Thursday 13th August 2015
8am-5pm
John Beveridge Lecture Theatre, Level 1
Sydney Children's Hospital, Randwick
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Welcome to the Australian Association of Developmental Disability Medicine (AADDM) Conference 2015. AADDM is delighted to bring people from diverse backgrounds together to share ideas, and to support and inspire each other. AADDM was formed in 2002 as a network of medical practitioners aiming to improve the health status of people with intellectual and developmental disability. The association has a substantial track record of contributing to improvements in healthcare through the support of health and disability professionals, as well as through our major contributions to evidence based health policy and practice changes, at the state and national level.

We are delighted to present a day with a focus on gastrointestinal disorders. These disorders cause unnecessary pain and suffering and even life threatening illness in people with intellectual disability. Dr Jane Law and her team have brought together experts to update you about these disorders, their impact on people and how you as practitioners can recognise and better manage them.

I feel sure this conference will contribute to the association’s mission to improve the health of people with developmental disabilities throughout Australia; not only by facilitating the transfer of skills and knowledge, but also by delivering you a timely and inspired revitalization. I welcome the diverse backgrounds of the conference delegates and wish to acknowledge how each of you are working to make a real difference to the lives of people with developmental disability.

Nick Lennox
President, Australian Association of Developmental Disability Medicine
CONFERENCE ORGANISATION

Conference Coordinator:
Dr Jane Law

Conference Committee
Dr Jane Law, Dr Seeta Durvasula, Dr Jacki Small, Prof Julian Trollor

Acknowledgements
The Conference Committee thanks Mr Dan Pua for his assistance in collating the conference and workshop promotional materials and programs.

PROGRAM INFORMATION

Sessions:
Please be seated 5 minutes prior to the beginning of a session.

Copies of conference papers:
No conference proceedings will be produced. Conference papers are available at the discretion of presenters, and delegates are asked to contact speakers directly in order to obtain copies.

Photography:
If you object to have your picture taken during the conference proceedings, please make yourself known to the reception desk.
## IT’S ALIMENTARY

A lifespan approach to gastrointestinal conditions in people with intellectual disabilities

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### AADDM Conference

Thursday 13th August 2015
Sydney Children’s Hospital

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<th>Topic / Title</th>
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<td>08:00 - 08:30</td>
<td>Registration</td>
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<td>08:30 - 08:50</td>
<td>Official Opening</td>
<td>Joanne Argent, Parent Housekeeping</td>
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<td>08:50 - 09:30</td>
<td><strong>Session 1 - Gastrointestinal Disorders 1</strong>&lt;br&gt;  ▪ Epidemiology of gastroenterological disorders in people with intellectual disability&lt;br&gt;  ▪ Survey of gastrointestinal disorders – Rett syndrome</td>
<td><strong>Chair: Dr Jacki Small</strong>&lt;br&gt;  Prof Nicholas Lennox&lt;br&gt;  Prof Helen Leonard</td>
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<td>09:30 - 11:00</td>
<td><strong>Session 2 - Dysphagia and Nutrition</strong>&lt;br&gt;  ▪ Speech pathology approach to dysphagia&lt;br&gt;  ▪ Nutritional supplements&lt;br&gt;  ▪ Enteral feeding/PEGs</td>
<td><strong>Chair: Dr Aline Smith</strong>&lt;br&gt;  Ms Tanya Govey&lt;br&gt;  Ms Jodie Ellis&lt;br&gt;  Dr Jacqui Dalby-Payne</td>
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<td>11:00 - 11:30</td>
<td>Morning Tea Break</td>
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<td>11:30 - 13:00</td>
<td><strong>Session 3 - Gastrointestinal Disorders 2</strong>&lt;br&gt;  ▪ Gastro-oesophageal Reflux Disease&lt;br&gt;  ▪ Case Studies and Discussion</td>
<td><strong>Chair: Prof Nick Lennox</strong>&lt;br&gt;  Dr Reuben Jackson&lt;br&gt;  Panel</td>
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<td>13:00 - 14:00</td>
<td>Lunch Break &amp; AADDM AGM</td>
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<td>14:00 - 15:30</td>
<td><strong>Session 4 - Obesity</strong>&lt;br&gt;  ▪ Epidemiology / New interventions/ Population based approaches – in children&lt;br&gt;  ▪ Surgical approaches&lt;br&gt;  ▪ Restrictive Practices</td>
<td><strong>Chair: Prof Julian Trollor</strong>&lt;br&gt;  Dr Shirley Alexander&lt;br&gt;  Dr Reg Lord&lt;br&gt;  Ms Amanda Wood</td>
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<td>15:30 - 15:45</td>
<td>Afternoon Tea Break</td>
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<td>15:45 - 17:15</td>
<td><strong>Session 5 - Gastrointestinal Disorders 3</strong>&lt;br&gt;  ▪ Gluten Intolerance /malabsorption&lt;br&gt;  ▪ Lower GI disorders</td>
<td><strong>Chair: Dr Seeta Durvasula</strong>&lt;br&gt;  Dr Samantha Tilakaratne&lt;br&gt;  Prof Martin Weltman</td>
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<td>17:15 - 17:20</td>
<td>Conference Close</td>
<td>Prof Nicholas Lennox</td>
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SPEAKERS

**Dr Shirley Alexander** has been working as a Staff Specialist at the Children’s Hospital at Westmead (CHW) in the Weight Management Services (WMS) since September 2008 and is one of only a handful of paediatricians with expertise in the area of childhood obesity. The WMS at CHW where she works is the only tertiary hospital multidisciplinary service within the public sector in NSW and one of only 3 similar services within Australia.

In addition to her WMS role, Shirley also holds positions within CHW in education and training from medical students (Clinical Lead in Paediatrics with the University of Notre Dame) to junior doctors in training (Director of Prevocational Education and Training).

Shirley has written a number of articles on paediatric weight management including review articles and book chapters, and presented at state, national and international conferences. She is passionate about health and wellness and helping people find their way toward optimal health.

**Joanne Argent** is the mother of a young woman with Cornelia de Lange Syndrome and severe intellectual disability. CdLS is a complex syndrome associated with multiple co morbidities including a number of gastrointestinal complications including dysphagia, severe gastroesophageal reflux disease, volvulus and chronic constipation.

We warmly welcome Joanne commencing our conference and setting the scene with her experiences and challenges as a mother / carer of a person with intellectual disability and gastrointestinal problems.

**Dr Jacqui Dalby-Payne** is a General Paediatrician with a special interest in the diagnosis and management of feeding problems in children. Dr Dalby-Payne is currently a Senior Staff Specialist and heads a General Medical Team at The Children’s Hospital at Westmead, a VMO in Paediatrics at Royal North Shore Hospital, Senior Lecturer with the University of Sydney and a founding member of the Multi-Disciplinary Feeding Team at The Children’s Hospital at Westmead.

Dr Dalby-Payne’s clinical work focuses on child and infant feeding problems both behavioural and medical. She works in the Multi-Disciplinary Feeding Team at The Children’s Hospital at Westmead and Royal North Shore Hospital.

Dr Dalby-Payne’s current research interest is in the area of feeding. She conducts research into the causes of feeding difficulties in children with specific medical conditions such as congenital heart disease, obstructive sleep apnoea and recurrent tonsillitis. She is also interested in the impact of a child’s feeding difficulties on families particularly those requiring enteral feeding with a tube.
Jodie Ellis is an Accredited Practicing Dietitian and the Team Leader Allied Health Small Teams at Calvary Health Care Kogarah. She has been working in disability for 15 years and is in her 8th year as the convenor of the Nutrition and Disability Interest group for the Dietitians Association of Australia.

Jodie is completing her PhD investigating the meanings of food and nutrition to palliative care patients and their carer’s and remains an active advocate for the nutritional care of people with disabilities.

Tanya Govey is a private speech pathologist with her own business covering greater Sydney and NSW. She specialises in dysphagia and mealtime management for people with a disability and the ageing, particularly those with high support needs and complex medical needs.

Tanya was a registered nurse prior to becoming a speechie and has also held positions in senior management. She has also been a consultant to the NSW Ombudsman Office (death review team) and is consultant to the Stateside Behaviour Intervention service.

She has been the co-author of manuals such as the ‘Nutrition & Swallowing checklist & Manual’ and author of ‘Guidelines for modified food and fluid consistencies’, ‘CICADA’ (Competency in Communication and Dysphagia Analysis) and ‘Pharmacology for speech pathologists’.

Her business name Talking Learning Growing and the creed is: “It is through Talking and Learning that we can Grow. Exceed your expectations!!!!”

Dr Reuben Jackson is a consultant Paediatric Gastroenterologist at the Prince of Wales Private Hospital and a conjoint Senior Lecturer at the University of Western Sydney Medical School. He has previously worked as a Staff Specialist in Paediatric Gastroenterology & Nutrition at the Sydney Children’s Hospital, The Canberra Hospital and The Hospital for Sick Children in Toronto, Canada. His special interest areas include gastro-oesophageal reflux disease (GORD) including the pharmacogenetics and pH/Impedance study of GORD, Cow’s Milk Protein Colitis, nutritional & GI management in Cystic Fibrosis and severe GI dysmotility.

Professor Nick Lennox FRACGP, PhD., Director of the Queensland Centre for Intellectual & Developmental Disability is a researcher, educator, advocate and medical clinician. He has been instrumental in development of the Developmental Disability Therapeutic Guidelines Book, performed the world’s three largest RCTs in people with intellectual disability and led the writing of Chapter 3 in the WHO World Report on Disability (2011). His research program with people with intellectual disability includes the areas of health interventions, physical and mental health and wellbeing, health professional education and attitudes, and health promotion and prison health research. He has successfully advocated for positive changes in health service policy and practice; including the development of a Medicare cover for annual assessments. He is President of the Australian Association of Developmental Disability Medicine (AADDM).
**Associate Professor Helen Leonard** was a National Health & Medical Research Council Senior Research Fellow from 2009-2014 and is currently a Principal Research Fellow at the Telethon Kids Institute in Western Australia. For twenty years her clinical practice primarily involved the management of children and adults with intellectual disability and rare diseases. In 1992 she first established the internationally unique population-based Australian Rett Syndrome Database and has maintained this register since that time. In 2002 she set up the International Rett Syndrome Foundation Phenotype Database, InterRett, is also a member of an exciting and innovative autism registry collaboration, and is now funded by NIH as a “virtual and global” Autism Centre of Excellence. Her role in the establishment and securing of the Western Australian Intellectual Disability Database (IDEA) - a population-based research resource - is a major contribution to the health and well-being of an oft-neglected sector in society.

Dr Leonard has co-authored over 170 journal articles as well as 12 book chapters. She is well cited with her seminal review on intellectual disability now cited over 270 times.

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**Professor Reg Lord** is an upper gastrointestinal surgeon in Sydney.

He leads the St. Vincent’s Gastroesophageal Cancer Research Program and is Head of Surgery at Notre Dame University School of Medicine.

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**Dr Samantha Tilakaratne** is a paediatric gastroenterologist involved in the care of infants and children with gastrointestinal issues. She completed undergraduate training at Flinders University in Adelaide, before moving to Darwin, where she began her career in Paediatrics. She started general paediatric training in Sydney, before transitioning to subspecialty training in paediatric gastroenterology. She spent several years in England, training at Birmingham Children’s Hospital in their Gastroenterology and Liver Units, and undertaking research at University of Birmingham. She has worked in a number of health settings in both public and private capacity, caring for children and young adults with complex medical and intellectual challenges.

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**Professor Martin Weltman** is an experienced consultant Gastroenterologist and Hepatologist, with a strong interest in liver disorders, capsule endoscopy, reflux oesophagitis, colon cancer screening and inflammatory bowel disease. He completed his medical degree at the University of Witwatersrand in South Africa in 1983. This was followed by specialist training in both South Africa and in Australia at Royal Hobart, St George and Westmead Hospitals (FRACP 1992). Professor Weltman subsequently obtained a PhD from the University of Sydney (1998) for his key studies into fatty liver disease.

Professor Weltman consults in private practice in Bondi Junction, Randwick and at Nepean Hospital. He is an Associate Professor of Medicine at the University of Sydney and works as a Staff Specialist at Nepean Hospital, where he is also the Director of the Gastroenterology and Hepatology Department.

He is the author of over 40 publications, multiple book chapters and a textbook in the field of gastroenterology (‘Gastroenterology and Hepatology: A Clinical Handbook’). Professor Weltman is a sought after speaker both nationally and internationally. He is also an editor and reviewer for specialist medical journals in the field of gastroenterology.
Professor Weltman has several areas of research interest including Non-alcoholic fatty liver disease (NAFLD) (natural history, prognostic indicators, pathogenetic mechanisms and therapies - Alcoholic hepatitis - Clinical trials and therapy for chronic hepatitis C and B infection - Genomics for HCV - Therapies for inflammatory bowel disease - Interventions for Barrett’s oesophagus - Epidemiology and natural history of functional dyspepsia and irritable bowel syndrome.

Amanda Wood is a registered Psychologist, with a Master’s Degree in Psychology. She has over 20 years of experience in the Disability and Community Sector. She has conducted research in the field of Autism and Disabilities and has worked for a number of Government Services including the Department of Community Services, Ageing and Disability and Juvenile Justice. She continues to contract to Government and non-Government Services. Amanda is an experienced supervisor of Psychologists and Behaviour Practitioners across NSW. Her transdisciplinary team of allied health professionals at Real Disability Care provide practical interventions to children and adults with disabilities. Amanda also consults to FACS and other non-government services providing support and advice in regards to Restrictive Practices.
ABOUT AADDM

The Australian Association of Developmental Disability Medicine (AADDM) was formed in September 2002 as a network of doctors with an interest in improving the health status of people with intellectual and developmental disability. The work of AADDM main focuses on the professional development of its members and their clinical colleagues, and political advocacy. The committee holds quarterly teleconferences and welcomes input from members. AADDM holds yearly conferences and produces excellent newsletters. AADDM has been and continues to be a major contributor to government policy with a remarkable history of successful advocacy leading to widespread changes in healthcare delivery throughout Australia.

In collaboration with the NSW Council on Intellectual Disability (NSW CID), AADDM successfully advocated over many years for the development of a Medicare item to fund general practitioners to perform year health assessments for people with intellectual disability. The Medicare item first became available in July 2006 and resulted in tens of thousands of health assessment being performed throughout the country. In 2009 AADDM provided the Hon Secretary Hon Bill Shorten MP with a literature review outlining the evidence for early intervention in children with intellectual disability, then in 2010 the Labor party announced funding for this process as part of their platform for re-election. These changes have now been delivered throughout Australia. In addition the National Disability Strategy sets out a ten year national plan for improving life for Australians with disability, their families and carers and includes specific suggestions made by AADDM & NSW CID under the sixth priority area; “Health and wellbeing—health services, health promotion and the interaction between health and disability systems; wellbeing and enjoyment of life.”

Join AADDM, support these activities and be part of an effective association that provides information and support and continues to improve the health of people with developmental disability in Australia.

http://ausaaddm.wordpress.com
AADDM EXECUTIVE AND COMMITTEE MEMBERS

President: Prof Nick Lennox

Deputy President: Prof Julian Trollor

Secretary: Dr Jane Law

Treasurer: Dr Jean Graham

Other Committee Members: Dr Jacqueline Small; Dr Helen Beange; Dr Margaret Kyrkou; Dr Seeta Durvasula, Dr John Entwistle, Dr Jenny Torr, Prof Helen Leonard, Dr Jim Xu, Dr Aline Smith, Dr Michaela Baulderstone; A/Prof Bob Davis.
AADDM MEMBERSHIP APPLICATION/RENEWAL

A person who is a legally qualified medical practitioner in good standing in Australia, is interested in improving the standard of medical care provided to people with an intellectual or other developmental disability and is supportive of the purpose and goals of the Association can apply for membership.

Please confirm that you meet these criteria Yes / No (circle correct)

Payment of $50 per annum to be made to AADDM Westpac BSB and Account Number 033-070, 23-2887, (Oakleigh Branch of Westpac, 44 Atherton Rd, Oakleigh Victoria)

Membership form to be sent to the AADDM administrator j.curtis1@uq.edu.au or fax 07 3163 2445

AADDM - http://ausaddm.wordpress.com/home/

Please complete the following:

Name ................................................................................................

Email ................................................................................................

Contact telephone ........................................................................

Postal address ..............................................................................

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Area of medical practice ........................................................

Signature of Applicant ................................................................

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1A Sydney Children’s Hospital
1B SCH South East Wing
1C SCH South West Wing
2A SCH Emergency Wing
2B High Street Building
3 Radiation Oncology
3A Nelune Comprehensive Cancer Centre and Australian Advanced Treatment Centre
4 Medical Superintendents Cottage
5 Edmund Blacket Building
6 Edmund Blacket Building West Wing
7 Parkes Building
8 Clinical Sciences Building
9 Hyperbaric Unit
10 Electrical Substation
11 Euroa
12 Catherine Hayes Building
13 McNevin Dickson
14A Administration Building 2
14B Diabetes Centre
15 Dickinson Building
15A Psychiatric Emergency Care Centre
16 Campus Centre
17 Royal Hospital for Women
18 Palliative Care
19 Mental Health Intensive Care Unit
20 Sydney Children’s Community Healthcare
21 Ronald McDonald House
22 POW Childcare Centre
23 Hut U
24 Metro Car Park 8
25 Kiloh Centre
26 Black Dog Institute
27 Neurosciences Research Australia
28 UNSW Bookshop

LEGEND
- Sydney Children’s Hospital
- Evacuation Assembly Points