

The Aotearoa New Zealand Cerebral Palsy Strategy

2020–2024 at a glance



Every three to four days, a child is diagnosed with Cerebral Palsy – Hōkai Nukurangi, somewhere in Aotearoa New Zealand. All children with Cerebral Palsy – Hōkai Nukurangi (CP) have varying levels of physical disability. Many will also develop secondary conditions, e.g. scoliosis, hip subluxation, chronic respiratory disease, further impacting their ability to move, be active and fully participate in society. There are also invisible aspects or non-physical challenges of Cerebral Palsy – Hōkai Nukurangi such as epilepsy, sensory and perceptual disorders, learning, social, communication and behavioural difficulties.

We cannot 'cure' Cerebral Palsy – Hōkai Nukurangi, but effective and timely interventions can mitigate the effects of physical disability and secondary health issues, so improving overall quality of life.

In Aotearoa New Zealand, we lack good evidence about the relationship between the starting level of physical disability, the treatment provided and the subsequent health outcomes. Preliminary data suggests gaps and variations in service provision and reactive healthcare rather than surveillance. Consequently, there are known inequities in health outcomes across regions and ethnicities, with poorer health outcomes for children who are Māori or Pasifika.

Introduction

In 2020, a collaboration of Australian and New Zealand Cerebral Palsy – Hōkai Nukurangi organisations, researchers, health professionals and people with lived experience released the Australian and New Zealand Cerebral Palsy Strategy. The Strategy:

- Provides a framework which outlines key priority areas
- Guides key decision makers to deliver support, promote excellence in research, leverage funding avenues and enhance community knowledge
- Aims to improve the health, function, participation, and quality of life for the approximately 10,000 people who live with Cerebral Palsy – Hōkai Nukurangi in Aotearoa New Zealand, and their families across four goal areas
- Provides Aotearoa New Zealand clinicians, researchers, and people with lived experience, with broad principles that can be adapted to the Aotearoa New Zealand context.

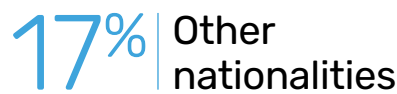
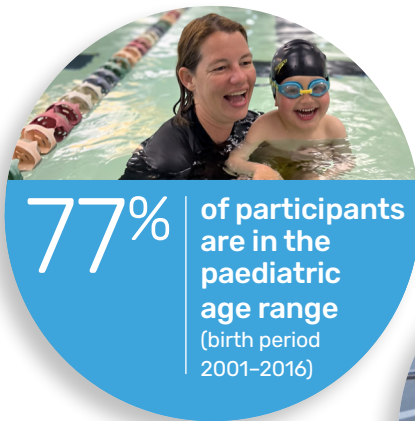
The strategy has supported remarkable growth both in Aotearoa New Zealand and internationally in the Cerebral Palsy – Hōkai Nukurangi field, with research success, new interventions, and wider engagement from the Cerebral Palsy – Hōkai Nukurangi community. While progress has been made, considerable work needs to be done so that the resources surrounding Cerebral Palsy – Hōkai Nukurangi match the numbers and complexities of this lifelong condition.



Snapshot of Cerebral Palsy Metrics in Aotearoa New Zealand:

CP Demographics

The New Zealand Cerebral Palsy Register (NZCPR) is young in comparison to its international counterparts, but we are developing Aotearoa New Zealand-specific information with a focus on equity. The NZCPR numbers are growing steadily and from the recent report cover approximately 1,750 people. These are the demographic breakdowns:



CP Profile

The profile of Cerebral Palsy - Hōkai Nukurangi amongst clinicians and researchers is rising both in terms of the condition in general, and specific areas of interest like the experiences of adults and use of outcome measures such as Hammersmith Infant Neurological Examination (HINE) and General Movement Assessment (GMAs).



Increased research funding in the area of CP

SINCE 2020

Grants committed for research in New Zealand by the Cerebral Palsy Alliance (CPA) Research Foundation.

\$400,000 AUD

New Zealand Health Research Council
\$1,257,914 NZD

Starship Foundation
\$392,826 NZD

Friedlander Foundation
\$2,900,000

Increased number of Aotearoa New Zealand publications on Cerebral Palsy - Hōkai Nukurangi
66 papers referenced in PubMed since 2020

150+ clinicians trained in early detection tools HINE and GMAs (2019-2022)



Priority Areas:

Profiling Cerebral Palsy

This area centres around raising the profile of Cerebral Palsy - Hōkai Nukurangi amongst the public, and in clinical settings outside those typically associated with Cerebral Palsy - Hōkai Nukurangi. This includes broadening the knowledge of general practitioners and promoting initiatives that prevent complications in fields such as dentistry and health surveillance programmes. The goal is also to enhance Aotearoa New Zealand's presence for World CP Day and increase awareness of the Cerebral Palsy Society's campaign, Be Green & Be Seen. This work includes:

- 1 **Be Green & Be Seen**
(World CP Day, 6th October)
- 2 **CPS media opportunities**
(regional and national papers, websites, radio engagement)
- 3 **Cerebral Palsy - Hōkai Nukurangi collective advocacy and health system reform involvement**
- 4 **Early diagnosis for whānau guidelines**



Equity and Advocacy

Equitable and fair access to necessary supports and services for people with cerebral palsy and their families is essential to someone achieving full participation in society. This work includes:

- 1 **Cerebral Palsy - Hōkai Nukurangi and Māori health inequities in Aotearoa New Zealand**
- 2 **Access Matters parliamentary work**
(Accessible New Zealand Legislation)
- 3 **NZ Cerebral Palsy Register Report 2022: The Impact of Cerebral Palsy in NZ**
- 4 **Indigenous Health Equity in Health Registers: Environmental Scanning**
- 5 **NZCPR: Māori Data Sovereignty Audit**

Early diagnosis

Earlier diagnosis and / or identification of infants at risk of Cerebral Palsy - Hōkai Nukurangi before 12-months of age will ensure better resourcing and equitable support for families across Aotearoa New Zealand.

- 1 **PĒPI ARC Early Diagnosis and Support Regional Hub** - a pilot project based in Wellington funded by the Cerebral Palsy Alliance (CPA) Research Foundation
- 2 **MoPed Study** (Moderate to late term prematurity study)
- 3 **Training in early detection for clinicians**

- 4 **Facilitating early identification of infants with Cerebral Palsy - Hōkai Nukurangi within the national Neonatal Intensive Care setting**

- 5 **CaPTuRE: Cerebral Palsy - Translating Research on Early Identification**

Education

This area sets out to increase the educational opportunities for researchers and clinicians around Cerebral Palsy - Hōkai Nukurangi. The focus was on the condition in general as well as expertise in areas such as diagnostic criteria and familiarity with timely and evidenced based interventions and their outcomes.

- 1 **Delivery of 30+ presentations** to a broad range of audiences including community occupational therapists, the Royal College of General Practitioners, community groups, junior doctors with an interest in paediatrics
- 2 **CP Clinical Network: Development of Best Practice Recommendations** for early detection of Cerebral Palsy - Hōkai Nukurangi, intervention, and monitoring, in addition to knowledge translation, awareness and clinical education

- 3 **Development of resources** in multimedia formats for main health websites such as Healthify (Health Navigator), KidsHealth, and Starship Child Health

- 4 **Connect and engage** with the latest tools for whānau such as apps and social media information campaigns



Future Directions:

As we look to develop the Australian and New Zealand CP Strategy 2025, the work will centre around two priority areas: research and advocacy. The two focuses have an interconnected relationship. Research is vital to promoting and sustaining advocacy, particularly at a government and ministerial level. There is an expectation that all research within the field of health has some advocacy or equity-based outcome measures in an Aotearoa New Zealand context.

The Te Reo Māori term for Cerebral Palsy is Hōkai Nukurangi – to achieve what is important to you. The translation centres around the idea that individuals may have different paths and environments (earth and sky), but they still have the right to achieve what is important to them even if the process looks different.

However, for individuals and families to achieve what is important to them, health and well-being needs to be optimised from cradle to grave, offering a lifespan approach. This means the ability to meet the changing needs of individuals living with Cerebral Palsy – Hōkai Nukurangi, from infancy well into adulthood.

On a practical level, the gap between the current approach and a lifespan approach means making the case for resourcing and capacity of

the infrastructure around Cerebral Palsy – Hōkai Nukurangi. This includes early detection and intervention hubs, building an adolescent specialty within paediatrics to effectively manage transition, and building up the adult rehabilitation workforce.

Underpinning this is a shift away from costly reactive, ‘crisis’ medicine to parental education, health surveillance and proactive care. This is driven through a Centre of Excellence model, encompassing Aotearoa New Zealand experts and monitoring population-based health outcomes through a sustainable register (New Zealand Cerebral Palsy Register). In turn, this provides best practice information to local healthcare providers and consumers.

The Aotearoa New Zealand contingent is going to use the principles and processes of the Strategy 2025 to work towards addressing this gap.

– July 2024

www.cerebralpalsystrategy.com.au



The New Zealand
Cerebral Palsy
Register

Te Rēhita a
Hōkai Nukurangi
Aotearoa



Australian & NZ
Cerebral Palsy
Strategy



Cerebral Palsy Society
freedom & choice