

Spring 2022 news flash



Forum 2022

You are invited to join us at Brisbane's Treasury Hotel for our 2022 forum, which will run from 12.30pm to 5.30pm on 21 October, followed by our ever-popular drinks and canapes in the courtyard.

The theme of this year's event is *Living well with Huntington's Disease*.

This year's line-up includes presentations from Professor Julie Stout from Monash University, Neurologist Professor John O'Sullivan, Occupational therapist Talisha, Social worker Deb, Palliative Care Queensland and personal stories from clients and family members.

There is no cost to attend the forum, which is funded through the generosity of gifts from Alecca McKinless and the Rogers family, but registrations are essential.

Please [CLICK HERE](#) or visit our website www.huntingtonsqld.org.au to book your place. If you have any questions please contact Cathy on 07 3064 3222 or email admin@huntingtonsqld.org.au. Hurry, as numbers are strictly limited.



Become a member

Have you considered becoming a financial member of Huntingtons Queensland?

Members have been the backbone of our organisation, now in its 46th year and as we work towards the next exciting chapter to ensure the continued growth of services to everyone who is impacted by Huntington's Disease we hope you will join us on this journey by becoming a member. Help us to keep delivering the valuable services that positively impact our HD community.

Members support has helped us grow from a small group of dedicated volunteers to an established professional organisation on the cusp of national impact. If you have thought about joining now is a good time.

Being a member enables you to vote at our upcoming Annual General Meeting including the special resolution vote for the proposed merger.

[CLICK HERE](#) or visit the membership tab on our website www.huntingtonsqld.org.au

What Support Group is right for me?



As well as providing advice, support, information and advocacy to people who are impacted by Huntington's Disease we also facilitate and promote a variety of groups around the state. You may receive various email invites from us for 'support groups' or coffee catch-ups', but what are each of these groups and what do they 'look' like?

Each group provides an opportunity to meet others, ask questions, share knowledge, seek information and get support. Most importantly, all these groups are a safe space and attendees can come along to talk up a storm or just sit back and listen. No matter the name of the group, anyone whose life may be impacted by Huntington's Disease is welcome to attend including partners, children, family, friends, and neighbours. Our attendees help shape each group into what works best for them so it can vary from region to region.

Our groups include:

- **Support Groups:** A formal, yet comfortable group which meets up in a private space. These groups may at times include speakers, special guests and topics on the agenda.
- **Online support groups:** An informal group that meets online via Zoom. These groups occasionally will have a guest speaker.



Brisbane social group enjoying a coffee this month

- **Coffee catch-ups:** An opportunity to meet with others in a comfortable public venue with coffee/tea and possibly cake!
- **Social lunch or dinner:** Just like coffee catch-ups except the attendees meet up while enjoying a meal.
- **Area visit:** One of our Huntington's Disease advisors will be in an area and available to meet. These areas may not have a formal regular group that gets together, but we offer the opportunity to meet either individually or as a group.
- **Social group:** A group run by members of the local Huntington's community, with a focus on informal socialising over lunch or fun activities.

If you feel a little daunted about attending one of our various groups but would really like to talk to us, please reach out and we can arrange to meet with you one on one while we are in your area or over the phone if that makes you more comfortable. Ultimately the key word here is **support** and that can mean different things from one person to the next.

If you have any ideas or suggestions on how we can support you in your area we would love to hear from you.

Please note - it is important that we do require attendees to RSVP to events. If no RSVPs are received, we will assume no one will be in attendance and the event will be cancelled.

For information about receiving notifications from Huntingtons Queensland or our different support groups and social opportunities, phone us on 3064 3222, email admin@huntingtonsqld.org.au or visit the Support and Services section of our website at www.huntingtonsqld.org.au

HDYO Congress Scholarship opportunity



HDYO have officially opened new scholarship applications to attend HDYO's international Young Adults Congress in March 2023 in Glasgow, Scotland!

Awardees will be selected based on need and maximising the impact of available funds.

To be eligible to apply:

- you must be a young person impacted by HD, over the age of 18
- you must be available to attend part or all of the congress on the 17th to 19th March 2023
- if outside the UK, you must have travel documents which will allow you to travel to Glasgow

[CLICK HERE](https://hdyocongress.org/funding/) to apply or visit
<https://hdyocongress.org/funding/>

Bowling for support



Get your tenpin shoes on and warm up your arms – we are going bowling! Huntingtons Queensland is thrilled to again be the beneficiary of Strathpine Bowl's Huntington's Cup on Sunday 20 November. Come along and join in the fun while raising funds to help us to continue the important work of supporting people impacted by Huntington's disease.

The event is a doubles event and is open to everyone. Bowlers can choose to participate in either the scratch or graded divisions. Check-in is from 9am with bowling starting at 9.30am. Raffle tickets will also be available on the day and there are some great prizes to be won.

Entry is \$100 per team for the scratch division and \$120 for the graded division (graded participants are eligible to win both divisions) A \$50 deposit is required to secure your spot. Please call the friendly staff at Strathpine Bowl to reserve your lane on 3205 5386.

A big thank you to Chloe Marks for again organising this event and Strathpine Bowl for hosting. We couldn't continue our work without your fantastic support.

Call 3205 5386 to reserve your spot.



Event organiser Chloe Marks and her mum, Karen.



Attention Occupational Therapist

Just a reminder ... Register now for our OT workshop on Friday 14 October from 10am to 12pm. Cost is \$30 per participant. A certificate of attendance will be provided to allow participating OTs to claim CPD hours.

The two-hour online workshop will feature guest speaker Talisha, team leader and a senior OT from OpportunOTy. Talisha has extensive experience working with people with HD.

PLEASE NOTE: This workshop will be for professionals only

[CLICK HERE TO REGISTER](https://app.etapestry.com/onlineforms/HuntingtonsQueensland/OTworkshop.html) or visit
<https://app.etapestry.com/onlineforms/HuntingtonsQueensland/OTworkshop.html>



An update from Shaun

A big thank you everyone who recently completed our 2022 Client Survey. We have received replies from all areas of Queensland with nearly half of the respondents from family members of people living with HD in the Brisbane Region, on the Gold Coast, from Far North Queensland, Central Queensland, the Mackay Region and on the Darling Downs.

The information from the survey informs us that people see our purpose across a wide variety of functions but particularly to provide support, information and to keep up to date with clinical trials being conducted.

The importance of our services were highlighted as providing families with support and counselling, assistance and advocacy with Centrelink, NDIS and Medicare, organising community events and support groups, and providing education for carers.

Whilst less than 5% of respondents were dissatisfied with the services we provide often it was due to a lack of representation in geographical regions. We were asked to consider more frequent connections to rural areas including north Queensland and additional fundraising events.

When asked if Huntingtons Queensland should provide NDIS services 92.5% said YES and directed to us to the following services to be provided under the NDIS program:

- Education for carers and support workers
- Support Coordination
- Specialised Support Coordination
- Occupational Therapy
- Other services; education for Dr's and medical centre staff, more connection with rural areas

Your input via this survey will provide real data which can then be used to develop strategies and plans and guide our leadership as we position for the future.

As previously communicated, Huntingtons Queensland along with the four State HD Associations of New South Wales/ACT, South Australia/Northern Territory, Tasmania and Western Australia formed a Consortium of Australian Huntingtons Associations (CAHA) over 12 months ago. CAHA has representatives from the five State Associations through Board members and operational managers.

CAHA has been considering whether the creation of a national body, merging together as one organisation is the best way forward for the five State Associations. At the heart of the considerations is whether this would be in the best interests of our HD community. The recommendation of CAHA to the Boards and Members of the five Associations is that the best interests of the HD community is best served with a single national entity with a focus to deliver better and additional programs and services, and to become more financially sustainable.

Each State Board has determined that the merger is the best path forward for people affected by Huntington's disease. At the upcoming Annual General Meeting of each State Association, a Special Resolution will be put to attending members asking whether they agree that their Association merge into a new, single, national entity and to eventually wind up their State Association, transferring all its assets (and liabilities) to the new entity.

Membership renewal letters have recently been sent to members and I urge all members to renew your membership, as being a member will also give you the benefit of being able to vote at our upcoming Annual General Meeting including the special resolution vote for the proposed merger.

If you have any questions about the merger, please don't hesitate to contact me via our office 07 3064 3222 or directly by email sriley@huntingtonsqld.org.au



Thank you
Shaun Riley
Operations Manager

Juvenile HD registry now open



Young people with Juvenile Onset Huntington's Disease (JoHD) and their families are being encouraged to register on the new global JOIN-HD registry.

The registry opened in February and is managed by the Huntington's Disease Youth Organisation (HDYO) which collects experiences from both young people who have JoHD and their caregivers. It is different to the Australian Map-HD Registry developed by the Huntingtons Disease Network of Australia.

JOIN-HD will be carried out in three stages, with increasing information being collected at each stage. At stage 1, participant's demographic data will be collected, along with information about any links they have with the HD community. At stage 2, information on both medical history and caregiver and patient experiences of JoHD will be collected. Stage 3 will incorporate a clinician-led interview and taking of family history. The information people add to the registry will help medical professionals understand more about JoHD.

The registry aims to:

- Identify and engage people with JoHD in the collection of information that will speed up research into this disease.
- Improve advocacy, care, and support for young people with JoHD and their families.
- Contribute towards creating a multinational network of leading healthcare JoHD professionals.
- Learn what people with JoHD and their families need so it can improve support and education programs.

The JOIN-HD team and its Scientific Oversight Committee work across America, Switzerland and the United Kingdom. It is the chance to connect with others globally, and to provide information that will propel future research for JoHD patients.

More information about the Registry can be found at <https://join-hd.org/> For any additional information or questions, email Rebecca at registry@hdyo.org



Education by the sea

Staff at the disability support provider Caregiva welcomed our Huntington's Disease educator Lauren to speak in Hervey Bay recently. Providing education about Huntington's Disease to health care and service providers is a key way Huntingtons Queensland can indirectly support people impacted by HD. The sessions are designed primarily to help service providers and professionals give patients with Huntington's the best care possible.

During these sessions, providers are given a thorough overview of Huntington's Disease in a practical and educational way, and have the opportunity to seek further knowledge from our experienced staff about best practice and what to expect as the disease progresses

If you would like to know more about our Information and Education program visit <https://huntingtonsqld.org.au/education/about-information-and-education-sessions/>



Research Updates

Keeping abreast of research news can be time-consuming. Here is some of the latest news from across the world.

Nested trials a critical next step in HD research: A new study has found long-term trials of interventions to promote physical activity for people with Huntington's Disease are feasible, with a "nested trial" approach that assigns some patients already taking part in an observational study to an activities group while others serve as controls. Huntington's Disease News reports the year-long effort was designed as a nested trial, also called a trial-within-cohort study, with its researchers considering this approach a "next critical step in progressing the evidence in support of non-pharmacological life-style interventions in Huntington's Disease management." The study, "Physical activity and exercise outcomes in Huntington's disease (PACE-HD): results of a 12-month trial-within-cohort feasibility study of a physical activity intervention in people with Huntington's disease," was published in *Parkinsonism and Related Disorders*.

You can read more here: <https://huntingtonsdiseaseneews.com/news/long-term-exercise-huntingtons-disease-trials-feasible/>

Scientists give us a glimpse of huntingtin protein clumps: A group of scientists from the EPFL in Lausanne, Switzerland have published a paper in the Journal of the American Chemical Society, describing clumps made up of a fragment of the huntingtin protein. A word that's commonly used to describe these is "aggregates." Using very powerful microscopes, the team was able to zoom in and look closely at the details of the 3D structures of these samples. The build-up of huntingtin protein aggregates is thought to be an important feature of Huntington's disease (HD), contributing to the progression of the disease. But until recently we knew very little about what they looked like. With these exciting new glimpses of aggregates under the microscope, scientists hope to build tools to visualize them in the brains of people with HD, or even send harmful aggregates to the trash can in brain cells.

Read more here: <https://en.hdbuzz.net/334>

New advancement aids HD research: Bit.Bio has launched a new human cell model to advance research and accelerate therapeutic development for Huntington's disease.

The cells, called ioGlutamatergic Neurons HTT-50CAG/T, are engineered to carry a specific mutation in the HTT gene that causes Huntington's. By carrying the same genetic mutation, a condition called isogenic, the cells serve as a potential new robust and scalable model to study the mechanisms of the disease in the lab.

Check the full story out here: https://huntingtonsdiseaseneews.com/news/bit-bio-launches-new-human-cell-model-huntingtons-research/?utm_source=HUN&utm_campaign=730c6de0ff-HUN_ENL_3.0_NON-US&utm_medium=email&utm_term=0_f42d6c3322-730c6de0ff-74492490



VIBRANT-HD trial suspended: Dosing has been paused in the Phase 2 VIBRANT-HD clinical trial of oral branaplam (LMI070) in adults with Huntington's Disease. A scheduled assessment found "early signs" that "branaplam might be causing peripheral neuropathy," a condition marked by pain or numbness in the extremities caused by damage to nerves outside the brain and spinal cord, trial sponsor Novartis stated in a letter to the Huntington's community.

You can read more here: https://huntingtonsdiseaseneews.com/news/branaplam-dosing-huntingtons-trial-paused-side-effects/?utm_source=HUN&utm_campaign=a3e7721d8b-HUN_ENL_3.0_NON-US&utm_medium=email&utm_term=0_f42d6c3322-a3e7721d8b-74492490

Staff Profile - Meet Lauren

Huntingtons Queensland disease advisor Lauren has travelled the state in support of people impacted by HD. But for those of you who are yet to put a face to the name at the end of an email or phone call let us introduce you.

What does your role at Huntingtons Queensland involve? My role is to work alongside colleague Theresa as part of the client services team, working with individuals and their families to navigate systems of support, provide opportunities to connect with others within the HD community, and provide information to make informed decisions in their future living well with Huntington's Disease.

My role also has a strong focus on our Information and Education Program - delivering information sessions to different service providers, medical centres, hospital facilities, and nursing homes.

How long have you worked for HQ? A wonderful seven years.

What was your background before working for HQ? My background is varied within the community services sector. I've worked in support coordination roles, program management and youth programs all with an emphasis on ethical client-focused care.

What do you find rewarding or what has inspired you in your role? I have been lucky enough to work with many different people and families over the years. All incredible people with individual stories and that's where I find my motivation. Learning about how HD impacts each person individually and working with them to maintain what is important to them.

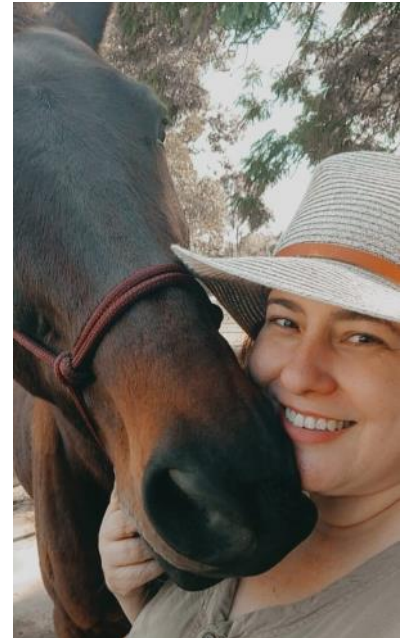
I also find working with professionals who are at the frontline of care rewarding. By skilling up staff and giving them the most relevant information we can see a rise in quality of the support people with Huntington's Disease receive.

What piece of advice would you offer our HD family? Connection is key. Many people express that they just don't know what they need and they don't know what to ask for. Being connected in some way can help with that. That can be with support groups in person or via online, being on an email list, or just making a call for a chat. Or anyway that suits you.

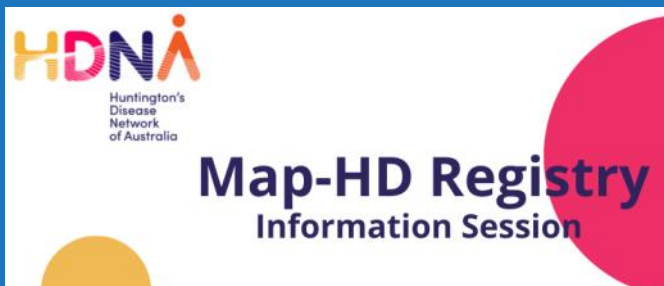
When you were young what job/career did you want as a grown-up? I wanted to be a foster mum like Pippa from *Home and Away*. Not quite the same but I have been lucky enough to be involved in fostering more than 60 dogs and finding them forever homes.

What do you like to do when you are not working? Connecting with family and friends is a top priority for me. I do love to get out and see live music and love to take the dogs to the beach.

Name three famous people you would invite to a dinner party, and why? Only 3!! Emma Thompson as she seems to be an incredibly authentic woman, Louie Theroux for the brilliant stories he would bring and both my grandmas - I know, not famous to you but certainly famous to me.



MAP-HD session a success



We at previously shared details about MAP-HD Registry, an initiative of the Huntington's Disease Network of Australia. In a bid to create awareness and understanding of the project we recently hosted an online information session over Zoom. The event featured HDNA's Audrey Hulme who spoke about who should register, how to register, what the registry information will be used for and the importance of collecting the information. There was also a time for questions and answers.

If you would like to watch the recording of this information session [CLICK HERE](#) or on our website under resources. www.huntingtonsqld.org.au

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.

October

- 11 – Ipswich coffee catch-up
- 12 – Brisbane South coffee catch-up
- 19 – Online Zoom for Carers
- 21 – Forum
- 26 – Bundaberg coffee catch-up
- 27 – Hervey Bay visit



November

- 9 – Brisbane North Xmas lunch
- 10 – Gold Coast coffee catch-up
- 15 – Cairns coffee catch-up
- 18 – Townsville visit
- 18 – Logan coffee catch-up
- 24 – AGM
- 25 18 – Townsville visit

December

- 1 – Online Zoom support group
- 9 – Sunshine Coast coffee catch-up
- 14 – Brisbane South Xmas lunch

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