



# Media Release

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## Australasian Neuromuscular Network national meeting being hosted in Melb

World-class scientists and professors will be gathering in Melbourne to focus on best practice models to ensure Australia and New Zealand are providing exceptional care and service to patients living with neuromuscular disorders, as well as safeguarding equal access to clinical trials and new therapies.

“This meeting of the *Australasian Neuromuscular Network* (ANN) is a significant event in world of neuromuscular disorders, in particular Muscular Dystrophy, because it provides a forum for multiple prominent organisations to join together and focus on how to improve the lives of patients,” said *Muscular Dystrophy Australia’s* (MDA) Executive Director, Boris M Struk.

The meeting is being hosted by the ANN in conjunction with the *National Health and Medical Research Council* (NHMRC) and will be held at the Murdoch Childrens Research Institute located at The Royal Children’s Hospital (RCH), Melbourne, on 27-28 March 2014.

The head of the Multidisciplinary Neuromuscular Clinic at the RCH, Associate Professor Monique Ryan, says that it is the close relationships between the research centres and industry associations such as MDA, which allows such premier service models to be developed and continually improved.

“The RCH Neuromuscular Unit has always worked very closely with MDA to improve patient outcomes and to provide support for members of the community affected by muscular dystrophies and other neuromuscular conditions,” said Assoc Prof Ryan.

“In recent years MDA has provided invaluable financial support, which has enabled establishment of a permanent neuromuscular nurse coordinator position and assisted with our neuromuscular fellowship for training young paediatricians in the diagnosis and management of these conditions. These positions are of immediate direct benefit to the families we care for,” said Assoc Prof Ryan.

MDA was established 30 years ago by a father, Boris M Struk, after his young son, Ryan, was diagnosed and he realised there was absolutely no family support and very little patient care available for the Muscular Dystrophy community.

Fast forward three decades and MDA is the major sponsor of the *National Muscular Dystrophy Research Centre* (NMDRC) based at the RCH and has provided in excess of \$5 million in funding in recent years.

“MDA is gratified to be a significant supporter of the NMDRC and the RCH because the outstanding research is also teamed with a drive to provide the best patient care and service. This is why this meeting of the ANN is so vital, as it ensures the focus is not only on results in a laboratory but also on best practice models for patients today,” said Mr Struk.

To arrange a **Media Pass** to the meeting or an **interview/photo opportunity** with either Assoc Prof Monique Ryan or MDA’s Executive Director, Boris M Struk, please contact:

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