



# HUNTINGTONS queensland



## Winter 2023 news flash



### Running for Nan

Dust off the running shoes and mark your calendar! After a highly successful comeback last year following the Covid hiatus Running for Nan's HD is back again this year on Sunday, July 30.

Organised by HD advocate Kelly Connolly in honour of her Nan, a very impressive 95 year old great great grandmother, who lived with HD. This wonderful event aims to raise money for Huntington's Queensland and is being 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. Exciting news, timing chips are available for anyone that is of a competitive nature. So if you want see if you can beat your PB or track your powerwalking skills this is an added bit of fun. However remember for anyone that wants to come and just have a wander please feel free to do so. Running for Nan's HD is about getting everyone involved!

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](https://huntingtonsqld.org.au/run)

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

### Merger Update

**"All good things to those who wait"**



As a valued member of the HD community, we continue to keep you up to date with Huntington's Australia (HA) developments.

The board of Huntington's Australia have made the decision to delay the merger until 1 October, to have the certainty that allows us to move forward and complete all those tasks.

In addition to our CEO and two members of the senior management team, we have now appointed Alison Weir as the Head of Business Development, Fundraising & Partnerships.

CEO Lenni, along with Lyn, our HR Specialist, have spent considerable time meeting with all employees in person over the last few months, to discuss new roles and the arrangements for transfer to the new organisation.

Please visit our website to read the full update from Chris Glasson, Chair HA.

<https://huntingtonsqld.org.au/updates/>

# Update on the Merger

## from Huntington's Australia's CEO



It doesn't seem that long ago that we were all attending AGMs to vote to enable the proposed merger of the 5 state Huntington's associations. Fast forward 8 months and here we are, less than 4 months away from the merger and well and truly in the thick of it, with a flurry and hive of activity! What have we learnt along the way ... that mergers are never easy, and they are rarely simple.

But why are they so challenging? Well, for a start you have the combination of three main things: people, operational structures/ processes and technology/services. The path to merger success isn't a steady, consistent, incremental process where each effort you make toward integration is matched by parallel gains. In the early stages of consolidation, you put forth a lot of effort but seem to get little accomplished. Then you hit the yield point, and that last little bit of effort required gives great rewards. It is this last bit of effort that makes an imperishable difference and will be the catalyst for lasting change.

Right now, we are at the "yield point" – it is like an invisible barrier, it's turbulent just before you reach it, but smooth as silk once you break through to the other side. We would not have gotten to this stage without each state all working together to make a difference. Along the way we have shared resources, and team members, supported each and may have sworn and shed a tear or 2! But we are nearly there, and we can see the new beginning, one that I know our families, communities and staff across Australia will benefit from and our collective and collaborative efforts to make Huntington's Australia a reality.

Cheers  
Lenni Duffield

## Visitors from the West

In March we were lucky to have Lenni, our new Huntington's Australia CEO and Chris Glasson, Chair of the Huntington's Australia Board visit us. While here we hosted a meet and greet and introduced them to some of the amazing people within our Huntingtons Queensland community.





# Young people have a voice

In March Huntingtons Queensland board member Angela Abell who comes from a HD family and is gene positive attended HDYO's (Huntington's Disease Youth Organisation) International Congress for young adults in Glasgow Scotland.

*"On the 17 to 19 of March, the Huntingtons Disease Youth Organisation [HDYO] held the very first International Congress for young adults in Glasgow Scotland. HDYO is an international non-profit organisation supporting, educating, and empowering young people up to the age of 35, impacted by HD. The vibe throughout the whole conference was that 'you are not alone' and 'young adults (including pre-symptomatic people) have a voice too!'"*

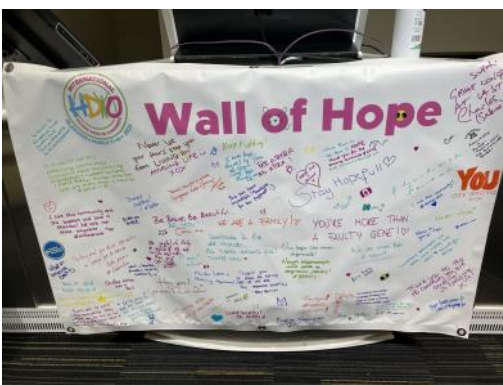
*I was fortunate enough to receive a scholarship from HDYO which allowed me to attend. As it was my first international trip, I travelled with my father Paul whose family originated in Scotland. Before the congress began, we travelled all over the Scottish Highlands where we saw many beautiful castles, breathtaking landscapes, and snow for the first time.*



*I was very excited about Congress, as HDYO had planned a busy agenda with incredible topics such as mental health, genetic testing, research updates, personal perspectives/stories, family planning, talking to kids about HD and so much more. As soon as we walked in the door on the first day, the nerves disappeared instantly. The atmosphere was filled with support, friendship, kindness and more importantly, having an instant connection with strangers from just understanding/being in a HD family.*



*In total 330 of us from all around the world travelled to Glasgow and we were all surprised when bagpipe players came out during the welcoming speech presented by Jenna (HDYO's executive director) & Charles Sabine (a famous television journalist). On the second day at Congress, I was incredibly thankful to share some of my IVF with preimplantation genetic testing (PGT) journey during the family planning session presented by Kelly Atkins.*



*Hearing about other people's perspectives from being in an observational study, family members being in a drug trial, and pharmaceutical companies speaking about research gave us all a lot of information! But it also gave us all a lot of hope for the future as we questioned representatives from pharmaceutical companies which gave us a sense of relief despite the recent clinical trials setbacks. It is clear though that in the next decade, clinical trials are going to be a crucial factor if we are ever going to have a treatment for HD.*

*Overall congress was astonishing, and we are all so grateful for this event. Many new friendships were gained, more and more young people are becoming an advocate for HD and a lot of information was shared which will hopefully help improve support and awareness in the future."*

To view sessions from Congress, <https://www.youtube.com/playlist?list=PLfha5f75-ixKOsdWfFokqsyRuvDzFILmY>

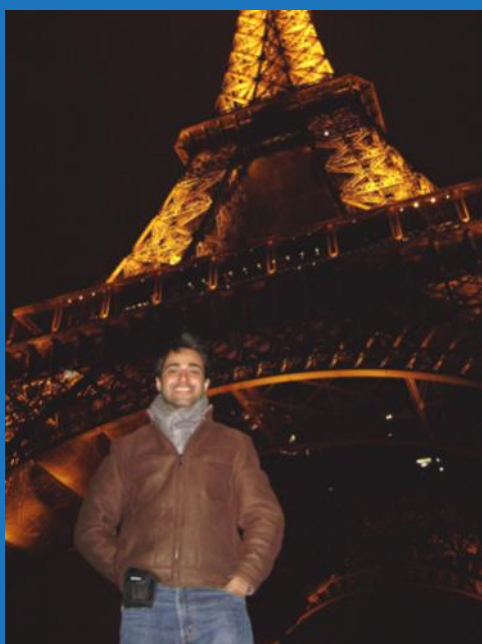
If you'd like to know more about Angela's story, you can watch her presentation from the Huntingtons Queensland 2021 HD Qld Forum <https://youtu.be/LOSlTzDgpA>

Angela's Instagram: <https://www.instagram.com/myhuntingtonsvifjourney/>

# NDIS

We are pleased to now offer NDIS Support Coordination in Queensland!

Our new NDIS Specialist Support Coordinator Sheryar Kazi can be contacted at [sheryar@hdnswact.org.au](mailto:sheryar@hdnswact.org.au) or 0466 595 406



*"I am the newly recruited NDIS specialist support coordinator and am based in the Brisbane office. I have previously worked in a similar role, however I am focused more around learning and supporting participants living with Huntington's disease and their families. I have a background in social work and public policy.*

*Prior to my career in disability support, I worked as an advocate and volunteer for the marginalized communities in South Asia. I am a proud recipient of amfAR scholarship at the University of Pittsburgh (2015), where I studied research methodology and technical writing.*

*I enjoy camping, travelling (I recently travelled across Tasmania and inner NSW-Queensland), karaoke, hanging out with my nephews and nieces and watching television series".*

## Genetic Testing

One of the most asked questions we receive regards genetic testing. We asked Genetic Health Queensland to help answer some of the questions people may have regarding testing.



Genetic Health Queensland (GHQ) is a state-wide genetics service that provides clinical services across Queensland. The team of specialist healthcare professionals cares for individuals with a known or suspect genetic condition or a family history of a known genetic condition. The service has genetics counsellors based in Brisbane, Gold Coast, Sunshine Coast, Toowoomba, Bundaberg, and Townsville and also provide genetics clinics to Rockhampton, Cairns and Mackay.

Huntington's disease (HD) genetics testing for Queenslanders is part of the service offering. Patients who may have signs or symptoms of HD can be tested through a genetics service but can also access genetic testing via a neurologist. There are public and private options available for both these services. The team can also arrange genetic testing for people who do not have any symptoms but have a family history of HD. This is known as predictive testing.

The predictive testing protocol through Genetic Health Queensland involves at least three appointments with a genetic counsellor. During these appointments the genetic counsellor will provide information about the genetics of HD and how the testing is done. They will also discuss the pros and cons of having this sort of testing done and find out what support is available. Predictive testing is not done in individuals under the age of 18 years for adult-onset conditions like HD. This allows individuals at risk the right to decide for themselves whether they want to know their genetic status or not.

To ensure all Queenslanders can access the service where required, patients can see a genetics counsellor in person or via telehealth (video call). Telehealth appointments can be arranged on your own device (smartphone or computer) or at your local Queensland Health facility if they have telehealth equipment. Another option may be to use telehealth facilities at your local GP if required.

If you would like to discuss genetic testing for HD, please obtain a referral to GHQ from your GP.

For further information, please contact Genetic Health Queensland on 07 3646 1686.



# Introducing Basil

**With the merger organisation structure taking shape we are pleased to have the new Huntington's Australia Head of Community programs and services based in the Huntingtons Queensland office. Welcome Basil!**

*"With 18 years of experience in sales, business, and disability sector, I am excited to bring my expertise and passion to enrich the lives of individuals in our community."*

*My background in sales and business has provided me with a strong foundation to transition into the human/community services field. Motivated by a deep desire to make a meaningful difference in people's lives, I have witnessed the transformative power of ubuntu, community support, and its invaluable impact on individuals and families facing various challenges. I am driven to be part of organisations that blend heartfelt dedication with sound business principles to ensure sustainable social support.*

*The presence of my young family has played a significant role in my decision to work in the non-profit sector. I am grateful to have a loving wife, Chi, who has been my rock and support system in my professional journey. Together, we have been entrusted with the joyful responsibility of raising our two wonderful children. Their presence inspires me daily to create a better world for future generations.*

*My commitment lies in fostering a strong sense of community, collaboration, and support within our organisation. I aim to work closely with our dedicated team, volunteers, health professionals, service providers, and community partners to develop innovative programs and services that address the unique needs of the individuals and families we serve".*



## Out and about



It has been a busy few months out in local HD community. Our support and social groups continue to gather new attendees. After a long break, it was also great to get back to Toowoomba and catch up with some of the wonderful people from the area. Funding from the Rural connection program also enabled us to take people from the Townsville area to see the North Queensland Cowboys play at Queensland Country Bank Stadium. Thank you to everyone who comes out to meet with us, have a chat or share a coffee. We love every opportunity to catch up the HD community.



# 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.

## Roche Phase II GENERATION HD2 study underway

Roche released a community letter last month, detailing how their Phase II clinical trial to study the huntingtin-lowering drug, tominersen, is now underway.

Tominersen is a type of drug called an ASO, which aims to lower levels of the huntingtin protein, and is delivered through spinal injections.

<https://en.hdbuzz.net/339>



## High huntingtin protein levels in saliva linked to worse disease

Higher levels of healthy and mutant huntingtin protein in saliva, but not in blood, are significantly associated with worse motor symptoms of Huntington's disease, a study showed.

According to the investigators, these findings support the use of non-invasive saliva tests to monitor Huntington's progression and predict clinical outcomes — which, in turn, can be immediately applied to clinical research applications.

<https://huntingtonsdisaseenews.com/news/high-huntingtin-protein-levels-saliva-linked-worse-disease/>



## Subtle speech changes may be first symptoms of Huntington's: Study

Subtle changes in speech are present before obvious symptoms of Huntington's disease appear, and could potentially be a quantitative biomarker for the neurodegenerative disorder, a small study found.

The changes in speaking identified among Huntington's patients were linked to age and an individual's number of disease-causing CAG repeats — as well as to problems with cognitive and motor function.

<https://huntingtonsdisaseenews.com/news/subtle-speech-changes-may-be-first-symptoms-huntingtons-study/>



## Hunting for balance: how the huntingtin protein compensates in HD

A group led by Dr. Sandrine Humbert from the French National Institute for Health and Medical Research published new work in the prestigious journal Science. Dr. Humbert's team did some really cool science in mice to look at how both the expanded and unexpanded copies of huntingtin (HTT) affect mouse "symptoms" of Huntington's disease (HD).

<https://en.hdbuzz.net/340>




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




# Introducing the faces of Huntington's Australia

With the excitement of the National merge we asked individuals across state associations 3 questions. Cathy, Staff Member in Qld, Therese, Board Member in NSW/ACT and Anne, community member in SA were asked:

- What excites you about Huntington's Australia?
- How did you get involved in the HD world?
- What is your ideal Sunday?



**Q: What excites you about Huntington's Australia?**



So many things! The collaboration of people from all over the country, bringing together all that knowledge and expertise. Becoming a louder collaborative voice to get federal government support. Providing more education to doctors and allied health professionals to enable individuals to get consistent and improved care. And most importantly our clients will benefit with services and information that will meet their needs and be more accessible across the country. Such an exciting time.

## Q: How did you get involved in the HD world?

Applied for a job which looked interesting (it was and still is) with Huntingtons Queensland. I have a big interest in genetic health after my daughter was born with a rare genetic condition and I remember how hard it was sourcing information when she was little. Being able to help people connect to find answers and support is what makes it so rewarding.

## Q: What is your ideal Sunday?

Either a really lazy day with brunch and Netflix or an early start with a good long walk (preferably near water or bush). But my favourite Sunday is always spending time with my children (who are now grown up)

## Q: How did you get involved in the HD world?

My first introduction to HD was way back in 1993. I saw a person from a HD family as part of the predictive testing programme. The enormity of the decision to get tested and his reaction really moved me.

## Q: What is your ideal Sunday?


Warning - nerd-alert! Early morning walk bird watching, either in the bush or by the sea. Home for late brekkie of eggs from my chooks, plus wordle. Pottering around the garden with our kelpie and greyhound in tow, reading non-fiction, family dinner with lots of laughing. New York Times mini crossword to end the day.




**Q: What excites you about Huntington's Australia?**



For decades, the Huntington's community has lacked a national voice. It is so exciting that we'll be able to pool the resources of the State Associations to improve the lives of HD family members, regardless of where they live in Australia. It's a scary time, but full of possibilities.



**Q: What excites you about Huntington's Australia?**



Quite a few things! With a national identity Huntington's will get more attention, more awareness, more funding, and more resources.

So many people I talk to haven't heard of Huntington's and it would be lovely to be recognised like Parkinson's and other diseases. Families will definitely benefit from more services and support.

## Q: How did you get involved in the HD world?

My mum had Huntington's and it has been in the family for a very long time. I recently lost my brother, Peter, who had Huntington's for about 20 years before he passed. One of my sons (Christian) has the gene, my second child (Simon) doesn't want to be tested, and my other two children don't have the gene (Karen and Shane). My goal is to end Huntington's with my grandchildren – what we can't control we must endure.

## Q: What is your ideal Sunday?

We have two granddaughters that sleep over every weekend and I love waking up with them on Sunday mornings. We usually have pancakes and then go the beach to play in the water and sand. If we aren't at the beach, we like to feed the Magpies in our garden.

## Lauren is on an adventure

Lauren, one of our dedicated HD Advisors is currently on secondment with Huntington's Tasmania in the role of Senior HD Advisor.

Lauren has worked with Huntingtons Queensland for over 6 years, and with her background in case management and assisting families in small community focused services she is looking forward to working with families in Tasmania.

*"My focus and drive has always been on support, inclusion and building community networks. I am beyond excited to meet everyone in the HD Tasmania community and build programs that are specific to your community."*



## Mark your calendar

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

- 4 – Gold Coast social group
- 18 – Mackay social lunch
- 26 – Brisbane coffee catch-up
- 28 – Logan Coffee catch-up



### August

- 1 – Gold Coast social group
- 2 – Redlands social lunch
- 9 – Online carers support group
- 16 – Cairns coffee catch-up
- 18 – Townsville visit
- 24 – Sunshine coast coffee catch-up

### September

- 5 – Gold Coast social group
- 15 – Toowoomba social lunch
- 26 – Ipswich coffee catch-up
- 28 – Online support group

## Can you help us to help families with HD?

The end of the financial year is just around the corner, and we need your help. You can support the valuable work of Huntingtons Queensland by kindly making a tax-deductible donation before June 30.

With your donation we can assist individuals and families impacted by Huntington's disease with one-on-one support and group activities, support groups across Queensland, and non-clinical counselling support. Our specialised support will enable people to connect with other families impacted by Huntington's disease at a support group and enable young adults and children to discuss the challenges that they are facing at school and home with our HD Advisors.

Please help us by considering a gift today, either scanning the QR code or [visiting our website](#).

Thank you so much.

