



HUNTINGTONS *queensland*



ANNUAL REPORT



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In the spirit of reconciliation Huntingtons Queensland acknowledges the traditional custodians of Country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

ABOUT US

Our people

President	Shane Kelly
Vice President	Gerry Doyle
Treasurer	Nick Murray
Secretary	Tamara Winch
Directors	Angela Abell Jason de Bakker
Qld Operations Manager & Head of Community Programs & Services	Basil Mabuza
Client Services	Theresa Byrne Kelly Lambourne Lauren Ward^
Finance	Jennifer Lysiuk
Administration & Communications	Cathy Holland

^ Transferred to Huntington's Tasmania

Resigned during the year:
Shaun Riley, Operations Manager
Lisa Kibsgaard, Communications officer

We are a registered charity (public benevolent institution) overseen by a volunteer board comprising HD family members, and skills-based professionals.

We have a small paid team whose professional experience includes social work, education, disability support, advocacy, finance, administration, marketing and communications, fundraising, human resources, organisational development, strategic planning, and project management.

Volunteers & Partners

Huntingtons Queensland gratefully acknowledges those members and others who have so generously volunteered their time and expertise, either within the Huntingtons community or within our organisation.

We also acknowledge the contribution made by our wonderful partners, including:

- Financial planner **Luke Muir**, whose tailored, professional advice helps HD families to navigate the pitfalls and challenges of planning for a life affected by HD;
- Psychologist **Cathy Dart**, for sharing her wealth of experience and knowledge of HD with those clients we refer to her service;
- **Minter Ellison** for their excellent, pro bono legal advice.
- **Stan Lysiuk** for pro bono support to our finance department.

On behalf of our team and everyone impacted by Huntington's disease in Queensland, we thank you for your service and support.

THANK YOU

The following individuals, families and businesses made donations of \$1,000 or more during the year:

Adam Wells	Gaminder Pty Ltd
Anonymous	Gwen Ware
Brian Turner	OpportunOTy Pty Ltd
Christine Gordon	PayPal Giving Fund Australia
Diane Allan	Roger's Family

The following individuals, families and businesses made donations of \$500 or more during the year:

Albany Creek Tavern Social Club	Kerry Milliner
Anonymous	Margaret Buchanan
Bob and Rhonda Goodair	Marissa Sivell
Carol Thornton	Peter Nash
Doug & Lesley Sivyver	Peter Noonan
James Callum	Riempke Kampen
Jean Heimgartner	Robyn Sheppard
Joyce Bennett	

The following individuals, families and businesses made donations of \$200 or more during the year:

Adrian Stephens	Judith Scarr
Anonymous	Maciej (Michael) Graczyk
Cathy Holland	Margaret Bruce
Eric Denham	Marlene Brazendale
Erin Giovenco	Shane Kelly
Fay Cutmore	Susan Howe
Irene Golby	Terry Stedman
Janine Lawrence	Vicky Nicholson
Jean Farmer	



DIRECTOR PROFILES



Shane Kelly – President (joined 2018)

With his family affected by HD, Shane is determined to support those directly impacted, while helping to raise funds for research and services. Shane has extensive experience in senior management roles, having worked for Telstra for more than 20 years and more recently in consulting roles across business transformation. Shane has been an active member of a national Project Steering Group providing oversight and support of the merger of State Associations into a single entity.



Gerry Doyle – Vice President (joined 1994)

Gerry has been associated with Huntingtons Queensland for more than 25 years and became a life member in 2010 in recognition of his tireless service on behalf of HD families. Gerry, a retired corporate manager, also has many years lived experience of HD as a parent, husband and carer.



Nick Murray – Treasurer (joined 2022)

Nick has an accounting background and assists a wide array of not-for-profit entities on a daily basis. Nick is a chartered accountant with a passion for assisting all clients to understand their economic position and meet their financial goals. He brings that same passion to Huntingtons Queensland.



Tamara Winch – Secretary (joined 2021)

Tamara joins the Huntingtons Queensland Board with a solid background in corporate payroll and HR administration. She brings with her valuable experience in working with charitable foundations and has a welcome understanding of the NDIS and related services.



Angela Abell – Director (joined 2021)

Angela joins the Huntingtons Queensland Board with a corporate background in accounting & banking. She is passionate about supporting the Huntington's Community and volunteers for Huntingtons Queensland, HDYO, and HD-CAB. Angela tested positive for Huntington's disease in 2017 when she was 20 years old.



Jason de Bakker – Director (joined 2018)

Jason has an extensive background in corporate services, compliance and organisational development gained over more than 20 years in the not-for-profit and community sectors. Jason is a graduate of the Australian Institute of Company Directors and has a particular interest in governance and strategy. As well as a Queensland Director, Jason is currently the Chair of the Consortium of Australian Huntington's Associations.

PRESIDENTS REPORT



Dear members and HD community

It is my pleasure to introduce this year's 2023 Annual Report.

It is my opportunity to share and celebrate some of the great work the team has achieved this year and update you.

It's been a historical year for Huntingtons Queensland as we joined 4 other states on agreed integration planning to form our first national body - Huntington's Australia. I am pleased to advise that operational transition was executed on the 1st October 2023 and we continue now in winding up Huntingtons Queensland affairs. A key final step for us will be proposing a motion at the AGM on 30th November 2023 to legally wind-up Huntingtons Queensland.

It is also a time of reflection and celebration of the 47-year history of Huntingtons Queensland and those who came before us and did such wonderful work creating the organisation and culture of Huntingtons Queensland. There are many to mention but I must recognise and thank some of the original members especially Cliff Farmer who supported by his wife Jenny started Huntingtons Queensland. Cliff became our first President, holding the first ever meeting at their home. Soon after he was supported by volunteer, Gwen Pratten who went on to become our first Welfare Coordinator and Board member. And of course, Gerry Doyle, who has served as President or Board member continuously for over 20 years and has steered the ship with care and diligence. Cliff, Gwen and Gerry we recognise your efforts and salute your dedication and the personal impact you have had on all those Huntingtons Queensland families. We thank you.

Of course like all NFP's we survive on the generosity of donors and Grants, in particular I would like to recognise the following:

- The Queensland Government
- Mintor Ellison Solicitors for over 20 years support to Huntingtons Queensland
- Alan and Alecca McKinless
- Richard Sivell
- Cliff Farmer
- QBE Insurance
- Dianne Allan
- The Rogers Family
- Thorsen Family Foundation
- Jan Szlapak
- Kelly Connolly and her husband Steve for organising the annual 'Running for Nan's HD' fundraiser
- And families in the HD community who make significant financial contributions but wish to remain anonymous

During the year gone our Queensland team remained focused on our number one priority - supporting Queenslanders and the families impacted by Huntington's disease. I am particularly proud of their personal commitment, loyalty and family support our long standing Queensland staff members Lauren Ward, Tressa Byrne, Cathy Holland and Jen Lysuik have provided every day to our Queensland HD families.

This year we also welcomed our first Huntington's Australia team members who will work for Huntington's Australia, but be based in Brisbane. Welcome.

I also wish to acknowledge our volunteer Board who have not only continued with normal Board commitments , but also went the extra mile on many matters to guide and assist the merging of Huntingtons Queensland into Huntington's Australia. They bring experience, passion, wisdom, selflessness and empathy in all they do. Our serving Board members are myself, Gerry Doyle, Jason De Bakker, Tamara Winch, Nick Murray and Angela Abell. My sincere thanks and appreciation to each of you for your unwavering commitment to the Huntingtons Queensland Board and HD families of Queensland.

There are increasing demands on many small charities and services like ours, including financial pressure, which means we continually review how we operate to ensure long-term sustainability and value to our clients, families and our team members.

To that end we believe the creation of Huntington's Australia to now operate at a National level will assure the long term sustainability and success of the care we seek to provide to the HD community in Australia.



*Huntingtons Queensland first and last Presidents!
L to R: Cliff Farmer and Shane Kelly*

Along the journey of planning integration and creation of Huntington's Australia, we have sought expert advice from Minter Ellison, our long-term legal support partners, Good Foundations Consultancy with extensive NFP merger experience and the expertise of the National working group (CAHA) and project steering committee.

The Huntingtons Queensland Board fully supports this important step to create a national HD body whilst maintaining local support in each State and local State advocacy committees to ensure every State has a voice and open access to the National Board and operational team.

We believe a national body is critical to raising our voice at a national level, lifting our profile with government, clinicians, medical research companies, fundraisers, supporters and, of course, our clients and their families. One of the key outcomes from this merger will be enabling HD support teams to better provide and support NDIS services for our clients.

As we reflect on the year, we remember, pause and are saddened by every loss, both individual and those families who suffer loss from Huntington's disease. The Huntingtons Queensland team send our deepest sympathies to all who have lost loved ones this year. Our thoughts are always with you.

I send you my personal best wishes to the HD community for a special and joyous Xmas period with our families and friends.

SHANE KELLY
President



During the year gone
our Queensland team
remained focused on
our number one
priority - supporting
Queenslanders



It is a time of
reflection and
celebration history of
Huntingtons
Queensland

TREASURER'S REPORT

Another year has flown by at Huntingtons Queensland and with a wide array of challenges and changes it has been a whirlwind.

A merger is never easy, let alone one that consolidates various states across the country. The wonderful staff at Huntingtons Queensland must be commended for their tireless work and efforts during the year.

Although Huntingtons Queensland has reported a net deficit of \$159,442, the charity has played a pivotal role in outlaying costs for the merger. The board is aware of over \$100,000 in spending relating to the merger, with every dollar contributing to the handover taking place on 1 October 2023.

While all staff and members should be congratulated, I would like to give special thanks to Jen Lysiuk for her commitment to Huntingtons Queensland and her handover to Huntington's Australia. Jen continued to work hard beyond merger date, ensuring all lodgement deadlines were met, which the Board were appreciative of.

NICK MURRAY
Treasurer



MANAGEMENT REPORT



Dear Members and HD Community,

I am pleased to provide an update on the operational developments within Huntington's Queensland (HQ) and the crucial strides we've made in supporting the HD community.

In January, the operational baton was handed over as Shaun Riley resigned, leading to my appointment as the Queensland Operations Manager for Huntingtons Queensland as well as the Community Programs & Services Executive for Huntington's Australia (HA) in March. Our immediate focus was ensuring the seamless continuity of existing services while ushering in a new era for Huntington's Australia.

Our dedicated team has been unwavering in its commitment to delivering critical services to the community, including:

- Facilitating referrals to government services, allied health professionals with HD expertise, and disability service providers.
- Assisting our community in accessing essential services such as the NDIS, DSP, and other crucial support programs.
- Providing non-clinical counselling services.
- Conducting training and educational programs for carers, support staff, and health professionals.
- Maintaining and supporting support groups, which have proven especially vital in the post-COVID-19 landscape.
- Extended our outreach efforts as we have established contacts in areas like Palm Island



Meeting members from the Queensland HD Community

With an eye toward expanding our services under Huntington's Australia, we successfully introduced Support Coordination in May as part of our NDIS Services, with valuable assistance from our counterparts in NSW/ACT.

As part of our collaborative efforts under Huntington's Australia, Lauren Ward relocated to Tasmania to provide HD Specialist services. Following Lauren's relocation, we welcomed Alyse Goodwin to the team in the same role.

Jen Lysiuk, who has been an invaluable part of our organisation for nearly 9 years, embraced the merger as an opportune moment to retire. We wish Jen a retirement filled with joy, travel, and flourishing gardens.

I am delighted to share that our service agreement with Queensland Health was successfully novated to Huntington's Australia, thanks to the unwavering support of the Queensland Health Department and its staff.

Looking ahead, we remain committed to furthering our mission of providing comprehensive and compassionate support to the HD community under Huntington's Australia. Your ongoing support and engagement continue to drive our efforts, and we look forward to a future of continued growth and impact.

Thank you for being an integral part of our journey.

BASIL MABUZA
Operations Manager, Huntingtons Queensland
Head of Community Programs and Services, HA



**Our dedicated team
has been unwavering
in its commitment to
delivering critical
services to the
community**



**I am delighted to
share that our service
agreement with
Queensland Health**

SERVICES REPORT

Our HD Advisers and support staff have worked hard to assist families impacted by Huntington's disease over the past 12 months.

In April HD Advisor Lauren was seconded to Huntington's Tasmania in the role of Senior HD Advisor and we welcomed Kelly Lambourne and Alyse Goodwin to our HD services team.

At a glance, Lauren, Tressa, Kelly and Alyse provided more than 310 hours of face-to-face support and many additional hours of non-clinical counselling and phone support to people impacted by Huntington's disease and their families this year.

Finding ways for people to stay connected was as always essential. Our HD services team clocked up more than 180 hours travel time to ensure they could see and assist as many people as possible.



Lauren, Tressa and Kelly provided more than 310 hours of face-to-face support



Our HD services team clocked up more than 180 hours travel time

SUPPORT GROUPS

Support groups remain a vital service provided by Huntingtons Queensland. It gives people in the HD community the chance to be heard, to listen to others' stories, learn, encourage, seek advice, and meet with people who understand what they are going through. Always present at the meetings is one of our HD Advisors who can advise and answer questions attendees might have.

Tressa, Lauren, Kelly & Alyse facilitated and attended over 40 support groups in Brisbane, Ipswich and around the State during visits to Cairns, Townsville, Mackay, Rockhampton, Gladstone, Bundaberg, Toowoomba, the Sunshine Coast and the Gold Coast.

Huntingtons Queensland continued to provide online support groups over Zoom including a dedicated carer's group for those who could not meet in person.

NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

Huntingtons Queensland continues to work with many individuals to help them access the NDIS.

This year, as in previous years, our team has been committed to helping people to gather the information and evidence they require to support their NDIS applications, while advocating for their needs and wishes at NDIS planning meetings.

In collaboration with Huntington's NSW/ACT our clients were able for the first time to engage the services of an NDIS support coordinator employed within the Huntington's community. The support coordinator and HD advisors continue to collaborate to support our clients.

As access to the NDIS grows, there is a clear and growing need for appropriate education and training for support workers, whether they are supporting a person in their own home, or those living in other community or aged care settings. Likewise, we have identified an increase in the number of allied health workers seeking information and training about Huntington's disease, attributed to the NDIS's preference for people to live in the community wherever practicable.

INFORMATION, EDUCATION AND TRAINING

We continue to support clients who are also receiving assistance from other parties. This includes clients living in their own homes, in the community or in aged care. As many allied health or NDIS service providers have limited exposure or information about HD, our advisors often engage with client's providers to help them develop the skills to support the client in the best and most appropriate way.

Our information services are intended to help people make informed choices and access appropriate services and care in line with their individual circumstances.

Information and education sessions can be supplemented with follow-up advice and information by phone for service providers as required. The aim is to ensure that standards of care can be maintained over time, either as the person with HD's needs increase, or if there are changes to personnel.

CLINICAL CARE

Queensland's vast space and a shortage of health practitioners who have a good knowledge of Huntington's disease and how to support a person impacted by it will always present challenges to our community.

In line with educating NDIS and other service providers about supporting people who have HD, also important is our responsibility to educate and inform other health practitioners who provide care to people impacted by HD. A coordinated approach to an individual's needs is proven to optimise the quality of life of someone impacted by a life-limited disease.



Mackay support group getting together for Christmas themed lunch.

Demand for access to secondary healthcare and clinical expertise, such as neuropsychiatry, is also high and trained clinicians are few and far apart.

Likewise, Queensland has very limited centralised services, where key clinicians are brought together in one place. For example, there is only one outpatients' clinic for Huntington's disease in Queensland, and that clinic is held only one day a month, in Brisbane.

Huntingtons Queensland is privileged to attend this monthly clinic, at the Royal Brisbane and Women's Hospital, and to offer our support to the highly skilled and hard-working clinicians who staff the service.

Pre-clinic, our team helps attendees to schedule, prepare for and get to their appointments where possible, and then stay with them at the clinic on the day. We also help to ensure that clinicians understand the person's concerns and questions during their clinical sessions, and then liaise with the person and other services post-clinic where required.

Waiting lists to see the clinic team stretch to months and, in many cases over 12 months. There has been a significant increase in Telehealth appointments with the clinical team. Telehealth is an increasingly important tool, especially for regional clients.

We believe there is a need for significant additional funding for outpatient clinics, both in Brisbane and elsewhere around the State, and for the employment of additional clinicians who have both a passion for and an understanding of Huntington's disease and other progressive neurological conditions.

There is a particular need for funded mental health support, including within the outpatients clinic, as families find themselves in crisis with very few avenues of finding help. Unfortunately, from our experience some mental health practitioners consider that Huntington's disease is not a mental health condition, despite people having very clear indications at times of being unwell but still not able to access mental health services in a timely manner.

ONE ON ONE SUPPORT

The support needed by clients is very individual and varied. Over the past financial year our advisors have set up referrals, accompanied people to medical appointments, provided support and advice to clients and family members who suspect a loved one has HD; encouraged people to legally record their wishes through wills, advanced care plans and other legally-binding documents, provided support to families who are struggling with parenting issues, and more.



Townsville HD community enjoying their local 'Cowboys' playing at the NRL



In many instances case meetings involving complex supports for individuals impacted by HD are ongoing. These complexities often centre around a lack of appropriate or long-term accommodation, medication, complex mental health issues, domestic violence and complex behaviour support.

Financial stability can also be a challenge, therefore our advisors often help clients to complete paperwork and find supporting documentation for the Disability Support Pension, the NDIS, Centrelink and other avenues of financial support.

ADVOCACY

Huntingtons Queensland staff are passionate about supporting our clients through advocacy on a social, medical and political level.

A significant amount of our frontline team's time is spent supporting individuals one on one as they interact with the health, welfare and disability sectors.

On the wider issue of social and policy advocacy - We continue to work closely with the Public Guardian, NDIS, Queensland Health and other relevant agencies to ensure people with HD are supported and understood as their symptoms progress.



Brisbane support members enjoying catching up over lunch

**Huntingtons
Queensland staff are
passionate about
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advocacy**

OUR COMMUNITY

EVENTS



Over 80 members of the HD community attended our 2022 Forum

We were pleased to once again hold our annual forum thanks to the Alecca McKinless gift and the Rogers family. More than 80 people attended in November 2022 with presentations from Julie Stout, Huntingtons Queensland's Shaun Riley, Tina Knight and her Social Worker Deb Field, John Haberecht from Palliative Care Queensland, Occupational therapist Talisha Bryden, RBWH Senior Neurologist Associate Professor John O'Sullivan and HD family member Angelika Straker.

Our annual Running for Nan's HD fundraiser was not held in May due to the passing of 'Nan' at the age of 94 whom the event is named after. Kelly, granddaughter of 'Nan' decided to postpone the event until the second half of 2023. We send our deepest sympathy to Kelly and her family and thank her and husband Steve for their commitment and organisation of this wonderful community event.

In November we were able to facilitate an online training and information session with Occupational therapist Talisha from OpportunOTy. Participants paid to attend and over 30 occupational therapists from around the country attended.

PARTNERSHIPS

The Royal Brisbane and Women's Hospital HD Clinic continues to play a vital part in the journey of people impacted by the disease. Telehealth continues to be an important service provided by the clinic for those living regionally or too unwell to attend in person. Our HD advisors Lauren and Tressa were a mainstay of the monthly clinic – always there to support the staff and clients.

This year we continued our relationship with the Huntington's Disease Network of Australia (HDNA) and the Map-HD registry. In July we hosted an online information session with Audrey from HDNA who provided information about the registry and answered questions. The Map-HD registry aims to help HDNA understand who is affected by HD and to give them better access to clinical care and support services.

DIRECT MAIL APPEALS

Over the past year Huntingtons Queensland continued to rely heavily on the generosity of our donor community, who stepped up in a fantastic way to support our annual end of financial year and Christmas appeals.

Donors responded generously to the two 2022-23 appeals,



Occupational Therapist Talisha from OpportunOTy provided online training



Huntington's
Disease
Network
of Australia



HUNTINGTONS *By your side*
queensland

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