

39th ANNUAL REPORT 2014 - 2015



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

BOARD/MANAGEMENT COMMITTEE FOR 2014/2015 FINANCIAL YEAR

Chair/President Gerald Doyle
Vice President Jeffrey Allen

Secretary Jan Szlapak (resigned 19.5.2015)

Treasurer Heather Whye
Committee Cate Barrett
Alan McKinless
Iris Broadhurst

LIFE MEMBERS

Athol Mewett (1988) (Deceased) Maida White (1991) Cliff Farmer (1994)

Eunice Brooks (2001) Alison Hopgood (2001) Gwen Pratten (2001)

Rob Farmer (2004) (Deceased)

Ray Bellert (2005) Barbara Gray (2005) Anita Smith (2005)

Tom Paterson (2009) (Deceased)

Gerald Doyle (2010)

Jean Paterson (2009)

HONORARY MEMBERS

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

TOWNSVILLE FAMILY SUPPORT GROUP

Chairperson Sue Bourne
Treasurer Janelle Mains
Secretary Bill Klaassen
Contact Person Jean Paterson

STAFF - JUNE 2015

Executive Officer Bernard Wilson (PT) Senior Welfare Officer Christine Fox (resigned 26.5.15 (FT) Client Services Officer Theressa Byrne (FT) Finance Officer Jennifer Lysiuk (PT) Service Support Officer Elicia Wright (PT) Fundraising & Caitlin Scarr (PT) Communications Officer

HONORARY SOLICITOR Mr Khory McCormick (Minter Ellison)

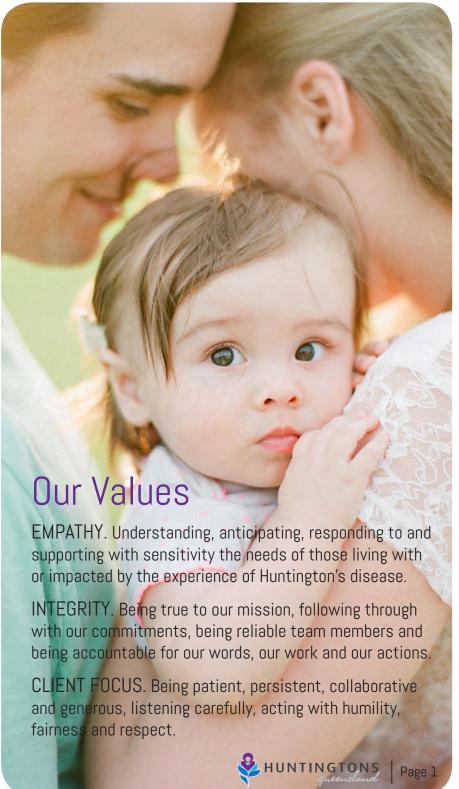
AUDITOR Mr Paul Gallagher (BD0)

Our Vision Our Vision



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 Plans and Goals

The three pillars of planning and prioritisation:

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

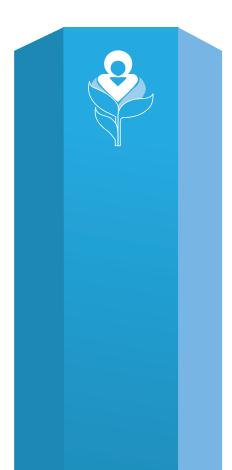
Ensuring sound and sustainable strategy, practices and accountability are observed.

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.







President Report

The challenges that Huntingtons Queensland has faced over the last few years have continued.

The Financial Reports show a loss of over \$150 000 inclusive of depreciation. During the year we have had to draw on cash reserves to continue to fund our operations which is not sustainable for the longer term. A new position has been created with a major focus on fund-raising. The total grant for the year from Queensland Health was \$160 890 and we sincerely thank Queensland Health for their ongoing support. Following many months of uncertainty, we are pleased also



to report Queensland Health funding levels will be continued for at least the next few years.

Very importantly, we have been advised of two significant pending bequests which should greatly relieve the current pressure on our financial position and future. We very much appreciate the sincerity and generosity of those involved.

A significant part of our future planning revolves around formal partnerships and becoming aware and ready for the NDIS. Huntingtons Queensland has joined the NeuroCare Network, an initiative of eight not for profit organisations who all work in the progressive neurological diseases space, with a view to offering care and support at a State-wide level supported by the specialised activities of the individual organisations.

In September 2014 Bernard Wilson joined HQ as Executive Officer. A number of staff — Christine Fox, Anne Stanfield, Helen Johnston and Jan Mealy left during the year and I would like to thank them sincerely for their work and support for HQ. New staff have joined us namely Jen Lysiuk, Caitlin Scarr and Elicia Wright covering administration, finance, fund-raising and marketing activities. We have also been very fortunate with keen volunteers to assist with our administration and welfare work and I would like to personally thank them one and all.

Welfare services continue to be the prime focus of our activities. Following the resignation of Christine Fox, Theressa Byrne and Bernard have continued to provide support, education services, guidance and advocacy for all of our families affected by Huntington's disease throughout Queensland. They have arranged support and carer group meetings throughout the state with these now occurring in Townsville, Toowoomba, the Sunshine and Gold Coast as well as Brisbane and surrounds. Unfortunately due to our financial position the day respite program ceased at the end of 2014.

Lastly I would like to thank my committee, staff, volunteers and all members of the Association for their support and assistance throughout the year.

Gerry Doyle

Executive Report

Discussion of the Huntington's community may best be undertaken with reflection and respect to the many hundreds of families living throughout Queensland and nationally, indeed throughout the world facing this most unique, pervasive and challenging neurodegenerative disease.

Huntingtons Queensland has registered over 250 people through the state living directly with Huntington's disease with many more living at risk of developing symptoms and with many more carers, families and friends sharing the burden.



These families live invariably with hope, love and pain. Each share the hope their generation will be the last, each dare to dream a cure or relief for themselves might come within their lifetime.

Our role at Huntingtons Queensland is to expertly support and understand the family journey, clearing a path and easing the burden where possible, and complementing the work being done throughout the health, community and research sectors. Our programs are based on providing timely and useful information, facilitating support groups and the provision of counselling; delivered with empathy and experience.

The team sees, speaks with or directly facilitates support for over 200 people every month and there is so much more we'd like to do.

We are optimistic about the year ahead, however we do not underestimate the challenge.

After quite a difficult and uncertain year with resourcing, in September 2015 we welcomed advice the Queensland government agreed to continue funding the Service Contract and which represents approximately one third of the current expenditure requirements.

With further resourcing from fundraising and with the organisation being the privileged recipient of several gifts in supporter wills we move forward. The key challenge remains however, how best we provide quality services to the Huntington's community within a sustainable business model and amidst a changing and competitive landscape.

The mainstay of our work throughout the year is in large part reflected in the valuable work of the Client Services team, being available for advice, support and advocacy to clients and families over the phone, in person, electronically, through Family Support Groups, Regional Visits, the HD Clinic at RBWH, community forums and gatherings.

In December last year the team coordinated a well attended family holiday occasion in Hervey Bay, and throughout the year a number of other events and activities for the younger HYPe participants including bowling, Movieworld, Seaworld, lunches and catch ups.

Executive Report CONT.

Our communications and fundraising activities included quite a significant direct marketing "Winter Appeal" which paid its way and generated several hundred new supporters, we continued our regular newsletters, the introduction of Facebook and conducted events including the Cam Wilson World Record Kart Race, the Bridge to Brisbane, the screening of "Twitch" and the HD ProForum for research, community and medical professionals.

Our challenges through the year reflected our uncertain resourcing. With diminishing reserves and state government intending to withdraw support, the organisation took up the case to convince government otherwise. Whilst ultimately successful maintaining government funding, most of the past year was within a climate of financial scarcity and concern. The possible sale of Florence Dannell House to maintain liquidity was actively considered, perhaps deferred only inasmuch as we received notification of the generosity of Ms Harding-Smith through her pending bequest.

A key impact and challenge for the organisation was the wind down of the Day Program at Florence Dannell House last year following a Management Committee decision taken much earlier in 2014. A difficult decision no doubt, and again a decision taken in a climate of financial scarcity.

The organisation also began to develop its fundraising capability and restructured to accommodate a part time fundraising and communications role to contribute to our target of financial sustainability.

Strategically the organisation additionally invested in the NeuroCare initiative, sponsored by MS Qld; a collaborative of eight Progressive Neurological Disorder (PND) organisations seeking to combine or resource a collective effort to better and more efficiently connect and reach out across the state to a shared client base. Whilst still in its developmental phase, there may be much to be gained by the conduct of a successful operational trial project.

The NDIS represents a fundamental change to disability and individualised funding intended to empower and resource the person living with disability or in the case of Huntingtons, debilitating and deteriorating symptoms. In addition to the role of assisting the Huntington's community understand the impact of the NDIS the organisation must also ensure its own relevance and funding stream to maintain viability.

Huntington's Queensland is a small team with a very significant statewide remit. Over the course of the past year we have farewelled personnel, a number with many years' service and we have welcomed others. On behalf of our wide stakeholder base I thank all those who have contributed, including members, families and volunteers, and I thank the current staff team, each part time but for the two full time Client Services staff and would mention especially Theresa Byrne for her commitment and exceptional empathy and service to clients and families.

Executive Report CONT.

At the Board/Management Committee level I would acknowledge and thank Gerry Doyle for his leadership and support as Chair and before handing over the reins to Jeff Allen in July 2015, and with whom we have all worked effectively. I thank all members of the Board for their care and concern, advice and support.

We acknowledge and thank financial partners in the Queensland government, the IOOF Foundation and Sunnybank Community and Sports Club. We thank additionally the many members and donors whom have contributed so generously at various junctures through the year.

We honour the life and memory of those who have so generously remembered Huntington Queensland in their wills and estates; in this past financial year; Mrs Patricia Ellen Parikka and Mr Cornelius Rote. The organisation has also received notification of pending and very generous bequests in memory of both Ms Thea Harding-Smith and Mrs Alecca McKinless. I note also the continuing legacy of Mr Raymond Burnip from the prior year, and many years before from Ms Florence Dannell. On behalf of the Huntington's community the organisation is privileged to receive such heartfelt and vital support in their memory.

The team looks forward to working with the Board throughout the year ahead, of better partnering, communicating and collaborating with the sector, adapting for the NDIS and consistently building and maintaining solid connections and support for families across the state.

Looking back over the year may I again conclude with lyrics from Leonard Cohen;

"Ring the bells that still can ring Forget your perfect offering There is a crack in everything That's how the light gets in"





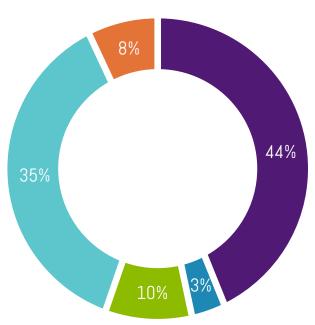
Finance

Total Members Funds/Equity of \$1.26M is largely represented by the unencumbered value of Florence Dannell House, value in 2014 at \$1.05M. Payments to Suppliers and Employee expenses increased to \$457 103 against the previous year and coupled with bequest income falling by \$45 285 resulted in net loss of \$155 074 inclusive of depreciation of \$47 898.

Where the Money Comes From

State Government funding represents less than half of the 2014/15 Financial Year income, complemented by other Grants, Fundraising and Donations, Bequest income and Interest, Fees & Sundry.

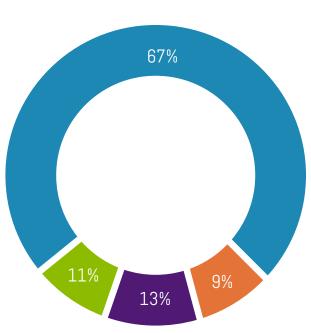
| State Government | 44% |
|-------------------------|-----|
| Grants Other | 8% |
| Fundraising & Donations | 35% |
| Bequests | 10% |
| Interest, Fees & Sundry | 3% |



Where the Money Goes

Our people represent more than 60% of the current expenditure program, providing services and support

| Program Delivery | 9% |
|-------------------------|-----|
| Employees & Contractors | 67% |
| Depreciation | 11% |
| Administration | 13% |



Client Services

Client Services is a team effort across the organisation. Led by the Board and the membership of Huntingtons Queensland and through the Executive Officer, from each of the Finance, Service Support and Fundraising roles, it's all hands to the wheel to support the Client Services staff comprising the Client Services Coordinator (CSC) and the Client Services Officer (CSO). The team combines and liaises to deliver the Programs and Services of the organisation to the individuals, carers, families and key stakeholders living with or impacted by Huntington's disease (HD).

HYPe (Huntington's Youth Program etc)

The HYPe program 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. Dozens of children and young people, along with their families, met at events across Bundaberg and south-east Queensland for bowling, MovieWorld, mini-golf, and one of the biggest family lunches seen yet in the program. Huntingtons Queensland is exceptionally proud to provide this respite and social program to at-risk children and young people in our community.

ANNUAL RESPITE HOLIDAY

A key event in the HYPe program is the annual respite holiday for families, funded in part by the generosity of the Sunnybank Community & Sports Club. In December, Huntingtons Queensland facilitated this respite event with lovely success. 32 family members from all across Queensland joined Client Services staff at Hervey Bay for outings to the beach, the waterslide park, the

aquarium, and a special group dinner at the local RSL. This wonderful holiday is a special opportunity for families to reconnect, enjoy respite and support, and build networks with other families.









HDYO(Huntingtons Disease Youth Organisation)

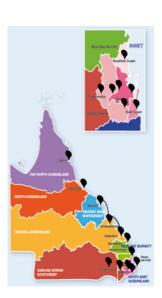
The HDYO forum in November was supported by Huntingtons Queensland as part of a national promotion by HDYO reaching out to impacted young people across Australia. A number of representatives spoke at the forum, outlining their motivation for involvement with HDYO, and many inspiring awareness and fundraising projects were presented.

Client Services CONT.

SUPPORT GROUP AND CATCH UP MEETINGS

Family Support Group (FSG) meetings and social catch-ups are a key and proud element of the vital services Huntingtons Queensland facilitates. Client Services staff ensured these meetings continued regularly across Queensland throughout the financial year, while also initiating a number of new support groups.

We are grateful to the many local family members who volunteered their time to assist in facilitating their local meeting group when Client Services staff were not available to attend. The Client Services team was pleased to provide coordination assistance in these circumstances.



Family Support Groups operate in the following locations:

- Brisbane North
- Brisbane East (Redlands)
- Gold Coast
- Logan

- Ipswich
- Toowoomba
- Sunshine Coast
- Hervey Bay/Bundaberg
- Gladstone/Rockhampton
- Mackay
- Townsville
- Cairns

Bundaberg's new support group for younger people is quickly gaining popularity, and in August, Client Services staff launched the inaugural Logan support group, attracting locals, people from Beaudesert and from Brisbane's southside. Gladstone's first support group had 10 people attend, with some travelling from as far as Yeppoon.

The Townsville support group works particularly hard to ensure they maintain monthly meetings, and this is facilitated and organised by dedicated local families. We are so grateful for their enthusiasm and commitment to the local community. New EO Bernard was delighted to visit the region in November to attend the local meeting and meet some of our north Queensland community.

Coffee Catch Up, the Brisbane-based group, was well-attended throughout the year, and attendees have used this group as a basis for forming solid support networks outside the meetings. The organisation acknowledges the support of the IOOF Foundation for their funding contribution to this program.

ADVOCACY

The team is regularly called on to offer advice and act as advocates for the special demands which may be presented for families and individuals. In 2014/2015, the team provided advocacy to individuals, families and professionals by: attending case conferences and QCAT hearings for clients; providing assistance and support to families preparing for relocation by working with Public Housing; assisting in the search for more appropriate schooling options; and assisting a number of families in regional areas in their decision to find permanent home placements for loved ones.



Client Services CONT.

Huntingtons Queensland staff liaise with companies to train service providers, contributing to better health outcomes for our community, while also participating in forums and education sessions to explain HD and its far-reaching impact on individuals and families. In support of a submission by Huntington's NSW to the Senate Enquiry on Younger People in Residential Aged Care in Australia, Huntingtons Queensland provided supporting statistics for people currently under 65, evidencing the significant shortage of appropriate residential care facilities for younger people with HD.

National

NDIS

disabilityinsurance Scheme

The NDIS represents a significant and welcome change for disability funding nationally. It will seek to empower the

person living with a disability or serious illness as they become the purchaser or customer of local support services. Scheduled to commence July 2016, the NDIS may represent a better model of funding and financial support for people living with HD, and Huntingtons Queensland will support the Huntington's community in representing their specialised requirements.

DAY CENTRE

After more than 20 years in service, the Day Centre program at Florence Dannell House was wound down in November, principally due to budget restraints. Where possible, participants were supported to be a part of other and mainstream community programs. The Management Committee would take this opportunity to thank and acknowledge the contribution of all those whom had been a part of this important program over the years.

HD CLINIC

Key to the Huntington's health network in Queensland, the HD Clinic is run on the first Friday of each month at the neurology department within RBWH. Clients see



a range of specialists and practitioners including dietician, speech pathologist, psychiatrist and neurologist, and have the opportunity to participate in HD research activities and programs.

Huntingtons Queensland is pleased to attend and support the HD Clinic and liaise with the Clinic team in coordinating and facilitating the Clinic schedule. HQ also acknowledges the financial support for sandwich catering at the Clinic provided in memory of Mrs Alecca McKinless.

INFORMATION SESSIONS

The Client Services team travels across the state providing education and information sessions to the variety of service providers supporting clients with Huntington's disease. In 2014/2015, staff provided at least one education session per month in response to queries and requests from service providers.

Client Services CONT.

COMMUNITY

The organisation supported a QUT Social Work student from August to complete a 500-hour social work placement. Through this time the student joined Client Services staff for a number of in-home visits, support group meetings, the HD Clinic, visits to nursing homes and assisted in the Day Care activities.

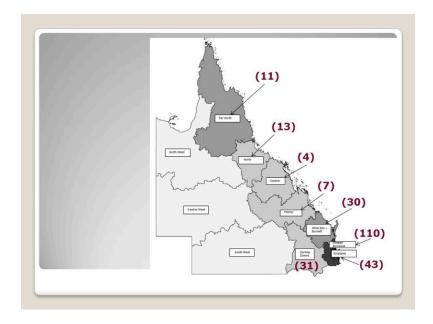
COMMUNITY ENGAGEMENT

Our engagement and contact within the community takes the form of phone, in-person, written, family support groups and community and education forums across the state and with the help and input of many supporters, families members, service providers and volunteers.

Huntingtons Queensland Services and Community Engagement in 2014/2015 Financial Year

| Service Type | Instances of Service throughout 2014/2015 | Personal Contacts at Provision through- out 2014/2015 | Average Instances of Service each month | Average Personal Contacts each month |
|--------------------------|---|---|---|--|
| Information Provision | 794 | 1350 | 66 | 113 |
| Non Clinical Counselling | 1697 | 2175 | 141 | 181 |
| Support Groups | 73 | 732 | 6 | 61 |
| TOTAL | 2564 | 4257 | 214 | 355 |

Client Distribution Across Queensland:



Fundraising & Communications

A key principle of Fundraising and Communications is a belief in the value and importance of the work and services HQ and the Client Services team provide! If ever there was a deserving community, it is the individuals, families and loved ones of people living with this most devastating disease.

What keeps the FunComs effort going is the commitment to ensure there is appropriate resources available to continue to stand alongside and deliver programs and support to the Huntington's community needs.

We can't do it alone. We need all of Queensland to get behind Huntington's!

Following on from the valuable telemarketing work done over the past many years the organisation undertook a modest restructure to introduce a Fundraising & Communications Coordinator (FRC) role (part time) in March. The four key pillars of Fundraising were direct marketing, bequests, major gifts and grants, trusts and foundations. The FRC also provides the coordination of publications, the website, newsletters, social media, events and community relations.



NEWSLETTERS

Huntingtons Queensland published four newsletters in the 2014/2015 financial year, reaching more than 700 recipients on each occasion. Newsletters are a useful snapshot into the recent goings-on of the organisation, and cover topics including client services updates and activities, important upcoming events, research updates, staffing updates, client stories, tips for carers, and a variety of other useful insights for clients, carers, members and friends.

SOCIAL MEDIA

We kicked off our social media presence in February 2015 on Facebook, and have seen it grow slowly and steadily over the months to accumulate close to 150 "likes", with larger reach per post, and steady interaction from followers. The page is used to post a variety of information and updates, with a



particular focus on research updates and stories from around the world, and allow a direct line of communication with a new, digital crowd.

GRANTS

In September 2014 Huntingtons Queensland gratefully received another round of annual funding from the Sunnybank Community & Sports Club for our important HYPe program. This funding helps us organise the annual Family Holiday, and a variety of other HYPe events, including children's outings and family lunches. In May we were thrilled to receive grants from the IOOF Foundation for our new website, atop their regular support for the Coffee Catch Up group.

Fundraising & Communications CONT.

DIRECT MARKETING

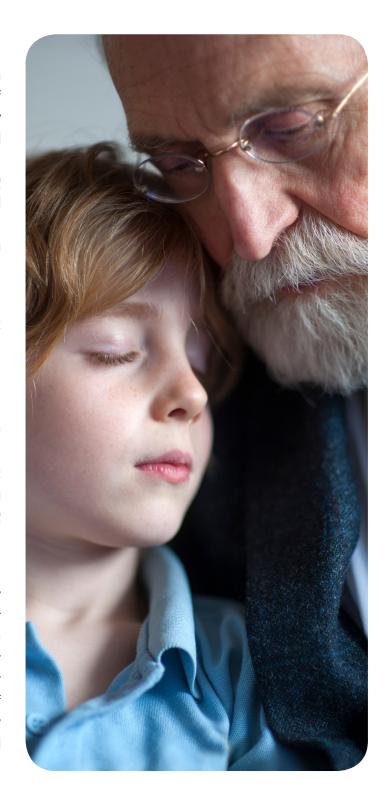
Direct marketing efforts were extended in May and June 2015 by targeting a new list of potential donors: the 3,000 contacts held by our partners at Multi Direct. These people had purchased an item in support of Huntingtons Queensland in the past 12 months, making them significant potential sponsors. We had a pleasing response, and our own personal database of supporters grew significantly as a result.

WEBSITE

We remain very grateful for the ongoing support of Diane Allan. Diane voluntarily created, and has continued to manage, the Huntingtons Queensland website for more than a decade, and we are so thankful for her wonderful efforts! Huntingtons Queensland will soon be launching an exciting new website which our staff will manage. We were thrilled to receive a grant from the IOOF Foundation to assist us with this, and look forward to the fast-approaching launch date!

DATABASES

Huntingtons Queensland is continually improving methods of communication with our many stakeholders. By improving our database system, we will be able to deliver faster and more targeted communications to our community, and improve access to our staff and resources. Our electronic news is now delivered through free MailChimp software, and has made a significant difference to our digital news.



Fundraising & Communications CONT.

ACTIVITIES & EVENTS

September Awareness Month 2014 was supported by the Salvation Army both in Queensland and New South Wales. We are very grateful for the support of all 33 local stores, who held special sales and donation opportunities for people to support Huntingtons Queensland and raised significant funds for our local community.

Cam Wilson really kicked 2015 off for us in February with a stunning World Record in endurance Indoor Kart Racing. For the second year in a row, he undertook a momentous challenge: the greatest team distance travelled in 24 hours. In 2013, Cam successfully challenged the individual distance in 24 hours, and 2014 was just as successful! His amazing team drove 774km – or 4,868 laps – in 24 hours to claim the Guinness World Record, while raising thousands of dollars for Huntingtons



Queensland. Congratulations once more to Cam and the team for their amazing effort, and for supporting people impacted by Huntington's disease. You are an inspiration!

Our office is never so busy that we can't include a few fun events along the way! For the first time in years, our organisation entered a team into the 2015 Bridge To Brisbane, held in August 2015. 30 people travelled across south-east Queensland to join "Team Huntingtons" and walk a very enjoyable 5km in the beautiful Brisbane sunshine. The event was so enjoyable we are already preparing for next year's event!

Huntingtons Queensland marked the 2015 September Awareness Month by hosting the inspirational Kristen Powers as she toured Australia with her documentary



Twitch. The free community screening at the Real Estate Institute of Queensland was followed by a Q&A with Kristen, and the supportive crowd of about 40 people from our community, including a local councillor, enjoyed the opportunity to mingle and quiz Kristen about the documentary and her plans for the future. Twitch is due to for digital release towards the end of 2015.

Vale John MacMillan

Huntingtons Queensland proudly and respectfully acknowledges the life and work of Associate Professor John MacMillan, who passed in December 2014. Professor MacMillan worked as a clinical geneticist, assisting the Huntington's community through research and his practice.

Begnests

Huntingtons Queensland is privileged to be the recipient of bequests from generous individuals who believed in leaving a lasting gift and legacy to support Queenslanders living with Huntington's disease.

Huntingtons Queensland is proud to honour their life, memory and generosity.

Mrs Patricia Parikka

Mr Cornelius Rote

Mrs Alecca McKinless



Thankyou to all our wonderful Sponsors

We are grateful for each and every donation we have received in the 2014/2015 financial year. Thank you to those who gave what they could to help us help our community.







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.

K Horton

COMMUNITY DONORS OF \$200 AND MORE _

Alan McKinless
AN Longland
Bernard Wilson
Beta Sigma Phi:
Epsilon
Bill van Heel
Carly Snodgrass
Damien Keune
Dan Tuite
Danielle Walton
Delmae Clark
Despa Sendra
Eric Denham
G Phillips
Gerry Doyle

Glen Sexton Pty Ltd
Graham Aston
Graham Scott-Hunter
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Jack Flitcroft
Jan Hall
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John Clark
John Stride
John Zamofing
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June Long

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Kay Ward
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Mrs M Lupton
MacDonalds (Pialba)
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Malcolm & Judy Scarr
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Transport
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Rebecca Johnson
Rob Turissi
Rotary Club of Cairns
S & J Gauci
Stephen Earl
Townsville Family
Support Group
William Norris
Grill'd South Bank
In Remembrance:
D'Arcy Osbourne
I&S Campbell

MAJOR DONORS _

Alethea Harding-Smith Betty Stabler Cliff & Jenny Farmer Joan Lawrence A.M. Jenny & Forde Williams Jody Williams Joyce Bennett Ken & Diane Allan Margaret Turner Chris Beecham Mel Deacon Norma Robertson Peter & Shirabdi Gordon Richard Sivell

COMMUNITY FUNDRAISERS

Cam Wilson Leisa Tuite Peta Banks

Hannah Blaine Heather James & Family Megan Evans

SUPPORTING ORGANISATIONS ___

















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