Australasian Neuromuscular Network

Improving Lives: A Roadmap For The ANN

An invitation was extended to ANN members to attend a workshop in conjunction with the official launch of the ANN at the Rare Diseases Symposium in Perth in April. Around 30 members and special guests participated in the workshop, the aim of which was to establish a roadmap for the ANN - short-term goals (achievable within 1 year with limited funding) and longer-term goals (that are likely to be bigger picture more complex issues that will require funding the implement) - that will result in improved health outcomes for patients.

The priority areas for discussion included:

- Clinical Care
  - Ready access to standards of care and registries
  - Multi-disciplinary clinics in every state
- Clinical Trials
  - Coordinate training of local evaluators/coordinators to increase access
  - Identify opportunities for collaborative studies
- Diagnostic Network
  - Increase link between diagnostic and research laboratories
  - Expand registries to include other disorders
  - What would the ideal national diagnostic network look like?
- Research
  - Promote investigator initiated national multi-centre studies
  - Coordinate patient data collection for joint research projects

INSIDE

The ANN roadmap identifies key areas to maximise health gain with limited resources in the short term, goals that are practical, realistic and attainable, and in the longer term will help secure additional resources to create a national framework of the highest quality for all individuals affected by neuromuscular disorders.

The full workshop report is available on the ANN website.

The 1 year and 5 year goals are outlined on page 2 of this newsletter, and are also included on the ANN website and in the workshop report (ann.org.au - follow the shortcut link to '1 Year and 5 Year Goals').

The ANN Steering Chairs would like to thank everyone who participated in the workshop. For those unable to attend and wish to comment/provide feedback, you are welcome to contact the Steering Chairs or send an email to info@ann.org.au

We are planning an ANN meeting as a satellite to the World Muscle Society meeting in Perth (October 9-13) - please mark this in your diaries!

If you know anyone who would be interested in joining the ANN, please forward this newsletter to them. Membership is free. Email: info@ann.org.au

	1 year goals	5 year goals
Clinical Care	Ready access to Standards of Care	Transition guidelines fully implemented
	Develop disease specific guidelines relating to clinical issues	Opportunity for other Special Interest Groups eg Allied Health
	Develop guideline for transition	Forum to discuss difficult clinical/ethical issues
	Engage adult clinicians, as well as professional groups including AAN and ANZAN	Collaborative clinical research
	Develop guideline for multi-disciplinary clinic	Integrated training programs
	Undertake a gap analysis study using DMD as a pilot (using Care-NMD as template)	
	Identify training opportunities	
	In partnership with TREAT-NMD, lead the development of Myotonic standards of care	
Clinical Trials	Training clinicians / local evaluators/coordinators	Establish multidisciplinary clinics – adult and children – in each state
	Circulation of information concerning new trials	Establish new clinical trial centres
	Identification of opportunities for collaboration	Expand existing trial programs
	Data seeding to national and international registries	
	Make clinical trials available to individuals in all states	
Diagnostics		
Pathology	Standard protocols around specimen collection for muscle, nerve and skin	Muscle bank (similar to Australian Brain Bank)
	Consent form – muscle biopsy	Use of modern communications/tele-pathology within the ANN ("the remote pathologist")
	List of tests and in which laboratories they are done (updated every 3 months)	
	Online discussion/education via website	
Molecular	List of tests and in which laboratories they are done (updated every 3 months)	Link diagnostic and research laboratories within Australasia
	Online discussion/education via website	Identify gaps and cross-over to rationalise resources, skills etc
	Implementation of next generation sequencing into diagnostics	Funding is needed to make testing equally available
National Network		Define what the ideal diagnostic network would look like
Prevention	Establish levels of interest	Run pilot studies of population screening for DMD
		Investigate acceptability and feasibility of preconception carrier screening for multiple severe recessive disorders based on next-generation sequencing.
Research	Circulate information relating to collaborative studies	
Funding	Submit infrastructures grants and identify fundraising opportunities	Secure sustainable funding
	Develop financial model	

ICNA&AOCNA

Brisbane, Queensland
27th May - 1st June, 2012

12th International Child Neurology Congress and 11th Asian and Oceanian Congress of Child Neurology

Confirmed speakers include:

Prof James Barkovich

Chief, Pediatric Neuroradiology, University of California, San Francisco Medical Center and the UCSF Benioff Children's Hospital/Professor of Radiology, Neurology, Pediatrics, and Neurosurgery, University of California, San Francisco

Prof Samuel F Berkovic

Australia Fellow and Laureate Professor, University of Melbourne, Australia

Prof Josep Dalmau

ICREA (Catalan Institute of Research and Advanced Studies) Research Professor at IDIBAPS/Hospital Clinic, University of Barcelona (Spain) and Adjunct Professor of Neurology at the University of Pennsylvania (USA)

Prof Gabrielle A. deVeber

Director of the Children's Stroke program, and a Paediatric Neurologist in the Division of Neurology at The Hospital for Sick Children (SickKids) in Toronto, Canada

Prof Donna Ferriero

University of California San Francisco Benioff Children's Hospital

Prof Ikuya Nonaka

Director General Emeritus, National Center of Neurology and Psychiatry, Japan

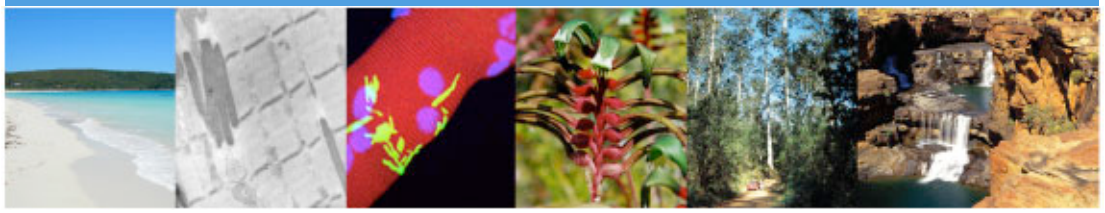
Abstract Submission Deadline: 30th September 2011

For more information, visit www.icnc2012.com

WMS 2012

Perth, Western Australia
9th-13th October, 2012

17th International Congress of the World Muscle Society



This is an outstanding opportunity for everyone in Australia in the neuromuscular diseases community to listen to and meet many of the world's leading researchers in this field.

The Local Organising Committee would particularly like to draw the attention of the ANN members to the associated Training Course (8th and 9th October) that includes both clinical and pathological teaching by some of the best in the world.

The Training Course, held in conjunction with each Annual Congress, is limited to 40 places and is highly recommended for junior clinicians, pathologists and molecular geneticists.

For more information about the conference, and to register your interest, visit www.wms2012.com

CALLING ALL CLINICIANS

Are you caring for patients with a strong clinical phenotype for neuroaxonal dystrophy?

The Royal Children's Hospital in Melbourne is collaborating with Desirée du Sart at the Molecular Genetics Laboratory of the Victorian Clinical Genetics Service to screen the PLA2G6 gene for mutations in patients with a strong clinical phenotype for neuroaxonal dystrophy. We are happy to receive a few more samples from paediatric neurologists within Australia to make up a batch for testing.

The testing would be performed on a research basis with the intent to publish the outcomes.

Therefore a summary of the patients' clinical details, MRI findings and nerve conduction study findings (+/- nerve biopsy, EEG and other investigation findings completed in the work-up) would be invited from the requesting clinician.

It is planned for the test to be run as a batch at the **end of October 2011** so this will be the deadline for receiving the DNA samples. We would only anticipate doing a dozen or so, so please ensure that you have a high pre-test probability!

If interested, email Clinical Associate Professor Monique Ryan: monique.ryan@rch.org.au

Funding Opportunity

The Duchenne Foundation is committed to improving the treatment, quality of life and long-term outlook for families affected by DMD and BMD through research, education and advocacy. The explicit goal of the Duchenne Foundation is to advance treatments for Duchenne muscular dystrophy. This includes a focus on improving care, outcomes based research, clinical studies and trials. Duchenne Foundation is interested in projects to extend our understanding of the disease and/or investigate unique approaches to treatment.

The Duchenne Foundation is inviting research proposals aimed at young men living with Duchenne muscular dystrophy.

- The Foundation expects to support one or more projects up to a total of $100,000.
- **Closing date for applications: 31st October 2011.**
- Applications will be assessed by the Board upon the advice of Duchenne Foundation's Scientific Advisory Committee and successful applicants notified by December 2011. Funds will become available to commence research from December 2011.

For more information and to access the online application form visit the Duchenne Foundation website