



2022 Annual Report

A Year of Accomplishments

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About Us

Registered Office	21 Chatham Road, West Ryde NSW 2114
Telephone	02 9874 9777
Email	info@hdnswact.org.au
Website	www.huntingtonsnswact.org.au
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 Health Promotion Charity, a deductible gift recipient and income tax exempt charitable entity. Registered for GST.	
ACNC registration	https://bit.ly/3RVyvpp
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

Chair	Katy Clymo	(elected 27 November 2021)
Secretary	Kim White	(elected 27 November 2021)
Treasurer	Mark Raven	(appointed 12 December 2021)

Board Members

Dr. Therese Alting	(re-elected 27 November 2021)
Stephen Garrard	(re-elected 27 November 2021)
Robyn Russell	(re-elected 27 November 2021)
Andrew Sully	(re-elected 27 November 2021; resigned 28 June 2022)

Community Advisory Committee Members

Robyn Russell	Chair	Wollongong
Viki Albring		Newcastle
Rachael Brooking		Orange
Nicholas Packham		Bathurst
Gabrielle Phillips		Wollongong University
Peter Stephen		Canberra
Michelle Turnbull		Newcastle

Staff

Giselle Beaumont	NDIS Senior Support Coordinator (F/T)
Amanda Dickey	Community Programs Officer
Malisha Fernando	NDIS Support Coordinator (F/T)
Amy Hale	Youth Social Worker
Lewis Kaplan	Chief Executive Officer
Vita Solano	Regional Social Worker (resigned March 2022)
Stewart Swales	Administration Officer
Alison Weir	Fundraising & Marketing Coordinator

Regional Support Team

Ellen Slater	Support Group Facilitator Coffs Harbour
Michael Collins	Community Builder (resigned February 2022)

Volunteers

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

Mark Bevan	Support Group leader Port Macquarie (retired March 2022)
Rachael Brooking	Support Group leader Orange
Jasmin Kohl	Events assistant and school training resource
Fiona Richards	Proof-reading services
Preetha Shrestha	Executive Assistant

We are most grateful for the support of our event volunteers, in particular the High Tea 4 HD volunteers who helped us get this event up and running in May 2022.



Chair's report

While we have been learning to live with COVID-19, its impact on the Association has been significant. Fortunately, we have accessed additional emergency funding, particularly from NSW Health to help cover the shortfall in fundraising income. We are very grateful to NSW Health and other partners for their support in these difficult times.

Consortium of Australian Huntington's Associations (CAHA)

This year has seen major steps forward in our work with CAHA, and our consideration of the idea of merging with four other state HD Associations into a single entity. We undertook the second phase of a feasibility study once we were clear that the five members of the Consortium were ready, willing and able to merge. We explored in detail the implications of a merger and what we would need to do to achieve it. All five state Association boards have been actively engaged in this process.

In June this year we were ready to consult with members and staff and I hope many of you either participated in or were able to view the recording of the meeting we held with members.

The annual general meeting at which this report is tabled is also when we will be asking members to vote on a special resolution to amend our Constitution in readiness for the proposed merger. Members will have received a detailed set of papers, briefing them on all aspects of the decision they are being asked to make to enable us to merge with other state HD Associations into a single entity. As such it is a momentous occasion for our Association, which has existed since 1976.

Growing our NDIS services

During the year the board agreed to extend the reach of our NDIS services from Support Coordination to include counselling, training, and behaviour support. This is a significant step forward for the Association, again based on the expressed needs of our community together with feedback from our support coordinators and the HD team at Westmead Hospital. While these new services are not yet available, our CEO and his very capable team are working on business plans and consulting with key stakeholders to make sure we get this expansion right.

Farewell and welcome to Board members

We farewelled Andrew Sully who made a strong contribution to the Association's marketing strategy during his time as a Board member. We welcomed Mark Raven as our new Treasurer. Mark's family has a long history of living with Huntington's disease, which has motivated him to improve the quality of life for those affected and their loved ones.

Thank you

Thank you to all who have contributed to the successful year, including my fellow board members, Lewis Kaplan, our hard-working staff, and all our valued volunteers.

Katy Clymo
Chair



CEO's report

Social Sector Transformation Fund (SSTF)

While we had another challenging year due to COVID-19, we weathered the storm focussing a lot of attention on improving our internal systems which were due for an overhaul. We won funding from the NSW Government's SSTF to upgrade our IT system and move into the Cloud, and to improve our client database. This has been no small undertaking and we thank all those involved in this complex process. We invited InfoXchange to take a leading role in assisting with the implementation of our upgraded IT system.

Using other SSTF funding, we obtained external support to build our "Theory of Change" (more details later) which focusses our attention on what outcomes we want to achieve and how best to measure them. A further SSTF grant contributed to phase II of the national merger feasibility study.

Social worker project

This project was generously funded for three years by The Co-Group. Unfortunately, we were unable to attract suitably qualified staff for what would have been a one-day per week HD social worker, either in Canberra or in Wollongong. We then re-thought the project and, with the support of the Board, Westmead HD Service and The Co-Group, we are re-focusing this funding to establish an HD specialist counselling service.

Advocacy - National Disability Insurance Scheme (NDIS)

We developed an advocacy plan with the other members of the HD Consortium to lobby the Commonwealth government on major concerns regarding access by people with HD to the NDIS. Many participants reported their Plans cut at times of increased need. Other participants found themselves being threatened (effectively forced) to move from living alone into congregate care in order to continue to receive adequate funding for their required supports. Other participants experienced major delays in getting their plans approved, to the point where service providers were threatening them with eviction due to unpaid bills, sometimes of many thousands of dollars.

Advocacy – Younger people with HD in residential aged care

We reached out to the Commonwealth Government's Younger People in Residential Aged Care (YPIRAC) Strategy Joint Agency Taskforce and the YPIRAC System Coordinator Program which aims to support younger people in residential aged care and their families in accessing age-appropriate accommodation and support. Our aim is to ensure that younger people with HD, both in and at risk of being admitted to residential aged care, are actively included in initiatives under this Strategy.

Research partnership with Summer Foundation

The Summer Foundation kindly agreed to undertake an international research study on the care and accommodation needs of people with HD as there was a dearth of literature on this important topic. The [report](#) of interviews with specialist HD providers in several countries and consumers in Australia, was published in June 2022. We used it to support our proposal to the Commonwealth to establish a network of HD specialist residential services across regional and metro NSW and the ACT.

Lewis Kaplan
Chief Executive Officer



Services

Community Support Group Program



Regions that met:
ACT
Coffs Harbour
Newcastle
Orange
Port Macquarie
Wollongong

Meetings 47

People interactions 223

COVID-19 impacts

Government Public Health mandates continued to force cancellation of face-to-face community support group meetings. As advice changed, we pivoted to alternate support methods, such as video conferencing, phone, email or Facebook check-ins. Reduced enthusiasm for online technologies was noticed in the July - September 2021 lockdown.

- clients expressed technology fatigue and chose to wait until face-to-face (quality) interactions were available again. West Ryde and Central Coast groups were postponed.

Partnerships and grants

- Mark & Karen Bevan retired as Port Macquarie Community connectors. Thank you for the kindness, caring and respect you both showed to Port Macquarie families over the past 3 years.
- HD Awareness Orange partnership continues for the Central West Support group.
- Carers ACT collaboration regarding their services and Carer Gateway options for HD Carers in and around Canberra.
- Carers NSW grants received for all regional support groups for luncheons or care packages.

Therapy services - social activities for people with HD in early to mid-stages

The Board decided this program was not viable to continue under its existing operating model.

Partnerships and grants

NDIS ILC national recreation project

Huntington's NSW ACT was unable to develop community interest in a regional pilot site, for the National Recreation Program (RP) project, due to the continued uncertainties of COVID-19.

Student Placement Program

Not run in 2021-22.



Information and Education Programs

Partnerships and Grants

HD Services liaison collaboration.

- HD education working group paused as the Westmead HD Service's Clinical Nurse Consultant resigned.
- Co-designed an association support & service flyer, with NSW health professionals, to hand out in Westmead & John Hunter Hospital HD Services.

Social Sector Transformation Fund

Cloud Migration, including 12 months of managed support

- Modern productivity tools implemented including email, calendars, online meetings, collaboration, file sharing and the latest Microsoft Office desktop software.
- Workstations configured with modern security controls.
- Cloud based document storage and sharing.
- Network infrastructure upgrade.
- Staff training.

Social Sector Transformation Fund (Advisory services)

Customer Relationship Management (CRM) review

- Collaboration with other state association CRM champions
- Collaboration with NSW Neuro (MND, MD, Parkinson's) re IT and fundraising development
- Conducted a health check on current CRM
- Attained a 'fit for purpose' CRM functional scope
- Interviewed potential CRM partners

Building organisational capacity and capability in the following areas:

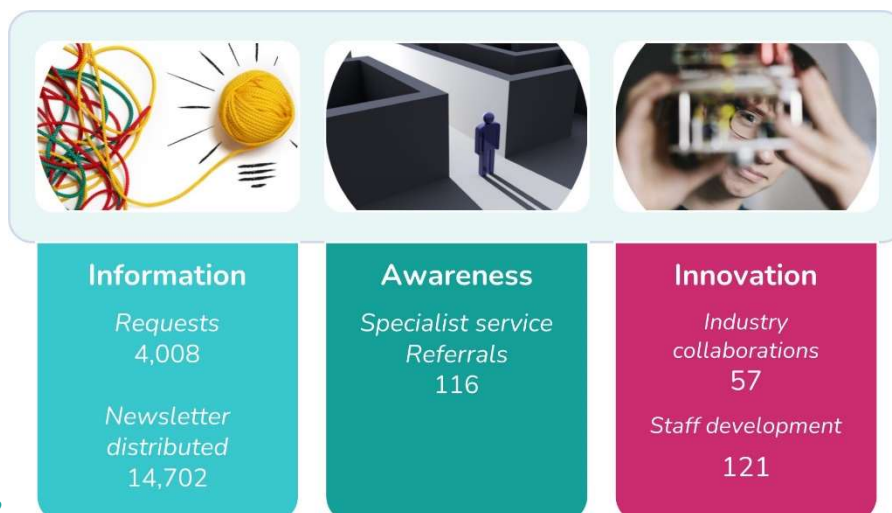
- strategic design driven by impact – for senior staff
- program monitoring and evaluation and associated data collection practices – for senior staff

NDIS market analysis

Social and community participation, through a Program of supports, was identified as a viable NDIS business stream. Alignment of business models will occur with other state associations next year.

NSW Health

Performance highlights:





Social Research and Development

Regional Support Teams (RSTs) project

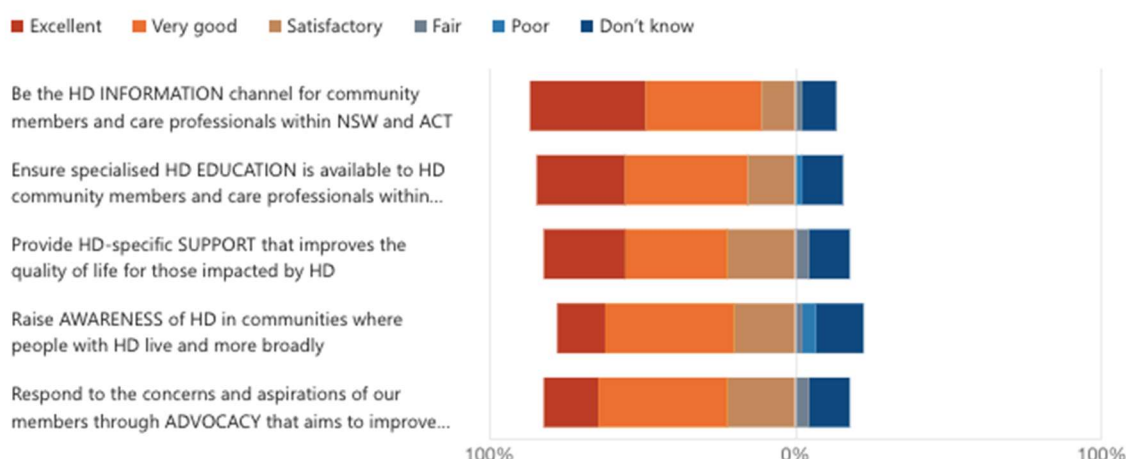
- Recruited Ellen Slater as a Support group facilitator for the Coffs Harbour region of Mid-North Coast LHD.
- Candidate for the Orange region of Western NSW LHD declined offer.
- Interviewed regional support group members of the Wollongong, Central Coast, Port Macquarie and ACT communities to understand their current support needs. A recalibration exercise is planned for these regions in the next quarter.
- Volunteer Community connector role description created to guide groups choosing Peer Support option.

Community participation

Association membership survey

This captured member perceptions of our performance against our strategic goals and objectives.

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



Participants expect their Huntington's NSW ACT membership to provide them:



A summary of the basic analysis of responses was made available to the community at:

<https://huntingtonsnswact.org.au/about/how-we-know-we-are-succeeding/>

Community engagement activities

- Co-designed a membership survey, with our Community Advisory Committee (CAC), to measure membership value and association performance.



- Collaborated with CAC and NSW health professionals to design a Theory of Change.
- Collaborated with CAC and NSW health professionals regarding new Social Work and Counselling service opportunities.
- Collaborated with CAC and NSW health professionals to identify NDIS expansion opportunities in training, counselling, and behaviour support.

Community development activities

- Carer Gateway NSW service providers: The Benevolent Society; Wellways Australia; Live Better and Carers NSW conducted HD Carer information sessions.
- Collaborated with Men's Table regarding their services and information session for Men's Health week.

Amanda Dickey

Community Programs Officer



NDIS Support Coordination

What we set out to do

In July 2019 Huntington's NSW ACT began the journey of providing NDIS support coordination to people in NSW and ACT who are affected by Huntington's disease. Huntington's NSW ACT recognises the unique and individual needs of people diagnosed with Huntington's disease and provides Support Coordination service with the experience, understanding and patience required to maximise NDIS plans for these participants. We work with the participant, carers/family and relevant stakeholders to optimise their NDIS funds, as well as focusing on a holistic approach to participants' health and wellbeing.

The role of support coordination within Huntington's NSW ACT is to provide participants with choice and control through encouraging autonomy and connecting them to a range of service providers that best suit their individual needs and goals.

During the first year, the service operated predominantly in the greater Sydney region and Wollongong. However, Huntington's NSW ACT has now expanded the service to the Central Coast, Mid North Coast, Illawarra and the ACT. We expect that we will continue to grow the service to reach more locations in NSW.

Our achievements

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

During the 2021-22 financial year, our clients were assigned \$448,444 total of funding in their plans for support coordination. A total of service delivered \$230,742, consisting of two full-time and one part-time support coordinators who supported 66 participants and a total of 93 NDIS plans.

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.
- Increased workload involved in applying for Specialised Support Coordination accreditation.
- Two clients not engaging with the service.
- Complexity of some clients' needs requiring intensive support which reduced hours available for other clients.



A key achievement for the past three years has been 23 participants successfully transitioned into Supported Independent Living (SIL) and Specialist Disability Accommodation (SDA). We have worked with a selected group of SIL and SDA providers to ensure they are providing quality care in suitable environments for our clients.

The second key achievement this year was hiring our second full-time support coordinator.

The impact of COVID-19

COVID-19 has impacted most Support Coordination participants. The impact on them and their carers/families made engagement more difficult due to fear of transmission. One positive outcome of this time was that it highlighted to several participants and their families the value of support coordination. This was indicated by an increase in service uptake.

Into the future

Huntington's NSW ACT is now in its third year of operation as a registered NDIS provider. As of August 2022, we have three full time support coordinators supporting 80 participants.

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 Support Coordination team plans to recruit a 4th full-time support coordinator when the 3rd support coordinator has a case load of at least 25 participants. As the recruitment and hiring process takes some time it is predicted that when the right person is employed, the 3rd support coordinator will have increased their caseload to approximately 30 to 40 participants and will be meeting all KPIs.

Key challenges

- Difficulty hiring a suitable support coordinator in a timely manner
- Increase in case load of senior support coordinator
- High case load of complex clients
- Continual changes with the NDIS
- NDIS cutting funding by half to participants living in SIL and SDA, putting clients at risk of being admitted to hospital and/or not having their needs adequately funded
- Ongoing complaints submitted to NDIS Quality and Safeguard Commission and time taken to manage these
- Providing high level of support to participants with only level 2 (standard) support coordination funding when participants should be receiving level 3 (specialist) support coordination
- Lower numbers than anticipated of specialised support coordination participants as many participants are incorrectly assessed to receive only standard funding when their complex HD needs require specialised funding.

These are just some of the challenges we face with and on behalf of our clients. Overall, NDIS funding has provided valuable opportunities to our most vulnerable population and given them increased hope and security, with access to HD specialist support.

Giselle Beaumont

Senior Support Coordinator



Youth Connection Program

Program data

Counselling, support, education, and group support have been provided to young people, their families, their educators, and their health providers with a focus on these **4 key service areas**.

During this 12-month period:

- **51** Huntington's focused *youth counselling* sessions have been delivered.
72% of last year's total (72).
- **50** Huntington's focused *parent/carer counselling* sessions have been delivered.
32% above last year's total (38).
- **103** Huntington's disease *education and information sharing* opportunities for children and their families were created.
92% of last year's total (111).
- **0** Huntington's disease *group support and activities* took place to connect young people affected by HD to each other (service area suspended in line with NSW Health COVID-19 guidelines).

Program summary

Throughout 2021/22, Youth Connection Program participants have continued to engage in three of the four service areas, resulting in over 100 direct engagements that have worked towards our project aim to improve the quality of life for these children, young people, and their families.

Young people and their families have engaged in both individual and group counselling and education sessions throughout this year; however, the decision was made to pause group activities for kids and young people in line with NSW Health COVID-19 guidelines.

Connections with HD organisations worldwide have been sustained throughout this year through regular online meetings. Youth workers across England, Scotland, Ireland, Australia and the USA have come together bi-monthly online to discuss their programs, offer peer support, and provide case studies for analysis and discussion. This has been a valuable experience for this program in sharing ideas and resources.

We are again extremely grateful to St George Foundation for its commitment to the ongoing work of this program. St George Foundation awarded a second grant of \$50,000 to supporting the 2021 operation of the program.

In September 2021 we received a one-off COVID-19 emergency grant of \$60,000 from the NSW Minister for Health in recognition of the Association's fundraising shortfall due to COVID-19. In April 2022 we received a one-off NSW Health early intervention in youth mental health grant of \$50,000 to assist in continuing the program through to the end of 2022.

In February 2022 we were invited to present at Genetic Alliance Australia's Rare Genetic Disease conference. This provided a great opportunity for Youth Social Worker, Amy Hale to speak to conference attendees – many of whom were employed in genetic medicine – about the challenges faced by young people growing up with HD in their lives and what our program can offer.



Continuing challenges of lockdowns and restrictions

This year has seen COVID-19 restrictions continue to impact upon families with HD, and the Youth Connection Program providing support for kids and young people in these families.

During the 2020/21 COVID-19 lockdowns restrictions placed on face-to-face engagements and school closures, we were required to cease all school visits; however, young people and their families were still keen to stay engaged and switch to online services. This year has been trickier. As lockdowns and restrictions have dragged on into 2021 and 2022 there has been an overall drop in enthusiasm and engagement in this cohort.

This dip in engagement has been concerning for us as we know some of these families have been experiencing more difficulty and at times worsening mental health than they had previously. Lockdowns have resulted in kids and young people spending an increasing amount of time with their HD-affected parents without the outlet that school, friends, and activities outside of the home provided for them prior to COVID-19. Formal drop-in support has also been limited due to restrictions and infections, resulting in kids and young people taking on more care work for their HD-affected parent.

In the majority of cases, the decrease in the uptake of counselling and support is likely due to kids and young people becoming bored and overwhelmed with online activities; however, the opposite has been observed in our clients living in lower socio-economic environments as their access was restricted through not having the technology and internet plans to allow them to engage online.

New program service opportunities

The COVID-19 restrictions during 2020/21 revealed opportunities for new client engagements such as parent and family counselling that has proved successful and is now a permanent part of the program. This year, with the challenge of re-introduced lockdowns in combination with limited availability of appointments with psychologists and counsellors in the community, the program was pushed to create and deliver another new service area - or extension of the counselling service area - to meet the needs of these kids and young people dealing with both HD and lockdown.

Research suggests that most kids and young people growing up in families affected by HD have higher rates of depression and anxiety. This appeared to be made worse by COVID-19 lockdowns and restrictions, making life particularly hard for some of the kids involved in the program. As school closures and lack of online enthusiasm meant that fewer clients were engaging with the program overall, clients who were willing and able to engage and who were experiencing depression and/or anxiety were offered structured appointments closer together and with more frequency using a different model of support. This model of support was developed and implemented throughout this year and incorporates structured evidence-based therapeutic modalities in combination with HD education.

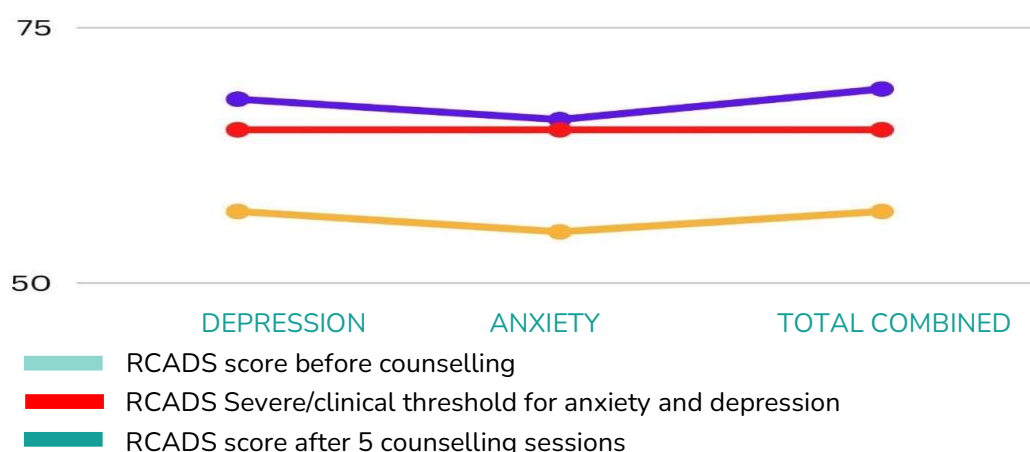
The benefits of having structured mental health support in combination with HD youth work have been observed as kids and young people have increased their understanding of, and acceptance of HD at the same time as working in a structured therapeutic way on minimising anxiety, depression, and in some cases, coping with loss and bereavement.



This evidence-based counselling required extra learning in order to develop skills to best support our clients. Various courses were undertaken by the Youth Social Worker during 2021/22 that helped to build competence in delivering this structured support. The topics covered included clinical trauma assessment and therapy, child and adolescent grief and loss counselling, Internal Family Systems training and creativity and play in psychotherapy.

The RCADS (Revised Child Anxiety and Depression Scale) has been used to track client progress. Below is an example of the improvements noted in one client over the course of five counselling sessions provided to a child after the loss of a family member from HD. Upon initial engagement, the client was experiencing intense anxiety that was restricting participation in school and community, displaying OCD behaviours as a way of coping, and was experiencing intense grief and loss.

RCADS results above 65 (threshold indicated below as a red line) are considered to be in the 'severe/clinical' range for depression and anxiety. As can be seen below, when first tested, both anxiety and depression for this client were above this line displaying an average depression and anxiety score of 69 (indicated below as a blue line). At this time both the client and their parent expressed concern about this and described the situation as being very difficult to manage.



During this engagement, both the client and parent expressed positivity that much progress had been made and that things seemed easier to manage at home and school. During these sessions the client worked very hard to learn about their own stress, depression, and anxiety, increased their HD knowledge and awareness, and was supported to explore their own processing of grief and loss implementing the clinical strategies offered. Engagement with this client continues, however the results above indicate substantial improvement after five sessions with both anxiety and depression now in the 'low severity' categories with a total score of 57.

It is hoped that this structured support can continue to be offered into the future alongside what is already available, as it appears to be making a positive impact on the mental health and wellbeing of program participants and their families.

Amy Hale

Youth Social Worker



Fundraising

We are sincerely thankful to the generous members of the community who kindly and tirelessly contribute to the funds needed for Huntington's NSW ACT to continue its work. With almost half of our income (excluding NDIS) coming from fundraising activities, we would not be able to deliver essential services to the HD community without the generosity of our supporters.

We have celebrated some great successes in the past twelve months, despite the challenges of the COVID-19 pandemic. A total of \$259,871 was raised through fundraising, donations and bequests.

Hunt 4 Hope

Huge congratulations to Matina and her team at Hunt 4 Hope Op Shop who were announced as finalists in the Randwick City 2022 Business Excellence Awards. Although they didn't win, it was a wonderful achievement to be named as a finalist. The shop was also named a finalist in 2021 but the ceremony was cancelled due to COVID-19. Matina's business donated \$49,349 to the association over the past year. Excellent effort!



High Tea 4 HD

We held our first High Tea 4 HD events in Orange and Penrith. A special thank you to our event sponsors Hotel Canobolas and Mulgoa Valley Receptions for all their assistance and support. The main goal for these events was to build awareness during HD Awareness Month, however we were blown away with community support raising \$11,853. These are planned to become annual events.



Walk 4 Hope

Walk 4 Hope 2021 went virtual for the second year in a row due to lockdown and restrictions. 99 people signed up to be a part of the fundraiser, keeping active and walking to create awareness of HD in their own neighbourhoods. We are extremely grateful for every single person who walked, registered, and donated. The virtual walk raised \$71,747. An outstanding result in the circumstances!



Hunt 4 Huntington's

F45 Singleton held a 24-hour row challenge in their gym, having 48 members pushing themselves to row for 1-hour timeslots on 3 rower machines. With a combined row distance of 914,000 m and a total of \$14,900 raised, it is fair to say this event was a success. The community really got behind Jaime's story and connection to HD and we are very thankful.



Alison Weir

Fundraising & Marketing Coordinator



Our Supporters

We would like to acknowledge the generosity of individuals, groups, and organisations who have supported Huntington's NSW ACT during the 2021 – 2022 financial year. Your support is very much appreciated. A special thank you to:

- Our major donors and foundations
- Our regular giving families and individuals
- Vikings Rugby Union Club in Canberra who chose us as their Charity Partner for 2022
- The generous benefactor who has partnered with us to initiate a Youth Scholarship Program

Corporate Partners

- The Co-Group Ltd.
- Macquarie Group Foundation
- St George Foundation

Government Partners

- NSW Health Western Sydney Local Health District
- NSW Health Minister's Emergency COVID-19 Support Fund
- NSW Health Mental Health Branch
- NSW Government Social Sector Transformation Fund (tranches 1, 2 & 3)

Health and Allied Health Professionals

- Prof Clement Loy, Director NSW Huntington Disease Service, Westmead Hospital
- Cecelia Lincoln, Felicity Stehouwer, Terence McGill, Sandra Barisic & Peter Kwong and the other outreach staff of the NSW Huntington Disease Service at Westmead Hospital
- Lincoln Hopper, CEO of St Vincent's Care Network
- Dr Therese Alting and the HD Research Team at Westmead Hospital
- John Conaghan, Huntington's Social Worker, John Hunter Hospital
- Blessy Merlin Joseph and the staff at Sister Maria Cunningham Centre, St Joseph's Hospital

We are members of

National (representing Consortium of Australian Huntington's Associations)

- Neurological Alliance Australia
- Genetic Alliance of Australia
- Australian Patient Advocacy Alliance
- National Disability Services (n.b. the CEO is a member of the NSW State Committee)
- Rare Voices Australia
- Accessible Product Design Alliance

State

- Health Care Consumers NSW
- Centre for Volunteering NSW
- Associations Forum



In Memory

We are deeply sorry to hear about the loss of any HD community member and extend our sincere condolences. Wishing you peace to bring comfort, the courage to face the days ahead and loving memories to forever hold in your hearts.

We light a candle in memory of HD community members who have lost their battle to HD during the last twelve months.

Lily Bodiam

Peter Burton

Gina King

David Knibbs

Michael Repeckyj

Andrew Smith

Stephen Wells

We will have an in-memory page each year. If you would like to include someone special in our next in memory page, please send through their photo and/or name to info@hdnswact.org.au.





Administration

IT upgrade

From an administrative perspective the highlight of 2021-22 has been more enhancements to our information technology arrangements.

Using our connection to the Social Sector Transformation Fund (SSTF) we were able to engage the services of Infoxchange, a not-for-profit social enterprise that has been delivering technology for social justice for over 30 years. Infoxchange have assisted with the implementation of –

- a Microsoft Teams environment
- Office 365
- Replacement of some of our ageing laptops
- Management of our IT services – helpdesk and hardware management

All this assists with our working flexibility and costs efficiency.

Bookkeeping

The role of Administration Coordinator grew this year to include preparing the monthly financial statements for the Board.

COVID-19

Managing the continuing challenges of COVID-19 included implementing social distancing guidelines and designating how many and where people could sit in our meeting room.

Mental health policy and training

The Association undertook mental health training for its staff under a policy developed by the Board with active staff input.

Stewart Swales

Administration Coordinator



Treasurer's report

The financial year 2021-22 closes with a modest surplus of \$5,987, being a solid achievement through the difficult COVID-19 pandemic.

This year, the Association consolidated its role as a provider of NDIS support coordination services with income of \$285,300 which brought overall turnover to \$811,442 (up from \$707,114 last year).

In response to this revenue growth, we have invested in our people in this financial year. Additional human resources support underpinning the expansion of our NDIS services include counselling, training and behaviour management expertise are planned. These additions to our team will generate additional revenue for the Association, whilst providing much needed specialised services for the HD community.

The health of the balance sheet remains robust. Our equity position on the balance sheet is almost unchanged from last year's figure, except for the valuation of our headquarters. In view of Sydney property price increases and the proposed merger, the property we use as our headquarters was independently re-valued. The new valuation of \$2,100,000 is reflected in this year's audit.

Looking forward, the 2022-23 budget has been approved by the Board, reflecting the sustainable growth achieved in the past couple of years. The budget remains in surplus, and there are no plans to divest any assets or adopt any new liabilities, in view of the proposed merger.

Should the proposed merger proceed, the NSW ACT Association will be subject to the FY2022-23 completion accounts being prepared for final audit and archived with the new entity.

In closing, I offer my sincere congratulations to Lewis and the team for managing the Association's resources so well. Such responsible stewardship is a hallmark of good leadership, and a blessing for the recipients of our services.

Mark Raven

Treasurer