

## 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.](#)

**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**

Dr Suzanne Sallevelt is a clinical geneticist with expertise in mitochondrial genetics and reproductive options. She is involved in various Australian national research projects, including the mitoHOPE program which has formed a consortium to conduct a mitochondrial donation pilot program.

11:15am AEDT | Morning Break

11:30am AEDT | Dr Shanti Balasubramaniam: The Genetics-First Approach to the Diagnosis of Mito

**Live Stream Available**

Dr Shanti Balasubramaniam is a metabolic geneticist with a passion for the health care of families with mito. She will discuss how diagnosis of mito has changed and the move to a genetics-first approach.

12:15pm AEDT | Lunch Break

1:00pm AEDT | Dr Alan Ma: The Promise of Precision Medicine

**Live Stream Available**

Dr Alan Ma specialises in clinical genetics and sees patients with genetic conditions and rare diseases. He will share updates on emerging research in the areas of genomics and precision medicine in the healthcare system.

1:45pm AEDT | Afternoon Break

2:00pm AEDT | Prof Carolyn Sue: Past, present and future efforts to improve diagnosis, treatment and prevention of mito

**Live Stream Available**

Prof Carolyn Sue is an internationally recognised clinician researcher in the field of mito. She will discuss developments in the diagnosis, treatment and prevention of mito.

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 recipients of the 2023 Mito Community Awards, everyday heroes of the mito community. Canapes and drinks will be served.

## Day Two, Saturday 21 October

9:15am AEDT | Registrations

9:30am AEDT | Professor David Thorburn: Mito Foundation Funded Research Update

Professor David Thorburn will provide an update on some of the active research projects funded by Mito Foundation. This includes mitoHOPE and mitoMDT, which involves a multi-disciplinary team working towards a 70% diagnostic rate for mito by 2025.

10:15am AEDT | Morning Break

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

This practical workshop with Exercise Physiologists Ashley and Nancy, 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 | Nathan MacArthur: Navigating the Health System: Strategies for Self-Advocacy

Nathan MacArthur is an accredited mental health social worker and specialist grief counsellor. In this interactive workshop, Nathan will discuss the important role of self-advocacy in health and work through strategies to strengthen self-advocacy.

12:15pm AEDT | Lunch Break

1:00pm AEDT | Mito Information Showcase — Mito Foundation Team and Guests

This will be an interactive session where you can meet the team and ask questions. Explore topics that are of interest to you, including:

- Mito Foundation's support services
- new resources about first steps with mito
- resources to educate your health professionals about mito
- the mitoHOPE program (including an opportunity to meet the team).

You will also be able to provide input into the work we do and meet mito community members doing great things.

1:45pm AEDT | Afternoon Break

2:00pm AEDT | Panel Discussion: Tips for Carers

Members of the mito community will share their experiences of receiving support from friends and family. The panel will discuss what works well on good days and bad days.

2:45pm AEDT | Summit Wrap-Up

3:00pm AEDT | Summit Close

## Speakers (alphabetical order)



### **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 centre, 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 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.



Nathan MacArthur is an accredited mental health social worker and specialist grief counsellor with his own practice Sydney Grief Counselling Services. Nathan has a Master of Arts in Psychology, a Master of Arts in Social Work and a Graduate Diploma in Relationship Counselling. After building his experience in the health system, Nathan works closely with the rare disease sector providing support to individuals and to organisations supporting individuals dealing with grief and loss.



**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.



**Professor David Thorburn BSc(Hons), PhD, FHGSA  
FFSc(RCPA), FAHMS**

Professor David Thorburn co-leads the MCRI Brain and Mitochondrial Research Group, which is primarily involved in research but also acts as the Australasian referral centre for diagnosis of mitochondrial disease in children. His lab has diagnosed more than 700 patients with mitochondrial disease and published over 200 scientific journal articles and reviews. David's research focuses on the genetic basis of mitochondrial energy generation diseases. He has had a particular interest in understanding how mitochondrial DNA mutations are passed on from mothers to their children, and translating this knowledge into approaches for genetic counselling, prenatal diagnosis and prevention. He also studies the roles of nuclear genes, which are inherited from both parents. His lab has identified over 25 novel "disease" genes using a range of genomic and cell biology approaches.



**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.