



**Huntington's**  
NSW ACT

## **Annual Report**

**2019 – 2020**

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## Huntington's NSW & ACT Inc.

Registered Office	21 Chatham Road, West Ryde NSW 2114 Australia
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Website	www.huntingtonsnswact.org.au
Postal Address	Post Office Box 178, West Ryde NSW 1685 Australia
Bankers	Commonwealth Bank of Australia, Sydney NSW
Auditor	Thomas GLC Chartered Accountants PO Box 1563 Hornsby NSW 1635
Australian Business Number	54 571 730 306
Incorporated in NSW, 1993	Registration No. Y16575-09

Endorsed as a Public Benevolent Institution, a deductible gift recipient and income tax exempt charitable entity

Registered for GST

ACNC registration: <https://www.acnc.gov.au/charity/ee4d45c9248ff6f9fc0366df067ee737>

Authority to Fundraise  
in NSW

Number CFN13153

Licence for Conducting  
Charitable Collections  
in the ACT

via our status as a registered charity with the Australian Charities and Not for Profits Commission (ACNC) – see above

Public Officer

Lewis Kaplan



## Board

The board members of the Association who held a position during the financial year 2019/20 were:

President	Brian Rumbold	(re-elected 23 November 2019)
Secretary	Dr. Therese Alting	(re-elected 23 November 2019)
Treasurer	Stephen Guthrie	(re-elected 23 November 2019)
Board members	Katy Clymo	(re-elected 23 November 2019)
	Alison Hill	(re-elected 23 November 2019)
	Craig Dalli	(elected 23 November 2019)
	Stephen Garrard	(elected 23 November 2019)

## Staff

The members of staff employed by the Association during the financial year 2019/20 were:

Chief Executive Officer	Lewis Kaplan
Administration Officer	Stewart Swales
Community Programs Officer	Amanda Dickey
Youth Liaison Worker	Amy Hale
NDIS Senior Support Coordinator	Giselle Beaumont
Marketing & Fundraising Consultant	Pauline Keyvar

All staff except Giselle Beaumont are part-time, 0.6 full-time equivalent or less. Giselle is full-time.

## Volunteers

We are grateful for the support of many volunteers over this year, particularly via the corporate support of Suncorp for our Walk for Hope in Parramatta Park (see page 21).

- Chris Gu gave us many hours of technical support working to improve our database system.
- Gabrielle Phillips assisted with the development of our advocacy work.
- Sam Crothers was a stand-out volunteer, helping us finalise the creation and launch of our new website.
- Pieter Lindhout from Cranfield Catalyst facilitated a staff business planning workshop.
- Kellie Atkins, PhD candidate at Monash University, coordinated the Dancing at the Vatican online screening Australian premiere.

## Strategic plan

A new strategic plan was adopted by the Board in November 2019. It can be read in full [HERE](#) on our website.

## Vision

We support people affected by Huntington's Disease to live their best possible life, while striving to eliminate the factors that make our organisation necessary.

## Mission

Provide leadership in Huntington's disease information, education, awareness, support, and advocacy

*We might not do all of this ourselves: we will also facilitate, promote, and support all these wherever we find them.*

## Core organisational values & behaviours

We operate with:

- Ethics and with integrity  
*We will always act honestly, openly, and directly with our constituents and the community to promote the best interests of the HD community.*
- Commitment to social justice  
*We want to see all people impacted by HD treated with equity by governments, other institutions, and their communities.*
- Compassion  
*We will recognise the personal hardship and sacrifice of many in the HD community, which impels us to advocate for their interests.*
- Respect  
*We will actively listen to our HD community stories, to inform shared decision making and action to address people's concerns and goals.*
- Close connection to our community  
*Our Association is owned by and governed on behalf of our members. We will seek to understand what our members and others in the HD community tell us and respond to their expressed aspirations and concerns to the best of our ability.*

## Chairman's Report

### Serving the HD community

Huntington's NSW & ACT exists to serve the needs of the HD community across NSW and ACT. In the last year we have run group programs, resourced support groups, advocated to governments on behalf of the community, continued our youth program, and established our NDIS Support Coordination service. We have achieved all this through our dedicated, hardworking and skilled team: our CEO, Lewis Kaplan along with Amanda Dickey, Amy Hale, Giselle Beaumont, Pauline Keyvar and Stewart Swales. The task of keeping our charity viable and effective has become more complex and challenging year by year. Finding reliable, ongoing sources of funding so we can support and advocate for community members remains a basic challenge. In the past year we have funded the Association from diverse sources: the NSW Health grant, foundation grants, donations from our generous supporters, fundraising, and NDIS fees for service.

### Strategic Plan

The Association developed a new strategic plan in late 2019, with active contributions from Board and staff, informed by the results of a community survey conducted earlier in the year. This was approved by the Board in November 2019 and now guides the Association's work.

### The year of the unexpected

Of course, our world, like everyone else's, was thrown into turmoil by the arrival of COVID-19. The pandemic affected all aspects of our operations; but the way our team responded was remarkable. Many of our activities were curtailed by health constraints, so our team found new ways to operate so that, where possible, clients' needs could keep being addressed. The Board wants to thank Lewis and the team for their flexibility and creativity in keeping so much functioning.

Financially, we've come close to breaking even — a great result given the circumstances. And we want to acknowledge the help of the Federal Government's JobKeeper program in making that possible *given the downturn in fundraising due to COVID-19*.

### NDIS

We signalled over the last two years our intention of engaging more with the opportunities presented by the NDIS. I want to highlight the completion of the first full year of our NDIS Support Coordination Service, now accredited to provide both support coordination and specialist support coordination. Giselle Beaumont has set high standards for the service and both she and it are already becoming known in the HD community for effectively helping HD clients get real value out of their NDIS packages. Next year the service will pay for itself as it continues to grow.

### Advocacy and National Cooperation

CEOs from a majority of State HD Associations have been meeting regularly to share information and seek out areas of joint activity. Our CEO co-ordinated preparing joint submissions from most of the State Associations to both the Aged Care and the Disability Royal Commissions.

In June five State Associations signed a Memorandum of Understanding to create a National Consortium. The Consortium will allow the Associations to pursue avenues for national cooperation in a more structured way. The aim is to look for opportunities where a single national approach will make more effective use of our limited resources. At this point, all the State Associations except Victoria have signed up to the Consortium.

## People

As you may be aware, Pauline Keyvar, our Fundraising Consultant, is stepping down in November 2020 after seven years of energetic, creative, and fruitful work for the Association. On behalf of the Board, I want to acknowledge her contribution as she has shaped, organised and run our fundraising activities. Her work in developing Walk 4 Hope has given us a wonderful community fundraiser that has engaged hundreds of people each year from across the community. We wish Pauline the very best for the years ahead.

To Alison Hill, who retires from the Board after three years, thank you for your service. The Board has appreciated your commitment to the role and your thoughtful perspective on the issues we have dealt with over that time.

On behalf of the Board and the Association, I also want to acknowledge Associate Professor Elizabeth McCusker's huge contribution to the HD community both in NSW and beyond as she headed up the HD Service and directed the Service's research programs. We look forward to hearing from Liz as special guest speaker at our AGM. We wish her the very best of times ahead as she pursues a slightly more private life.

In stepping down from the Board, I would like to thank Board Members for their commitment to seeing that the Association truly serves the HD Community in all that it does. It has been my privilege to serve the Association and the many remarkable people in the HD community.



Brian Rumbold  
Chairman

## Chief Executive Officer's Report

The last quarter of this year has of course been dominated by the COVID-19 pandemic and the major changes it has brought to all aspects of life. The JobKeeper allowances have been very helpful in keeping our finances in reasonable shape and we are grateful to the Commonwealth Government for its support.

### NDIS

We started the financial year with the establishment of our NDIS Support Coordination service, which has gone from strength to strength under the expert guidance of our senior support coordinator, Giselle Beaumont. By the end of 2019 we were ready for our accreditation and are now registered and accredited to provide both support coordination and specialised support coordination (for additional high or complex needs, e.g. behavioural management). By year end we were ready to expand staffing to two full-time equivalent positions and extend the reach of the service beyond greater metropolitan Sydney.

### National collaboration

The conversation with most other State HD Associations has progressed and CEOs now meet quarterly. There are many things we do individually which would be just as good if not better done collectively and more cost-efficiently. While there is no national Association on the horizon, good will and trust are building between most of the State Associations which can see the advantages of working more closely with each other.

### National conference

All State Associations agreed that NSW should host the next Australian National Huntington's conference. The original date in mid-November 2020 has been postponed till mid-2021 due to COVID-19.

### Fundraising and Marketing

The 6<sup>th</sup> annual Walk for Hope in September 2019 was largely successful, drawing larger crowds than previous years in most locations. We continue to be most grateful to the many volunteers who support the Walks both on the day and in the many and complex tasks required behind the scenes.

The Association's fundraising hit a big bump in the form of COVID-19, which put a stop to all community fundraising.

We had become aware of a documentary launched in late 2019 called "Dancing at the Vatican". The film tells the story of a number of poor villagers with HD and their families from Venezuela, Colombia and Argentina making the journey of a lifetime to the Vatican for an audience with Pope Francis. We eventually screened the documentary as a national live online event in May, with Charles Sabine, a key international HD advocate introducing the event and responding with very interesting answers to the post film Q&A.

### Services

Our Youth Connection Program continues to deliver effective engagement with younger people at risk of HD, and we thank both St George Foundation and Ansvar Insurance for their financial support of this activity.

### Advocacy

Our recent efforts have been strongly focused on increasing our government funding, partly because it's the right thing for governments to fund services such as ours, and partly to reduce the pressure on our community fundraising, which relies so heavily on our members and their families when we know they are often doing it tough.



## Governance

I thank the Board Directors for their commitment and support, and especially our Chair, Brian Rumbold for his unfailing good humour and unerring judgement. I would like to thank the staff for their hard work and commitment and for maintaining good team spirits during challenging times.

## Volunteers

I'd also like to thank our volunteers, too many to name all, particularly those who lead support groups, help coordinate Walks For Hope and those who have lent a hand to some of the tedious but necessary back office tasks like cleaning up our database.

## Looking to the future

- We are aiming to extend our Huntington's specific NDIS Support Coordination service which has now been successfully operating for a full year.
- The Board has approved us to run the next national Huntington's conference as a virtual event in mid-2021. Watch this space.
- Discussions between five of the six State Associations are progressing from the Consortium mentioned by the Chairman above, with plans to collaborate on the delivery of a range of needed services including some to be funded via the NDIS.



Lewis Kaplan  
CEO

## SERVICES

### Community survey and strategic direction

	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT	EXTREMELY IMPORTANT	TOTAL	WEIGHTED AVERAGE
Running social (lunch) clubs	17.93% 26	27.59% 40	33.79% 49	20.69% 30	145	2.57
Running an annual holiday camp	24.66% 36	26.71% 39	34.25% 50	14.38% 21	146	2.38
Providing localised family support	5.56% 8	7.64% 11	31.25% 45	55.56% 80	144	3.37

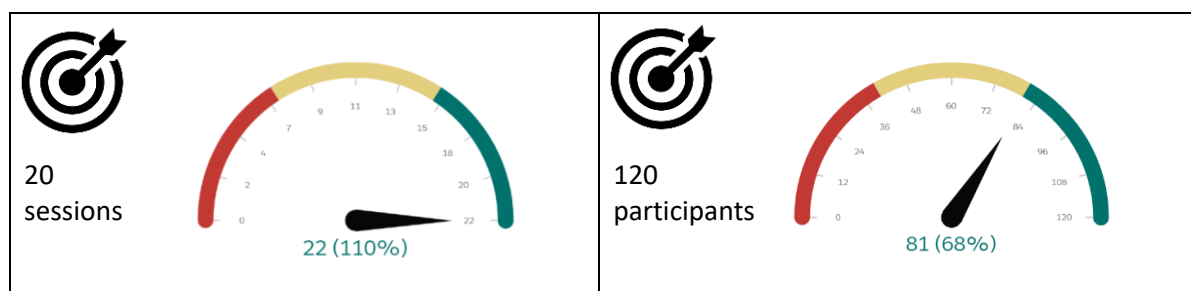
**Strategic Goal 3:** Provide HD-specific SERVICES that improve the quality of life for those impacted by HD  
**Objectives:**

- People with HD have access to support groups and social programs
- Carers of people with HD have access to support groups
- People with HD eligible for NDIS have access to support coordination
- Children and young people impacted by HD have access to support
- Build academic evidence base and evaluation
- Seek out high quality services which fill service, support, and knowledge gaps

### Therapy Services - Social activities for people with HD in early to mid stages

Westpac Foundation granted \$10,000 toward Therapy Services (Sept 2019)

#### NSW Health KPIs and what we achieved



- COVID-19 Government Public Health mandates forced the cancellation of face to face activities to minimise any risk to our very vulnerable community (March-July).

### Music & Social club

Music therapy is an evidence-based, non-pharmacological intervention for people with HD (pwHD): research shows that pwHD are responsive to music stimulation; have a high demand for emotional expression and maintenance of a social relationship; and that music therapy interventions improved the quality of life for pwHD, in the dimensions of physical, mental, emotional and social functioning.



The reins of our new look Music and Social club were handed to Cathy from Delicious Harmony Music Therapy, for two terms while Xiaoyon enjoyed maternity leave. Cathy considered her time with our members as a “privilege” and was grateful for the warm welcome she received at each session. Members particularly enjoyed playing the drum where they were challenged to use their hands to cross the midline of their body and to use their voices to improvise/vocalise while they played. Handbells were used by participants to follow the beat and play on time for their note. The smiles on members’ faces demonstrated that they were having a wonderful time playing music together.

Thanks to Cathy for her willingness to learn about HD and for treating our members with respect. They are happy to have broadened your musical tastes into the Beatles, Pearl Jam, and Glen Campbell.

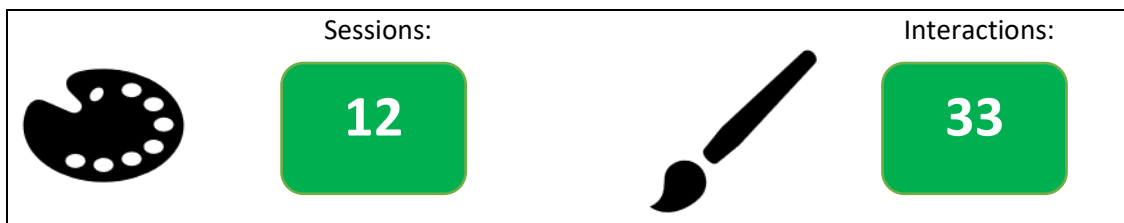
*“I am enjoying this, I like music, I love playing music.”*

*Created on the spot and sung by Michael M (Sept 2019)*

Xiaoyon Lu (Harmony Direct Music Therapy partnership) returned in October to teach our members Christmas carols for our annual concert. In February she was contracted as the Therapeutic officer to assist with growing our Therapy services and raising awareness of the benefits that music and art therapy brings to people with HD. Unfortunately, this activity ceased in March due to COVID-19 restrictions.

### 'MyVoice' art club

The philosophy of this art program is phenomenological in nature: promoting the development of self-awareness. The art experience provides a forum for memory and an opportunity to exercise the hands.



Stephen Dernocoure, our art guide, carefully considers each person’s unique circumstances and assists in navigating our members’ art journey. Our Art club focused on creating personalised canvas, life drawing and poetry.



*I like the green  
forest green:  
a cooling envelope*

*The river  
The green river*

*A nice cool swim after  
a long bushwalk.*

*The earth and the river  
surging into me*

*Who knows.*

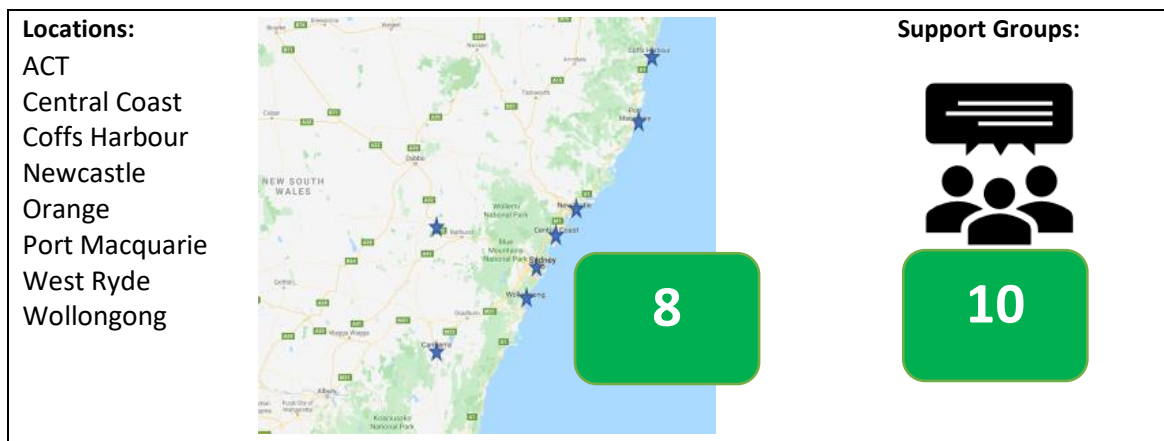
*Pieces of the river;  
throw them off into the wind*

*group reflection on a club member's  
landscape image (Oct 2019)*

### Holiday camp

We didn't offer a camp this year due to funding constraints.

## Community Support Group program



### NSW Health KPIs and what we achieved



- COVID-19 Government Public Health mandates forced us to cancel face to face community support group meetings from March-July to minimise any risk to our very vulnerable community.

Our new strategy focuses on balancing structure with the unique requirements of each region. This year the following occurred:

- Our CEO visited each region to say hello. Thank you to everyone who shared their stories, concerns, and aspirations. Lewis deepened his understanding of the needs of our HD community and the unique requirements of each region. This knowledge is considered in every interaction.
- Wollongong and Coffs Harbour pilot sites were extended for a further 12 months.
- Central Coast family support group was handed over by the community to the Association to manage. We are grateful to Dianne Faulkner for her years of service to the groups. Her efforts in the background have kept HD families on the Coast connected and well informed. Dianne is still a support group and fundraising member and has agreed to take on the challenge as a local advocate, with Debra Faulkner and Fran Copland, voicing the concerns of the Central Coast.

### Policy and COVID-19

- The Commonwealth's Regional Carer Gateway initiative launched the policy change that forced an end to our ability to employ a Regional Support worker in 2018.
- Online Support groups (OSG) options were born from the COVID-19 restrictions as an alternative avenue of support. Support group members were contacted to understand people's appetite for staying connected, transitioning to an OSG option and any technology constraints.
  - Wollongong and Newcastle moved their meetings to video conferencing.
  - Coffs Harbour transitioned to teleconferencing.
  - Port Macquarie family support and Central Coast carers chose a monthly phone check-in.

### Grants and partnerships

- SNOW, Greater Bank and NDIS ILC grant submissions were unsuccessful.
- Partnered with HD Awareness Orange to pilot a regular support group for the Central West.
- University partnership for annual program evaluation paused until a research partner is secured.

## Social Research and development

- Discussions with Carers NSW and Dementia Australia regarding best practice for support groups ceased until their models of operations within the Commonwealth Government's new Regional Carer Gateway initiative are understood.
- We submitted a Community Support Group research proposal to the HNSW ACT board for consideration. The purpose of this research is to:
  - understand why people attend support groups
  - understand the operational requirements of different support group models
  - define the role of HNSW ACT within the operating model – ownership or leadership
  - test the 'Regional Support Teams' conceptual model.

What's next:

- Source an academic partner for the Community Support Group research project
- Source skilled volunteers to assist with compiling HD-specific Support Group guidelines
- Source grant funding to structure and support this program.

## Information and education programs

### Community survey and strategic direction

	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT	EXTREMELY IMPORTANT	TOTAL	WEIGHTED AVERAGE
Providing information about HD	0.68% 1	6.08% 9	26.35% 39	66.89% 99	148	3.59
Providing information about caring for someone with HD	2.72% 4	5.44% 8	26.53% 39	65.31% 96	147	3.54
Providing information about accessing health services for HD	2.68% 4	4.03% 6	22.15% 33	71.14% 106	149	3.62
Educating health care professionals about HD	2.67% 4	2.67% 4	26.67% 40	68.00% 102	150	3.60

**Strategic Goal 1:** Be the peak organisation providing HD INFORMATION to community members and care professionals within NSW and ACT

Objectives:

Promote knowledge acquisition and sharing

Everyone affected by HD has access to information in a form suitable to their needs

Information is up to date, high quality and accessible

Promote service and support linkage and referral points

Promote access to up to date and accessible research reports

**Strategic Goal 2:** Ensure high quality EDUCATION is available to HD community members and care professionals within NSW and ACT

Objectives:

People with HD are provided services by people and organisations who understand HD

Provide the HD community with strategies for coping, care, and support

Provide access to HD related forums and conferences

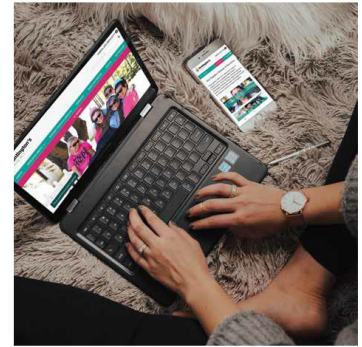
### Huntington's NSW ACT website development project

Yes, it has been a long time coming and thank you for your patience.

A lot of sweat and tears have gone into our new website

<https://huntingtonsnswact.org.au/> There is a whole lot of great stuff...

- Your stories • Regional support, services, and events • Latest research feeds from HD Buzz
- New Resource Library (searchable by Audience, Region & Topic) • More ways to 'Get Involved'
- Better explanations for why we exist; where the money is spent; what services we provide you, who we partner with; and what advocacy we are working on.

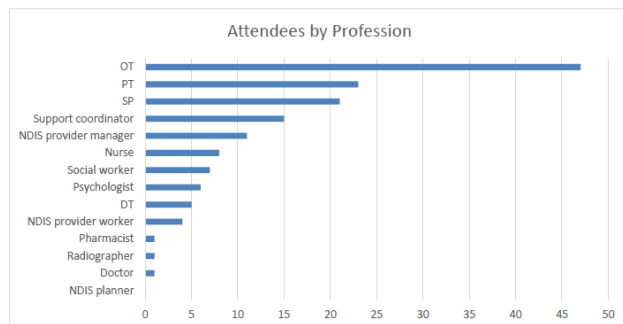


Many, many thanks go out to Mara and the team at MARA MEO DESIGN, and to our wonderful volunteer Sam at SpaceCheck. This website would never have made it to life without your dedication to our cause.

### Education Seminars

A Huntington's disease seminar (for professionals) was facilitated in August 2019 run by Westmead HD Service staff at the Hunter Medical Research Institute and through webinar format.

It was attended by 120 professionals – 50 in-person and 70 online.



The feedback showed webinar participants were responsive to the new platform and made suggestions to enhance the online experience for future events. This is exciting as it opens HD education up to a broader audience. It also started us on a process of planning more online education both for HD families and for professional carers and others involved in the support of people with HD.

Topics covered: Introduction to HD, How does HD change behaviour and how we can help, Nutrition and Swallowing in HD - Change early – benefit longer!, Mobility management: the role of the physiotherapist, OT interventions in progression of HD, Social aspects of HD and a Q&A session.

The 'Living Well with HD' information sessions (for newly diagnosed people and families) were not conducted this year due to staffing constraints within the Westmead HD Service.

### Student placement program

The WSU student placement program did not run this year due to exploration of research options.

Amanda Dickey  
Community Programs Officer

## NDIS Support Coordination

The Association launched this service in July 2019 in response to the expressed need of people with Huntington's disease who had become NDIS participants but were not receiving appropriate support due to the lack of understanding of the complexities of HD by the majority of NDIS service providers. The first full year of this new service has proved to be of great value to the 36 clients who have asked us to take on the support coordination of their NDIS plans.

With the strong support of the Board and particularly of Chairman, Brian Rumbold, we established the required policies and procedures and hung up our shingle as a registered NDIS service provider. We achieved accreditation in early 2020, not only for support coordination as expected, but also for specialist support coordination, so we can work with people with HD with behavioural issues. This double accreditation means we can maintain our engagement with clients throughout their journey as NDIS participants.

Our senior support coordinator, Giselle Beaumont has established a strong reputation as a caring, knowledgeable but also incredibly tenacious worker who has been tireless in her efforts to secure the best possible services and accommodation for her clients.

As the service grew, we were lucky to be able to add some additional hours from Amy Hale, our Youth Social Worker, while we worked on recruiting a second full-time support coordinator.

We have been very grateful for the positive engagement between this new service and Westmead Hospital's Huntington's Outreach Service.

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### What we set out to do

This unique and individualised service was specifically designed for individuals with a Huntington's disease diagnosis and an NDIS plan. Prior to the creation of this service, people with HD were required to utilise non-HD specific Support Coordination often resulting in less than ideal outcomes for these individuals in understanding and utilising their NDIS funding.

Huntington's NSW ACT recognises the unique and individual needs of people diagnosed with Huntington's disease and provides this Support Coordination service with the experience, understanding and patience required to maximise NDIS plans for these participants. Through working in consultation with them to optimise how they use their NDIS funds, participants are provided explanation and advice about the different ways they can use and maximise their plans. Through consultation and encouraged autonomy, they are then connected to a range of service providers to best suit their individual needs and goals.

During this initial year, the service operated predominantly in the greater Sydney region and Wollongong. However, as this service grows, we aim to extend its reach further across NSW and the ACT.

### What we have achieved

This first year of operation saw Huntington's NSW ACT take on and work with 36 participants, signing with them 59 individual NDIS support coordination service agreements.

Clients were assisted with the choice and facilitation of:

- A range of allied health services to meet their needs such as physiotherapy, occupational therapy, behavioural therapy, speech therapy, psychology, and more
- Community support access and transport



- Accommodation that more adequately meets living and care needs
- Transition from the home into supported independent living
- Transition from hospital into supported living
- Assistive Technology to facilitate more independence
- Preparing for NDIS plan reviews
- Home modifications to assist in safety and mobility
- Complaint to the NDIS Quality and Safeguards Commission
- Complaints to service providers
- Resolved points of crisis

In its first year, our clients were assigned a collective total of \$267,919 from the NDIS for Support Coordination and Huntington's NSW ACT worked with its 36 participants to deliver for them support coordination close to the value of \$108,000.

Factors preventing full use of these funds have included:

- Participants' change of circumstances (usually due to an inadequate plan or heightened care needs due to an increase in symptoms) requiring plan reviews resulting in plans with remaining funds being cancelled and new plans issued
- Participants not wanting as much support as their plan allows them, resulting in unused funds including support coordination hours
- The majority of plans starting after July 2019 remaining open into the next financial year with their funding still being utilised by participants for the 12 months following their initial starting dates but not reportable in this current period
- Increased workload involved in applying for Specialised Support Coordination accreditation
- Two clients exiting Huntington's NSW ACT Support Coordination during the reporting period
- The increased workload required initially in getting this service up and running which decreased potential hours available for working with participants

A key achievement during this period was made in Huntington's NSW ACT being given accreditation from the NDIS to provide Specialised Support Coordination as well as Support Coordination. The application for this took a considerable amount of time and effort. This accreditation allows this service to take on Specialised Support Coordination participants with greater needs.

A second key achievement was assisting the first Huntington's participant to receive Specialist Disability Accommodation (a higher level of NDIS funding).

### **The Impact of COVID-19**

Covid-19 impacted a majority of Support Coordination participants. March and April in particular saw a significant increase in time and effort going into meeting with clients and liaising with services to get the results for participants that pre-COVID-19 would have taken considerably less time. This required considerably more creativity and flexibility.



One positive outcome of this time was that it highlighted to a number of participants and their families the value of Support Coordination. This was indicated by an increase in service uptake at this time.

### **Into the Future**

During the last part of 2020 and into the future it is expected that the Huntington's NSW ACT Support Coordination service will continue to grow. It is also expected that it will experience an increase in efficiency as teething problems continue to be ironed out. The employment of a second support coordinator is expected in the latter part of 2020. This will make a huge impact on the program's efficiency and outcomes.

Giselle Beaumont  
Senior Support Coordinator

## Youth Connection Program



### What we set out to do

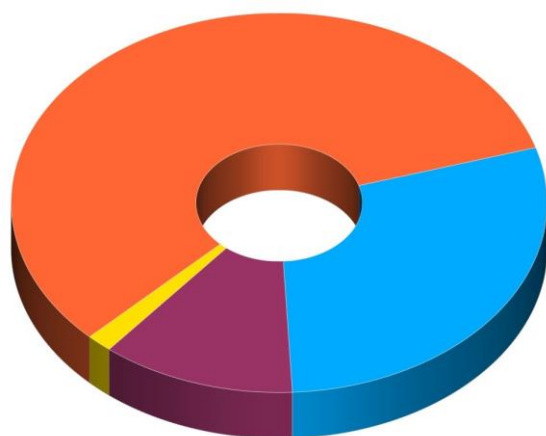
The overarching goal for Huntington's NSW ACT Youth Connection Program is to build resilience in and empower children and families in our Huntington's community. This will enhance their psychological and emotional wellbeing and improve their quality of life in their difficult and unique circumstances.

### What we have achieved

For the 2019/2020 reporting period, Huntington's NSW ACT's Youth Connection Program has met all project goals.

We have:

- conducted 72 individual child/young person counselling sessions
- had 111 opportunities to educate families, kids and professionals in our community about Huntington's disease
- carried out 37 counselling sessions with parents; educating and enabling them to best understand Huntington's disease and support their children
- conducted 2 group activities connecting kids affected by Huntington's
- facilitated 15 school staff information sessions.



#### 2019-2020 INTERVENTIONS

**Orange: child/young person individual counselling/education sessions**

**Blue: Parent/carer counselling/education sessions**

**Yellow: Child/young person groupwork sessions**

**Purple: NSW ACT school staff information sessions**

## Funding opportunities

Throughout the last half of 2019, the program was funded primarily with the assistance of the St George Bank Foundation Community Grant. In December 2019, this grant was acquitted. Over the course of 2019 our program applied for a handful of community funding opportunities, and in February we received this email from ANSVAR Insurance after making an application for their community education program grant:

*Ansvar Insurance are delighted to confirm that your organisation has been successful in our Community Education Program grants and would like to contribute \$50,000 towards your outstanding program – Huntington's Youth Connection.*

This news was very well received as it allowed us to focus on addressing the needs of our community with the knowledge that we had some external financial assistance.

## Changing it up for COVID-19

The first few months of this reporting period saw our youth social worker conducting face-to-face engagements with our young people, their families and educational supports with visits to homes, schools, and engagements in the community. However, in March this year this changed dramatically with the onset of COVID-19 in Australia.

During April, May, and for most of June, school closures and increased COVID-19 transmission safety protocols resulted in all our face-to-face home visits, school visits and teacher/staff education sessions being put on hold. This was a worrying prospect for our program as we know firsthand how heavily some of these kids and young people rely on the counselling they receive from our service.

After speaking to clients, teachers and other national and international HD services, an 'emergency' re-think of our service delivery and swift jump into video and telephone counselling resulted in us shifting to provide a similar degree of support and assistance for our clients, albeit remotely. This temporary change in service delivery has proved to be successful, with us being able to reach around 80% of our clients on a regular basis.

During this restricted three-month period, the rethink of our service allowed us to conduct:

- 18 one-on-one social worker HD targeted counselling sessions for kids/young people (mostly via zoom)
- 19 one-on-one HD targeted parent support and education sessions (mostly via zoom/telephone)
- 8 school teaching staff HD specific education sessions (all via telephone)

Although in most cases face-to-face visits are preferred over online consultations, these are still very effective from a therapeutic perspective. The internet and phone allowed us to stay in contact with the majority of our young clients and their families whilst keeping safe and adhering to all NSW Health guidelines. We were pleased with this outcome, as we were able to offer and provide supports similar to those our clients were getting before COVID-19 restrictions came into place. For our more vulnerable clients without access to this technology, we made a big effort to connect remotely with their teachers, community services and school staff and assisted these professionals to provide some extra HD supports where we could not.

A big change in the way we support kids and young people came about during this lock-down period when we extended our services to include parent counselling via video and/or telephone. This was highly successful and resulted in a number of families staying connected with the service during this time. The idea behind offering professional support to parents and carers as a way of meeting our kids' and young clients' needs was based on understanding that well-supported parents and carers have greater capacity

to meet their kids' and young people's emotional needs more effectively if they themselves are supported.

As COVID-19 restrictions across NSW ease, school visits have started again for most students. As soon as these restrictions were lifted, visits with the more vulnerable students who were not able to access the service during the lock-down were prioritised. We have since been able to see all clients who missed out during this period and are gradually getting all visits at school and in the community back to their usual rate as well as continuing to offer online counselling and support where needed and convenient.

## **Into the Future**

### **COVID-19 influenced changes**

The service delivery changes that came about through COVID-19 opened up some new possibilities for the youth connection program. The success of online counselling via video has highlighted the potential to have more counselling and support for clients and families who cannot travel or are in more remote areas of NSW or in distant ACT. The COVID-19 restrictions created an opportunity for the program to trial this kind of client support without having face-to-face contact with our clients. Although not ideal from a therapeutic perspective, this is something that we hope can continue when face-to-face visits are not possible.

Counselling for parents and carers is also something that we would like to see continue if capacity allows for this after kids and young people have been offered counselling and support. This change in service saw a 280% increase in parents accessing one-on-one HD counselling and support, with our client contacts increasing from 5 sessions in the three months prior, to 19 sessions during the COVID lock-down. This is an objective and outcome that was not proposed in the initial program description but as it has proven to be successful, it is expected that this will remain as part of an extended service offered by the program.

### **Evidence and reporting**

We will continue to build on an evidence base for our work to secure government or other funding that will enable us to keep meeting the needs of our community and continue building relationships with our clients into the future. In 2020 the program introduced some measures to track the mental health of our clients. Unfortunately, this has not been utilised to its full potential due to COVID-19. This is something that has now resumed but there are not enough data to draw any useful insights at this stage.

### **New resources**

This year we designed a resource to help us to talk to kids (aged between 6-13) about HD. This has been introduced and is working well. It has now been shared with youth workers from Western Australia and Queensland. In addition to this, our program is currently developing other resources to help us work specifically with parents starting to experience symptoms of HD. These resources will focus on how they would like to plan their parenting around their expected disease progression and get the most out of their engagement with their children.

As COVID-19 restrictions continue to ease, and the program shifts further out of crisis mode and back into more standard service delivery, it is expected that more time will be available for the creation and introduction of new ideas, resources and planning for this program to ensure it continues to meet the needs of our community as we learn how to do this more effectively.

Amy Hale  
Youth Social Worker

## Fundraising Highlights

### Parramatta NSW to Barwon Heads Victoria



Bob Montgomery and his grandson Tom took on the challenge together to cycle from the Walk 4 Hope at Parramatta to Barwon Heads in Victoria.

Bob said “This is the third year that we have been helping to raise funds and awareness for Huntington's, particularly with the help of our friends at Rotary and business and friends.

“Over the past few years I have raised funds by riding my bike around Australia on my own with great support crews but this year I am both pleased and proud to have one of my grandsons, Tom Malcolm, riding with me.

“Tom is 11 years old and is a very proficient rider and has been training very hard for this ride. He is up for the challenge.”

**HUNT 4 HOPE**  
*Op Shop*

The Hunt 4 Hope Op Shop in Maroubra has been thriving this year except for a hiccup due to COVID19 restrictions when the shop was closed for a couple of months. This allowed Matina Moutzouris to spring clean (in winter) and to re-calibrate the shop in readiness for re-opening in May. With the help of JobKeeper and various grants she was able to keep her staff employed and the shop moving forward.

All the profits from the Hunt 4 Hope Shop are donated to Huntington's NSW ACT – the Moutzouris family show their amazing commitment to the community wherever they can.



#### **Need a Spring Clean? Hunt 4 Hope Shop wants to hear from you:**

- Quality women's, men's or children's clothing
- Fashion accessories like scarves, hats, jewellery, shoes and handbags
- Homewares, Manchester, kitchenware and bric-a-brac.

Hunt 4 Hope 775 Anzac Parade, Maroubra

Tel: 02 8957 6881

Facebook: <https://www.facebook.com/hunt4hope/>

## Year 6 for Walk 4 Hope

There was plenty going on in September:

- Walk 4 Hope – Speers Point, Canberra, Orange and Parramatta, also supported by
- St Joseph's Hospital Stall
- Westmead Hospital Stall
- Nutrimerics
- Spray Pave Australia
- Settler's Tavern Golf Day

**Walk 4 Hope 2019 raised over \$136,000 across all four walks and various other activities in the month.**

It was wonderful to see people teaming up with their families and friends to take up the Walk 4 Hope challenge and asking local businesses to promote the walk. In fact, 10 of the 25 teams who took part raised almost \$45,000! A very big thank you to:

- Walk 4 Hope Orange – Rachael Brooking and her team of volunteers
- Walk 4 Hope Speers Point – Peta Brennan, Nat Myers, Angela & Dennis Hiscock and their team of volunteers
- Walk 4 Hope Canberra – Glen Allardyce and the volunteers from EJ EH Holden Club and Glen's family
- Walk 4 Hope Parramatta – Suncorp Volunteers, Parramatta Lions Club, St Joseph's Hospital, Country Women's Association, Nutrimerics, Spray Pave Australia



Whilst fundraising is certainly a key goal of the Walk 4 Hope it is definitely not the only one. In the six years that we have run the walks it is evident that families use the opportunity to come together and want to be involved with Huntington's NSW ACT and the wider Huntington's community. We see new faces but also many of the same families and people coming along to support the Huntington's community.

Registration fees assist with the infrastructure and back office costs such as public liability insurance necessary to host the walks each year. It is understandable that for some people the fees may be prohibitive, and they may feel they are unable to afford to join the walks. However, fees may be waived on application as the walks are available for everyone to enjoy and take part, so no one needs to miss out.

## **Congratulations and thank you to all our fundraisers for your support and generosity**

None of these fundraising events would have been possible without the many volunteers, staff and participants who put their hand up to fundraise and signed up to be part of the Walk 4 Hope.

## Thank You

Special mention and thanks to the following people and organisations for rolling up their sleeves to raise funds and increase the awareness for Huntington's disease throughout the year.

Abbruzzo Family, Veronica and Robert Ali, Glen Allardyce, Therese Alting, Neville Barrett, Andrew Beeston and Family, Mark Bevan, Nicole & Atilla Bihary, Clare Bosbach, Peta Brennan, Rachael Brooking, Katy Clymo, Beckie and Frances Copland, Jon Copson, Rebecca and Susan Crichton, Craig Dalli, Marg & Dianne Crook, Brooke Davis, Kirsty Dickens, Debra, Dianne, Mark and Mitch Faulkner, Jodene Fillery, Karen Fleming, Alexandra and Eva Ford, Naomi Fraser, Julie George, Cheryl and Jacob Goodwin, Catherine Gualtieri, Gemma Hadden, Catherine Hall, Amanda Hill, Alison Hill, Jacob Hill, Jade Hill, Jeffrey Hill, Kevin Hill, Alex Hilton, Angela and Dennis Hiscock, Alycia Honey, Sarah and



Wendy Hughes, Kate Iacono, Kylie Jacobs, Rachel Jones, Lewis Kaplan, Pauline Keyvar, Robyn Kapp, Peter Kwong, Glenette Jeffrey-Konig, Jasmin Kohl, Anna Lashko, Clement Loy, Piper Lowe, Xiaoyan Lu, Louise Macan, David & Alison Malcolm, Tom Malcolm, Katie McManus, Jillian McMillan, Bob and Jenny Montgomery, Matina Moutzouris, Nat Myers, Melissa Oake, Kimberley Nisbet, Emma O'Donoghue, Renee Oldfield, P. O'Sullivan, Bill & Sallee Pixton, Julia Reilly, Nicole Reynolds, Loughlin Richards, Trish Rooney, Brian Rumbold, Natalie Scarpignato, Ashlee Screen, Christine, David, Rachael and Stephen Sharp, Debra Sharp, Stephanie Slattery, Natasha Sneddon, Donna Solomonson, Jody Sowter, Peter Stephen, Nicole Tabone, Todd Taylor, Naomi Van Dijk, Kathleen Walsh, Kim Wells, Ken Wyper. ... *If I have missed anyone Mea Culpa!*

ANSVAR Insurance, Bingara RSL, EJ EH Holden Club, HD Support Group – Central Coast, Lions Clubs of Parramatta and Elmore Vale, Lake Macquarie Council, Macquarie Bank Foundation, McCormack Barber, Neverfail Water, North Ryde RSL Baseball Club, NPV Roofing, Polaris GPS, Rotary, Orange and Upper Blue Mountains Sunrise, Polaris, Settler's Tavern Social Golf Club, Sister Maria Cunningham Huntington's Unit, Spray Pave Australia, Suncorp, Westmead Hospital, Westpac Foundation.

All in all, it was a busy and challenging second part of the year when COVID-19 disrupted all our lives and made us re-think the way we do our fundraising and undertake business activities.

Some people choose to support us by making regular monthly donations, others choose to remember a loved one by collecting donations, and others simply respond to a letter. Without the mixing pot of all these donations we would not be able to function and to provide the help and support that we give for the families impacted by HD.

We are once again looking forward to working with HD families and friends to support new ideas for successful fundraising and awareness in the coming year.

Pauline Keyvar  
Fundraising & Marketing Consultant

## Regional Support / NSW Health / ACT Health Directorate

We have actively lobbied the NSW and ACT governments to fund HD-specific regional social worker positions in all local health districts. We won't know the outcome of our advocacy until next year's state budget in May or June 2020 (now postponed due to COVID-19).

Just before year's end we received advice from NSW Health (via Western Sydney Local Health District) that our funding would be continued for a further three years but at the same inadequate level. We do not expect any additional funding for HD specialists in regional NSW with COVID-19 being a strong excuse that there is no spare cash.

We heard nothing more from ACT Health apart from an invitation to submit our proposal via the public recommendation process to inform ACT budget planning. (p.s. the Canberra Liberals included a commitment to fund a Huntington's social worker in their October 2020 election platform, but the ALP was returned to government).

We are keen for members and supporters to get behind our lobbying activities as MPs often respond better to us if this is complemented by local approaches, particularly if they are made by lots of people.

## Representation and Relationships

Our CEO, Lewis Kaplan, continues to represent Huntington's NSW ACT and the other Huntington's state associations on the Neurological Alliance Australia. The Alliance provides an opportunity for a number of national groups working to support people with neurological diseases to find common cause and lobby together. This year a joint submission to the Aged Care Royal Commission was submitted in August 2019 and position papers on telehealth in aged care and disability services were developed in response to COVID-19.

Lewis also represents the state associations on the Genetic Alliance Australia group which meets quarterly in Sydney. Most of its members are organisations even smaller than Huntington's!

We continue to enjoy a close strategic and working relationship with the HD Clinic and Outreach Service at Westmead Hospital and John Hunter Hospital, Newcastle with quarterly liaison meetings. The relationship with St Joseph's Hospital and the Sister Maria Cunningham Centre (SMCC), Auburn underwent a significant change at the start of 2020 when St Vincent's Health Network determined that the Committee was no longer adding value and it was disbanded. Huntington's NSW ACT had represented consumers on this committee since the establishment of SMCC. It is to be replaced by a quarterly intersectoral liaison group meeting, but this is not likely to deliver the same level of engagement.

Two meetings of the national CEOs group were held in the second half of 2019. Unfortunately, the Victorian Huntington's Association has chosen to exclude itself from these meetings. The other five states have committed to developing a Memorandum of Understanding as a basis for more structured and formal collaboration, with the potential of forming a consortium to apply for funding when this is appropriate.

As of 30 June 2020, the Association was a member of

- Carers NSW
- NSW Council of Social Service (NCOSS)
- National Disability Service (NDS)
- Volunteering NSW



## Administration

The highlights of 2019-20 from the administration perspective centred around changes and improvements to our information technology and telecommunication arrangements.

Late in the previous financial year we were successful in obtaining a grant via our local Federal Member of Parliament from the Stronger Communities Program. The purpose of the grant was to fund not-for-profit organisations seeking to implement a small capital project. Each project must be 50% funded by the recipient up to the value of \$20,000.00. We needed funds to:

- Implement a NDIS management system – with Giselle Beaumont commencing as NDIS Support Coordinator at the beginning of 2019-20 we needed appropriate software to complement her role
- Purchase new laptop computers – our existing desktop computers were over 10 years old and replacements were overdue
- Install a new file server, VPN connection and firewall – this would allow staff to be more flexible with their working arrangements and access work related documents remotely.

Little did we know at the time, but this initiative has been of great help during this COVID-19 period as we have all been able to work reasonably effectively from home.

The Stronger Communities grant was vital for these much-needed IT enhancements.

Not long into the new financial year our PABX system broke down. With the imminent arrival of the NBN to West Ryde, we had in any case been looking at a replacement phone system. The failure of the PABX sped up the process. We began by looking at our job roles and decided that a more flexible approach would best suit. So instead of installing an expensive new phone system with multiple lines, we reduced our service to one line and purchased mobile phones for our key staff. The end result was a move from Telstra to Optus, a more than 50% reduction in our monthly phone bill and no expensive outlay for a new phone system.

The NBN was installed in early September 2019 and while there have been some minor hiccups, the technology was required to allow us to be more flexible in the way we work. It also saw an upgrade to our office security system.

Finally, we thank an HD family for providing us with a large variety of office and IT equipment from an excess supply at their business. We received additional monitors, office chairs, phones, iPads, video equipment and even a sofa bed for our back room. All much appreciated.

Stewart Swales  
Administration Coordinator

## Treasurer's report

If we thought the financial situation for 2018-2019 was tough, 2019-2020 brought unprecedented challenges for Australia, for nearly all charities and for the Association – due to the COVID-19 pandemic – which will clearly continue well past the end of the financial year.

From a revenue perspective, we suffered the loss of all community fundraising from March, although Walk for Hope in September 2019 was as good as, if not better than previous years. The Commonwealth Government's JobKeeper scheme was very welcome across the sector and greatly assisted our financial viability.

Our NDIS support coordination service was launched in July 2019, but it was always expected that it would take many months to become financially self-sustaining. By year end we had billed \$79,325 against an expenditure of \$98,176.

Income Breakdown 2019-20	Income	Percentage
Fundraising and donations	\$ 253,861	48.7%
Government grants	\$ 64,200	12.3%
Foundation grants	\$ 60,000	11.5%
NDIS billed income	\$ 79,325	15.2%
Government COVID-19 support	\$ 55,000	10.6%
Membership	\$ 1,400	0.3%
Bank interest	\$ 7,389	1.4%
TOTAL	\$ 521,175	100.0%

In expectation of a tough year, we budgeted in 2019-20 for a deficit of \$66,000, with the Board and CEO clearly understanding that we had to turn around our finances. In fact, on paper we finished the year with a loss of only \$9,982, primarily due to \$55,000 of COVID-19 Government support and some grants in advance.

We fell short of our budgeted income targets, in part due to COVID-19, but the final total receipts of \$521,175 was 47% above the previous year's achievement of \$355,463. Fundraising from Walk 4 Hope continues to be the most important source of income for the Association.

The year ended with expenditure \$42,624 below budget, again largely due to the constraints of COVID-19. The Board looked to save funds wherever possible during the difficulties of this last year.

The Board has also taken the step of recognising a revaluation of \$150,000 in the carrying value of the West Ryde property, Elsie Court Cottage at year end.

Stephen Guthrie  
Hon. Treasurer

## Special acknowledgements

The Association acknowledges the following with sincere appreciation for their contributions throughout the year:

- Western Sydney Local Health District, NSW Health
- Commonwealth Government Stronger Communities Program
- St George Foundation
- Ansvar Insurance Community Education Program
- Westpac Foundation
- Our donors including those who give through our telemarketing program which we are gradually winding up from July 2019, hoping that telemarketing supporters will continue their generous donations.
- Organisations and health professionals who have worked alongside the Association, especially:
  - Prof Clement Loy, Director, NSW Huntington Disease Service, Westmead Hospital
  - Cecelia Lincoln, Terry McGill, Felicity Stehouwer and the staff of the NSW Huntington Disease Service at Westmead Hospital
  - Dr Elizabeth McCusker, Dr Therese Alting and the HD Research Team at Westmead Hospital
  - John Conaghan, Huntington's Social Worker, John Hunter Hospital
  - The staff of the Sister Maria Cunningham Centre at St Joseph's Hospital, Auburn.