's HD fundraiser
- 25 – Brisbane North coffee catch-up



June

- 1 – Redlands social lunch
- 2 – Online Zoom support group
- 8 – Brisbane South coffee catch-up
- 14 – Ipswich coffee catch-up
- 14 – Cairns coffee catch-up
- 17 – Townsville visit

YOUR DONATION TRULY MAKES A DIFFERENCE — THANK YOU!

Name: _____

Postal address: _____

Email: _____ Phone: _____

Donation amount: \$ _____ Card number: _____

Name on card: _____ Card expiry date: _____

Signature: _____

Donations \$2 and over are tax deductible. Please provide your details so we can send you a receipt.
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