Australian
POTS
Foundation

PRE-BUDGET SUBMISSION

2026/27

TABLE CONTENTS

> ‘Eighty per cent of people with long COVID also live with POTS, shining a light on this common but poorly diagnosed condition. We have an incredible opportunity to better diagnose, treat and reduce the financial and societal burden of POTS and make a genuine difference in millions of lives’.
>
> **Professor Brendan Crabb AC**
> Director and CEO, Burnet Institute

Executive Summary

The Australian POTS Foundation (APF) is the only national organisation dedicated to supporting Australians living with postural orthostatic tachycardia syndrome (POTS). Our mission is to improve health and social outcomes for Australians living with POTS, through research, education, advocacy, and community support.

POTS is a complex, chronic disorder affecting the autonomic nervous system. Estimated to affect up to 1 million Australians, it is particularly prevalent among young people and women, severely impacting quality of life and leading to significant social and educational disengagement. POTS remains under-recognised and underfunded in Australia, with individuals facing long diagnostic delays and limited and inequitable access to appropriate care.

Through educating clinicians, funding research, raising the public profile of POTS, and developing and distributing the only Australian resources for consumers and key stakeholders, the APF have achieved positive outcomes. Our efforts in driving vital epidemiological research into POTS have garnered significant international recognition.

To build on these successes, we are requesting critical funding to support research and health policy initiatives focused on POTS. Additionally, we seek direct support for the APF as the only consumer body dedicated to POTS in Australia, ensuring that as a peak consumer body, we can continue providing vital resources, advocacy, and education in a sustainable manner. This funding will enable us to expand our impact, advocate for improved healthcare policies, and continue offering essential services to key stakeholders across the healthcare and consumer sectors.

> ‘The Heart Foundation is a proud partner of the Australian POTS Foundation and strongly supports the call in this document for targeted investment in research, clinician education, and patient support.
>
> POTS represents a significant and under-recognised burden on Australian health—particularly for women and young people—and the proposals developed here align closely with our commitment to improving cardiovascular outcomes across the lifespan.
>
> We welcome the opportunity to collaborate with the POTS Foundation on initiatives that bridge critical gaps in care, including peer mentorship programs and rehabilitation pathways that could benefit people living with autonomic disorders. This submission reflects the kind of strategic, evidence-informed advocacy that drives genuine system improvement’.
>
> **David Lloyd | Heart Foundation CEO**

Executive Summary cont'd

The Australian POTS Foundation is calling on the Federal Government to invest **$4.4 million over three years** to address critical gaps in the diagnosis, treatment, and support of Australians living with POTS.

This submission outlines a nationally coordinated plan with four core funding pillars:

1. Research Investment – $3 million
Delivered through the Medical Research Future Fund (MRFF) and national research bodies, this investment will support clinical trials, patient registries, and research infrastructure to build the evidence base for diagnosis, treatment pathways, and equitable models of care.

2. Clinician Education and Training – $300,000
Funding to scale the APF's RACGP-accredited programs, update national clinical pathways, and deliver education to GPs, specialists, and allied health professionals across urban and rural Australia.

3. Consumer Education and Support – $500,000
Targeted investment to deliver peer mentorship programs, digital support tools, culturally inclusive resources, and national engagement initiatives to reduce isolation and improve quality of life.

4. Public Health Access and Rehabilitation – $600,000
Funding to adapt and evaluate scalable digital rehabilitation models for POTS and support integration into chronic care pathways in partnership with public health providers.

This modest, high-impact investment will unlock national momentum in an overlooked area of women's health—improving lives, reducing long-term costs, and accelerating structural reform.

About The Australian POTS Foundation [APF]

Founded in 2021, the APF is a consumer-led, not-for-profit, DGR-1 health promotion charity registered with the Australian Charities and Not-for-Profits Commission. Representing Australians with POTS, as well as health professionals, families, and carers, the APF stands as the only registered charity addressing the unique needs of individuals with POTS and autonomic disorders in Australia.

POTS often results in debilitating symptoms such as severe fatigue, light-headedness, and difficulty standing upright (orthostatic intolerance). Many individuals also experience cognitive dysfunction, often described as brain fog, caused by reduced blood flow to the brain. This makes it difficult to concentrate, process information, or perform everyday tasks.

The cumulative impact of these symptoms can be life-altering. Australian research has shown that quality of life in POTS is worse than in most other major chronic health conditions, including chronic kidney, respiratory, and heart diseases and cancer.[1] Studies indicate that 3.4% of all COVID-19 infections result in POTS, leading to a significant and rapid increase in its prevalence.[2,3]

POTS is the most common condition linked with other hidden illnesses, affecting ~40–70% of those with ME/CFS [4, 5] and up to 80% with long COVID [6–8]. It is also frequently seen in fibromyalgia and connective tissue disorders, underscoring its overlap with other under-recognised chronic conditions.[9,10,11]

Uniquely, POTS is one of the few conditions within this spectrum that has an objective, measurable clinical marker for diagnosis and targetable consensus-based treatment options, including pharmacological interventions, offering hope for symptom management and improved quality of life across all these conditions.

[1] Seeley MC et al. Poor health-related quality of life in postural orthostatic tachycardia syndrome in comparison with a sex- and age-matched normative population. Clin Auton Res. 2023;33:469–477.
[2] Kwan AC et al. Apparent risks of postural orthostatic tachycardia syndrome diagnoses after COVID-19 vaccination and SARS-CoV-2 infection. Nat Cardiovasc Res. 2022;1:1187–1194.
[3] Blitshteyn S et al. The risks of POTS after COVID-19 vaccination and SARS-CoV-2 infection: more studies are needed. Nat Cardiovasc Res. 2022;1:1119–1120.
[4] Stewart JM et al. Patterns of orthostatic intolerance: the orthostatic tachycardia syndrome and adolescent chronic fatigue. J Pediatr. 1999;135:218–225.
[5] Schondorf R et al. Orthostatic intolerance in the chronic fatigue syndrome. J Auton Nerv Syst. 1999;75:192–201.
[6] Seeley MC et al. High incidence of autonomic dysfunction and postural orthostatic tachycardia syndrome in patients with long COVID: implications for management and healthcare planning. Am J Med. 2023.
[7] Davis HE et al. Long COVID: major findings, mechanisms and recommendations. Nat Rev Microbiol. 2023;21:133–146.
[8] Hira R et al. Objective hemodynamic cardiovascular autonomic abnormalities in post-acute sequelae of COVID-19. Can J Cardiol. 2023;39:767–775.
[9] Staud R et al. Autonomic dysfunction in fibromyalgia syndrome: postural orthostatic tachycardia. Curr Rheumatol Rep. 2008;10:463–466.
[10] Roma M et al. Postural tachycardia syndrome and other forms of orthostatic intolerance in Ehlers-Danlos syndrome. Auton Neurosci. 2018;215:89–96.
[11] Peebles KC et al. The prevalence and impact of orthostatic intolerance in young women across the hypermobility spectrum. Am J Med Genet A. 2022;188:1761–1776.

The Australian Experience of POTS

The health and societal impact of POTS in Australia has previously been overlooked due to the lack of a unique International Classification of Diseases (ICD) code, which has hindered health tracking and limited formal health department oversight. To address this gap, the Australian POTS Foundation (APF) collaborated with the University of Adelaide to investigate the diagnostic and healthcare access experiences of Australians with POTS. The published findings which included 500 participants revealed:

Diagnostic Journey and Access to Care

- Australians with POTS face the longest diagnostic delays globally—6.7 years [12]
- More than 50% of patients visit emergency departments, averaging 5 visits prior to diagnosis, as they seek management for debilitating symptoms. [12]
- On average those with POTS consult over 5 doctors prior to diagnosis.[12]
- Australian women face the worst gender disparity in diagnostic delay reported globally, nearly double that of men (7 years verses 3.8 years).[12]
- 70% of female and 52% of male POTS patients report having their symptoms dismissed as anxiety prior to diagnosis.[12]
- The odds for being placed on a mental health treatment plan are 2.6 times greater for females than males.[12]
- 67% of long-COVID patients with POTS report difficulty in accessing care for POTS and 69% had to suggest POTS as a diagnosis to their doctor.[13]
- First-line pharmaceutical treatments for POTS are not subsidised under the Pharmaceutical Benefits Scheme (PBS) creating inequalities in access to treatment.

Economic Burden

To better understand the economic burden of POTS on Australians, the APF collaborated with the University of South Australia to conduct a comprehensive economic survey. These preliminary findings from over 600 participants reveal a significant economic impact at individual, familial, and societal levels, including:

- 58% permanently quit their job.
- 37% are unable to engage in any work or educational pursuits.
- 56% borrow money to afford treatments not covered by the PBS/MBS.
- 37% are unable to maintain employment, and 58% permanently leave or change their careers due to POTS.
- 57% of adults with POTS earn less than the Australian minimum wage.
- 8% report that a family member has permanently left their job to provide care.

These statistics contribute to already published data from the University of Melbourne which estimates the economic cost of long COVID to the Australian economy in 2022 was 10 billion AUD.[14]

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[12] Seeley MC et al. Biological sex-dependent differences in postural orthostatic tachycardia syndrome (POTS). Eur J Cardiovasc Nurs. 2025.
[13] Seeley MC et al. Impact of long COVID on Australian sufferers: implications for healthcare planning. Heart Lung Circ. 2023.
[14] Angeles MR et al. The economic burden of long COVID in Australia: more noise than signal? Med J Aust. 2024;221 Suppl 9:S31–S39.

The Impact of POTS

People with POTS face significant impediments in accessing care and support through federal health and disability schemes

Australians with POTS on average lose

$40,000

in personal income a year

Their carers lose

$21,000

yearly

60%

of people who get POTS from COVID are unable to return to work

On average people see

5

doctors before diagnosis

Out of pocket costs for treatments averages

>$500 a month

7 years

diagnostic delay in Australia

60%

attend an Emergency Department on average 5 times prior to diagnosis

70%

report symptoms were dismissed as anxiety

35%

report a reduction in a loved one's work hours for caregiving

Only 6%

of those applying for the NDIS are successful in their applications

Available treatments are not currently government funded in Australia

68%

face moderate to extreme limitations in performing daily activities

Impact of POTS Cont'd

Due to the absence of national data on education disruption in POTS, the Australian POTS Foundation conducted a community survey. Responses from over 400 individuals across Australia highlight the significant impact of POTS on school, university, and training participation among young people.

EDUCATIONAL DISRUPTION:

The Impact of POTS on School & Study

EDUCATION

85% Say POTS **negatively affects their academic** performance

2.79 years of **absenteeism**

88 Days of missed **school** per year

33% Withdrew from school or university...
Of them, **24% permanently**

17% repeated a year
(Up to **42%** in Year 11 & 12)

41% changed schools

99% unable to participate in sport

CARERS

61% of carers forced to reduce working hours

27% **quit all paid work**

$ ~$120,000 average carer income loss (~3 yrs)

EMPLOYMENT & FUNCTION

68% say POTS **limits their future** employment goals

58% are unable to work (even part-time)

28% Unable to complete driving hours

8% Medically ineligible to drive

Data from
Australian POTS Foundation's
2025 Lived Experience Survey

Critical Gaps in Understanding

Australians living with POTS continue to face unacceptable delays to diagnosis, fragmented care, and limited access to evidence-based treatments. Despite the implementation of a dedicated ICD-10-AM code in July 2025, clinical awareness remains low. Most individuals attend multiple appointments before receiving a diagnosis, often being misdiagnosed with anxiety or unrelated conditions. A 2025 national survey of over 2,100 GPs—led by the APF and HealthED in partnership with the Sydney University –confirmed widespread gaps in clinical education and training.

GP EDUCATION IN FOCUS:

Insights from Over 2,100 Australian GP's (2025)

Training & Awareness on POTS

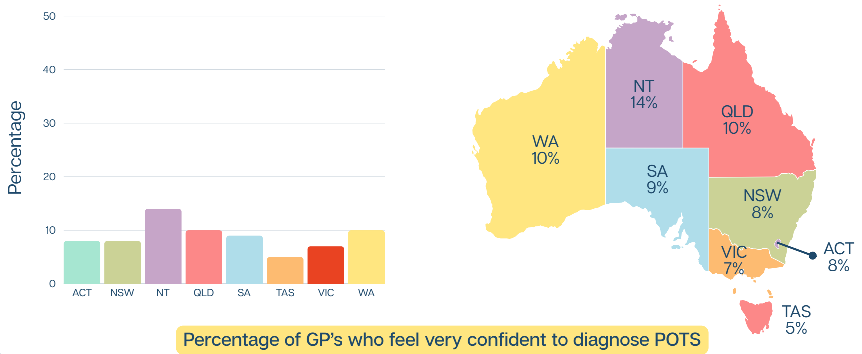
Four in five clinicians (80%) report never having education on POTS.

Only 2% of GP's say they received adequate education on POTS during medical school.

≈90% of GP's report no recent CPD on POTS.

80% of GP's stated they did not receive post graduate fellowship training in POTS.

Confidence in Diagnosing POTS (by State)



Percentage of GP's who feel very confident to diagnose POTS

Knowledge Gaps

Less than 3% recall learning about POTS during university.

4 in 5 never received any formal training.

Most training accessed **only through CPD** modules.

55% did not know POTS can develop as part of Long COVID.

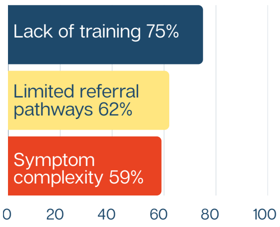
Confidence in Care

Nearly **1 in 2** clinicians say they are "not at all confident" diagnosing POTS.

Confidence in management is **even lower**.

Systemic Barriers

Australian clinicians identify the top barriers to POTS care



Critical Challenges Facing Australians Living with POTS

Despite growing awareness, POTS remains overlooked within Australia's public health and research systems. Four key systemic challenges continue to disadvantage those with lived experience:

1. Clinician Education

Most health professionals receive little to no formal training in diagnosing or managing POTS. This persistent education gap contributes to widespread misdiagnosis, delayed recognition, and fragmented, inconsistent care across primary and specialist services.

2. Community Support

All resources to date have been developed by the Australian POTS Foundation—the unfunded peak and only organisation dedicated to this condition. As POTS falls outside mainstream chronic care umbrella bodies, the APF has shouldered the responsibility for education, advocacy, and community support in the absence of government or sector-wide investment. Sustainability requires urgent recognition and resourcing of these functions to support services for people with POTS in Australia.

3. Public Health Access

The majority of POTS diagnoses occur within the private sector, where access depends on personal financial means. Dedicated expertise and public clinics remain extremely limited, contributing to long wait times, inequity of care, and heavy out-of-pocket costs for essential therapies not covered under PBS or MBS.

4. Research Deficits

To date, no specific POTS research has been funded through the Medical Research Future Fund (MRFF), National Health and Medical Research Council (NHMRC), or national chronic disease programs. The only funding has come via small community support grants. This lack of targeted investment has stifled epidemiological understanding, innovation in treatment, and equitable policy development.

This systemic neglect underscores the urgent need for comprehensive government action to support those living with POTS and autonomic disorders in Australia.

The Australian POTS Foundation – Impact and Reach at a Glance 2025

Since its inception in 2021, the Australian POTS Foundation has become a vital lifeline for individuals living with autonomic disorders. As a volunteer-led organisation operating without government funding, the Foundation has nonetheless achieved major milestones in national education, advocacy, research and community support—filling critical gaps in care, awareness, and access.

Recognition · Research
Advocacy · Community

2025 IMPACT REPORT

POTS officially recognised with ICD code G90.81

Improves diagnosis tracking to drive research funding and enhance care pathways.

RACGP education accreditation achieved

Enabling broader GP access to trusted, evidence-based POTS education.

Included in National Clinical Guidelines development

Helping shape structured care pathways to guide diagnosis and management.

Fundraising & Research Support

$250,000+

Raised to drive improvements in research, clinician training, and care systems.

$30,000

Dedicated to local research identifying biomarkers for POTS.

2	PhD students funded by scholarships advancing POTS research.
1	Australian physician sponsored for US autonomic training.
6	MRFF grant submissions supported to embed lived experience of POTS in national research.

Education & Community Reach

Health Professionals
4,000+ health professionals educated at live events.

Newsletters
14,000+ newsletters delivered.

Website
250,000+ website visits.

Webinars
6 webinars sharing clinical & lived experience insights.

Social Media
500,000+ social media reach.

Patient Resources
14 new patient resources (guides, fact sheets, tools).

Lectures
32 lectures delivered to advance clinical and research understanding of POTS.

Podcast collaborations
Challenges That Change Us, Standing Up To POTS POTSCAST, Endo Untangled, and Women's Health **26,593 listeners.**

Advocacy & Policy

20
meetings with Federal & State politicians.

19
members in Lived Experience Advisory Network.

10+
GP HealthPathways across 3 states.

2,500
responses in national surveys on education & GP knowledge.

What is Needed to Redress Gaps in POTS Research, Care, and Education - Federal Budget Allocation Summary: $4.4 Million (Targeted Priorities)

This represents a modest and strategic investment to address systemic gaps in care, research, and education for a condition affecting up to 1 million Australians.

Category	**Administering Body /Partners**	**Funding**
Research Investment	NHMRC/MRFF – Delivered via Adelaide University, SAHMRI, The Hospital Research Foundation, Burnet Institute	$3 million
Clinician Education and Training	Australian POTS Foundation (in collaboration with Adelaide University)	$300,000
Consumer Education and Support	Australian POTS Foundation (with Heart Foundation and RMIT)	$500,000
Public Health Access & Rehabilitation	CardiHab and Rosemary Bryant AO Research Centre (with Heart Foundation)	$600,000

> ‘Persistent scepticism and lack of education among clinicians, along with limited access to formal haemodynamic testing, may all contribute significantly to the (POTS) diagnostic delay. Targeted interventions to improve clinician education with official care pathways are necessary to reduce acute care presentations and diagnostic delay.’ [15]

[15] Lau DH et al. Postural Orthostatic Tachycardia Syndrome: A State-of-the-Art Review. Heart, Lung and Circulation (2026)

What is Needed to Redress Gaps in POTS Research, Care, and Education Cont'd

1. Research Investment - $3 million total over 3 years

Strategic research funding is needed to redress longstanding inequities in data, diagnostics, and innovation for POTS. Despite increasing prevalence and clinical burden, there has been no dedicated investment through the MRFF, NHMRC, or Department of Health. The APF proposes three nationally coordinated research streams:

National POTS Registry – $600,000

Led by the Rosemary Bryant AO Research Centre, in partnership with the SAHMRI Registry Centre and the Australian POTS Foundation, this funding will nationalise the APF's successful single-site pilot registry (>700 registrants) –seed funded by the APF at $50,000 per annum.

The registry has demonstrated strong feasibility, lived experience engagement, and willingness for longitudinal follow-up. Government investment will extend its geographic reach, improve data equity, and allow for linkage to MBS and PBS datasets.

Funding will support registry governance, database infrastructure, site engagement, epidemiological analytics, and ongoing lived experience input through the Foundation's LEAN advisory network.

Midodrine Clinical Trial – $2 million

We propose targeted MRFF investment to support a TGA directed medicine repurposing pathway for midodrine, administered through the SAHMRI Clinical Trials Centre and led by autonomic researchers from the Adelaide University's Australian Dysautonomia and Arrhythmia Research Collaborative (ADARC).

Following an unsuccessful repurposing submission in 2024, the TGA advised that future applications would require robust real-world registry data and adult randomised controlled trial evidence, despite midodrine being used in clinical practice for POTS for more than two decades. In response, this MRFF-supported RCT will generate the high-quality adult evidence required to address the identified regulatory gap.

More than $7 million worth of midodrine was prescribed in Australia last year, with the majority likely used off-label for POTS rather than its TGA-approved indication. The TGA has acknowledged this evidentiary deficit, and this trial will directly support a renewed TGA and PBS submission, improving regulatory alignment, prescribing certainty, and patient access.

National Autonomic Disorders Research Agenda – $400,000

In collaboration between the Australian POTS Foundation and national research bodies, this initiative will develop a national research roadmap to autonomic disorders.. The program will bring together researchers, clinicians, consumers and policymakers to establish priority areas for future MRFF and NHMRC funding. Deliverables include expert working groups, lived experience engagement, strategic scoping papers, and publication of a consensus roadmap to inform investment.

What is Needed to Redress Gaps in POTS Research, Care, and Education cont'd

2. Clinician Education and Training
$300,000 total over 3 years

Led by the Australian POTS Foundation, this stream will scale clinician education nationally—embedding best-practice care across general practice, allied health, and specialist networks.

- A total of $150,000 will fund a full-time Education Officer for 3 years (0.5 FTE allocated here), responsible for leading national curriculum design, managing the Foundation's LMS, developing RACGP-accredited education content, overseeing HealthPathways updates, and delivering digital teaching tools for primary and allied health providers. This role will also support LEAN engagement and education coordination across the sector.
- $30,000 will support annual travel, registration, and logistics to enable APF-led education delivery via the HealthEd conference circuit, which reaches over 10,000 clinicians each year.
- $50,000 is allocated to support the APF's biennial clinical education conference, including venue hire, hybrid infrastructure, and outreach for key speakers and clinician attendees.
- $15,000 will cover RACGP accreditation fees, platform subscriptions, and content licensing across the three years.
- $55,000 will fund LMS hosting, podcast and webinar production, and ongoing content updates in partnership with Adelaide University and lived experience leaders.

All education content will remain free for clinicians and mapped to international best practice, ensuring equity in access and uptake nationally.

3. Consumer Education and Support
$500,000 total over 3 years

This stream supports the expansion of APF-led initiatives that provide psychosocial connection, information access, and peer support for people with POTS across Australia.

> 'POTS is a debilitating and often invisible illness which affects many people in the prime of their productive working life. Funding the Australian POTS Foundation to educate clinicians and patients is crucial'.
>
> **Sophie Scott OAM**
> Adjunct Professor at University of Sydney
> Former Medical Reporter ABC

What is Needed to Redress Gaps in POTS Research, Care, and Education cont'd

- $150,000 will fund the shared Education Officer (0.5 FTE allocated here), who will coordinate lived experience-led education delivery, manage consumer-facing content, and lead national support initiatives. This includes development of culturally appropriate toolkits, factsheets, digital courses, and webinar resources tailored to patient and carer needs.
- $150,000 will be subcontracted to the National Heart Foundation to deliver a national peer mentorship program in collaboration with the APF. The program will train volunteer mentors, host hybrid and in-person workshops, and provide targeted outreach to carers and priority populations in regional and remote areas.
- $50,000 will be allocated to RMIT to co-develop and pilot an AI chatbot to enhance access to support and education—especially for people living with cognitive or fatigue-related barriers. The tool will draw on lived experience data and undergo testing through the APF's LEAN network.
- $60,000 will support consumer engagement events and workshops over three years, scaling APF's national peer network and building capacity for psychosocial support.
- $90,000 will fund resource production, podcast/webinar dissemination, platform maintenance, and LMS hosting for consumer education delivery across all states and territories.

4. Public Health Access and Rehabilitation
$600,000 total over 3 years

This funding will address the current lack of scalable, evidence-based rehabilitation and accessible public care models for POTS.

- $300,000 will be allocated to CardiHab to adapt its TGA-listed digital cardiac rehabilitation platform for POTS, in partnership with the Australian POTS Foundation. The program will be co-designed to reflect the symptom patterns and care pathway relevant to autonomic disorders, including tailored content for adolescents and rural communities.
- $300,000 will be provided to the Rosemary Bryant AO Research Centre at Adelaide University to co-develop the adapted rehabilitation framework in partnership with the National Heart Foundation. This collaboration will ensure the inclusion of autonomic disorders such as POTS—alongside broader forms of heart disease beyond acute coronary syndromes—into a nationalised, scalable rehabilitation model. The work will include clinical evaluation, stakeholder consultation, and integration planning to support implementation across public hospitals and chronic care programs.

Total Funding Requested: $4.4 million

This targeted funding plan addresses critical gaps in POTS research, care, and education while empowering organisations like APF and to lead transformative change. By prioritising consumer input, scientific innovation, and equitable access, this plan will significantly improve outcomes for Australians living with POTS.

Our Capacity and Partnerships

Our volunteer-run organisation is led by a female CEO and supported by an expert Board of Directors, 70% of whom are women and 85% of whom have lived experience with POTS, reflecting the community we serve. The team brings together expertise from major charitable, clinical, research, and corporate organisations, as well as legal and governance skills, ensuring accountability and impactful results. We have established key partnerships with leading organisations in health, research, and consumer engagement:

- **Consumer Engagement:**

Consumer engagement is at the centre of our work. As members of the Australian Patient Advocacy Alliance, Australian Women's Health Alliance, and Consumer Health Forum, the APF has utilised resources from these key organisations to create the Guiding Principles of Consumer Engagement. This resource draws on co-designed consumer tools, ensuring gender-inclusive approaches to care and support. These collaborations also inform our own Lived Experience Advisory Network, a diverse group of consumers who guide our work through their expertise in lived experience, ensuring that our initiatives remain aligned with the needs and priorities of the community.

- **Research Partnerships**

The APF is affiliated with Adelaide University, RMIT, and the South Australian Health and Medical Research Institute (SAHMRI), driving evidence-based research and enabling the ready leverage of expertise within these organisations, including Health Translation SA, Wardliparingga Aboriginal Health Equity Research Unit, and the Registry Centre. Additionally, the APF organisation is partnered with the Rosemary Bryant AO Research Centre, where we collaborate on consumer-driven interdisciplinary research. We have formerly partnered and collaborated on over ten MRFF grant submissions with other key national research institutes including University of Melbourne, Burnet Institute, Sydney University and the University of New South Wales.

> 'On behalf of the Rosemary Bryant AO Research Centre we believe that funding research and equitable care pathways will reduce diagnostic delays, improve patient outcomes, and address the broader societal and economic impact of POTS. It is a public health challenge, that cannot be neglected'.
>
> **Professor Marion Eckert Director,**
> **Rosemary Bryant AO Research Centre**

Our Capacity and Partnerships cont'd

- **Collaborative Work in Female-Dominated Systemic Disorders:**

Within the broad scope of female-dominated systemic disorders, we collaborate and have formed partnerships with like-minded consumer organisations, including Connective Tissue Disorders Network Australia and Sjogren's Australia sharing experiences and working on shared priorities to mutually support our communities.

- **Clinical Education:**

The Heart Foundation has partnered with the APF to drive advocacy and education for Australians affected by POTS, supporting equitable access to care and informed policy reform. The APF is accredited with the Royal Australian College of General practitioners (RACGP) to deliver Continuing Professional Development (CPD) programs, equipping GPs to recognise, diagnose, and manage POTS in primary care settings. We also partner with the Riverland Academy of Clinical Excellence (RACE) to strengthen rural clinical training and research. An informal collaboration with HealthED supports the delivery of national webcasts, podcasts, and live education events, expanding the reach of evidence-based resources across the clinical community.

- **Health Policy:**

The APF has demonstrated a proven ability to collaborate effectively and influence national health policy change. In partnership with the Independent Hospital Pricing Authority (IHACPA), the Foundation nominated and supported the adoption of the first dedicated ICD-10-AM code for POTS, implemented across Australia and New Zealand in July 2025. APF representatives also contribute to the NHMRC ME/CFS and long-COVID Clinical Guidelines Development Committee, ensuring autonomic conditions are included in national care standards. We have worked directly with the Department of Health to review and refine MBS items related to autonomic testing, helping improve access to diagnosis for patients across the country. In recognition of this policy leadership, the APF CEO was awarded a Federal Health Department-sponsored Churchill Fellowship to investigate international models of autonomic education and systems integration.

Summary:

With a strong foundation of partnerships across consumer organisations, national research institutes, not-for-profits, and health policy bodies, the Australian POTS Foundation is well-positioned to scale its impact. These collaborations reflect our leadership in delivering structural reform, advancing research, embedding consumer voice, and building national capacity to improve outcomes for all Australians living with POTS.

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SOUTHERN XP

Australasian Nursing and Midwifery Clinical Trials Network

CTDNA Connective Tissue Disorders Network Australia

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reach for the many