Australian
POTS
Foundation

Issue 7
Spring
Edition
2025

NEWSLETTER

Welcome!

Welcome to the latest edition of the Australian POTS Foundation Newsletter – your source for updates, support, and inspiration from the POTS community.

Inside, you'll find research news, upcoming events, lived experience stories, and practical tips for navigating life with POTS. Whether you're newly diagnosed, a long-time warrior, a carer, or a health professional, we're here to inform, empower, and walk alongside you.

Together, we're raising awareness, building connection, and creating change.

Webinar: Balancing the Nervous System - TVNS and Biofeedback for POTS Explained

18/09/25 LINK HERE

RACGP CPD Accredited Webinar: Diagnosis and Management of Postural Orthostatic Tachycardia Syndrome (POTS) in Primary Care

25/09/25 LINK HERE

Dysautonomia Awareness Month is just around the corner. Help us raise awareness

From the desk of our CEO

Dr. Marie-Claire Seeley

2025 has been a landmark year for the Australian POTS Foundation, with major strides in national recognition, clinical education, and systems change.

One of our biggest milestones was the long-awaited implementation of a unique ICD code for POTS, which came into effect on 1 July. This important change means POTS can now be formally recorded in health systems, improving diagnosis, data collection, and access to care over time.

We also supported the development of the first Australian POTS HealthPathway—an online tool that helps GPs diagnose and manage POTS using best-practice guidance. Created with input from Dr Gallagher and Dr Seeley, this pathway is now being adopted across Primary Health Networks, with a national rollout expected soon.

On the education front, we've released a series of new fact sheets for both clinicians and patients, achieved RACGP accreditation for our first GP webinar, and are putting the finishing touches on a major website upgrade designed to make information even more accessible.

Looking ahead, we're excited to confirm our next national conference, Converge 2026, will be held in Adelaide on 4–5 June. We're delighted to welcome US cardiologist Dr Alexis Cutchins and Professor David Putrino (Mt Sinai Long COVID rehabilitation specialist) as keynote speakers for this event, which will bring together our community, clinicians, researchers and decision-makers to shape the future of POTS care in Australia.

We're also proud to announce that two Australian trainee doctors have been awarded Research Residency placements to attend a three-day autonomic medicine traineeship in Florida in January 2026. This is a unique opportunity to invest in the next generation of clinicians and improve understanding of POTS within the medical system.

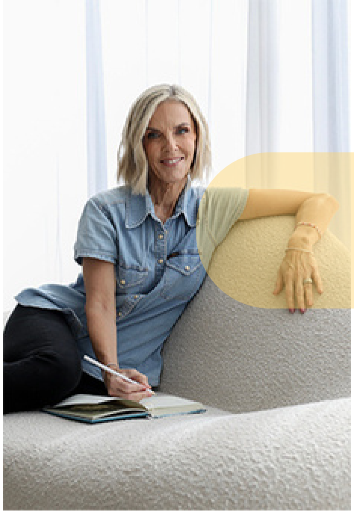
As we head into October, we're looking forward to engaging our community in fundraising for POTS—so we can ensure these programs continue into the future.

Again, I want to thank our wonderful community for all your support and belief in the work we are doing. We simply couldn't do this without you.

Yours in advocacy,
Marie-Claire Seeley

Congratulations!

Congratulations to our CEO Marie-Claire Seeley – she has been awarded an Australian Health Department–sponsored Churchill Fellowship. Marie-Claire will spend 6–8 weeks in the United States observing advanced autonomic testing and education implementation, with the aim of developing similar programs in Australia to help reduce diagnostic delay.



How To Feel Happy when you feel Crappy

By Sophie Scott, APF Ambassador

Is it possible to be in a good mood when you have physical symptoms? I want to talk to you about how you can use the power of your mind-body connection to change how you feel on challenging days. These techniques help me when I have to manage sensations like migraine, low blood pressure and dizziness. (As well as lots of salt and water!) I hope they help you too.

In neuroscience, what you tell yourself over and over (repetition) as well as your beliefs and your inner dialogue changes how your brain functions. This is good news! It means you can take action to reframe your thoughts, to shift from hyper-focusing on feeling unwell to focusing on feeling safe in your body.

Affirmations: I tell myself and write down where I can see it:
'These sensations are only temporary. I am safe.'
(Notice I use the word 'sensations' rather than 'symptoms').
This is not "woo-woo" or an attempt to think your way out of illness.
There's robust science to back up the power of affirmations to change how you feel.
Repeated self-affirmations have been shown to reduce the hormone cortisol, regulate stress and increase your sense of motivation. (Cascio et al., 2016)
Repeating affirmations helps you reframe your thoughts and can stop you spiralling into over-thinking.

Think about changing your environment to boost your mood

You might pay little attention to the impact your environment has on your emotions.
A valuable technique to improve your mood is intentionally putting yourself in calming and nurturing spaces.
Being near water (beach, lakes, rivers) can help you feel happier.
One paper found being around water had a dramatic effect on wellbeing. Being in a 'blue space' gives you the opportunities to recover and recharge.
Read more: (White et al., 2020) https://pubmed.ncbi.nlm.nih.gov/32971082/
If you can't physically be near water, I love listening to ocean sounds on a free meditation app like Insight Timer.

Mindful movement

No matter what your capacity for movement, your mind will feel better if you are able to move your body in some way. Going for a short walk or spending time outside can boost your creativity and problem solving ability. When you go for a short walk and allow your mind to wander, different parts of your brain come together. This is called the 'default mode network'. (If you have ever had a good idea while you were on a walk, this is why!) When the default mode network in the brain is switched on, it improves your ability to problem solve, and you become more creative. With chronic illness, you have to treat yourself with compassion and work within your limits. If you are feeling less than sparkling, even 10 minutes of stretching or being outside can help your mood.

While we know movement can be good for you, doing whatever feels right for you such as sitting outside in the sunshine can boost your mood. Giving yourself self compassion is important too and not comparing yourself to others who may not be living with a chronic illness.

Self compassion has been so important to managing my mood, particularly on days when I am feeling unwell.
Being OK with doing less on the days when you are not feeling great...
Understanding that sensations come and go...
Leaning on your support people who understand 'chronic illness' without judgement...
And finally, focusing on what you can control.
Your own thoughts, feelings and actions.
Remember, every action you take today for your wellbeing is a gift to your future self. SS

Let's connect so I can share more resources with you.
Soph IG https://www.Instagram.com/sophiescott2 Website https://www.sophiescott.com.au

Dedicated to make change

Meet Elena Christopoulos - PhD Scholar

Elena is a PhD student supported by a PhD scholarship from the APF, at the University of Melbourne and her research focuses on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Postural Orthostatic Tachycardia Syndrome (POTS). She currently works within the Baker Institute's Cardiometabolic Health and Exercise Physiology on a clinical trial using upright and supine cardiopulmonary exercise tests to observe differences in haemodynamics and metabolism in ME/CFS patients with and without POTS.

Elena completed her bachelor's degree in science with a major in physiology and went on to do her honours degree at The University of Melbourne where her research focused on orthostatic hypotension in older adults within the Royal Melbourne Hospital.

She is especially interested in cerebral blood flow in ME/CFS and POTS and utilises cerebrovascular doppler ultrasound scans during exercise to observe fluctuations in cerebral blood flow which occur before, during and after exercise. Elena collaborates with the Schneider-Futschik/Armstrong laboratory at Bio21 Institute, where she utilises metabolomics and proteomics to find potential biomarkers of ME/CFS and POTS.

The goal of her research is to be able to further understand the underlying cause of ME/CFS and POTS and to be able to improve diagnostic accuracy which may lead to future treatment options for patients.

Emma-Louise and her new found confidence in asking for accommodations in relation to POTS.

I'm not one for "putting people out". In fact, I actively avoid it, whether consciously or not. It took me about 5 years to get comfortable with people bringing me coffee, and anything else I might need, when working on professional television productions.

But I'm happy to report that I have a newly-found confidence in asking for the things I need when it comes to my POTS. Whether it's jumping the large, outdoor queue I encountered when I went to vote at the last election, or requesting an aisle seat near the doors at the theatre, in case I need to duck-out for the loo after drinking more water than some people drink in a week.

It turns out, that these were actually very simple requests and my needs were met. At the polls, all I had to say was, "I have an invisible illness" and I was ushered to the head of the line. At the theatre, my seat was perfect. I still worry about "putting people out" or a confrontation if my need for accommodations is misunderstood, but I know that it's really important that I ask as well as a great opportunity to educate others about POTS.

Emma-Louise

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:

Gemma W (SA) Owen N (NSW) Danielle H (QLD)

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

Our team will be completing the City to Bay, Adelaide to raise vital funds for POTS research in Australia.

Despite repeated requests, Health Minister **Mark Butler MP has refused all meetings with the Australian POTS Foundation**. We wish it were different – that those with lived experience of POTS had the same recognition and support as others with chronic illness. Until that happens, we rely on our community and supporters to drive change. Every donation helps fund local research that is urgently needed.

Together, we can make POTS visible and ensure no voice goes unheard. You can support Marie-Claire and the team here:

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. Paul Muffet

Current fundraisers to support

- Olivia & Crew
- Harriet Wilson
- Tamara Galbraith
- Olivia Powrie
- Kristina Comacchio
- Piper Drawwater
- Gemma Wilson
- Celine Gallagher
- Sophie Dunow
- Caelum Schild

DYSAUTONOMIA AWARENESS MONTH IS ALMOST HERE

How will you be raising awareness?
Be sure to tag us in any social posts and email us admin@potsfoundation.org.au so we can share and support your efforts

To support us in our work, all donations are gratefully received and can be made using the QR code or direct into our account below

THE AUSTRALIAN POTS FOUNDATION
BSB: 015208
Account Number: 153059214

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