

CYN_et



Newsletter of the Advisory Group for National Child and Youth Networks

Issue 2 2014

From the Chairs



At the end of June it was with mixed feelings that I stepped down as chair of the Clinical Networks Advisory Group. It has been a privilege to be part of bringing an innovative way of delivering child health services to the children and young people of New Zealand. It has been a privilege to work with a great group of passionate and committed people. As in any project there have been frustrations

and challenges but overall I would like to believe that our children and young people are better off for the work that has been done by so many people over the last 4 years. I am confident that in handing the chair on to Richard Aickin, the programme is in a safe pair of hands.

In this issue we again profile the increasingly important role of information technology in delivering health care in the twenty-first century.

On Monday June 23 the new Clinical Networks website quietly emerged on the internet. The site is hosted on the Starship Internet site www.starship.org.nz Why Starship you may wonder? We debated the best option at length. As many paediatricians and child health professionals around the country regularly use the Starship Clinical Guidelines, we decided that hosting the Clinical Networks information in the same area would provide easy access. The Paediatric Society of New Zealand has been very grateful for the welcome from

Starship and the willingness to collaborate in this venture. Susan Cato-Symonds has done a great job in bringing the website together and you can read her item on how popular the site is proving. We have a new logo coming soon.

We also have an article from Katherine Lissienko, *kidshealth* website editor. I keep the *kidshealth* tab up on my internet page in clinic so that I can toggle quickly to the page if I want to show parents a particular factsheet. The reaction is always "that looks interesting; I will take a closer look when I get home". Katherine provides a picture of how the website is continuously developing and improving with some great quotes from website visitors. And do not forget that you can contribute to this excellent resource by helping with factsheet development. If you are a member of the Paediatric Society, just email Denise and ask to join the Parent Information Special Interest Group. And if you are not a member...well just go to the website www.paediatrics.org.nz and find out how you can join!

We also have an update on the rollout of the Children's Teams and the Children's Action Plan as well as a report from one of our embryonic networks. Julian Vyas explains the challenges of providing integrated multidisciplinary care for children with Cystic Fibrosis and how a Clinical Network will support local teams with the care of these children and their families.

Last but not least Richard Aickin shares his vision for the future.

Rosemary Marks Inaugural Chair 2010 – 2014



As incoming chair I want to acknowledge the fantastic job that Rosie Marks has done in leading this program from the beginning.

I am delighted that the Ministry of Health has provided further funding for the next three years. This has been the result of the high quality of the work which is underway in the six networks currently supported, and the ongoing hard work and expertise of Mollie Wilson in managing the program.

I look forward to continuing to work with the existing CYN_et Clinical Advisory Group members and would like to draw the attention of PSNZ members to the call for expressions of interest for new members for the Advisory Group.

Working as a Paediatric Emergency Medicine "generalist" in a tertiary children's hospital I have ready access to sub-speciality

expertise every day, through the availability of up to date guidelines, conversations with colleagues and more formal case review and update sessions. This local networking is essential to enable me to be effective in my work in Children's ED.

Paediatric clinical networks are a way that we can enable access to the best possible healthcare for children in New Zealand, regardless of where they live. We need to make best use of the skills and insights of health professionals working in different settings and find ways of bypassing the constraints of geography, funding and interdisciplinary boundaries. We have the advantage of starting with a small and relatively simple health system in which most of us already have our own informal networks. More formal networks can add strength through a better defined structure, multidisciplinary, primary care and consumer participation, data collection and review and much else.

Networks can't solve all the problems we face in Child Health in New Zealand, but they are providing creative solutions in many areas.

Richard Aickin Incoming Chair

Protecting vulnerable children a shared responsibility

Local solutions to local problems

The opportunity to develop local solutions to support vulnerable children is being taken up by communities across New Zealand, as the Children's Action Plan gains momentum.

The Children's Action Plan is the Government's strategy to improve the wellbeing of New Zealand children, and in particular, to support vulnerable children before they come to harm.

A key part of the Plan, as announced by the Government in May, is the establishment of Children's Teams with local leadership.

Eight new teams are being set up over the next year in Foxton/Levin/Otaki/Shannon, Blenheim /Picton, Hamilton, Clendon/Manurewa/Papakura, Gisborne, Whakatane, Whanganui and Christchurch. These are in addition to the two demonstration sites established last year in Whangarei and Rotorua.

Children's Commissioner Dr Russell Wills says Children's Teams introduce a good model for the future.

"We already have some good examples of health, education and social services working together but still nowhere near often enough. Children's Teams should mean all children with complex needs get the comprehensive assessment and single plan they need."

Dr Wills says all children's professionals will have training in child abuse and will work in organisations with child protection policies. He says this is a positive step forward.

"The days when child protection was seen as an optional or specialist skill are over. These are core skills for the children's workforce in 2014," he said.

National Children's Director, Sue Mackwell says the

new approach is about everyone taking responsibility for vulnerable children.

"Work in communities to set up Children's Teams is being supported by what's happening at a national level."

Fundamental changes at national level

New legislation was passed in July and Ms Mackwell says it will fundamentally change the way we work together to support families and protect and improve the lives of vulnerable children.

"The law changes make it easier to monitor how our children are doing and hold people accountable in a way we haven't seen before in child welfare. These measures will really help to reduce child abuse. For example, for the first time ever, five chief executives of government agencies are now jointly accountable for the plan to protect our children from harm."

The legislation includes new vetting and screening checks for government and community agency staff, which, in time, means around 280,000 paid children's workers will be safety checked and covered by workplace child protection policies.

"We have to ensure we have an open, safe and competent workforce looking after the interests of our vulnerable children."

How the Children's Teams will work

Sue Mackwell says the model for how Children's Teams will operate was co-produced by a wide range of people and agencies, including government and NGO service providers, iwi, professionals and practitioners.

Local leadership is essential. In each area, a Local Governance Group will be established, with Children's Teams led by a locally appointed Children's Team Director.

"In each case a Lead Professional is assigned to each child

and their family. This person is the child's main point of contact. It is their responsibility to bring together everyone involved in the child's situation and develop a coordinated and actionable plan for that child's wellbeing. The Lead Professional then reports to, and is supported by, the Children's Team."

The operating model builds on the experience from the Rotorua and Whangarei demonstration sites where about 140 children are now being supported.

"In each area where teams are being set up, we're reaching out to a wide network of community members, practitioners and professionals at the earliest opportunity. The whole focus for Children's Teams is bringing together all of the people involved in a child's life to work together to provide the support that child needs. It has to fit within the local environment – this means Children's Teams are appointed

from the community, by the community."

Ms Mackwell says the local leadership is supported by a series of national building blocks such as a set of core competencies for people working with children and a process for vetting and screening the children's workforce.

The national framework also includes a consistent approach to the criteria for entry to a Children's Team, an assessment and outcomes frameworks, consent and information sharing protocols, and what the roles and responsibilities are within each of those Children's Team.

"We're just about to launch the Children's Team that covers Horowhenua and Otaki. We're seeing a huge amount of support from the community in coming together to create a team that will really work for the local area."

"It's exciting to see ideas about how we can work better together, being translated into action."

Starship website

The Starship Children's Health website has always been a go to place for clinical guidelines. Over the past two years the scope of information available to health professionals has been expanding and evolving, to reflect a culture of shared paediatric clinical resources. Along with the Starship Clinical Guidelines there are also the National Child Cancer Haematology and Oncology Guidelines, and Radiology Procedural Techniques. Incorporating the National Child and Youth Clinical Networks (NCYCN) is a great opportunity to add to this portfolio, and promotes interfacing between the spectrum of nationally available guidelines and resources.

The NCYCN web page (<https://www.starship.org.nz/for-health-professionals/national-child-and-youth-clinical-networks/>) was launched in late June 2014, so is still in its early days of development. Since its launch, there have been over 1,700 page views. Some of the networks are in the process of finalizing information to be loaded, while others such as the Eczema



Clinical Network have put together a comprehensive portfolio of information that will appeal to a wide range of health professionals involved in caring for children with eczema.

It's a 'watch this space' over the coming months as the information continues to build and develop.

kidshealth website

www.kidshealth.org.nz is a joint Paediatric

Society of New Zealand and Starship Foundation parent information online resource.

kidshealth's mission is to provide accurate and reliable information about children's health for New Zealand parents, caregivers, family and whānau. *kidshealth* is also a website for the range of professionals who work with parents every day, including doctors, nurses, early childhood staff, teachers, mental health professionals and others.

We hope these professionals will refer parents to the site, or download and print its information for the parents they are working with.

"Fantastic website but didn't even know it existed... What a wealth of information and great starting point for those facing medical or behaviour challenges with their children.... Will be looking in depth at many of your areas as you appear to have info on most areas of need for us. Guess I am asking how come 'someone' didn't show me or refer me to your site earlier? ..."

This is one of the positive comments recently received about *kidshealth* from one of the 1½ million visitors to the site in the year ending 30 June 2014. Visitor numbers have more than doubled over the course of the most recent 12 month period – from 198,484 in the April to June 2013 quarter to 507,863

"Thank you, I needed something brief, concise, and most of all correct to send to my mother (now the grandmother and frequent caretaker who was concerned and understandably confused and sought guidance ..."

And another visitor:

"This has helped me so much I had no idea about any of this 5 minutes ago now that I have read this I know what to do and what not to do".

Foreskin care page, [kidshealth.org.nz](http://www.kidshealth.org.nz)



in the corresponding 2014 quarter. New Zealand visitor numbers have almost doubled in the same period - from 59,536 (April to June 2013) to 107,284 (April to June 2014).

Other notable trends are the large number of visits to *kidshealth* from smartphones and tablets – these now account for 66% of all visits to *kidshealth*. In the April to June quarter 2014 there were 334,287 visits from smartphones and tablets, up from 119,133 in the corresponding 2013 quarter.

kidshealth content needs to display well on all smart phone and other small-screen devices and considerable work has gone into this. The development of a *kidshealth* app is a future consideration.

"This site is very informative, it saved me from having a nervous break-down, my grandson felt hot and now he's okay! Keep up the good work!!!

From fever page, [kidshealth.org.nz](http://www.kidshealth.org.nz)

kidshealth can support clinical networks by providing authoritative and engaging information for families. A recent example has been the creation of an eczema section developed in conjunction with the Paediatric Society's Eczema Clinical Network. The highlight of this section has been four new videos which aim to provide guidance about managing eczema for families and health professionals. These aim to support equity of access to specialised advice for families irrespective of where in New Zealand they live. The videos stress the three really important steps when caring for a child with eczema – moisturiser, bathing and steroid use. You can view the videos at <http://www.kidshealth.org.nz/eczema-care-3-easy-steps> (available on YouTube and Vimeo).

Feedback on the eczema resources has been very positive,



use and accessible regardless of literacy level, language skills and geographic location. A series of videos seemed the best way to do this, and Katherine was really helpful in guiding us through the process. Making the videos was harder than I expected but it has been pleasing to hear positive feedback from patients and colleagues who have used them”.

Katherine Lissienko, *kidshealth* Website Director, would like to see clinical networks lead further development of online parent information and says there is already a strong foundation to build on. She is particularly interested in discussing possibilities for developing engaging video content where appropriate. Parent information relevant to the following clinical networks is already available on *kidshealth* and complements the health professional guidelines recently added to the Clinical Networks’ section of the Starship website:

“I just wanted to say how great your website is at giving guidance for health concerns. It’s a great help for a mum with small children to find guidance on non serious illness or worries before taking them to doctors (otherwise I would be there every day!) Thank you”
Sore throat page, [kidshealth.org.nz](http://www.kidshealth.org.nz)

including the following from a primary care health professional: “I wish to applaud the recent educational material you have developed and made available through *kidshealth* NZ / *Starship* website. The eczema videos are particularly useful both for our staff (doctors included) and certainly the many patients we have with eczema. We have received a lot of positive feedback and we as the clinicians feel more confident in the advice we give. Looking forward to future “pearls”.

Diana Purvis, Paediatric Dermatologist and Medical Lead of the Eczema Clinical Network comments that “We wanted to make some resources for families that would be simple, easy to

“Hi Thanks for your fact sheet on this problem. Not since I have known about my daughter having this problem have I read online or received this amount of useful information which has answered all of my questions. Not even the paediatrician we consulted gave us such full and helpful information as you have presented here. Thank you so much”.
From constipation page (from an Australian user), [kidshealth.org.nz](http://www.kidshealth.org.nz)

- Child Protection <http://www.kidshealth.org.nz/tags/child-protection>
- Diabetes <http://www.kidshealth.org.nz/tags/diabetes>
- Eczema <http://www.kidshealth.org.nz/eczema>
- Paediatric Palliative Care <http://www.kidshealth.org.nz/tags/palliative-care>
- Newborn Services <http://www.kidshealth.org.nz/vitamin-k> and <http://www.kidshealth.org.nz/jaundice-babies>
- Paediatric Gastroenterology <http://www.kidshealth.org.nz/tags/liver> and the Gastroenterology Special Interest Group has plans to develop content for *kidshealth* on Ulcerative colitis, Crohn’s and Coeliac

The National Child Cancer Network also has a significant body of parent information available at <http://www.kidshealth.org.nz/tags/childhood-cancer>.

Future plans include the development of 15 new topics in the 2014-2015 year. A final list is currently being agreed with the Ministry of Health but is likely to include some of the following topics: Gastro Reflux; Sleep; Bullying; Attachment/Importance of early years; Mild Brain Injury; Headaches - when should you worry; Acne; Unsettled baby; Anaemia and possibly some agreed teen topics (eg Parenting teens, Sexual health). Key to increasing the breadth of content on *kidshealth* is broadening the contributor base. Clinical Networks, together with Paediatric Society Special Interest Groups have an important role to play in this.

National paediatric cystic fibrosis network

The inherited condition of cystic fibrosis (CF) affects around one in 7,000 newborns in New Zealand every year. It affects Caucasian children much more commonly than Maori or Pasifika children and is currently incurable. International best practice recommends that a tertiary specialist centre should have care of at least 50 patients. The population of people with CF in New Zealand is approximately 500, of which some 250 are in Paediatric services. This means that, in effect, only Auckland and Christchurch have Paediatric CF clinics of sufficient size to be considered as specialist centres. Median life expectancy is shortened at around 30 - 40 years, although it is thought even this lifespan is very dependent on the patient's ease of access to multi-disciplinary clinical expertise.

To ensure equity of access to specialist paediatric CF services for all children with CF (CwCF), wherever they are in New Zealand, a system of regular visiting CF clinics has evolved in the last few years. These clinics are currently supported by three SMOs and a physiotherapist from the Starship CF service. This model, which has several benefits, is one which the SCH CF service is keen to support and develop further where possible. The clinics allow direct clinical case review and discussion between the local and visiting staff. In doing so, there can be effective sharing of ideas and consensus decision making about individualised patient care. The inevitable strengthening of mutual working relationships also means subsequent contact between professionals is also much more fruitful for both parties.

In addition to the obvious benefits to collegiality, the fact that the SCH staff travel to the child's host DHB makes it much easier for families to receive the same level of contact with CF specialists without the need to journey to Auckland for clinic review. By negating a need for several families to travel to Auckland, there is also a substantial cost saving for the local DHBs.

Unfortunately, current funding does not support other CF sub-specialists e.g. dietitians, nurse specialists, respiratory physiologists or psychologists, to also attend the visiting clinics. Thus whilst the current model is seen as a definite step forward,



it still has areas of shortcoming which need to be addressed. In order to do this a collaboration between the Paediatric Society, the CF Association of New Zealand and NZ CF clinicians (AHPs as well as Medics) will examine ways to further develop the ease of interaction and mutual support that direct contact with peers always confers. This project is currently being led by Dr Julian Vyas.

It is intended this work will develop means of using information technology to facilitate 'real time' discussions, sharing of information and opinion which will support clinicians providing care to CwCF and their whaanau and families. This CF Network now has draft terms of reference almost ready to be approved by the wider network group, and then be submitted to participating DHBs. The next step will be to agree to the constitution of the network and to set up a steering group, which will address specific CF educational needs for the different disciplines.

While some face-to-face interactions will still be needed, it is hoped that tele-conferencing and video-conferencing plus the use of other electronic aids will greatly enhance the support of, and collaboration with, health professionals working with CF throughout the country. In doing so, it is hoped this will improve the equity of quality of care for all children with CF, wherever they live in New Zealand.

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