



**Swapping Zoom for the zoo!** Huntingtons Queensland staff Lauren, Cathy and Tressa swapped their day jobs for a quick cuddle with Blinky Bill at our recent community day. See page three for details.

## Register now – our annual forum is back

Take some leave, throw a sickie, or chuck your washing behind the sofa – the only place to be on Friday 12 November is at the Huntingtons Queensland annual forum.

Yes! We are pleased to say this key event is back, and only 18 months later than usual, thanks to the impact of COVID-19 on all our lives.

You are invited to join our team at Brisbane's Treasury Hotel for the forum, which will run from 12.30pm to 5.30pm on 12 November, followed by our ever-popular drinks and canapes in the courtyard.

The theme of this year's event is *By Your Side*.

The line-up includes presentations on planning for a life impacted by Huntington's disease, an overview of Huntingtons Queensland's services, the current state of research, a new initiative coming out of Monash University, and the personal stories of people connected to the HD community in Queensland.

There is no cost to attend the forum, which is once again funded through the generosity of the Alecca McKinless Gift, but registrations are essential.

Please register online at [www.huntingtonsqld.org.au](http://www.huntingtonsqld.org.au), email [admin@huntingtonsqld.org.au](mailto:admin@huntingtonsqld.org.au) or phone Cathy on 07 3064 3222 to book your place. Hurry, as numbers are strictly limited.

*Note: Attendees will be required to observe all COVID-safe practices and social distancing in line with current government orders, as well as the Treasury's own policies and procedures. Should Brisbane go into lockdown, we are planning to hold the forum virtually via Zoom.*

# 'Education a key' to quality of life for people with HD

In response to client and support worker demand, Huntingtons Queensland is launching a new education service aimed primarily at service providers in the community, aged care and disability sectors.

The new fee-based service aims to:

- Improve workers' understanding of HD
- Share strategies and insights that can lead to better quality care, and
- Offer an ongoing resource for workers caring for a person with HD.

While support for individuals and families has always been at the heart of what we do, the advent of NDIS packages has highlighted a lack of awareness and knowledge of HD in the broader community care sector.

"Everyone wants to do their best for the people they are caring for," says HD Adviser Lauren Ward, "but not everyone knows how to go about it.

"Through our education service for providers we can share our knowledge and understanding of HD and help workers to understand the person they are there to assist.

"Our information and education sessions are very accessible, taking clinical and scientific information and making it relatable for people in their day-to-day work. And because Huntingtons Queensland has been working with and supporting families impacted by HD for 45 years we can bring together our knowledge and experience and really show what living with HD can be like.

"Living with HD is tough," says Lauren. "We know that when workers receive quality information, advice and tools to help them do their jobs better they are more confident and can really focus on understanding the person with HD's needs and wishes.

"Empowering everyone leads to a better experience all round."

Sessions are particularly popular with service providers who are already caring for a person with HD and can be tailored to meet both the individual's circumstances and the organisation's needs.

For rates and bookings please contact [admin@huntingtonsqld.org.au](mailto:admin@huntingtonsqld.org.au) or call 07 3064 3222.

## Roll up, roll up! It's annual general meeting time

Financial members of Huntingtons Queensland are invited to take part in the Association's annual general meeting, on Thursday 25 November at 6pm. To allow members from all over the state to take part, the meeting will be held online via Zoom.

Members will have a chance to ask questions of the President, directors and CEO, review the annual report and audited financial statements, and vote for office-bearers for the year ahead.

Invitations, the agenda and how to register will be sent to all current financial members in the first week of November. In the meantime, if you would like more information, please contact our CEO at [jsamuels@huntingtonsqld.org.au](mailto:jsamuels@huntingtonsqld.org.au).

If your membership is not current, or if you would like to join the Association, you can renew or join online on our website.

Alternatively, you can email [admin@huntingtonsqld.org.au](mailto:admin@huntingtonsqld.org.au) or call Cathy on 07 3064 3222. Membership is \$22 a year for an individual or \$33 a year for a family.



# Sooper-doooper zoo day a big hit with families

While Queensland has escaped many of the pandemic restrictions endured by those in southern states, it has been a very tough year for lots of families. That made our recent big day out at Australia Zoo all the sweeter for those who could make it to our first community day in many months.

Nearly 50 people from our HD community enjoyed a happy day at the Zoo, which included a group lunch and opportunities to watch some of the spectacular free shows available. The community day was funded by the Alecca McKinless Gift, and it was unfortunate that Alecca's husband - long-term supporter Alan McKinless - was unable to attend the community day this year. Alan's presence was sorely missed.

Huntingtons Queensland CEO Jan Samuels says, "The late Alecca McKinless wanted her gift to directly support HD families through some of the many challenges they face. Our community days and forums play a very important part in achieving Alecca and Alan's goals.

"We are hopeful that in 2022 we will be able to offer more community activities around the state, and are looking for ways to achieve this, COVID permitting.

"Our 2021 tax appeal also focused on raising funds for community days and local events. I want to thank the many supporters of Huntingtons Queensland who donated to this campaign, which raised more than \$13,000 to help kids (and their parents) build precious memories that can last a lifetime."



## Regional visits are back on the map



After a highly disrupted year, our team is pleased to be back on the road and making visits to regional parts of Queensland.

Tressa recently travelled to Gladstone, Rockhampton and Mackay, where she caught up with the local social group (left) and Lauren has just got back from her first trip to Cairns in several months. During her trip, Lauren visited families and discussed education sessions with care providers. Next up, Lauren is going to Bundaberg, Hervey Bay and Gympie, while Tressa is supporting people on the Gold and Sunshine Coasts.

Additional trips are being pencilled in for the new year, subject to COVID restrictions and available funds. We are also keen to hold some small local events in the regions and welcome your input so we can do our best to meet the community's needs.

# Shaping the future - your say on our services

More than 100 people responded to our recent survey, in which we asked you to rate our services and tell us what you want us to do (or not do) to support families impacted by Huntington's disease in Queensland.

"We are so grateful for the time people took to complete the survey, which was emailed or posted out in August to members and clients of Huntingtons Queensland," says CEO Jan Samuels. "People put a lot of effort into telling us their concerns and sharing their opinions of what matters in terms of services and support.

"We received responses from all over the state, and from all ages groups – including several young people under the age of 18 who provided their own unique experience of what it is like to live in a family impacted by HD."

A snapshot of the survey results indicated that:

- Offering support for people with HD and their families, providing information and education, and raising awareness of HD are seen as core functions for Huntingtons Queensland
- Social isolation and lack of contact with other HD families is a concern for many respondents, especially those in regional areas
- Taking part in support groups, family days and other activities was rated as either very important or important by more than 81% of people who completed the survey

- Huntingtons Queensland does not have enough people 'on the ground' to meet the expectations of some HD families, especially in regional areas
- The NDIS is having a positive impact for many individuals, but there are concerns about the quality of support offered by workers who have little understanding of HD or lack appropriate training and experience
- Around three per cent of survey respondents were not aware of the full range of services provided by Huntingtons Queensland
- Access to information, resources and a caring, knowledgeable person 'at the end of the phone' are highly valued.

"The results also show that unfortunately Huntingtons Queensland simply cannot be all things to all people," says Jan.

"This will always be a challenge for a small team trying to cover complex needs across a huge state. We have fewer than five FTE [fulltime-equivalent] staff and less than a third of our services are government funded.

"We are looking at ways we can spread our reach and resources as effectively as possible, and after 45 years remain as committed as ever to being by your side during your journey with HD."

The survey will be on the agenda at our forum on 12 November for further discussion.

## Unmasking HD

Does thinking about HD keep you up at night? If so, why not take advantage of your insomnia by joining an international online event, *HSG 2021: Unmasking HD*, which will be held from 4 to 6 November by the Huntington Study Group (HSG).

Since 1993 the Huntington Study Group (HSG) has conducted clinical research trials and studies for Huntington's disease. It is the world's first and largest clinical research network focused exclusively on HD.



The annual HSG meeting is the largest gathering of HD researchers, clinical experts, advocacy and HD families at a single event.

The first session will kick off at 10am US Eastern Standard Time, which equates to midnight in Queensland, and will go through to the early hours of our morning.

For more information go to [huntingtonstudygroup.org/about/our-annual-meeting/hsg-2021/](https://huntingtonstudygroup.org/about/our-annual-meeting/hsg-2021/)

# Research study into sleep and gut health

Researchers from Monash University are undertaking two important new projects to investigate gut health in HD and its relationship to sleep, weight, mood and cognition.

The first project is looking at the gut and sleep in Huntington's disease, investigating the bacteria in the gut and its relationship to gut health and clinical indicators of HD such as mood, weight, thinking and memory.

The second project, on sleep, aims to determine sleep quality and diurnal rhythms as well as their impact on cognition and disease severity in HD compared to people without HD. Data from the project will be used to inform the development of interventions that may improve cognition.

Dr Yifat Glikmann-Johnston (pictured) is one of three researchers working on the initiatives, under the supervision of Professor Julie Stout at Monash University.

Her project – on gut health and HD – is being funded by the Huntingtons Disease Society of America HD Human Biology Project.



Dr Glikmann-Johnston explains, "Huntington's disease commonly causes sleep problems and gastro-intestinal disturbances such as unintended weight loss, diarrhoea and such like, which affect people's quality of life."

"As people with HD struggle with symptoms that lack adequate treatments there is a need to understand how non-pharmacological interventions such as diet, sleep and exercise can be used to enhance quality of life."

Participation will include a cognitive assessment, questionnaires, monitoring sleep at home, and providing a stool sample.

Participants will also be asked to wear an activity monitor for 14 days and keep a bowel movement and sleep diary.

Dr Glikmann-Johnston says the study is a great way for people to take part in research who may not normally have the chance to do so.

"The research project is run completely remotely, meaning participants do not need to leave their home to take part," she explains. "We post all materials needed and provide a pre-paid return envelope. We will also do any cognitive testing required by Zoom and a mobile app that people can download on their phones."

Those who complete both components of the study will receive a \$120 Woolworths gift voucher.

A summary of the aggregated research findings will be made available to participants at the end of the study, which is expected to be in late 2022.

For more information, contact researcher Meg Rankin direct at Monash University by phoning (03) 9903 4695 or email [Med-HDsleppgutstudy@monash.edu](mailto:Med-HDsleppgutstudy@monash.edu)

## Make a donation to Huntingtons Queensland

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