

HD News

AUTUMN
2019



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our new EO

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HD science

WHAT IS ADVOCACY?

All the latest advice and developments on how to advocate in today's system **WORDS** LEWIS KAPLAN

The following article reflects the very real need that people living with Huntington's disease and their families have for support to best

“People with Huntington's disease receiving disability or aged care services can access free, independent, individual advocacy services.

manage their disability and aged care services. In addition to support coordination for the NDIS, there are

independent individual advocacy services, funded by the Commonwealth Government which you are free to (and indeed encouraged) to use if you are not getting satisfactory service from your provider.

In future editions of this newsletter we will examine various advocacy issues from an individual as well as a collective basis and explore what we can do together to address these issues. As the Huntington's community is so small (compared e.g. to Alzheimer's or Parkinson's), we need to understand how to collaborate both within the Association and with external partners to achieve our advocacy goals.

ADVOCACY IS THE PROCESS OF STANDING BESIDE SOMEONE AND SUPPORTING THEM TO:

- understand and exercise their rights
- have their voice heard.

ADVOCACY COMPRISES

- speaking, writing or acting on behalf of another person
- going into bat for another person
- being on your side and no-one else's.

...CONTINUED PAGE 3



WALK 4 HOPE - 2019 DATES

31 AUGUST
8 SEPTEMBER
14 SEPTEMBER
22 SEPTEMBER

Robertson Park, Orange
Weston Park, Yarralumla
Speers Point Park, Lake Macquarie
Parramatta Park, Parramatta

Early Bird Registrations available NOW don't miss out. Go to the website Register: www.huntingtonsnsw.org.au or www.everydayhero.com.au/event/walkforhope2019



FROM THE DESK *Lewis Kaplan*

LEWIS KAPLAN

**Executive Officer
Huntington's NSW & ACT**

AS THE NEWLY appointed Executive Officer of Huntington's NSW & ACT, I feel that Robyn Kapp's shoes are so impossible to fill that I won't even try. As I'm only here 3 days per week, please bear with me if I'm slow to respond to any questions or concerns.

I'm committed to meeting members via our various support groups over the next few months. By the time you read this, I will already have visited Canberra and Newcastle. I will be planning visits to our other support groups in Orange, Coffs Harbour, Port Macquarie, Central Coast and Wollongong in coming months.

Knowing that we lost government funding last year for our regional and rural support worker (through no fault of our own – more due to a re-design of the government's funding priorities), I'm particularly keen:

- a) to maintain active contact with regional members and
- b) to find other funds for this important work.

The Association and I are committed to re-building our capacity to reach all the way across NSW & ACT.

Members have already been advised that we are starting a Huntington's NDIS Coordination of Support service. The full-time senior coordinator position is being recruited and we are working hard to ensure we pass the accreditation required of all NDIS service providers.

In some positive funding news we are very excited this year to be the recipients of the St George Foundation grant for \$50,000 to go towards the running of our youth program. This sought-after grant was established to help charities improve the lives of

The Association and I are committed to re-building our capacity to reach all the way across NSW & ACT.

children in their communities. We feel this will go a long way with us and allow us to grow our youth project in sustainable and exciting ways.

You will see a few changes over the coming months: our newsletter is having a refresh in its design and we hope to make it more immediately relevant to the Huntington's family. We are launching a new website very soon, so watch out for it, together with a bit more activity on social media, for those who use Facebook, Twitter or LinkedIn.

I have started meeting with other

neurodegenerative associations to understand the range of issues we are collectively working on and how collaboration can improve a) our chances of successful advocacy and b) possibilities for sharing resources such as neurodegenerative nursing specialists in regional areas.

We have re-established regular liaison meetings between the Association and the Huntington's Disease Outreach Service at Westmead Hospital. It is important that we both understand service gaps and how best to complement each other's efforts. We have lobbied the Minister and Secretary of NSW Health to have the service's staffing gaps filled ASAP.

I am replacing Robyn Kapp as the consumer representative on the Sister Maria Cunningham unit Management Committee. Please let me know if you have any issues you want me to raise.

In other news, I travelled to Brisbane in May with Amy Hale, our youth social worker, at the invitation of Huntington's QLD. Amy presented at their national youth forum, and I attended the first national meeting of state CEOs for some time. I believe that appropriate collaboration can make us all more efficient and effective, and we have a duty to make this work better so that more of our scarce resources can be applied where most needed, in providing support to Huntington's families.

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



NOT JUST A PRETTY FACE!

BY THE NEXT NEWSLETTER DROP WE WILL HAVE A NEW WEBSITE

A whole new look and some other great stuff...

- Your stories
- Community profiles and events
- Latest research feeds from HD Buzz
- New Resource Library (searchable on Audience, Region & Topic)
- More ways to 'Get Involved'
- Ways you can 'Give Feedback'
- Better explanations for why we exist; where the money is spent; Yes, we have heard you and we thank you for your patience.

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Individual advocacy is not the same as systemic advocacy which is often managed by peak bodies such as People with Disability, NSW Council of Social Service or Consumers Health Forum. Independent individual disability and aged care advocacy services are funded by the Commonwealth government.

WHAT IS AN ADVOCATE?

While anyone can be an advocate, an advocate in a funded organisation is a trained, impartial person who:

- takes the time to understand your views and wishes
- informs you of your rights and responsibilities
- assists you to explore your options and make informed decisions
- supports you to raise your concerns and work towards resolving them
- provides practical assistance such as help to write a letter or raise your concerns at a meeting with your provider
- speaks for you in situations where you don't feel able to speak for yourself
- increases your capacity to self-advocate if this is what you want.

Advocates can also support you in making formal complaints about a service or indeed about the NDIS/NDIA or My Aged Care.

NSW ADVOCACY SERVICES

In NSW aged care advocacy is provided only by Seniors Rights Service, a member of the Older Persons Advocacy Network: PHONE: 1800 700 600 www.opan.com.au

Disability advocacy is provided by around 20 different services across NSW. Some of them are region-specific and some are disability-specific.

The best place online to find the right type of service in your location is:

dss.gov.au/disability-and-carers/programmes-services/for-people-with-disability/national-disability-advocacy-program/models-of-disability-advocacy/national-disability-advocacy-agencies-funded-by-the-commonwealth-by-state-or-territory/disability-advocacy-agencies-new

If you are struggling to find the right disability advocacy service for your needs, give me a call at Huntington's NSW & ACT on 02 9874 9777 and we can talk through what's best for you. ■



COMMUNITY Questions

MOVING FROM HOME INTO RESIDENTIAL CARE. WHAT IMPACT WILL THIS HAVE ON YOUR NDIS SUPPORT? WORDS AMANDA DICKEY

Q My dad has turned 65, and he is currently living at home. Will he still receive support through the National Disability Insurance Scheme (NDIS) when he moves into residential aged care?

A No. The NDIA advised, Section 29 1(b) of the NDIS act 2013 states:

29 When a person ceases to be a participant

(1) A person ceases to be a participant in the National Disability Insurance Scheme launch when:

... (b) the person enters a residential care service on a permanent basis, or starts being provided with home care on a permanent basis, and this first occurs only after the person turns 65 years of age;...

Recommendations: For people approaching 65 years, ensure residential care and home care planning is part of the NDIS plan review discussions with your NDIA planner and support coordinator. Think about what equipment may be needed to make this transition.

Note: your equipment can be taken with you when moving into residential care facilities.

If you need guidance, contact your key-worker or the HD Service at Westmead, (02) 8890 9960.

In each edition of HD News we will be featuring a new community question. If you have a question you'd like answered email us at info@huntingtonsnsw.org.au ■



A gift in your Will allows you to make a difference in the fight against Huntington's disease beyond your lifetime. **WORDS PAULINE KEYVAR**

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 future generations of families faced with Huntington's disease. It has been said that it is the cruellest disease known to mankind.

I have left a gift in my Will to Huntington's NSW [& ACT] so that families can continue to get the help they need when they are in trouble.

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 removing the social isolation and fear for families who have been impacted by Huntington's disease: these are the tasks we're asking for your support to continue.

One such person, is our friend Mavis who knows only too well the impact that Huntington's disease

can have on families; Mavis said "I have never lived with anyone who had HD but I've lost aunts, uncles and cousins. I'm so grateful my Dad didn't inherit the gene from his father. I know all the problems it brings... I have left a gift in my Will to Huntington's NSW [& ACT] so that families can continue to get the help they need when they are in trouble."

Mavis has great belief in family connections and has personally collected stories, photos and hand written her entire Family History.

We understand that remembering your family and loved ones is the first priority when making a Will and recommend that you discuss your intentions with them.

Miss Elsie Court left a generous gift in her will in 1989 which enabled Huntington's NSW to purchase the property at West Ryde that became Huntington's NSW & ACT head office. This enabled us to move from a temporary office in Lidcombe Hospital and means we no longer have to raise funds for our office accommodation.

For a confidential discussion on how you can leave a gift in your Will, please contact Pauline by email pauline@huntingtonsnsw.org.au or phone 02 9874 9777. ■

YOUTH SPACE Update



Our youth program - talking to kids about HD, school visits and how to get in touch **WORDS AMY HALE**

IN JANUARY our youth program was the recipient of a St George Foundation Grant. This is such exciting news for HNSW & ACT as it allows us to keep meeting the needs of kids and young people in our HD community. We are very grateful to the St George Foundation for helping our program meet its full potential.

This year has seen our youth social worker Amy out in the field visiting kids, young people, parents and school teachers and delving with them into the difficulties that face families and kids affected by HD.

An increasing number of engagements in the early part of this year have been with parents knowing they want to speak to their kids about HD but struggling with how they might do this.

This is such a challenge for so many families. When should I talk to my kids about HD? How much information do they need from me? What will it do to our family? What should they tell their friends? Although it is widely accepted that kids do so much better when they know about HD from an early age, this sometimes doesn't make deciding to tell them any easier. This is one area in which our youth program has been really helpful for families.

Amy's role here is to first sit with parents and create a space where they can explore all of the worries, fears, responsibilities, relief and concerns speaking

to their kids about HD can bring up for them. With the help of time, conversations and some amazing guidebook resources, parents can work through their concerns with Amy. Most often after this process, parents/carers find the confidence to clearly decide what discussion approach will best suit their kids. They then choose some age appropriate language and information and then embark on sharing their HD stories with them in the gentlest, most informative ways possible giving their children the best opportunity to take in this information in the environment that best supports them.

Some parents/carers decide on a sit-down formal approach because they feel this is the best fit for their family, while others end up having their initial HD conversations in the car or during a relaxed family activity, ensuring that they leave the door open for many more conversations to come.

After these initial conversations, Amy can then meet and engage with the kids one-on-one, or with all of the siblings in a family together, helping them navigate HD, school, home and friends and build a good therapeutic support base and someone to turn to when HD leads to things in the home getting tricky.

As well as this initial work with families, Amy has also been out visiting kids at school. Sometimes with parents working and feeling the effects of HD on their time and resources, it can be hard to find time to get their kids to youth work appointments. This is where school visits have been so successful for the youth program. Amy is out and about each week visiting kids at school, sitting for an hour or so, drawing, talking and building a good base for dealing with the tricky, emotional things that can come up. Parents and teachers have reported that these engagements have been very positive for the kids and families involved.

If you are a child, parent, young adult or teacher and would like more information on our youth program, please call Amy at Huntington's NSW&ACT on 9874 9777 or 0499 031 231 or email amy@huntingtonsnsw.org.au ■



Change to the design of Roche's ongoing huntingtin lowering trial - known as the GENERATION HD1 study **WORDS COURTESY OF HD-BUZZ**

THE PHARMACEUTICAL giant Roche ran an earlier, smaller, study with antisense oligonucleotides or ASOs as potential HD treatments. That was a safety study - designed to determine whether or not giving ASOs via the spinal fluid led to any unexpected bad outcomes. The trial was a success - none of the participants had a bad reaction to the drug or stopped attending their monthly visits for injections and treatments.

At the end of that small safety study, Roche and Ionis made the decision to start giving all the participants, including those who had been receiving placebo treatments, the drug every month. Technically this is called an open-label extension study. Open-label just means that in this type of study, both participants and their physicians know what they're receiving, which is different from the earlier double-blind study.

Assuming a drug is safe, and has a reasonable chance of working, being in an open-label extension study is a nice reward for the brave volunteers who signed up for the first trial of these drugs. It's also good for the community and the drug company sponsoring the trial,

because they get a sort of sneak peek into the long-term effects of treating with the drug.

Roche have recently explained that they'd been treating people in the open label extension either

“We can't predict the future, but we think you should stay tuned over the next year for more exciting updates on developments in huntingtin lowering treatments.”

monthly or every other month. The letter goes on to state: Review of nine-month data showed effects on lowering mutant huntingtin protein levels in the cerebral spinal fluid that support the exploration of less frequent dosing. Based on the totality of the data, including safety and tolerability, there appears to be no overall advantage to treatment monthly versus every two months..

It seems that Roche have seen results suggesting that lowering of the Huntingtin protein was good enough with 2 months between doses that they feel giving

the drug every month might not be necessary. In fact, they're making changes to the design of the GENERATION HD1 study to see if they can go even longer between treatments, by including a new group treated only every 4 months.

Needing to arrange injections of drug 3 times a year, compared to 12, would make a huge difference if this drug is approved for HD. But regulators are going to require that we demonstrate this is possible, so Roche are modifying the GENERATION HD1 study to include three treatment groups: a placebo group, a group treated every 2 months and another treated every 4 months.

A very important message here is that **there's no evidence that treatment with this drug has influenced HD symptoms in any patients.** All these decisions are based on lab tests suggesting the drug is having its desired effect in the brain (that is, lowering the amount of huntingtin protein), but we still don't know whether this will be associated with an improvement in HD symptoms in treated patients. To do that, we have to run the full scale GENERATION HD1 trial.

These rapid advances in huntingtin lowering treatment are starting to come quickly. We can't predict the future, but we think you should stay tuned over the next year for more exciting updates on developments in huntingtin lowering treatments.

In other research news, Dutch-American company uniQure has received approval from the US drug regulator to begin the first ever gene therapy trial in Huntington's disease. Their plan is to use a virus, injected into the brain, to turn cells into a factory that makes a weapon to lower the harmful huntingtin protein.

More on this next time, or here's the link if you want to read the full HD-Buzz article <https://en.hd-buzz.net/267>. ■



THE HD SPOTLIGHT ON...

John Conaghan

JOHN CONAGHAN, SOCIAL WORKER Hunter HD Service, John Hunter Hospital, Newcastle NSW

Q Why did you decide to become a social worker?

A I think I had been pondering for a while about what to do with my life. I liked the humanities at uni and it probably grew from there. I also think that various life experiences propelled me to have a genuine interest in the relational and emotional self. Social work seemed to be the best fit for me.

Q How did Huntington's disease become your specialty?

A I first was introduced to HD when I was studying social work in Melbourne in the early 1980's. I ended up working as a care assistant at a place called Mary's Mount which was a care facility for people with HD. It was this experience which then acted to make me interested in HD and hence applying for the job I currently have back in 1991. I remember being challenged by how I could be helpful to people with an incurable disease and this stuck

with me for some time before I went into the work.

Q What's the best part about working with HD families?

A Without a doubt the longer term nature of the relationship with families, bearing witness to people's courage, resilience, compassion, sadness and love for each other.

Q What keeps you enthusiastic about your job?

A The idea of working in the service of others, the development and maintenance of the relationship with people who have HD and their families and the hope of a better treatment.

Q What is your ideal Sunday?

A Knocking over a few jobs around the house, a pot of ginger infused chai tea with my partner Suzie over lunch and playing some cricket with my son Tomas at the nets in the afternoon. ■

AGED CARE

ROYAL COMMISSION

Please consider making a submission to this Royal Commission **WORDS** LEWIS KAPLAN

• The rest of the terms of reference and the submission form can be found at www.agedcare.royalcommission.gov.au

placed in aged care facilities. This is due to a lack of alternative age appropriate residency options, and staff who are sufficiently skilled to meet the specific needs of community members affected by Huntington's disease."

ROYAL COMMISSION INTO VIOLENCE, ABUSE, NEGLECT AND EXPLOITATION OF PEOPLE WITH DISABILITY

The Terms of Reference, detailed in the Letters Patent indicate that Commission should inquire into what should be done to:

- prevent, and better protect, people with disability from experiencing violence, abuse, neglect and exploitation
- achieve best practice in reporting, investigating and responding to violence, abuse, neglect and exploitation
- promote a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation. ■

The Commission is open to receiving submissions from organisations and individuals until September 2019. We strongly encourage everyone with a point of view to tell the Commission which will consider everything sent to it. The more submissions the better. Around 10% of those under 65 living in aged care homes have Huntington's disease. We are aware of a mix of issues but would be very pleased to receive copies of any submissions you make, to inform our own organisational submission.

Huntington's Vic made a submission in 2015 on the Adequacy of Existing Residential Care for Young People, which is worth reading before making your submission (www.huntingtonsvic.org.au/data/Fed_Govt_submission_FINAL130215.pdf):

"Unfortunately, despite the best intentions of all key stakeholders, those living with Huntington's disease and its unforgiving progression continue to be inappropriately

and to get your business name and branding out to the general public.

SOME IDEAS ON HOW CAN YOU HELP?

- Donate a raffle prize,
- Take a stall at one or all of the walks,
- Sponsor a walking team,
- Provide some entertainment,
- Sponsor set up,
- Walk with your business colleagues.

There are many ways you and your business can get involved, just like Atila and Nicole from Spray Pave Designs who have come on board for the Parramatta Walk said "We are so excited to be involved. Can't wait for the walk."

So, let's chat. Call Pauline or Lewis 9874 9777 or send an email info@huntingtonsnsw.org.au. ■

THE COMMISSION is inquiring into a number of matters including:

- the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;
- how best to deliver aged care services to people with disabilities residing in aged care facilities, including younger people; and
- the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;

WALK 4 HOPE

WILL YOU HELP?

WE WOULD LOVE TO hear from you if you are interested in coming on board as a sponsor or getting involved for any of the upcoming walks in September. A great opportunity to show your support for the Huntington's community



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@huntingtonsnsw.org.au
Web Site: www.huntingtonsnsw.org.au

Our team

LEWIS KAPLAN
Executive Officer
0407 108 667

AMY HALE
Youth Social Worker
0499 031 231

AMANDA DICKEY
Programs Officer
0456 013 612

STEWART SWALES
Administration Co-ordinator

PAULINE KEYVAR
Fundraising & Marketing
0409 363 987

HD SERVICE
Westmead Hospital

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

FELICITY STEHOUSER
Social Worker
(02) 8890 6699

TERRY MCGILL & GILLIAN
DICKSON
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?

COMMUNITY SUPPORT GROUPS

JUNE & JULY MEETINGS

CARER GROUPS

NEWCASTLE Jesmond
Neighbourhood Centre, 44
Mordue Parade

10:00am - 12:00pm,

- Thursday, 13th June
- Thursday, 11th July

SYDNEY 21 Chatham
Road, West Ryde

10:30am - 12:30pm,

- Wednesday, 26th June
- Wednesday, 24th July

CENTRAL COAST LooLoo's
Coffee Warehouse, 12/11
Cochrane St, Kincumber

10:00am-12:00pm,

- Saturday, 15th June
- Saturday, 27th July

FAMILY SUPPORT GROUPS

ACT lunch Ainslie Football Club,
52 Wakefield Avenue, Ainslie

12:30pm - 02:30pm

- Saturday, 1st June

WOLLONGONG Wollongong
Golf club, 151-161 Corrimal St,

10:00am - 12:00pm

- Monday, 3rd June
- Monday, 1st July

PORT MACQUARIE Westport
Club, 25 Buller Street

11:00am - 1:00pm

- Friday, 7th June
- Friday, 5th July

CENTRAL COAST Niagara
Park Stadium, 16 Washington
Ave, Niagara Park

06:30pm - 08:30pm

- Wednesday, 12th June

COFFS HARBOUR Joyland
Carers Retreat, 5B Breakers
Way, Korora

11:00am - 1:00pm

- Friday, 21st June
- Friday, 19th July

ORANGE & CENTRAL WEST
The Live better hub,
127 Byng St, Orange

10:30am - 12:30pm

- Friday, 21st June
- Saturday, 20th July

For further details about any of
these meetings can be found on
our website, by contacting us
on 02 9874 9777 or email:
info@huntingtonsnsw.com.au.

NO BREAKAWAY IN 2019

We have had to make a few changes
to our social programs this year
because our funding and staffing
resources have shrunk.
Sadly, this means that we will not
be running a Holiday camp at Camp
Breakaway this year.

We are hoping this is only a
temporary measure.

STAY INFORMED!

Join our community:
[www.huntingtonsnsw.org.
au/association/join](http://www.huntingtonsnsw.org.au/association/join)