



Duchenne ACTT Now 2018

DRAFT Agenda

Thursday 6th September

8:00 – 8:30am REGISTRATION, REFRESHMENTS, EXHIBIT HALL OPEN

8.30- 10:30am MORNING SESSION

Welcome to country Aunty Margret Campbell (Djunghutti & Jerrinjha Nations) Conference opening Klair Bayley and Carolyn Campbell - McLean	
Duchenne Genetics 101 Assoc. Prof. Kristi Jones, The Children's Hospital at Westmead	
Duchenne Network Australia and The Duchenne Registry Australia Klair Bayley and Dr Kristina Elvidge, Save Our Sons Duchenne Foundation	

10:30 – 11:00am BREAK, EXHIBIT HALL OPEN

11:00 – 12:30pm CONCURRENT SESSIONS

EDUCATION	ADULT RESPIRATORY
Learning Problems and Neurobehavioral Disorders in Duchenne Dr James Poysky, Baylor College of Medicine, USA.	Respiratory Physiotherapy Workshop – teens and adults with Duchenne A/Prof Amanda Piper, Royal Prince Alfred Hospital and Jan Robinson, The Prince Charles Hospital
Panel Discussion/Q&A James Poysky, Donna Anderton, Deb Bailey, Michelle Pomeroy	Take a Breath DMD Dr. Jodi Wolff Santhera Pharmaceuticals

12:30 – 1:30pm LUNCH, EXHIBIT HALL OPEN

1:30 – 3:00pm CONCURRENT SESSIONS

SESSION A	SESSION B
Mental Health and Relationship Advice for Caregivers: Strengthening caregiver relationships and preventing burnout. Dr James Poysky, Baylor College of Medicine, USA	Standing Wheelchair Study and Wearable Technology Dr Jenny Downs and Nita Vorster (Telethon Kids Institute, Perth) and Helena Young (Children's Hospital at Westmead).
	Targeting heart rate in the prevention of cardiomyopathy in Duchene Muscular Dystrophy Dr Julian Ayer, The Children's Hospital at Westmead

3:00 – 3:30pm BREAK, EXHIBIT HALL OPEN

3.30 – 5:30pm CONCURRENT SESSIONS

NDIS SESSION		REGULATORY and CLINICAL TRIAL LANDSCAPE
NDIS overview Carolyn Campbell – McLean and Michelle Pomeroy		What's new at the TGA? Adjunct Prof John Skerritt FTSE FIPAA (Vic) Deputy Secretary for Health Products Regulation Department of Health (TGA)
Planning for the NDIS - kids Michelle Pomeroy	Planning for the NDIS - teens and adults Joan Martin	The Australian Clinical Trial Landscape TBC
Wrap-up and Q and A session		Panel discussion



Friday 7th September

8:00 – 8:30am REGISTRATION, REFRESHMENTS, EXHIBIT HALL OPEN

8.30- 10:30am MORNING SESSION

Welcome and World Duchenne Awareness Day Celebration Klair Bayley, Save Our Sons Duchenne Foundation		
The Importance of Dental Health A/Prof Richard Widmer, Head of Paediatric Dentistry at the Westmead Children's Hospital		
Emergency Care Update Dr Anita Cairns, Lady Cilento Children's Hospital, Brisbane		
Putting the International Duchenne Care Guidelines into an Australian Perspective Professor Monique Ryan The Royal Children's Hospital, Melbourne	Overview of Adult Care Standards Dr Christina Liang Royal North Shore Hospital, Sydney	Adjustment/Coping and Promoting Independence for Teens and Adults with Duchenne Dr James Poysky, USA.

10:30 – 11:00am BREAK, EXHIBIT HALL OPEN

11:00 – 1.00pm CONCURRENT SESSIONS

CLINICAL CARE	CLINICAL CARE	FUNDING FOR NEW THERAPIES
Endocrine issues – including steroids, bone health TBC	Adult Cardiac Care TBC	Funding for new medicines in Australia – the PBAC Michelle Burke, PBAC committee member - Industry Nominee
Nutrition in Duchenne Rachel Lindeback Sydney Children's Hospital	Nutrition and gastroenterology in Duchenne (Adults) TBC	Consumer Advocacy & Consumer Involvement in the PBAC Process Jo Watson, Deputy Chair of the PBAC and Consumer Representative
Paediatric Respiratory Health Dr Adelaide Withers Perth Children's Hospital	Physiotherapy Overview (Adults) Nita Vorster (Telethon Kids Institute Perth)	
Paediatric Cardiac Care Update Dr Claire Irving, Sydney Children's Hospital Network	Physiotherapy Overview (Paediatric) Dr Kate Carroll and Katy de Valle	Panel Discussion

1.00 – 1:45pm LUNCH, EXHIBIT HALL OPEN

1:45 – 3:45pm CONCURRENT SESSIONS

RESEARCH AND CLINICAL TRIALS	PHYSIOTHERAPIST PROFESSIONAL DEVELOPMENT
Targeting Inflammation Professor Monique Ryan	The current standards of care and clinical trial readiness Dr Kristy Rose, Dr Kate Carroll, Katy de Valle and Rachel Kennedy
Taurine as a Therapy for Duchenne Dr Peter Arthur, University of Western Australia	
Improving Muscle Mechanics Dr Ian Woodcock The Royal Children's Hospital Melbourne	
Restoring or replacing dystrophin TBC	

3:45 – 4:15pm BREAK, EXHIBIT HALL OPEN

4.15 – 5:30pm CONCURRENT SESSIONS

INDUSTRY PIPELINE UPDATES	WORKSHOP FOR TEACHERS	NURSING AND ALLIED HEALTH WORKSHOP
Sarepta Therapeutics Wave Life Sciences Solid Biosciences PTC Therapeutics Catabasis Capricor Therapeutics Santhera Pharmaceuticals Pfizer	Opportunity for teachers to network, share experiences and problem solve Dr James Poysky	Networking and problem-solving workshops Sandra Holland, Kate Munro, Jodi Mann, Lisa Tang, Paula Bray and TBC.

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