HA Highlights



The Power of Hope: Huntington's Australia's first National HD Conference

In early May, Huntington's Australia hosted its inaugural National HD Conference at the Adelaide Convention Centre. With the theme "The Power of Hope", the conference was an inspiring space where our community came together to share information, tell stories, and make connections.

Joined by over 250 participants in person and online, including people living with HD, family members, carers, researchers, and health professionals, we were thrilled at just how many attended. Split into two streams, community and professional, everyone had the opportunity to attend the sessions that were most meaningful to them.

Staying true to its theme, the day was full of emotional and impactful stories and learnings from people living with, researching, and advocating for Huntington's disease. Gene positive twin sisters, Sally McKay and Alicia Linley, spoke about their personal protocol to optimise brain health and help delay the onset of HD symptoms. Melanie Clarke shared stories about providing care on Country and how HD impacts our indigenous population. For promising updates on the latest clinical trials, we heard from Pannie Trifillis of Skyhawk Therapeutics and Rita Ghandhy MD from Roche.

With over 20 speakers throughout the day, each one delivered something rewarding. As the speakers wrapped up, our MC Amelia Mulcahy asked them: What does hope mean to you? Every answer was an inspirational one. But the most touching came from two members of our HD community, Daryl and Chris. Daryl shared that, to him, hope means he is alive. Chris said that hope means he has a chance.

As the conference wrapped up, we took a walk to the Parliament of South Australia, which was lit up in blue and purple to support Light It Up 4 HD—the perfect end to an amazing day. And although it was our first annual conference, it certainly won't be the last.

Thanks to everyone who attended, as well as the speakers and sponsors who made the day possible.

▶ A recording of the conference will be made available in the coming months, so please keep an eye on our social media channels. For photos of the day, check out page 3 of this newsletter.

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Around the Community

Photos from our latest community catch-ups, and an introduction to the newest members of HA's NDIS Services team.

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Research Recap

Understanding TFC scores and the role they play in HD clinical trials.

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Focus on Fundraising

After a busy quarter, we have a lot of fundraising news and photos to share, and a look at what's coming up.



> Together, through hundreds of small, deliberate actions, we can continue bringing Huntington's disease out of the shadows and into the national conversation.
>
> Because every voice gives hope.

CEO Insight

Words Lenni Duffield

As CEO of Huntington's Australia, I have been reminded in recent months of both how far our community has come — and how much work still lies ahead.

Our inaugural National Conference in Adelaide was a landmark moment for families, clinicians, researchers, advocates and supporters from across the country. It was a powerful reminder that while Huntington's disease changes lives, it does not erase hope, connection or possibility. The conference created space for learning, honesty, advocacy and, most importantly, community.

One of the most moving moments for me was Mel's presentation, which powerfully highlighted the urgent need for greater support and services in Indigenous, regional and remote communities. Her message resonated deeply with attendees and reinforced the reality that too many Australians impacted by Huntington's disease continue to experience isolation, limited access to care, and the ongoing challenges that come from a lack of understanding and awareness of Huntington's disease — particularly outside metropolitan areas.

At the same time, I was incredibly grateful to see the Tasmanian Government recognise the importance of local, on-the-ground support through its recent budget announcements, funding the return of a dedicated HD Community Practitioner in Tasmania and restoring vital face-to-face support for individuals and families impacted by Huntington's disease.

However, I was also deeply disappointed that our Federal Government submission to continue and expand our Indigenous regional and remote outreach work was not funded for a second year.

Despite this setback, our commitment remains unwavering.

At the conference, I spoke about HOPE — Health, Optimism, Possibilities and Empowerment — not as abstract ideas, but as a practical way of working together to create meaningful change. I also spoke about the importance of doing "100 small things, deliberately and with intent." Because often it is the small actions — a conversation, an email, a moment of advocacy or support — that create lasting impact.

As we continue advocating strongly for sustainable funding, I encourage every member of our Huntington's disease community, along with families, carers and supporters, to reach out to their local Members of Parliament and Federal representatives. Every conversation matters. Every email matters. Every voice matters.



Because one voice creates awareness.
Ten voices shine a light.
One hundred voices make governments listen.
And thousands of voices can create real change for families living with Huntington's disease.

Continued funding is essential to ensuring we can continue delivering the services our community relies on — including individual and family support, counselling, social work, support groups, physiotherapy, support coordination, training and education workshops and vital outreach services for regional and rural families.

Huntington's disease remains one of the most misunderstood and under-recognised neurological conditions in Australia.

But together, through hundreds of small, deliberate actions, we can continue bringing Huntington's disease out of the shadows and into the national conversation.

Because every voice gives hope.

Huntington's Australia

Your gift supports families living with Huntington's when **they need it most.**

Make a tax-deductible gift by June 30.
https://huntingtonsaustralia.au/donate



SA Coffee & Co





NSW Central Western Carers Support Group




National HD Conference










NSW West Ryde Support Group




AROUND THE COMMUNITY

Meet the team: say hello to our new NDIS Services team members

Words Layla Valinoti, Marketing & Communications Officer

The NDIS is beneficial for many members of the HD community, but it can be challenging to navigate. At Huntington's Australia, our NDIS team provides the vital link between people living with disability, and the supports and services available to them.
For this edition of HA Highlights, we spoke with our newest NDIS Services team members, Cherie and Robyn, about their roles supporting our community.

Meet Cherie



Cherie Jolly
NDIS Support Coordinator, South Australia

With 35 years of experience in disability and community services across regional and metro areas, Cherie has helped individuals through tailored community programs, disability employment services, and by helping them navigate and access the NDIS.

Q: What drew you to this work, and Huntington's Australia specifically?

Cherie: My father had a very strong sense of social justice, and we grew up with conversations around inequity. My cousin lives with physical and intellectual disability, and we were playmates as kids. Our parents encouraged inclusion and normalisation, shaping my values and leading me to work in community services.
When I saw the role advertised with HA, and spoke to Julie, I liked the ethos and HA values that she shared. This role gives me the opportunity to use my skills to have a positive impact in the community.

Q: What does an average day look like for you as an NDIS Support Coordinator?

Cherie: Every day is different, just like the people we work with.
Support coordination is about building capacity. I could be onboarding a new participant, introducing them to the NDIS and the community supports available in their community, helping them access their chosen providers and implement their plans, or preparing for a review of their plans.
I'll also coordinate focus meetings with allied health and support providers to ensure there's a cohesive plan that best meets the participants' goals, set funding budgets, and monitor support quality and funding usage. I'll also support families by providing information about supports that are available to them.
In SA specifically, I hope to help build the caseload and increase community awareness of HD and the services HA offers.

Q: What are you hoping to achieve as a Support Coordinator with HA?

Cherie: I hope that I can build relationships with participants, their families, and support teams that have a positive impact on the lives of the individual and those closest to them. I am also looking forward to being part of the HA team and helping build the HA profile in SA.

Meet Robyn



Robyn Hendricks
NDIS Administration Officer, NSW

Robyn has worked in Community Services and Employment Services throughout her career, including most recently as a Group Home Manager in a residential setting. She is passionate about broadening her knowledge on HD and getting to know our community.

Q: What inspired you to join HA?

Robyn: A former colleague joined Huntington's Australia and always had wonderful things to say about the organisation, role, and the team. So, when a position became available, I researched further and was wholly impressed by what I discovered: HA is very highly regarded within the sector.

Q: What do you enjoy most about your job?

Robyn: I really love assisting and engaging with the team here at HA and learning more about the positive impact we can have on the individuals we support. Being able to see first-hand the dedication and the high level of service that our team delivers is very rewarding.

Q: What do you hope to achieve in our NDIS Services team?

Robyn: Every day I'm learning something new. I would very much like to continue to expand my knowledge in order to be an effective support to our participants and the various teams in Huntington's Australia.

Need help accessing the NDIS?

Contact Huntington's Australia on 1800 244 735 or email admin@huntingtonsaustralia.au. Our Support Coordinators can assist with understanding and implementing your NDIS plan, and helping find support and services that are meaningful to you.

Understanding the TFC score in Huntington's Disease

Words: Layla Valinoti, Marketing & Communications Officer



The Total Functional Capacity (TFC) score has been used in HD care and research for decades. The clinical tool assesses how HD affects a person's ability to manage daily life, including finances, work, and household chores, and is part of the Unified Huntington's Disease Rating Scale.
TFC scores have been in the spotlight recently, with researchers and doctors relying on them to determine suitability for some clinical trials. In this article, we explain what TFC assesses, what it doesn't, and why it's become such an important tool for HD research.

What is the Total Functional Capacity (TFC) score?
The TFC score was first developed in 1979 by researchers Dr Stanley Fahn and Dr Ira Shoulson. Instead of focusing solely on movement symptoms, the score aimed to assess how well someone is managing the practical demands of daily life, giving insight into how HD develops over time.
Covering domains such as occupation, finances, household chores, activities of daily living, and care level, individuals are assessed and given a result. A score of 13 indicates they're fully functioning across all domains, and a score of 0 indicates a need for full-time care.

Are there limitations to what the TFC score can tell us?
Understandably, discussing TFC can be emotional or difficult for many families. A changing score can show a loss of independence, which might be hard to accept. Still, it's important to view the score as just one part of the bigger picture, not as a prediction of someone's future happiness or their quality of life.
The score can be helpful, because it shows how HD affects someone's capacity, not their level of activity. A person might seem physically fine but still have trouble planning, organising tasks, managing money, or keeping a job. For carers, these changes are often some of the first and most noticeable challenges.
In a recent study, most people with HD held the maximum TFC score of 13 for many years. These results support what we already know: that HD progresses slowly and differently for everyone.

How are researchers using TFC scores in HD clinical trials?
Today, many clinical trials use TFC scores to assess suitability and whether new treatments are helping to slow symptoms. Recently, the INVEST-HD Phase 3 trial included a TFC score of 13 among its eligibility criteria.
Along with other requirements, the trial was open to a specific group of people who:

- Are genetically confirmed with HD
- Show early motor symptoms
- Have a meaningful burden of disease based on their age and CAG length
- Are fully functional in all five TFC domains

As research on Huntington's continues, tools like the TFC score remain important for connecting scientific progress to the everyday lives of people and families affected by HD.

Messages that matter to us

Huntington's Australia receives many wonderful messages from our community, and we love to share with them with you. Here is some recent feedback we received, highlighting the support and services we offer.

On recent HD training delivered by our Community Programs team to healthcare staff

This was a great session for our team to attend, both new and experienced staff alike. For our experienced staff, going over the general impact of HD acts as a reminder of what the person endures. And for our newer staff, this gives much better understanding and insight into HD.
This training has also highlighted some areas in which the staffing group could use more support, which will in turn lead to better care and outcomes for our clients.

From Sally McKay, speaker at the HA National Conference and individual living with HD

Congratulations on an extraordinary HA conference! You did such an AMAZING job!

When Clement noted that this was the first time such a large gathering of HD professionals and community members had come together in a decade, it crystallised just how significant your work was.

THANK YOU so much for giving Alicia and me the opportunity to speak! Being able to share our story of hope through our protocol with the HD community meant a great deal to us both.
Read more about Sally and Alicia's story at: https://huntingtonsaustralia.au/6-ways-to-improve-brain-health/

Receiving your messages means the world to us. Have something you'd like to share? Please send us an email at: admin@huntingtonsaustralia.au.

Want to find out more?
For more information on HD clinical trials and participant requirements, visit **https://www.australianclinicaltrials.gov.au/ or https://clinicaltrials.gov**



Cheers to High Tea 4 HD

What better way to raise money for a good cause than by sipping and snacking with friends? In May, members of our community hosted their own high teas to raise awareness and funds for HD at the annual High Tea 4 HD events around the country.

Each fundraising group designed the day exactly as they wanted, with picnics, comfy stay-ins, and extravagant high teas. With all the contributions, our amazing community raised almost $4,000, going directly to support our families living with HD.









Alyssa Smith with friends and family at her colourful High Tea 4 HD event.



Eyes down for HD

Thanks to the Nairne Lions and their Adelaide Hills Bingo Project for spreading joy and raising funds for local charities and community groups. Recently, their generous bingo community selected Huntington's Australia to be the recipient of their latest round of fundraising. Collected over six weeks of games at the Mt Barker CWA Hall and the District Hotel in Nairne, we were grateful to be on their bingo card.

Deb from HA collects a generous contribution from the Nairne Lions' Adelaide Hills Bingo Project.



Australia shines with Light It Up 4 HD

Landmarks lit up around the country in May to celebrate HD Awareness Month.

This May, we witnessed communities across Australia come together for International Huntington's Disease Awareness Month.

One of the month's biggest and brightest highlights was the global #LightItUp4HD campaign. Landmarks, bridges, and buildings around the world lit up in blue and purple to show support for the HD and Juvenile Huntington's disease communities. And Australia joined in the fun, too.

The HA team was lucky enough to join our community in places like the Story Bridge in Brisbane, Wrest Point in Hobart, and Manly Town Hall in Sydney, to watch these landmarks light up. In Canberra, the EJ & EH Holden Club of ACT even held a Light It Up 4 HD dinner and drive by, as well as donating all proceeds of its Chrome Bumper Show & Shine car show.

Beauty aside, it was a wonderful reminder that the HD community is not alone. Lighting up these well-known places sparked conversations, brought more attention, and raised awareness of HD.

Thanks to every business, council, and organisation that joined in by lighting up Australia's famous buildings and landmarks. And to every person who showed up and shared pictures on social media, the HD community is grateful for your support.



Walk 4 Hope is on the way

The upcoming Walk 4 Hope fundraiser will once again bring together people, families, friends, carers, and supporters impacted by HD together for a day of fun. The friendly 4km walk recognises the isolation that people and families living with HD often experience. And most importantly, it gives our community a chance to connect, raise awareness and funds, and share stories. With the money raised, HA can continue providing services and support for our HD community.

Registrations for Walk 4 Hope are open now, so head to www.walk4hope.org.au to sign up.

This year, walks are taking place across Australia—and even virtually—at the following locations and dates:

- Brisbane – 30 August
- Perth – 13 September
- Canberra – 20 September
- Parramatta – 27 September
- Newcastle – 11 October
- Adelaide – 18 October
- Launceston 25 October

WHAT'S HAPPENING?

Community Support Groups for the period of July - September



NEW SOUTH WALES

Group	Date
Newcastle/Hunter Carer's Group	9 July, 13 August, 10 September
Newcastle Support Group	10 August
Central Western NSW Carer Support Group	1 September
West Ryde Carer Support Group (Northern Sydney LHD)	1 July, 5 August, 2 September

QUEENSLAND

Group	Date
Gold Coast Support Group	20 August
Logan/Redlands Support Group	28 August
Brisbane Support Group	8 July
Toowoomba Lunch Support Group	21 August

SOUTH AUSTRALIA

Group	Date
Coffee & Co	1 July, 22 July, 5 August, 19 August, 2 September, 16 September

WESTERN AUSTRALIA

Group	Date
Day Centre Support Group	1 July, 22 July, 5 August, 19 August, 2 September, 16 September
North Suburbs Carer Support Group	20 August
Central Perth Carer Support Group	17 September
South Metro (Rockingham) Carer Support Group	15 July
Southwest Support Group	27 August
WA Carers Lunch	2 July

We update this list regularly. For the latest information, check huntingtonsaustralia.au/support groups or our Facebook page.

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

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

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

/HuntingtonsAustralia
@huntingtonsaustralia