ANNUAL REPORT 2025



Huntington's Australia

NOVEMBER 2025

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ACKNOWLEDGEMENTS

Huntington's Australia is the peak national body for Huntington's disease (HD) that works to improve the quality of life for individuals and families impacted by HD.

This report was made possible through the collective effort and dedication of Nikka Biasotto, Cathy Holland, Alison Weir, Leah Atkinson, Rebecca Miles, Monica Cazzolli, Julie Neil, Samantha Brietmeyer, Lenni Duffield, Chris Glasson, Charlotte Jeffrey-Bannister and Fiona Richards.

Huntington's Australia acknowledges the Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We acknowledge and pay respect to elders of all Aboriginal and Torres Strait Islander nations that have passed before us, and those that continue to be the strength of their families and communities today. Thank you for your guidance and wisdom.





MESSAGE FROM THE CEO

Reflecting on the past year, I am proud to share a story of resilience, innovation, and meaningful progress as we continue our journey toward becoming a truly sustainable organisation.

In what has been a dynamic and challenging environment for the not-for-profit sector—where many organisations have struggled to remain viable—HA has remained steadfast in our mission: to ensure that those impacted by Huntington's disease (HD) can thrive with the support they need.

Delivering meaningful services within ongoing financial and resource constraints has not been easy. This is especially true as demand for our supports continues to grow.

Yet, despite these challenges, we achieved several significant milestones this year:

- **Growth & performance**: We achieved **26% revenue growth,** expanded into new NDIS markets including Social Work and Allied Health, and further strengthened our core operations.

- **Innovation:** We delivered two additional regional and remote neuro clinics on country — the only clinics of their kind in Australia — bringing vital, culturally appropriate services to some of our most vulnerable and First Nations communities impacted by Huntington's disease.

- **Sustainability & responsibility:** We progressed initiatives to transition roles to self-funded models and introduced new fee-generating services under the NDIS.

- **People & culture:** We invested in leadership and overall talent, cultivating a positive workplace culture, as evidenced in our staff survey. A particular highlight was bringing our entire team together in Sydney for our first all-staff workshop—an invaluable opportunity to connect, collaborate, and build a shared sense of purpose.

Looking ahead, we see tremendous opportunity. Our strategic focus for 2026 centres on raising awareness and advocacy — **making Huntington's disease a known rare disease** — while expanding our service offerings and increasing our reach and impact.

While the road ahead will continue to bring its share of challenges, I am confident that, with our incredible staff and dedicated Board members, we have the ability to adapt, lead, and continue delivering essential services and support to our HD clients, families, stakeholders, and the broader community well into the future.



Lenni Duffield
CEO



MESSAGE FROM THE BOARD CHAIR

After our first full year of operating as Huntington's Australia (HA), we have grown our services to meet some of the increasing needs from the HD community.

Whilst there are promising new treatments being trialled internationally and here in Australia, the reality is that HD is not yet going away, and demand for our services remains high.

Since our merger, we have strengthened and expanded our organisation, continuing to grow our revenue base and increasing our capacity across programs and services. While this growth has been significant, it hasn't all been plain sailing. We have had to make some difficult organisational decisions along the way as the demand for support continues to outpace our resources. This remains an ongoing challenge for us.

This challenge comes at a time when a lot of not-for-profit (NFP) organisations are struggling to retain their viability. Indeed, recently, some very significant and long-standing NFPs, household names, have gone into administration. We have worked hard to strengthen our financial sustainability, and while it remains a challenge in these uncertain times, we are confident in the direction we are heading.

Our goal for HD to be recognised as **a known rare disease** has taken an important step forward through expanded marketing and fundraising activities that are now reaching more people than ever before.

We have continued to work hard on delivering our now core NDIS support coordination services across the country, while also expanding the range of direct services we provide. We stay committed to growing these offerings – and are uniquely positioned to do so.

We have received overwhelmingly wonderful feedback from clients and the community, who consistently recognise our talented and dedicated workforce and volunteers. I cannot stress enough how proud I am of our committed team, guided by a very capable Executive and a Board that ensures we stay on track financially and strategically.

While we cannot do everything, we are exploring ways we can partner with others to provide needed services. Governments are looking for joint ventures to provide more integrated care, and we are pleased to be part of these conversations. The Queensland Government's commitment to deliver eight Neuro Wellness Hubs across regional Queensland – with HA involved in the early planning – is one example. Another is our project proposal for HD and other neurological services to support First Nations communities across northern Australia.

The future is full of hope and opportunity, and HA will continue to work tirelessly to ensure the best outcomes for our HD community – helping them live their best lives.



Chris Glasson
Board Chair



WHO WE ARE

Huntington's Australia is dedicated to improving the lives of individuals and families impacted by HD across the country.

We provide support, advocacy, and education to ensure that everyone impacted by HD, no matter where they live, has access to the care and resources they need.

Whether you're at risk, have tested positive or negative, are showing symptoms, or have received a diagnosis, we are here for you. Our support extends to families, carers, friends, and loved ones who share this journey.

Through advocacy, education, and compassion, we strive to bring comfort, understanding, and hope to the HD community.

About Huntington's disease

Huntington's disease is a genetic, neurodegenerative disease that causes the progressive breakdown of nerve cells in the brain. This results in gradual changes in:

- **Cognition, thinking and memory**
- **Movement and coordination**
- **Behaviour and emotions**

Each person experiences HD differently, and progression is not linear. Symptoms vary in severity, and presentation and progression may differ even within the same family.

Symptoms often begin between the ages of 30 and 50 but can appear earlier or later. Cognition refers to how we think, focus, remember, problem-solve, and plan. HD causes gradual changes to areas of the brain responsible for these abilities.

There is currently no known treatment to stop, slow, or reverse the condition, but supportive therapies, routines, and medical care can make a significant difference in quality of life.

SUCCESS STORY

A gentle journey to finding connection

Sarah* lives with symptomatic HD, and for a long time, was hesitant to reach out for support. Everyday tasks were becoming more difficult as changes in movement, thinking and behaviour began to affect her routine and relationships.

Things started to shift when Sarah joined a local HD support group. There, she and her family found understanding, reassurance, and small but practical ways to manage the challenges they faced. With gentle guidance from the HD Specialist, Sarah was supported through a strengths-based approach that focused on what mattered most to her.

As trust grew, Sarah felt more comfortable exploring services and support options. She's now experiencing greater stability and a renewed sense of wellbeing.

Sarah's story reminds us that when we meet people where they are, emotionally and practically, we can build trust and pave the way to meaningful connection and support.

*Name has been changed to protect the privacy of the people we work with.

OUR NATIONAL IMPACT



1,242
clients supported

203
active members

30
regular donors

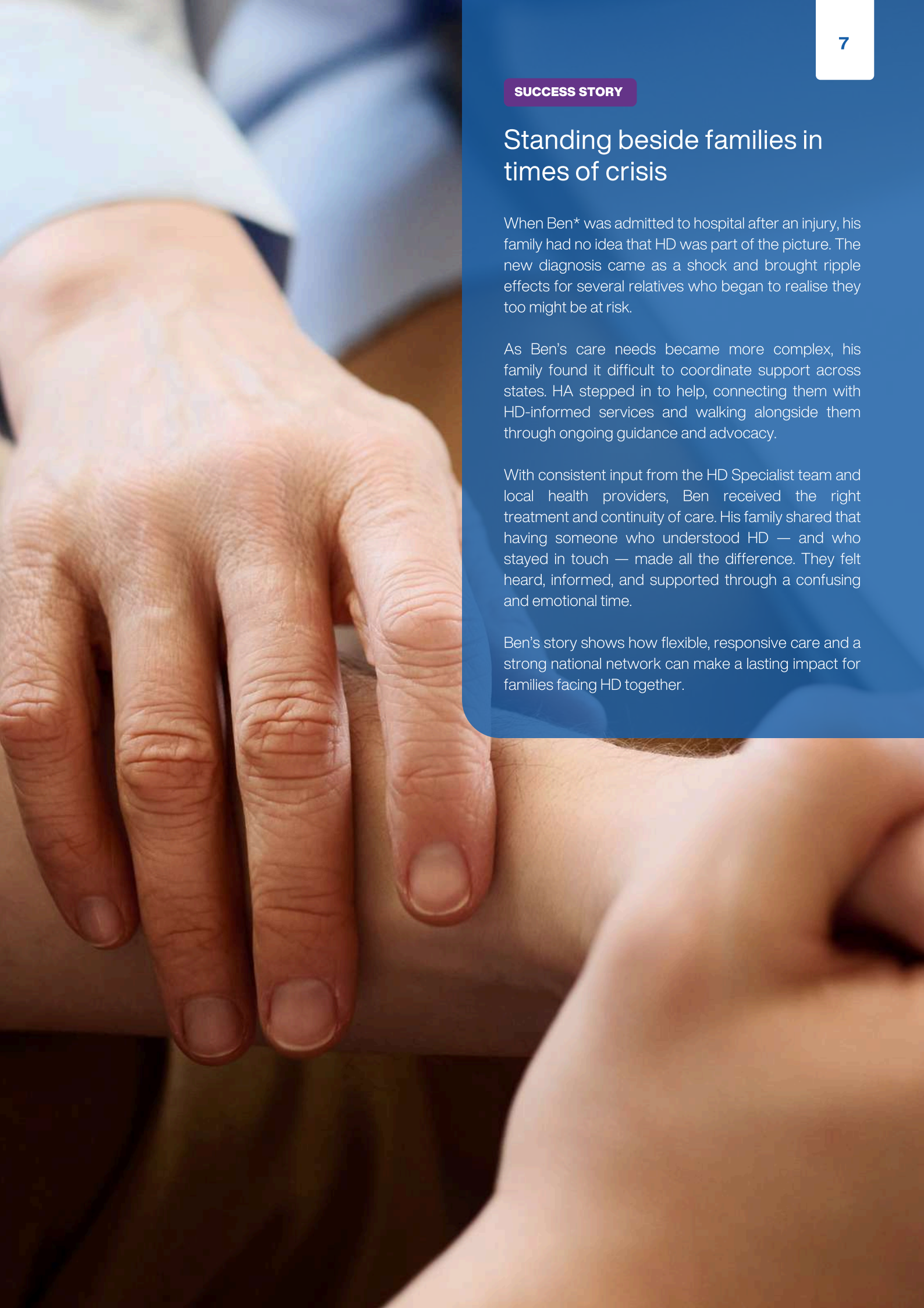
110
support groups facilitated

18
training and information sessions conducted

28
volunteers

202
Support Coordination participants supported

$462,472
funds raised



SUCCESS STORY

Standing beside families in times of crisis

When Ben* was admitted to hospital after an injury, his family had no idea that HD was part of the picture. The new diagnosis came as a shock and brought ripple effects for several relatives who began to realise they too might be at risk.

As Ben's care needs became more complex, his family found it difficult to coordinate support across states. HA stepped in to help, connecting them with HD-informed services and walking alongside them through ongoing guidance and advocacy.

With consistent input from the HD Specialist team and local health providers, Ben received the right treatment and continuity of care. His family shared that having someone who understood HD — and who stayed in touch — made all the difference. They felt heard, informed, and supported through a confusing and emotional time.

Ben's story shows how flexible, responsive care and a strong national network can make a lasting impact for families facing HD together.

WHERE WE WORK

With teams across the country, we support people living in both central and regional communities. We help individuals and families access the guidance, services and care they need to thrive.

35

staff nationwide





SUCCESS STORY

Strengthening awareness and support in Palm Island and Townsville

HA, together with Connectivity TBI, visited Palm Island and Townsville in response to needs identified by the local community. The visit aimed to strengthen awareness, share resources, and build capacity to support people impacted by HD.

During the visit, HA staff met with community leaders, local health services, and community programs. They joined community gatherings, visited homes, and delivered education sessions for health professionals. More than 200 people took part in a joint information event, which provided an opportunity to learn, share stories, and connect with others who understand the impact of HD.

Palm Island, home to the Manbarra and Bwgcolman peoples, is a close community where several residents are diagnosed with HD and many families may be at risk. Movement between Palm Island and Townsville is common, showing the need for consistent and connected regional support. Staff also observed community members who may be showing signs of HD, reinforcing the importance of education and early awareness.

Next steps include creating culturally adapted HD resources for Aboriginal communities and offering follow up online training for local health professionals to build understanding and continue supporting families in the region.



OUR SUPPORT AND SERVICES

Over the past year, Huntington's Australia has grown its Community Programs to provide even more support for people living with HD and their families. Our programs are open to anyone impacted by HD and include a mix of social, support, and recreation groups, available both in-person and online. These gatherings offer a safe, welcoming space to connect, share experiences, and access professional guidance.

Support groups that make a difference

Support groups remain at the heart of our work. In the last 12 months, we facilitated **110 support groups**, providing vital opportunities for people to come together, share experiences, and access professional guidance. In South Australia, Coffee & Co has become a welcoming hub for social interaction and practical support. Our Day Centre in Western Australia delivers structured activities and skill-building to keep participants active and engaged.

Where we can't be on the ground, we collaborate with partners to deliver and facilitate online support groups, such as our Newcastle support group, to reach more people in regional and remote areas.

Expanding clinical and specialist services

To meet growing demand, we introduced new NDIS services to provide more holistic care:

- **Physiotherapy** to support mobility and physical wellbeing
- **Assistance in the community** for everyday tasks and participation
- **Skill development and coaching** to build independence and confidence
- **Social work** for personalised emotional and practical support
- **Specialist behaviour support** to address complex care needs

These services complement our existing programs, strengthening our support across the country. In the past year, we supported **1,242 clients** and assisted **202 Support Coordination participants**, connecting people with the right services and helping them navigate their individual plans.

We also launched **two new regional and remote Neuro Clinics** on country, offering the only services of their kind in Australia. These clinics bring essential, culturally appropriate care to First Nations communities.

Building knowledge and quality care

Education and training are central to our efforts. We equip carers, support staff, allied health professionals, and clinical services to provide informed, high-quality care. Guided by community feedback, we continue to refine our programs and invest in our teams, ensuring person-centred support for those impacted by HD.

OUR IMPACT

1,242
clients received essential support

202
Support coordination participants supported

110
support groups facilitated

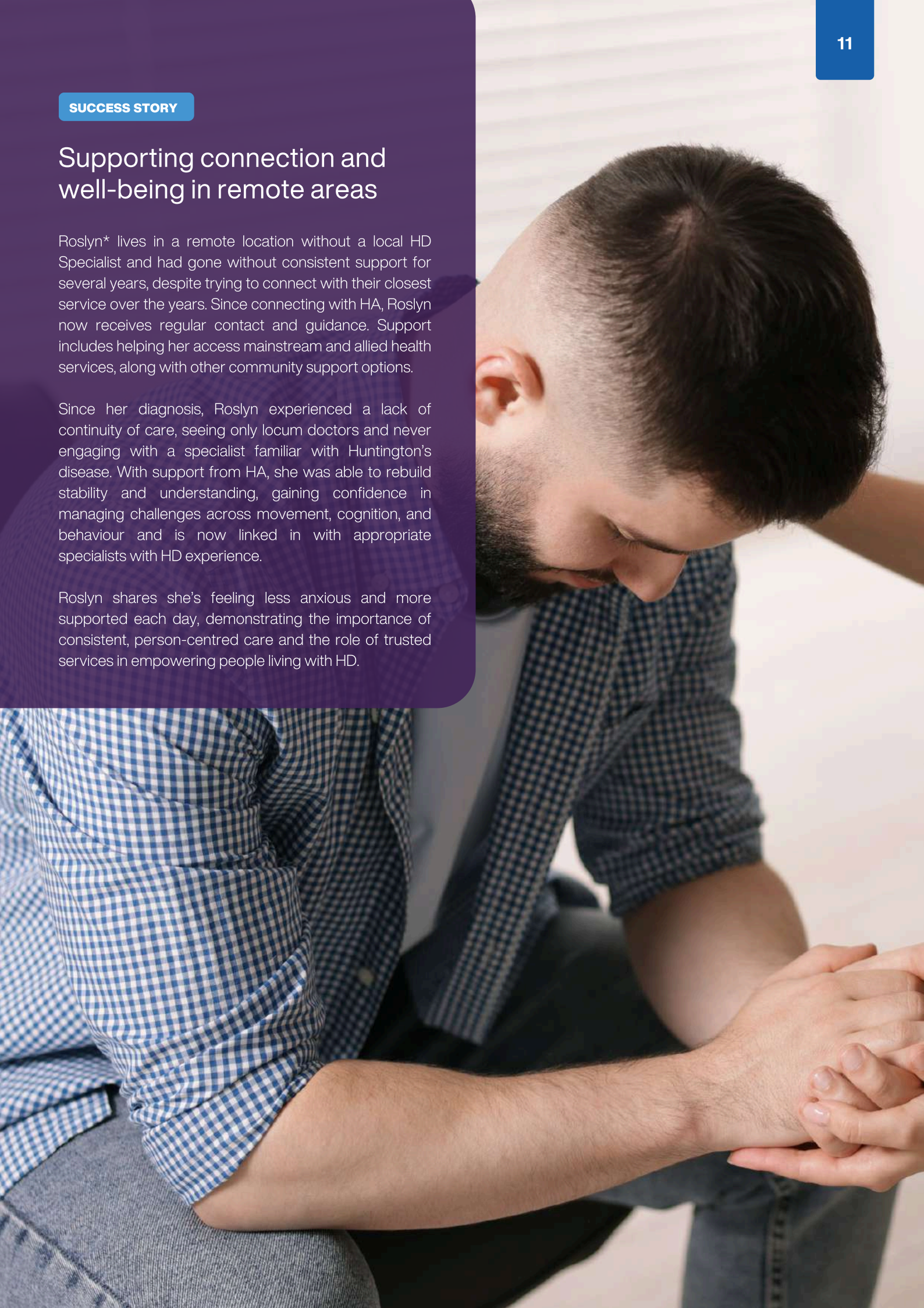
SUCCESS STORY

Supporting connection and well-being in remote areas

Roslyn* lives in a remote location without a local HD Specialist and had gone without consistent support for several years, despite trying to connect with their closest service over the years. Since connecting with HA, Roslyn now receives regular contact and guidance. Support includes helping her access mainstream and allied health services, along with other community support options.

Since her diagnosis, Roslyn experienced a lack of continuity of care, seeing only locum doctors and never engaging with a specialist familiar with Huntington's disease. With support from HA, she was able to rebuild stability and understanding, gaining confidence in managing challenges across movement, cognition, and behaviour and is now linked in with appropriate specialists with HD experience.

Roslyn shares she's feeling less anxious and more supported each day, demonstrating the importance of consistent, person-centred care and the role of trusted services in empowering people living with HD.





FUNDRAISING MILESTONES

Our fundraising efforts in 2024–2025 reflect the remarkable passion and unity of the Huntington's community.

Together, we've raised over **$462,472** through national events, peer-to-peer fundraising, and heartfelt community-led fundraisers. Every dollar brings us closer to improving care, raising awareness, and providing hope to families impacted by HD.

$462,472

funds raised



Walk 4 Hope 2024

Walk 4 Hope began in NSW and grew into a national event in 2024. Held across **seven locations** nationwide, it united families, friends and supporters from every corner of Australia. 2024 marked HA's inaugural Walk 4 Hope, with more than **700 participants** walking in solidarity to show that no one walks alone with HD.



High Tea 4 HD

Our High Tea 4 HD events were organised as DIY fundraisers by passionate community members around the country. Across the country, **12 high teas** brought people together for an afternoon of connection, raising more than **$13,000** to support people living with HD. We extend our heartfelt thanks to our incredible hosts, venues, and raffle donors who made these gatherings such a success.



Light It Up 4 HD

Throughout May, landmarks around Australia lit up in blue and purple for Light It Up 4 HD, shining a light on HD awareness. Supporters from coast to coast shared photos using #LightItUp4HD, sparking conversations and helping raise visibility for our cause. Community events were also held during the month of May in Perth, Hobart, Brisbane, Adelaide, and Sydney to celebrate this powerful movement.



Running 4 Nan's HD

This inspiring QLD initiative celebrated its 10th year in 2024. Organised by Kel and her husband Steve in honour of Kel's beloved nan, the event once again brought runners and walkers together along the Wynnum foreshore to raise awareness and vital funds for HD. It continues to be a heartfelt reflection of love and commitment to the Huntington's community.



Hoops 4 Huntington's

Albury high school student Tom, with the help of his friends, held a 24-hour basketball shooting challenge for his year 9 school project. Tom wanted his project to 'go bigger than himself' while also raising funds and awareness for Huntington's Australia. From the court to the community, Hoops 4 Huntington's brought people together through sport and support.



Self Care for a Cause

Bella, a proud advocate and carer for her father who lives with HD, partnered with her friend Catriona to host a wellness workshop featuring two hours of Yin, Breathwork, and Reiki. As a fifth-generation HD-positive individual, Bella used the event to raise much-needed support for families living with HD, while encouraging others to pause, connect, and care for themselves.



Family Fun 4 HD

Long-time supporters HD Awareness Orange & Central West hosted a new community event, *Family Fun Day 4 HD*. The day featured games, a jumping castle, music, face painting, footy activities, and a relay for HD, bringing families together for a day filled with laughter, movement, and awareness.



NRL Legends Charity Game

Troy and Cherrish from *Tackling Life* organised an incredible afternoon of NRL football, with Huntington's Australia chosen as one of the charity recipients. Attendees watched NRL legends go head-to-head in a friendly match that raised nearly **$8,000** to support our work.



EJ & EH Holden Club of ACT

Led by long-time supporter Glen, the EJ & EH Holden Club of ACT raised vital funds for Huntington's Australia through a series of community events. The group also provided on-the-ground support at our Canberra Walk 4 Hope, continuing their proud tradition of advocacy and local engagement.



Members, supporters and funding partners

We are deeply grateful to our members, donors, and major supporters for their generosity and ongoing commitment. Your contributions make it possible for us to continue supporting individuals and families impacted by Huntington's disease. Together, these efforts have raised vital funds and strengthened the sense of community that defines Huntington's Australia.

We also extend our thanks to our valued partners:

- Ailsa's Legacy Scholarship Funding
- Brightwater Care Group
- Dynamic Support Services
- Hunt 4 Hope Op Shop
- NSW Health (Western Sydney Local Health District)
- NSW Health (Ministry of Health)
- Programmed Care
- Queensland Department of Health
- SACare
- Stan Perron Charitable Foundation
- Skyhawk Therapeutics
- Tasmania Department of Health
- The Co-Group Ltd
- The Hall Foundation
- WA Department of Health
- WA Department of Communities



FINANCIALS

The 2024–2025 financial year marks Huntington's Australia's first full year as a unified national organisation. It has been a year of transformation, investment, and consolidation as we continue laying the foundations for a strong and sustainable future. Despite sector-wide challenges, we are proud of our achievements in expanding services, strengthening partnerships, and deepening our engagement with the Huntington's community across Australia.

Our financial statements have been prepared in line with the Australian Charities and Not-for-Profits Commission Act 2012 and relevant accounting standards, reflecting our commitment to transparency, accountability, and sound financial management. The accompanying summary provides an overview of our key financial results for the year ending 30 June 2025, with the full audited statements available on our website.

Financial Performance Overview

For the financial year ending 30 June 2025, Huntington's Australia recorded a deficit of $640,888, compared to a part-year deficit of $225,913 in FY2024. This result aligns with the Board-endorsed budget and reflects planned investments to establish our national operating model following the merger of the former state and territory entities. These strategic investments were necessary to build the systems, processes, and capacity required to deliver sustainable services to the Huntington's community nationwide.

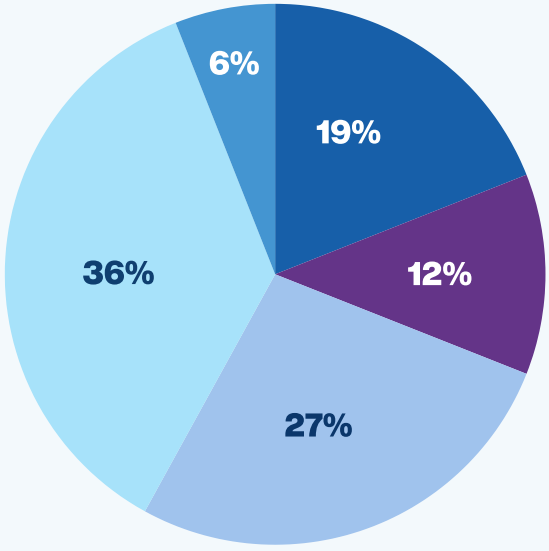
Operational Progress and Growth

Throughout the year, we experienced growth in our NDIS service delivery and increased income from sponsorships and national fundraising initiatives. These developments demonstrate the growing recognition of our work and the community's continued trust in our mission. We also made significant progress in unifying our systems, strengthening governance, and creating pathways for future growth as a national entity.

KEY HIGHLIGHTS

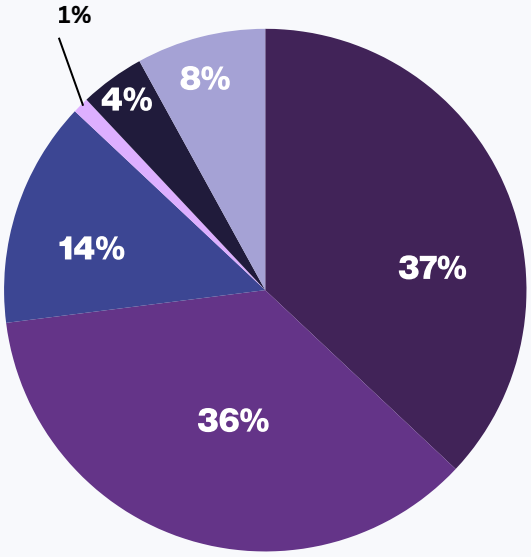
- First full year as a unified national entity.
- Strategic investments to strengthen systems and service delivery.
- Growth in NDIS services, sponsorships, and fundraising.
- Ongoing advocacy for sustainable funding.
- Continued focus on transparency, accountability, and long-term financial sustainability.

For the financial year 2024-2025, our funding supported the HD community nationwide, reaching the following locations:



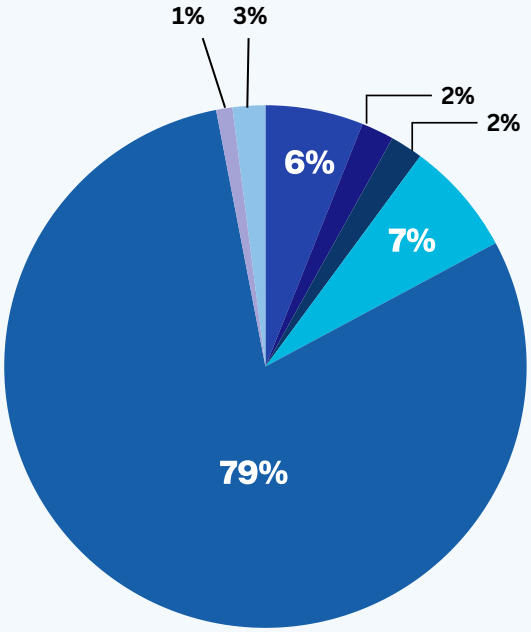
WA	36%
SA/NT	6%
QLD	19%
TAS	12%
NSW/ACT	27%

INCOME



Grants & external funders	37%
NDIS services	36%
Donations and fundraising	14%
Fee for service	1%
Investments	4%
Other	8%

EXPENSES



Administration	6%
ICT	2%
Marketing & fundraising	2%
NDIS & programs	7%
Employment costs	79%
Facilities & equipment	1%
Non-operating expenses	2%

Challenges and Financial Sustainability

We continue to operate in a challenging environment, with factors such as award wage increases and stagnant NDIS pricing affecting the broader not-for-profit sector. These pressures have impacted profitability across the industry. Huntington's Australia remains focused on addressing these challenges through prudent financial management, advocacy for fair funding at both state and federal levels, and diversification of income streams.

Our priorities include improving operational efficiency, developing new partnerships, and expanding community-based services to ensure the organisation remains financially resilient and mission-driven.

Transparency and Accountability

We are committed to full transparency in how our funds are managed and used. Our financial statements outline how we allocate resources to programs, advocacy, and support services for individuals and families impacted by HD. This accountability underpins our relationships with donors, funders, and the broader community.

A full copy of Huntington's Australia Limited's Audited Financial Statements for the year ending 30 June 2025 is available on our website.

Income and Expenditure Statement

Below is the Income Statement for the period ending 30 June 2024, showing a deficit of $226,913.

	NOTE	2025 $	2024 $
INCOME			
Grants & Service Agreements		1,101,118	1,142,212
NDIS Services		1,076,425	626,763
Donations, Bequests & Partnerships		424,647	326,352
Sales		37,825	35,149
Investment		119,743	91,967
Interest		5,572	7,467
Other		211,856	134,191
		2,977,186	**2,364,074**
EXPENSES			
Audit & Legal Fees		19,056	12,600
Bank Charges		9,879	3,622
Bad Debt		801	-
Building - Operational		29,449	21,223
Building - Rent		13,742	21,233
Consultants		111,460	27,550
Depreciation		75,526	57,691
General Administration		24,517	20,027
Information & Communication Technology		79,326	67,480
Insurance		56,906	38,617
Marketing & Fundraising		61,978	45,472
Merger Expenses		-	115,288
NDIS & Programs		239,978	178,933
Recruitment		5,242	5,690
Research Grant		27,227	44,277
Salaries & Wages - Superannuation		299,009	179,621
Salaries & Wages - WAges, AL & LSL		2,481,717	1,696,008
Staff Amenities & Training		13,709	8,885
Travel & Accommodation		70,753	55,363
		3,617,275	**2,590,987**
Net surplus/(deficit)		**(640,088)**	**(226,913)**

Balance Sheet

Below is the Income Statement to Assets and Liabilities Statement for the period ending 30 June 2025, showing a deficit of $ 3,350,402.

	NOTE	2025 $	2024 $
CURRENT ASSETS			
Cash & Cash Equivalents		365,725	722,550
Income Accrued		25,622	23,784
Trade Receivables & Prepayments		63,946	50,937
TOTAL CURRENT ASSETS		**455,923**	**797,271**
NON-CURRENT ASSETS			
Financial Assets		1,268,407	1,553,039
Property, Plant & Equipment		2,141,564	2,149,487
Right of Use Assets		29,555	75,081
TOTAL NON-CURRENT ASSETS		**3,439,526**	**3,777,607**
TOTAL ASSETS		**3,894,819**	**4,574,878**
CURRENT LIABILITIES			
Trade & Other Payables		128,860	105,454
Lease Liability		26,441	44,498
Provisions		344,833	298,861
TOTAL CURRENT LIABILITIES		**500,134**	**448,812**
NON-CURRENT LIABILITIES			
Lease Liability		10,652	40,642
Provisions		33,631	26,237
NON-CURRENT LIABILITIES		44,283	66,970
TOTAL LIABILITIES		544,417	515,782
NET ASSETS		3,350,402	4,059,096
EQUITY			
Bequest Reserves		1,090,299	1,158,904
Asset Revaluation Reserve		1,862,302	1,862,302
Donations		1,264,803	1,264,803
Accumulated Funds		(867,001)	(226,913)
TOTAL EQUITY		**3,350,402**	**4,059,096**

THANK YOU

Your support ensures no one faces Huntington's disease alone.

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