

HD News

SPRING
2022



COMMUNITY **2**
In Memory of
Pauline Keyvar

FUNDRAISING **4**
Walk 4 Hope
wrap up

SUPPORT **6**
Youth Connection
Program Update

PROPOSED MERGER

WORDS LEWIS KAPLAN

WHAT IS A MERGER?

A merger is an agreement between organisations to come together to make one larger organisation. In this case Huntington's organisations such as ours that are spread out across Australia will stay where they are and keep servicing their communities, but they will officially exist as one national organisation.

WILL MY SERVICES CHANGE?

We would like to assure you that the proposed merger will make services that already exist in NSW and the ACT stronger and make it more possible for new services to be created.

WHY IS THIS HAPPENING?

HD is a rare disease, and all five collaborating State Associations are small. By coming together to form a single larger organisation we will have a louder voice to raise HD awareness, compete for funding, and lobby national politicians to listen to us and make changes the HD community needs. Coming together will also allow experienced staff across all five organisations to share ideas, resources, awareness campaigns, business plans and funding, to provide the same quality services for everyone affected by HD.

WHEN WILL THIS TAKE PLACE?

At least 75% of each state's Members must vote in favour of this merger for it to go ahead at their annual general meetings in November. If the vote is successful, we expect to officially launch our new national body (five State and Territory organisations merged into one) on 1 July 2023.

If you'd like to find out more, please reach out to us. You can do this by phoning or emailing Lewis Kaplan, our CEO on 0407 108 667 or lewis.kaplan@hdnswact.org.au.



FROM THE DESK *Lewis Kaplan*

LEWIS KAPLAN, CEO Huntington's NSW ACT

It feels like the year 2022 is rushing to a close and there's so much to do! We have recently sent all financial members an invitation to our Annual General Meeting at which we will be asking you to vote on changes to the Constitution which will allow us to merge our Association with those of Queensland, South Australia, Tasmania and Western Australia into a new single entity. We believe this will create a more viable organisation with a stronger national voice and greater capacity to generate funds to invest in services for the HD community.

Members and stakeholders have received detailed communications about the proposed merger for some months now, and I take this

opportunity to remind you that we will be offering staff roles in the new organisation and will be increasing not reducing local services. The Community Advisory Committee which we established in 2021 will continue and will in fact become the model for all states in the new national structure, should this proceed.

Fundraising

Fundraising has been challenging this year, as much of the emergency COVID-19 funding has dried up. While it was wonderful to see so many people at our Walks 4 Hope this year, numbers were well down on 2019 (except in Canberra where we welcomed the ACT Minister for Health!); and fewer people who came to the Walks had sought sponsorship, so we must find other ways to raise much needed funds, ideally ways which don't involve us asking our own HD community for money. The trouble is (as so many of you already know) that it's only the HD community which knows or cares about HD!

Services - NDIS

We were very pleased to welcome Kate McNamara to our NDIS team which now has 3.2 staff. This team

has extended its reach beyond greater Sydney to include clients as far away as: Wollongong, Central Coast, Mid-North Coast, and Canberra. While we continue to search for a suitable person to undertake the counselling role, we are grateful to those who have been providing stopgap counselling support in the interim.

MEMBERSHIP RENEWAL

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



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

IN MEMORY

Recently we lost a much loved and respected member of our work family, Pauline Keyvar. Pauline started with Huntington's NSW ACT in 2014 and worked tirelessly to establish a fundraising program, and an event that brought our HD community together, the Walk 4 Hope. Many of you would have met Pauline over the years and will no doubt miss her big smile, dedication, passion and ability to bring people together.

As we reflect on our own loss, we want to share with you some words that describe her: compassionate, loving, generous, energetic, kind, hardworking, trustworthy and cheerful.

An in memorial space will be present at the Walk 4 Hope events, as a place for the HD community to remember their loved ones. This is an idea Pauline had spoken of and we think it will be a lovely addition.

💚 💖 RIP PK





GROWTH OF OUR NDIS TEAM

WORDS GISELLE BEAUMONT

Due to the growing number of people with HD seeking our specialist HD Support Coordination service, we have recruited another full-time Support Coordinator, Kate.

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 the 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 HD on individuals and their family. Working with a 'niche' provider means you get the right support, service, and advice.

If you would like further information on our NDIS Support Coordination services please contact us on info@hdnswact.org.au or 02 9874 9777.

COMMUNITY PARTICIPATION

THE JOURNEY TOWARD EMPOWERMENT

WORDS AMANDA DICKEY

Hearing from our community helps to prioritise objectives that reflect your concerns and aspirations.

Voice of the community survey

This survey was codesigned with our Community Advisory committee and aims to capture people's opinions to help this Association to better understand this HD community's concerns and aspirations.

Online access to the survey will be communicated in November.



WELCOME

Kate

Kate works within our Support Coordination team to service NDIS participants. Kate has experience in the disability sector working with a Supported Independent Living Provider and on the ground as a support worker, with her most recent role as a Support Coordinator assisting participants with various conditions, including HD.

WALK 4 HOPE WRAP UP

This year we were able to re-introduce our Walk 4 Hope events at Newcastle, Canberra, Orange and Parramatta. We also had a community walk in Bingara, thanks Veronica, and Wollongong, thanks Cram Foundation. I am very proud to announce that to date we have raised \$77,286.

Over the course of the four walks, we saw 500 people attend and walk! There were over 120 people actively fundraising online through their own networks and families! Our top 10 fundraisers raised a massive \$30,120. What an outstanding achievement by everyone considering we've been in and out of lockdown since our last walk in 2019.

1. Craze Family
2. Team Haddy
3. Team Bingara
4. Walk 4 Jo
5. Team Smith
6. David Family
7. Paul Brothers
8. Team Sharp
9. Walk 4 Dan
10. Anna's Amazing Ambulators

A very big thank you to all the businesses who donated prizes for our raffles. Also, thank you to our suppliers who provided us with food, beverages and entertainment at each event. Lastly a special mention to our volunteers who came and set-up and helped with the running of the day; without you we would not have been able to make the days happen.



A big thank you

- Lions Club of Warners Bay
- Kape Nueva
- Craft Unfolded
- Mark Lee entertainment
- Hampers with Bite
- Broken Bean
- Willow Grove accommodation
- EJ-EH Holden Club of ACT
- Coffee Loco
- Dickson Aquatic Centre
- Capital Country Holiday Park
- DECO Hotel
- Vikings Group
- Parramatta Lions Club
- Screaming Beans
- Jack Sharp Magic
- Entertainment by Bella and Tom
- Coles Myer
- Coca-Cola Amital
- Rotary group of Orange
- Orange Tribal Fusion Dance Group



VIKINGS RUGBY CHARITY PARTNERSHIP

Thank you, Vikings Rugby, for choosing us as your charity partner for 2022. A special mention to all the hardworking staff, volunteers, generous sponsors and wider rugby community for making the year successful. This partnership saw a total of \$15,498 raised. Incredible!

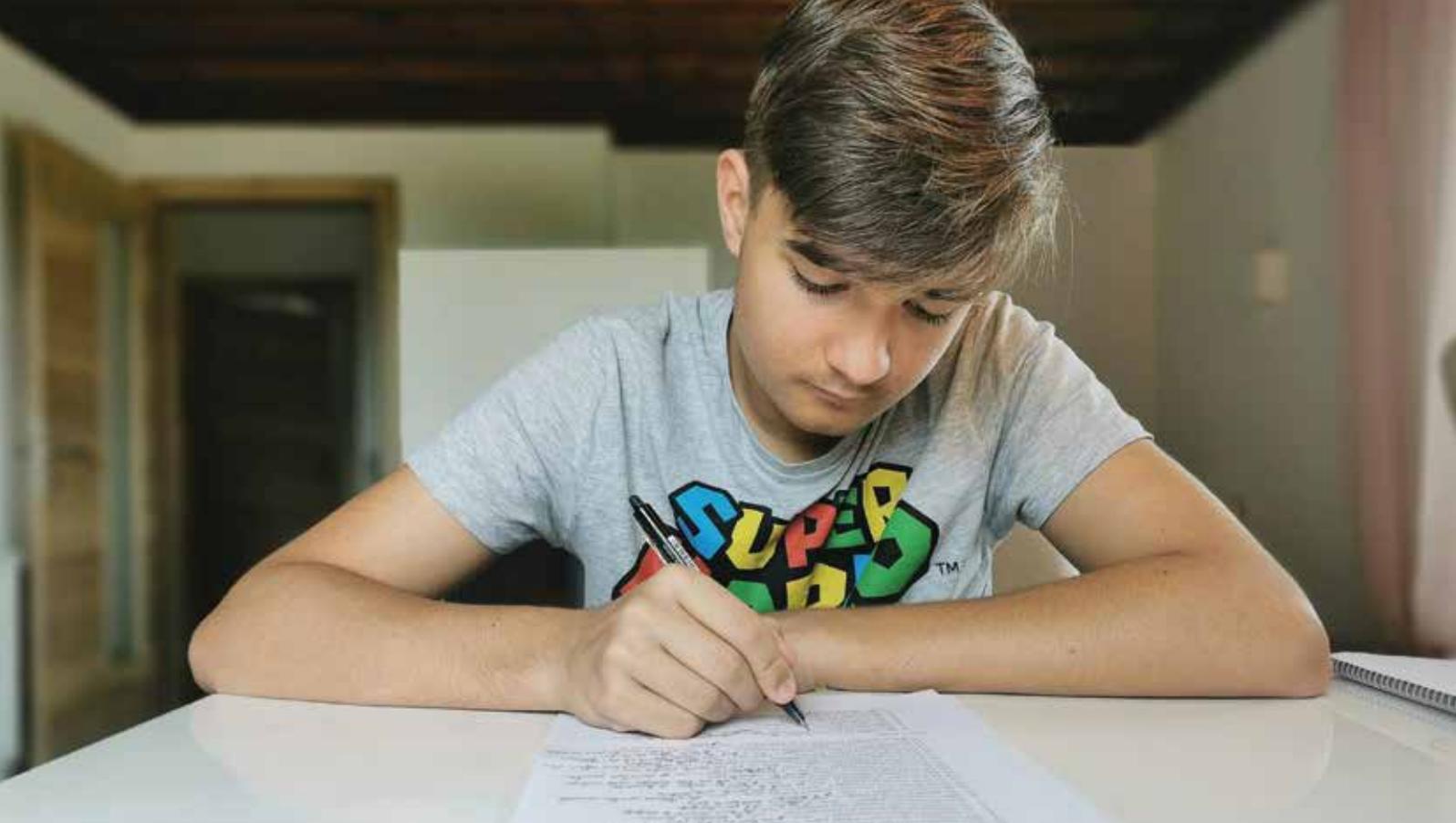
To the Vikings community a sincere thank you for your generous support and for embracing the pink and green. Whether you did the mini Walk 4 Hope, donated at the gate, put a bid on a jersey, purchased a charity hoodie, bought a raffle ticket, or attended a Vikings function during the year, you have helped us tremendously.



CITY 2 SURF

The world's largest fun run took place in Sydney on Sunday 14 August, bringing over 80,000 people together from all walks of life to run, jog, walk or stroll the 14km course from Sydney CBD to Bondi Beach. 18 members of the community registered for the event and proudly raised funds and awareness for Huntington's NSW ACT. Together these guys raised \$9,065, something that they should all be proud of.





YOUTH CONNECTION PROGRAM UPDATE

WORDS AMY HALE

Over the last 12 months young people and their families involved in the Youth Connection Program have engaged in individual counselling, group counselling and family support sessions over video and in person resulting in over 100 interactions that have all continued towards our program's aim to improve the quality of life for kids, young people, and their families living with HD.

This year has seen the Youth Connection Program finally able to visit kids and young people again in schools,

cafes, homes, and parks as COVID-19 restrictions have eased and face-to-face visits are back. It's been so great to get out and about again - but one positive thing COVID-19 and lockdowns have shown us is how much of an asset technology can be. Video calling has allowed us to keep up with counselling sessions and check-ins over the lockdown as well as enabling us to extend the youth program beyond Greater Sydney and into areas of NSW and the ACT that we can't reach in person.

EXCITING PROGRAM DEVELOPMENT - 2023 HD YOUTH EDUCATION SCHOLARSHIPS

This year the Youth Program received some very generous support with a benefactor pledging over \$10,000 annually in HD youth education scholarships to help kids and young people in NSW and the ACT in families affected by HD find easier paths to starting, continuing, or returning to education.

Balancing education with the extra challenges of living with a HD-affected parent or carer can be hard. Whether you are just struggling to find a quiet space to learn or trying to find a balance between caring for a parent with HD and keeping up with work, we know how much more difficult it can be for you to stay engaged in school, TAFE, or uni.

If this sounds like you and you are thinking of studying in 2023, we really want you to apply and be in the running to take advantage of the opportunity to get some help with your education staying on track. As Dr Seuss says... ***"The more that you read, the more things you will know, the more that you learn, the more places you'll go."***

We will be launching this amazing initiative in early 2023. Stay tuned for more information and instructions on how to apply.

NEW YOUTH HD MENTAL HEALTH SUPPORT SERVICE AREA

In response to the changing needs of the community post COVID-19 restrictions, the Youth Connection Program has introduced a new service area involving structured counselling sessions that utilise evidence-based psychological strategies to help kids and young people navigate specific mental health issues such as depression and anxiety with an HD understanding.

Even with the easing of restrictions, we have seen COVID-19 continue to impact in different ways on the kids and young people involved in the program. Depression and anxiety appear to be more common, making life particularly hard for some of these kids as they have had to navigate new mental health challenges whilst re-integrating into social circles and school groups post lockdown. Often they have had to spend

an increased amount of time with their HD affected parents without the outlet that school, friends, and activities outside of the home provided for them prior to COVID-19.

These factors, in combination with extensive waiting lists for psychologists and counsellors in most communities in NSW and the ACT, pushed the youth program to create and deliver this extension of the already existing counselling support service to meet these recently increasing needs.

It is hoped that this structured psychological support can continue to be offered into the future alongside what is already available, as it appears to be making a positive impact on the mental health and wellbeing of program participants and their families.

If you think this or other support offered by the program would be helpful to you or someone you know – please get in touch with the Youth Connection Program social worker, Amy Hale on 0499 031 231 or amy@hdnswact.org.au.

THE HD SPOTLIGHT ON

Gabby Phillips

Research Fellow and Community Advisory Committee member



Q How did you get into the HD world?

A I was at a crossroads in my career and someone close to me was diagnosed. I looked into the research in Australia and saw very little on Huntington's disease, and I wanted to contribute.

Q Why did you become a Community Advisory Member?

A I wanted to support people living with and caring for people with Huntington's. My work can be very science-focused, and I always like to bring it back to the people.

Q What is the best part about working with HD families?

A Being reminded of the people behind the disease and why we need to develop better options for these people is the most important part. I've been very surprised in my life at the people I've met with HD, all around me, but I'd never know it unless I started a conversation about my work with them first. It feels very special to know them.

Q What keeps you enthusiastic about your job?

A Again it is all about those outcomes for people with HD. The hopeful prize at the end of our

work is having a real effect; saying to someone 'You have Huntington's, here's a treatment option for you.' Research will make that difference and we never know when we'll find something!

Q What is your ideal Sunday?

A Morning markets and an afternoon cooking with a glass of wine. Slow Sundays are perfect!



Huntington's NSW ACT

Huntington's NSW ACT Inc.
PO Box 178, West Ryde, NSW 1685
21 Chatham Road, West Ryde, NSW 2114

Telephone: (02) 9874 9777
Free Call: 1800 244 735 (Country NSW only)

Email: info@hdnswact.org.au
Web Site: www.huntingtonsnswact.org.au

Our team

LEWIS KAPLAN

Chief Executive Officer
0407 108 667

GISELLE BEAUMONT

NDIS Senior Support
Coordinator
0422 604 737

MALISHA FERNANDO

NDIS Support Coordinator

KATE MCNAMARA

NDIS Support Coordinator

AMANDA DICKEY

Community Programs Officer
0456 013 612

AMY HALE

Youth Social Worker
0499 031 231

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

FELICITY STEHOUSER

Social Workers
(02) 8890 6699

SANDRA BARISIC

Clinical Nurse Consultant
(02) 8890 9960

PETER KWONG

Clinical Nurse Specialist
(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 <https://www.genetics.edu.au/SitePages/Genetic-Services.aspx>

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/>

Huntington's Disease Network of Australia (HDNA)

The map-HD registry.
(03) 9902 0081
<https://hdna.com.au>

WHAT'S HAPPENING? COMMUNITY SUPPORT GROUPS



Most people are
choosing to meet in
person again in a
COVID safe manner.

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

PEOPLE LIVING WITH HD SUPPORT

WOLLONGONG (Social)

Wollongong, 11:30am – 1:30pm
1st Monday monthly.

CARER SUPPORT

CENTRAL COAST

Postponed until a facilitator is recruited.

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

Seeking interest.

Online Carer Support group (metro and regional)

Westmead Outreach

COMMUNITY SUPPORT

ACT

Ainslie, 11:00am - 1:00pm
1st Saturday bi-monthly.

ORANGE & CENTRAL WEST

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

PORT MACQUARIE

Seeking interest.

**Latest details 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.**