



Sponsors Patrick Ivey and Jewlie Halliday with Kelly Woodland, creator of Running for Nan's HD

# ANNUAL REPORT

## 2018-2019





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*From top: Marie & Rocco Heatherington at the Bundaberg community day; youth retreat activities; hikers completing Hike for Huntington's in Noosa Hinterland; and Jenny Farmer & Gwen Pratten at the 2018 AGM*



*Hike for Huntington's through Noosa hinterland*

*Throughout this report you will see some names marked with an asterisk. Names have been changed to protect client privacy. All images are used with permission.*

## ABOUT US

Huntingtons Queensland is the only organisation in this state dedicated solely to the support and wellbeing of individuals impacted by Huntington's disease.

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

We have a small paid team (the equivalent of 4.6 full-time staff) whose professional backgrounds include social work, education, finance, administration, marketing, project management and fundraising, led by a highly experienced CEO whose career has included the establishment or growth of several small to medium sized charities over the past 18 years.

While Huntingtons Queensland is a member-based organisation, membership is not required to access our services.

## Volunteers

Huntingtons Queensland gratefully acknowledges those members and others who so generously volunteer their time and expertise, either within the community helping to support people living with Huntington's disease, or within our organisation to ensure our business runs smoothly.

We also acknowledge those staff who volunteered their time outside their paid hours to support our events, assist clients or represent Huntingtons Queensland in the community.

We estimate that nearly 600 volunteer hours were donated by supporters, community members and staff over the 2018-19 year. On behalf of everyone impacted by Huntington's disease, we thank you for your service.

## Our People

<b>President</b>	Jason de Bakker
<b>Vice President</b>	Cate Barrett
<b>Treasurer</b>	Janifer Willis
<b>Secretary</b>	Jan Szlapak
<b>Directors</b>	Donna Burns^ Gerry Doyle Shane Kelly Susanna Mantovani
<b>CEO</b>	Jan Samuels
<b>Client Services</b>	Theressa Byrne Elena Fontaine^ Lauren Ward
<b>Finance</b>	Jennifer Lysiuk
<b>Communications</b>	Caitlin Scarr
<b>Service Support</b>	Cathy Holland
<b>Hon. Solicitor</b>	Adrian Rich Minter Ellison
<b>Auditor</b>	Paul Gallagher BDO Audit

^Resigned during the year



*Volunteer Grandall Manning (centre) with young people at the youth retreat*





## DIRECTOR PROFILES

*L to R: Susanna Mantovani, Jason de Bakker,  
Jan Szlapak, Gerry Doyle, Janifer Willis,  
Shane Kelly and Donna Burns  
Absent: Cate Barrett*

### **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 NFP and community sectors. Jason is a graduate of the Australian Institute of Company Directors and has a particular interest in governance and strategy.

### **Cate Barrett - Vice-President (joined 2014)**

Cate is a speech pathologist and psychologist with more than 20 years' experience in caring for people and their families affected by Huntington's disease.

### **Janifer Willis - Treasurer (joined 2015)**

Janifer is a qualified FCPA, who has worked in the community sector for most of her professional career. She has held finance and management roles at several not-for-profits and is currently Executive Manager Corporate Services at St Vincent's Private Hospital Brisbane.

### **Jan Szlapak - Secretary (joined 2006)**

Jan is a strong advocate for families impacted by Huntington's disease, having lived experience as a carer, and as a long-standing volunteer of Huntington's Queensland, both at board level (for more than 10 years) and as a volunteer facilitator of her local support group. A former small-business owner, Jan claims to be retired – but we know better!

### **Gerry Doyle - Director (joined 1994)**

Gerry has been a stalwart of Huntingtons Queensland for more than 25 years, and is well known in our HD community as a determined and forthright advocate for families impacted by Huntington's disease. Gerry, a retired corporate manager, also has many years' lived experience of HD as a parent, husband and carer.

### **Shane Kelly - Director (joined 2018)**

Shane is a keen and active supporter of the HD community. With Shane's family affected by HD, he is determined to support all those directly impacted, their families and the goal for a cure. Shane has extensive experience in senior business management roles, having worked for more than 20 years for Telstra, and most recently in consulting roles across business transformation.

### **Susanna Mantovani - Director (joined 2018)**

Susy has a long professional history with neurodegenerative disease, including Huntington's disease, as a researcher in neuroscience. She has a PhD in Physiology, and has held a number of research roles in Italian and Australian institutions. She is currently working in a contract research organisation, in the field of clinical trials, and brings a highly valued scientific perspective to our work.

### **Donna Burns - Director (2018 - 2019)**

Donna joined us in September 2018 and brought great energy and a thoughtful approach to collaboration to our team. Donna began her career as a registered Emergency nurse before moving into organisational change management. Unfortunately for us, Donna resigned in June after she was lured away by the Greens to become a candidate in the upcoming Brisbane council elections.



*Director Shane Kelly and Craig Madsen, co-organiser of the Hike for Huntington's*



*Donna Burns, Lauren Ward and Janifer Willis at a board and staff strategy day*





# GOVERNANCE

## PRESIDENT'S REPORT

It is a pleasure to present this year's annual report – my first as President of Huntingtons Queensland – and to provide members and supporters with an update on our work.

Before I do, I would like to thank outgoing President Gerry Doyle for his unparalleled commitment to HD families and the Association over the past 25 years, and thank him for staying on as a director.

For more than 40 years Huntingtons Queensland has worked for and with families living with HD. Over this time our role has included linking families to services and to each other, providing information about HD, raising awareness among the community and service providers, and advocating for the rights and dignity of people impacted by HD.

Our purpose remains just as relevant today.

- There is still no treatment or a cure for HD, although new drugs and clinical trials offer some hope;
- The struggles of day-to-day life have not diminished, and in many cases the pressures on families have increased;
- The radical redesign of Australia's health, welfare and disability sectors and funding models across the country continue to present enormous challenges;
- And demand for appropriate services far exceeds supply.

But the news is not all bad.

*L to R: Founder Cliff Farmer (left) with director Shane Kelly. In the background: supporter Alan McKinless, Professor Julie Stout, treasurer Janifer Willis and former director Jeff Buchanan*



*Jason de Bakker*



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The NDIS is providing some people with HD unprecedented access to funding – and our team's skill and experience to helping clients to access the scheme increases almost daily.

We also thank Queensland Health for continuing to fund some of our core services for the next three years, including provision of information, non-clinical counselling and some outreach services. While this funding is very welcome, so much more is needed. Government funds equate roughly to \$286 for every person currently on our books.

In 2018 our board undertook a survey of members and clients to determine your priorities and concerns, ahead of a strategy planning session held in February 2019.

Some of the issues that came up included:

- Difficulties accessing safe and affordable housing;
- The fragmentation, pressure on providers and unequal access to timely mental health services;
- Concerns that people with HD in aged care facilities or hospital for long periods may not receive quality care, or may not get access to properly trained staff;
- Frustration that services for people impacted by HD are not available equally across the state;
- Pressures on the state's only HD clinic, at RBWH;
- Not all people with HD qualifying for the NDIS; and
- The importance of encouraging research and clinical trials, whether in Queensland or more broadly.

We hear you. We will continue to advocate for improvements in these areas, and seek new sources of revenue to expand our services over time.

In closing, I would like to acknowledge our dedicated team, board and volunteers, and thank our generous donors, supporters and members for your involvement with us.

Huntingtons Queensland exists for you, and I encourage every member of the HD community to join us in helping to link families, health professionals, service providers and researchers – with a common goal of one day seeing an end to Huntington's disease.

**JASON DE BAKKER**  
**President**



*Jason de Bakker and Donna Burns*

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# CEO'S REPORT

2018-19 has been a busy year at Huntingtons Queensland. While our Client Services team (Lauren, Tressa and Elena) were 'out in the world' on behalf of families, the rest of our team (Jen, Cathy and Caitlin) and I were working hard behind the scenes to maximise our organisational effectiveness.

A high priority this year has been a focus on improving our processes, systems and capacity to offer quality services. Our goals were twofold: to streamline our operations and to free up more time to focus on supporting families.

Projects included completing the roll-out of our new client management system and database, reviewing all policies, and piloting a performance development framework that also focuses on a healthy work/life balance.

I would like to thank our team for their willingness and enthusiasm in undertaking these projects. I believe we are now stronger and better equipped to embrace future challenges and opportunities as they arise.

This year has marked greater engagement nationally. Several state HD association CEOs came to our forum in May and stayed on to discuss ways we can work together. We are already sharing resources, collaborating on joint funding opportunities (where appropriate), and contributing to submissions for Royal Commissions and Inquiries.

Finally, a word about the Huntingtons Queensland crew. I am so grateful for the support our team has offered me this year. I also acknowledge the contribution each person makes - whether it is planning events, paying bills, connecting people through social media, or supporting people directly.

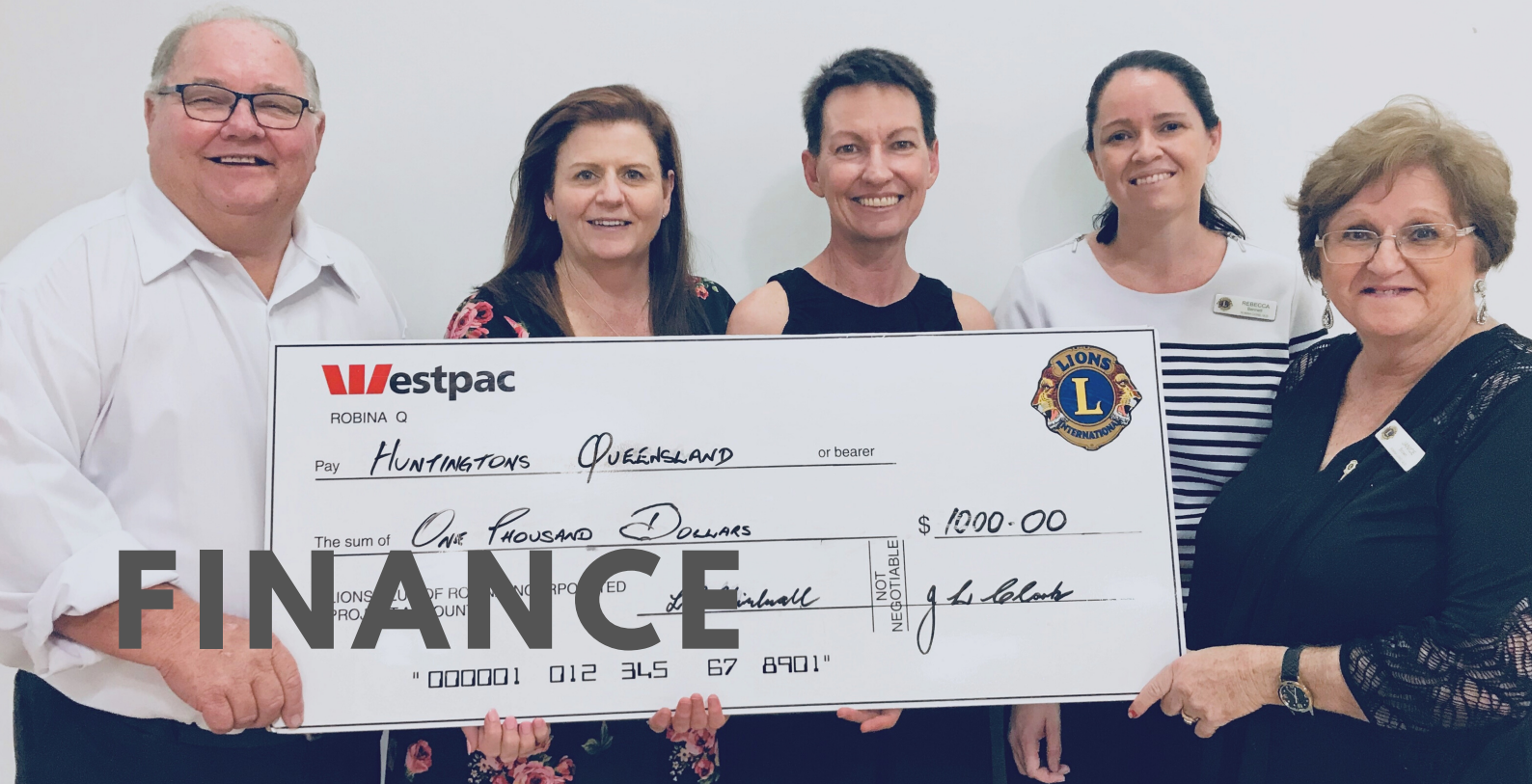
We are all indebted to them for their integrity, resilience and determination to do their best.

On their behalf, thank you for your ongoing support, and for your trust and confidence in us.

**JAN SAMUELS**  
**Chief Executive Officer**



*Jan Samuels*



## TREASURER'S REPORT

I am pleased to report that the 2018-19 financial year has ended with a positive result in terms of government funding. Our current funding from Queensland Health was due to conclude in June 2019, with no assurance of further monies being made available.

In May we learned that Huntingtons Queensland will continue to receive funding from Queensland Health until June 2022, with a possible two-year extension beyond this date. We would like to thank and acknowledge Queensland Health for the ongoing support, without which it would be extremely difficult to deliver many of our core services.

The funding we receive through the Queensland Health Community Self Care Program supports delivery of non-clinical counselling, provision of information and support groups in regional Queensland – all essential for the wellbeing of families impacted by Huntington's disease.

While welcome, government support covers only a percentage of our service delivery and operating costs.

Pressure continues on governments to do more with less funding available. Systemic changes to Australia's social services continue to impact organisations such as ours. For example, the NDIS has been beneficial for many families in the scheme.

*L to R: Lion John Clark, staff members Cathy Holland and Tressa Byrne, and Rebecca Bennett and Janice Brown, handing over a donation cheque from Robina Lions Club.*

**\$585,481**

TOTAL 2018/19  
EXPENSES

**\$424,346**

TOTAL 2018/19  
INCOME



Supporting individuals through their NDIS journey has become an increasingly important service provided by our team, but we are not funded to provide this service, resulting in additional operating costs.

Like many small not-for-profits, the organisation continues to face challenges managing our financial resources to ensure the long term viability of the organisation. To meet our responsibilities in this regard, the Association has in place sound governance policies; reviews finances and expenditure at monthly board meetings; and undertakes regular monitoring of operational practices.

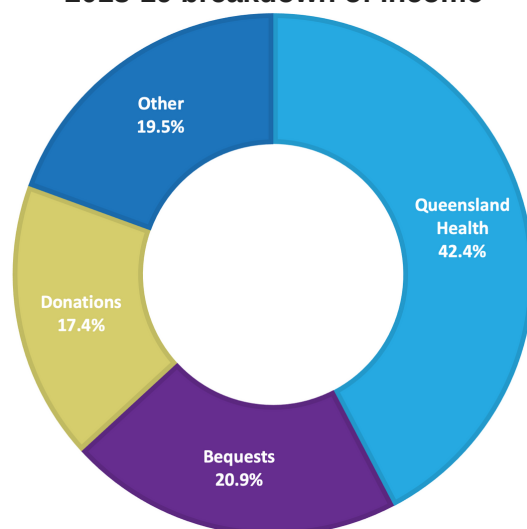
We also draw on the professional services of investment advisers Bell Potter to manage our investment portfolio – which was established after the receipt of a generous bequest in the 2015-16 financial year. The generous gift we received from the late Alecca McKinless also continues to support families impacted by Huntington’s disease, for example funding community days and the annual HD forum.

Notwithstanding the good news from Queensland Health, our financial challenges continue, with 2018-19 being the third year in a row our expenses have exceeded our revenue. The board is well aware that this is unsustainable, and is considering options to manage this risk while maximising our resources. This includes the likelihood that our current premises in Annerley – which are bigger than we need – will be sold to free up our capacity for service delivery.

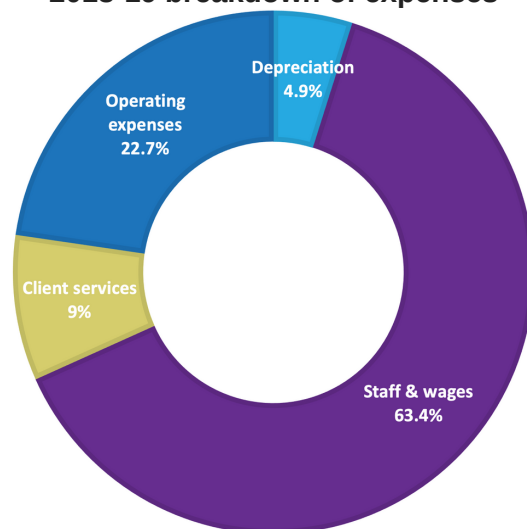
Our small team continues to punch above its weight to support our families in need. We must stay agile and continue to utilise our resources to achieve maximum results for stakeholders, and remain committed to our mission: to support people impacted by Huntington’s disease.

**JANIFER WILLIS**  
Treasurer

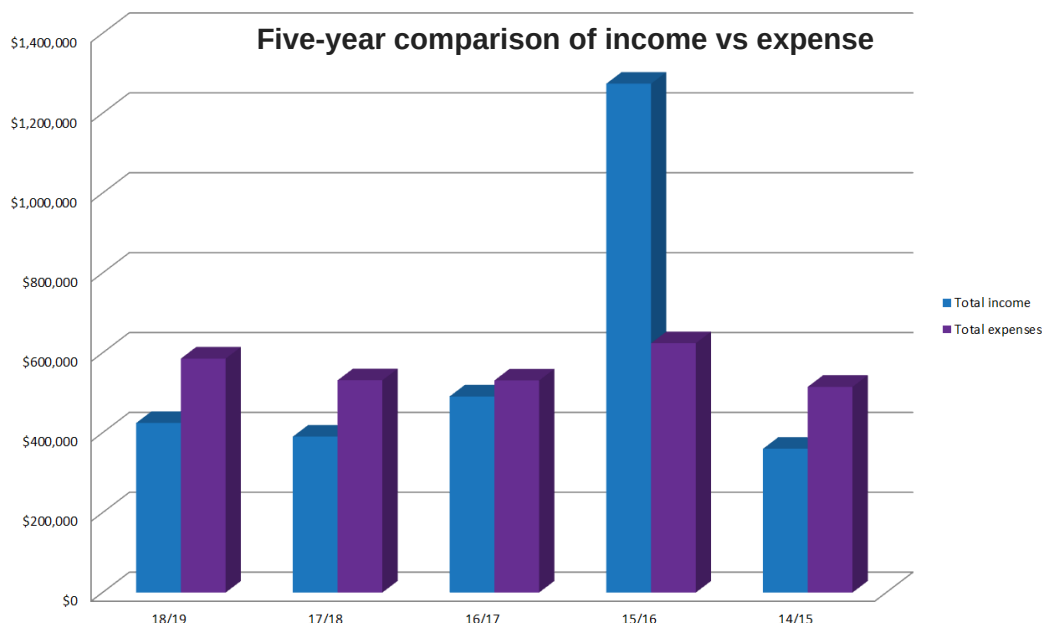
**2018-19 breakdown of income**



**2018-19 breakdown of expenses**



**Five-year comparison of income vs expense**





## Planning & linkages

*Guests at our 2018 support group Christmas party, with Finance Officer Jennifer Lysiuk (front)*

Our Client Services team assists clients in navigating different departments and organisations, including Queensland Health, Centrelink, and the National Disability Insurance Scheme (NDIS).

We work with individuals to help them prepare, approach and manage their NDIS applications and funding. We are not an NDIS provider, so we are able to maintain independence in our support and recommendations. We assisted 19 individuals in applying for, amending or managing their NDIS plans this financial year.

**Purpose:** *Access to appropriate services; ability to make informed decisions and choices.*

### **Our services in action**

*As his HD progressed, Doug\* had to stop working. The change in routine and the financial stress caused Doug to develop serious depression. He needed access to financial security and support, and he didn't know where to start.*

*Huntingtons Queensland supported Doug to navigate the NDIS. Our team helped collect evidence to support his application, accompanied Doug to his assessment and planning meetings, and connected Doug with service providers to build an extensive support network for him to lead a life of his choosing. With this support and structure, Doug was even able to return to part-time work.*



# One-on-one support

Every impacted person's journey is different, and there is no such thing as a one-size-fits-all approach. One-on-one support is Huntingtons Queensland's most significant time investment, with the smallest outreach and the greatest impact. We provided an average of 93.5 hours per month of one-on-one support, including visits, phone calls and digital exchanges, this financial year.

This service provides clients with direct, tailored support through in-person, phone and online contact. Services include mediation, non-clinical counselling, and attendance at medical and government appointments.

This can also include our team's response to heightened or crisis situations. Our Client Services team assists in a wide range of other important tasks to ensure individuals have the opportunities to maximise their quality of life.

**Purpose:** *Individualised, tailored support, often in response to heightened or crisis situations; ability to cope and manage challenges associated with HD.*

## Our services in action

*Barb\* has been supporting her adult daughter, Karen\*, who lives with HD. Barb helps Karen care for her three young children, while also helping Karen attend mental health appointments. Despite living rurally, Barb has also been the main person helping Karen to access and implement her NDIS payments, and negotiate court systems.*

*Although Barb is excelling in her role as carer, her rural location sometimes makes her feel alone. Huntingtons Queensland has dedicated many hours over the phone for one-on-one support with Barb, enabling her to debrief about her stresses, seek advice, and share her worries about the progression of her daughter's disease.*

*Huntingtons Queensland will continue to be there for Barb and Karen through each stage of their journey.*



## 2018-19 CLIENT SERVICES INSIGHTS

5,015 occasions of service delivered this year



21.1 services delivered each day



39.7 hours of phone support each month



19 NDIS meetings



3.1 education sessions per month



# Support groups

Support groups are one of the most important services available to our community. They provide individuals with a local social network, offering attendees connections with others who understand what it's like to live with the impact of HD, and can provide information, advice and a non-judgemental shoulder to lean on in the tough times.

Our support groups are well-attended, with 32 held throughout Queensland in the 2018-19 financial year. Some regions have monthly meetings, while others are held between every two and six months, based on demand. We welcomed 169 people to support groups this financial year.

While most of our support groups are facilitated by Huntingtons Queensland staff, some are organised by volunteers. We gratefully acknowledge their assistance and commitment to helping families impacted by HD around Queensland.

**Purpose:** Encouraging local connections; fostering peer-to-peer support; providing information and education; building resilience.



*Members of the Townsville social group making recyclable bin liners*



*Brisbane support group attendees with Novacorr presentation*

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### ***Our services in action***

*After her husband received an unexpected diagnosis of Huntington's disease, Mary\* was lost. She didn't know what type of support she needed – she just knew she needed help.*

*Her relationship was fractured, her husband had been laid off from his job, and she had been diagnosed with depression. She became the sole income earner and carer for her husband in a very short period of time. She also faced the task of explaining to her two adult children the hereditary nature of HD.*

*Overwhelmed and exhausted, Mary engaged with Huntingtons Queensland, seeking help. After some initial phone advice, Mary decided she would like to attend her local support group.*

*Mary and her husband became regular attendees, and through these meetings have been given direction and support for managing this complex disease.*

*Through the group's shared information and advice, they have been able to seek appropriate medical treatment, relationship support, access to the NDIS and individual services. Mary and her husband were also able to connect with others to reduce their isolation.*

*Mary says her wellbeing has improved significantly, and she shows great confidence and hope during meetings.*

*She has become the welcoming light for newcomers and now guides others in their journey.*



*Femminge and Tina Kampen  
enjoying birthday celebrations*

# Advocacy

Advocacy means a broad range of things to different people, and it remains one of the most impactful services our team can provide. We are positioned to be the key advocates for people impacted by Huntington's disease in Queensland, and work on an individual and higher political level to ensure the best outcomes are achieved for our clients.

Our team regularly attends meetings in an advocacy role between clients and government departments or other relevant agencies.

Where our resources allow, we also stand alongside families involved in workplace discussions, legal proceedings or when making choices about issues such as advance care planning. While we cannot provide professional advice in any of these areas, we are a major link in ensuring that clients are not left vulnerable or at risk of falling through the cracks.

We supported 41 individuals through advocacy this financial year.

**Purpose:** *improved independence and quality of life; support for potentially vulnerable individuals in complex or high-pressure situations; better opportunities for individual choice and control.*



## 2018-19 REGIONAL OUTREACH INSIGHTS



15 towns & cities visited

2.3 average visits per town this year



201 hours this year travelling to clients



32 support group meetings facilitated



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## **Our services in action**

*When we met Peter\*, he'd been on Newstart for more than seven years, living in difficult circumstances in a caravan park. Although he was very symptomatic, Peter had only just been diagnosed with Huntington's disease. Peter's family lived interstate, with no visits and had only exchanged infrequent messages for more than 20 years.*

*Despite Peter being unable to work due to his health, Centrelink had rejected his disability support pension applications twice, forcing Peter to repeatedly meet with a job provider in an attempt to find work.*

*Huntingtons Queensland advocated for Peter, providing evidence of his situation, and attending multiple meetings with government departments with him. The team also sourced reports and evidence for Peter and accompanied him to GP and specialist appointments, to assist with his NDIS application.*

*Through our advocacy, Peter was registered with the Department of Housing and was found to be eligible for accommodation, giving him a safe, comfortable home for the first time in many years. He was also approved for the disability support pension, and connected with the Huntington's disease clinic at the Royal Brisbane and Women's Hospital.*

*Our team provided weekly updates to his interstate family, encouraging them to re-engage and eventually visit Peter. We also advocated for Peter's mother to be appointed as his financial administrator, so he can now access his superannuation.*

*Before we met Peter, he found it difficult to leave his caravan park home. Now, Peter's life has improved so dramatically that we rarely find him at home, and we hear from him infrequently, as his time is filled with social events, trips to the movies, or planning interstate visits with his family.*



*Peter at a salsa dancing lesson*



# Education

Huntingtons Queensland estimates that more than 100 people with HD are currently living in residential aged care facilities, hospitals and supported accommodation throughout the state.

We have tailored education sessions for residential facilities, government departments, care workers and allied health providers, helping attendees better understand Huntington's disease, and provide more appropriate and empathetic care.

In 2018-19, our team held a monthly average of 3.1 education sessions, with an average of 33 attendees per meeting.

**Purpose:** *greater knowledge of HD; improved standards of care; better quality of life for clients; less disruption to people impacted by HD and those who care for/live with them.*

## Our services in action

*Craig\* had been living in a nursing home for a few months, and things were not going well. The staff had never had a resident with Huntington's disease, and they were struggling to support Craig and understand the disease.*

*Staff reported that Craig was aggressive and showed inappropriate behaviours, and were considering asking his family to find a new residential facility for him. Luckily his family reached out to Huntingtons Queensland, who attended the home and provided staff with an in-depth education session about HD.*

*The staff gained knowledge on the complexities of HD, the impact symptoms can have, and how Craig may not have had the opportunity to express himself, causing him frustration, which the staff perceived as aggression. They have learned strategies to support Craig more effectively, and through their new knowledge, developed empathy and understanding for Craig.*

*Within a few weeks, the staff reported back to Huntingtons Queensland that they had successfully implemented positive strategies, in line with person-centred practices, to improve Craig's quality of care. Craig was also more settled and relaxed, and was no longer at risk of losing his place at the home.*

*"I thought it was excellent. I took a lot out of the session."*



Lauren Ward presenting an education and information session



# OUR COMMUNITY

Attendees at the 2019 youth retreat

## EVENTS

### Youth retreat

In June, we welcomed 17 young people to a special one-off youth retreat in Currumbundi on the Sunshine Coast. The retreat, funded through the generosity of the Gambling Community Benefit Fund, was facilitated by Huntingtons Queensland staff.

The retreat provided attendees with a range of workshops and presentations to stimulate a conversation about HD in their lives.

Over the four days attendees also enjoyed plenty of fun events and social downtime, including rock-climbing, swimming and late-night chats.

Special thanks to Amy Hale from Huntingtons NSW, and volunteer Grandall Manning, who worked with our Client Services team to deliver this outstanding event.

We also thank Dr Rob Adam for volunteering his time to drive up to the Sunshine Coast to discuss research and treatment issues with attendees.

*“You girls at  
Huntingtons Queensland  
are AMAZING!  
I couldn’t ask for a  
better support system.”*

*“Would love to attend  
another retreat in the  
future. It was great to  
meet people our age.”*

*“It helps people  
understand what  
Huntington’s is. Good  
to meet people going  
through the same thing.”*

# Community days

As part of Huntingtons Queensland's dedication to providing our community with social opportunities and brief respite days, we have continued to host community fun days throughout Queensland.

These family-friendly events have been fully subsidised through the generosity of the Alecca McKinless gift, and provide people impacted by Huntington's disease with a fun outing and lunch with a community of friendly, supportive people.

We welcomed:

- 47 people to the Currumbin Wildlife Sanctuary
- 31 people to our annual Christmas party in Brisbane (with other similar events held in local and regional areas as part of our support group program)
- 26 people to the Bundaberg Barrel followed by lunch at Grunske's on the River
- 49 people to the Queensland Science Museum.

A scheduled community day at the Cairns Aquarium had to be postponed, but we were happy to provide entry passes to those who had RSVPed to the event.

**Purpose:** Building social support networks for individuals and families, including children; brief respite from the pressures of daily life; fostering community support and engagement; building resilience.



2018 Brisbane support group Christmas party

*"It was a great opportunity to meet other families, relax and chat over lunch afterwards. Great activities for adults and kids."*

*"It was so nice to catch up, meet some new friends and have some awesome chats."*



Community day science museum attendee with staff member Tressa Byrne



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## Alecca McKinless forum

Huntingtons Queensland hosted our second annual Alecca McKinless forum, *Planning for the Future*, at Brisbane's Treasury Hotel in May 2019. This signature event is for people impacted by Huntington's disease, and is fully subsidised through Alecca McKinless's generous gift.

We welcomed 76 people, including eight speakers, for a full day of presentations, discussion groups, and a very jovial post-forum cocktail evening. The theme, 'planning for the future', was reflected in the day's topics.

Speakers discussed research trials, personal journeys, and important life discussions like advance care planning. The discussion groups were diverse, covering topics from financial planning to talking to children about HD.

Our keynote speaker, Catherine Martin, the Executive Director of Huntington's Disease Youth Organisation (HDYO), flew from Scotland to speak to attendees about her personal and professional journey with Huntington's disease. HDYO is a major international organisation for Huntington's disease, and Huntingtons Queensland is proud to support their endeavours, including the first international youth conference, which will be held in Scotland in May 2020.

We would also like to thank the Ian Potter Foundation for their generous funding of Cat's travel to attend the forum.

*"I am gene positive and this was the first outing to get to know more, meet people and to help myself grab hold of this and OWN IT!"*

*"Very professional event. The social event at the end was such a great way to chat to everyone including the presenters. Everyone was so welcoming."*

*"All the presenters were amazing. I've been thoroughly impressed!"*



Keynote speaker Catherine Martin and forum supporter Alan McKinless, whose late wife Alecca's gift funds the forum

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## Professional workshop

In addition to her keynote presentation at our annual Alecca McKinless forum, HDYO's Catherine Martin held a professional development workshop at Huntingtons Queensland, designed for social and support workers currently engaging with children and families impacted by a life-changing diagnosis.

Cat's workshop was very well received, with attendees reporting great satisfaction with the concepts delivered and the skills they learned.



*HYDO's Catherine Martin delivering her workshop for professionals at Huntingtons Queensland*

*"Great morning with lots of new tools to share with patients."*

*"Excellent presentation. Very in tune with subject and generous with experience."*

## The Friday Social

A series of relaxed information sessions, followed by a friendly social catch-up, were trialed throughout the 2018-19 financial year, under the title of 'The Friday Social.'

Feedback from our community indicated that people aged 25 to 40 were under-represented in our activities, and would be interested in information topics more relevant to their current stage of life.

Guest presenters were invited to present on a range of topics including insurance, advance care planning and other topics, such as family planning and HD and the workplace.

Due to challenges with the timing of the sessions, the Friday Socials will not continue, but we will be bringing information sessions to our community other, accessible formats, including online videos and blog posts.



# FUNDRAISING Grants

We are grateful to the trusts and foundations that selected Huntingtons Queensland as a grant recipient this financial year. We were approved for or acquitted six grants this financial year:

- A scholarship funded by Ethical Jobs for our CEO to attend the Not-for-profit People conference in Melbourne
- \$1,000 from the Brisbane Airport Corporation for a collapsible wheelchair and family resource kits
- \$3,800 from the Ian Potter Foundation toward the cost of HDYO's Catherine Martin to attend our forum as keynote speaker and facilitate a workshop for service providers
- \$4,950 from the Department of Social Services to support a volunteer training and development program
- \$10,000 from the Thorsen Family Foundation towards research
- \$15,000 from the Gambling Community Benefit Fund for our youth retreat.

## Play for Purpose

Huntingtons Queensland was proud to join the new Play for Purpose charity lottery. This independent lottery was established with support from Tabcorp's Charitable Games Commission as a way of supporting ACNC-registered charities.

There are no costs involved for participating charities, and we receive 50% of every ticket purchased under our organisation. Play for Purpose and our supporters raised \$1,565 for Huntingtons Queensland with zero commission or administrative fees, and we look forward to continuing our partnership in the coming financial year.

## Direct mail appeals

We rely heavily 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 2018-19 appeals, raising a total of \$30,680 or 7.2% of our total annual income.



### 2018-19 INCOME INSIGHTS



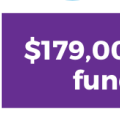
**\$30,680 generously  
donated across two  
fundraising campaigns**



**60 families & businesses  
donated more than \$200**



**Three dedicated  
community fundraisers**



**\$179,006 in government  
funding and support**



*2018 Christmas appeal feature image,  
with models for illustrative purposes*

# Community champions

## Running for Nan's HD

In September 2018, Kelly Woodland hosted her third annual Running for Nan's HD event in support of Huntingtons Queensland. This year, the event moved to the Wynnum foreshore, where participants paced out 5km or 10km while the sun rose over the bay. Other events to support Running for Nan's HD were held in places such as Mackay.

Running for Nan's HD is a community event, created by Kelly and inspired by Kelly's grandmother, Isobel, who lives with HD. The fun run raises funds for Huntingtons Queensland, while also raising awareness of HD in the general community.

The event continues to grow and improve each year, and this year there were a total of 146 registrations. Total income raised was \$6,183.51, which came from registrations, ticket sales and donations.

We offer our heartfelt thanks to Kelly for her role as a volunteer ambassador and community fundraiser, and we thank her and all supporters of this event for making it such a wonderful success!



*Kelly Woodland with volunteer Alan McKinless*



*Running for Nan's HD participants in Mackay*



*Running for Nan's HD participants in Brisbane*



## The Huntington's Marathons

Steven Blaine set off on a marathon effort in 2017, with a goal of completing 12 marathons or half-marathons in 12 months to raise funds for Huntingtons Queensland. He completed this mammoth achievement in December 2018 when he crossed the finish line of the GC50 race at the Gold Coast.

Steven's efforts were inspired by his mum, Lenore Blaine, who lived with Huntington's disease. Sadly, Lenore passed away in July 2018, just before Steven completed his seventh race, but Steven was determined to finish what he started, saying he was more motivated than ever to complete this challenge.

Through Steven's hard work, and the generosity of his wide network of friends and colleagues, Steven raised \$12,918.58 for Huntingtons Queensland. We are so grateful for the support of the Blaine family, and we hope Steven has enjoyed a bit of rest and relaxation after running those many hundreds of kilometres.

## Hike for Huntington's

Huntingtons Queensland director Shane Kelly rallied his friends, colleagues and wider network to come along for a beautiful weekend of hiking through the scenic Noosa hinterland, all in support of Huntingtons Queensland.

It was a wet and windy weekend, but it certainly wasn't miserable. Shane gathered a group of 30 hikers, who raised \$3,530.19 towards our work.

Our gratitude to Shane and his lovely wife, Sue, and all their friends and family for making the most of this wonderful weekend in the great outdoors!



*Steven Blaine celebrating a marathon effort with his daughter.*



*Hike for Huntington's got a little muddy*



*Shane, his sons and friends also raised money for Huntingtons Queensland in December 2018 by hiking the Brisbane Valley Rail Trail*



## RESEARCH

### Wave trial

As announced at our forum in May 2019, Wave Pharmaceuticals are setting up a research trial site in Brisbane, scheduled to commence in late 2019, and overseen by clinical neurologist Dr Robert Adam.

Huntingtons Queensland is very proud to support the trial this coming year, and through our supporters we have made a modest financial contribution towards the project. We will also be providing any other support we can to Dr Adam and those interested in participating in the trial.



*Dr Robert Adam presenting at our 2019 forum*

### Roche trial

In February our CEO, Jan Samuels, travelled to New York to represent Australasia at the second HD COPE meeting.

During the trip, Jan took part in a briefing by the Roche Pharmaceuticals team regarding trial updates and future planning. Roche shared their plans to expand their trial sites around Europe and the United States, and talked through a number of issues with consumers involved in the HD COPE global initiative.

Consumers were very engaged, and it was pleasing to note Roche's commitment to the HD community in helping to shape the trial and how it is delivered.

While Roche is not planning a trial site in Australia yet, we know they know where we are: one of their key leadership team hails from regional Queensland!



*HD Cope meeting attendees in New York in 2019. Our CEO is third from the left.*

# Trent Woodruff

*Dr Trent Woodruff has provided the following update on his research project, for which Huntingtons Queensland has provided \$30,000 over three years.*

Our research has previously shown that the immune system can contribute to brain cell death in animal models of Huntington's disease (HD) by increasing inflammation in the blood and brain. We have developed a drug that blocks this inflammation, which shows promise as a way to slow the progressive decline of HD.

In our Queensland Government innovation partnership grant, we are working with multiple partners, including Huntingtons Queensland, to progress PMX205 towards human clinical trials. To get there, we must first complete a range of pre-clinical safety and pharmacology studies to ensure the drug is safe for human administration.

With our industry partner, Alsonex Pharmaceuticals, we have now completed the manufacture of a large scale chemical synthesis of our drug, PMX205, for animal preclinical and human clinical studies. We subsequently tested the bioactivity of the drug on human blood cells, validating its therapeutic efficiency at blocking inflammation, and identified a biomarker in HD patients that could be used in conjunction with the human trials.

A route of administration was determined based on pharmacokinetic and biodistribution studies, and validated for use in human trials. We are currently administering this drug in mouse HD models to assess its blood and brain distribution, and neuroprotective efficacy.

The drug has now completed formal preclinical toxicology testing in multiple animal species, clearly demonstrating the drug is safe at the proposed clinical doses. We are also continuing to obtain blood samples from HD participants to test the levels of inflammation in patients.



*Dr Trent Woodruff presenting at the 2018 Alecca McKinless forum*

*"We are extremely grateful for the support of Huntingtons Queensland and the HD community that have allowed us to progress these studies to enable the future testing of our drug in HD patients."*

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## PARTNERSHIPS

### HD clinic

Huntingtons Queensland continues to support the monthly HD clinic, held at the Royal Brisbane and Women's Hospital. Our HD advisers attend in a support role, to assist those waiting for appointments, and to liaise between the clinic's health professionals and patients. We also provide catering for those who spend the day at the clinic waiting for their appointment.

The HD clinic is an essential service for families impacted by Huntington's disease, and its capacity is severely stretched. Huntingtons Queensland is proud to be part of this important initiative and we look forward to continuing our strong relationships with the clinic's team in the years ahead.

### HDYO

Huntington's Disease Youth Organisation (HDYO) has been a great friend to Huntingtons Queensland, and we were delighted to welcome their Executive Director Catherine Martin to Australia.

HDYO is the leading global organisation for young people impacted by HD, and we are pleased to support their work. You can find out more about their work at [hdyo.org](http://hdyo.org).



*Forum attendees with HDYO's Catherine Martin and Sabrina Palham from Advance Care Planning*

## Advance Care Planning

Huntingtons Queensland has developed a strong relationship with the Australian Government-funded Advance Care Planning Australia service after their very popular presentation at our annual forum. We will be working closely with them in the coming year to assist clients in developing their advance care plans. You can find out more at [advancecareplanning.org.au](http://advancecareplanning.org.au).



*Advance Care Planning's Sabrina Palham presenting at our 2019 forum*

### Minter Ellison

Huntingtons Queensland is very grateful for our continued relationship with Minter Ellison, who offer us pro bono legal advice and support on a range of legal matters.

We greatly value their generosity and expertise, and thank the partners for their commitment to Huntingtons Queensland and the HD community.



## Novacorr

Novacorr have been a long-term partner of Huntingtons Queensland, providing equipment to people living with HD, and supporting and attending many of our events.

We are grateful for their willingness to participate in our events, bringing equipment and information, and we look forward to working with them in the future.

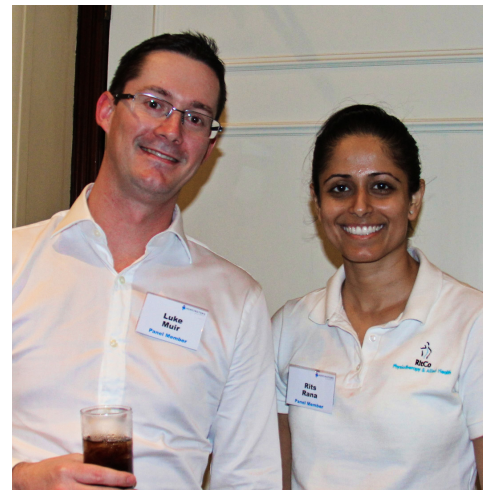


*Novacorr representatives with forum attendees*

## Rits Rana

Rits has been a wonderful partner of Huntingtons Queensland for more than 12 months, supporting clients in a range of physiotherapy services.

Rits is an NDIS provider, but has gone above and beyond for her clients, donating significant amounts of time, and attending events, to ensure her services are available to those who require it. We look forward to working with Rits in the coming year.



*Luke Muir and Rits Rana at our 2019 Alecca McKinless forum*

## Luke Muir

We were thrilled to welcome financial adviser Luke Muir to our HD community this year. Many of our clients have concerns about financial planning, superannuation and how to prepare for the future. Luke provides a wide range of services at low cost to our clients to assist them in achieving better financial security.

## Jan Tipping

Luke was referred to us by our HR and workplace consultant extraordinaire, Jan Tipping, and we are proud to be involved with two such passionate advocates for our clients and our team.

We also thank Jan for her excellent work on reviewing our policies and procedures over the past few months.



*Jan Tipping and Jan Samuels at our 2019 Alecca McKinless forum*

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## HD COPE

Our CEO, Jan Samuels, was privileged to represent Australasia at the second annual HD COPE global meeting in New York in February 2019. HD COPE – the HD Coalition on Patient Engagement – aims to add quality to all aspects of clinical trials through patient representative input, providing a coordinated and knowledgeable mechanism to share HD community experience with regulators, industry and researchers.

The meeting gave Jan the opportunity to meet and network with some key players in research and patient engagement, and we will continue to foster and develop these relationships as we move forward with research trials within a stronger global network.

The HD COPE global advisory group has plans to expand the program into Australia in the not-too-distant future.



*CEO Jan Samuels (far left) at the HD COPE meeting in New York*

## Interstate partnerships

Huntingtons Queensland continues to build strong links with our interstate counterparts. We were pleased to welcome the CEOs from the HD associations in New South Wales, Western Australia and Tasmania to our forum in May, and have been working with them on sharing resources and shared advocacy projects (such as submissions to the Royal Commission into Aged Care Quality and Standards).

Closer collaboration is a goal for the state organisations in the year to come.



*Huntington's WA Executive Director Lenni Duffield presenting at our 2019 forum*

# THANK YOU

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

Anonymous	Order of the Eastern Star,
Naomi Barka	Mackay chapter
Cate Barrett	Peter Nash
Charmaine Blaine	Richard Orr
Eric Denham	Play for Purpose
Gerry Doyle	Surf Parade Realty
Condon Charles Lawyers	Dorothy Smyth
Stephen Earl	Appelien & John Stride
Derek Fitzgerald	Townsville Northern Suburbs
J Hartkopf	Lions Club Inc
Jean Heimhartner	Bill Van Heel
David & Margaret Holmes	Chris Welsh
Susan Howe	Maida White

We acknowledge our generous donors and volunteers for supporting people impacted by Huntington's disease.

Your support is crucial in keeping our services available, and we are so grateful for your trust in our work.

## **The following individuals, families and businesses made donations of \$500 or more the reporting period:**

1-World Charity	Joan Lawrence
Ann Johnson	Jaylea Lubczynski
Anonymous	Bill Merrilees
Cindy Benjamin	Peter Noonan
Joyce Bennett	PayPal Giving Fund Australia
Steven Blaine	Faye Phillips Estate
Boston Brewing Co	c/-Roma Wood
Brisbane Airport Foundation	Norma Robertson
Jeff Buchanan	Robina Lions Club
James Callum	Robina Roos Football Club
James Doble	Rotary Club of Ipswich North
Estate of William Leslie	Jan Samuels
Norman Dowling	Sigmattech Services
Cliff & Jenny Farmer	Richard Sivell
Jean Farmer	Julie Stout
Gambling Community	The City Golf Club Inc
Benefit Fund	Thorsen Family Foundation
Christine Gordon	Kelly Woodland
Ian Potter Foundation	Cameron Wilson
Shane Kelly	

**We couldn't do it without you.  
Thank you.**





Image from our end of financial year campaign. Model for illustrative purposes.



**HUNTINGTONS**  
*queensland*

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