

## Winter 2022 news flash



*Brett is cooking up a storm now that he has the right support*

### Living life to the full

On our recent area visit to Toowoomba we caught up with Brett and his mother. They originally contacted us in June 2021 asking for support. Neither Brett nor his mother knew exactly what support they needed but just knew that it was needed. This is common - many families dealing with a diagnosis of Huntington's do not know where to start or what will be needed during the days, months and years ahead.

After meeting with our Huntington's Disease advisor Lauren an action plan was developed to assist Brett in accessing the NDIS. Brett was supported through the access request process, consulting with his specialists, accessing the Huntington's Disease Clinic, completing required forms and supported during the NDIS planning meeting.

What a difference it has made! Less than a year later with the assistance of the right support coordinator and support worker Brett was able to move into a more suitable home that met his needs. He was very excited to show off his new home to Lauren when she visited and proud to announce he is now cooking his own meals.

Brett's mother is also benefitting from the change. She is now able to go on holidays and visit family knowing that Brett has regular support and people in his world that will ensure his everyday is the life that he chooses.

**Do you need assistance and support in your HD journey or know someone that does? We are here to help. Phone us on 07 3064 3222 or email [admin@huntingtonsqld.org.au](mailto:admin@huntingtonsqld.org.au)**

**DON'T  
MISS THIS**

WEDNESDAY,  
JULY 27 AT 6PM



An online Zoom information session about the Map-HD Registry will be hosted by Huntington's Queensland on **Wednesday, July 27 at 6pm.**

The registry is a Huntington's Disease Network of Australia (HDNA) initiative to help the organisation understand who is affected by HD and to give them better access to clinical care and support services.

It will feature HDNA's Audrey Hulme as guest speaker. Audrey will talk about the registry, who should register, how to register, what the information will be used for and the importance of collecting the information.

**This information session is open to everyone** - clients, family members, friends, service providers, community members and professionals.

Visit ['What's on'](#) on our website [www.huntingtonsqld.org.au](http://www.huntingtonsqld.org.au) or **[CLICK HERE](#)** to register.

*\* You must register to receive Zoom details. Details will be emailed to participants the day before.*

# Strength in collaboration

Huntingtons Queensland along with the four other State HD Associations of Tasmania, South Australia/ Northern Territory, New South Wales/Australian Capital Territory and Western Australia, have commenced a process to consider whether or not to form a single entity, joining together as one organisation. Huntingtons Victoria has decided to remain independent and are not part of this process.

The five State Associations believe there are a number of potential benefits in forming a single entity that need to be explored. We have undertaken a feasibility study, conducted by an expert external independent organisation to assess whether forming a national entity is both feasible and desirable. At the heart of our assessment of whether this would be the right way forward is if it would be in the best interests of our HD community.

Some of the benefits of forming a national entity would include:

- having a bigger voice collectively and being able to better advocate for the whole HD community;
- improved, consistent services through the pooling of collective knowledge and best practices;
- being able to generate additional revenue on a national scale / from national sources;
- being more efficient so we can improve the quality and scope of local services; and
- enabling strong state operations to focus on local delivery of care and services and local relationships especially with state governments and funders.

We expect that changes resulting from forming a single entity would only be positive. At the core, the creation of a single entity would enhance local state-based services and supports for people with, and families impacted by, Huntington's Disease.

We believe that collectively we can provide and sustain the best possible support and services to the HD community. We believe a single entity can deliver enhanced services to HD communities across Australia.

We are still working through a number of issues and are now undertaking extensive stakeholder engagement to share the current thinking and to obtain input and feedback from various stakeholder groups. We expect this stakeholder engagement to take about two to three months. A date of September 2022 has been set for each State Association Board to formally vote on whether it supports forming a single entity or not.

The process from there is that the members of each State Association will then vote yes or no to joining a single entity. The members have the ultimate say. This is expected to occur by the end of November 2022. If Boards and members support the formation of a single entity, a transitional phase will commence in January 2023 leading to a formal single entity as of July 1, 2023.

We know that any uncertainty can be challenging for those affected by decisions such as this one, and that includes our staff. There may be some refocussing of roles to match the operating model but we would hope to retain the skills and experience of our existing staff in any new entity, as we value our staff immensely. If we do form a national entity, we would expect to be growing so we envisage needing more, not less, staff than we currently have.

The membership structure of a single entity is also being looked at as part of the project. We will present existing members with the membership options once these have been determined.

We think this is potentially a very exciting opportunity for our State Association. We can see many benefits in being part of a national organisation that works hard and effectively on behalf of the HD community across Australia. We believe it is worth exploring.

**Huntingtons Queensland is open to feedback and input in this process. You can provide feedback to our Operations Manager Shaun Riley via email to [sriley@huntingtonsqld.org.au](mailto:sriley@huntingtonsqld.org.au) and/or telephone 3064 3222.**



# Record raising Running for Nan's HD

The drizzling rain could not dampen the spirits of almost 200 people who stepped out to raise funds for Huntingtons Queensland in the Running For Nan's HD funrun in late May.

An early wet start in the dark at Wynnum was met with passion and drive to push through the weather – with the runners and walkers ending the 5km and 10km courses wet and a bit muddy from puddles but full of encouragement and in good spirits.

Their efforts raised just over \$9300 for Huntingtons Queensland (a new record!) with money coming from registrations, raffle ticket sales, a \$2000 donation from Harcourts Property Centre and sales of pre-loved athletic clothing.

Running for Nan's HD was organised by Huntingtons Queensland longtime supporter Kelly Connolly whose Nan, a great-great grandmother aged 94, lives with HD.

Kelly worked tirelessly seeking sponsors, raffle prizes and wonderful community support to make the event the success it is. Thankyou Kelly.



A BIG thank you to all the sponsors on the day and those who donated raffle prizes. Our gratitude goes to:

- Harcourts Property Centre
- Fullerton Photography
- Inspire Athletic
- JT Signs
- Blood, Sweat and Beers (BSB) Club
- Triple Black Solutions
- Wynnum Plaza centre management
- Earth Palette Studio
- Outdoor Connection
- Riffs and Licks Music
- Steve Kelly and family
- Sharon Dorward and Arna Chauncey
- BlackKandleS
- Nexia Australia



L to R: Shaun Riley - Huntingtons Qld, Jewlie Halliday - Harcourts Property Centre and event creator Kelly Connolly



Images by Fullerton Photography

## Tell us what your think!



As part of our mission to provide the best services we can to you and our HD community, our team is seeking your feedback on our services.

Please complete the survey, which should take about 10 minutes. We would appreciate your honest opinions to help to improve our services.

**Your feedback will help to shape the work we do with you, your family, and many others.**

The survey will close at 5pm on Monday 1 August. **All responses are anonymous.**

**[CLICK HERE](#)**

or visit our website

[www.huntingtonsqld.org.au](http://www.huntingtonsqld.org.au)

## Thank you!

Thank you so much to everyone who supported our annual tax appeal raising over \$14,000. Your generosity will benefit individuals and families across Queensland .

We couldn't do it without you!



# Advance Care Planning

Huntington's Disease leaves individuals and families with a myriad of emotions and matters to consider and plan for. Very few want to talk about planning for the latter part of having the disease but it is essential in ensuring a person's preferences for future care are known and respected. This is called advance care planning (ACP).

ACP allows you to plan what healthcare needs you would like or not like when you become seriously ill or injured and are unable to communicate your preferences or make decisions. ACP should be considered by all adults, no matter your age or medical history.

In Queensland, ideally those who consider ACP would document the plan in a legally-binding Enduring Power of Attorney or Advance Health Directive, or a non-binding Statement of Choices.

Conversations around ACP are not quick. You can devise and discuss your plan with family, friends, a carer or other healthcare provider. Ideally, advance care conversations should begin when a person is medically stable and comfortable.



According to Advance Care Planning Australia, the sort of topics to consider and discuss include:

- Your wishes and preferences in relation to your future treatment and care, and the feelings, beliefs and values you have that may influence these;
- Your preferred place of care and how this may affect treatment options available e.g. home, hospital, hospice, care home;
- The people that you would like to be involved in decisions about your care, e.g. family members, significant others, a legal proxy or independent advocate;
- Interventions that may be undertaken or considered such as resuscitation, artificial feeding or artificial ventilation (breathing); and
- What you would like to happen after you die, e.g. the possibility of organ donation.

Planning does more than lay out your preferences and ensure you get the treatment you want. It has a powerful impact on your loved ones too - families of people who have undertaken ACP have less anxiety, depression and stress, and are more satisfied with care. ACP is

If you would like more information phone 1300 007 227 or visit [www.metrosouth.health.qld.gov.au/acp](http://www.metrosouth.health.qld.gov.au/acp) to find out more.

# An update from Shaun

I am continuing to meet a variety of people within the Huntingtons community. Last month I was able to attend another of our support groups, a coffee catchup in Brisbane. I also attended the RBWH clinic and met with neurologists Dr John O'Sullivan and Dr Rob Adams.

Thank you to Kelly Connelly and her family for organising the Running for Nan's HD 2022 event recently held on the Wynnum Esplanade, and a big thank you to the HD community for your wonderful support of the event. It was a fantastic morning and I enjoyed chatting to the participants and volunteers.

Our annual Forum will be on Friday, October 21 at the Treasury Hotel . We are awaiting confirmation of attendance from a number of interesting and informative speakers but I am delighted to announce that Professor Julie Stout from Monash University and Dr John O'Sullivan, a neurologist at the RBWH, have confirmed their attendance as speakers.

I am excited to be involved in the feasibility study with the other State HD associations in regards to forming a single entity. The collaboration between Tasmania, New South Wales/ACT, South Australia/NT, Western Australia has been very encouraging. (Full story on page 2).

We recently sent out an email inviting you to 'Have your say' in our annual survey. If you haven't already done so I encourage you to complete the survey. The information we collect will help us, help you.

Finally I am delighted to let you know that my fixed-term contract has been extended until June 2023. I am looking forward in continuing to work with everyone associated with Huntingtons Queensland.

Shaun Riley  
Operations Manager



## Out and about

Huntington's Queensland has played host to a number of support group meetings and regional visits over recent weeks. Thank you to everyone who has attended these across the state including in Ipswich, Townsville, Cairns, Brisbane, Redlands, Toowoomba and the Sunshine Coast. Remember, if you would like more information on our groups or other ways we can support you we are only a click or phone call away. 07 3064 3222 or [admin@huntingtonsqld.org.au](mailto:admin@huntingtonsqld.org.au)



# Lachlan pulls no punches

Gold Coast resident Lachlan O'Shea has an inspiring story. ***This story, courtesy of News Corp journalist Nick Wright, originally appeared in the Gold Coast Bulletin. Photo courtesy of Tertius Pickard.***

Try as he might to put on a brave face in the throes of his internal struggle, Lachlan O'Shea could not keep the demons at bay forever.

As the enormity of his Huntington's Disease diagnosis two months ago locked the boxer in a stranglehold he had two choices: trap himself in his room and the "mental prison" he was in, or ensure his remaining years were spent vying to make his family proud. He chose the latter, as his quest for the Australian welterweight title began.

Hailing from Townsville, O'Shea made the move to the Glitter Strip at the end of 2020 to care for his mother who suffers from the same disease.

The rare, inherited condition causes the progressive breakdown of nerve cells in the brain, with symptoms often surfacing in a patient's 30s. After diagnosis, a sufferer is expected to have anywhere from 10 to 30 more years left.

Since his move from North Queensland, O'Shea became the Queensland champion of his division.

But in the lead up to his state belt defence against Nathan Watson, O'Shea received the results of a Huntington's genetic test and made the gut-wrenching decision to withdraw.

At that stage, he said he was in no mental state to compete, deciding his plans of one day having a family of his own had been taken from him.

Now he has started the process of reinventing himself, returning to training at Matrix Boxing Gym to launch his pursuit for the Australian welterweight mantle.

"I was wondering why bother? What reason? and the more it lingered I didn't want to do much," O'Shea said.

"I was taking the easy options trying to make myself feel better with quick fixes like going out drinking and eating junk food.



"I stepped away from the simple things that make me feel good about myself like being active outdoors or at the gym training. That was my biggest mistake.

"But now that I've accepted I won't have kids, and I've just had to re-evaluate why I want to do it (boxing). A lot of it is still for myself to be honest, and for my mum."

O'Shea's comeback to the ring has hit even further hurdles, having just recovered from surgery in his left hand while he braces to go under the knife for a torn labrum in his right shoulder.

Slowly but surely, with the help of fellow pugilist Jacob Ng and his trainer and father Steve, he has been training and getting himself back on track, with a goal of returning to the ring in the coming months.

Now ranked number four in the nation's welterweight rankings, O'Shea is hopeful one more triumph will give him the chance to take on belt holder Ben Kite.

"My biggest fight is to get out of bed, it's not training. You have to get out of bed and take the first step of your day, it's getting the momentum started," O'Shea said.

"I feel like everyone thinks you're meant to have a good run. I've had a nice little hiccup in the middle, now it's shake it off and keep pushing forward.

"I want to get back to training, have some fights and win the Australian title."

# Research Updates

There have been a lot of updates in the HD research world since our last newsletter. You can find below a synopsis of the news with links to more information about each.

**Vitamin therapy for HD:** A research group in Spain is planning a clinical trial to explore if biotin and thiamine supplementation may help treat motor symptoms of Huntington's Disease. This strategy emerged from their observations that some protein changes in both mice and people with the HD gene mutation resembled those seen in another rare brain disorder called biotin-thiamine responsive basal ganglia disease (BTBGD). Like HD, BTBGD affects a part of the brain called the striatum and causes movement problems. Daily biotin and thiamine vitamin supplementation is an approved treatment for BTBGD and has been used with success for individuals with this condition. A recent publication provides some evidence that this treatment could be worth a try in HD too but a rigorous clinical trial in people with HD would be needed first.

More information here: <https://en.hdbuzz.net/324>

**Artificial intelligence enhancing HD research:**

Scientists at IBM and the CHDI Foundation have developed a new model that maps out the different stages of Huntington's disease in detail. Using artificial intelligence approaches, the researchers were able to sift out information from large datasets gathered during observational trials contributed by Huntington's disease patients. The team of researchers have published a new model of HD progression in the journal *Movement Disorders* that they hope will improve how HD clinical trials are designed in the future.

Read more about this here: <https://en.hdbuzz.net/326>

**Update to Annexon clinical trial:** California-based Annexon recently released final data from an open-label phase II clinical trial, showing that its drug candidate ANX005 safely stabilized disease progression in patients with Huntington's Disease.

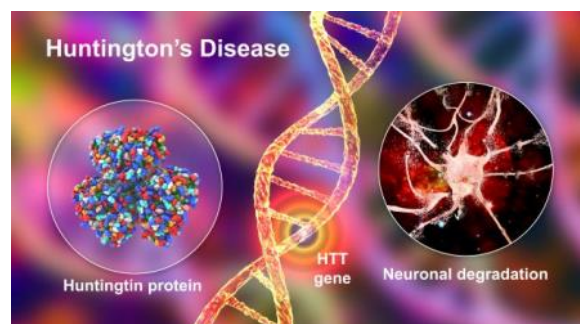
The findings revealed that over a six-month treatment period, Annexon's drug successfully prevented significant worsening of disease symptoms and preserved motor and cognitive function, as well as functional capacity, in HD patients. These effects remained durable over the next three months despite participants being off-treatment.

For more on this visit: <https://www.biospace.com/article/annexon-engages-the-target-sees-stabilization-in-phase-ii-huntington-s-trial/?s=68>



**New HD staging system:** Researchers have updated the system that classifies Huntington's disease progression. Tracking progression in four stages will make clinical trial screening and data interpretation easier and faster, and pave the way for pre-symptomatic trials. The Huntington's Disease Integrated Staging System (HD-ISS) combines information from brain scans, clinical tests, and day-to-day abilities to determine where HD patients are in their disease. This new scoring system takes into account the entire life of the individual, classifying every age, from birth to death.

More information here: <https://en.hdbuzz.net/325>



# Expressions of Interest

## Occupational Therapy Professional workshop



We are lucky to partner with occupational therapy experts with extensive experience working with people with Huntington's Disease. We have the opportunity to offer a professional workshop in October and are looking for expression's of interest. The workshop will include navigating systems such as NDIS, my aged care and specialty equipment and resources.

To register your expression of interest go to <https://app.etapestry.com/onlineforms/HuntingtonsQueensland/OTinterest.html>

**PLEASE NOTE: This workshop will be for professionals only**

## Mark your calendar

Visit [huntingtonsqld.org.au/support/whats-on/](http://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.

### July

- 14 – Gold Coast coffee catch-up
- 20 – Brisbane North coffee catch-up
- 22 – Logan coffee catch-up
- 27 – May-HD registry info session

### August

- 3 – Gympie visit
- 17 – Brisbane South coffee catch-up
- 26 – Sunshine Coast coffee catch-up



### September

- 1 – Online Zoom support group
- 6 – Mackay social lunch
- 7 – Rockhampton visit
- 8 – Gladstone social dinner
- 9 – Toowoomba visit
- 14 – Brisbane North coffee catch-up
- 28 – Redlands social lunch

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