

Summer 2021 news flash



Event organiser Chloe Marks and her mum, Karen.

Chloe bowls us over!

A huge shout out to Strathpine Bowl, who hosted a community fund-raiser for Huntingtons Queensland on 6 November. More than 20 keen bowlers and their families turned out to support the event, which was organised by 17-year-old Chloe Marks.

Chloe was looking for a worthy cause to support and a Google search turned up Huntingtons disease. Chloe got in touch, confirmed we would be grateful for every dollar she could raise, and set to work to promote her inaugural Huntingtons Cup.

Local businesses and customers got behind Chloe and donated some great raffle prizes. Nearly \$1,300 was raised on the day!

The funds raised by Chloe and her supporters will go toward the services we offer to families impacted by Huntington's disease.

The event was so successful that Chloe is planning to run it again next year.

In the meantime, if you are looking for an enjoyable day out, please consider a trip to Strathpine Bowl.

In addition to the standard lanes, the centre has specially adapted lanes for disability access, kid-friendly equipment, a café with very reasonably priced meals and snacks, and a pro shop. There's also ample parking on site.

Oh, and don't forget to say Huntingtons Queensland sent you!

StrathpineBowl.com.au

95 Gympie Road, Strathpine - (07) 3205 5386

The year in review

Following the Association's annual general meeting on 25 November, our annual report and audited financial accounts for 2020-2021 are now available. You can download your personal copy (or read them online) from our website or contact the office on 07 3064 3222 if you would like a printed copy sent to you.

We would also like to acknowledge the following members, who have been appointed to the board for the coming year: Shane Kelly (President), Gerry Doyle (Vice-president), Tamara Winch (Secretary), Jason de Bakker (acting Treasurer) and Angela Abell. Their voluntary service is greatly appreciated. You can read about their connections to HD on our website.



Christmas closure

Our office will close for Christmas on Friday 24 December and reopen on Monday 10 January. On behalf of all our team, we wish you, your family and friends a safe and peaceful festive season.





Happy days: It was all smiles when the Townsville support group got together for Christmas lunch.

New registry aims to map HD families

People impacted by Huntington’s disease have a new way to help shape the future: by joining the Australian Map-HD Registry.

The Registry is the first part of a multi-year initiative, the Huntingtons Disease Network of Australia (HDNA), led by Professor Julie Stout from Monash University.

The HDNA has three main goals:

To map families, clinicians and support services to create a complete picture of HD across Australia;

To develop an Australia-specific HD model of care, to address the disparities and unmet needs of people impacted by HD across Australia; and

To bring rapid uptake of treatments and interventions for HD when they become available.

The first part of the project aims to develop a complete map of Australia showing where families with HD live.

Professor Stout says the new Registry will be a “key enabler for understanding the unmet needs of patients, facilitating the matching of patient needs to services, and collecting data to inform applications to the Therapeutic Goods Administration” [to list drugs as they become available].

Anyone affected by Huntington’s disease, including family members and carers, can join the HD Registry.

The second phase of the project, which will get underway in 2022, aims to create a model of care to “articulate the standards of care that all people with HD in Australia should expect”.

Professor Stout says, “We know that families affected by HD have much to bring to the table. We want to work with them to create the tools they need to navigate the systems and support each other in their HD journey.”

The final phase of the project will build on the earlier work, recognising that it could be some time before there are drugs that will be suitable for all people impacted by HD.

“We do need to start paving the way for treatments,” says Professor Stout, “but not all treatments include drugs.

“We must also be looking at alternatives that encourage everyone to tap into treatments that can improve their lifestyle – such as exercise, dietary changes, psychotherapy, improved sleep, mindfulness and stress reduction – all of which hold great promise.”



Learn more at [HDNA.com.au](https://hdna.com.au), email info@hdna.com.au or call 03 9902 0081.

By your side annual Forum

It was a great thrill to see more than 70 people attend our Alecca McKinless Forum in Brisbane recently, and so nice to see members of the HD community in person after such a long time.

Speakers at the forum included Professor Julie Stout, financial planner Luke Muir, speech pathologist Shana Taubert and neuropsychiatrist Dr Rhys Thomas.

It was also a special privilege to hear Geri Kampen and Angela Abell share their personal stories as member of HD families.

For those who were unable to attend the forum, the sessions will be available on our You Tube channel soon – we'll keep you informed.



L to R: Rhys Thomas, Shana Taubert and Shane Kelly (HQLD President).



Huntingtons Queensland supporters should have received our annual Christmas appeal letter by now.

This year we are aiming to raise \$12,000 to help people living with Huntington's disease to live safely at home for as long as possible. Your donation could help to:

- Purchase important safety aids;
- Fund an HD Adviser to help a person prepare an NDIS funding application;
- Or maybe even keep someone out of early entry to an aged care facility.

Please consider a gift today, using either the form below or the QR code, which will take you directly to our secure online donation page. Thank you so much.



Please give the gift of peace of mind this Christmas



Name: _____

Postal address: _____

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.

ABN 45 130 081 598