

# HA Highlights



## Save the Date: Huntington's disease Conference 2026

Join us for a day of knowledge and connection for everyone impacted by Huntington's disease.

Huntington's Australia invites you to **Adelaide** on **Thursday, 7 May 2026** for our annual Huntington's disease Conference.

The conference will bring together families, carers, researchers, and health professionals to share knowledge, strengthen connections, and explore new ways of improving life with Huntington's disease.

Participants will hear directly from leading experts on the latest research, advances in clinical care, and practical strategies for everyday support. Families and carers will also have the chance to connect with others

who understand the challenges of living with Huntington's disease, while researchers and professionals can collaborate and exchange ideas that shape future care and treatment.

Further details, including the program, keynote speakers, and registration, will be released in the coming months. For now, please mark your calendar and plan to join us in Adelaide for a day of learning and collaboration.

Keep up with the latest news by visiting [huntingtonsaustralia.au](http://huntingtonsaustralia.au) and following us on our social channels on Facebook and Instagram at @huntingtonsaustralia.



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### Around the Community

Huntington's Australia is expanding support with Specialist Behaviour Support, Social Work, and Physiotherapy services, alongside monthly online sessions to help families and carers stay informed.

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### Focus on Fundraising

Fundraising efforts, from generous donors to community initiatives, continue to drive vital support for our Huntington's community.

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### Research Recap

The FALCON-HD trial of SKY-0515 is progressing across Australia. Recruitment continues, aiming for full enrolment by year's end.



## CEO Insight

Over the past few months, there's been the usual mix of fantastic opportunities to spend time in community and with our sector peers, sharing insights and continuing to learn.

This included meeting with **Mhairi Cowden**, Deputy Director General of Disability WA, to discuss the challenges our community faces within the changing landscape of NDIS and foundational supports, as well as highlighting the amazing work happening within our regional and remote Neuro Clinics on country—the first of its kind in Australia.

I was also fortunate to have the opportunity to meet with **Dr Lorraine Anderson**, Medical Director of Kimberley Aboriginal Medical Services, to talk about the devastating impact of HD in our indigenous communities and what needs to be done to support them.

I also managed to squeeze in some travel, including a trip to Brisbane, where I visited the

**Neuro Wellness Hub** in Milton, established by MS QLD. The hub is an exciting initiative designed to provide comprehensive care by bringing multiple specialist providers under one umbrella. While it's not yet fully integrated, the recent QLD Government's commitment to fund the creation and rollout of eight Neuro Wellness Hubs across the state is welcome news for Queenslanders impacted by a neurological condition. HA has also joined the newly formed **Neurological Alliance of QLD** and the **Queensland Neuro Alliance Advisory Group**, which will provide expert advice on delivering five election commitments to improve access to care for people with neurological conditions, including the new hubs.

On the political front, both state and federal momentum is building to put neuro firmly on the agenda. Huntington's Australia was honoured



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to have attended the launch of the **Blueprint for a National Action Plan for Neurological Conditions** at Parliament House in Canberra on 4 September 2025.

The Blueprint outlines a coordinated, nationwide approach to improve prevention, diagnosis, treatment, and care for the one in three Australians affected by neurological conditions. Led by the Neurological Alliance Australia, it aims to ensure these conditions are recognised and prioritised in national health policy.

We kicked off this year's **Walk 4 Hope** with a fantastic event in Brisbane and Newcastle, setting the tone for the walks still to come across the country in September and October.

Alongside these events, we were thrilled to launch our new promotional video at the **Dolphins v Titans NRL Match** at Suncorp Stadium. With more than 20,000 spectators in attendance, it was a powerful opportunity to raise awareness of Huntington's disease with a wider audience. The **50-50 charity raffle** on the day was also a great success, raising over **\$10,000** for our HD community. We are grateful to everyone who purchased tickets and showed their support.

Finally, I want to say a big thank you to those who fundraised and donated to HA over the past couple of months. Whether through our recent tax appeal, our regular monthly donor program, rallying a team for Walk 4 Hope, or giving generously through donations or gifts in wills — your support makes all the difference. It's a tough and competitive funding landscape, but your contribution ensures we can keep delivering vital services and supports to our community. We simply wouldn't be here without you.

Warm regards,  
**Lenni**



## 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.

 [Become a member](#)

WA Day Centre



HD Specialist Maggie visits Far North clinic in WA



Community Visit in Palm Island, QLD



Walk 4 Hope Brisbane



50/50 Charity Raffle in Brisbane



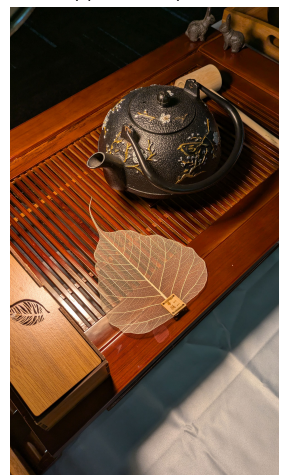
HD Specialist Tressa visits a client in QLD



NSW West Ryde Support Group



WA Support Group



SA Coffee & Co



Teams across Australia join R U OK? Day



## AROUND THE COMMUNITY

## Connecting carers across Australia

**Words** Monica Cazzolli, Team Leader, Community Programs



For carers and family members supporting a loved one on their HD journey, having timely access to reliable information can make all the difference in knowing where to turn for additional support.

Open to HD carers and family members across Australia, Huntington's Australia now offers monthly non-therapeutic online education and information sessions. These sessions are centred on topics relevant to caring for a loved one with HD and are facilitated by two Huntington's Australia HD Specialists. From time to time, experienced allied health professionals or other experts may also be invited to present on specific topics.

**Upcoming sessions include:**

- **September:** Visual Routine Board - practical strategies for daily routines
- **October:** Palliative Care - guidance for supporting someone in the later stages of HD
- **November:** Mindfulness for Carers - techniques to support wellbeing

Each session runs for 2 hours, with participant numbers capped to create a warm, supportive, and inclusive environment. The aim of each session is to explore how the information can be applied to build a personalised, ever-expanding toolkit of knowledge and resources.

RSVP is essential. Registration details and session information are available on our [website](#), or by calling 1800 244 735.

## Introducing Specialist Behaviour Support and Physiotherapy

**Words** Julie Niel, Head of Community Programs and Services

### Meet the team



**Shelly**  
Specialist Behaviour  
Support Practitioner  
with experience in behaviour  
support, training, and mentoring



**Deb**  
HD Specialist  
with professional expertise in  
physiotherapy

HA is committed to providing services that meet the unique and changing needs of people impacted by HD. We are pleased to announce three new services designed to improve quality of life, promote independence, and support families: Specialist Behaviour Support, Social Work and Physiotherapy.

**Specialist Behaviour Support**

In Queensland, HA has rolled out Specialist Behaviour Support to help manage the behavioural and emotional changes often associated with HD. The disease can affect mood, personality, impulse control, and decision-making, creating challenges for both individuals and families. Behaviour Support Practitioners work closely with clients and their networks to develop practical strategies, manage symptoms, connect families with resources, and plan for the future. The aim is to reduce distress, strengthen wellbeing, and maintain independence wherever possible.

**Social Work**

Also in Queensland, HA now offers NDIS-registered Social Work services. Social workers assess individual needs and goals, then develop tailored plans to promote wellbeing. They provide practical support to help people remain independent, advocate to ensure voices are heard within the NDIS, and guide families through its processes when a Support Coordinator is not allocated. This

service combines guidance with advocacy, giving families greater confidence in navigating daily life and the system around them.

**Physiotherapy**

In South Australia, HA is introducing Physiotherapy to address the physical impact of HD. Focusing on movement and function, physiotherapists use evidence-based techniques such as exercise, manual therapy, massage, and heat treatment to improve mobility, reduce discomfort, and support independence. By addressing stiffness, balance, and coordination, physiotherapy helps individuals stay active and engaged, while setting achievable goals and coordinating care with other health professionals.

**Working together for the HD community**

These new services reflect HA's commitment to supporting the whole person and walking alongside families at every stage of the HD journey. Whether through behaviour strategies, social work, or physiotherapy, the goal remains the same: to improve quality of life and create a supportive environment for everyone impacted by Huntington's disease.

For queries, contact us on [admin@huntingtonsaustralia.au](mailto:admin@huntingtonsaustralia.au) or 1800 244 735.

A photo contribution showing a CAG count of 43.

# Inside the Hidden World of HD

**Words** Travis Cruickshank (PhD), Senior Research Fellow and Founder of the Hidden World of HD project

The [Hidden World of HD](#) project is giving people impacted by Huntington's disease (HD) a new way to share their stories. Using a creative approach called photovoice, participants capture images and words that reflect life with HD, revealing moments and realities that are often unseen or misunderstood.

During May and June 2025, the project collected more than [120 contributions](#) from people with HD, family members, health professionals and researchers. Each one offers a unique insight into the challenges, strengths and hidden experiences that shape life with HD. These contributions are now being collated and analysed by researchers at Edith Cowan University's Centre for Precision Health.

Looking ahead, an exhibition is planned for early 2026 at ECU's new City Campus. Selected contributions will be displayed to government, health professionals, academics, and the wider community. A second exhibition will take place in May 2026 at the Huntington's Australia National Conference, offering a national platform to showcase lived experience and raise awareness.

The project has also already sparked international interest, with collaborations forming in Europe, South America and Israel. Protocols are being translated into Chinese, Portuguese and Italian to expand its reach globally.

Led by PhD researcher Cassandra Caretti, who brings

both academic and lived experience, the project is supported by Dr Travis Cruickshank, Senior Researcher Melanie Clark, Associate Professor Julia Morris, Associate Professor Chris Kueh and Dr Kelly Moes, alongside Huntington's Australia and the Centre for Precision Health. Together, they are pioneering new ways of sharing voices, strengthening advocacy and building global understanding of HD.

Among the many contributions, two powerful examples stand out. One image portrays a carer "wearing many hats," symbolising the dedication, responsibilities, and countless roles carers take on while supporting a loved one with HD. Another contribution arranges IVF medicines to spell out the words HD FREE. Shared by a participant who ensured her child would not inherit the condition, the image is a striking expression of hope, resilience, and courage.

By opening a window into the hidden world of HD, the project is creating space for overlooked perspectives, building stronger community awareness, and offering a path toward more compassionate and informed care. At its heart, it is about honouring voices that too often go unheard and making them central to the way HD is understood.

For more information on how to get involved with the project, email [t.cruickshank@ecu.edu.au](mailto:t.cruickshank@ecu.edu.au).

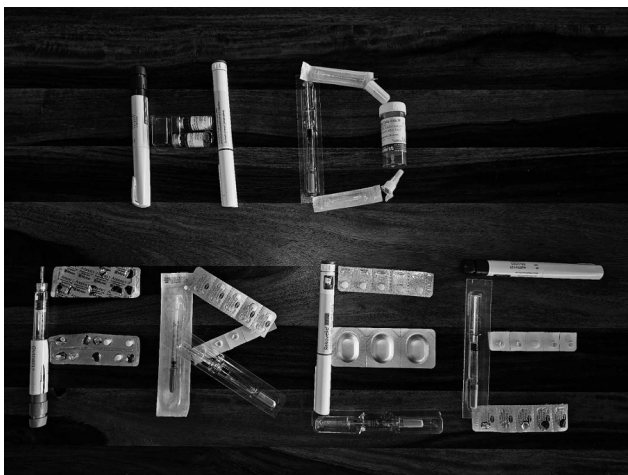
## Meet the team



**Dr Travis Cruickshank and  
Melanie Clark**



**Cassandra Caretti**



"HD Free"



"Wearing many hats"

## FOCUS ON FUNDRAISING

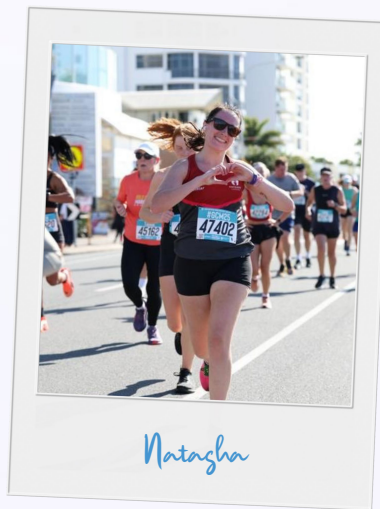
# Celebrating our amazing fundraisers and inspiring new ways to give

**Words** Cathy Holland, Fundraising & Events Coordinator

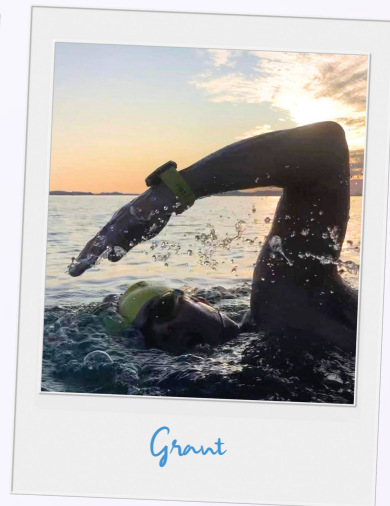
**Meet the inspiring supporters going the extra mile for Huntington's Australia.**



Hugh



Natasha



Grant

Recent months have seen remarkable efforts from fundraisers of all ages, showing that every contribution—big or small—makes a difference.

Fourteen-year-old **Hugh** completed an extraordinary 42.2-kilometre swim over the weekend in August, raising more than \$3,000 for a cause very close to his family. His swimathon was part of his Year 9 personal project in school, challenging himself to complete the marathon over 48 hours.

**Natasha**, another remarkable supporter, took on her very first full marathon at the Sydney Marathon and raised over \$2,000. Running in memory of her late grandad, who lived with HD, Natasha's challenge is a powerful reminder that fundraising can be both personal and meaningful.

Taking this to an extraordinary level, **Grant** is preparing to swim the English Channel, one of the toughest open-water swims in the world, in support of his wife, who has Huntington's disease. This massive feat will not only push Grant to his physical and mental limits but will also shine a spotlight on Huntington's disease, inspiring communities across Australia and beyond to support this cause. His dedication is a powerful reminder of what is possible when passion meets purpose.

These fundraisers are just a glimpse of the many ways people can make a difference. What stands out most is their creativity and the personal connection they bring to fundraising. Whether it's running, swimming, baking, hosting a virtual event, or something completely unique, there are countless ways to support the HD community.

One platform that has been particularly effective for fundraisers is Facebook. It's an easy way to share your story, set goals, and reach your network while directly supporting Huntington's Australia. Every effort counts, and every donation helps fund vital services and provides support for families living with HD.

Thank you to Natasha, Hugh, Grant, and all our supporters for showing us the power of community, creativity, and compassion. If you're inspired by their efforts, there's never been a better time to take action and make your own mark in the fight against Huntington's disease.

[Learn how to fundraise with us](#)

## WALK 4 HOPE

### UPCOMING EVENTS

[Register](#)

**ADELAIDE**  
**PARRAMATTA**  
**PERTH**  
**CANBERRA**  
**LAUNCESTON**

**21 SEPTEMBER**  
**28 SEPTEMBER**  
**12 OCTOBER**  
**19 OCTOBER**  
**26 OCTOBER**

## RESEARCH RECAP

# FALCON-HD Trial Expands Across Australia and New Zealand

**Clinical trial recruitment by Skyhawk Therapeutics gains momentum across Australia as multiple sites actively enrol participants in the FALCON-HD study for Huntington's disease.**

Skyhawk Therapeutics' FALCON-HD clinical trial of SKY-0515, a potential disease-modifying treatment for Huntington's disease (HD), continues to make steady progress in Australia.

Recruitment is actively underway at Flinders Medical Centre, Calvary Health Care Bethlehem, The Royal Melbourne Hospital, Perron Institute, John Hunter Hospital, and three sites in New Zealand. Additional sites at Westmead Hospital and Queensland Univeristy are soon to be activated, bringing the total to 10 active sites—7 in Australia and 3 in New Zealand.

SKY-0515 is an investigational oral small molecule designed to reduce the production of two proteins, huntingtin (HTT) and PMS1, both implicated in HD pathology. In earlier Phase 1 studies, the treatment showed dose-dependent reductions in HTT of up to 72%, while showing favourable safety and tolerability.

The study is a randomised, double-blind, placebo-controlled trial involving participants with Stage 2 and early Stage 3 HD. A total of 120 participants are expected to be enrolled, each receiving a daily oral dose of SKY-0515 at one of three dose levels, or placebo, for at least 12 months. The trial is designed to evaluate pharmacodynamics, safety, and clinical efficacy.

The first patient was dosed early this year at Flinders Medical Centre in Adelaide, making an important milestone. Reflecting on this step, Dr Karyn Boundy, Principal Investigator at Flinders, noted: "Given the lack of approved disease-modifying treatments for Huntington's disease, we are hopeful that SKY-0515 could offer a new therapeutic option for patients."

Ensuring the trial stays on course will depend not only on investigators and clinical staff but also on the broader support networks around families. Social workers, in particular, play a vital role in encouraging participation and helping eligible families consider enrolment.



We are hopeful that SKY-0515 could offer a new therapeutic option for patients.

With multiple hospitals now actively dosing patients and more sites soon to open, the coming months will be crucial in shaping the progress of the trial. Skyhawk Therapeutics has shared that FALCON-HD is a significant step toward developing a treatment capable of altering the course of Huntington's disease. Each participant brings the study closer to answering that question and to the possibility of a new therapy for the HD community. For more information and updates, visit [skyhawktx.com](https://skyhawktx.com).

# WHAT'S HAPPENING?

Community Support Groups for the period of October - December

## NSW

Group	Date
ACT Support Group	24 November
Central Coast Carer Support Group	8 October, 10 December
Central West	21 October
Newcastle/Hunter Carer's Group	9 October, 13 November, 11 December
Newcastle Support Group	13 October, 8 December
West Ryde Carer Support Group	1 October, 5 November, 3 December

## QLD

Group	Date
Brisbane North Support Group	3 December
Brisbane South Support Group	27 November
Gold Coast Support Group	23 October
Logan & Redlands Support Group	31 October
Sunshine Coast/Gympie Support Group	12 December

## SOUTH AUSTRALIA

Group	Date
Coffee & Co	22 October, 5 November, 19 November, 3 December, 17 December

## TASMANIA

Group	Date
North Support Group	6 October, 5 November
North West Support Group	30 October
South Support Group	2 October, 6 November



## WESTERN AUSTRALIA

Group	Date
Day Centre Support Group	22 October, 5 November, 19 November, 3 December, 17 December
Northern Suburbs Carer Support Group	11 December
Central Perth Carer Support Group	11 December
South Metro (Rockingham) Carer Support Group	11 December
Southwest Support Group	28 November

## NATIONAL

Group	Date
Online Carer Group	22 October, 26 November

Visit our website for more information: [huntingtonsaustralia.au/support-groups](https://huntingtonsaustralia.au/support-groups)