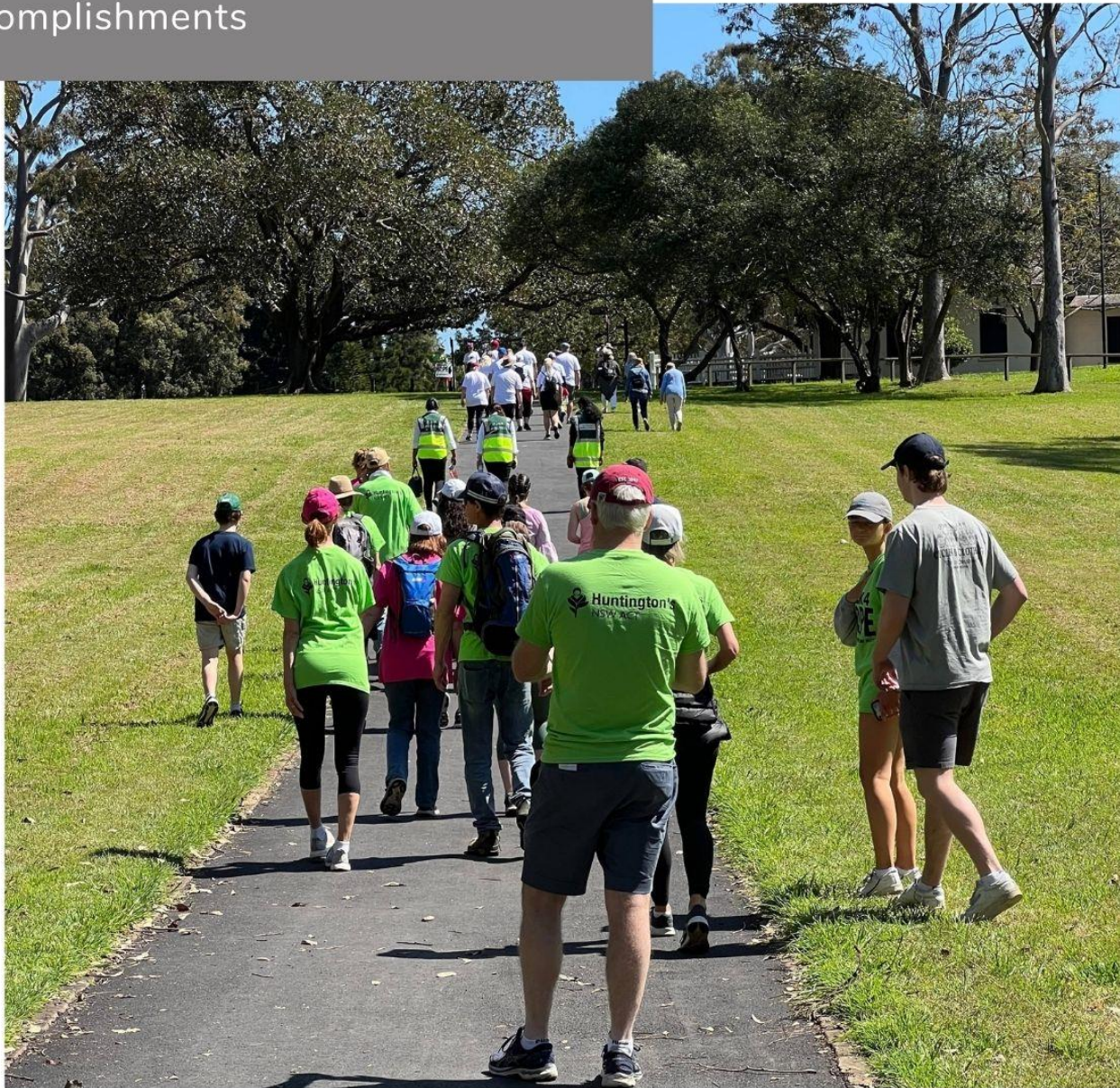


2023 Annual Report

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/3RVyppp>

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	(re-elected November 2022)
Secretary	Kim Hart	(re-elected November 2022)
Treasurer	Mark Raven	(re-elected November 2022)

Board Members

Dr. Therese Alting	(re-elected November 2022)
Stephen Garrard	(re-elected November 2022)
Robyn Russell	(re-elected November 2022)
Naomi Fraser	(re-elected November 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 (resigned Nov. 22)

Staff

Justine Amos	Support Services Administrator
Giselle Beaumont	Senior Support Coordinator (resigned Feb 2023)
Amanda Dickey	Community Programs Officer
Malisha Fernando	NDIS Senior Support Coordinator (F/T)
Amy Hale	Youth Liaison Worker (resigned Mar 2023)
Grace Joo	HD Youth Specialist (started Jun 2023)
Lewis Kaplan	Chief Executive Officer
Julie Leto	HD Specialist Counsellor (started Jan 2023)
Kate McNamara	NDIS Support Coordinator (F/T)
Mia Small	NDIS Specialist Support Coordinator (F/T)
Stewart Swales	Administration Officer
Alison Weir	Fundraising & Marketing Coordinator

Regional Support Team

Ellen Slater	Support Group Facilitator Coffs Harbour
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Volunteers

Rachael Brooking	Support Group leader Orange
Jasmin Kohl	Events assistant and school training resource
Fiona Richards	Proof-reading services
Ian Tifere	Graphic design services

We are grateful for the support of our many event volunteers, in particular the Walk 4 Hope and High Tea 4 HD volunteers who helped with set-up, pack-up, ticketing, registration, traffic control and the BBQ.



CHAIR'S REPORT

As this will be our final year of operation as a state-based organisation, it is worth reflecting on some key moments in our history as we merge into the newly established Huntington's Australia.

Huntington's NSW ACT was established in 1976 as the Australian Huntington's Disease Association – NSW by a few stalwart HD family members including the mother of our first Executive Officer, Robyn Kapp, who was appointed in 1983.

Our first annual grant of \$34,100 from NSW Health came in 1996-97, the same year that we were able to purchase our current offices with a bequest from the late Elsie Court.

Also in 1997, the International Huntington's Association's World Congress was held in Sydney with our active support.

Three attempts were made between 2000 and 2016 to establish a national body to work alongside the state associations. The different states built a level of collaboration, shared information and were referred to collectively by the International Huntington's Association as the Australian Huntington's Disease Association.

The first specialist residential service for people with HD in NSW was opened at Lidcombe Hospital in 1988. When it was closed, the unit was moved to Lottie Stewart House and then to the Sister Maria Cunningham Centre at St Joseph's Hospital in Auburn, where a purpose-built facility was established in 2011 with 14 long-stay beds. Co-located with this unit was a 4-bed short-stay unit funded by NSW Health.

We continued to work closely with our clinical partners at Westmead Hospital and created a small specialist residential service in the Hunter region between 2005 and 2007.

In 2020, the NSW/ACT Association proposed to the other state associations a more formal collaboration which resulted in the signing of a Memorandum of Understanding between all state associations except Victoria. The five associations quickly started to focus on the potential to create a national body through a merger.

The first draft document about a possible merger was written in July 2020, only a few months after five of the six state associations had agreed to collaborate. The first formal monthly meeting of what became the "Consortium of Australian Huntington's Associations" was held (online) in August 2020. Following a detailed feasibility study undertaken in 2021-22, we were ready to ask members if they agreed to merge! At our Annual General Meeting in November 2022 the resolution was passed. Members from the other four collaborating State HD Associations all agreed.



This year has been heavily focused on developing the new national body, Huntington's Australia and on working through the myriad complexities of merging five long-standing associations into a single operation.

Notwithstanding this inward-looking set of activities, we have remained focused on the strategic outcome: more and better services and support for the HD community across Australia.

The NSW/ACT Association has continued to grow during the past year, with additional staff in our expanding NDIS coordination service. We were pleased also to receive a further one-off grant of \$100,000 from NSW Health for our Youth Connection Program. We continue to negotiate for a grant from the NSW Health Movement Disorders Program for funding for our work with community support groups.

I take this opportunity to thank our committed board members who agreed to a further year of service in the expectation that it would be their last due to the forthcoming merger. The workload associated with the merger has been significant, and I am very grateful for the board's time, patience and collaborative nature.

I also thank our CEO, Lewis Kaplan and his dedicated team, particularly as they work through the complexities of transitioning clients, staff, programs, services, contracts, relationships and data systems from a long-standing state-based organisation to a new national body.

Katy Clymo
Chair



CEO'S REPORT

While the establishment of Huntington's Australia has taken up some of our resources, we continued to work closely with the HD community and as many service providers as possible with the aim of improving the quantity and quality of services available to those affected by HD.

We continue to expand our NDIS service and received a most positive audit report when our NDIS service provider registration was due for renewal. We were approached by Huntington's Queensland to employ a support coordinator in Brisbane as there was clearly demand for this specialist service. Huntington's Queensland was not a registered NDIS provider while we are registered to deliver services Australia-wide. Our board saw the merit in this proposal, and we moved to create a new Brisbane-based support coordinator position ahead of the merger.

We learned in late June 2023 that St Joseph's hospital is closing down, along with the 4-bed unit which we understand may be located to Westmead Hospital. The 14-bed long stay facility will remain under the management of St Vincent's Care Service, but we continue to advocate for this to become a disability residential service rather than an aged care home as nearly all residents are under 65 years of age and would receive much larger packages under the NDIS.

I thank my wonderful team for their dedication. They have often worked harder than we would have liked to ensure our services are both as responsive as possible and delivered in a respectful and competent manner to those who seek them.

I also thank our board members, in particular Katy Clymo, who agreed to take the position of Chair for twelve months, but has ended up most ably guiding the board, our national Consortium colleagues and me for three years. Thanks also to Board Secretaries, Therese Alting and Kim Hart for the extra work in drafting meeting minutes.

While this will be my final formal annual report to members, we expect to give you an update on the merger process at the AGM later this year.

Lewis Kaplan
CEO



SUPPORT SERVICES

Community Support Group Program



Support group locations:
ACT
Central Coast
Central West (Orange)
Coffs Harbour
Newcastle
Port Macquarie
Wollongong

Meetings

40

People interactions

172

Community engagement

Because of membership feedback Support Groups were recalibrated as follows;

- ACT (Family) – chose to continue as a Social Group and catch up quarterly.
- Central Coast (Carer) – chose to become a facilitated Support Group. Meetings have ceased until a facilitator is recruited.
- Orange (Family) - chose to become a sponsored Social Group and catch up quarterly.
- Newcastle (Carer) – chose to continue as a facilitated Support group and meet quarterly.
- Port Macquarie (Family) – chose to become a facilitated Support group and meet quarterly with the assistance of the local Health Department Movement Disorder Services.
- West Ryde (Carer) – chose to continue as a facilitated Support Group. Meetings have ceased until a facilitator is recruited.
- Wollongong (pwHD) - chose to become a Social Group and catch up monthly.

Partnerships and Grants

- Karen van Dooren was an ACT Community connector who sadly passed away in late November 2022. Karen will be remembered for the kindness she offered to ACT families when organising their quarterly social gatherings, over many years. Thank you, Karen, you are missed.
- HD Awareness Orange partnership for the Central West Support group wound up in August 2022. We are grateful to Rachael Brooking and her dedicated team for holding a space for the region's HD community.
- **New!** Movement Disorders Services, through the Mid North Coast LHD, assists our Association to facilitate the Port Macquarie Family support group. This group re-commenced in November 2022 and continues to meet quarterly.

ILC Social and Community Participation grant – multi-state collaboration

During Nov 2022 – Jan 2023, HNSWACT consulted with two disability services to collaborate on social programming for pwHD, but discussions ceased when it was realised that the identified population would yield low participation rates for the required resource investment.

Discussions with the national project manager will continue in the next quarter to pivot this project focus to supporting people who are newly diagnosed or pre-symptomatic.



Student Placement Program

Not run in 2022-2023.

Information and Education Programs

Partnerships and Grants

HD Services liaison collaboration.

- o HD education working group discussed opportunities for how the association and Westmead HD Service can offer complimentary educational service offerings.
- o Establishing working relationships with Huntington's Australia will be the focus of this collaboration for the next two quarters.

Social Sector Transformation Fund

Open grant, IT Connectivity for Huntington's workforce

- o Approval granted to pivot this project toward the implementation of a national Customer Relations Management (CRM) system.
A National CRM will support scaled service delivery (National) through an enhanced client record management and program measurement platform, provide greater data security, and leverage resource and knowledge sharing.
- o CRM project is due to be delivered with the merger on 01/10/2023.

NSW Health NGO Funded activity

Performance highlights:

The performance requirements of this grant were mostly over-achieved with the exception of the number of inbound telephone calls. The reasons for the reduction in this category of activity are complex but include: more clients accessing information online from our website, better linkages with the NSW Health Huntington's Outreach Service at Westmead Hospital and more active service engagement with clients due to the operation of our own NDIS support coordination service which was established in mid-2019.



The Association's strategic engagement with key partners and stakeholders was significantly enhanced during this contract period with the assistance of the grant from NSW Health.

We were pleased to learn in June 2023 that our Health NGO grant from NSW Health was to be extended for a further three years.



Social Research and Development

Regional Support Teams (RSTs) project

- Surveying of other areas...
- Further analysis indicated an appetite for facilitated / structured groups and an operational need for a common trauma-informed model that the association can easily manage.

Community Participation

Association Membership survey

Due to the impending Huntington's Australia merger, HNSWACTs annual survey program did not run in 2022-2023.

Community engagement activities

- Co-designed a Voice of Community survey, with our Community Advisory Committee (CAC). Capturing people's thoughts, opinions and feelings helps the Association better understand our community's concerns and aspirations and assists to assess people's understanding of the Association's purpose.

Community development activities

- Movement Disorders Services Information sessions were conducted in Port Macquarie and Coffs Harbour.

Amanda Dickey

Community Programs Officer



NDIS SUPPORT COORDINATION

Huntington's NSW ACT is now in its fourth year of operation as a registered NDIS provider. Our journey commenced July 2019 providing NDIS support coordination to participants across NSW and ACT affected by Huntington's disease. Huntington's NSW ACT understands the unique needs of people diagnosed with Huntington's disease and provides support coordination services with the experience, understanding and patience required to maximise Participants' NDIS plans to meet their individual support needs.

It has been a successful year delivering Support Coordination services. The NDIS support coordination team over the last 12 months has grown from two to four mostly full-time staff, dedicated to working with participants, carers/family and relevant stakeholders, ensuring the Participants (and their decision makers) are at the centre of their supports to work towards an enriched and comfortable life. In total, with the growth of our team and ability to provide an increased level of support to our Participants, Huntington's NSW ACT has delivered approximately 3,700 hours of support coordination to the community during the 22/23 financial year. An extraordinary achievement for the team and Association!

We have also seen growth across our level 3 specialist support coordination for Participants who require more complex support coordination from our Specialist Support Coordinator who comes from a social work background. We expect our level 3 specialist support coordination cohort to grow over the next 12 months as we continue to advocate more successfully for our Participants. Ensuring that NDIS Participants have the appropriate funding and supports through specialised and personalised support requires a greater level of advocacy.

NDIS Participants throughout their plan were able to achieve a number of their personal goals, including:

- Engaging with allied health services such as physiotherapy, occupational therapy, behavioural therapy, speech therapy, psychology, dietetics and podiatry
- 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 points of crisis

During the 2022-23 financial year, Huntington's NSW ACT's three full-time support coordinators delivered support coordination services to over 85 participants and a total of 209 NDIS plans, claiming approximately 50% of all NDIS plans on average.

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.
- Multiple Participants want to remain as independent as possible and want very limited support coordination or NDIS services, resulting in unused funds including support coordination hours even though these are approved.



- Complexity of some clients' needs requiring intensive support which reduced support coordinators' hours available for other participants.

A key achievement over the FY22/23 has been 10 participants successfully transitioning into Supported Independent Living (SIL) and Specialist Disability Accommodation (SDA). The process of assisting in this area of support often requires a significant amount of time and involvement from all stakeholders. We are thrilled to have supported a number of our participants into safe accommodation. We have worked with selected groups 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 two full-time and one part-time support coordinators – significant growth compared to previous years. As of FY22/23, we are supporting over 85 participants. As we merge into Huntington's Australia next year, it is expected that the support coordination service will continue to grow and service improvements will lead to increase in efficiency.

Key challenges over the last 12 months have been:

- 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 need for submission of review requests to NDIS due to poor NDIS Plan outcomes despite the provision of sufficient evidence to be considered and assessed
- 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
- Difficulty in engaging and building positive relationships with stakeholders for shared participants due to systemic challenges
- Providing high level of support to Participants with only level 2 (standard) support coordination funding when many of them should be receiving level 3 (specialist) support coordination
- Lower numbers than anticipated of specialised support coordination Participants as many 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 people.

Despite the change and adversity faced in during the year, Huntington's NSW ACT continues to provide excellent support, guidance and assistance through our NDIS support coordination service. I would like to acknowledge and thank our staff and broader team for their ongoing contribution, dedication and resilience as we continue to have the privilege of providing support to our NDIS Participants. We look forward to an even bigger and more successful year ahead as we come together and join forces with other states to become Huntington's Australia.

Malisha Fernando
Senior Support Coordinator



YOUTH CONNECTION PROGRAM

Program Summary

2022/23 has been a period of transition for the Youth Connection Program with a change of staff. The inaugural Youth Program Officer, Amy Hale decided to move on, with the Association's best wishes. This period allowed for the Association to demonstrate collaborative teamwork across the states as Monica Cazzoli from Huntington's WA provided interim support for NSW clients before the commencement of the new HD Youth Specialist in June 2023.

Another significant update is the establishment of the annual youth scholarship grant. This project was developed from a proposal by a generous benefactor who has committed to provide \$11,000 each year to fund vulnerable young people impacted by Huntington's disease in NSW. Thus, an annual scholarship program was founded and named Ailsa's Legacy (after the benefactor's sister who died with HD). The scholarship will grant successful applicants up to \$2,000, with each application being reviewed by the scholarship committee. Since its launch, the scholarship has supported 6 young people with their education goals and extracurricular activities. One young person was able to attend the HDYO International Young Adults Congress in Glasgow in March 2023 with the assistance of scholarship funds.

Regarding direct client support, there has been enthusiastic response from existing participants and their families since the commencement of the new HD Youth Specialist, Grace Joo in June 2023. Several virtual and in person counselling sessions have been provided as well as upcoming plans for school education and regional outreach. The level of client engagement has been an encouraging start.

Challenges

The lasting impact of COVID-19 has continued into 2022/23 as the face-to-face social group activities, which were planned to take place regularly, ceased during lockdown. It has been difficult to regain the momentum along with staff changes in the first half of 2023. However, several participants have requested informal gatherings to be arranged again as they have attended HDYO Youth Camps and pub meets in the past and found these to be a cathartic outlet. The lack of avenues to meet and share their experiences with others in similar a situation has been highlighted as a pressing need for this cohort.

New Program and Service Opportunities

With the approaching merger of the state Associations, there is an opportunity for the Youth Connection Program to expand on a national level. This process would involve establishing a structured framework for HD Youth Advisors across the states to deliver services in uniform practice with NSW to lead this development. This prospect means an increased area of reach to support youth and young adults which is a significant step in the HD community as young carers are often overlooked in healthcare settings. Although various general carer support programs already exist, young people affected by HD present with unique support needs which must be addressed in a youth specific approach.

Some common themes presented by the youth population within the HD community include:

- Navigating changed family dynamics with a member affected by HD
- Assuming added responsibilities as a young carer
- Difficulty understanding HD when age-appropriate information may not be readily available
- Dealing with anxiety and depression which impact day to day life and education
- Navigating romantic relationships and future family planning
- Which services to contact for support.



Educational materials around some of the topics listed above can be accessed through the international HDYO platform. It would be helpful to adapt some of these existing materials to serve different age groups and locations.

The Youth Connection Program continues to prove to be an important channel of service for Huntington's NSW ACT. It is planned that the program continues to grow and empower the next generation through its holistic approach.

We are most grateful to NSW Health for a further one-off grant of \$100,000 towards the running costs of the program.

Grace Joo
HD Youth Advisor



FUNDRAISING

We are genuinely grateful to the members of our community who kindly and tirelessly contribute to the funds needed for Huntington's NSW ACT to support people impacted by HD and their families. A total of \$309,343 was raised through fundraising, donations and bequests in the 2022-2023 financial year.

Our community are very generous and whether it is coming to an event, giving through an appeal, participating in a fun run or competition, creating your very own PayPal campaign, creating an in-memoriam campaign, or buying something from the Hunt 4 Hope Op Shop, we want to thank each and every one of you! Together we are helping to provide support and services for people impacted by HD.

Walk 4 Hope

2022 was our first year's face to face since COVID-19, and we held events at Newcastle, Canberra, Orange and Parramatta. We also had a community walk in Bingarra, thanks Veronica, and Wollongong, thanks Cram Foundation. With over 500 people in attendance at the walks, we are hoping to grow the attendance in 2023. The total raised was \$78,136.



High Tea 4 HD

In 2023 we introduced a third location in Newcastle. Holding our High Tea 4 HD again in Penrith and Orange saw over 250 people in attendance at the three locations. We are extremely grateful for the support given by Mulgoa Valley Receptions, The Hotel Canobolas, Novotel Newcastle Beach, and HD Awareness Orange. The total raised was \$19,161.



Hunt 4 Hope Op Shop

The Op Shop in Maroubra continues to thrive since opening its doors in 2018. The shops accept all types of goods, then inspects, cleans and prices them to sell. With 100% of profits being passed to our charity we truly are grateful for the support that Matina continues to provide, she is one in a million! The total donated was a record \$68,081.



Community Support

Thank you to everyone from our community who supports us! Some of the activities were the Blackmores Sydney Running Festival, City2Surf, HBF Fun Run, baking and selling Christmas puddings, don't break the chain campaign, Step Up 4 Jenny, EJ-EH Holden Club show, High Tea at home, Walk 4 Hope Bingarra and Wollongong. Plus, we have some wonderful recurring donors and major donors.



Volunteers

We have many people who volunteer their time to assist at events and behind the scenes. Thank you so much for supporting our charity! Volunteers like you genuinely change the world, and we are forever grateful. We hope you will join us next time. We'd love to see you!



Alison Weir
Fundraising & Events Coordinator



OUR SUPPORTERS

We would like to acknowledge the generosity of individuals, groups, and organisations who have supported Huntington's NSW ACT during the 2022 – 2023 financial year. Your support is very much appreciated.

- Our major donors and foundations
- Our regular giving families who wish to remain anonymous
- The generous benefactor who has partnered with us to initiate the Youth Scholarship Program

Corporate Partners

- The Co-Group Ltd.
- Macquarie Foundation

Government Partner

- NSW Health – Western Sydney Local Health District
- NSW Health – Regional Health Division

Health and Allied Health Professionals

- Prof Clement Loy, Director NSW Huntington Disease Service, Westmead Hospital
- Cecelia Lincoln, Felicity Stehouwer, Sandra Barisic & Peter Kwong and the 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 Joseph and the staff at Sister Maria Cunningham Centre, St Joseph's Hospital

MEMBERSHIP

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 was a member of the NSW State Committee)
- Rare Voices Australia
- Accessible Product Design Alliance

State

- Health Care Consumers 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 passed during the last twelve months.

Karole Wilson (October)

Jenny Woodcock (December)

Pam Burton (January)

Kim Burgess (June)

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@huntingtonsaustralia.au.



ADMINISTRATION

The Association introduced MS Teams as its e-operating environment this year. This process involved a good deal of spring cleaning and archiving of old files as well as training in how best to use this tool efficiently and effectively.

Due to the increase in staffing at the office, and the return to work post COVID-19, the CEO moved to a small alcove room to allow his larger office to accommodate three workstations.

Most staff continue to work under hybrid conditions but enjoy coming to the office at least once a week to hold face-to-face meetings and pop out for coffee and the occasional lunch together.

A substantial effort was undertaken to further clean up our client database in readiness for the merger.

The additional work involved in preparing for the expected transition / merger into Huntington's Australia has been considerable, and the daily workload did not reduce to accommodate it. However, we all somehow buckled down and achieved the desired outcomes.

Stewart Swales
Administration Coordinator



TREASURER'S REPORT

The 2022-23 financial year has required *Huntington's NSW ACT* to maintain a focus on our organisational values and objectives, whilst ensuring our post-Covid 19 recovery strategy and friendly merger with *Huntington's Australia Ltd.*, is well planned and delivered.

It's heartening to note that the needs of our clients and their families have continued to be at the forefront of decision making throughout this challenging period. It's also positive to share that all but two of our staff have been offered employment in the new entity, with their entitlements transferring across. We are all optimistic that the result will be a sustainable and high-quality service for the Australian Huntington's community.

This year, *Huntington's NSW/ACT* provided *Huntington's Australia Ltd.* with financial, human and intellectual property assets and resources to ensure a smooth transfer of services, clients and staff. The deficit on this year's balance sheet shows the impact of providing these resources to Huntington's Australia Ltd., but also reflects our strategic objective and is in line with expectations.

Notwithstanding this requirement, it is a pleasure to report that our income has grown to \$930,353 in FY23, representing an increase of 14.65% over FY22. Some funding highlights from this year include:

- A significant grant from *NSW Health* for our 'Youth Connection Program' was secured;
- The establishment of the Huntington's Disease 'Specialist Counselling Service' with funding support of *The Co-Group* under a three-year agreement;
- NDIS Support Coordination income growth from \$285,299 to \$362,594: an increase of 27.1%;
- Approval by *NSW Health* for two years' funding of \$226,000 for a Huntington's Specialist Advisor (shortly after the end of the financial year reported on here – funding re-directed to *Huntington Australia Ltd.* to reduce costs, and not appearing in our accounts).

The transfer of Huntington's NSW ACT's assets and liabilities to Huntington's Australia, is estimated at a net value of around \$2.5 million. This will be a boon to enhancing service delivery around NSW and the ACT and nationally.

In conclusion, this year represents the final full year of trading for Huntington's NSW ACT. A set of completion accounts will be drafted to represent the period 1 July 2023 to the de-registration date of the Association, which is yet to be determined by the membership. The Board will take advice to ensure compliance with the *Associations Incorporation Act 2009 (NSW)* and *Australian Taxation Office* reporting requirements, as well as our agreement with *Huntington's Australia Ltd.* through the wind-up process.

I would like to make a special acknowledgement of our CEO *Lewis Kaplan*, noting his tireless efforts in securing new funding, all while preparing the baton for handing to *Huntington's Australia*. Likewise for our Chair, *Katy Clymo*, who was instrumental in managing the complex merger process to completion.

Thank you to our dedicated volunteers, our amazing staff and fellow Board Members, each of whom has played a critical crucial role in making our Association effective and worthwhile.

Most of all we thank our members and clients for supporting the vision of a national organisation and coming on this journey with us!

Mark Raven
Treasurer