



# Summer 2018-19 news flash



Steven Blaine's final marathon of the year will be at the Gold Coast on Sunday 9 December

### A marathon effort!

12 magnificent months have nearly come to an end, and with it, Steven Blaine's marathon effort!

Steven set out at the start of the year to complete 12 marathons in 12 months, with the incredible goal of raising \$10,000 for Huntingtons Queensland while raising awareness about Huntington's disease.

With the support of family, friends and businesses, Steven has managed to raise well over his target, with the latest tally (at time of printing) \$11,592.89. These funds will go directly toward supporting people living with HD and their families through the services we offer.

We are so grateful for Steven's determination this year. Our team has sat back and marvelled at his efforts all year, and we are so excited to see him complete this great personal challenge.

Thank you for your commitment and enthusiasm, Steven!

Steven's final run will be on the sunny Gold Coast, on Sunday 9 December at the GC50 race. We are so glad to welcome him to the Sunshine State to see in his final race for the year.

If you are in the area on the day please take time to turn up and cheer him on.



### Come to our Christmas party

We are so excited to welcome families to our annual Christmas party on Wednesday 12 December!

Please join us from 11am at our office (Florence Dannell House, 385 Ipswich Road, Annerley), before we share a light lunch at midday.

We've also been told, on good authority, that a certain gentleman in a red suit will be leaving a few small goodies for the little ones!

If you would like to come along, and are yet to RSVP, please let us know as soon as possible by calling us on **07 3435 4300** or emailing **events@huntingtonsqld.org.au**.

We can't wait to celebrate the festive season with you!

#### Office closure dates

Our team is taking a much-needed break over the Christmas period.

Our office will be **closed from Monday 24 December – Friday 4 January**. We will reopen on Monday 7 January.

If you require urgent support during this time, you can contact Lifeline 24 hours a day on **13 11 14**.

Please also note that our office will be closed on Monday 28 January for the Australia Day public holiday.

## Support group calendar

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

#### January

**9** - Brisbane

**29** - Gympie

17 - Townsville

#### **February**

**12** - Toowoomba

27 - Bundaberg

13 - Brisbane

**19** - Logan

28 - Hervey Bay

#### March

**5** - Redlands

26 - Ipswich

8 - Sunshine Coast

26 - Mackay

12 - Gold Coast

27 - Rockhampton

13 - Brisbane

28 - Gladstone

# **Did you Play For Purpose?**

The inaugural *Play For Purpose* – *Australia's Sports & Charity Raffle* was drawn in September.

We were delighted to find out that 21 Huntingtons Queensland supporters were lucky enough to win something in the draw!

Congratulations to those lucky individuals – we hope you've won something great!

We are proud to continue our charity partnership with *Play For Purpose – Australia's Sports & Charity Raffle* as they host six raffles throughout 2019.

Play For Purpose – Australia's Sports & Charity Raffle has been designed to support charities and grassroots sporting clubs throughout Australia.

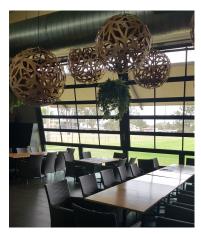


Charity partners receive 50% of ticket sales as a donation, with no commissions or fees! So when you nominate Huntingtons Queensland with your ticket purchase, 50% of your total purchase price goes directly to us!

When you purchase a raffle ticket, you have a 1 in 34 chance of walking away with part of the \$500,000 prize pool. And ticket prices have now been reduced to \$10 each, so you can get more tickets for less money!

The current draw will be open until 27 February. Visit <u>playforpurpose.com.au</u> to purchase your winning ticket, and **remember to nominate Huntingtons Queensland as your charity.** 

# Thank you to our supporters



Huntingtons Queensland receives support in many different ways throughout the state. We would like to make special mention of the **Brothers Leagues Club** in Ipswich.

We have been using their venue for some time now to host our Ipswich support group meetings, and the staff have continually gone above and beyond to ensure a comfortable, welcoming environment.

Thanks Brothers Leagues Club – we are very grateful to you for supporting your local community!

Huntingtons Queensland is very grateful for the support of the Robina Lions Club, who raised an incredible \$1,000 at their high tea event in October.

These donations make such a difference to our services, ensuring that we are able to continue to meet individuals for non-clinical counselling, provide advocacy work and support families as they navigate the National Disability Insurance Scheme. Every dollar makes a difference.

Thank you so much, Robina Lions Club!



Pictured left to right, president John Clark, Cathy & Tressa from Huntingtons Queensland, Rebecca Bennett and Janice Brown.

## **AGM** and board updates

The Annual General Meeting (AGM) was held at Florence Dannell House on Thursday 16 November, with 41 people in attendance.

The evening kicked off with an opening speech by outgoing president Gerry Doyle, who spoke about his history with the organisation, and his motivation for supporting our endeavours.

You can read Gerry's speech on the next page.

The annual report was released at this meeting, and you can access it through our website.

You may also request a hard copy by contacting our office on admin@huntingtonsqld.org.au or calling 07 3435 4300.

We are pleased to announce the incoming Board directors for the 2018-19 financial year:

President	Jason de Bakker
Vice president	Cate Barrett
Treasurer	Janifer Willis
Secretary	Jan Szlapak
Directors	Donna Burns Gerry Doyle Shane Kelly Susanna Mantovani

We would like to acknowledge that our directors are all volunteers, donating their time and expertise to oversee the governance and growth of Huntingtons Queensland.

We were delighted to welcome Professor Julie Stout, from Monash University, as special guest speaker for the AGM.

Professor Stout arrived at the meeting fresh from an HD conference in Texas, USA, where she met Nancy Wexler, the scientist who discovered the HD gene, and Charles Sabine, an internationally renowned journalist and HD advocate.

Professor Stout spoke about the Roche clinical trial, and the meaning of the different phases.



Left to right: Professor Julie Stout, CEO Jan Samuels, Susanna Mantovani (director), Jason de Bakker (president), Jan Szlapak (secretary), Gerry Doyle (director), Janifer Willis (Treasurer), Shane Kelly (director), founder Cliff Farmer, Alan McKinless (life member and donor) & Donna Burns (director).

Absent: Cate Barrett (vice-president)

### **Looking forward**

Outgoing president Gerry Doyle officially opened our 2018 Annual General Meeting with a message of hope for the future:

My journey with HD started in 1993 and the reason I am here tonight is Alison.

Alison and I were married for 49 years and have been the proud parents of three children and six loving grandchildren.

In 1993, the year of the discovery of the HD gene, Alison started her journey with HD.

I now know her challenge started much earlier. It was because of the strength and courage of Alison that I stand before you tonight. Her request to me was that she wanted to be the last generation to die of HD.

We have come a long way since our foundation in 1976:

- A successful Huntingtons Queensland organisation
- A provider of information on HD
- Welfare services for HD affected families
- Helped bring HD out of the closet
- The HD clinic operating since the mid-1990s
- Queensland-based research into HD

The future for us all is the hope for a treatment or cure for HD. We have many challenges that we face, but I am sure we will face and overcome all of these.

Thank you,

Gerry Doyle

Huntingtons Queensland would like to publically acknowledge and thank Gerry for his many, many years of service on the Huntingtons Queensland board, including many years at the helm as president.

Gerry's guidance, compassion and commitment have enabled our organisation to grow, without ever losing sight of what matters: family.

Thank you Gerry. We are proud to have had your leadership.



Our heartfelt thanks to outgoing president Gerry Doyle

### **Hervey Bay callout**

Are you in the Hervey Bay and Maryborough region and wanting to catch up with some other friendly locals?

Our Client Services team is hoping to establish a regular support group in the region, and we are looking for expressions of interest.

Support groups are held on a regular basis – usually every three months, depending on the region and need – and are facilitated by a member of our Client Services team.

These catch-ups are friendly, informal, and are a great opportunity to speak directly with our staff, meet some friendly people in your local area, and get valuable updates on research and services in your region.

If you would be interested in coming along or finding out more, please contact our Client Services team on **07 3435 4300** or email **supportgroups@huntingtonsqld.org.au**.



2018 AGM. Clockwise from top left: Jenny Farmer, Gwen Pratten, Professor Julie Stout, Alan McKinless, physiotherapist Rits Rana, Angelika Straker, Michael Zeremes

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

- support group attendee

### Make a donation this Christmas 2018

Donations of \$2 and over are tax deductible. Please provide your contact details so we can send you a receipt.

Name:	
Postal address:	
Email:	Phone:
Donation amount:	
Visa or MasterCard:	
Card Number:	Card expiry date:
Name on card:	
Signature:	