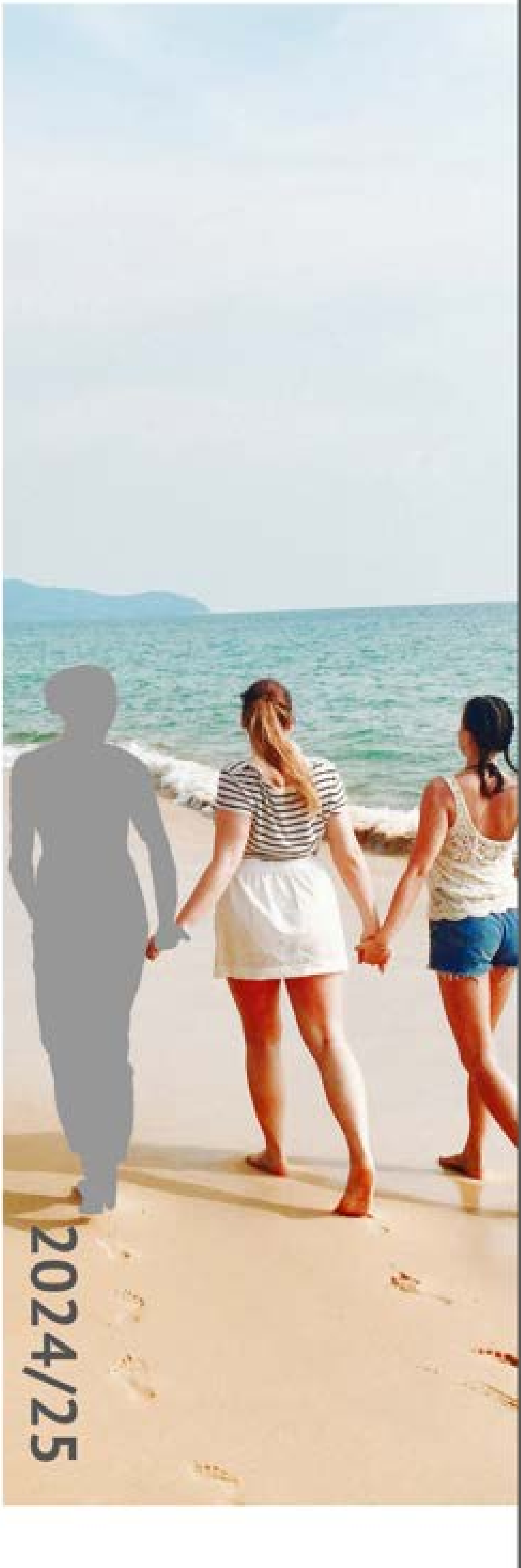
AUSTRALIAN
POTS
FOUNDATION



PRE-BUDGET SUBMISSION

AUSTRALIAN
POTS
FOUNDATION

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Executive Summary

Postural Orthostatic Tachycardia Syndrome (POTS) has presented a growing challenge to the Australian healthcare system, with a notable surge in diagnosis exacerbated by the impacts of the global SARS-CoV-2 pandemic. The substantial increase in POTS cases places strain on health services, demanding urgent attention and comprehensive strategies to address the unique needs of affected individuals and the burden on healthcare resources.

The Australian POTS Foundation (APF) stands as the sole representative body for Australians effected by POTS and related autonomic nervous system disorders. Governed predominantly by individuals with lived experiences of POTS, the APF focuses on advancing outcomes through research, clinical education, advocacy, and support.

To support our Foundation in responding to the increased community and health sector needs, we request the Australian Government prioritise funding in the 2024/2025 Federal Budget to assist us to:

1. Work with our community to identify, map and document health risks, socio-economic burdens, and barriers to accessing existing healthcare and disability schemes.
2. Expand our patient registry to a nationwide platform; ensuring a sustainable data resource that represents all Australians with POTS and which informs health policies and facilitates the development of effective strategies for POTS management.
3. Build capacity for key stakeholders by developing and disseminating customised educational resources aimed at promoting health literacy, self-advocacy, and workplace engagement. This action aims to empower individuals with POTS; reducing barriers to diagnosis and improving symptom management.

In addition to these immediate measures, the APF urges the Australian Government to invest in the future by:

4. Allocating funding from the Medical Research Future Fund to POTS research; incentivising and promoting POTS research ensuring that Australia positions itself to reduce the health and socioeconomic impacts of the rising incidence of POTS.

These measures are imperative to address the challenges posed by the increasing prevalence of POTS and will contribute significantly to improving outcomes for effected individuals in Australia.

About The Australian POTS Foundation [APF]

The Australian POTS Foundation (APF) is a consumer-led, not-for-profit, DGR-1, health promotion charity registered with the Australian Charities and Not-For-Profit Commission.

The board of governance maintains a 70% representation of individuals with lived experience of POTS, with a deliberate focus on female representation, reflecting the community we represent. The APF is the sole body to represent the needs of Australians with Postural Orthostatic Tachycardia Syndrome (POTS) and other autonomic nervous system disorders.

Our mission is to improve outcomes for those with POTS by promoting dedicated, consumer-led research, clinical education, advocacy, and support for our community and key stakeholders. Our charitable purposes (detailed in point 6 of our constitution) work to promote and protect human rights by acting as an advocate for people disabled by POTS and their families. Our community members encompass Australian individuals living with this condition as well as key stakeholders including health professionals, families and carers of those with POTS.

The Australian POTS Foundation is the only registered charity representing the unique needs of those with POTS and autonomic disorders in Australia.

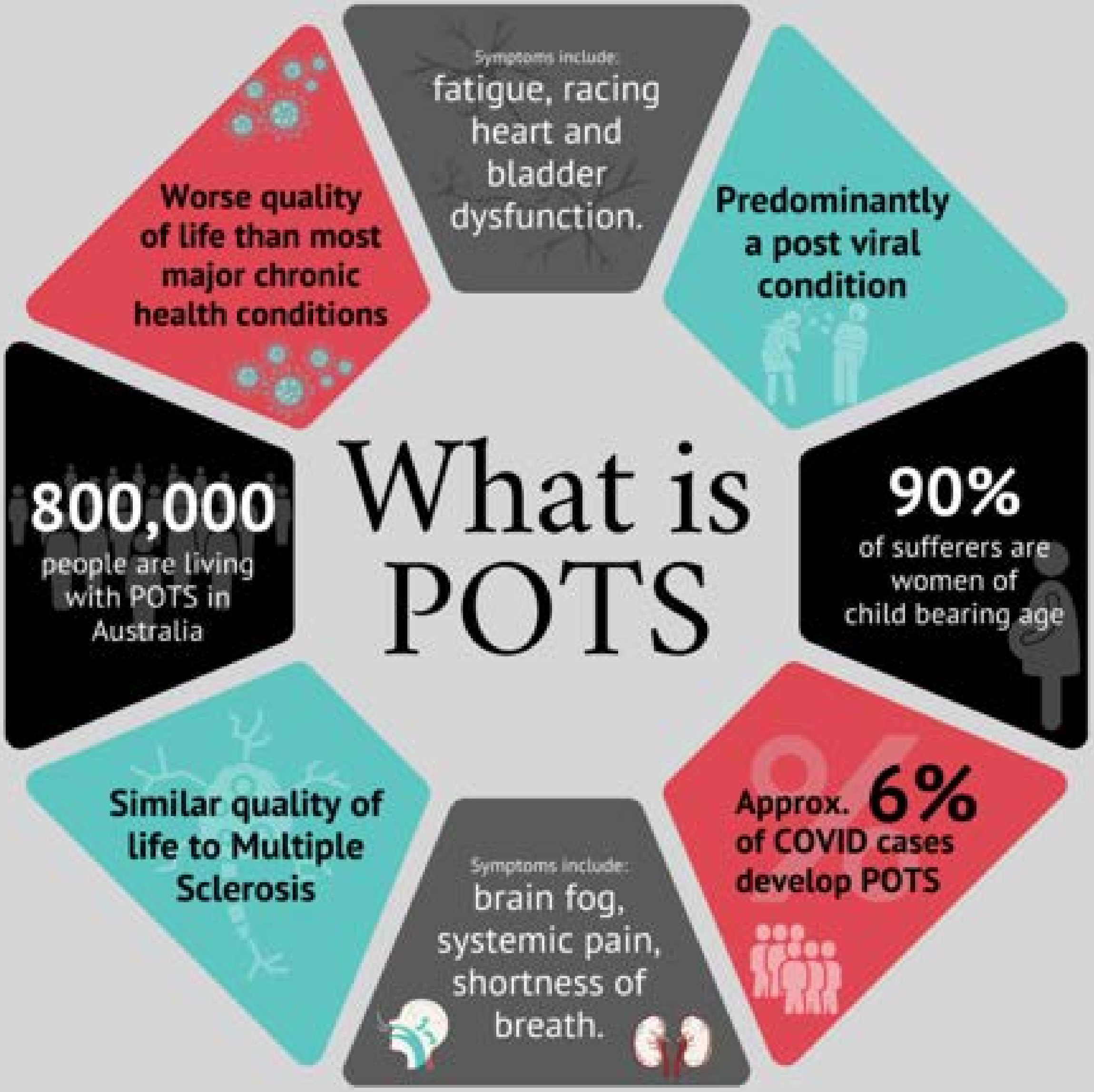
This unique position highlights the APF's pivotal role in advocating for and supporting the thousands of Australians affected by this debilitating, chronic health condition.

> **"Sufferers struggle with delays to diagnosis, few effective treatments and little support to learn how to manage their condition.**
> We have much work to do, and the POTS Foundation is a giant leap forward for those living with this challenging and complex condition."
>
> Dr Celine Gallagher | Clinical Nurse | Researcher

Postural Orthostatic Tachycardia Syndrome and Autonomic Disorders

POTS is an autonomic nervous system disorder most commonly triggered by viral infection. The condition predominantly affects women of childbearing age and results in debilitating symptoms which impact cognitive, cardiac, respiratory, gastrointestinal, and bladder function, often resulting in profound functional disability.

With the advent of the COVID pandemic the prevalence of POTS has increased from an estimated 1.5% to 3.5% of the total population[1]. This means that >800 000 Australians are currently estimated to be affected by POTS. This surge in prevalence has intensified the burden on the Australian health system and the community demands for assistance from the APF[2].



What is POTS

Worse quality of life than most major chronic health conditions

Symptoms include:
fatigue, racing heart and bladder dysfunction.

Predominantly a post viral condition

800,000
people are living with POTS in Australia

90%
of sufferers are women of child bearing age

Similar quality of life to Multiple Sclerosis

Symptoms include:
brain fog, systemic pain, shortness of breath.

Approx. 6% of COVID cases develop POTS

See Page 14 for the full list of statistic references.

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

See Page 14 for the full list of statistic references.

The Australian POTS Foundation | Achievements to Date

- Established the first Australian patient registry for POTS in collaboration with the University of Adelaide.
- Authored a submission to the National Women's Health Advisory Council detailing the inequity of provision of care for women and girls with POTS in Australia.
- Presented a submission to the Australian Parliament Inquiry into Long COVID and Repeated Infections, presenting compelling research showcasing the prevalence of POTS in Long COVID.
- Successfully advocated to the Independent Health and Aged Care Pricing Authority (IHACPA) for the recognition of POTS through the adoption of a unique ICD code in Australia.
- Established and facilitated the Long COVID Consumer and Community Advisory Body which informed the recent round of Long COVID MRFF grants exemplifying our commitment to consumer driven research.
- Conducted lectures and conferences across Australia, educating over **500 clinicians** about POTS.
- Raised over **$300,000** to support the foundation's crucial work in community support.
- Established a clinician registry of over **130 practitioners** and growing.
- Achieved growing recognition nationally and internationally with multiple invitations to present our research at medical conferences.
- Delivered a series of webinars, which have attracted over **1,200** registrations.
- Expanded its reach through various platforms, with over **20,000** users engaged via our website and social media channels.
- Invested in the future of POTS research by providing scholarships to postdoctoral fellows, PhD students, and summer research interns, fostering a community of scholars dedicated to advancing the understanding and management of POTS.
- Collected over **3,000** signatures on a petition, urging funding for critical POTS-related research initiatives in Australia.


[redacted]

Summary of Recommendations

POTS presents unique challenges for patients, clinicians, and caregivers, and there is an urgent need for targeted initiatives to enhance awareness, diagnosis, understanding and treatment of the syndrome.

Guided by the latest advancements in POTS research and driven by our commitment to improving the lives of individuals affected by POTS, we are seeking a modest allocation of $900 000 in funding spread over the next three years, which we will aim to match through fundraising and engagement of philanthropic partners.

This comprehensive approach will empower us to make a lasting impact on the POTS community and health sector in Australia, as set out in the following **4** detailed recommendations.

1. Mapping Inequity and Socio-Economic Burden

Objective | To systematically map and document health risks, socio-economic burden inequities, and barriers to healthcare and disability access for those affected by POTS and their carers.

- In collaboration with existing research partners from the University of Adelaide, South Australian Health and Medical Research Institute (SAHMRI), RMIT, Burnet Institute and Deakin University, we will research the economic burden and financial toxicity of POTS. Our aim is to identify disparities but also contribute essential data to economic research, facilitating a holistic understanding of the challenges faced by individuals with POTS in priority populations.

- Through consumer engagement methodologies, we will actively involve community members in exploring and documenting their experiences with federal healthcare access, education, workplace environments, and disability support schemes, ensuring a focus on priority populations. This data will enrich and inform government health and disability policies that affect persons with autonomic disorders.

Financial Allocation: $300,000 over three years to facilitate community and researcher engagement and data collection which will inform development of policies, resources and health guidelines.

PROGRAM	FINANCIAL YEAR	FUNDING
Research	2024-25	$100,000
Research	2025-26	$100,000
Research	2026-27	$100,000

"I have had POTS symptoms for 23 years but only recently was diagnosed due to lack of education and a medical code for the disease.

There are treatments available that have helped me manage and improve the symptoms which could have made a difference to my life decades ago had they been recognised."

Change.org petition

2. Expanding the POTS Patient Registry

Objective | To develop a sustainable source of socioeconomic and health data that informs future health policy and initiatives.

The Australian POTS Registry was established as a 'proof of concept' through investigator led work at the University of Adelaide. Over three years the registry has enrolled >500 participants, predominantly from South Australia. Data from the registry has been published in multiple high standing international peer reviewed journals and has informed submissions to Australian parliamentary hearings:

- Building on three years of research work, expansion of the registry to a nationwide platform will allow for an enriched view of epidemiological aspects of POTS in Australia. This objective will enhance understanding of sociocultural, geographic, and health risk profiles of those with POTS.

- Leveraging existing partnerships with SAHMRI and the University of Adelaide, the registry will be expanded to include multiple clinical enrolment sites across Australia ensuring a nationwide representation and fostering partnerships with clinicians and medical institutions across different states.

Financial Allocation: $450,000 over three years to facilitate the expansion of the Australian POTS Registry.

PROGRAM	FINANCIAL YEAR	FUNDING
Patient Registry	2024-25	$150,000
Patient Registry	2025-26	$150,000
Patient Registry	2026-27	$150,000

> **"An illness doesn't need to be life threatening, to be utterly life changing.**
> I am deeply appreciative of the care provided by my family, my team of caring health professionals and the incredible people at the
> **Australian POTS Foundation for providing the gateway to recovery and living well with POTS."**
>
> Catherine Munster | Long COVID sufferer

3. Development of Educational Resources

Objective | To enhance the capacity of those affected by POTS and key community stakeholders by:
Using co-design and consumer engagement methodologies, we will:

- Develop customised community educational resources which promote health literacy, self-advocacy and workplace engagement, enhancing access and inclusion for our community.
- Develop a suite of key stakeholder educational resources with an aim to reduce barriers to diagnosis, improve symptom management and improve health outcomes.
- Equip and train clinical educators to promote awareness and understanding of autonomic disorders amongst health professionals.

The use of online and digital platforms for delivery of these initiatives will ensure national accessibility overcoming geographical barriers to equitable care for priority populations with POTS.

Resource Allocation: $150,000 over three years to create and disseminate educational resources targeting clinicians, patients, carers, workplaces, and educational institutions.

PROGRAM	FINANCIAL YEAR	FUNDING
Education Resources	2024-25	$100,000
Education Resources	2025-26	$25,000
Education Resources	2026-27	$25,000

> "Educating myself via an **Australian POTS Foundation free online webinar, was my pathway to a diagnosis by a cardiologist – after languishing for almost a year untreated,** because no 'pathway' presently exists in our medical system for this really quite common illness."
>
> Change.org petition

4. Investment in Research

Objective | To reduce the health and socioeconomic impact of POTS in Australia through innovative and clinically translatable research initiatives.

The APF urges the allocation of funds from the Medical Research Future Fund to specifically encourage and incentivise Australian POTS research. Funds should be directed towards development of:

- Competitive and prestigious researcher programs to retain, sustain and grow the pool of high-quality researchers in Australia; individuals who have excelled or show potential to excel in POTS and autonomic disorder research.
- Consumer led research that characterises the prevalence, risk profile, epidemiological, socio-economic and long-term impacts of POTS in Australia with an emphasis on women and girls.
- Consumer co-design research that explores the effectiveness of interdisciplinary models of management and POTS.
- Pre-clinical studies that explore the biomechanisms of POTS to enable the effective development of treatments.
- National clinical trials and Australian arms of international clinical trials.
- Investment to establish, build and audit national care pathways.

Building Capability for Long-Term Sustainability

The Australian POTS Foundation is committed to building internal capability and systems for long-term sustainability. This includes the implementation of a clear and comprehensive strategic plan aligned with the evolving needs of the POTS community, strengthening governance structures through regular reviews, leadership development, and a focus on financial sustainability.

Diversification of funding sources are regularly explored, including grants, donations, partnerships, and other potential income streams. Evaluation frameworks for all programs ensure effectiveness and data-driven decision-making, while the utilisation of technology for streamlined internal processes, communication, and data management enhances our efficiency.

As we navigate the complex landscape of POTS advocacy, the APF remains resolute in its mission, poised to make enduring advancements that positively impact the lives of those affected by POTS.

> "There is an urgent need for dedicated efforts to improve the understanding of the causes of POTS, as well as its diagnosis and treatment.
> **The Australian POTS Foundation has the potential to raise awareness of POTS in Australia and to improve health outcomes of many who suffer from this debilitating condition."**

Professor Dennis Lau | Cardiologist | Researcher

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Footnotes

[1]Blitshteyn, S. and A. Fedorowski, The risks of POTS after COVID-19 vaccination and SARS-CoV-2 infection: more studies are needed. Nature Cardiovascular Research, 2022. 1(12): p. 1119-1120.

[2] Seeley, M.C, et al., High incidence of autonomic dysfunction and postural orthostatic tachycardia syndrome in patients with long-COVID: Implications for management and healthcare planning. American Journal of Medicine, 2023.

[3] Seeley M.C, et al. Impact of Long-COVID on Australian Sufferers: Implications for Healthcare Planning. Heart, Lung and Circulation. 2023. DOI: 10.1016/j.hlc.2023.09.002.

[4] Seeley M.C, The socioeconomic impacts of POTS in Australia: The Australian POTS Registry [manuscript in preparation]

[5] Seeley M.C, et al., Poor health-related quality of life in postural orthostatic tachycardia syndrome in comparison with a sex- and age-matched normative population. Clinical Autonomic Research. 2023 Aug;33(4):469-77. DOI: 10.1007/s10286-023-00955-9. Cited in: Medline.