



HUNTINGTONS
queensland

Celebrating 45 years



ANNUAL REPORT

2020-2021



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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

Huntingtons Queensland is the only organisation in the state dedicated solely to the support and wellbeing of people impacted by Huntington's disease (HD).

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 (the equivalent of 4.6 fulltime staff) 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.

While Huntingtons Queensland has been a member-based association for 45 years, membership is not required to access our services.

Volunteers & partners

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

We estimate that volunteers contributed more than 300 hours of their time to supporting the Huntingtons community and our team in the 2020-2021 financial year, despite the many challenges wrought on our work by COVID-19.

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; and
- **Minter Ellison** for their excellent, pro bono legal advice, notably this year during the sale of our premises to the Women's Legal Service of Queensland.
- **Sigmatech IT Services** for their generous assistance.

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

Our people

President	Jason de Bakker
Vice President	Shane Kelly
Treasurer	Della Nicholson
Secretary	Tamara Winch [^]
Directors	Belinda Jane Dolan [^] Gerry Doyle

[^] Joined during the year

Resigned during the year: Cate Barrett,
Susanna Mantovani, Shane Stoddart

CEO	Jan Samuels
Client Services	Theresa Byrne Lauren Ward
Communications	Caitlin Scarr
Finance	Jennifer Lysiuk
Human Resources	Jan Tipping
Administration	Cathy Holland

THANK YOU

\$1,000

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

Anonymous	PayPal Giving Fund Australia
Dancing at the Vatican	Robina Lions Club
Cliff Farmer	Marisa Sivell & Richard Sivell
Christine Gordon	

\$500

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

Anonymous	Peter Noonan
Joyce Bennett	Play for Purpose
James Callum	Jan Samuels
Halcyon Management Unit Trust	Sigmattech IT Services
Warren and Jacinta Kane	Doug & Lesley Sivyer
Kerry Milliner	Sharyn Woodward
Peter Nash	

\$200

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

Anonymous	Alana Hill
Cate Barrett	Shane Kelly
Cindy Benjamin	Margaret Moss
Margaret Buchanan	Bob Rankin
Susan Campbell	Malcolm Scarr
Brett Collins	Dorothy Smyth
Fay Cutmore	Appelien Stride
Eric Denham	Amaya Stubbs
Jean Farmer	Carol Thornton
Final Touch Australia	Bill & Caroline Van Heel
J Hartkopf	Janifer Willis

DIRECTOR PROFILES

Jason de Bakker – President (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.

Shane Kelly – Vice 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.

Della Nicholson – Treasurer (joined 2020)

Della joined the Huntingtons Queensland board with a strong background in accounting and business management. Della's work allows her to engage with people from all walks of life and she has valuable experience with the NDIS and not-for-profit organisations. Della is a proud volunteer, supporting a range of community organisations and social networks.

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.

Belinda Jane Dolan – Director (joined 2021)

Belinda Jane is the CEO of a leading peak performance and leadership company. She has served on boards and committees in eight countries and has won 13 international awards, including Entrepreneur of the Year in 2017 and Company of the Year in 2018. In 2019 Belinda Jane's company won the Gold Stevie Award for Australasia's first Chief Happiness Officer's program. Belinda Jane is completing her PhD and in her spare time takes on extreme adventures, such as tackling Mt Everest and ultra-racing in the North and South Poles.

Gerry Doyle – Director (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.



PRESIDENTS REPORT



Dear members and HD community

It is my pleasure to introduce this year's annual report, and to share with you some of the work your board and team have been working on over the past 12 months in serving the Huntingtons community in Queensland.

This year a key priority for the board has been to focus on the organisation's ongoing sustainability and ensuring we meet the current and future needs of the HD community.

There are increasing demands on services like ours, including pressure on our financial resources, which means we need to remain agile and resilient in the face of change.

Like many other small charities, we are moving away from the outmoded concept of being 'not for profit' and repositioning ourselves in a more contemporary way, with a focus on 'profit for purpose'. This shift in strategic mindset is drawing us away from being wholly dependent on others, while retaining our charity/tax deductible donation status. It simply means we will be taking a more entrepreneurial approach to raising funds in new ways that can be poured back into our services for the HD community. You will read more about our new initiatives elsewhere in this report.

Our success will depend on continuing to adapt to change, respond to opportunities, adopt new technologies, further streamline our processes, and partner with others to achieve our goals.

Another important development this year has been further consolidation of national initiatives, most notably the Consortium of Australian Huntingtons Associations (CAHA), which was nurtured into existence in early 2020.

CAHA comprises the Chair and CEO or executive leader of five State HD Associations, who now meet monthly by video conference to consider opportunities and issues that affect us all. Its primary aim is for members to act collaboratively, where this is more effective than acting independently at a state level, to improve the lives of Australians impacted by Huntington's disease.

We do this by considering strategies for sustainability, fostering greater cooperation between Associations, working on nationally consistent statements and policy positions, and where appropriate, submitting joint funding applications.

With the approval of State Association boards, CAHA members have also commenced a feasibility study which is looking at models and options to achieve greater outcomes for the Australian Huntington's disease community. This is a very exciting initiative, and we are looking forward to how the project evolves in the year ahead.

CAHA is also working with one of Huntingtons Queensland's great friends, HD researcher and academic Professor Julie Stout, from Monash University. Professor Stout has secured a significant grant from the National Health and Medical Research Council (NHMRC) to develop a national plan for HD. You can read more about this initiative, the Huntington's Disease Network of Australia (HDNA), in our CEO's report on the following pages.

On the subject of research, we were all saddened by the cessation of the Roche and Wave trials earlier this year.

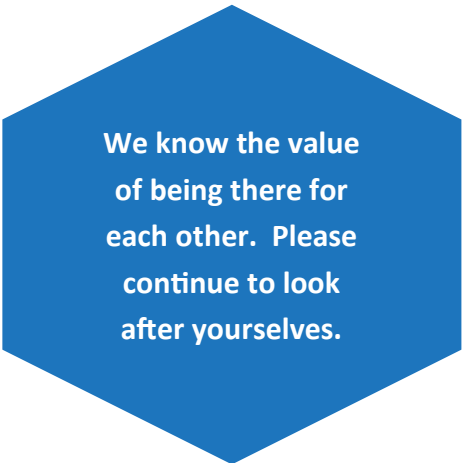
Our hearts go out to the many dedicated researchers and clinicians who contributed to these trials – many of whom were as devastated as our community was by the setbacks to their ground-breaking work. We wish them courage and godspeed as they continue their crusade to find a treatment and cure for Huntington's disease.

As an organisation we remain committed to supporting research efforts to find treatments and a cure for HD. We know this is one of the most important issues for our members. To that end, Jan Samuels continued to represent Australia as a member of HD-COPE, the international HD Coalition on Patient Engagement, which is overseen by the HD societies of America and Canada. While the HD-COPE model has changed in recent months, it remains firmly committed to its goal: to ensure the HD community is heard in the development of research, clinical trials and potential treatments. There is powerful evidence to show that patient engagement can lead to passionate and innovative collaboration, while ensuring that the human cost of HD is not lost in a laboratory environment.


Next, I would like to acknowledge my colleagues and fellow travellers.

To all members of the Huntingtons Queensland board, past and present, thank you for your commitment to the HD community. This year we've farewelled several board directors due to work and family commitments. I'd like to acknowledge Cate Barrett, Donna Burns, Susanna Mantovani and Shane Stoddart for their generosity in sharing their time, knowledge and expertise with the board and the organisation.





We know the value
of being there for
each other. Please
continue to look
after yourselves.



My deepest
sympathies are with
those who have lost
loved ones this year.
You are in our
thoughts.

I would like to especially thank Cate Barrett, who has supported Huntington's Queensland for more than seven years, including in the position of Vice President. This year we welcomed Belinda Jane Dolan as a Director and Tamara Winch as Secretary.

On behalf of the board, I would also like to thank our small, dedicated and committed staff team. Notwithstanding the ongoing challenges of COVID-19 and other significant events, you have continued to provide services and support for the HD community, to be with them during these difficult times. We are also grateful for the leadership of our CEO, Jan Samuels, who is stewarding the team and organisation through change and ensuring the organisation is in good stead to seize the opportunities ahead of us.

The services and activities we offer are only possible thanks to the generous contributions from Queensland Health, our benefactors and donors. Thank you for your ongoing support.

This will be my last report to our members as President of Huntington's Queensland. I have stepped down from this role to accept the position of Chair of CAHA, the Consortium of Australian Huntingtons Associations. This new role will enable me to focus on improving the services and outcomes for all Australians living with Huntington's disease. It has been a privilege to serve Huntingtons Queensland, and I will remain engaged with the board as a director and will continue to be involved in state activities.

We are fortunate to have Shane Kelly step in to the role of President. Shane has been a member of the Huntingtons Queensland board since 2018 and brings extensive professional experience from his commercial and consultancy career. Shane is also a passionate fundraiser for our organisation and has family members impacted by HD.

The year ahead will come with a new set of challenges as we continue to learn to live with COVID-19 and the other challenges we as individuals, families and a community face. We also have much to look forward to through increased opportunities to come together, upcoming trials and research, online events connecting us to our interstate and international communities, and the projects initiated through CAHA and HDNA. As a community and an organisation, we know the value of being there for each other. Please continue to look after yourself and each other, and know that we will be there by your side.

JASON DE BAKKER
President

TREASURER'S REPORT

The 2020-2021 financial year has continued to present Huntingtons Queensland with challenges with regard to delivering services and increasing revenue.

In common with many other businesses, our ability to support clients and their families has been somewhat restricted by the ongoing disruption caused by the pandemic, while several of our community-led fundraising events were cancelled due to COVID uncertainty and lockdowns in south-east Queensland. In particular, we missed the annual Running for Nan's HD and Hike for Huntingtons weekend, both of which were cancelled for the second year running. We hope they will be back on our community agenda in the not-too-distant future.

Despite such challenges, our team fulfilled the services we are contracted to deliver by Queensland Health, including non-clinical counselling, information services and support groups (most of which were forced to move online). We were also fortunate to receive a one-off funding grant from Queensland Health to deliver support to families impacted by Huntingtons disease in the reporting period. The COVID-19 Immediate Support Measures package enabled us to:

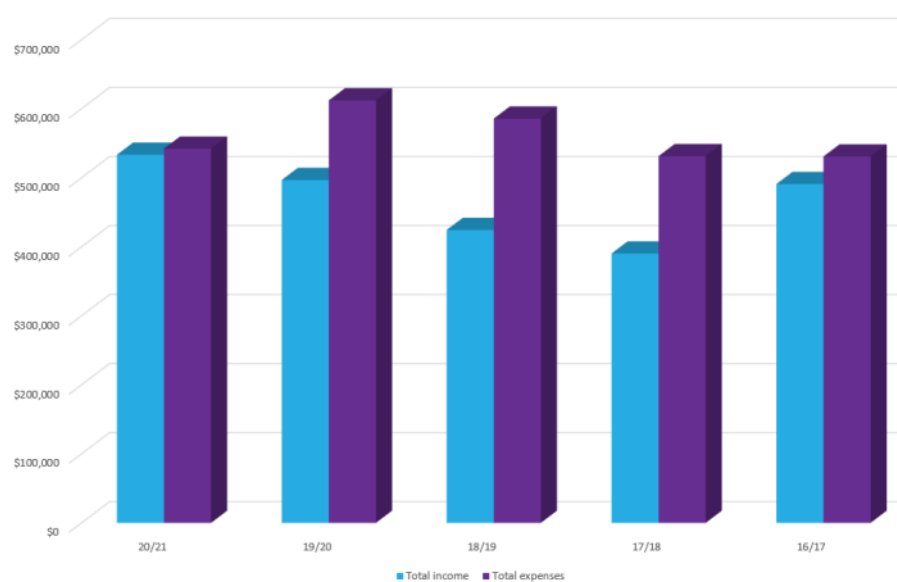
- **Provide communications and IT equipment** to vulnerable Queenslanders living with Huntington's disease, with the goal of keeping them connected to family members, our frontline service team, and relevant health professionals; and
- **Offer telehealth counselling services** with a psychologist experienced in the challenges of Huntington's disease, with the goal of helping people impacted by HD to maintain wellbeing and build resilience.

Given the demand for telehealth support, Huntingtons Queensland made the decision to keep funding gap payments for our clients who continued to access the psychologist's assistance after the grant ended. To help continue the program, our 2020 tax appeal centred on raising funds for this purpose, and I am pleased to note that more than \$13,000 was donated to this cause.

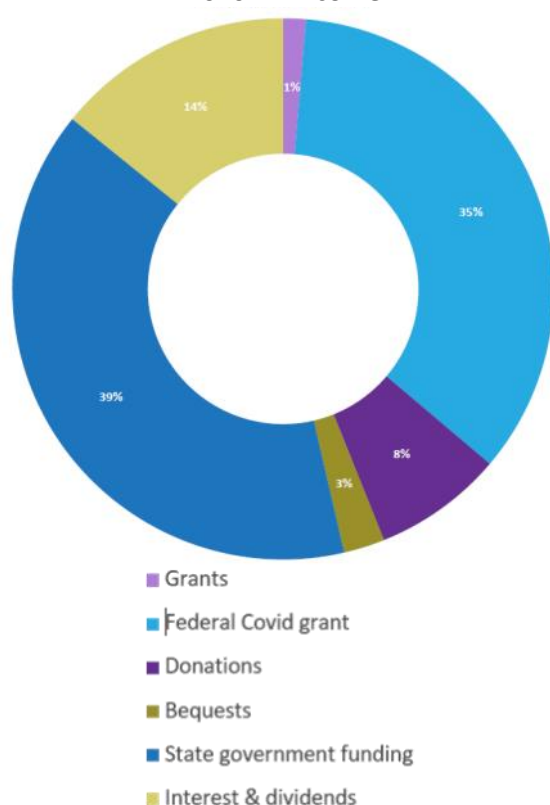
As noted in the financial accounts, Huntingtons Queensland recorded a deficit in the 2020-2021 reporting period.



Five-year comparison of income vs expenses



2020-21 income



While the Association currently has solid reserves due to the sale of our premises in February 2020, the board is well aware of its responsibility to ensure the long-term sustainability of the organisation. To that end, we are implementing a range of strategies to halt any further decline and increase revenue in the year ahead. This includes continuing our vigilance in managing costs while identifying new income streams through fundraising, fee for service activities, the pursuit of grants and possibly new government funding.

Our investment advisers, Bell Potter, continue to monitor and manage our investment portfolio. During the reporting period the board has made the decision to rebalance our existing portfolio and invest some of the proceeds from the sale of Florence Dannell House into making our investments work harder. With the market providing opportunities for growth – at the time of writing – we look forward to positive results in the year ahead to support our ongoing sustainability.

Many of our essential services are not government funded and can only be offered thanks to the generosity of our donors and supporters. Unfunded work includes:

- Assisting people impacted by HD to plan for and prepare their applications for NDIS funding;
- Supporting families (and staff) at the severely stretched monthly HD outpatients clinic at the Royal Brisbane and Women's Hospital;
- Offering education for service providers who are caring for a person living with HD; and
- Putting on special community days and events to help families take a break from HD and connect with others who may be going through similar experiences.

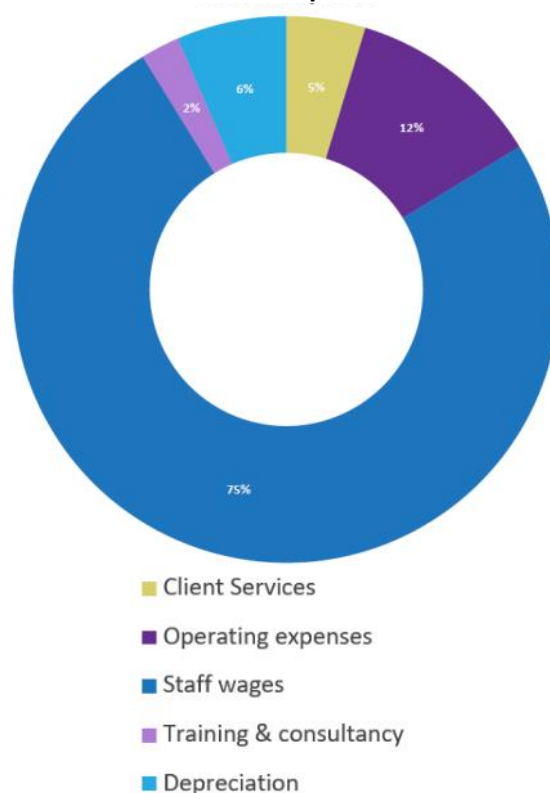
These services are fundamental to our mission and purpose, and we remain committed to delivering them across the state as best we can.

In closing, I would like to acknowledge the pro bono support Huntingtons Queensland has long enjoyed from Minter Ellison, our legal advisers. Minter Ellison gave us excellent advice and support during the sale of our premises in early 2020 and continue to provide truly valuable counsel on several strategic initiatives that are currently under consideration by the board.

I would also like to thank our hard-working team, who have continued to support HD families to the best of their ability and within the resources we have available, making a positive impact on the lives of many around the state.

DELLA NICHOLSON
Treasurer

2020-21 expenses



MANAGEMENT REPORT

As with many other businesses and not-for-profit organisations, 2020-2021 year has proved to be another challenging year, thanks to the ongoing impact of COVID-19 on our clients and our own work. However, it has also presented a great opportunity for us to reflect on our services and how we might improve and extend the support we offer to families impacted by Huntington's disease.

As we all learn to live with – and shape – the 'new normal' our team has used the past few months to review your feedback on our services and the role we are privileged to share in your lives. Under our board's direction we are also working on some new strategic priorities that aim to optimise the quality of life for people impacted by HD and contribute to the sustainability of the Association.

One exciting development is the introduction of a new service to help educate support workers and services providers who are caring for a person with HD. The need for such training has been highlighted by the advent of the NDIS, and the financial packages that some individuals with Huntington's disease are now able to access. We will be ramping up our information and education program in the 2021-2022 financial year, with the aim of ensuring support workers are aware of the unique challenges of HD and have the necessary awareness and strategies to provide quality and appropriate care.

The impact of isolation, the importance of nurturing good mental health, and the difficulty in maintaining meaningful connections have been broad themes across the country in 2020-2021. Sadly, these are not new issues for the HD community, and have indeed been compounded by the pandemic.

I am pleased to note the ongoing impact of a COVID-19 Immediate Support grant that we secured in the early part of 2020 to assist our community. This special grant, funded by Queensland Health, enabled us to buy computers, iPads and other equipment to help families stay connected with each other and their health providers, as well as offering a means for respite from the challenges of living with HD in lockdown.

While our ability to offer face-to-face support and to travel regionally was somewhat restricted in the reporting period, we have added online services and virtual groups to our services to help people stay connected and feel supported. Of course, this is no substitute for personal contact, and we recognise that not everyone has either the means or the interest to take part in virtual activities.



However, the uptake of online connections has been encouraging and your feedback has shown the value of this approach in increasing access to our team and other resources.

Other casualties of the corona virus in 2020-2021 were the cancellation of annual events such as the Alecca McKinless Forum, our ever-popular community days, and fundraising activities held by supporters to raise much-needed funds for our services. We have all felt the loss of these events and the chance they have for people to connect and build a sense of community.

These cancellations also help to explain why our annual report is a bit short of images this year – and we hope for bigger and brighter things in the year ahead.

While face-to-face events undoubtedly proved a challenge this year, we were pleased to take part in an online national conference, hosted by Huntingtons NSW/ACT, in May.


It was the first national Huntington's disease conference in some years, and we were pleased to be on the organising committee. The conference was held over several days and times to allow as many people as possible to participate. Sessions were recorded and made available to delegates later. Highlights included presentations by several overseas speakers, who we could not have afforded to bring to Australia under normal circumstances.

2020-2021 also brought opportunities for Huntingtons Queensland to work more collaboratively with our state association counterparts. Building on work initiated by Queensland in 2019, the state HD association CEOs have met regularly by videoconference to share resources and knowledge, and to begin developing a national 'voice' to raise awareness and achieve better outcomes for the HD community.

Initiatives in the reporting period have included the development of joint statements on a range of policy issues, including support for Deutetransazine to be added to the PBS, and submissions to:

- The Disability Royal Commission
- The Younger Persons in Residential Aged Care national strategy
- The Aged Care Royal Commission and
- The parliamentary inquiry into independent assessments within the NDIS.

It is well recognised that organisations that have a national reach and consistency have a far more likely chance of 'cutting through' at a political level. As such, we are committed to continuing our collaborative approach in the year ahead.



We are working on new initiatives to help optimise quality of life for people with HD.

This year brought new opportunities to work collaboratively with other states.

Huntingtons Queensland has also played an active role in an exciting new initiative being led by Professor Julie Stout at Monash University. Professor Stout has secured a significant amount of funding over several years to develop a national HD network, which has three key aims to:

- Phase one: Capture in-depth data about families impacted by Huntington's disease, including the mapping and establishment of an HD registry;
- Phase two: Ensure Australia is ready to lobby for and benefit from advances in treatments and a cure, should they come to hand; and
- Phase three: Advocate for more appropriate models of support and care for people impacted by HD.

Long-term director Gerry Doyle and I are part of the initiative's HD mapping group, and other members of our board and team stand ready to take part in phases two and three of the project.

One of the major milestones for Huntingtons Queensland this year was the sale of our premises in Annerley. The property was purchased thanks to a very generous bequest from the late Florence Dannell, who left her estate to the Association after receiving ongoing visits from one of our long-serving (and now retired) former staff members/volunteers. Florence's gift will keep on giving for the benefit of HD families across Queensland.

I would like to thank our fantastic Administration Coordinator, Cathy Holland, for her precision and good humour in organising our team and supervising every aspect of the move.

Huntingtons Queensland relies very heavily on community support and the generosity of our donors to keep our services going. Your support is crucial in keeping our services available, and we are so grateful for your trust in our work. We couldn't do it without you. Thank you.

We were very fortunate to receive support from the government's JobKeeper package in this reporting period. This made a significant contribution to our coffers, and enabled us to keep the doors open, our team in work, and



Clockwise from above: Jen, Cathy and Tressa pack up and relocate our operations from Annerley to Yeerongpilly.



our services operating – even if it was in a virtual world from time to time. Financial sustainability to a challenge for many small organisations such as ours and remains a top priority for both the board and our team.

We cannot round off the 2020-2021 year without acknowledging one of the great disappointments for the HD community worldwide: the abandonment of both the Roche and Wave clinical trials within a week of each other in March.

While the treatments being tested appeared to have merit, external evaluations indicated that the benefits of the Roche drug were not enough to warrant the trial's continuation, while the Wave drugs appeared not to be working effectively.

It was crushing news, but both trials have provided essential knowledge and valuable learnings that will help to guide next steps in developing treatments for HD.

Both Wave and Roche have confirmed they remain committed to research into HD, and we remain hopeful of new developments and innovations in the years ahead.

It is 45 years since Huntingtons Queensland was established. As we look back over the past year, I would like to offer my thanks to the many people who work by your side.

- First, thank you to our volunteer board of directors for their generous commitment of time, experience and passion. Your skills, experience and direct links to HD inform everything that we do.
- Next, my deep thanks and gratitude to our team for their ongoing dedication to the HD community and their determination to make a difference in the lives of others.
- Thirdly, I acknowledge and thank my interstate colleagues for their strategic intelligence and willingness to work together.

Finally, I would also like to thank you, our members, supporters and the broader HD community, for your patience and understanding – and for the support you offered our team as we worked hard to be here for you.

We look forward to being of service to you as together we front up to the challenges, impact and some-time triumphs of living a life impacted by Huntington's disease.

JAN SAMUELS
Chief Executive Officer



SERVICES REPORT

Our HD Advisers and support staff have worked hard to assist families impacted by Huntington's disease over the past 12 months, despite the many challenges we have all faced in the second year of life in a pandemic.

At a glance, Lauren and Tressa provided more than 330 hours of face-to-face support and a further 364 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 essential in 2020-2021. Despite COVID restrictions our team still managed to deliver regional outreach services and clocked up more than 200 hours travel time to ensure they could see and assist as many people as possible.

Tressa and Lauren facilitated and attended nearly 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.

The team also offered carer support groups via videoconference, and during the South-East Queensland lockdown in early 2021 had a set time on Zoom for people to simply log in if they wished to talk about any issues or concerns.


NATIONAL DISABILITY INSURANCE SCHEME

Since the National Disability Insurance Scheme (NDIS) was introduced in 2016, Huntingtons Queensland has been privileged to work with many individuals who now receive NDIS packages.

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.

Data from the National Disability Insurance Agency shows that as of March 2021 some 945 people with Huntington's disease around Australia now have an approved NDIS plan.

While the increase in NDIS packages is pleasing to see, it is still a long way short of meeting the needs of all people whose symptoms are progressing over time. Helping people to access the NDIS remains a priority for our team, and a service that we will continue to offer and promote in the year ahead.



1,100 hours of
direct client
advocacy

200 hours
spent travelling
around the
state

40 support
groups held in
person and
online

More than 330
hours of face to
face support

364 hours of
non-clinical
counselling

18 information
and education
sessions

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

Providing information, advice and strategies that help to optimise the quality of life for people impacted by Huntington's disease has been a key element of our work on behalf of HD families since the Association's inception 45 years ago.

Our information services are intended to help people make informed choices and access appropriate services and care in line with their individual circumstances. We do this by offering a range of resources (such as our website, social media platforms, printed materials and newsletters) and activities (such as support groups, non-clinical counselling, and special events like our annual forum).

We also work with service providers to ensure their workers have the knowledge, skills and strategies to support a person living with Huntington's disease, whether at home or in settings such as supported accommodation, aged care facilities or hospitals.

In the reporting period our team delivered 18 fee-for-service information and education sessions to service providers. Our sessions are designed to optimise the care of the person with

HD, with topics tailored according to the person's needs and any gaps in knowledge or skill identified by the support workers and their managers.

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.

Left: Lauren (on screen) delivered education by Zoom to a regionally-based care team during the COVID lockdown.



The Australian Institute of Health and Welfare (AIHW) data indicates that in the reporting period there were more than 350 people with Huntington's disease living in residential aged care – including 74 people in Queensland (21 people under 65 and 53 people aged 65 or over).

Huntingtons Queensland provides information about Huntington's disease and its impact to the healthcare sector, including allied health workers and GPs, who may only rarely come across a patient with HD in their daily practice.

Offering tailored education and training sessions for service providers, healthcare workers and allied health practitioners is a key strategic priority for our board, and we will continue to increase our profile and delivery of such sessions in 2021-2022.

A recent client survey indicated that many people are concerned about the general public's lack of awareness about Huntington's disease and urged us to do better in educating and informing the public. While we agree that this is a concern, our very limited resources and the rarity of HD make general awareness-raising both difficult and costly.

To help mitigate against this, one of our priorities in the 2021-2022 financial year is to revamp our website structure and content to offer resources that can be downloaded and shared by community members as required. We are also committed to working with our interstate colleagues to improve consistency and messaging to raise awareness of HD and the challenges it can present for those impacted by the disease and their families.

CLINICAL CARE

As many families around Queensland know, it can be incredibly difficult to access appropriate clinical care in a timely manner right around the state. The problem is compounded by a dearth of general health practitioners who have either the knowledge of or experience in supporting a person with Huntington's disease.

Over the past year, Huntingtons Queensland has worked with health services and GPs in both metro and regional areas who have a person living with HD on their books, often for the first time. In these circumstances our team provides information for the GP and their patient, and if requested to do so, advocates for the person on occasions where the health professional may have little knowledge of HD or when neurodegenerative symptoms make the person's care needs increasingly complex.



Getting together at a support group in Mackay.

Finding ways to stay connected was an essential part of everyone's lives this year.

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 stays 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. Huntingtons Queensland receives no government funding to provide this highly valued service, which can only be offered thanks to the generosity of our donors and supporters.

Waiting lists to see the clinic team stretch to months and, with COVID restrictions causing the cancellation of several clinics in the reporting period, lists are growing ever longer. While the clinic team always does its best to offer alternatives such as telehealth consultations, face-to-face assessments and appointments are critically important to managing HD well.

Government funding for clinical support is also in short supply.

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.

"I just wanted to thank you for the group chat. I really appreciated hearing from other carers."

"Thank you sincerely for your assistance. Without you I don't believe this outcome would have been possible."

For all these reasons, encouraging the investment in, and support for, greater clinical services around the state is a high priority for our members and clients.

We also believe that Huntingtons Queensland could play a valuable role in future, by helping to reduce pressure on clinicians and the Brisbane HD clinic. For example, it may be possible for our team to either offer or coordinate non-clinical support and access to allied health and other professional care outside the hospital setting – services which are currently unfunded but sorely needed.

Our aim would be to complement, not replace, the valuable and expensive clinical care required by people living with the progressive physical, cognitive and psychological symptoms of HD, not only in ‘well serviced’ metro areas but in the regional and rural parts of the state as well.

ADVOCACY

Huntingtons Queensland’s advocacy program has two parts:

- Working with and advocating for people living with HD as they navigate social services such as healthcare, housing, disability and support pensions; and
- Working with our state HD association counterparts to advocate for social and policy changes.


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

Australia’s state and federal government systems can be highly complex and navigating them takes time, experience and often a great deal of resilience.


Feedback from clients and our team’s own experience confirms that people living with Huntington’s disease often have additional challenges, because HD does not fit neatly into one category or another and the risk of ‘falling through the cracks’ is high.

The nature of HD means that people often come face to face with the police and justice system, where advocating for their rights and better understanding are an important part of our work.

We also work closely with the Public Guardian, Public Trust and other relevant agencies to ensure the needs of people with HD are both understood and supported as their symptoms progress.



Funding for additional clinical services is a high priority for our members.



Spirited advocacy can make a big difference in the quality of a person’s life.



One of our clients benefiting from the purchase of equipment funded by a one-off grant from Queensland Health.

Other agencies with whom we interact are Genetic Health Queensland, Centrelink, advisers involved in advance care planning and the establishment of enduring powers of attorney (EPOAs), and private services such as financial planners, legal services and on occasion individual employers.

Housing is another area where spirited advocacy can make all the difference in a person's life. Access to appropriate housing remains a significant issue for many people living with Huntington's disease and their families.

The crisis in housing is not a new issue.

However, the COVID pandemic has undoubtedly exacerbated the risks for people impacted by HD, with escalating housing shortages, expensive rents and poor housing stock availability. 2020-2021 has seen several of our clients being evicted from their homes or forced to live in substandard and often dangerous conditions, while others have been admitted to hospital for long periods of time or moved prematurely into aged care.

Huntingtons Queensland strongly supports people having access to accommodation that meets their needs and optimises their quality of life – including their physical and mental wellbeing. Advocating to achieve this goal featured heavily in our work this year.

In 2020-2021 our two frontline HD advisers spent more than 1,100 hours on direct client advocacy and support. This included identifying service needs (and providers), setting up referrals and coordinating appointments, gathering evidence and writing letters of support, attending meetings (and following up on them afterwards), underpinned by extensive notetaking and record-keeping activities.

Again, this type of work has been a core part of Huntingtons Queensland's work since our earliest years and continues to be a high priority. While some of these services are funded by Queensland Health, most of this work is funded through donations and bequests.

Such support is essential in helping us to service the HD community and we very much look forward to continuing our service in the year ahead.

**Thank you from
all our team for
trusting us to
be by your side.**



A big thank you to our community heroes.



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