

HD News

WINTER
2021

Canberra - Sunday 12th September
Orange - Saturday 18th September
Speers Point - Sunday 19th September
Parramatta - Sunday 26th September



REGISTER NOW

GIVING YOUNGER PEOPLE WITH HD OPTIONS TO LEAVE RESIDENTIAL AGED CARE

WORDS
LEWIS KAPLAN

The state HD Associations have received feedback over many years about the inappropriateness of younger people with HD who need residential care being housed in secure dementia wards in residential aged care (RAC).

The Associations have also been receiving on-going feedback that service providers and care staff across the board frequently do not have an adequate understanding of the complexities of HD and thus cannot provide quality care.

Younger People in Residential Aged Care (YPIRAC) Strategy – what does this mean for people with HD?

The Commonwealth Government adopted its *Younger People in Residential Aged Care Strategy* in 2020, partly in response to recommendations from the recent Aged Care Royal Commission. This strategy creates a real opportunity for the HD community to mount an advocacy campaign to ensure:

1. People with HD (both currently living in RAC and / or facing the

prospect of requiring residential care) are offered high quality care in NDIS-funded settings, including nursing care and behavioural support, by providers and staff with a good understanding of HD.

2. Disability residential care providers are supported to offer this specialist care in regional locations as well as capital cities, with a hub and spoke model so regional providers can call on a specialist service for staff training, support and on-going development of a quality HD service.

How to achieve these outcomes

In order to achieve these outcomes, the state HD Associations will need resourcing to create and support a network of residential facilities (both disability and aged care) with training, and potentially specialist quality accreditation.

It is clearly the responsibility of the Commonwealth Government to support the processes described in its YPIRAC strategy.

Key elements of an advocacy strategy to gain these resources:

- **Community engagement** – push from the grassroots: we hear concerns at the Association level, but will members write to / seek meetings with MPs, Ministers etc.?
- **Policy alignment** – in this case with the Commonwealth's YPIRAC strategy
- **Cogent arguments** – proposed course of action which does not involve huge changes in the machinery of government and can demonstrate outcomes in line with the strategy
- Specific proposal with measurable outcomes and reasonable budget in context of YPIRAC strategy
- **Media interest** – HD families need to tell their stories, particularly if currently in RAC. Without a human-interest side, media will be unlikely to engage with policy heads.

Please contact Lewis Kaplan, CEO if you wish to become involved in any way (see back page).



FROM THE DESK *Lewis Kaplan*

LEWIS KAPLAN, CEO Huntington's NSW ACT

NATIONAL CONFERENCE

The national conference has come and gone. Many thanks to all who contributed to making this a successful event and to the 413 people who registered (a new national record). All the sessions of this online event were recorded, and delegates have password protected access to the recordings.

If you haven't yet registered, you can still do so by going to our website and clicking on the national conference banner. You will get to view more than eight hours of quality content.

PRE-IMPLANTATION GENETIC DIAGNOSIS (PGD)

On the same day I received an email from a member asking for advice about how to afford this very expensive procedure, the Commonwealth Government's health budget announced it would now become free for people at risk of a genetic disease such as HD. Details are yet to be announced, but HD is definitely covered. See the article on our website [here](#).

NDIS SUPPORT COORDINATION

This specialist HD service goes from strength to strength. Having started in July 2019 with one staff member, we now have 2.2 full-time equivalent staff and are recruiting a third full-time staff member. We expect to extend the service across the whole of Greater Sydney this year. We are hoping that the government will make participants' plans more

flexible in the future, so we can for example provide more intensive support coordination on a temporary basis if required, without having to wait for a plan review or "change of circumstances" form to be approved by the Agency.

NDIS CHANGES

Huntington's NSW ACT have joined countless others to advocate against proposed changes to the NDIS, in particular the expected requirement for independent assessments. We are already concerned that too many people with HD don't get the right assessments or supports from the current process, with input from their own health workers. So we continue to argue for the special circumstances of people with HD. If you feel able to write to your local Federal Member of Parliament about this issue, this would be very helpful.

YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

The Commonwealth Government now has a strategy to support people under the age of 65 leave residential aged care for residential disability care should they choose to do this. There are around 150 people with HD under the age of 65 living in aged care homes. At the Association we believe this change of accommodation could be a good thing, but only if the quality of care available can be shown to be better. Even though people with HD will generally receive more funding via the NDIS than from the Aged Care Program, if nursing care and behavioural supports are not available (among other things), care may not be better. We are discussing this issue with the Commonwealth Government.

Again, if you felt able to raise your concerns with your local Federal MP, it would strengthen our case. In fact we have a draft letter available for you to personalise if you feel this would make it easier for you

to make your views heard. Please contact me (details on the last page of this newsletter) if you would like to discuss your situation and get support to lobby your MP about it.

CLINICAL TRIALS UPDATE

The announcements in March that not one, but two trials had been halted sent devastation through the HD community. Whilst Roche and Wave Life Sciences have both come forward with an explanation to the community and a promise that they are still committed, there were many families who were relying on these trials.

In the case of Wave's PRECISION-HD trials, the gene silencing treatments weren't performing as scientists had hoped: the treatment was safe but simply did not lower huntingtin. However, Wave is developing a third treatment with an improved chemical structure that will be tested in clinical trials in the near future. In the case of Roche, dosing in the GENERATION-HD1 trial was stopped because of a recommendation by an independent committee who can see and access all of the unblinded data. The data showed Tominersen had no benefit for those taking the drug every 16 weeks versus the placebo group. Those taking the drug every 8 weeks potentially showed a worsening of symptoms compared to the placebo group.

It is important to remember that trials are not treatments. Trials are some of the biggest and most complex experiments scientists can run and even if they don't pan out as we might hope, they provide a wealth of information and data which can help inform future decisions and design of treatments. Both Wave and Roche have stated that they are committed to developing treatments for Huntington's disease.



PHYSICAL THERAPY AND HUNTINGTON'S DISEASE

The hallmark of Huntington's disease is difficulty with both involuntary movement, such as reflexes, and voluntary movement, such as walking.

An example of an involuntary movement problem is akathisia, or restlessness. This is difficulty maintaining one position, or engaging in constant movement. Another is dystonia, muscle spasms or contractions, typically in the arms, head, or trunk. But the most common involuntary movement problem in Huntington's is chorea, or jerking or twisting movements.

An example of a voluntary movement problem is bradykinesia, or very slow movement. Another is difficulty controlling the force of movement, which leads to big bursts of movement when a person intends small bursts. This is common in later stages of Huntington's. Still another problem is a delayed start to movement. There's also uncoordinated movement. This leads to alterations in rhythmic, repetitive movements, such as walking, chewing, and even breathing.

Physical therapy, also known as physiotherapy, has the potential to improve Huntington's patients' quality of life by improving their movement.

WHAT PHYSICAL THERAPY CAN DO

Although the exercises recommended for Huntington's patients train different areas of

the body, all aim to prevent falls, promote correct walking and body control, build coordination, and encourage a positive and confident attitude toward the body.

STUDIES ON THE BENEFITS OF PHYSICAL THERAPY

One survey revealed that only 8 percent of Huntington's patients had met with a physical therapist. One reason may be that few studies have measured exercise's effectiveness.

A two-year study dealing with a comprehensive approach to treatment concluded that physical therapy was beneficial. It helped patients maintain their ability to function, plus their movement and cognitive abilities, researchers said. But the study was not conclusive because of lack of control groups and of common standards for measuring movement functioning, scientists said.

In contrast, a study of 12 Huntington's patients who received physical therapy focusing on posture and walking for six weeks used what scientists considered objective measures to determine movement capabilities. Researchers used a GAITRite mat, which assesses gait, or how a person walks, and a force plate, which measures the force a person lands with when jumping. Other barometers were the Unified Huntington's Disease Rating Scale Total Motor Score, which measures the severity of movement impairment; the Timed Up & Go test,

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 out cards, please contact the office.

MEDICAL IDENTIFICATION	
Name:	_____
Address:	_____
Phone:	_____
I have been diagnosed with Huntington's Disease (HD) <small>see over for details</small>	



which assesses the risk of falling; and the Berg Balance Scale, which, as its name implies, assesses balance.

Patients showed significant improvements in GAITRite measures after physical therapy. Improvements were also seen in the Timed Up & Go test and Berg Balance Scale. Force plate measures and total movement scores did not change. The results suggested that physical therapy improves patients' walking. Researchers called for larger studies using objective measures to confirm the results.

A review of studies about the benefits of physical therapy and exercise suggested they can improve patients' movements, walking speed, and balance, as well as offer them additional physical and social benefits. The researchers who did the review called for additional studies to confirm its findings.

WANT TO FIGHT BACK AGAINST HUNTINGTON'S DISEASE?

Take action and join us to support families across NSW and ACT affected by Huntington's disease.

You can join an event, start your own, become a member or volunteer your time. Every action you take will help raise more awareness and assist families affected by Huntington's disease.

WALK 4 HOPE

Walk 4 Hope is back in September – and with last year not possible because of COVID-19 we would like to ensure that we make this year even more memorable.

The Walk 4 Hope began in 2014 with the aim of raising both awareness and funds to support families impacted by Huntington's disease.

Bring your family, bring your friends, get your work colleagues involved too. We would love to see the community at the Walk and will have a BBQ for everyone who likes a sausage sizzle, a raffle and something for the kids to do.

The Walk is offered at four locations, dates are now confirmed.

- **Parramatta** - Parramatta Park on Sunday 26 September



- **Speers Point** - Speers Point Park on Sunday 19 September
- **Orange** - Cook Park on Saturday 18 September
- **Canberra** - Weston Park on Sunday 12 September

To find out more and register please visit <https://huntingtonsnswact.org.au/get-involved/walk-4-hope/>.

We'd love to see you there!

CYCLE 4 HD – TO BROOME

Erica and her partner Bill decided to cycle some 4,500km to Broome and have generously offered to fundraise for Huntington's NSW ACT. Here's the latest update from Erica "we are in Halls Creek tonight and probably less than a week till we are in Broome! It's been such a wonderful trip and thank you so much to our supporters, esp Janet and Max for lending us the Prado, and to everyone who made a donation. It is so heartening to see we have raised over \$7000 for Huntington's NSW ACT. Thank you everyone."

When we asked why Huntington's Erica shared her story "Over the last 10 years, I have seen how the

disease has impacted on Lynne's life. Lynne is a very private and independent person, and the slow loss of her independence, such as giving up her car, hit hard. Lynne is well aware of the road ahead. She completed her nursing training at Royal Prince Alfred Hospital in 1971, and interestingly most of her work was in Neurosurgery and Neurology."

If you would like to show your support to Bill and Erica, or follow their journey visit <https://huntingtonsnswact.org.au/fundraise-for-us/cycle-to-broome-for-huntington-s>



GROWTH OF NDIS SUPPORT COORDINATION

The introduction of NDIS Support Coordination services at Huntington's NSW ACT in 2019 has seen a steady growth in numbers of participants seeking assistance in implementing their NDIS plan. Optimising the funds allocated in a participant's plan, we work alongside participants to achieve their goals and link them to relevant clinical and community-based support services.

Due to the growing number of participants seeking Support Coordination services, we have recruited a new full-time Support Coordinator Malisha and are open to new referrals.

The Support Coordination team can assist you to navigate and understand the NDIS system, ensuring that you are always exercising your choice and control, staying true to the ethos of NDIS. Every individual has different needs as there is no 'one size fits all' approach when supporting you to work towards your individual goals.

As an exclusive service supporting those with a diagnosis of Huntington's Disease, the Support Coordination team understand the impact of this disease on individuals and their family. Working with a 'niche' provider means you get the right support, service, and advice.

The Support Coordination team services a broad geographic area, covering Sydney metropolitan area, Blue Mountains, Illawarra, and Central Coast.

If you are currently looking for a change in Support Coordinator or have recently acquired a new plan with Support Coordination, you can contact Giselle our Senior Support Coordinator who can assist you further.

For Referrals, simply call us, speak to your key worker at your HD Clinic, ask your local NDIS Planner or Local Area Coordinator for Support Coordination services.

MEMBERSHIP RENEWAL

It is time to renew your membership. Memberships currently cost \$22 per year, including GST, and are valid for one year.

The more active members we have, the better we can understand the needs of the HD community and speak on your behalf.



To renew your membership, visit our website or call the office to get a paper copy sent to you. <https://huntingtonsnswact.org.au/get-involved/become-a-member/>

MEMBERSHIP – WHY JOIN?

One important way to support the Association is to join Huntington's NSW ACT, paying a small annual membership fee. A healthy community association needs members to support and guide it.

Becoming a member allows you to vote at the Annual General Meeting or Special General Meetings on changes put forward by the board of directors. You can also nominate yourself or vote for others to serve on the board.



WELCOME
Malisha

Malisha has worked in the disability sector for the last 9 years across a range of roles including employment, outreach support, group homes and now support coordination.

Having been involved in the transition from block funded programs to the NDIS scheme,

Malisha understands the challenges and complexities that come with the ever-changing world of NDIS.

If you would like advice around receiving support through the NDIS, Malisha would be more than happy to assist.

Together, We Create!

WORDS AMANDA DICKEY

WE'VE ESTABLISHED A COMMUNITY ADVISORY COMMITTEE

WHY?

The Board wants a formal mechanism that assists them to hear the voices of its community so they can place them at the centre of Huntington's NSW ACT's planning, communications, and processes.

WHAT IS IT?

The purpose of the Community Advisory Committee (CAC) is to support us to become a stronger consumer-facing organisation to better meet the diverse needs of people with Huntington's disease (HD) and those who care for them by providing advice, information and guidance to the Board and Management on:

- the policies, services, and practices essential to support people with HD and their carers.

- the development and delivery of the Huntington's NSW ACT consumer engagement strategy.

SELECTION

This first year's committee members were invited based on their HD activism within their respective regions. Subsequent years will be open to other members by competitive application.

CHAIR

Robyn Russell, Board Director

More information about the CAC can be found at:
<https://huntingtonsnswact.org.au/about/our-governance/>

ENGAGING WITH COMMUNITY

A JOURNEY TOWARD EMPOWERMENT

Community participation is a framework used by government, service agencies and the social sector to assist with strategic planning. There are typically 5 levels of community participation: inform, consult, involve, collaborate and empower.

In other words, there is a big difference between informing you about our direction, and being empowered to assist in defining the goals, strategies and actions of your association.

In this strategic cycle the Board have chosen to strengthen community participation by developing our capabilities in community engagement and community development.

Community engagement (CE) refers to the varied ways in which we connect with our community: through everyday interactions; events; and, in the design, implementation and measurement of our programs, services and advocacy. It is a planned process that involves working with identified groups for a specific purpose.



Community development (CD) refers to our acknowledgment that our community are the experts, and that we support you to identify 'what is important' and empower you to take collective action on your concerns and issues.

The journey toward empowerment begins.

FOCUS OUTSIDE OF SYDNEY

WORDS
AMANDA DICKEY

BUILDING SUPPORT WHERE YOU LIVE

In 2020/21 the Board allocated research funds to pilot a community development project we call Regional Support Teams (RSTs).

This place-based project will begin in July 2021 and aims to offer

- 1) localised “Emotional support” through support group facilitation and,
- 2) the creation of a community profile of supports and services.

The regions currently holding a support group meeting will be the beneficiaries of this pilot. It is hoped that the project results will assist us with planning and growing this RST program out to more local health districts.

Vital to the success of this project are our new Community facilitators. We would like to welcome Michael and Ellen to our team.



INTRODUCING



Michael Collins – Wollongong Community Facilitator

Hi I'm Michael, and live on the South Coast of NSW.

I'm a facilitator who focuses on empowering groups of people.

My curiosity about people is based on the belief that I can learn something from everyone. My journey has taken me from Africa, working with young people on nature projects; back to the South Coast NSW, where I curate safe spaces for men to serve men in improving their mental wellbeing; and most recently, working with local government to help support community healing in the aftershock of crises like COVID, flood and bush fires.

I enjoy working with groups as something magical happens when people come together. I bring to this group a firsthand understanding of the impacts a degenerative illness has on a person and their family, and I'm looking forward to learning how I can best support this HD community to build on what they have created.



Ellen Slater – Coffs Harbour Community Facilitator

Hi I'm Ellen, and live on the Mid North Coast of NSW.

I'm a local registered counsellor and qualified group facilitator.

I have provided direct support and counselling to carers and their families, coordinated a National Carers Counselling Program, provided clinical supervision, and am a director of the Joyland Carers Retreat.

I enjoy working with groups to encourage and inspire them to be at their best. I am also looking forward to mapping out who's who in the zoo, collaborating and building a HD networking, education and referral base for this region.

You can follow our progress in the annual report

<https://huntingtonsnswact.org.au/about/how-we-know-we-are-succeeding/>



Huntington's NSW ACT

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Our team

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0407 108 667

GISELLE BEAUMONT

NDIS Social Worker
NDIS Support Coordination
0422 604 737

AMY HALE

Youth Social Worker
0499 031 231

AMANDA DICKEY

Community Programs Officer
0456 013 612

STEWART SWALES

Administration Co-ordinator

ALISON WEIR

Fundraising & Marketing
0419 465 612

HD SERVICE

Westmead Hospital

Dr CLEMENT LOY

(Director), Dr SAM KIM,
Dr FLORENCE CHANG
Neurologists
(02) 8890 6793

CECELIA LINCOLN & FELICITY STEHOUSER

Social Workers
(02) 8890 6699

TERRY MCGILL

Clinical Nurse Specialist
&

PETER KWONG

Registered Nurse
(02) 8890 9960

HD Clinic Appointments
Outpatients Department
(02) 8890 6544

HUNTER HD SERVICE

John Hunter Hospital

JOHN CONAGHAN

Social Worker
(02) 4922 3076

HUNTINGTON'S UNIT

St Joseph's Hospital

(02) 9749 0215

PREDICTIVE TESTING

Find your nearest Genetics
Clinic at www.genetics.edu.au/genetic-services

EDUCATION RESOURCES

Huntington Study Group

Global HD cooperative
therapeutic research org.
<https://huntingtonstudygroup.org>

HDYO

Support and education to
young people (aged up
to 35) impacted by HD
around the world.
<https://en.hdyo.org/>

RESEARCH QUERIES

Dr Therese Alting

Enroll-HD Study
(Westmead Hospital)
(02) 8890 6310 or
0438 604 719

HDBuzz

Research news. In plain
language. Written by
scientists. For the global
HD community.
<https://en.hdbuzz.net/>

WHAT'S HAPPENING?



Due to the COVID-19 pandemic and changing government restrictions, our support groups are meeting in a variety of ways. RSVPs are now essential for all meetings as there are COVID protocols that need to be followed to keep everyone safe. Take a look at how your region is choosing to connect.

CARER SUPPORT

CENTRAL COAST

Postponed. Seeking interest.

COFFS HARBOUR

Korora, 11:00am - 1:00pm
3rd Friday monthly.

NEWCASTLE

Jesmond, 10:00am - 12:00pm
2nd Thursday monthly.

Note: Meeting room limited to 12 attendees

SYDNEY

West Ryde, 10:30am - 12:30pm
3rd Wednesday monthly.

Note: Meeting room limited to 12 attendees

COMMUNITY SUPPORT

ACT

Ainslie ACT, 12:30pm - 2:30pm
1st Saturday bi-monthly.

CENTRAL COAST

Postponed. Seeking interest.

ORANGE & CENTRAL WEST

Orange, 10:30am - 12:30pm
1st or 2nd Saturday monthly.

PORT MACQUARIE

Port Macquarie, 11:00am - 1:00pm
2nd Friday monthly.

Note: Meeting room limited to 10 attendees

WOLLONGONG

Wollongong, 10:00am - 12:30pm
1st Monday monthly.

Latest detail and to register your

interest can be found on our website at:

<https://huntingtonsnswact.org.au/support-groups/>
or contact us on 02 9874 9777.