



From the Chair

Tēnā Koutou

It is my pleasure to provide this editorial for CYNet, the newsletter for the New Zealand Child and Youth Clinical Network (NZCYCN) programme. This is my first editorial as chair of the

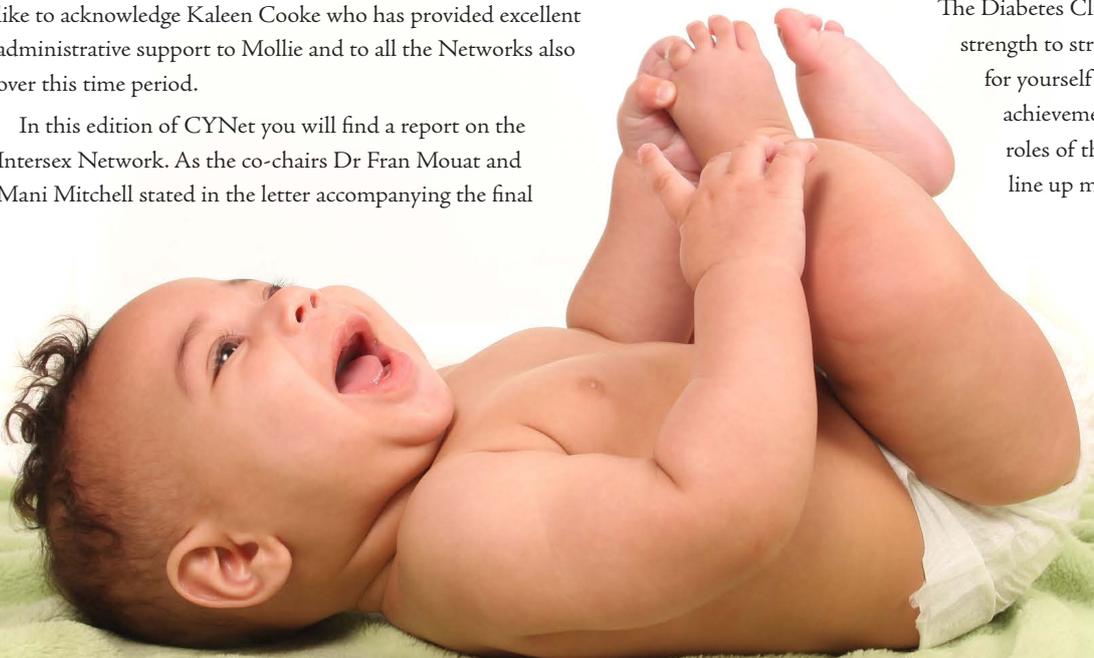
Governance Group that oversees the NZCYCN programme. I would like to first acknowledge my immediate predecessor in the role, Dr Richard Aickin, who in his six years as chair oversaw the ongoing expansion of the Network programme. Thank you Richard for your leadership over this period. Much has been achieved over the years since the first Network was established. This progress from 'seed' to 'sapling' to a mature 'tree' is outlined in more detail in the article by Mrs Mollie Wilson, our outgoing Chief Executive. Mollie has been part of this process from the beginning and we are very grateful for her commitment and expertise in overseeing the development of the Networks over the last 11 years. We wish you well in your retirement Mollie and thank you for all you have contributed to the improvements in health care facilitated for pepi, tamariki and rangatahi in Aotearoa New Zealand. I would also like to acknowledge Kaleen Cooke who has provided excellent administrative support to Mollie and to all the Networks also over this time period.

In this edition of CYNet you will find a report on the Intersex Network. As the co-chairs Dr Fran Mouat and Mani Mitchell stated in the letter accompanying the final

report from this Network, the work that the Clinical Reference Group (CRG) set out to do was bold, especially as it was achieved over just a two year period. The group brought together individuals with lived experience of variations of sex characteristics, health professionals, psychosocial perspectives, and human rights expertise to advance the care of intersex infants, children and youth in regard to some specific objectives. The CRG is to be congratulated on its achievements.

This newsletter also highlights the work of the Neurology Clinical Network and their support in facilitating education about the management of Epilepsy in childhood. As you will read the main attendees to these workshops have been paediatricians, but in line with the multidisciplinary nature of our clinical networks the attendees have also included epilepsy educators, physiotherapists, nurse practitioners and EEG technicians. As Dr Davis notes, upskilling general paediatricians in the management of epilepsy enables tertiary level paediatric neurologists to reserve their clinic spaces for the more difficult and complex neurological presentations. The end point is better outcomes not only for children and youth with epilepsy but also those with other neurological presentations.

The Diabetes Clinical Network as gone from strength to strength and you can read for yourself their considerable list of achievements. One of the important roles of the Clinical Networks is to line up management across Aotearoa



New Zealand so that children receive the same care wherever they live. This is in line with the Ministry of Health's policy of care 'closer to home'. national guidelines and advocacy in relation to the availability of new treatments aim to ensure that no child with diabetes is disadvantaged by where they live or by their social circumstances.

After 11 years it is time for a refresh of some of our processes. It is my pleasure to welcome on to the team Pam Henry in the newly defined role of Programme Director for the Paediatric Society of New Zealand and the Clinical Networks. Also Karyn Sanson in the new role of Support Manager for the Clinical Networks. At our recent strategy meeting the NZCYCN Governance Group affirmed that there is still work to be done and we want to bring our focus in particular to issues of equity, and, in particular, health equity for Māori pepi,

tamariki and rangatahi and also our Pacific children and youth. We welcome the appointment of Rachael Heteraka (previously a member of the Child Protection CN CRG) as Pou Tikanga - Principal Advisor Māori, Child and Community Health at the Ministry of Health. I hope to bring you some detail on the development of this strategy in the next newsletter.

Finally I would like to acknowledge my colleagues in the Paediatric Society of New Zealand executive and secretariat for their ongoing support and acknowledge our strong ties with our colleagues and funders in the Ministry of Health.

He waka eke noa

We are all in this together.

Dawn Elder

Chair, NZCYCN Governance Group

NZCYCN for Diabetes

New Zealand Child and Youth Clinical Network (NZCYCN) for Diabetes Clinical Reference Group (CRG) is made up of healthcare professionals from a range of disciplines, plus consumer advocates. It is our privilege to work for and help represent the amazing and brave children and young people living with diabetes across Aotearoa and their whanau. Our aim is to help promote and maintain the wellbeing of this group by helping to ensure evidence-based, consistent, equitable and easily accessible care across the country.

The CRG has an important role to play in highlighting the needs of children and young people with diabetes. Based on submissions and evidence from the CRG to PHARMAC, the decision to include criteria that would effectively deny access of SGLT-2 agents (new treatment for type 2 diabetes) to children and young people with diabetes was reversed. The CRG is currently working with the Ministry of Education to ensure that access to Schools High health funding for teacher aide support for children is equitable and fair across the country.

One of the main objectives of CRG is to help support and

equip patients and consumers to be informed and involved in their own health. One way of doing this is by overseeing the development and updating of consumer information on the KidsHealth and Starship Websites. Technological advances in the management of diabetes have been rapid in recent years, including the availability of glucose monitoring devices which require significantly less finger pricks and provide more information on glucose levels. However not all devices are funded, which can make it challenging for families to decide what is best for their child. An example of this is the development of a consumer resource on glucose monitoring devices using evidence-based information from a non-commercial source.

Another key role of the CRG is to support clinicians working in paediatric diabetes and encourage the use of evidenced based guidelines such as the protocol for Diabetic Ketoacidosis. We are currently working on a clinical protocol for peri-operative management of children with diabetes.

The CRG also contributes to the development of



Some of the CRG team (left to right) Yiing Yiing Goh, Caroline Griffin, Jo McClintock, Ann Faherty, Martin de Bock, Karen Reed and Gilli Lewis



Thanks to Diabetes Youth, Auckland for sharing their Youth Camp 'mealtime' enjoyment.

programmes in scientific meetings to ensure that paediatric diabetes is included as well as organising special interest group meetings for interested clinicians.

The CN aims to help healthcare providers to keeping families informed on issues important to them. For example providing guidance on when children and young people with diabetes were safe to attend school when the COVID-19 pandemic arose.

A small sample of the type of resources recently produced or supported by the CN includes:

- Diabetes School action and management plans which are updated and made available for clinicians, schools and families yearly
- Diabetes Camp guidelines to ensure the health and safety of children and young people attending diabetes camps
- Adolescent transition resources and educational material for consumers and healthcare professionals

The CRG collaborates with a number of organisations such as Diabetes New Zealand (DNZ), NZ Society for the Study

of Diabetes (NZSSD), NZNO Aotearoa College of Diabetes Nurse Specialist, Diabetes young people special interest group and Dietitians NZ diabetes special interest groups. A recent example is the development, distribution and analysis of a National survey on school camps and excursions with DNZ.

An important area we wish to address is equity of care. Furthermore, the CRG is trying to ensure diversity in its membership and we aim to have more Māori and Pacifica representation in the near future.

The CRG encourages innovation, research and emerging technologies to build capability and capacity in the paediatric diabetes sector. Examples of this are the development of a national database of children and young people living with diabetes in Aotearoa, which will help to collate information about their health, care and acute and long term outcomes This will allow us to implement a workforce survey in the sector, and benchmark our services.



Children with diabetes meeting others at the Auckland Zoo.

Update from the Intersex Clinical Network

The Paediatric Society of New Zealand's New Zealand Child and Youth Clinical Network Programme, the Ministry of Health and interested parties established a working group which collaborated with health and intersex community stakeholders to develop professional guidelines for a newborn baby with 'Differences in sexual development', based on principles of best practice. These guidelines were published on the Starship Neonatal Guidelines website on the 10th of November 2020. The guideline link is: www.starship.org.nz/guidelines/differences-of-sex-development-atawhai-taihemahema

Auckland Regional HealthPathways are the lead region for the first development of the 'Differences of Sex Development' HealthPathway. The Auckland version of the pathway can then be localised for each HealthPathway region by the local HealthPathways team. In this way national consistency is achieved.

HealthPathways provide concise best practice guidance for

primary care providers (GP's, NP's, nurses, midwives and others in primary care) on a very large range of health topics. The 'Differences of Sex Development' HealthPathway will draw on the content of the guideline, providing the best practice information and advice on local referral pathways. It will be concise to the needs of the primary care audience and provide consistency with the guideline. An example of the benefit will be guidance on the appropriate language to use when talking with a family whose newborn baby has differences in sex development.

With the guideline, and once the primary care HealthPathways are localised, consistent information will be available to primary, secondary and tertiary providers in New Zealand on best practice management of 'Differences in Sex Development' including advice and support from people with expertise in this specialised area of healthcare.

Pam Henry, Project Leader, Intersex Clinical Network

A snapshot of the development of the NZCYCN quality improvement programme

The New Zealand Child and Youth Clinical Network (NZCYCN) Programme started its life journey as a proposition from Dr Nick Baker, the President of the Paediatric Society of New Zealand (PSNZ) in 2007. The proposal was that the PSNZ could help 'bring fragmented services across District Health Boards (DHBs) together to focus on some of the challenging issues for children/tamariki and youth rangatahi'. The aim was, and continues to be, to strengthen and support quality improvements in child and youth health services in New Zealand (NZ). The ultimate goal being improved health for this population group.

Following many meetings with Ministry of Health (MoH) representatives, input from a number of clinicians and other key stakeholders, in late 2009 a contract was signed between the MoH and the PSNZ (the contract holder) to 'Develop a strategic approach to a national clinical networks for child and youth in New Zealand (NZ)'. So the journey to develop this national quality improvement (QI) programme started, from the 'seed' of the proposal to a fledging 'sapling', to the strong and supportive 'tree' the QI has now become.

Background. A number of MoH documents, the 1999 Health Funding Authority - PSNZ Specialist Service Review, 'Through the eyes of child' and a range of other service reviews helped inform gaps in child and youth health services in NZ. Clinical networks are not new. There was however, increasing commentary in the early developmental phase of the benefits of structured clinical networks in NZ and internationally. This resulted in a range of discussions and meetings with "like type" services within NZ and internationally. The fledgling programme held five regional hui with clinicians and managers across the NZ health sector and feedback identified some core practices that would support QI activities within specialist services. These included (but are not limited to) the need to support



multidisciplinary (MD) education across services, the development of best practice recommendations and or guidelines, the identification and support for clinical MD experts who could support services at all levels through a coordinated approach.

From its initial development, through to current times, the NZCYCN has operated in partnership with MoH representatives, strongly supported by specialist, multidisciplinary teams of clinicians and managers and often with associated consumer support groups.

NZCYCN infrastructure

The PSNZ – MOH contract required a Governance Group to provide oversight to the development of a 'formal approach' to how new and approved Clinical Networks (CNs) functioned. All new CNs start the process with a formal business case that is reviewed by the Governance Group and has final approval from the MoH.

In support of this process the programme has required the development of a wide range of infrastructure documents to be developed and, as required over time, documents and processes have been modified, refined and updated as the 'formal approach' to network development has progressed.

A range of documents and papers have been produced and these have been shared widely with key partners and interested external parties. And so, the NZCYCN programme commenced a formalised process, nurturing the 'sapling' required to support a stable programme.

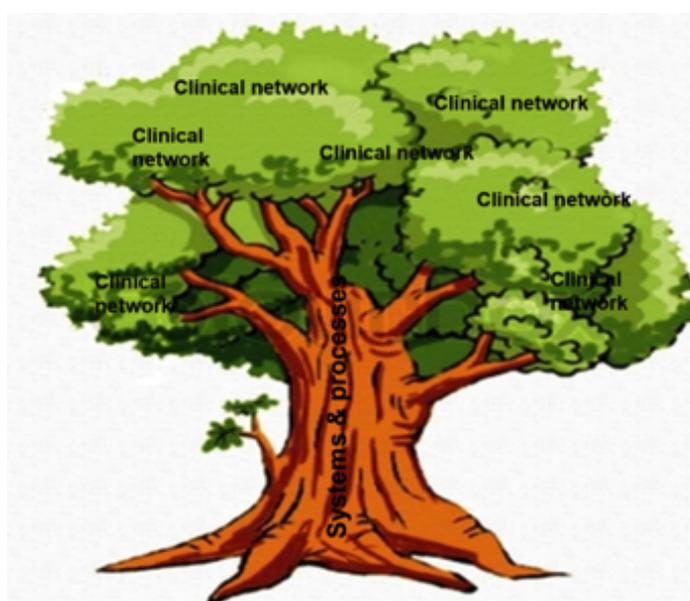
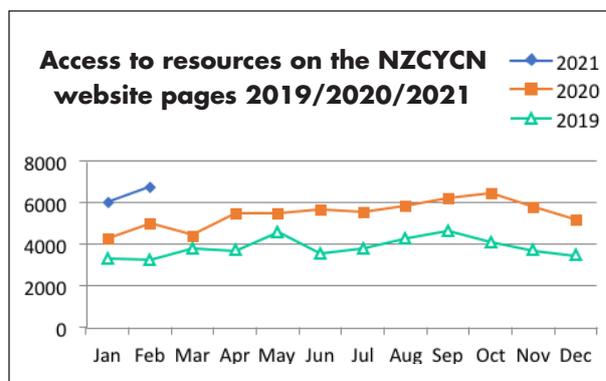
Summary of achievements

- The first CN was established late 2010 and by December 2020, 12 CNs were in varying phases of consolidation. 12 subspecialty CNs remain operational at March 2021: Child Protection, Palliative Care, Diabetes, Eczema, Newborn, Gastroenterology, Cystic Fibrosis, Neurology, Sleep Medicine, Allergy, Cerebral Palsy, Child Development and Disability.

- Per prior agreement, two CNs have been disestablished: Tube Feeding and Intersex.
- All CNs have Terms of Reference, a clinical leader/chair and a multidisciplinary (MDT) Clinical Reference Group (CRG) that agrees the deliverables for that CN's work plan, key performance indicators (KPIs) and the CN's Strategic Plan. All CNs provide quarterly reports on KPIs, work plan achievements and these reports inform the NZCYCN's quarterly and annual reports to MoH.
- By June 2020, more than 200 MDT members and consumers had or were contributing to the various CNs and/or supported a range of activities. Contracted 'Facilitator' support is provided to each CN. Half the subspecialty CNs have been developed at the request of MoH.
- The Starship website is supported by their senior management team and is the repository for the NZCYCN's resources. Over 250 website resources/best practice recommendations /links /videos to related websites have been established and can be viewed at www.starship.org.nz/health-professionals/child-youth-clinical-networks/ and to retain currency all resources have a review date. This includes more than 62 contributions to the KidsHealth parent information site.
- A biannual publication of the NZCYCN's newsletter CYNet has continued www.paediatrics.org.nz
- CNs usually engage in one or two face-to-face meeting annually; however, these were halted March 2020 due to Covid-19 and recently re-established early 2021. Several reference and NZCYCN documents have been development and are regularly updated; e.g.'A summary of the development, implementation and achievements of the NZCYCN Programme' is updated three – four monthly and is available as an electronic handout to new CN members, consumers, external parties and a comprehensive 'Profile of Clinical Networks for Children and Youth in New Zealand' has been developed.
- A Secretariat has been established and maintains comprehensive records of resources, planning and related update requirements, current lists of CN CRG members, contacts, meeting schedules and other business management records.
- An evaluation of the NZCYCN programme was commissioned and completed in 2017. A number of additional projects have been funded to support the CNs
- Established links are in place with 25 PSNZ Special Interest Groups (SIGs), KidsHealth, NZ Child and Youth Epidemiology Service, regional health alliance groups, RNZ Plunket Inc, Telemedicine Trust, DHB Child Health Managers & Portfolio management groups, the Violence Intervention Programme, Child Protection Alert System and a range of other professional organisations.
- Five formal memorandums of understanding/agreements (MoU/ MoA) have been established and have review

dates scheduled. Links have also been established with international network organisations and multidisciplinary professionals.

The graph below shows access to resources on the web site and all CNs have an individualised, monthly update that tracks access of national information / resources.



So, from the seed of a proposal, the sapling has been strengthened to support the programme's structure

MoH contracts and reporting

From the start of the NZCYCN programme there have been eight variations to the MoH contract and over time, the deliverables have become more specific. An annual and quarterly reports are provided to the MoH.

Conclusion

This will be my last CYNet publication and it has been my privilege and pleasure to work alongside so many passionate clinicians, managers, consumers and administrators. The NZCYCN programme is unique, it is 'NZ made' with the ultimate goal to support improvements in front line child and youth health services in NZ. My best wishes for a flourishing future.

Mollie Wilson

PSNZ Chief Executive Officer 2008 – 3/2021

Summary of New Zealand Paediatric Epilepsy Training (PET)

We initially became aware of the British Paediatric Neurology Association (BPNA) programme of epilepsy training for paediatricians (PET) in 2016 when the BPNA approached the Australia and New Zealand Child Neurology Society (ANZCNS) regarding the extension their programme to the Asia-Pacific Area. The BPNA had been running the PET courses in the UK for more than 10 years at the time, and we had excellent feedback from local neurologists and paediatricians who had attended the courses. Unfortunately, the ANZCNS decided not to take up the BPNA proposal at their AGM in 2016.

In 2013 the paediatric neurology team was under stress with increasing workload and no prospect of increasing manpower in the coming years. At the time many of us were participating in a Ministry of Health (MOH) initiated technical advisory group (TAG) for the improvement of epilepsy services in New Zealand. As epilepsy was a major component of paediatric neurology consultations, we considered that the upskilling of paediatricians in the management of epilepsy in children and young people would increase our effectiveness in providing services to our community. We took two actions 1) we created New Zealand guidelines for the management of epilepsy in children, and 2) negotiated with the BPNA to provide a programme of PET courses in New Zealand.

The aims of BPNA in creating the PET courses are to improve care worldwide for children and young people with seizures and epilepsies using collaboratively designed educational materials linked to published clinical guidelines. They seek to embed recommended best, safe practice into local health services and to form networks. The course content is reviewed and updated every three years.

The aims of PET 1 are

- a) to provide an introduction to the epilepsies and related conditions for health professionals contributing to the care of children and young people with seizures and epilepsies in acute and community settings,
- b) to develop skills in the diagnosis and initial management of

children and young people with epileptic and non-epileptic seizures,

- c) to develop skills in supporting the ongoing management of children and young people in the acute and community setting.

The aims of PET 2 and 3 are to develop skills in the diagnosis and management of epilepsies and related conditions for health professional leading secondary care of children and young people with epilepsies.

The New Zealand League Against Epilepsy (NZLAE) agreed to be responsible for the programme and the Starship Foundation offered to provide registration and financial services. In May 2017 we were visited by five UK paediatric neurologists and one administrator from the BPNA. Eight paediatric neurologists and four paediatricians attended the PET 1 and 2 courses and the Train the Trainer course. We then ran a PET

1 course for local paediatricians under supervision. Since May 2014 we have run two or three PET courses every year, covering all three PET courses (PET 1, 2 and 3) each year. The courses consist of both lectures and small group workshops.

In the first four years our New Zealand PET courses have been attended by 10 paediatric neurologists, 168 consultant paediatricians, 45 paediatric trainees, 21 nurses, 4 nurse practitioners, 9 EEG technicians, 2 physiotherapists, and 14 Epilepsy NZ educators.

We continue to run our programme in either Auckland or Wellington with the courses fully attended, constrained only by the availability of our volunteer faculty and being cognisant of Covid-19 requirements. In 2021, the March PET 1 will be held May 31, and PET 2 to June 1-2. Registration is open on the Starship Foundation website for PET 1 on October 27, and PET 3 on October 28-19.

We can thank our supporters the NZLAE and Starship Foundation, and our faculty Suzanne Davis, Lynette Sadleir, Erik Andersen, Melinda Nolan, Claire Spooner, Cynthia Sharpe, Gina O'Grady, Simone Ardern-Holmes, Phillipa Clark, Bobby Tsang, Marguerite Dalton and Pratima Giri for the ongoing success of this programme.

Suzanne Davis



YOUR CONTRIBUTIONS We welcome thoughts, contributions and articles and notices of upcoming events.

Please email the editor, Lauren Young on lauren@laurenyoung.co.nz