2024 ANNUAL REPORT

AUSTRALIAN
POTS
FOUNDATION

MORE THAN 800,000 AUSTRALIANS ARE NOW THOUGHT TO BE AFFECTED BY POTS.

OUR YEAR IN REVIEW

CEO REPORT

The past year has been a transformative one for the Australian POTS Foundation (APF). While we've made significant strides in community engagement and research at a national level, the rapid growth of our community, largely driven by the impact of the COVID-19 pandemic, has brought increasing urgency and challenges in the health advocacy space. We've deepened relationships with federal and state politicians, health committees, and key departments, making meaningful progress in raising awareness and improving the lives of those affected by Postural Orthostatic Tachycardia Syndrome (POTS) across Australia. However, with these advances come new challenges, as we work to meet the growing needs of our expanding community.

Photo: Dr Celine Gallagher & Gemma Wilson
City2Bay Adelaide

Advocacy: National Engagement and Strategic Influence

The APF welcomed the recent announcement by Federal Health Minister Mark Butler regarding the allocation of $1.1 million to the National Health and Medical Research Council for the development of clinical guidelines, which will include POTS. This inclusion is a significant step forward in ensuring that POTS patients receive the attention and care they deserve.

We were disappointed to learn from the Therapeutic Goods Administration (TGA) that our application for Midodrine repurposing was rejected due to insufficient evidence for its use in POTS. This underscores the urgent need for more funding to build a robust evidence base for therapeutics in POTS.

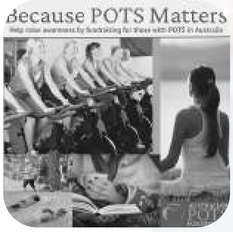
The TGA has encouraged the APF to continue collecting data through the Australian POTS Registry, providing a foundation for a future submission to the repurposing scheme. We remain resolved to continue advocating for funding to ensure that research and clinical trials can progress, ultimately improving treatment options and outcomes for those living with POTS.

Community Support: Expanding Our Reach and Impact

Supporting our community remains central to our mission. The ‘Better Together’ conference was a landmark event, drawing over 400 participants from various sectors, including healthcare professionals, students, and consumers. The positive feedback underscores the value of these connections and the strength of our community.

In March we launched our membership program which has grown to 270 members, with a target of 400 by year-end. This program provides valuable benefits to our members, such as exclusive discounts, and helps build a sustainable foundation for future initiatives.

We extend our gratitude to everyone who initiated or supported GoFundMe events in 2024, which have been instrumental in raising both awareness of POTS and essential funds. At the time of writing, over $26,000 has been raised by our community through these events, with an additional generous match by one of our philanthropic donors, bringing the total to over $46,000. This has provided a strong start to the 2025 financial year and the APF plans to use these funds to launch an open research grant call aiming to incentivise and support crucial research into POTS.



Photos: Marie-Claire Seeley delivering petition to Mark Butler's office Marie-Claire & Dr Celine Gallagher, Professor Dennis Lau and Professor Satish Raj at our Better Together conference & Members of our community participating in City to Bay in Adelaide

Research: Driving Innovation and Collaboration

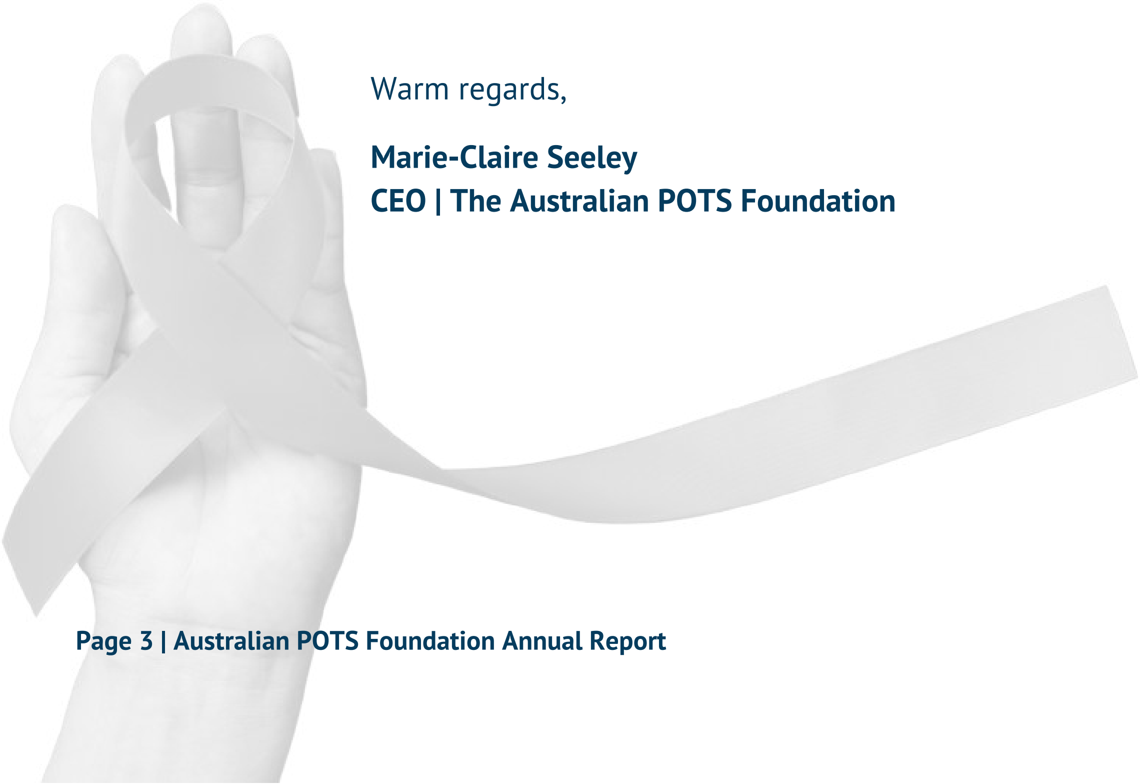
SAHMRI Research Team

In line with our mission, research continues to be a cornerstone of the APF's work. As noted in our Scientific Chair's report, our commitment to supporting and expanding POTS research remains unwavering, despite the very small pool of dedicated researchers in Australia. Our goal is to grow this pool and incentivise robust, evidence-based studies to better understand and treat this complex condition.

While we faced challenges in securing additional funding this year, including negative outcomes to multiple grant applications and pre-budget submissions, this only fuels our determination to ensure that POTS is firmly represented in national research priorities. We have taken significant steps to foster relationships with national funding bodies to advocate for increased research support.

Acknowledgment of Volunteers and Community

None of our achievements would have been possible without the dedication and hard work of our volunteers. Their commitment to our mission is the backbone of our success, and we are deeply grateful for their contributions. We also extend our heartfelt thanks to everyone who has participated in or supported our fundraising efforts, helping to ensure that the APF can continue its vital work.



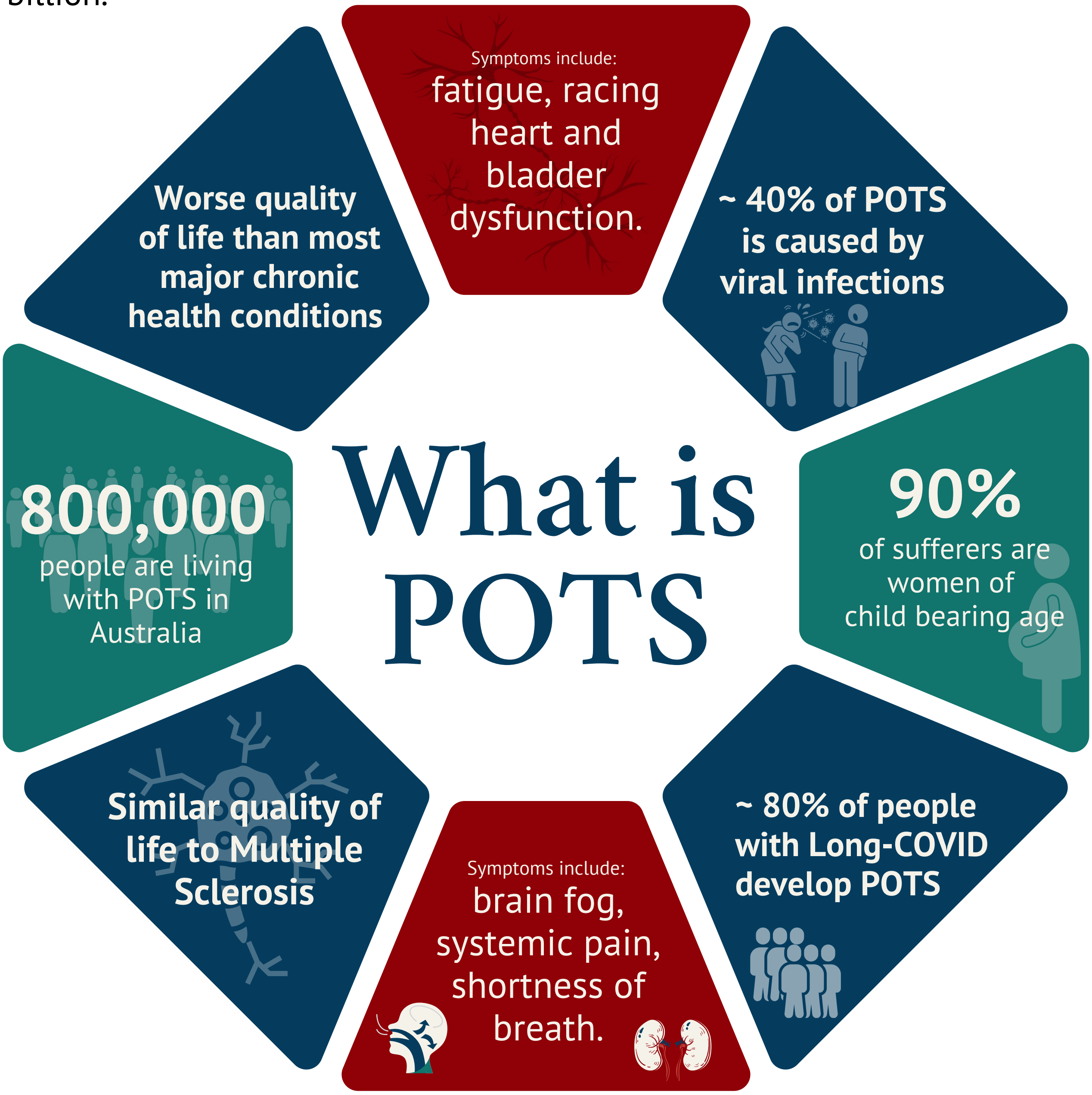
Warm regards,

Marie-Claire Seeley
CEO | The Australian POTS Foundation

What is Postural Orthostatic Tachycardia Syndrome?

POTS is a disorder of the autonomic nervous system, often triggered by viral infections. It mainly affects women of childbearing age and leads to debilitating symptoms that impact cognitive function, as well as the heart, lungs, digestive system, and bladder, often resulting in significant disability.

Since the onset of the COVID-19 pandemic, the prevalence of POTS has increased to an estimated 3.4% of the population. More than 800,000 Australians are now thought to be affected by POTS. This surge in cases has placed increasing pressure on the Australian healthcare system, with the lost productivity due to long-COVID in Australia estimated to be $10 billion.



What is POTS

Symptoms include:
fatigue, racing heart and bladder dysfunction.

~ 40% of POTS is caused by viral infections

90%
of sufferers are women of child bearing age

~ 80% of people with Long-COVID 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

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

58% of Australians with POTS are forced to permanently quit their jobs.
56% borrow money to cover treatment costs

57%

earn less than the Australian minimum annual wage while 38% live on less than $25K a year

On average people see

6

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

37%

are unable to work due to their health

8% of people with POTS report a family member or friend has permanently quit their job to help care for them

Available treatments are not currently government funded in Australia

80%

face moderate to extreme limitations in performing daily activities

Our achievements so far

Established the first Australian patient registry for POTS in collaboration with the University of Adelaide.

Authored multiple reports to inform Government Inquiries, contributing to the development of treatment pathways and health policy changes for POTS and 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

Founded the Long COVID Consumer and Community Advisory Committee, pioneering consumer engagement in long-COVID research

Conducted webinars, lectures and conferences...... educating over 1800 health professionals

Raised over **$580,000** to support the foundation's crucial work in research and community support

Established a clinician registry of over **130 practitioners** and growing.

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.

Established a community membership program, engaging sponsors to offer members valuable discounts on pertinent products.

CHAIR REPORT

Over the past year the APF has made some extraordinary achievements thanks to our exceptional team of volunteers who strive to serve the POTS community.

I wish to sincerely thank our CEO, Dr Marie-Claire Seeley, Dr Celine Gallagher; APF Scientific Committee Chair and Claire Clark our Community Engagement Officer for their tireless work to support our community, they are the driving force behind the foundation. Research has been supported through Summer Internships, a PhD Top-up Scholarship, a Post-Doctorate Scholarship, and this year, a significant research grant.

We continue to engage with policymakers to keep POTS on the health policy agenda, aiming for better patient outcomes and equitable access to care. We thank our Ambassadors, Sophie Scott, Emma Louise Wilson, and Tracey Spicer, for raising awareness through their lived experiences. We have also focused on educating the POTS community and clinicians, launching a membership program, and hosting the successful ‘Better Together’ conference, which included dedicated sessions for patients and healthcare professionals.

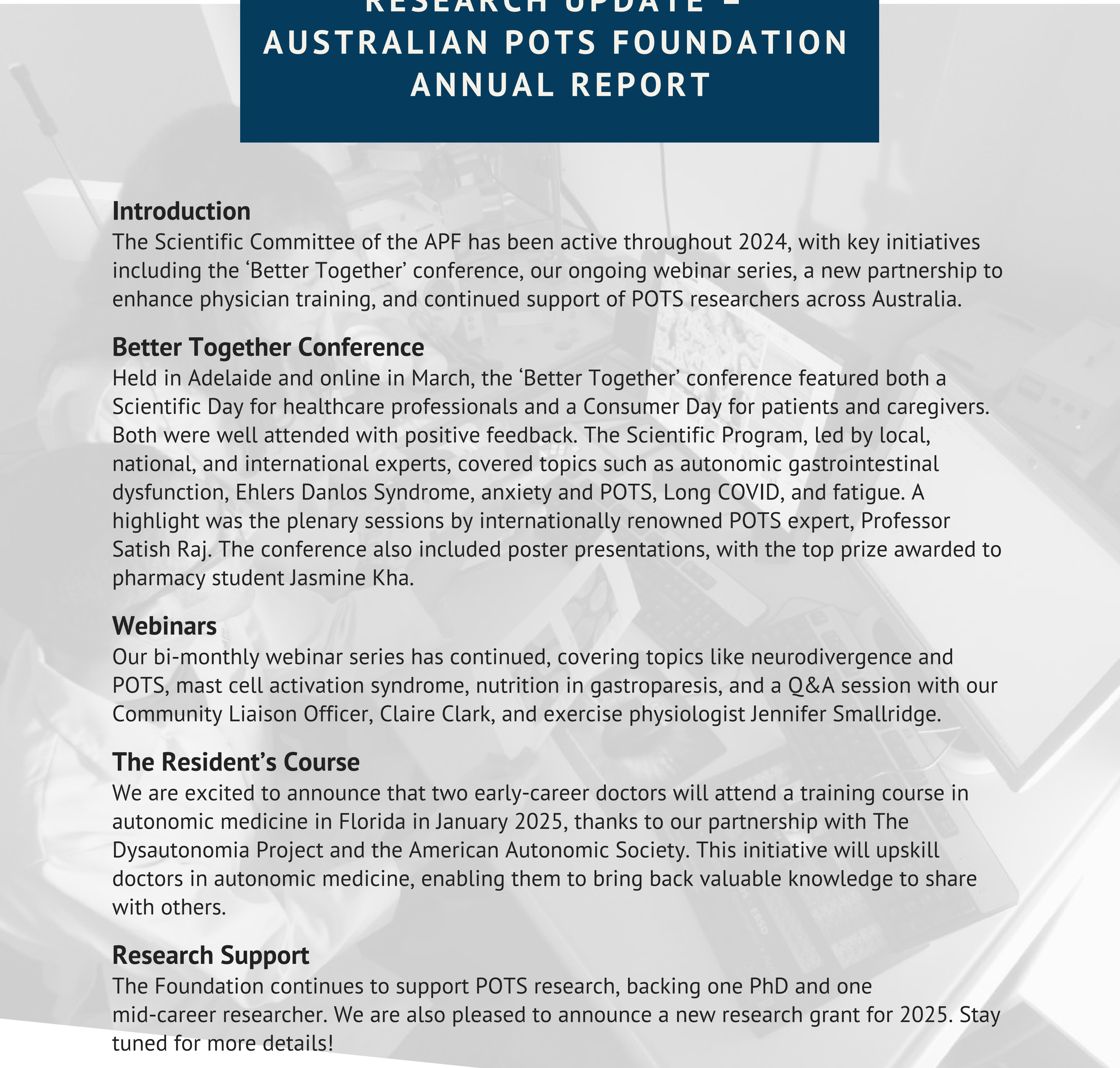
Thanks to the extraordinary work undertaken by Marie-Claire and Celine to advance the recognition and improved diagnosis of POTS, the much-needed unique International Classification of Disease (ICD) code has been approved and will be available for use from 2025.

To our Board, I extend my thanks for their ongoing support of the Australian POTS Foundation, its strategic direction, governance and financial management.

The APF Board sincerely thanks our volunteers who generously contribute their time, our donors and philanthropic funders for investing in the APF work on behalf of those with POTS.

Amanda Burgan | Board Chair

RESEARCH UPDATE – AUSTRALIAN POTS FOUNDATION ANNUAL REPORT



Introduction

The Scientific Committee of the APF has been active throughout 2024, with key initiatives including the ‘Better Together’ conference, our ongoing webinar series, a new partnership to enhance physician training, and continued support of POTS researchers across Australia.

Better Together Conference

Held in Adelaide and online in March, the ‘Better Together’ conference featured both a Scientific Day for healthcare professionals and a Consumer Day for patients and caregivers. Both were well attended with positive feedback. The Scientific Program, led by local, national, and international experts, covered topics such as autonomic gastrointestinal dysfunction, Ehlers Danlos Syndrome, anxiety and POTS, Long COVID, and fatigue. A highlight was the plenary sessions by internationally renowned POTS expert, Professor Satish Raj. The conference also included poster presentations, with the top prize awarded to pharmacy student Jasmine Kha.

Webinars

Our bi-monthly webinar series has continued, covering topics like neurodivergence and POTS, mast cell activation syndrome, nutrition in gastroparesis, and a Q&A session with our Community Liaison Officer, Claire Clark, and exercise physiologist Jennifer Smallridge.

The Resident’s Course

We are excited to announce that two early-career doctors will attend a training course in autonomic medicine in Florida in January 2025, thanks to our partnership with The Dysautonomia Project and the American Autonomic Society. This initiative will upskill doctors in autonomic medicine, enabling them to bring back valuable knowledge to share with others.

Research Support

The Foundation continues to support POTS research, backing one PhD and one mid-career researcher. We are also pleased to announce a new research grant for 2025. Stay tuned for more details!

A special thank you to our volunteer Scientific Committee members, who ensure the success of our programs: Dr Chris O’Callaghan, Professor Dennis Lau and Dr Fraser Burling. The APF would also like to welcome Dr Kate Anderson who recently joined the scientific committee.

Dr Celine Gallagher | Scientific Chair

TREASURER REPORT

PETER BURGAN

The 2023/24 Financial Year was a period where the financial position of the foundation continued to evolve thanks to a combination of organisational donations as well as private donors.

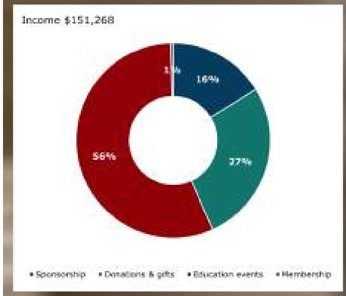
A second larger very successful conference continued to contribute to both the exposure and understanding of POTS within the medical community as well as providing a source of income for further investment.

The Board has acted to expand our investment in POTS research by launching the APF's inaugural Australian Research Grant, which will soon be announced. This grant will focus on supporting vital research to foster innovation and deepen our understanding of POTS across Australia. In addition, we will continue supporting PhD students through top-up scholarships and provide further backing for post-doctorate researchers and Internships, strengthening the pipeline of future researchers dedicated to this condition.

Thank you to the Board, our donors, supporters, members and volunteers whose efforts continue to make a difference to our community.

Peter Burgan | Treasurer

Opening balance	$221,409
Total revenue	$151,268
Total expenses	-$202,309
Closing balance	$170,368



POTS Foundation

Strategic Plan

We Believe In

- ✓ Enabling community informed and driven research, advocacy and support
- ✓ Equity of access to diagnosis and treatment of POTS
- ✓ Enabling 'consumer voices' to inform policy and research
- ✓ Improving care through development of best practice guidelines
- ✓ Influencing change within government and the health care system to better support those with POTS
- ✓ In building an inclusive community to support those with POTS and their families
- ✓ **Transforming understanding and enacting change through the power of lived experiences**

Our Values

COMMUNITY | **KNOWLEDGE** | **RESPECT** | **INCLUSION** | **CARE**

Key Themes

Providing education, resources, and advocacy grounded in lived experiences

Fostering research and innovation by funding priorities driven by community needs

Key Enablers – Fundraising, Communications and Operations

Research

Research Grants

- Ph.D. top-up scholarship
- Post-doctorate support grant

Grants Round

- Research equipment grants for autonomic equipment
- Research topic grants

Advocacy

- Submissions to parliamentary inquiries, TGA, IHACPA
- Community focus groups
- Meeting with MP's/Politicians
- Ambassador program
- Community letters to politicians
- Raising awareness through branding
- Social media campaigns
- POTS registry – advocacy data source

Support

- Community and clinician education resources
- Scientific conferences and educational webinars
- Lectures at hospitals, universities, and schools
- Clinician database development
- Social media for information, connection, and inclusion
- Community events and initiatives
- Residents course for clinician education

ECONOPOTS

ALMOST 60% OF INDIVIDUALS LIVING WITH POTS REPORT HAVING TO PERMANENTLY LEAVE THEIR PREVIOUS JOBS DUE TO THE IMPACT OF THEIR HEALTH CONDITION

The APF conducted a comprehensive economic analysis of our adult community, using validated health economic surveys to assess the financial and social impacts of living with POTS in Australia. Over 600 community members participated, providing detailed insights into their experiences.

BETTER TOGETHER 2024

The "Better Together" POTS Conference in March 2024 was truly buzzing with energy, offering a unique opportunity to connect, share, and learn. As a board member living with POTS, I can say firsthand that this two-day event brought a profound sense of community, especially on the second day, dedicated to patients, parents, partners, carers, and friends living with POTS.

Sophie Cartledge, a fellow attendee, shared, "I really liked the breadth of topics and depth of information covered." Another participant, Caitlin Risstrom, expressed, "It was reassuring to see that there are doctors who actually care and are fighting for us." These reflections captured the essence of the event– a space that not only provided up-to-date research but also created a true sense of belonging and validation.

Living with POTS can often feel isolating, with many of us spending countless hours, days, or even weeks lying down, removed from the rhythm of everyday life. This conference offered a rare chance to hear stories from others navigating similar challenges, sharing their personal strategies, tips, and hacks for coping. It was a blend of inspiration, information, and practical advice that was empowering for everyone present.

What stood out was the supportive and inclusive atmosphere. The option to lie on bean bags at the back of the room was a thoughtful touch that acknowledged our reality – a simple but profound gesture that made it clear this was a space designed for us.

Overall, the "Better Together" conference felt more than just an event – it was a gathering that offered hope, knowledge, and a sense of solidarity. It reaffirmed that, despite the challenges POTS brings, we are stronger as a community, and we truly are better together.

Ali Flynn
Director

‘DESPITE THE CHALLENGES POTS BRINGS, WE ARE STRONGER AS A COMMUNITY, AND WE TRULY ARE BETTER TOGETHER.’

AMBASSADOR PROGRAM

WELCOMING EMMA-LOUISE WILSON

Emma-Louise Wilson has joined the team as an Ambassador. Emma-Louise is an Australian actress. She is best known for her role as Katie in the Logie Award and AACTA Award-winning comedy series Utopia.

Emma-Louise was diagnosed with POTS having lived with the condition for some years. After seeking out answers for herself, she found the Australian POTS Foundation and took the diagnostic criteria to her GP.

> ***'POTS awareness is crucial. I was symptomatic for nearly 5 years before I suggested POTS to my GP which finally led to a diagnosis. Thankfully she'd heard of it when so many haven't.***
> ***We need the Australian POTS Foundation to raise awareness and help us advocate for our needs. I'm honoured to become an Ambassador for the APF and hope by doing so I can use my voice to raise awareness for those with POTS '.***
>
> ***Emma-Louise Wilson***

VOLUNTEER
IN FOCUS
MICHAEL MILLS

What inspired you to volunteer with the APF?
It came about because of the devastating impact of POTS on an important person in my world, and the helplessness I felt over what I could do to help her. I'm not the only person who has sat there, numb, with no idea of what to do. I went through a phase of being sad and dumbfounded. In the end, you put your hand up, even if you don't know what you're going to actually be doing to help.

The things that resonate with me about what the Foundation does is its commitment to get information out there that helps people with POTS live their lives. It's also in getting information out there that helps those of us who are friends and family know that it's a thing that is real, and to work out what we can do. We're still in a place where not enough is known about POTS, and have a long way to go. Thanks to the Foundation, we're on our way.

Can you share a memorable experience or from your time volunteering with us?
We're recording a series of videos that we're planning to share later in the year. The most memorable part for me has been in hearing the stories of those with POTS, of the challenges they are facing, and how they are dealing with them, and sometimes, not dealing with them. It's in hearing the challenges of the search for that silver lining, and where in some cases there isn't one or it's not yet been found. It's in hearing how to live the fundamentals. I'm overwhelmed by the honesty with which people have shared their stories with me, a total stranger. It's been emotionally draining for all of us, at times.

At a personal level, I have learnt so much from those who have shared their stories, and how they are finding ways forward that I can share with my friend. I am so very grateful that by sharing a part of their world, they are helping to make the lives of people they will never meet, better. I hope they understand the value of what they are doing, and the gratitude I and so many have for their bravery in being open to these conversations.

One of the clear things from listening to POTS patients I've heard is 'please persist with us. Please keep calling or messaging us, even if we don't get back to you. Often, we just can't. Please don't forget us'. By volunteering, I'm showing I'm doing more than not forgetting and I recommend it to anyone.

OUR TEAM


Marie-Claire Seeley
Founder & CEO


Amanda Burgan
Chair


Peter Burgan
Treasurer


Nick Baldock
Secretary


Catherine Cooper
Director


Jon Seeley
Director


Ali Flynn
Director


Yasmin O’Brien
Assistant to the board


Celine Gallagher
Scientific Chair


Dennis Lau
Scientific Committee


Fraser Burling
Scientific Committee


Chris O’Callaghan
Scientific Committee


Claire Clark
Community
Engagement Officer


Tracey Spicer
Ambassador


Sophie Scott
Ambassador


Emma-Louise Wilson
Ambassador

Platinum Partner sodii

How You Can Help:

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

We are the only organisation in Australia dedicated to clinical research, advocacy, and support for the 800,000+ Australians living with POTS.
Our Foundation is run entirely by volunteers, and we currently receive no government funding. We rely solely on donations while working to advocating to relevant government bodies to invest in POTS research and support. This investment will not only improve the quality of life for those affected but will also drastically reduce healthcare spending and alleviate the economic burden caused by lost productivity and long-term disability associated with POTS.

In just three years, APF has made significant strides in raising awareness and building momentum towards securing recurring government funding for POTS research and support, but we still have more to do. Your donation at this pivotal time will enable us to continue our essential work. We can allocate your gift to where it’s most needed, or direct your contribution to one of our key projects below:

Project 1: Develop New Educational Resources

This project will focus on creating and promoting essential new digital and print resources for healthcare providers and patients. These resources will equip clinicians with tools for more accurate diagnosis and effective management of POTS, while providing patients with accessible information to support their health journeys.

Project 2: Expand the Australian POTS Registry

The goal is to transition the current Australian POTS Registry into a national clinical database. This expanded registry will be essential for collecting comprehensive data, guiding healthcare policy, and improving treatment access for POTS patients across Australia.

Project 3: Fund Registrar Training in Autonomic Medicine

This project will support the specialised training of Australian registrars in autonomic medicine, ensuring healthcare providers gain the knowledge and expertise required to diagnose and manage POTS. This investment is crucial for ensuring the best possible care for POTS patients in Australia.ays, healthcare providers will be better equipped to make timely and accurate diagnoses, leading to improved outcomes and quality of life for POTS patients.

How to Give:

We welcome donations via the bank details provided below or the QR code, or by credit card on our website at https://potsfoundation.org.au/contribute

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

Business owners may wish to support our work through our Partner Program—please refer to our Partner Prospectus which can be found here: https://tinyurl.com/mtunre84 for more details.

If you would like to contribute to a specific research project or resource development initiative, please contact us to discuss how best to allocate your donation for maximum impact.

Your support will make a direct and lasting difference.

BRINGING VISIBILITY TO THE INVISIBLE

YOUR SUPPORT **MATTERS**

Make a donation

potsfoundation.org.au/get-involved/#give

Email

admin@potsfoundation.org.au

Become a member

https://potsfoundation.org.au/associate-membership

Connect

potsfoundation.org.au