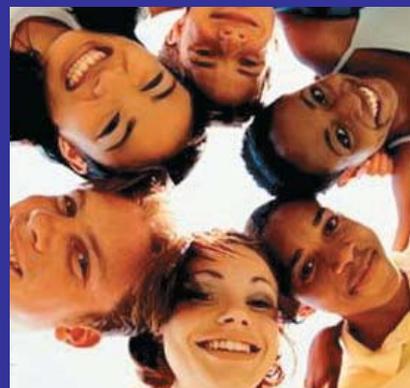


CyNet



Health of our children: Wealth of our nation



Newsletter of the Advisory Group for National Child and Youth Networks

Issue 1 - 2015



From the Chair

This is my first contribution to the CyNet newsletter since taking over the Chair of the Advisory Group from Dr Rosie Marks late last year. As incoming chair I want to acknowledge the fantastic job that Rosie Marks has done in leading this program from the beginning.

The NZ National Child and Youth Clinical Networks are now well established and the Ministry of Health has committed to a further three years of funding from last year.

This newsletter introduces a new Clinical Network (Sleep Medicine) and new Clinical Advisory Board members for your information.

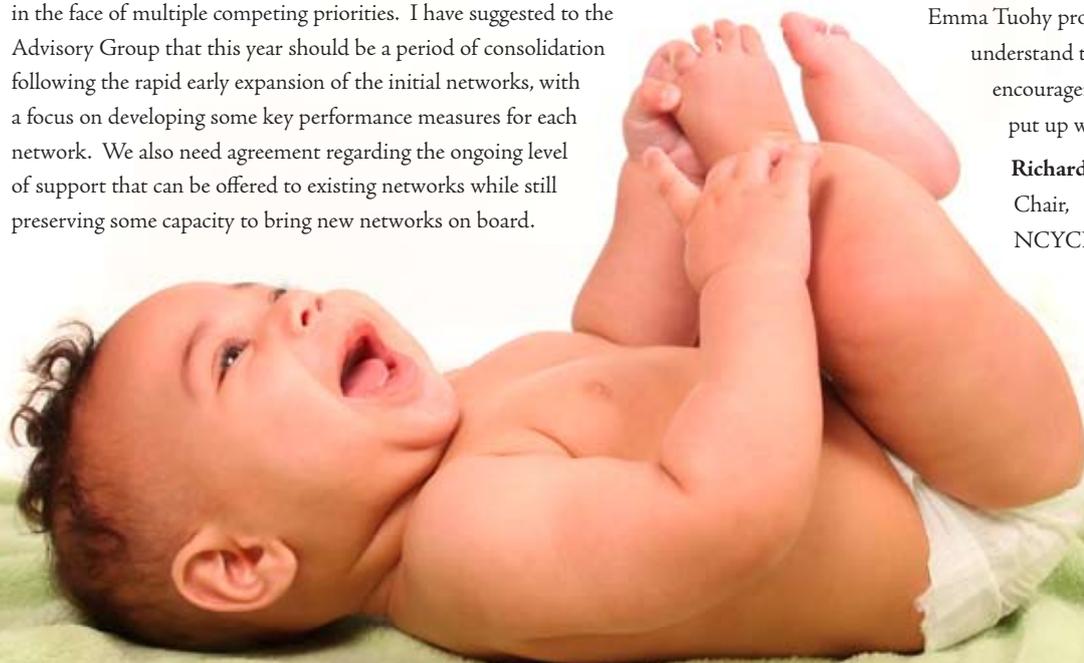
In March, Mollie Wilson, David Newman and I met with the Minister of Health along with Pat Tuohy. The Minister was very positive regarding the work that our networks are performing, and mentioned that he thought this was the type of approach that other areas in health could benefit from.

Regardless of strong political support, it is important that our Clinical Networks are able to clearly measure and report on the benefit of the activities that are undertaken if we are to secure ongoing funding in the face of multiple competing priorities. I have suggested to the Advisory Group that this year should be a period of consolidation following the rapid early expansion of the initial networks, with a focus on developing some key performance measures for each network. We also need agreement regarding the ongoing level of support that can be offered to existing networks while still preserving some capacity to bring new networks on board.

To assist us with this we are delighted to be hosting Prof. Steven Cropper from Keele University on his visit to New Zealand in June. Prof Cropper has considerable practical and academic experience with managed clinical networks in the United Kingdom. We are looking forward to his input to our discussions at workshops with our Child Youth Epidemiology Service on 6th June, and our Clinical Network Leaders/Advisory Group in Wellington on 8th June. Prof. Cropper will also be visiting Auckland and speaking at the Starship Paediatric Update on Wednesday 10th June. As usual this session will be available live around the country on Telepaeds and a recording will be accessible on the website. Our existing Networks are in various stages of development, and I think they demonstrate a useful range of different approaches to suit the aims of each. These different network models offer tested templates for those who are considering transitioning from a SIG or similar group to a managed clinical network. Our Advisory Group members and Network Leaders would be happy to discuss with those who are interested.

Finally, after much vigorous debate and multiple drafts, we have introduced the new NCYCN logo to brighten up your day with its lively colours and clean modern design. (Ms. Emma Tuohy produced the logo for us. I understand that she may have received some encouragement from a close relative to put up with working with us).

Richard Aickin
Chair,
NCYCN Clinical Advisory Group.



National clinical network to support the clinical management of Paediatric Sleep Disorders

Dr Liz Edwards is the clinical lead for the new National Clinical Network for Paediatric Sleep Medicine. She describes why a national approach to facilities and management of paediatric sleep disorders for New Zealand (NZ) children is needed and the aims of the clinical network.

The aim of the National Clinical Network for Paediatric Sleep Medicine is to provide clinical leadership in the development and maintenance of a nationwide clinical service for children and youth up to 15 (and when appropriate 18) years of age to basic international benchmark standards. While a productive, informal team has been functioning for some years there was a pressing need to move work forward and a successful business case was submitted to Paediatric Society of New Zealand (PSNZ) to 'formalise' a clinical network. The move to establish a network will provide a robust platform on which to support multidisciplinary teams to provide a more accessible and standardised service nationally.

Why is Paediatric Sleep Medicine important?

In the Ministry of Health (MOH) and PSNZ 1998 document, 'Through the Eyes of a Child' under the umbrella of Respiratory services, paediatric sleep issues were highlighted as being "underdiagnosed and undertreated". Over the last 15-20 years there has been increased recognition of the importance of sleep for child's health. Along with advances in neonatal and paediatric care, we have seen an increased prevalence of chronic paediatric conditions. While there are over 60 different diagnosable paediatric sleep disorders, the most common disorder is obstructive sleep apnoea (OSA) affecting an estimated 3-5% of normal children, in comparison with 7% of adults. Sleep disorders, especially OSA, should be particularly considered in the following conditions, due to the high prevalence rates and secondary consequences;



obesity, Down syndrome, Prader-Willi syndrome, neuromuscular disorders (Duchenne's muscular dystrophy, cerebral palsy), craniofacial abnormalities (Achondroplasia), storage disorders (mucopolysaccharidosis), prematurity and spina bifida.

In more recent years, research has mushroomed bringing increasing recognition that untreated OSA may result in significant adverse consequences even in very mild cases. In children, episodes of upper airway obstruction during sleep may lead to brief arousal from sleep without desaturation. These arousals can be associated with increases in heart rate and blood pressure which over time become sustained and lead to second generation health effects in a wide range of medical comorbidities including cardiovascular complications (hypertension, cor pulmonale and death), diabetes, metabolic syndrome, and may also be the mechanism by which OSA affects development, learning and behaviour.

Adenotonsillar hypertrophy is the most common cause of OSA in children and adenotonsillectomy is the treatment of choice. Shortage of resources to investigate these children can delay surgery. As it is possible to detect and treat the majority



of sleep disorders it is vital that NZ children have access to the necessary tools and expertise to engage with the task.

What is the rationale for development of a National Clinical Network for Paediatric Sleep Medicine?

In 2001 the PSNZ was contracted by MOH to produce some evidence based guidelines for common conditions and Paediatric Sleep was identified as one of the conditions. A team was established and *The Best Practice Evidence Based Guidelines for Assessment of Children with Sleep Disordered Breathing* was finalised a few years later (PSNZ, 2004). A prediction was that within 5 years there would be a need for the development of a funded national network of coordinated services for sleep disorders in children to address basic international benchmark standards. Standards to encompass local, regional and national levels of facility and expertise. While these services have grown over recent years, over a decade later there is no recognised centralised funding and services remain inadequate to address the needs of NZ children to an international standard. In 2008 and 2013 audits have been undertaken of national facilities for paediatric sleep medicine services. The provision of such services for children continues to lag considerably behind that provided to adults with similar conditions around New Zealand and has not progressed since 2004 in fact in many ways the gap has widened. Significant investment is needed to address this critical deficiency in paediatric sleep services.



The 2004 Guidelines aimed to highlight the need for:

- Increased recognition of OSA symptoms.
- Increased ENT referrals for adenotonsillectomy.
- Increased use of overnight oximetry as a screening tool
- Increased training for test limitations & interpretation of oximetry results.
- Increased national provision of comprehensive sleep studies (polysomnography)

Again while some progress has been made with some of these needs, on the whole The Guidelines were poorly disseminated and had limited impact external to members of the PSNZ who have an interest in sleep disordered breathing. Despite this the aims remain relevant and will inform the work of this network in the future.

What has been achieved to date?

A comprehensive review of the original 'NZ Guideline for the Assessment of Sleep Disordered Breathing in Childhood' is in a final stage of revision by the special interest group and soon will be sent to the sector for further consultation.

Expressions of Interest have been sought for a Clinical Reference Group (CRG) who will provide leadership over the next 12 months for health professionals who care for paediatric sleep disorders throughout NZ. The Group will be meeting in March at which time a 12 month work plan will be agreed. Included in this work plan will be proposals to:

- provide educational and collegiate support for NZ health care professionals who care for children with sleep disorders
- support appropriate and timely dissemination and implementation of the re drafted Guidelines (2014) to support the provision of high quality care of children with sleep disorders
- update information on the Starship's National Clinical Network page and Kidshealth web site.

Network Scope

The scope of the Clinical Network encompasses all health care settings (community, primary, secondary and tertiary) and organisations where paediatric sleep medicine services and related services are provided for children, youth up to 15 (and when appropriate 18) years of age and their families/whanau, throughout NZ.

The Network will develop strong alliances with key services providing paediatric sleep medicine services including primary health care organisations, secondary and tertiary health services and other relevant services and organisations.

If you are interested in being part of the wider network please contact Kaleen Cooke (kaleen@healthnetworks.co.nz) in the first instance.

Introducing new members of the Clinical Network Advisory Group

Kate Russell

Kate has had 25 years in the NGO sector and is currently CEO of the Canterbury Medical Research Foundation and Commercial Director of the NZ Brain Research Institute. She chairs the Pharmac Consumer Advisory Board and the Fundraising Institute Ethics Committee and is a Fellow of the Institute.

Kate is also a Board member on the Pacific Pathways Foundation which sends school supplies to the Pacific Islands and a member of the Canterbury District Health Board Research Committee. Kate provides

advice and mentoring to smaller not for profits on Strategic Planning, Sponsorship and Change Management.

Born in Wellington, has lived in Christchurch for 45 of her 49 years.



Jon Buchan

Jon Buchan came to New Zealand from the UK ten years ago to work as a RN within Whanganui emergency department. He arrived with a particular interest in paediatric services having achieved dual adult and paediatric nurse registration within the UK within Southampton Emergency Department.

He is currently working as the maternal, child and youth portfolio manager within Whanganui District Health Board, responsible for the full spectrum of child, and youth service provision including

antenatal care. This position is accountable for both general and mental health services for children and youth. This gives a much more comprehensive perspective of across the board funding and planning influences on health services for children and youth.

The comprehensive nature of the role ensures his contact with the portfolio manager groups is extensive. He is included in all national level conversations and attends a significant number of hui which ensures he meets with a range of other portfolio managers regularly. Through this he is able to maintain contact and expand his networks within the maternal, child and youth arenas nationally. Since joining the strategic advisory group, he has proactively escalated his contacts with others within the planning and funding groups across the country.

Prior to becoming a portfolio manager, he established extensive linkages with paediatric stakeholders across the country, through his previous roles as nurse manager for surgical services (which included maternal and paediatrics) and TrendCare coordinator.



Professor Dawn Elder

MB ChB, DCH, FRACP, PhD.

Dawn is Head of the Department of Paediatrics and Child Health at the University of Otago, Wellington and works as a paediatrician at Capital & Coast DHB. Dawn has clinical paediatric specialist qualifications in both neonatal

medicine and paediatric sleep medicine. She also works clinically in the area of child protection and in particular in the area of child sexual abuse.

Dawn Elder has research interests in sleep and breathing in preterm and term infants as well as in the older paediatric age range. She also has research interests in cause of perinatal death and SUDI and is a co-investigator on the HRC-funded national SUDI case-control study.

Dawn is a past member of the Perinatal and Maternity Mortality Committee (PMMRC) and a current member of the Family Violence Death Review Committee (FVDRC). She is a member of the Child Protection Clinical Network and also a member of the newly formed Sleep Medicine Clinical Network.



Dr Glenn Doherty

Born and raised in South Auckland, Dr Glenn Doherty of Maori (Ngati Porou) descent, Glenn has always had an affinity with the rich mix of cultures he grew up with, which has led to his current position as CEO and Clinical Director of the Tongan Health Society. He has worked in areas as diverse as Sydney's Centre for Immunology developing test kits for HIV/AIDS and

AIDS screening programmes to advising the NZ Ministry of Health on Maori Health. Glenn has spent over 30 years working at all levels of policy, research, management, clinical medicine and clinical governance.

He is especially passionate about Maori and Pacific health issues and still regularly travels to Tonga when he can to do charity work on Tongatapu - and not just medical work. He helps out with food and clothing distribution, immigration issues and helps in preschools. Clearly an advocate for those in need, Glenn's varied grassroots experience in Maori and Pacific health is a very welcome addition to the Clinical Networks Advisory Group. Glenn is also a member of the RNZCGP Education Advisory Group and has been the school doctor for Kelston Boys High School for the last 10 years.

Visit of Professor Stephen Cropper

In early June Professor Steve Cropper will visit New Zealand to hold meetings with the National Child and Youth Clinical Network Advisory Group, leaders of the various clinical networks and other interested professionals and groups.

Steve is Professor of Management, specialising in public services. He is Director of the MBA (Education) and the Masters in Professional Leadership and Management and a member of the core academic team for the MBA (Health Executive) and Professional Doctorates in Health and in Education, School of Social Science and Public Policy, Keele University, Staffordshire, UK. He has been external examiner to Masters programmes in health management, at Universities including Manchester, Durham and the Open University. He served as Head of School 2012-2014. Steve was the initiating chair of the regional grants committee for the National Institute of Health Research 'Research for Patient Benefit' Programme, as a school governor was initiating Chair of a partnership of 16 schools, and is Academic Adviser to 'Partners in Paediatrics'.

'Partners in Paediatric' (PiP) <<http://www.partnersinpaediatrics.org/>>, is a West Midlands paediatric clinical network group that has been operating over the past 17 years. Steve has been an advisor to the group from the start. He (and his associates) have also written a number of academic papers on clinical network development and sustainability.

Steve will share with us some of the experiences and learnings from PiP's development and from the experience of clinical networking in the UK more widely, and facilitate a workshop on how these insights could be adapted to the NZ context.

Steve's research interests are in

- the organization and governance of public services,
- inter-organisational relations – partnerships, alliances, networks, and
- public and community engagement in public policy and public services.



Professor Steve Cropper will visit New Zealand in early June.

These are reflected in long-term projects funded by central and local agencies to evaluate and support

- partnership as a means of addressing health inequalities and promoting community health and wellbeing and
- the improved organisation of children's health services through the development of managed clinical networks
- the improvement to educational provision through professional networks and partnerships.

If you would like more information on Steve's visit and / or attend a workshop please contact Mollie Wilson, mollie@healthnetworks.co.nz

Current clinical networks and proposed new networks

- Child Protection
- Paediatric Palliative Care
- Treatment of Diabetes in Children and Youth
- Treatment of Eczema in Children and Youth
- Newborn Services
- Paediatric Gastroenterology Services
- Cystic Fibrosis
- Paediatric Neurology
- Paediatric Sleep Medicine Services
- (Proposed) Paediatric Rehabilitation Services

Check <https://www.starship.org.nz/for-health-professionals/national-child-and-youth-clinical-networks/> for more information

Your contributions We welcome thoughts, contributions and articles and notices of upcoming events. We anticipate publishing updates around every three months. Please email the editor, Lauren Young on lauren@laurenyoung.co.nz