Australian POTS Foundation

Annual Report

2025

More than 800,000 Australians live with POTS

Our Year in Review

2024/25 has been one of momentum and maturity for the Australian POTS Foundation. Building on four years of focused advocacy, we entered 2025 with renewed energy and achieved an historic milestone: the introduction of Australia's first ICD-10-AM diagnostic code for Postural Orthostatic Tachycardia Syndrome (G90.81). This long-fought for recognition represents a turning point for patients and clinicians alike, paving the way for improved diagnosis, research, and access to care.

Sustained entirely by volunteers and strengthened through collaboration, the Foundation continues to grow in reach and impact, building a future where every person living with POTS can access understanding, evidence-based care, and hope.

'Before finding APF, I felt isolated and unheard. Now I feel part of a community that truly understands'.
Anonymous Participant, Resource Survey

"Untangling the myriad of life altering symptoms that developed after a COVID infection left me confused, scared and isolated. Finding the POTS foundation was pivotal to transition to managing my condition and adapting to a new normal. I found resources, strategies and most importantly- hope."
Melissa Frankcomb - LEAN Member

Message from the Incoming Chair

This year marks an exciting new chapter for the Australian POTS Foundation as we approach our fifth anniversary. I am honoured to follow founding Chair Amanda Burgan, whose leadership helped establish the Foundation's strong governance and strategic direction. I also extend our sincere thanks to Peter Burgan for his contribution in overseeing our financial management and governance during the Foundation's formative years.

Over the past year, we have made significant progress – from the recognition of POTS with its own ICD-10-AM code, to strengthening research collaborations, expanding clinician education, and building national awareness. Our community of members, volunteers, and partners continues to grow, reflecting the increasing recognition of POTS across Australia.

Looking ahead, our focus is on deepening research partnerships, expanding education and advocacy programs, and developing sustainable funding to support our mission. Together, we will continue driving meaningful change, improving understanding, diagnosis, and care for all Australians living with POTS.

Catherine Cooper
Chair of the Board

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.

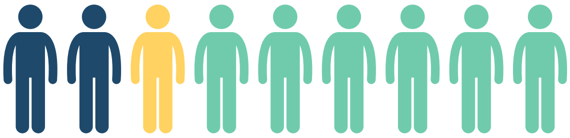
Fundraising & Research Support

$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.

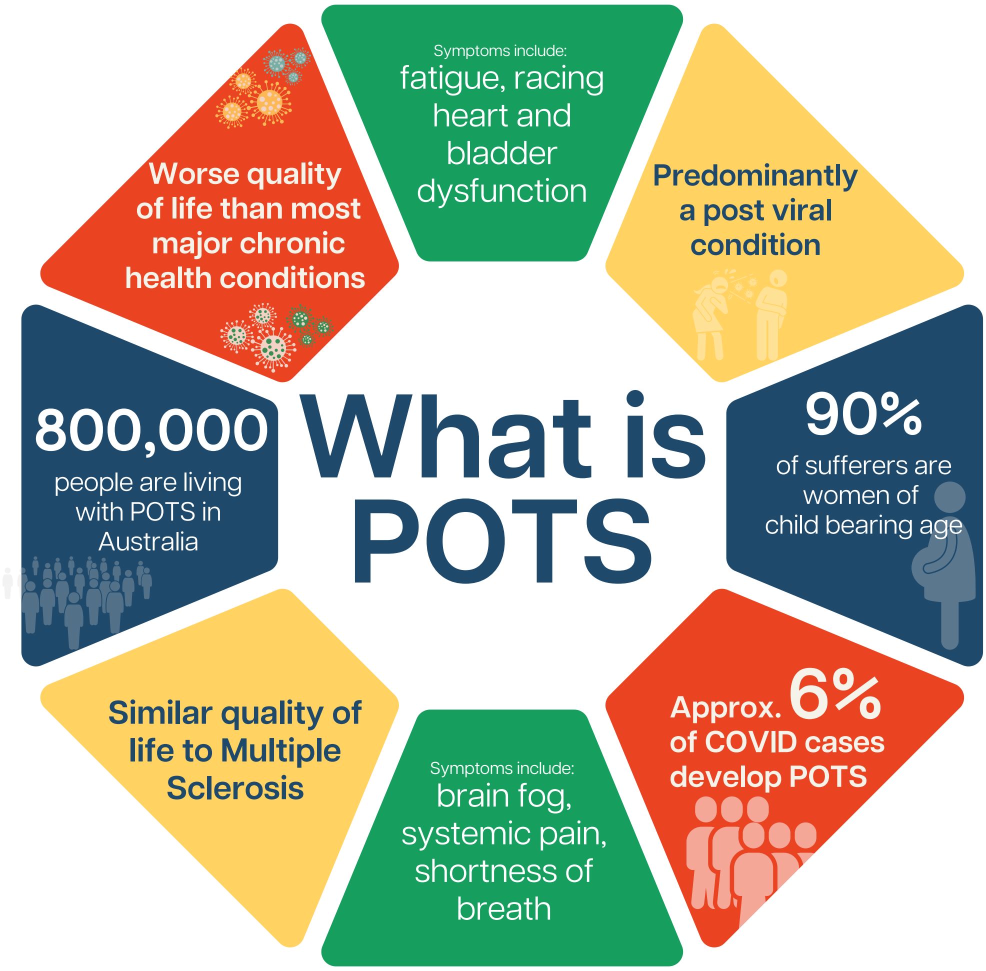
2,500 responses in national surveys on education & GP knowledge.

What is POTS?

POTS is a condition that affects the autonomic nervous system, which controls automatic body functions such as heart rate, blood pressure, and digestion. Around 90 per cent of those affected are women, with symptoms most often beginning during adolescence or early adult life. The condition causes a range of disabling symptoms including fatigue, dizziness, brain fog, and a rapid heartbeat.

Since COVID-19, the number of people developing POTS has risen sharply, with more than 800,000 Australians now living with the condition. Life with the disorder can be extremely challenging. Research shows that people affected often have a poorer quality of life than those with many other major chronic illnesses, and around 58 per cent are forced to give up work or their careers because of its impact.

Yet in Australia, the condition remains poorly recognised and frequently overlooked. On average, it takes around seven years to receive a diagnosis. There is still no access to government-subsidised medications, and diagnostic testing and treatment are often unavailable outside a few specialist centres, leaving many people without appropriate care or support.



What is POTS

Symptoms include:
fatigue, racing heart and bladder dysfunction

Predominantly a post viral condition

90%
of sufferers are women of child bearing age

Approx. 6% of COVID cases develop POTS

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

Similar quality of life to Multiple Sclerosis

800,000
people are living with POTS in Australia

Worse quality of life than most major chronic health conditions

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

CEO Report 2025

As a volunteer-run organisation, I'm incredibly proud of how much we've achieved this year. In 2025, the Foundation continued to punch well above its weight – driving national advocacy, expanding research collaborations, and strengthening support and connection within the POTS community across Australia.

Advocacy

This year our advocacy focused on achieving practical, system-level change to improve diagnosis, care, and recognition of POTS across Australia. A major milestone came on 1 July 2025 with the introduction of Australia's first official diagnostic code for POTS (G90.81). This long-awaited step allows accurate recording within medical systems, improving national data, awareness, and visibility.

We continued to work with the Federal Department of Health to progress revisions to the Medicare Benefits Schedule, advocating for broader access to tilt table testing in both hospital and community settings. This change would ease pressure on specialist centres and support faster, local diagnosis.

In parliament, Questions on Notice confirmed that no funding from the Medical Research Future Fund or National Health and Medical Research Council has ever been directly allocated to POTS research—highlighting the urgent need for investment and policy attention.

Throughout the year, the Foundation has strengthened relationships with policymakers, Primary Health Networks, and national health organisations to ensure POTS is represented in planning, policy, and education. Encouragingly, two federal senators have expressed support for key advocacy goals that will guide our 2026 agenda. These commitments mark real progress toward lasting, system-wide reform for people living with POTS.

Rebecca Morse
(Open Medicine Foundation)
with Marie-Claire

Sue Hutley (CTDNA)
and Marie-Claire

Marie Ludlow and Vanessa Poulsen (Heart Foundation), Celine and Marie-Claire

CEO Report 2025 cont'd

This year also marked the first full year of our Lived Experience Advisory Network (LEAN) – a diverse group from across Australia who bring lived experience into every aspect of our work. Members generously give their limited energy to share insights and feedback that shape programs, research, and priorities. Their honesty and commitment have made LEAN a vital part of the Foundation's direction.

We also partnered with HealthED, one of the nation's largest GP education providers, to deliver POTS education on a national platform. Our in-house clinical training program continues to expand, engaging and educating registrars, physiotherapists, nurses, and physicians across multiple states in both public and private healthcare settings.

Collaboration with national Primary Health Networks has also led to the inclusion of POTS in several Community HealthPathways, providing guidance for thousands of GPs on recognition, diagnosis, and management.

Together with our growing suite of digital education resources, these multipronged initiatives are now reaching tens of thousands of Australian clinicians each year.

> *I was motivated to become a LEAN member because of my awareness of the gaps in healthcare for people with chronic illnesses, both from my lived experience and as a healthcare professional. I have a strong desire to contribute to driving change on both individual and systemic levels. Disha*

> *A desire to improve people's lives is what motivated me to become a member of the LEAN. I have faced horrid medical gaslighting at the hands of those in the hospital system who were supposed to help me, and so I wish to turn this betrayal into something positive. I am a passionate youth advocate and I want to use and develop my skills and experience in order to try to lessen our suffering. Matthew*

Find out more about our LEAN
https://potsfoundation.org.au/community-engagement

HealthEd Brisbane 2025

CEO Report 2025 cont'd

Education

Outcomes from our national GP Education Survey in 2025 showed that 80% of GPs had never received education or training in POTS. To directly address these deficits, we upscaled our clinical education program. After securing RACGP accreditation, we launched Australia's first RACGP-approved continuing professional development program for POTS.

They can't diagnose what they don't know.

GP EDUCATION IN FOCUS:

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

Training & Awareness on POTS

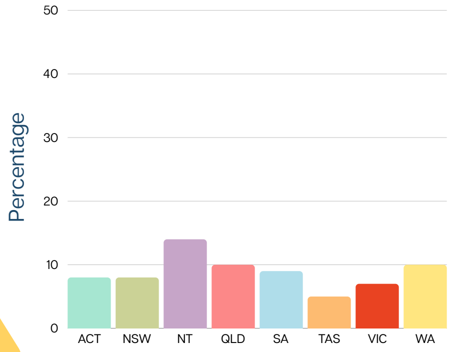
Four in five clinicians (80%) report never having education on POTS.

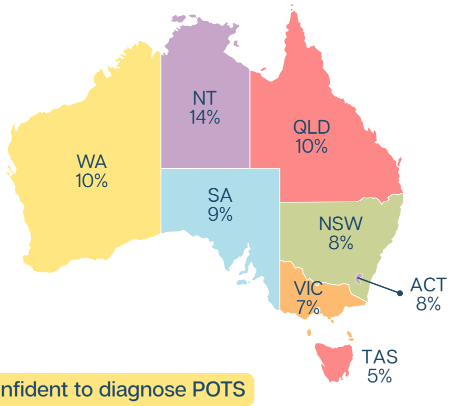
Only 2% of GP's say they received adequate education on POTS during medical school.

≈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 confident to diagnose POTS

A lack of training directly contributes to widespread uncertainty and low confidence in managing 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.

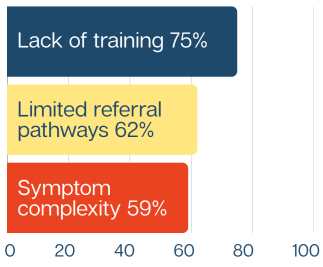
Confidence in Care

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.



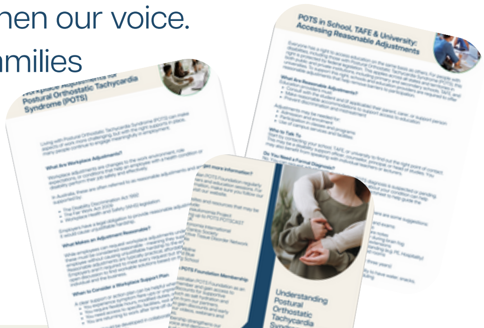
CEO Report 2025

Community Support

It has been a big year for community engagement and connection. The redevelopment and launch of our new national website, supported by a grant from Pubs with Heart and developed by EnvyUs Design, has transformed how people find and share information about POTS. Now attracting over a quarter of a million visitors each year, it serves as a trusted national hub for reliable, evidence-based information.

The Resource Hub now hosts more than 150 materials, including 14 new patient information sheets, free webinars, podcasts, conference recordings, and government submissions – making it easier for people with POTS, their families, and clinicians to access credible Australian content in one place.

As I reflect on our work across education, advocacy, research and community support, I am grateful for the people who make it possible. Our skilled Board continues to guide the Foundation with care, and we are supported by volunteers who contribute their time and expertise. Special thanks to Claire Clark, who gives so much of her limited energy to keep us moving forward, and to Yasmin O'Brien, who supports our finance and governance functions. I also want to thank our ambassadors Sophie Scott, Tracey Spicer and Emma-Louise Wilson for helping to raise awareness and strengthen our voice. Finally, to our community of people with lived experience, their families and those who stand beside them, thank you. Your experiences and encouragement continue to drive our work.

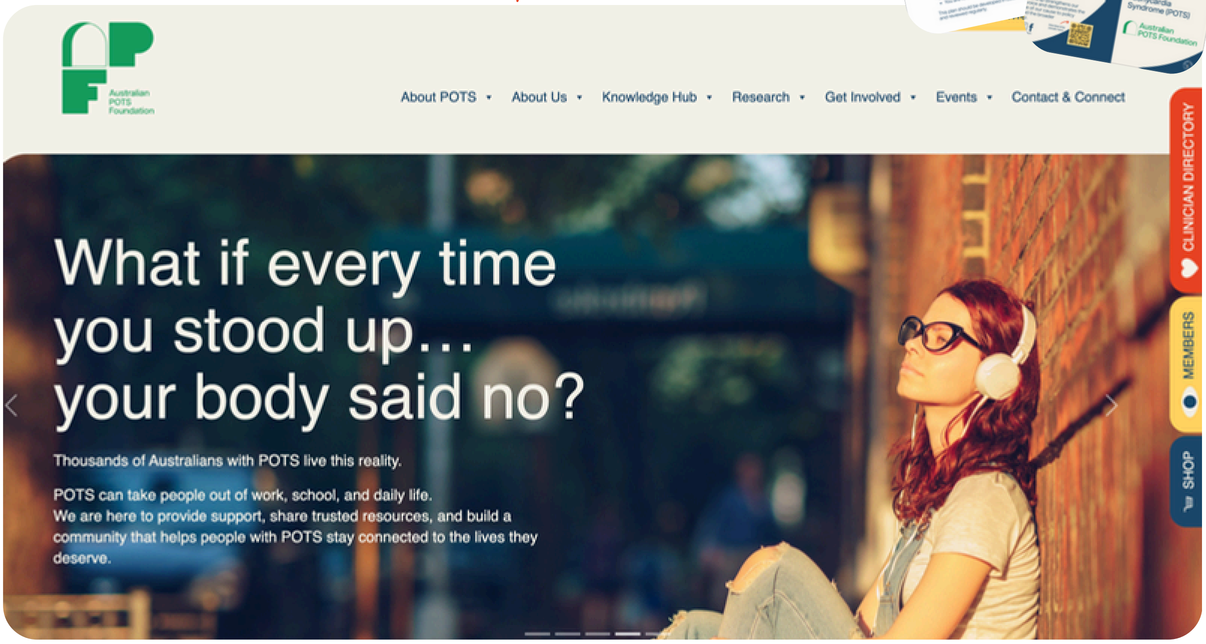


POTS in School, TAFE & University: Accessing Reasonable Adjustments

Workplace Adjustments for Postural Orthostatic Tachycardia Syndrome (POTS)

Understanding Postural Orthostatic Tachycardia Syndrome (POTS)

Yours,
Marie-Claire



What if every time you stood up… your body said no?

Thousands of Australians with POTS live this reality.

POTS can take people out of work, school, and daily life. We are here to provide support, share trusted resources, and build a community that helps people with POTS stay connected to the lives they deserve.

Education Impact

This year we conducted our first national Education Survey examining how POTS affects schooling and study. Results showed high rates of absenteeism and a significant impact on family routines and wellbeing.

Educational Disruption: The Impact of POTS on School and 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% of them **quit all paid work**

$40,046 annual income loss (**2.85 years'** worth)

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% Unable to obtain **driving license**

Data from Australian POTS Foundation's 2025 Lived Experience Survey

Research

In 2026, the APF will support a $50,000 Research Grant, supporting the redevelopment and expansion of the Australian POTS Registry in collaboration with the University of Adelaide. This initiative aims to establish a robust, secure, and scalable national database to advance research and clinical understanding of Postural Orthostatic Tachycardia Syndrome (POTS). The earlier version of this database has supported many pivotal publications and informed understanding of POTS in Australia, and we look forward to the opportunity to expand on this fabulous initiative.

Over the past year, APF has fostered new collaborations with national partners through multiple Medical Research Future Fund (MRFF) grant applications, ensuring consumer representation and lived experience is firmly embedded in all our partnerships. This has included support for applications from the Burnet Institute, RMIT, the University of Melbourne, the University of Sydney and the University of Adelaide to name but a few!

The APF has continued to advance research, with support for one Research Fellow, two PhD students with top up scholarships, and one physician to attend an autonomic training course in Florida USA with a view towards sharing their newfound knowledge with their colleagues and peers.

There have been multiple national and international presentations from our CEO and supported researchers in addition to multiple publications arising from their fabulous work– see our newly renovated website for further information on how the APF's leadership is advancing research, collaboration, and care for individuals living with POTS in Australia.

'The primary goal of my research is to demonstrate the need for more effective diagnostic pathways, and publicly funded clinics to support patients with POTS and their families. We know that the majority of patients in Australia have no choice but to seek private care, which is unaffordable for many. Research that can improve universal access to care for this condition, is paramount right now'.

Gemma Wilson
PhD Scholar

Research cont'd

This year, we're proud to announce the expansion of our Scientific Committee into the newly named Scientific and Medical Advisory Committee, reflecting our commitment to multidisciplinary, evidence-informed care and research.

We are proud to welcome three distinguished experts who bring valuable knowledge and experience to our already well-established Scientific and Medical Advisory Committee.

Dr Michelle Scoullar, a paediatrician, global health specialist, and Senior Research Fellow at the Burnet Institute, brings a strong focus on health equity and child health outcomes. She leads the paediatric stream of a Long COVID specialist clinic, providing compassionate, evidence-based care for children and adolescents affected by post-viral conditions.

Dr Emma Tippett, is an infectious diseases physician and clinician-researcher with more than a decade of experience in immunology, public health, and complex patient care. She completed her PhD in HIV immunology at the Burnet Institute and now leads a private specialist clinic supporting patients with Long COVID and related conditions.

Caelum Schild, is a senior Accredited Exercise Physiologist known widely within the POTS community for his leadership in movement-based care. With over 15 years of clinical experience and personal insight into living with orthostatic intolerance, Caelum leads APF's guidance on exercise in POTS and continues to contribute to research through the Australian Dysautonomia and Arrhythmia Research Collaborative.

Together, our expanded committee strengthens the Foundation's capacity to inform research, influence policy, and support best-practice care, anchored in lived experience and clinical excellence.

POTS clinicians and researchers at Cardiac Society of ANZ 2025

Celine

Dr Celine Gallagher
Scientific Chair

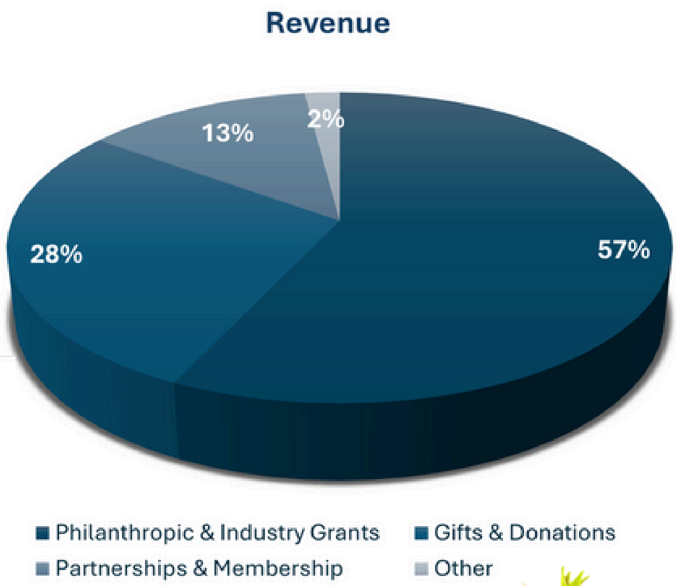
Financial Snapshot

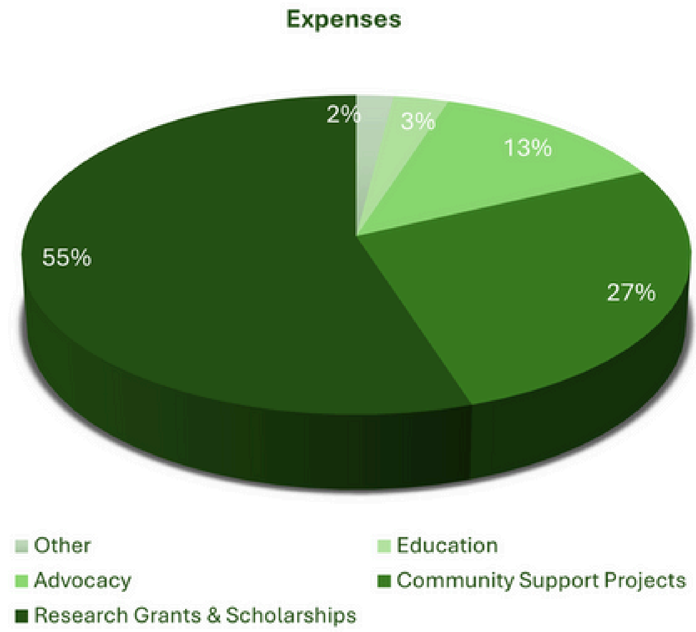
In 2025, the Foundation strengthened its financial position, thanks to the generosity of our community and increased support from corporate and philanthropic partners. Total income rose by 73% compared to the previous year, with donations and bequests playing a major role. Careful financial management resulted in a surplus of $55,708.

During the year, we marked a major leadership transition, with Peter Burgan, a founding Director and our long-standing Treasurer, stepping down from his role. Peter was instrumental in establishing a strong financial foundation for the organisation, and we are deeply grateful for his service and dedication. With his retirement, we implemented Xero as our new accounting platform and successfully completed an independent audit with William Buck Chartered Accountants, strengthening our financial systems for the future.

Investments in 2025 focused on research grants, website redevelopment, and planning for our national conference in 2026. Looking ahead, our financial strategy remains focused on sustainability, income diversification, and supporting long-term impact through strategic growth.

Total Revenue	$265,681
Total Expenses	$209,973





Stories From Our Community

As I neared the end of Year 12, ready to embrace independence and new beginnings, my life was upended by a diagnosis of POTS. What started with confusing symptoms quickly became debilitating, experiencing overwhelming fatigue, pain, and nausea, that altered by ability to study, work, socialise, and manage daily life. Very quickly I went from active and dancing every day, to struggling to get out of bed. Over the past four years, I have tried many treatments and strategies to manage my symptoms and while I have gradually seen some improvement, POTS continues to be a significant part of my life.

Navigating an often misunderstood condition means facing uncertainty and searching for solutions that aren't always simple. The difference a truly supportive health professional can make cannot be overestimated. Learning to live with what may not always be fully resolved, while still holding hope for progress, has become an important part of my journey.

Illness doesn't just affect the body, it reshapes everyday life, relationships, and how you approach the world. As a young person, navigating POTS has been unexpected and, at times, profoundly isolating. Yet through this journey, I have learnt to value every day, to lean on family, and to deepen my compassion for others. Kindness, listening, and understanding can go further than we often realise.

Raising awareness and investing in research are vital. No one should face this journey alone. There is hope, for better care, for connection, and for a future where every person with POTS feels seen, supported, and empowered.

Edie Lives with POTS

Stories From Our Community

Running has kept me healthy and somewhat sane during my adult life. Entering the big Marathons around Australia and even the world has always been a dream for me, but running the Sydney Marathon dressed as a flowerpot?? Well, not exactly on the bucket list!

One day this winter on a training run, I was questioning my motivation and feeling a bit flat. I'd had a busy week of consulting and had seen a few patients with POTS. One in particular was debilitated with her condition. She was trying so hard to stay well and functional. That consult was quite profound. It struck me that I was able-bodied, and that I shouldn't take that for granted. So I came up with the idea to run for POTS, "Because I can". And it worked!

The training was more purposeful, the fundraising successful and the race all the more enjoyable running for this cause. I could not have anticipated the massive crowd reaction to seeing me run in a silly Flowerpot outfit ! So much fun. Thanks to the POTS Foundation for supporting the project - its been a pleasure supporting you. Dr Paul Muffet

Olivia is an Accredited Exercise Physiologist, PhD Student and a passionate POTS Advocate.

Three years ago, I accepted a referral for a patient who was referred to our Cardiac Rehabilitation service with an ‘unknown condition’ that began shortly after a COVID-19 infection. She went from being an active 20-year-old to being debilitated by fainting, fatigue, palpitations, dizziness, brain fog, and exercise intolerance.

During each rehabilitation session, I gained further ‘clues’ which pointed to POTS being the likely cause of symptoms for her. A diagnosis that was initially rejected as a possibility but eventually confirmed after months of persistence and diagnostic testing.

Walking alongside this patient from uncertainty to diagnosis, and observing the hurdles along the way, in addition to seeing firsthand the impact of POTS in the lives of friends, has sparked my passion for supporting & advocating for individuals with POTS.

Since this patient, I have worked clinically with other individuals with POTS and have more recently launched a pilot POTS-specific pathway through the Chronic Conditions Service I work for. It is my hope that this will increase opportunities for individuals with POTS to access tailored care in the public health system. I have also recently enrolled in a PhD program, through which I hope to contribute to furthering research into exercise-based interventions tailored for POTS. Olivia Powrie

Looking Ahead to 2026

2026 will mark the Foundation’s 5th anniversary– quite a milestone for a volunteer-led organisation operating without government funding. Our focus remains on driving advocacy to secure financial, structural, and policy support for research, national education programs, and health reforms that improve recognition and care for people with POTS.

New collaborations with national health bodies are positioning the Foundation within a supportive network of like-minded organisations. These partnerships will strengthen our voice, broaden expertise, and increase our impact.

Keynote Speakers

Professor David Putrino – Professor of Rehabilitation and Human Performance at the Icahn School of Medicine, Mount Sinai, and Director of the Cohen Center for Recovery from Complex Chronic Illness. A 2019 “Global Australian of the Year,” his pioneering research has shaped care for thousands living with Long COVID, ME/CFS, and chronic tick-borne illness.

Dr Alexis Cutchins, MD – Recognised globally for her clinical expertise in POTS, MCAS, Long COVID, and Ehlers-Danlos Syndrome, Dr. Cutchins has published extensively on best-practice management and the role of pelvic venous disease in orthostatic intolerance. After 13 years as Assistant Professor at Emory University, she now leads Cutchins Cardiovascular Medicine in New York City.

https://www.apfconference.com.au

Our Team

Dr Marie-Claire Seeley
Founder/Director/CEO

Catherine Cooper
Director/Chairperson

Nick Baldock
Director/Secretary

Amanda Burgan
Director

Dr Celine Gallagher
Director/Scientific
Chair

Jon Seeley
Founder/Director

Ali Flynn
Director

Professor Dennis Lau
Scientific Committee

Dr Fraser Burling
Scientific Committee

Dr Michelle Scoullar
Scientific Committee

Dr Kate Anderson
Scientific Committee

Dr Emma Tippett
Scientific Committee

Caelum Schild
Scientific Committee

Yasmin O'Brien
Assistant to the Board

Claire Clark
Community
Engagement Officer

Tracey Spicer
Ambassador

Sophie Scott
Ambassador

Emma-Louise Wilson
Ambassador

Our Supporters and Partners

We are grateful to the organisations and individuals who support the Australian POTS Foundation in a variety of meaningful ways. Whether through funding, professional expertise, advocacy or in-kind contributions, our partners help ensure that our mission to improve diagnosis, treatment and quality of life for those with POTS continues to progress. Together, we are building a future with better care, stronger community support and increased awareness.

Every partnership and every donation, no matter the size, makes a real difference to this community. You can also choose to become an Education, Research or Lived Experience Patron, ensuring your support is directed to the area that matters most to you. If you would like to explore how you or your organisation could support our work, we welcome a conversation. This includes opportunities to partner with us for Converge 2026, our national Community and Scientific Conference.

PARTNER WITH PURPOSE

> “Australia is well behind other countries in recognising POTS and providing good treatment pathways.
>
> I am honoured to be an ambassador for the Australian POTS Foundation. Too many patients are misdiagnosed or waiting for treatment to improve their quality of life. The POTS Foundation does an excellent job in providing evidence-based information and raising awareness of this neglected condition. Sophie Scott OAM”

“Through our partnership with APF, we reached an audience that truly benefits from what we offer. Their professionalism, passion, and grassroots reach make them an ideal partner in both impact and integrity.”

Cale, Co-Founder @ Sodii Hydration
Platinum Partner 2025

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Tissue
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DIVIDE

FMS
Finapres Medical Systems

EnvyUs Design

Healthed

University of
South Australia
Rosemary Bryant AO
Research Centre

Support a Project and Fuel Change

You can make a lasting difference by supporting one of our key initiatives designed to improve care, connection, and outcomes for people living with POTS in Australia.

1. Expanding the Australian POTS Registry

Help us transition Australia's only POTS registry into a national clinical database. This expanded registry will inform treatment, support earlier diagnosis, and drive health policy change to ensure equitable access to care.

2. Creating Essential Educational Resources

Fund the development of evidence-based tools for both healthcare professionals and the community. This includes clinical training materials, culturally appropriate patient guides, and support packs for schools and families.

3. Launching a Peer Support Program

Combat isolation and improve mental health by helping us build a national peer support network. This program will train lived-experience mentors to provide connection, guidance, and hope for newly diagnosed individuals and families.

4. Training Future Specialists in Autonomic Medicine

Support the training of registrars and clinicians in POTS care. Your donation will help grow Australia's workforce of informed providers, improving diagnosis, treatment, and long-term outcomes.

Help Us Drive Change for the POTS Community

Your contribution fuels real progress in research, education, and advocacy for those living with Postural Orthostatic Tachycardia Syndrome (POTS) in Australia. Every donation, small or large, brings us closer to a future where timely diagnosis, equitable care, and empowered voices are the norm.

98 cents in every dollar you donate goes directly to our core activities: advancing research, improving clinician education, providing community resources, advocating for health policy reform, and developing vital resources for those with lived experience.

Ways to Donate:

Online via Credit Card: potsfoundation.org.au/donate

Direct Deposit:
The Australian POTS Foundation
BSB: 015 208
Account: 153 059 214

Scan the QR Code to give quickly and securely.

Partner With Us

Business owners and organisations can create lasting impact by joining our Partner Program. Learn more in our Partner Prospectus.
https://potsfoundation.org.au/our-partners

If you’re interested in supporting a specific research project or resource development initiative, please contact us directly to ensure your gift is used for maximum impact.

YOUR SUPPORT MATTERS

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