



HUNTINGTONS
queensland

Spring 2018 news flash



A few photos from the 2016 & 2017 Running for Nan's HD fundraising events, with Nan featured on the left.

Running for Nan's HD 2018

We are excited to welcome people to Wynnum **this Sunday 9 September** for the annual *Running for Nan's HD* event, a fundraiser for Huntingtons Queensland organised by Kelly Stannas.

Kelly's Nan is a much-loved lady living with HD whose smile lights up the room. Kelly has been so inspired by her Nan, and the desire to help, that she has been running and raising funds and awareness for Huntingtons Queensland for a number of years.

The run will kick off at 6.30am on the Wynnum foreshore, and entry is just \$25. All are welcome to attend, and can either walk or run the 5km or 10km distance (your choice entirely).

If you'd love to participate but can't be there in person, you can still register, and then complete the distance 'virtually' – you select your favourite walking or running track, complete the distance, and we send you a finisher's medal in the mail.

We also have a few raffle tickets available for sale – tickets are \$2, and you can win a wonderful array of prizes, including two tickets to see Bon Jovi live in December in Brisbane.

Register or purchase raffle tickets online by visiting huntingtonsqld.org.au/run or call our office on 07 3435 4300.

We hope to see you there.

Thank you, Rotary!

We're enormously grateful to the Ipswich North Rotary Club for their recent generous support. On 3 July, our CEO Jan joined the Rotary Club at a dinner event in Ipswich to speak with attendees about the impact of Huntington's disease on many families throughout Queensland, and to accept a generous donation to Huntingtons Queensland.

Huntingtons Queensland was chosen as one of a handful of recipients by outgoing president Richard Horne during their annual changeover process.

This donation is accepted gratefully and will be used to support the wide range of services our team provides throughout Queensland. Thank you so much to Ipswich North Rotary Club for your generosity – we are very thankful for your support.



Left to right: CEO Jan Samuels & outgoing president Richard Horne

Include a Charity Week

Starting 10 September, Australian charities will acknowledge 'Include a Charity Week', the annual fundraising event.

'Include a Charity Week' was designed to make Australians to think about long-term support of their favourite charities, and to encourage individuals to consider leaving a gift in their will to their preferred charities.

Huntingtons Queensland has been the humble recipient of a number of gifts donated through wills.

It is a donation that we take very seriously, as we understand how emotional the decision, and the situation, is for the donor and their family.

If you would like to know more about the value of leaving a gift in your will, or would like to know how to do so, you can contact our CEO on 07 3435 4300, email fundraising@huntingtonsqld.org.au or talk with your solicitor about how to do this.

Thank you so much to those who have made the decision to support a charity in your will – we are so grateful for your generosity.

Support group calendar

Visit huntingtonsqld.org.au/support/whats-on for a list of all upcoming events and support groups.

October

2 - Gympie	10 - Brisbane
3 - Bundaberg	19 - Townsville

November

13 - Toowoomba	23 - Logan
14 - Brisbane	27 - Ipswich
16 - Townsville	

December

4 - Redlands	14 - Sunshine Coast
11 - Gold Coast	21 - Townsville
12 - Brisbane Christmas party	

Family Fun Day

We're planning another Family Fun Day before the end of the year, with details coming soon

Welcome to the board!

In August, Huntingtons Queensland welcomed three new board directors who will fill casual vacancies until the AGM. Donna Burns, Shane Kelly and Susanna Mantovani bring a wide range of skills and experience to their roles as directors, and we are excited to welcome them.

They will join our existing directors, who have direct family or professional experience in supporting people with HD.

Board directors all provide their time and expertise voluntarily, and we are very grateful for their generosity and dedication to the organisation.

Donna Burns

Donna is Director of Optimism Consultancy Group, and joins the Huntingtons Queensland board with a wealth of experience implementing positive changes for organisations.

Donna has worked as Change Manager for a wide range of organisations, including Queensland Health and Alzheimer's Australia (Qld) Inc. We are delighted to welcome Donna to the Huntingtons Queensland board.



Shane Kelly

Shane joins the board with significant experience in customer relations and staff engagement. Shane has worked for Telstra, LimeBridge, and most recently as Executive Consultant at the Shane Kelly Group.

Shane is passionate about supporting Huntingtons Queensland, and will be a valuable contributor to the organisation's governance. We are delighted to welcome Shane to the board.



Susanna Mantovani

Dr Susanna Mantovani has a long history with Huntingtons Queensland as a local researcher in clinical neuroscience. She has a PhD in Physiology, and has worked in a number of research roles.

Dr Mantovani's professional experience with neurodegenerative disease has given her a deep understanding of many of the challenges faced locally. We are delighted to welcome Dr Mantovani to the board.



HD in the media

In early August, Huntington's disease had a major day in Australian news with an ABC story about a local Queensland man with HD.

Brett Kelly, a Brisbane resident and single father of two, was facing significant challenges accessing government financial support as a result of poor parameters in the National Disability Insurance Scheme (NDIS) and Disability Services Pension (DSP).

Brett was interviewed by the ABC, and his story made national headlines, with overwhelming support and compassion from the community for his situation.

The article (below and next page) highlighted some of the challenges that Brett and many others have faced in accessing government financial assistance to which they are likely entitled.

The article was published widely online, and a video and radio version were also aired throughout Australia the same day.

We were delighted to hear from Brett, who advised us that shortly after the story aired, he was contacted by the relevant government departments, and is now receiving the appropriate assistance.

This positive outcome allows Brett to focus on his health and his family.

Huntingtons Queensland is thrilled with this outcome. We are aware, though, that his situation is not unique, and many people in the Huntington's disease community continue to face challenges accessing NDIS and DSP payments.

Our Client Services team have worked with impacted individuals, their families, health care professionals and the government departments, as advocates and liaisons to achieve better outcomes in these scenarios. If you are concerned about financial support, contact our team who can provide information and advocacy.

The team assists a number of clients with preplanning for NDIS or those with new packages.

If you have questions about how to access the NDIS, how best to prepare, or what to do now you have your package, our team has plenty of experience helping out. Give us a call today: 07 3435 4300.

Huntington's disease falling through cracks in NDIS, disability pension criteria, advocates say

This article by Zoe Coleman was published by the ABC on 4 August 2018, and can be viewed online at: <http://www.abc.net.au/news/2018-08-04/huntingtons-disease-ndis-disability-pension-case/10071342>



A Brisbane father diagnosed with a terminal neurological disease fears he will "wake up dead one day with no assistance" after being rejected for Commonwealth financial help.

Last year, 46-year-old Brett Kelly (*left*) was diagnosed with Huntington's disease, a rare genetic disease which affects about 1,800 Australians.

As a result, he suffers from continuous involuntary movements, cognitive issues, tremors, depression, and anxiety.

"It's very hard. There's a sway and the constant rocking which is certainly irritating, especially when you're trying to get to sleep at night," he said.

Huntington's disease falling through cracks in NDIS cont.

Despite his diagnoses, Mr Kelly said he recently received letters telling him he did not meet the criteria for the disability support pension or the National Disability Insurance Scheme (NDIS).

"I've been approved for a 'disability house', so obviously the Queensland Government considers me disabled enough to get a house, but the Federal Government doesn't think I meet their disability claim," Mr Kelly said.

"I'm just worried I'm going to wake up here dead one day with no assistance," he said.

The condition has plagued Mr Kelly's family for generations.

His 69-year-old mother died from Huntington's disease last year after spending the final five years of her life in a nursing home.

The same disease killed his uncle and grandfather.

Mr Kelly's three children now have a 50 per cent chance of inheriting the disease.

The former security guard said the symptoms had a huge impact on his life as a single dad.

"I don't like people seeing me and judging me because I saw my mother go through the exact same thing. I saw the other reactions of other people to her in public," he said.

Symptoms for Huntington's disease generally appear between the ages of 30 and 55, with a life expectancy of 10 to 25 years following diagnosis.

Huntingtons Queensland CEO Jan Samuels said it was a devastating illness for sufferers.

"It's often described as being a cross between dementia, Parkinson's disease and motor neurone disease all at once, so it's a pretty nasty condition," she said.

She said the organisation was supporting several people in the same situation as Mr Kelly.

"They are being rejected by one part of the system but are unable to access another part of the system and they really are falling through the cracks."

Mr Kelly said he had to attend regular job interviews in order to keep receiving unemployment benefits, but that he felt "disgusting" when being assessed by employers.

"It's hard enough just to motivate myself to shower once a week let alone bloody trying to get up and go to a job every day," he said.

Local community volunteer Desley Griffiths delivers food to Mr Kelly and his family on a weekly basis.

She said Mr Kelly suffered horrendous stress by being forced to attend regular job interviews.



Brett and his children

Brett Kelly and h

All images related to this article were taken by the ABC for this story

Huntington's disease falling through cracks in NDIS cont.

"I have seen him deteriorate, his involuntary movements have become a lot more severe," Ms Griffiths said.

"It just makes you wonder who might be eligible if somebody with his kind of disability, and a terminal illness, is not."

In a statement, Department of Human Services general manager Hank Jongen said they were trying to work with Mr Kelly.

"We understand that this is difficult time for Mr Kelly and we are working closely with him to ensure he is receiving the most appropriate support and payments," he said.

Mr Jongen said the department received 100,000 disability support pension claims a year, but 70 per cent of people were rejected for not meeting eligibility criteria.

"Less than 20 per cent of DSP appeals resulted in the original decision being changed," Mr Jongen said.

The NDIS will provide Australians under the age of 65 who have permanent and significant disability with the reasonable and necessary supports they need to live an ordinary life.

In a statement, a spokesman for the NDIS said a person must meet the disability requirements specified in the NDIS Act.

"For privacy reasons, the NDIA [National Disability Insurance Agency] cannot comment on individual access decisions," the spokesperson said.

Mr Kelly said he would appealing against both decisions.

Insurance lawyer Paul Watson said the support issue was not limited to Huntington's disease.

"We're seeing the vast majority of disability support pension applications rejected. The guidelines are just too harsh," he said.

"There are instances where someone who is a paraplegic could not be entitled to the disability support pension in certain circumstances.

"People who are often profoundly disabled are having their claims rejected, often for technical reasons, and it's really unfair."



Save the date!

Huntingtons Queensland's Annual General Meeting (AGM) will be held on Thursday 15 November, during which the annual report will be presented, directors will be nominated and any governance issues will be discussed and voted upon.

Professor Julie Stout from Monash University in Melbourne has also confirmed she will attend as guest speaker.

Professor Stout is very involved in Huntington's disease research, leading the Clinical and Cognitive Neuroscience Laboratory at Monash University in the development of strategies and tools to assist the understanding and treatment of HD.

Professor Stout is well-known to Huntingtons Queensland, having recently presented the key note speech at our Lighting the Way forum.

More details are to come, so **please save the date.**

On the road with Client Services

It has been a busy quarter for the Client Services team, with plenty of client engagement and travel throughout the state.

The team engaged with more than 450 individuals each month, with increasing requirements with support throughout the NDIS process.

If you are looking for support or information on accessing or navigating the NDIS, our team has experience supporting people with HD through the process.

Regional visits included Maryborough, Bundaberg, Gympie, Gladstone, Monto, Mackay, Toowoomba, Townsville, and a number of regions in Brisbane and surrounds.

If you work in a support or services capacity and would like to engage our services to better support people with HD, we encourage you to contact our office on 07 3435 4300 or email admin@huntingtonsqld.org.au.

These regional visits are built and centred around support group meetings, education sessions and engagements with local service providers, and meetings with individuals and families in need of direct support.

We delivered an average of seven education sessions each month, including a request from the Townsville Office of the Public Guardian, who provide services to a number of families impacted by Huntington's disease.

These education sessions cover the science and symptoms of HD, strategies for assisting people with HD, with special focus on understanding movement and behaviour, and utilising other local resources including the HD Clinic.

The Huntington's Marathons

We are always so humbled by the generous support we receive from our many donors and fundraisers. You would have read previously about Steven Blaine, who is completing 12 marathon races in 12 months, and raising funds for Huntington's Queensland.

Steven was inspired to support people impacted by HD as his mother Lenore was living with HD in Queensland.

We were very saddened to learn of Lenore's passing recently, and we made contact with Steven to see if we could support him. Steven encouraged us to share his mother's story with the community, and simply stated that he was more motivated than ever to complete the challenge he had set this year.

He now has four races left – one per month for the rest of the year – with the last one at the Gold Coast. We are continually in awe of Steven's efforts, and are so proud to share his story with everyone.



Steven after his 7th marathon in 7 months, in honour of Lenore.

If you would like to support Steven's efforts and contribute to the more than \$11,000 he has already raised, you can do so by visiting his Everyday Hero page, sharing it with your friends and family, and making a donation. You can find it by searching '**The Huntington's Marathons**' on Everyday Hero, or by finding the link through our Facebook page.

Thank you Steven – good luck for the next few races!

Buy a ticket for HD

There are less than three weeks to go before the first Play for Purpose lottery is drawn, and one lucky person wins a \$500,000 gold bullion!

Huntingtons Queensland is excited to be involved in the Play for Purpose charity lottery, where participants have a 1 in 19 chance of winning a prize, and the participating charities receive commission-free income.

You can still buy your entries and support Huntingtons Queensland by visiting playforpurpose.com.au.



When purchasing your tickets, simply select Huntingtons Queensland as your chosen charity recipient.

Don't miss your chance to win big on this ticket-limited lottery. Ticket sales close on 25 September.



Thank you for supporting our work

Make a donation this Spring '18

Donations of \$2 and over are tax deductible

Name: _____

Postal address: _____

Email: _____ Phone: _____

Donation amount: _____

Visa or MasterCard?: _____

Card Number: _____ Card expiry date: _____

Name on card: _____

Signature: _____