ISSUE #2

Mito Monthly Newsletter

Australian Mitochondrial Disease Centre | NeuRA Discover — Conquer — Cure

April 2025

PROFESSOR CAROLYN SUE

In this newsletter you can expect:

Here's what has happened in the last month and what's to come!

Dear Mito Community,
Welcome to our latest newsletter! As we move forward in 2025, our commitment to improving care, advancing research, and supporting our mito community remains stronger than ever.

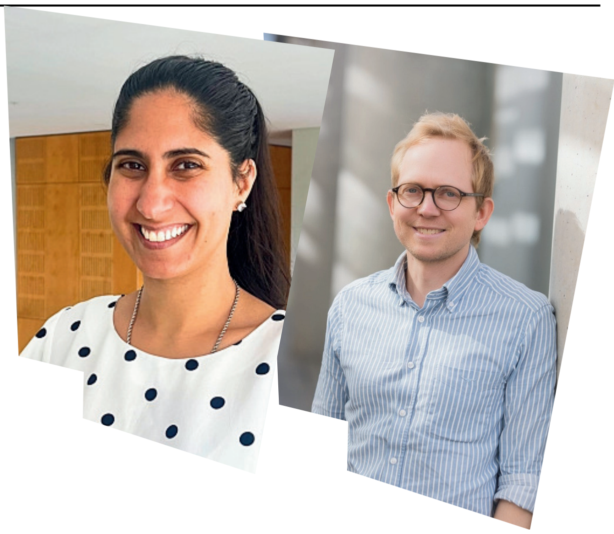
This year, we are excited to welcome new neurology fellows who will bring fresh expertise and dedication to our clinical and research efforts. We also continue to expand our services, providing better access to diagnostic tools, genetic counseling, and patient resources to ensure comprehensive care for everyone affected by mitochondrial disease.

In this edition, you'll find important updates on emergency preparedness, the latest clinc news, and upcoming events, all aimed at helping you stay informed and empowered. We're also featuring an incredible resource—the R.A.R.E. Portal, a valuable hub of information for rare disease patients and families.

Thank you for being part of this journey with us. Your resilience and strength inspire everything we do, and together, we are making meaningful progress toward better treatments and, one day, a cure.

Warm regards,

Carolyn Sue



What is a Neurology Fellow?

A "neurology fellow" is a medical doctor who has completed their general medical residency and is now undergoing further specialized training in the field of neurology, focusing on the diagnosis and treatment of diseases affecting the nervous system, through a dedicated fellowship program after their residency.

This year we say farewell to William and Delara - our wonderful neurology fellows who were with us for 2024 and made a wonderful impact in all areas of mitochondrial research and patient care. Both have returned to Perth to continue their medical careers.

This year we will welcome 2 new neurology fellows - Sebastian and Serge.
Stay tuned for their introductions throughout the year!

Special Event!

Mito-ducation: A Primer for Mitochondrial Disease

Thursday 8th May @ 6:30 p.m.
Betty and Lynch Seminar Room, Level 3,
Margarete Ainsworth Building (139 Barker Street, Randwick)
Light refreshments on entry
Free to ALMA NSW members

Speakers:

Prof. Carolyn Sue
An internationally recognised clinical research leader in Parkinson's and mitochondrial disease

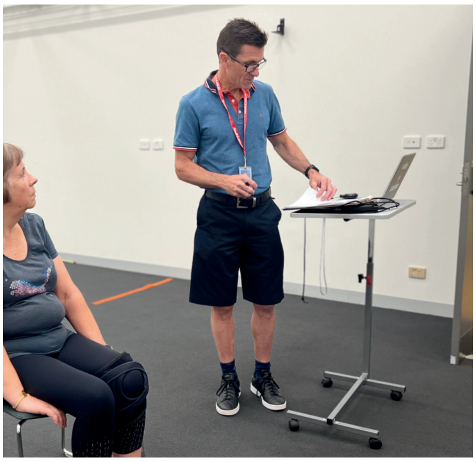
Dr. Serge Geara
Neurologist and Mitochondrial Research Fellow at Neura

RSVP by **4th May** here

The **Australian Lebanese Medical Association** warmly invites all healthcare professionals to our upcoming CPD event on Mitochondrial Disease, featuring Prof **Carolyn Sue** and Dr **Serge Geara**, on Thursday 8th May at 6:30 PM.

RSVP and details: **https://lnkd.in/g8h9Riyu**

In a Mito Minute.....



Did you know that staying active is one of the most important ways to manage mitochondrial disease?

While mito is complex and often misunderstood, research shows that movement - done safely and consistently - can improve long-term health and quality of life. Physiotherapy isn't just about exercise; it's about education and empowerment for both patients and caregivers. A personalised, goal-based approach helps people with mito move more, stay motivated, and manage symptoms effectively.

💡 Key Takeaways:
✓ Movement should be safe, consistent, and tailored to your needs.
✓ Setting achievable goals keeps activity engaging and sustainable.
✓ Physiotherapists can guide and support you in staying active long-term.
Your body thrives on movement—small, regular steps make a big difference!

Resource of the Month

In this issue, we're highlighting the R.A.R.E. Portal, an essential platform by Rare Voices Australia (RVA). Designed for individuals and families living with rare diseases, it offers trusted information, support, and education.

rare voices
AUSTRALIA®

Key Features

- Comprehensive resources: Fact sheets, guides, and toolkits tailored to rare diseases.
- Educational modules: Build understanding and advocacy skills.
- Community connection: Share experiences and access support.

Visit the R.A.R.E. Portal today to explore these resources and empower your rare disease journey.
https://rarevoices.org.au/rare-awareness-rare-education-r-a-r-e-portal/

RACHAEL'S CORNER

Hi everyone! Rachael here, your clinical nurse at the Australian Mitochondrial Disease Centre. I'll be sharing practical tips, helpful reminders, and a bit of encouragement to help you on your mitochondrial journey. Here's what I've got for you:

This Month's Tip: "Emergency Planning"
I want to talk about the importance of being prepared for emergencies. Having an ID bracelet or a patient card with essential medical information can make a critical difference in ensuring you receive the right care in urgent situations.
Here's why they're important:

- Quick access to vital information: Helps medical teams understand your condition immediately.
- Improved safety: Reduces the risk of inappropriate treatments.
- Peace of mind: You and your loved ones can feel more secure knowing you're prepared.

We have patient cards available at the clinic—please ask for one during your next visit! Let's make safety a priority.

Got a question for me? Submit it to ausmitodc@gmail.com, and I might feature it in next month's edition!

Clinical Trial Update

Clinical Trial - Natural History of Mitochondrial Disease

Thank you to everyone who has already enrolled in our current clinical trial.
If you are interested in learning more please email clinics@neura.edu.au

Thank you for reading!