

## Summer 2022 news flash



## Merger Update

As previously communicated members who attended recent AGMs of the five Huntington's State Associations – SA&NT, WA, Tasmania, NSW/ACT and Queensland – have agreed to merge into a new, single entity, Huntington's Australia (HA). We are all very excited about the opportunities to enhance and sustain the services we provide to the Huntington's community.

The merger will bring together five associations with a shared vision of enabling those impacted by Huntington's disease to live their best lives. This is a momentous occasion - a culmination of lots of hard work from many people and the start of a new era of national unity of purpose and effort.

Huntingtons Australia has already been registered as a company with ASIC, with the ACNC as a charity, and are now seeking tax concessions for the company through the ATO. A governing body for HA has also been established, with the following Directors who make up this foundational Board – all are currently board members of their state associations:

- Chris Glasson, Chair (SA&NT)
- Martyn Jenkins, Public Officer & Secretary (WA)
- Jason De Bakker (Queensland)
- Stephen Garrard (NSW/ACT)
- Kaila Stevens (WA)
- Elizabeth Thompson (SA&NT)

Thank you all so very much for your understanding and support in moving us forward towards this brave new world of unified and sustainable services to our national HD community.

## Annual Report



Following Huntington's Queensland Annual General meeting our 2021-2022 annual report and audited financial accounts are now available. You can download a copy from our website by clicking [HERE](#), visiting our website under Resources or contact our office on 07 3064 3222 if you would like a printed copy sent to you.

## Christmas closure

Our office will close for Christmas on Friday 23 December and reopen on Monday 9 January. On behalf of all our team, we wish you, your family and friends a safe and peaceful festive season.



# An update from Shaun

It has been a very eventful few months with several important announcements in relation to the merger with other Huntington's associations around the country. I was very pleased to hear that all members of the five Huntington's State Associations – SA&NT, WA, Tasmania, NSW/ACT and Queensland agreed to merge into a new, single, national entity, Huntington's Australia. This is very exciting and a historic moment for us all.

A lot of hard work from many people have made this possible and we all look forward to the start of a new national unity, supporting people impacted by Huntingtons disease on a national level. We have a detailed Merger Implementation Plan which we have been slowly progressing with in anticipation of a positive vote, which will now kick into full swing as we head to the 1st of July 2023 when the national entity becomes a reality.



And of course our new national identity needs a new leader. I was delighted to hear of the appointment of Lenni Duffield from WA. I have had the pleasure in working closely with Lenni over the past few months and am confident that the national board have made an excellent decision in appointing Lenni as Huntington's Australia first CEO.

As the year comes racing to an end it is a good time to reflect on the year that was. Since the ending of lockdowns in March earlier this year we have been able to reintroduce face to face meetings, support groups and community days. Our wonderful HD advisors Lauren and Tressa have travelled across the state holding face-to-face meetings and facilitating support groups with clients and families. Huntingtons Queensland continues to work with many individuals often helping them to access the NDIS and interact with the health, disability and welfare agencies.

We also introduced an information and education service for service providers to assist their support workers who provide support services to people within the HD community. Lauren has facilitated several education sessions across Queensland, providing information for service providers to better understand their clients needs and challenges.

Lauren and Tress continue to provide support to people attending the monthly HD Clinic held at the Royal Brisbane and Women's Hospital and appreciate the ongoing working relationship with the staff there. We have a great team of people who support the work of Lauren and Tressa in administration, finance and events planning, a big thank you to Cathy, Jen and Lisa.

We were delighted to receive very positive feedback from the annual Huntingtons Queensland Forum held in October. Attended by approximately 80 people, attendees heard presentations from Huntingtons Queensland Director Jason de Bakker, Professor Julie Stout from Monash University, Social Worker Deb Field, John Haberecht from Palliative Care Queensland, Senior Neurologist Associate Professor John O'Sullivan and Tina Knight and Angelika Straker who shared their personal stories.

In May, we were once again able to put on our running shoes for the Running For Nan's HD fundraiser. With more than 100 people and a few loveable dogs pounding the pavement on the Wynnum Esplanade the event proved a huge success in bringing the HD community coming together and raised over \$9,000. A big thank you to Kel Woodland and family who organise this annual event.

I would also like to extend a thank you to everyone who donate or are involved in fundraising for Huntingtons Queensland as we really are dependent upon financial donations and fundraising events to fund 70% of our costs.

The board members and staff of Huntingtons Queensland would like to wish clients, HD families and supports of our service a peaceful Christmas and New Year.

Thank you  
Shane Riley  
Operations Manager

# Meet Huntington's Australia first CEO

Huntingtons Australia is excited to announce the appointment of our new CEO! Lenni Duffield from Huntington's WA has been unanimously endorsed by the Huntington's Australia Board as the inaugural CEO of Huntington's Australia.

Lenni has held senior roles and provided business consulting services in health and community service sectors, has qualifications in business, management and leadership, community sector management and is currently in the process of completing her Master in Business Administration with the Australian Institute of Management, with whom she is an Associate Fellow.

Lenni comes equipped with a range of skills, knowledge, qualifications, experience and personal attributes that make her a stand out candidate. Her commitment to and passion for bettering the lives of people with and impacted by Huntington's disease is unquestioned.

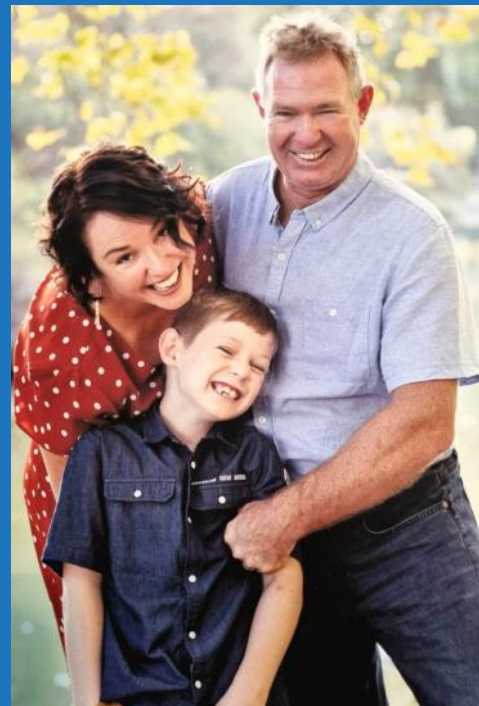
Fortunately for us, we have been able to see what Lenni can do in person over a good period of time, through her work as CEO in WA and thorough her Project Management work with the merger feasibility study and more latterly planning for the merger implementation. Her consistent, high quality work and standards over an extended period of time give us great confidence that we have the right person to take the new organisation forward.

This is a proud and momentous occasion in the thus far very short history of Huntington's Australia. The Board has confidence that Lenni will lead us into a better future for our Huntington's communities.

*"This is my family, myself, my husband Adam and our gorgeous son Lawson. We are a busy little family juggling working life and living on a working property looking after a menagerie of farm animals, it's always hectic with something to do, but we love it! We have fruit trees, grow veggies and run our own sheep.*

*I'm fiercely passionate about the for purpose sector and championing the roles and vital contributions that organisations such as the HD state associations and Huntington's Australia contribute to communities and the government.*

*When I'm not doing the work I love, I'm in the garden (a labour of love), or entertaining friends and family at home when not studying for my MBA or volunteering on local community projects. Also when time permits I love being creative!"*



## Annual General Meeting

Our annual general meeting was held on the 15 November. We are delighted to acknowledge the following members who have been appointed to our last ever Huntingtons Queensland Board. Shane Kelly (President), Gerry Doyle (Vice-president), Tamara Winch (Secretary) Nick Murray (Treasurer) and directors Jason de Bakker and Angela Abell. We thank them all for their voluntary service and commitment to everyone impacted by HD.

# Santa is coming

With Christmas approaching some of our support groups and other social group gatherings came together to share a little Christmas cheer. We feel so honoured to be able to meet up with various groups around the state and share a coffee, a bite to eat, information and a chat. Thank you!



Top to Bottom: Brisbane Support Group, Lauren had a great time catching up in Townsville and lunch crew in Mackay



# Annual Forum

## Living Well with Huntington's Disease



It was a full house for our annual form in October! We were thrilled to have around 80 people attend our 'Living well with Huntington's Disease' forum.

Speakers included crowd favourite Professor Julie Stout from Monash University, Social worker Deb Field, Interim CEO John Haberecht from Palliative Care Queensland, Occupational therapist Talisha Bryden, Senior Neurologist Associate Professor John O'Sullivan from RBWH and personal stories from Tina Knight and Angelika Straker. We thank all our speakers for generously donating their time.

For those who were unable to attend the forum, all presentations were recorded and will be available on our You Tube channel early in the new year. We will let you know as soon as they are available.



Top to Bottom, L to R: Board members Jason de Bakker and Gerry Doyle with Cliff and Jenny Farmer, Tina Knight and Social Worker Deb Field, John Haberecht from Palliative Care Queensland, Angelika Straker, Occupational Therapists Talisha and Kathleen, Associate Professor John O'Sullivan with guests Linda and Monica

# Staff Profile - Meet Tressa

Huntingtons Queensland disease advisor Tressa is our longest serving staff member, supporting (in some cases) generations of people impacted by HD.



**What does your role at Huntingtons Queensland involve?** Lauren and I are often the first point of contact for people with HD, their families, friends or neighbours. We might meet with someone only once for a coffee, or alternatively, spend years building relationships with people and assisting them to access the support they require. We're involved in bringing together people from within the community across the state and providing opportunities to alleviate some of the isolation and aloneness that might occur with a complex disease that is not well known and even less well understood.

**How long have you worked for HQ?** I was employed for sixteen hours a week back before my first daughter was born. She's about to turn 27 in January.

**What was your background before working for HQ?** I worked in disability support roles with children, both in institutional settings and in the community when I was very much younger. I also had roles working with older people and families living with other forms of dementia.

**What do you find rewarding or what has inspired you in your role?** The grace and resilience of families impacted by H.D. I find particularly humbling the decisions and choices that young people impacted by H.D are challenged with. It's extraordinary to me that young adults, some just teenagers, are forced to think about their futures in ways that very few others ever have to consider.

**What piece of advice would you offer our HD family?** I think being involved with others who can appreciate and understand where you're coming from and sharing your experiences. I think alleviating some of the isolation that comes with thinking there is no one else who understands your life and can walk alongside you is empowering.

**When you were young what job/career did you want as a grown-up?** I wanted to be a high school teacher, but then realised I was terrified of teenagers.

**What do you like to do when you are not working?** I love an op shop, although you can really only bring so much of other people's stuff home to your own place before it becomes an issue. I like reading but haven't done as much of it as I would like because I stay up too late when I start something. I also really enjoy listening to audiobooks which are much easier to fit in when doing other things and I try and go to Pilates as regularly as I can.

**Name three famous people you would invite to a dinner party, and why?**

Margaret Olley, because I'd love some art lessons and she also seems to have been a woman who was a bit of a character, so perhaps I wouldn't have to say much. Maggie Beer because she appears to be a cook who could whip up a bit of a feast without raising a sweat, enjoy doing it and have a conversation at the same time, and Paul Kelly, because he's been the background music to my life.



# Research Updates

Keeping up with all the latest research news can be time-consuming. Here is some of the latest news from around the world.

## Non-genetic Factors Can Play Great Role in Mortality Risk

A greater number of CAG repeats within the *HTT* gene — the genetic cause of Huntington’s disease — is linked to earlier disease onset and death, but is not an independent predictor of mortality in people with the neurodegenerative disease, a study shows.

These findings suggest that “non-genetic factors contribute to mortality status and warrant further investigation,” the researchers wrote.

<https://huntingtonsdiseasenews.com/news/non-genetic-factors-role-mortality-risk-study-cag-repeats/?fbclid=IwAR1nybnfTNOMxLg6LJrGSZy84XWm3CkR4-ePA8CFHI937Y9aVrBh8WoeUQ>

## uniQure gets the green light to resume testing HD gene therapy

In August 2022, uniQure announced a pause in new recruitment for their trial of AMT-130, an HD gene therapy delivered via brain surgery. The decision was made after 3 out of 14 participants who had received a high dose of the drug experienced serious side effects after the procedure. The trial’s Data Safety Monitoring Board (DSMB), an independent panel of experts who track the safety of the drug during the trial, have been carefully reviewing the safety data since August. They recently determined that new high dose surgeries can continue, with some additional monitoring for participants. Let’s talk about this news and what it means for AMT-130 going forward.

<https://en.hdbuzz.net/337>



## Long-term Austedo Safely Leads to Reductions in Chorea: 3-year Data

Long-term treatment with Austedo (deutetrabenazine) safely led to sustained reductions in chorea for people with Huntington’s disease, including those who had switched from treatment with Xenazine (tetrabenazine).

That’s according to about three years of follow-up data in the Phase 3 ARC-HD trial (NCT01897896), a study jointly conducted by Austedo’s developer, Teva Pharmaceuticals, and the Huntington Study Group.



Not only do the data support Austedo’s long-term tolerability and effectiveness, but they highlight that patients switching from Xenazine can do so safely.

[https://huntingtonsdiseasenews.com/news/long-term-austedo-safely-leads-reductions-chorea-3-year-data/?fbclid=IwAR3zKqBY\\_pyLVmNqGTtpgit\\_C-tmXSzJhUG3h7wliiCz2r6mMFM5HjYJx0s](https://huntingtonsdiseasenews.com/news/long-term-austedo-safely-leads-reductions-chorea-3-year-data/?fbclid=IwAR3zKqBY_pyLVmNqGTtpgit_C-tmXSzJhUG3h7wliiCz2r6mMFM5HjYJx0s)

## Disappointing news from Novartis about branaplam and the VIBRANT-HD trial

The pharmaceutical company Novartis has released a community update which announces that they are ending development of branaplam, a huntingtin lowering drug, for possible treatment in Huntington’s disease (HD). This news comes following recent bad news about side effects of branaplam in HD patients, being tested in the VIBRANT-HD clinical trial, dosing of which was paused earlier this year. In this article we will break down this announcement and what this news means for the HD community.

<https://en.hdbuzz.net/338>

Follow us on Facebook, we endeavour to share research as it becomes available.

# Occupational Therapy training success

We were excited to have nearly 50 occupational therapists from across Australia participate in our online workshops recently with guest speaker Talisha from OpportunOTy. Talisha a team leader and senior occupational therapist has had extensive experience with clients with HD and shared her knowledge and experience. Thank you to Talisha for being so generous with her time. The feedback has been amazing! We are always grateful to professionals who are willing to share their experience, our clients appreciate being able to engage with professionals who have knowledge with Huntington's Disease.



## Can you help us help others?



Huntingtons Queensland supporters should have received our annual Christmas appeal letter by now.

This year we are aiming to raise money for our emergency response fund to help clients in need – those who, for various reasons, become powerless to respond to emergencies. At times like this we have provided supermarket vouchers, money for petrol and mobile phones, a new washing machine, vital school equipment for a hard-working student and even helping a family to relocate to a safer location. Recently we were able to use our emergency response fund to help single parent Rachel purchase a fridge to enable her to store food safely for her young family.



At Christmas time we receive more requests than at any other time of the year. Please help us keep this life-changing fund going by considering a gift today, using either the form below or by online by either scanning the QR code or [visiting our website](#). Thank you so much.

**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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