

HD News

SPRING
2020



Congratulations to Team Beeston for raising \$6939.06 on their virtual Walk 4 Hope Bondi to Watson's Bay

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2020 HUNTINGTON'S HEROES THE SMALL WALKS THAT MADE A BIG DIFFERENCE

This year's (virtual) WALK4HOPE wrap up **WORDS** PAULINE KEYVAR **PHOTOS** OUR AMAZING WALKING TEAMS

WALK4HOPE MAY have been virtual this year, but that did not stop people from pounding the pavement and doing the walks their way, any-

where, anytime. Although Speers Point was a 'no go' on the designated day of the walk, many families still turned up to walk along the edge of Lake Macquarie.

Crook and her trusty team tramped along Bulli Beach and Marg Crook enjoyed her walk at Lake Macquarie, then went on holiday! Marg is missing overseas travel and finding her way around New South Wales.

Rachael Brooking as usual was busy flying the flag all through September in Orange, with a new pink and green outfit every day and counting steps – well done Rach.

Team Beeston walked 13.6 kms from Bondi to Watson's Bay, just a few more kilometres than the usual 4 kms around Parramatta Park. A great scenic way to do the Walk4Hope.

Team Haddy managed to split their walk into two groups, Dianne

...CONTINUED PAGE 3

COMMUNITY SURVEY 2020

You will find a copy of our 2020 community survey inside your newsletter if you receive a hard copy. If you are reading this on your computer, please click [HERE](#). It takes about 5 minutes to complete and we'd really value your input to guide us.

The top ten teams collectively raised \$30,734 overall. The 79 people who raised funds with their very own on-line fundraising page managed to raise \$50,224...



FROM THE DESK *Lewis Kaplan*

LEWIS KAPLAN, CEO Huntington's NSW ACT

COVID-19

We are gradually and cautiously opening our services again, starting with support groups, where members want to come together physically. We have also been offering virtual support groups, but, assuming COVID-19 cases continue to reduce and NSW Government permits, we will be re-opening the office (part-time) and getting back to whatever the new normal is to become. The Association's offices in West Ryde are registered COVIDSAFE, and we ask anyone attending the office to follow the simple and now well-known instructions regarding registration, physical distancing, and hand sanitising. Of course, if you have any symptoms at all, please do not attend.

YOUNGER PEOPLE IN RESIDENTIAL AGED CARE (YPIRAC)

The Government released its "Younger People in Residential Care Strategy 2020-25" on 30 September 2020. The Australian Government's YPIRAC targets, apart from in exceptional circumstances, seek to ensure there are:

- no people under the age of 65 entering residential aged care by 2022
- no people under the age of 45 living in residential aged care by 2022
- no people under the age of 65 living in residential aged care by 2025.

This should be great news for people living with HD, as long as the disability sector steps up to provide world-class care, including on-site registered nurses as required. We are working with several disability providers who are willing to support people living with HD. Funding under the NDIS is generally much more generous than is available via aged care.

SMALL ADVOCACY WIN

Last year we mounted an advocacy campaign to get funding for an HD specialist social worker in Canberra. In the ACT elections this October, the Liberals announced their healthcare policy platform which included "a new, dedicated social worker for families impacted by Huntington's Disease". We immediately contacted the ALP to ask them to match this commitment as we are a non-party partisan organisation. No response received to date.

NOTICE OF 2020 ANNUAL GENERAL MEETING – 21 NOVEMBER, 12 NOON

If you are reading a hard copy of this newsletter you will find a Notice of AGM as an insert. If you are reading it online, **please follow this link** to the notice and invitation. Due to COVID-19 restrictions, we are holding the meeting virtually so you can attend from your home as we must assume current restrictions on indoor and outdoor gatherings may still be in place.

In the last newsletter it was announced that we were seeking new Board members. We have had a good response, both from within the Huntington's community and more broadly from three free advertisements we placed on Board recruitment websites. As always, members are encouraged to nominate for the Board – please see the Notice of AGM or just ring or email the office for a nomination form.

PAULINE KEYVAR

Many of you will have met Pauline over the last seven years that she has spent working so diligently to establish our fundraising program. Walk4Hope is Pauline's baby, as are pretty much all the other fundraising program initiatives the Association has undertaken since 2014. Anyway, the reason for this section is that Pauline is resigning to explore new challenges, and her replacement is Alison Weir, starting early November.

GIFTS IN WILLS

One of Pauline's recent achievements was to create a bequest brochure (If reading online, **click HERE**) and we sincerely hope you will take the time to read it and think of your Association when writing or updating your Will. If you don't yet have a Will, PLEASE organise this TODAY. My family has had to look after the estates of two relatives who died intestate (without a Will), and even though neither was at all wealthy, it was a long and hugely frustrating process.

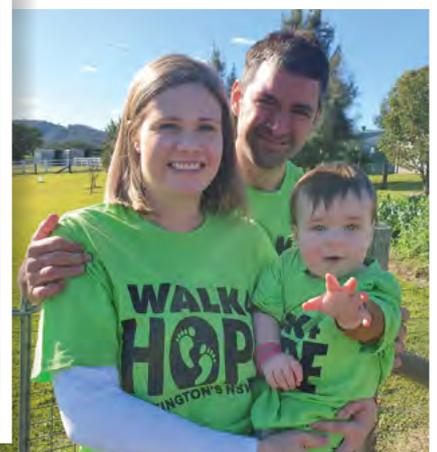
WALK4HOPE

More detail on this in the fundraising pages, but I want to thank everyone who helped keep the flag flying for Walk4Hope this year. The only place we could legally run a small walk was Canberra, where nearly 50 stalwart supporters turned up. Pauline also went to Orange and Speers Point and I did go to Parramatta just in case anyone came, but it was pouring with rain. New (informal) walks this year in Wollongong and Bingara may become a permanent fixture in future.

Email Lewis on:

lewis.kaplan@huntingtonsnsw.org.au

SINCERE THANKS TO EVERYONE FOR YOUR HELP & COMMITMENT!



...CONTINUED FROM PAGE 1

Team Veronica organised her own walk in the little town of Bingara, located in the New England region of NSW. Veronica had the wonderful support of members of the local community and the Bingara RSL, who all know her family and wanted to help her to raise as much as possible for Huntington's. Her son Chris received great support from the Manning Valley Bowling Club with a donation of \$1310.

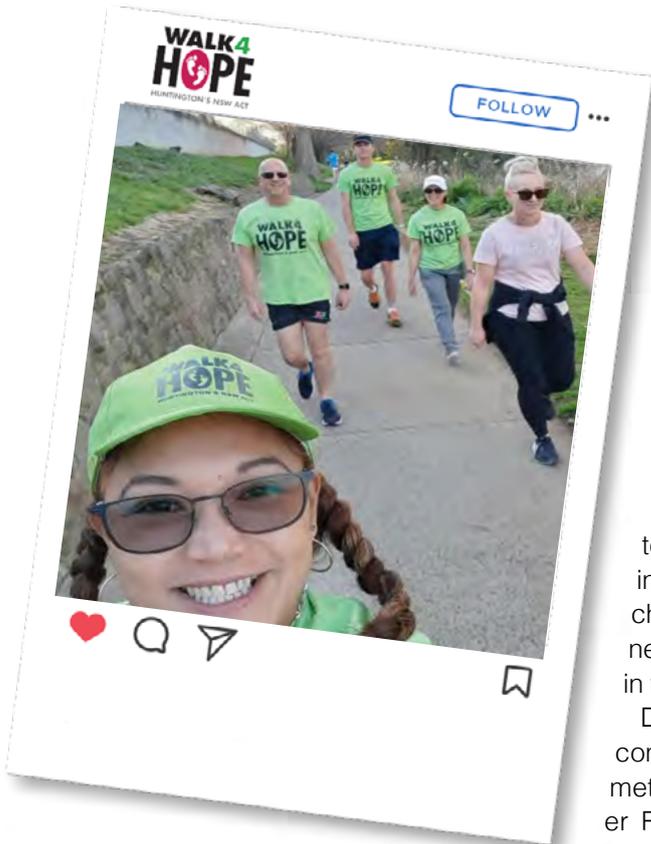
Team Glen was at the only endorsed walk in Weston Park, Canberra with his friends from the EJ EH Holden Club and all his family. It was great to see around 50 people walking around Weston Park (we were legal as COVID-19 restrictions in the ACT were not as stringent as NSW), but sadly no sausage sizzle after the walk this year.

The very first person to sign up this year was Peter Kwong from the Sister Maria Cunningham Centre. He is always at the

Parramatta walk, but this year in spirit only.

The top ten teams collectively raised \$30,734 overall, the 79 people who raised funds with their very own on-line fundraising page managed to raise \$50,224. As we go to print there are still some funds to come including \$2587 from the Vivability team and a further \$2260.25 from the Settlers Tavern Social Golf Club.

A wonderful result from a virtual event – Thanks to everyone involved. ■



VIVABILITY

GET CREATIVE

Vivability takes up the Challenge in the Central West

60 employees split into 5 teams which have taken part in weekly exercise walks/challenges to raise awareness of Huntington's disease in the local community.

During September they completed 204 laps (510 kilometres) of the Macquarie River Run and 54 laps of Mount Panorama (335 kilometres) totalling 845 kilometres with still one week to go at the time of writing.

That is the equivalent distance of Bathurst direct to Noosa.

They have also reached their donation target and plan to exceed

that even more in the last week.

Vivability is a leading provider of services to people with disability in the Bathurst and Lithgow areas. Formerly known as Interchange, it has operated for the last 32 years in Bathurst.

Vivability is actively involved in the community where services are based. It has established strong local networks with partner organisations, businesses, and residents.

We thank Vivability for its support for Walk4Hope.

For further information about the work of Vivability go to its website <https://vivability.org.au/> ■

VIVABILITY HAS BEEN taking part in this year's Walk 4 Hope, but due to restrictions they decided to get creative with their participation in the walk and set up their own challenges.



GOOD 360

Doing good for the community **WORDS PAULINE KEYVAR**

merchandise and recently gave us some empower packs filled with goodies that we were able to share with some families.

So, what is Good 360? Have you ever wondered what happens to the stock in department stores that doesn't sell or has been superseded by new items?

Good360 is a matchmaker. They connect the brand-new, surplus goods of business to Australians in need, via a national network of char-

ities and eligible schools.

Good360 registration is free to charities and some community organisations, and because it's spare stock, so are the goods. The goods donated are by some of Australia's leading brands including BIG W, Colgate, Woolworths and Harvey Norman. The charity pays a small shipping and handling cost to get the goods delivered.

For further information about this amazing organisation go to their website <https://good360.org.au/> ■

OVER THE PAST FEW years Good 360 have provided us with some incredible

Planning FOR AN NDIS PLAN

WORDS LINDA DAVIES



I'VE JUST FINISHED my fourth NDIS assessment for my friend Mark. Each time they become easier, but this time was different because of COVID-19. For Mark, like many people living in residential care, 2020 has been an isolated one.

Lockdown has a whole new meaning when you live in a residential facility and answering the question on how the plan has benefitted Mark in 2020 was difficult.

There was a new wheelchair, more like a sleek new car than just a way of getting around. His need for a specialist wheelchair was not evident when his last plan was signed off, so we didn't include it, whereas lots of outings with his carer were. But we went back and asked – and we were well rewarded.

NDIS plans are not 'set' rather they are a fluid relationship that changes as the participant's needs change. And with Huntington's, fluidity of needs is a given. Progressive diseases do just that – they progress. What was planned as a year of going to the footy, movies, cricket with a pie and the odd sneaky pint turned into a year of staying at home.

So how did we approach this year's plan?

When you start to think about your NDIS plan it is important your goals are clear. It might be more independent living, it might be more socialising, it could be technology to make your life easier. Dream big – think what will

make your life enjoyable. So, think of more than just some new tech or a new wheelchair. These are important but maintaining a full social life with the ability to get out and into the community is vital.

For Mark, the crux of his plan is going out. Huntington's disease can be lonely. Friends fall away and the simple pleasures like going for a meal or a coffee in the sun become increasingly difficult. Social interaction was his main goal and we asked for it – a carer at a minimum of three times a week for both short and long interactions. Full days at the cricket, shorter trips to the movies.

“NDIS plans are not 'set' rather they are a fluid relationship that changes as the participant's needs change.”

So, here are a few hints.

Remember this is an informed conversation so gather all your support material. The assessor will ask for some specific documentation but gather as much as you need to support the 'ask'. We have a report from the carer organisation, the account from the facility and the letter for fees from the Department of Human Services. A report from his fantastic support co-ordinator and his care plan from the facility.

For our first planning meeting we had his photo album to help their under-

standing of who he is and what his life was like before Huntington's. Be prepared to talk about Huntington's. Some assessors have lots of knowledge – others have little. But my experience is they are very willing to learn and understand.

If you need support at the meeting, take it – but have a plan of what you are going to say. I take his support co-ordinator and we meet beforehand to discuss our strategy.

If it is your first meeting and you are wanting a carer, then calculate the number of hours you might need and ask for them. Don't hold back.

Although the process can feel bewildering and bureaucratic, concentrate on the meeting rather than the complexity of the forms and the process. If you ask for something they cannot provide, they will tell you. There are limitations and these differ whether you are living at home, in assisted living or residential care.

The NDIS has allowed us to squeeze everything we can out of what time Mark has left. This year we asked for additional help for a holiday. I hope we get it and 2021 will bring a new year of socialisation outside of the boundaries of COVID-19 and the restrictions of Huntington's.

All the official information for your NDIS plan **can be found here** or ring 1800 800 110 to ask for brochures to be sent to you if you don't use the internet. ■



THE HD SPOTLIGHT ON

Terence McGill

TERENCE MCGILL

CLINICAL NURSE CONSULTANT,
HUNTINGTON'S DISEASE
SERVICE, WESTMEAD HOSPITAL

Q Why did you decide to become a nurse?

A After returning from a year of overseas volunteer work in my teens, I had decided to try to find the best way to make myself useful for society. Nursing was on the national priority list at that time for study and is an extremely practical and useful function.

Q How did Huntington's disease become your specialty?

A I had worked in community nursing (including palliative) in the first years after study and found that establishing long term relationships was by far the superior way to really support people. I saw the advertisement for the newly opened HD unit and thought that the care goals for those caring for people with HD lined up with what I had found regarding long-term support as the best solution.

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

A I am still regularly seeing the same people with HD, their families, and colleagues that I met on the first day of

work. We've been through thick and thin and it has been extremely rewarding.

Q What keeps you enthusiastic about your job?

A So many of the people with HD, their families and my colleagues have such great perspectives on life. Seeing how people get through one challenge after another is inspiring.

Q What is your ideal Sunday?

A If I could get through a Sunday without running away with my thoughts and getting myself into trouble, that would be a dream come true! ■

A GIFT OF HOPE

A gift in your Will is a gift of hope that allows you to make a difference beyond your lifetime in the fight against Huntington's disease.

OUR OFFICE AT WEST RYDE is a lasting legacy from the gift in the Will of Elsie Court. Every gift in a Will, whatever the size, has a big impact on the support we

can offer families who may have nowhere else to turn.

To assist you when thinking about organising your Will, we have prepared a free booklet: The Gift of Hope.

For further information on how to obtain a copy, or to speak to someone, please contact our Gifts in Wills Manager on 61 2 9874 9777 or email info@huntingtonsnsw.org.au.



HD & GUT BACTERIA

World first study reveals altered gut bacteria in Huntington's which may be a potential drug target in future studies

THE STUDY WAS LED by Monash University's Turner Institute for Brain and Mental Health, with collaboration from the Florey Institute for Neurosciences. Lead researchers, Neuropsychology Doctoral Candidate Cory Wasser and Professor Julie Stout recently published in *Brain Communications* the first clinical study that investigates the environment of the gut in people with Huntington's disease (HD). Here's a summary they have provided us.

Although a lot of research in HD focuses on the brain, we know that that the genetic information of HD is in every cell in the body, and that there are subtle effects of HD on other body systems. Findings in our study of the gut, using faecal samples, show that the gut microbiome is different in HD compared in people without HD.

Specifically, we found reduced diversity in the variety of bacterial species in the gut. Some of the gut measures in HD were associated with the disease's symptoms, such as impaired movements and think-

ing. The gut and the brain are known to be in close communication, and the findings highlight that HD is not just a disease of the brain, but also of the body.

“Although a lot of research in HD focuses on the brain, we know that that the genetic information of HD is in every cell in the body

It has been known for some time that the gut and the brain are in close communication, and therefore it is not surprising that specific gut bacteria were associated with HD symptoms, including cognition and motor signs.

The study included 42 participants with the HD gene, including 19 people with HD, 23 people with the HD gene but not yet showing HD symptoms, and 36 healthy controls who did not carry the gene mutation.

According to the researchers, “It

is also possible that the changes in these trillions of gut bacteria (which outnumber the trillion or so human cells in each person's body), which are known to ‘talk to the brain’, could also affect symptoms of HD such as depression and dementia.”

In people with HD, the researchers found major shifts at the level of bacterial Families, altering the potential of the gut for sending signals to the brain and other organs. These findings may also mean that changing gut bacteria may be a cause or precursor to some of the more debilitating symptoms associated with HD, according to the researchers.

These findings are important, because we know that the gut and brain communicate with each other, and there is a lot of evidence in other neurodegenerative diseases, such as Alzheimer's and Parkinson's disease, that the gut is affected. We hope that further research investigating the relevance of the gut in HD, might help us understand whether the gut is a viable therapeutic or treatment target in HD. ■



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.huntingtonsnswact.org.au

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

PAULINE KEYVAR

(ALISON WEIR from 9 Nov)
Fundraising & Marketing
0409 363 987

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 &
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?

OCTOBER, NOVEMBER, DECEMBER MEETINGS

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

- Saturday, 21st Nov
- Saturday, 12th Dec

CENTRAL COAST - Postponed
due to COVID-19

PORT MACQUARIE

Venue closed due to COVID-19

NEWCASTLE - Online – video
conference: 10:00am - 12:00pm

WOLLONGONG

Online – video conference
10:00am - 12:00pm

- Thursday, 8th Oct
- Thursday, 12th Nov
- Thursday, 10th Dec

- Monday, 12th Oct
- Monday, 2nd Nov
- Monday, 7th Dec

SYDNEY - West Ryde,
10:30am - 12:30pm

*Note: Meeting room limited to
8 attendees only*

- Wednesday, 21st Oct
- Wednesday, 18th Nov
- Friday, 4th Dec

To register your interest for any
of these events please contact us
on 02 9874 9777 or email: [info@
huntingtonsnsw.com.au](mailto:info@huntingtonsnsw.com.au).
Latest detail can be found on our
website at: [https://www.huntingtonsnswact.org.au/
support-groups/](https://www.huntingtonsnswact.org.au/support-groups/)

COMMUNITY SUPPORT

ACT

Postponed due to COVID-19

CENTRAL COAST

Venue closed due to COVID-19

COFFS HARBOUR

Korora, 11:00am - 1:00pm

- Friday, 16th Oct
- Friday, 20th Nov
- Friday, 18th Dec

ORANGE & CENTRAL WEST

Orange, 10:30am - 12:30pm

- Friday, 16th Oct

THERAPY SERVICES

The following groups have
been suspended due to the
COVID-19 pandemic.

SYDNEY – West Ryde

'MyVoice' art club

SYDNEY – West Ryde

Music & social club

Latest detail can be found
on our website at: [https://
huntingtonsnswact.org.au
/therapy-services/](https://huntingtonsnswact.org.au/therapy-services/)