

Spring 2023 news flash



SPORTING LEGENDS
RUGBY LEAGUE CHARITY GAME

GATES OPEN 12.30PM: 1.30PM
WAVELL SHS VS CARMEL COLLEGE
MAIN GAME KICK OFF 3PM

Saturday 14.10.2023
@ Kayo Stadium (Dolphins Oval)

ANY INQUIRIES CONTACT
Troy Clarkson
0401 843 030

CARLWEBB
FOUNDATION FOR MOTOR NEURONE DISEASE
a footballer's fight for life

HUNTINGTONS
queensland

THE MND LEGENDS TEAM

BEN BARBA
BRENTON BOWEN
MATT BOWEN
PETERO CIVINOCIEVA
BEN CROSS
GREG INGLIS
DALLAS JOHNSON
DUNAMIS LUI
CHRIS LYNN
BRAD MYERS
MICHAEL ROBERTS
DARREN SMITH

DAVID STAGG
BRAD THORN
ESI TONGA
WILLIE TONGA
LOTE TUQUIRI
ADRIAN VOWLES
PIRI WEEPI
JHARAL YOW YEH
BAILEY LIPKE (LIPKE DASH REPAIRED)
RYAN WESCHE (IRELANDS JWC)
TRENT HENRICKS (WYTHAM JWC)
LUKAS HALL (CANNA JWC)

HUNTINGTON'S LEGENDS TEAM

GREG BIRD
TODD CARNEY
WILL CHAMBERS
STAV DAVIDSON
JAMIE FEENEY
MATT GYER
BEN HAMPTON
SCOTT HILL
JOSH HOFFMAN
MARK HUNT
ISSAC LUKE
JOSH MCGUIRE
STEVE MENZIES
JOEL MOON

DAVE PEACHEY
BEN ROBERTS
SAM TAGATAESE
JOHN TE REO
MARK TOOKEY
CLINTON TOOPI
BRENT WEBB
KYAL BEMET (HOF)
CRAIG FREDRICKS (IT & C PLASTERED)
WILL SCANLAN (WYTHAM JWC)
KALIN ROPATA (CURRUMBIN EAGLES)
DANIEL WESTWOOD (HOF)
CRAIG MCGAVLEY (CURRUMBIN EAGLES)

COACH
ANDREW MCCULLOUGH

COACH
RYAN JAMES

TICKETEK <https://premier.ticketek.com.au/shows/show.aspx?sh=CARLWEBB23>

It's D-Day!



The Queensland team. L to R: David, Basil, Jen, Tress, Kelly, Alyse and Cathy

We are here!

After years of consultation, months of planning, hours of work and collaboration from staff from all over the country, we are super excited to officially become part of Huntington's Australia on October 1.

Huntington's Australia brings five associations with a shared vision of enabling those impacted by Huntington's disease to live their best lives. This is a momentous occasion - a culmination of lots of hard work from many people, and the start of a new era of national unity of purpose and effort.

From the first meeting over 45 years ago at the home of founder Cliff Farmer, we are proud of the work that we have been able to do as Huntingtons Queensland, and look forward to continuing to support our clients and community with the backing of a National Association.

Thank you to everyone for your support during this transition period.
Huntingtons Queensland

Footy for Charity!

WE HAVE EXCITING NEWS!

Huntingtons Queensland has been selected along with the Carl Web MND foundation, to receive the proceeds of the Sporting Legends Rugby League Charity Game on Saturday October 14 at Kayo Stadium, Redcliffe.

This is a great opportunity to witness 34 NRL legends in their element while supporting Huntingtons Queensland.

Tickets are still available and are only \$15 per adult. Visit Ticketek to secure your tickets to what will be a fun afternoon.

<https://bit.ly/hqfootball>



Running for Nan's HD



A beautiful sunrise greeted all the eager participants at the 2023 Running for Nan's HD. Over 160 runners, walkers, adorable babies and 4 legged friends came out to support Huntington's Queensland. As the runners and walkers finished their 5km and 10km course along the Wynnum foreshore the sun was shining, the sausage sizzle was ready and everyone had a smile on their face. Close to \$7,000 was raised for Huntingtons Queensland.

Running for Nan's HD is organised by Huntingtons Queensland longtime supporter, Kelly Connolly whose Nan, a great-great grandmother, lived with HD. Kelly and her wonderful husband, Steve work tirelessly seeking sponsors, raffle prizes and wonderful community support to make the event the success it is. Thank you Kelly and Steve.

Thank you to everyone who came out and supported this amazing event. A BIG thank you to all the sponsors on the day and those who donated raffle prizes. Our gratitude goes to JT signs, Inspire Athletic, Pat Ivey, Harcourts Property Centre and Photography2envy.



Images by Photography2envy

An Update from Basil

Where has the time gone?!

As we hurtle at great pace towards the merger, we are thrilled to share some significant developments and achievements within our organisation over the past few months.

In May, as part of our collaborative efforts under Huntington's Australia (HA), Lauren made the move to the Tasmanian association. We are delighted to announce that she is now permanently based there, contributing her expertise and dedication to our mission. We will miss her physical presence in the Queensland office, but know that she will be a welcome addition to the Tasmanian Huntington's community.

In collaboration with the NSW/ACT association, we have expanded our services to include NDIS support coordination, a crucial aspect of our commitment to assisting our community. We welcome David, who is leading this initiative, ensuring that individuals receive the support they need to navigate the NDIS effectively.

Our HD specialist Kelly has taken on the role of Community Programs Team Leader within Huntington's Australia. Additionally, we welcomed Alyse to our team, and she has seamlessly stepped into Kelly's previous role.

Throughout this period, we have continued to support and facilitate various support groups across the state. These groups play a vital role in fostering connections and providing valuable support to the community. Our efforts culminated in a heart-warming Currumbin community meet-up in August, where we witnessed the strength of our community bonds.

In July I was lucky enough to attend the annual Running for Nan's HD event. We are truly grateful for the overwhelming support. Thanks to the dedication of Kelly and her husband Steve a remarkable 193 individuals registered for the event, making it a resounding success.

We were excited to find out we are the recipients of the Tackling Life Charity NRL game on October 14 at Kayo Stadium in Redcliffe. This promises to be a fantastic opportunity to see your favorite legends in action.

We are incredibly proud of the progress and remain deeply grateful for the unwavering support of our community. These achievements would not have been possible without your continued dedication and bode well for the future as we transition into Huntington's Australia.

Thank you
Basil Mabuza
Head of Community Programs and Services
Huntington's Australia



Reflections from our Founder Cliff!

Over 45 years ago Cliff Farmer was instrumental in the development of the first Queensland based Huntington's Association. From the beginning the associations aim was awareness and support for everyone impacted by Huntington's Disease. We asked Cliff to share the journey.

When one is asked to write an article about something like an organisation's journey it is inevitably about people; the people who travelled with you, the people you met along the way and who shared experiences with you, the people you were challenged by and the people you challenged.

The journey of Huntington's Queensland and my involvement was no different.

The journey started long before the association existed as individual, families, friends, doctors and researchers sought to come to grips with this baffling and horrible disease.

The documented journey in Queensland commenced when two doctors successively tried to document the genealogy of families in Queensland as part of their doctor of philosophy studies. The first was David Wallace and the second Neville Parker and the material became the property of the Queensland Institute of Medical Research. Family history and recognition of symptoms were the only aid to diagnosis. Their research method took the form of door knocking on houses of families. They were not always welcome and had stories of physical threats to their presence.

I became aware of the disease through the diagnosis of a close cousin. Her husband was diagnosed and they were advised that no treatment or support could be offered.

Fortunately I had a close friend who was an Anglican priest then living in Victoria and he rang to tell me of some research he heard about on the News. He found a contact for me and with my cousin we visited Victoria and met Dr Eddie Chui a psychiatrist and Betty Telsher a social worker. They provided us with more information about the disease and we returned to Queensland with our need for knowledge satisfied.

I soon had a phone call from the President of the Association in Victoria who told me they had Queenslanders on their mailing list and we should start an Association in Queensland.

The list was used, a meeting called and the Association formed. It was attended by some family members, friends and a small numbers of workers in the community and mental health areas who were working with families. I was privileged to be elected as our first President.

How do you form an Association for people from fractured families who trust nobody, whose needs are specifically excluded from support by State Government disability services workers? We initially ran a house party at our home. It was attended by about thirty people and included cousins from families who had heard of each other but had never met. It was an amazing experience.



Cliff with current Queensland Board Chairman Shane Kelly

We tried to network with the state Department of Mental Health, the Queensland Institute of Medical Research, Royal Brisbane Hospital and the local mental asylums where many Huntington's disease patients spent their final years. The formation of the Association was welcomed on all fronts.

Fortunately all the senior doctors of the state government Department of Mental Health had a good knowledge of Huntington's disease because they had worked at one of the mental asylums during their careers.

Our next challenge was on how to promote the Association. We wanted to do this in a positive way and with the encouragement and support of the QIMR and the Health Department convened a seminar.

We were advised that no one would come to a conference on Huntington's disease so it was promoted as "A Conference on Degenerative Brain Diseases hosted by the Huntington's Disease Association". It was highly successful and we increased our mailing list to over 100 people.

One of the key things which is different about HD from almost any other medical condition is the close relationship between researchers, clinicians involved with the disease and the associations throughout the world as the representatives of the families. This is reinforced by the meetings of the International Huntington's Association being held in conjunction with the World Federation of Neurology Conference.

One of our early clinicians Dr Joan Lawrence attended a WFN Conference during the 1970's. We made an effort for someone to attend IHA conferences and Jenny and I attended several where we learned a lot, not only about the disease, but also about what other associations were doing throughout the world. These included the regional structure of the Canadian Association, the amazing social and welfare support being done in Aberdeen in Scotland and the constructive support of young people in Wellington in New Zealand. Their experience assisted us in Queensland in our own development.

Our key strategies were to enable families to live with Huntington's Disease until there was a cure or treatment which we all believed was not far off. Central to this was the establishment of the welfare service, the establishment of a day centre and the conduct of Hhilday weekends for people who were symptomatic. These latter two strategies helped to provide respite for carers in families.

We also had a number of volunteers who helped with shopping or other day respite activity to relieve families.

Because of the secretive nature of the disease in families and the time between affected persons the need for information was always critical and the welfare service work was also supported by the conduct of "Family meetings" which were partly social and partly educational.

The key strategy was the welfare service. This has been written about by Gwen in this Newsletter. I won't say a lot about it here; except that it was the key strategy developed by the Association and rapidly was recognised as such by the mental health branch of the Department of Health. It was the finest example of "Learning by Doing" I have ever seen. The natural talent that Gwen brought to the job, coupled with her amazing empathy for families and ability to relate to them and their needs ensured that families came to depend on her contact.

Our major funding boost came when nuns of a catholic parish told their local member who was Minister for Health to make sure he supported the Association and families they served. They saw first hand the enormous need and the work the Association was doing through the welfare service.

The other amazing thing was the service it provided and still provides to the nursing home sector. Most nursing homes have no experience with Huntington's residents and admission of a resident is an enormous challenge requiring rapid learning and adaption to meet new needs on their part.

Finally, probably the greatest privilege of my life has been the opportunity to make a small contribution to improving the life of Huntington's families in Queensland. The people affected by the gene have been inspirational in their courage in dealing with what life meant in being affected by the "Worst Disease in the World"

The professional people who supported the Association and families and the amazing volunteers, staff and committee members who worked side by side with us over the journey. You all made major contributions to the work of the Association and what it has done.

Thank you.
Cliff Farmer



Cliff with former Queensland CEO Jan Samuels

Gwen's story

Gwen Pratten has a long association with Huntingtons Queensland. Gwen was a Volunteer, Welfare Coordinator and Board member. Gwen agreed to share her story.

The Huntington's Disease Welfare service in Queensland was established in the early 1980's. A Canadian social worker was employed on a part time basis for a couple of years. There was limited HD knowledge at that time, so the decision by the HD committee to provide support to Queensland families was both required and sort after by HD family members around the state.

There was no government funding available, so the committee and willing volunteers raised funds by way of street stalls, lamington drives, sausage sizzles at Bunnings, raffles and donations.

I recall a phone call at home from Dr Perc Tucker, who was head of Mental Health in Queensland, informing me the association had been granted \$1,000 from the Queensland government. I was overcome and shed a few tears. This really meant a lot, not only from a financial perspective, but recognition of the needs of HD affected families in Queensland and the work we were doing as an association.

In 1986 I was employed as 'Welfare Coordinator' on a part time basis, having worked as a volunteer for several years. I didn't have a degree, however I married into a family challenged by HD so had firsthand experience at some of the hardships this poorly understood condition presented.

I was able to visit regional Queensland on an irregular basis to meet in person with family members struggling with both experiencing HD symptoms, caring for loved ones, and communicating with family members 'at risk' of developing HD.

During these visits I contacted ABC radio stations, where I was interviewed, thus increasing community awareness and informing families of the association's existence. This resulted in regional family support groups being established in several Queensland cities.

My primary method of communication on a regular basis was by telephone and the majority of my work with country families was after 8pm as phone calls were greatly reduced in the evenings (cost wise).

One of the very successful services the association provided, was regular 'day respite' at our then Annerley facility. This was of benefit not only to HD affected people, but to their carers as well. Many friendships developed between the attendees.



Other services we provided included short holidays for 6 to 8 clients at any one-time involving staff and volunteers at suitable residential facilities at the Gold Coast and Tin Can Bay.

I wish to acknowledge the continuing support provided by the welfare staff, supported by admin staff and board members.

In closing I wish to express my sincere appreciation to Cliff Farmer who was Committee President for several years and my mentor and sounding board during all the years of my involvement. Queensland families owe this man an enormous 'Thank You' for his leadership and dedication, as his involvement shaped the nature of services and the direction of the organisation going forward. His input is requested by staff and board members to this day. THANK YOU, CLIFF!

It was a privilege to be involved in HD Queensland for many years and during that time I witnessed courage, love, determination and acceptance of this challenging condition and made many lifelong friendships.

Gwen Pratten

Meet our newest team members

With Huntington's Australia now in full swing, We are happy to have new team members joining the Queensland team.



Kelly - Community Programs Team Leader

I have had a varied career having studied psychology, nursing, business and previously worked in domestic violence prevention, the NDIS and disability sectors. I also have lived experience caring for family members with chronic health conditions and ASD. While working in challenging socio-economic situations, I have many years of experience in supporting people to achieve life-improving outcomes.

I live on the Gold Coast, am the proud mum to 3 children and 2 fur babies! In my spare time, I love spending time at the beach, walking the dogs and being creative with my passion for interior design.

David - NDIS Specialist Support Coordinator

I am a qualified Rehabilitation Counsellor and have worked in many Support Coordination, Rehabilitation Consulting, Counselling and Allied Health Case Management roles over the past 30 years.

My personal interests include: Regular Bush Walking activities, Tennis, Squash, Snorkelling/ Scuba Diving, Indian/ Asian cooking, BBQs, Surf and Sand and great outdoors as much as possible...

My family, partner and close friends are the most important things to me in this world..!



Alyse—HD Specialist

I am a registered Social Worker and have worked in many different health, welfare settings and services supporting people from 0 – 100. I have particular interest in utilising therapeutic and counselling approaches to social work and am continuing my learning through completing a Masters of Counselling. My approach to social work is holistic and person centred. I have a passion for working with people with a disability, carers, children and families, women and LGBTIQ+ community members to achieve individual goals, connect with services and support and promote social justice.

In my free time I love to garden, spend time with friends and family as well as restore and upcycle furniture. I am a vintage fan and love old fashion, Audrey Hepburn movies and 1920's furniture.

An Animal Adventure



In August on a beautiful sunny spring like day we hosted a community day at Currumbin Wildlife Sanctuary with some of our wonderful clients and families. We got to sit down together and enjoyed a lovely lunch after spending time looking at all the amazing animals. Thank you to everyone who was able to join us on the day.



Mark your calendar

Visit huntingtonsqld.org.au/support/whats-on/ for a full list of upcoming events and support groups. Please note that some events may be changed or cancelled, check our website for the most up-to-date information. RSVP is essential. If we receive no RSVPs the event will be cancelled.

October

- 3 – Gold Coast social group
- 11 – Hervey Bay area visit
- 12 – Bundaberg coffee catch-up
- 18 – Brisbane coffee catch-up
- 20 – Logan coffee catch-up
- 25 – Rockhampton area visit
- 27 – Gladstone area visit



November

- 7 – Gold Coast social group
- 9 – Sunshine Coast coffee catch-up
- 15 – Cairns coffee catch-up
- 17 – Townsville area visit
- 22 – Redlands social lunch
- 28 – Mackay social lunch

December

- 5 – Gold Coast social group
- 13 – Online carers support group
- 15 – Toowoomba social lunch
- 19 – Ipswich coffee catch-up