

HD News

AUTUMN 2021

SURVEY 3
2020 Community results are in!

FOCUS 4
on W4H and all things fundraising

SPOTLIGHT 7
on Board Member, Robyn Russell

NATIONAL HD CONFERENCE

Everyone can attend this virtual event **WORDS** LEWIS KAPLAN



HUNTINGTON'S NSW ACT is very proud and pleased to announce it will be hosting the next national HD conference as a series of virtual events from 25 May – 2 June 2021.

“As a result of being virtual, we are able to bring you many more international speakers than we could afford to fly to Sydney for a live event

This conference was originally scheduled for November 2020. In March 2020, the choice to delay the conference until we could meet in person appeared to be an option when we decided to postpone it due to COVID-19. Now it makes sense to go virtual as we have no idea when a real event might again be possible.

As a result of being virtual, we are able to bring you many more international speakers than we could afford to fly to Sydney for a live event, so we hope this is a small compensation the mostly late timing and for not all meeting

physically together – always a preferable way to hold a conference.

We have decided to focus on four key themes:

- Achieving quality of care
- Achieving better policy outcomes
- Achieving better consumer outcomes
- Research update

Many thanks to Roche Products and the Commonwealth Government for their generous sponsorships. ■



FROM THE DESK *Lewis Kaplan*

LEWIS KAPLAN, CEO
Huntington's NSW ACT

NEW FUNDING

We are very pleased to announce two substantial grants towards our work.

The Co-Group has very kindly agreed to fund a new, part-time social worker position for the ACT and surrounding region. This grant (for an initial three years) will allow us to employ a specialist Huntington's social worker, something we have been wanting to do for some time. We aim to create partnerships with ACT Health, local services and NGOs to ensure this project is well supported and connected into other services, which people with HD and their families need. This is a fantastic commitment from the Co-Group.

St George Foundation has generously decided to fund a 2nd year of our Youth Connection Program, having supported the program in 2019. Last year's funding came from Ansva Insurance. We are most grateful to St George Foundation for seeing the value of this program in such a concrete way.

COVID-19

We are hopeful that we will be permitted to run Walk 4 Hope properly this year, and we continue to be very dependent on these events for our core fundraising income. So please sign up early on our new platform on www.grassrootz.com (we'll tell you when it's all launched) and let's try to make up for lost time. Support groups are now able to meet (although with restricted numbers for

now), so we encourage you to connect where these are available (see back page) and let us know if HD families in your area are interested in developing a local group.

QUALITY OF CARE FOR PEOPLE WITH HD

Monash University

Professor Julie Stout, from Monash University is leading a major research project into the quality of care for people with HD and their families. We have encouraged her to reach out via our Association to anyone wishing to contribute their thoughts, stories, or concerns. Prof. Stout is also talking to clinicians, researchers, allied health professionals and service providers.

Summer Foundation

The Summer Foundation has agreed to start a research study in partnership with us to explore what quality care means for people with HD in residential settings. One of the main drivers for this research is the expectation that the approximately 150 people with HD who are under 65 years of age but currently living in residential aged care homes may wish to explore options under the NDIS instead.

While there is still debate about the best place to care for people with advanced HD, it is the Association's view that quality specialised care should be available in whatever type of facility a person with HD finds themselves.

See page 6 for more details on this project and request for community involvement.

NDIS SUPPORT COORDINATION

We have recently completed a very positive review of our NDIS support coordination service and are in the process of hiring a 2nd full-time coordinator. We now have over 50 clients across greater Sydney and the

Illawarra and can expect the service to continue to grow over the next few years. We are lobbying the government for a better deal for people with HD who are also NDIS participants.

NDIS COMPLAINTS

If you have any complaints about your NDIS service provider (or indeed your support coordinator) please do use the formal complaints service provided by the NDIS Quality & Safeguards Commission (www.ndiscommission.gov.au/about/complaints). If enough people in our community complain about the lack of HD specific care, we're more likely to see some systemic improvements in the NDIS services our community receives.

ROYAL COMMISSION REPORT

The Aged Care Royal Commission released its final report in early March. One key recommendation affects around 150 people with HD who are under 65 years old but living in residential aged care: we will explore this and other recommendations in more detail in our next newsletter. We don't expect the Government's formal response until May 2021.

The report recommended, and the Australian Government has already committed to ensure that, apart from in exceptional circumstances:

- no person under the age of 65 years enters residential aged care from 2022;
- no person under the age of 45 years lives in residential aged care from 2022;
- no person under the age of 65 years lives in residential aged care from 2025.

Email Lewis on:
lewis.kaplan@huntingtonsnsw.org.au



Thank you for helping us with our planning. It's important that we continue to seek and respond to your views and concerns. **WORDS AMANDA DICKEY**

MANY THANKS to all who took the time to fill out our latest community survey.

This survey was to gauge how we are performing against our new strategic plan, gain insight into your experience with NDIS and youth services, and understand your education requirements.

You ranked how well we are doing against our strategic goals: 1) information, 2) awareness, 3) education, 4) services, and 5) advocacy. You want

us to do better in services and awareness. Regrettably around 20% of you could not tell us how we were performing in: advocacy, education, services and awareness.

You ranked the following five strategic objectives as very important:

- Campaign for HD specialist residential services in regional NSW and ACT,
- Provide the HD community with strategies for coping, care and support,
- Lobby Governments to adequately fund Huntington's NSW ACT,
- People with HD are provided services by people and organisations who understand HD, and,
- Lobby the NSW and ACT Governments to fund HD specialist social workers in each Local Health District.

'Provide access to HD related forums and conferences' and 'Formally evaluate our programs' were of the least importance.

A quarter of respondents have a person with HD in their household who is an NDIS participant. The majority are happy with the support and services they receive and provide some valuable information regarding the need for improvement

in some areas. Those people engaging in our NDIS Support Coordination service have advised us they are grateful that we have specialised and competent staff to support and advocate for their needs. You also advised us that you'd like another survey asking about your satisfaction levels as participants in the Aged Care system.

The majority had heard of or are engaging in our Youth Connection program and the remainder provided us with insight into the main barriers for engagement. Then you advised that you'd like us to produce education material as follows: Coping/Support tips, Living well with HD, Assisting professionals to help me, Life planning, Research updates explained, and then Connecting with HD community.

We have carefully read your additional comments, criticisms and compliments. They are shared across the Association and help us in learning and adjusting our planning. Please don't hesitate to contact us with your concerns and aspirations and we'll do our best to respond to them.

More detail is available at: <https://huntingtonsnswact.org.au/about/how-we-know-we-are-succeeding/> ■

A GIFT OF Hope

A gift in your will is a gift of hope that allows you to make a difference in the fight against Huntington's disease beyond your lifetime. We need your help to ensure that we can keep on being the voice for current and future generations of families facing Huntington's disease.

Our goal is to continue to reach out and be there in those tough times when everything may seem so hopeless. Lobbying government, providing education, and raising awareness to remove the social isolation and fear for families who have been impacted by Huntington's disease. Leaving something behind is a lovely legacy that can help others.

For more information or to obtain a copy of the Gift of Hope flyer please make contact.



HUNT 4 HOPE SHOP

HUNT4HOPE OP SHOP

The Hunt4Hope Op Shop has been open in Maroubra since 2018 and is celebrating two years of success. This talented lady, Matina, has recently taken the opportunity to freshen up the look and has re-branded the store.

This is a store where donations of pre-loved goods are always welcome; perhaps you have some items that are lying around? People love a good bargain and now is the time to clean out after Christmas.



(02) 8957 6881 or
info@hunt4hope.net



Welcome Alison!

Huntington's NSW ACT would like to introduce our new fundraising and marketing coordinator, Alison Weir.

Alison has worked in marketing and events for several years, with a focus on brand development and major events planning. If you get the chance please introduce yourself, we know that Ali would like to hear from you.

100 days WITHOUT ALCOHOL



Noah kicked off 2021 with a challenge to himself. This young man decided to refrain from alcohol for 100 days and is doing it for his dad. "I thought it would be the perfect time to try and raise some money for Huntington's NSW as it is something that affects me directly as my old man has the disease and I also have a 50% chance of having Huntington's." Aiming to raise \$800, Noah's fundraising tally has already reached over \$2,500 and he is only 30 days in. Thank you for your support Noah, we hope you are proud of your fundraising campaign – you should be!

CHRISTMAS WRAPPED UP

A Christmas appeal letter was sent out by the Association which saw over \$7,000 raised. Thank you for your continued support; it means so much to our families.

The COVID-19 pandemic certainly had an unimaginable impact on all of us and created a whole new virtual world of support for our families. As restrictions ease and we adjust to a new normal, we are here to support families, individuals, and young people. The most important thing to us is the health and wellbeing of our members, client families and friends.

Thank you again for your support to the Association. If you have any ideas on fundraising events and would like to share them, please make contact.

BE SEEN - WEAR PINK AND GREEN WALK4HOPE 2021 SAVE THE DATE

THE WALK4HOPE began in 2014 with the aim of raising both awareness and funds to support families impacted by Huntington's disease.

Why a Walk? Isolation is experienced by many people with HD and with that in mind the walk was purposely designed to be inclusive for everyone to take part in their very own Walk4Hope. It is an opportunity for families and friends to come together, to share their stories and to know they are not alone in their battle with HD. When you sign up for Walk4Hope, you can choose the location and date that suits you best. Walk Locations:

- Orange** - Robertson Park on Sunday 5 September
- Canberra** - Weston Park on Sunday 12 September
- Speers Point** - Speers Point Park on Saturday 18 September
- Parramatta** - Parramatta Park on Sunday 26 September

WOULD YOU LIKE TO GET INVOLVED THIS YEAR?

- Register for the Walk
- Set up a fundraising page and raise funds
- Take a stall
- Play some music

- Donate a prize
- Sell raffle tickets
- Face painting
- Volunteer – lots of different roles

REGISTRATION COSTS

- Family (4) \$50**
- Adult (over 18 years) \$25**
- Children (under 18 years) \$10**

We are always looking for sponsors and ambassadors in our community. If you have any questions about the Walk4Hope, would like to volunteer, or would like to check how you can sponsor please contact Alison alison@huntingtonsnsw.org.au or 0419 465 612.





SUMMER FOUNDATION RESEARCH Into HD residential care

Effective Housing and Support for People with Huntington's Disease Community Group.
DR ELISE DAVIS, SUMMER FOUNDATION (In partnership with Huntington's NSW ACT)

WOULD YOU LIKE TO SHAPE RESEARCH ON HOUSING AND SUPPORT FOR PEOPLE WITH HUNTINGTON'S DISEASE?

RESEARCHERS at La Trobe University and the Summer Foundation are looking for people to help shape a research project. This research project is in partnership with Huntington's NSW ACT.

The research project is trying to understand the best housing and support options for people with Huntington's disease. We would like people with Huntington's disease or people who are carers to help design and shape this project. We are looking for five to seven people to be part of this group.

This project includes three parts:

1. A review of past research
2. Interviews with professionals who work in the area of Huntington's disease
3. Interviews with people with Huntington's disease/carers

The project is shaped by two main groups:

1. Professional Reference Group - service providers and clinicians with expertise in Huntington's disease

2. Community Reference Group, which has people who have lived experience of Huntington's disease.

As part of the Community group, you will be asked to help shape the design of the research, help with understanding the data and sharing the results.

WHAT DO I NEED TO DO?

As you are part of the Community group, you will be asked to:

- Attend three meetings for the project from February-June 2021. The meetings will last about 90 minutes. These will be held online using a computer program called Microsoft Teams. If you don't have access to Microsoft Teams, we can help.
- Read any material before meetings and share your ideas in meetings.

As you are part of the Community group, you can expect to:

- Be sent information about what we will do at the meetings one week before the meetings.
- Be able to share your ideas about the project.
- Have enough time to give your view on any documents.
- Be given a voucher of

\$60 for each meeting you attend to thank you for your contribution.

WHO WILL BE ON THE COMMUNITY GROUP?

The following people will be involved in the Community group:

- **Dr Elise Davis** who works at the Summer Foundation
- **Emily Gosden - Kaye** who works at the Summer Foundation
- **Five to seven members** with lived experience of Huntington's disease

If you choose to be involved, you will be asked to attend three virtual meetings from February - June 2021. Each meeting will be 90 minutes and you will be given a \$60 Coles/Myer voucher for each meeting to thank you for your contribution.

If you would like more information about the study and the community group, please contact:

Emily Gosden-Kaye by email on emily.gosdenkaye@summerfoundation.org.au

or Elise Davis on elise.davis@summerfoundation.org.au

or phone on 0436 345 578. ■



THE HD SPOTLIGHT ON

Robyn Russell

ROBYN RUSSELL BOARD MEMBER AND CHAIR OF THE COMMUNITY ADVISORY COMMITTEE

Q How did you get involved in the HD world?

A Like so many other people I first heard and learnt about Huntington's Disease when a family member was diagnosed. That was over 30 years ago now and back then there wasn't a great deal of user friendly information or support.

Q Why did you become a Huntington's NSW ACT board member?

A I decided to put my hand up to join the Huntington's NSW ACT board as a way of being able to give something back to the Association. Many times over the years our family has turned to the Association for advice and help. This support has been invaluable and given us peace of mind. It's my goal now to pay it forward.

Q What excites you about being appointed as Chair to our newly established Community Advisory Committee?

A As Chair of the Community Advisory Committee, I am extremely excited and looking forward

to the opportunity to meet and work with people with a shared passion. The Community Advisory Committee has so much positive energy – our aim is to harness this positive energy to increase awareness of HD, feedback to the Association and to generally do our bit to improve the lives of those affected by HD.

Q What makes you laugh?

A Other people laughing make me laugh! It's infectious! As children my younger sister and I would lie awake at night and play the "laughing game" by taking it in turns to laugh – before long we would both be laughing our heads off and at risk of getting into trouble. When I hear about laughter therapy workshops now I remember those nights and just how good those out of control big belly laughs made us feel.

Q What is your ideal Sunday?

A My ideal Sunday starts by waking up without an alarm. That's closely followed by a lazy coffee before heading to the beach either to swim some laps in the ocean pool or to walk our beloved pooch. My next favourite thing to do on a Sunday is to cook for family and friends. I love it when we set a table up in the garden under our persimmon tree to eat and spend some quality time together. ■

Meet our new BOARD DIRECTORS

The other new board directors (in addition to Robyn Russell featured in this edition's spotlight) are:



Andrew Sully who has joined the board to make a difference and raise the awareness of the disease that impacts many families in Australia. Andrew has 15+ years' experience in building recruitment/talent acquisition businesses from developing the end to end strategy including the sales; marketing of these businesses. Andrew hopes to transfer these skills to increase the awareness and funding efforts to support the HD community.



Kim Hart who is an IT Project Manager and brings to the board more than 20 years of experience in the public (Defence) and private sector and has experience as a non-profit director of soldiers clubs in NSW. Kim has a strong background in strategic planning, project management and regulatory compliance. ■



Huntington's NSW ACT

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Email: info@huntingtonsnsw.org.au
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Our team

LEWIS KAPLAN

Chief Executive Officer
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
amanda@huntingtonsnsw.org.au

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 STEHOUWER
Social Workers
(02) 8890 6699

TERRY MCGILL &
PETER KWONG
Clinical Nurse Specialists
(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](http://www.genetics.edu.au/genetic-services)

EDUCATION RESOURCES

Huntington Study Group

Global HD cooperative
therapeutic research org.
[https://huntingtonstudygroup.
org/education/](https://huntingtonstudygroup.org/education/)

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.

WE'RE
COVID
SAFE

CARER SUPPORT

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
Alternates between 3rd Friday and Saturday monthly.

PORT MACQUARIE

Port Macquarie, 11:00am – 1:00pm
2nd Friday monthly. *Note: Meeting room limited to 10 attendees*

WOLLONGONG

Wollongong, 11:00am – 1:00pm
1st Friday monthly.

Latest detail and to register your interest can be found on our website at: <https://www.huntingtonsnswact.org.au/support-groups/> or contact us on 02 9874 9777.