



**Annual report 2016-2017** 

#### **Contents**

Our mission & strategic plan	3
President's report	4
Treasurer's report	5
CEO's report	6
Our impact	8
Partnerships	16
Research	17
Communicating our work	18
How we raise funds	19
Our community champions	20
Donors & Bequests	22
Life & Honorary Members	22
Supporters	23
Contact us	24

#### **Board**

President	Gerry Doyle
Vice President	Cate Barrett
Treasurer	Janifer Willis
Secretary	Jan Szlapak
Director	Jeff Buchanan
Director	Gwen Pratten
Director	Peter Weekes

# **Honorary solicitor**

Khory McCormick, Minter Ellison

# **Auditor**

Paul Gallagher, BDO

# **Staff**

Chief Executive Officer
Client Services Coordinator
Client Services Officer
Finance Officer
Service Support Officer
Fundraising & Communications

Jan Samuels^ Lauren Ward Theressa Byrne Jennifer Lysiuk Despina Gomez\*, Susan Conaghan Kate Brooks\*, Caitlin Scarr\*\*

^Acting CEO Sonja Gilchrist 11/16-02/17
\*Left during year \*\*Communications only



The Huntingtons Queensland team at June 2017.

#### **OUR MISSION**

To support individuals, families & carers impacted by Huntington's disease.

#### **OUR STRATEGIC PLAN**

In 2016 Huntingtons Queensland marked 40 years of service to the HD community, thanks to the dedicated support of our members, donors, volunteers and staff. As we look to the future, we have recently developed

a new strategic plan for 2017 to 2020. The new plan continues to build on the legacy and wisdom of those who have guided our organisation while responding to the dynamic changes in how social services are now delivered.

Our strategic plan for 2017 to 2020 focuses on three key priorities:

- Improving the **quality of life** for people living with Huntington's disease, their families and those who care for them;
- Supporting efforts to end HD; and
- Ensuring the **sustainability** of our organisation.

#### **OUR VALUES**

**Client focus** People are at the heart of everything we do.

**Integrity** We do our best, with honesty and transparency.

**Agility** We are flexible and responsive to changing needs.

**Collaboration** We are all stronger by working together.



#### PRESIDENT'S REPORT



Huntingtons Queensland continues to face many challenges as the not-for-profit industry has changed in recent times regarding government policy changes, the NDIS and the like.

The Financial Report for 2016-17 shows a loss of \$39,997 for the year. Although our cash reserves remain strong, having a sustainable financial base for our future remains a key priority for the Association.

The total grant for the year from Queensland Health was \$169,965 and we sincerely thank Queensland Health for their ongoing support.

The other items of revenue – donations, other grants, bequests and fundraising events – are becoming much more important for our future. I would like to sincerely thank all those who have contributed to this effort.

As mentioned previously Queensland Health advised that our current funding will cease from 30 June 2019.

A significant part of our future revolves around building formal partnerships. In 2014, Huntingtons Queensland joined The NeuroCare Network. Through this partnership we have seen HD families utilise their NDIS packages in the rollout in Townsville and this has now extended to Toowoomba.

Our CEO, Jan Samuels, has led our team of staff in a most professional and capable manner and I would like to express my thanks to her and the Huntingtons Queensland team for their work in helping to make the lives of those affected by HD better.

They have arranged support and carer group meetings throughout the state with these now occurring in Townsville, Toowoomba, the Sunshine and Gold Coasts as well as Brisbane and surrounds.

During the year we have seen an increase in the number of HD clients registered with Huntingtons Queensland. We are currently supporting some 300 families throughout Queensland, including some new families who have connected with us this year.

Lastly, I would like to thank my Board, staff, volunteers and all members of the Association for their support and assistance throughout the year. I do not intend to remain as President past 2018 and so the Association is looking for new people to become involved with HQ at the Board level.

Gerry Doyle
President

#### TREASURER'S REPORT

The majority of funds are from government but this year we have made a good move with better use of the asset. Total Members Funds/Equity is represented by the unencumbered value of Florence Dannell House (\$1.047M) and financial assets of \$873,363.

The Board has invested the very generous bequest from the Harding-Smith estate under the management of Morgan Stanley. We have seen the value of these funds, under prudent management, increase by \$93,000 in the past year.

Capital works on Florence Dannell House last year has enabled the organisation to better utilise the asset and assist with rental income, decreasing our reliance on generous State Government funding.

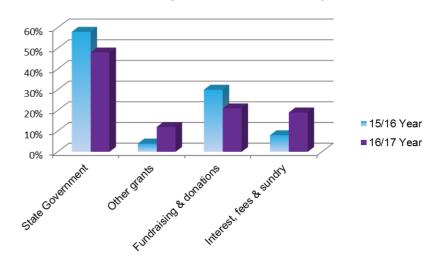
Other grants have enabled specific projects to be initiated for the betterment of the organisation.

Excluding generous bequest income, State Government funding represents 45% of income, decreasing from 58% last year.

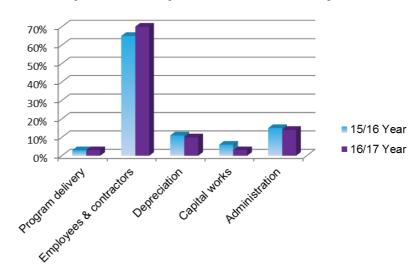
Our people represent 70% of the current operating expenditure providing services and support directly to our members and those requiring our support.

Janifer Willis Treasurer

# Percentage breakdown of income sources for past two financial years



# Percentage breakdown of expenses for past two financial years



#### CHIEF EXECUTIVE OFFICER'S REPORT

The 2016-17 financial year has been a busy time of transition for Huntingtons Queensland.

Major impacts have included the introduction of the National Disability Insurance Scheme (NDIS), and ongoing changes to the aged care system - the largest structural changes in the Australian health and welfare sectors in decades. How services are funded, and how governments interact with smaller agencies such as our own, are also radically altering how community and social services operate.

Internally, we have also undergone a period of change.

I am proud that our team has continued to focus on supporting families while the board and I work to ensure the sustainability of Huntingtons Queensland.

I was privileged to join the Huntingtons Queensland team in October 2016, working with a board who combine professional and business skills with first-hand understanding of living with HD.

I was assured by the expertise of our Client Services team, Tressa Byrne and Lauren Ward, who have such long experience with HD and disability, and by the calm, focussed approach of our Finance Officer, Jen Lysiuk. (I'd also like to acknowledge and thank Stan Lysiuk, who has so kindly volunteered hours of his own time to help audit and support our book-keeping and accounting needs.) In 2017 we farewelled two staff but welcomed back Caitlin Scarr as Communications Coordinator, and recruited Susan Conaghan as Service Support person extraordinaire.

I am also pleased to report that through the very generous gift of the late Alecca McKinless we will soon add a third person to our Client Services team, directly supporting individuals and families living with HD. It has been a great pleasure to work with Alan McKinless, Alecca's devoted husband and long-term supporter, to finally see Alecca's wishes brought to fruition.

We rely heavily on members and donors to fund services, backed by the grant we have received from Queensland Health to provide client services across the state. While very welcome, this government funding expires in June 2019, presenting great challenges to our future.

Finally, I would like to make special mention of an extraordinary meeting in Rome in May, when families impacted by HD met Pope Francis. While I respect the fact that many people prefer not to talk about HD, the Pope's proclamation that Huntington's disease should be "Hidden no more!" was a major opportunity to bring the challenges and reality of living with Huntington's disease into the open.

As our 40th year draws to a close, I would again like to thank our members, volunteers, donors, supporters and partners for working with our team to make a positive difference in the lives of people impacted by Huntington's disease.

Jan Samuels Chief Executive Officer



Life member and long-term supporter Alan McKinless with CEO Jan Samuels.

300 families

supported

661
face to face
support sessions

319 email support sessions 815
phone support sessions

785
non-clinical
counselling
sessions

1,517
people engaged in person

# How we operate

Huntingtons Queensland was established in 1976 by a dedicated group of people who were concerned about the lack of information and support for families impacted by Huntington's disease.

Today our organisation is an incorporated association and registered charity with tax deductible status. We have a volunteer board, drawn from the Association's membership, and a small team of paid full- and part-time staff based in Brisbane who provide services across Queensland as resources and capacity allow.

The board meets monthly to oversee governance and strategy, and to direct the CEO. Executive and management duties are separated, but further overseen by a board committee structure, including the Finance, Audit and Investment Committee (FAIC). Risk is managed at board and management level, as well as through contracts and service agreements.

Huntingtons Queensland is a membership-based organisation and new members are warmly welcome, however anyone can access our services at any time.

66 You enter the support group with a dark cloud hanging over your head and leave with sunshine and light.

- Client

#### **OUR IMPACT**

Our Client Services team is in the business of supporting families. The number of connected HD families across Queensland has grown this year, and our services reflect this growth. We offer one-on-one and group support, information, advice and non-clinical counselling, advocacy, education, and assistance for individuals accessing the NDIS.

#### **Tailored services**

Providing flexible, client-focused options can be challenging in a small workplace. Our Client Services team offers customised services to families and service providers across the state every day.

Demand fluctuates throughout the year, and requests for assistance often have short time-frames, especially if families are in crisis.

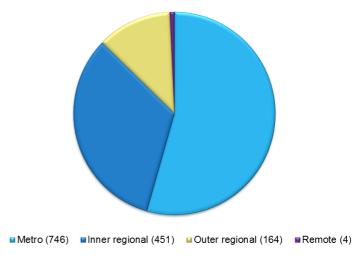
# **Support groups**

Local support group meetings are one of the most important support tools available to HD families, and the Client Services team works hard to ensure that this has remained an option for families throughout Queensland.

Families meet periodically to catch up on the latest research and treatment information, seek advice on a wide range of topics and issues, and simply socialise in a supportive, friendly environment.

Support group meetings have evolved from client feedback to suit the interests and needs of families in different regions, and will continue to be a focus of the Client Services team in coming years.

#### **Client distribution across Queensland**



Many families confirm that our support groups are one of the few opportunities they have to meet and talk openly with others who truly understand what they are experiencing. Huntingtons Queensland is grateful to Queensland Health for funding this much-

individuals attended
30
support group meetings this year

needed service.

Most who attended were carers or people at risk of HD, wanting to access the support of other carers, or who were seeking information and preparation.

The main topics of interest were treatment, research, recommendations for medical professionals, options for IVF treatment, and mental health.

# **One-on-one support**

Weathering HD alone can sometimes feel insurmountable. That's why Huntingtons Queensland offers **one-on-one**, **tailored support** for individuals and their families in challenging circumstances or when navigating complex systems.

This service remained the most sought-after option throughout the financial year, with our team receiving many **phone calls** and **emails** each day requesting their support or assistance in a wide range of areas.

Non-clinical counselling also makes up a significant amount of the work done by the Client Services team. This services helps clients make informed choices and understand the challenges and options available to them.

One-on-one support is about assisting clients to access the services they need to achieve **better quality of life**.

Our team assists clients to navigate systems like **Centrelink** and the **NDIS**, source **accommodation**, interact with family during challenging circumstances, and simply provide advice and someone to talk to.

Individuals and families choosing one-on-one support have been able to find more appropriate accommodation, engage in conflict situations with support to achieve a resolution, and complete difficult government department requirements for financial or social support.

Client Services Officer Theressa has worked closely with individuals to ensure improved support and better quality of life.



# **Advocacy**

People with HD often face difficulties in the workplace or when dealing with government agencies, largely due to **lack of public awareness or understanding** of the disease.

Our Client Services team works at grassroots level to help **educate** and **inform** these companies as to how best support their employee, customer or client.

We have also seen an increase in demand for our team to support clients in liaising with government and other agencies since the **launch of the NDIS** and believe this will be an area of work that will continue to grow in coming years.

Clients have also requested support and advocacy when seeking accommodation, mental health and work-related services.

These services can be complex, and are made more challenging for clients when their contact does not know of or understand Huntington's disease.

# **National Disability Insurance Scheme (NDIS)**

The NDIS is now more than halfway through its rollout in Queensland.



Celebrating the first anniversary of the NDIS in Townsville, the Hon Coralee O'Rourke, Minister for Disability Service & Seniors; and Minister Assisting the Premier on North Queensland. Several of our Townsville clients have already secured significant NDIS packages.

Our Client Services team **directly supports clients** by providing information about the scheme, and assisting people to prepare for their interviews with NDIS assessors.

We are also supporting clients with identifying suitable service providers and **working with providers** to ensure the clients' needs are understood and can be met.

For the majority of clients who were successful in receiving NDIS funding, many of their packages were substantial in providing funding for a wide range of necessary services.

Prior to the NDIS rollout, many people in Queensland impacted by Huntington's disease **did not receive any funding** or government support.

Huntingtons Queensland is continuing to monitor the rollout and support clients as they apply and proceed through the transition and funding process.

# **HYPe & young people**

The impact of Huntington's disease can be challenging, particularly for children, teens and young adults. This is often compounded when they don't know anyone else their age going through the same thing.

The Huntington's Youth Program etc (HYPe) was established to provide a **peer support network for and young people** impacted by HD based around social outings and activities.

A significant opportunity for young people is the increased presence of the international Huntington's Disease Youth Organisation (HDYO) in Australia.

Huntingtons Queensland actively supports HDYO, and will continue to work with the HDYO team in 2017-18 to support young people across Queensland as well as further afield. See pages 12 & 13 for more.

# **Spark NeuroCare**

Huntingtons Queensland is proud to be a founding member and financial contributor to Spark NeuroCare, an initiative of The NeuroCare Network which supports people living with progressive neurological diseases (PND) to access the NDIS.

Phase one of the Spark program was launched in Townsville in 2016 and had secured funding worth more than \$3 million for registered clients, including several people with HD, by the close of the 2016-17 financial year.

Our team works with Spark NeuroCare staff to ensure our clients in Townsville have access to professionals who understand HD and its complexities. We also provide **education and training** to our Spark colleagues and are available as an expert resource as required.

Phase two of the Spark NeuroCare initiative will be rolled out in Toowoomba and potentially other regional centres in 2017.

We are pleased to confirm that Huntingtons Queensland will continue to play an active role in funding and supporting service delivery for the program.





# **Family events**

Families are the driving force behind Huntingtons Queensland's focus. Families are at the centre of Huntington's disease and its impact.

Our team is very aware of the significant impact and strains that HD can place upon families – particularly those with children and young people, who often perform roles in the family usually reserved for parents, grand-parents or carers.

In response to client requests to extend support for families with younger members, Huntingtons Queensland is planning a range of regional family-friendly events.

Our goal is to assist families in developing local peer support networks to provide opportunities to **build resilience** and create some wonderful memories for all involved.

Families have told us that these events are invaluable in developing strong **social connections** and providing short-term respite for everyone.

We will continue to support other events that are targeted to children, teenagers and young adults – such as the Huntington's Disease Youth Organisation (HDYO), which you can read about on the next page.

# HDYO camp 2017

We are proud to have participated in the inaugural Australasian Huntington's Disease Youth Organisation (HDYO) camp held at the Sunshine Coast in January 2017.

Hosted by HDYO, an international organisation that supports children and young people impacted by Huntington's disease, this camp was free for attendees, and saw **42 young people aged 14 to 25** come from around Australia and New Zealand for four days of support, peer networking and fun.

Activities were designed to promote resilience and a deeper understanding of how to deal with the emotions associated with HD.

Campers participated in everything from scientific research seminars to rock-climbing, and the staff and volunteers facilitated discussion groups and one-on-one support.



HDYO 2017 Australasian camp.

Responses to the camp were overwhelmingly positive, and we have maintained contact with a number of young people – including some who were not previously connected to Huntingtons Queensland – as a result.

A second HDYO camp will be held at the Sunshine Coast in early 2018, and we are pleased to note that our team will again be involved in facilitating and assisting at the camp.



# Why are these events important?

"Considering I have never met anyone else (beside family) with HD. To know that there are people (especially youth) who are in similar situations is empowering and relieving. Oh, and it's also a great respite for carers!"

"I felt like I am normal, which I missed out on as a kid. So it was great to feel like we are all connected."

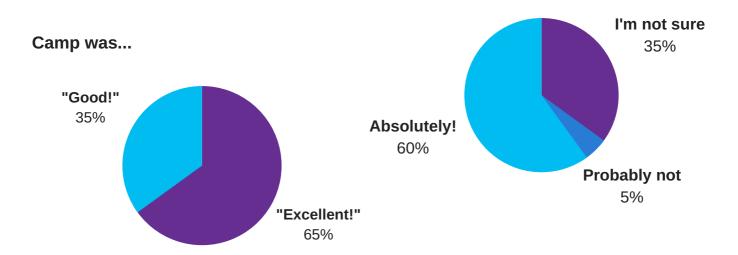
"It has been encouraging and hope-building, and I feel like maybe all is not lost and something good might happen in research. I have never felt so understood in all my complexities in my entire life! Thank you from the bottom of my heart. It really makes me feel less isolated."





"It has been amazing to get to know people in the same boat as me and also at a similar age. Camp has been an amazing way to hear about people's experiences with HD and to learn more info about it"

#### Camp will help me cope better



#### **EDUCATION & TRAINING**

The growth in education opportunities has been a highlight in the 2016-17 financial year. Huntingtons Queensland delivers education to a wide range of industry, government and family stakeholders, with the aim of achieving long-lasting positive impacts on the wellbeing and care available for people living with HD.

"Lauren shared her passion with us and it made the presentation pleasant and easy to engage."

"We would love you to come back regularly."

"Excellent information and clear understanding of Huntington's was gained."

"Thank you for the work you do."

"It was concise and educational."

"I now know a lot more about HD and how it affects individuals."

"Thank you, clear information, easy to understand, explained well."

"Very informative as a practical application base."



30+
education sessions delivered this year.

Sessions are customised to meet the needs and interests of each audience, with a range of 'toolbox' resources and follow-up sessions provided to ensure recipients feel comfortable and confident in their training.

The greatest demand came from residential facilities and supported accommodation, where staff caring for a person with HD recognised a need for better understanding of the complexities of HD in order to provide appropriate care.

These requests often come at a time when the person with HD is experiencing a change in health or behaviour.

Our sessions focus on sharing strategies for managing change, ensuring staff are better equipped to support the individual.

The ultimate aim is for the person with HD to maintain **quality of life** throughout the various stages of their disease, while offering **reassurance** to family members wherever possible.

Evidence suggests that our education program has had a **positive and tangible impact** for many clients living with HD in the past year.

Examples include clients whose accommodation is now more stable and secure than in the past, families who report that their family member seems more comfortable in their living environment, and staff who report that they feel better able to provide appropriate care.

#### A case for education

Sarah (not her real name) was living in supported accommodation with staff who simply didn't understand her disease.

What the staff perceived as "behavioural issues" resulted in Sarah being sent to hospital regularly while **being put at risk** of losing her accommodation.

At the request of Sarah's family, and with encouragement from the staff where Sarah lived, our Client Services team delivered a number of training sessions. Our team also drew on the assistance and intervention of Dementia Support Australia, with the result that the residential staff gained a **better understanding** of Sarah's condition.

The staff have since introduced strategies to support Sarah, stopping the continual hospital admissions, and ensuring she is both **comfortable and more secure** in her accommodation.

# A wider impact

Sarah's sister Anna (not her real name) has seen the improvements in Sarah's mood and quality of life. It has not always been easy, but with Huntingtons Queensland's support and services, things are much better now.



My family has been supported by Huntingtons Queensland in countless ways, for several

years now: from helping us negotiate available services, mediating frayed relationships in the community, supporting us at the HD Clinic, running the support groups, providing education to health and residential care providers, to advocating for the rights and well being of our vulnerable family members.

Living interstate, I've never met Lauren and Theressa in person, but every phone call is answered with empathetic support, in a way that makes the future possible even though that day brings another exhausting challenge.

Thank you for helping us to look after ourselves whilst we work together to support affected family members.

Living with or being impacted by HD is an epic battle and I feel our combined efforts are making a difference.

Thank you for celebrating the special moments with us - for understanding that playing the piano or enjoying a warm shower, or wearing clothes named for the person who brought them, are victories over the ravaging effects of HD on our family member's sense of self.

To all the staff and management team at Huntington's Queensland, we could not travel this path without your help.
Thank you for your work and the skill and compassion you bring to this work.

#### **PARTNERSHIPS**

Building partnerships enables us to offer more services and options to members and clients.

We have a range of partnerships with private, NFP and government bodies, and work with them to ensure families living with HD are supported to access the services they need, while remaining safe and as independent as possible. Referrals are also important.

Our team regularly works with agencies such as Centrelink and the Office of the Public Guardian, as well as those involved with housing, financial services, employment, family violence and the justice system.

We are also working with the NDIS's Local Area Coordinators and new NDIS service providers.



The official Spark launch at James Cook University, Townsville, attended by the Hon. Coralee O'Rourke, Minister for Disability Services & Seniors and Minister Assisting the Premier on North Qld.

#### Key relationships this year have included

- Dementia Support Australia, formerly the Dementia Behaviour Management Advisory Service (DBMAS)
- Homeless Connect (Micah Project)
- Ozcare
- · Queensland Health

- Royal Brisbane & Women's Hospital neurology clinic
- Spark NeuroCare
- The NeuroCare Network
- The Public Trust
- Numerous residential and supported accommodation facilities throughout Queensland.

# **RESEARCH**

In response to client interest, Huntingtons Queensland has placed a priority on supporting and promoting local, national and international research projects wherever possible.

Through donor and supporter gifts, we are currently part-funding an exciting research program that is looking into possible links between sleep and Huntington's disease.

The research is being undertaken by Dr Susanna Mantovani, a researcher for the University of Queensland and Wesley Medical Research. We also share information about other research projects and clinical trials, with the aim of helping families to access information or take part in projects that may be of benefit to them both now and in future generations.

Current opportunities are shared on our website and through social media channels as they come to hand.

We look forward to extending our involvement in Queensland-based research projects in coming years as resources allow, while continuing to focus on our core services and support for clients and members.

#### **Palliative Care Forum 2016**

In August 2016 Huntingtons Queensland was proud to co-present the Huntington's Disease Palliative Care Forum with our partners the Royal Brisbane and Women's Hospital and Brisbane North PHN.

The one-day event, held at RBWH's Education Centre, brought together nursing, medical and other healthcare professionals working in hospital, residential care and community settings.

The forum provided participants with an opportunity to improve their knowledge of Huntington's disease and palliative care practices while earning RACGP continuing education credits. There was also an opportunity for delegates to network and share their experiences with HD and palliative care issues.

Speakers included Dr John O'Sullivan, Senior Visiting Neurologist, who provided a clinical overview of advanced HD symptoms and their treatment, and Dr Rodney Marsh, Senior Visiting Neuropsychiatrist, whose presentation focused on the management of late stage psychiatric symptoms in people with HD.

Palliative care specialist Dr Carol Douglas also provided insights and advice on advance care planning and palliative care in HD.

Feedback from participants commented on the complexities associated with end of life and speech pathology for HD patients, with several attendees requesting copies of resources and videos depicting day-to-day life for a person with HD.

Several presentations from the Forum are available on our website.

#### **COMMUNICATING OUR WORK**

We have worked hard to increase our engagement with the HD community this year, particularly through the use of digital technology. This has led to more personalised, timely, two-way communication between our team and stakeholders, while enabling us to cut costs and divert resources into direct services for clients and members.

#### **Newsletters**

Feedback suggests that our newsletters have always been popular with members and clients. They are a great way to provide organisational updates, share information about the latest on research, and promote the great work that our supporters and donors are doing on behalf of people impacted by HD.

We will continue to share members' and supporters' stories, important updates, and exciting research through our newsletters, which are now available online as well as by hard copy.

# **Digital communications**

Huntingtons Queensland's digital revolution has continued, with our website and Facebook pages providing 24-hour information and engagement opportunities for individuals and families in Queensland - and throughout the world!

We are pleased to report that through our online and social media presence we have linked in with several new HD families in Queensland, and have been able to support and promote the activities of others who are working to raise awareness and funds to support families impacted by Huntington's disease.

#### Information resources

Huntingtons Queensland is committed to providing quality resources that are relevant to clients, families, members, service providers and health professionals.

Resources developed this year include NDIS information packs, brochures for the HD clinic, general fact sheets and information about Spark NeuroCare.



We will continue to develop our digital strategy for the coming year to encompass greater outreach and social connection.

We are also working to track our reach more effectively, which helps us to target our communications and provide greater value to our community, while saving precious time and cutting administrative costs.

#### **HOW WE RAISE FUNDS**

Huntingtons Queensland relies on funding from a range of sources to finance our operations.

Channels include grants, sponsorships, investments, bequests, and the generosity of our members and supporters, who respond so positively to our campaigns and who undertake a range of community-based activities to raise funds for our services.

In 2016-17, some 48% of our funding came from Queensland Health, for the purpose of providing information, advice and non-clinical counselling to people impacted by Huntington's disease and their families.

Our funding from Queensland Health expires on 30 June 2019 and it is fair to say that if it is not renewed, we will face significant challenges in being able to provide services to the Huntingtons community.

# Mail-outs & appeals

Huntingtons Queensland relies heavily on mail-outs to raise funds to support our work.

Our fundraising campaigns use clientinspired stories to provide insights into some of the challenges of living with HD, while providing opportunities to make a real, tangible difference.

We are very grateful for the generosity of so many in the wider community for supporting people living with Huntington's disease through our mail-out campaigns.

Despite a greater focus on digital communications, our team is aware that not everyone has – or wants – to access to computers, the internet and emails.

As such, we are very happy to mail hard copies of important documents, including our newsletters, to anyone who cannot access information online or to those who simply prefer to receive information the good, old-fashioned way!



An image from our 2017 Winter Appeal, highlighting issues of homelessness for people living with Huntington's disease.



#### **SALUTING OUR COMMUNITY CHAMPIONS**

# **Running for Nan's HD**

The inaugural Running for Nan's HD event was held in September 2016 in Kangaroo Point, Brisbane.

Local member Kelly Stamnas developed, organised and hosted the event as a fundraiser for Huntingtons Queensland, inspired by her grandmother, who lives with Huntington's disease.

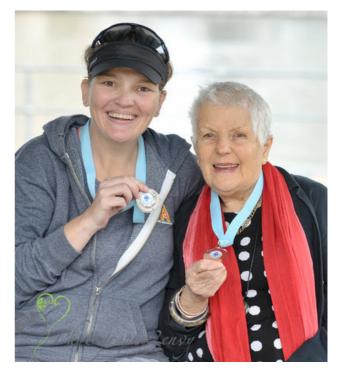
Kelly's event – a fun-run in the park – was her fundraising grand finale after completing three half-marathons.

More than 60 participants (and a dog!) faced the drizzly early Sunday morning to run in support of Huntingtons Queensland.

Through Kelly's efforts and through the support of this community, she was able to raise more than \$11,000 to support our services for people living with Huntington's disease.

At the time of writing Kelly was well into preparations for her second Running for Nan's HD event, scheduled to take place in the latter part of 2017.

We hope this will become an annual event, and sincerely thank Kelly, her family and friends for such a massive undertaking.





# **Andrew's 100km challenge**

Family member Andrew McGuckin threw comfort to the wind when he signed up to walk the 100-kilometre Oxfam Challenge in Brisbane in June 2016. Andrew chose to walk in support of Huntingtons Queensland, and raised an amazing \$8,364 for people living with Huntington's disease.

Andrew and his team raced for a gruelling 20 hours and 27 minutes through bushland and up some very steep hills, arriving at the end line at about 3.30 in the morning, two hours ahead of schedule and in 13th place overall! An amazing effort, and for two very important causes.



#### **Forte School of Music**

Forte School of Music (Windsor) hosted an inspiring fundraising event for their young music students, with friends and family pledging donations based on the students' learning over the semester.

These young pupils worked hard, and together raised \$3,368.30 for people living with Huntington's disease.

Congratulations and gratitude are offered to all who participated, and to the lovely Angel McIntosh, owner of Forte School of Music (Windsor), for organising and facilitating the fundraiser.



#### **WE CAN'T THANK YOU ENOUGH!**

# **Major donors**

Charmaine Binnie

James Callum

Cliff & Jenny Farmer

Christine Hammond

Joan Lawrence

Richard Sivell

**Betty Stabler** 

Forde & Jenny Williams

Natasha Weaver

Janet Sutherland

We also acknowledge several major donors this year who have requested anonymity.

# **Bequests**

Susan Arnison

# **Honorary members**

Iris Broadhurst

**Gary Johnston** 

Joan Lawrence

**Khory McCormick** 

**Christine Oley** 

John O'Sullivan

John Rowell

Arnold Waugh

# **Donors \$200 - \$500**

Joyce Bennett

Deb Cook

James Callum

Delmae Clark

Ed Craven

Gerry Doyle

Catherine Fitzpatrick

Michael Gattas

LV & JM Hartkopf

June Long

D & S Howe

Janelle Mains

Alan McKinless

Old Shared Services

Jan Samuels

Alastair Scarr

Dorothy Smyth

Appelien & John Stride

**Jody Williams** 

#### Life members

Ramon Bellert

**Eunice Brooks** 

Gerry Doyle

Cliff Farmer

Rob Farmer (deceased)

Barbara Gray

Alison Hopgood

Alan McKinless

Athol Mewett (deceased)

Jean Paterson

Troy Paterson (deceased)

Gwen Pratten

Anita Smith

Maida White

# **Organisational supporters**

On behalf of families living with Huntington's disease, we acknowledge the generous support we have received this year from the following organisations. It would not be possible to deliver services to our community without you.



















ABN 45 130 081 598

Florence Dannell House 385 Ipswich Road (PO Box 635) ANNERLEY QLD 4103

Phone: 07 3435 4300

Fax: 07 3391 8833 admin@huntingtonsqld.org.au

huntingtonsqld.org.au

