

ACTT Conference Agenda

Wednesday 13th September

8:30 – 9:00am REGISTRATION, REFRESHMENTS, EXHIBIT HALL OPEN

9.00- 10:30am CLINICAL CARE FOR DUCHENNE:

- **Welcome and session introduction**
- **The Importance of Coordinated Care**
Professor Brenda Wong - Cincinnati Children's Hospital
- **Respiratory Care Update**
TBC
- **Q and A Panel**

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

11:00 – 12:30pm SHORT RESEARCH PRESENTATIONS

- **Cardiac MRI and echocardiography and its application for analysis of cardiac strain and synchrony in Duchenne** – Dr Kan Hor, Nationwide Children's Hospital
- **Standing Wheelchair Study** - Dr Jenny Downs – Telethon Kids Institute
- **New Zealand families experience of diagnosis of Duchenne** – Miriam Rodriguez
- **TBA**

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

1:30 – 3:30pm CONCURRENT SESSIONS

CLINICAL TRIALS	NURSING AND ALLIED HEALTH WORKSHOPS
Australian clinical trial environment and incentives Mr Adrian White – Australian Government, Department of Industry, Innovation and Science	Supporting boys and their families to use standing wheelchairs effectively Dr Jenny Downs (Telethon Kids Institute) + demonstration by Levo representative
Industry perspective on running a trial in Australia TBC	
DuchenneConnect Australia Kristina Elvidge and Klair Bayley	Psychosocial support for boys with Duchenne and their families Sandra Holland and TBC
Q and A panel	

3:30 – 4:00pm BREAK, EXHIBIT HALL OPEN

4.00 – 5:30pm CONCURRENT SESSIONS

ADVOCACY	NURSING AND ALLIED HEALTH WORKSHOPS
Working together to overcome advocacy challenges Klair Bayley	The role of nursing and allied health in multidisciplinary care of both children and adults with Duchenne Dr Paula Bray, Dr Zoe Davidson, Mary Dunford and Dani Villano
Patient engagement in research and health policy TBC	
Clinical trials from the family perspective Two parents share their experience.	Round table discussion and problem-solving session
Q and A panel	

5.30 – 7:00pm COCKTAIL RECEPTION



Thursday 14th September

8:15 – 8.45am REGISTRATION, REFRESHMENTS, EXHIBIT HALL OPEN

8.45- 10.45am CLINICAL CARE FOR DUCHENNE

- **Welcome and introduction to session**
Klair Bayley – Save Our Sons Duchenne Foundation
- **The Landscape for Clinical Care in Australia**
Professor Monique Ryan – Royal Children’s Hospital Melbourne
- **Steroids – insulin resistance and metformin**
Professor Brenda Wong – Cincinnati Children’s Hospital
- **Cardiac care update/Cardiac MRI**
Associate Professor Kan N. Hor, MD
Nationwide Children’s Hospital
- **Q and A Panel**

10:45 – 11:15am BREAK, EXHIBIT HALL OPEN

11:15 – 12:30pm CLINICAL TRIAL UPDATES

- **Australian Duchenne clinical trial update**
Professor Monique Ryan – Royal Children’s Hospital Melbourne
- **Industry short presentations**
Overview of clinical development pipeline (no presentation of results)

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

1:30 – 3:00pm CONCURRENT SESSIONS

THERAPIES – APPROVALS AND ACCESS	NURSING AND ALLIED HEALTH WORKSHOPS
Approval process for new prescription medicines in Australia – reforms, orphan drugs and special access Adj. Prof. Tim Greenaway, Chief Medical Adviser, Therapeutic Goods Administration	Outcome measures, physios and clinical trials Kate Carroll and Katy DeValle
Funding for new medicines in Australia – the PBAC Michelle Burke	The role of nursing and allied health in clinical trials Daniella Villano, Jemima Mitchell and Sandra Holland
Q and A panel	

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

3.30 – 6:00pm CONCURRENT SESSIONS

ROUND TABLES	NURSING AND ALLIED HEALTH WORKSHOPS
Clinical care round table - closed session	Respiratory physiotherapy Assoc. Prof. Amanda Piper
Industry round table – closed session	Round table discussion and problem-solving session

Note: Exhibit hall will have display tables for sponsors and posters.