AUSTRALIAN
POTS
FOUNDATION

2025/26

PRE-BUDGET SUBMISSION

REGISTERED CHARITY

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> “Consumers with POTS face enormous challenges to find the right interprofessional team to support their care in our current fragmented health system. POTS is an example of the need for policy frameworks, funding pathways, research agendas and multidisciplinary models of care which cross sectors to deliver effective consumer centred healthcare”.
>
> Professor Gerry O’Callaghan MB BCh BAO FICA FCICM
> Associate Dean, Faculty of Health and Medical Sciences,
> The University of Adelaide
> Professor of Interprofessional Practice.

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 over 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, 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 through established government programs 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.

Executive Summary cont'd

We are calling on the Federal Government to allocate $25 million in the upcoming budget to address the critical gaps in POTS healthcare provision, research, clinical education and community support:

1. Research Funding – $12 million: Delivered through established national research funding bodies, including the NHMRC and MRFF, to support biomechanistic research, clinical trials, patient registries, and scholarships.
2. Access to Care – $10 million: Funding provided to the Department of Health and Aged Care to subsidise essential treatments and develop adapted rehabilitation frameworks and programs for POTS patients.
3. Stakeholder Education and Consumer Support – $3 million: Invest in the Australian POTS Foundation, the only national consumer organisation for POTS, to lead and adapt key stakeholder education programs, enhance community resources, reduce social isolation and support societal engagement.

This targeted funding will drive transformative change, improving lives and reducing the economic burden of this overlooked condition.

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.

The Condition – POTS and its Impact
POTS is a complex disorder of the autonomic nervous system that disrupts heart rate, blood pressure, and the body's ability to regulate essential unconscious functions. It is estimated to affect 1 million Australians, with 80–90% of these being females of childbearing age.

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 also the most predominant condition associated with other hidden illnesses, affecting approximately:
- **40-70%** of individuals with myalgic encephalitis/chronic fatigue syndrome [4, 5]
- **80%** with long COVID [6-8]
- **60%** with fibromyalgia [9]
- **40-47%** with connective tissue disorders, such as Ehlers-Danlos syndrome. [10, 11]

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

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]

Given the high prevalence of POTS in long-COVID it is imperative that critical gaps in care and support for this community are addressed in the next Federal Budget.

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

6.9 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

Critical Challenges for the Australian POTS Community

Despite evidence of its prevalence and impact, postural orthostatic tachycardia syndrome (POTS) remains stigmatised and under-recognised in Australia, leaving those with this chronic, debilitating condition unsupported and without access to adequate care.

To date, no government funding through the Department of Health and Aged Care, the National Health and Medical Research Council (NHMRC), the Medical Research Future Fund (MRFF), or community grants has been allocated specifically to address POTS, leaving a critical gap in research, educational resources, and community support. Additionally, generic chronic health funding consistently fails to reach the POTS community.

POTS often fails to meet the criteria for inclusion in umbrella funding programs in cardiovascular, pulmonary, and kidney health, leaving patients without representation, resources, and targeted support. This has resulted in critical gaps in support and care, including gaps in:

Training and Education

- A lack of dedicated resources leaves patients and carers isolated and unsupported, particularly in culturally and linguistically diverse populations.
- Medical and allied health training on POTS is critically lacking, leaving providers ill-equipped to recognise, diagnose, and manage the condition.
- Critical resources to help schools and universities support and maintain student engagement in education are lacking, leaving families to manage alone.

Research Funding and Support:

- A lack of targeted research funding has led to inadequate Australian-based studies on POTS, including its epidemiology and biomolecular mechanisms.
- A lack of investment in early- and mid-career researchers has created a critical expertise gap, undermining research efforts, evidence-based care and health policy translation for POTS in Australia.

Critical Challenges for the Australian POTS Community cont'd

Accessible Public Health Care:

- Only two private POTS-specific medical clinics exist in Australia, alongside one public clinic offering limited services with a 24-month waiting list.
- Essential treatments (e.g., Ivabradine, Midodrine, compression wear, and high salt/low carbohydrate supplements) are not covered by PBS/MBS.
- Funded chronic care programs (5 allied health visits per year) are insufficient for addressing POTS patients' multisystem and complex needs.
- Funded pulmonary and cardiac outpatient rehabilitation programs are inaccessible to young POTS patients, fail to address the systemic nature of the condition, and require significant adaptation to meet the unique needs of POTS and ensure acceptability and outcome benefits.

Consumer Support

- There is currently no government funding for programs aimed at empowering young people with POTS, improving their ability to manage their health, or addressing social isolation.
- Federal demand for consumer engagement in grants has increased, but the lack of pre-engagement funding places an undue burden on under-resourced consumer organisations, leaving them to facilitate critical collaborations without support.

This systemic neglect underscores the urgent need for comprehensive government action to support the POTS community in Australia.

The Australian POTS Foundation |

Impact & Reach at a Glance in 2024

Unique ICD code Successfully advocated for the inclusion of a unique POTS ICD code into ICD 10.13th edn.

Clinical Guidelines
Successfully advocated for the inclusion of POTS into the NHMRC Clinical Guidelines

>$45,000 Raised for research through community led events
>$100,000 Distributed to support Australian POTS research

>20 submissions and advocacy letters to parliament
>20 Meetings held with federal and state Government officials and stakeholders

316 New associate members & **105** Professional associate members

>2,000 Healthcare professionals – educated through live events

>1,800 Responses to economic, resource and consumer engagement surveys

>250,000 Website visits – page views by **>125,000** individual visitors

>75,000 People visited our ‘Living with POTS’ Webpage to get support
>45,000 People visited our ‘POTS for Practitioners’ Webpage to understand POTS treatment
>25,000 People visited our ‘Clinician Directory’ - seeking support to find a health practitioner

>87,000 People reached through Meta
>6,000 Social Media followers – 181% increase in 2024

>4,700 E-newsletters sent

6 National news articles, interviews Highlighting POTS and long-COVID

6 National MRFF grants – facilitation of consumer engagement in co-design

The Australian POTS Foundation Achievements to Date:

Since its inception in 2021, the Australian Pots Foundation has become a vital lifeline for individuals living with POTS. Although we are a volunteer-run organisation operating without government funding, the Foundation has already achieved some significant milestones in POTS education, advocacy, and community support.

Education & Awareness	**Advocacy & Policy**	**Research**	**Community Support**
Delivered impactful conferences and webinars, educating over 2,000 stakeholders nationally.	Successfully advocated for the adoption of a unique International Classification of Diseases (ICD) code for POTS, scheduled for rollout in July 2025.	Invested in Australian research by funding postdoctoral fellows, PhD candidates, and research interns to advance POTS studies.	Developed comprehensive digital resources, including pharmaceutical guides, patient rights advice, diagnostic tools, and a clinician directory.
Engaged with RACGP to deliver Continuing Professional Development programs, improving GP recognition and management of POTS.	Collaborated with the National Health and Medical Research Council to develop clinical guidelines for POTS.	Facilitated consumer engagement in six national Medical Research Future Fund grant applications, ensuring community needs were prioritised in research.	Engaged over 125,000 website visitors, offering real-time support through resources, tools, and community connections.
Showcased expertise at 12+ global and national conferences. Delivered impactful clinical education to hospitals, GPs, universities, and school nurses.	Represented community needs and shared stories through submissions to the Women's Health Advisory, Parliamentary Inquiry into Long COVID, and TGA Repurposing Framework.	Partnered with leading universities and research institutes to conduct and publish community surveys on the economic and social impact of POTS.	Secured sponsorships to provide community-wide discounts on essential first-line treatments for POTS, helping to reduce the financial burden for patients.
Built a powerful digital presence on X, Meta, LinkedIn, and YouTube, engaging audiences and amplifying advocacy.	Held face-to-face meetings with state and federal MPs, raising awareness of POTS' economic burden and advocating for equitable care and resources.	Launched an open grant call to support and advance POTS research in Australia.	Reduced isolation by sharing powerful community stories through digital platforms, print publications, podcasts, and video media, fostering connection and understanding.
Raised awareness of diagnostic delays and gender bias through media features in The Conversation, The Age, The Advertiser, and The Sydney Morning Herald.	Spearheaded a community petition with over 3,000 signatures to the Federal Health Minister.	Collaborated on and supported six high-impact, peer-reviewed publications to advance and disseminate POTS research.	Strengthened community engagement through initiatives such as a consumer conference, virtual book club, and online events, creating opportunities for connection and support.

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

Federal Budget Allocation Overview: $25 Million
This funding is categorised into three distinct areas to address critical gaps:

Category	Administering Body	Funding
Research Funding	NHMRC/MRFF	$12 Million
Access to Care	Department of Health	$10 Million
Consumer Support and Education	Australian POTS Foundation	$3 Million

1. Research Funding – $12 Million (NHMRC/MRFF)
To be administered by the National Health and Medical Research Council (NHMRC) and the Medical Research Future Fund (MRFF), this funding will address urgent research needs:

- **Biomechanistic and Epidemiological Research ($5M):**
- Investigate biomechanistic similarities between POTS and related conditions, including connective tissue disorders, autoimmune diseases, post viral syndromes, and neurodivergent conditions.
- Explore genetic and proteomic mechanisms, as well as the role of female hormone influences.
- Assess socioeconomic impacts, such as financial burdens, access disparities, and economic costs.
- Conduct longitudinal studies to evaluate cardiovascular and other health impacts associated with autonomic dysregulation over time.
- **Clinical Trials ($2M):**

Evaluate pharmacological interventions, and non-pharmacological therapies to develop scalable, evidence-based care for POTS patients.

- **Equity Research ($1M):**

Investigate barriers to care for culturally and linguistically diverse (CALD) and Indigenous populations and develop culturally adapted solutions.

- **Research Scholarships ($1M):**

Fund NHMRC early- and mid-career researchers to build long-term research capacity in POTS and autonomic disorders.

- **National Patient Registry ($3M):**

Allocate funding to the South Australian Health and Medical Research Institute (SAHMRI) to collaborate with the Australian POTS Foundation in expanding its state-specific POTS patient registry into a nationwide program. This registry will track prevalence, patient outcomes, and healthcare utilisation, providing robust data to inform policy, research, and clinical practice.

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

2. Access to Care – $10 Million (Department of Health)

Administered by the Department of Health, this funding will enhance access to essential care for Australians with POTS:

- Subsidised Compression Garments ($6M):

Provide subsidies for compression garments through the Medicare Benefits Schedule (MBS), an essential non-pharmacological treatment for POTS patients.

- Adaptation of Rehabilitation Frameworks ($2M):

Develop POTS-specific rehabilitation guidelines in collaboration with the APF and allied health professionals to address the unique needs of younger POTS patients.

- Pilot Programs for Rehabilitation ($2M):

Roll out adapted rehabilitation models across select facilities, informed by APF's consumer engagement, to test their scalability and effectiveness.

3. Community Support and Education – $3 Million (Australian POTS Foundation)

Administered through the Australian POTS Foundation, this funding will empower the organisation to lead national education, awareness, and support initiatives:

> *"Funding the Australian POTS Foundation to educate clinicians and patients is crucial. POTS is a debilitating and often invisible illness which affects many people in the prime of their productive working life. Funding is needed to ensure more good work can be done by the hard-working team at the Australian POTS Foundation to educate GPs and patients on how best to treat and manage this condition."*
>
> Sophie Scott
> Associate Professor (Adj) Notre Dame University
> Former Medical Reporter ABC

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

Stakeholder Education ($2M)

- **Clinical Education ($300,000):**

Resource the APF to collaborate with the Royal Australian College of General Practitioners, the Australian College of Nursing, and national universities and allied health organisations to develop and deliver Continuing Professional Development (CPD) modules for health professionals.

- **School Resources ($200,000):**

APF to partner with 'Missing School' to create tailored resources and education for schools, supporting students with POTS to remain engaged and achieve improved educational outcomes.

- **Resource Integration ($200,000):**

Collaborate with ME/CFS Australia, Emerge Australia, Connective Tissue Disorders Australia, and Long COVID forums to ensure POTS management resources are accessible across related conditions.

- **Culturally Tailored Materials ($200,000):**

Develop resources for CALD and Indigenous communities in partnership with SAHMRI's Health Translation SA and Wardliparingga Aboriginal Health Equity unit.

- **Social Media Outreach ($100,000):**

Launch national campaigns to raise public and clinical awareness of POTS, targeting underserved populations and improving recognition among healthcare professionals.

Consumer Support and Education ($1M)

- **Facilitating Consumer Engagement ($400,000):**

Support APF initiatives to enable consumer involvement in pre-grant collaboration, policy input, and research translation by funding recruitment, facilitation, and remuneration of consumer representatives. This includes invest in community upskilling, accessibility, and capacity-building initiatives to ensure diverse and meaningful engagement, aligned with health policy and MRFF and NHMRC guidelines.

- **Capacity Building for APF Operations ($200,000):**

Build and enhance the capacity of the APF to effectively support POTS patients, families, and carers by strengthening critical infrastructure, resourcing tailored programs, developing educational resources, and advancing scientific research expertise to drive evidence-based advocacy and care improvements.

- **Cultural Adaptation and Resource Development ($200,000):**

Upgrade and adapt digital platforms and resources to better serve the needs of underserved populations, including CALD and Indigenous communities. This initiative ensures accessibility, cultural relevance, and inclusivity for patients, carers, and healthcare providers.

- **Reducing Social Isolation ($200,000):**

Develop community programs that foster connections, reduce social isolation, and improve education and workplace engagement for individuals with POTS.

Total Funding Requested: $25 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

The APF is uniquely positioned to scale its impact and drive meaningful change for Australians living with POTS through our extensive network of partnerships, proven expertise in consumer engagement, and strong leadership. With the support of government investment, we can expand our reach and enhance the lives of those affected by this condition.

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**:

APF key personnel are affiliated with The University of Adelaide, 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 Centre of Excellence for Registries and Registry Science. Additionally, the APF organisation is partnered with the Rosemary Bryant AO Research Centre, where we collaborate on consumer-driven interdisciplinary research.

Our Capacity and Partnerships cont’d

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

Within the broad scope of female-dominated systemic disorders, we collaborate with like-minded consumer organisations, such as EMERGE Australia, ME/CFS Australia, and the Connective Tissue Disorders Network Australia, sharing experiences and working on shared priorities to mutually support our communities.

- **Health Policy:**

Through key relationships with the Independent Hospital Pricing Authority (IHACPA), we are supporting the adoption of the ICD code for POTS, and our personnel are represented on the NHMRC ME/CFS and long-COVID Clinical Guidelines Development Committee.

- **Clinical Education:**

APF is partnering with the *Royal Australian College of General Practitioners (RACGP)* to deliver *Continuing Professional Development (CPD) programs*, supporting General Practitioners to recognise, diagnose and manage POTS in the primary health care setting. Additionally, we are partnering with the *Riverland Academy of Clinical Excellence* to foster rural research and clinical excellence in POTS management. Our close relationships with *The University of Adelaide, The University of South Australia* and *RMIT* facilitate ready engagement in medical, nursing, and allied health education initiatives.

With these partnerships, the APF is well-positioned to scale its impact and lead change in healthcare, research, and education for Australians living with POTS.

> *‘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 this under-recognised condition. A condition that predominately impacts young women, it devastates lives, late diagnosis can lead to significant debilitating life impacts and result in further burden on the individual and the health system. It is a public health challenge, that cannot be neglected’.*
>
> **Professor Marion Eckert**
> **Director, Rosemary Bryant AO Research Centre**

Contact

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Footnotes

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