Neurological Council of WA

ANNUAL IMPACT REPORT

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

"We feel buoyed by the growing interest, cross-sectoral collaboration and momentum these efforts are generating"

It is our privilege to present the Neurological Council of WA's Annual Impact Report for 2024/25. This past year has been marked by outstanding progress in realising the goals of our 2022-2025 Strategy and championing the importance and prioritisation of brain and nervous system health across our state. Our collective efforts have driven meaningful outcomes for individuals, families and communities affected by neurological conditions.

With the growing demand on our critical community neurological nursing services, we secured philanthropic support to increase NeuroCare service capacity and reach, and to expand NeuroKids into the South-West so that more WA families can access essential, cost-free services and supports that positively impact their health and wellbeing.

The Neurological Council's most significant achievement in 2024-2025 was to convene the successful Australasian Neurological Conference and Expo. We also invested in mapping the community neurological ecosystem and worked collaboratively with state and national neurological not-for profits, research institutions and government in order to identify and address gaps in neurological data, strategy and workforce. We feel buoyed by the growing interest, cross-sectoral collaboration and momentum these efforts are generating, and we are hopeful that they will lead to significant advancement in the prevention, diagnosis, treatment and care of neurological conditions.

We extend our thanks to the Neurological Council Board for their strategic leadership and steadfast governance, which have been instrumental in navigating a complex and rapidly changing health, disability and aged care landscape. To our dedicated staff, whose passion and commitment underpin every achievement, and to our valued members and volunteers, whose voices and support drive our mission forward, we thank you. Your contributions are the foundation of our shared success.

As we look ahead to the coming year, the Neurological Council remains focused on serving our community to advance neurological health outcomes for all Western Australians. We will continue to innovate, advocate and lead with compassion and purpose.

On behalf of the Council, thank you for your ongoing trust and support.

Professor Charles Watson,
Chairman

Ms Etta Palumbo,
Chief Executive Officer

Our Mission:

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

Our Vision

A community where:

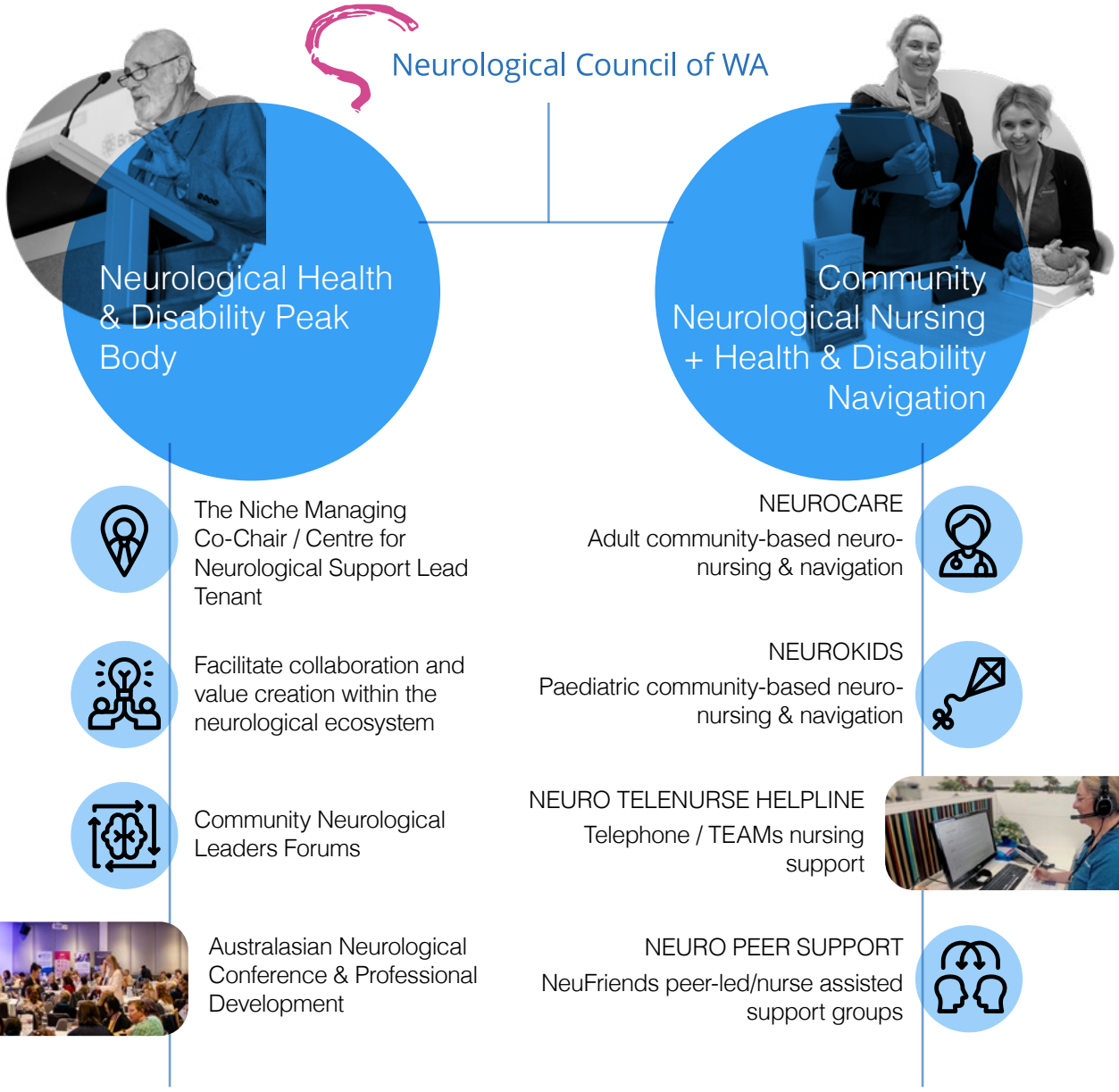
- neurological disorders are understood, prevented, detected, treated, managed and cured;
- brain and nervous system health is valued, protected and promoted across the life course; and
- every person affected by a neurological condition can access the right information, treatment, care and support at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

Our 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.



OUR PATRONS

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.

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 BOARD OF DIRECTORS

Emeritus Professor Charles Watson AM
Chairman

Dr Linda Friedland
Deputy Chair

John McLean
Treasurer
Retired Oct 2024

Tanya Tindall
Treasurer
Appointed Oct 2024

Karene Primrose
Secretary
Retired Oct 2024

Chelsea Quirk
Secretary
Apointed Oct 2024

David Freedman
Director
Retired Oct 2024

Dr Darshan Ghia
Director

Emeritus Professor Alan Harvey
Director

Pam Lewis
Director

Ian Passmore OAM
Director

Etta Palumbo
Chief Executive Officer

STRATEGIC PLAN

2022 - 2025

Mission:

Leadership and community-based services for people affected by neurological conditions in Western Australia.

❶ Our Community

- Foster valued relationships with people affected by neurological conditions, based on care, respect, dignity, and mutual trust, with an emphasis on empowerment and autonomy through their life-course.
- Deliver person-centred, timely, effective, and efficient health care, including assistance with navigation, education, advocacy, support, and information for clients, carers, and families.
- Provide 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.
- Provide accessible, equitable and affordable services that are responsive to regional, cultural, and social challenges.

❷ Our Sector

- Identify, strengthen, and amplify the voice of people impacted by neurological conditions to influence policy, plans, legislation, and funding.
- Collaborate with government, business, research organisations, and community stakeholders to advance the availability of multidisciplinary and multisectoral neurological services.
- Build stakeholder, funder and donor awareness, trust, and engagement to support the Council's mission, growth, and sustainability.
- Collaborate with organisations with a common purpose to create collective impact through ongoing communication, research, mutually reinforcing activities, sharing resources, advocacy, and sector representation.
- Create neurological health promotion campaigns aimed at increasing awareness of the importance of promoting and protecting brain health and preventing neurological disorders.

❸ Our People

- Create a modern, safe, adaptable and well-functioning work environment.
- Inform, empower, and provide resources to staff to enable them to perform at their best.
- Build a high-performance team culture that is positive, productive, respectful, collaborative, and inclusive.
- Build capacity through continuous improvement of service offerings, models of care, consistency, professional development, and refinement and understanding of scope of practice.

❹ Our Business

- Maintain a sound and ethical corporate governance framework with legislative, regulatory & program compliance.
- Develop a best practice organisational model that is contemporary and strategically aligned.
- Strengthen financial sustainability through funding security, aligned diversification, and revenue growth.
- Embrace and invest in business improvement, environmental sustainability, innovation, and data systems to improve customer value, improve community experience, and to monitor and report on client outcomes.
- Improve recognition of the Neurological Council as a leading provider of community neurological services.

IMPACT

AT A GLANCE

Our Peak Body work improved community understanding of neurological conditions and championed lifelong brain health. Working with state and federal colleagues, we facilitated intersectoral collaboration across the neurological landscape and strongly advocated for the prioritisation of planning and investment in neurological health, disability and wellbeing.

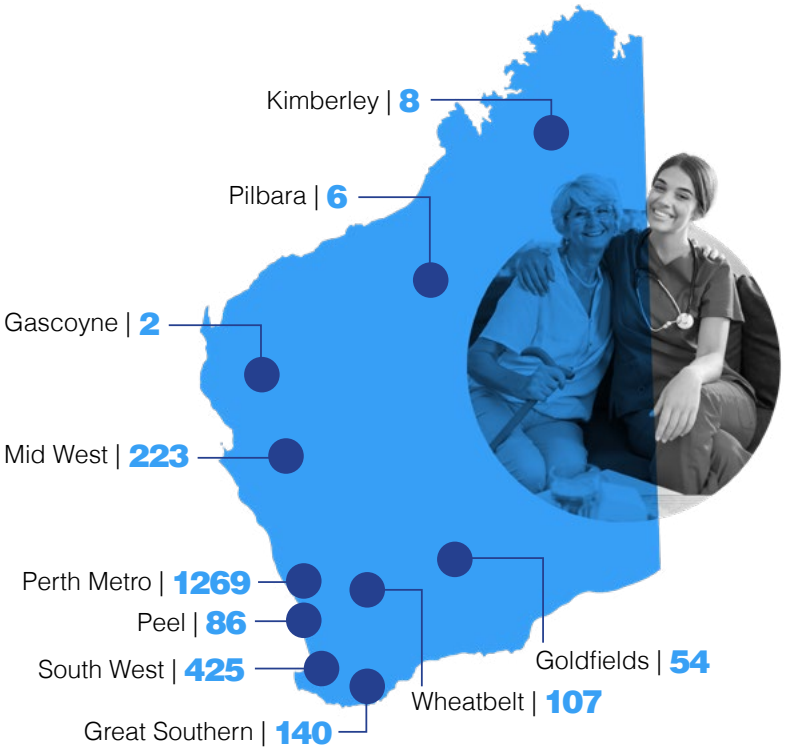
- Convened Australasian Neurological Conference & Expo 2025
- Facilitated Quarterly Community Neurological Leaders Forums
- 108 professional/community education sessions, 284 hrs
- Led WA Brain Awareness Week 2025 and World Brain Day 2025 Campaigns
- Community Neurological Sector Mapping Project completed
- Partnered to launch of UWA Micro-credential Course - NEURM502 Intro to Medical Neurology

"...we facilitated intersectoral collaboration across the neurological landscape..."

In 2024–25, our NeuroCare and NeuroKids services delivered short- to medium-term clinical intervention in the form of community neurological nursing and health and disability navigation services. Our evidence-based, person-centred model of care has helped improve the health, wellbeing and quality of life of thousands of Western Australian individuals, carers and families.

- *34 Staff (25.5 FTE)*
- *22 Community Neurological Nurses (17.8 FTE)*
- *Nurse Practitioner-led Headache & Migraine Clinic Pilot*
- *22 nurse-led support groups convened (319 participants)*
- *2,320 clients supported*
- *18,356 appointments*
- *16,928 hours of direct care*
- *5,468 home visit care hours*
- *1,236 hospital-based multidisciplinary care meetings/ clinics (1,869 hours)*
- *8,477 telehealth / virtual care hours*
- *605 free-calls Neuro TeleNurse Helpline*
- *1,125 new clients from 1,293 new referrals*
- *1,406 clients discharged, 49 deceased*
- *167 different health conditions / symptoms managed*
- *95% NeuroCare, 5% NeuroKids*
- *77 NDIS clients (523 hours)*
- *51% Female 49% Male*
- *70% over 55 yrs, 6% under 24yrs*
- *65% Australian born, 95% English primary language*
- *3.5% identified as ATSI*
- *PACIC-HCA client survey score 4/5*

2024/25 Client Location



4 offices – Perth, Bunbury, Albany, Geraldton

3 mobile teams – Peel, Goldfields and Wheatbelt

36 regional towns supported with at least one outreach visit

55% Metro 45% Regional

Diagnosis Categories

Diagnosis	Qty.
Cerebral palsy	7
CVD Cerebral ischaemia	447
CVD Cerebral vasoconstriction vascular syndromes	21
CVD Intracranial haemorrhage	63
Disorders of cerebrospinal fluid pressure or flow	8
Disorders of neuromuscular junction or muscle	50
Dissociative neurological symptom disorder	147
Epilepsy or seizures	204
Headache disorder	57
Infections of CNS	6
Injuries to head or spinal cord	94
Motor neuron diseases or related disorders	199
Movement disorder Ataxic	25
Movement disorder Choreiform	3
Movement disorder Dystonic	7
Movement disorder Parkinsonism	233
Movement disorder Tic	3
Movement disorder Tremor	18
Multiple sclerosis or other white matter disorders	52
Neoplasms of brain or CNS	53
Neurocognitive disorder	112
Neurocognitive impairment	37
Neuropathies cranial nerve disorders	68
Other nervous system disorders	71
Other system disorders	49
Pain disorders	22
Spinal cord disorders excl. trauma	18
Structural developmental anomalies	12
Symptoms signs or clinical findings of cognition or nervous system	226
No Diagnosis	8
Total	2320

TREASURER'S REPORT

"Our surplus funds through the financial year were invested to generate interest income to support the administrative costs of the organisation"

I have pleasure in presenting the Treasurer's Report for the year ended 30 June 2025 in support of our audited financial statements.

The statement of profit or loss shows an increase in income in 2025, from $3,184,451 to $3,865,278, an increase of 21%. This is largely attributable to increased grant income and additional sundry income from the conference and profit on asset sales (fleet).

Our key grant income continues to be from the Department of Health (DOH), and it is expected that the agreement will be extended for a further 12 months.

We continue to discuss a more fixed term ongoing contract with key figures in the department and believe this will be forthcoming given our invaluable services to the community. We continue to explore new opportunities for the Neurological Council to expand our outreach in the community and this was demonstrated with our very successful conference which was well received in the neuro community.

Our surplus funds through the financial year were invested to generate interest income to support the administrative costs of the organisation, generating $99,000 of interest income as compared to $89,000 last year.

Our expenses have increased from $3,127,572 to $3,778,292, with the variance attributable to higher wages and additional staff to support additional funded projects and costs of running our first conference which was widely acknowledged as a success.

Overall, the result is a surplus of $86,986, a small increase from $56,879 last year.

Our balance sheet remains strong, with $2,597,000 in cash and deposits. This includes unspent grants of $678,946 as they are received in advance for the 2025/26 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.

I would also like to commend Milinda Walker and her team on the high quality of financial reporting presented to the Board.

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

Tanya Tindall
Treasurer

FINANCIAL REPORT

SUMMARY 2024/25

Income	**24/25**		**23/24**	
Grant - Department of Health	$	2,597,058	$	2,620,472
Grant - Other	$	602,506	$	79,013
Fees for Services	$	90,082	$	92,120
Rent Income	$	254,442	$	244,905
Others	$	321,190	$	147,941
Total Income	**$**	**3,865,278**	**$**	**3,184,451**
Expenditure				
Operational Expenses	$	202,661	$	81,358
Rent and Office Expenses	$	255,127	$	234,487
Depreciation / Amortisation	$	210,463	$	216,939
Transport & Travel Costs	$	114,476	$	107,238
Wages & Salaries	$	2,691,325	$	2,253,913
Administration & Others	$	304,240	$	233,637
Total Expenditure	**$**	**3,778,292**	**$**	**3,127,572**
Assets				
Cash & Cash Equivalents	$	2,597,413	$	2,439,392
Sundry Debtors & Prepaid Expenses	$	91,862	$	72,176
Motor Vehicle, Office Furniture & Equipment	$	898,414	$	984,026
Total Assets	**$**	**3,587,689**	**$**	**3,495,594**
Liabilities				
Employee Entitlements	$	270,540	$	243,317
Trade & Other Payables	$	255,222	$	207,424
Unexpended Grants Carried Forward	$	704,641	$	768,883
Total Liabilities	**$**	**1,230,403**	**$**	**1,219,624**
Total Net Assets / Equity	**$**	**2,357,286**	**$**	**2,275,970**

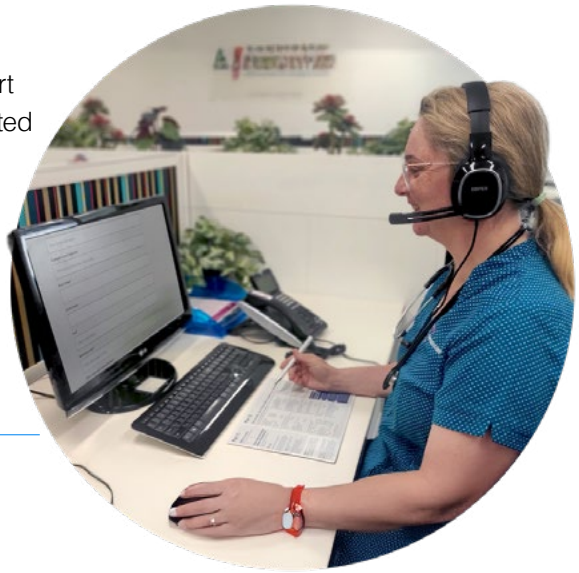
NEUROCARE:

PERSONALISED, PRACTICAL COMMUNITY NURSING AND NAVIGATION

Unique to WA, **NeuroCare** is a community neurological nursing and health and disability navigation service that supports people with any neurological condition to improve their health, wellbeing and quality of life, by helping to understand and manage their condition or symptoms, navigate treatment and care options, regain or maintain functional capacity, live confidently and safely at home and feel in control of decisions that affect them.

NeuroCare Community Neurological Nurses have broad clinical knowledge and skills. Through a mix of home visits, clinic appointments, telehealth and our statewide Neuro TeleNurse line, nurses provided:

- **Expert Holistic Care Coordination** – Nurses connected with relevant medical, mental health, social and welfare professionals to support cross-sector needs and concerns, ensuring complete well-being.
- **Comprehensive Neuro-Nursing Assessments & Care Planning** – Reviewed history, co-morbidities and nursing assessments to prioritise care needs, established health and well-being goals and developed personalised care plans.
- **Clinical Education** – Empowered individuals and carers with essential knowledge about conditions, symptom management, treatments, medication, assistive technology, lifestyle adjustments and self-care strategies, promoting informed decision-making.
- **Health and Disability Care Navigation** – Provided support to navigate complex, fragmented systems, ensuring timely access to required services and supports, preventing gaps, facilitating referrals and assisting with medical appointment planning and attendance.



"NeuroCare Community Neurological Nurses have broad clinical knowledge and skills."

- **Hospital discharge planning –** Bridged the gap 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 –** Nurses advocated for services, entitlements and needs. Supported improvements in 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, preventing emergency situations and unnecessary medical appointments.

With offices in Perth, Geraldton, Bunbury and Albany and mobile teams in the Peel, Wheatbelt and Goldfields regions, NeuroCare Nurses provided high value services across all conditions and acted as a safety net to fill critical gaps for individuals and families where few or no other neurological services exist.

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

COMMUNITY AND HEALTH PROFESSIONAL EDUCATION AND OUTREACH

Our Community Neurological Nurses play a vital role in delivering education for both community and health professionals participating in more than **108 engagement activities** across metropolitan and regional WA, including interagency meetings; information sessions for general practitioners, allied health professionals, aged care providers, hospital staff and regional health networks; and school and community forums to improve understanding of neurological conditions and awareness and access of available support.

NeuroCare Nurse Adrienna Elliott is part of the national MND Guideline Panel led by University of Adelaide and supported by FightMND.
Photo: Nelson Da Silva, Richards Rose.

"STAYING AHEAD OF THE CURVE"

A PERSONAL JOURNEY WITH PARKINSON'S

"It was a bit of a shock," Greg says of his 2020 Parkinson's diagnosis. "I thought I was reasonably healthy… it came out of left field."

A now retired maths and IT teacher, Greg had noticed in the classroom that his hand was shaking, but he didn't think much of it at first. What stood out more though, was how he was feeling. "I was finding it a bit difficult," he says. "I felt stressed — a bit emotional, which isn't like me." Later, he learned these emotional changes weren't just reactions to the situation, but part of the condition itself — a symptom of Parkinson's that many people don't realise.

It was only after a GP visit — where his doctor quickly recognised the signs — that tests were arranged to confirm the diagnosis.

"Music has also remained a steady presence in Greg's life. A lifelong guitarist, he still plays often. "

Since then, Greg has approached Parkinson's in a way that reflects his character: with calm resolve, practical thinking and a respect for information. He considers himself fortunate to have a diagnosis, knowing that many people live with neurological symptoms for years without understanding the cause. For him, it's better to know than not know. "Learning about the condition, preparing where you can and making adjustments," he says.

He's the first to acknowledge that navigating Parkinson's is a lot to manage — appointments, medications, symptom tracking and daily routines. "You need to keep on top of things." His wife Glenis plays a key role in helping him stay organised and supported, particularly with the ever-evolving challenges of the condition. She keeps notes about his medications, helps prepare for appointments and supports his routines. Their teamwork — steady, practical and supportive — is central to how Greg continues to live well.

One of the external supports Greg values is the Neurological Council's NeuroCare neurological nursing service. His visits with neurological nurse Deb Barndon provide a touchpoint between specialist appointments and help him stay across symptoms, changes and available services.

Continued next page

"Deb's been really helpful," Greg says. "She knows what to look for and what to ask. She'll check in on things I hadn't thought of. It's reassuring. She understands the system — and she gets the Parkinson's-specific stuff. That makes a difference."

Parkinson's WA was one of the first organisations Greg turned to. "They've been helpful," he says. "They have information and support." Alongside NeuroCare, he sees them as part of a broader network that provides guidance and reassurance throughout the Parkinson's journey.

"... rather than dwell on what's uncertain, he focuses on what helps: structure, rhythm and staying engaged."

Greg is also part of our NeuFriends Coffee Club in Geraldton — a support group for people living with neurological conditions. While he's not usually drawn to structured gatherings, he's found enjoyment in the familiarity of the NeuFriends sessions. "You hear ideas, you learn from what others are doing — and you don't feel like the only one."

He appreciates the group's down-to-earth nature — a place where people share strategies, frustrations, even a few laughs. "It's not just talking about illness. Sometimes someone mentions a bit of tech or a service that makes life easier. That's useful."

Music has also remained a steady presence in Greg's life. A lifelong guitarist, he still plays often. "I thought that would go, but it hasn't," he says. "The tremor goes away when I'm concentrating on playing. It keeps my mind going. And it feels like part of me."

Like many living with Parkinson's, Greg faces daily fluctuations. Fatigue, word-finding difficulties and medication side effects are all part of the picture. But rather than dwell on what's uncertain, he focuses on what helps: structure, rhythm and staying engaged. He still exercises regularly — using weights at home or heading out for walks. "I don't always feel like it," he admits, "but I push myself because I know it's good for me and when I don't push, my wife does."

Greg doesn't claim to have all the answers, but he has a good sense of what works for him. "Try and stay ahead of the curve," he says. "If you notice something changing, don't ignore it — act on it. Get the information, find the support."

He encourages others not to do it alone. "There are people out there who understand — nurses like Deb, support groups like NeuFriends. You've just got to find what works for you."

Greg's message is a reminder that support can take many forms — whether it's services like NeuroCare, allied health professionals, condition-specific organisations or local community networks.

And while the path is different for everyone, he says the mindset makes a difference. "There's no one way to manage Parkinson's. But there's always something that helps. Keep learning. Keep doing what you enjoy. Keep looking forward."

ONCE YOU ACCEPT, IT YOU BEGIN TO LIVE

HOW ACCEPTANCE, SUPPORT AND A POSITIVE MINDSET HELP ROY LIVE WITH MND

Roy doesn't shy away from the truth. Diagnosed with Motor Neurone Disease (MND), he hit rock bottom — emotionally and physically.

"Every morning was worse than the last," he recalls. "I'd sit on the bed and think, I can't get through today." For two years, he lived in near-complete isolation, barely speaking to anyone, carrying the weight of his diagnosis in silence.

It hadn't been a straightforward journey to that point. Before his diagnosis, Roy experienced a long period of uncertainty and misdiagnosis, which left him frustrated and disengaged with the health system. "They thought it was a stroke," he says of the early symptoms. "But it kept getting worse." By the time MND was confirmed, the condition had already impacted his independence — both physically and emotionally.

But everything changed when he finally accepted help.

At the centre of that turning point was Deb Barndon, our regionally based NeuroCare Community Neurological Nurse. "Without her, I don't know where I'd be," Roy says. "She didn't give up on me. I wasn't just another patient — she made sure I got the help I needed."

Roy had previously rejected contact, but Deb kept messaging or calling. "She was persistent, and when I finally answered, it was the best thing I ever did." Deb's support helped him access the services he needed in Geraldton and cut through barriers he didn't have the strength to navigate alone. "She's not boxed in by the system. She works with it. That kind of care gives you your life back."

Roy's outlook today is unrecognisable from where he began. He speaks with warmth and energy, his humour and honesty shining through. "Once you accept it, you begin to live," he says — a message he returns to often. "You stop focusing on what might happen, and start making the most of now," he says. He even brings lightness to medical appointments. "I go to the doctor and say, 'I just came in to see how you are doing.' Then I sit back and wait for the reaction," he laughs.

He's now a regular at the Neurological Council's NeuFriends Coffee Club in Geraldton. "I didn't want to go at first," he admits. "But I started showing up — and it helped." There, he found connection and understanding.

"Everyone's different, but they get it. There's no judgement. It's real."

Roy now draws on a wide range of support — from allied health professionals to carers and community groups — and says it's that combination that's helped him feel in control again. "You've got to take what's on offer. Sometimes it's just a little thing that makes the day easier. It all adds up."

For Roy, wellbeing isn't just physical — it's about the mind, the environment, and the people around you. "You can feel physically okay, but if your mind's not in the right place, it's just as hard," he says. "When your mind feels good, everything changes."

That mindset shift is clear when you meet him. Roy's outlook is unshakeably positive and while his MND hasn't gone away, the joy he finds in everyday moments is unmistakable.

He credits music, the outdoors, and small daily joys as part of what keeps him grounded. "You've got to do what lifts you," he says. "A bit of sun, a good tune — whatever helps."

His advice to others facing an MND diagnosis?

"Don't give up. Say yes to help. Work out what makes you feel good. And get rid of the stuff — and the people — that drag you down."

Roy's story is a reminder that while MND can take away many things, it doesn't take away the capacity to connect, adapt, and keep living with meaning.

NEUROKIDS:

SUPPORTING CHILDREN, ADOLESCENTS AND FAMILIES

Neurological symptoms and conditions can have a profound impact on children and young people — affecting their health, development, learning and everyday life. NeuroKids provided free, statewide support to children and adolescents living with neurological conditions, and the families who cared for them.

Our specialist paediatric Community Neurological Nurses, provided clinical support, care coordination and health system navigation to help families understand their child's condition, access the right services and manage the complex challenges that come with living with neurological symptoms — including for children without a confirmed diagnosis.

Nurses provided flexible and family-centred support, offered in homes, schools, community settings and/or via phone or video. Nurses worked closely with neurologists, GPs and other health, disability and social care providers to achieve well-coordinated, multidisciplinary care.

A NeuroKids client, aged 3, who receives support for Chiari malformation, ADHD and Autism traits

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

PROUDLY SUPPORTED BY telethon 7

STAN PERRON CHARITABLE FOUNDATION

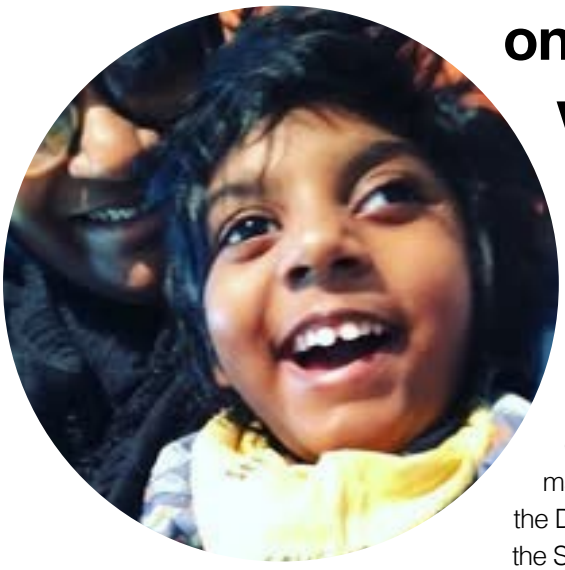
Expanding Access in the South West

Etta Palumbo, CEO, Hon Don Punch MLA, Pam Lewis, Board Member and Emeritus Professor Charles Watson, Chairman

In July 2025, NeuroKids opened in the South West, extending access to children and families in one of Western Australia's fastest-growing regions. The expansion was made possible through generous support from the Stan Perron Charitable Foundation, building on Telethon 7's existing investment in metropolitan-based delivery.

The Hon Don Punch MLA, Member for Bunbury, formally launched the NeuroKids SW and welcomed it as a much-needed addition to local health care — bringing vital paediatric neurological nursing support closer to home for South West families.

Helping a non-resident family access ongoing support for their child with complex needs



An 8-year-old boy with cerebral palsy, uncontrolled epilepsy, acquired brain injury, and PEG feeding requirements was referred to NeuroKids by Carer's Gateway-Helping Minds. His parents — both working — share 24/7 care responsibilities and face significant challenges due to their son's complex needs and non-Australian residency status.

Recognising the family's non-residency status and the financial strain of ongoing care, the CNN researched services and supports specifically available to non-Australian residents that were free or low-cost. As a result, referrals were made to Epilepsy WA, Variety WA, the Disability Gateway, Advocacy WA, the South West Multicultural Group, and Ability WA's AssistKids medical equipment loan library. In parallel, Kiind was able to refer the family to Ronald McDonald House.

The child was also referred to Kiind, with support provided for attending appointments at Perth Children's Hospital. The family accessed necessary medications through the hospital pharmacy, ensuring continuity of care.

After local options had been exhausted, the family chose to continue with NeuroKids for nursing assessment and ongoing support. This led to a further referral — via recommendation from Kiind — to the Department of Communities. The family has since attended an initial assessment for Continuity of Support Arrangements (COSA), which may provide long-term assistance. If COSA funding is declined, the Department has committed to identifying alternative support pathways, and NeuroKids will continue to assist the family as needed.

This case demonstrates how personalised, persistent support can make a meaningful difference for families navigating multiple barriers — including complex medical needs and residency-related limitations. NeuroKids helped reduce stress, connect the family to essential services, and advocate for longer-term stability and care.

"We were unaware of your service and from the moment you connected to us, you put all your energy into finding ways to connect us to appropriate services and exploring potential supports. You were always very proactive in supporting us and ensured that you were still respectful of our space. This service is not a tick box, which is what a lot of regional services tend to be given the lack of appropriate funding, which made it easier to engage in given that I could see the service provision is genuine. Please continue this service as regional families will continue to benefit from this service and coordination."

Supporting a young child with rare neurological disorder through tailored care and NDIS navigation

Parents of a 2-year-old girl with Segawa Syndrome (Dopa-responsive Dystonia)

When the parents of a two-year-old girl living with Segawa Syndrome reached out to NeuroKids, they were managing a rare neurological condition that causes painful muscle contractions (dystonia), stiffness, and episodes of unresponsiveness. Known medically as Dopa-responsive Dystonia, the condition can dramatically affect movement, sleep and comfort — often worsening without precise medication management.

The child was experiencing frequent dystonic episodes, pain in her legs and feet, and severe sleep disruption. These symptoms significantly disrupted daily life and placed high emotional and physical demands on the family. With one parent working FIFO, much of the day-to-day care fell to the mother, who needed support in navigating the healthcare and disability systems.

A comprehensive home-based nursing assessment allowed our Paediatric Community Neurological Nurse to observe the child's condition firsthand, gather a detailed history, and identify key concerns — including pain management, sleep disruption and the side effects of recent medication changes. The mother was given the time and space to speak openly about her experiences, helping her feel heard and supported. She later shared that this had given her renewed confidence and emotional reassurance in her caregiving role.

The Community Neurological Nurse provided tailored education on the child's medications, including the use of carbidopa-levodopa and recently introduced gabapentin. Together, they discussed side effects such as increased emotional lability, and strategies for monitoring response. The mother expressed increased confidence in communicating with the child's neurologist and in adjusting care based on observed changes — an important step towards achieving better symptom control.

"It has been extremely helpful knowing you are available should we need more support. It was so helpful having you start the process for NDIS through facilitating contact with Kiind. This has meant we are finally at the point of receiving an NDIS plan and funding. You took the feeling of overwhelm away and helped us get started. Thank you."

The family also received practical support around accessing the National Disability Insurance Scheme (NDIS). A previous application attempt had stalled due to uncertainty about eligibility and next steps. The Paediatric Community Neurological Nurse reviewed the process, explained the criteria, and outlined the kinds of supports the child might receive — including therapy services, home modifications and specialised equipment. A clear plan was developed to progress the application, and the mother expressed relief and gratitude for the assistance navigating what had felt like an overwhelming system.

This case highlights the value of early, relationship-based nursing support for families caring for a child with a rare and complex condition. Through home-based assessment, medication education and NDIS navigation, NeuroKids empowered this family to take the next steps in improving their daughter's comfort, function and quality of life. Ongoing nursing input will continue to support both the child's development and the parents' confidence as primary caregivers.

NEUFRIENDS:

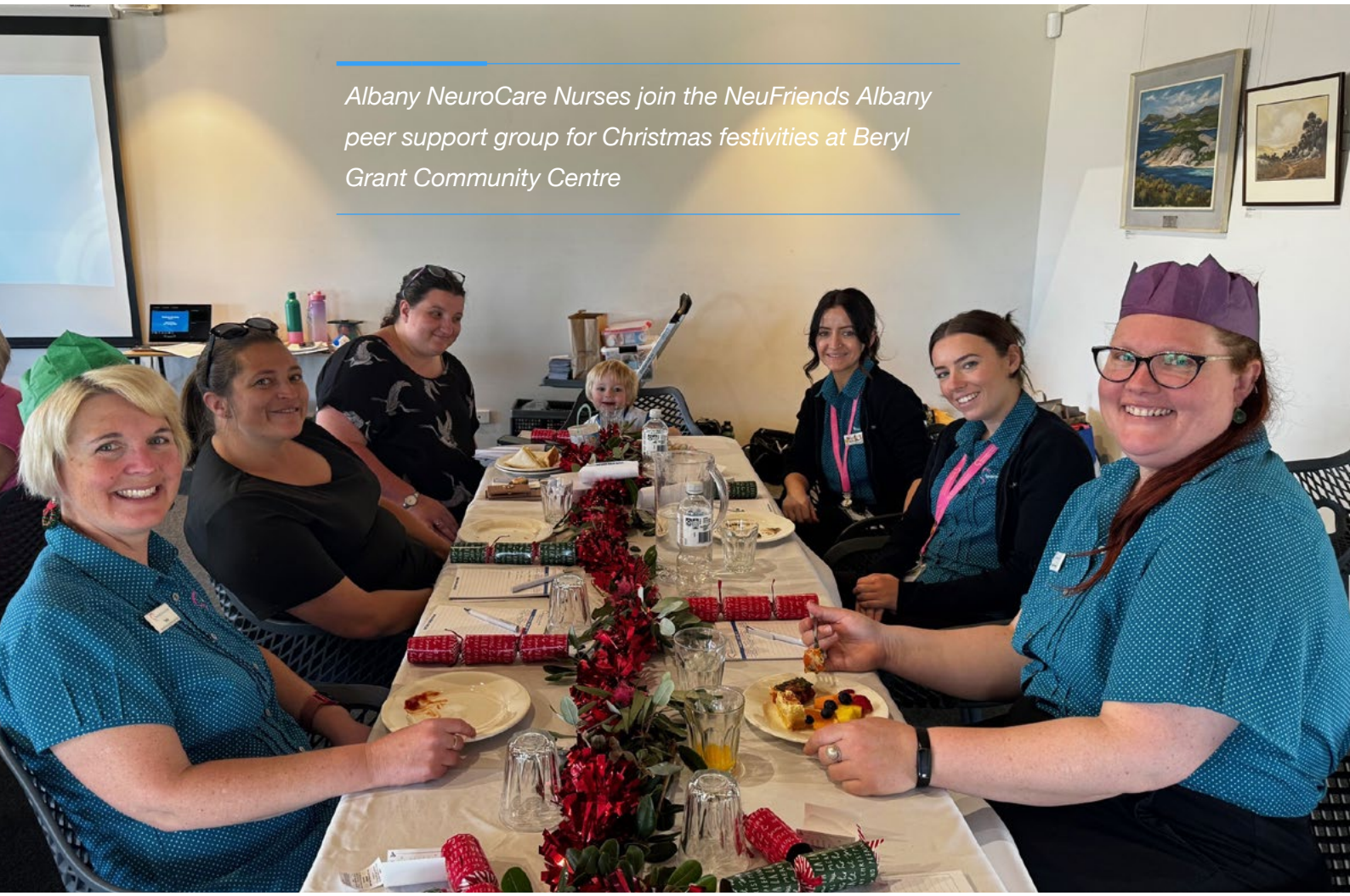
CONNECTION, UNDERSTANDING AND SUPPORT

Living with a neurological condition can be isolating — not just for individuals, but also for families and carers. The Neurological Council's NeuFriends peer support program brings people together in local communities to share experiences, build connections and support one another through the ups and downs of living with a neurological condition. NeuFriends is open to people of all ages and diagnoses and focusses on connection and community.

Building on the success of our Perth and Albany Peers Support Groups, in 2024/25, we launched NeuFriends in Geraldton and Mandurah. We were proud to partner with the City of Mandurah to establish NeuFriends Mandurah through a three-year Community Partnership Fund Grant.

"Meeting others with similar conditions has been so important," she says. "We share ideas. We laugh. There's an understanding in the room — no one has to explain themselves."

-Sharon, Geraldton NeuFriends Member



Albany NeuroCare Nurses join the NeuFriends Albany peer support group for Christmas festivities at Beryl Grant Community Centre

LEADERSHIP, COLLABORATION AND SECTOR ENGAGEMENT

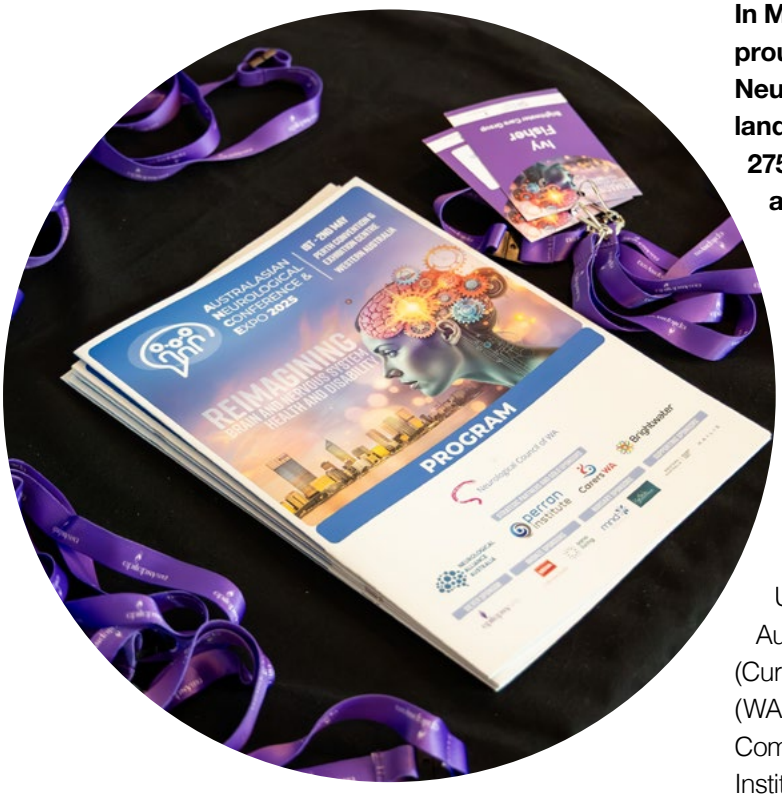
The Neurological Council continued to play a key leadership role in strengthening the response to neurological conditions in Western Australia. While our work is grounded in frontline service delivery, we also focus on systemic impact — elevating the voice of the neurological community, identifying shared needs and goals and advocating for prioritisation, planning and investment in neurological care.

Established over 30 years ago as a Western Australian peak body for people with neurological conditions and the organisations that support them, the Neurological Council has continued to foster connection and information-sharing, and improve understanding, coordination and outcomes by bringing people and organisations together — across government, health, community and research.

Throughout the year, the Neurological Council facilitated relationship building and collaboration through a range of initiatives that contributed to a more informed, connected and coordinated approach to identifying and addressing neurological health and disability challenges in our state, including convening conferences, hosting metropolitan and regional education events and leading or participating in sector-led forums and strategic working groups.

... elevating the voice of the neurological community, identifying shared needs and goals and advocating for prioritisation, planning and investment in neurological care.

Australasian Neurological Conference and Expo 2025 - Collaboration in Action



In May 2025, the Neurological Council of WA proudly convened an inaugural Australasian Neurological Conference & Expo (ANCE 2025) — a landmark event that brought together more than 275 delegates, 20 exhibitors, and over 40 nationally and internationally renowned speakers for two days of cross-sector collaboration, research insights and sharing of information and lived experience. The conference united clinicians, researchers, policy makers, community leaders and individuals with lived experience to advance neurological health and disability understanding and care across our region.

We thank our outstanding program of speakers including Ms Georgina Carr (Neurological Alliance UK), Mr Rohan Greenland (Neurological Alliance Australia / MS Australia), Professor Blossom Stephan (Curtin University / Dementia Australia), Dr Shirley Bowen (WA Health), Dr Mhairi Cowden (WA Department of Communities), Professor Merrilee Needham (Perron Institute) and Dr Darshan Ghia (Fiona Stanley Hospital). Their insights, along with contributions from many others, shaped a compelling program of knowledge-sharing and sector dialogue.

We also thank our strategic partners and sponsors who helped make ANCE 2025 possible:

Professor Charles Watson, Chair, Neurological Council of WA

Dr Shirley Bowen, Director General, WA Department of Health

Dr Linda Friedland Dr Shirley Bowen, Dr Merrilee Needham, Dr Darshan Ghia and Professor Charles Watson

Governor Champions Brain Health for World Brain Day

To mark World Brain Day 2024, the Neurological Council's Joint Patrons, His Excellency the Honourable Chris Dawson AC APM and Mrs Darrilyn Dawson, generously hosted a reception at Government House for neurological, government and community leaders to promote and value brain health and support the prevention, diagnosis and treatment of neurological disorders and related functional decline, and local implementation of the World Health Organization's Intersectoral Global Action Plan (IGAP). We thank our Patrons for their continued support of Western Australia's neurological community.

His Excellency the Honourable Chris Dawson

Quarterly Community Neurological Leaders Forum

The Neurological Council convened a series of quarterly Community Neurological Leaders Forums to bring together CEOs and senior leaders from over 40 community neurological not-for-profit organisations. Alongside health, disability, GP and research representatives, the forum served as a platform for engagement on issues of strategic importance including prioritising the collection and availability of data to inform strategy and policy development, service sustainability and community services commissioning. The Forum also contributed to Neurological Alliance Australia forums and projects, including the national 'Count us in' campaign.

... Alongside health, disability, GP and research representatives, the forum served as a platform for engagement on issues of strategic importance

Members participated in Neurological Council research to map WA's community neurological landscape to build a clearer picture of neurological services and service delivery across the state, laying groundwork for future collaboration and investment.

The Niche QEIIMC Lotteries House: Australia's first Neurological Hub

Now in its 24th year as a head tenant of The Niche QEIIMC Lotteries House, the Neurological Council of WA continued to provide affordable accommodation and shared community facilities for 11 co-located community neurological organisations under the banner of the 'Centre for Neurological Support'. While managing and maintaining the building involved considerable effort and investment, The Niche is testament to our enduring commitment to our members through collaboration and service provision.

...The Niche is testament to our enduring commitment to our members through collaboration and service provision.

Community Events and Engagement

The Neurological Council participated in a broad range of community and sector events to raise awareness, share information and strengthen community connections. These opportunities are a vital part of our mission — helping us reach people where they are, promote brain health, and connect individuals, families and professionals with neurological supports.

Two standout events included:

- **Telethon Family Festival (October 2024)**

As first-time Telethon7 beneficiaries, we were proud to join the Telethon family to showcase our NeuroKids services at this high-profile event with an estimated 20,000 attendees during Telethon weekend. Our team engaged directly with families and carers to raise awareness of neurological conditions and the supports available.

- **Have a Go Day – Seniors Week (November 2024)**

Our Community Neurological Nurses joined forces with the Stroke Foundation and Meningitis Centre WA at this major LiveLighter Seniors Week event attended by over 15,000 seniors. We shared neurological health information, reinforced messages of early intervention and proactive ageing, performed blood pressure checks and offered mini stroke risk assessments.

THANK YOU

Thank you to all our people, partners, donors and supporters who helped make 2024/25 a success. We wouldn't exist without you. Everything you do makes a difference – partnering with us to serve WA's neurological community, caring for others, donating or fundraising, pledging a gift in your Will, raising awareness, sharing personal stories, joining our forums and social media groups, participating in surveys and consultations, campaigning with us and spreading the word about our services to others who need them and translating research into practice – every little bit helps.

Special thanks to our major funders for helping us support Western Australians with neurological conditions:

NeuroCare

Government of Western Australia
Department of Health

NeuroKids

PROUDLY SUPPORTED BY telethon 7

STAN PERRON CHARITABLE FOUNDATION

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