



From the Deputy Chair

Welcome to this edition of CYNet Newsletter.

I have been deputy chair of CYNet advisory group since it was formed. I believe that network developments are critical to

the way we will practice paediatrics in the future – a NZ inc approach rather than a Auckland or Christchurch or Hamilton approach. Based on careful discussion and with regular audit and benchmarking of process and outcomes, this is the way we now need to work to improve our care of children in NZ. It is not so much new knowledge we need now, but better and more equitable delivery of care.

This brings us to new and important reasons for you to support our annual scientific meeting in Dunedin in November this year. As a group of clinicians, many of us tend to focus on our own area of sub-speciality. However, with the emergence of Child and Youth Networks, it is even more important now that we get together and forge those bonds that will enhance the work we do. Further, it is only going to get more important that we work together in more and more innovative ways and find solutions to combating the tyrannies of distance and financial constraint.

CYNet is very much part of an evolving process and we are all part of it – or should be. As a small country, we have to learn to use what we have more efficiently. Patch protection is no longer an option. This is the forum for us to come together and create the vision for the future. For instance, do we all know that a new Child Health Information System is being developed in the Midlands with the aim of expanding to a NZ wide system – what will it look like and what will it enable us to do better? How will it link with the new National Maternity IT system? Come and share what you know and be part of this future! The Dunedin town hall has been renovated and will be a great conference venue. Many of you would have memories of Dunedin as student city – come back now and see it again with different eyes – I think you will like it, and the chance to walk around central Dunedin and talk and make plans! The dates are 20 – 22 November – with satellites potentially before and after.

Finally – think about presenting your research or audit or interesting case. Abstracts close 28 August – so still a bit of time to think and get it ready! Go to <http://www.psnz2013.co.nz/>

Prof Barry Taylor

Deputy Chair



Managing children with diabetes

Managing children with diabetes is a big ask – any parent will tell you that. Add in adolescence and the challenges this brings add a whole new dimension to trying to keep children in a balanced and safe state. Given the variable treatments around the country for diabetes complications, including ambulance and first responder protocols it is unsurprising that our outcomes, depending where the child lives, may differ. Trying to standardise the treatment protocols across New Zealand of one of the most dangerous acute complications of diabetes keto-acidosis, (DKA) is the job of Doctors Fran Mouat and Priscilla Campbell-Stokes .

DKA can cause death so it is critical that best practice is known by all first responders. And the fact that up to 15% of newly diagnosed children, with diabetes (around 200 each year) may have DKA at presentation, means that 30 or so children are at risk of serious morbidity if they are not treated correctly. Adolescents who push their insulin boundaries, children with infections and children who for whatever reason are not managing their insulin well, are especially at risk of DKA. As with any chronic illness, hospitals do get their 'frequent flyers' as well; e.g. children who present with DKA more than once a year.

The protocols and algorithms have been signed off by the Executive Committee of the Clinical Network for the Treatment of Children with Diabetes, and will be

presented to the NZ Society for the Study of Diabetes in June and later in the year to the Paediatric Society of NZ. In the near future they will be uploaded onto the Starship clinical guidelines website, used by most Paediatric clinicians around New Zealand, and easily accessible to all. The guidelines will also be promoted within DHBs (for example to Emergency Departments) and externally to St John's, in order to standardise early treatment.

One of the major changes that first responders will note is that to minimise the risk of brain swelling (cerebral oedema), fluid changes to bring about a slow correction of the metabolic abnormalities are: less aggressive initial fluid management (fluid bolus only if low blood pressure); reduction in the degree of dehydration used to calculate rehydration fluids; normal saline is continued as the base fluid for the first 12 hours of rehydration and insulin is delayed until fluids have been running for an hour.

A new algorithm and fluid calculator have been devised to improve understanding, minimise calculation errors and support monitoring of progress during treatment. Other recommendations were made regarding use of capillary ketone measurement, admissions to Paediatric Intensive Care Unit and/or High Dependency Unit, when to consider anticoagulant prophylaxis and management of cerebral oedema.

Priscilla Campbell-Stokes

Diabetes database

We know that type 1 diabetes is a significant problem in New Zealand children. However, we don't exactly know how many children we have in the country with diabetes. We also don't know how well our children with diabetes are doing, according to Dr Jinny Willis, from Canterbury DHB, who is coordinating a national database of children with diabetes. The MoH, routinely collects information around in-patient visits, retinal screening and prescriptions for insulin and other diabetes-related products. Working with the MoH, Jinny is collating information to produce a national register of diabetes in children aged 0-15 years. The lead clinician in each DHB will validate cases identified by the MoH, and add in any children that were missed. In the first year the register will identify all cases of type 1 diabetes up to the end of 2011. The intention is to do this annually to work out the true incidence in New Zealand and to measure how well children are doing.



There are large gaps in our knowledge. "The idea is for us to collect data from all DHBs for benchmarking, such as HbA1c averages, height and weight and that sort of thing. Also, we need to know what screening young people have had for diabetes

complications, such as investigating kidney disease by measuring of urinary creatinine." From this, it will be possible to determine if there are children in particular areas that are not doing so well. "It would be really good to see standardised care right across the country," said Jinny.

Andrew Day, paediatric gastroenterologist

As the only paediatric gastroenterologist in the South Island, Professor Andrew Day has a formidable territory to cover, especially given his 0.5 University role. Andrew is tasked with setting up a gastroenterology outreach service to cover the South Island, from Nelson to Invercargill, catering to the complex needs of children with liver disease such as biliary atresia or previous liver transplant, and those with gut problems such as inflammatory bowel disease or coeliac disease. Andrew has also recently taken on a role as chair of the newly formed Paediatric Gastroenterology Clinical Network.

Paediatric gastroenterologists are thinly spread over all of the country, with just the one in the South Island and 4 serving the North Island. Given that the workload has rapidly increased as more and more children are diagnosed with increasingly complex gastroenterology conditions, it is unsurprising that the service was identified as vulnerable in the MoH Paediatric Tertiary Services Review in 2009.

The key initiative arising from this review was to establish a Service Improvement Program with goals to clearly identify issues affecting gastroenterology services around NZ. The service appeared quite variable around the country, and one of the first steps undertaken by Andrew and colleagues was to survey all DHBs about their management of gastrointestinal problems in children. Although the survey tool was not able to provide all the required details, Andrew notes that it showed big variations in DHB structure, service provision and pathways to tertiary services. The children in some smaller centres don't have the same access to specialist nurses, specialist dieticians and specialist allied health care as children in larger centres do. The survey also gave guidance by identifying a number of gaps in how service management processes are administered and where the inequities lie. The plan is to circulate the survey

results back to DHBs shortly so that the providers can see how their service compares. One result already arising from this has been to develop additional outreach services so that our Paediatric Gastroenterologists can provide support to paediatricians in the regions.



Until recently the Ministry of Health's business unit, the National Health Board, was managing this network within their Service Improvement Plan. Since early 2013 the programme has been transitioned to PSNZ to be developed into a national Clinical Network. The key goal for this change is to support the ongoing development of paediatric gastroenterology services in NZ. The clinical advisory group for this network includes NZ's five paediatric gastroenterologists, two general paediatricians, paediatric gastroenterology nurses and members of key patient groups. Since the Clinical Network was established in March, a number of work streams have been instituted and initial projects identified. One of these is the formulation of a national guideline for the management of inflammatory bowel disease (IBD) in children and youth. New Zealand is known to have high rates of IBD and around a quarter of patients with IBD are diagnosed as children. Another work stream is looking at guidelines for the management of biliary atresia, of which affects 15-20 infants each year [there are 15 – 20 diagnoses a year] in New Zealand.

The Clinical Network will then set up further initiatives and work streams to ensure that its goals are met and that the children of NZ have equity of access to high quality care and management.

Childhood eczema national network

It was when an experienced paediatrician expressed surprise at the amount of emollient being applied to a child with eczema that Paediatric Dermatologist Diana Purvis realised the level of education that was needed to optimally treat children with this common condition. This telling moment has led to the development of resources such as hand outs (parent information leaflets) and videos, which include guidance on applying emollients and topical steroids, as well as guidelines for primary care and continuing work with the Greater Auckland Integrated Health Network* (GAIHN), amongst others. The Eczema Network, which is made up of nurses/nurse practitioners, dermatologists, paediatricians, a general practitioner and a consumer representative meets once a year and teleconferences every 3-4 months. "We have made some really good inroads into developing resources for clinicians and their patients. Our aim is to have a nationally coordinated

continuum of care and for children to get the same best practice wherever they live," according to Diana.

Eczema affects as many as 15 -20% of New Zealand school children. It is a leading preventable cause of serious skin infections and significantly affects the quality of life of affected children and their families. Poor adherence to prescribed treatment is the commonest cause of treatment failure. "If we can get good skin care management in place, it can make an incredible difference to a child's life," says Diana. "We are currently providing specialty eczema training to primary care providers, nurses, Plunket, general practitioners as well as a Pharmac seminar series on the management of childhood eczema. Secondary child health nurses and nurse practitioners are also running nurse-led clinics in a number of DHBs. It is really exciting to see eczema being treated as the serious problem that it really is."

*GAIHN is one of nine greater Auckland Health Alliances implementing the Government's 'Better, Sooner, More Convenient' care initiatives. The purpose of GAIHN is to reduce hospital admissions by strengthening integration between primary and secondary care, and improving the regional capacity of primary care; www.gaihn.health.nz for further details.

Drowning in eczema

Eczema is a chronic disability which in our community is colour blind but disproportionately affects the poor and young

So, in 2005 Newtown Union Health Services, as part of WellHealth PHO "Service to Improve Access" funding, established the Eczema Skin Care Project, with the goal to Improve Eczema Skin care in our community and to decrease hospital admissions for skin infections.

Liaising with the hospital based Community Paediatric Eczema Nurse Specialist we developed consistent messages around eczema care, hosting education sessions for clinicians and pharmacists in the region. Referral processes were established for more severe or uncontrolled eczema. Risk factors for eczema severity or management difficulties were identified.

Over the last 8 years through a combination of closer primary/ secondary communications, community outreach nursing care, consistency and reinforcement of the key messages of eczema management and empowerment of the families caring for their children with eczema, we have

Drowning in eczema 2004

every day at the door
banging and scratching
oozing and weeping
word after word
made no change
to their burden
or our load

stopped drowning.

Our patients still live with eczema, we haven't made it go away, but our families increasingly know how to manage this chronic disease and disability. Our goal is that our families come and tell us what they need next to manage their eczema. This cross sectorial model of eczema care has already changed the lives of many patients, families and clinicians in our community. It is why we are committed to help promote this model of care nationwide.

Dr Annie Judkins GP Newtown Union Health Service

Other clinical networks

Here is a snapshot of activities for the three other PSNZ supported national clinical networks.

Child Protection. A recent report to the Minister of Health noted that the Better Public Services Target of seven DHBs being accredited to provide the Child Protection Alert System by 30 June 2013 has now been met. The two latest enrolments brings the number of DHBs working towards accreditation to eight. This means the work of this CN, plus the Violence Intervention Programme are on track to meet the Ministry's Statement of Intent Objective to have twelve DHBs accredited by 30 June 2014.

The recruitment of a clinical leader for this network is on hold while MOH changes, related to the implementation of the government's national Children's Action Plan, are worked through. Support for this network is being maintained through the strong (PSNZ) Child Protection, Special Interest Group.

A national strategy supporting improved child protection is the Shaken Baby Prevention Project. Eight DHBs are in varying stages of implementation with another six planning to start before the end of 2013. Four more DHBs have indicated interest sometime in the future.

Paediatric Palliative Care. MOH has funded a contract to undertake a literature search and recommend guidelines

for this sub speciality. The time line to employ a contractor and initiate this two phased piece of work is very tight with the first phase now completed. A small working group has been working with the contractor to provide feedback on recommendation(s) for guideline development.

A survey of clinicians at DHBs and NGOs on current, palliative care services and interest in future education sessions, has been completed. Feedback is being collated and will be provided to all respondents in the near future.

A MOU between New Zealand Hospices and the Paediatric Palliative Care Clinical Network has been drafted and is being reviewed by the clinical reference group.

Newborn Services. TOR have been signed off and work streams established. These include:

- Collating information on the capacity of all units. This includes throughput and HR capacity
- Agreeing recommendations/ guidelines for the treatment of retinopathy of prematurity
- Oxygen saturation targets
- Reviewing and making recommendations on Capex requirements/ replacement programmes (aligned to projected bed capacity)
- Resuscitation updates.

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