



# anri news

Australian Neuromuscular Research Institute

Western Australia

Issue 8, Winter 2010

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LONGEST  
RUNNING  
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MEDICAL  
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## Australian Neuromuscular Research Institute

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THE UNIVERSITY OF  
WESTERN AUSTRALIA  
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## ANRI provides a holistic approach to Neuromuscular diseases



The ANRI is embarking on an holistic approach to neuromuscular and neurological disorders with the addition of a Clinical Psychology Research Unit to compliment the research and clinical work already being undertaken, headed by Dr Michelle Byrnes.

Dr Byrnes' career began with a Bachelor of Science at UWA (triple major in Psychology, Physiology and Pharmacology). She completed her Honours and first PhD through the Department of Physiology, followed by two Graduate Diplomas – one in Science and one in Psychology. She has now

completed a Master of Psychology (Clinical) and a second PhD – this time in Psychology (Clinical Program) while enrolled in the Master of Psychology (Clinical)/PhD program at UWA.

Between 1994 and 2005, Dr Byrnes worked in the Brain Research Laboratory at the ANRI with Professor Thickbroom and Professor Mastaglia. She gained extensive experience in the use of **brain stimulation and imaging techniques**, including Transcranial Magnetic Stimulation and Functional Magnetic Resonance Imaging.

With research interests in neuroplasticity, neurorehabilitation and the use of holistic biopsychosocial individual and group therapeutic programs, Dr Byrnes is currently carrying out research with people who have neurological disorders affecting motor control and those with language dysfunction.

Using a **Neurotrauma Research Program** grant, Dr Byrnes will undertake a project in evaluating the effectiveness of a mindfulness-based cognitive therapy program to improve an individual's ability to cope with issues such as anxiety, stress, depression and pain after neurotrauma.

## BioGENEius

ANRI will once again host a BioGENEius student from Shenton College.

The Sanofi-aventis BioGENEius Challenge supported by the WA Department of Commerce is held annually, in which school students are paired with a mentor from the science and innovation community to complete a high-level biotechnology project.

This year Chris Norman will join the Molecular Genetic Therapies Research Group and undertake a project into looking at potential off-target effects of splice switching oligomers under the mentoring of Professors Steve Wilton and Sue Fletcher.

The ANRI hosted its first BioGENEius student in 2009. Kayla Mizza undertook a project into "Identification of branch points and investigation of the splice motifs as an additional target for exon skipping in the dystrophin gene transcript", for which she and Professor Fletcher travelled to Atlanta Georgia, USA to present her work.

## ANRI Student Symposia

The ANRI currently has 15 PhD Students and three Honours Students undertaking a variety of projects.

The Institute is extremely proud of the caliber of work its students produce, so to showcase them, two Student Symposia will be held this year. The first in June and the second in November.

A student from each of our research groups; Stroke Research, Molecular Genetic Therapies, Clinical Research, Brain Research and Molecular Neurobiology Groups will present their work.

If you wish to attend either symposium please RSVP to anri-info@uwa.edu.au or for more information on how you can become a student at the Institute, call 9346 2818 or see our web site: [www.anri.org.au](http://www.anri.org.au)

## Enid and Arthur Home Memorial Scholarship

It is with great sadness we report the passing of Mrs Enid Home.

Mrs Home and her late husband Dr Arthur Home both worked tirelessly for the benefit of those less fortunate than themselves. They have left a legacy of an ANRI Scholarship in their name, so that their work may continue into the future.

The Inaugural Enid and Arthur Home Memorial Scholarship was awarded to Dr Arada Rojana-Udomsart. Dr Rojana-Udomsart arrived in Perth in early March eager to commence her PhD into the causes and new treatments for inflammatory diseases of the muscle.

Arada was born in the south of Thailand and was trained as a doctor and neurologist in Bangkok. From 2004-2010 she has been the only neurologist in Yala hospital, a referring 500-bed hospital. She was encouraged to obtain further training and research in neuromuscular diseases, since the region is lacking a neuromuscular specialist or specialised facilities for investigation of patients with these disorders. Arada was sponsored by the Endeavour scholarship to work as a research fellow at the Centre for Neuromuscular and Neurological Disorders under Professor Frank L Mastaglia for six months in 2008 and gained a great deal of knowledge.

Her PhD project aims to identify the genes that influence susceptibility to develop myositis and to determine the most effective forms of treatment. During her studies she will clinically evaluate all patients with **myositis** seen and at the Inflammatory Myopathy clinic at ANRI over the past 15 years to determine which forms of therapy are most effective.



*Dr Arada Rojana-Udomsart with Mr Stephen Home*

Patients with various types of **inflammatory** and other **myopathies** will also be investigated and will help to establish the diagnostic value and cost-effectiveness of immunostaining.

She will also be investigating the group of patients with **inclusion body myositis**, which is the most common muscle disease after the age of 40 years, and will be trialing new forms of treatment for this condition.

Mr Stephen Home (grandson of Mrs Enid Home) presented Dr Rojana-Udomsart with her scholarship at a morning tea held at the Institute on 12 March.

## Spinal Muscular Atrophy – Swim-Off



SMA Europe recently announced that they awarded €650,000 for research into Spinal Muscular Atrophy. Professor Steve Wilton was amongst those who were awarded this grant.

SMA is a rare but devastating disease. Approximately one in every 6,000 children is born with it; it is the largest genetic killer of babies and knows no national or racial boundaries. Muscle strength is gradually reduced until even breathing unassisted is not possible for those worst affected.

SMA Europe was founded in early 2007, bringing together a group of European patient groups involved with Spinal Muscular Atrophy. All the SMA Europe representatives are affected by SMA or are parents of affected children, and have personal experience of its effects on patients and their families.

Despite going down to Susie O'Neill in spectacular fashion (even after being given a 25 meter head start) at last week's Spinal Muscular Atrophy Swim-Off at Yeronga Park, Peter Dick (a radio announcer for 4BC in Brisbane) has already set his sights on his next challenge.

The event was organised by Karni Lidell (a Para-Olympic swimmer who has SMA) to raise the profile of SMA. Steve and Simone Parry who recently raised the \$100,000 were there with their son Jack. Jack is two years old and a dynamo in an electric wheelchair!

But the day was about more than just the race, as it gave the families of SMA sufferers an opportunity to speak with leading researcher Professor Steve Wilton, who heads the Molecular Genetic Therapies Group at the Australian Neuromuscular Research Institute.



# New CEO for MDAWA



John Gummer joined the MDAWA as their Chief Executive Officer earlier this year.

MDAWA has been fundraising for the past 43 years raising money not only towards the research being undertaken at the Institute, but also during this time ensured that every child with Muscular Dystrophy in the WA community has access to a cough assist machine (that assists children with

a weak diaphragm and lungs to cough) and to prevent them being hospitalised each year for breathing difficulties.

John's background was in the pharmaceutical industry where he held senior positions in Victoria and Western Australia.

John's brief is to raise funds to ensure a balance of research funding and family/patient support services. He said "We need to appropriately fund and resource each of these areas, by increasing and diversify our income streams to guarantee the Association's ability to achieve these goals".

Fundraising by MDA not only supports research into their primary interest "muscular dystrophy" but also supports many of the other neurological and neuromuscular diseases affecting many people in the community, such as:

- Stroke
- Parkinson's disease
- Alzheimer's disease
- Multiple Sclerosis
- Epilepsy
- Spinal muscular atrophy
- Spinal cord injury
- Stuttering
- McArdle's disease
- Inclusion body myositis
- Genetic diseases
- Huntington's disease
- Inflammatory Myopathies

For more information of how you can support the research undertaken at ANRI visit our website on [www.anri.org.au](http://www.anri.org.au)



Professor Byron Kakulas was invited to attend the 9th AOMC meeting in Seoul Korea on 25 -26 March 2010, where he chaired the Plenary Session on Advances in Muscular Dystrophy and was a Panel Member.

He has also been asked to attend the 10th AOMC Business Meeting as Honorary President in Auckland New Zealand between 25-26 February 2011.

## Research Groups

### **Molecular Genetic Therapy:**

Developing new experimental therapies for Duchenne muscular dystrophy and other hereditary diseases.

**Gene Therapy:** New approaches for gene replacement and gene correction for inherited muscle disorders.

### **Molecular Neurobiology:**

Investigating the mechanisms involved in neurodegeneration and ways of slowing down the degenerative processes in the brain.

**Brain Research:** Investigating how the nervous system adapts after injury and ways of increasing brain plasticity.

**Stroke Research:** Developing new neuroprotective therapies to diminish brain damage following stroke.

**Parkinson's Disease:** Research into the genetic and environmental causes and treatment of Parkinson's disease.

**Movement Control:** Investigating the function of motor areas of the brain and how they compensate after injury.

## Clinical Services

The Clinical Research Unit collaborates with the Departments of Neurology and Neurosurgery at Sir Charles Gairdner Hospital and the Neurosciences Clinical Service Unit to provide specialised services for patients with neuromuscular diseases, movement disorders such as Parkinson's disease and dystonia, multiple sclerosis and epilepsy.

**Movement Disorders and PD:** For the diagnosis and management of Parkinson's disease (PD), dystonia, essential tremor and other extrapyramidal disorders.

**Multiple Sclerosis:** Clinical expertise in the management of patients with MS and other neuroimmunological disorders.

**Neuromuscular Disorders:** Diagnostic and management strategies for complex neuromuscular diseases such as inclusion body myositis, dermatomyositis, polymyositis and overlap syndromes.

**Epilepsy:** Specialist medical care for patients with refractory epilepsy.

**Motor Neurone Disease:** Coordinated services with the Motor Neurone Disease Association of WA and Sir Charles Gairdner Hospital.

**Clinical Trials:** Collaboration with Neuroscience Trials Australia (NTA) for research, commercially-sponsored clinical trials and interaction with biotechnology and pharmaceutical industries.

**Demyelinating Diseases Centre:** To improve the therapy and management of those suffering from multiple sclerosis and other demyelinating diseases.

**Parkinson's Centre for Research and Treatment:** Aims to determine the genetic and environmental causes of Parkinson's disease and develop better therapies for the disease and its consequences.

**Neurogenetics and Muscular Dystrophy:** A/Professor Phillipa Lamont, Head of Neurology, Royal Perth Hospital has recently set up a clinic at the ANRI to provide genetic diagnosis for a wide range of inherited neurological conditions. Patients with a Neurogenetic disease including Muscular Dystrophy are supported in the clinic and have access to services at Sir Charles Gairdner Hospital.

## Founder of the first Inflammatory Myopathies Clinic in Australia hangs up his stethoscope after 20 years

It was with sadness that we said goodbye to our long-term colleague and friend Dr Paul Zilko MBBS FRACP FRCPA MRCP(UK) in May, after he concluded his last clinic at the ANRI. With Professor Frank Mastaglia (Professor of Neurology), Dr Zilko who is a Clinical Immunologist and Rheumatologist, set up the first Inflammatory Myopathies Clinic in Australia back in 1989. (The first of many clinics which have since been set up at ANRI). Over the past 20 years this Clinic has been the only referral Clinic of its type for patients with all forms of Myositis in Western Australia, and has also provided advice to clinicians in other parts of Australia and the World on the management of Myositis.

Professor Peter Hollingsworth, Head of Clinical Immunology at the QEII Medical Centre will take over from Dr Zilko in August 2010.

The staff of the Australian Neuromuscular Research Institute Clinic held a presentation for Dr Zilko at the end of his last Clinic and wished him well for the future.

### Planning workshop

ANRI continues to look forward to the future and is excited by the growth and changes the future goals and implementations will provide.

A one-day workshop took place on Wednesday 10 March.

The workshop was attended by senior staff of the Institute and hosted by Mr Geoffrey Hick, a former Director of Grant Thornton.

The day was extremely productive, with goals set, succession planning under way and strategies for the future put in place.

The Institute looks forward to moving into a specially designed Clinical Neurosciences building, which will commence construction at the end of this year on the QEII Medical Centre site.

## Announcing MD2010 conference

9 and 10 September 2010  
at the UniClub, UWA

Specialists from around the world will congregate be in Perth on 9 and 10 September to attend the MD2010 conference.

Attendees will be informed of the latest therapies available, what the future will hold, where we are going with research, and what treatments are just around the corner, as well as providing information on life style challenges faced by those with a muscular dystrophy, providing information on support and social networking and be able to chat to some of the worlds authorities in the area.

To register your interest contact Brooke on 9382 2700 or email MDA@cyllene.uwa.edu.au



We will overcome the challenges we face

### I would like to support research at the Australian Neuromuscular Research Institute



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