



# 2021 Annual Report

A Year of Accomplishments



**Huntington's**  
NSW ACT

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## ABOUT US

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Postal Address	Post Office Box 178, West Ryde NSW 1685
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	<a href="https://www.acnc.gov.au/charity/eefd45c9248ff6f9fc0366df067ee737">https://www.acnc.gov.au/charity/eefd45c9248ff6f9fc0366df067ee737</a>
Authority to Fundraise	CFN13153 in NSW
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)	
Public Officer	Lewis Kaplan





## OUR PEOPLE

### Office Bearers

President	Brian Rumbold	(retired 21 November 2020)
	Katy Clymo	(elected 21 November 2020)
Secretary	Dr. Therese Alting	(retired 21 November 2020)
	Craig Dalli	(appointed 21 November 2020)
Treasurer	Stephen Guthrie	(re-elected 21 November 2020)

### Board Members

Dr. Therese Alting	(re-elected 21 November 2020)
Katy Clymo	(until 21 November 2020)
Craig Dalli	(until 21 November 2020)
Stephen Garrard	(re-elected 21 November 2020)
Kim Hart	(elected 21 November 2020)
Alison Hill	(retired 21 November 2020)
Robyn Russell	(elected 21 November 2020)
Andrew Sully	(elected 21 November 2020)

### Staff

Staff employed by the Association during the 2020/21 financial year were:

Giselle Beaumont	NDIS Senior Support Coordinator
Amanda Dickey	Community Programs Officer
Malisha Fernando (from 29/3/21)	NDIS Support Coordinator
Amy Hale	Youth Liaison Worker
Lewis Kaplan	Chief Executive Office
Pauline Keyvar (until 9/12/20)	Marketing & Fundraising Consultant
Stewart Swales	Administration Officer
Alison Weir (from 9/11/20)	Fundraising & Marketing Coordinator

All staff except Giselle and Malisha are part-time, 0.6 full-time equivalent or less. Giselle and Malisha are full-time.

### Volunteers

Volunteering was significantly constrained by the COVID-19 pandemic this year.

Mark Bevan	Port Macquarie support group leader
Rachael Brooking	Orange support group leader
Olivia Kaplan	Conference video editing
Jasmin Kohl	Events assistant and school training resource
Fiona Richards	Newsletter proof-reading
Preetha Shrestha	Executive Assistant
John Walker	IT upgrade submission writing

We are grateful for the support of our Walk 4 Hope volunteers, listed under Fundraising.



## CHAIR'S REPORT

This has been a big year for our Association – dealing with COVID-19 while focusing on moving forward on a number of fronts. Many of us have become, if not experts, at least familiar with videoconference meetings, which is how your Board stayed active and engaged during the lockdown. The Association had to stop offering many face-to-face activities, but we were able to continue our key client services in NDIS support coordination and Youth Connection.



We were very pleased to continue to engage actively with other state Associations and became a member of the newly formed Consortium of Australian Huntington's Associations (CAHA). CAHA's membership includes all the state Associations except Victoria which has chosen to operate independently for the time being.

CAHA has applied for and even won some national funding. This is one of the key advantages of a national consortium, as state Associations are generally unsuccessful in applying for national funding. Other discussions are underway about how best to work together to ensure maximum benefit for people with HD, their families and carers.

Our State Association budget has increased significantly since 2019, mostly due to our growing delivery of specialist HD support coordination services for NDIS participants. This service is much in demand, and we now have 2.25 full time equivalent staff with a commitment to hire one more full-time staff member. This service is primarily available in Greater Sydney and the Illawarra. While we would love to make it state-wide (and include the ACT), we have to approach its growth in a businesslike manner to ensure we break even.

### Fundraising

This year we farewelled our first ever professional fundraiser, Pauline Keyvar who set up Walk 4 Hope seven years ago and ran it (and many other activities) successfully ever since. Best wishes Pauline in your next fundraising role and welcome Alison Weir to the role of Fundraising and Marketing Coordinator. Over half our funding (excluding NDIS) comes from fundraising, and so Alison's role is vital to ensuring our ability to continue to provide quality services and representation for families impacted by HD. We continue to be challenged by the COVID-19 pandemic but are working to find new ways to connect our community while raising much needed funds.

### Drug trials

News of the abandonment of not one but two international drug trials in April hit the HD community pretty hard. Roche and Wave were both carrying heavy expectations and it was upsetting to learn that neither trial will proceed. The research experts tell us that most trials are not successful, but each one provides learnings for future efforts.

### National Conference

When the NSW / ACT Association agreed in 2019 to run the next national conference, it was to be held in November 2020. COVID-19 caused us first to postpone it by up to 12 months and then realise that an online event would be a better medium-term solution. Our target was 300 delegates (matching the reported number from the last national conference held in Victoria in 2016). By the end of the four sessions there were 413 delegates including 238 HD families. Thanks to Roche for its sponsorship and support from the Commonwealth Government's National Disability Conference Initiative for enabling us



to make the conference free for HD family members. The conference proceedings were recorded as many delegates could not attend the live online sessions. Anyone wishing to view the content is now welcome to register for free.

### Community Engagement

The Board agreed to establish a new Community Advisory Committee (“CAC”) which has now met twice. The purpose of the CAC is to support us becoming a stronger consumer-led organisation by providing feedback on how we can best meet the diverse needs of the HD community. As most members are from regional NSW, the meetings are held by videoconference. Key agenda items include community awareness and advocacy.

### Thank you

As incoming Chair, I wish to record a very special thank you to Brian Rumbold who so ably chaired and steered the Association for the last decade, retiring at the November 2020 AGM.

Thanks also to Alison Hill who also retired this year – for her contributions to the Board over the past three years.

We welcomed Kim Hart, Robyn Russell and Andrew Sully to the Board in November 2020 following a campaign to attract new board members, led by our board renewal sub-committee.

Many thanks to our dedicated team: CEO Lewis Kaplan, Amanda Dickey, Amy Hale, Giselle Beaumont, Malisha Fernando, Stewart Swales and Alison Weir who have all worked incredibly hard to make this a successful year. Thank you to my fellow board directors for their service throughout the year, and as always, to all our generous volunteers. Every bit of effort helps to increase our effectiveness.

Katy Clymo  
Chair





## CEO'S REPORT

We finished the year to June 2021 in surplus which was a very significant achievement given the constraints we worked under, having started this year in the middle of the COVID-19 pandemic, not knowing what the future might hold.

While the COVID-19 lock-downs changed how we work, and unfortunately interrupted a number of face-to-face services, they did not change our goals and aspirations. Indeed, the opportunity to have more detailed conversations across the state HD associations has created a new optimism for our work, sharing with and learning from each other.



### Fundraising & Marketing

Following the departure of Pauline Keyvar after seven successful years as our inaugural fundraiser, we hired Alison Weir who has ably filled Pauline's shoes and brought a fresh pair of eyes to our work in both fundraising and marketing. Ali's digital skills have allowed us to connect more strongly with the community via various social media platforms. Fundraising has been a very tough environment for most charities during COVID-19, so we eagerly await the opportunity to re-establish community events and resurrect Walk 4 Hope. Best wishes to Pauline in her future endeavours.

### Youth Connection Program

We are very grateful to Ansvr Insurance and St George Foundation for their support for this program which continues to provide a crucial link in our support for people from HD families. Amy's stewardship of this crucial program is much valued by clients and the rest of the team. We have largely managed to meet our program targets in spite of COVID-19.

### Regional Social Worker

We are most fortunate to have received funding from the Co-Group to allow us to employ a part-time Huntington's specialist social worker. While we initially hoped to run this project in the ACT, we were unable to recruit a suitably qualified social worker there. We apologised to our members in the ACT and worked with Carers ACT to offer them additional supports. We re-focussed our project to the Illawarra region where we aim to have a social worker on board in the near future.

### Advocacy

It has been a challenging year for advocates. While we carefully developed a proposal for NSW Health to increase our core funding from around \$60,000 per year to a more realistic \$500,000, the arrival of COVID-19 put an end to any hopes of this, and we are grateful to NSW Health for making a further three-year commitment (at current levels) to support the work of the Association.

### Aged Care and Disability / NDIS

Advocating for changes to improve the quality of care for people with HD further developed with a focus on submissions to the Aged Care and Disability Royal Commissions, and an active partnership with the Neurological Alliance of Australia.

We also advocated strongly for better engagement and support from the NDIS, particularly regarding the need to recognise in participants' plans the complex and often rapidly changing needs of people with HD. When we reviewed the first year of operation of our NDIS Support Coordination service, it



became clear that up to 75% of client hours should have been delivered at “level 3 – behavioural support” whereas less than 5% was actually funded at this level.

The Association has a vision that people with HD should be able to access quality care near their families. This will involve more advocacy to ensure both aged care and disability care providers have adequately trained and supported staff. The Association partnered with the Summer Foundation to research best practice “models of care” for people with HD both in Australia and internationally. While the research has found little published on this issue, quality care is being defined across a number of “models of care”. The research report should be available before the end of 2021, and we will use it to support our advocacy campaigns.

Lewis Kaplan  
Chief Executive Officer



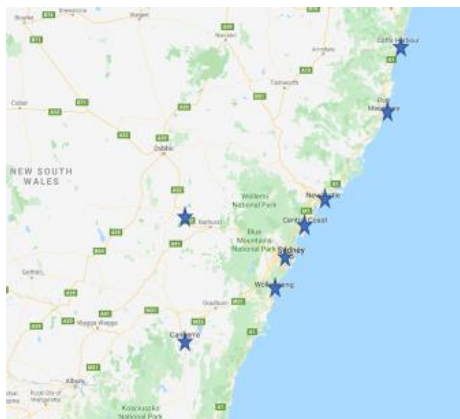


# SERVICES

## Community Support Group Program

### Locations:

ACT  
Coffs Harbour  
Newcastle  
Orange  
Port Macquarie  
West Ryde  
Wollongong



### Support Groups:



Meetings

47

People supported

243

### COVID-19 impacts

Government Public Health mandates forced us to cancel face to face community support group meetings from June - August to minimise any risk to our very vulnerable community.

Central Coast support groups ceased.

Alternative avenues of support continued as follows:

- Coffs Harbour obtained an exemption and continued to meet face to face.
- Wollongong and Newcastle meet via video conferencing.
- Port Macquarie and Orange family support chose phone, email or Facebook check-in.

Face to face meetings resumed in most regions from September 2020.

Our CEO visited the ACT to gain this community's perspective on social working need for the region.

### Partnerships

Joyce Jones, our Wollongong Support group facilitator, retired in January 2021 after a 2-year tenure.

Thank you to Joyce for creating a safe caring place where Wollongong families felt free to share their experiences, have a laugh or a cry and make long lasting friendships.

HD Awareness Orange partnership continues for the Central West Support group.

We collaborated with Huntington's Disease Network of Australia (HDNA), an initiative of the Turner Institute at Monash University regarding Community Support research and program evaluations.



We initiated discussions with Physical Disability Council of NSW regarding seasonal guest speakers and the exchange of ideas, useful links and contacts within NSW.

We established a relationship with Carers ACT that will see ACT families connected into local supports and services and a therapeutic support group for interested carers.

Invited as a guest speaker for the newly endorsed Community Advisory Committee (CAC).

### Social Research and Development

A Community Support Group research proposal was approved by the Board in June 2020. This research aims to increase our understanding of the unique requirements for each region.

Funding has been carried over to FY 2021-22.

We joined an HDNA peer collaboration to explore research opportunities for Community Support.

The [Carer Gateway](#) was launched in 2020. We are increasing our understand of what this Commonwealth initiative offers and are advocating for clearer support pathways for our carers through the formation of relationships with the NSW service providers: The Benevolent Society; Wellways Australia; Live Better and Carers NSW. Note: Carers ACT is already forming the ACT Carer Gateway.

We kicked off the 'Regional Support Teams (RSTs) project to test stage one of our community development strategy. So far, we have:

- Developed the Community facilitator position, which is central to RSTs success. From July 2021 half this role will be funded by our research grant.
- Recruited Michael Collins as a Community facilitator for the Wollongong region of Illawarra Shoalhaven Local Health District (LHD) and are progressing recruitment for the Coffs Harbour region of Mid-North Coast LHD and the Orange region of Western NSW LHD.

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

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### COVID-19 impacts

This program was not run in 2020-2021. To minimise any risk to our very vulnerable community and specialised staff, the Association decided not to reopen these face-to-face activities. Unfortunately, this meant the contracts of our specialised Therapeutic officer and Art facilitators were put on hold.

### Partnerships and Grants

We send a heartfelt thank you to Stephen Dernocoure who has sadly retired his charcoals, paints, brushes, and poetry after three magical years as our Art facilitator. It was a pleasure co-creating a space with you where people felt safe to recall their story and then retell it using their own hand. You are a wonderful human and we wish you well in your life journey.

Thank you also to Xiaoyon Lu for stepping into the role of the Therapeutic officer. It was unfortunate that we were unable to further explore the potential of your expertise but look forward to working with you again when circumstances allow.

**Westpac Foundation** generously allowed \$4,000 of the 2019 grant funding to be carried over and utilised once this program sabbatical ceases and activities can be run again in a safe manner.



During this time this program is under review to explore NDIS and MyAgedCare business streams, learn from similar practice operating models, consider regional options and connect with new specialised therapists.

As part of the **Consortium of Australian Huntington's Associations (CAHA)** we became joint recipients of a **Department of Social Services** Information, Linkages and Capacity Building (ILC) – Social and Community Participation (SCP) grant. In 2021-22 we will join a national project piloting the South Australian (SA) Recreation Program (RP) which enables people with Huntington's disease (HD) to come together in a safe environment to learn, socialise and enjoy structured, supported, fun and engaging activities. A regional location will be put forward as the NSW/ACT pilot site.

What's next:

- Continue adapting within this changing COVID-19 environment
- Recruit Community Facilitators for remaining Support group regions
- Participate as a pilot site for the 'ILC Recreation Program'
- Co-design service activities in consultation with the CAC and clients to further advance our community development and community engagement strategies
- Review Therapy Services program.
- Seek sponsorship and skilled volunteers for the Community Support group program.

## Information and Education Programs

### Partnerships and Grants

HD Services liaison meetings have moved online.

The meetings are now a collaborative brains-trust that aims to identify gaps in services and supports and a forum to sound out program proposals for our HD community. We're strengthening this relationship through open dialogue, data sharing and analysis, knowledge acquisition and sharing and peer support.

A HD education working group has also been established across the two organisations.

In July we entered into a new three-year agreement cycle with NSW Health securing funding for 2020-2023. Our agreement objectives were aligned with our 2019 – 2022 strategic direction and have NSW Health supporting Huntington's NSW ACT to provide quality HD information, raise awareness and embrace innovation.

New performance measures are reflective of our strategic plan and results are as follows:

Note Green figures indicate our agreed KPIs were met  
Pink figures indicate our agreed KPIs were not met

Objective	Performance measures	
<i>Provide Huntington's disease INFORMATION to community members and care professionals within NSW.</i>	Number of requests for general information	102
	Number of requests for information via:	
	• Website (AU sessions)	5,258
	• Social media (Facebook/Instagram/Twitter)	15
	Number of referrals to specialist services, health providers etc.	96
	HD News - newsletters distributed	1,218 mailed 8,572 mailed



Raise AWARENESS of HD in communities where people with HD live and more broadly.	Number of awareness raising events	13
	Referrals to HNSW ACT services	35
	Conduct specialised HD information sessions	11
Embrace innovation regarding HD care and support through community & industry partnerships.	Member and community survey	1
	HD Services project collaboration	8
	Strategic collaboration - CEO	20+
	Strategic collaboration - Peers	24
	Staff development	33

### Student Placement Program

Not run this year due to COVID-19 restrictions.

### Community Survey

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

Participants ranked how well we are doing against our strategic goals as follows:

Note - goals with the same ranking number returned an equal score.

Strategic Goals	Ranking
Provide HD INFORMATION to community members and care professionals	1
Raise AWARENESS of HD in communities where people with HD live and more broadly	2
Deliver ADVOCACY that aims to improve government policies and services within disability, health and social care and justice systems	2
Ensure high quality EDUCATION is available to HD community members and care professionals	4
Provide HD-specific SERVICES that improve the quality of life for those impacted by HD	5

Participants ranked the level of importance against our strategic objectives as follows:

Note - objectives with the same ranking number returned an equal score.

Strategic Objectives	Ranking
Provide the HD community with strategies for coping, care and support	1
Lobby Governments to adequately fund Huntington's NSW ACT	2
Campaign for HD specialist residential services in regional NSW and ACT	2
Campaign for HD specialist community services in regional NSW and ACT	2
People with HD are provided services by people and organisations who understand HD	5
Campaign for NDIS planners and providers to understand the needs of people with HD	6
Children and young people impacted by HD have access to support	7
Seek out high quality services which fill service, support and knowledge gaps	7
Lobby the NSW and ACT Governments to fund HD specialist social workers in each Local Health District	7
People with HD have access to support groups and social programs	10
Everyone affected by HD has access to information in a form suitable to their needs	11
Carers of people with HD have access to support groups	12
Represent the HD community at relevant industry forums and conferences	13
Promote specialised HD education opportunities	14
Promote access to up to date and accessible research reports	15
Campaign for appropriate care for people with HD within the justice system	16
Formally evaluate our programs	17
Provide access to HD related forums and conferences	18



A quarter of respondents have a person with HD in their household who is an NDIS participant. The majority were happy with the support and services they receive and provided some valuable information regarding the need for improvement in some areas. Those people engaging with our NDIS Support Coordination service have advised us they are grateful that we have specialised and competent staff to support and advocate for their needs. You also advised us that you'd like another survey asking about your satisfaction levels as participants in the Aged Care system.

The majority had heard of or are engaging in our Youth Connection program and the remainder provided us with insights into the main barriers for engagement.

Participants ranked the order of the production of education material as follows:

<b>HD education</b>	<b>Ranking</b>
Coping/Support tips	1
Living well with HD	2
Assisting professionals to help me	3
Life planning	4
Research updates explained	5
Connecting with HD community	6

A summary of basic analysis of responses was conducted and made visible to the community at: <https://huntingtonsnswact.org.au/about/how-we-know-we-are-succeeding/>

Amanda Dickey  
Community Programs Officer



# NDIS SUPPORT COORDINATION

## What we set out to do

In July 2019 Huntington's NSW ACT extended its options for the Huntington's community to include a much-needed NDIS Support Coordination service. This unique and individualised service was specifically designed for individuals with an NDIS plan and a Huntington's disease diagnosis. 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, they 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 the initial years, the service operated predominantly in the greater Sydney region and Wollongong. However, as this service grows, we aim to extend our reach further across NSW and the ACT.

## What we have achieved

The 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. The second year of operation saw us supporting 44 participants.

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
- Complaints to the NDIS Quality and Safeguards Commission
- Complaints to service providers
- Resolution of (many) points of crisis

During 2020 - 2021, our second year of operation, our clients were assigned \$216,834 from the NDIS for Support Coordination and Huntington's NSW ACT worked with its 44 participants to deliver for them support coordination close to the value of \$172,104.





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 2020 remain 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.

A key achievement during this period was placing 11 participants into Supported Independent Living (SIL) and Specialist Disability Accommodation (SDA).

A key milestone was hiring our second full-time support coordinator.

### **The impact of COVID-19**

COVID-19 impacted the majority of Support Coordination participants. The impact on the participants and their carers and families made engagement a little more difficult due to fear of transmission.

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 - 2021 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. The employing of another support coordinator is expected in the later part of 2021 which will bring a total of 3 support coordinators. This will make a huge impact on the program's efficiency and outcomes.

Giselle Beaumont  
Senior Support Coordinator



# YOUTH CONNECTION PROGRAM

## 2020/21 Program Data

Counselling, support, education, and group support has been provided to young people, their families, their educators, and their health providers with a focus on these 5 key service areas.

During this 12-month period:

- **72** Huntington's focused youth counselling sessions have been delivered.  
**Equal to last year's total (72).**
- **38** Huntington's focused parent/carer counselling sessions have been delivered.  
**3% above last year's total (37).**
- **130** Huntington's disease education and information sharing opportunities for children and their families were created.  
**17% above last year's total (111).**
- **20** Huntington's disease education and information opportunities for school staff and professionals were created  
**33% above last year's total (15).**
- **2** Huntington's disease group support and activities took place to connect young people affected by HD to each other.  
**Equal to last year's total (2).**

## 2020/21 Program Summary

Throughout 2020/21, Youth Connection Program participants have continued to engage in all five service areas resulting in over 150 direct engagements that have worked towards our project aim to improve the quality of life for these children, young people, and their families.

Although COVID-19 stay-at-home orders were not in place throughout the last half of 2020 and the first half of 2021, the NSW Department of Education was still not allowing outside professionals to enter school grounds to engage with students. This presented a challenge, as prior to COVID-19 restrictions, almost all engagements the program had with young people between 8-17 years took place in the school environment. Fortunately, however, there was a 4-month window between February and June 2021 where schools were open to counselling visits allowing program participants to reconnect with program services and their school support networks.

Although COVID-19 restrictions have resulted in the Huntington's community as well as Huntington's professionals being under increased levels of stress for prolonged periods of time, these restrictions have also revealed opportunities for various engagements that have seen the program move into new counselling and support areas.

Online support continues to feature largely with Zoom and social media being used for mental health check-ins and counselling through video, voice, and text-based apps. Children and young people have also continued to be supported indirectly through the provision of counselling for their parents or carers. This has been successful and has continued to be utilised by families even after COVID-19 restrictions were eased.



In late 2020, a second \$50,000 grant was awarded to the program by St George Foundation. This allowed for around half of the program to be grant funded for 2021 and indicated St George's commitment to the ongoing work the program undertakes. We are most grateful for this support.

In April 2021 Huntington's NSW ACT started exploring increased youth involvement in the hope that ways could be found in which Huntington's NSW ACT and young people could mutually benefit from working together. Although still in its early stages, if successful, it is hoped that this might help drive the organisation forward into directions that are considered important to the youth cohort whilst giving them the opportunity to gain skills and experiences that are beneficial to them.

In this 12-month reporting period, the Youth Connection Program has met all program goals and has continued to run at 100% capacity. This is particularly important considering the challenges and limits that have been and continue to be presented by COVID-19 restrictions. Recent engagements with program participants have indicated that many are finding being 'locked down' particularly difficult when a family member has HD. With these restrictions looking like they are going to be back in place for the foreseeable future, the program is committed to maintaining connection as much as possible and will endeavour to continue finding new and creative ways to connect with and engage participants during this challenging time.

Amy Hale  
Youth Social Worker



## CASE STUDY

Jo\* was referred to the youth connection program by NSW hospital social workers in 2017. She was in year 12 at high school and struggling to achieve the results she wanted due to her role as a young carer living alone with and caring for her dad. Her dad had Huntington's disease and was relying solely on Jo to feed him, bathe him, deal with his significant cognitive decline, and provide 24-hour emotional care and support for him whilst still meeting all of her own school commitments and trying to get good enough results to get into university.

During this first engagement, Jo was able to utilise Huntington's specific youth counselling for emotional and practical support around her own feelings and her readiness to find an alternative care arrangement for her dad within structured disability care.

Since this initial engagement, Jo has called on the Huntington's Youth Connection program whenever she has needed support. She has sought counselling over the years in managing thoughts and feelings around her own future, and the very difficult decision around whether or not she should have the genetic test to find out if she has inherited the gene from her dad that will result in her too developing Huntington's disease.

She has sought counselling, support, and guidance from the program around how best to support other extended family members also suffering from Huntington's disease, about the news that her sister had tested positive to the gene that will lead her to develop Huntington's disease, and how to manage the ongoing feelings of grief around her dad being so unwell and not able to live in the family home. She has connected with other people her age through Huntington's Youth Connection group sessions, finding support from others experiencing challenges similar to her own.

2021 saw Jo very actively engaged in the program as she went through the incredibly difficult experience of her dad's end of life journey. She met with our youth social worker many times during the first few months of 2021 and was assisted to make a practical plan around how best to advocate for and support her dad in the hospital and disability care settings. She had many sessions around preparing for the grief she would feel, and what she might expect. The Huntington's Youth Connection Program social worker was able to advocate with and for Jo with doctors, nurses, and care staff for her to have as much control around this final process with her dad as possible.

After her dad's death in July this year, Jo accessed the program and continues to do so for grief counselling and practical support in relation to when and how to return to university and how to balance her day-to-day responsibilities with grieving this tremendous loss.

The structure of the program has allowed Jo to access Huntington's specific support whenever she has needed to, at no cost to herself, or her family. The continuing of this program will allow Jo and other kids, young people, and their families access to the same level of support.

Jo's story demonstrates just one set of experiences and tremendous challenges young people can face when dealing with Huntington's disease. The support she was able to access from the Huntington's Youth Connection Program significantly changed her experience of these challenges and helped her deal with them in the best way possible for her.

*\*Name has been changed to protect participant identity.*



## FUNDRAISING

We are very grateful to everyone who supports the vital work of Huntington's NSW ACT by holding external events or activities to help raise funds. Fundraising helps us to provide essential services for people with Huntington's disease and their families. Below is a spotlight of some of the fundraisers that have been held during the 2020-2021 financial year.

Two big accomplishments for fundraising were publishing an In Memoriam brochure and a Bequest brochure. Our In Memoriam brochure 'A gift of hope' allows people to make a difference in the fight against Huntington's disease beyond their lifetime. Our Bequest brochure aims to create awareness and a take-home message for people about the longer-term benefits of more substantial gifts to the Association.



### Cycle to Broome

Erica and Bill set off in April on a cycle to Broome. Erica was the support driver for her partner Bill as they covered over 4,500km to reach Broome in June. This was not an easy fundraiser but through their journey they raised over \$7,000 and enjoyed a well-deserved rest after reaching Broome.



### 100 days without Alcohol

Noah kicked off 2021 with a challenge to himself - to refrain from alcohol for 100 days. "I thought it would be the perfect time to try and raise some money for Huntington's NSW as it is something that affects me directly as my old man has the disease and I also have a 50% chance of having Huntington's." Amazingly he raised \$3,800 - thanks Noah.



## HUNT 4 HOPE SHOP

### Hunt 4 Hope Op Shop

The Hunt4Hope Op Shop celebrated 2 years in business and took the opportunity to re-brand. With a fresh new logo, the store continues to grow each quarter and is a very popular Op Shop in Maroubra. Donations of pre-loved goods are always welcome, so if you have items make sure you think of Hunt 4 Hope. Owner Matina donated almost \$50,000 to our charity this financial year. WOW! What an amazing effort.



### Walk 4 Hope

COVID-19 impacted our annual Walk 4 Hope, which was the 7<sup>th</sup> one to take place. The Walk may have been virtual, but that did not stop people from doing the walks their way, anywhere, anytime. The top 10 teams are listed below. Collectively they raised \$30,000.

- Team Glen and EJ EH Holden Club
- Team Veronica
- Team Hiscock/Brennan
- Team Kellaway/Wilson
- Settlers Tavern Social Golf Club
- Manning Point Bowling Club
- Team Beeston
- Team Haddy
- Lions Club Parramatta
- Team Brooking

### Vivability took up the Challenge

60 employees split into 5 teams took part in weekly walks/challenges to raise awareness in their local community in Bathurst. During September they completed 204 laps (510kms) of the Macquarie River Run and 54 laps of Mount Panorama (335kms) totalling 845 kilometres. That is the equivalent distance of Bathurst direct to Noosa. Thank you, team Vivability.

## Social Media

We use social media to facilitate interaction with our community through sharing of research updates, personal stories, local news, motivational content, and general entertainment. At the end of June 2021 Huntington's NSW ACT had 2,832 Facebook followers, which was an increase from 2,702 followers in July 2020.

As well as linking in on Facebook and Instagram, many of our community members connect with support services through private Facebook messaging.

Alison Weir  
Fundraising & Marketing Coordinator





## OUR SUPPORTERS

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We would like to acknowledge the generosity of individuals, groups, and organisations that have supported Huntington's NSW ACT during the 2020 – 2021 financial year.

- Our major donors and foundations
- Our regular giving families who wish to remain anonymous
- The Rowden Family
- Genevieve and Ray Long

### Corporate Partners

- Ansvar Insurance Community Education Program
- Macquarie Foundation
- St George Foundation
- Westpac Foundation
- The Co-Group Ltd.

### Government Partner

- NSW Health – Western Sydney Local Health District

### National Conference

- Roche Products
- Novacorr
- Australian Government National Disability Conference Initiative

### Health and Allied Health Professionals

- Prof Clement Loy, Director NSW Huntington Disease Service, Westmead Hospital
- Cecelia Lincoln, Felicity Stehouwer, Terry McGill & Peter Kwong and the staff of the NSW Huntington Disease Service at Westmead Hospital
- Dr Therese Alting and the HD Research Team at Westmead Hospital
- John Conaghan, Huntington's Social Worker, John Hunter Hospital
- Blessy Joseph and the staff at Sister Maria Cunningham Centre, St Joseph's Hospital

## WE ARE MEMBERS OF

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### National (representing Consortium of Australian Huntington's Associations)

- Neurological Alliance Australia
- Genetic Alliance of Australia
- Australian Patient Advocacy Alliance
- National Disability Services
- Rare Voices Australia
- Accessible Product Design Alliance

### State

- Carers NSW
- NSW Council of Social Service (NCOSS)
- Health Care Consumers NSW
- Centre for Volunteering NSW



## ADMINISTRATION

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The highlights of 2020-21 from the administration perspective centre around further enhancements to our information technology arrangements.

In March 2021 the NSW Government announced it would be providing grants to small and medium-sized charities and not-for-profits working in health and social service to help them modernise their operations, through their Social Sector Transformation Fund (SSTF). The funding will flow through to June 2022. For this financial year we were able to use some of the funds for:

- IT health checks on our general IT operations and our Salesforce database
- IT and telecommunication requirements for new staff

A review of our Business Insurance was undertaken with the engagement of an Insurance Broker. This has resulted in improved coverage and a reduction in premium.

From a maintenance perspective there has been an ongoing concern about an intermittent roof water leakage. Two contractors have been engaged over the past few years with minimal success, one indicating the solar hot water system was at fault and should be replaced. The good news is the hot water system was not the culprit, only requiring some minor maintenance. A new roofing contractor was able to identify the cause of the leak and it has been fixed.

During the COVID-19 lockdown the office was very little used but was attended regularly by the Administration Coordinator to ensure business continuity as we are classed as an essential service. Following the easing of restrictions imposed during the 2020 lockdown, some staff continued flexible working from home arrangements, but all staff aim to attend the office on Tuesdays to hold meetings and catch up with each other.

Stewart Swales  
Administration Coordinator



## TREASURER'S REPORT

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This will be my last report as Treasurer of Huntington's NSW ACT. After five years in the role, it is time to pass the baton.

The results for the 2020-21 financial year were surprisingly and encouragingly positive, given the constraints of the COVID-19 pandemic. For the first time in a few years, I am pleased to report to members that we generated a surplus of \$94,314.

With the help of \$52,500 received under the Commonwealth Government's JobKeeper program, we weathered a significant drop in community fundraising income. No community fundraising events were held after March 2020 and the Walk 4 Hope was a very marginal affair even after we made registration free. We have also benefited greatly from the funds received from the Maroubra Charity Store, Hunt 4 Hope, operated by Matina Moutzouris.

Even so, fundraising contributed 40% of our income, or 52% if excluding NDIS income which is based on fee for service arrangements.

The NDIS Support Coordination service has grown considerably, increasing the Association's cash flow, and just breaking even in the reporting period. As new staff are engaged in this service, cash flow drops until they are up to speed and serving as many clients as they are able.

Expenditure was down in a number of areas, notably direct services such as the social therapy program which we could not operate during lockdown. Travel was also greatly reduced.

The Association instituted a 15% administration overhead charge on all its project and service activity this year in order to better reflect the reality that services cannot run effectively without such items as insurance, IT, compliance requirements, governance etc. being met by the Association as the auspice body.

It is particularly pleasing that the Association has benefited from a number of grants awarded during the 2020-21 year, including \$70,000 under the Social Sector Transformation Fund (which we will spend in 2021-22) and \$35,000 from The Co-Group Ltd for the Illawarra Social Worker program. Since 30 June 2021 we have received notice of a further \$60,000 grant from NSW Ministry of Health for emergency COVID-19 support for our Youth Connection Program.

Stephen Guthrie  
Treasurer



Income by category	\$	%
Fundraising, donations & bequests	\$281,789	40%
Foundation / other grants	\$72,000	10%
Government grants	\$65,900	9%
NDIS fee for service	\$156,511	22%
Government subsidies	\$70,828	10%
Membership	\$4,540	1%
National conference & other income	\$55,546	8%
<b>Total Income</b>	<b>\$707,114</b>	<b>100%</b>

