

## Mito Community Summit Program 2023

Bringing the mito community together to learn, connect and collaborate.

The Mito Community Summit 2023, will take place on Friday 20 October and Saturday 21 October at the NSW Teachers Federation, Sydney. [Click here for more information on the speakers.](#)

[Register for the summit now!](#)

**Please note, all times are in Australian Eastern Daylight Time (AEDT).**

### Day One, Friday 20 October

9:30am AEDT | Registrations and Morning Tea

10:15am AEDT | Official Welcome

#### **Live Stream Available**

Introduction to the event and information about the Mito Foundation.

10:30am AEDT | Dr Suzanne Sallevelt: Understanding the Reproductive Options for People with Mito

#### **Live Stream Available**

11:15am AEDT | Morning Break

11:30am AEDT | Dr Alan Ma: The Promise of Precision Medicine

#### **Live Stream Available**

12:15pm AEDT | Lunch Break

1:00am AEDT | Dr Shanti Balasubramaniam: The Genetics-First Approach to the Diagnosis of Mito

**Live Stream Available**

1:45pm AEDT | Afternoon Break

2:00pm AEDT | Prof Carolyn Sue: Topic TBC

**Live Stream Available**

2:45pm AEDT | Afternoon Break

3:00pm AEDT | Activity: Music Therapy

We will conclude day one with a fun and mindful group drumming session. We will learn some easy rhythms that connect to a strong common pulse, creating a solid rhythmic union.

3:45pm AEDT | Free Time

5:30pm AEDT | Mito Foundation Awards Night

We will acknowledge and celebrate the everyday heroes of the mito community with this awards night.

## Day Two, Saturday 21 October

9:30am AEDT | Registrations

10:30am AEDT | Exercise Physiology Workshop with Nancy van Doorn & Ashley Boniface — EPs

This practical workshop will discuss the benefits of exercise. There will be opportunities to try movements to improve mobility and function.

11:15am AEDT | Morning Break

11:30am AEDT | Showcase of Mito Foundation's Support Services — Including the Launch of New Resources

12:15pm AEDT | Lunch Break

1:00pm AEDT | Panel Discussion: How You Can Help Me

Members of the mito community will share their experiences on receiving support from friends and family. The discussion will focus on how they can best provide support in the good and bad times.

1:45pm AEDT | Afternoon Break

2:00pm AEDT | Self-Advocacy Workshop

Advocacy can be an important tool to manage chronic illnesses like mito. This workshop will explore tips on what effective self-advocacy looks like and techniques you can use to get the emotional and physical support you need.

2:45pm AEDT | Summit Wrap-Up

3:00pm AEDT | Summit Close

## Speakers



### **Dr Shanti Balasubramaniam**

Dr Shanti Balasubramaniam is a Metabolic Geneticist, the first to be appointed in the state of Western Australia where she headed the Metabolic Service from 2012 to 2015. As the clinical lead of a statewide referral center, she actively participated in several clinical trials geared towards the development of new therapeutic strategies and was also involved in collaborative diagnostic research endeavours with both national and international colleagues. She was privileged to be a member of the Advisory Group for the Western Australian Rare Diseases Strategy, a strategic framework which focussed on advocating rare diseases as a public health priority and in addressing equitable access to healthcare services for the rare diseases community.

Shanti is currently a Senior Staff Specialist at The Children's Hospital at Westmead, Sydney Children's Hospital Network.



### **Ashley Boniface MSc CEP(Hons), ESSAM**

Ashley is an Accredited Exercise Physiologist based in Brisbane at Bodytrack Exercise Physiology. Ashley completed her Masters in Clinical Exercise Physiology (Hons) at the University of Auckland in 2016. She believes

exercise is medicine, excels in prescribing exercise for cardiopulmonary and metabolic conditions and has a special interest in endocrine related conditions. Ashley uses an evidence-based approach to manage long-term health, movement and symptoms through exercise therapy in a fun and safe environment. She enjoys seeing clients make behavioural changes and incorporate exercise into their lifestyle, as she knows it will allow them to move and live better.



**Dr Alan Ma BBS, FRACP**

Dr Alan Ma is a clinician researcher based at Sydney Children's Hospitals Network - Westmead. He specialises in clinical genetics and sees patients with genetic conditions and rare diseases in urban and rural NSW. He has completed a PhD in the genomics of blinding eye conditions. He is also a senior lecturer with the Specialty of Genomic Medicine at the University of Sydney, and helps run the postgraduate Masters of Genomics and Precision Medicine. His research interests are in genomics, and the implementation of genomics and precision medicine into the healthcare system. He is a Sydney Health Partners Research Translation Fellow, and a member of the SHP Clinical Academic Group in Genomics and Precision Medicine, and the NSW Health

Genomics Strategy as an advisor on education, curriculum, and workforce working groups.



**Dr Suzanne Sallevelt MD, PhD, FRACP**

Dr Suzanne Sallevelt is a clinical geneticist originally from the Netherlands; she studied Medicine and undertook her training in clinical genetics in Maastricht, The Netherlands and was subsequently appointed as a consultant in the Clinical Genetics Department, Maastricht University Medical Center+ (MUMC+) in 2013, where she worked until April 2020.

More recently she held a locum clinical geneticist role at Royal North Shore Hospital in Sydney and currently she is employed as a senior consultant in the Paediatric and Reproductive Genetics Unit of the Women's and Children's Hospital, Adelaide where she started in December 2020. Since February 2022 she also works as a Clinical Geneticist at Repromed (Monash IVF group).

Besides being trained all-round in adult and paediatric clinical genetics, her specific areas of expertise are reproductive genetics, including prenatal diagnosis (PND) and preimplantation genetic testing (PGT), and mitochondrial genetics in the context of these reproductive options. She completed her PhD through Maastricht University in 2017 with her thesis entitled "Preventing the transmission of mitochondrial diseases".

As part of this she developed new and optimised existing strategies to prevent transmission of mitochondrial diseases, and incorporated these choices in reproductive counselling.

Suzanne is currently involved in various Australian national research projects, including being chief investigator in the mitoHOPE (Healthy Outcomes Pilot and Evaluation) program which has formed an Australian-wide consortium to conduct a mitochondrial donation and reproductive options pilot program.



**Professor Carolyn Sue AM, FAAHMS**

Professor Carolyn Sue, MBBS, PhD, FRACP, the Kinghorn Chair, Neurodegeneration at Neuroscience Research Australia (NeuRA), is an internationally recognised clinician-scientist, a leader in Parkinson’s and mitochondrial disease and a medicine alum of UNSW who trained at Prince of Wales Hospital and at Columbia University in the United States.

Professor Sue was the head of the Departments of Neurogenetics and Neurology at Northern Sydney Local Health District, while also leading Royal North Shore Hospital’s clinic for mitochondrial disease patients — the largest mitochondrial disease clinic in Australia. She is the immediate past Executive Director of the Kolling

Institute, where she positioned the institute as a centre of world-leading translational research excellence.

Carolyn's experience, expertise and contribution have been widely recognised. She is a Fellow of the Australian Academy of Health and Medical Sciences and serves on the Council of the National Health and Medical Research Council. She is also a founding member of the Mito Foundation and holds leadership roles at the Movement Disorder Society of Australia and New Zealand, International Parkinson's Disease and Movement Disorder Society and Australian Mitochondrial Disease Medical Network. In 2019, Carolyn was awarded a member of the Order of Australia (AM) in recognition of her significant services to medicine, particularly mitochondrial disease.



**Nancy van Doorn BSc(Hlth&SpSc), MClInExpPhys, ESSAM**

Nancy van Doorn has been an AEP at the Children's Hospital Westmead for the past 10 years, working with children and adolescents with a range of chronic conditions, with a special interest in disorders of energy metabolism and a strong passion for improving the health and wellbeing of young people.

More speakers will be announced shortly.