



Towards a Brighter Future

2010 Neuromuscular Disorders Conference

Sponsorship and Exhibitor Information

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

Presented by:

Duchenne Foundation
Institute for Neuroscience and Muscle Research

From

The Conference Convenors



It has been estimated that one person in every 1000 has a disabling inherited neuromuscular disorder. Most neuromuscular diseases are incurable. For many it is a devastating disease that results in muscle wasting, loss of mobility, breathing difficulties and early death. For many parents a diagnosis is like a death sentence. Duchenne Muscular Dystrophy (DMD) affects approximately 1 in 3500 live male births causing death in the late teens or early twenties. It is a genetic disease resulting from a mutation in a gene on the X-chromosome known as the dystrophin gene. The dystrophin gene is the largest gene in the human body which means that it has a high rate of spontaneous mutations. Consequently, one in three cases of DMD result from novel mutations without any previous family history.

The Duchenne Foundation (formerly Parent Project Australia) is a not-for-profit organisation that supports families affected by Duchenne Muscular Dystrophy, the most severe form of muscular dystrophy. The Duchenne Foundation recognises that scientific research aimed at solving medical problems is the answer to providing those affected with improved health outcomes.

The Institute for Neuroscience and Muscle Research (INMR) comprises a large multi-disciplinary translational research team of approx. 40 scientists, research students, clinicians, physiotherapists, occupational therapists and psychologists. The INMR research team is integrated with the clinical service that cares for hundreds of children and adolescents with a range of neuromuscular disorders. Many patients are participating in international and national clinical trials run by the INMR that have been made available to the children of NSW for the very first time. The latest discoveries in the field internationally are now available for our children in Australia. Advances in research and improvements in medical care are already resulting in longer survival and improved quality of life for children with muscular dystrophy.

The disorders are complex and demand a multi-disciplinary approach to care and treatment, and involve a range of health professionals, including clinicians, physiotherapists, occupational therapists, genetic counsellors and psychologists. For many disorders, life-long care is required from the family GPs and allied health professionals to prolong life and ensure quality of life. It is therefore critical that communication between the GP, the specialist paediatrician, carers and allied health staff is open and ongoing. The conference aims to ensure that patients have access to early and accurate diagnoses and that there is awareness of improvements in prevention and management and new interventions to enhance quality of life for children through to adults. This in turn will lead to a progressive reduction in the community and healthcare costs due to decreased morbidity, decreased demand for inpatient care, increased well-being and increased productivity of affected individuals.

The conference will deliver a stimulating, informative and topical program involving national and international speakers in the field of neuromuscular conditions to present the latest information for researchers, students, health professionals (doctors, allied health and nursing), educators (teachers, teacher's aides and special needs educators), parents and those impacted upon by the disease.

The Institute for Neuroscience and Muscle Research, Sydney in partnership with Duchenne Foundation invite you to participate in our national muscular dystrophy conference. We look forward to seeing you in Sydney in 2010!

Conference Program

We aim to provide sound medical and scientific information to reassure parents that 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.

The conference aims to:

- To bring families affected by Duchenne and other common neuromuscular disorders together to update world standards of care and research progress - firsthand, rather than in a diluted or technical written form
- To focus on the most common without neglecting other major neuromuscular diseases
- To encourage Australian medical specialists, doctors and therapists to grow in their proactive approach to the diagnosis and treatment of persons affected by neuromuscular diseases reducing surgical interventions and hospitalizations.
- Increased awareness of the positive outcomes of such proactivity should eventually encourage more specialists and therapists into the field and it is not uncommon to register a number of medical & allied health students seeking accreditation.
- To address family, cognitive, social, psychological and palliative care issues to reinforce that quality of life is more important than quantity of life
- Everyone, particularly delegates who are disabled, will contribute more to society
- Greater overall quantity and quality of life for all.

Case Study

Duchenne Muscular Dystrophy (DMD) is the most common and most severe form of muscular dystrophy. Ten years ago the best care that could be offered to a child affected by DMD was to manage the patient’s physical and emotional wellbeing through physical and speech therapy, orthopaedic devices, surgery and medications as no information relating to the pathogenesis of disease was known. Typically, by the age of 3 the child would have difficulty keeping up with other children their own age, they would fall often, and have trouble with running, hopping and climbing. Over the following years their muscles would become weaker, and by around 12 most would be confined to a wheelchair, and by their late teens they would have major problems with movement, including with breathing and swallowing. Most would die in their early 20s.



Today the future is not so bleak for children with DMD. Improvements in medical care and advances made by researchers in Australia and around the world have resulted in slowing down the progress of muscle weakness, reducing the frequency of severe scoliosis and delaying the need for ventilatory support. The INMR is one of only two Australian sites to participate in two large multi-centre US funded international clinical trials programs. For the first time in Australia, experimental medications such as PTC124 – which aims to correct the gene defect leading to muscular dystrophy is a subset of patients with DMD - can be made available to patients. These clinical trials bring hope to patients and their families as the search for a cure gains momentum.

Conference Sponsorship

	Platinum	Gold	Silver	Dinner	Exhibitor
	\$10,000	\$5,000	\$2,500	\$5,000	\$2,000
Exhibitor Booth	Yes	Yes	Yes		Yes
Registrations	3	2	1	1	1
Dinner Tickets	3	2	1	2	1
Signage	Yes	Yes	Yes	Yes	
Logo Display	Yes	Yes	Yes	Yes	
Program Pages	1	1/2		1/2	
Satchel Insert	Yes	Yes	Yes	Yes	
Named award	Yes	Yes			

Exhibitor Booth: Exhibition booth in prime location

Registrations: Tickets allowing full attendance to the conference

Dinner Tickets: Tickets allow attendance to the cocktail dinner

Logo Display: Sponsor recognition and company logo will be displayed as follows:

- Company logo and weblink on official conference website (colour)
- Company logo displayed on projection screen between sessions (colour)
- Company logo in the official conference proceedings (black and white)
- Company logo displayed on all marketing materials (print and electronic) which advertise the conference
- Opportunity to display company signage throughout the conference venue

Program Pages: Page or part page editorial/advertisement displayed in the program (black and white)

Satchel Insert: Company information included in the satchel that is provided to each attendee (company logos of Platinum, Gold and Silver sponsors will be displayed on the outside of the satchels)

Named Award: The keynote speaker session will be named in recognition of the Platinum sponsor and the Young Investigator Award in recognition of the Gold sponsor

Sponsorship Confirmation Form

Towards a Brighter Future: 2010 Neuromuscular Disorders Conference

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

Salutation: _____

Given Name: _____ Surname: _____

Company/Organisation: _____

Position: _____

Postal address: _____

Suburb: _____ State: _____ Postcode: _____

Phone: _____ Fax: _____

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Signature: _____

Please select your preferred sponsorship:

Platinum sponsor
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Gold sponsor
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AUD\$2,000 (plus 10% GST)

Dinner sponsor
AUD\$5,000 (plus 10% GST)

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AUD\$2,000 (plus 10% GST)

Sponsorship Total AUD\$: _____

Please note other sponsorship options such as speaker fees for one plenary session are available so please do not hesitate to contact the conference organisers for further information.

For more information, please contact the INMR (NSW) or Duchenne Foundation (QLD):
Paula Bray - Ph: (02) 9845 3004 or email: paulam2@chw.edu.au
Deborah Robins - Ph: (07) 4057 5731 or email: deborah.robins@duchennefoundation.org.au

Completed forms can be faxed to (02) 9845 1317. Once received a member of the conference organising committee will be in contact with you shortly.