



HUNTINGTONS queensland

Autumn 2020 news flash



Lauren was delighted to deliver a virtual education session to the OT team at Opportunity in Townsville

Virtual learning

Our team has been adapting quickly to our new way of working, as Lauren proved a few weeks ago when she delivered an online education session for occupational therapy team "Opportunity" in Townsville.

Although a little different to Lauren's normal in-person education experience, it went really well, and still gave the team the chance to ask questions and learn together.

Virtual education, information and advice is an important part of our new way of working, and we look forward to supporting you with the use of online video conference technology.

If you'd like to access our virtual learning service, just call or email us on **07 3435 4300** or **admin@huntingtonsqld.org.au** to find out more.

A little note from Jan

Since our last newsletter, there have been some significant social changes that have forced us to adapt and change how we are delivering our services.

We would like to thank the many members of our community who have been overwhelmingly positive and supportive of these changes, which we've put in place to try and keep our clients and staff safe.

One of the biggest changes is the temporary closure of our office space, the transition of our team to a work-from-home structure, and the complete suspension of face-to-face services.

It has certainly been a learning curve, and our team is missing the direct contact with clients, and catching up with one another in the office.

While it appears that all Australians will be working this way for quite some time, we are doing our best to support families and each other with the challenges that living with HD can bring.

The office phone number is still operational and we are still answering and returning calls during office hours. Our HD advisors, Lauren and Tressa, are also working hard to keep up with phone and email support, and you can also contact us via Facebook or our website.

I would also like to take this opportunity to thank our wonderful board of directors. Our directors – all volunteers – continue to oversee our operations, despite some difficult personal and professional challenges of their own, and have reached out to ensure our team and clients are ok.

They are also continuing to work in the background on our strategic priorities and to oversee Huntingtons Queensland to ensure we make it through the Covid-19 pandemic and continue our 40-plus years of service to the HD community.

Stay strong, stay safe and please – stay at home.

JAN SAMUELS
CEO

The key points:

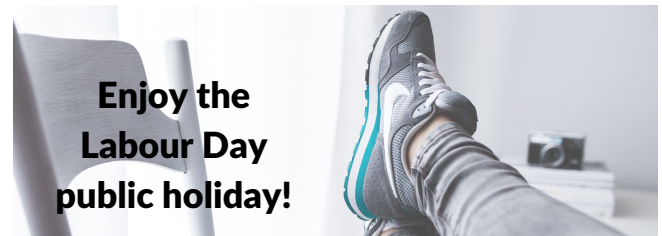
- Our **phones are still operational** – call us on 07 3435 4300, and we will respond during office hours
- Our **website, Facebook and emails** are operational, and you are welcome to contact us through these
- **Our team are now working remotely** – we are unable to offer any face-to-face services at this point in time
- **Face-to-face support groups are also on hold** for the foreseeable future
- **Our office is temporarily shut** – please don't drop in or visit.



The Huntingtons Queensland team is adapting to our new work environment

Public holiday closures

Our team will be taking a short break for the Labour Day holiday (**Monday 4 May**). You can still leave us a message (07 3435 4300) and we will respond as soon as we are back to work.



NDIS priority delivery

The government has announced that **NDIS participants may now be able to receive priority access to grocery home delivery services** from participating supermarkets, including Woolworths, Coles and IGA.

What does this mean?

Priority delivery ensures you receive your items delivered to your home before the general public. The items you select will be prioritised for your order, to ensure you aren't missing out on essentials.

How does it work?

If you are an NDIS recipient, you should receive a unique priority home delivery code.

If home delivery services are available at your participating supermarket, you can:

- complete your grocery shopping online,
- select home delivery, and
- when prompted, enter your unique priority home delivery code.

You can find out more by visiting ndis.gov.au/coronavirus/priority-home-delivery-service

Telehealth services available

The Queensland Government has released temporary new ways of ensuring Queenslanders can access health support without in-person contact. Support is available for general health or mental health concerns.

You can access telehealth services by audio or video call, though video is strongly recommended. This service is not available if you are admitted to hospital at the time, including a virtual ward.

Further information is available at health.qld.gov.au/telehealth.

You can also call 13 HEALTH (13 43 25 84) for information.

HD CLINIC

Please be advised the HD Clinic at Royal Brisbane and Women's Hospital has moved to contactless support. All upcoming appointments will now be done via video or telehealth conference. You can call **07 3646 3111** for more information or to enquire about your upcoming clinic.

All telehealth services will be bulk billed for:

- Commonwealth Concession Card holders
- Children under 16
- Patients considered vulnerable to Covid-19:
 - including those who are required to self-isolate or self-quarantine as recommended health or government bodies; or
 - who are more than 70 years old;
- People who identify as Aboriginal or Torres Strait Islander descent and are more than 50 years old;
- Pregnant women;
- The parent of a child under 12 months;
- Those being treated for a chronic health condition or who are immune compromised; or
- People who meet the current national triage protocol criteria for suspected COVID-19 infection.

If you are participating in the Wave clinical trial, you can contact them for information by emailing hdresearchqld@gmail.com or calling Liz Arnold on **07 3365 5147**.

Changes to our services

Support groups

Our highest volume service – our support group meetings – have been put on hold indefinitely until the Covid-19 pandemic restrictions are fully lifted. We made this difficult decision a few weeks before government restrictions were put in place, as we felt that the risk to our clients was too great.

Although we cannot provide a timeframe for when these will be re-established, our team is looking into alternatives, such as digital meetings and increased phone support. We will email out more information and invitations when we have confirmed these measures, but for now, you are welcome to call or email us as usual if you'd like to chat.

In-person contact

As part of work-from-home restrictions, all face-to-face services are on hold. A large portion of our work included home visits throughout the state, and support and advocacy by attending meetings with other services like Centrelink.

If you need one-on-one assistance from our team, please call us and our HD advisors will do their best to support you from a distance. We are also looking at ways we can connect families to mental health services offered by other providers and clinicians via telehealth, and will provide more information as it comes to hand.

The Alecca McKinless Forum 2020

We were deeply saddened to cancel this year's annual Alecca McKinless forum. It has been one of the highlights for our team for the past two years, and is popular with attendees, providing great information and a great social opportunity.

But we've got some good news! We have booked in our date for the 2021 Alecca McKinless forum, so we hope you can join us on Friday 28 May 2021 at Brisbane Treasury. Registrations will become available through our website later in the year.



Huntington's Disease Youth Organisation (HDYO) director Catherine Martin at the 2019 Alecca McKinless Forum

HDYO's Young Adult Conference

You may have already seen the announcement from Huntington's Disease Youth Organisation (HDYO) that their inaugural International Young Adult Conference has been postponed.

This incredible event was scheduled for 9-11 May 2020, and was due to welcome young adults impacted by HD from all around the world, including a number of Queenslanders.

The conference is now scheduled for **12 – 14 March 2021**, and will feature the same incredible line-up of speakers. You can find out more by visiting their website at **hdyo.org**.

Huntingtons Queensland will be working with donors and supporters to get several young Queenslanders to the rescheduled conference. We look forward to your support for this fantastic initiative.

Australian HD national conference

Due to the impacts of Covid-19, the national Huntington's disease conference scheduled to be held in Sydney in November 2020 has been postponed for 12 months. It is now scheduled for November 2021.

Running for Nan's HD

Kelly Woodland, the organiser of Running for Nan's HD, was excited to bring the event back for its 5th year in a row. There were already a number of sponsors on board, and we were looking forward to the largest turnout yet!

Due to the restrictions in place for social distancing, Kelly will be postponing her event this year. Keep an eye out for new dates – we look forward to this great event soon.



Sponsors Patrick and Jewlie with organiser Kelly Woodland at Running for Nan's HD 2019

Hike for Huntington's

Our wonderful director Shane Kelly had scheduled another Hike for Huntington's in the Sunshine Coast hinterland in May but this has now been cancelled.

Last year's successful event welcomed 30 hikers and raised more than \$3,500 in urgently needed funding for Huntingtons Queensland.



Hike for Huntington's participants in 2019

IMPORTANT UPDATE:

Status of current HD clinical trials in Australia

In 2019, the HD community in Australia welcomed three new international clinical trials from the sponsors Wave Life Sciences and Hoffman-La Roche. These trials are all planned to continue for some time, at least into 2021.

The trials are very important because they are testing novel drugs in people with Huntington's disease (HD). All three trials have been progressing well in terms of recruitment and participant activity.

We wanted to inform the community of necessary changes to the trial activities due to the COVID-19 pandemic. The doctors and site staff for all three HD trials in Australia are following the guidance of the trial sponsors regarding how to manage the trials during the COVID-19 outbreak.

In addition, they must follow requirements in the states and hospitals where these trials are taking place to minimise the risk of exposure to the virus for trial participants and staff. Specific changes in trial activities vary site to site due to differences in site policies and guidelines.

Importantly, sites will continue to remotely monitor the health and safety of all trial participants currently enrolled in these trials. If you are a participant in one of these ongoing trials, the site staff will keep you informed about changes to scheduling or temporary suspensions of trial visits.

We are in close contact with the sponsors responsible for these trials and the governance officials at each site where these trials are conducted. They will inform us when it is safe for the trials to recommence. When this happens, trial participants will be contacted regarding next steps in their trial participation.

We trust that you understand that this important decision has been made to protect the health and safety of all trial participants and staff, as well as the wider community. We hope you remain safe and healthy during these uncertain and challenging times.

Julie Stout & Alison O'Regan
Monash University

Supporting Huntingtons Queensland

Huntingtons Queensland is extremely grateful to the many wonderful donors whose generosity helps us deliver services throughout Queensland.

As we approach the end of the financial year, we would normally prepare to reach out to our community and ask for your support. Donations make up a significant proportion of our total annual income.

However, **times are very different now**. Following on from drought, floods and bushfires, many people have now lost their jobs, or have reduced hours, and things are a bit scary.

In recognition of these difficult times, for the first time in many years, **we will not be sending out a tax appeal**.

Donations are the lifeblood of our organisation, and if you would like to help us carry on, we would very gratefully welcome your support.

Donations can be made directly via a secure payment gateway on our website, and tax receipts can still be sent to you.

We will still be sending out membership renewals closer to the end of financial year and now, more than ever, we would welcome your continued membership of Huntingtons Queensland, both to keep our vital services going and to provide a way to keep HD families connected.



Make a donation to Huntingtons Queensland

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

ABN 45 130 081 598

Name:

Postal address:

Email: Phone:

Donation amount:

Visa or MasterCard:

Card Number: Card expiry date:

Name on card:

Signature:
