

NEUROMUSCULAR INFORMATION & RESEARCH DAY

SAT 29 AUG 2026 | 1-4:30 PM

Program

1.00 - 1.10 pm



Welcome

- **Carolyn Campbell-McLean**
Senior Community Support Specialist,
MDNSW



- **Tom Giumelli**
MDNSW Community Member

1.10 - 1.50 pm Panel

From Research to Reality: Understanding Trials & New Therapies



- **Emma Weatherley** – CEO, FSHD Global Research Foundation
- **Dr Sandi Kariyawasam** – Paediatric Neurologist, Sydney Children's Hospital Randwick
- **Dr Michelle Lorentz** – Paediatric Neurologist, Sydney Children's Hospitals Network

1.50 - 2.20 pm



Advances in Neuromuscular Research and Treatments

- **Dr Christina Liang**
Neurologist, Royal North Shore Hospital

2.20 - 2.50 pm



Dental Health Essentials

- **Dr Avanti Karve**
Special Needs Dental Specialist, Mind Body Teeth

2.50 - 2.55 pm Break

2.55 - 3.35 pm Q&A

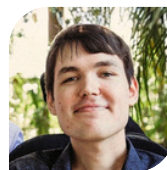
Current Best Practice for Children with Neuromuscular Conditions



- **Prof. Michelle Farrar** – Paediatric Neurologist, Sydney Children's Hospitals Network
- **Assoc. Prof. Kristi Jones** – Clinical Geneticist, The Children's Hospital at Westmead
- **Belinda Ryan** – Family Carer & Emergency Nurse

3.35 - 4.05 pm

Hey Google! Tips for Getting the Most from Assistive Tech and AI



- **Christina Pullen** – Senior Occupational Therapist, Muscular Dystrophy Queensland
- **Sam Watts** – MDNSW Community Member
- **Jaxon Taylor** – MDNSW Community Member

4.05 - 4.15 pm



What's New at MDNSW?

- **Allyce Rui**
MDNSW Service Delivery Manager

4.15 - 4.20 pm Closing

Held online via Microsoft Teams

Visit ow.ly/aypS50ZvFy6 to register for this **FREE** event

NIRD 2026 MEET OUR *SPEAKERS*

Speaker Profiles



Carolyn Campbell-McLean

is MDNSW's **Senior Community Support Specialist**, bringing lived experience and 30+ years in community education and empowerment.



Tom Giumelli

is a Communications Graduate. He is a **MDNSW Young Adults Program participant** who lives with SMA (Type 2).



Emma Weatherley

is CEO of the FSHD Global Research Foundation and a proud member of the FSHD community. She leads global collaborations across research, clinical trials, advocacy and health policy.



Dr Sandi Kariyawasam

is a **Paediatric Neurologist** at Sydney Children's Hospital and Lecturer at UNSW. She leads the national implementation of newborn screening for SMA in Australia.



Dr Christina Liang

is a **Neurologist** at the Royal North Shore Hospital, and a Clinical Lecturer at the University of Sydney. An Honorary Research Fellow at NeuRA, she conducts research and is involved in clinical trials.



Dr Avanti Karve

is a **Special Needs Dental Specialist** at Mind Body Teeth, supporting people with complex healthcare needs, and a Clinical Lecturer at the University of Sydney.



Belinda Ryan

is an Emergency Nurse and researcher with lived experience as a **mother and family carer** to her son with SMA.



Prof. Michelle Farrar

is a **Paediatric Neurologist** at Sydney Children's Hospitals Network, Professor at UNSW and Senior Principal Research Scientist at Neurosciences Research Australia, leading rare disease research.



Dr Michelle Lorentzsoos

is a **Paediatric Neurologist** at Sydney Children's Hospitals Network, and Clinical Lecturer at the University of Sydney. She specialises in advanced gene therapy treatments and trials.



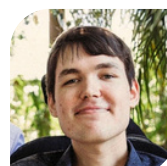
Dr Kristi Jones

is a Clinical Geneticist at The Children's Hospital at Westmead, and a Clinical Professor of Genetics and Paediatrics at the University of Sydney.



Christina Pullen

is a **Senior Occupational Therapist** at Muscular Dystrophy Queensland, specialising in equipment, therapy and support planning for people with neuromuscular conditions.



Sam Watts

lives with SMA and is a **MDNSW Young Adults Program participant**. He is a dedicated Scouts leader and volunteer.



Jaxon Taylor

is an MDNSW **Young Adults Program participant** living with Merosin Deficient MD. He's a Skills Acquisition Coach with the NSW Powerchair Football Association, a Journalism student and passionate podcaster.

Held online via Microsoft Teams

Visit ow.ly/aypS50ZvFy6 to register for this **FREE** event