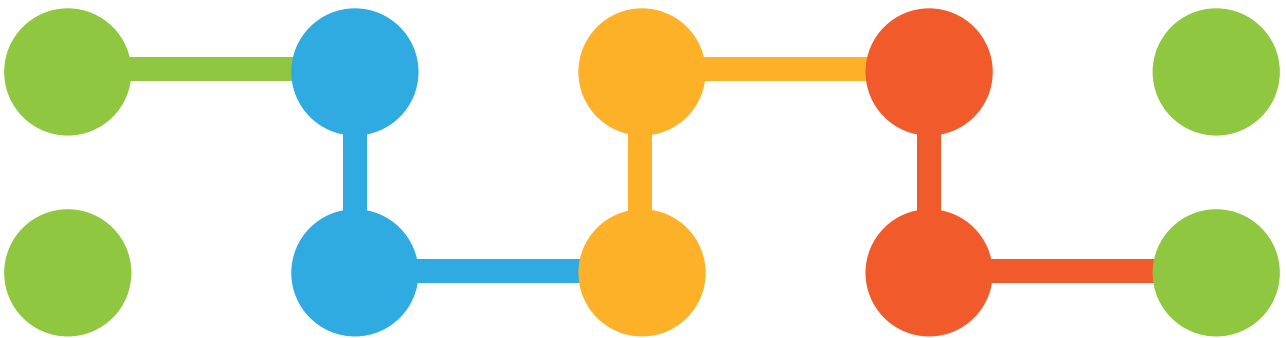
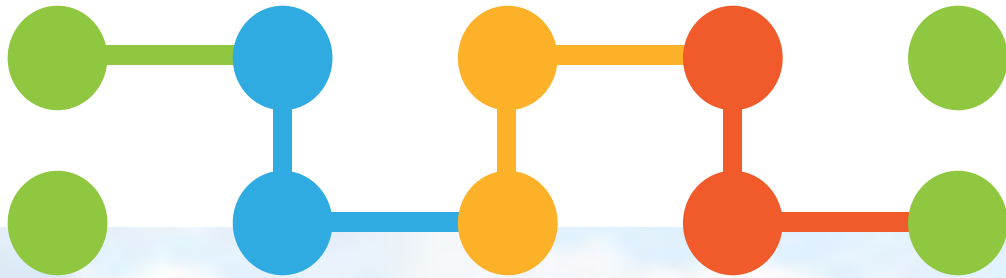




New Zealand Child Youth Clinical Networks

# Annual Report 2021-2022





**Poipoia te kākano kia puawai**  
Nurture the seed and it will blossom

# Message from the Chair

I am pleased to introduce this Annual Report, the first for two years. Despite the difficulties of operating during the Covid-19 pandemic the NZCYCN programme continues to develop. The Governance Group is extremely grateful to the many network members who continue to commit their time, energy and expertise despite the challenges of the current clinical environment.

Since its inception in 2007, the NZCYCN programme has been a partnership between the Ministry of Health (MOH) and the Paediatric Society of New Zealand (PSNZ) - Te Kāhui Mātai Arotamariki o Aotearoa. We acknowledge the MOH funding that makes this work possible and look forward to an ongoing relationship with Te Whatu Ora, Te Aka Whai Ora and Whaikaha. In line with the strategic direction of the PSNZ, the NZCYCN programme will focus future planning in four main areas: Equity, Partnership and Connectiveness, People: Tāngata o Tamariki, and Improving Practice.

Currently, there are 12 Networks with one Network in a process of change. The Cerebral Palsy Clinical Network (CN) has developed recommendations to improve early diagnosis for tamariki with cerebral palsy to facilitate early intervention. The Child Development and Disability CN supports a successful 'Lunch and Learn' education programme. It is also updating national guidelines for the management of tamariki with Down syndrome. The Newborn CN continues to promote the optimal care of our youngest and most vulnerable health system users, including the development of practice recommendations for follow-up of high-risk infants. These three networks have interests in common and we anticipate further collaboration between these groups.

The Eczema CN continues to produce guidelines on the management of eczema. Their collaborative relationship with Māori has led to the gifting of a Te Reo name for the network. The Allergy CN is working on a project for the MOH regarding the use and availability of EpiPens in schools. The Diabetes CN continues to produce clinical practice recommendations for a range of settings. These three networks recognise the importance of best practice care of tamariki and rangatahi across all aspects of their lives so are working across the tertiary, secondary and primary care interface and with schools.

The Gastroenterology CN has been focussing on practice recommendations for the management of inflammatory bowel disease and advocating with Pharmac for equity in access to treatment. The Neurology CN has supported the training of secondary care providers in the management of paediatric epilepsy and also the alignment of epilepsy health pathways with national health pathways. The Paediatric Sleep Medicine CN is concerned about the state of paediatric sleep services in Aotearoa and is planning to work on the design of an integrated national service. The Paediatric Palliative Care Network provides regular education sessions and

has updated its paediatric palliative care guidelines. The Child Protection CN has been updating MOUs with Oranga Tamariki and the NZ Police, and continuing their advocacy for the role of health in child protection and training of clinicians. The Cystic Fibrosis CN has produced a range of practice recommendations regarding cystic fibrosis management which are currently being updated. This network will then become a workstream in a new Respiratory Clinical Network with a wider focus on paediatric respiratory illness.

The Governance Group is committed to strengthening our commitment to Te Tiriti o Waitangi and equity. In alignment with the updated PSNZ strategy, Clinical Networks are now developing workplans to address equity. Disparities in access to care and outcomes for Māori, Pasifika and socioeconomically disadvantaged pēpi, tamariki and rangatahi are well documented. What we need to focus on now, is how we break down the barriers that contribute to these inequities. This is our ongoing challenge for the years ahead as we focus on building pae ora (healthy futures) for all.

Despite significant progress, there is still much to be done to ensure that the specialty health services available for tamariki and rangatahi in Aotearoa are equitable, accessible and evidence-based. This report differs from past NZCYCN reports by focussing on current issues in health service provision for tamariki and rangatahi rather than past achievements of the programme. The Clinical Networks are very keen to work closely and co-operatively with Te Whatu Ora, Te Aka Whai Ora and Whaikaha as we seek to improve access to paediatric specialty services and expertise across the motu.

Tamariki and rangatahi are our taonga. If we can ensure their health needs are optimally met, then we will improve their health as adults. This is an important investment for the future of our national health services as well as for our people.



**Professor Dawn Elder**  
CHAIR, NZCYCN GOVERNANCE GROUP



# About New Zealand Child and Youth Clinical Networks (NZCYCN)

**Clinical Networks (CNs) are made up of experienced child health professionals from a range of health related disciplines, who work collaboratively to provide leadership, resources and best practice recommendations across child health in Aotearoa.**

The NZCYCN programme strongly supports improving equitable access to healthcare and health outcomes for all tamariki and rangatahi.

Clinical Networks are guided by the Child and Youth Clinical Network (NZCYCN) Governance Group and PSNZ Executive and follow the 2021-2026 [PSNZ Strategy](#) with its main principles of equity, partnerships and connectedness, people/ngā tangata, and improving practice.

Currently, there are 12 Clinical Networks which focus on a wide range of speciality areas. Broadly all networks aim to provide health professionals with the resources to improve practice, and to promote the delivery of equitable child and youth health services that improve health outcomes for all tamariki and rangatahi.

Clinical Networks also provide a national voice to promote service improvements where child health issues and gaps are recognised in health service provision. This can be through submissions and consultation with Government and other healthcare providers. Many of the networks have developed unique strategies to support professional education, such as webinars and recorded sessions on YouTube. The network's newsletter, CYNeT, is produced twice a year and is delivered to more than 750 health professionals.

Further information on each of our networks listed below can be found on pages 8 to 31 of this Annual Report.



## Our networks

- Paediatric Allergy Clinical Network
- Cerebral Palsy Network – Te Tūhononga ā-Whare Haumanu Hōkai Nukurangi
- Child Development and Disability Network
- Clinical Network for Child Protection
- Child and Youth Cystic Fibrosis Clinical Network
- Clinical Network for children and young people with Diabetes
- Child and Youth Eczema Clinical Network – Te Rōpū Kiripai Hapori
- Child and Youth Clinical Network for Gastroenterology Services
- Paediatric Neurology Clinical Network
- Newborn Clinical Network
- Paediatric Palliative Care Clinical Network
- Paediatric Sleep Medicine Clinical Network

## Our strategic priorities

### **EQUITY:**

improve access to healthcare and outcomes for all tamariki and rangatahi including Māori, Pasifika, disabled and other populations impacted by structural barriers

### **PARTNERSHIPS AND CONNECTIVENESS:**

work with networks across the sector that impact tamariki health and wellness

### **PEOPLE; NGĀ TĀNGATA:**

promote health workforce development and ensure whānau voice

### **IMPROVING PRACTICE:**

enable national quality improvement in child health

## How we achieve change

**PROMOTE** change to address equity and improve child health outcomes

**IDENTIFY GAPS** in service provision and make recommendations nationally

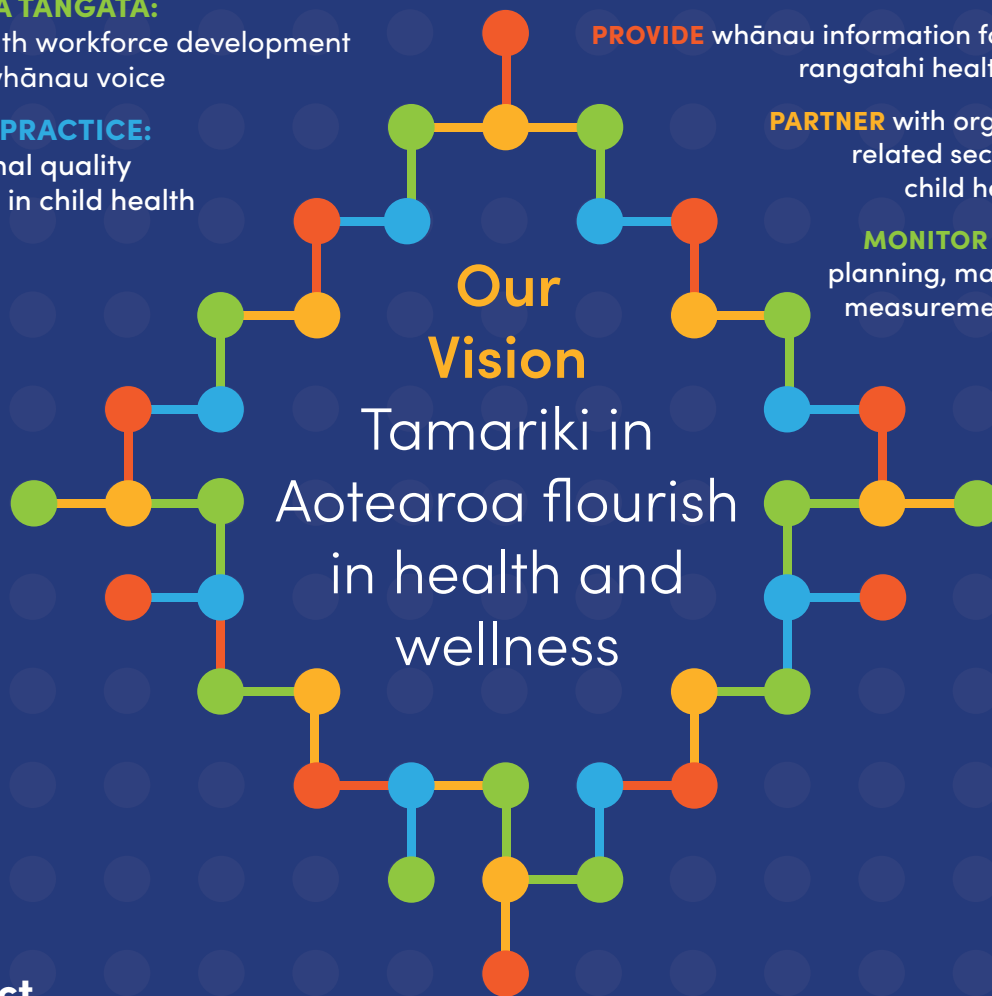
**PRODUCE AND SOCIALISE** clinical guidelines nationally

**INFLUENCE** decision-makers to prioritise health and wellbeing of tamariki and rangatahi

**PROVIDE** whānau information for tamariki and rangatahi health and wellness

**PARTNER** with organisations and related sectors to improve child health outcomes

**MONITOR DATA** to inform planning, management and measurement of outcomes



## Our Impact

**National reach** to deliver consistent equitable child health services and outcomes for tamariki and rangatahi

**KidsHealth information** – empowers whānau to support tamariki and rangatahi to flourish in health and wellness

**Well engaged and informed child health workforce** across the spectrum of child health service delivery

# Paediatric Allergy Clinical Network



## Overview

Allergy symptoms can affect your airways, sinuses and nasal passages, skin, and digestive system. In some severe cases allergies trigger a life-threatening reaction known as anaphylaxis. Having a child with food allergy is particularly challenging for whānau.

The Paediatric Allergy Clinical Network aims to promote evidence-based practice for the health workforce. This includes a focus on national quality improvement of service design to ensure access to care and resources is available.

The network achieves this by:

- Promoting accessible service delivery
- Socialising resources
- Developing guidelines
- Supporting workforce development.

Allergies affect over 20% of New Zealand's tamariki. This causes significant challenge for affected tamariki and whānau. Early diagnosis and appropriate clinical management supports improved quality of life.

The Paediatric Allergy Network has produced a range of guidelines, information, resources and training for health professionals.

The network is actively working with KidsHealth to develop whānau-centred resources in multiple formats to promote active participation in the development and implementation of management plans.



## Model of care development

Promoting access for tamariki and rangatahi with allergies to provide:

- Whānau-centered care as close to home as possible
- Care based on need, from diagnosis to treatment and management plans
  - Collaborative decision-making
- Multidisciplinary service delivery including healthcare providers with paediatric training and experience.





## Looking to the future

Recognising and addressing the needs of children with allergies to ensure every child has access to services and the opportunity to flourish in health and wellbeing.

A plan to improve equity of access to EpiPens in schools has been supported by the MoH in response to consumer advocacy. Collaboration and understanding of the needs across both education and health sectors is required to identify solutions. This work is likely to be a focus for the 2022-23 workplan.

## Achievements

- Guidelines and resources updated and published throughout the year such as a guideline for Eosinophili Oesophagitis developed in collaboration with the Gastroenterology Clinical Network.
- Building relationships with the Australasian Society of Clinical Immunology and Allergy (ASCI) has allowed shared use of resources and links to specialised information being available to NZ clinicians including topics such as Oral Immunotherapy. Other professional guidelines are in development/ nearing completion and will be available to clinicians in the near future.
- Collaborative working relationships have been established between the Network, KidsHealth, the Australasian Society of Clinical Immunology and Allergy to develop shared resources for whānau via the KidsHealth website.
- Bee/wasp sting clinical guideline published.
- National equity data collected relating to access/availability of specialist dietitian support for severe allergy.
- Collaborative connections with the Ministry of Health (MoH) and Ministry of Education (MoE) were established regarding the management of severe allergy and EpiPens in schools. A survey distributed to the education sector resulted in almost 1000 responses. Funding has been allocated to analyse findings and the results will be reported. This will inform next steps determining how to ensure equity of access to EpiPens for children in schools.
- Consumer representation with a focus on Māori, Pasifika and Asian ethnicity is being promoted.

# Te Tūhononga ā-Whare Haumanu Hōkai Nukurangi – Cerebral Palsy Clinical Network



## Overview

- Cerebral palsy (CP) is the most common cause of childhood physical disability and is estimated to affect 7000+ individuals in NZ.
- A 2007 Australian Cerebral Palsy Economic Impact report found CP in the top five most costly conditions on a per capita basis (Access Economic Report, 2007).
- Recommended best practice principles include early detection and goal-directed intervention.

## Areas of concern in the current NZ system

### Variable Planning of Health Care Delivery for Tamariki with CP


- NZ data shows late diagnosis compared to international figures:
  - 14% of tamariki with CP are diagnosed at six months;
  - 41% at 12 months; and
  - 24% are not diagnosed by two years.
- Regional inequities result in wide variation in interventions offered; and access to 'best practice' specialist paediatric multidisciplinary services.
- Suboptimal surveillance can mean more complicated and costly salvage surgical procedures later in life and varied service planning for transition to adult services.
- There is no national strategic service delivery plan, clinical guidelines or population-based data for reference and no benchmarking to measure outcomes against international best practice.

### Ethnic Disparities Highlighted by NZ CP Register Data

- The NZ CP Register holds health information for approximately 60% of individuals with CP in Aotearoa. 28% of the Register include tamariki of Māori ethnicity.
- Māori have greater severity of CP compared to non-Māori, but reduced utilisation of orthopaedic surgical intervention. It is likely there are significant access gaps for Māori tamariki in service provision.

### Family Feedback around Quality and Types of Services Provided

- Families consistently report concerns around the impact of late diagnosis, and the disparity of services delivery nationally (e.g., access to Botulinum toxin A treatment).
- Families are aware of limited services being available in NZ. For example, there is limited access to intensive therapies and no access to selective dorsal rhizotomy.
- Families are seeking healthcare overseas or privately at significant personal cost.



Te reo term for cerebral palsy: Hōkai Nukurangi – to achieve what is important to you.

Work proposed within this document is aligned with the Good Start in Life and Enabling Good Lives (EGL) approach, vision and principles.

## Looking to the future

Te Tūhononga ā-Whare Haumanu Hōkai Nukurangi proposes the following actions in collaboration and partnership with stakeholders:

### A. Regional 'Early Detection' Hub planning across the four Te Whatu Ora regions

- Each of the four regions should have a plan for provision of early detection and intervention alongside specialist rehabilitation services.
- A pilot study is being developed for trial in one region. The learning from this will inform development of other hubs.
- Other services such as transition and therapies not currently provided in NZ need to be developed to promote best practice care.
- Development of national guidelines for best practice would provide additional resources for improving outcomes of tamariki and rangatahi with CP.

### B. Recognition and development of Essential National Services at Starship Children's Health

- The CPCN proposes accessible and equitable services should be available for all tamariki with CP in NZ who meet the criteria for established pathways and guidelines for referral.
- In the proposed hub model, Starship Children's Hospital is the national referral centre for complex orthopaedic surgery and selective dorsal rhizotomy (SDR), supporting the delivery of complex rehabilitation, and providing tertiary level assessments such as 3-D gait analysis.

#### (i) Selective dorsal rhizotomy

- SDR is a neurosurgical procedure considered international best practice for CP.
- SDR is not offered in NZ.
- Tamariki undergoing SDR overseas require ongoing care from the NZ health sector

once they return. This care is expensive and challenging to provide due to lack of funding.

- CPCN supports the development of a NZ SDR programme and are well placed to support the development of national guidelines and pathways. This would include; formal referral pathway including assessment, suitability and appropriate intervention pre and post-surgery.

#### (ii) 3-D Gait Analysis to support complex surgery, including orthopaedic surgery and SDR

- There is currently limited access to this assessment.
- Offered to approximately 100 tamariki per year but with capacity to increase numbers.
- There are currently no guidelines for this service, with variable referral patterns resulting in fragmented care and inequitable regional outcomes.
- CPCN will develop national guidelines for referral for gait analysis.

### C. Ongoing funding for NZ CP Register to monitor CP prevalence and capture national quality outcomes relevant to clinicians and family, and act as a central point for whānau support/ education and GP education/support

- Pathway-driven care so tamariki with CP receive appropriate local, regional, and national service delivery.
- Outcomes for tamariki with CP and ethnic disparities must be monitored and benchmarked.
- Benchmarking is best aligned to a national system, given that tamariki with CP have other health needs throughout childhood.
- NZ CP Register to build relationships with key stakeholders such as Te Aka Whai Ora and Whaikaha.

# Child Development and Disability Network

## Overview

The Child Development and Disability Clinical Network (CDDCN) aims to improve health and social participation outcomes for tamariki with developmental disabilities and their whānau.

The CDDCN includes multi-disciplinary, cross-sector, tangata whenua and consumer representation.

The Clinical Reference Group of the CDDCN is comprised of members from multiple disciplines, regions, and clinical backgrounds including primary, secondary, and tertiary care services.



## Recommended national solutions to address issues facing this sector

This is a period of significant change for both the Health and Disability Sectors, with the recent establishment of Whaikaha – the new Ministry for Disabled People. The Enabling Good Lives principles (EGL) will underpin all work within Whaikaha, and this will require a shift in the way disability services are delivered. There will need to be a strong focus on:

- Relationship building between Health and Disability agencies as changes are developed and implemented within the sectors.
- Advocating for evidence-based services that are underpinned by EGL principles.

- 1. RESOURCE:** Substantial review of funding structures, distribution and quantity (particularly in health and education sectors) to align resource allocation to tamariki and whānau need with a particular focus on equity.
  - a. Scale up application of telehealth with investment in physical spaces, IT resource (data) and training.
  - b. Cultural and practical support to whānau to engage in developmentally supportive activities e.g. travel to treatment, and data to access telehealth.
  - c. Nationally consistent entry and exit criteria and pathway to services.
  - d. National IT system to increase efficiency e.g. shared data between child development services, inpatient services, mental health and social services.
  - e. Buildings that need basic universal design e.g. disability accessible toilets.
- 2. EQUITY:** Benchmarking on access to treatment in line with evidence-based practice.
- 3. WORKFORCE RESILIENCE:** Sustainable workforce with CPD opportunities for all staff.

## Current progress/work in progress

### 1. RESOURCE

- a. Create nationally relevant evidence syntheses for the NZ context for Trisomy 21 (Down syndrome) and ADHD to be publicly available.
- b. Develop an evidence synthesis of current service pathways and supports offered for tamariki after NICU/SCBU admission in the first 100 days.

### 2. EQUITY

- a. National benchmarking of service pathways, model of care, and resourcing for tamariki after NICU/SCBU admission.

### 3. WORKFORCE RESILIENCE

Connection, engagement and education across professions, sectors and stakeholders:

- a. Creating opportunities to connect, engage, share, disseminate and apply evidence-based information through monthly online 'Lunch and Learn' sessions. Open access and no cost.
- b. Annual study day with hybrid in-person and online delivery, open access and no cost.

## Looking to the future

### RESOURCE

To continue to advocate at local and national levels for fair, equitable resourcing and support to tamariki and rangatahi with neurodiversity and their whānau.

### EQUITY

To continue to work with our Te Tiriti partners, whānau and professional communities to address their priorities.

### WORKFORCE RESILIENCE

To continue to respond to the learning, support and connection needs of the professional workforce to enable care providers to provide the best possible care for tamariki and rangatahi with neurodiversity and their whānau.

# Clinical Network for Child Protection

## The Role of Health Services in Child Protection



### The problem

One in four tamariki in Aotearoa is notified to a statutory social worker by age 18 and one in ten experience substantiated abuse.<sup>1</sup>

Another 60,000 tamariki and rangatahi are logged every year as a contact record because they were present in the home when the police were called to an episode of family violence - most receive no intervention at all.

"... the wider child protection system is not currently effective at preventing harm, and nor is it adequately addressing the factors that cause tamariki to be re-victimised."<sup>2</sup>

Senior clinicians on the Child Protection CN have worked alongside the failed statutory child protection system at the frontline through 15 reorganisations.

They continue to witness first-hand its harmful and inequitable impact, especially on Māori and acknowledge and share the distress of tangata whenua expressed in multiple reports.<sup>3,4</sup>

The CN commends and supports the focus on partnership with iwi identified as a priority in current thinking. The network is astonished and dismayed that there remains an almost complete blindness to the potential role of the health system in that partnership.

## The health system has a critical role in supporting child wellbeing:

- There are many more health professionals in Aotearoa with expertise in child and youth health than there are Oranga Tamariki Social Workers.
- Much of the most serious abuse and neglect occurs in preverbal tamariki, a time where health professionals are uniquely engaged in the lives of whānau.
- The long-term consequences in young tamariki are particularly severe. The early years are crucial for the development of stable and secure tamariki and adults.
- The health system remains engaged with tamariki (who grow to become adults) and their whānau forever – long after statutory authorities close their files.
- Many health professionals have limited experience of child abuse and distrust Oranga Tamariki, but have no access to expert advice and support within the health system.
- Child health professionals have a high level of training in child and family health and behaviour, but minimal training in child protection. With better training and support they could become very effective partners in achieving better outcomes.
- For 30 years, health professionals and statutory social workers alike have been taught that child protection is not the business of health, and the solution is to make a Report of Concern. In essence, the health provider can wash their hands of the problem.

## A multidisciplinary approach in health

In 1990, Starship partnered with Te Rūnanga o Ngāti Whātua to create a health-based multi-disciplinary child protection team (Te Puaruruhau), and in 2002 expanded that commitment into the first multi-agency child advocacy centre in Aotearoa (Puawaitahi). Te Puaruruhau has become a centre of excellence for world-class health services for the victims of child abuse and neglect and their whānau, and for supporting better and more consistent practice among health professionals all across the motu.

In contrast, although many tamariki at risk reside in every health district, most health districts allocate them no priority and little dedicated resource. Pae Ora is a once-in-a-generation chance to fix the post-code lottery: to create skilled and dedicated health-based teams to work with whānau and other partners for better outcomes as a shared priority with shared accountability.

## Specific proposals for the future

- That every health district establish multi-disciplinary teams to work in partnership with whānau, iwi and others (such as education providers) to address the needs of those at risk.
- This will require funded partnerships with local iwi and dedicated funded roles for lead maternity carers, mental health professionals, nurses, paediatricians, and social workers.
- These teams will train and support primary and secondary healthcare providers, iwi providers and other community networks, develop and support safe child protection systems and processes, work collaboratively across the motu, and collaborate in the research necessary to develop and evaluate evidence-based interventions.
- These teams will provide the expertise to support clinicians to work effectively in partnership with whānau, iwi, Oranga Tamariki and the Police in cases which do require formal statutory processes such as Family Group Conferences and legal proceedings.

## References

1. Rouland B, Vaithianathan R. Cumulative Prevalence of Maltreatment Among New Zealand Children, 1998–2015. *Am J Public Health*. 2018;108(4):511–513.
2. Modernising Child, Youth and Family. Expert Panel: Interim Report. <https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/evaluation/modernising-cyf/interim-report-expert-panel.pdf>. Published 2015.
3. Cram F et al. Oranga and Māori health inequities, 1769–1992. Wai 2575, #B25. Wellington: Waitangi Tribunal; 2019.
4. Waitangi Tribunal. He Pāharakeke, He Rito Whakakīkinga Whāruarua. Wai 2915. Lower Hutt: Legislation Direct; 2021.



# Child and Youth Cystic Fibrosis Clinical Network

## Overview

The Child and Youth Cystic Fibrosis Clinical Network was established in 2014 and has focused on the development of clinical guidelines. In alignment with the PSNZ Strategy the NZCYCN Governance Group has agreed to transition this Clinical Network into a broader respiratory network.





## Current work in progress

Updating cystic fibrosis guidelines that are currently posted on the Starship website.

## Looking to the future

Transition the Cystic Fibrosis Network into the Respiratory Network for tamariki and rangatahi with a focus on addressing Ambulatory Sensitive Hospitalisation.

The Respiratory Network will develop a work-plan with a focus on equity and improving outcomes. The network will link and align to activity already underway in Aotearoa to support implementation of best practice models that are broad and include the wider determinants of health. Activity will be promoted with evidence-based outcome measures to ensure tamariki most in need are targeted.

## Model of care

- Chronic and serious respiratory illness is a major contributor to admission of tamariki to hospital and Aotearoa's health burden.
- There is a high degree of inequity across the socioeconomic spectrum and between ethnic groups in rates of respiratory disease.
- Chronic lower respiratory diseases are a component of the health status of individuals and also reflect the environments within which tamariki live, work, and play.
- Common risk factors include poverty, poorly heated homes and household crowding, poor nutrition, frequent or severe lower respiratory infections during early childhood, exposure to tobacco smoke and environmental air pollution<sup>1</sup>.
- Bronchiectasis is a chronic lung disease that causes a decline in lung function and is associated with repeated acute lower respiratory infections, both before and after diagnosis.
- Nationally there is activity to implement a model of care for tamariki admitted to hospital in their early years, aiming to prevent ongoing respiratory morbidity associated with repeated lower respiratory tract infection and frequent hospitalisation.
- Te Kāhui Matai Arotamariki Aotearoa has a role to support regional work be implemented nationally to ensure standards of practice and models of care are equitable and accessible.
- The goal will be to have a number of projects underway in different aspects to improve of respiratory health for tamariki and tai tamariki, each led by a different member of the group.



<sup>1</sup> THE HEALTH OF CHILDREN AND YOUNG PEOPLE WITH CHRONIC CONDITIONS AND DISABILITIES IN NEW ZEALAND 2016 NZCYES. Department of Women's and Children's Health University of Otago October 2018

# Clinical Network for Children and Young People with Diabetes

## Overview

The Diabetes Clinical Network (CN) includes representation from a range of clinical disciplines as well as consumer representation (through Diabetes New Zealand).

1. The Diabetes Clinical Network is actively working to diversify representation on the Clinical Reference Group and to work more closely in partnership with whānau goals and aspirations in the future.
2. The Diabetes Clinical Network has provided feedback on Pharmac proposals; identifying equity gaps that are occurring due to current Pharmac special authority funding (with specific reference to continuous glucose monitoring, and insulin pumps).
3. In 2022 the draft National 5-year Diabetes Action Plan was circulated for consultation nationally. A child health lens was missing from the draft plan. The Network has promoted improved outcomes for tamariki and rangatahi to be integrated into the plan. This is important because the Diabetes Action Plan guides implementation priorities and associated funding mechanisms.
4. Education is a core function for the Diabetes Clinical Network. National documents are hosted on relevant websites to provide information for clinicians and whānau. The network is planning to develop a national education strategy for diabetes to improve equity from both geographical perspective (postcode lottery) and to cultural responsiveness.
5. The Diabetes Clinical Network continues to produce diabetes management plans for consumers and clinicians. Content includes diabetes camps, new technologies, management of diabetic ketoacidosis, and nutrition.





## Achievements

- The 2021 and 2022 New Zealand Society for the Study of Diabetes (NZSSD) and SIG annual meeting days were replaced by a series of webinars. Members of the Clinical Reference Group have contributed to these through moderating and presenting including June and October 2021 and March and July 2022.
- School camp guidelines were completed and launched widely via extended networks.
- The 2021 New Zealand Society for the Study of Diabetes (NZSSD) and SIG annual meeting days were replaced by a series of webinars throughout the year presented by the Chair. These occurred in June and July 2021.
- A critical review of pump funding criteria was submitted, and the information was received with thanks from Pharmac diabetes sub-committee.
- Diabetes Clinical Network Chairperson also submitted the Australian Continuous Glucose Monitoring (CGM) update papers and analysis papers from their CGM rollout.

## Looking to the future

1. MOU with New Zealand Society for the Study of Diabetes (this is the main adult diabetes clinical society). This should be finalised in 2023.
2. Hold a study day as part of the 2023 New Zealand Society for Study of Diabetes Annual Scientific Meeting
3. Submit a funding request to contract delivery of a diabetes education strategy in 2023; ensuring partnership with Māori and Pasifika.

# Te Rōpū Kiripai Hapori - Child and Youth Eczema Clinical Network



## Why eczema is important

Eczema affects approximately 20% of tamariki in Aotearoa thus making it one of the most common chronic diseases in tamariki. Māori and Pasifika tamariki have similar prevalence but more severe disease.

Eczema has long-reaching effects on sleep, learning, development, behaviour and relationships. In Quality of Life studies, tamariki and rangatahi rate their quality worse than tamariki with diabetes, cystic fibrosis and epilepsy (Beattie et al, 2006).

The Clinical Reference Group (CRG) is a small multidisciplinary team with members from primary through to tertiary care services. The aim is to work with other relevant organisations such as Tamariki Ora and Pharmac.





## Overview

Te Rōpū Kiripai Hapori is a national multi-disciplinary network that supports clinicians working across community, primary, secondary and tertiary services to deliver high-quality, cost-effective and integrated eczema treatment programmes for tamariki, youth and their whānau.

In 2022 the network strengthened its commitment to Te Tiriti o Waitangi – a collaborative relationship with Māori – and was gifted the Te Reo Māori name; Te Rōpū Kiripai Hapori. The name combines Te Rōpū “group” and Hapori, “community/society” with Kiripai, “good/ wellness/healing skin”.

## Current issues for Aotearoa

### Large equity gaps in care

Rates of hospitalisation for skin infections are increasing in Aotearoa with paediatric hospitalisation rates for eczema nearly four times higher in Māori and Pasifika tamariki. Historical data suggest this is due to structural barriers to accessing care.

The network is promoting equitable access to high-quality service for tamariki and rangatahi regardless of where they live in the country. Over time, less funding has led to limited chronic health care management, fewer referrals and subsequently less service provision.

Nationally there is extremely poor access to paediatricians or publicly funded dermatologists to treat tamariki and rangatahi with moderate to severe eczema. Aotearoa has the lowest number of paediatric dermatologists in the first world for our population. Newer biological medications may require paediatric dermatology specialist approval. Practitioners often have limited access to treatment modalities e.g. phototherapy units.

### Community and GP management

The majority of eczema is seen in primary care, acutely, and not followed as a chronic condition with education or long-term management plans. There is opportunity to strengthen access by promoting nurse-led models of care in primary care. There are funding limitations in primary care that need to be explored and promoted to achieve this. There are a number of primary care asthma funding models that may align to this activity.

### Education of workforce and whānau

The network has produced resources and guidelines and these are socialised nationally, being published on the Starship Guideline website for example. Whānau information is published on the KidsHealth and Health Navigator website. Primary care pathways are socialised on Health Pathways. There is close collaboration with Well Child Tamariki Ora Providers to develop creative strategies to facilitate improved access to specialist advice and support, interacting with whānau through digital platforms.

There is great value including primary care representatives in the CRG membership as they bring experience and knowledge to understanding the complexity of workforce and funding models that impact access to care.

## Looking to the future

- Promoting a national specialist service that includes increased access to primary care training for the workforce to reduce inequity.
- Increasing engagement with primary care.
- Engaging whānau and Well Child Tamariki Ora Providers to improve the wellbeing of tamariki with moderate to severe eczema.
- Incorporating findings from the AHEAD study to encourage new models of care in the community through to access to specialist Paediatric dermatology care.
- Workforce development.

# Child and Youth Clinical Network for Gastroenterology Services



## Overview

**Paediatric Gastroenterology is a vulnerable service.**

- The distribution of specialist time has dictated a hub-and-spoke model of service delivery; with shared care arrangements for medical management in place in centres excluding Starship, Canterbury (and soon Wellington).
- This presents postcode inequities for whānau driven by the variance in access to specialty multidisciplinary team care.
- Need for specialty care in paediatric gastrointestinal disease is made further evident by the relative rarity of conditions like biliary atresia and intestinal failure.
- These conditions disproportionately affect Māori and Pasifika families. Therefore there is a need to deliver effective local subspecialist care.



## Clinical Network priorities

### Early identification of neonatal liver disease:

- Centralisation of care of biliary atresia patients has led to streamlined diagnostic pathways with straightforward escalation to liver transplantation as needed.
- However, the age at presentation of Māori and Pasifika tamariki has remained unchanged over two decades.
- Given the disease is three times more common in these groups, the network strongly promote consideration of a national screening programme through the use of stool colour card screening as practised routinely in other countries.
- Attempts to integrate 'Beware Yellow' with the Well Child Health Book have not been achieved.
- Therefore, the CN plans to approach funders within Te Whatu Ora to fund stool colour screening by whānau with an Aotearoa specific app.
- The CN considers there is opportunity to leverage learnings from the COVID-19 experience about understanding the feasibility to integrate with centralised health records, NHI demographic data, and the newborn screening reporting system.

## Identified issues

**Guidelines:** Socialisation, implementation and associated change management is necessary to positively impact patient outcomes across the motu.

**Research and registries:** Within paediatric gastroenterology there is a need for a centralised patient-driven research agenda; research questions are largely driven by individual clinician questions.

**Unmet need:** Similar to international observation, there is an increasing gap between available psychological services and documented need for referral to address known anxiety and depression in patients with IBD and other chronic gastrointestinal conditions associated with increased experience of physiological pain such as intestinal failure; The inability to address mental health difficulties promptly will certainly lead to worse patient outcomes<sup>2</sup>.

## Implementation of ESPGHAN 2020 guidelines for the diagnosis of coeliac disease

- Coeliac disease (CD) is one of the commonest paediatric gastrointestinal diseases.
- In 2012, ESPGHAN introduced guidelines for biopsy-free diagnosis of CD in tamariki in whom coeliac serology is highly elevated.<sup>1</sup>
- These were refined in 2020 and have been validated in the Auckland paediatric population in 2018. Starship Hospital has adopted these guidelines.
- Audit shows this approach can be used in 60% of tamariki referred with probable CD, saving time to diagnosis, reduction of risk and cost savings.
- Reduction of endoscopic CD diagnosis has improved capacity for diagnosis of other diseases, e.g. eosinophilic oesophagitis which is rising in prevalence.
- Nationwide implementation of biopsy-free diagnosis of CD is limited by laboratories around the country offering inconsistent coeliac serology. The CN promotes that laboratory practice become streamlined and consistent.

## Safe paracetamol prescribing and administration:

- Tamariki continue to present with hepatotoxicity related to paracetamol ingestion, throughout the country.
- Those affected are often young infants who have received multiple, cumulative doses in the setting of febrile intercurrent illness.
- The network has identified this in a recent NZPSU surveillance study where, again, Māori and Pasifika tamariki were over-represented.
- There are many over-the-counter preparations of liquid and tablet format paracetamol available for purchase by whānau.
- However, it would seem that guidance on the safe administration of the medication is NOT always simultaneously supplied.
- A community and clinician education approach is indicated.

## Population health impacts:

- Fatty liver disease in tamariki has become increasingly common as obesity has increased in the population.
- The disease is significantly more common in Māori and Pasifika people and has long-term health implications.
- Modelling suggests that fatty liver disease will become the predominant indication for liver transplantation in adult populations within the next decade or two.
- It can be recurrent after transplant if the underlying contributors i.e, obesity and the metabolic syndrome, have not been addressed.
- Prevention of the development and progression of fatty liver disease in the young requires multi-speciality, multi-agency collaboration and significant investment.
- NZCYCN is well positioned to be able to bring together the necessary expertise to begin to address the issue of obesity and its complications in tamariki.

## References

- <sup>1</sup> Husby, S., Koletzko, S., Korponay-Szabó, I., Kurppa, K., Mearin, M., & Ribes-Koninckx, C. et al. (2020). European Society Paediatric Gastroenterology, Hepatology and Nutrition Guidelines for Diagnosing Coeliac Disease. *Journal Of Pediatric Gastroenterology and Nutrition*, 70 (1), 141-156. doi: 10.1097/mpg.000000000000024
- <sup>2</sup> Equally Well | Physical health equity. Te Pou. URL: <https://www.tepou.co.nz/initiatives/equally-well-physical-health>

# Paediatric Neurology Clinical Network



## Model of care

Delivery of healthcare promoting wellbeing for all tamariki and rangatahi who experience neurological conditions:

- Whānau-centered care as close to home as possible.
- Care that is based on need, from diagnosis to treatment and rehabilitation.
- Collaborative decision-making in partnership with tamariki, whānau and healthcare providers.
- Multidisciplinary service delivery including healthcare providers with paediatric training and experience.

This will be achieved by establishing and maintaining a Paediatric Neurology Clinical Network that is:

- Connected, multi-disciplinary, diverse, and responsive.
- Inclusive of all healthcare providers.
- Provides a services model that supports the continuum of care across community, primary, secondary, tertiary and quaternary services nationally. The goal is to deliver equitable, high-quality and cost-effective management of tamariki and rangatahi to 15 years of age (and when appropriate 18 years of age) to basic and beyond international benchmark standards who experience neurological conditions.

## Achievements

- Hub-and-spoke network delivery model developed.
- Collaborative working group across many disciplines, specialist, generalist, nursing, primary health and community established.
- Working collaboratively across the regions within Aotearoa.
- Revision of four outdated guidelines completed.
- Implementation of eight new guidelines.
- Paediatric Epilepsy Training course implemented.

## Looking to the future

Paediatric Neurology remains a vulnerable clinical service within Aotearoa. Despite an increase in childhood population, there has been no recent increase in funding for service provision across the regions. There is increasing complexity of neurological conditions, diseases and treatments along with the increasing need for targeted rehabilitation. This requires workforce development to include qualified paediatric trained clinicians.

Workforce issues including retention and succession planning requires investment in a workforce that is small and specialised. A robust strategy to address the significant inequities and gaps in clinical service and care across Aotearoa needs to be developed.

The Paediatric Neurology Clinical Network is well placed to collaborate in the planning of future development for Paediatric Neurology Service with Health New Zealand.





## Overview

The Paediatric Neurology Clinical Network (NZPNCN) aims to enable our colleagues throughout Aotearoa to provide equitable access and service to tamariki and their whānau with regard to paediatric neurological conditions.

The role of the network is to provide leadership and support in the development and implementation of agreed quality improvement activities.

The network actively promotes developing service provision across the continuum of care to include primary, secondary and subspecialist access, limiting structural barriers.

# Newborn Clinical Network



PHOTO CREDIT: New Zealand Breastfeeding Alliance.

## A summary of issues concerning the Newborn Clinical Network (CN)

Internationally, an estimated 10-15% of infants require admission to a neonatal unit for an episode of care starting in the neonatal period<sup>1</sup> (defined as the first 28 days of life). A significant proportion (circa 7.5%) have been born prematurely and the remainder have a combination of acquired conditions and congenital anomalies requiring specialist neonatal services.

The purpose of the Newborn CN is to support clinicians working across primary, secondary and tertiary services to deliver high-quality, cost-effective and integrated newborn care for babies and their whānau, as close to home as practicable. It provides clinical leadership through a multidisciplinary Clinical Reference Group (CRG) of medical, nursing, and allied health professionals.

The CRG acts to develop strong alliances including linkage with key groups such as the Maternal Fetal Medicine Network, Maternity Quality and Safety Committees, NZ College of Midwives, primary care organisations and Well Child Tamariki Ora providers. Furthermore, the inter-disciplinary contribution from linked services such as Radiology, Paediatric Surgery, Genetics, Paediatric Endocrine, Cardiology, Respiratory and other sub-specialists services is fully acknowledged. Finally, the CRG recognises the principles of Te Tiriti in providing the framework for working respectfully and effectively with Māori to achieve equitable health outcomes.



## References

- <sup>1</sup> Braun D, Braun E, Chiu V, Burgos AE, Gupta M, Volodarskiy M, Getahun D. Trends in Neonatal Intensive Care Unit Utilisation in a Large Integrated Health Care System. *JAMA Netw Open.* 2020 Jun 1;3(6): e205239. doi: 10.1001/jamanetworkopen.2020.5239.
- <sup>2</sup> Review of neonatal care in Aotearoa. <https://www.health.govt.nz/publication/review-neonatal-care-new-zealand>

## Issues, gaps and challenges

In addition to the regular ongoing work of the Newborn CRG, as detailed above, there are three areas of work/issues that would have considerable benefit for service provision if resolved:

### Bed state, implementation of transitional care beds and workforce development

- Tertiary and secondary neonatal units are chronically over capacity.
- Newborn services need to be able to respond to urgent surge requirements.<sup>2</sup>
- Up to 85% occupancy is recommended for safe practice but occupancy remains much higher.
- Since 2015 there has been a rise in level 2 unit occupancy which is indicative of overloaded adaptive mechanisms<sup>2</sup> with workload shifted to the postnatal wards and level 2 centres.
- Transitional care units have been proposed but rollout has been very slow in the current Covid-affected environment.
- To ensure robust and future-proof services, there needs to be adequate investment in building capacity and developing the workforce.
- This includes building Māori representation across a range of disciplines.
- To avoid overloading centres and the transfer of babies away from their domicile, it is vital to preserve services such as paediatric surgery across the centres.
- Actions to improve capacity need to occur alongside the advancement of family integrated care and transitional care cots to allow flexibility and a model of care that the network aspires to.



### NZ neonatal formulary

- Currently, each of the six tertiary units has its own manual resulting in considerable variation in practice and potential for errors.
- The New Zealand Formulary for Children illustrates the benefits of a standardised central resource but does not contain adequate information for neonatal use.
- The resource would need to be electronic and available throughout the units.
- As the level 2 units use the same manual as their local tertiary unit, prescribing and administration of neonatal medications could be standardised across all units.
- This project will need both pharmacist and clinical FTE plus administrative and IT support for an estimated two years to establish the resource.
- Moving forward, approximately 0.2 Pharmacist FTE to maintain and update the formulary.

### Information technology and technological innovation

- The piecemeal process whereby the individual neonatal units build database and clinical information functionality is inefficient and struggles to enable optimum communication across the maternity sector, newborn units, general paediatrics and community services.
- Databases are not able to share clinical information and benchmarking is not enabled, plus (unlike the UK) there is no process to utilise national data for research.
- Clinically, there have been issues of failed communication associated with transfer.
- Opportunities for economies of scale and standardisation of processes in technology are missed or fail to be optimised for performance in the Aotearoa NZ healthcare environment.
- A program of cohesive national IT strategy combined with purchasing agreements would give benefits including compatibility and economies of scale.



Photo credit:  
Heartfelt NZ

# Paediatric Palliative Care Clinical Network

## Overview

The Paediatric Palliative Care Clinical Network (PPCCN) aims to enable a coordinated approach and consistency of care across Aotearoa for tamariki, rangatahi and their whānau with palliative care needs.



## Looking to the future

Paediatric palliative care remains a vulnerable service across NZ, with no increase in funding for service provision despite the *Guidance for Integrated Paediatric Palliative Care* [ MoH 2012].

In contrast, *The End of Life Choice Act, 2019*, the assisted dying service for eligible adults, is fully funded.

Inequities and gaps in paediatric palliative care services need to be addressed. This will require funding to maintain the national guidelines, clinician education opportunities, and support for clinical services.



## Achievements

1. Paediatric Palliative Care Clinical Guidelines reviewed and are due to be released to clinicians late in 2022. These require regular review to ensure safe and robust information. These guidelines are well utilised which has been confirmed through website hits and general feedback. [Web Report June 2022 NZCYNCN]
2. Resources available through KidsHealth website including guidelines on grief and loss in response to the COVID-19 Pandemic.
3. Monthly education sessions via zoom nationally (40 – 50+ zoom log-on's each month with, at times, multiple people on each zoom connection).
4. Links with an international research group (RAPID) looking at interventions in paediatric palliative care. These include use of gabapentin for pain, opioids in breathlessness, telehealth and use of cyclizine in palliative care.
5. Links with local and international organisations to improve access, communication and enhance working relationships, in particular, with The Victorian Paediatric Palliative Care Programme, Melbourne.
6. Continue to promote the need for mandated services and funding to enable equitable delivery of care.
7. Development of resources for clinicians and services such as Consumer Feedback Survey and use of Advance Care Plan. These surveys are available via Paediatric Society or through the PPCCN to clinicians nationally to enable review of their services as they consider helpful to on-going care delivery.

## Model of care

The *Guidance for Integrated Paediatric Palliative Care Services in New Zealand* document was released by the Ministry of Health in 2012. Key recommendations include:

- adherence to the World Health Organization definition of paediatric palliative care
- philosophies of tamariki and whānau-centred care in a preferred setting
- care that is based on need, from the point of diagnosis to bereavement
- collaborative decision-making between the tamariki, whānau and providers
- multidisciplinary service delivery including providers with paediatric training and experience
- respite care with 24-hour support/365 days a year.

# Paediatric Sleep Medicine Clinical Network

## Why are paediatric sleep services necessary?

- Good quality sleep of an adequate duration is vital for a child's health and well-being.
- Ignoring children's sleep is ignoring 50-60% of their lives and their future health.
- Around 25% of tamariki have a sleep problem that warrants medical attention.
- Increasing childhood obesity is making Obstructive Sleep Apnoea (OSA) more common.
- Education to prevent and manage sleep problems in infancy (first 1,000 days) can prevent ~50% of child obesity measured at five years.
- Māori and Pasifika tamariki are disproportionately affected by OSA and other sleep problems.
- Untreated OSA risks adverse consequences for cardiovascular and neurocognitive health.
- Access to diagnostic tests (sleep studies including 'PSG') are often required to identify and monitor those affected, especially those at high risk e.g. obese, Down syndrome, neuromuscular conditions (DMD, SMA).
- Effective treatments available (e.g. adenotonsillectomy, Non-Invasive Ventilation (NIV)/CPAP), have significant benefits for health and are cost-effective.
- There are limited specialist clinical psychological services for behavioural sleep problems.
- Access to treatment (ENT surgery; respiratory support e.g. CPAP/NIV; psychological expertise) is geographically inequitable.
- Paediatric sleep services in Aotearoa are not "world-class" and lag behind countries like Australia and the UK.



## Current diagnostic services

- Current diagnostic services are severely limited by lack of facilities, FTE for specialist staff, retention and succession planning.
- At best ~350 PSGs are undertaken nationally on NZ tamariki. Reality is far less than this in recent years. If ~ 1 million tamariki <15 years in NZ this equates to 1:2857 per capita per year.
- Benchmarking with Australia five years ago (2017) the rate varied by state, mean 1:800 (range 1:300-1:1300).
- To be able to achieve equitable rates, the number of studies per year would need to at least triple to quadruple (1:1000 would be ~1000 studies annually nationally).
- However, it's unlikely to be able to achieve or sustain this without significant increased resources and staffing:
  - Auckland – while resources and FTE (specialist SMO and physiologist) are at capacity for two sleep beds three nights per week, the reality is much lower and waitlists have blown out to 12 months due to the impact of Covid/RSV epidemics, loss of beds to inpatient use and retirement of critical staff. As well as managing an exponential increase in all types of respiratory support as well as those on life support ventilation, which is unfunded and unrecognised as a national service. No clinical nurse specialist (CNS) FTE except for limited life support LTV.
  - Wellington – currently two beds two nights per fortnight in a private adult accredited sleep laboratory (WellSleep) with paediatric sleep specialist attending. Accommodates some referrals from external secondary centres by contract. CNS support available.
  - Christchurch – new paediatric SMO sleep specialist one-bed one-night per week. Limited physiology support and equipment via adult sleep medicine services and no CNS.

## Current surgical and other treatment services

- NZCYES data on surgical intervention rates for OSA suggest that the per capita adenotonsillectomy rate is lower than Australia's 4-6/1000 vs NZ's current ~3/1000. Access is geographically inequitable.
- Data also shows that NZ European children have double the ENT surgery for OSA than Māori.
- Data are not easily available to demonstrate trends in interventions such as surgical or respiratory support.



## Paediatric Sleep Services in the context of the Health NZ reform

- A nationwide service with a three hub (sleep expert centre) model is proposed to undertake a full range of sleep studies (level 1-4) as well as treatment with NIV.
- Starship Children's Hospital has developed a pathway for care and resources for sleep services to support tamariki on life-support long-term ventilation (LTV), who are some of the most medically vulnerable. This needs to be recognised as an essential national service to improve care for tamariki requiring LTV and their whānau.
- Clear pathways are required for referral of tamariki with sleep issues or disorders to secondary level resources such as to ENT, general paediatric services and clinical psychological services for behavioural intervention.
- All paediatric units should be able to undertake level 4 studies (home overnight oximetry) competently even if reporting is externally sourced.
- Clear guidelines with specific entry criteria are required for referral to tertiary sleep services for consideration of sleep studies (e.g. PSG and other therapies such as NIV).
- Tamariki with co-morbidities such as Down syndrome, obesity, neuromuscular conditions (e.g. spinal muscular atrophy, Duchenne's muscular dystrophy) need to be highlighted as high risk.
- To undertake one sleep study per 1,000 NZ tamariki per year there would need to be equivalent of at least eight paediatric sleep beds (three-four Starship; two Christchurch; two Wellington) nationally (requiring at least 0.4 SMO FTE/bed plus technologist FTE to cover shifts, score studies and NIV; CNS support NIV/LTV).
- The Paediatric Sleep Medicine Clinical Network is committed to working on a plan for developing a national, integrated multidisciplinary service.



# KidsHealth

## Delivering child health messaging for parents and whānau

Paediatric Society NZ - Te Kāhui Mātai Arotamariki o Aotearoa oversees the development, governance and maintenance of high-quality digital child health content. The Society is uniquely placed to develop and endorse nationally consistent messaging on tamariki and rangatahi health and wellness for parents and whānau via the:

- KidsHealth Programme (with funding from Te Whatu Ora - Health New Zealand)
- 650+ multidisciplinary members and subject matter experts
- Child and Youth Clinical Networks
- Special Interest Groups
- Partnerships and relationships, especially developing relationships with Māori organisations whose mahi is to improve outcomes for tamariki and rangatahi
- PSNZ/KidsHealth partnership with Health Navigator - towards a national digital health content hub.

## Content available for all

KidsHealth makes its content available for sharing across other websites as part of an MOU with Health Navigator and the national content hub. Collectively, this collaborative and digital hub can leapfrog the effort that would otherwise be required for Te Whatu Ora - Health New Zealand, Te Aka Whai Ora - Māori Health Authority, the Public Health Agency and Whaikaha - Ministry for Disabled People to develop, publish and maintain the consumer content they will need for their public-facing websites.

The health and education sectors can be confident in sharing KidsHealth content.

Sample shares of KidsHealth content across channels in response to COVID-19 and meningococcal disease:

- Te Whatu Ora - Te Tai Tokerau shared KidsHealth meningococcal content in the wake of Northland cases of meningococcal disease in July 2022.
- Te Puawaitanga ki Ōtautahi Trust is a Kaupapa Māori community trust providing a range of health, education, social and community services for Māori and Pasifika wahine and their whānau. The Trust shared KidsHealth content on COVID and tamariki in March 2022.



# KidsHealth

[www.kidshealth.org.nz](http://www.kidshealth.org.nz)

## Website traffic

12 months

**2.3 million+**

Total visits

**800,000+**

NZ visits



## KidsHealth Twitter followers



**500+**



## KidsHealth YouTube Channel



**4,250+**  
subscribers

**889,000**  
video views in 12 months

**Widely  
shared COVID-19  
section for NZ  
parents & whānau**

*"I just wanted to say thank you for this incredible resource. As a new parent, I find it very informative and useful. So thank you very much!"*




Accurate and reliable information for NZ parents & whānau about the health and wellbeing of tamariki & rangatahi in Aotearoa.

Content developed & approved by the Paediatric Society NZ | Te Kāhui Mātai Arotamariki o Aotearoa.

Scan the QR code with your phone to go to the KidsHealth website



# Our people

Governance Group				
ROLE	NAME	PROFESSIONAL ROLE(S)/AREA OF EXPERTISE	LOCATION	REGION
Chair	<b>Dawn Elder</b>	Professor / Paediatric Sleep Physician	Wellington	
President PSNZ	<b>Mike Shepherd</b>	Paediatrician, Interim District Director - Te Toka Tumai Auckland	Auckland	
Co-opted Member	<b>Timothy Jelleyman</b>	Community Paediatrician / Child Health Advisor MOH	Auckland	
Co-opted Member	<b>Rachael Hetaraka-Gotz</b>	Nurse, Acting Manager: Well Child Tamariki Ora, Child and Community Group	Wellington	
Member	<b>Nicola Austin</b>	Neonatologist	Christchurch	
Member	<b>Megan Bryant</b>	Consumer Representative	Kaipoi	
Member	<b>Emma Darby</b>	Speech-Language Therapist / Child Development Lead Clinician	Auckland	
Member	<b>Bridget Farrant</b>	Senior Lecturer / Adolescent Physician	Auckland	
Member	<b>Cameron Grant</b>	Professor / General Paediatrician	Auckland	
Member	<b>Rebecca Hayman</b>	General Paediatrician	Auckland	
Member	<b>Toriana Hunt</b>	Kaimahi Hauora Māori	Christchurch	
Member	<b>Mal Joyce</b>	Nurse, Operations Manager, Child Health Service	Wellington	
Member	<b>Karen Magrath</b>	Nurse / Principal Clinical Advisor - Plunket	Wellington	
Member	<b>Loren Mooney</b>	Paediatric Nurse Practitioner / Public Health Nurse Practitioner	Whanganui	
Member	<b>Mary Roberts</b>	Nurse, General Manager - Moana Research	Auckland	
Member	<b>Owen Sinclair</b>	General Paediatrician	Auckland	
In attendance. Te Whatu Ora	<b>Grant Pollard</b>	Group Manager, Commissioning / Child & Community Health - Te Whatu Ora	Wellington	
In attendance. Te Whatu Ora	<b>Leonie McCormack</b>	Manager, Family & Community Health / Child & Community Health - Te Whatu Ora	Wellington	
In attendance PSNZ	<b>Pam Henry</b>	Programme Director - PSNZ	Auckland	
In attendance PSNZ	<b>Karyn Sanson</b>	Support Manager - NZCYCN	Tauranga	

-  Northern Region
-  Te Manawa Taki Region
-  Central Region
-  Te Waipounamu Region

Northern  
Region

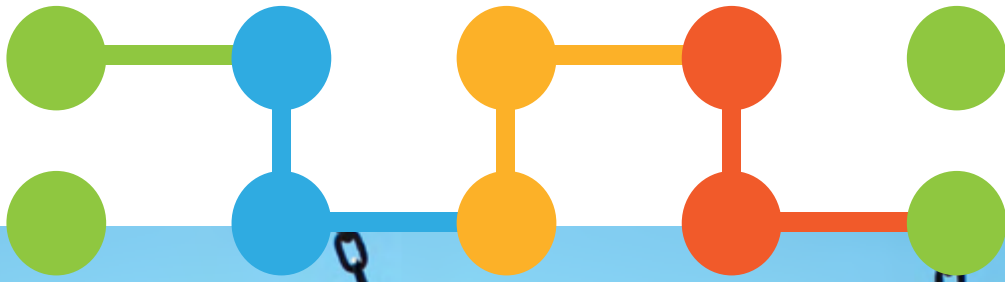
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Taki  
Region

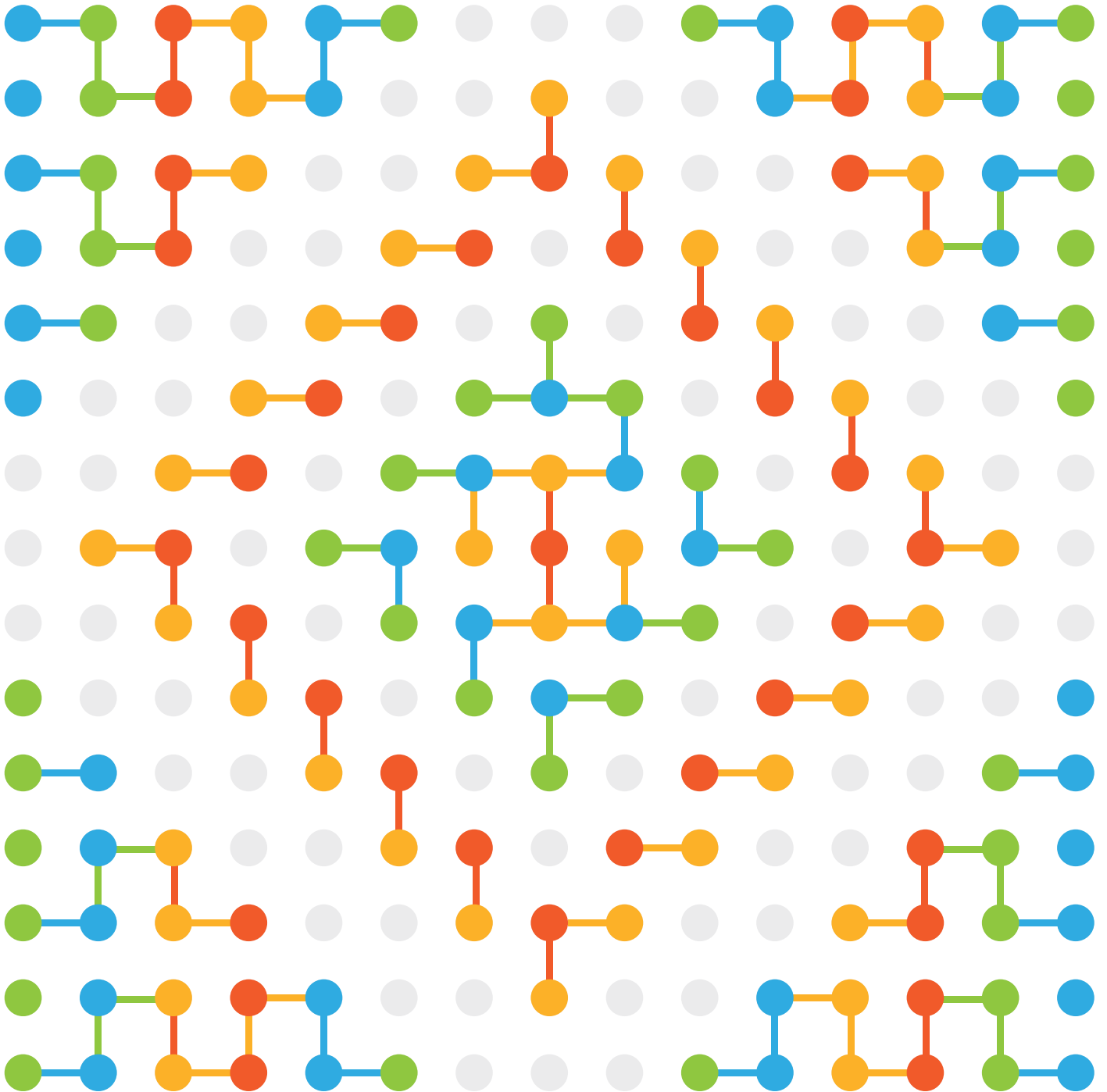
Central  
Region

Te  
Waipounamu  
Region

Clinical Network Leadership					
CRG	ROLE	NAME	PROFESSIONAL ROLE(S)/AREA OF EXPERTISE	LOCATION	REGION
Allergy	Co-Chair	<b>Shannon Brothers</b>	Paediatric Immunologist	Auckland	●
Allergy	Co-Chair	<b>Pauline Brown</b>	Nurse Practitioner	Whangārei	●
Allergy	Project Coordinator	<b>Rosalie Hornung</b>	Nurse Practitioner	Auckland	●
CDD	Co-Chair	<b>Fi Graham</b>	Associate Professor / Occupational Therapist	Christchurch	●
CDD	Co-Chair	<b>David Newman</b>	General & Developmental Paediatrician	Hamilton	●
CDD	Project Coordinator	<b>Parimala Kanagasabai</b>	Research Fellow / Physiotherapist	Wellington	●
Cerebral Palsy	Chair	<b>Sue Stott</b>	Professor / Orthopaedic Surgeon	Auckland	●
Cerebral Palsy	Project Coordinator	<b>Gaela Kilgour</b>	Paediatric Physiotherapist	Timaru	●
Child Protection	Chair	<b>Russell Wills</b>	General & Developmental Paediatrician	Hastings	●
Child Protection	Project Coordinator	<b>Sandra Braithwaite</b>	Project Manager	Tauranga	●
Cystic Fibrosis	Chair	<b>Cass Byrnes</b>	Associate Professor / Paediatric Respiratory Specialist	Auckland	●
Diabetes	Chair	<b>Martin de Bock</b>	Senior Lecturer / Paediatric Endocrinologist	Christchurch	●
Diabetes	Project Coordinator	<b>Sandra Braithwaite</b>	Project Manager	Tauranga	●
Eczema	Chair	<b>Angela Craig</b>	Paediatrician	Hastings	●
Eczema	Project Coordinator	<b>Rosalie Hornung</b>	Nurse Practitioner	Auckland	●
Gastroenterology	Chair	<b>Cate Fraser-Irwin</b>	Clinical Nurse Specialist	Auckland	●
Gastroenterology	Project Coordinator	<b>Amy Andrews</b>	Advanced Clinician / Paediatric Dietitian	Auckland	●
Neurology	Chair	<b>Rakesh Patel</b>	Paediatric Neurologist	Auckland	●
Neurology	Project Coordinator	<b>Rebecca Berry</b>	Nurse Specialist	Auckland	●
Newborn	Chair	<b>Malcolm Battin</b>	Neonatologist	Auckland	●
Newborn	Project Coordinator	<b>Claire Annan</b>	Nurse Educator	Auckland	●
Palliative Care	Chair	<b>Karyn Bycroft</b>	Nurse Practitioner	Auckland	●
Palliative Care	Project Coordinator	<b>Jo Truscott</b>	Clinical Nurse Specialist	Christchurch	●
Sleep Medicine	Acting Chair	<b>Dawn Elder</b>	Professor / Paediatric Sleep Physician	Wellington	●
Sleep Medicine	Project Coordinator	<b>Sandra Braithwaite</b>	Project Manager	Tauranga	●

- Northern Region
- Te Manawa Taki Region
- Central Region
- Te Waipounamu Region





**Ehara taku toa**    **My strength is not**  
**I te toa takitaki,**    **As an individual**  
**He toa takitini**    **But as a collective**