Australian
POTS
Foundation

Issue 8
Summer
Edition
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# NEWSLETTER

## Welcome!

Welcome to the latest edition of the APF Newsletter!

We’re keeping it light this summer, knowing everyone has a full plate at this time of year. Here’s hoping you’re staying cool, minimising stress, and taking a little time to recharge.

2025 has been a big year for the Foundation, as we look ahead to 2026, we’re excited to continue connecting, supporting, and raising awareness for everyone living with POTS – and we can’t wait to share what’s coming next.

### 2025 Webinar Series

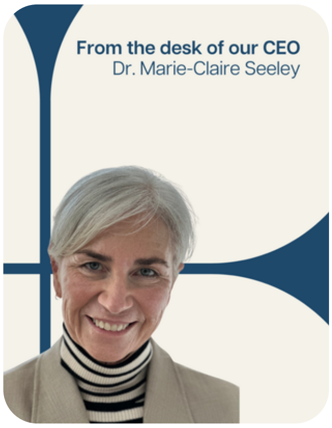
A huge thank you to our wonderful hosts for another successful year of webinars. Members, your recordings are ready – the email is waiting in your inbox.

### 2025 Annual Report

can be found in our Resources Hub

### Dont Send Me A Card

Save some time and energy by sending e-cards this season and support APF at the same time! Visit: https://www.dontsendmeacard.com/ecards/charities/australian-pots-foundation



A Message from Marie-Claire – Christmas 2025

As the year winds down, I've been reflecting on what a big year it's been for the Foundation, for our mission, and for our community.

We're a small team of volunteers. We're not tireless – we get tired. But we are lifted by your generosity, encouragement, and belief in what we're building together. Our community's support helped us reach some important milestones this year, including the introduction of the unique POTS ICD code in Australia.

In October, we raised over $50,000 for POTS research – an incredible result in the middle of a cost-of-living crisis and increasingly limited access to research and community grants. This is a much-needed investment in building the evidence, care and recognition that people with POTS deserve.

Christmas will be a busy time for me as I prepare to travel to the US in January on my Churchill Fellowship, funded by the Federal Department of Health. I'll be learning from leaders in autonomic medicine – including The Dysautonomia Project, American Autonomic Society, Mayo Clinic, the University of Auckland, Professor Satish Raj in Calgary, and Professor David Putrino at Mount Sinai, with the goal of bringing home the tools and knowledge we need to strengthen care and education here in Australia.

I'm looking forward to connecting with our network of patients, carer's and practitioners in person, and sharing these learnings with our community at Converge in June 2026.

I'd love to share my Fellowship journey with our community – if you'd like to follow along, please stay connected with me on my Fellowship Instagram account: **@autonomicjourneys**.

I hope this season brings you rest, peace, and time to appreciate the people around you. The recent tragedy in Bondi is a heartbreaking reminder of how deeply we need compassion, connection, and community – especially at this time of year. Our hearts are with all those affected.

Yours in advocacy,
Marie-Claire Seeley

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Australian POTS Foundation

## CONVERGE

Examining Common Pathways in Invisible Illness

Adelaide |June 4 - 5 2026

# Supporting the Next Generation of Autonomic Medicine Clinicians

### The Residents' Course

We are pleased to partner with The Dysautonomia Project and the American Autonomic Society to support two Australian residents to participate in the 2026 Course in Autonomic Medicine, to be held in Florida.

This important initiative is focused on building clinical knowledge and confidence in autonomic medicine – an area that remains under-recognised yet critically important for people living with conditions such as POTS and other forms of dysautonomia. By supporting clinicians early in their careers, we are helping to strengthen future care pathways and improve outcomes for patients across Australia.

Through this course, participating residents will gain access to specialist education, evidence-based approaches, and international expertise. Importantly, the knowledge and skills they acquire will be brought back and shared within the Australian medical community, helping to grow awareness and capability in autonomic medicine.

We wish Dr. Ahthavan Narendren and Dr. Ainsley Goff safe travels and every success in their studies. We look forward to sharing their reflections and learnings with our community in 2026.

### Applications are now open for the APF's 2026 PhD Top-Up Scholarship.

We're offering one top-up scholarship to support an Australian researcher whose primary PhD project directly addresses Postural Orthostatic Tachycardia Syndrome (POTS). This scholarship aims to strengthen dedicated POTS research in Australia and support the next generation of emerging researchers in this field.

**Key dates**
Applications close: 31 January 2026
Outcome notified: 2 March 2026

**Eligibility**

- Enrolled full-time in a PhD program at an Australian university
- Residing in Australia for the duration of the PhD
- Recipient of an RTP, NHMRC or similar competitive scholarship
- Within the first 18 months of candidature at the time of application (pro-rata payments apply)

Full details and the application portal are available here:
https://potsfoundation.org.au/grants-and-scholarships/

# A Gentle Guide to Surviving Summer with Chronic Illness
By CC, APF Community Engagement Officer

Summer often brings a busier schedule – family gatherings, holidays, social events, and extra commitments can all add up. For those living with a chronic illness, this increase in activity can be especially challenging. The key is planning with intention and being gentle with yourself.

Start by prioritising your commitments early. Decide which events are essential and which can be postponed or skipped. I personally try to see people one-on-one, which allows me to truly engage and nurture connection without feeling overwhelmed. I like to organise picnics somewhere quiet – it avoids crowds and noise and lets me prepare meals I know won't spike or flare my symptoms.

It's also normal to feel lonely at times, even when surrounded by people. Loneliness can feel heavier during the holidays or busy seasons, and it's important to acknowledge it. Simple actions like reaching out to a friend for a chat, joining a small community activity, or sending a thoughtful note can help you feel connected. Remember, quality matters more than quantity – even small, meaningful interactions can lift your spirits. I've recently added a Free Little Library and love seeing people stop and peer in  - no interaction needed but rewarding all the same.

My favourite thing to do is regift my favourite, impactful reads of the year, with a small note explaining why I chose them. It's a simple way to share a meaningful connection without extra stress and people love it! Often I will hear from the receiver as they read the book and it creates bonus interactions.

Finally, I make space for self-care: adding five minutes for a breathing exercise when stress arises – my favourite is box breathing, which always helps me feel calmer. This year, my focus is on creating a quiet, joyful summer, maintaining wellness, and setting myself up for a balanced 2026, even with a few big events planned.... I'm talking about you Converge Conference!

Box breathing is a relaxation technique used to calm the mind and body, reduce stress, and regain focus. The name comes from the four "sides" of a box, representing four equal steps: inhale, hold, exhale, hold.

**How to Do Box Breathing**

1. Inhale slowly through your nose for 4 counts, filling your lungs.
2. Hold your breath for 4 counts.
3. Exhale slowly through your mouth for 4 counts, emptying your lungs.
4. Hold your breath again for 4 counts.

Repeat this cycle 4–6 times (or longer if you like) until you feel more relaxed.

**Tips**

- Sit comfortably with your back straight and shoulders relaxed.
- Focus your mind on your breath and the counting – this helps distract from stress or anxious thoughts.
- You can adjust the count to suit your comfort level (e.g., 3 or 5 seconds each step).

Box breathing is quick, portable, and effective – perfect for a few minutes whenever stress hits, whether at home, work, or in a busy summer schedule.

**Please note: While this works well for me, people with POTS or other autonomic conditions may respond differently – especially to the breath-holding parts. If you feel dizzy or uncomfortable, it's best to stop or try gentler breathing without the holds. Always listen to your body.**

# Membership

Did You Know? The Australian POTS Foundation membership is open to everyone in the POTS community – and beyond! Whether you're:

❤ Living with POTS ❤ A carer, friend, or family member
❤ A health professional supporting people with POTS...there's a membership for you!

We offer:

- Family Memberships – for households
- Practice Memberships – for clinics or practices with 4+
- Concession Rates – to ensure accessibility for all
- Bonus for Practices – our Platinum Sponsor Sodii offers a free trial kit for any practice not familiar with their product!

As a member you'll receive fabulous discounts from our partners, discounted webinar tickets, entry into our quarterley prize draw and lots more. Through our affiliate program, every purchase made with our partners also gives back to the Australian POTS Foundation, helping us continue our work in awareness, advocacy, and resources for people living with dysautonomia.

## Member Prize Draw – Winners Announced!

We're excited to announce the winners of our Winter Member Prize Draw, with special thanks to our generous partners Sodii, Supacore, and Vitassium for providing our fabulous prizes:

**Matilda Atkin** **Mitchell McKinlay** **Ebony Bohr**

Winners – please email admin@potsfoundation.org.au to claim your prize

Not a member yet? Join today and you'll automatically go into the running for our next prize draw! Be part of a community that supports, informs, and advocates for people living with POTS

# Help us make 2026 the Year of Visibility by becoming an Awareness Champion.

**By sharing your journey – whether as a patient or a family member – you can help strengthen our advocacy efforts in Canberra, raise awareness, and ensure more people in our community feel seen, heard, and less alone.**

**Your lived experience is powerful. With your permission, we'll amplify your voice through social media campaigns and awareness initiatives throughout 2026, helping to educate, connect, and drive meaningful change. Together, we can turn personal stories into collective impact. DM our socials or email us at: admin@potsfoundation.org.au**

To support our work, you can donate via the QR code, or by direct deposit using the bank details provided.

**THE AUSTRALIAN POTS FOUNDATION**
**BSB: 015 208**
**Account Number: 153 059 214**

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