



HUNTINGTONS queensland

Autumn 2021 news flash



Florence Dannel House in Annerley; insert: Florence Dannel, whose generous bequest enabled the purchase of the building in 1996

We're on the move

It has been a busy and exciting few weeks for the Huntingtons Queensland team – we have officially moved to a new office location!

Our beautiful office building, Florence Dannel House in Annerley, Brisbane, has been our home and headquarters for more than two decades, and we have welcomed thousands of clients, members and supporters through the doors during that time.

Please note we have a new phone number: 07 3064 3222

We are delighted to pass the keys to our friendly neighbours – Women's Legal Service (WLS) – who have purchased the building.

This has been an important financial step to build a more sustainable organisation, and safeguard our future. Our new office space is located in Yeerongpilly, not too far from our old office, and the team is almost finished settling in.

Announcing
**Huntington's Australian
National Conference 2021**



25 May - 1 June 2021
Virtual conference
Register now
www.huntingtonsnswact.org.au

Moving office (cont.)

We have a few immediate neighbours in our new space, as we share the building with a number of other businesses.

If you'd like to catch up with us in person, we recommend giving us a call, as we may not be able to welcome you to our new office without notice.

Importantly, please take note of our contact details, as our phone number has changed:

Phone number: **07 3064 3222**

Email: admin@huntingtonsqld.org.au

Postal address: PO Box 635, Annerley QLD 4103

We need to say thanks to some key people involved in this big endeavour. Our team would like to thank the Board for their guidance and trust when making the decision to move on from our long-term home. There is a lot of history and love in Florence Dannell House, and the decision came after much discussion about what is best for our clients and the organisation's longevity.

We also want to thank our office superwoman Cathy for orchestrating this mammoth project. From overseeing the removalist to detailed checklists for our team to the gentle and constant reminders to clean out the staff fridge, this move simply would not have happened without Cathy. Thank you!!



Who said moving was stressful? The team managed to keep smiling throughout the move. Cathy (top left), Tressa (top right) and Jen (middle left); and a few sneak peeks inside our new office space.

A little update on our services

Welcome to the 'new normal'! We are excited to relaunch a number of services that were put on hold last year. This means we are now running support groups throughout Queensland, and can provide more one-on-one services in person.

Our team is looking forward to once again meeting with clients face-to-face. We will also continue our online and phone services, to ensure that you can chat with our team when you need it, regardless of where you are.

We have developed Covid-safe procedures and protocols to keep our clients and team safe, so you may notice additional steps or requirements when you see us. This includes:

- recording details of support group attendees to assist with contact tracing
- sanitising meeting spaces before and after use
- providing face masks and hand sanitiser when meeting in person or travelling in cars with our team
- no catering provided at meetings (you are welcome to bring your own morning or afternoon tea)
- maintaining appropriate social distancing for all in-person services directives.

HD acknowledgements

We are delighted to share the news that **Ann Jones**, Secretary for the Huntington's WA Board of Management, was awarded the Member of the Order of Australia. This significant achievement was in recognition of Ann's long history of service to people living with Huntington's disease, including carers. Congratulations to Ann on this wonderful recognition!

The founder of Huntington's Disease Youth Organisation (HDYO), **Matt Ellison**, has received one of the highest honours available to people in the UK. Matt was awarded an MBE, which he accepted from the Queen at Buckingham palace earlier this year.

The MBE was given to Matt in recognition of his dedication to young people impacted by HD, and the development and management of HDYO. HDYO have contacted and assisted young people in 90 countries, and Huntingtons Queensland is proud to support their work. Congratulations Matt!

We also ask that you do not attend any in-person service if you or a member of your household:

- is displaying any symptoms of Covid-19 (cough, sneezing, sore throat, runny nose, headache, fever, shortness of breath, other signs of illness)
- has tested positive for Covid-19, or been in contact with someone who has tested positive for Covid-19 within the last 14 days
- has been instructed to self-isolate
- is awaiting the results of a Covid-19 test.

These protocols should help us to keep our clients safe, and our team is taking them very seriously. If you have questions about these new protocols, or want more information, please give us a call on 07 3064 3222.

We will also be continuing our online support group meetings through Zoom. We will be holding two each month – one during the day, and another from 5pm. We will email invitations a few days before the meeting, and all are welcome to attend. If you are not already receiving these emails and would like to, please let us know by giving us a call (07 3064 3222) or email us at admin@huntingtonsqld.org.au.

Michele Giles-Clark, the CEO of Huntington's SA, was one of 112 individuals awarded a Churchill Fellowship in late 2020. This prestigious award is given to individuals who have demonstrated drive and passion in their field, and wish to bring global best practices to their local Australian communities.

Michele will be offered the opportunity to meet and work with leaders in her field in Peru, Chile, Venezuela and Brazil, to address the gap in care for Australians with HD living rurally and remotely. Congratulations Michele on this fantastic achievement – we look forward to hearing about your experiences!

Longtime friend of Huntingtons Queensland, **Catherine Martin**, has left her role as Executive Director at HDYO to pursue work as a consultant. We are so grateful for her wonderful contributions to supporting young people impacted by HD, and wish her the best in her future ventures.

Dancing at the Vatican

The documentary *Dancing at the Vatican* premiered online in Australia in June, inviting viewers from all over the country to watch the film from the comfort of their own home.

Dancing at the Vatican documents the journey of Huntington's disease-impacted families from all around the world, including from some of the poorest areas of South America, as they travelled to the Vatican for an assembly with the Pope.

The project, named HDden no more, was spearheaded by renowned war reporter Charles Sabine, who is also a global HD advocate, and is gene positive.

Sabine was instrumental in organising the meeting with the Pope, which became the first time a world leader publically acknowledged the presence of Huntington's disease.

Charles Sabine joined a number of leading Australian doctors and researchers for a special Q&A following the documentary screening.

Huntingtons Queensland was pleased to be a part of this unique event, and we highly recommend this moving documentary. It may be available for viewing online in the future.



Promotional images from the documentary 'Dancing at the Vatican'

Thanks Luke

You may have met or heard of our wonderful friend Luke Muir, a financial advisor from LM Wealth Partners. Luke met many of our clients for the first time at our 2019 Alecca McKinless Forum.

Since then, Luke has been working with a number of clients to ensure they are financially secure and supported. Luke has been a wonderful supporter of our organisation and clients, and we wanted to publicly thank him for his generosity and hard work.

You can access Luke's expertise by contacting him directly on 07 3118 1760.



Luke with Lauren from Huntingtons Queensland at the 2019 Alecca McKinless forum

Meet our new treasurer

You may have seen some recent changes to our Board, as we welcome a new director – we are delighted to introduce you to Della Nicholson!

Della has joined us as Treasurer, and brings with her a wealth of experience in accounting and business management, as well as working experience in NDIS and not-for-profit organisations.

With a proud history of community volunteering, we are delighted Della has chosen to volunteer her time and expertise to us.



Della Nicholson

Volunteer directors needed - share your expertise

Huntingtons Queensland is keen to recruit new directors who can bring a range of skills and experience to our team. Our board meets monthly for two to three hours and also has special sub-committees for Strategy and Finance, Risk and Audit. Information about our organisation and services can be found at www.huntingtonsqld.org.au

Ideally you will have previous experience on a NFP board, or professional experience in areas such as governance, strategy, fundraising or administration. For more information, or a confidential chat in the first instance, please contact our CEO, Jan Samuels, on **0414 964 040** or email jsamuels@huntingtonsqld.org.au.

Moratorium on genetic testing for life insurance

In 2019, changes were introduced for new life insurance applicants. Between 1 July 2019 and 30 June 2024, life insurers will not use genetic test results as part of the assessment process for people applying for death and Total & Permanent Injury (TPI) policies up to a certain amount.

Paul Watson, from Berrill & Watson Superannuation and Insurance Lawyers, has been a supporter of Huntingtons Queensland for many years, providing advice and services to our clients and team.

Paul and his colleagues recently wrote about the moratorium on their website, and what it means for people with genetic disease seeking life and TPI insurance.

You can read their blog post through their website – visit www.berrillwatson.com.au and search for 'moratorium' in their blog posts.

If you would like to find out more about the moratorium, Paul has offered to provide advice free of charge. You can contact Paul on **07 3013 4300** or pwatson@berrillwatson.com.au.



Paul Watson

Have your say on housing

Are you impacted by Huntington's disease, and have had difficulty finding suitable housing and support?

Researchers from the Summer Foundation and La Trobe University are conducting a study investigating housing, services and supports for people living with Huntington's disease, including carers.

The study is hoping to include people impacted by HD who have had good or poor housing experiences. It will comprise an hour-long one-on-one interview with a researcher, either via zoom or on telephone. Participants will receive a \$60 gift card.

If you would like more information about the study, you can contact Professor Jacinta Douglas on **03 9479 1797** or **J.Douglas@latrobe.edu.au**. If you would like to participate in the study, you can contact the researchers on **1300 626 560** or **research@summerfoundation.org.au**.

Thank you

We would like to say thank you to each and every person who generously supported our Christmas appeal. We understand it has been a difficult year for many, and your ongoing support is truly appreciated.

The funds raised in this campaign are helping to fund critical counselling services with psychologists who have experience with HD. Your generosity is helping people access vital support when they need it most. Thank you.



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.

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