Mito Monthly Newsletter

Australian Mitochondrial Disease Centre

NeuRA Discover —— Conquer —— Cure

December 2024

PROFESSOR CAROLYN SUE

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

Dear Mito Community,
I am thrilled to welcome you to the first edition of our newsletter, where we celebrate the resilience and dedication of our patients, families, and clinical teams.

At our mitochondrial clinics, we are committed to providing the highest standard of care, support, and innovation to ensure each of you receives personalised and effective treatment.

Every day, our team is working hard to improve your experience and outcomes, whether through enhancing our clinical services, advancing research, or collaborating with the incredible specialists within the Mito Medical Network.

We are expanding access to genetic counseling, increasing diagnostic options, and striving to understand this complex condition better with every patient we meet.

Our mission is to bring you cutting-edge care and to remain by your side in this journey with compassion and expertise.
Thank you for being part of this community. Together, we are making strides toward a future with better treatments and, one day, a cure.
Wishing you a wonderful holiday season!

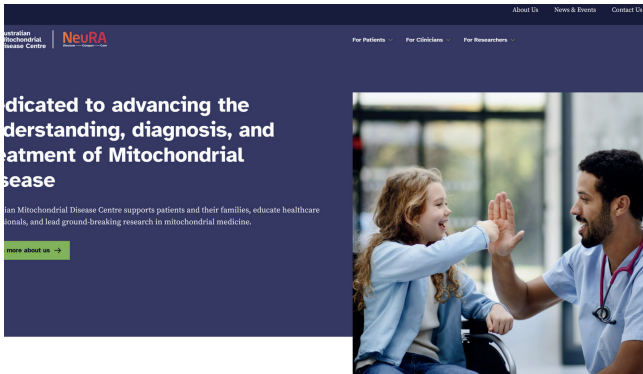*Carolyn Sue*

In this newsletter you can expect:

Clinic News and Updates

Rachael's Corner

Meet your Mito team

Resource of the month

Highlights

Clinic News and Updates

We're excited to bring you this first edition of our Australian Mitochondrial Disease Centre Newsletter, a new way for us to stay connected with you every month. Through this newsletter, we'll share updates that matter most to you—important information on patient care, the latest in mitochondrial research, and helpful resources from our clinics.

This newsletter also marks the launch of our new website, designed with you in mind!

The site will be your go-to destination for trusted information on mitochondrial disease, easy access to clinic resources, and up-to-date news on research developments. We hope it will be a valuable resource that supports you and keeps you connected with our community.

Click the link and check it out - there will be more on each page over the coming months so do check back regularly and subscribe to receive updates!

Rachael's Corner

Hi everyone! Rachael here, your clinical nurse at the Australian Mitochondrial Disease Centre. Each month, 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:

This Month's Tip: "The Power of Little Wins"
Living with mitochondrial disease can be exhausting, and it's easy to feel overwhelmed. But every small step you take is a victory—whether it's getting out for a short walk, managing your meds like a pro, or simply resting when your body tells you to. Celebrate those little wins, and don't be hard on yourself. You're doing amazing!
Got a question for me? Submit it to ausmitodc@gmail.com, and I might feature it in next month's edition!

Meet your Mito Team!

William Wallefeld

Dr. Wallefeld sees patients with neurogenetic conditions and mitochondrial disease in the outpatient clinics.
His research activities include recruiting patients for the Natural History of Mitochondrial Disease study and working on a project aimed at discovering biomarkers for mitochondrial disease using mitochondrial autofluorescence in urinary specimens, in collaboration with researchers from the UNSW School of Biomedical Engineering.

Rachael McKinnon

Rachael Mackinnon is a highly skilled and compassionate Clinical Nurse Consultant with a specialised focus on related movement disorders. With extensive experience in both clinical care and patient education, Rachael has dedicated her career to improving the quality of life for individuals and supporting families through the challenges of this condition.
Her expertise encompasses a holistic approach to care, addressing the physical, emotional, and social needs of her patients.

Resource of the Month

Mito Medical Network (MMN) is a medical society committed to raising the profile of mitochondrial disease for medical practitioners and academics. MMN is committed to improving:

- Understanding of mitochondrial disease
- Recognising potential symptoms
- Diagnosis
- Therapeutic management

MMN achieves this by:
- Consolidating existing medical knowledge
- Education about current best practices
- Promoting clinical research
- Disseminating accurate information
- Promotion as a representative professional body

CELEBRATING 30 YEARS OF MITO CLINCS WITH THE LAUNCH OF THE AUSTRALIAN MITOCHONDRIAL DISEASE CENTRE.
5TH SEPTEMBER 2024

All the highlights from the day and what the centre will be doing for you.

Our Mito Open Day in September was a wonderful celebration of community, knowledge, and progress.

The event featured insightful talks on all things mitochondrial, from the latest research to updates in patient care, sparking vibrant discussions among attendees.

We paused the session with essential stretches led by our fantastic physio, Jeremey, who showed patients how to incorporate simple, effective movements into their daily routines.

The day also marked a significant milestone as we celebrated 30 years of mito clinics with a delicious cake that was enjoyed by all.

Lunch was a special treat, with none other than Carolyn Sue's "Mito Dogs" on the menu, fueling excellent conversation between patients, scientists, and clinicians alike. It was a unique opportunity for everyone to share stories, ask questions, and build connections.

A highlight of the day was officially launching the Australian Mitochondrial Disease Centre which will have an ongoing partnership with the Mito Medical Network. Together, we aim to advance patient care through collaboration and innovation. We are working toward better outcomes for all affected by mitochondrial disease

We thank everyone who joined us for making it such a special and memorable day, and we look forward to more events like this in the future!

From the team here at AMDC and NeuRA we wish you all a very *happy holidays*

Australian Mitochondrial Disease Centre | **NeuRA** Discover — Conquer — Cure   ausmitocentre.org   X ⓘ f in