

CONFERENCE PROGRAM



February 26th-27th, 2010
Eastern Avenue Auditorium
University of Sydney

Welcome Message

Welcome to Sydney and the Towards a Brighter Future Conference.

The vision for the conference is to ensure that patients and their families have access to early and accurate diagnosis, create awareness of improvements in prevention and management and present interventions to enhance quality of life for all affected individuals.

The conference aims to:

- Deliver up-to-date research on neuromuscular disorders
- Provides information about all neuromuscular conditions to health professionals (doctors, allied health and nursing), educators (teachers, teacher's aides and special needs educators), parents and affected persons.
- Deliver a stimulating and progressive conference program that disseminates only the most up to date research in the field of neuromuscular conditions

Whilst there is no “one size fits all” miracle cure for each disorder, the future is going to be much better for many of our children. We know that world standards of care are changing every year via new drug therapies, practices and research findings and it is critical that we keep abreast of new information.



Conference Speakers

International

Louis Boitano	Respiratory Care, and Pulmonary and Critical Care Medicine, University of Washington Medical Centre, USA
John Bourke	Cardiology, Freeman Hospital, Newcastle Upon Tyne, UK
Kate Bushby	Coordinator, TREAT-NMD, Action Research Professor in Neuromuscular Genetics, Newcastle University UK
Jeff Chamberlain	Director, Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Center, USA
Pat Furlong	Founding President & CEO, Parent Project, Muscular Dystrophy, USA
Jos Hendriksen	Department of Child Neurology and Child Psychiatry, University Hospital of Maastricht, Netherlands
Jes Rahbek	Danish Institute of Neuromuscular Disorders, Denmark



Conference Speakers

National

Geoff Askin	Department of Orthopaedics, Mater Children's Hospital, Brisbane
Paula Bray	Institute for Neuroscience and Muscle Research, Sydney
Joshua Burns	Institute for Neuroscience and Muscle Research, Sydney
Nigel Clarke	Institute for Neuroscience and Muscle Research, Sydney
John Collins	Head, Pain and Palliative Care, Children's Hospital at Westmead, Sydney
Alistair Corbett	Director Neuromuscular Clinic, Neurologist, Concord Hospital, Sydney
Zoe Davidson	University of Queensland Children's Nutrition Research Centre & Royal Children's Hospital
Heather Johnston	Director, Neuromuscular Service, Sydney Children's Hospital, Sydney
Kristi Jones	Director, Neuromuscular Service, Children's Hospital at Westmead, Sydney
Andrew Kornberg	Director, National Muscular Dystrophy Centre at the Howard Florey Institute, Melbourne
Nigel Laing	Head, Molecular Neurogenetics Laboratory, Western Australian Institute for Medical Research, Perth
Phillipa Lamont	Department of Neurology, Royal Perth Hospital, Perth



Conference Speakers

National (continued)

Craig Munns	Department of Endocrinology, The Children's Hospital at Westmead, Sydney
Garth Nicholson	Head, Northcott Neuroscience Laboratory, ANZAC Research Institute, Concord, Sydney
Kathryn North	Head, Institute for Neuroscience and Muscle Research, The Children's Hospital at Westmead, Sydney
Robert Ouvrier	T.Y. Nelson Department of Neurology & Neurosurgery, The Children's Hospital at Westmead, Sydney
Helen Posselt	MontroseAccess (Neuromuscular clinic coordinator and senior physiotherapist), Brisbane
Kristy Rose	Institute for Neuroscience and Muscle Research, Sydney
Monique Ryan	Paediatric Neurologist, Neurosciences Department, Royal Children's Hospital, Melbourne
Steve Wilton	Head of the Experimental Molecular Medicine Unit, Australian Neuromuscular Research Institute, Perth
Sarah Wright	Paediatric Neuromuscular Respiratory Therapist, Royal Children's Hospital, Brisbane.



Program Overview

Friday 26th February 2010

8am	Registration
8.20am	Welcome from Prof Kathryn North
8.30am – 10.00am	Session 1: Keynote Lectures Prof Kate Bushby – The journey: past, present and future Prof Jeff Chamberlain – Separating the hype from the hope
10am – 10.30am	Morning Tea
10.30am – 12.30pm	Session 2: Concepts in the diagnosis and therapy of neuromuscular disorders Prof Kathryn North – General Approach to the Diagnosis of the Child with Weakness Prof Nigel Laing – Molecular Diagnosis and Newborn Screening Dr Jas Rahbek – Management of INMD in Denmark (an ICF perspective)
12.30pm – 1.30pm	Lunch
1.30pm – 3pm	Session 3: Ask the Experts – Muscular Dystrophies and Inherited Neuropathies
3pm – 3.30pm	Afternoon Tea
3.30pm – 5pm	Session 4: Ask the Experts – Behaviour, Mobility, Respiratory, CMT Workshops



Saturday 27th February 2010

8am	Pat Furlong – Parents Project USA - Changing the world for neuromuscular conditions
8.30am – 10.30am	Session 1: Topics in Neuromuscular Disease Dr Craig Munns – Endocrine Issues and Bone Health Dr Geoff Askin – Orthopaedic Surgery for the Spine Mr Louis Boitano – Respiratory issues in Neuromuscular Disorders Dr John Bourke – Cardiac involvement in Neuromuscular Disorders
10.30am – 11am	Morning Tea
11am – 12.30pm	Session 2: Breakout Sessions I Update in Molecular Therapies All about SMA Enhancing Learning
12.30pm – 1.30pm	Lunch
1.30pm – 3pm	Session 3: Breakout Sessions II Topics to include Occupational Therapy, Physiotherapy, Dietetics Early stage SMA, Transition to adulthood, Sibling Issues Research Presentations
3pm – 3.30pm	Afternoon Tea
3.30pm – 4.30 pm	Session 4: Breakout Sessions III Topics as above
4.30pm – 5.30pm	Panel Discussion - The power of one and the power of many
5.30pm	Conference Close

