



Acknowledgement of Country

The Neurological Council of WA acknowledges the Traditional Custodians of Country throughout Western Australia. We recognise their continuing connection to land, waters and community. We pay our respect to all Aboriginal and Torres Strait Islander peoples, their cultures and Elders past and present.

Diversity Statement & Lived Experience

The Neurological Council of WA values the richness that different perspectives bring and actively incorporates these insights to improve outcomes and create more inclusive and equitable responses for all Western Australians with diverse characteristics and life experiences. We acknowledge all people in our community who live with neurological symptoms and conditions, and the people who care for them, and we recognise the important contribution their lived experience makes to our work.

A joint message from our Chair & CEO



Emeritus Professor Charles Watson
Chair

Etta Palumbo
Chief Executive Officer

Reflecting on the 2025-26 financial year, we are proud of the impact the Neurological Council continues to make for people living with neurological conditions, their families and carers across Western Australia, as well as the many dedicated neurological not-for-profit organisations that support them.

The past year has been one of growth, advocacy, collaboration and service expansion, underpinned by our commitment to ensuring every Western Australian affected by a neurological condition can access the information, care and support they need to live well.

As demand for neurological services continues to grow, we have responded by strengthening both our frontline services and leadership role as WA's neurological peak body. Through NeuroCare and NeuroKids, our teams delivered specialised neurological nursing, health system navigation and practical support to individuals and families across metropolitan, regional and remote communities. Through increased generous support of Telethon, we expanded NeuroKids into the Midwest and Great Southern, bringing specialist paediatric neurological nursing support closer to home for more regional children and their families. Despite the rising costs, we maintained and strengthened our NeuroCare footprint supporting adult Western Australians through regional outreach, telehealth and local partnerships, helping to address inequities in access to care.

In our peak body role, we strongly advocated for greater recognition, planning and investment in neurological health at both state and National level in collaboration with members and

sector leaders within our Community Neurological Leaders Forum and Neurological Alliance Australia network. We worked closely with government, health services, researchers, community organisations and consumers to elevate the needs of Western Australians living with neurological conditions. We welcomed the invitation to actively contribute to the development of the Department of Health's WA Neurological Health Strategy as an Advisory Committee member, ensuring that community perspectives, service navigation, regional access and lived experience remained part of the conversation shaping the future of neurological care in our state.

We were delighted to convene the World Brain Day Neurological Summit, which brought together more than 130 leaders, clinicians, researchers, policymakers and community representatives championing Brain Health and the 2026 theme Access for All. The Summit provided a powerful opportunity to strengthen partnerships, showcase neurological expertise and advance discussions around prevention, diagnosis, treatment, care and support across the lifespan. Our World Brain Day and Brain Awareness Week campaigns and initiatives worked to reinforced the growing importance of brain health as a lifelong priority.

Community involvement remained at the heart of everything we do. We launched our Consumer and Carer Advisory Council in June and were overwhelmed by stories of strength and resilience shared by Council Members. Our growing NeuFriends peer support network created new opportunities for people to connect, learn from one another and reduce the isolation, anxiety and depression that can often accompany neurological conditions. Across the state, NeuFriends groups fostered understanding, belonging and hope, demonstrating the power of peer support in improving physical and mental health, wellbeing and quality of life.

None of this would be possible without the support of our members, consumers, carers, staff, volunteers, partners, funders and philanthropic supporters, particularly WA Health, Telethon7, Stan Perron Charitable Foundation and Fight MND. Their shared commitment enabled us to extend our reach, strengthen our services and advocate for lasting change.

As global momentum builds to prioritise and improve neurological care, and reduce the growing burden of neurological conditions, we remain committed to strengthening the sector and creating a future where brain and nervous system health is better understood, supported and valued at every stage of life.

Our Story

Neurological Council of WA Chair, Prof. Chaires Watson, welcomes delegates at the Australasian Neurological Conference and Expo 2025



Our Mission: *Leadership and community-based services for people impacted by neurological conditions in Western Australia.*

Our Vision: *A community where:*

- neurological disorders are understood, prevented, detected, treated, managed and cured;
- brain and nervous system health is valued, protected and promoted across the life course; and
- every person affected by a neurological condition can access the right information, treatment, care and support at the right time.



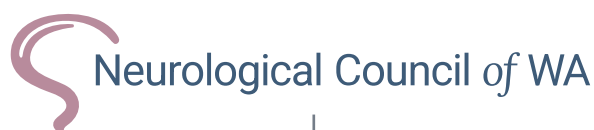
Our Story

Our Work

The Neurological Council of WA is dedicated to reducing the incidence and impact of brain, spinal cord and nervous system disorders. The Neurological Council is a not-for-profit peak body for Western Australia's neurological community including neurological not-for-profits, people living with neurological conditions and symptoms, and their families, carers and support network.

We have two main functions:

- Act as a neurological health and disability peak body to support collaboration and value creation within the neurological sector.
- Deliver state-wide community neurological nursing and health and disability system navigation for Western Australians of all ages impacted by any neurological condition or symptom.



Neurological Health & Disability Peak Body



The Niche Managing Co-Chair / Centre for Neurological Support Lead Tenant



Facilitate collaboration and value creation within the neurological ecosystem



Community Neurological Leaders Forums



Australasian Neurological Conference & Professional Development

Community Neurological Nursing + Health & Disability Navigation



NeuroCare

Adult community-based neuro-nursing & navigation



NeuroKids

Paediatric community-based neuro-nursing & navigation



Neuro TeleNurse Helpline

Telephone / TEAMS nursing support



Neuro Peer Support

NeuFriends peer-led/nurse assisted support groups



Our Patrons



His Excellency the Honourable Chris Dawson AC APM, Governor of Western Australia, and Mrs. Darrilyn Dawson

The Neurological Council of WA is honoured to have His Excellency the Honourable Chris Dawson AC APM, Governor of Western Australia, and Mrs. Darrilyn Dawson as joint Vice Regal Patrons. Their patronage brings valuable recognition to our cause and highlights their commitment to the wellbeing of people affected by neurological conditions across the state. Our work strongly aligns to the Governor's priorities of supporting youth development, Aboriginal communities and strengthening institutional trust.

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Our Board of Directors



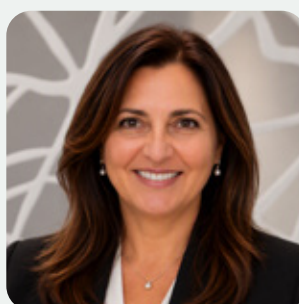
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Our impact: leadership that changes systems, care that changes lives

In 2025–26, the Neurological Council combined statewide sector leadership with specialist community neurological nursing, navigation and peer support. Our work connected lived experience with policy, strengthened collaboration across health, disability, research and community services and delivered practical support closer to home for many Western Australians living with neurological conditions, families and carers.



Neurological conditions affect millions of Australians and are the leading cause of ill health and disability worldwide. The World Health Organization estimates that more than 3 billion people — over one in three globally — were living with one or more of over 600 recognised neurological conditions in 2021. Based on recent data analysis of more common conditions, AIHW and the Neurological Alliance Australia conservatively estimate that around 7 million Australians — one in four — live with a neurological condition, with an annual economic impact exceeding \$100 billion. Many more individuals with rare neurological conditions, as well as families and caregivers are physically, psychologically, emotionally and financially impacted. Through advocacy, education and specialist neuro-nursing, navigation and support, the Neurological Council of WA helps improve outcomes for individuals, families and communities.

Over 600
recognised neurological conditions

1 in 4
Australians live with a neurological condition

Annual economic impact exceeds
\$100 billion



World Brain Day Summit:

Neurological Council Deputy Chair, Dr. Linda Friedland, Professor Merrilee Needham and Hon Meredith Hammat MLA with Neurological Council CEO, Etta Palumbo.

WA's Neurological Peak: Leading a stronger neurological sector

As Western Australia's peak body for neurological conditions, the Neurological Council continued to play an important role in shaping a more connected, informed and responsive neurological sector in 2025-26. We worked to influence broader systems and outcomes by championing the needs of people living with neurological conditions, fostering collaboration and advocating for greater recognition of neurological and brain health across policy, planning and service development.

The Neurological Council brought people, evidence and organisations together to strengthen the sector's collective voice and influence health strategy and investment. We created trusted forums for lived experience, community organisations, clinicians, researchers and decision-makers to shape priorities together, while building public understanding of brain and nervous system health across the life course.

- **Convened the 2026 World Brain Day Neurological Summit**, bringing together more than 130 leaders, clinicians, researchers, policymakers and community representatives to champion 'Brain Health: Access for All'.
- **Led statewide Brain Health awareness and education campaigns** including World Brain Day, Brain Awareness Week including community engagement, events and promotions aimed at improving neurological and brain health, prevention, early action and access to support.

- **Provided informed and trusted sector advocacy and representation** through representation on Dept of Health WA Neurological Health Strategy, contribution to Neurological Alliance Australia National Neuro Survey, Priority Action Plan for a Neurological Nursing Workforce Strategy and Count us in campaign.
- **Convened quarterly Community Neurological Leaders Forums**, connecting CEOs and senior leaders from more than 40 neurological not-for-profits with health, disability, primary care and research partners to address data, commissioning, sustainability, shared sector priorities and collaboration opportunities.
- **Built sector capability and connection** through the Neuro Small & Mighty Not-for-Profit Capacity Building Program, professional development, shared learning and mentoring and support of volunteer leaders.
- **Strengthened lived-experience leadership** by establishing the Consumer and Carer Advisory Committee, creating a formal pathway for people living with neurological conditions, families and carers to inform advocacy, service development and organisational priorities.
- **Provided a platform for collaboration and infrastructure support** through The Niche QEIIIMC Lotteries House, supporting 13 co-located neurological organisations with affordable accommodation and shared facilities.
- **Strengthened partnerships and collaboration** with Perron Institute for Research and Translational Sciences, The Kids Research Institute Australia, WA Department of Communities, Rare Care Centre, Silver Chain, Carers WA, Palliative Care WA, Volunteers WA, McCusker Centre for Citizenship, Pilbara for Purpose, WA HSPs and ACCHOs, local governments and community organisations across the state.



Quarterly
Community
Neurological
Leaders Forum

Neuro-Nursing Services



Midwest NeuroCare Community
Neurological Nurse, Debra, with Geraldton
MND champion, Roy

Neuro-Nursing Services: Specialist support closer to home

Through NeuroCare, NeuroKids and NeuFriends, the Neurological Council provided specialist community neurological nursing and health and disability system navigation for people of all ages and with any neurological condition or symptom. Our nurses worked alongside individuals, families and carers to make sense of complex information, manage symptoms, coordinate services and turn clinical advice into practical action at home and in the community. This short- to medium-term support helped people access the right care earlier, build confidence in managing their health and remain safer, more independent and connected.

- Local offices, bigger regional teams: Four offices in Perth, Bunbury, Albany and Geraldton offering the full suite of NeuroCare, NeuroKids and NeuFriends supporting all ages and all neurological conditions.
- Boots on the ground. Three mobile teams providing regular and reliable neuro-nursing services across Peel, the Wheatbelt and Goldfields, bringing specialised neuro-nursing and system navigation support direct to individuals and families who may otherwise face distance, transport and service accessibility barriers.
- Regional and remote outreach: Continued our commitment to reduce geographic inequity and connect people with support in their own communities with 28 regional and remote towns each receiving at least one outreach visit including Gascoyne, Pilbara and Kimberley.
- Leading the way with Australia's first, largest and only comprehensive community-based neurological nursing team: Established since 2003, we continued to service WA neurological community across all symptoms, conditions and ages. Our 26 (19.8 FTE) community neurological nurses, provided specialised neurological nursing assessment, clinical education, complex care planning, system navigation, advocacy and mental health and family support tailored to each person's needs regardless of diagnostic status, location and ability to pay.
- Highly skilled, lean and productive community-based team: Despite growing cost pressures, we're proud to be recognised as 'punching above our weight' with 39 staff (25.5 FTE) successfully delivering high output and impact statewide across all operational KPIs.
- Innovative Nurse-Practitioner Led Clinics and Models of Care: Our new Nurse Practitioner-led Headache and Migraine Clinic received 160 referrals and delivered 397 appointments, with 77 per cent of clients reporting significantly improved symptom control, functional capacity and quality of life.

Who we supported

Measure	2025–26 result
Clients supported	2,521
Appointments	20,132
Hours of direct care	18,203
Home visit care hours	3,634
Neuro TeleNurse Helpline calls	1,484
Peer support groups convened	62
Peer support attendances	1,223
Regional towns reached	28

Profile or service indicator	Result
New clients	1,422
New referrals	1,748
Clients discharged	1,596
Different health conditions or symptoms managed	167
NDIS clients	49
NDIS hours	622
Metro / regional	60% / 40%
Over 55 years / under 24 years	65% / 11%
NeuroCare / NeuroKids	92% / 8%
PACIC-HCA client survey score	4 / 5



Neurological Council CEO, Etta Palumbo at the Neurological Alliance Australia Summit, Parliament House Canberra 2025

Diagnosis Categories

Diagnosis	Qty
CVD Cerebral ischaemia	438
Symptoms signs or clinical findings of cognition or nervous system	234
Movement disorder Parkinsonism	212
Headache disorder	196
Motor neuron diseases or related disorders	192
Epilepsy or seizures	177
Neurocognitive disorder	160
Dissociative neurological symptom disorder	158
Injuries to head or spinal cord	96
Other system disorders	95
Other nervous system disorders	79
Neuropathies cranial nerve disorders	77
CVD Intracranial haemorrhage	66
Disorders of neuromuscular junction or muscle	47
Neoplasms of brain or CNS	45
Multiple sclerosis or other white matter disorders	44
Neurocognitive impairment	38
Movement disorder Ataxic	33
Pain disorders	24
Spinal cord disorders excl. trauma	17
Cerebral palsy	16
Structural developmental anomalies	15
CVD Cerebral vasoconstriction vascular syndromes	13
Movement disorder Tremor	12
No diagnosis	9
Infections of CNS	8
Disorders of cerebrospinal fluid pressure or flow	7
Movement disorder Tic	6
Movement disorder Dystonic	4
Movement disorder Choreiform	2
Unknown	1
Total	2,521

NeuroCare Community Neurological Nursing & Health System Navigation

NeuroCare bridges critical gaps between hospital, community and disability services, facilitating continuity of care and coordinated, person-centred services and supports.



NeuroCare: Supporting Better Lives Through Specialist Community Neurological Nursing

Every day, Western Australians living with neurological conditions face complex challenges that extend far beyond their diagnosis. Neurological conditions can affect every aspect of daily life, including mobility, communication, cognition, mental health, relationships, finances and independence. Managing symptoms, responding to functional impairment or decline, coordinating care and navigating health, disability and aged care systems can be overwhelming for individuals and families.

NeuroCare bridges critical gaps between hospital, community and disability services, facilitating continuity of care and coordinated, person-centred services and supports. NeuroCare provided the specialist neuro-nursing services and assessments, trusted information, clinical education and clinically focussed navigation, advocacy and support individuals needed to tackle these challenges with confidence, optimise their health and wellbeing and achieve better long-term outcomes.



NeuroCare – Specialist support. Statewide impact.

NeuroCare delivers **free** community neurological nursing and health system navigation across Western Australia through home visits, telehealth consultations and the NeuroCare TeleNurse Helpline, providing a neurological safety net for all Western Australians so they can access to specialist clinical care regardless of their circumstances or where they live.

NeuroCare Community Neurological Nursing & Health System Navigation



How NeuroCare Makes a Difference

NeuroCare Community Neurological Nurse's broad clinical knowledge and skills helped people:

- Access the right support at the right time
- Understand and access treatment, clinical trials and care options
- Feel in control and make informed decisions about their care and future needs
- Regain or maintain functional capacity
- Navigate complex health, disability and community services
- Improve health, wellbeing and quality of life
- Remain safe, independent, involved and connected to their communities

NeuroCare Nurses helped individuals, care givers and families by delivering:

- **Expert Holistic Care Coordination** – Connected with relevant medical, mental health, social and welfare professionals to support cross-sector needs and concerns for complete wellbeing.
- **Comprehensive Neuro-Nursing Assessments & Care Planning** – Reviewed history, co-morbidities and nursing assessments to prioritise care needs, establish health and well-being goals and develop personalised care plans.

- **Clinical Education** – Empowered individuals with essential knowledge about conditions, symptom management, treatments, medication, assistive technology, lifestyle adjustments and self-care strategies to promote informed decision-making.
- **Health and Disability Clinical Care Navigation** – Supported navigating complex, fragmented systems to ensure timely access to required services and supports, prevent gaps, facilitate referrals and assist with medical appointment planning and attendance.
- **Hospital discharge planning** – Acted as a bridge between hospital neurology teams, GPs, allied health services and community organisations to enhance communication, facilitate continuity in care from hospital to home, address unmet care needs, home modifications and condition changes, and minimise relapse and hospital readmissions.
- **Advocacy & empowerment** – Advocated for services, entitlements and needs. Support to improve health literacy and skills to independently access future services and resources, where and when needed.

- **Ongoing monitoring & early intervention support** – Encouraged self-management with proactive check-ins for early identification of potential complications or deterioration to prevent emergency situations and unnecessary medical appointments.

By helping individuals and families understand their neurological condition, manage symptoms, navigate services and adapt to changing needs, NeuroCare helped improve health, wellbeing, confidence and independence. Earlier, coordinated support also prevented deterioration and crisis, reduced avoidable hospital presentations and admissions, and eased the demands placed on carers. These benefits beyond each individual and family with our social return on invest studies reporting broader impacts such as freeing up capacity in general practice and hospitals, supporting more effective use of health and community services, and helping build healthier, more resilient and connected communities.



Government of Western Australia
Department of Health

We thank the WA Department of Health for their continued NeuroCare WA Preferred Service Provider funding.

“I’ve been just surviving from day to day, not living”:

Carrie-Anne’s Life After Stroke



Before her stroke, Carrie-Anne was always on the move. A chef, keen runner and busy mum, she worked up to 70 hours a week, ran 10 kilometres in the mornings and helped keep her household running. Then, without warning, her life changed.

Carrie-Anne experienced a catastrophic subarachnoid haemorrhage followed by multiple strokes. Until then, she had thought of stroke as something that happened primarily to older people.

“Nothing could have prepared me for it happening, especially at my age,” she says. “My understanding of stroke before was that it was an older person’s condition. It’s so life-changing.”

The Day Everything Changed

Carrie-Anne was at home with her 14-year-old son, Jack, when she began feeling unwell. She developed a severe headache and a stiff neck, then called out to him for help.

“He just stayed so calm,” she recalls. “He called his dad and we rushed to the hospital. The neurologist said if Jack hadn’t acted the way he did, I wouldn’t be here now.”

She spent three weeks in intensive care and four weeks in hospital overall. Her memories of that time are limited, but she remembers arriving at hospital and seeing medical staff gather around her.

“I wanted to see my kids,” she says. “They said, ‘You don’t have time. You have to go now.’ They were rushing me straight to Charlie’s, and that’s all I remember.”

Surviving the initial medical emergency was only the beginning.

Learning to Live in a Changed Body

The effects of the strokes continue to shape almost every part of Carrie-Anne’s life. She experiences weakness and heaviness in her left arm and leg, falls, vision loss and neurological fatigue that means she needs 2-3 hours of sleep during the day. She can struggle to find words or process large amounts of information.

For someone who had always been active and independent, adjusting to these limitations has been devastating.

“The hardest part has been adapting to this new form of what I can and can’t do,” she says. “I’ve always been a doer.”

Carrie-Anne is not yet cleared to drive and cannot go out alone. She continues to use walking aids because of her falls, while her impaired vision creates an additional barrier. Everyday outings that many people take for granted may require careful planning and support.

“It’s very lonely,” she says. “Even if it’s just sitting out in the sun having a coffee, something so simple is not simple for me.”

Falling Through the Gaps

After leaving hospital, Carrie-Anne expected follow-up care. It did not come.

“All I was told was, ‘You’ll have a follow-up.’ The follow-up never came,” she says.

Her GP advocated for her and tried to find assistance, but Carrie-Anne and her family were largely left to navigate an unfamiliar and complicated system themselves.

Eighteen months after her stroke, she was still leaning when she walked, falling and living without many of the answers or supports she needed.

“We had no answers, no follow-up, no help,” she says.

The complexity of the healthcare and disability systems was compounded by the effects of her brain injury.

“The medical system is very complex, and you add brain injury into that and there’s another barrier,” she says. “I struggle for words, I struggle to comprehend, and trying to sit there and break those barriers down is so hard for me.”

Continued next page

Carrie-Anne's Life After Stroke *cont.*

Finding the Neurological Council of WA

A turning point came when Carrie-Anne's GP found information about the Neurological Council of WA and helped her make a referral. She was connected with NeuroCare Community Neurological Nurse, Rachel.

"I had never heard of the Neurological Council before, but it is so needed," Carrie-Anne says. "Rachel has given me hope. Hope that there are better things, hope that I don't have to stay in the same spot and hope that there is help out there."

Rachel began by explaining Carrie-Anne's condition in language she could understand and absorb.

"She explained a lot of my condition to me, and she did it in a way that I could understand and process," she says. "She advocates for me as a person and for my medical needs. We do it at a pace I can cope with that gets me to the next step."

Rachel visits Carrie-Anne at home and can accompany her to medical appointments. She has supported her through GP and neurology appointments, phone consultations and meetings connected with the NDIS.

"Comprehending so much at an appointment can be very overwhelming," Carrie-Anne says. "Rachel takes it all in and then explains it to me so I can grasp it and understand it. Until you need this service, you don't know how much you need it. It's life-changing."

Carrie-Anne's stroke has also had a significant impact on her family, with her husband and two children having had to adjust their routines, responsibilities and expectations. Rachel has played an

important role in helping the family understand Carrie-Anne's condition and also referring her son, who helps with her medication, meal prep and care, to Young Carers WA.

"He's a teen boy in high school. Mental health, you need to take care of it, but we didn't know where to start," she says. "Within the first meeting, Rachel did his referral and he got the support."

From Surviving Towards Living

According to Carrie-Anne, Rachel achieved more in their first two months together than she had been able to access during the previous 18 months. Rachel helped connect her with occupational therapy and physiotherapy, begin the NDIS process and pursue practical supports to improve her mobility and independence.

"It will stop me from just surviving and get me back to living and thriving," she says. "Right now, I feel like I've just been surviving from day to day, not living. I look forward to getting back to that thriving path."

Rachel's support also extends to the small but deeply meaningful parts of life. When Carrie-Anne wanted to attend a sporting event with her family but worried about fatigue and holding them back, Rachel helped break the outing into manageable steps. She provided accessibility information, discussed using a mobility scooter and suggested noise-cancelling earplugs.

"I don't want to keep sitting on the sidelines," Carrie-Anne says. "Neurologically it's been very hard, but



Rachel said, "We can make this easier for you. We can do this."

Through all the setbacks, Carrie-Anne remains determined. Her husband and two children are a powerful source of motivation and she looks forward to sharing their future milestones.

"I have a lot to live for," she says. "I have two beautiful children and the most amazing husband."

Her message to other people at the beginning of a stroke recovery journey is honest, but hopeful.

"It's a hard journey. It's one of the hardest fights I've ever had," she says. "There is hope, there is support and there is a reason to keep going. You find your own reason and you fight."

For Carrie-Anne, Rachel's support has changed not only the services she can access, but what she believes may still be possible.

"I will advocate for the Neurological Council and its nurses for as long as I'm breathing. Rachel has changed my life. I don't know where we would be if it wasn't for her."

“Persistence and Tenacity” – Barry and Nola’s Journey with MSA

When Barry Campbell – known to many in Mount Barker as “Baz the Butcher” from his years of work in the local community – began to slur his speech and stumble occasionally, his partner and carer, Nola Hopper, feared he might have had a stroke. That was back in 2022. “His speech had become really slow,” Nola recalls. “We thought it might have been a stroke, but the scans came back clear.”

The couple faced a lengthy wait to see a neurologist in Perth, involving long drives and significant out-of-pocket costs. After months of uncertainty, further tests finally confirmed the real cause: **Multiple System Atrophy (MSA-C)**, a rare, progressive neurological disorder marked by a distinct “hot cross bun” sign on MRI scans.



Navigating a Rare Diagnosis

The diagnosis explained Barry’s troubling symptoms, though having a name for the condition didn’t make it easier. MSA is often described as having features of Parkinson’s and Motor Neurone Disease combined – a confusing picture for patients and families, and one that remains poorly understood.

Barry and Nola soon learned how rare the condition is – affecting only around five people in every 100,000. They also realised that Barry’s history of vivid dream enactment, known as REM sleep behaviour disorder, had been an early warning sign. “He would act out his dreams – running or kicking in his sleep,” Nola says. “Back then, we had no idea it was connected to something like this.”

Looking back, Nola reflects that if they had known what the signs meant, they might have done more before Barry’s mobility declined. Sharing this information now, they hope, may help others learn about the condition and recognise the warning signs – so people can seek neurological advice and get support earlier.

The Battle for Support

Receiving a diagnosis was only the beginning. Accessing services and funding through the NDIS quickly proved to be another challenge. Their first application was denied and had to be resubmitted with additional evidence. It was completed with the assistance of the Neurological Council of WA’s Community Neurological Nurse, Charlotte. “We had to go back and get the neurologist and GP to re-write everything, just so it matched,” Nola explains.

Even once approved, the plans often struggled to keep pace with Barry’s rapidly progressing condition. At times they ran short of funding for continence products, were unable to secure all the equipment recommended by allied health professionals and are still waiting for additional support worker hours to be confirmed.

Continued next page

Barry and Nola's Journey with MSA cont.

"It feels like a full-time job," Nola says. "I'm constantly on the phone, chasing things up." The process has been draining, particularly alongside her own work and caring responsibilities. Nola recalls, "At one point, someone even told me to put Barry in hospital or quit my job. That was hard to hear."

The financial pressure adds another layer. Barry currently travels from Mount Barker to Albany up to four times a week for hydrotherapy — a routine that is tiring, costly, and heavily reliant on NDIS support worker hours and mileage payments. Nola points out that more practical, cost efficient local solutions — such as access to a hydrotherapy pool closer to home — would make a huge difference.

For Barry, physical activity isn't optional. Exercise helps maintain muscle strength, mobility and quality of life — every session matters. Yet the time and energy spent navigating systems and logistics often overshadows the moments they would rather devote to simply living life.

The Weight of Care

Nola works three days a week at the local bank while also managing Barry's daily care, appointments, medications, and their three-acre property. Much of her energy is consumed not in caring for Barry directly, but in navigating the systems designed to provide support. While those services are vital and valued, the process of accessing and coordinating them can be overwhelming. "It's like having a second job — advocating, sending paperwork, chasing calls," she says. "It leaves so little time for actually living well."

For Barry, the hardest part has been losing the things that once defined him — sport, the ability to move easily, and the freedom of camping and caravanning. Simple tasks like walking or bending down are fraught with risk, and the sports he once loved are out of reach.

Music is a source of enjoyment for Barry. Talking about songs and past gigs brings back memories of moments with friends where music brought people together. Singing along and listening still lift his spirits, and Nola encourages him to keep that connection alive.

For Nola, Charlotte is more than a nurse — her support makes her feel less alone in the fight to keep Barry's care on track.

Support That Makes a Difference

Amid the pressure, a service that stands out is NeuroCare, the Neurological Council of WA's nurse-led community program. Their Community Neurological Nurse, Charlotte, provides not just clinical oversight but vital moral support. She reviews Barry's progression, checks medications, follows up on referrals, and makes sure nothing is falling through the cracks.

"Charlotte's amazing," Nola says. "She remembers what Barry could do last time, compares it to now, and gives advice. If she doesn't know the answer, she finds out and gets back to us. She's even helped us work through medication changes." For Nola, Charlotte is more than a nurse — her support makes her feel less alone in the fight to keep Barry's care on track.

Day by Day

Barry and Nola lean on each other in different ways. Nola admires Barry's even temperament and his ability to take life one day at a time. Barry, in turn, credits Nola's persistence. "She never gives up," he says.

Behind their humour and determination, however, lies the reality of a couple managing a heavy load. Regional living brings extra challenges, and navigating services requires energy that might otherwise go toward enjoying life and small daily pleasures.

Barry's advice to others with MSA is straightforward: "Keep active. Do what you can. Take each day as it comes."

Their story is less about easy inspiration than about tenacity — showing the strength required to live with a rare condition while making the most of the support that is available. And amid the strain, there are still moments of joy: music, friends, and gratitude for the connections that make a meaningful difference.

Specialised Nurse Practitioner-Led Clinics

Neurological Council of WA Nurse Practitioner, Adrienna Elliot, attended the National Motor Neurone Disease Conference 2026, bringing back valuable insights to support the development of the Neurological Council's MND Clinic.



Our Nurse Practitioner-led clinics extend community neurological nursing beyond RN services by providing advanced clinical assessment, diagnosis and treatment. With authority to prescribe medications, order and interpret diagnostic investigations, and refer to specialists, the clinics enable earlier intervention and more integrated care in the community.

FightMND Nurse Practitioner Clinic

Supported by FightMND, the clinic's model of care was co-designed with people living with Motor Neurone Disease (MND), a progressive neurological condition that can affect movement, speech, swallowing and breathing, and carers, clinicians and community stakeholders to reflect complex and rapidly changing needs. Working alongside neurologists, GPs and other health professionals, the clinic established an advanced-practice pathway for comprehensive assessment, symptom and medication monitoring and management, diagnostics, clinical education referrals and future-care planning. Early implementation demonstrated the value of timely, coordinated specialist care delivered closer to home. The service helped individuals and families navigate the complexities of MND, providing faster access to specialist expertise, improving care coordination and supporting people to maintain comfort, independence and dignity throughout their disease progression.



Headache and Migraine Clinic

Led by a Nurse Practitioner, and supported by community neurological nurses, the Headache and Migraine Clinic provided advanced assessment and treatment for people living with complex and chronic headache disorders, including migraine, tension-type headache and cluster headache. The Nurse Practitioner was able to prescribe relevant medications, order diagnostic investigations where clinically indicated, monitor treatment response and side effects, and coordinate referrals to neurologists and other specialists. This expanded scope enabled more timely, integrated care in a community setting.

During 2025–26, the clinic received 160 referrals and delivered 397 appointments. Following personalised treatment, education and self-management support, 77% of clients reported significantly improved symptom control, functional capacity and quality of life. The clinic helped clients better understand and manage their condition, access appropriate treatment sooner and reduce the disruption that persistent headaches and migraine caused to daily life.

South West NeuroKids Paediatric
Neurological Nurse, Tara



NeuroKids: Supporting Children, Adolescents and Families

Neurological conditions and symptoms can influence many aspects of a child's life, from their overall health and development to education, social participation and family wellbeing. NeuroKids delivered statewide specialist paediatric neurological nursing across WA for children and young people living with neurological conditions or symptoms and supported their families and carers.

Taking a flexible, personalised, family-centred approach, NeuroKids nurses serviced both children with diagnosed neurological conditions as well as those experiencing neurological symptoms while seeking answers about their health. NeuroKids nurses partnered closely with neurologists, GPs and other health and social care professionals. Services were delivered in homes, schools, community settings and via telehealth for families in remote areas or where home visits are not possible.

NeuroKids launches in the Great Southern and Mid West

In March 2026, the Neurological Council of WA added NeuroKids nurses to their Geraldton and Albany regional offices, improving access to specialised paediatric neurological nursing support for children and young people living with neurological conditions across the Mid West and Great Southern.

Made possible through the support of Telethon and the WA community, the expanded NeuroKids service strengthened local support networks, helping ensure regional families have access to the vital specialist neurological nursing and guidance they need, when and where they need it most. NeuroKids also supports health, education and community professionals through clinical advice, practical education and referral pathways.



NeuroKids is proudly supported by Telethon 7 and the Stan Perron Charitable Foundation.



NeuroKids Team



Geraldton Team with Mayor Gerry Clune and Local Member, Mrs Kirrilee Warr MLA



Photo: Andrew Richie

Keeping Olive Home: How NeuroKids and Nurse Nicola Changed a Family's Life

For Olive's parents, Nadia and Brayden, watching their little girl experience the sudden effects of Segawa syndrome can be heartbreaking.

After a long global search for answers, local paediatric neurologists at PCH diagnosed Olive with a rare neurological disorder, also known as dopa-responsive dystonia, that causes painful muscle contractions, stiffness and frequent and frightening seizures and episodes where Olive is unable to move or respond. Although medication has helped her regain abilities such as speaking, walking and running, she still experiences episodes of dystonia, nerve pain and muscle pain.

Yet Olive's warmth and determination shine through.

"She is the light of our life," Nadia says. "She is the most kind, thoughtful, empathetic little girl for such a young child."

Caring for Olive involves managing complex symptoms, medication changes, appointments and difficult decisions about when hospital care is necessary. While Brayden is at work, much of the day-to-day responsibility falls to Nadia.

That is where NeuroKids has made a profound difference.

NeuroKids provides specialised community nursing support for children living with neurological symptoms or conditions. For Olive's family, that support comes through paediatric neurological nurse, Nicola, whose regular home visits provide practical help, reassurance and a trusted connection between the family and Olive's healthcare team.

"Having NeuroKids WA has changed our life for the better because we can keep Olive home, we can keep her supported and cared for," Nadia says. "She can see a nurse in her own home where she's comfortable. It's less traumatic."

During home visits, Nicola can observe Olive in a familiar environment, assess her symptoms and invests time to listen closely to the family's concerns. She provides education about medications, helps the family monitor side effects and supports communication with Olive's neurologist, GP and other specialists.

"We provide symptom management, we perform clinical observations," Nicola says. "Our aim is to keep the families and the children out of hospital and in their own homes."

For Nadia, having an experienced nurse available when Olive is unwell has relieved some of the uncertainty that comes with caring for a child with a rare condition.

"She keeps us out of hospital so often because there's times when Olive's unwell and I go, 'Do we need to go into the children's hospital or do we not?' And Nicola is my first port of call," she says.

Nicola's support has extended far beyond clinical care. She has trained Olive's school so staff better understand her needs, advocated for the family and helped them navigate the National Disability Insurance Scheme.

A previous attempt to access the NDIS had stalled, leaving the family unsure about eligibility and the next steps. NeuroKids helped explain the process, identify potential supports and connect the family with Kiind. That assistance turned an overwhelming task into a clear way forward.



Metro Paediatric Neurological Nurse Nicola

"It was so helpful having Nicola start the process for NDIS through facilitating contact with Kiind," Nadia says. "This has meant we are finally at the point of receiving an NDIS plan and funding. She took the feeling of overwhelm away and helped us get started."

Most importantly, Nicola has given the family something every parent caring for a child with complex needs deserves: the reassurance that they do not have to face each challenge alone.

"It has been extremely helpful knowing you are available should we need more support," Nadia says.

For Olive's family, NeuroKids is more than a nursing service. It is compassionate care delivered where Olive feels safest, expert guidance when decisions feel daunting, and a steady, trusted presence through an uncertain journey.

"The amount Nicola has done for us is huge," Nadia says. "We couldn't thank NeuroKids enough. They have been absolutely incredible."

References: "A little girl trapped", written by Bethany Hiatt

Supporting Ezraïne and his family through a rapidly changing neurological condition

For families caring for a child with a complex neurological condition, symptoms and needs can change quickly. Having someone in your care team who understands both the clinical picture and the systems surrounding it can make a significant difference to the child's quality of life and the support their family receives.



Photo: Ross Swanborough / The West Australian

Nine-year-old Ezraïne lives with X-linked adrenoleukodystrophy (X-ALD), a rare genetic metabolic disorder that is causing childhood dementia. Over the last three years, his abilities have changed significantly. He is now unable to see, speak, move or eat, and communicates with his family through blinking to indicate 'yes' or 'no'.

Behind the complexity of Ezraïne's care is a devoted family determined to keep him connected to the people and experiences he loves. "Neurological conditions were not often talked about and navigating a loved one through one was extremely difficult," says mother Lizzie. For families of children with progressive neurological conditions, care can involve multiple clinicians, therapists, disability supports, hospitals and community services. As Ezraïne's condition has progressed, his care needs have become increasingly complex. He receives NDIS-funded nursing support during the week and participates in regular therapies, while his family provides the remainder of his care.

NeuroKids Paediatric Community Neurological Nurse Nicola Goddard works alongside Ezraïne's family to coordinate the services, supports and health care he needs.

"Childhood dementia is certainly something we're seeing. It's quite common, just not very well known," she said. "As it progresses, they lose skills they have learned. Like with older people, they experience neurological decline. That's what Ezraïne is going through at a very young age. Previously he could talk, walk and play. He was a happy healthy little boy. Now he can't see or walk and it's happened relatively drastically and quickly. It's a case of getting supports in place to slow the decline and getting into clinical trials."

As Ezraïne's condition continues to change, Nicola provides a consistent point of contact, helping the family understand options, access appropriate supports and respond to changes and ensure the many different parts of his care remain connected, reducing the burden on his parents and helping them navigate an increasingly complex health, disability and community support system. This coordination helps the family spend less time navigating systems and more time focusing on Ezraïne's comfort, wellbeing and participation in family life.

"It's very much up and down. When Ezraïne is well, everyone in the house is okay and not so stressed out," Lizzie says. "I would love for him to stay stable, away from the hospital, happy and healthy, and not be limited by his disease. And for him to be included in everything."

NeuroKids demonstrates how specialist neurological nursing can support not only a child with a complex condition, but the entire family caring for them.

References: Telethon 2026: A family's hope amid the heartbreak of childhood dementia" Angela Pownall. The West Australian

Geraldton-based NeuroCare Community Neurological Nurses Janet and Deb, and NeuFriends volunteer Belinda, were presented with the Regional Changemakers Award by Caitlin Morgan, Senior Grants Development Officer at Lotterywest.



NeuFriends Peer Support: Connection, Understanding and Support

For many people affected by neurological conditions, connection with others who understand their experiences can make a meaningful difference. Our NeuFriends peer support groups continued to provide opportunities for individuals, families and carers to connect locally, share stories and build supportive relationships within their communities. NeuFriends is designed to be inclusive and accessible – open to people of all ages and diagnoses.

In 2025/26, we continued to build on the success of our established NeuFriends groups in Geraldton, Mandurah Lakelands, Albany and Northam, and launched new groups in Perth (Nedlands), Mandurah Falcon and Bunbury. Most groups are currently peer-led and nurse assisted.

We delighted to win the Alike WA Regional Changemakers Award in August 2025, recognising Geraldton NeuFriends as a regional peer group that has made a significant difference in their local community.

NeuFriends is locally funded in Peel by the City of Mandurah and Great Southern by City of Albany. We thank our volunteer facilitators and guest speakers who provide tremendous support for our peer groups each month. We plan to continue supporting the expansion of our NeuFriends peer support groups across WA.

At first I thought I was the only one. At NeuFriends I've met people who get it, including others with FND. We share stories and swap tips. Even if our conditions are different, we learn from each other."

Andrea, NeuFriends community member



In March 2026, NeuFriends Mandurah Lakelands enjoyed an accessible and inclusive chair yoga session with a local practitioner.

Community Events and Engagement



Community Neurological Nurse Amber, with member NFP Epilepsy WA CEO, Emma Buitendag, at Telethon family Festival

Throughout 2025/26, the Neurological Council contributed to a wide range of community and sector engagement activities across Western Australia. These included public expos, professional development and sector forums, awareness-raising days, family events and targeted education sessions. These activities expanded the reach of neurological health messaging, supported knowledge sharing among professionals and increased the visibility of neurological conditions and available services.



Telethon



Telethon



Telethon

- **Telethon Family Festival (October 2025)**

As a Telethon beneficiary, attending the annual Telethon Family Festival has become a highlight of our community event calendar. Our team were proud to join this a major community event with an expected attendance of more than 20,000 people, providing an opportunity to connect directly with families and raise awareness of neurological conditions and our NeuroKids support services.



Have a Go Day

- **Have a Go Day – Seniors Week (November 2025)**

The Neurological Council of WA participated in Have a Go Day at Burswood Park during Seniors Week, joining thousands of older Western Australians for a day focused on active ageing, connection and access to information. Community Neurological Nurses shared brain health resources, referral information and free health checks and stroke risk assessments. With more than 15,000 attendees, the event provided a valuable opportunity to promote neurological health and connect community members with relevant information and support.

Community Events and Engagement

- **Greater Bunbury Mental Health Youth Forum (February 2026)**

NeuroKids nurses Tara and Nicola engaged with students at the Bunbury Mental Health Youth Forum, raising awareness of neurological health, sharing information about NCWA's NeuroKids service and fostering conversations about the important role of community neurological nurses.

- **Carers Week 2025**

Carers Week October 2025 - Supporting events like Carers Week 2025, provides an opportunity to highlight the vital contribution of family and unpaid carers and the importance of working closely with aligned not-for-profits, including Carers WA. These partnerships strengthen referral pathways, share expertise and help carers access timely information, practical support and services.

- **Regional Outreach**

The Neurological Council expanded its regional NeuroCare and NeuroKids outreach across Western Australia, including two visits each to the Kimberley and Pilbara. These visits provided direct client support, strengthened local relationships and identified opportunities to enhance access to neurological care, services and community-based support across the North West.



Greater Bunbury Mental Health Youth Forum



Carers Week 2025



Regional Outreach

The Niche QEII MC Lotteries House

The Niche QEII MC Lotteries House: Australia's first Neurological Hub

Now in its 25th year as head tenant of The Niche QEII MC Lotteries House, the Neurological Council of WA continued to manage this shared hub, providing affordable accommodation and community facilities for 12 co-located neurological organisations under the banner of the 'Centre for Neurological Support'.



Managing and maintaining the building required considerable effort and investment, but The Niche remains a testament to our enduring commitment to supporting members through collaboration and shared services.

As the end of the 30-year lease approaches, the Neurological Council

together with member not-for-profits commenced discussions to consider the future needs of the neurological community and create a vision for a central and satellite NeuroHubs or neurological health wellness centres across the state.

Small & Mighty Neurological Not-for-profits'



Small and mighty not-for-profits and peer support groups play a vital role in Australia's neurological and rare disease landscape. Often founded by people living with a condition, or by families seeking support where none existed, these volunteer-led organisations are built on lived experience, passion and need. Many have been sustained for decades through the dedication of volunteers, carers and community champions. They provide trusted information, advocacy, peer connection and practical support that helps individuals and families navigate the challenges of living with a condition. For many, these groups offer understanding, belonging and hope that cannot be found through clinical services alone. The Neurological Council strengthens this ecosystem through the provision of office and meeting spaces, capacity building, succession planning, mentoring and governance training, helping ensure these valued community organisations remain sustainable and effective for future generations.

Treasurer's Report



Tanya Tindall (CA)
Treasurer

I have pleasure in presenting the Treasurer's Report for the year ended 30 June 2026 in support of our audited financial statements.

The statement of profit or loss shows an increase in income year on year, from \$3,865,278 to \$3,989,344, growth of 3.2%. This is attributable to increased grant income.

Our key grant income continues to be provided by the Department of Health, and we remain in ongoing discussions regarding future funding arrangements. While a fixed-term commitment has not yet been confirmed, the Neurological Council continues to demonstrate strong leadership in neurological services and expanding support across regional communities. Excess funds through the financial year were invested to generate interest income, which partially fund administrative costs. This generated \$90,026 of interest income, slightly less than \$99,169 earned in 2025.

Expenses in 2025 of \$3,778,292, have increased in 2026 to \$3,908,710. The increase in costs is due to rises in salaries and wages and operating costs aligned with additional services provided.

Overall, the result is a surplus of \$80,634. This is a small decrease from the surplus in 2025 of \$86,986.

Our balance sheet remains strong, with \$2,986,658 in cash and deposits. This includes unspent grants of \$841,847 that are received in advance for the 2026/27 financial year.

Our auditors Moore Australia have completed their independent audit of our accounts and have provided a "clean" audit report. We thank them for the highly professional manner in which they have discharged their duties.

We thank Milinda Walker, our CCSO, and her finance team for their diligent work and consistently timely, accurate financial reporting to the Board.

The Board has endorsed these accounts and recommend them to members for consideration and, if thought fit, to be adopted.

Financial Report Summary 2025/26

Income	25/26	24/25
Grant - Department of Health	\$2,692,206	\$2,597,058
Grant - Other	\$711,132	\$602,506
Fees for Services	\$103,516	\$90,082
Rent Income	\$296,673	\$254,442
Others	\$185,817	\$321,190
Total Income	\$3,989,344	\$3,865,278

Expenditure

Operational Expenses	\$98,040	\$202,661
Rent and Office Expenses	\$294,927	\$255,127
Depreciation / Amortisation	\$209,435	\$210,463
Transport & Travel Costs	\$124,913	\$114,476
Wages & Salaries	\$2,943,010	\$2,691,325
Administration & Others	\$238,385	\$304,240
Total Expenditure	\$3,908,710	\$3,778,292

Assets

Cash & Cash Equivalents	\$2,986,658	\$2,597,413
Sundry Debtors & Prepaid Expenses	\$137,196	\$91,862
Motor Vehicle, Office Furniture & Equipment	\$811,261	\$898,414
Total Assets	\$3,935,115	\$3,587,689

Liabilities

Employee Entitlements	\$289,693	\$270,540
Trade & Other Payables	\$316,347	\$255,222
Unexpended Grants Carried Forward	\$860,931	\$704,641
Total Liabilities	\$1,466,971	\$1,230,403

Total Net Assets / Equity	\$2,468,144	\$2,357,286
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Strategic Plan 2025-2028

Our Purpose

Provide leadership and community-based services for people impacted by neurological conditions in Western Australia.

Our Vision

A community where:

- neurological disorders are understood, prevented, detected, treated, managed and cured;
- brain and nervous system health is valued, protected and promoted across the life course; and
- every person affected by a neurological condition can access the right information, treatment, care and support at the right time.

Cornerstone Pillars & Priorities:

Servicing our Community

- Foster valued relationships with people affected by neurological conditions, based on care, respect, connection and mutual trust, with an emphasis on empowerment and autonomy through their life-course.
- Develop integrated, evidence-based programs, health care pathways and services to reduce the impact and burden of neurological disorders and to maximise quality of life and wellbeing.
- Deliver value-based, person-centred, timely, effective and efficient neurological nursing, navigation and for children, adults, carers and families.
- Provide accessible, equitable and affordable services that are responsive to regional, cultural and social challenges.
- Seek, strengthen and amplify the voice of people impacted by neurological conditions to influence policy, plans, legislation, and funding.
- Lead neurological & brain initiatives and communications aimed at increasing awareness of the importance of promoting and protecting brain health and preventing neurological disorders.

Supporting our Sector

- Be recognised and funded as the peak body for neurological and brain health in Western Australia, leading collaboration and sector coordination.
- Advocate for the needs and rights of individuals living with neurological conditions, and for the growth and sustainability of the sector that supports them.
- Provide systemic advocacy to influence policy, funding and service improvements across the neurological landscape.
- Strengthen collaboration with the national neurological body to align strategies, share knowledge, and amplify advocacy efforts for greater impact.
- Collaborate with government, business, research, philanthropic and community-based organisations to advance the availability of multidisciplinary and multisectoral neurological services.
- Deliver high-quality sector and community professional development, events and communications that showcase latest research, promote innovation and strengthen collaboration across the neurological and brain health ecosystem.
- Partner with universities and research institutes to support neurological research, influence curriculum development and increase the number of graduates entering the neurological workforce.

Backing our People

- Maintain a modern, innovative, safe, agile and well-functioning work environment that supports best practice
- Align organisational structure, roles and resourcing with current and projected service needs to optimise growth and impact and ensure effective succession for long-term success.
- Maintain a high-performing, values driven culture and informed, empowered, positive, productive, respectful, collaborative and inclusive team.
- Grow knowledge, skills and capacity through continuous improvement of service offerings, models of care, consistency, professional development, and refinement and understanding of scope of practice.
- Maintain diverse board representation that includes lived experience, neuro expertise and commercial acumen to strengthen governance and decision-making.

Building our Business

- Maintain a best practice, ethical and effective corporate and clinical governance that complies with legislative, regulatory & program accountability and compliance obligations.
- Safeguard and strengthen financial resilience and sustainability through funding security, aligned diversification and revenue growth.
- Embrace and invest in business improvement, environmental sustainability, innovation and digital and data systems and security to improve client and community value and experience, and to monitor and report on outcomes and impact.
- Enhance the organisation's positioning, credibility, and visibility to increase awareness of its work and impact among individuals, the neurological sector, and key stakeholders.
- Secure and maintain leased premises across WA that meet the current and future needs of the Neurological Council and its member organisations, supporting organisational growth, accessibility, effective service delivery, collaboration and resource sharing.

Thank you

To everyone who supported the Neurological Council of WA throughout 2025/26, thank you.

Our impact is only possible because of the generosity, commitment and passion of our community. Whether you partnered with us, volunteered your time, donated, fundraised, pledged a gift in your Will, shared your lived experience, joined our forums and social media communities, participated in consultations and surveys, advocated for change or simply helped spread awareness of our services, you played an important role in supporting Western Australians living with neurological conditions.

Your collective efforts have helped strengthen neurological care, amplify community voices, expand access to support and ensure more people can live well with neurological conditions. Every contribution, big or small, has made a meaningful difference.

We gratefully acknowledge our major funders and partners whose support helps make our work possible:

- **NeuroCare**



Government of Western Australia
Department of Health

- **NeuroKids**



STAN PERRON
CHARITABLE
FOUNDATION

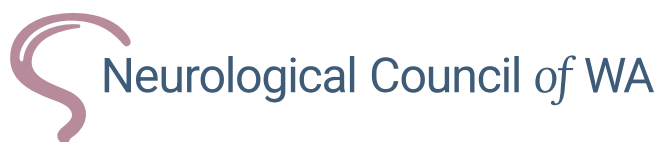
- **Nurse Practitioner-Led MND Clinic**



- **NeuFriends Peer Support, Youth and Community Projects**



Government of Western Australia
Department of Communities



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