HUNTINGTON'S AUSTRALIA
NATIONAL CONFERENCE

PROGRAM

www.huntingtonsaustralia.au

Huntington's Australia

SKYHAWK THERAPEUTICS

Brightwater

Roche

VIVAbility CREATING OPPORTUNITY

Welcome from Huntington's Australia

Dear friends, families and colleagues,

On behalf of the entire Huntington's Australia team, it is our honour and privilege to welcome you to our inaugural 2026 National Conference - Power of Hope.

This gathering brings together people living with HD, families, carers, allied health professionals, researchers. and advocates from across Australia. Whether you are joining us in person in South Australia or connecting online, we are so glad you are here.

Today's programme has been designed to reflect the breadth of the HD community's experience — from the latest in clinical research and trials, to practical support, care planning, and stories of resilience that remind us what hope truly looks like.

We extend our deepest gratitude to our sponsors, partners, presenters and volunteers without whom this event would not be possible. Most of all, we thank you - for your courage, your advocacy, and your unwavering commitment to a future free from Huntington's disease.

Together, we hold the power of hope.

Lenni Duffield
CEO, Huntington's Australia



Huntington's Australia acknowledges the Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We acknowledge and pay respect to elders of all Aboriginal and Torres Strait Islander nations that have passed before us, and those that continue to be the strength of their families and communities today. Thank you for your guidance and wisdom.

Speakers



DR KELLY ATKINS

Teaching and Research Academic
Monash University

Dr Kelly Atkins is a Clinical Neuropsychologist and researcher who works alongside people and families affected by Huntington's disease. Her work focuses on understanding the cognitive, emotional, and real-world challenges of HD, and on improving access to diagnosis, care, and support across Australia. Kelly has worked internationally in dementia and neurodegenerative disease research and is committed to research that is co-designed with the HD community. She is actively involved in HD advocacy and youth organisations, and is focused on ensuring that research leads to meaningful, practical change for people impacted by HD.



DANIELLE BECHELET

Principal
Bechelet & Co

Danielle Bechelet is the Principal of Bechelet & Co and has practised exclusively in wills and estates in Perth for 11+ years. Danielle's ultimate goal is to ensure her clients are at peace about their affairs. Danielle is a leader in Estate Litigation, dedicated to advocating for clients in will disputes, inheritance claims, and contested estates, ensuring their rights are protected and justice is achieved. Danielle regularly deals with the administration of both complex and straightforward deceased estates, supporting families through difficult times and keeping them informed throughout the process. Danielle is the current Chair of the Society of Trust and Estates Practitioners, Western Australia (STEP WA) and is a Director of STEP Australia.



PATRIK BRUNDIN MD PHD

Therapeutic Area Leader for Movement Disorders
Roche

Patrik Brundin MD PhD joined Roche in 2022, where he is Therapeutic Area Leader for Movement Disorders and leads discovery research and early development (through Phase 2 clinical trials) for Huntington's (HD) and Parkinson's (PD) diseases. Prior to this, he researched HD and PD in academic settings for 40 years and he published more than 440 scientific papers. He started the Gordon Research Conference series on HD in 2001 and co-founded the European HD Network in 2003.



CATHERINE CHRISTIAN

Social Worker
SA Huntington Disease Service

Catherine is a Social Worker who began working with the South Australian HDService in 1992 and has had 24 years of learning from families impacted by HD.



MELANIE CLARK

Senior Research Scientist
North Metropolitan Health Service Mental Health

Melanie Clark is a Public Health Researcher focused on Huntington's disease. Melanie leads outreach in remote Aboriginal communities and coordinates Huntington's clinical trials in Western Australia. She founded the Aboriginal Huntington's Working Group and the Hidden World of Huntington's Photovoice project which both aim to improve health equity by providing access to clinical care and research opportunities to underrepresented Huntington's communities.



HARRIET DENNING-KEMP

Principal OT
Every Body Rehab

Harriet Denning-Kemp is the Principal and Lead Occupational Therapist at Every Body Rehab, Brisbane. With advanced expertise in complex assistive technology, seating, and 24-hour positioning, Harriet specialises in progressive neurological conditions including Huntington's Disease. She is committed to evidence-based, person-centred care across the NDIS landscape.



ALEX GIANNARIS

Senior Occupational Therapist
Calvary Healthcare Bethlehem

Alex is a Senior Occupational Therapist and Huntington's Disease Clinician based in Melbourne. With over eight years at Calvary Health Care Bethlehem, Alex has developed expertise through the Statewide Progressive Neurological Disease Service (SPNDS) and the specialist NDIS Provider Service. Alex has presented at Huntington's Disease and Motor Neurone Disease conferences, webinars, and workshops, sharing practical strategies for supporting individuals with progressive neurological conditions.



RUTH HOSKEN

Nurse Practitioner
Calvary Healthcare Bethlehem

Ruth Hosken has been working with people with HD for over 15 years, now as a Nurse Practitioner. She has worked in a range of settings at the intersection of health & disability.

Speakers



SALLY KNIGHT
Owner
Novacorr Healthcare

Sally Knight is the Owner of Novacorr Healthcare and brings 16 years of industry experience to the design and supply of specialist HD equipment. Sally is passionate about partnering with OTs and clients to achieve meaningful, safe outcomes in seating and sleep systems for people with complex and high-care needs.



PROFESSOR CLEMENT LOY
Executive Director Medical Services
Western Sydney Local Health District

Clement is a cognitive Neurologist with research interests in molecular genetics and clinical epidemiology. He has had the privilege of caring for families with Huntington Disease (HD) since 2003. Clement has contributed to the majority of international clinical trials for people with HD since 2008, and leads a number of Australian studies for families with HD. He has served as Dean of the Macquarie Medical School, a member of the Pharmaceutical Benefits Advisory Committee, a member of the Therapeutic Goods Administration, and contributed towards the governance of several health services & not-for-profit organisations.



SALLY MCKAY & ALICIA LINLEY
Brain Health Twins

Sally and Alicia are twins impacted by Huntington's Disease who have transformed personal adversity into a pioneering preventive neurology protocol. Sally holds a Master's in Artificial Intelligence for Preventive Neurology (UNSW) and Alicia is a qualified Acupuncturist and Physiotherapist (Melb University). Together, they have spent the last 14 years building a evidence-based prevention protocol with a team of researchers and clinicians. Their presentation explores brain health optimisation through preventive neurology — they will share how they implement daily, evidence-based lifestyle modifications that delay cognitive decline.



JESS MACLENNAN
HD Community Practitioner
Huntington's Australia

Jess has been an Occupational Therapist since 2012, joining the team at Huntington's Australia as a HD Community Practitioner in the past 18 months. She brings a holistic lens of person-centred approaches to the services offered in South Australia.



DR ALLAN NELSON
Consultant Psychiatrist
SA Huntington Disease Service

Dr Allan Nelson has been a Psychiatrist with the SA Huntington Disease Service since 2013. He is an investigator in the SKY-0515 trial, a potential disease modifying treatment for HD.



DEB PAIX
HD Community Practitioner
Huntington's Australia

Deb is a Physiotherapist with over 34 years experience in many diverse areas including community rehabilitation and tertiary clinical education. She is extremely dedicated and passionate about assisting and empowering people to keep moving, stay engaged and live their lives to the fullest. Her approach focuses on fun, practical activities tailored to each individual ability, goals and life stage. You will often see her dancing with a client, to their favourite tunes, as they complete incidental exercise! Movement is Medicine is definitely her motto. Deb joined the team at HA in 2025.



RYAN SCHERINI
Senior Financial Advisor
Viridian Financial Group

Ryan is a Senior Financial Advisory with Viridian Financial Group. He has over 15 years experience working with clients and employer groups. He has worked previously with Huntington's Australia to educate members and staff on important considerations around financial matters. He has helped clients to navigate insurance & superannuation claims as well as Centrelink applications. Away from work, Ryan's a husband and father of 3 children and loves his sport.



TIMOTHY SHEEHY
APA Titled Neurological Physiotherapist
Calvary Healthcare Bethlehem

Timothy is an APA Titled Neurological Physiotherapist working at Calvary Health Care Bethlehem in Melbourne as a Senior Physiotherapist and HD Clinician. He is the lead physiotherapist for wheelchair prescription in HD and the Botox clinic for movement disorders at CHCB. His research and publications focus on neck weakness in MND, for which he received the Ella Whaley Grant in both 2020 and 2023. He has presented at multiple MND and HD international conferences and delivered webinars and workshops related to HD and MND.

Speakers



PANNIE TRIFILLIS

VP and Head of Medical Affairs
Skyhawk Therapeutics

Dr. Pannie Trifillis, is a global medical affairs leader dedicated to advancing therapies for rare diseases and ensuring patient access worldwide. In her career, she has launched five rare disease drugs and led two - Translarna and Evrysdi - from discovery through clinical development to patients with Duchenne Muscular Dystrophy and Spinal Muscular Atrophy. As PTC Therapeutics' first employee, she spent 25 years in roles spanning research, alliance management, and global medical affairs. She now serves as Vice President and Head of Medical Affairs at Skyhawk Therapeutics. A Fulbright Scholar from Cyprus, she holds a PhD in molecular biology from the University of Pennsylvania.



VEER WOOJAGEER

Operations Manager - Disability Accommodation
Brightwater Care Group

Veer has dedicated his entire career to supporting people with complex needs to live with dignity, independence, and purpose. As Operations Manager for Supported Independent Living, he oversees specialised services for individuals with complex neeeds, including those living with Huntington's Disease. Previously, Veer led disability services across Tasmania, supporting both children and adults, while strengthening the support networks around them, recognising that effective care extends beyond the individual. Known for his compassion, commitment, and calm leadership, Veer blends deep practical experience with a genuine dedication to improving quality of life for the people and families he serves.

THE POWER OF HOPE: PERSPECTIVES, PROGRESS AND POSSIBILITY

Panel with Q & A



Professor Clement Loy
Executive Director Medical Services
Western Sydney Local Health District



Chloe Kempe
CEO
SA Care



Monica Cazzolli
Manager Community Programs
Huntington's Australia



Carmen Stockman
Carer



Cassie Caratti
Community Member
The Hidden World of Huntington's Disease

Huntington's Australia

Tree of Hope

We invite everyone to contribute to our "Tree of Hope" throughout the conference

1. Take a leaf-shaped sticker from the station
2. Reflect on one of the prompts provided
3. Write or draw your response on the leaf
4. Attach your leaf to the tree display

PROMPTS TO CONSIDER

- "Hope in my community is..."
- "One strength we already have is..."
- "Something I can do differently after today..."

There are no right or wrong answers - this is a space for personal reflection, shared ideas, and inspiration

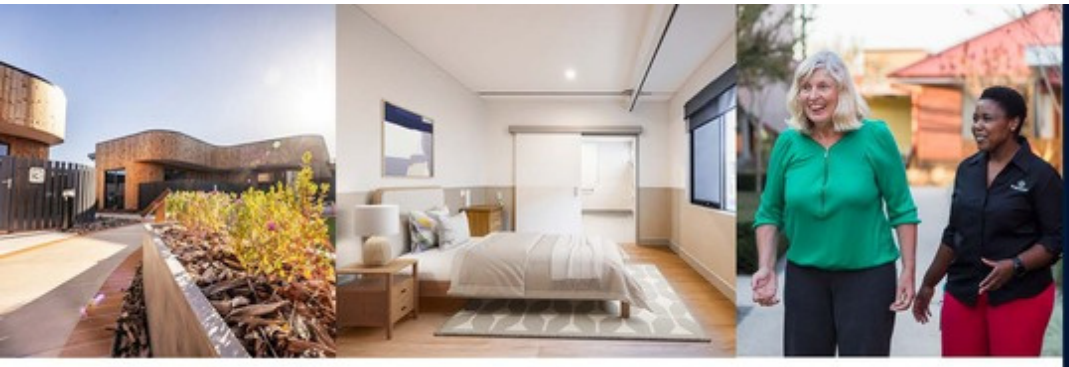


PURPOSE

As the tree fills with contributions, it becomes a collective expression of hope, strength, and action. By the end of the conference, it will stand as a shared symbol of resilience and the power of community.

8:00 AM	Registration open	
9:00 AM	Welcome by MC - *Amelia Mulcahy*	
9:10 AM	Welcome to Country - *Kaurna Elder Karrl Tamaru Smith*	
9:20 AM	Address by MC - *Amelia Mulcahy*	
9.30 AM	Opening Address - *Senator Anne Ruston,* Senator for South Australia & Shadow Minister for Health and Aged Care	
9.45 AM	From Research to Reality: Insights from Skyhawk Therapeutics and Roche - *Pannie Trifillis & Patrik Brundin MD*	
10.30 AM	An Overview of HD Clinical Trials: Progress, Challenges, and Hope - *Professor Clement Loy*	
11:00 AM	**MORNING TEA**	
TIME	**PROFESSIONAL STREAM**	**COMMUNITY STREAM**
11:30 AM	Meaningful engagement in practice: group setting *Jess MacLennan & Deb Paix*	Planning for Tomorrow, Living for Today – financial clarity for families navigating Huntington's *Ryan Scherini & Danielle Bechelet*
12:05 PM	A Clinical Approach to Seating and Wheelchair Prescription in Huntington's Disease *Timothy Sheehy & Alex Giannaris*	Hope Has a Protocol: Our Journey to Delay HD *Sally McKay & Alicia Linley*
12:40 PM	CAUSEd; a model for a team approach to understand and respond when people communicate unmet needs through their behaviour *Dr Allan Nelson & Catherine Christian*	The Huntington's Disease Clinical Trial Landscape *Dr Kelly Atkins*
1:15 PM	**LUNCH BREAK**	
1:45 PM	Co-Designed for Living Well: Brightwater Care Group *Veer Woojageer*	End of Life and Advanced Care Planning *Ruth Hosken*
2:20 PM	From front yards and swing sets: delivering Huntington's care on Country *Melanie Clark*	When Standard Equipment is no longer enough: Occupational Therapy Decision-Making in Seating and Sleep Systems *Harriet Denning-Kemp & Sally Knight*
3:00 PM	**COFFEE BREAK**	
3:15 PM	The Power of Hope: Perspectives, Progress, and Possibility *(Panel & Q&A)*	
4:00 PM	HOPE: Health, Optimism, Possibilities, Empowerment. Reimagining tomorrow for Australians impacted by HD - *Lenni Duffield*	
4:20 PM	Closing by MC	
4:30 - 6:00 PM	**NETWORKING CANAPES FEATURING PHOTOVOICE AND LIGHT IT UP 4 HD**	

Please note: program is subject to change. All times are ACST (Australian Central Standard Time)



Brightwater Disability Services

Backed by our own Research Centre, Brightwater delivers specialist care for people living with complex neurological conditions, including Huntington's Disease.

Co-designed with families, clinicians and advocacy partners, Piara Waters is Brightwater's purpose-built Huntington's Disease campus, setting a new standard in specialist care.

Through an integrated model of care, we combine accommodation, clinical expertise and Capacity Building support to maximise independence, wellbeing and quality of life.

Our Services
- Supported Independent Living
- Specialist Disability Accommodation
- Capacity Building
- Behaviour & Clinical Support

Prepare for the possibilities
To find out how we can help you, get in touch – we're only a phone call away.

T 1300 223 968
E welcome@brightwatergroup.com
W brightwatergroup.com

Brightwater

GOLD PARTNERS

SKYHAWK THERAPEUTICS

Skyhawk Therapeutics is a clinical-stage biotechnology company based in Boston, USA, developing novel small molecule therapies for neurological diseases, including their lead HD program SKY-0515. Their Phase 2/3 FALCON-HD trial — currently underway across 10 sites in Australia and New Zealand — is evaluating SKY-0515's potential to lower mutant huntingtin protein and slow disease progression in people with Huntington's disease.

Brightwater

Brightwater Care Group is a Perth-based not-for-profit with over 120 years of experience in aged care and disability support, and one of Australia's leading providers of specialist Huntington's disease care. Home to the Piara Waters HD campus — co-designed with families and clinicians — Brightwater brings a unique, community-centred perspective to supporting people living with HD.



SILVER PARTNERS

Roche

Roche is a global healthcare company headquartered in Basel, Switzerland, and one of the world's most active investors in Huntington's disease research. Their GENERATION HD2 trial is currently evaluating tominersen — an investigational huntingtin-lowering therapy administered via spinal injection — in people with prodromal and early manifest HD, with the fully recruited study expected to complete in 2026.

VIVAbility
CREATING OPPORTUNITY

Vivability Limited is a not-for-profit, registered charity and disability service provider based in Bathurst regional NSW, proudly supporting people living with Huntington's disease through specialist accommodation services. For more than seven years, they have delivered tailored support in this area, including purpose-designed homes that enhance dignity and quality of life.

VIVAbility

CREATING OPPORTUNITY

Vivability Limited is a not-for-profit organisation based in Bathurst regional NSW, proudly supporting people living with Huntington's disease through specialist accommodation services.
For more than seven years, we have delivered tailored support in this area, including purpose-designed homes that enhance dignity and quality of life.

Alongside this work, Vivability is a leader in inclusive employment through its social enterprises. It operates Café VIVA, The Bathurst Cleaning Company, and VIVA's 3 Veg Farm, with a fourth venture, St John's Coffee Lounge and Wine Bar, set to open later this year.

These enterprises create real jobs in the community, with all employees paid at or above award wages, a deliberate commitment that ensures people living with disability are recognised for their contribution through fair pay.

This approach has been recognised through multiple awards and reflects our belief that employment is central to inclusion, independence, and community connection.

Café VIVA · The Bathurst Cleaning Company · VIVA's 3 Veg Farm Bathurst · THE BIG LUNCH

www.vivability.org.au



Making a real difference to people's health

We work to provide real and positive change for patients, the people they love and the professionals who care for them.

Huntington's Australia

You don't have to go through Huntington's disease alone.

Huntington's Australia walks alongside families impacted by HD for generations — providing support at every stage of HD with information, support groups, specialised services and community events like Walk 4 Hope.







NDIS REGISTERED

Specialist NDIS Services

- Specialist Support Coordination
- Support Coordination
- Social Work
- Counselling
- Physiotherapy
- Positive Behaviour Supports

To find out more please reach out via phone or email.

ANNUAL EVENT

WALK 4 HOPE

Our signature national event uniting families, carers, and supporters. Raise funds, raise awareness, and walk together for the HD community.

Register at walk4hope.com.au

WALK4 HOPE Huntington's Australia

Get in touch today

1800 244 735 admin@huntingtonsaustralia.au

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