HA Highlights

Huntington's Australia



Huntington's Australia announces first National HD Conference

Huntington's Australia is proud to host its **inaugural National Conference** on Thursday 7 May 2026 at the Adelaide Convention Centre. This landmark event will bring the HD community together under the inspiring theme "*The Power of Hope.*"

With an expected 200 in-person attendees and many more joining online from across the country, the conference offers a unique opportunity to connect with others who understand the Huntington's disease journey.

Whether you're living with HD, a family member, carer, health professional, or researcher, this is your chance to be part of a powerful day of learning, connection, and community.

The program features a professional stream packed with the latest research updates and expert sessions led by leading health professionals. Attendees will gain valuable insights into current developments in HD care and research, while contributing to important conversations about the future of the HD community.

The event is proudly supported by confirmed sponsors Skyhawk, Brightwater, and Roche.

As the conference draws to a close, attendees are invited to stay for networking drinks and canapés — the perfect opportunity to unwind, make new connections, and continue the conversation in a relaxed setting.

The conference is available both in-person at the Adelaide Convention Centre and online for those unable to travel, ensuring everyone has the opportunity to participate.



Visit **huntingtonsaustralia.au/nationalconference** for all the details, including how to secure your tickets.

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Around the Community

Meet our Social Worker Karin, find out how to access the NDIS, and hear from Carmen about her journey with our support group in South Australia.

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Focus on Fundraising

May is HD Awareness Month and we have a packed lineup of activities — our national campaign Light It Up 4 HD, High Tea 4 HD, and Running 4 Nan's HD in Brisbane.

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Research Recap

Promising results have emerged from the SKY-0515 trial, with recruitment still underway across Australia. Data showed the drug was well-tolerated — an encouraging step as the trial continues.



> Advocacy and awareness will be a major focus for 2026.
>
> Together, we will continue working to ensure Huntington's disease is better understood, better supported, and more visible.

CEO Insight

Words Lenni Duffield

We've made a strong and energising start to 2026, and it's clear that the momentum we built last year is continuing to grow.

Thank you to everyone in our community who contributes to this progress — whether through advocacy, partnership, service delivery, or lived experience leadership.

Work will soon commence on HA's new Strategic Plan, which will guide our next phase of development. This plan will focus on consolidating our current achievements while positioning us for sustained growth and greater impact across the Huntington's community.

Advocacy and awareness will be a major focus for 2026. Together, we will continue working to ensure Huntington's disease is better understood, better supported, and more visible in policy and service discussions.

We are also gearing up for HA's first Conference, to be held in Adelaide on 7 May. This will be a significant milestone for our organisation and community. More details will be shared shortly — we look forward to bringing people together for connection, learning and collaboration.

Our newly introduced Social Work and Physiotherapy services are beginning to grow, and it's encouraging to see the positive response. If you would like more information about these services, or are interested in accessing support, please reach out to our team.

At the end of last year and the beginning of 2026, we lodged several state (QLD, TAS, NSW) and national funding submissions. Advocacy at every level makes a difference.

You can support this work by contacting your local MP or your state Minister for Health to share how vital local Huntington's services are



— and what they mean to you, your family, or someone you care about.

I look forward to a positive and productive year ahead as we continue building momentum, strengthening our impact, and working together to achieve meaningful outcomes for our community.

Together, we can make Huntington's a KNOWN rare disease.



Sign up to become a member

Join the Huntington's Australia community today and make a difference.

By becoming a member, you help support families living with Huntington's disease, fund vital services and strengthen advocacy efforts. Members receive exclusive updates, access to events, and opportunities to connect with the HD community. Your support ensures that no one faces Huntington's alone. Sign up now and be part of a movement that brings hope, awareness, and lasting impact to those impacted by this disease.

Visit huntingtonsaustralia.au/become-a-member

SA Coffee & Co





NSW St Vincent Care Services



QLD Ipswich Support Group



QLD Toowoomba Support Group



Staff Christmas Gatherings







WA Day Centre Group





AROUND THE COMMUNITY

Meet our team: a chat with Social Worker Karin

Words Nikka Biasotto, Communications Coordinator

Meet Karin



Karin
HD Community Practitioner/
Social Worker, QLD

With more than two decades of experience in disability and community services, she's passionate about making sure every person and family feels understood and supported.

Social work plays a vital role in supporting individuals and families affected by Huntington's disease. Beyond clinical care, social workers address the emotional, practical, and social factors that shape a person's overall well-being, from navigating complex systems to providing a listening ear during difficult times.

We sat down with Karin, our Queensland-based Social Worker, to learn more about her work and what drives her passion for supporting the HD community.

Q: What drew you to social work?
Karin: I was drawn to social work as it's a career that values people. I have a strong desire to fight social injustices and create tangible positive changes for individuals and their communities.

With over 20 years in the disability sector and qualifications including a Master of Social Work, Karin brings a wealth of experience to her role.

Q: What does a typical day look like?
Karin: A typical day is fast-paced and diverse from supporting individuals and families with practical resources, non-clinical counselling, housing, court support, food relief, to NDIS navigation, psychosocial assessments, and advocacy. The work is deeply rewarding, albeit challenging.

Q: What do you find most rewarding?
Karin: Building trusting and meaningful relationships, working alongside individuals and families through complex journeys. Supporting people to preserve their autonomy and dignity, and celebrating the small yet meaningful wins.

To access social work support, contact Huntington's Australia on 1800 244 735 or email admin@huntingtonsaustralia.au.

Social work can be accessed through your NDIS plan under "Improved Daily Living," but as Karin emphasises: "Reach out whether you have an NDIS plan or not. We can support you to access and navigate the NDIS and health systems."

To learn more about how social workers support NDIS participants, view the AASW fact sheet on **bit.ly/AAWSfactsheet**.

Access to the NDIS: Where do I start?

Words Julie Niel, Head of Community Programs and Services

Whether you're just beginning your NDIS journey or supporting a loved one, planning ahead is key. Many families wait until they're in crisis before reaching out, but accessing the scheme takes time — so don't leave it too late.

Q: Am I eligible?
You may be eligible if you're aged 9–65, an Australian citizen or permanent resident, living in Australia, have a diagnosis of HD from your neurologist, and need specific supports for daily activities. This could include physical assistance, supervision, assistive technology, equipment, home modifications, or family training to support you.

Q: How do I apply?
Start by visiting your GP to complete an NDIS Access Request Form. Book a longer appointment as this takes time. You'll also need supporting evidence, ideally recent reports from health professionals. A Functional Capacity Assessment from an Occupational Therapist is particularly helpful. If you don't have recent assessments, your GP can complete a Supporting Evidence Application form. A Carer Impact Statement outlining how HD affects your family is also valuable.

Q: What happens next?
The NDIS has 21 days to respond. If approved for a planning meeting, consider requesting a Plan Nominee, Support Coordinator, Plan Manager, and funding for counselling, social work, and carer training, especially in your first plan.

Need help?
You don't have to navigate this alone. Contact your Local Area Coordinator or reach out to Huntington's Australia at **admin@huntingtonsaustralia.au** or call **1800 244 735.** Our team can guide you through every step of the process.



Carmen's Journey with Coffee & Co







Carmen and Chris at a Coffee & Co session

There's something powerful about sharing a cuppa with people who truly understand.

Coffee & Co, a support group in South Australia, has become exactly that kind of space: a lifeline for families navigating life with HD. Led by Deb and Jess, our HD Community Practitioners in SA, with the support of our Administration Officer Charlie, Coffee & Co is a welcoming support group for individuals living with Huntington's disease who come along with their loved ones, carers, and family members. Among its dedicated members is Carmen, who has been a volunteer at Coffee & Co since October 2018.

She helped run Coffee & Co alongside friends whose families had also been impacted by Huntington's disease. Over the years, Coffee & Co has grown into something truly special. While the group always enjoys the warmth of a good cuppa and conversation, they also get out and about together — exploring botanical gardens, and taking trips to museums and art galleries. The group has also attended local festivals, enjoyed animal visits, and taken part in cultural talks that celebrate and explore traditions from around the world. These outings bring joy, connection, and a sense of adventure that HD can so often take away.

Before her husband's diagnosis, life looked quite different. Chris and Carmen travelled a lot, overseas and in Australia, but that has become more difficult as time has gone on; today, her husband requires daily support, yet Carmen's outlook remains one of appreciation.

"I'm grateful for the life and experiences we've had together before HD," shares Carmen.

Coffee & Co has been so valuable to the Huntington's community, connecting with others who understand the unique path HD families walk. Whether it's over a coffee, a stroll through a garden, or a shared laugh at a festival, the group reminds its members that there is still so much life to be lived — together.

If you'd like to join Coffee & Co or one of our other support groups, visit huntingtonsaustralia.au/support-groups.

When care makes all the difference

We recently received heartfelt messages from family members of our HD community:

"From the very first phone call, I felt an overwhelming sense of relief. Linda knew exactly what to say, how to support me, and how to guide me through what was happening with Mum. She kept me informed every step of the way, including when she had spoken with my step-dad and when she liaised with the hospital.

Her care, compassion, and calm professionalism made such a difference during a really difficult time. I honestly felt heard, supported, and not alone in navigating everything. I just wanted you to know what an incredible asset Linda is to your team, and how grateful I am for the support she has provided."
— Kara*, on working with our NSW HD Community Practitioner Linda

"We cannot speak highly enough of Kimberley and the ongoing assistance she provides to our family. Kimberley was an integral part of the success we had in moving Megan* into her new home yesterday, where she will receive the much deserved support and care.

Kimberley consistently goes above and beyond to ensure we are supported, which includes Megan's* care team being kept updated. Kimberley truly cares for the people she supports and is invested in the best possible outcome for the participant."
— Bea* on working with our WA NDIS Specialist Coordinator Kimberley

This is why we do what we do.

Our support and services teams are here to ensure no family feels alone during life's most difficult moments.

**Names has been changed to protect privacy.*

FOCUS ON FUNDRAISING

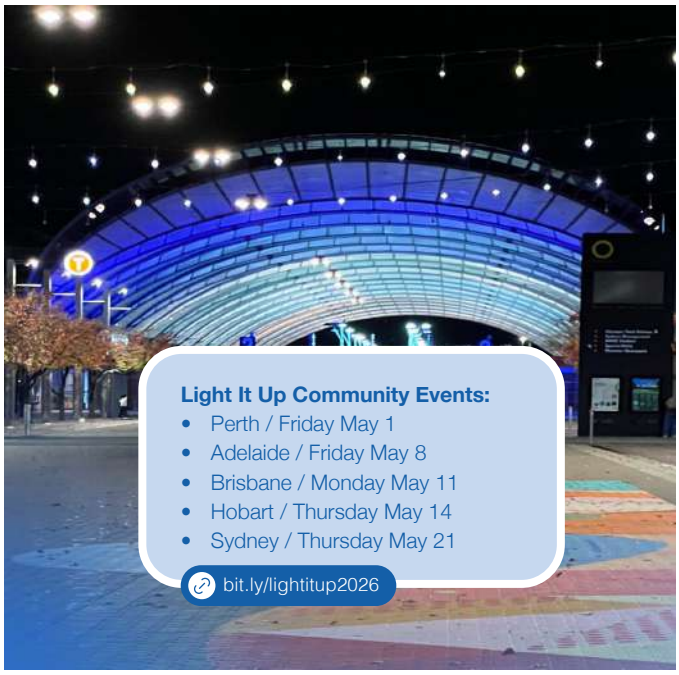
Shine a light this May

Words Cathy Holland, Fundraising & Events Coordinator









May is International Huntington's Disease 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.

Throughout the month, Huntington's Australia will host events and initiatives designed to educate, engage, and inspire. From 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.

A highlight of the month is the International #LightItUp4HD campaign, where buildings, bridges and landmarks are lit up around the world in blue and purple lights, respectively representing Huntington's disease (HD) and Juvenile Huntington's disease (JHD) to show solidarity with the HD community throughout the month.

Check out our Light it Up 4 HD page, to the find date of your closest landmark lighting up to support HD. Take photos and share them on social media to help raise awareness – don't forget to tag the landmark and us, using the tag #LightItUp4HD #huntingtonsaustralia and help raise awareness. Not on social media but would love to share your photos? Email them to us at fundraising@huntingtonsaustralia.au and we will share them for you!

We encourage workplaces, schools, and households to get involved, attend a Light It Up event, host a morning tea, or organise a local fundraiser. Every effort, big or small, helps us support more people impacted by HD.

For more information on how you can participate, visit **bit.ly/lightitup2026**. Let's make this May a month of awareness, compassion, and hope.

High Tea 4 HD returns

Host your own High Tea this May

Last year, we took a fresh direction with High Tea 4 HD, inviting you to host your own event in a fun and creative way, and it went so well that we're doing it again.

Whether you're gathering friends at home, enjoying a picnic in the park, or partnering with a local café or venue, we can't wait to see how High Tea 4 HD pops up across the country this May.

The best part? You can make your event as simple or elaborate as you like. A few scones and a cuppa with neighbours, an elegant afternoon spread, or anything in between, it all makes a difference. We're here to support you with tips, inspiration, and digital resources to help you get started.



Ready to host?

Registeronlineathuntingtonsaustralia.au/hightea4hd, set up your event page, and download a custom flyer to share with friends and family.

Thank you for your continued support. We look forward to seeing your creative High Tea 4 HD events this May and making a meaningful impact together for those impacted by Huntington's disease.

Running 4 Nan's HD is coming



Our hugely popular Running 4 Nan's HD event at the Wynnum foreshore in Brisbane is back for its 10th year. This meaningful community event is organised by dedicated HD advocate Kelly and her supportive husband, Steve, in loving memory of their Nan, who lived with Huntington's disease.

We're currently working with Kelly, our volunteer organiser, to confirm the best date in June. We'll share all the details, including the date and how to register, once everything is locked in.



RESEARCH RECAP

Promising Early Results for Investigational HD Treatment SKY-0515

In January, Skyhawk Therapeutics announced encouraging results from a nine-month interim analysis of their Phase 1 study of SKY-0515, an investigational once-daily oral medicine being developed for Huntington's disease. While these findings are preliminary and further research is needed, they represent meaningful progress in the search for treatments that could slow or halt HD progression.

What is SKY-0515?

SKY-0515 is an orally-administered small molecule designed to reduce levels of two proteins implicated in HD: mutant huntingtin (mHTT) — the abnormal protein that causes HD — and PMS1, a protein believed to be involved in disease progression through its role in somatic CAG repeat expansion. Developed using Skyhawk's proprietary RNA-splicing platform, SKYSTAR®, SKY-0515 aims to target two core mechanisms driving HD pathology.

What did the study find?

The Phase 1 trial evaluated SKY-0515 in healthy volunteers and individuals with early-stage HD. The nine-month interim analysis from the patient cohort revealed several encouraging findings.

On safety, SKY-0515 has been generally well tolerated across all doses tested, with no significant safety concerns identified. The medicine was also confirmed to reach the brain, a critical factor for any treatment targeting a neurological condition.

On biological effects, participants showed meaningful reductions in key disease-related proteins. At the higher 9mg dose, mutant huntingtin levels were reduced by approximately 62%, while PMS1 was reduced by about 26%. These reductions demonstrate that SKY-0515 is having the intended effect on its biological targets.

On symptoms, exploratory assessments using the Composite Unified Huntington's Disease Rating Scale (cUHDRS) showed that participants' scores were generally stable, with small average improvements observed. At nine months, participants showed a mean improvement of +0.64 points from baseline—compared to an expected worsening of -0.71 points based on natural history data. This divergence from expected decline is encouraging, though this early data should be interpreted with caution.

Expert perspectives

Professor Ed Wild from University College London, who has been involved in the trial, commented on the findings: "SKY-0515 continues to reduce mHTT protein to the greatest extent demonstrated so far in patients, with clinical and biomarker data showing the drug is well tolerated at all doses tested."

He added that these open-label trial results, which will be validated in the ongoing placebo-controlled FALCON-HD trial, "give an expectation of meaningful impact for people living with HD across the world, for whom an orally administered huntingtin-lowering treatment such as SKY-0515 will be truly transformative."

What happens next?

The Phase 2/3 FALCON-HD study is now underway to further evaluate SKY-0515's safety and efficacy. This randomised, double-blind, placebo-controlled trial will enrol over 500 participants with Stage 2 and early Stage 3 HD. Importantly for our community, the trial is open at twelve sites across Australia and New Zealand, with additional sites now open worldwide.

A note of cautious hope

These are early but meaningful steps forward. It's important to remember that Phase 1 trials are primarily designed to assess safety and biological activity. The results are promising, but further research through larger, controlled studies like FALCON-HD is essential before we'll know what this may truly mean for people living with HD.

Currently, there are no approved treatments that slow or halt HD progression. The HD community has experienced setbacks before, and we understand the complex emotions that come with research updates. We share this news with cautious optimism and a commitment to keeping you informed as the science evolves.

Want to learn more?

For more information about the FALCON-HD trial, including participating sites and eligibility criteria, visit **FALCON-HD.com** or **ClinicalTrials.gov**.

Read more on **huntingtonsaustralia.au/skyhawk-update**.

WHAT'S HAPPENING?

Community Support Groups for the period of April - June

NEW SOUTH WALES

Group	Date
Central Coast Carer Support Group	8 April, 10 June
Central West	19 May
Newcastle 36+ Carer's Group	13 April, 1 June
Newcastle Support Group	9 April, 22 April, 14 May, 11 June
West Ryde Carer Support Group	1 April, 6 May, 3 June

QUEENSLAND

Group	Date
Brisbane South Support Group	18 June
Ipswich Support Group	9 June
Sunshine Coast & Gympie Support Group	26 June

SOUTH AUSTRALIA

Group	Date
Coffee & Co	8 April, 22 April, 6 May, 20 May, 3 June, 17 June
Young Adults Support Group	15 May, 19 June





WESTERN AUSTRALIA

Group	Date
Day Centre Support Group	22 April, 6 May, 20 May, 3 June, 17 June
Northern Suburbs Carer Support Group	21 May
South Metro Carer Group	15 April
Southwest Support Group	28 May
All Carers Lunch	18 June

NATIONAL

Group	Date
Online Carer Group	22 April, 27 May, 24 June

Visit our website for more information: huntingtonsaustralia.au/support-groups

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