



HUNTINGTONS
queensland



ANNUAL REPORT

2015 - 2016

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AUSTRALIAN HUNTINGTON'S DISEASE ASSOCIATION (QLD) INC ABN: 45 130 081 598

Board/Management Committee for 2015-2016 Financial Year

Chair/President	Jeffrey Allen (<i>resigned August 2016</i>)		
Deputy Chair	Cate Barrett		
Treasurer	Janifer Willis		
Directors	Gerald Doyle Gwen Pratten Heather Whye*	Iris Broadhurst Jan Szlapak Jeff Buchanan	Peter Weekes

Life Members

Athol Mewett (1988) (Deceased)	Gwen Pratten (2001)	Jean Paterson (2009)
Maida White (1991)	Rob Farmer (2004) (Deceased)	Tom Paterson (2009) (Deceased)
Cliff Farmer (1994)	Ray Bellert (2005)	Gerald Doyle (2010)
Eunice Brooks (2001)	Barbara Gray (2005)	
Alison Hopgood (2001)	Anita Smith (2005)	

Honorary Members

Gary Johnston (1995)	Iris Broadhurst (2001)	John O'Sullivan (2010)
Joan Lawrence (1995)	Arnold Waugh (2001)	John Rowell (2010)
Christine Oley (2001)	Khory McCormick (2010)	

Staff

Executive Officer	Bernard Wilson*	Finance Officer	Jennifer Lysiuk
Client Services Coordinator	Lauren Ward	Service Support Officer	Elicia Wright*
Client Services Coordinator	Tuija Lindstrom*	Fundraising & Communications Officer	Caitlin Scarr*
Client Services Officer	Theresa Byrne		

Honorary Solicitor Auditor

Khory McCormick (Minter Ellison)
Paul Gallagher (BDO)

*Resigned in 2015-2016



Our Vision

A world free of Huntington's disease

Our Mission & Purpose

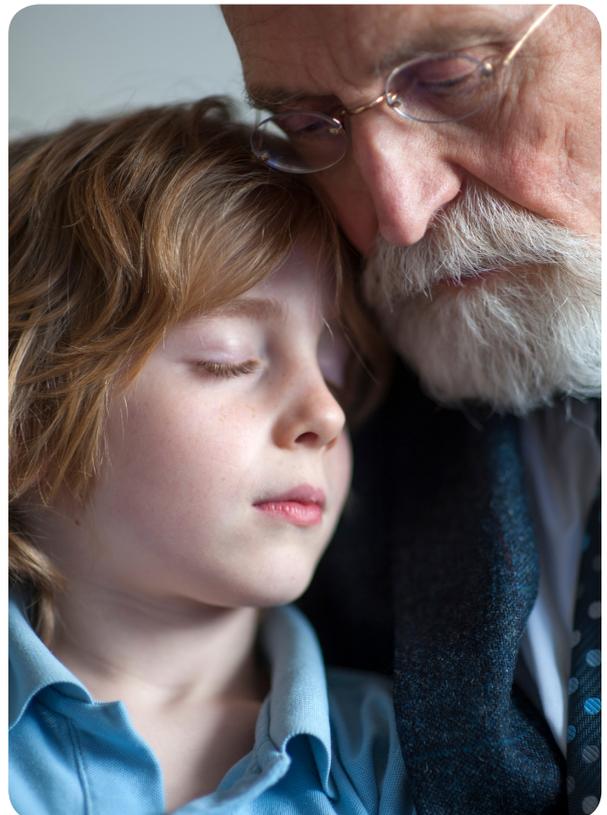
To provide professional advice and support to clients, their families and carers in the management and care of people at risk of and affected by Huntington's disease.

Our Values

EMPATHY. Understanding, anticipating, responding to and supporting with sensitivity the needs of those living with or impacted by the experience of Huntington's disease.

INTEGRITY. Being true to our mission, following through with our commitments, being reliable team members and being accountable for our words, our work and our actions.

CLIENT FOCUS. Being patient, persistent, collaborative and generous, listening carefully, acting with humility, fairness and respect.



Board Report

We are pleased to be celebrating the 40th anniversary of Huntingtons Queensland with you this year.

Huntingtons Queensland supports more than 250 people throughout Queensland living with Huntington's disease. Many more people are at risk of developing symptoms and many carers, families and friends share this challenge.

Our work this year has focussed on supporting individuals and families who are directly affected by the impact and progression of the symptoms of Huntington's disease – including those who find themselves under significant economic and social difficulty. We have worked hard to provide timely and useful information, facilitate support groups and deliver empathetic counselling.

Huntingtons Queensland has continued to share its challenges with many similar not-for-profit organisations in the midst of the National Disability Insurance Scheme (NDIS) implementation. The NDIS is the new way of providing support for Australians with disability, their families and carers.

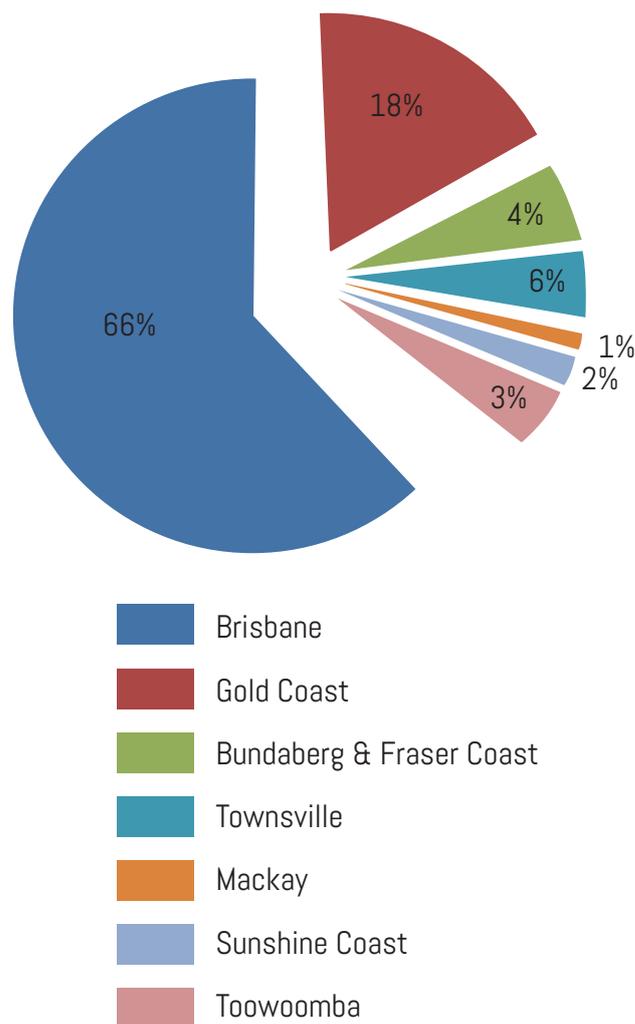
The NDIS will help people with disabilities to access mainstream public services, access community services, maintain informal support arrangements and receive reasonable and necessary funded supports.

The NDIS has been a major influence within Huntingtons Queensland as it is a significant change in the way organisations are funded to provide health, care and disability services.

It aims to ensure that all clients receive the level of services they require, when and where best meets their needs and the needs of their families.



Areas serviced by Huntingtons Queensland.



Board Report CONT.

Our Plans and Goals

Client Services & Support

Knowing and responding effectively to client needs and expectations.

Providing quality information and support services to people living with Huntington's disease, their families and carers.

Governance Performance & Sustainability

Ensuring sound and sustainable strategy, practices and accountability are observed.

Providing the organisational structure, financial support and organisational systems for a sustainable future.

Business Development Fundraising & Communications

Growing the business and effectively reaching as many stakeholders as possible.

Communicating the organisation mission, challenges and achievements across stakeholder groups and generate community awareness, goodwill and resources.

As a consequence, Huntingtons Queensland is unlikely to receive block funding after the end of June 2019. With this in mind, there was a need to carefully develop innovative methods to ensure services remain available to the more than 250 people and their families who are part of the Huntingtons Queensland family. One initiative has been our involvement in the Spark NeuroCare pilot. Since early 2015, facilitated by Jeff Allen, we have worked with seven other financial partner organisations to develop this exciting new service model.

Commencing in May 2016 in Townsville, Spark has provided additional staff to assist all people with progressive neurological diseases

in the development of support plans to meet the NDIS requirements for service. Early indications show strong signs that Spark will offer them greater support in service planning.

We continue to be indebted to Jeff Allen, who resigned as Chair of Huntingtons Queensland in August 2016, as he continues to facilitate the Spark Trial. Jeff's expertise and knowledge of Federal and State Government planning and initiatives cannot be underestimated. His ability to negotiate with seven other organisations facing the same challenges is testament to his commitment to the work of organisations such as ours.

Board Report CONT

Our Financial Report shows a net surplus of \$649,762 inclusive of depreciation. This surplus is largely thanks to generous bequest income of \$990,000 from the Harding-Smith Estate. This, combined with ongoing grants and Queensland Government funding, has enabled us to fund our operations effectively this financial year. Part of the bequest income included an investment portfolio and we have engaged Morgan Stanley to manage these financial assets. We very much appreciate the generosity of those who have chosen to leave bequests to us this past year, and whose support allows us to continue our services for the Huntington's community.

The Board and staff of Huntingtons Queensland participated in a strategic planning workshop in February to update and renew key planning priorities. Stakeholders should expect to see more growth as these plans continue to develop and advance.

Our **Client Services** team continues to travel throughout Queensland to provide support as resources allow. Support groups are facilitated and attended throughout the State and phone support to families is a major portion of our work. Highlights from this year's Huntingtons Youth Program etc (HYPe), run by our Client Services team, included events at WhiteWater World, Dreamworld and Sea World. Four families also had the opportunity to go on a family holiday to Turtle Beach Resort which was subsidised and supported by Huntingtons Queensland.

An inaugural **Supporters Gathering** was held in February to thank our donors and sponsors for their charity and kindness for the Huntington's community. Events such as the screening of the Twitch documentary, the Bridge to

Brisbane Day and the HD ProForum were also successful this year.

Huntingtons Queensland has made a pledge of \$30,000 in total to the Advance Queensland Innovation Partnership (AQIP) Program to support the University of Queensland grant application for a three-year program titled New Treatments for Brain Disease. We are listed as one of the collaborating not-for-profit organisations and are additionally assisting with recruitment of patients with Huntington's disease for clinical studies. Research continues to be a priority for our organisation in addition to our direct client services.

Our **Fundraising & Communications** area undertook several initiatives this past year including the Winter Family Appeal and Christmas Appeal. We have also refreshed our branding and launched our new website (huntingtonsqld.org.au). We extend a large thanks to the IOOF Foundation for their support in substantially funding the website upgrade.

This past year we have entered into a commercial agreement with our office neighbours, The Women's Legal Service, who are leasing the ground floor of Florence Dannell House. The added income will be most valuable, and we thank the legal team at Minter Ellison Solicitors for their support and Benn from Harvey-Walker Enterprises for undertaking the necessary building works.

Our thanks are extended again to the outstanding generosity of the late Thea Harding-Smith and the late Margaret Turner for their generous legacy gifts within their estates. These bequests, coupled with the support of our members and donors, enable our team to keep supporting clients and families affected by Huntington's disease.

Board Report CONT.

It is also important to acknowledge the many family and individual donors who support our work, including those who have been a valued part of our organisation for the past 40 years. We also thank our event and **community fundraisers**, including Kelly Stamnas, Andrew McGuckin, Katie Young and friends who have gone out of their way over the past 12 months to fundraise on our behalf.

In July 2016 we farewelled Bernard Wilson, Executive Officer since September 2014. Bernard's strong business planning and negotiation skills resulted in many significant achievements including the lease of our office's lower floor, which further assures us of regular income. Another of Bernard's many skills extended to fundraising, and with Caitlin Scarr appointed to the marketing and communications role, we secured grants for database and computer upgrades and benefited from several fundraising activities such as Cam Wilson's Slideways.

We recently welcomed Jan Samuels as our new CEO. Jan has an impressive history with many skills and broad experience in this sector in both Queensland and New South Wales. We warmly welcome her to our organisation and look forward to working closely with her to lead Huntingtons Queensland to further success.

Without the dedicated, highly skilled and professional staff of Huntingtons Queensland, past and present, we would not have achieved the results that enable us to provide services to people with Huntington's disease in Queensland. Theresa Byrne, Tuija Lindstrom, and Lauren Ward have been our tireless and amazing Client Services team. Caitlin Scarr and Kate Brooks have excelled in the fundraising and communications areas.

'Behind the scenes' we extend our thanks to Elicia Wright, Despina Gomez and Jennifer Lysiuk who ensure the cogs of our organisation continue to turn.

To the Board, and our advisors in Cliff and Jenny Farmer and Alan McKinless, we extend our deepest gratitude for the countless hours of voluntary work and support that enable Huntingtons Queensland to continue our work supporting those with, or affected by, Huntington's disease.

In our quest to support research and people with Huntington's, our expectations were exceeded this year, not only by the generous bequests of the Harding-Smith and Turner estates, and the ongoing support of the Peta Seymour Foundation, but also by the goodwill, best wishes and many donations made by so many Queenslanders.

And finally, we extend our best wishes for support and wellbeing to all families in the Huntington's community, and look forward to continuing our positive relationships in the new financial year.



Cate Barrett
Acting Chairperson

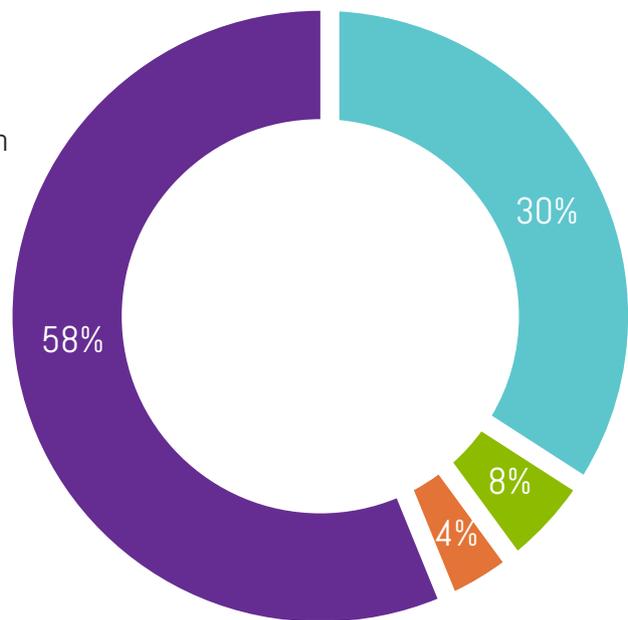
Finance Report

As the 2015-2016 Financial Year closes we are pleased to report total Members Funds/Equity of \$1,915,000 largely represented by the unencumbered value of Florence Dannel House (valued in 2014 at \$1,050,000) and financial assets managed by Morgan Stanley. Bequest income for the year was substantial at \$990,000 due to the very generous gift from the Harding Smith Estate. The Estate was made up of both cash and an investment portfolio. Payments to suppliers and employee expenses for the year were \$558,970 and bequest net income of \$925,767 was received, resulting in a net surplus of \$649,762 being achieved inclusive of depreciation of \$63,222.

Where the Money Comes From

Excluding the very generous bequest income, State Government funding represents more than half of the 2015-2016 Financial Year income, complemented by other grants, fundraising and donations, interest, fees and sundry.

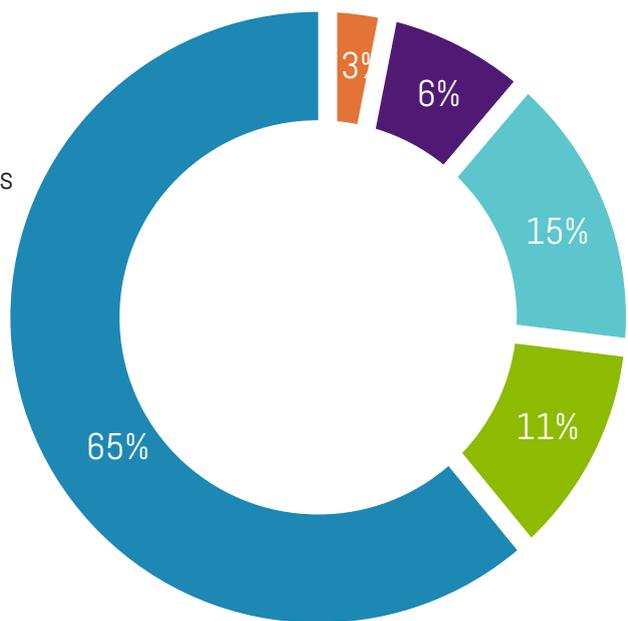
● State Government	58%
● Grants Other	4%
● Fundraising & Donations	30%
● Interest, Fees & Sundry	8%



Where the Money Goes

Our people represent more than 60% of the current operating expenditure, providing services and support. Capital works were completed on Florence Dannel House to enable the organisation to rent out the ground floor.

● Program Delivery	3%
● Employees & Contractors	65%
● Depreciation	11%
● Capital Works	6%
● Administration	15%



Client Services

The Client Services team continues to deliver support, advocacy and education to individuals and families affected by Huntington's disease across the State, while also working with colleagues and peers in the health sector to raise awareness of Huntington's disease and its impact.

Our team currently supports more than 250 clients across Queensland, including 80 people under the age of 50, and more than 110 people aged between 51 and 64. More than half of our clients live in the community, while just over 80 people (including those in their 50s and 60s) live in aged care facilities.

Queensland Demographic & Residential Setting	<50yrs	51-64yrs	>65yrs
Living in community with informal carer	41	46	20
Living in community without carer	18	23	7
Living in community with government-funded support	2	1	0
Residential aged care	7	35	47
Supported accommodation	3	3	0
Age appropriate residential care facility	1	0	0
Hospital	4	1	0
Acquired brain injury unit	0	2	0
No fixed address / address unknown	4	2	0
TOTAL 267	80	113	74

As at April 2016

Given the complex nature of Huntington's disease, our clients and their families have a broad range of support needs, and much of our work involves linking clients with the other services and support as their journeys progress. Likewise, outreach services and support by phone are important components of our work, as more than a third of our clients live in regional centres and towns.

Thanks to the financial support of Queensland Health, our Client Services team provided more than 1,000 non-clinical counselling sessions, shared information with more than 900 people, and facilitated support groups attended by nearly 300 people with Huntington's disease or their families around the state.

Huntingtons Queensland Services and Community Engagement Figures - 2016 Financial Year

Service Type	Instances	Recipients	Average Instances per month	Average Recipients per month
Information Provision	594	909	49.5	75
Non Clinical Counselling	1049	1347	87.4	112.25
Support Groups	31	276	2.5	23
Referrals	55	46	4.5	3.8

Client Services CONT

Huntingtons Youth Program etc (HYPe)

HYPe brings families and children together across the State to share experiences, renew friendships, have fun as a family, and allow young people to develop support networks within their age group.

This year HYPe delivered three programs for young people and their families. In September 2015 a wonderful was had by all at SeaWorld on the Gold Coast. In January we splashed into White Water World with a group of 18. In March we assisted four families to enjoy a family holiday at Turtle Beach Resort on the Gold Coast.

We would like to extend our great appreciation to Sunnybank Community & Sports Club for their longstanding support of HYPe and families living with Huntington's disease.

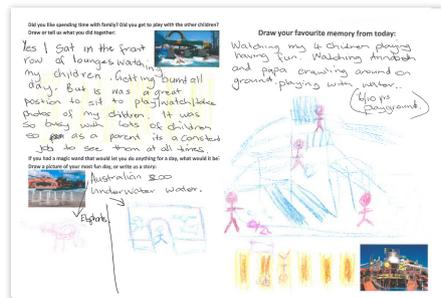
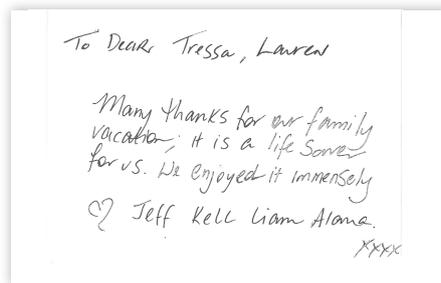
Case Study

We were thrilled to be able to offer a subsidised holiday to Turtle Beach Resort on the Gold Coast this past Easter. Four of the families who participate in our HYPe program attended along with our Client Services team. This was a wonderful break for the families and a great opportunity for them to create some exciting memories.

"Many thanks for our family vacation; it is a life saver for us. We enjoyed it immensely" – Jeff, Kell, Liam & Alana



Children thank you for Seaworld and Turtle Beach



Client Services CONT.

Support Groups

Huntingtons Queensland has established a number of Family Support Groups throughout the state, which provide a valuable opportunity for people to engage and interact with others in similar situations. Whenever possible, Family Support Groups are run in conjunction with our client services staff, but we also encourage and support community-facilitated groups to ensure members can meet on a regular basis.

Family Support Groups cover a variety of discussion topics, from daily life with Huntington's disease through to research and treatment options. They are a supportive and informal opportunity to seek information and support in a safe and friendly environment.



Groups are held in the following areas:

- Brisbane North
- Logan
- Townsville
- Gladstone
- Bundaberg
- Sunshine Coast
- Gold Coast
- Ipswich
- Toowoomba
- Redland Bay

Gatherings and supporters groups



Client Services CONT

Advocacy & Education

The Client Services team works with a number of other agencies acting as advocates, championing for the specific needs of people with Huntington's disease and their families. Throughout the 2015-2016 Financial Year our team helped clients in various areas providing direct support, including assistance to secure housing, navigate Centrelink, and access regional support.

Our **education tools and training resources** have also received positive feedback as we work with support agencies, aged care facilities and community centres to raise awareness of the unique needs and circumstances encountered by people living with Huntington's disease.



National Disability Insurance Scheme (NDIS)

With the implementation of NDIS beginning in 2016 our Client Services team are working with families to prepare for the upcoming changes. This includes liaising closely with the team at Spark NeuroCare in Townsville, assisting with referrals and education, and developing user-friendly documentation to help navigate these new systems.



RBWH Huntington's disease clinic

Huntingtons Queensland maintains a professional and collaborative approach with the Royal Brisbane & Women's Hospital (RBWH) Department of Neurology and the Huntington's disease clinic. The clinic is run monthly and we assist by providing emotional support to attendees, assisting with referrals, and funding and coordinating the provision of a light lunch for patients.



Fundraising & Communications

'Thank you!' This has been the catch cry for our Fundraising & Communications team as we have moved through a wealth of change and support in the organisation this year.

Highlights include the adoption of new branding and an improved ability to engage with stakeholders, which have contributed to a stronger fundraising finish than 2014-2015.

The year ahead presents even greater opportunities to promote our work and foster support, and the team is working cohesively to achieve the best outcomes possible.



REBRANDING

With the help of local design company Mollydookers, we have updated our branding, marketing collateral and signage this year. Huntingtons Queensland is now aligned with other Australian and international associations that use the blue and purple themes, which will lead to greater cohesion and effectiveness as we work to raise awareness and funds for services for people affected by Huntington's disease.

Original logo

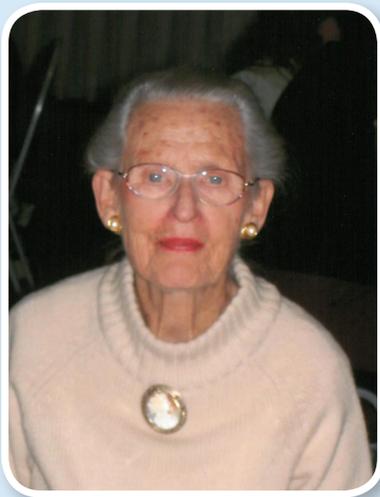


DL Brochure cover

Pull up display

Bequests

Huntingtons Queensland is honoured to have been remembered in the wills of Alethea Harding-Smith and Margaret Turner. By leaving a bequest, or gift in their will, these supporters entrusted us to honour their memories by supporting those in need.



Ms Harding-Smith, or 'Thea' as she was affectionately known, was a long-term and dedicated supporter of the work we do, and her generosity, both during her lifetime and in her passing, has had an immense impact. Thea was passionate about supporting families with Huntington's disease, and believed that the time that could be provided through support and respite was invaluable. We will continue this work in her memory.

Mrs Margaret Turner was another long-term supporter and was known to our staff as a very friendly lady who was passionate about supporting people living with Huntington's disease. We are so grateful to Margaret for ensuring that through her generosity we can continue to offer services that help to build hope for the Huntington's community.

Fundraising & Communications CONT.

GRANTS, TRUSTS & FOUNDATIONS

Huntingtons Queensland is grateful for the following support:

Gambling Community Benefit Fund

For providing funding towards a new database system. This new system will help us streamline our services for all our stakeholders, while improving our efficiency, effectiveness and engagement with supporters.



Peta Seymour Foundation

The Peta Seymour Foundation has provided a very generous grant that will enable our services staff to visit key regional areas and provide support in person. Through the Foundation's support our team will establish new connections and strengthen existing relationships, with the aim of encouraging sustainability and resilience for individuals and families affected by Huntington's disease at a local level.



IOOF Foundation

The IOOF Foundation has been a long-time supporter of Huntingtons Queensland, and the grant they awarded our organisation in March 2015 enabled us to construct a responsive new website. With 24/7 access, our new website is a valuable information tool that is helping us to reach and engage with more people across the state.



Sunnybank Community & Sports Club

The Sunnybank Community & Sports Club (SCSC) has been the key sponsor for our HYPe program for a number of years. The SCSC also provided significant in-kind support throughout the year, allowing us to connect with clients and their families in ways that would not be possible without their assistance.



Fundraising & Communications CONT.

DIRECT MARKETING

Direct marketing is a fledgling area for Huntingtons Queensland but we have seen solid growth over the past two years, which means we can now communicate directly with nearly 4,000 members of the community. Funds raised by direct communication are an important contributor to our sustainability and our capacity to offer services to people affected by Huntington's disease. We look forward to continuing our direct marketing campaigns to raise awareness and funds, and have plans to expand into the digital sphere in the near future.

COMMUNITY FUNDRAISING

Huntingtons Queensland is fortunate to enjoy the support of an enthusiastic and highly successful group of community fundraisers, who help to raise funds for services and operations. Taking part in everything from the annual Bridge to Brisbane Day to running their own amazing events, our community fundraisers play an invaluable role in supporting people with Huntington's disease and their families. We salute you.



INDIVIDUAL SUPPORTERS

Our individual supporters are the backbone of Huntingtons Queensland, and critical to our ability to offer services and raise awareness across the state. Donations, gifts and bequests comprise a significant portion of our income and will become even more important in future as changes to the way community services are funded come into effect over the next two to three years. We are privileged to receive assistance from many individuals whose generosity has such a positive impact on people whose lives are affected by Huntington's disease.



Fundraising & Communications CONT.

SUPPORTERS GATHERING

Huntingtons Queensland is proud to offer a special supporters' club known as The Torch Society, and we were pleased to host a small event in February, with thanks to the Sunnybank Community & Sports Club who provided the venue free of charge. The event was an opportunity to thank supporters in person while giving attendees a chance to hear a research update from Dr Susanna Mantovani.

Huntingtons Queensland will be partnering with Dr Mantovani and her team, providing financial and in-kind support to their research project, and we look forward to providing research updates to members, supporters and our broader community in due course. We recognise and appreciate the support given by the Thorsen Family Foundation into research into cures and treatment for HD via their financial support of the Wesley Research Institute.



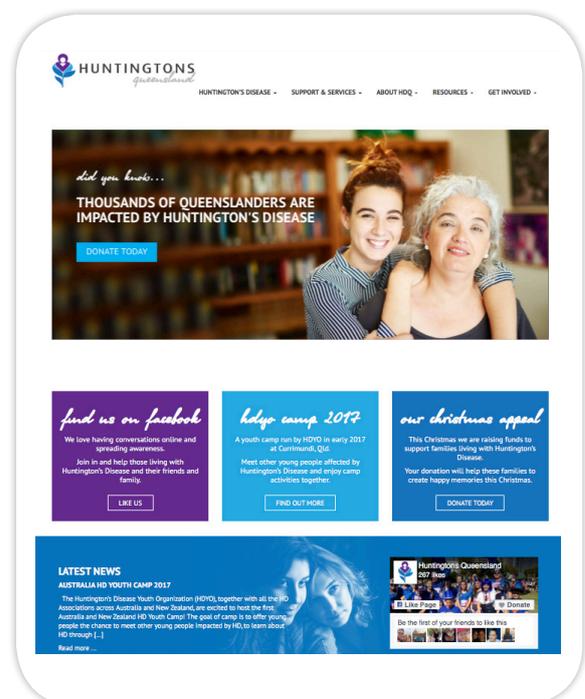
WEBSITE

Our new website (huntingtonsqld.org.au) was launched in November 2015, which now offers an integrated, user-friendly resource that includes up-to-date information about Huntington's disease and our organisation.

SOCIAL MEDIA & DIGITAL

Huntingtons Queensland has enjoyed a steady following on Facebook where we share research news, organisational updates and community media.

Our communications tools now include MailChimp, a user-friendly cloud-based email newsletter which allows us to communicate with stakeholders on topics they have identified as directly relevant to them. We look forward to developing this service further in the new financial year.



Thankyou to all our wonderful Sponsors



We are grateful for each and every donation we have received in the 2015/2016 financial year.

Huntingtons Queensland would like to acknowledge the funding support of the Queensland Government in delivering support and services to people living with Huntington's disease.



MAJOR DONORS

Barbara & Donald Gray
Betty Stabler
Chris Beecham
Cliff & Jenny Farmer
Dan Tuite
Dianne & Ken Allan
Eric Denham
Estate of Alethea
Harding-Smith

Forde & Jenny Williams
Heather Whye & Trish
Tritton
J & L Hartkopf
Joan Lawrence A.M.
Jody Williams
Joyce Bennett
Ken & Christine Gordon
Ken Horton

Margaret Turner
Norma Robertson
Order of the Eastern Star
Peta Seymour Foundation
Peter & Shirabdi Gordon
Richard Sivell
Sue Woodland
Tim Doyle

COMMUNITY FUNDRAISERS

Andrew McGuckin
Anita Wilson
Cassandra Buckley
Chantelle Youngberg
Hannah Blaine

Heather James & Family
Jaime Colley
Jared Smith
Julie Davies
Katie Young

Kelly Stamnas & Family
Lyn Griffiths
Sarah Crellin
Victoria Marie
William Wilson

COMMUNITY DONORS OF \$200 AND MORE

Alexandra Smith
Alistair Scarr
Andrew McGuckin
B. Gillespie
Bill Van Heel
C. Binnie
Clive Beecham
D. Clark
David Lennon
Ellen Noonan

Estate of
Cornelius Rote
G. Milliner
Gerry Doyle
Glynis McGuckin
Greg Ovenden
Gwen Pratten
I & S Campbell
Ian McGuckin
Janifer Willis
K. Neilson

Kate Speechley
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Lisa Milliner
M. Lupton
M. Scarr
Maida White
Marty Packer
Menzies Refrigerated
Transport
Narelle McGuckin
Paul Barnes

Peta Seymour
Foundation
QBE Insurance
R & M Turner
R & R Goodair
S & J Gauci
Scott Oxford
Sue Gossage
Sue Nadollek
W & C Van Heel

SUPPORTING ORGANISATIONS





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