

2023 Annual Report



AUSTRALIAN
POTS
FOUNDATION
a brighter future for people with POTS
through advocacy, support and research





Our Year in Review

As we look back at the year that has been, it fills me with immense pride to reflect on the remarkable journey of the Australian POTS Foundation.

Established in May 2021, our organisation embarked on a mission to make a difference in the lives of those battling with postural orthostatic tachycardia syndrome (POTS). We set our sights high, and I am thrilled to report that we have achieved beyond even our most optimistic expectations.

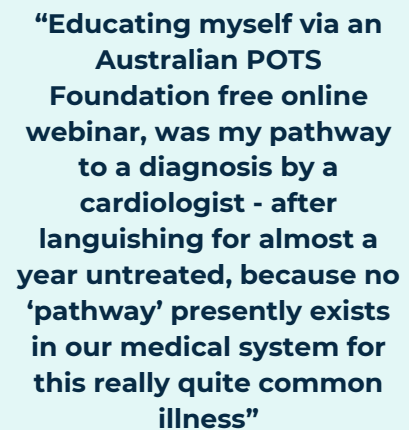
First and foremost, I extend my heartfelt gratitude to our community who have been generous in their support and whose journeys provide inspiration for us to continue the fight to establish a more positive future for those diagnosed with POTS in Australia.

As I reflect on the past year, I am so proud of what the organisation has accomplished in such a short time.

Board Expansion and Strategic Development:

We welcomed a new board member, Ali Flynn, who not only brings valuable skills in marketing and community engagement but also shares lived experience with POTS. This diversity of perspective is a testament to our commitment to have those with 'lived experience' drive and inform the directions of the POTS Foundation.

Our executive team also set about to establish a comprehensive strategic plan which places consumers at the forefront of our work, empowering them as the drivers and innovators of policies aligned with our mission.



“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”



Our Year in Review cont.

Community Engagement and Advocacy:

Our commitment to community engagement has resulted in the recruitment and development of dedicated volunteers. These individuals play a pivotal role in providing guidance and support across our numerous programs. Our community liaison officer, Claire Clark, has been instrumental in expanding our reach through all social media platforms, all while navigating the complexities of life with POTS. Her dedication has been a source of inspiration.

We have been tireless advocates, engaging with the Australian Government on multiple fronts. Our representations before the Parliamentary inquiry into long COVID our collaborative work with the University of Adelaide being incorporated into their report. Submissions to the IHACPA committee led to the recommendation to adopt a unique ICD code in the 13th edition. The recommendation will be considered during the final consultation process in November 2023. A unique ICD code for POTS will change the landscape of POTS research and care in Australia. Our Leadership team is proud that the Foundation has been at the forefront of this initiative. Future generations will continue to reap the benefits of the hard work our Foundation has undertaken to effect meaningful change in the Australian health landscape.

We have also raised our voices through submissions to the Women's Health Advisory Committee, highlighting the disparity in care for women with POTS in Australia while our petition to the government for more resources and funding for POTS has garnered over 2,500 signatures. More recently, the launch of our ambassador program promises to raise our profile as we engage higher profile community members to help raise awareness of POTS in Australia.

Commitment to Education and Research:

Our dedication to education remains unwavering. Our Scientific Chair Dr Celine Gallagher has developed and championed a webinar series providing evidence-based information for both consumers and clinicians and have embarked on the organisation of our first combined consumer and scientific conference which will be held in March 2024. Our contributions to media through podcasts, news, and journalism involvement have helped disseminate vital information and raise awareness of the virtual tsunami of Australians developing POTS post COVID-19 infection. We have published articles in prominent outlets such as The Age, The Herald, The ABC, SBS national news, and The Conversation and there is an increasing demand for our services to provide speakers and educators across a vast array of health sectors.



Our Year in Review cont.

Our research goals are becoming a reality and we now are entering our third year of supporting summer research interns. We also proudly support a PhD student as well as a postdoctoral and a senior data researcher, ensuring POTS research has a place in the Australian research landscape.

Fundraising and Community Engagement:

Fundraising continues to be a major focus, and our community has responded with enthusiasm through social media engagement and private funding events. Their generosity fuels our initiatives and ensures that we can continue our vital work.

Our financial status remains sound, thanks to the diligent oversight of our treasurer, Peter Burgan and the incredible generosity of our community. It is their support that enables us to continue driving programs of research, advocacy, and community support that will have a lasting impact on our community for years to come. Our community's trust and contributions empower us to work tirelessly toward our shared goals.

In closing, I want to express my gratitude to the dedicated members of our governing board. Their unwavering commitment, wealth of expertise, and invaluable guidance have provided the much-needed stability during this early phase of development as a Foundation. With their support, we have been able to set a solid foundation for our endeavours.

Together, with our community we are making a tangible impact on the lives of those affected by POTS. Our achievements in this short time have been truly remarkable, and I am excited about the journey that lies ahead. Thank you for your resolute support, and here's to another year of progress and success.

Warm regards,

Marie-Claire Seeley
CEO | The Australian POTS Foundation

IMPACT REPORT



SUPPORTING OUR COMMUNITY

136

Practitioners registered on our Clinician Directory

500

patients enrolled in the Australian POTS Registry

SIX

Educational webinars delivered with **1200+** registrations

500+

Clinicians educated through GP network, webinars and conferences

Clinician confidence improved to **90%**

from 50% after attending education session

Provision of **SEVEN** Research Grants

>\$300k Raised for POTS support and research

ADVOCACY

Submissions to Government:

- Parliamentary inquiry into Long COVID and repeated COVID infections
- Women's Health Advisory Council Submission independent Health & Aged Care Pricing Authority
- Independent Health & Aged Care Pricing Authority : ICD amendment submission

Influencing Policy:

- Successfully advocated for a **unique POTS ICD Code**
- Delivered **in-person advocacy** to Members of Parliament
- Ran a successful community **'write to your MP'** campaign
- Received **3000 signatures** on our petition advocating for government support for research funding

OUR REACH

17,000+

users reached through our website and social media platforms

Including:



6,500 Facebook accounts reached



>1000 Instagram Followers



3000+ YouTube views



7000 average monthly impressions on Twitter





Ambassador *Program*

Welcoming Sophie Scott OAM

Sophie is a highly sought-after international keynote speaker on topics such as preventing burnout, managing your mental well-being during times of change, the science of high-performance habits, and how to use neuroscience to stick to new habits and overcome unwanted ones.

An award-winning journalist and former National Medical Reporter for the Australian Broadcasting Corporation, Sophie now helps tens of thousands of people around the world using evidence-based science and her own personal journey.

She has an extensive presence on social media, has been an invited speaker at the World Congress on Positive Psychology, has written two books (Live a Longer Life (ABC Books) and RoadTesting Happiness (Harper Collins), and has won major awards for her journalism and medical reporting including a prestigious Eureka Award.

Sophie's message

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. Australia is well behind other countries in recognising POTS and providing good treatment pathways.

The Foundation does an excellent job in providing evidence-based information and raising awareness of this neglected condition.



Board Chair Report

The past year has been a significant period to further the establishment of the Australian POTS Foundation (APF) which registered with ACNC as a charitable organisation in 2021. We continue to embark on our journey to raise awareness and funds to facilitate research and improved support and outcomes for those living with POTS in Australia.

I wish to sincerely thank our CEO, Marie-Claire Seeley, and all of those who volunteer and have supported the Foundation as we move from establishment to ongoing operations.

Through Marie-Claire's leadership the team has worked to support our community. We are proud of the commitment and drive that is entrenched in their passion to make a difference to those with POTS and those impacted by its debilitating effect on their loved ones.

A number of significant activities have been undertaken to address the APF Strategic Pillars of:

- **Research**
- **Advocacy**
- **Support**

We have assisted to advance POTS Research, through our Summer Internships, PhD Top-up Scholarship and Post-Doctorate Scholarship.

Advocacy has been a major area of focus with the appointment of our Community Engagement Officer; Claire Clark. Her drive continues to assist in raising awareness and support through Social Media campaigns, community letters to politicians and responding to the needs of our community. Of great note, is the extraordinary work undertaken by Marie-Claire Seely and Celine Gallagher; APF Scientific Committee Chair, to advance the recognition and improved diagnosis of POTS with submissions to Parliament as well as health and governance bodies for a unique International Classification of Disease (ICD) code. Something which is of increasing importance as the prevalence of POTS increased with the effects of Long COVID.



Board Chair Report cont.

Following the success of our inaugural Medical Practitioner Conference - POTS Unmasked in October 2022 our efforts to Support the community through the education of Clinician and Allied Health Workers continued with Dr Lawrence Afrin's March 2023 speaking tour in Adelaide. In addition, the ongoing webinar program for both clinicians and the community continues to build awareness and understanding. Our sights are now clearly set on the next conference - 'Better Together' in March 2024, with an expanded program and separate agendas to educate Medical Practitioners as well as the POTS community.

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

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

Amanda Burgan, Board Chair

Our Mission

Our work is focused on supporting the almost 1 million Australians estimated to be living with POTS and Long COVID

Our mission is focused three key areas

- Motivating and supporting meaningful Australian and consumer driven research into POTS
- Providing support for our community by empowering them through provision of evidence-based consumer and clinician education materials
- Advocating for health and research policy changes to improve equitable access to diagnosis and care for those living with POTS in Australia.

Australian POTS Foundation

Our Mission

To provide a brighter future for those living with POTS, through advocacy, support and research

Our Values

We value lived experience in the delivery of research, advocacy and support for those living with POTS using:

Care | Knowledge | Respect | Inclusion | Community

Quality of life of those with POTS in Australia is **WORSE** than most of the major chronic health conditions including cardiac, respiratory and kidney disease.

48% of those with Post COVID POTS are unable to return to work.

7 On average people in Australia wait almost years for a POTS diagnosis

Women experience almost **TWICE** the diagnostic delay compared to men

70% of our community report misdiagnosis of anxiety prior to being diagnosed with POTS

69% of people with POTS report their doctors were unaware of how to diagnose the condition

Our Strategic Plan



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
- ✓ In leading 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
- ✓ Our stories can change lives and in doing so, change the world

Our Values



Key Themes

Value lived experience in research, advocacy and support

Foster research to improve care and outcomes for those with POTS

Key Enablers – Fundraising, Communications and Operations

Research

Research Grants

- Summer internships
- Ph.D. top-up scholarship
- Post-doctorate scholarship

Grants Round

- Research equipment grants for autonomic equipment
- Research topic grants.

Advocacy

- Submissions to parliamentary inquiries, TGA, IHACPA
- Community focus groups
- Meetings with MPs/Senators
- Ambassador program
- Community letters to politicians
- Raising awareness through branding
- Social media campaigns
- Media campaign

Support

- Community education/resources
- Clinician education/resources
- Scientific conference / education webinars
- Lectures - hospitals/universities/schools
- Clinicians database
- Social media | information | connection | inclusion
- Community events



Future Directions

As we look ahead to the future, the Australian POTS Foundation remains committed to our mission of enhancing the lives of those affected by postural orthostatic tachycardia syndrome (POTS).

Our dedication to advocacy, community support, education, and research will continue to drive our efforts in the coming year and beyond.

Advocacy for ICD Code Implementation

We are resolute in our commitment to ensuring the implementation of a unique ICD code for POTS in the 13th edition, scheduled for 2025. We will persist in advocating for this vital change, which will significantly impact POTS research and care in Australia. Our goal is to see the ICD code through to the implementation phase and make a lasting difference for the POTS community.

Engaging Health Authorities for Funding Models

In addition to advocating for the ICD code, we will initiate discussions with health authorities to establish funding models that support the implementation of programs subsidising first-line treatments, including compression garments and high-salt supplements for POTS patients. By working with health authorities, we aim to improve access to these critical treatments for individuals living with POTS.

Continuation of Petition and Pre-Budget Submission

Our ongoing petition will play a pivotal role in supporting our efforts toward a pre-budget submission for the 2024-2025 Australian Federal Budget. We believe that this submission will help secure the necessary resources to further our mission and positively impact the POTS community.

Enhancing Community Support Programs

Our commitment to providing resources for both consumers and clinicians remains unwavering. We will continue to focus on reducing the time to diagnosis for those with POTS and improving access to evidence-based treatment advice. We will also work to expand our community support programs, seeking input and feedback from our community to ensure that we address their most pressing needs effectively.

Future Directions cont.

Education and Research Initiatives

Our Scientific Committee will guide the development of high-quality education and research initiatives. We will expand resources for clinicians, offering valuable insights and guidance. We are also committed to delivering high-level conferences and webinars, furthering the dissemination of knowledge about POTS.

Ambitious Fundraising Activities

In the upcoming year, we plan to embark on more ambitious fundraising activities. To support these initiatives, we will develop a comprehensive strategic plan focused on realistic ways to secure the necessary financial resources. Your generous contributions and support will be instrumental in enabling us to continue our vital work.

The Australian POTS Foundation looks forward to the future with optimism and determination.

Together with our community, we will work tirelessly to make a lasting impact on the lives of those affected by POTS. Your unwavering support is invaluable, and we are excited about the journey that lies ahead as we strive to bring about positive change for the POTS community.

Thank you for your ongoing dedication and commitment to our mission.





Volunteer *in focus*

Claire Clark

Community Engagement Officer

My life changed dramatically 4 years ago when I developed POTS.

You once would have found me working as a paramedic, hosting international mindfulness retreats, teaching SCUBA diving and yoga and generally being an outgoing, fun loving person.

That all changed when I got injured at work. As a result of being flexible and fit, my back injury took an extended time to heal and I was impatient. I went back to work sooner than I should have and re-injured my back. After a rehab swim, I collapsed getting out of the pool which was the onset of my POTS.

Seeking a diagnosis was a very challenging time with specialists ordering numerous tests both invasive and non invasive. Even though I failed the stress test after only 2 minutes - all reports were without findings.

I was at my wits end, unable to function, drastically losing weight, constantly nauseated, and could barely stand. Posting my symptoms on an international paramedic forum was the first glimmer of hope as I had 30 responses overnight all pointing to POTS. It wasn't until I heard Marie-Claire our CEO interviewed on the POTScast, when it all clicked into place.

My clinical story from here would be the same as many. I was very lucky to be diagnosed within 4 months of onset unlike most. I was never well enough to return to the career I loved and I fell into a deep depression having not only lost my job but also all the other things I enjoyed in life.

I knew I needed to find purpose again and by offering my skills as a volunteer with the foundation, I slowly began to create a life I now love to lead. I have embraced pacing and a slow, mainly stress free life. Raising awareness, advocating for and supporting the POTS community is now my mission, together, I know we can make a difference.

Finance

Summary

The 2022/23 Financial Year has seen a year of growth following the "start up" year with financial support being received from a combination of organisational donations as well as private donors.

A very successful inaugural conference also contributed to both the exposure and understanding of POTS within the medical community as well as providing a source of income for further investment.

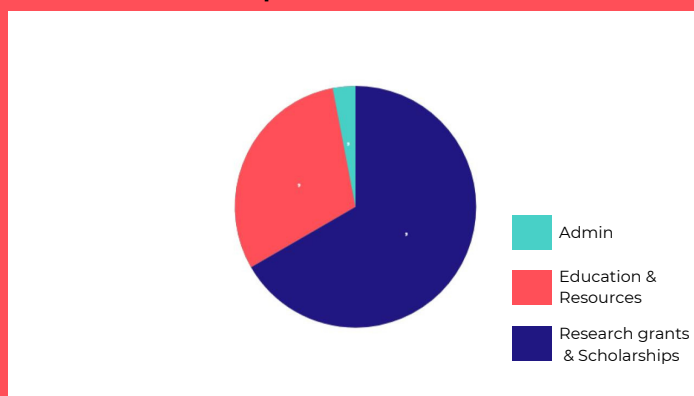
The Board made the decision to invest in furthering the understanding of POTS by supporting a combination of a PhD student via a top-up scholarship along with both Research Doctorate and Internship support.

A big thank you to the Board, our donors, supporters, members and volunteers who make a difference to our community.

Peter Burgan FCPA; GAICD; Treasurer

The Australian POTS Foundation is an **ENTIRELY** volunteer based organisation

Expenditure



>\$300,000 raised to support our Australians living with POTS

\$135,060 committed to advocacy, research and education to support our community

Finance Summary

						FY23	FY22
Revenue							
	Revenue from Government					-	-
	Other Revenue:						
	- Donations & Bequests					165,266	107,202
	- Sale of Goods & Services:						
	Conference Income					41,680	-
	- Investment Income					-	-
				TOTAL REVENUE		206,946	107,202
Expenditure							
	Research Grants made for use in Australia					53,500	5,000
	Grants made for use outside Australia					-	-
	Interest expense					-	-
	Employee expenses					-	-
	Other expenses:						
	Conference Expense					13,879	500
	Comms, Marketing, Website, Social Media					16,660	3,790
	Insurance, Bank fees					968	825
				Total Other Expenses		31,507	5,115
				TOTAL EXPENDITURE		85,007	10,115
				SURPLUS / (DEFICIT)		121,939	97,087

Catherine's story



I contracted Covid in November 2022 when I was working part-time as a hospital chaplain. Within three weeks of the Covid infection, I was significantly fatigued and feeling very concerned about my symptoms.

By early December I was on sick leave from work. Due to fatigue, dizziness and brain fog, I needed to lie down for 15 minutes, after every 5 minutes upright. This went on every day for months and life as I knew it was put on hold. My sense of hunger completely disappeared. I lost 15% of my body weight as I was too tired to finish eating meals. **My GP was empathetic but said it would take 18 months to see a specialist and there were no medications he could prescribe me before then.** I felt like my world had fallen apart.

In mid-December I spotted Marie-Claire Seeley in an ABC News article discussing POTS and Long Covid. In January 2023 I spoke with her and flew to Adelaide for initial testing. A POTS diagnosis and the medications Ivabradine and Midodrine followed, the latter of which was a game-changer and marked the starting point of my recovery.

The early months of 2023 were characterised by many hours of rest, and connecting with a supportive Exercise Physiologist, Dietitian, Psychologist, Rheumatologist and Clinical Pharmacologist. Pacing my activities made an immediate difference. I attended a hospital out-patient rehabilitation program and completed a clinic-based 15 week group program designed for POTS, fatigue and chronic pain conditions. **I watched webinars from the Australian POTS Foundation and read their online resources to better understand my condition**, and listened to podcasts and audio books about POTS and Long Covid.

I sought to find meaning and purpose in my POTS diagnosis, as I had explored with patients so many times before. POTS was a massive 'wake-up call' that I needed to live differently, express emotions in a healthy way rather than suppress them and to listen to my body's needs rather than constantly pushing through.

POTS continues to bring many frustrations including expensive medications, and heat and noise sensitivity leading to fatigue.

However, I can honestly say that despite the challenges, almost a year on from the POTS onset I am happier now and I would like to think that I'm a calmer and more patient person to be around. **An illness doesn't need to be life threatening, to be utterly life-changing.** I am deeply appreciative of the care provided by my husband Paul and 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.**

Our Team



MARIE-CLAIRE SEELEY
FOUNDER & CEO

CLINICAL NURSE | RESEARCHER



AMANDA BORGAN
CHAIRPERSON

CONSULTANT



NICK BALDOCK
SECRETARY

SOLICITOR



JON SEELEY
DIRECTOR

*MANAGING DIRECTOR |
CHARTERED ACCOUNTANT*

Our Team

CATHERINE COOPER
DIRECTOR

SOLICITOR | DIRECTOR



PETER BURGAN
TREASURER

DIRECTOR



ALI FLYNN
DIRECTOR

DIRECTOR | PERFORMANCE COACH



DR CELINE GALLAGHER
SCIENTIFIC COMMITTEE CHAIR

POST-DOCTORAL FELLOW | CLINICAL NURSE



Our Team



PROFESSOR DENNIS LAU
SCIENTIFIC COMMITTEE

CARDIOLOGIST



**ASSOCIATE PROFESSOR
CHRIS O'CALLAGHAN**
SCIENTIFIC COMMITTEE

CLINICAL PHARMACOLOGIST



FRASER BURLING
SCIENTIFIC COMMITTEE

RHEUMATOLOGIST



CLAIRE CLARK
COMMUNITY ENGAGEMENT
OFFICER

Our Team

YASMIN O'BRIEN
ASSISTANT TO THE BOARD



ANDREW CARSWELL
ADVOCACY ADVISOR



SOPHIE SCOTT OAM
AMBASSADOR



MAJOR SUPPORTERS

Peter and Sammy Lincroft

Jon and Claire Seeley

Tracy Finnegan

Neill Stacey

SODII Hydration

HOW YOU CAN SUPPORT US

The Australian POTS Foundation is committed to improving outcomes for those with POTS by raising funds for improved research, advocacy and support for those living with POTS.

There are a number of ways you can show support:

Make a donation

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



Register/search on our Clinicians Directory

potsfoundation.org.au/clinician-directory/

Book tickets for our Better together Conference

auspotsconference2024.com.au/

Sign our Change petition for research funding

change.org/p/support-funding-for-postural-orthostatic-tachycardia-syndrome-pots-research-in-australia

Volunteer

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

Connect



admin@potsfoundation.org.au



**AUSTRALIAN
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a brighter future for people with POTS
through advocacy, support and research