

HA Highlights



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ENROLL-HD AT WESTMEAD

WORDS DR THERESE ALTING

The Enroll study began in 2014, but the study still needs more people. You can join the tens of thousands of generous people from around the world who have dedicated their time to this important scientific platform. Enroll-HD has sites in Melbourne, Perth and Sydney (Westmead). Our Westmead site was lucky enough to recruit the 30,000th person last year!

WHY?

HD is not a common disease. In order for scientists to learn more, we need large numbers of people to participate in research in the quest for effective treatments. Enroll is a worldwide study, with each site collecting the same information.

A second important part of the study is for each site to have participants "study-ready". When drug trials come up, we can search our Enroll database to see which participants meet the criteria for the different studies.

WHAT?

The study does not involve taking a drug, just gathering information to better understand HD. It involves yearly visits, which take a couple of hours and include a blood test, medical examination, questionnaires, and thinking tests.

WHEN AND WHERE?

The visits take place at Westmead Hospital, Sydney, usually on a Monday or Thursday morning.

WHO IS ELIGIBLE?

The current focus for recruitment are people who are early in the course of the disease with mild symptoms, and people who have tested positive but are not showing symptoms yet. However anyone from an HD family is eligible.

WHO ARE WE?

The research team are part of the Huntington Disease Service at Westmead Hospital.

Westmead Enroll 10th Anniversary



To find out more information please see contact details below.

NSW

Westmead: 0438 604 719 or therese.alting@health.nsw.gov.au.

WA

Perth: 08 6159 6464 or melanie.clark@health.wa.gov.au.

VIC

Calvary: 03 9834 9429 or krasniqui@calvarycare.org.au.

Melbourne: 03 8387 2767 or joanna.neath@mh.org.au.

For more information about the study in general, visit the website <https://www.enroll-hd.org>

CEO INSIGHT

WORDS LENNI DUFFIELD

It has been a busy start to the year with a whirlwind of activity and continual growth for our new national entity. Commencing with just 24 staff, we have now grown to a team of 29 in the last 6 months. This is certainly something to be proud of and celebrate! Our hope is that we will continue to grow, enabling us to provide additional services to our families and communities across Australia.

To help guide this growth, we have been working on developing our first strategic plan and have pledged our commitment to be better connected to all of the Huntington's community by 2026. Being able to support our clients and families is the cornerstone of HA and one that we hope to strengthen and build on.



Over December and January, we supported 276 individuals, spent 485 hours working directly with our community, facilitated 14 support groups and delivered 915 hours of NDIS supports.

During February we said goodbye to Basil, our Head of Community Programs & Services. The Board and I took the opportunity to relook at our HA organisational structure to see if it was fit for purpose and meeting our needs now and in the future. As such we have made the decision to split this role into two, an Executive Manager of NDIS and an Executive Manager of Community Programs. Recruitment for these positions will commence shortly.

Work continues on forming our Community Advisory Committee (CAC) to support HA to better meet the diverse needs of people impacted by HD. Whilst the original intention was to have a Community Advisory Committee in each state, with such an imbalance it is

not possible at this stage to take this path. The Board has made the decision to start with one national CAC with the intention of having representation from each state. As HA evolves, we will revisit the option of having a committee in each state.

As we move into Autumn, we are busy finalising last-minute details on the various events and activities being held across the country for May Awareness Month, including LightItUp4HD and we hope to see many of you come and join us as we raise awareness. HD may be a rare disease, but our aim is to make HD a known rare disease.

Warm regards

Lenni

HD ID CARD

We are often asked if we have any ID cards for people to carry – and the answer is yes. If you'd like us to send you our cards, please contact the office on 1800 244 735 or email admin@huntingtonsaustralia.au

MEDICAL IDENTIFICATION

Name: _____

Address: _____

Phone: _____

**I have been diagnosed with
Huntington's Disease (HD)**



OUT AND ABOUT

Queensland Toowoomba Picnic



Tasmania South West Support Group



South Australia Coffee & Co (Fish n Chips at the Park)



Western Australia Day Centre

NEUROCLINIC LAUNCHED FOR KIMBERLEY AND PILBARA REGIONS

Over the next two years Huntington's Australia (HA) will hold a yearly clinic in the Kimberley and Pilbara regions which will see a team of multi-disciplinary health professionals visit the region for 4 days to deliver support and education. People impacted by neurological conditions, in particular HD, are in desperate need of support in these under resourced rural, regional and remote areas of Australia.

We have partnered with Lyfe Languages to improve the communication between health professionals and Indigenous language-speaking clients. Lyfe Languages are in the process of developing appropriate HD educational materials, which we hope will improve the way in which we deliver health care to the Indigenous community.

Our goal for the project is to improve people with neurological disability's inclusion and participation in regional and remote communities. This will result in social connection and wellbeing, as well as improving attitudes and understanding of neurological disability in the Kimberley and Pilbara regions.



BRIGHTWATER GROUP VISIT

WORDS MONICA CAZZOLLI

Recently staff from the WA office of Huntington's Australia were invited for a site tour of the new Brightwater specialist Huntington's homes at Piara Waters and to see firsthand the progress that has happened since development commenced back in April 2023. Accompanied by Janet Waglan, General Manager at Brightwater Care group, Abiha, Maggie and Monica toured the construction site. It was a wonderful opportunity to see the building and gardens progressing. The thoughtful design of the space and calming finishes coming together along with landscaping underway really made the space come to life. Keep an eye on our socials for more updates and follow Brightwater Care Group for more details of this innovative build.



NDIS SUPPORT COORDINATION IS AVAILABLE

WORDS ABIHA ASGHAR

The National Disability Insurance Scheme (NDIS) provides funding to people with a permanent disability to gain greater independence, access to new skills, jobs or volunteering in their community, more time with family and friends, and an improved quality of life.

Our Support Coordinators have an in depth understanding of Huntington's disease and its impacts on clients and their families. We strive to assist clients to maximise benefits out of their NDIS plan, as well as connect clients to specialist, community based and mainstream services that will help them develop necessary skills and supports to achieve their NDIS goals.

Services we provide under NDIS stream include:

SUPPORT COORDINATION

Support coordination is aimed at assisting participants to understand and use their NDIS plan to pursue their goals. Our Support Coordinators will apply their knowledge and experience of HD to ensure a mix of support services are used to build capacity, maintain relationships, manage day to day living activities, and live independently while engaging in the local community.

SPECIALIST SUPPORT COORDINATION

This level of support coordination is available for people whose situations are more complex and who need specialist support. The specialist support coordination can be included in the participants plan to assist in achieving specific goals such as finding suitable home and living supports.



"We are delighted to share some good news about one of our support coordination clients, who is 70 years old. Despite the usual challenges faced by older individuals that are linked into the NDIS system seeking funding for SIL and SDA, our client has been approved for 24/7 support with specialised accommodation and essential assistive technology funding. This is a fantastic outcome for them, offering greater independence, choice and control, and an improved quality of life."

Kate NDIS Support Coordinator

"Words cannot describe how grateful I am to have Malisha as my father's Support Coordinator. Malisha is very professional, compassionate, proactive, and always checks in with me to see how things are going with my father's current care needs. As I imagine, with a large number of clients Malisha supports, she still always finds the time to respond promptly to emails and phone calls, updates me, attends important meetings with me, is always ensuring we have my father's needs met and still manages to deliver her service with positivity and a smile. We live remotely and there has not been any disadvantage in level of service provided. Malisha has a very good understanding of my father and his requirements and is across the level of care my father currently has.

Thank you very much for your service you provide to people with HD as you truly make a big difference."

Daughter of NDIS participant

If you would like to find out more about support coordination and how our team can assist you please email NDIS@huntingtonsaustralia.au or call the office 1800 244 735.

Each year the global Huntington's community unites during the month of May in a shared mission to raise awareness for Huntington's disease (HD).

In May we will be taking part with a range of events, activities and news stories. Huntington's Australia will devote the month to bringing much needed awareness to the HD community.

Our main goals are:

- **build awareness by getting people to talk about HD**
- **engage people outside the HD community**
- **inspire people to get involved with Huntington's Australia**

HIGH TEA 4 HD

With the High Tea 4 HD being a big success in 2023, we have decided to run the events again in NSW. Please put the dates in your diary and help us to share them with as many friends, family members and colleagues as possible. We'd love to see you there.

Why not host your own High Tea 4 HD awareness event and fundraiser? If you enjoy a morning of yummy treat, cups of tea and a chat this is a perfect way to get together with your friends and family. If this is something that interests you please reach out to **fundraising@huntingtonsaustralia.au** for more information.



Please check our socials and our website for more information.

For tickets please visit <https://bit.ly/hightea4hd>

LIGHT IT UP 4 HD

This year we will once again be lighting it up 4 HD not only in WA, but across the Country. On May 3 and 4 multiple locations across Perth (WA) and surrounding areas, Brisbane (Qld) and Launceston (Tas) will light up with blue and purple. South Australia's Parliament House will light up on May 10. More locations to follow!

We encourage our supporters to take photos and post them on social media with the hashtag #LightItUp4HD to help raise awareness, make connections, and garner support for the HD community.



GOOD 4 YOU

Doing good, is good 4 you. We have a dedicated team of volunteers that assist with our community programs and our awareness events. Their willingness to give their time and service is greatly appreciated. Support of HA allows us to continue to fulfill our mission and serve people in our HD community.

A very big thank you to our SA team of volunteers for their efforts in organising and running BBQs to help raise much needed funds and awareness for HD.



If you would like to find out more about volunteering please reach out to fundraising@huntingtonsaustralia.au.

ENTERTAINMENT BOOK

Do you love dining out, travel, activities and retail discounts? We have partnered with the Entertainment Book to offer incredible bargains and experiences. Best of all our members embrace the opportunity to GET great offers and GIVE back to their community and cause. With 20% of a membership sale supporting Huntington's Australia and we think this is a great fundraising opportunity.

If you'd like to find out more about the Entertainment Book and how you can take advantage of this offer please visit the link below.



<https://subscribe.entertainment.com.au/fundraiser/9n48444>



PLAY FOR PURPOSE

Huntington's Australia is part of Australia's strongest fundraising community. **Play For Purpose** is a raffle where people can win big prizes and support a charity at the same time. With a minimum of 50% of your raffle ticket supporting HA. Tickets are \$10 and will be emailed straight to you. This means that for every ticket purchased HA receives \$5. Every ticket gives you the chance to win hundreds of amazing prizes!

If this sounds like something that you could tell your friends about or look at buying a ticket please visit the link below.

https://www.playforpurpose.com.au/huntingtons_aust



Huntington's Australia

Huntington's Australia

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Take a look at how your region
is choosing to connect.

What's Happening?

COMMUNITY SUPPORT GROUPS FOR THE PERIOD MARCH – MAY 2024

NSW

Group	Date
Coffs Harbour Carer's Group	15 March, 19 April, 17 May
Newcastle/Hunter Carer's Group	14 March, 11 April, 9 May
Newcastle Support Group	8 April
Online Support Group	23 May

SOUTH AUSTRALIA

Group	Date
Coffee & Co	March 6, 13 and 20 April 3, 10 and 17 May 1, 8, 15 and 29
Online Coffee & Co	27 March 24 April, 22 May
Online Support Group	23 May

QUEENSLAND

Group	Date
Brisbane Coffee Catch-up Support Group	17 April
Ipswich Coffee catch-up Support Group	26 March
Logan Coffee Catch-up Support Group	19 April
Redlands lunch Support Group	15 May
Sunshine Coast Coffee Catch-up Support Group	21 March, 16 May
Toowoomba Lunch Support Group	22 March
Mackay Lunch Support Group	30 April
Cairns Coffee Catch-up Support Group	13 March
Townsville area visit	15 March
Online Support Group	23 May

TASMANIA

Group	Date
North Support Group	13 March, 10 April, 8 May
North-West Support Group dinner – Burnie	20 March, 15 May
North-West Support Group dinner – Devonport	17 April
South Support Group dinner	7 March, 4 April, 2 May
Online Support Group	12 March, 9 April, 14 May

WESTERN AUSTRALIA

Group	Date
Day Centre Support Group	6 March, 20 March, 17 April, 1 May, 15 May, 29 May
North Suburbs Support Group	25 April
Central Perth Support Group	9 April
Day Centre - VIRTUAL Support Group	13 March, 27 March, 24 April, 8 May, 22 May

NATIONAL ONLINE

Online Carer's Group <i>Please note: This online session is for unpaid carers, informal supports and family members only</i>	3 April
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Visit our website for more information and to RSVP <https://huntingtonsaustralia.au/community-programs>