HA Highlights



SA Coffee & Co Support Group

Have Your Say in 2025

Your voice matters. Help shape our priorities, services and advocacy efforts by completing our community survey.

Words Nikka Biasotto

Our 2025 Community Survey is happening in July — and it's your chance to tell us what matters most to you, your family, and your community.

At Huntington's Australia, we believe that real impact starts with listening. Your feedback will guide our work over the next year and help us better support people impacted by Huntington's disease. Whether it's improving the services we provide, strengthening our advocacy efforts, or focusing our communications on what you need most, your voice makes a difference.

This survey is open to everyone connected to the Huntington's community — including people living with HD, family members, carers, support workers, clinicians, researchers and advocates. It's completely anonymous and takes a few minutes to complete.



What's working well? Where can we do better? What issues are most important to you in 2025? Tell us honestly — because we're listening.

By sharing your experiences and insights, you're helping us make informed decisions that reflect the needs and values of our community.

To learn about the survey, visit www.huntingtonsaustralia.au/haveyoursay25.

If you need help completing the survey or have any questions, please contact us at admin@huntingtonsaustralia.au or 1800 244 735.

Let's work together to make sure every voice is heard.

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CEO INSIGHT

Words Lenni Duffield, CEO



Lenni with Masoud Mokhtarani and Maddy Mokhtarani of Skyhawk Therapeutics

Wow, where have the last 3 months gone?

It seems that time continues to fly, and as I pack away our son's summer uniform to welcome winter, I realise there has been no time to sit down and reflect on the last few months.

Whilst there has been a flurry of activity, May is arguably one of the most significant months on our HA calendar, filled with events and opportunities to connect as we recognise HD on a global scale. Throughout the month, we hosted community events in each state and participated in the International Light It Up 4 HD campaign, with over **100 landmarks and sites** lighting up for HD. These events attracted over **240 community members** and provided an opportunity for them to come together and draw strength from each other.

May also marked a first for us — our entire national team gathered in Sydney for a full-day **All Staff Forum**. We shared learnings from our unique roles, discussed challenges openly, aligned on goals, and explored ways to collaborate more effectively across the board. We also took time to celebrate some incredible milestones — staff who've been with us for 5, 10, even 25 years of dedicated service.

Whilst in Sydney, our team was fortunate to take part in a workshop on the **SKY-0515 clinical trial**, hosted by Skyhawk Therapeutics. Participants from HA and like-minded organisations, including researchers, neurologists, and allied health professionals, came together to share insights and explore how we can better engage the community in clinical trials and research. It was a powerful day of learning and collaboration, and an exciting time in the HD Research space.

Amongst all of this, we also navigated the federal election, meeting with ministers and government departments, and welcoming newly appointed representatives. Health Minister Mark Butler's reappointment was expected, but it was a surprise to see his responsibilities expand to include the NDIS. I'm looking forward to meeting with his office in the coming months to highlight the numerous challenges HD families face within the NDIS, and to advocate for a deeper understanding of degenerative neurological conditions as NDIS reforms progress.

Although the election has passed, we will continue to **build on our strong national advocacy work** to move HD out of the shadows and into the forefront of policy and advocacy spaces. Because too many people living with HD are still not getting the support they so desperately need.

The last three months have been full of anticipation and excitement, and as we move into a new financial year, the next 12 months promise to be just as defining for HA and for our sector.

As time races on, I find myself asking whether it's a friend or foe. But I'm reminded, even as I fold that uniform, that **it's in these ordinary moments we often find the most meaning.** The courage and spirit of our HD community continues to inspire me and it drives us to keep passionately moving forward.

> "The next twelve months promise to be just as defining for HA and for our sector."

Warm regards,

Lenni

Building connections through research: Skyhawk forum highlights

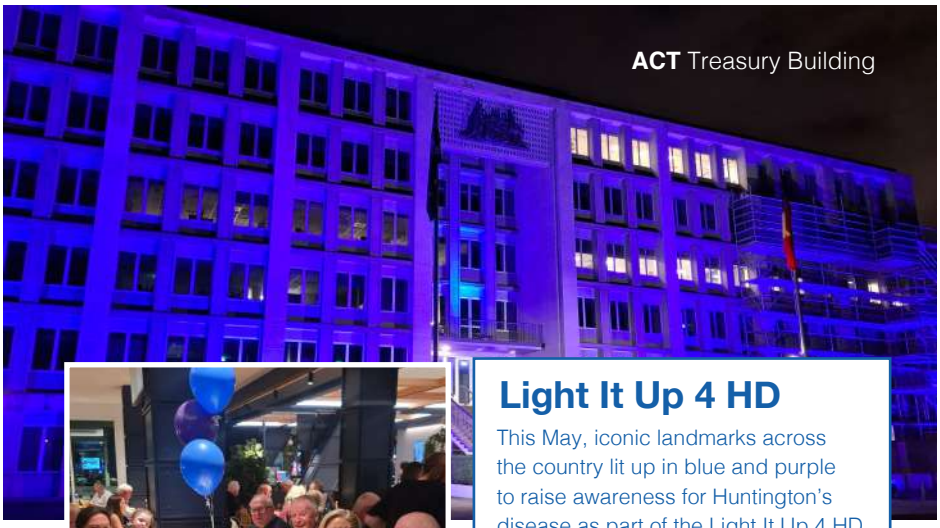
Huntington's Australia recently joined a workshop on the SKY-0515 clinical trial, hosted by Skyhawk Therapeutics. The event brought together researchers, clinicians, and community organisations to share insights and explore how to better engage the HD community in research. It was an inspiring day of learning and collaboration.

To learn more about the trial, visit https://huntingtonsaustralia.au/skyhawk/.



The Skyhawk Therapeutics Team

OUT AND ABOUT



ACT Treasury Building



QLD



NSW



TAS

Light It Up 4 HD

This May, iconic landmarks across the country lit up in blue and purple to raise awareness for Huntington's disease as part of the Light It Up 4 HD campaign.



WA



NSW





SA Coffee & Co



SA Community & Online Forum



ACT Support Group



NSW All Staff Forum

NDIS Update: Changes to Funding Periods

Words Abiha Asghar, NDIS Services Team Leader

From 19 May 2025, the National Disability Insurance Scheme (NDIS) will change how funding is managed for new plans approved from this date. This change affects plans under section 33 of the NDIS Act 2024.

What's changing?
NDIS plans will now be split into smaller funding periods, usually every three months (quarterly). This means supports like daily assistance will be paid in instalments each quarter. Some supports, such as high and low-level supports, will be paid monthly, while others like assistive technology or home modifications will be funded as a one-off payment.

If a participant doesn't use all their funding in a period, the remaining money will roll over to the next period—until the plan ends. After the plan expires, unused funds cannot be carried forward.



Who does this affect?
Only new plans approved from 19 May 2025 will follow this new funding method. Plans approved before this date will continue as usual until they are reassessed.

What does this mean for providers?
Support Coordinators and Plan Managers will have new tools to see the breakdown of funding periods in their portals. Other providers won't have this detailed view. They will also need to adapt to new claiming rules: invoices must be submitted separately for each funding period, and claims won't be paid if there's insufficient funding in that period.

Providers cannot use funds from future periods early, but unused money from previous periods will carry over.

Important tips

- Service agreements may need to match funding periods, possibly requiring updates every three months.
- Support Coordinators should work closely with participants and families to plan for times when more support is needed, like holidays, to ensure enough funding is allocated.
- If more funding is needed outside these periods, a plan reassessment or variation is required.

This new system aims to improve funding management but will require careful planning from everyone involved.

Meet the newest members of our Specialist Support Coordination team



Kimberley
Perth, Western Australia

Kimberley holds a Bachelor's degree in Social Science and is currently completing a Master's in Neuroscience. With around three years of experience in support coordination, she brings a strong background in health, disability, and community services. Kimberley's journey into support coordination comes from both personal and professional experience with the NDIS and a genuine desire to create positive change. Based in Western Australia, she supports many participants remotely. Outside of work, she enjoys spending time with her teenagers and energetic dog, as well as reading, bushwalking, swimming, and making art and music.



Vinay
Brisbane, Queensland

Vinay holds a Master of Social Work and five years' experience in the disability sector. He specialises in supporting people with complex needs, working closely with participants, families, and providers to ensure tailored support and advocacy. Vinay is currently accepting new referrals but, due to his caseload, is focusing on in-person support for local clients. Outside of work, he enjoys family movie nights and playing badminton to keep active and balanced.



Tamara
Launceston, Tasmania

Tamara comes from a strong background in advocacy for mental health, older people, and those who use drugs. She transitioned to the NDIS to better understand and help people living with disability, especially neurological and cognitive conditions. After working as a Local Area Coordinator and support coordinator, Tamara joined Huntington's Australia, focusing on supporting participants remotely from Hobart, though she is keen to expand local support. Tamara treasures time with her family, including her grown children and granddaughter, and enjoys politics, history, art, movies, and theatre.

Our coordinators are here to support you, no matter where you live. If you'd like to connect with them or learn more, please get in touch by contacting us on 1800 244 735 or NDIS@huntingtonsaustralia.au.

AROUND THE COMMUNITY



All staff from across the country gathered in Sydney

All Staff Forum 2025

On 15 May, the Huntington's Australia national team came together in Sydney for our first face-to-face All Staff Forum – a day centred on connection, collaboration, and shared purpose.

The forum opened with a simple but powerful message: today is about *you*. It was a chance to reflect on the work we do, share challenges, and explore ways to grow together as an organisation.

The gathering brought together team members from across the country, offering a rare chance to connect face-to-face, share knowledge, and strengthen bonds across roles and regions.

Staff engaged in open discussions, strategy sessions, and informal catchups that deepened their understanding of each other's work and renewed their shared commitment to supporting the Huntington's community.

As Lauren, HD Specialist from TAS, shared, "It has been wonderful to see everyone in person, as sometimes my role can be isolating. It has been refreshing to hear different perspectives."

Sam, Finance Officer from WA, reflected, "Being part of these conversations helped me see the real-world impact of what we do behind the scenes. It reminded me why our work matters."

A highlight of the day was recognising our long-serving staff, whose unwavering commitment and dedication reflect the very heart of Huntington's Australia. We took a moment to celebrate and thank team members who have been with us for over 5, 10, 15, and even 25 years.

The forum was a meaningful reminder that together, we are stronger and that the best ideas come when we take the time to listen and connect.





Congratulations to our Service Awardees!

Over 5 Years



Lenni
CEO



Cathy
Fundraising & Events Coordinator



Lauren
HD Specialist

Over 10 Years



Stewart
Administration Officer



Monica
Team Leader, Community Services



Maggie
HD Specialist

Over 25 Years



Tressa
HD Specialist

FOCUS ON FUNDRAISING

Words Cathy Holland

Brewing hope with High Tea 4 HD

High Tea 4 HD is blossoming into a national movement, bringing together families and communities across Australia to raise awareness and funds for Huntington's disease.



Tanya with her friends and loved ones



Alyssa, a long-time supporter

In **Queensland**, Tanya and her husband, Shane, hosted a beautiful afternoon at The Glen Hotel in Brisbane, where over 30 guests gathered to support Huntington's Australia. Thanks to the generosity of local sponsors and the community, they raised over $3,000. Tanya, who lives with Huntington's disease, has faced many challenges, but with Shane by her side, they've worked hard to keep hope steeped in their lives. "We've been together for 18 years, and I just want her to get the most out of life while she can," Shane shared.

Meanwhile, in **Sydney**, Alyssa, who cares for her mum living with Huntington's disease, hosted her own High Tea 4 HD event, raising over $2,000. Alyssa's fundraiser brought friends and family together, creating a warm and welcoming space to learn about Huntington's and show solidarity with the HD community.

Both events highlight how High Tea 4 HD has grown from intimate gatherings to a nationwide campaign. It's about much more than fundraising. It's about starting conversations and building a supportive community from Queensland to New South Wales and beyond.



Tanya's gift bags for her guests



Alyssa's friends and family

The hope is that these events become annual traditions. What began with a cup of tea has grown into a movement that brings people together and creates real change.

Running 4 Nan's HD is just weeks away

Brisbane supporters, it's nearly time to lace up those running shoes. Running 4 Nan's HD is back on **Sunday, 15 June** at the Wynnum Esplanade.

Now in its 8th year, this special event is organised by long-time HD advocate Kelly and her husband Steve, in loving memory of their Nan, who lived with Huntington's disease.

Can't make it in person? You can still take part as a virtual participant, and we'll post your medal after the event.

Entry is just $25, and raffle tickets are available for $2 each, with great prizes to be won.

Registration opens at 5:30am, with the run starting at 6:30am from the Wynnum Wading Pool.

To register or buy raffle tickets, visit **www.bit.ly/running4nan2025**.

Let's run together in support of families impacted by HD.



Kel and her nan, Isabela



Taking control: new research shows we can influence brain health before symptoms appear

Words Sally McKay, brain health advocate

New research from PSL University Paris offers encouraging news for people who carry the Huntington's disease (HD) gene but are not yet showing symptoms. Scientists have found that we have more control over brain health than previously thought.

By identifying several modifiable risk factors such as lifestyle choices that can influence the brain, this groundbreaking study offers practical ways for the pre-symptomatic HD to potentially delay the disease's progression. These findings complement the 2024 Lancet Commission on dementia, adding to the growing body of evidence that lifestyle choices can significantly impact neurological health outcomes:

The power of modifiable risk factors
Researchers at PSL University followed 2,636 individuals who carry the HD but are pre-symptomatic, tracking them over three years. They identified several modifiable lifestyle factors linked to slower disease progression:

Brain power

- Higher levels of education after age 35 were especially protective.
- This may reflect the concept of cognitive reserve—the brain's ability to compensate through lifelong mental stimulation.

Body weight - age matters

- Under 40: Being on the leaner side (but not underweight) was associated to slower disease progression.
- Over 40: Carrying slightly more weight within a healthy range seemed to be more protective.
- This suggests the need for age-appropriate strategies to support both brain and body health.

Diet and substance use

- Moderate alcohol intake (up to 15 units per week – roughly 1.5 bottles of wine or 6 standard beers) was linked to slower progression.
- Not smoking was strongly associated with better outcomes.

Mental wellbeing

- People with no history of depression or anxiety histories showed slower disease progression
- This underscores the vital role of early mental health support and ongoing emotional wellbeing.

Your brain health action plan
If you carry the HD gene and are pre-symptomatic, consider these proactive steps:

1. Keep your brain active

- Enrol in adult learning courses or try learning a new language.
- Engage in mentally stimulating hobbies like reading, puzzles, or cooking new recipes.

2. Stay at a healthy weight (age-appropriate)

- Work with your GP to determine the ideal weight strategy based on your age.
- Under 40: Focus on staying fit and lean (but not underweight) – you could focus on cardio fitness.
- Over 40: Avoid being underweight – you could focus on muscle strength.

3. Make healthy lifestyle choices

- Say no to smoking or get help to quit.
- If you drink, keep it moderate and consider alcohol-free options.
- Prioritise nutritious meals and regular exercise.

4. Prioritise mental wellbeing

- Watch for early of signs of anxiety or depression and seek support promptly.
- Use mindfulness, counseling or stress-reduction techniques.
- Schedule regular mental health check-ups with your GP

What you can do today
While we await further breakthroughs, even small lifestyle changes may help protect your brain health. Think about what's realistic for you or a loved one: a new hobby, a mindful eating change, or a conversation with your GP.

This article is based on findings from: Modifiable factors associated with Huntington's disease progression in presymptomatic participants 2024
Always consult with your healthcare provider before making major lifestyle changes.

WHAT'S HAPPENING?

Support Groups for the period of July – September



NSW

Group	Date
ACT Support Group	25 August
Central Coast Carer Support Group	13 August
Central West	15 September
Newcastle/Hunter Carer's Group	10 July, 14 August, 11 September
Newcastle Support Group	11 August
West Ryde Carer Support Group (Northern Sydney LHD)	2 July, 6 August, 3 September
NSW Carer Support Group | ONLINE	15 September

SOUTH AUSTRALIA

Group	Date
Coffee & Co	30 July, 13 August, 27 August, 10 September, 24 September
Coffee & Co | ONLINE	6 August, 20 August



TASMANIA

Group	Date
North Support Group	9 July, 13 August, 10 September
North-West Support Group Dinner	16 July, 17 September
South Hobart Support Group	7 August

WESTERN AUSTRALIA

Group	Date
Day Centre Support Group	30 July, 13 August, 27 August, 10 September, 24 September
Northern Suburbs Carer Support Group	7 August
Central Perth Carer Support Group	11 September
Southwest Support Group	28 August
Day Centre | ONLINE	6 August, 20 August

Visit our website for more information and to RSVP: https://huntingtonsaustralia.au/support-groups

Huntington's Australia

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