



Clockwise from top left: Forum attendees raising candles for #LightItUp4HD; Alan McKinless with the banner featuring his late wife, Alecca, whose gift made the forum possible; Noobis the assistance dog on his best behaviour; attendees in the morning session.

2019 Alecca McKinless forum draws a crowd

From research updates to discussions on advance care planning to inspiring personal journeys, this year's forum – *Planning for the Future* - was a huge day for all involved.

The forum is funded through the Alecca McKinless Gift, with support from Alecca's husband, Alan.

The event is designed to share information, inspire attendees, and help people build connections and support networks. It is also a very enjoyable day!

This year's forum was extended to a full day, with presentations in the morning, and break away discussion groups in the afternoon, where attendees could ask questions, discuss their stories and make some new friends.

The evening social hour was popular again, with many staying back for a chat and a drink with new friends.

This year's keynote speaker was Cat Martin, the Executive Director of Huntington's Disease Youth Organisation (HDYO).

Cat spoke about her journey with Huntington's disease, and the work that HDYO is doing around the world to support children and young people impacted by HD.

Cat's travel from Scotland was generously sponsored by the Ian Potter Foundation.

Other speakers included Professor Julie Stout, Dr Rob Adam, Dr Michael Gattas, Clinical Nurse Consultant Sabrina Palham, Huntington's WA Executive Director Lenni Duffield, our president Jason de Bakker and CEO Jan Samuels.

Continued on page 4

Good news!

We are thrilled to report that the Queensland Health funding we currently receive under the department's Community Self-Care Program will continue to 2022.

This core funding supports our Client Services team and enables the delivery of information, education, non-clinical counselling and support groups around the state.

The news is very welcome, as our core services would have been significantly impacted without these funds.

All other services provided by Huntingtons Queensland are made possible by our generous donors, or are sourced from grants.

Farewell Donna

It is with regret that we announce Donna Burns' departure from the Huntingtons Queensland board, following her nomination as the Greens candidate for Paddington in the upcoming Brisbane City Council elections.

Donna has been a wonderful advocate for our clients as well as supporting events and playing an active role in our governance and continuous improvement processes.

**All the best for the future, Donna.
We will miss you.**



Office closure dates

Our office will be closed for the Brisbane Ekka public holiday on **Wednesday 14 August** and Queen's Birthday public holiday on **Monday 7 October**.

We will not be available to answer phones or respond to messages on these days.

If you need urgent help during these public holidays, please call Lifeline on 13 11 14 or call emergency services on 000.

If your enquiry is not urgent, you can call and leave us a message on **07 3435 4300** and we'll return your call during office hours.

Event calendar

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

August

7 - Brisbane support 14 - Ekka public holiday
13 - Toowoomba visit 28 - Bundaberg support

September

3 - Redlands support 13 - Sunshine Coast support
10 - Gold Coast support 20 - Logan support
11 - Brisbane support 24 - Ipswich support

October

7 - Queen's birthday public holiday 17 - Townsville info group
9 - Brisbane support 22 - Gympie support

November

12 - Toowoomba support 22 - Logan support
13 - Brisbane support 26 - Mackay support
21 - AGM 28 - Gladstone support

Grab your running shoes - it's time!

It's that time of year again! Lace up your running shoes and mark your calendar for Sunday 15 September, then come along for a revitalising morning walk or jog along beautiful Wynnum foreshore.

Running for Nan's HD is in its fourth year, and is organised and run by our wonderful supporter Kelly Woodland.

Kelly's Nan (after whom this event is named) lives with HD, and was the inspiration for this annual get together.

The event is a 5km or 10km distance, and you can walk or run it as quickly or slowly as you like. All participants receive a finisher's medal and there will be a free barbeque at the end.

Registration is \$25 (not tax deductible) or if you are not up for a jog you can support the event by purchasing \$2 raffle tickets online. All money raised goes to Huntingtons Queensland!

Go to huntingtonsqld.org.au/run to register and purchase raffle tickets.

As always, we are so very grateful to Kelly for her incredible attitude and amazing support. We love you, Kel!



*Nan at a previous
Running for Nan's
HD fundraiser*



Thank you!

Thank you so much to everyone who supported our annual tax appeal, raising more than \$20,000 to help our team raise awareness and improve links between researchers, clinical trials and HD families.

We couldn't do it without you!

#LightItUp4HD

Huntingtons Queensland was pleased to participate again this year in the global #LightItUp4HD initiative.

This campaign, led by the Huntington Society of Canada, encourages businesses and governments around the world to light up significant structures in blue and purple to show support for people impacted by Huntington's disease during the month of May.



Planning for the Future: 2019 Alecca McKinless forum

[continued from front page]

Attendees also heard a beautiful presentation by Janice Brown, who supports her daughter Rebecca. Rebecca lives with Huntington's disease, and Janice spoke about their wonderful lives, and the many activities and social groups in which they participate.

We are delighted at the response to the forum, and will be looking at how we can host something special again next year.

If you missed this year's forum, videos of the presentations will be available soon through our website, or through our YouTube channel. Just go to youtube.com and search for "Huntingtons Queensland."



Top left row left to right: Helen Weston, Sally from Novacorr & Julie Bjorem testing out the Novacorr chair; Jeanne Clark, HDYO's Catherine Martin, Sabrina Palham from Advance Care Planning & Tim Clark; Huntington's WA Executive Director Lenni Duffield
Bottom row left to right: Chris Beckwith, Nicole Colledge & Michael Wedemeyer; Dr Michael Gattas; Ted Bjorem, Jennifer Rickward and James Steadman.

Research on the home front

Thanks to our generous donors and supporters, Huntingtons Queensland is proud to be supporting a small upcoming clinical trial in Brisbane, under the leadership of Dr Rob Adam from the Royal Brisbane and Women's Hospital HD clinic.

We hope the Wave trial will be one of several to take place in Queensland, and look forward to working with Rob and his team in the months ahead.

Dr Adam says recruitment is about to begin. For more information, or to express your interest, please email him direct at hdresearchqld@gmail.com

You can also follow our Facebook page, where we will post updates on this as they come through.



Dr Rob Adam presenting the new trial information at our recent Planning for the Future forum in May

Play for Purpose starts soon

The latest round of Play for Purpose closed on 17 July, and the next round will be opening shortly.

Play for Purpose is a charity lottery set up to benefit both players and charities! Each round, players have a 1 in 34 chance of winning a prize, and tickets are only \$10.



For every ticket bought, Huntingtons Queensland receives a \$5 donation from the ticket sale.

Prizes range from great vouchers to high quality products for your home to amazing overseas holidays!

Thank you to everyone who has supported us and bought a ticket – we really hope you won something amazing!

To purchase tickets in the next round, visit: playforpurpose.com.au/huntingtons-qld or follow the link on our homepage.

Young crowd takes over Currimundi

Huntingtons Queensland was delighted to host a youth retreat on the Sunshine Coast in June. We welcomed 17 young people from around Australia, joined by four staff, including youth worker Amy Hales from Huntington's NSW, and volunteer Grandall Manning for this special four-day event.

Thanks Amy and Grandall for all your help!

Attendees on the retreat participated in group discussions on the impact and complexities of HD, grief and loss, and the testing process.

We were also delighted to welcome clinical neurologist Dr Rob Adam who spoke with attendees about research and answered plenty of questions. Thanks Dr Adam!

There were plenty of opportunities for attendees to let their hair down, with paddle boarding, rock climbing, and a few trips to the beach.

We are so grateful to the Gambling Community Benefit Fund for making this wonderful experience possible!



Clockwise from top left: Youth retreat attendees with guest speaker Dr Rob Adam, making new friends, learning to paddle board, and enjoying the beach.

Scotland is calling!

As you may already have heard, Huntington's Disease Youth Organisation (HDYO) is hosting the world's first International Young Adults Congress in Scotland from 9 - 11 May 2020.

Huntingtons Queensland is proud to support this exciting event, and we hope to see many young Australians joining 500 of their peers from around the globe in Edinburgh.



HDYO Executive Director Catherine Martin presenting at the 2019 Alecca McKinless forum

We are also thrilled that **Queenslander Jenni Rickward** has been selected by HDYO to be the Australian social media rep at the event.

Jenni's travel, accommodation and registration will be covered by HDYO in return for Jenni filing stories back to Australia while she is away!



"This is such a cool opportunity to travel to SCOTLAND! And to talk with people going through the same thing... it's a really great way to create something positive!" - Jenni Rickward

Make a donation this winter

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: _____
