



*The HD Cope and Roche pharmaceutical representative team in New York in February 2019.  
Our CEO is third from the left.*

## Global HD initiative to come to Australia

In late February Huntingtons Queensland was honoured to represent Australasia at the second HD COPE global meeting, held in New York.

HD COPE (which stands for the HD Coalition on Patient Engagement) was established in 2018 by the peak Huntingtons associations in America, Canada and Europe.

As the initiative expands, four new members were added to the HD COPE Global Advisory Board this year, with representatives attending from South America, Africa, China and Australasia.

Our CEO, Jan Samuels, was nominated by the Australian state HD associations, and supported by the HD associations in New Zealand, to take part.

Louise Vetter, the CEO of the Huntingtons Disease Society of America, and co-founder of HD COPE, says the aim of the initiative is to “add quality to all aspects of clinical trials through patient representative input, providing a coordinated and knowledgeable mechanism to share HD community experience with regulators, industry and researchers”.

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# Thank you for supporting our cork donation drive.

## Now we're recycling!

After many years, and hundreds of kilograms of donations, we're no longer able to accept cork donations as the company we worked with is no longer operating.

**Thank you so much** to everyone who collected their corks for us over the years, and for taking the time to drop them to us.

If you're looking for another easy way to support us, we're excited to announce that **we are now participating in the Queensland recycling refund scheme.**

When you drop your recycling goods to the nominated recycling centres, simply choose to donate your refund to us!

Nominate **charity ID C1011 1805** and we receive your refund amount as a donation!

For more information visit

**[www.containersforchange.com.au](http://www.containersforchange.com.au)**



## Office closure dates

Our office will be closed over the Easter break, from **Friday 19 April – Monday 22 April** inclusive.

We will also be closed for the Anzac Day public holiday on **Thursday 25 April**, and again on Labour Day public holiday on **Monday 5 May**.

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.

Enjoy the public holidays!

## Event calendar

Visit **[huntingtonsqld.org.au/support/whats-on](http://huntingtonsqld.org.au/support/whats-on)** for a list of all upcoming events and support groups.

### April

- 10 - Brisbane support
- 11-12 - Cairns visit
- 30 - Gympie support



### May

- |                              |                         |
|------------------------------|-------------------------|
| 8 - Brisbane support         | 21 - Toowoomba support  |
| 17 - Brisbane forum          | 29 - Bundaberg support  |
| 18 - Brisbane family fun day | 30 - Hervey Bay support |

### June

- |                             |                                      |
|-----------------------------|--------------------------------------|
| 4 - Redlands support        | 20 - Townsville visit                |
| 11 - Gold Coast support     | 21 - Logan support                   |
| 12 - Brisbane support       | 25 - Ipswich support                 |
| 14 - Sunshine Coast support | 26-29 - Sunshine Coast youth retreat |

### July

- |                          |                             |
|--------------------------|-----------------------------|
| 10 - Brisbane support    | 25 - Gladstone support      |
| 23 - Mackay support      | 26 - Brisbane Friday Social |
| 24 - Rockhampton support | 30 - Gympie support         |

# News from New York

*[continued from front page]*

Highlights of the meeting included a full-day discussion on the initiative by the Global Advisory Board, and briefings on the new drugs currently under development by Wave and Roche.

Delegates also attended a meeting with senior executives from the CHDI Foundation, a privately-funded NFP biomedical research organisation.

The CHDI Foundation pours many millions of dollars every year into funding research and clinical trials to help develop drug treatments for HD.

You can see a video of the day here: [vimeo.com/319443801](https://vimeo.com/319443801)

The Australian state HD associations will be discussing HD COPE and how it could work in this country in coming months. We will provide further information as it comes to hand.



*The HD Cope global advisory board, with Australasian representative and Huntingtons Queensland CEO Jan Samuels far left*

Learn more at:

[chdifoundation.org](http://chdifoundation.org) and [huntingtonsociety.ca/hdcope/](http://huntingtonsociety.ca/hdcope/)

## Come along to the Friday Social!

We are very excited to welcome attendees to the next Friday Social on **Friday 29 March** at our office, 385 Ipswich Road Annerley.

The Friday Social is a **new series of information sessions** covering topics that haven't previously had much focus.

We will be covering topics like **financial planning, family planning, HD and the workplace**, and a wide range of other topics.

Each session will have a different presenter – someone experienced in that topic – and attendees will have the chance to ask questions and chat over a friendly Friday afternoon cheese platter.

The upcoming Friday Social is about **understanding your rights with insurance**, presented by experienced Brisbane-based lawyer and firm director Paul Watson.



with  HUNTINGTONS  
*queensland*

We hope you can make it – come along from **5pm for a 5.30pm presentation**, followed by a social catch up.

If you can't make it, you can still get all the information! We'll be **live-streaming the presentation on our Facebook** page where you can also post questions during the presentation and we'll ask them on your behalf.

Please RSVP at [huntingtonsqld.org.au](http://huntingtonsqld.org.au) or 07 3435 4300 by **Monday 25 March** for catering purposes.

## Announcement: *Planning for the Future* - register now!

Following the great success of our inaugural Alecca McKinless Forum – *Lighting the Way* – in 2018, we will be hosting another forum this year!

This year's forum – *Planning for the Future* – has been extended to a **full-day event**.

Come along from 9.30am on **Friday 17 May** at **Treasury Brisbane** in **Brisbane city**.

**The forum will focus on planning and preparation** – planning around work, insurance, families, and a number of other practical topics.

We will have a wide range of **presentations in the morning**, including keynote speaker Catherine Martin, CEO of Huntington's Disease Youth Organisation (HDYO), Brisbane neurologist and researcher Dr Rob Adams, geneticist Dr Michael Gattas, and Professor Julie Stout.

**The afternoon will break into two sessions**, taking a practical look into some important topics such as supporting young people living in HD families, and planning for the future.

**We will then complete the evening with a social hour of drinks and canapés.**

We are grateful to the Alecca McKinless Gift for supporting and subsidising this event once again. Because of this generosity, participants will be able to attend **free of charge**.

We will also record the presentations to ensure everyone can watch them in the future.

We warmly extend an invitation to our wide community! Invitations will be sent via email, and registration is now available through our website. Space is limited, so don't delay – **register early to avoid missing out!**

## Response to survey

Thank you to everyone who took part in our recent survey, telling us what you think of our services and making suggestions for new or different services you would to see.

We are working on analysing your responses which will be used to review our work, and contribute to our continuous improvement processes. Watch this space!

THANK  
YOU



## Board planning & strategy

On 16 February our board and staff met for a strategy and planning day.

This was the first time we have undertaken such an exercise under the chairmanship of new president Jason de Bakker, and it was a productive and interesting day in so many ways.

We look forward to sharing the board's plans with members and families in the months ahead.

# Win big with *Play For Purpose*

We're delighted to continue to participate in the new charity lottery *Play for Purpose*.



This exciting new lottery offers you the chance to win big, with tickets only \$10 each!

And with each ticket you buy, we receive \$5! So not only are you giving yourself a chance at winning a holiday, a car, or a number of other exciting prizes, but you're supporting a worthy cause at the same time.

The next draw will close at the end of April, so don't miss your chance to enter this amazing draw for your chance to win big and support us!

Visit **[huntingtonsqld.org.au](http://huntingtonsqld.org.au)** and follow the Play for Purpose link to get your winning tickets today.

## Client Services out and about

Our Client Services team has had a busy start to the year, with trips to Townsville for a newly established quarterly information session, Hervey Bay, Toowoomba and Gympie.

Most recently, Lauren and Tressa spent time in Bundaberg for one of our regional family fun days.

**We'd like to say a very special thank you to The Bundaberg Barrel and Grunske's by the River restaurant for hosting the event.**

While visiting regional areas we host support group meetings, one-on-one meetings with families and individuals, and meet local service providers to offer education and information about Huntington's disease.

See our upcoming support group dates for more information, or call our team on **07 3435 4300** to find out when we'll be in your area.



Taste testing at  
The Bundaberg Barrel



Family Fun Day in Bundaberg - all smiles! Thanks to everyone for coming along!

# Youth retreat seeking expressions of interest

**Attention young people!** Huntingtons Queensland will be hosting a youth retreat from **26 – 29 June in Currimundi**, Sunshine Coast, and we'd love you to join us!

**Everyone aged 16 – 25 who has been impacted by HD in some way is welcome to apply.**

The four-day retreat is **free for attendees**, and will include a number of workshops and presentations, relaxed social and networking opportunities, and other fun activities like paddle-boarding and rock-climbing.

We believe attendees will leave the retreat with a better understanding of HD, new coping strategies, and a wider support network.



We are grateful to the Gambling Community Benefit Fund for making this retreat possible. Through their support, this retreat will be completely free for attendees.

Invitations have been sent by email, and **applications can be made through our website.**

Places are limited, and applications will close at **5pm, Monday 8 April.**



**Gambling  
Community Benefit Fund**  
Queensland Government



## Make a donation this end of financial year 2019

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: \_\_\_\_\_