



HUNTINGTONS *By your side*
queensland



ANNUAL REPORT

2021-2022



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OUR COMMUNITY

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 Gerry Doyle
^ Joined during the year	
Resigned during the year: Belinda Jane Dolan, Della Nicholson	
Operations Manager	Shaun Riley
Client Services	Theresa Byrne Lauren Ward
Finance	Jennifer Lysiuk
Administration	Cathy Holland
Communications	Lisa Kibsgaard
Retired February 2022: Jan Samuels, Chief Executive Officer	

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 4.2 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.

A big thank you to all the wonderful people who have volunteered their time in support of the HD Community.

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.
- **Sigmattech IT Services** for their generous assistance; and
- **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.

THANK YOU

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

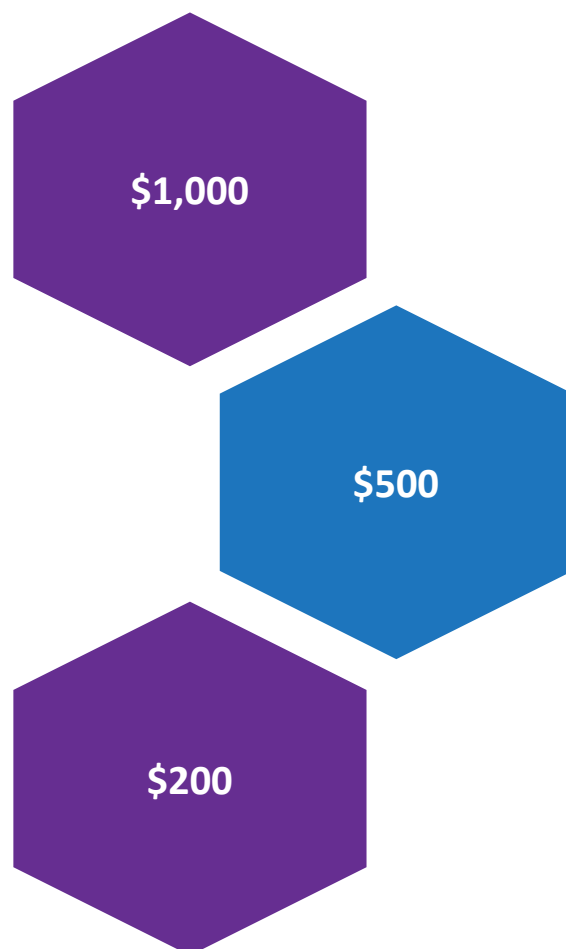
Anonymous	PayPal Giving Fund Australia
Adam Wells	QBE Insurance
Angelika Straker	Ray Huggins
Gaminder Pty Ltd	Robina Lions Club
Harcourts Property Centre	Strathpine Bowl

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

Anonymous	Margaret Buchanan
Deborah Howe	Mavis Pilla
Doug & Lesley Sivyer	Pete Hill
James Callum	Peter Nash
Jan Samuels	Peter Noonan
Jean Heimgartner	Richard Sivell
Jennifer Lysiuk	Sue Kelly
Joyce Bennett	Susan Howe
Kelly Connolly	

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

Anonymous	June Long
Brett Collins	Kaye Jeffery
Bruce Perkins	Malcolm Scarr
Carol Thornton	Margaret Bruce
Cheryl Dowling	Margaret Moss
Christine Taylor	Marion Cottee
Cindy Benjamin	Nicole Lofting
Eric Denham	Roslyn Cooper
Irene Golby	Sharon Dorward
J Hartkopf	Shirley Timmins
Jarrold Shandley	Susan Campbell
Jean Farmer	Tony Samuels
Jillian Kriedemann	Vicky Nicholson
Joan Cogill	



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 is a member of a national Project Steering Group providing oversight and support to the feasibility study to merge existing 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 annual report.

It is my opportunity to share and celebrate some of the great work the team has achieved this year and update you on our key priorities at present. It has been a year of difference with COVID-19 still affecting our daily operation well into the year. The team has remained focused on our number one priority - supporting Queenslanders and the families impacted by Huntington's disease. I am particularly proud of the personal commitment and family support our client services team, Lauren Ward and Tressa Byrne, provide every day to our Queensland HD families.

This year we also welcomed our new Huntingtons Queensland Operations Manager Shaun Riley as the lead of our team. Shaun has extensive experience in aged care, community services, NDIS, at Director level and has hit the ground running leading the team with care and compassion and immersing himself in the HD community. He has also stepped into the Consortium of Australian Huntington's Associations (CAHA) working group and added much value to what a national model should look like. Of course, all this only happens with our office running efficiently and effectively. I extend thanks and acknowledge Cathy Holland, Jen Lysiuk and Lisa Kibsgaard who work tirelessly to keep the office, events, finances and our communications to such a high standard.

I also wish to acknowledge our volunteer Board who bring experience, passion, wisdom, selflessness and empathy in all they do. We have welcomed two new Board members this year, Angela Abell and Nick Murray, who have added immense value and insight to the board. Along with the longer serving Board members, myself, Gerry Doyle, Jason De Bakker and Tamara Winch, we have continued to serve the interest of the Queensland HD community and families. My sincere thanks and appreciation to each of you for your unwavering commitment to the Huntingtons Queensland Board and those we support.

We continued this year to focus on the Board's key priority - the organisation's ongoing and long-term sustainability and ensuring we meet the current and future needs of HD families and community.

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 value to our clients, families and our team members to ensure long-term sustainability.



Our success will depend on continuing to adapt to change, respond to opportunities, collaborate more, adopt new technologies, further streamline how we engage clinicians and NDIS, and partner with others to achieve our goals.

To this end, we have worked hard to progress another important development this year, most notably the Consortium of Australian Huntingtons Associations (CAHA), which commenced in early 2020. Five states have worked very collaboratively through the feasibility phase, due diligence of each state and finally developing an end-to-end detailed transition plan on every step, consideration and possible risk identified and documented.


To demonstrate the importance of this collaboration our former Huntingtons Queensland president, Jason de Baker, stepped back from chairing Huntingtons Queensland, to enable him to focus on and Chair the CAHA national working group with the five states. Even with these additional responsibilities, Jason has remained an active Board member of Huntingtons Queensland. In addition, I have been a member of the CAHA Project Steering Committee since inception.

Along the journey, 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 CAHA working group and Project Steering Committee.


Huntingtons Queensland Board 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 and voice with government, clinicians, medical research companies, fundraisers, supporters and, of course, our clients and their families. One of the key outcomes from this merger would be enabling HD support teams to better provide and support NDIS services for our clients.

Every one of the five states HD Boards have now voted to support the implementation of the merger with execution occurring from January 2023 to completion on 30th June 2023. We hope you have received the communication updates on this proposed merger to form a National HD body. Please feel free to reach out to Shaun sriley@huntingtonsqld.org.au if you would like more information.



We believe a national body is critical to raising our voice at a national level



For the year ahead please know the Huntingtons Queensland team will always be there for you and your family

The next and final step before embarking on the transition is propose a Special Resolution asking our members to vote on supporting the implementation of the National Body. This will occur in conjunction with our yearly AGM on 15 November 2022.

CAHA has already improved how we think nationally about HD, working together to consider sustainability, fostering greater cooperation between Associations, working on nationally consistent statements and policy positions and, where appropriate, submitting joint funding applications.

Throughout the year, CAHA has also continued 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. Professor Stout has progressed a number of initiatives during the year including the start of mapping to locate people impacted by HD and what services may be required into the future. The three key priorities of the Map-HD Registry are:

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

You can read more about this initiative at the Huntington's Disease Network of Australia's (HDNA) website hdna.com.au.

On the subject of research, we stay engaged with researchers and medical companies and continue to update in our regular newsletters and our website all available information on HD initiatives. We remain passionate that the researchers and clinicians find treatments and a cure for Huntington's.

After a two-year break due to covid, we again enjoyed hosting our Huntingtons Queensland Forum held in November 2021. It was a great opportunity to catch up in person with our members and hear from researchers, clinicians and those working in our support fields of HD.



Shane and forum speaker Luke Muir

Important to note, the services and activities we offer are only possible thanks to the generous contributions from Queensland Health, our benefactors and donors. Thank you all for your ongoing support. Financial sustainability is the major challenge to Huntingtons Queensland.

We rely on community support and the generosity of our financial donors to enable people and families impacted by HD to receive information and support from our specialist advisors.

We thank those who consistently donate to our service and fundraisers, who volunteer their time to raise funds, people who respond to appeals, and for the bequests left by people in their wills that are vital to keep our services operating. The common theme here is people and their generosity, thank you.

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.

The year ahead will come with a new set of challenges and opportunities. We have the work and projects of CAHA and HDNA now reaching a new level of activity and opportunity. We will have opportunities to come together, with community events, information sessions, online events and engaging with international communities, particularly via HD Cope and HDYO helping our young HD family members to engage with others and access information.

For the year ahead please know the Huntington Queensland team will always be there for you and your family.

SHANE KELLY
President

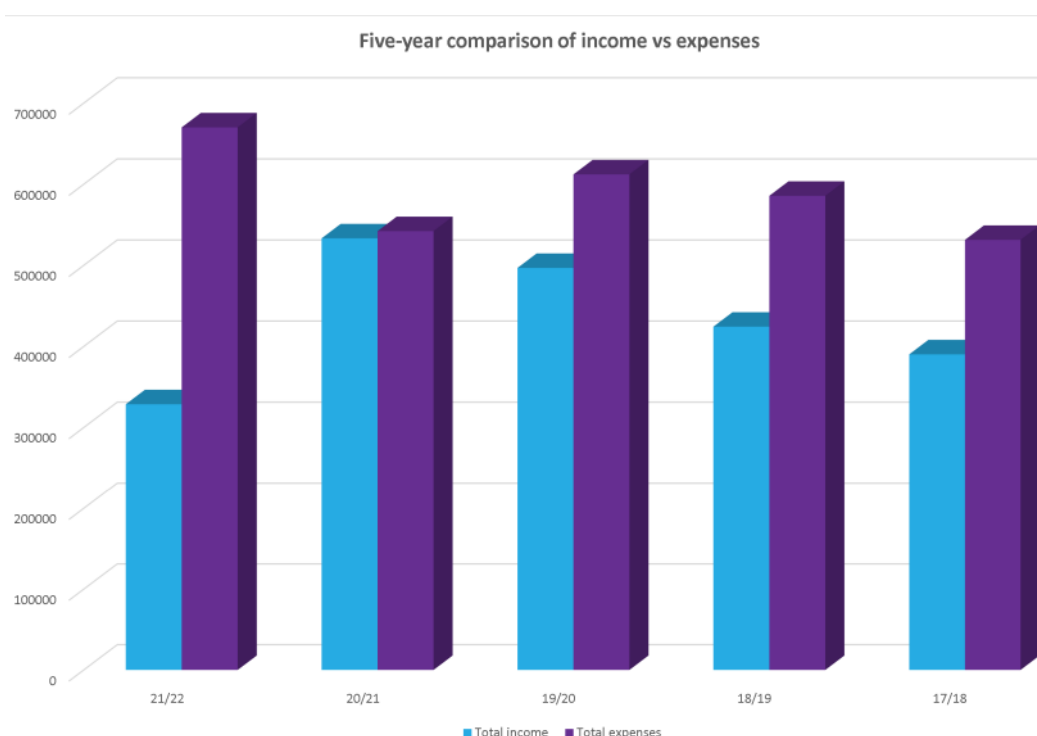
TREASURER'S REPORT

There have been numerous changes during the 2021-2022 financial year, from both an internal and external perspective at Huntingtons Queensland. This also includes a change in the treasurer position. I was fortunate enough to become treasurer of Huntingtons Queensland in February 2022, and must compliment all staff, volunteers, and directors on their tireless work for the Huntington's community.

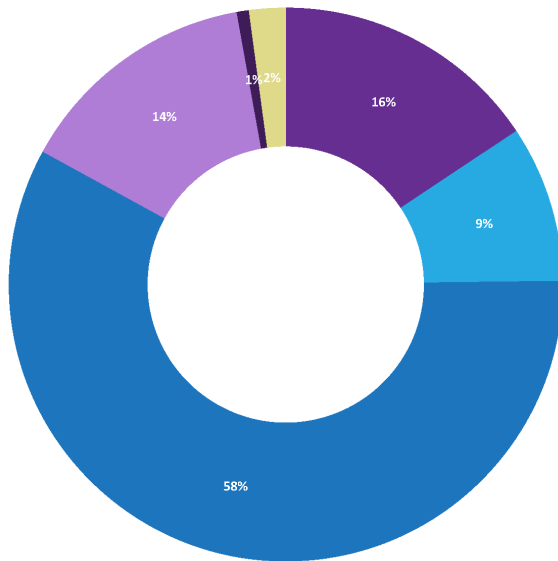
The COVID-19 pandemic has interrupted Huntingtons Queensland's ability to deliver all services, especially during the first few months of the financial year, with travel still being limited. Other external factors have also impacted travel costs. Flight and accommodation costs have increased dramatically, as well as motor vehicle fuel prices. These factors negatively impacted staff and reduced the opportunity to arrange support and group meetings across the state.

Excluding Western Australia, cost of living pressures have been felt more in Queensland than any other state. The consumer price index (CPI) in Queensland for June 2022 was 7.3% which is 1.2% greater than the Australia CPI for June. This is likely to have played a role in not only an increase in expenditure incurred by Huntingtons Queensland but also a downturn in potential donations received.

Huntingtons Queensland's investment advisors, Bell Potter, continue to oversee the investment portfolio held by us. Bell Potter is in communication with the Board, and provide detailed investment reports on a monthly basis to ensure we are kept abreast of the market.



2021-22 Income



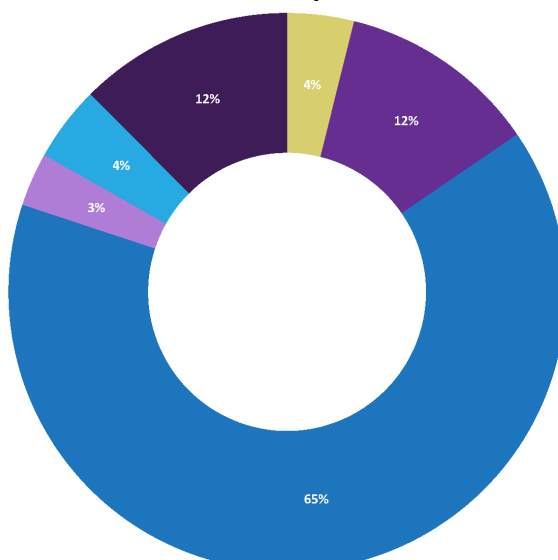
- Donations
- Bequests
- State government funding
- Interest & dividends
- Profit on Sale of Asset
- Membership
- Other income

External factors have resulted in a tumultuous equity market and, unfortunately, investment declines. The Board is diligent in respect to the investment portfolio held by Huntingtons Queensland and will continue to pursue Bell Potter's comments and advice.

As stated in the financial statements for the year ended 30 June 2022, Huntingtons Queensland recorded a net deficit. The Board consistently reviews the financial results and strives to improve them. While Huntingtons Queensland do have cash reserves that it can call on, it should be stated that we do need to ensure sizable deficits are not a common theme. Periodic expenditure reviews are conducted and discussed with management. Additional sources of funding have been considered by management and the Board, with research into various additional grants and NDIS funding. Alternative 'revenue streams' pave an exciting future for Huntingtons Queensland, which the Board hopes will mean that a larger number of people can continue to receive high levels of service.

As readers will be aware, Huntingtons Queensland has been in discussions with various other states in forming a national entity to better serve the needs of people impacted by Huntington's disease. I believe that a national entity will have more 'pull' in securing grant funding as well as receiving alternative 'revenue streams'. I believe additional revenue will ensure that all Huntington's disease stakeholders will continue to receive a high level of service, plus the potential for assistance in other ways.

2021-22 Expenses



- Client Services
- Operating expenses
- Staff wages
- Training & consultancy
- Depreciation
- Investment Loss

I would like to thank all Huntingtons Queensland stakeholders, but in particular the following:

- Minter Ellison, Huntingtons Queensland's legal advisors. They have continued to provide an amazing level of service to us at no cost. Minter Ellison has also assisted the wider Huntington's community with advice in respect to forming an Australia-wide charity.
- Bell Potter, Huntingtons Queensland's investment advisors as discussed previously.
- Shaun Riley, Operations Manager. Shaun was appointed as Operations Manager in February 2022 and continues to strive for improvements at Huntingtons Queensland.
- Jen Lysiuk, Finance Officer. Jen and I have worked closely together from a financial aspect, and I appreciate all her hard work.

NICK MURRAY
Treasurer

MANAGEMENT REPORT

The baton of the previous year was handed over to the new 2021-2022 financial year as we worked and provided services under the “new normal” of COVID-19 restrictions placed on businesses and the communities. The restrictions of lockdowns and isolation periods challenged the work and services of Huntingtons Queensland which often relies on face-to-face contact with clients and families.

Our staff met the challenges of the “new normal” and we adapted positively to operate and provide services in new and innovative ways. Working from home is now an accepted way of attending work, online team meetings are part of our communication with one another and with clients and families.

Jan Samuels, Chief Executive Officer with Huntingtons Queensland from 2016, resigned in February 2022 to retire to her native New Zealand. Staff past and present, and clients benefited from Jan’s direction and guidance during her operational leadership of Huntingtons Queensland and our best wishes went with Jan into her retirement. I, Shaun Riley, have been employed in the role of Operational Manager in replacement of Jan’s position. My career has been within health services, particularly in aged and community care services working at Director level within not-for-profit organisations.

Following the move of premises towards the end of the previous financial year our staff have settled into the new offices in Yeerongpilly. I would like to acknowledge the late Florence Dannell whose generous bequest to Huntingtons Queensland included our former premises in Annerley.

We introduced an information and education service to assist in the education and experience of support workers employed with direct service organisations caring for a person with HD. This new service has seen some demand in the latter months of the year when COVID-19 restrictions eased, enabling in-person training to take place. We will promote this service in the 2022-2023 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.

Our staff have embraced the greater use of technology within our work and in communication with government agencies, service providers and families enabling ongoing communication with each other. While our ability to offer face-to-face support and travel regionally was restricted in the reporting period, we have added online services and virtual groups to our services to help people stay connected and feel supported.



I am pleased to report that the Alecca McKinless Forum 2021 occurred after having been cancelled in the previous year due to COVID-19. We were delighted to welcome speakers from around Australia including Professor Julie Stout, a leading researcher into HD from Monash University. Presentations at the Forum covered mental health, speech and feeding issues, financial planning and research.

The year was a tale of two parts with the COVID-19 restrictions from July 2021 to February 2022 negatively impacting on community days and fundraising activities before easing of restrictions from March 2022 onwards.


Despite the COVID restrictions and lockdowns, I am delighted to inform that we were able to organise and share in a number of community and fundraising events. In August 2021, Huntingtons Queensland organised a community day at Australia Zoo for HD families and after an absence of 2 years the Running for Nan's HD fundraiser was held in May 2022. Running for Nan's is organised by Kel Connolly, a HD advocate whose Nan lives with HD. This wonderful event raises vital funds for Huntingtons Queensland. Participants can choose to walk or run 5km or 10km on routes along the Wynnum Esplanade.

Huntingtons Queensland, along with the four other State HD Associations of Tasmania, South Australia/Northern Territory, New South Wales and Western Australia formed a Consortium of Australian Huntingtons Associations (CAHA).


The five State Associations are represented on CAHA through Board members and operational managers. CAHA financed the engagement of external business consultants experienced in mergers of not-for-profit organisations, with the remit to consider whether the creation of a national body, joining together as one organisation is the best way forward for the five State Associations. At the heart of the considerations is whether this would be in the best interests of our HD community. CAHA worked with the external business consultants throughout the year.

The recommendation of CAHA to the Boards and Members of the five Associations is that the best interests of the HD community is best served with a single national entity with a focus to deliver better and additional programs and services, and to become more financially sustainable. The Boards and Members of the five Associations will consider the recommendation of CAHA in the new financial year.

Our administrative and financial processes are compliant with the guidelines of our funding bodies and Australian Accounting Standards.



Our staff met the challenge of the (COVID-19) "new normal" and we adapted positively



The Running for Nan's HD event provided a positive sense of community

Staff payroll, salary sacrificing, superannuation, PAYG, BAS and Government reports were compiled and delivered within prescribed timescales.

A full set of financial reports are regularly distributed to Board members.

Periodic financial and operational reports are compiled and sent to funding bodies within prescribed timescales.

As we look back on another tough year for the service and HD communities, I would like to offer my thanks to the people who make our work possible.

I express my thanks to our volunteer board of directors for their generous commitment of time, experience and passion.

I would like to thank our fantastic staff; Cathy Holland, Jen Lysiuk, Lauren Ward, Lisa Kibsgaard and Tressa Byrne for their work in support of clients, families and my position. Their work is invaluable and often goes unnoticed which is the sign of nothing going wrong. Well done and thank you.

I acknowledge and thank my interstate colleagues for the welcome they have afforded me and their strategic intelligence and willingness to work together for the benefit of the HD communities we serve.

I would also like to thank clients, family members and supporters for your patience and understanding and the support you offered our team.

We look forward to serving you and being by your side as together we face the challenges and of living a life impacted by Huntington's disease.

SHAUN RILEY
Operations Manager



This year we farewelled Chief Executive Officer Jan Samuels who has returned to her native New Zealand (with Huntingtons Queensland founder Cliff Farmer)



*Running for Nan's HD.
L to R: Shaun with Jewlie Halliday from Harcourts Property Centre and event creator Kelly Connolly*

SERVICES REPORT

Building networks, creating support systems and making a positive difference in the lives of our clients and their families are key to our work over the past financial year. Despite the challenges people in our HD community and others have faced since COVID-19 took its toll we have built on Huntingtons Queensland's strong foundation to continue delivering services and support in ways that bring positive change to our clients. All in all our HD advisors spent 267 hours in face-to-face meetings with clients and/or their families, and spent 190 hours travelling across the state. Mackay, Cairns, Rockhampton, Gladstone, Gold Coast, Brisbane, Gympie, Toowoomba, Logan, Ipswich, Townsville, Hervey Bay, Maryborough, Bundaberg and Sunshine Coast were all points of destination.

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.

Support groups in the first half of the financial year kicked up a gear after face-to-face meetings in the first half of 2021 were limited by COVID-19 lockdowns. It was wonderful to get on the road again and visit our regional communities once more. Tressa and Lauren facilitated 29 support groups throughout the year with 106 people attending. This allowed clients to continue fostering local connections, friendships and peer-to-peer support.

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


NATIONAL DISABILITY INSURANCE SCHEME

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

A key part of this service is helping clients collate what is needed to support their NDIS applications. These processes, such as completing paperwork and accompanying clients to medical appointments to obtain necessary evidence, are often too onerous for clients to complete without assistance.



"Everyone at Huntingtons Queensland is doing fabulous work on our behalf and we are very appreciative"



"This organisation is amazing it has helped me in a huge way"

Our HD advisors also advocate by participating in NDIS assessments and planning meetings to help our clients have their needs and wishes met.

Demand for NDIS funding has continued to increase considerably. With this increase our HD advisors are not only helping our clients navigate the NDIS application process but also receive multiple requests for NDIS providers who have experience with HD and from providers looking for information about HD.

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 NDIS service providers and their staff, or allied health providers, have limited information about or exposure to HD, our advisors often engage with individual clients' providers to help them develop the skills to support the client in the best possible and most appropriate way. During the financial year our team delivered 10 fee-for-service information and education sessions to providers. We expect this aspect of the service to continue growing.

During the financial year Huntingtons Queensland developed the ability to accept enquiries about education programs through our website. This has several benefits including efficiently capturing more information initially allowing for more accurate quotes and adapting the program to service the needs of an individual provider.

Huntingtons Queensland also has a range of resources available to help people learn more about the disease, how to access services and care in line with their individual circumstances. These resources are spread across a range of media including our website, social media, printed materials and our quarterly newsletter. Topics of interest include HD genetic testing, its impact on children, managing symptoms of HD, and updates on clinical trials from around the world. Information also is provided through our annual forum, support groups, non-clinical care and other special events.

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.

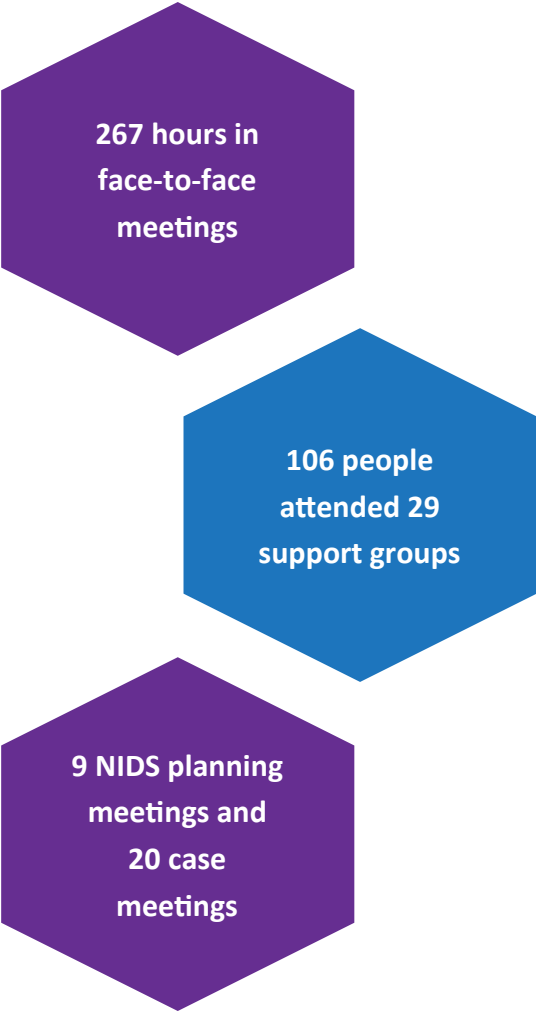


Townsville support group getting together for Christmas themed lunch.

10 information
and education
sessions

190 hours
spent travelling
around the
state

235 hours of
phone calls



267 hours in
face-to-face
meetings

106 people
attended 29
support groups

9 NIDS planning
meetings and
20 case
meetings

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.

Throughout the year our HD advisors have assisted doctors and other allied health providers in a bid to bridge any gaps in knowledge or skills and to ensure the best possible care for the client as their needs increase.

It also has been a privilege to advocate on behalf of clients for improved clinical care outcomes through meetings with behavior support specialists, mental health teams, support coordinators, families and others involved in caring for someone impacted by HD.

Our advisors continued to play a significant role in the monthly HD Clinic held at the Royal Brisbane and Women's Hospital. Support is offered to clients attending the clinic but also to the dedicated clinicians who staff the service.

Pre-clinic our advisors help clients to schedule, prepare for and get to their appointments and then stay with them on the day. We also ensure our client's needs and concerns are understood by the clinicians and any questions clients have are answered. Follow up with the person and any post-clinic services they require is also important.

This past year the clinic has provided both in-person as well as telehealth appointments due to COVID-19, the 2022 Brisbane floods and a client's ability to access the clinic.

The clinic is booked months in advance and wait lists continue to grow. The demand for services from the clinic further highlights the pressure on existing clinic staff, and their reliance on Huntingtons Queensland to help support clinic attendees. We are extremely grateful for the close working relationship that has been established between our HD advisors and the RBWH clinic. This partnership has proven to be of great benefit to people impacted with HD.

ONE ON ONE SUPPORT

Almost everyone who reaches out to Huntingtons Queensland has individual challenges that require time and one-on-one support from our team. This support takes up a large proportion of our time with about 235 hours spent on almost 500 phone calls, 267 hours in meetings with clients and 660 hours spent on client administration.

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.

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

ADVOCACY

No voice is too soft when that voice speaks for others.” – actress Janna Cachola.

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

Much of our individual advocacy is offered through one-on-one support as we help people interact with the health, disability and welfare sectors. In the 2021-2022 financial year our advisors spent more than 1100 hours on direct client advocacy and support.

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.



Brett is now living life to the full after accessing NDIS with the help of HD Advisor Lauren

**1100 hours in direct
client advocacy and
support**

OUR COMMUNITY

EVENTS



It was nice to see over 70 members of the HD community in person at our 2021 Forum

As COVID-19 continued to run its course and we began to live with a “new normal” Huntingtons Queensland was pleased to be able to resurrect some small group and key events on our annual calendar.

We were so pleased to be able to host the annual Alecca McKinless Forum after having to cancel the 2020 event. More than 70 people attended the November 2021 forum which included presentations from Professor Julie Stout, Huntington Queensland’s Jan Samuels and Lauren Ward, speech pathologist Shana Taubert, financial planner Luke Muir and neuropsychiatrist Dr Rhys Thomas. It was also a privilege to hear Angela Abell and Geri Kampen share their stories as members of HD families.



Running for Nan’s HD 2022

In May 2022 we were once again able to put on our running shoes for the Running For Nan’s HD fundraiser. With more than 100 people and a few loveable dogs pounding the pavement the event proved a huge success with almost \$10,000 raised. A huge thanks continues to go to event organiser and Huntingtons Queensland longtime supporter Kelly Connolly whose Nan, a great-great grandmother aged 94, lives with HD. Also our thanks to all of the participants and sponsors.

Running shoes weren’t the only type of shoe being worn during Huntingtons Queensland events this past financial year! More than 20 individuals and their families donned bowling shoes in November 2021 for the inaugural Huntington’s Cup community fundraiser in support of Huntingtons Queensland. The event was organised by teenager Chloe Marks and hosted by Strathpine Bowl with nearly \$1300 raised on the day. Thank you to Chloe, Strathpine Bowl and everyone who took part.

COMMUNITY DAYS



Our first community day in 2 years at Australia Zoo

Australia Zoo was the destination of our first community day in over two years! After a very tough few months of COVID-19 restrictions nearly 50 people from our HD community enjoyed a day at the zoo in August 2021. Huntingtons Queensland staff, clients, their families and carers loved the chance to get together and have some fun as well as building connections and boosting support networks. It could not have been possible without the generous funding from the Alecca McKinless gift.

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. After several months of operating in a telehealth format due to COVID-19 restrictions, the clinic again started accepting in-person appointments. Our HD advisors Lauren and Tressa were a mainstay of the monthly clinic – always there to support the staff and clients. Their efforts have been very much appreciated by all associated with the clinic.

In early 2022 Huntingtons Queensland offered its support to the Map-HD Registry, an initiative of the Huntington's Disease Network of Australia (HDNA). The registry aims to help HDNA understand who is affected by HD and to give them better access to clinical care and support services. Huntingtons Queensland has been instrumental in sharing information about the registry and encouraging families and individuals to take part in order to gain a fuller picture of HD across a national level.

At the same time Huntingtons Queensland also has fostered awareness of another HD initiative – the global JOIN-HD Registry managed by the Huntington's Disease Youth Organisation. Some of its aims include identifying and engaging people with Juvenile Onset Huntington's Disease in the collection of information that will speed up research into this disease; improving advocacy, care, and support for young people with JoHD and their families; and learning what people with JoHD and their families need so it can improve support and education programs.

A key partnership this year has been the ongoing work by five of our HD State Associations to merge into a single national entity. You can find out more about this partnership, the Consortium of Australian Huntington's Associations, in the President's Report on page 6.

RESEARCH

Research into Huntington's disease continued to move forward in the financial year, both in Australia and internationally.

While not having any direct role in research or clinical trials this year Huntingtons Queensland has worked tirelessly to help our clients stay connected with the latest research, and trial news and opportunities presented nationally and globally. Information in our newsletters and via social media has allowed us to get word out in a timely manner in a bid to advance any opportunities and keep people informed.



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Professor Julie Stout - a longtime and passionate advocate for people impacted by HD

On an Australian front, Melbourne's Stout Lab has continued its research into HD. The Lab, led by Professor Julie Stout of Monash University, conducts clinical research to improve understanding of Huntington's disease and other young onset neurocognitive disorders. Its research has focused on whether gut changes are linked to thinking and mood changes in HD, and also the effects of sleep, exercise and depression on HD.

People living with Huntington's disease in Queensland were invited earlier this year to take part in a new research project into health and ehealth literacy - the ability to find, understand, and use online and offline health information. Dr Travis Cruikshank, from Perth's Edith Cowan University, led the project which aimed to provide researchers with information needed to develop interventions for people living with neurological conditions and caregivers.

On an international level Roche Pharmaceuticals announced in January 2022 its Tominerson research program would continue with a new Phase II trial. The decision to proceed was based on findings from its GENERATION HD1 study in adults with manifest HD.

Throughout the year the results of several drug trials were updated. These included trials by Annexon, Wave Life Sciences, Novartis, PTC Therapeutics, Neurocrine Biosciences, Vaccinex, Uniqure, Triplet Therapeutics and Prilenia amongst others.

Other international research over the past financial year has included a focus on vitamin therapy for HD (Dr Jose Lucas); artificial intelligence and HD (IBM and the CHDI Foundation), and a new roadmap to track HD progression (Huntington's Disease Regulatory Science Consortium).

DIRECT MAIL APPEALS

As in previous years, Huntingtons Queensland has relied heavily over the past year on the generosity of our donor community, who step up in a fantastic way to support our annual end of financial year and Christmas appeals.

Donors responded generously to the two 2021-22 appeals, raising a total of \$22,230.



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