HA Highlights



Shining a Light on Hope: HD Awareness Month 2025

Words Nikka Biasotto

May is **Huntington's disease (HD) Awareness Month**, a time when our community comes together to shine a light on this rare, inherited neurological condition and the thousands of Australians impacted by it. This month is about raising awareness, fostering hope, and rallying support for those living with HD, their families, and carers.

Throughout May, Huntington's Australia will be hosting a variety of events and initiatives designed to educate, engage, and inspire. From local community gatherings and fundraising events to online campaigns and powerful personal stories, we invite everyone to join us in spreading awareness and advocating for better care and support.

One of the highlights of the month is our annual **'Light It Up 4 HD'** events, where landmarks across the country are illuminated in blue and purple to show solidarity with the HD community. We encourage workplaces, schools, and households to participate by attending these light-up events, hosting morning teas, or organising local fundraisers. Every effort, big or small, helps bring us closer to a future free from HD.

This month is also a chance to acknowledge the strength and resilience of those impacted by Huntington's disease. Their stories remind us why it's essential to continue advocating for better services, more research, and greater understanding.

By supporting HD Awareness Month, you are helping to ensure that no one faces this disease alone. Stay connected with us on social media, share your own HD journey, and encourage your networks to get involved. By working together, we can raise awareness and light the way for the Huntington's community.

Visit our website to learn how you can participate.

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CEO INSIGHT

Words Lenni Duffield, CEO



Welcome to 2025!

I hope you all enjoyed a well-deserved break over the holiday period and spent your time investing in what makes you happy or brings you joy!

I was fortunate to spend my time off visiting family and friends in Adelaide, enjoying the lovely beaches and coastline South Australia has to offer. Of course, there was plenty of overindulging in food, chocolate, and cheese, but this was accompanied by much laughter and love.

This year is already off to a cracking pace! Planning is well underway for our 'Light It Up 4 HD' events happening across Australia in May. Support groups are back up and running post-Christmas, and the team is focused on finding efficiencies and improving our services. I'm hoping to be at an event or two for Light It Up and meet as many of our HD community members as I can.

While it's wonderful that our reach and awareness have grown, and we're receiving more requests for support and services, this comes with its own challenges. To address this, we've been working over the Christmas break with various state and federal government departments to secure additional funding so that we can continue to deliver and expand our support. We encourage anyone wanting to help us in this mission to contact their local Member of Parliament and urge the government to prioritise this matter. To learn how you can help, please reach out to us on admin@huntingtonsaustralia.au.

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On the clinical trial front, 2025 is shaping up to be a very exciting year for HD. We are fortunate to continue working with Skyhawk Therapeutics, a biotechnology company, as they prepare to roll out the next stage of their SKY-0515 clinical trial in Australia. We'll provide updates to our community soon about the trial, how to express interest in participating, and details on upcoming community information sessions. Learn more information for the SKY-0515 Phase 1 study, including participating sites and eligibility criteria, on www.skyhawktx.com.

While Christmas and New Year may already seem to be a distant memory, it's important to take the opportunities to relish in the small things that bring joy and make sure we don't get swallowed up by the busyness of the year. I recently heard the phrase "2025 Thrive," which certainly resonated with me. I thought it summed up HA's approach to the year ahead nicely. While we have challenges ahead, including changes to the NDIS, looming state and federal elections, and the potential shifts that may bring, we will face these head-on and thrive.

Warm regards,
Lenni

Bridging Gaps in Palliative Care

Lenni Duffield, CEO of Huntington's Australia, delivered a powerful presentation at the 2024 Palliative Care Summit in WA, highlighting the urgent need for reform in quality palliative care for neurodegenerative diseases.

She addressed the systemic underfunding of community palliative care services, using Huntington's disease as a key example of a life-limiting condition. Despite 70% of Australians preferring to die at home, only 14% do, with most spending their final days in hospitals or aged care facilities. Ms Duffield argued that palliative care remains an "optional extra" instead of a core part of the healthcare system, despite recommendations from the Royal Commission into Aged Care.

A major theme was the economic inefficiency of the current model. People receiving palliative care at home have fewer hospitalisations and shorter stays, saving the government money. Yet, funding often falls short, forcing nonprofits to bridge the gap through fundraising or volunteer efforts — an unsustainable approach that shifts the financial burden onto charities.

Ms Duffield shared Harley's story, a young man with Juvenile Huntington's disease, whose mother is fighting for him to receive care at home under the NDIS. His situation exemplifies how bureaucratic barriers often force vulnerable people into unsuitable care, stripping them of dignity and choice.



From left to right: Lenka Psar-McCabe, CEO of Palliative Care WA; Vicki Barry from the WA Young Onset Dementia Network, YPINH; Lenni Duffield, CEO of Huntington's Australia and Di Darmody, the conference MC.

To address these challenges, Ms Duffield proposed three solutions:

- Normalise conversations about death to improve understanding and advocacy for palliative care at home.
- Demand government accountability to ensure recommendations from inquiries and reports are implemented.
- Strengthen collaboration between nonprofits, governments, and stakeholders to drive systemic change.

Ms Duffield closed with a call to make palliative care a core, accessible service for all, urging the nonprofit sector to keep advocating for dignity, choice, and humanity in end-of-life care.

OUT AND ABOUT



WA Carer Christmas Party



SA Coffee & Co Farewell Summer Party



WA South West Support Group



QLD Brisbane Support Group



TAS North Support Group Dinner





WA Day Centre Animal Farm Visit



TAS HA supporters wear Walk 4 Hope shirts at a local run event

Huntington's Australia Expands Services in South Australia

Words Monica Cazzolli, Team Leader, Community Programs

We're excited to share that Huntington's Australia is growing its support network in South Australia. With new staff on board and a renewed focus on community engagement, we're working hard to increase supports for individuals and families impacted by Huntington's disease (HD).

Meet our new team members

We're delighted to welcome Jess, Patrick, and Charlie to our South Australia team.

Leading our operational support is Charlie, our new Administration Officer. Originally from England, Charlie brings nearly 10 years of experience as a photo lab technician. In her role, she'll be managing communications and ensuring the smooth running of day-to-day operations. Driven by a deep sense of community, Charlie is honoured to join HA to help create safe, supportive spaces where people feel seen, heard, and respected. Off the clock, she's a talented artist and DJ.

Joining Charlie are Jess and Patrick, our new HD Specialists who are passionate professionals committed to make a meaningful impact.

Jess, an experienced Occupational Therapist, brings a decade of expertise supporting people living with neurological conditions, including HD. Based in Adelaide, Jess enjoys spending time with her husband and son, and kayaking at the beach. She's particularly excited to support our Coffee & Co group and looks forward to deepening her connections with the community.



Jess



Patrick



Charlie

Completing the team is Patrick who has a background in social work and over seven years of experience in the Community Services sector, specialising in mental health, NDIS, and homelessness support. His passion lies in empowering individuals to navigate life's challenges, access critical resources, and improve their quality of life. With his strong understanding of the NDIS and dedication to serving others, Patrick is eager to create a positive difference.

What's Next?

In just six weeks, Jess and Patrick have hit the ground running. They've facilitated two in-person Coffee & Co groups, participated in online sessions, and collaborated with Lesley and Catherine from SAHDS. They're also reaching out to other relevant stakeholders, learning more about the community's history and exploring opportunities for new programs.

As we continue to build our presence in SA, we're listening closely to the community to understand what supports are needed most.

We're excited about the future and continuing to build South Australian support services.

Changes around the NDIS

Words Julie Niel, Head of Community Programs & Services

The National Disability Insurance Scheme (NDIS) continues to evolve to better serve its participants. With leadership changes, new funding guidelines, and upcoming regulations, it's important to stay informed about what these changes mean for you and your supports. Here's a breakdown of the key updates and how they might impact you.

New Leadership

Minister Bill Shorten has stepped down, and Minister Amanda Rishworth has assumed the NDIS portfolio, bringing new direction and leadership to the scheme.

Clearer Funding Guidelines

A definitive list of what the NDIS will and will not fund has been developed to provide greater transparency for participants and providers, ensuring clarity around available supports. Visit the NDIS wesbite to learn more.

Impairment Notices

Starting January 1, 2025, all new participants will receive an impairment notice when they join the NDIS, while existing participants will receive theirs over time.

These notices classify participants based on the functional impact of their condition rather than a specific diagnosis, recognising that individuals with the same diagnosis may have different support needs. Impairments will be categorised into six groups: Intellectual, Cognitive, Sensory, Neurological, Physical, and Psychosocial.

Foundational Supports

A proposed new tier of disability supports, Foundational Support, aims to bridge the gap between mainstream services and specialised NDIS-funded services. General supports that include capacity building, information, and peer support available will be accessible to both NDIS participants and non-participants.

Targeted supports will provide assistance for people needing lower-intensity disability support, such as children with developmental



delays who do not qualify for the NDIS. At this stage, the approval of this new tier is still pending.

Mandatory Provider Registration

All NDIS-funded providers must be registered by June 30, 2025. If you use non-registered providers, speak with your Support Coordinator or Local Area Coordinator (LAC) to understand how this may impact your services.

Work with our Support Coordinators

At Huntington's Australia, we recognise the unique challenges faced by individuals with Huntington's disease and their carers. Our Support Coordinators work closely with you at your pace to ease your daily stress by managing your supports.

For more information or to get in touch with one of our NDIS Support Coordinators, call 1800 244 735 or email NDIS@huntingtonsaustralia.au.

MEET OUR TEAM

We're thrilled to see our team grow, now reaching **32 staff members nationwide**, all dedicated to supporting and empowering communities.

Our committed team works tirelessly to improve the lives of individuals and families impacted by HD, offering resources, guidance, and a compassionate community to help navigate the challenges they face.

Brisbane



Alyse
HD Specialist



Tressa
HD Specialist



Kylie
Administration Officer



Julie
Head of Community Programs & Services



Vinay
Specialist Support Coordinator



Cathy
Fundraising & Events Coordinator

Perth



Lenni
CEO



Monica
Team Leader, Community Programs



Karen
Administration Officer



Abiha
Team Leader NDIS Services



Janine
NDIS Specialist Support Coordinator



Arpita
NDIS Support Coordinator



Kimberley
Specialist Support Coordinator



Roy
Management Accountant



Samantha
Finance Officer



Maggie
HD Specialist



Nerilee
HD Specialist

Sydney



Alison
Head of Business Development & Fundraising



Stewart
Administration Officer



Malisha
NDIS Support Coordinator



Kate
NDIS Support Coordinator



Sharon
Specialist Support Coordinator



Linda
HD Specialist



Nikka
Communications Coordinator

Adelaide



Jessica
HD Specialist



Charlotte
Administration Officer



Patrick
HD Specialist

Launceston



Lauren
HD Specialist



Tamara
NDIS Support Coordinator



Irene
NDIS Support Coordinator

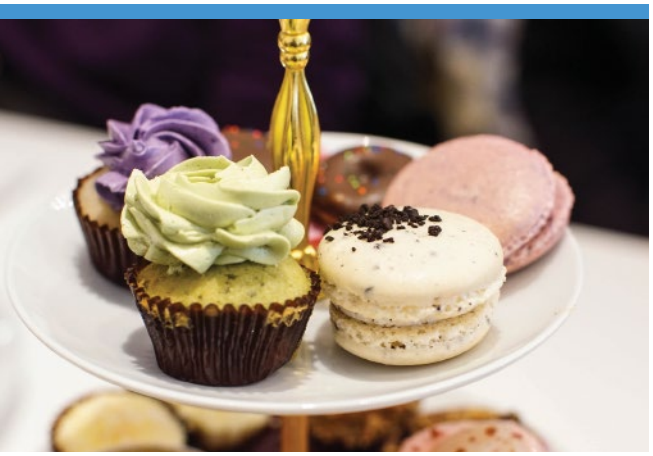
FOCUS ON FUNDRAISING

Words Cathy Holland

High Tea 4 HD

This May, we're bringing a fresh twist to **High Tea 4 HD**, inviting you to host your own event in a fun and creative way. Whether you're it's a cozy gathering at home, a picnic in the park, or partnering with a local venue, we can't wait to see how High Tea 4 HD pops up across the country.

You can keep it simple or go all out. We're here to support you with tips, inspiration, and digital resources to help you get started. Plus, your registration page doubles as a fundraising page, so every cup of tea supports individuals and families impacted by HD.



Thank you for your support!

We look forward to seeing your creative High Tea 4 HD events in May.

Ready to host? Register online, set up your event page, and download a custom flyer to share with friends and family.

To learn how you can host a High Tea event, visit https://huntingtonsaustralia.au/high-tea-2025/.

Running 4 Nan's HD

For our Brisbane supporters, it's time to lace up those running shoes and save the date.**Running 4 Nan's HD** is back on Sunday, June 15 on the Wynnum Esplande, Wynnum. Now in its 8th year, this special event is organised by passionate HD advocate Kelly and her supportive husband, Steve, in loving memory of their Nan, who had HD.

Can't make it on the day? Not a problem — you can register as a virtual participant and we will post your medal after the event.



Entry is still only $25, and for an extra chance to win exciting prizes, raffle tickets are available for just $2 each. Registration opens at 5:30am, with the event kicking off at 6:30am at the Wynnum Wading Pool on Wynnum Esplande, Wynnum.

To register and purchase raffle tickets, visit www.bit.ly/running4nan2025.

Fundraise with us

Starting your own fundraiser for Huntington's Australia is an impactful and fulfilling way to support those impacted by Huntington's disease and it's easy to set up. Whether you're running a marathon, hosting an event, honouring a loved one's memory, or raising awareness, every effort helps us to provide vital support to people with HD and their families. If you are participating in a major event, you'll set up a fundraising page as part of your registration. If not, setting one up is a quick and easy process.

Steps to Start Your Fundraiser

1. Tell Your Story
The most compelling fundraisers are personal. Share your journey — why you're fundraising and what supporting families impacted by HD means to you. Whether you have a loved one with the disease or simply feel passionate about making a difference, your story will inspire others to contribute. Add a photo or two to make it more impactful.

2. Set a Fundraising Goal
Choose a fundraising target that's both meaningful and achievable. Setting a clear goal helps motivate you and your supporters. Remember, every dollar counts in bringing hope to our HD community. Don't forget to update your target as you make progress!

3. Spread the Word
Get the word out. Share your fundraiser through email, social media, and word of mouth. Ask your friends, family, and colleagues to support your cause and help spread the word.

4. Celebrate Your Impact
Keep your supporters updated on your progress, and don't forget to thank them for their generosity. Showing how their donations make a difference whether through messages, photos, or videos, will keep them engaged and connected to the cause.







Setting up your fundraiser means joining a compassionate community committed to improving the lives of those impacted by HD. Get started today by visiting www.bit.ly/fundraise4ha.



Brain Gym: Staying Mentally Active May Slow Huntington's Disease

Words Maille (Molly) Gracey

We all know that exercise is good for our bodies, but what if working out your brain could slow down Huntington's disease (HD)?

Dr. Estela Càmara and her wonderful team from IDIBELL, a research institute in Spain, have uncovered some exciting news: staying mentally active throughout your life might actually help slow brain shrinkage and symptom progression in people with HD.

Measuring Mental Workouts

HD gradually damages brain cells, leading to problems with the individual's mood, movement, and mind. But new research suggests that cognitive engagement - keeping your brain busy with activities like reading, puzzles, or learning new skills - could help protect the brain, possibly slowing down progression of symptoms of HD.

Using high-tech brain imaging, the researchers were able to track changes in the brains of people with HD over time. The technique they used is like taking a time-lapse video of the brain.

All participants completed one questionnaire at the start of this study, which measured how much mental exercise had been done over each person's lifetime – basically a brain workout scorecard!

Following this, participants completed a number of questionnaires that provided measures of how well their mind functions, as well as questionnaires that assessed their mood.

Tracking Brain Gains

Once this study was complete, researchers then applied some complicated mathematical models to track how mind and mood symptoms changed over time in people with HD, factoring in their brain workout scorecard. Essentially, they wanted to see if more "brain workouts" meant a slower decline in mind and mood symptoms.

Mental Reps: Lifelong Learning Builds Brain Strength

Keeping your brain active with things like puzzles, books, learning, creating, and socialising are all good ways to flex your mental muscles.

The researchers stated that people who regularly challenged their minds throughout their lives tended to show slower progression in movement, mind, and mood symptoms of HD. In short, perhaps staying mentally active might not just keep your brain sharp, but it could also help hold some HD symptoms at bay.

However, one question you might be asking is, how does being mentally active relate to slower progression in HD symptoms? Dr. Càmara and her team considered one possible explanation for this slower progression in HD symptoms by looking at the brain images taken in this study. These brain images showed that people with HD who engaged in lifelong mental workouts had stronger brain resilience. This means that their brain structures stayed healthier for longer.

Specifically, key areas of the brain involved in mind (such as decision-making and self-control), mood (such as emotional regulation), and movement symptoms were better preserved. So perhaps this stronger brain resilience could be one reason behind why HD symptoms progress more slowly in those who have had their regular sessions in the brain gym over their lifetime.

Flex Those Brain Muscles

The good news is that you don't need a PhD to give your brain a workout! Here are some fun ways you can stay mentally active:

Puzzles & Games: Crosswords, Sudoku, and memory games can keep your brain on its toes.

Read & Learn: Books, audiobooks, or even podcasts can spark new ideas and strengthen brain connections.

Language: Learning a new language is a strenuous mental workout that deeply challenges various areas of your brain.

Music & Creativity: Playing an instrument or learning a new craft can challenge different parts of the brain.

Socialising: Chatting with friends, debating topics, or even storytelling can help to keep thinking skills sharp.

A Mental Workout Against HD

HD is a tough opponent, but science is showing us that mental activity may help slow it down. While it's not a cure, keeping your brain busy is a simple, fun way to fight back against Huntington's. So, grab a book, solve a puzzle, or try something new - your brain will thank you.

This article has been edited for length. Read the full article on https://en.hdbuzz.net/411

WHAT'S HAPPENING?

Community Support Groups for the period of March – June

NSW

Group	Date
Central Coast Carer Support Group	12 March, 9 April, 14 May, 11 June
Newcastle/Hunter Carer's Group	13 March, 10 April, 8 May, 12 June
Newcastle Support Group	14 April, 2 June
West Ryde Carer Support Group	2 April, 7 May, 4 June
NSW Carer Support Group | ONLINE	26 March, 23 April, 28 May, 25 June

QUEENSLAND

Group	Date
Ipswich Support Group	25 March
Logan & Redlands Support Group	13 March
Sunshine Coast/Gympie Support Group	23 April
Toowoomba Lunch Support Group	4 April

SOUTH AUSTRALIA

Group	Date
Coffee & Co	2 April, 30 April, 14 May, 28 May, 11 June, 25 June
Coffee & Co | ONLINE	9 April, 7 May, 21 May, 4 June, 18 June





TASMANIA

Group	Date
North Support Group	9 April, 14 May, 11 June
North-West Support Group Dinner	21 May
South Hobart Support Group	3 April, 5 June

WESTERN AUSTRALIA

Group	Date
Carer Support Group	13 March
Day Centre Support Group	2 April, 30 April, 14 May, 28 May, 11 June, 25 June
North Suburbs Carer Support Group	8 May
Central Perth Carer Support Group	19 June
South Metro (Rockingham) Carer Support Group	9 April
Southwest Support Group	29 May
Day Centre | ONLINE	7 May, 21 May, 4 June, 18 June

Visit our website for more information and to RSVP: **https://huntingtonsaustralia.au/community-programs**

Huntington's Australia

Huntington's Australia
11 Aberdare Road, Nedlands, WA 6009

T 1800 244 735
E admin@huntingtonsaustralia.au
W www.huntingtonsaustralia.au