



Issue 9
Autumn
Edition
2026

NEWSLETTER

Welcome to our Autumn edition

Our favourite time of year – leaving the heat behind and (hopefully) finding POTS management just that little bit easier.

It's been an impressive and energetic start to the year, and 2026 is already shaping up to be a momentous year for APF. This month we're celebrating our 5th anniversary, and looking back on what has been achieved by our small team feels truly remarkable.

Thank you for being part of this journey and for helping build a supportive and informed POTS community.



TUNE IN:

2026 Webinar Series

31 March 2026

Making Work and School Work with POTS: Practical Supports from an OT Perspective

*with Melanie Weeks,
Senior Occupational Therapist*

Navigating study, employment, and daily expectations with POTS can feel overwhelming – but the right supports can make a meaningful difference.

The event is free for members. We have also released 250 free tickets for non members - if these are sold out, now is the perfect time to join as a member (membership is pro rata'd).



For many in our community, the journey to a POTS diagnosis has been long, frustrating, and isolating.

Research led and supported by the Australian POTS Foundation has consistently shown how limited clinician understanding of autonomic disorders remains, and how this lack of education directly contributes to delayed diagnosis and poor access to care. This is not because POTS is rare, but because our health system has not yet invested adequately in training clinicians to recognise and manage these conditions.

To help address this gap, I was honoured to be awarded a Churchill Fellowship, funded by the Australian Government Department of Health and Wellbeing, to explore how leading international centres train clinicians in autonomic medicine and deliver high quality, evidence based care.

One of the most encouraging experiences during the Fellowship has been attending the world-leading Residents Course delivered jointly by The Dysautonomia Project and the American Autonomic Society in Florida. These discussions have created an opportunity to explore developing a similar course in Australia in collaboration with these organisations.

Throughout the Fellowship, I am also visiting international centres that lead the world in autonomic testing, rehabilitation, and research. What stands out is how much becomes possible when health systems invest in education. Earlier diagnosis, more confident clinicians, and care that reflects the lived experience of people with POTS and related conditions are all achievable.

This Fellowship is about hope, progress, and action. The learnings will inform advocacy for improved clinician education, better access to autonomic testing, and models of care that work for people living with POTS, so that future patients face fewer barriers and better outcomes.

You can follow along with my Churchill Fellowship journey and behind-the-scenes updates on Instagram at [**@AutonomicJourneys**](#).



*Yours in advocacy,
Marie-Claire Sedley*

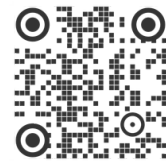




Scientific Committee update with Dr Celine Gallagher

We are delighted to share the publication of a new State of the Art on POTS review led by researchers at Adelaide University. This comprehensive review brings together the latest international evidence on POTS – spanning pathophysiology, diagnostic pathways, and current management approaches. It includes many esteemed national and international clinicians and researchers in POTS who have come together to author this expert review. Importantly, it reinforces growing recognition of POTS as a complex, multi-system condition and highlights key priorities for future research. Reviews like this help shape clinical practice, guide education, and strengthen advocacy for sustained research investment here in Australia.

The review is available for everyone to read in our Knowledge Hub
<https://potsfoundation.org.au/the-knowledge-hub> or use the QR



We are proud to celebrate the return of two Australian physicians who attended a special training course led by The American Autonomic Society and The Dysautonomia Project on Autonomic Disorders. The Resident's Course was held in Florida in late January. Despite some inclement weather, the course went ahead and we look forward to hearing more from our attendees about their experience in upcoming events. The knowledge, skills and professional networks developed through this experience will directly improve local knowledge – ultimately benefiting Australians living with POTS through improved recognition, diagnosis and care.

Looking ahead, preparations are well underway for the upcoming Converge conference. The Scientific Committee has been carefully reviewing submitted abstracts and curating the program so that our health care professionals and community can get the most out of this special event.

We look forward to an upcoming webinar with specialist Occupational Therapist Melanie Weeks, with a special focus on work and school modifications for people living with POTS. This has been a topic many of you have been requesting and we look forward to learning more about this with Melanie on 31 March. A recording will also be available on the website later this year for members to view.

With thanks, Celine



"I, for one, am enormously grateful that it's Autumn! Summer was particularly tough this year. My autonomic nervous system struggled to cope with the Sydney heatwave, especially when our air conditioning broke down. I'm really grateful for the work of the POTS Foundation during these times. Your research and advocacy are crucial in helping us understand our own bodies. Thank you." Tracey Spicer
APF Ambassador

From CC – Autumn Reflections

As the seasons shift into autumn, many in our community notice their symptoms shifting too. Changes in temperature, barometric pressure, and routine can all influence how our bodies respond day to day. Some days might feel steady, while others remind us just how unpredictable living with POTS can be.

During these times, I often try to return to a simple check-in with myself. If my energy is low, I pause and ask: Does this have to be done today? Could it wait? Is this something someone else could help with? These small questions can help create a little more breathing space when our bodies are asking us to slow down.

This is also the time of year I lean into the “dump bag” method for meals. When I’m feeling up to it, I’ll prep a few freezer bags with chopped vegetables, protein, and a simple base. Then when the time comes, it’s as easy as tipping the contents into a pot, slow cooker, or pan and letting it cook. Sometimes I’ll prepare a few versions of the same base ingredients but add different herbs or seasonings so they become completely different meals later on. It’s a small bit of preparation that can make low-energy days feel much more manageable.

Learning to listen and adjust doesn’t always come easily – especially for those of us who are used to pushing through – but allowing ourselves that flexibility can make the changing seasons a little gentler to navigate.

As always, I hope this newsletter brings you useful insights, connection, and a reminder that you’re not walking this path alone.

CC



ZEBRAS *australia* **ZEBRAS** *australia* **ZEBRAS** *australia* **ZEBRAS** *australia* **ZEBRAS** *australia*

Welcome Zebras Australia

We are delighted to welcome Zebras Australia as a new partner of the Australian POTS Foundation.

Based in Melbourne, Zebras Australia is a healthcare organisation dedicated to supporting people living with rare, chronic and complex conditions, including Ehlers–Danlos syndromes, dysautonomia, and POTS. Their work centres on compassionate, whole-person care – bringing together practitioners across disciplines to support the physical, emotional and functional aspects of living with chronic illness.

Founded with the vision of supporting those who are often misunderstood or overlooked within traditional healthcare systems,

We’re thrilled to have them join our growing network of organisations committed to improving care and understanding for people living with POTS. Partnerships like this help strengthen the bridge between community, clinicians, and education – something that benefits us all.

We look forward to seeing the Zebras Australia team at Converge and continuing to work together to support and empower the POTS community.

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An Interview with Nurse Practitioner Candidate Emma D'Arcy:

Can you tell me a little bit about your background and what made you decide to specialise in Postural Orthostatic tachycardia Syndrome (POTS).

I began my nursing career as an Enrolled Nurse in 2008, initially working in cardiac nursing. I soon undertook a Bachelor of Nursing at UniSA and continued working in cardiology following completion of my graduate year. In 2016, I completed postgraduate studies in Cardiac Nursing and am currently undertaking a Master of Nursing (Nurse Practitioner). I continue to work in a coronary care unit alongside my role as a POTS clinical nurse. I am grateful for the flexibility and support that allow me to maintain both roles, as they complement each other and enable ongoing knowledge transfer, professional development, and growth.

Nurses are not only required to engage in continued professional development to maintain their registration each year, but they are also presented with invaluable opportunities to learn and grow. I have been fortunate to specialise in POTS, where I've received tremendous support in a nurturing environment. This has fuelled my passion to continually improve and offer more to a community of individuals who have taught me so much along the way.

What have you found to be the most rewarding and challenging aspects of working in the field?

Where do I begin. Working in a field where so much research is still unfolding can be challenging. We don't have all the answers. However, our eagerness to learn drives us forward. I am excited to continue learning from my colleagues, both locally and internationally, and to collaborate on new projects with global health professionals, gaining insights that help us all grow. Surrounding myself with people who are more knowledgeable has strengthened my skills and broadened my perspective. Likewise, learning through exposure to patients has been a privilege; the opportunity to listen to and learn from them has been particularly rewarding and has profoundly shaped my practice.

Can you tell me a little more about the role of a Nurse Practitioner (NP) and what made you decide to go down the pathway of becoming one.

In Australia, an NP is an advanced practice registered nurse who has completed additional education, training, and clinical experience to provide a higher level of autonomous care. I see the role of an NP as bridging the gap between nursing and medicine. Patients with POTS often experience unequal access to care including long diagnostic delays. While awareness of the condition among healthcare professionals is growing, other barriers –such as extended wait times for publicly funded centres, limited access to specialist services due to geographic location, and the costs associated with chronic illness– continue to impact care. My hope is that, as an NP, I will be able to address some of these challenges and improve access and outcomes for this patient population.



How does Australia compare to other countries regarding the role of the Nurse Practitioner?

To provide a brief timeline of the NP role, the first NP program originated in the United States in 1965. It was another 35 years before the first NPs were authorised to practise in Australia in December 2000. In December 2025, Australia marked 25 years of NP care.

A 2016 cross-country analysis of the NP workforce in six countries revealed that the United States has the highest number of NPs per 100,000 population.

- USA: 40.5 per 100,000
- The Netherlands: 12.6 per 100,000
- Canada: 9.8 per 100,000
- Australia: 4.4 per 100,000
- Ireland and New Zealand: 3.1 per 100,000 each

While Australia has a lower number of NPs per 100 000 population, this is partly because the profession was introduced here several decades later than in countries like the USA. Like many nations facing healthcare provider shortages, Australia can benefit from greater recognition and integration of Nurse Practitioners. Given the consistently positive outcomes NPs provide in patient and community care, I hope that continued growth in this workforce can help bridge gaps in access to care for our communities moving forward.

How do organisations such as the Australian POTS Foundation align with the work of NP's working with people with POTS?

The Australian POTS Foundation plays a vital role in promoting awareness of POTS within the community and supporting education through initiatives such as the conference and webinar program.

The APF's recent partnership with the Heart Foundation is an exciting opportunity to further expand awareness and advocacy for patients with POTS. The Foundation's website offers a wealth of resources that are invaluable not only to patients and their families but also to clinicians. I frequently refer my patients to the list of POTS-aware practitioners, providing them with greater choice and access to comprehensive care for their broader health needs.

Because exceptional care deserves recognition.

Have your say.

Nominate the people who show up, listen deeply, and change outcomes for our community.

The Australian POTS Foundation Excellence in Care Awards recognise clinicians and care teams who have made a meaningful difference to people living with POTS.

These awards are community-nominated and celebrate care that is compassionate, collaborative, and grounded in lived experience. They provide an opportunity to acknowledge those who listen, advocate, and go the extra mile.

Nominations close at 5:00pm ACDT on Saturday 29 March 2026.

Learn more here:
<https://potsfoundation.org.au/clinical-excellence-awards>



Converge 2026

4/5th June

Featured Speakers



Professor David Putrino
Physiotherapist
Mount Sinai,
New York, USA



Dr Alexis Cutchins
Cardiologist
Cutchins Cardiology,
New York, USA



Associate Professor Susan Evans
Gynaecologist &
Pain Physician
Pelvic Pain Foundation
of Australia



Dr Marie-Claire Seeley
Clinical Nurse
CEO, Australian POTS
Foundation



Professor Dennis Lau
Cardiologist &
Electrophysiology
Royal Adelaide Hospital,
Adelaide



Megan Gilmour
Co-Founder
MissingSchool



Dr Adrian Lee
Clinical Immunologist
Westmead Hospital,
Sydney



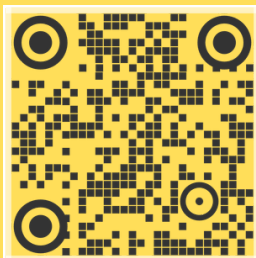
Professor Tracey Wade
Flinders University
Adelaide



Dr Sam Whittle
Senior Consultant
Rheumatologist,
Queen Elizabeth
Hospital, Adelaide

Get Your Tickets!

In person & Virtual Earlybird Tickets
available until 7th April



Australian
POTS Foundation

CONVERGE

Examining Common Pathways
in Invisible Illness

Adelaide | June 4 - 5 2026

CONVERGE

Examining Common Pathways in Invisible Illness

Clinical Day – 4 June 2026

A program for clinicians, researchers and allied health professionals



08:00 – Opening & Lived Experience Perspective – Dr Michael Cusack, Chief Medical Officer for South Australia.

Followed by Lived Experience Presentation.

08:30 – Opening Plenary – Dr Alexis Cutchins – POTS in Perspective:

Treating the Whole Patient, Not Just the Syndrome

09:00 – Plenary – Professor David Putrino – Restoring Function in the Face of Fatigue:

Lessons from Long COVID Rehabilitation

09:30 – Expert Panel Discussion – Moderated by Sophie Scott OAM

Concurrent Symposium 1: Women's Health in Focus – Understanding Complex, Overlapping Conditions

Dr Phillip Puckridge – Vascular and Visceral Compression Syndromes in POTS	Associate Professor Susan Evans – Endometriosis and Pelvic Pain as Systemic Conditions	Professor Stephen Birrell – Hormone Management in Women's Health: Evidence-Based Approaches for Clinicians	Dr Kate Levick – Supporting Women with POTS in Pregnancy: Navigating Risks, Care Pathways & Holistic Health
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Concurrent Symposium 2: Decoding Chronic Pain – Musculoskeletal, Neurological & Immune Perspectives

Dr Fraser Burling – Managing Musculoskeletal Pain in Joint Hypermobility – impact of prolotherapy	Dr Samuel Whittle – Fibromyalgia: Advances in Diagnosis, Mechanisms & Holistic Treatment	Professor Alberta Hoi – Sjögren's Syndrome: Beyond Dry Eyes – Recognising Systemic & Pain Manifestations
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Lunch

Concurrent Symposium 3: The Hidden Load – Mental Health in Chronic Illness

Professor Tracey Wade – Understanding Eating Disorders in Chronic Illness: Recognition, Risk & Recovery	Dr Rebecca Nelson – Neurodivergence & Chronic Illness: Supporting Cognitive, Emotional & Functional Needs	Dr Elizabeth Walsh – Building Psychological Resilience: Evidence- Based Strategies for Clinicians	Ms Megan Gilmour – Helping Students Stay Engaged: Clinical & Educational Strategies for Missed School
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Concurrent Symposium 4: Beyond the Diagnosis – Common Comorbidities in POTS

Dr Alexis Cutchins – Navigating MCAS in Clinical Practice: Stabilisation, Triggers & Treatment Pathways	Professor Dennis Lau – Medications That Make a Difference: Optimising Symptom Control in POTS	Dr David Fineberg – Understanding ME/CFS: Clinical Approaches to a Complex Neuroimmune Condition
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15:20 – Australian POTS Foundation Presentation – Dr Marie-Claire Seeley

15:45 – Nursing & Allied Health Prize Session

16:15 – Panel Discussion – From Fragmentation to Coordination:

Building Models of Care for Invisible Illness

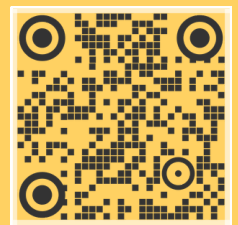
16:45 – Plenary – Dr Marc Gladman – The Gut-Body connection:

Understanding gastrointestinal manifestations in POTS and invisible illness

17:15 – Plenary – Dr Marie-Claire Seeley – Hypermobility in Clinical Practice:

Recognition, management and ongoing challenges

**In person & Virtual
Earlybird Tickets
available until 7th
April**





CONVERGE

Examining Common Pathways in Invisible Illness

Community Day – 5 June 2026

A program for people living with POTS and associated conditions, families and carers

09:45 – Opening Plenary – Professor David Putrino –

Managing Fatigue in Complex Chronic Conditions

10:15 – Lived Experience Panel – Advocacy, navigating healthcare, and living with invisible illness

11:15 – Plenary: Dr Alexis Cutchins –

POTS in Perspective: Managing the Individual, Not the Syndrome

11:45 – Sophie Scott OAM –

Living Well with Chronic Illness (including guided breathing and wellbeing strategies)

Concurrent Symposium 1: The Gut Matters – Everyday Strategies for Digestive Health

Dr Marc Gladman – Understanding Functional Gut Symptoms: What They Are & How to Manage Them	Ms Kaitlin Day – Food as a Tool: How Diet Can Support Better Digestive Health	Dr Mia Pellizzer – Understanding Eating Disorders: Recognising Signs and getting the Right Support
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Concurrent Symposium 2: Beyond POTS: Practical Approaches to Common Overlapping Conditions

Dr Chris Armstrong - Innovations in research for ME/CFS	Dr Adrian Lee - Sjögren's Syndrome: Recognising Features & Managing Chronic Symptoms	Dr Sam Whittle - Fibromyalgia: Mechanisms, Diagnosis & Multidisciplinary Management
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Lunch

Concurrent Symposium 3: Growing Up With Chronic Illness: Challenges and Supports for Young People

Dr Michelle Scoullar – Understanding Long COVID in the Paediatric Population	Ms Megan Gilmour – Keeping Students Connected: Practical Approaches to Chronic Illness & Education	Dr Rebecca Nelson – Neurodiversity in Young People With Chronic Illness: Strengths, Needs & Supports
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Concurrent Symposium 4: Thriving With Chronic Illness: Practical Strategies and Emerging Knowledge

Dr Emma Tippet – Long COVID in Adults: What We Know, What's Emerging & How to Support Recovery	Mr Caelum Schild - Accessible Autonomic Care: Simple, Evidence-Based Interventions That Make a Difference	Dr Elizabeth Walsh - Supporting the Whole Person: Psychological Care in Chronic Illness Management
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15:15 – Panel - From Lived Experience to Evidence:

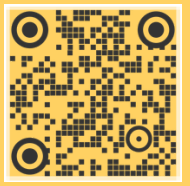
Strengthening Australian Research in POTS and associated conditions

15:45 – Australian POTS Foundation Address

16:00 – Afternoon tea

17:00 – Close

In person & Virtual
Earlybird Tickets
available until 7th
April



Inspiring POTS Champion – Tayla Garwood

Year 12 student Tayla Garwood from Tenison Woods College has shown extraordinary resilience while completing her SACE. Diagnosed with Postural Orthostatic Tachycardia Syndrome (POTS) in Year 11, Tayla managed significant symptoms, frequent absences, and long daily travel – all while navigating a major family health crisis just weeks before her final exams.

With determination and strong support from her school and family, she graduated alongside her peers

with outstanding results, including two A grades, three A+ grades, a SACE Merit for Religious Education, and an ATAR of 95.00.

Working closely with teachers, Tayla developed a flexible study plan that prioritised both health and learning. She credits open communication, self-advocacy, and pacing her workload to what she felt capable of each day as key to her success. Despite the unpredictability of POTS, Tayla remained focused on progress – even when progress was slower than planned.

Inspired by the support she received, Tayla has accepted an early offer to study a Bachelor of Education (Primary) with Charles Sturt University. Her story is a powerful reminder that with understanding, flexibility, and community support, young people living with POTS can continue to pursue their goals and shape meaningful futures.

We're so proud of your achievements, Tayla – you're an inspiration to us all!

For the full story visit: <https://sevoice.com.au/straight-a-student-a-lesson-in-determination/>



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





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

- Polly C, NSW**
- Bonny W, QLD &**
- Stace L, VIC**



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.

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

Advertise in our Converge Conference Programme

Advertise in Our Converge Conference Programme!

Do you have a product, service, or resource that supports people with POTS? Reach our engaged community by featuring in the Converge Conference programme.

- **¼ page: \$250**
- **½ page: \$500**
- **Full page: \$1,000**

Share your offering with those who will benefit most – secure your spot today and be part of the conversation!

Email cc@potsfoundation.org.au

Would you like to exhibit? We still have a couple of spaces available but don't delay, we're finalising our conference partners this month!

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

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@potsfoundation