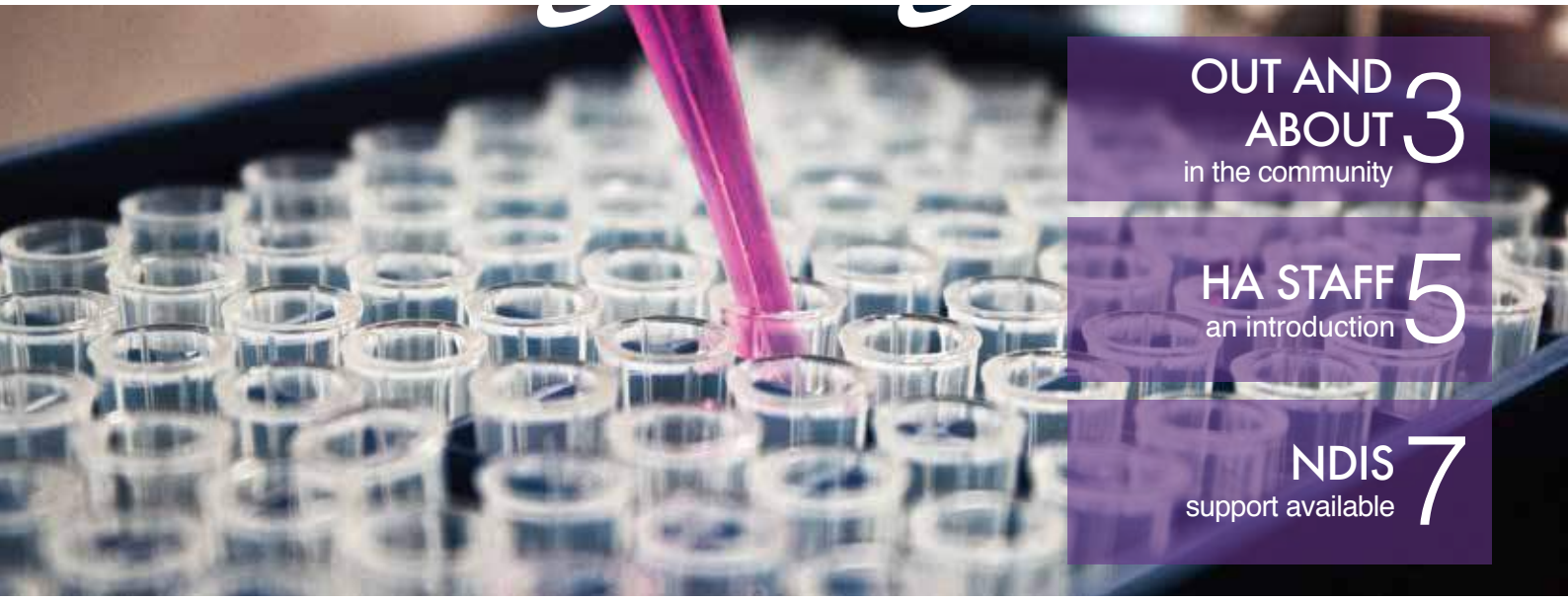
HUNTINGTON'S AUSTRALIA NEWSLETTER

SUMMER 2023 -2024

HA Highlights



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HD COMMUNITY LETTER

WORDS CHELLEY CASEY, HEAD OF PATIENT ADVOCACY

At Wave, we are committed to keeping you informed on the continued progress of our SELECT-HD clinical trial investigating WVE-003 for people living with Huntington's disease (HD). We are happy to share that enrolment in the 30 mg every eight-week multiple-dose group of SELECT-HD is complete. This means we are another step closer to data to inform how multiple doses of WVE-003 may impact biomarkers of the disease, as well as safety and tolerability.

WHAT IS WVE-003 AND SELECT-HD?

WVE-003 is an investigational antisense oligonucleotide (ASO) designed to selectively reduce mutant huntingtin (mHTT) protein considered to be the cause of HD, while sparing the fully functional, or wild-type, huntingtin (wtHTT) protein.

SELECT-HD is a Phase 1b/2a clinical trial studying WVE-003 for people with Huntington's disease. It is an adaptive trial, which means there is an independent committee that reviews the data at specific points during the trial and decides what the next dose will be and how often the drug should be administered.

CURRENT STATUS

We completed enrolment in the 30 mg multiple-dose group of the SELECT-HD clinical trial, which is evaluating doses administered every eight weeks. Participants from the single-dose groups rolled over to participate in the 30 mg multiple-dose group.

We will now evaluate the completed single-dose and multiple-dose groups together and we expect to report data from the 30 mg multiple-dose group with extended follow-up, along with all single-dose data, in the second quarter of 2024.

It should be noted that we cannot conclude that WVE-003 is efficacious and benefit/risk must still be established through continuation of SELECT-HD.

OUR GRATITUDE

We are grateful to the HD community, in particular the SELECT-HD participants and their families, study sites, and clinicians, for their continued partnership and support of this program.

WAVE LIFE SCIENCES

For further information visit https://wavelifesciences.com/for-patients/#huntingtons-disease

CEO INSIGHT

WORDS LENNI DUFFIELD

As I sat down to write my first blurb as the CEO for Huntington's Australia, I found myself reflecting on the last 3 years when we first started out on the merger process, plagued by long hours, intense workloads, fear, anxiety and doubt. While pondering the magnitude of the journey, I stumbled across a quote by William James, a renowned American philosopher and psychologist.

> *"The great use of life is to spend it for something that outlasts it."*

William's quote encapsulates the profound significance of leaving a lasting impact in our journey through life. It's a call to embrace a purpose beyond our finite time on Earth. James suggests that true fulfillment lies not in the accumulation of wealth or success for personal gain, but rather in dedicating our energy, talents, and resources to a cause or endeavor that carries on beyond our own mortality.

Three years ago, we set out to make a lasting difference to HD families across Australia. We embarked on something that had been tried previously before (and more than once) but this time with renewed enthusiasm and a real desire to create tangible outcomes that would not have been possible if we had remained as individual state entities. We were determined to make the merger a reality.

Whilst there is no doubt the merger has been messy and at times accompanied by a frantic level of work, HA has been focused on building on the past and embracing the new.

However, not all has gone to plan, and along the way, we've all been impacted at some point by the challenges a merger presents, especially our staff, but collectively, we have found a way through and have continued to forge a clear path forward.

Through all this disruption and change, the merger has showcased our resilience, adaptability, and shared vision. At its core, is the coming together of 5 remarkable



HD state teams with shared values, showcasing our unwavering commitment to delivering better outcomes and improved services for our HD communities across Australia, that will live on well past our own use by date.

Whilst HA's work is not done, our ability to pivot quickly from integration to operations has been evident in our first few months of operations. In October alone, HA delivered over **241hours of support** to HD families, **serviced 227 clients,** onboarded **36 new clients,** raised **$48,130 in fundraising & donations**, continued to grow our workforce and NDIS services, and **facilitated 10 Support Groups**... all in 22 working days! And as James's quote suggests, by devoting ourselves to something greater than ourselves, be it a legacy, an idea, or an act of kindness, we create an enduring ripple effect of meaning and inspiration, ensuring that our time on Earth remains significant even long after we are gone.

From my family to yours, I wish you a Merry Christmas and a safe, relaxing holiday season.

Warmest regards,

Lenni Duffield
CEO

MEMBERSHIP

Huntington's Australia (HA) would like to invite you to become a member.

We recognise that the more active members we have, the better we can understand the needs of the Huntington's disease community. As we work towards the next exciting chapter, we hope you will join us on this journey.

Membership fees for the first year have been waived by the Board and are valid to 30 June 2024.

To apply to become a member of Huntington's Australia we encourage you to fill in the form. You may complete the form online, https://bit.ly/hamember, or call the office on 1800 244 735 to request a printed copy.

OUT AND ABOUT

South Australia Volunteer Christmas Party







South Australia Coffee & Co





Queensland
Townsville Christmas Party





Tasmania North West and South Support groups





Tasmania End of Year Party

INTRODUCTION TO ALL STAFF



Lenni
CEO



Leah
Head of Finance & Corporate Services



Karen
Administration Officer



Abiha
Team Leader NDIS Services



Janine
NDIS Specialist Support Coordinator



Maggie
HD Specialist



Monica
HD Specialist



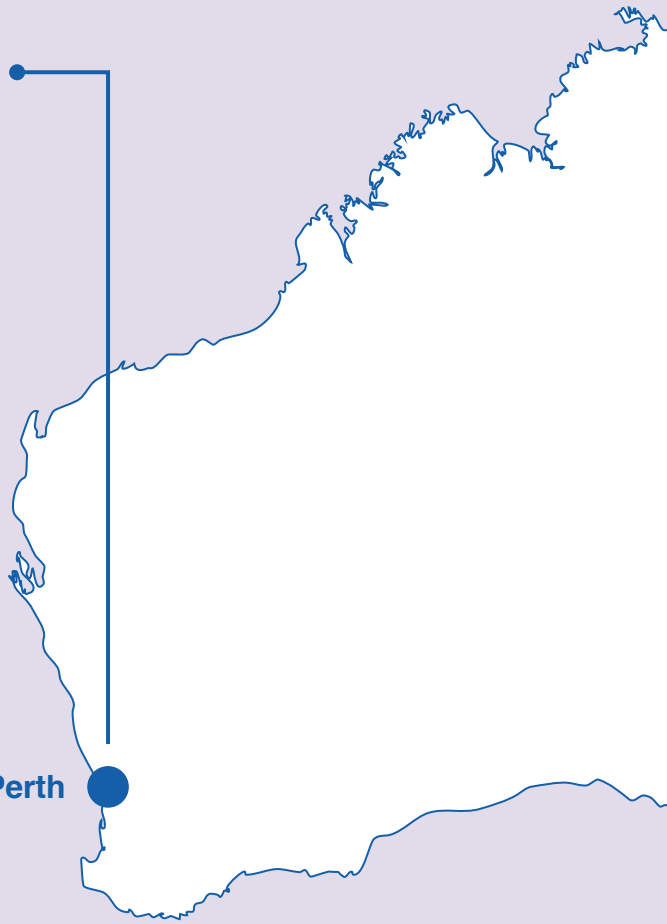
Rebecca
Assistant Accountant



Gerry
Grants Coordinator



Arpita
NDIS Support Coordinator





Lauren
HD Specialist



Mandy
Administration Officer



Irene
NDIS Support Coordinator



Basil
Head of Community Programs & Services



Lyn
HR Advisor



Kylie
Administration Officer



Alyse
HD Specialist



Tressa
HD Specialist



Cathy
Fundraising & Events Coordinator



Michele
HD Specialist



Alison
Head of Business Development & Fundraising



Stewart
Administration Officer

Malisha
NDIS Support Coordinator



Kate
NDIS Support Coordinator



Justine
NDIS Support Coordinator

FOCUS ON FUNDRAISING

WORDS ALISON WEIR

HIGH TEA 4 HD

On October 12, we held our very first fundraiser as Huntington's Australia at Claremont Football Club WA. The High Tea 4 HD was a successful sell out and raised $16,000 for the Huntington's community. To every person that attended and supported the event - thank you. Marg and her team of volunteers did a fabulous job in organising and running the event.

No detail was left out and although the event hasn't run for a few years, thanks to COVID, the first one back was sensational. A BIG thank you to Marg, for all the hard work and for raising funds for families impacted by HD. We'd also like to thank our guest speaker, Sandra Harris-Ramini, ABC broadcaster and highly respected interviewer in London.



TACKLING LIFE FOOTBALL

On October 14, we were the selected charity, along with the Carl Webb MND Foundation, for a NRL Sporting Legends Rugby game at Kayo Stadium Redcliffe QLD. Over 34 former NRL legends as well as local celebrities, former All Blacks, Cricketers and fighting icon Mark Hunt all laced up their boots to help raise much needed funds. Organised by HD family 'Tackling Life' the event raised over $16,000 for each of the charities. Thank you to all the players and volunteers for donating their time. Thank you to everyone who came along and a BIG thank you to Troy and Cherrish from Tackling Life for organising this incredible event.



You have an opportunity to be the proud owner of a one of a kind NRL Jersey and football signed by players of both teams on the day! Bid on our silent auction, BIDDING CLOSES 5PM AEDT 30/01/24. The highest bidder will be declared the winner and will be notified 31/01/24.

Visit https://bit.ly/nrlbid to place your bid!



WALK 4 HOPE WRAP UP

During September NSW held their annual Walk 4 Hope in Newcastle, Canberra, Orange, and Parramatta. We also had a community walk in Wollongong, thanks to Cram Foundation. These events combined raised $50,000 for the Huntington's community. A very big thank you to all of the businesses who donated prizes for our raffles, and to the volunteers who helped source and collect the prizes. Thank you to our suppliers who provided us with food, beverages, and entertainment at each event. Lastly a special mention to Angela, Glen, Rachael, Ian and all our volunteers who gave up their time to assist with the events; without you we would not have been able to make these events happen.







AN UPDATE FROM THE CHAIR

WORDS CHRIS GLASSON

Well, after three years of thinking, talking, planning and doing, we are finally where we once only dared dream of being. I sometimes have to pinch myself to appreciate that we are now well into our third month of being operational. What an incredible outcome. What an incredible effort from so many.

Thank you to everyone, from the State CEOs and State Chairs and Board members to so many of you, staff and volunteers, who have all contributed to the journey and the transition, whilst still keeping operations going and serving our community, which, after all, is why we are all here.

I would, however, like to pay special thanks and appreciation to the initial Project Manager and now CEO of HA, Lenni. Without her passion, expertise, drive and herculean efforts we would not be where we are now. Thank you, Lenni. It is a great foundation you have laid.

Also, thanks to Lenni's management team: Leah who has been just wonderful, Basil, who has worn more hats than the 'Cat in the Hat' and Ali for her tireless work seamlessly blending NSW and the other states.

I cannot forget Stephen Penny and Good Foundations for their tremendous help and guidance and the MinterEllison team for such fantastic and generous support. Many thanks.

So, with the foundation laid, a new business model and a plan for the next few years, our challenge now is to bed down the organisation, to create a working environment that we all want to be a part of, and to grow our revenue, our services and offerings to the HD community.

On behalf of the Board, I'd like to wish you all a Merry Christmas, we look forward to working with you in the New Year.

NDIS SUPPORT COORDINATION IS AVAILABLE

WORDS ABIHA ASGHAR

The National Disability Insurance Scheme (NDIS) provides funding to people with a permanent disability to gain greater independence, access to new skills, jobs or volunteering in their community, more time with family and friends, and an improved quality of life.

Our Support Coordinators have an in depth understanding of Huntington's disease and its impacts on clients and their families. We strive to assist clients to maximise benefits out of their NDIS plan, as well as connect clients to specialist, community based and mainstream services that will help them develop necessary skills and supports to achieve their NDIS goals.



Services we provide under NDIS stream include:

SUPPORT COORDINATION

Support coordination is aimed at assisting participants to understand and use their NDIS plan to pursue their goals. Our Support Coordinators will apply their knowledge and experience of HD to ensure a mix of support services are used to build capacity, maintain relationships, manage day to day living activities, and live independently while engaging in the local community.

SPECIALIST SUPPORT COORDINATION

This level of support coordination is available for people whose situations are more complex and who need specialist support. The specialist support coordination can be included in the participants plan to assist in achieving specific goals such as finding suitable home and living supports.

If you would like to find out more about support coordination and how our team can assist you please email NDIS@huntingtonsaustralia.au or call the office 1800 244 735.

Huntington's Australia

Huntington's Australia
11 Aberdare Road, Nedlands, WA, 6009

T 1800 244 735
E admin@huntingtonsaustralia.au
W www.huntingtonsaustralia.au

Christmas Message

Our office will be closed for the Christmas break after Friday 22 December until Monday 1 January. We will return to the office on Tuesday 2 January 2024.

During this time our NDIS team will be available if specialised support is needed. Please call us on 1800 244 735.

If there is an Emergency, please call 000. Anyone across Australia who is experiencing a personal crisis, contemplating suicide, or caring for someone in crisis can contact Lifeline: 13 11 14.

Alternatively, if you have any need for support over this period, please use the following contacts in your state.

NEW SOUTH WALES

- NSW Mental Health Line: 1800 011 511
- Carer Gateway phone counselling: 1800 422 737

QUEENSLAND

- Qld Public Mental Health Service: 1300 642 255

SOUTH AUSTRALIA

- Mental Health Crisis: 13 14 65

TASMANIA

- Access Mental Health: 1800 332 388

WESTERN AUSTRALIA

- Mental Health Emergency Response Line: 1300 555 788 (metro) or 1800 676 822 (peel)
- RuralLink: 1800 552 002 (outside metro area)

WHAT'S HAPPENING?



The calendar for our support, carer, and social groups is currently being worked on. It will be available early in 2024.

In the meantime please email programs@huntingtonsaustralia.au or call the office on 1800 244 735 to find the location closest to you.



MAKE A DIFFERENCE THIS CHRISTMAS

This Christmas season, we will have staff on standby to help people impacted by Huntington's disease (HD) and their families through an unexpected crisis. If you would like to support the valuable work of Huntington's Australia, please visit our website or scan the QR code to make a tax-deductible donation.

CLICK HERE TO
DONATE NOW