

Summer-Autumn 2022 news flash



They're off: Flashback to Running for Nan's HD 2019, the last time our community got together to raise funds for Huntingtons Queensland.

Save these dates

We're (nearly) on the road again

With 2022 well underway and Queensland opening again, our team is busy planning some community events for the first part of the year.

First up is a community day, to be held in Gladstone on **Saturday 19 March**.

Tressa and Cathy will be in town to host a barbeque and catch-up for Central Queensland families (and any other HD families who might be passing through) at East Shores Precinct. Invitations will be sent toward the end of the month.

We hope this will be the first of several community days in regional areas, and you are welcome to contact the team if you have ideas for activities and events your local HD community would enjoy.

Next, we have our fingers, toes and everything else crossed for the return of Kelly Woodland's ever-popular event *Running for Nan's HD*, on **Sunday 22 May**. Visit our website to register www.huntingtonsqld.org.au/run/

Covid has meant the cancellation of Kel's Brisbane bayside run for the past two years, and we have sorely missed both her company and the wonderful donations that come in to support the HD community. *(That's Kelly and her beloved Nan pictured above.)*

Then on **Friday 27 May**, we will hold our annual Alecca McKinless Forum at the Treasury Hotel in Brisbane. Planning is still in the initial stages but if you have suggestions for speakers and sessions please let us know by emailing admin@huntingtonsqld.org.au.



'By your side' forum videos now available

If you missed the 2021 Forum, *By Your Side*, here's your chance to catch up, with many of the presentations now available on our [website](#).

Sessions include:

Professor **Julie Stout** from Monash University, talking about research and the new HDNA Registry;

RBWH speech pathologist **Shauna Taubert**;

Financial planner and friend to HD families, **Luke Muir**;

Neuropsychiatry Registrar **Dr Rhys Thomas**;

Huntingtons Queensland HD Adviser **Lauren Ward** and CEO **Jan Samuels**;

HD family members **Geri Kampen** (*below right*), sharing her experiences with the NDIS; and

New Huntingtons Queensland director **Angela Abell** (*below left*), who generously shared her journey with HD and recent genetic testing.

We are grateful to our speakers for granting permission to share their sessions and appreciate the opportunity to share the forum with people across Queensland.



Research opportunity for HD families, carers

People living with Huntington’s disease in Queensland are invited to take part in a new research project into health and e-health literacy.

Dr Travis Cruikshank (pictured), from Perth’s Edith Cowan University, is leading the project.

“Health literacy is the ability to find, understand, and use online and offline health information,” says Dr Cruikshank.

“The aim of this study is to provide us with information needed to develop interventions for people living with neurological conditions and caregivers.”

The project is observational and involves completing an online survey. Participants may also take part in workshops on e-health interventions.

If you are interested, please scan the QR code above or go to <https://redcap.link/miikb66x> for more information.



Huntingtons Queensland founder Cliff Farmer with Jan Samuels.

Farewell to our CEO

After more than five years steering the Huntingtons Queensland ship, CEO Jan Samuels is pulling up anchor and heading off into the sunset on 11 February — or, more precisely, into a stint in quarantine before being allowed into her native New Zealand.

“It has been such a gift to be part of the Huntingtons Queensland team,” says Jan. “I have worked in many NFPs but the challenges of living with HD would have to be among the hardest.

“I am so humbled by the stories of courage I hear every day, and so proud of the wonderful people I work with. Lauren, Tress, Cathy and Jen—I will truly miss you.

“I would also like to acknowledge our hard-working board, and send special thanks to our founder, Cliff Farmer, for his guidance and wisdom, to Alan McKinless for his dedication in honouring his late wife, Alecca, with truly amazing support, and to Gwen Patten for being there back in 2016 when I really, really needed her.

“Finally, I offer my deep gratitude to the many brave, kind and generous families and supporters I have met here over the years. It has been a privilege to walk by your side.”

Jan’s replacement is our new Operations Manager, **Shaun Riley**.

YOUR DONATION TRULY MAKES A DIFFERENCE TO HD FAMILIES—THANK YOU!

Name: _____

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Email: _____ Phone: _____

Donation amount: \$ _____ Card number: _____

Name on card: _____ Card expiry date: _____

Signature: _____

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

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