

NEWSLETTER

HUNTINGTON'S DISEASE TASMANIA

Providing a voice for people with Huntington's disease and their families

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It's been a little while since our last newsletter and there have been some exciting events held to raise awareness and funds for Huntington's Disease Tasmania - see pages 7 and 8.

In this issue we have our Huntington's Tas Chair report, which touches on the national merge to Huntington's Australia.

On page 4 we introduce the Chair of Huntington's Disease Australia and the new CEO of the organisation.

Lightitup4HD will be happening again in May 2023, we cant wait to see landmarks across the world light up in purple and blue in support of Huntington's Disease.

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Chair Report

THE NEW STRUCTURE AND A CHANGE OF PERSONNEL

Members who attended our AGM last November would have heard how under the new Huntington's Australia organisational structure we will have 3 new positions in Tasmania: a HD Specialist Practitioner; an NDIS Support Coordinator and an Administrative Officer. This structure will replace the current single Executive Officer role we have enjoyed of recent times. Our Executive Officer, Michael Frankland, has been very open in stating that he did not see himself fitting in that new structure but at the same time being very supportive of the new positions. Those roles will collectively be able to provide a more comprehensive service to our HD community.

In cooperation with all parties and particularly with the support of Huntington's Australia, the Tasmanian Board has agreed to bring forward the new structure arrangements, well before the merger date. This means that Michael has exited our Association a little earlier than was first expected and that we are now currently advertising for the HD Specialist Practitioner role. The other positions will follow later. The HD Specialist Practitioner role will be responsible for delivery of outreach, personal support and advocacy to people impacted by HD and their families and communities. The role will also provide information and programs to people with HD and deliver education and training to HD service providers; and of course raise awareness about HD in the wider community. A critical front line role. Along with myself and the Huntington's Australia CEO, Lenni Duffield, we are looking to have a community member join us on the selection panel. We will let you know the outcome of the selection process.

The NDIS Support Coordinator is a new role for us here in Tasmania. Providing support coordination for people with NDIS Plans has been a service offering in WA and NSW for a while and under Huntington's Australia, all States will be providing that option for the HD community. This is an exciting and welcome addition to the services we provide here in Tasmania.

If you need to contact the Association my phone, 0417309818 is available 24/7.

Lastly, I want to take this opportunity to thank Michael Frankland for all his efforts and wish him well for the future. I'm sure we will see him about and still supporting the local HD community where he can.

Pam Cummings

Thank you.



CEO announcement

To all State Association members, clients, volunteers, partners and stakeholders

Re CEO Appointment for Huntington's Australia

Following on from the previous announcement about State Association memberships agreeing to proceed with the merger, I am writing to announce the appointment of our CEO.

It is with great pleasure that I announce that Lenni Duffield from Huntington's WA has been unanimously endorsed by the HA Board as the inaugural CEO of Huntington's Australia.

Lenni has held senior roles and provided business consulting services in health and community service sectors, has qualifications in business, management and leadership, community sector management and is currently in the process of completing her Master in Business Administration with the Australian Institute of Management, with whom she is an Associate Fellow.

Lenni comes equipped with a range of skills, knowledge, qualifications, experience and personal attributes that make her a stand out candidate. Her commitment to and passion for bettering the lives of people with and impacted by Huntington's disease is unquestioned.

Fortunately for us, we have been able to see what Lenni can do in person over a good period of time, through her work as CEO in WA and thorough her Project Management work with the merger feasibility study and more latterly planning for the merger implementation. Her consistent, high quality work and standards over an extended period of time give us great confidence that we have the right person to take the new organisation forward.

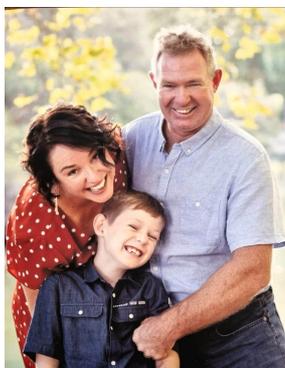
The CEO role will be very challenging, but I am sure everyone will get behind Lenni and provide the support needed to enable her to lead us through implementation of the merger plan over the next 7 months, bed the organisation down over the following 12 months and also grow and develop it and our people as per our aspirations.

But for now, this is a proud and momentous occasion in the thus far very short history of Huntington's Australia. The Board has confidence that Lenni will lead us into a better future for our Huntington's communities.

Regards,
Chris Glasson
Chair Huntington's Australia

Introductions

We are very excited to share with you all faces behind the scene. On page 3 Chris shared information on Lenni's professional career, she would also like to share her family and personal information with you all.



This is my family, myself, my husband Adam and our gorgeous son Lawson. We are a busy little family juggling working life and living on a working property looking after a menagerie of farm animals, it's always hectic with something to do, but we love it! We have fruit trees, grow veggies and run our own sheep.

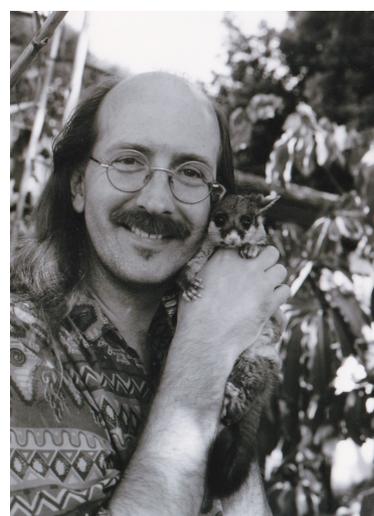
I'm fiercely passionate about the for-purpose sector and championing the roles and vital contributions that organisations such as the HD state associations and Huntington's Australia contribute to communities and the government. When I'm not doing the work I love, I'm in the garden (a labour of love), or entertaining friends and family at home when not studying for my MBA or volunteering on local community projects. Also, when time permits I love being creative!"

Lenni Duffield
CEO Huntington's Australia



Chris has served on the Huntington's SA & NT Board for 6 years and has been Secretary for all but the first of those years and Treasurer for the last three. He was a member of the Consortium of Australian Huntington's Associations (CAHA) that initiated and guided the merger feasibility and is now serving on the Huntington's Australia Board as its inaugural Chairperson, working with the new CEO Lenni Duffield to implement the merger.

Chris is passionate about HA having clear and accountable strategic directions, good governance and policies, and as a member of a family with Huntington's disease, is focused on ensuring provision of the best supports available for the HD community, including through community involvement and input. He has a diverse background in human resources, senior management, strategy development, governance, communications, facilitation, program development, especially for disadvantaged groups, coaching and mentoring, transition and change management and project management for large service and infrastructure projects.



Chris Glasson
Chair Huntington's Australia

Research Update



We are pleased to share an important update on the clinical development program for Sage Therapeutics Inc.'s investigational drug, SAGE-718. The PERSPECTIVE Program, a set of clinical studies, will evaluate the safety and effect of SAGE-718 on cognitive symptoms in people with Huntington's disease (HD) at clinical trial sites opening up around the globe. The U.S. Food and Drug Administration (FDA) granted Fast Track Designation to SAGE-718 for development as a potential treatment for HD in September 2021. Fast Track is a process designed to facilitate the development and review of new treatments for serious conditions with unmet medical need such as HD.

WHAT IS THE DIMENSION STUDY?

The DIMENSION Study, a Phase 2 clinical research study and our first study in the PERSPECTIVE Program, is now open and recruiting in select regions of the United States, Canada, Australia, and the United Kingdom. The DIMENSION Study is a randomized, placebo-controlled, double-blind study evaluating the safety and effect of SAGE-718 on cognitive symptoms in adults with premanifest or early manifest HD. Cognitive symptoms may include impaired judgment, forgetfulness, difficulty paying attention, and trouble thinking through steps of an activity or complex problems.

WHO CAN PARTICIPATE?

The DIMENSION Study lasts for up to four months, with nine in-person clinic visits required over the course of the trial. Subjects will self-administer either the investigational compound or placebo once daily every morning for 12 weeks. Eligibility criteria for the DIMENSION Study include:

- Aged 25 to 65 years old at time of screening
- Meet all the following criteria for HD:
 - CAG expansion ≥ 36
 - UHDRS-TFC score >6 and <13
 - No features of juvenile HD
 - Experience cognitive / thinking difficulties
- Meet a list of other health requirements, including but not limited to:
 - Being ambulatory (use of assistive devices such as a walker or cane is acceptable)
 - Not participating in another clinical study within the past 30 days.
 - (Observational only studies – where no treatment is administered – is allowed)

Other eligibility criteria apply.

Participation in any clinical research study is completely voluntary, and participants may choose to leave the study at any time for any reason.

WHERE CAN I LEARN MORE?

You may visit the DIMENSION Study website to learn more: [FocusOnCognition.com](https://www.FocusOnCognition.com). Additional information including individual site status in each country and a complete list of inclusion and exclusion criteria, is available on clinicaltrials.gov (ID: NCT05107128), [ISRCTN.com](https://www.ISRCTN.com) (ISRCTN17896603), as well as [hdtrialfinder.org](https://www.hdtrialfinder.org).

We respect the role of healthcare providers in the treatment of brain health disorders, and a healthcare provider is the best resource for information and to understand eligibility for clinical trials.

Please note that not all sites are fully activated and recruiting at this time, but we are working to have all sites up and running as quickly as possible.

WHAT'S NEXT?

An open-label safety study, which will provide more information about the long-term safety of SAGE718, is planned to begin recruiting towards the end of 2022. Individuals who take part in the DIMENSION or SURVEYOR Studies may be eligible to participate in the open-label extension study where all participants will receive SAGE-718. Additional details on the open-label safety study will be shared once available.

Please note, SAGE-718 is an investigational compound. The safety and efficacy of investigational compounds have not been established. There is no guarantee that the outcome of these studies will result in approval by a Health Authority. For more information about Sage Therapeutics, SAGE-718, and our neuropsychiatry program please visit www.sagerx.com.

We are committed to developing novel medicines to potentially treat patients with brain health disorders. Participation in a clinical study of any kind is a significant commitment, and we want to extend our immense gratitude to the patients and families who volunteer to participate. Without you, we would not be able to conduct new research to discover and deliver new potential medicines to support brain health. The entire Sage team is looking forward to continued work with the HD community and is committed to sharing important information about the SAGE-718 program as it becomes available.

Emily Gusse

Our Community

Walk 4 Hope

Supported by the Rotary Club of Wynyard on Saturday October 29th we enjoyed our first Huntington's Tasmania. 'Walk 4 Hope'.

It was a wonderful Community Event with over 27 people walking through Gutteridge Gardens and along the foreshore of beautiful Wynyard.

Thank you to everyone's support for our inaugural walk including those who travelled from as far as Hobart and Launceston. A light shower 15 minutes into the walk didn't deter the enthusiasm of the group.

The good atmosphere continued with a BBQ provided by the Rotary Club following the walk.

Our sincere thanks go to The Rotary Club of Wynyard for their support.

A grand some of \$1072 was raised on the day.

A big thank you to those who donated as we walked down main street, in particular Lifeline and The Waterfront Wynyard Accommodation Precinct. Thank you to our prize sponsors Rusty iron Thai restaurant Wynyard.



Our Community

Ulverstone Twilight Rodeo

Our Association was invited to attend the prestigious Ulverstone Twilight Rodeo as their chosen Charity this year. The event was held at Batten Park in Ulverstone on Saturday 4th. February 2023 after a 3-year hiatus. The atmosphere was amazing with over 4000 people attending the event, many of whom wore our HD Tasmanian colours of Purple, Blue and Teal.

A big thank you to Alison Weir from our sister state of New South Wales who gave up her weekend to come and help support us.

Whilst most of our time was spent writing raffle tickets, we enjoyed the opportunity to talk about HD here in Tasmania with many of the patrons.

We were the recipients of the raffle, which was held on the night, raising the amazing amount of \$4374, including a small portion from the sales of our merchandise.

We are forever grateful to the Ulverstone Rodeo committee for allowing us to be part of their special event and for helping drive awareness of Huntington's Disease.





HD Tasmania are supporting the HDYO International Congress on March 17-19, 2023 in Glasgow, Scotland.

This is the FIRST opportunity to meet the international community of young people, families and professionals impacted by Huntington's disease.

Scholarships to assist with cost of travel are available so get in touch!
(up to age 35)



LIGHT IT UP 4 HD THIS MAY



May is just around the corner and we are asking buildings and landmarks around Tasmania to Lightitup4HD to raise awareness for Huntington's Disease.

We will be approaching businesses and councils across the state, if individuals would like to participate and light up their house in purple and blue, we would love to see photos!

#lightitup4HD

Huntington's Disease Tasmania

Phone: 0458 176 669

Email: info@huntingtonstasmania.org.au

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