

# CYNet



Health of our children: Wealth of our nation

Newsletter of the Advisory Group for New Zealand Child and Youth Clinical Networks

Issue 2 - 2015



## From the Chair

Welcome to the second edition of the CYNet newsletter for 2015.

Below you will find updates regarding the development of key performance indicators for our established Paediatric Clinic Networks which I expect will allow us to more clearly report on the benefits resulting from the Ministry

of Health's financial investment and the hard work of the clinical network participants. Earlier in the year the Clinical Advisory Group had discussed the need for these KPIs as an element to support the ongoing sustainability of the program. We held a meeting in Wellington for representatives of all networks to share ideas on this. Feedback from the meeting was positive and the benefits of discussion between people in different networks went beyond the focus on KPIs to the more general issues facing networks. We now plan to hold an "all networks" meeting annually to provide further opportunity for sharing ideas and discussion of issues.

We had been keenly looking forward to the visit by Prof Steven Cropper earlier this year. Unfortunately Prof Cropper had to cancel his trip at short notice due to family illness. He remains very interested in visiting NZ to look at our Networks program and we are exploring opportunities for this in 2016.

Over the course of 2015 there has been strong progress in network development. We have a new network supporting tube fed infants/tube weaning, with the Clinical Reference Group led by Tim Jelleyman. Tim has done a great job in getting this up and running very quickly and we recognise

that this has become an area requiring a lot of support.

The Paediatric Neurology network is underway with membership of the Clinical Reference Group (led by Rakesh Patel) to be confirmed very shortly and a first meeting planned for before Christmas.

The Clinical Advisory Group is also considering a business case for a further possible additional network which was submitted recently. More information will follow when this has been given full review.

Finally this edition of the newsletter includes a patient/family story relating to the benefits of a connected multidisciplinary approach, in this case for severe eczema. I hope that we will be able to include more patient stories relating to the work of other networks in future newsletters.

Lastly, it was found that when one of our Clinical Networks started developing links with Australian services that the name "National Child and Youth Clinical Networks" did not provide clarity that this referred to the New Zealand networks group. In order to address this we are making a small change to our title and logo. Future documents will now refer to "New Zealand Child and Youth Clinical Networks".

Let us know if there is anything that you would like to see covered in future newsletters. In the meantime I hope that you all have at least some time off to enjoy with family/friends during the coming holiday period.

**Richard Aickin**

Chair, Paediatric Clinical Networks  
Advisory Group.



# Eating is not always an option...

One of our thrice-daily pleasures is sometimes not an option for children. The inter-related processes involved in the normal ingestion of food is extremely complex, sometimes presenting a range of problems in children. Issues may range from oral aversion and behavioural difficulties around food to physical difficulties with swallow and airway protection.

Underlying factors may include prematurity, medical conditions and behavioural components. In some cases the challenge of feeding requires tube feeding (e.g. nasogastric or gastrostomy), which may become a long-term intervention for the child and the family. Knowing when, and how to progress towards normal feeding in these children requires a multi-disciplinary approach that considers all of the components of the puzzle and effectively engages with the family in supporting the changes towards oral feeding.

In a survey through child health services nationally in 2013 we found that there were at least 630 children identified as on long term tube feeding in some form (i.e. greater than 3 months duration). The reporting teams suggested how many under their care they thought had potential to progress to full normal feeding, providing an overall estimate of one in four. Which ever way this is considered, this represents a significant group of children receiving health care in relation to their tube feeding. The same survey indicated a wide range of clinical team approaches to the issue across the country.

There have been a number of families in NZ who have collectively been requesting greater support for intensive intervention to wean off tube feed dependency and also improved



information from the placement of a tube for feeding. They have lobbied government and the Ministry of Health in this regard. In response to this, support was provided to develop a clinical network to improve the approach at a number of levels.

Consequently a nationally representative, multi-disciplinary group of interested clinicians has been drawn together to initiate the development of a plan of action around the following purpose statement:

- A multidisciplinary clinical network to support optimal management of tube fed children.
- Our goal is for each child to reach their maximum potential for oral feeding

The group that includes representatives

from speech therapy, dietetics, psychology, community nursing, and paediatric medicine has just welcomed a consumer advisor which provides an important link with families who experience this challenge. The group has members from Northland through to the South Island, and includes metropolitan and provincial settings. I have been encouraged by the enthusiasm and expertise in the group which had its first meeting in August to initiate development of a work plan. Key strategic interests of the group include:

- better information for families;
- consistent guidelines with support for clinical teams;
- qimproved monitoring to learn what is working most effectively.

As a pathway of care the start of tube feeding should include active planning for when to try stopping and consistent clinical support along the journey. The opportunity to learn from the system will be better realized if systematically collected data can be collated and examined through a continuous quality improvement framework. There will also be the potential to form links with current and future researchers working on interesting questions around tube feeding as an intervention.

*If you are interested in being part of the workstreams for this network, or want to make contact with the Clinical Reference Group please email [mollie@healthnetworks.co.nz](mailto:mollie@healthnetworks.co.nz) or [Timothy.Jelleyman@waitemataadhb.govt.nz](mailto:Timothy.Jelleyman@waitemataadhb.govt.nz).*

“ In a 2013 survey we found that there were at least 630 children identified as on long term tube feeding in some form

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# Quality Improvements

## examples of Key Performance Indicators (KPIs) within clinical networks

Clinical networks for children and youth are a quality improvement activity, designed to improve health outcomes for patients and provide consistent advice and resources to families /whānau. The process to achieve these results is through a range of activities that include improved access to service coverage (nationally and locally); development of nationally developed guidelines; the building of capacity through shared education and workforce development opportunities; relevant and current resources for patients and families (these are increasingly becoming web based); and collective

governance and accountability systems. The systematic approach to having these processes and systems are through the appointment of a clinical lead and an expert clinical reference group for each network, agreed terms of reference and an agreed work plan that have performance activities which are time bound, measureable and reportable.

In recent months, the established clinical networks have been working on providing 2- 3 KPIs that are aligned to each network's work plan. Examples of some of these KPIs follow.

### Treatment of Diabetes in Children and Young People

KPI	Measure
To undertake an annual survey with key stakeholders (e.g. Diabetes NZ, DHB specialist clinicians) relevant to consumers with diabetes	Update and refresh the 2015 'Diabetes in schools survey'
To develop, update and / or share clinical protocols and information relevant to the NZ paediatric, adolescent and young adult diabetes population	Develop a MOU with Diabetes Victoria, Australia, to share resources between both organisations. Agreement reflected in numb of shared resources and available on the web site
	Links and shared information with Australasian Paediatric Endocrine Group (APEG)
	Strategic alliance developed between Aotearoa College of Diabetes Nurses (ACDN) NZNO and PSNZ/Diabetes CN to shared information and support families / clinicians
	Paediatric & Adolescents Diabetes Ketoacidosis management guidelines developed and are reviewed regularly
To facilitate collaborative bench-marking/audit/research projects	Development and review of educational resources relevant to children, adolescents and youth with diabetes, and their families
	Comparison of measures of diabetes control access to care and complication screening across paediatric clinics
	Workforce survey

### Child and Youth Eczema Services

KPI	Measure
Provide web based guidelines and resources to support cross sector healthcare professionals	Number of hits to Eczema Network website broken down by: <ul style="list-style-type: none"> <li>+ use of guidelines/family resources</li> <li>+ time spent on site</li> <li>+ number of views of videos on kidshealth website</li> <li>+ number of views of Pharmac seminar series Childhood Eczema Review evidence-supported guidelines</li> <li>+ Review (DHB) inpatient guidelines</li> </ul>
Assess implementation of Model of Care	Survey DHBs ( <i>Survey Monkey</i> ) regarding services for children with eczema including: <ul style="list-style-type: none"> <li>+ access to specialist eczema nurses at primary/secondary level</li> <li>+ access to dermatology (phototherapy, patch testing, specialists)</li> <li>+ any specialised eczema/skin health services/programmes</li> </ul>
Develop and support ongoing workforce development (capacity building) events	Annual Education events: <ul style="list-style-type: none"> <li>+ PSNZ ASM Wellington</li> <li>+ FRACP and Dip Paeds teaching</li> </ul> Training and education of medical and nursing students, midwives, Well Child / Tamariki Ora providers and primary / secondary care practitioners

## Paediatric Palliative Care

KPI	Measure
Clinical Guidelines developed and on the web site	How many people use the guidelines?
	How many hits on each guideline?
	How long spent on each guideline?
Interactive VC Education Forum established	How many sites are attending forums?
	How many people attend per site?
	Consider short survey (3 questions) to assess value of forum
Paediatric ACP use	How many DHB's are using a paediatric ACP form?

## Paediatric Sleep Medicine Services

KPI	Measure
Measure access to NZ Guidelines for the Assessment of Sleep-Disordered Breathing (SDB) in Children	The number of website hits of the SDB executive summary and guidelines are identified
Improve access to, and use of, home overnight oximetry for assessment of SDB in secondary care	Conduct a survey ( <i>Survey Monkey</i> ) on oximetry use in DHB Paediatric/ENT Departments
Stocktake national specialist facilities for undertaking Paediatric Sleep Studies	Repeat 2013 survey ( <i>Survey Monkey</i> ) of national facilities

## Paediatric Gastroenterology Services

KPI	Measure
The IBD guideline will be developed by the Network and will be made available electronically	The guideline is available on the network's web page
The guidelines are being used to guide care	Will be monitored via the website and demonstrate growth in use using hits on the web page as a proxy measure
Diagnosis of Biliary Atresia will be made earlier than the current median of 58 days with a step wise goal approach	At December 2016, 65% of affected babies with biliary atresia will be diagnosed and improving to 85% of affected babies by December 2017
Conjugated fraction bilirubin testing will be automatically undertaken by labs when specific parameters are met.	90% of DHBs will have implemented reflex fraction testing
All infants with suspected biliary atresia should be reviewed by a paediatric Hepatologist prior to Kasai	No Kasai operations will be performed without previous assessment by a paediatric Hepatologist
Develop NZ appropriate Standards of Care	Standards of care have been accepted by NZ endoscopy professionals via the NZSG
2-3 key standards will be identified within the document and adhered to by all services providing paediatric endoscopy services	An evaluation survey of set standards will be undertaken on an annual basis

## Child Protection Services

KPI	Measure
To continue to support the implementation of the Children's Action Plan as indicated	Number of clinical network members who participation on Advisory Groups- as requested
To complete the process of approving DHBs for utilisation of the national Child Protection Alert System (CPAS) as required by the Ministry of Health	All DHBs to be approved by 30 June 2016
To continue the process of biennial re-reviews of approved DHBs to ensure consistent implementation on CPAS	All DHBs reviewed biennially (First re-review completed by site visit, subsequent review by VC or conference call)
To continue to provide an annual workshop for multi-disciplinary child protection clinicians via the Child Protection Special Interest Group (CPSIG) or another multiagency forum	An annual workshop will be held in New Zealand each calendar year either led by the CPSIG or another multiagency forum



## Cystic Fibrosis Services

KPI	Measure
Clinical Guidelines reflecting current best practise will be available to inform the care of Children with Cystic Fibrosis (CF) in New Zealand (NZ)	A phased approach to comprehensive guideline revision allowing prioritisation, review and electronic release of sections are available nationally in electronic format
To establish baseline information informing the CRG about current CF services available to families in NZ	Collation of data is ongoing and will be integrated into action plans
To establish a reliable and accessible database to document key clinical outcomes to inform future clinical practice	The database is established and relevant information is utilised to inform clinical treatment and direction

## Newborn Services

KPI	Measure
Transportation: based on clinical need (rather than DHB capacity)	The 6 level 3 NICU's report annually the transfers due to insufficient capacity,
Continue the development a range of quality indicators to support service improvements	The number of consensus statements, practice recommendations and guidelines on the network's web site increase by a minimum of 3 annually

All the above examples have status updates and specified timelines that is available from the clinical leads and each expert clinical reference group. Further information on achievements and 'work in progress' for each network is available at <https://>

[www.starship.org.nz/for-health-professionals/national-child-and-youth-clinical-networks/](https://www.starship.org.nz/for-health-professionals/national-child-and-youth-clinical-networks/)

KPIs for new networks will be profiled in future CYNet publications.

# Hannah's story

Jodine Lee knew from the moment her newly-born daughter, Hannah sported red spots and dry skin at birth that she had eczema. Despite her midwife assuring Jodine that it was just baby acne, Jodine knew better. She had been there before, with her then 3 year old son Sam, who was under intensive treatment for eczema.

Jodine was under the care of Dr Ameratunga during her pregnancy with Hannah. She had followed a strict diet (no peanuts or fish) during pregnancy. She took probiotics and further eliminated dairy products once she gave birth. Despite this, Hannah was a fussy feeder and her skin worsened.

By the time Hannah was a few weeks old, she was prescribed 1% Hydrocortisone cream. She was born on the 95th percentile for weight and ninth for height. After about her first week, Hannah started to drop through the percentiles for weight. By around 3 months old she was back to the 9th percentile. Jodine was seeing Plunket almost weekly to check her weight.

At 12 weeks, Jodine contacted Dr Tosh Stanley to have Hannah allergy tested. Her eczema was difficult to control despite wet-wrapping most days and using melted emulsifying ointment and Janola in the bath. Son Sam was already under the care of Dr Stanley. Hannah was skin prick tested for all the standard allergens and did not show a reaction to any. Dr Stanley advised at this point that some formula might be a good idea and for the family to see a dietician.

Hannah was not keen on a bottle, having been exclusively breast fed from



*Hannah Lee's eczema is difficult to keep under control.*

birth. The first attempt Jodine made to give her formula she spat it up. Jodine noticed that within a few minutes hives started to appear on Hannah's face and neck. She sent photos to Dr Stanley and less than a few days later was back for more allergy tests. This time, Hannah tested positive to dairy allergens.

As a result of the dairy allergy, Jodine switched to a soy formula. On further advice from the dietician she started to wean Hannah, who was now reacting to wheat, peanut and egg. At last, Hannah started gaining weight,

Things started to stabilise as Hannah started solids and took to the soy formula. Then in summer this year, Hannah's eczema worsened. Jodine went back to see Dr Stanley and Hannah tested positive to dust mites. She also had a staph infection and was put on antibiotics. At Easter, Hannah developed cellulitis in her lower leg and had a 5 day stay in hospital - i/v antibiotics then 3 months of oral antibiotics. Since then, Hannah has stabilised again, as the family continue to actively manage her diet and have dust mite covers on sofas and beds.

Jodine says it is hard work keeping the eczema under control. "Both kids needed constant supervision when they were little so they didn't scratch until they bled. This impacted their sleep as they get hot and itchy in bed. We slept with our son until he was two and a half years old, and have just got Hannah back in her own bed post her hospital stay," Jodine says. "We have a wonderful nanny who looks after our kids and their skin as well as we do. Without her, and the support my husband and I have for each other, it would be very hard."



Above: Hannah and brother Sam, below, Mum Jodine with Hannah.

Jodine has found managing severe eczema has a significant financial impact. Both children are wheat and dairy free. Their bread costs \$7 per loaf. Both children wear special eczema sleeves to bed and have Mite Guard dust mite covers on their beds that retail for over \$100 each. Jodine hot washes all their bed linen and clothes to keep staph at bay and get emulsifying cream out. She gets a disability allowance for both children which helps to alleviate some of these costs.

Jodine is happy now with the supports she has around for her and her children. She has found a fantastic GP, who has children with allergies so gets where she is coming from. She sees Dr Tosh Stanley and Dr Jennifer Pilgrim privately with both children and has recently started seeing Debbie Rickard with her daughter. "All the practitioners we are working with now have given me their phone numbers, and stressed they are just a phone call away. This is hugely important for me as I don't use their direct dials or emails often, but when I do I really, really need their help."

"My kids' eczema is now, for the most part, under control, but we still get our moments where things flare up. My son is now six and his needs have shifted from managing his diet (i.e. what he can't have) to not being able to keep up with his growing appetite. We have had to find new ways to increase his calories without reaching for dairy products. Each age and stage has new challenges. So it is great to know we have a team of professionals around us who can help," says Jodine.

**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](mailto:lauren@laurenyoung.co.nz)