



2017-2018
**ANNUAL
REPORT**

Lighting the Way forum 2018



HUNTINGTONS
queensland



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Images in this report were taken at events during the 17/18 year and used with permission



ABOUT US

Huntingtons Queensland is the only organisation in this state that is 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 17 years.

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

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 2017-18 year. On behalf of everyone impacted by Huntington's disease we thank you for your service.

Our People

| | |
|-----------------------|--|
| President | Gerry Doyle |
| Vice President | Cate Barrett |
| Treasurer | Janifer Willis |
| Secretary | Jan Szlapak |
| Directors | Jason de Bakker* Jeff Buchanan^ Gwen Pratten^ Peter Weekes^ |

| | |
|------------------------|--|
| Chief Executive | Jan Samuels |
| Client Services | Lauren Ward Theresa Byrne Elena Fontaine |

| | |
|------------------------|-----------------|
| Finance | Jennifer Lysiuk |
| Communications | Caitlin Scarr |
| Service Support | Cathy Holland |

| | |
|-----------------------|--------------------------------------|
| Hon. Solicitor | Adrian Rich <i>Minter Ellison</i> |
|-----------------------|--------------------------------------|

| | |
|----------------|------------------------------------|
| Auditor | Paul Gallagher <i>BDO Audit</i> |
|----------------|------------------------------------|

* Appointed during the year
^Resigned during the year



GOVERNANCE

PRESIDENT'S REPORT

In my final year as President of Huntingtons Queensland, it is my pleasure to report on the progress of our team in 2017-18, and to note some of the developments we have seen in the international Huntington's disease community this year.

As always, our work this year has focused on families. Our team has worked diligently to offer information, education, support, non-clinical counselling and advocacy for people living with HD, their families and carers.

We also held several events aimed at helping families to connect with each other, and ventured into the brave new world of the National Disability Insurance Scheme (NDIS), advocating for people with HD to access the funding they need to cope with the impact of the disease on their daily lives.

Globally, we celebrated the most exciting news since the Huntington's gene was identified 25 years ago: The discovery of a potential treatment in the form of a huntingtin-lowering drug called Ionis HTRx.

Initial human trials of the drug proved safe, and to reduce harmful levels of huntingtin protein in trial participants.





While the Ionis/Roche breakthrough is far from a cure, and there are many steps to go through before – or even if – a drug is available, the discovery offers something very rare in our community: Greater hope for the future.

While the news was very welcome, we all understand that people impacted by HD face tremendous challenges every day.

These include accessing quality, timely health, mental health and medical services, and being able to live in safe, appropriate accommodation.

These issues are a major concern for families, and for Huntingtons Queensland, and we will continue our efforts to raise awareness, educate service providers, and advocate for better services and care for HD families.

I have been personally involved with Huntingtons Queensland since 1993, and have had the privilege of serving as a board member or President for many of those years.

During this time we have faced and overcome many challenges, including the continued sustainability of the Association. These continue today and I am positive that we will successfully address all of the challenges when they arise.

As I step down, I wish to thank all of our staff, committee and the HD community for their support and friendship.

For more than 40 years Huntingtons Queensland has been there for families living with HD, and I am confident that with our committed board, CEO, and highly skilled team we will continue this proud tradition of service in the years ahead.

GERRY DOYLE
President





CEO'S REPORT

The 2018-18 financial year has been a busy time of growth and renewal for Huntingtons Queensland, resulting in our improved ability to support individuals and families impacted by Huntington's disease. This year our team assisted more than 1,500 people across the state.

While our resources certainly remain stretched, we have had an opportunity this year to increase our frontline services team, streamline many of our operational practices, and implement strategies aimed at ensuring the ongoing sustainability of our services and organisation.

We have made good progress on several key projects in our strategic plan (see page 11 for details), while ensuring that families living with HD remain the focus of everything we do.

I have been heartened by the feedback we have received from people who have accessed our services or attended our events this year – some of which you will read about in this report. This information is invaluable as we strive to continuously improve the services we are able to offer.

However, we also know that much remains to be done. Demand for support continues to rise, and systemic changes within the health, disability and aged care sectors continue to have an enormous impact on organisations such as ours.

While this operating environment makes for challenges ahead, it also gives us a chance to stretch ourselves. With a small team and limited 'tagged' funding, we have the advantage of flexibility to explore new ways of working.

As you will read in our Treasurer's report, sustainable funding remains our greatest challenge. We acknowledge the significant grant we have received from Queensland Health in recent years and trust we will continue to receive this funding in years to come.





I wish to thank the many people who have assisted families living with Huntington's disease this year by supporting our fundraising appeals, events and community fundraisers. We could not do it without you.

I offer my thanks to our board for their support and guidance, and acknowledge the generous gift of time and wisdom I have received from the Association's Founder, Cliff Farmer, and volunteers Alan McKinless and Gwen Pratten.

Finally, it is my pleasure to acknowledge the work of our amazing team:

- HD Advisers Lauren Ward and Theresa Byrne (and our recent addition, Elena Fontaine) for their extraordinary empathy and determination to do everything they can for people impacted by Huntington's disease;
- Finance Officer Jen Lysiuk, for her diligence in managing the Association's money and assets;
- Communications Coordinator Caitlin Scarr, for her work at all hours of the day and night to ensure members and clients are kept up to date with news, research updates, and stories about families impacted by HD; and
- Service Support Officer Cathy Holland, for her boundless energy and fantastic efforts to keep our office and our team working smoothly.

We are all here for one purpose: To support people living with HD, their families and those who care for them. It is a privilege none of us takes lightly, and we look forward to being here in the years ahead.

JAN SAMUELS
Chief Executive Officer





FINANCE

TREASURER'S REPORT

Like many small not-for-profit organisations, Huntingtons Queensland continues to face challenges in securing funding and managing our financial resources to achieve our mission.

This is largely the result of the ongoing systemic changes within the social and community services sectors – including the introduction of the National Disability Insurance Scheme, reform of the aged care system, and increasing pressure on health and mental health funding at both state and federal levels.

Many of our families have benefited from these changes.

The past year has seen some significant changes in the sector, with a range of amalgamations and some smaller charities merging or closing their doors. While financial security remains a concern, in many respects Huntingtons Queensland is well placed to survive and thrive.

We have a small, agile team that is able to respond quickly to a changing environment; we operate a lean business, with good financial and cost controls in place and a solid governance framework.

That is not to say we should be complacent.

\$536,643

TOTAL 2017/18
EXPENSES

\$371,653

TOTAL 2017/18
INCOME



While our team has managed the business well, our income was lower than forecast (particularly in relation to income from donations, trusts and foundations) and we face ongoing uncertainty over the future of the funding we receive from Queensland Health.

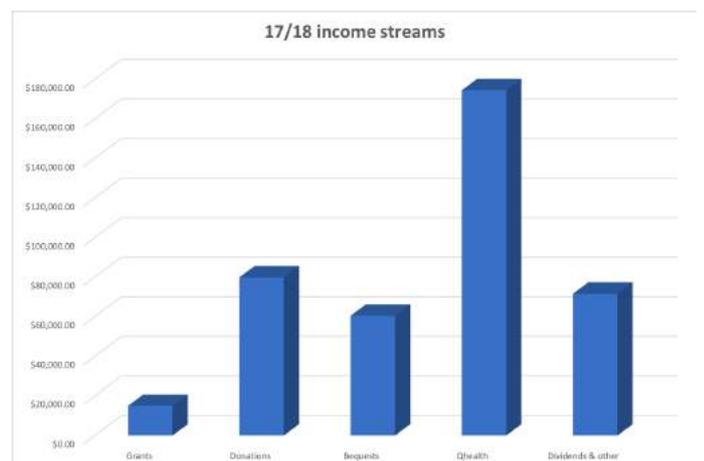
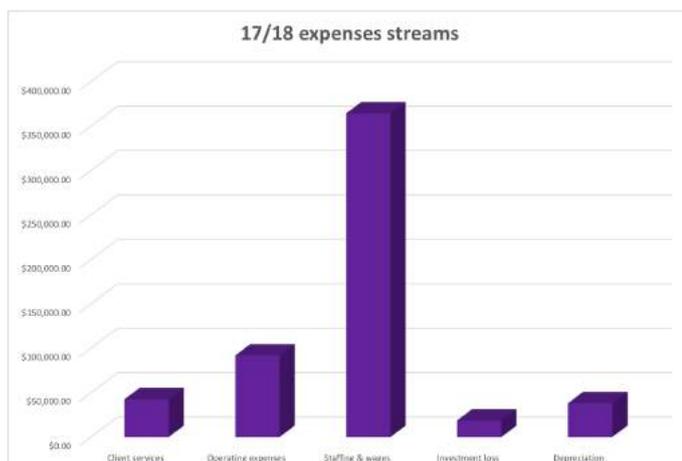
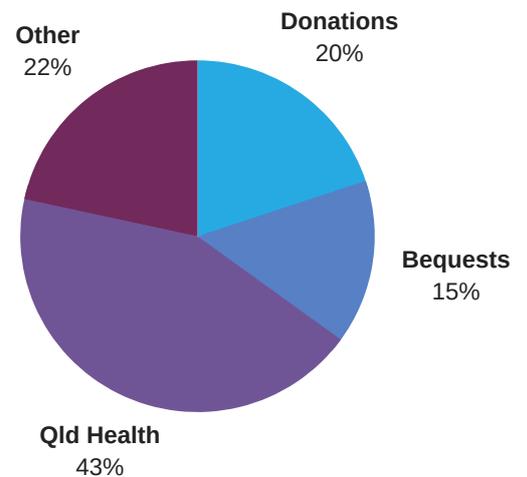
Our current funding from Queensland Health expires in June 2019 and to date we have received no assurances about the future of the Community Self-Care Program, or if it will be replaced by any other source of funds.

This is obviously a concern, as the Queensland Health grant pays for many of our frontline services (including the provision of information, support for families, and non-clinical counselling).

Huntingtons Queensland would like to acknowledge and thank Queensland Health for the ongoing support of the organisation over many years. It is important because with the introduction of the NDIS we have seen some evidence of cost-shifting with services previously funded under the Health budget being transferred into Disability funding.

While this approach has worked in favour of some people with Huntington's disease (who have received solid packages under the NDIS) it does not take into account that the majority of people impacted by HD do not qualify for NDIS packages until they are very symptomatic.

17/18 breakdown of income





However, members may be assured that the Board and staff of Huntingtons Queensland are very aware of our responsibility to increase our financial resources and ensure the sustainability of our services and organisation.

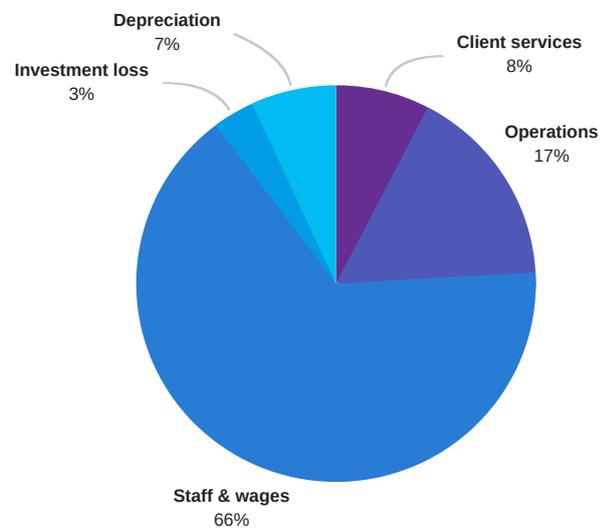
Strategies under consideration include the need to invest in our fundraising and business development capability, and options for freeing up the equity in Florence Dannell House.

On a positive note, this year we were very grateful for a gift from the late Alecca McKinless, which contributed significantly to the services we can offer families impacted by Huntington’s disease.

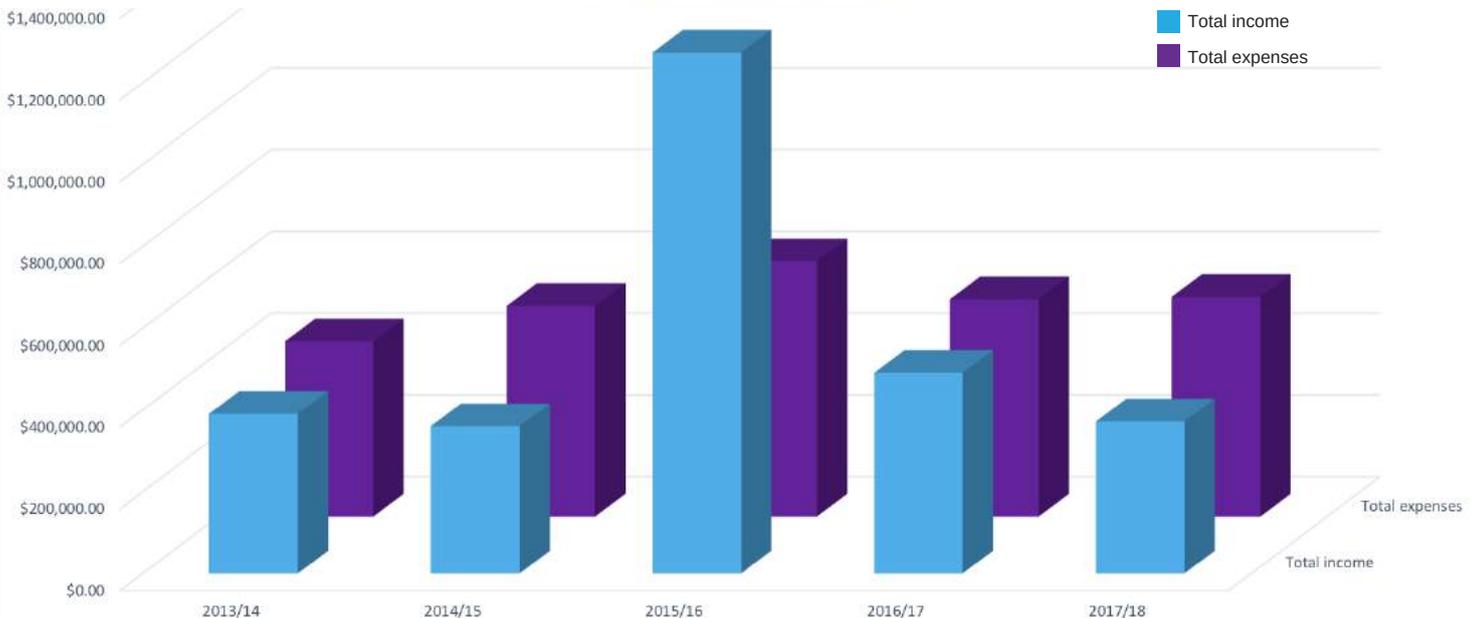
Alecca’s gift will fund a third Client Services position for two years, enabling our team to reach more families and offer a greater level of support to people around the state, as well as covering the cost of key events such as the new annual forum and our family fun days.

JANIFER WILLIS
Treasurer

17-18 breakdown of expenses



5 year financial snapshot





PLANNING AND STRATEGY

To ensure we make the greatest use of our resources and achieve the best impact we can, Huntingtons Queensland has developed a strategic plan for 2017-2020.

The strategic plan is operationalised annually, with the board and staff undertaking regular reviews against progress. Our strategic plan for 2017-2020 has three key priorities (outlined to the right), supported by a range of strategies that will be implemented over three years.

In the reporting period, key activities have included:

Priority 1

- Mapping our current services and identifying unmet need
- Employing a third Client Services HD Adviser
- Developing our education program for service providers
- Holding events for families to connect with each other

Priority 2

- Extending our information and communication services
- Holding a forum for younger people to learn about research developments and living well with HD
- Preliminary discussions to promote Queensland as a site for future clinical trials and observational studies

Priority 3

- Reviewing and updating all policies and procedures
- Streamlining internal systems and processes
- Implementing a new database and client relationship management (CRM) system
- Implementing our board renewal strategy.

Our mission
To support families,
individuals and carers
impacted by
Huntington's disease

1. To optimise
quality of life for
people living with HD
and their families

2. To support
efforts to end HD

3. To ensure the
sustainability of
our services and
our organisation



OUR IMPACT

YEAR IN REVIEW

Huntingtons Queensland's Client Services team provides one of the most important functions in our organisation: Frontline support and services that aim to optimise the quality of life for people impacted by Huntington's disease.

With a wide network of stakeholders, including clients, community and government agencies, and direct service providers, our team has maintained its role as the leader in Huntington's disease information and support throughout Queensland.

The 2017-18 year has been both challenging and rewarding, with demand for our services continuing to grow, and greater complexity in our operating environment.

In particular we note:

- The impact of the National Disability Insurance Scheme,
- Tightening of criteria for some people trying to access the Disability Support Pension,
- Shortages in accommodation, and
- A lack of political clarity over where complex conditions such as HD should sit within the health/mental health/disability triangle – leading to difficulties in coordinating care and making sure people with complex conditions do not fall through the cracks.



2017/18 SERVICE HIGHLIGHTS



Multiple trips around Queensland

A growth in client numbers



Welcoming a third HD Advisor to the team

Clients found safer accommodation





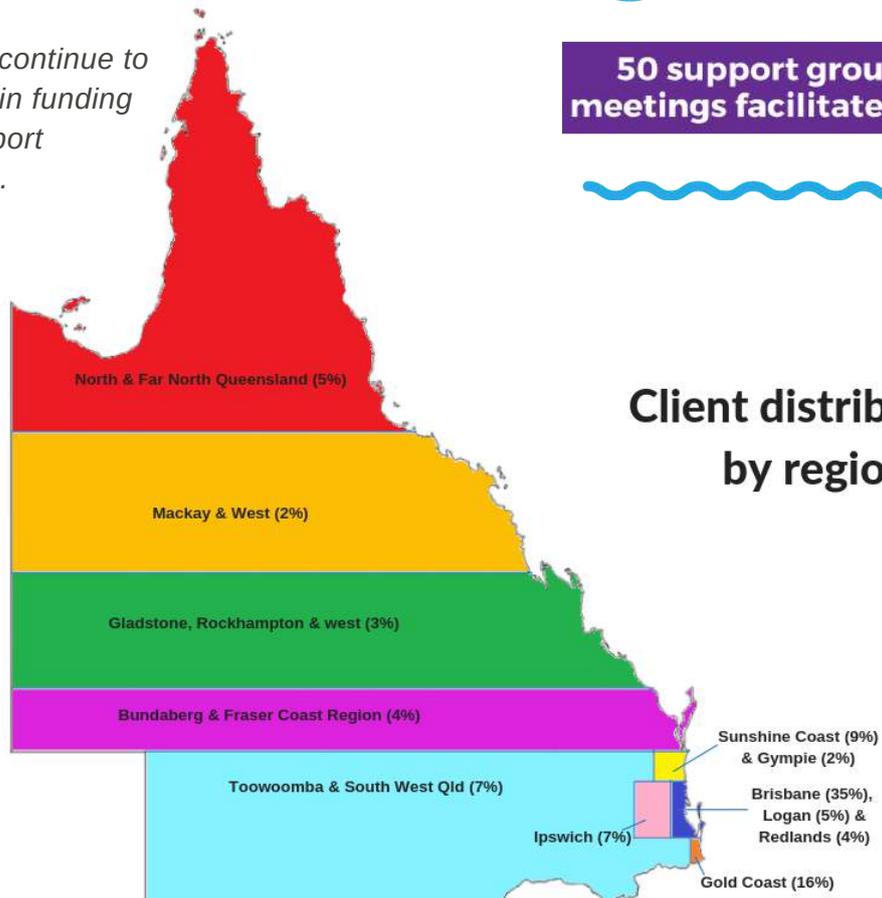
SERVICES

Regional outreach

HD families tell us that face-to-face time with our HD Advisers invaluable, and the team has clocked up many hundreds of kilometres trying to meet that need. With only 2.3 fulltime equivalent Client Services staff, this is no easy task! Our outreach service is currently funded by a Queensland Health grant through its Community Self-Care Program.

With the goal of building resilience and helping to foster connections between families, regional visits often include support group meetings, as well as one-on-one support for those who have requested this service. Where possible, the team also schedules education sessions for service providers, with the aim of ensuring that staff feel comfortable and confident in supporting a person living with HD.

Looking ahead: We will continue to lobby government to retain funding and explore ways to support families in regional areas.



2017/18 REGIONAL OUTREACH INSIGHTS

13 towns & cities visited

3.8 average visits per town this year

45 education sessions delivered

50 support group meetings facilitated



Support groups

Peer-to-peer support groups were one of the first services ever offered by Huntingtons Queensland – starting back more than 40 years ago.

Today, we host or facilitate structured meetings throughout the state to assist attendees to gather information, share experiences and forge support networks.

Some support groups feature guest speakers. This year we welcomed a physiotherapist, a youth social worker and partner Novacorr, who make specialised equipment for people living with HD.

Client feedback indicates that the support group program has an immediate positive outcome for many attendees, providing support, understanding, and information.

Attendees report they have left meetings feeling encouraged, and have taken comfort in sharing their story and hearing the stories of others.

We also acknowledge and thank the very generous volunteers who run HD support groups and social groups for families around the state, including those in Townsville, Redland Bay and the Gold Coast. Your knowledge, wisdom and understanding – often gained from first-hand experience – is priceless.

Looking ahead: Support groups are a key service for Huntingtons Queensland and our team will continue to look for ways to enhance the experience and outcomes for attendees. We are also considering options for a program of educational sessions on key topics to complement our support group program.

"You walk in the door holding this dark storm cloud over you, and you walk out filled with sunshine."

- Support group attendee





Non-clinical counselling

Non-clinical counselling is a critical service offered by Huntingtons Queensland, which is also funded by Queensland Health.

This service is generally offered in response to high- and low-level crises, requiring immediate, compassionate and professional engagement with the Client Services team.

Non-clinical counselling is offered by phone, email and sometimes face-to-face. Each team member spends an estimated one-fifth or more of their week engaging in non-clinical counselling.

NDIS planning & support

With the systemic changes brought by the National Disability Insurance Scheme, our team actively works to support families wishing to access funding through the scheme, and to ensure those who do not yet require NDIS support are prepared to apply when the time comes.

We support people through a combination of information, education and advocacy – working with families on pre-planning, attending meetings where NDIS packages are negotiated, and supporting both the individual and their service providers to receive the best support possible. Huntingtons Queensland is not an NDIS provider, enabling us to provide independent and unbiased support for NDIS applicants and recipients.

Looking ahead: *We are committed to increasing our knowledge of and connection to those working within the NDIS system. We believe there is an important role for Huntingtons Queensland to advocate for and support families with HD, while developing an education and information hub for service providers to meet our strategic goal of being the go-to organisation for Huntington's disease-related issues.*



2017/18 CLIENT SERVICES INSIGHTS



2,073 instances of support & services

8.4 services delivered each day



8 hrs/staff/week spent in unscheduled support

560 service provider staff received education



49 NDIS-related supports & services



Advocacy

Advocacy is a vital part of our work, where we support clients engaging with service providers, government departments and other agencies.

Examples include assistance with workplace relations issues, attending meetings to advocate for appropriate welfare or pension outcomes, and ensuring external agencies understand the possible and likely impact of HD on a person's ability to live safely and with dignity.

Advocacy is highly resource-intensive but essential to our mission of supporting people impacted by HD.

***Looking ahead:** We will continue our role in individual advocacy, however we recognise that advocacy is also important at a more political and systemic level. Where resources allow, our aim is to increase our visibility and advocacy work at this level in the year ahead.*

Information

The sharing of knowledge and dissemination of quality, trusted information in a range of accessible formats remains one of our most important and cost-effective services.

We are committed to providing timely updates on research and other developments through our links with international services such as HD Buzz (hdbuzz.net) and the Huntingtons Disease Youth Organisation (hdyo.org).

We value our role as the first port of call for anyone seeking information about Huntington's disease, and work to ensure that people are aware of the range of services available to them across the state, whether offered by Huntingtons Queensland or other agencies.

Looking ahead

In the coming year we will seek feedback from stakeholders as to their needs and preferences for information and review our existing information resources and channels.



Education

Growth in our education program this year has been very pleasing to see. This program helps service providers to improve their care for people impacted by HD, while offering workers strategies and tools to help them cope with the sometimes stressful nature of the disease.

Education sessions can be tailored and are delivered on a per-request basis, often in response to heightened crisis situations. Requests are often prompted by staff expressing concern over a lack of knowledge about the disease progression, or from increased difficulty providing care due to an individual's changing needs.

Sessions provide an overview of the science of Huntington's disease, the physical, emotional and cognitive symptoms, and various stages or progressions that staff may encounter.

Over the reporting period we also provided education to government agencies such as CentreLink and the Public Guardian in Brisbane and regionally, with the aim of increasing workers' understanding of HD and the complex needs of people seeking assistance.

Looking ahead: *We will develop our education program and resources further, and explore options for new services (eg. partnerships with allied health workers, financial planners, and health/wellbeing services).*



Based upon session feedback, approximately 90% of education sessions are delivered to staff and carers who have minimal to no experience with or knowledge of Huntington's disease.

"I will definitely encourage service providers with care recipients with HD to contact you for assistance and training. The knowledge I gained will definitely help me."
- Service provider feedback



RESEARCH UPDATE

On 11 December 2017, the biggest HD news in 25 years broke that an early clinical drug trial for Huntington's disease had proven both safe and, in its early stages, successful in reducing the levels of huntingtin protein.

The key things to know:

- It's currently called IONIS-HTTRx
- The drug has successfully passed the very first human safety trial. Initial results also showed a reduction in harmful levels of huntingtin protein
- Researchers do not yet know if a reduction in huntingtin protein will provide symptom relief - that will likely be tested in phase 2.
- Phase 2 trial sites have not yet been announced. It is unlikely there will be a site in Australia
- It is not possible to self-nominate for the trial. Participants are selected through current research cohorts and other methods. For now, people in Australia can participate in Enroll-HD (enroll-hd.org)

While we are cautiously optimistic about what the breakthrough means for people impacted by Huntington's disease, the reality is that available treatments will still be many years away. It is important that Huntingtons Queensland remains a steadfast support to those impacted by the disease today, tomorrow, and in the future.

Looking ahead: *Huntingtons Queensland is working behind the scenes with key partners to see how we can increase our chances of bringing a trial location to Queensland, even if this is some years away. We are also looking at how to improve our advocacy efforts.*

For up-to-date information on the Ionis/Roche trials, you can follow our Facebook page and **HD Buzz**, a blog by scientists for the public about Huntington's disease research.



ENGAGEMENT

EVENTS

Family fun days

Finding time to relax as a family can be a challenge, and when a family is dealing with the day-to-day impacts of Huntington's disease, spending quality time together is crucial. Time out allows everyone to recharge their batteries, engage with support in a relaxed environment, and encourage kids to be kids.

As part of Huntingtons Queensland's strategic plan to optimise the quality of life of people impacted by Huntington's disease, and with the generous support of the Alecca McKinless bequest, a series of Family Fun Days were hosted to provide no-cost respite days for families throughout Queensland.

While two regional Family Fun Days were planned in the reporting period, changing circumstances meant these could not proceed.

Looking ahead: *The response to these events was overwhelmingly positive, and with assistance from the Alecca McKinless bequest we will continue to hold Family Fun Days with little or no cost to participants.*

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

"Loved the casual flow of the day and the late lunch to finish things off."

*"I'm emailing to say
THANK YOU!
We had a lovely day
and enjoyed meeting
other families."*



Lighting the Way forum

Knowledge is power. Knowledge will light the way.

This was the message shared with more than 90 people at the inaugural *Lighting the Way* forum hosted by Huntingtons Queensland on 11 May 2018.

The *Lighting the Way* forum was created to provide information and connection for adults in the pre- or early-symptomatic stage of their lives.

The forum was designed as an opportunity for this target group, and others impacted by Huntington's disease, to come along, network, hear research information and engage with others in the community.

Registrations were fully subsidised by the Alecca McKinless bequest to ensure all attendees could attend free of charge.

The forum supported Huntingtons Queensland's strategic goal of distributing timely and high-quality information, raising awareness of the disease, and forging connections to better support people impacted by Huntington's disease.

The forum provided opportunities for a wide range of speakers, including researchers, psychologists, service providers, and individuals with personal experience of Huntington's disease.

A representative from the National Disability Insurance Agency was invited to speak, but pulled out the day before the forum.

Looking ahead: An annual forum will remain a key event in the Huntingtons Queensland calendar, with 17 May 2019 booked in for the next event. As with this year, the 2019 forum will be funded through the generosity of the Alecca McKinless bequest.

"It is better to light a candle than stumble in the darkness. That candle is information – let it guide you."

- Cliff Farmer, Founder

"For the first time in a long time, I felt like I could honestly be myself without having to explain myself or apologise for my movements. It's been a long time since I've felt this comfortable around a group of people."

- Forum attendee





HDYO Camp

Huntingtons Queensland is a proud partner and supporter of Huntington's Disease Youth Organisation (HDYO), which provides support and information to children and young people around the world impacted by Huntington's disease.

HDYO's website (hdyo.org) and interactive forums are a priceless resource for young people, and parents seeking information about how to talk to their children about HD, and we encourage anyone impacted by HD to visit the site and draw on its many evidence-based and age-appropriate resources.

In January 2018, Queensland was again host to the HDYO Camp in Australasia, where 60 campers and volunteers descended on the Sunshine Coast for four days of networking, information, support, workshops and fun.

Huntingtons Queensland supports HDYO's marketing and promotion for the event, and also attended in a voluntary capacity to support the activities and engage with campers.

Looking ahead
We will be working with HDYO to promote and encourage attendance at the inaugural youth conference, to be hosted in Scotland in 2020.





#LightItUp4HD

Huntingtons Queensland joined the global Huntington's disease community to acknowledge Huntington's Disease Awareness Month in May 2018. Throughout this month, communities impacted by Huntington's disease around the world share stories, encourage education about Huntington's disease, and work to raise awareness of the disease and support research to find a cure.

Part of the global awareness campaign included the #LightItUp4HD movement – a social media-driven public campaign to light up many public buildings around the world in blue and purple.

Huntingtons Queensland was proud to participate in #LightItUp4HD.

Involvement in this global campaign was important for Huntingtons Queensland's strategic goal of supporting efforts to end Huntington's disease by raising awareness about Huntington's disease in the general community, and gathering support of local government.

We are grateful to the following companies and councils that supported us by lighting up sites throughout Queensland

Treasury Brisbane
Brisbane City Council
Fraser Coast Council
Toowoomba Regional Council
Townsville Regional Council





FUNDRAISING

Huntingtons Queensland is proud and humbled to have community support for our work. We have a number of generous donors and community supporters whose generosity has enabled us to continue to provide services to people impacted by Huntington's disease in Queensland.

Government support

Huntingtons Queensland is grateful to receive support from Queensland Health to deliver many of our services to families around the state.

Grants

Huntingtons Queensland was grateful for the support of the Gambling Community Benefit Fund, which approved a \$13,000 grant to go toward a youth camp and \$1,500 for a new laptop for use in education sessions and client visits.

Direct mail appeals

Huntingtons Queensland runs two appeals a year to raise funds for services – just before Christmas and at the end of the financial year. These appeals were both very successful, raising a combined total of \$31,120.60. Pictured below is an image from our end of financial year campaign.



2017/18 INCOME INSIGHTS



\$31,120.60 generously donated across two fundraising campaigns

2 generous individuals left gifts in their will



Three dedicated community fundraisers

\$174,427 in government funding and support





Community champions

Community fundraising is a huge part of Huntingtons Queensland's community engagement.

Community fundraising is all about individuals who want to make a difference, raising money for causes they believe in, and rallying their communities to participate.

Huntingtons Queensland is lucky to have some amazing supporters.

Running for Nan's HD has become an annual event, organised and hosted by Brisbane runner Kelly Woodland, to raise awareness of Huntington's disease and raise funds for Huntingtons Queensland.

In September 2017, 50 runners pulled on their jogging shoes and gathered together at the bottom of Brisbane's Story Bridge to run together for Huntington's disease.

The run ended with a free sausage sizzle, plenty of smiles, and well over \$7,000 raised to support people impacted by Huntington's disease.

Our deepest gratitude goes to Kelly for organising the many participants, donors, supporters and members of the public to get behind this worthy cause in honour of her grandmother.





The Huntington's Marathons started in January 2018. Steven Blaine, whose mum Lenore was diagnosed with Huntington's disease, decided to raise funds for Huntingtons Queensland, and set about preparing to run a marathon each month throughout 2018, with a target of \$10,000.

At the end of the financial year, Steven was half-way towards his goal, and still running strong. Only a few days into July 2018, Lenore passed away peacefully. Steven made the decision to continue his challenge – to finish what he started, in honour of his mum.

Huntingtons Queensland is so proud of Steven and his family's marathon efforts, and their desire to help build a world free from Huntington's disease. We can't wait to see how the second half of his races unfold.



In the European autumn of 2017, Tony Davidson spent a week cycling along the extraordinary Italian and Austrian mountain ranges: **the Trans Alpine Crossing**.

Tony used this amazing trip to make a difference, and went about fundraising through family and friends. Through his close circle of supporters, Tony raised an incredible \$905.50 for Huntingtons Queensland. Thank you so much for using your cycling trip for good, Tony!



In February 2018, young Holly decided she could make a difference to two communities, so she created **Holly's Haircut for HD**. Holly will donate her hair to people undergoing cancer treatment, with all sponsor donations going to Huntingtons Queensland. Holly has already raised nearly \$200. Thanks Holly for your amazing support!





PARTNERSHIPS

HD Clinic

Huntingtons Queensland continues to work closely with the Queensland Health-operated Huntington's Disease Clinic (HD Clinic), which is held monthly at the Royal Brisbane and Women's Hospital.

Our Client Services staff and volunteers attend the clinic to provide support to clinic staff, chat with attendees and provide on-the-spot support where possible.

Novacorr

Queensland-based company Novacorr has developed and supplied Huntington's disease-appropriate furniture for many years.

Huntingtons Queensland is delighted to partner with Novacorr, and help clients access equipment that is safe and comfortable.



Spark NeuroCare

The partnership between Huntingtons Queensland and Spark NeuroCare continued in 2017-18, as services rolled out in Toowoomba.

Huntingtons Queensland was a founding member of Spark NeuroCare, alongside several organisations supporting people impacted by progressive neuro-degenerative diseases (PNDs).

Client Services worked closely with Spark workers during the reporting period to assist individuals with National Disability Insurance Scheme (NDIS) pre-planning, and utilising their approved packages.

The two-year pilot for the initiative ended on 30 June 2018, with several partners, including Huntingtons Queensland, deciding to withdraw.





THANK YOU

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

- | | |
|----------------------|------------------------------|
| Lech Blaine | Alys Longland |
| Susan Campbell | Mavis Pilla |
| Delmae Clark | Gwen Pratten |
| The Colley family | Roger Pratten |
| Eric Denham | Nathan Rowe |
| J & D Donnelly | Malcolm & Judy Scarr |
| Gerry Doyle | Graham & Louise Scott-Hunter |
| Eagle Bay Brewing Co | Denise Simmons |
| Stephen Earl | Dorothy Smyth |
| Michaela Eley | Appelien & John Stride |
| Jean Farmer | Townsville North Lions Club |
| Karen Fuller | Carol Thornton |
| J & L Hartkopf | Two Birds Brewing |
| Jaime Hicks | Bill Van Heel |
| Natasha Hills | Jody Williams |
| Jan Hoskings | Janifer Willis |

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

- | | |
|----------------------|------------------------------------|
| Diane Allan | Dr Joan Lawrence |
| Anonymous | Kerry Milliner |
| Cate Barrett | Peter & Ellen Noonan |
| Beecham Holden | Norma Robertson |
| Cindy Benjamin | Rockville State School |
| Joyce Bennett | Jan Samuels |
| Jeff Buchanan | Robyn Sheppard |
| Ron Butler | Richard Sivell |
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We offer our deep gratitude to Beryl Gillespie and Alecca McKinless whose kind bequests were realised this year.

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.

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



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



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