



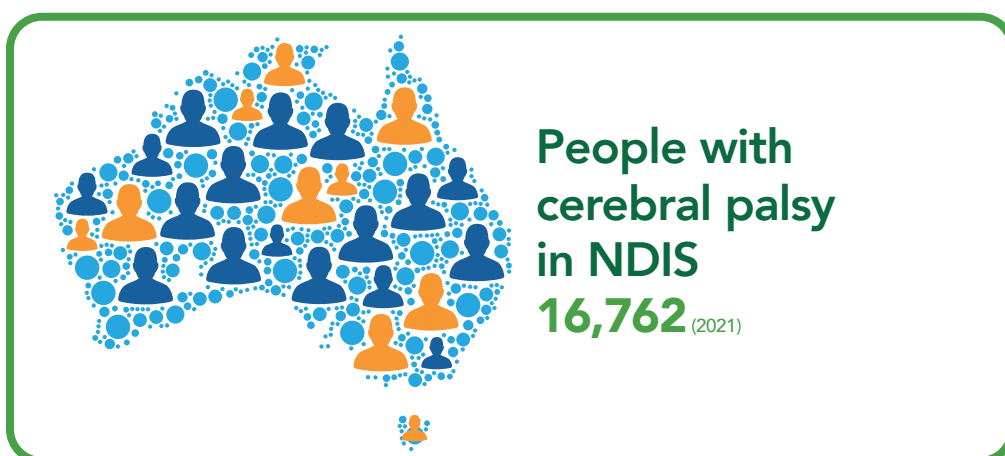
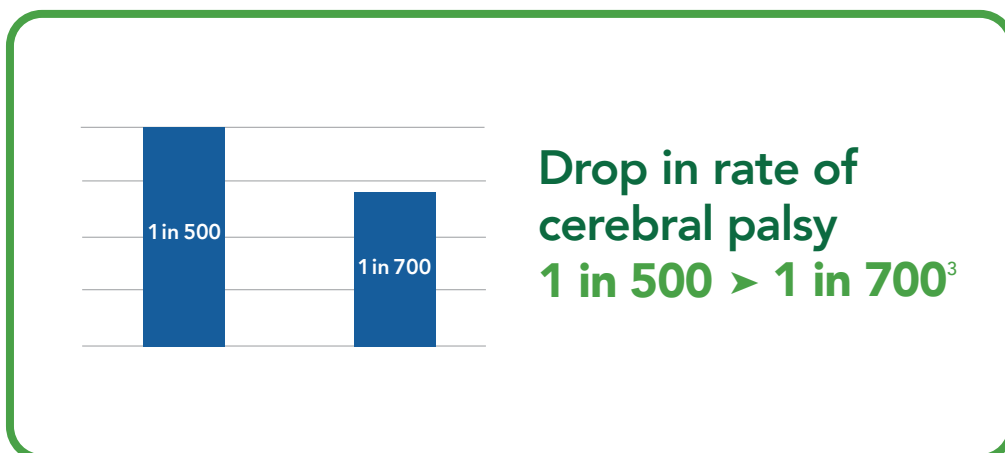
Australian Impact Report 2022

Australian and New Zealand Cerebral Palsy Strategy



What is cerebral palsy?¹

Cerebral palsy is the most common physical disability in childhood. People with cerebral palsy experience significant barriers in everyday life, including complex and lifelong physical, medical, educational, employment and social barriers.



¹ <https://cerebralpalsy.org.au/our-research/about-cerebral-palsy/what-is-cerebral-palsy/>

² Cerebral Palsy Alliance; <https://cerebralpalsy.org.au/our-research/about-cerebral-palsy/what-is-cerebral-palsy/facts-about-cerebral-palsy/>

³ <https://cerebralpalsy.org.au/our-research/about-cerebral-palsy/what-is-cerebral-palsy/>



Why the Strategy?

The cerebral palsy field has seen remarkable growth in recent years, with the exponential expansion of the research evidence base, a reduction in the rate and severity of cerebral palsy, and new opportunities created by the National Disability Insurance Scheme (NDIS).

In spite of this, before 2020 there was no national or Trans-Tasman Strategy for cerebral palsy. In 2020, a collaboration between Australian and New Zealand cerebral palsy organisations, researchers, health professionals and people with lived experience released the Australian and New Zealand Cerebral Palsy Strategy ('the Strategy').

The Strategy provides a framework to outline key priority areas and is intended to be used as a guide for key decision makers to deliver support, promote excellence in research, leverage funding avenues and enhance community knowledge.

Under four goal areas (Prevention and Cures; Intervention and Disability Support; Health and Wellbeing; and Inclusion and Engagement), the Strategy aims to improve the health, function, participation, and quality of life of people with cerebral palsy and their families.

The Strategy Collaboration

The Australian and New Zealand Cerebral Palsy Strategy was authored by “the Collaboration”, a broad coalition of national cerebral palsy focused organisations, service providers, researchers, professionals and people with cerebral palsy and their families from Australia and New Zealand. The goals, priorities and success indicators included in the Strategy were informed by the field of cerebral palsy across Australia and New Zealand via a comprehensive and iterative consultation process. An expert panel was consulted throughout the Strategy development, who provided in depth discussion on sensitive topics and critical review of the document.



Ability First Australia is a not-for-profit strategic alliance between 14 of Australia’s leading disability service providers, with member organisations in all states and territories. Our members have a long and trusted history, having supported people with disability for between 50 and 85 years.



Cerebral Palsy Alliance is an international pioneer in research into cerebral palsy and is a leading not for profit organisation committed to providing world-class services for people living with a broad range of disability and their families.



Cerebral Palsy Australia is the national peak body of organisations that work with people with cerebral palsy as well as people with similar disabilities and their carers.



Australasian Academy of Cerebral Palsy and Developmental Medicine is a multidisciplinary professional academy that provides scientific education for health professionals and promotes research and high-quality clinical care standards for people with cerebral palsy and developmental conditions.



Cerebral Palsy Society of New Zealand aims to enhance the lives and well-being of people with cerebral palsy in New Zealand by empowering them to make their own choices. Through its membership, the Society offers practical everyday programs and awards grants for people with cerebral palsy to enable access to items of service that assist in promoting independence and quality of life.



Cerebral Palsy Clinical Network brings together a diverse multi-disciplinary group of clinicians, researchers, individuals with CP and families of children with CP, working together to promote best possible care for all infants, children and adolescence with CP or at risk of CP, from birth to transition into adulthood.



People with Lived Experience are members of the Collaboration who are people with cerebral palsy or who are family members of people with cerebral palsy.

Australian Impact Report 2022

Halfway through the five-year term of the Strategy, the time is right to take a snapshot look at four success indicators from the Strategy, spanning the four goal areas. This report endeavours to provide an overview of research, projects, and opportunities within each success indicator currently underway across Australia, to recognise gains, and identify areas of ongoing need. These success indicators were selected by the Collaboration from the full Strategy document.

Whilst the Strategy is a Trans-Tasman initiative, this report takes an Australian focus, to contextualise progress and opportunities within the national economic, political and social environment. The content in this report reflects the contributions of teams Australia-wide and international collaborations; not only those within the Collaboration. The authors also acknowledge the exceptional work underway towards achieving the vision of the Strategy, but which falls outside of these four success indicators, and is therefore not included in this report.

Since the release of the Strategy, circumstances such as the COVID-19 pandemic have shaped the lives of Australians with cerebral palsy, leading to changes within the field with huge implications on individuals, their families and community.

This environment has created significant barriers to accessing healthcare, employment and disability supports for people with disabilities, leading in turn to far greater social and economic disparities for individuals with cerebral palsy. Despite these obstacles, the field has made remarkable advances, yet more can be done with support and contributions from government, business and the wider community.



Image supplied courtesy
of Cerebral Palsy Alliance

Projects achieving strategy goals since 2020:



Grants awarded by Cerebral Palsy Alliance Research Foundation since 2019
\$17,988,087



STEPtember 2022
124,000 Participants
\$10,362,087 Raised



People trained to assess General Movements
220 Basic, 92 Advanced



World CP Day
193 countries participating
9 million people reached (2022)



MY CP Guide website launch
184,000 engagements
12,415 new users since July 2022

Projects addressing the 4 chosen priority areas in Australia



Priority 1:

Reducing the age of cerebral palsy diagnosis to enable early intervention

1. Early Diagnosis Guideline Implementation
2. Hammersmith Infant Neurological Examination and General Movement Assessment Training
3. Early Diagnosis Clinics (NSW)
4. Automated screening for GMs scoring
5. DRIVE CP: Directing Research In Very Early Cerebral Palsy
6. BAMs for BUBS: National Early Screening Proposal



Priority 2:

Improving outcomes through partnership with the National Disability Insurance Agency (NDIA)

1. CP Strategy Collaboration's capacity to support the NDIA and Government fulfill the vision of the National Disability Strategy
2. Providing service and NDIS participant data to the NDIA and government
3. Establishing a formal advisory body to NDIA
4. NDIS participant data linkage research



Priority 3:

Improved health and wellbeing for people with cerebral palsy across the life-span

1. CP-Achieve: Australian Centre for Health, Independence, Economic Participation and Value Enhanced Care for adolescents and young adults with cerebral palsy
2. EPIC-CP: Equity Pathways and Integrated Care for children and young people with cerebral palsy
3. GAME; Goals Activity Motor Enrichment
4. BetterStart workshops
5. TRANSMIT; A multifaceted knowledge TRANslation Strategy iMproving funcTion in children and youth with cerebral palsy
6. Assistive Technology: Remarkable
7. Assistive Technology: Research into communication, cognition and mobility
8. Genomics



Priority 4:

Improved community understanding of cerebral palsy including complex communication

1. CPActive
2. World CP Day
3. CMV Awareness Month
4. My Voice Library
5. STEPtember

Reducing the age of cerebral palsy diagnosis to enable early intervention

Success Indicator: Earlier diagnosis of children with cerebral palsy before 12-months of age (from 52% to 70% diagnosed before 12-months).

Goal area: Prevention and Cures

Early diagnosis of cerebral palsy is essential. It enables timely, evidence-based treatments during the first years of life, when the ability of a damaged brain to repair itself and adapt to injury is highest. This ability, known as neuroplasticity, is most active in the first 1000 days, which is why early intervention is so important – the earlier children start retracing neural pathways using therapies, the better their outcomes are. Crucially, early intervention can also enable the prevention of complications and secondary impairments, meaning that individuals with cerebral palsy will have the highest possible quality of life. Late diagnosis also limits vital research to discover new interventions to promote best outcomes for children with cerebral palsy.

Some key projects underway to reduce age at diagnosis of cerebral palsy include:



Underway but facing significant barriers

Early Diagnosis Guideline Implementation

Clinical guidelines for the early diagnosis of cerebral palsy were published in 2017. Implementation of these guidelines and General Movements Assessment (GMA) training is occurring, with 23 Neonatal Intensive Care Units (NICU's) now having GM-trained staff and undertaking GMs. An estimated 10% of babies in NICUs in NSW, VIC and WA are currently screened for cerebral palsy. However, this is highly variable across states/centres, and higher uptake is needed.

What Next?

- **Guideline implementation will continue across Australia at a steady rate. However, 50% of babies with cerebral palsy are not admitted to NICUs or Special Care Units. Many of these infants are born from high-risk pregnancies, have growth restriction, or have congenital anomalies, but are not screened. Processes for screening outside of NICUs and Special Care Nurseries for babies with risk factors needs to be devised and implemented.**

² General Movements Assessment – is a 3–5-minute observational (videoed) assessment of baby movement, completed between birth and 20 weeks (corrected) of age, which is used to help identify children at risk of cerebral palsy and/or other developmental disabilities.

³ GMA videos are scored by trained professionals. Videos must be taken at specific ages and in a specific way to be scoreable. An app to support parents to capture high quality videos, and infrastructure to securely share the videos with trained professionals and securely store digital data is necessary.

- There is an absence of dedicated funding/personnel time available for screening, limiting the ability for centres to implement widespread screening. There is a need for recognition and support of the requirement of clinical staff to undertake early screening for cerebral palsy and the associated time requirements, so that they can be appropriately staffed to enable screening. Moreover, nationwide infrastructure to support the data capture app, video storage and data sharing is essential.
- Despite Magnetic Resonance Imaging (MRI) forming one of the two preferred pieces of information used together to enable early diagnosis, MRI resources are still scarce. Some children wait up to a year for a scan. Further work to harmonise timing, sequence, and prioritisation of children for MRI scanning is critical for early diagnosis.



Achieved but needs funding/support to be sustained

Hammersmith Infant Neurological Examination (HINE) and General Movement Assessment Training (GMA)

To enable widespread early diagnosis of cerebral palsy, a train the trainer model, initially supported by the Advancing Cerebral Palsy in Queensland project, Cerebral Palsy Alliance, and The Australasian CP Clinical Trials Network, has been established. Skilled trainers are now training clinical staff across each state, in the use of the recommended assessments to diagnose cerebral palsy. These tools include the Hammersmith Infant Neurological Examination (HINE) and GMA, which between them can detect cerebral palsy with 98% accuracy. State-based training is ongoing, with all developmental follow-up clinics across Australia are now using the HINE.

What Next?

Ongoing, permanent funding is necessary to support trainers to continuously upskill clinical staff in the administration of the HINE and the GMA in line with early diagnosis guidelines. Embedding training programs within hospitals across Australia and New Zealand and supporting and resourcing managers to run training would optimise processes.



Achieved but needs
funding/support to
be sustained

Early Diagnosis Clinics operational in NSW

In a world-first, cerebral palsy Early Diagnosis Clinics are operational in NSW, creating a model for other locations. One clinic opened in 2018 (Prairiewood), another in mid-2022 (Randwick) and a third is scheduled to open in early 2023 (Hunter region). Since 2018, the Prairiewood clinic has screened approximately 230 babies and the average age of cerebral palsy diagnosis has been eight months.

What Next?

A more streamlined approach of referrals so the conversion of diagnosis (i.e. from high-risk to confirmed cerebral palsy diagnosis) once referred back to specialist is consistent. Continuity of funding needs to be acquired to ensure the ongoing viability of the clinics, which are currently operated by Cerebral Palsy Alliance and funded by private supporters.



Underway but facing
significant barriers

Automated screening for GMs scoring

Work is underway to explore whether scoring of the General Movements Assessment can be automated using Artificial Intelligence. The current program of work is funded until 2027. This would reduce workload and demand on clinicians and enable roll-out nationwide with reduced funding requirements.

What Next?

Preliminary results of automated screenings are promising, but more research and development is needed.



DRIVE CP: Directing Research In Very Early Cerebral Palsy

To Led by Cerebral Palsy Alliance, with national co-investigators from the University of Queensland, CSIRO's e-Health Research Centre, Curtin University, Deakin University, Griffith University, Monash Children's Hospital, Queensland's Department of Health, the University of Melbourne, University of Sydney, Department of Health Queensland and the University of Western, DRIVE CP was awarded \$2.5M across five years by the National Health and Medical Research Council (NHMRC), commencing in 2022. Research aims to address a continuing reduction in the severity of cerebral palsy and to support children towards full participation in society. More specifically, children at high risk of cerebral palsy will be detected in the first three months of life (using early diagnosis guidelines, paired with new universal screening) and fast tracked to receive early evidence-based rehabilitation in multi-centre clinical trials, underpinned by enhanced value-based care. Advancements will be achieved through knowledge creation, translation, capacity building, and collaboration. Previous clinical trial findings will be implemented into practice and policy through clinical practice guidelines, mobile health aide and partnership with the NDIS.

DRIVE CP, through the following aims, addresses many of the "next steps" to the early diagnosis and intervention research projects outlined above:

What Next?

- (a) Move the timing of first motor intervention from childhood down to newborn period;**
- (b) Generate new knowledge in under-researched priority areas including speech, feeding, social skills, executive function, behaviour and parent supports;**
- (c) Establish universal screening of all Australian births for cerebral palsy,**
- (d) Use data to develop Artificial Intelligence (AI) algorithms for automating the screening for diagnosis, as well as commercialise the AI to enable global screening, and;**
- (e) Study the prospective population screening cohort to identify biomarkers, and to identify and understand genetic causes of cerebral palsy**




National Early Screening proposal: “BaMS for BUBS”

Currently, there is no standardised system for early screening for cerebral palsy in Australia. This results in delayed intervention during a critical window of neuro-development and missed opportunities for generations of children. To bridge this gap, Cerebral Palsy Alliance is proposing a targeted early screening program pilot in advance of any national early screening program for all infants born in Australia. The proposed ‘BaMS for BUBS’ program would screen all babies for cerebral palsy (and some similar disabilities) using the internationally adopted GMA screening protocol. The proposed program would be overseen by a global expert leadership team who have helped to accelerate early detection and intervention for at-risk infants in Australia and around the world.

What Next?

Since the completion of the proposal, Cerebral Palsy Alliance has presented and held multiple discussions with a range of key decision-makers and health experts, including former federal Health Minister Greg Hunt and the Medical Research Future Fund (MRFF). Further discussions are ongoing with stakeholders from state health departments, local health districts and community health organisations to determine the practicalities of piloting the proposed program.



Early diagnosis of cerebral palsy is essential. It enables timely, evidence-based treatments during the first years of life, when the ability of a damaged brain to repair itself and adapt to injury is highest.

⁴ “BaMS for BUBS”: Baby Movement Screening for babies: A universal assessment to screen for cerebral palsy and similar conditions between 12 -16 weeks of age.

In a world-first, cerebral palsy Early Diagnosis Clinics are operational in NSW, creating a model for other locations.



Improving outcomes through partnership with the National Disability Insurance Agency (NDIA)

Success Indicator: Establish a working relationship between the Collaboration and the NDIA to improve outcomes for people with cerebral palsy and the community

Goal area: Intervention and Disability Support

Timely and equitable access to necessary supports and services for people with cerebral palsy and their families is key to achieving personal goals for full participation in community life. The Strategy seeks to address this goal area through establishment of a working relationship with the Strategy Collaboration and the NDIA. The NDIA, as the body in charge of implementing the NDIS, plays a central role in supporting people with cerebral palsy to achieve their goals through the provision of funding to access necessary interventions and disability supports.

As experts in cerebral palsy, and as stewards of the Australian and New Zealand Cerebral Palsy Strategy, the Strategy Collaboration is uniquely placed to work in partnership with the NDIA to provide up-to-date information about evidence-based interventions and supports for people with cerebral palsy. A working relationship between the Strategy Collaboration and the NDIA will allow an integrated approach to research and service provision, developing and evaluating evidence-based interventions and disability supports.

The Strategy Collaboration is partnering with the NDIA to best support the following projects and engagement:



Achieved but needs
funding/support to
be sustained

CP Strategy Collaboration's capacity to support the NDIA and Government to fulfill the vision of the National Disability Strategy

The capacity of Strategy Collaboration members to support NDIA/Government to better meet the needs of people with cerebral palsy is demonstrated by the successful delivery of an Information Linkages and Capacity Building (ILC) Grant to implement a national information program for people with cerebral palsy.

A consortium between key members of the CP Strategy Collaboration – Cerebral Palsy Australia (project lead), Cerebral Palsy Alliance and Ability First Australia, with the consumer-based Cerebral Palsy Support Network has used a significant ILC grant to build an online platform; My CP Guide, to empower all Australians with cerebral palsy with information to better navigate mainstream services. This project aims to overcome the current fragmentation of information and resources on a consolidated national program. My CP Guide demonstrates an ability to work with all tiers of government to secure funding to deliver outcomes for people with cerebral palsy. Since the launch of the My CP guide in July 2022, engagement across the website has reached 54,000 people, 5,600 new users, as well as 350 downloads of the Parent and Carer Wellbeing booklet.

What Next?

My CP Guide is live and has government funding through till June 2024. Funding in addition to existing government grants will allow the project to realise further ambitions and opportunities for Culturally and Linguistically Diverse (CALD) and Easy English readers, and to develop powerful information resources to fill significant gaps in accessible information about mainstream services for people with cerebral palsy. Further, it will support the ongoing viability of the platform after ILC funding ceases in June 2024.



Achieved and
ongoing

Providing service and NDIS participant data to the NDIA and government.

Ability First Australia, a not-for-profit strategic alliance of 14 leading disability service providers, has developed a number of service offerings that facilitate knowledge sharing, problem solving and best practice across the sector. These offerings provide powerful, evidence-based insights regarding people with cerebral palsy and the services valued by government: The Ability Roundtable as a subsidiary of Ability First is a unique national platform that supports disability service providers to benchmark their performance by service type, with capacity to benchmark cerebral palsy specific issues. Roundtable collects service-related benchmarking data for over 30% of the NDIS market. It provides insight into services delivered to over 7,000 of people with cerebral palsy.

Ability Forum is a world-first online community that gives a voice to people with disabilities in service delivery and government policy, including surveys specifically designed for people with cerebral palsy. The Ability Forum has a current reach of more than 3,000 panel members, providing significant opportunities for real-time co-design by people with cerebral palsy.

What Next?

Ability Forum has recently opened to non-member organisations, providing further opportunities to strengthen the voice of people with cerebral palsy to government and influence policy. Further opportunities exist to gain insights via Ability Roundtable and the Forum to support people with cerebral palsy on a range of issues, particularly in relation to the ANZ CP Strategy. The Ability Roundtable and the Ability Forum are able to provide evidence-based white papers to support the NDIA and government in their policy making for people with cerebral palsy.



To be commenced

Establishing a Formal advisory body to NDIA

The Strategy recognises the need to launch a formal advisory body to the NDIA, to ensure cerebral palsy is at the forefront of decision making. Currently, the Alliance20 and Ability First Australia model formal relationships with the NDIA, advocating solutions to strengthen the NDIS, deliver better services and outcomes for participants. Ability First Australia and Alliance20 have had great success in engaging people with disability, governments, the NDIA and others to find practical solutions to key issues relating to the NDIS.

What Next?

The Collaboration partners will establish a representative body to be the “go-to” group for the NDIA, as well as Federal, State and Territory Governments, to ensure policy appropriately addresses the needs and aspirations of Australians with CP.

⁵ Alliance20 brings together Australia’s largest disability service providers across the country to advocate solutions which strengthen the National Disability Insurance Scheme (NDIS), focusing on shaping policy to enable choice, ensure value, minimise complexity, and deliver better outcomes.



To be commenced

NDIS Participant Data linkage research

CP-Achieve and key stakeholders including Cerebral Palsy Alliance, Cerebral Palsy Australia and Cerebral Palsy Support Network (CPSN) are seeking to commission work by Melbourne Disability Institute to understand if there are inequities and drivers of NDIS plan allocation and spending. The NDIA holds seven years of NDIS participant data, however quarterly reports provide insufficient insights into participants with cerebral palsy. The University of Melbourne's Disability and Health unit aims to use NDIS data to determine if there are inequities in plan size and spending, as well as to fully understand how plans are changing over time for people with cerebral palsy. The data linkage study will help to characterise baseline life outcomes for participants in the NDIS with cerebral palsy considering other influencing socio-economic factors.

What Next?

The project aims to produce varying reports over a 12-month timeline detailing main findings of the data linkage. With these findings, CP-Achieve and key stakeholders can better understand the size and spending of NDIS plans, as well as life outcomes for participants with cerebral palsy.

Timely and equitable access to necessary supports and services for people with cerebral palsy and their families is key to achieving personal goals for full participation in community life.



Improved health and wellbeing for people with cerebral palsy across the life-span

Success Indicator: Establish an increase in funding and access to prevention and treatment strategies, aimed at maintaining and improving the health and wellbeing of people with cerebral palsy, across the life span.

Goal area: Health and Wellbeing

Positive health and wellbeing are fundamental to an individual's overall quality of life. Unfortunately, health and wellbeing outcomes, including life expectancy, for people with cerebral palsy continue to lag behind the broader population, and bridging this gap is a key priority of the Strategy. A lack of knowledge and competency in meeting the complex needs of people with cerebral palsy, and access to appropriate, accessible health services continue to contribute to poorer health and well-being outcomes for the cerebral palsy community. This is exacerbated by the lack of funding for research projects examining, addressing and translating research targeting health outcomes for people with cerebral palsy and their families. The Strategy Collaboration aims to address these concerns with an increase in funding for research projects, as well as targeted active surveillance of treatments.

There are multiple projects that aim to address health and well-being related needs that the collaboration is in support of, including:



On track but not yet complete

CP-Achieve: Australian Centre for Health, Independence, Economic Participation and Value Enhanced Care for adolescents and young adults with cerebral palsy

Led by researchers from the Royal Children's Hospital and Murdoch Children's Research Institute, Victoria, CP-Achieve is a five-year (2020-2024), \$2.5M NHMRC-funded Centre of Research Excellence (CRE) that supports collaborative research focussing on young people with cerebral palsy. The CRE includes a multidisciplinary group of national and international co-investigators as well as adolescents and young adults with cerebral palsy, families, clinicians and students. CP-Achieve addresses the health, social and participation inequities of adolescents and young adults with cerebral palsy aged 10-30 years. Some 15 projects are underway, nested under two programs of research: Program One - Physical and Mental Health; and Program Two: Building Supportive Environments. Five PhD students and four Post-Doctoral Fellows are supported, significantly expanding and upskilling the cerebral

palsy research workforce. Consumer involvement is an overarching theme of the CRE, with consumer co-ordinators with lived experience of cerebral palsy employed, and three consumer advisory groups, with two more groups under development.

What Next?

A major data linkage between the Victorian CP Register and Australian Institute of Health and Welfare is currently underway to compare service use (hospital admissions, emergency department presentations, primary care visits and medications) by young people with cerebral palsy to aged-matched controls from the general population. This project will provide a deeper understanding of health service use with a view to service improvement. Randomised trials of participation-focussed interventions with the aim of incorporating them into mainstream practice are under development, as is the design of novel, evidence-informed modules that equip young people with cerebral palsy with the knowledge and skills they need to increase their participation in seven key life areas of adult life. Pathways and indicators for recognising health problems, including mental health issues, for general practitioners and allied health professionals are under development. More funding will be needed for completion of all projects and authentic consumer involvement and extensive knowledge translation is required.



On track but not yet complete

EPIC-CP: Equity Pathways and Integrated Care for children and young people with cerebral palsy

EPIC-CP is co-designing and piloting a global first research project to identify and address unmet social needs of families of children with cerebral palsy. The program aims to support families to navigate the complex health and social services ecosystem and address their unmet social needs to improve family functioning and quality of life. This collaborative project is led by researchers and clinicians from University of New South Wales, Sydney Children's Hospitals Network, and John Hunter Children's Hospitals, in partnership with research advisors with lived experience of cerebral palsy. The current formative research is supported by funding from the Cerebral Palsy Alliance Research Foundation and Sydney Children's Hospitals Foundation.

What Next?

In 2022-2023, researchers will test the feasibility and acceptability of novel EPIC-CP social prescribing program at the three NSW Children's Hospitals. The EPIC-CP team needs additional funding for expansion of the program to other sites and a large-scale study to evaluate the efficacy of social prescribing, implementation evaluation, and economic evaluation.

Positive health and wellbeing are fundamental to an individual's overall quality of life.





On track but not yet complete

GAME; Goals Activity Motor Enrichment

In 2017, Cerebral Palsy Alliance, The University of Queensland, The University of Melbourne, and Curtin University were funded to conduct a randomised controlled trial of early intervention therapy for babies at risk of cerebral palsy called 'GAME (Goals Activity Motor Enrichment)'. The research team received a \$2.7M NHMRC grant to investigate whether the home-based GAME intervention is more effective at improving motor and cognitive outcomes for high risk infants at two years of age, when compared to standard care. With more than 300 infants enrolled, GAME is Australia's largest-ever clinical trial of cerebral palsy treatment in infants.

What Next?

Participant enrolment was completed in 2021 and data collection is estimated to be completed by 2023. The project aims to improve motor and cognitive outcomes, while assessing the financial cost-benefit of early intervention in cerebral palsy. A further study, funded \$1.9M from 2021-2025, is underway to examine school readiness of children who participated in early intervention trials.



Achieved and ongoing

Cerebral Palsy Australia BetterStart Workshops

Cerebral Palsy Australia, with its partners in the First Steps Alliance, deliver the national roll-out of the BetterStart Workshop program. The workshops focus on parents early in the journey with their child with cerebral palsy (and other disabilities) that benefit from Early Childhood Early Intervention (ECEI) services. The aim of the workshops is to orient parents in the disability and health service landscape, and to build their capacity to navigate services in the early years. Since their inception the workshops have facilitated 504 sessions and 3215 participants. These workshops are for all families and carers of children under seven who experience disability, developmental delay or are displaying signs of delay.

What Next?

Continued funding is needed to continue and expand the BetterStart program, enabling greater access to parents for continued support for their children with cerebral palsy.



TRANSMIT: A multifaceted knowledge TRANslation Strategy iMproving function in children and youth with cerebral palsy

Researchers in partnership with the NDIS, Cerebral Palsy Alliance, NSW Health, Vic Health, QLD Health, University of QLD, International Alliance of Academies of Childhood Disability and Montreal University have been awarded \$1.42M across five years, commencing in 2022, to work together to close the research-practice translation gap. This project will develop a mobile health aide (mHealth) that streamlines and filters evidenced-based intervention options for children with cerebral palsy. This aide includes knowledge translation strategies that directly overcome implementation barriers identified by three stakeholder groups – consumers, clinicians, and policymakers.

What Next?

The anticipated outcomes from the three-tiered knowledge translation approach are a 10% improvement in function (independence of daily living) to expedite long-term independent living and employment, and a 20% reduction in NDIS costs. Through nationwide partnerships, mHealth will ultimately reach 100% of the Australian cerebral palsy population.



Assistive Technology - Remarkable

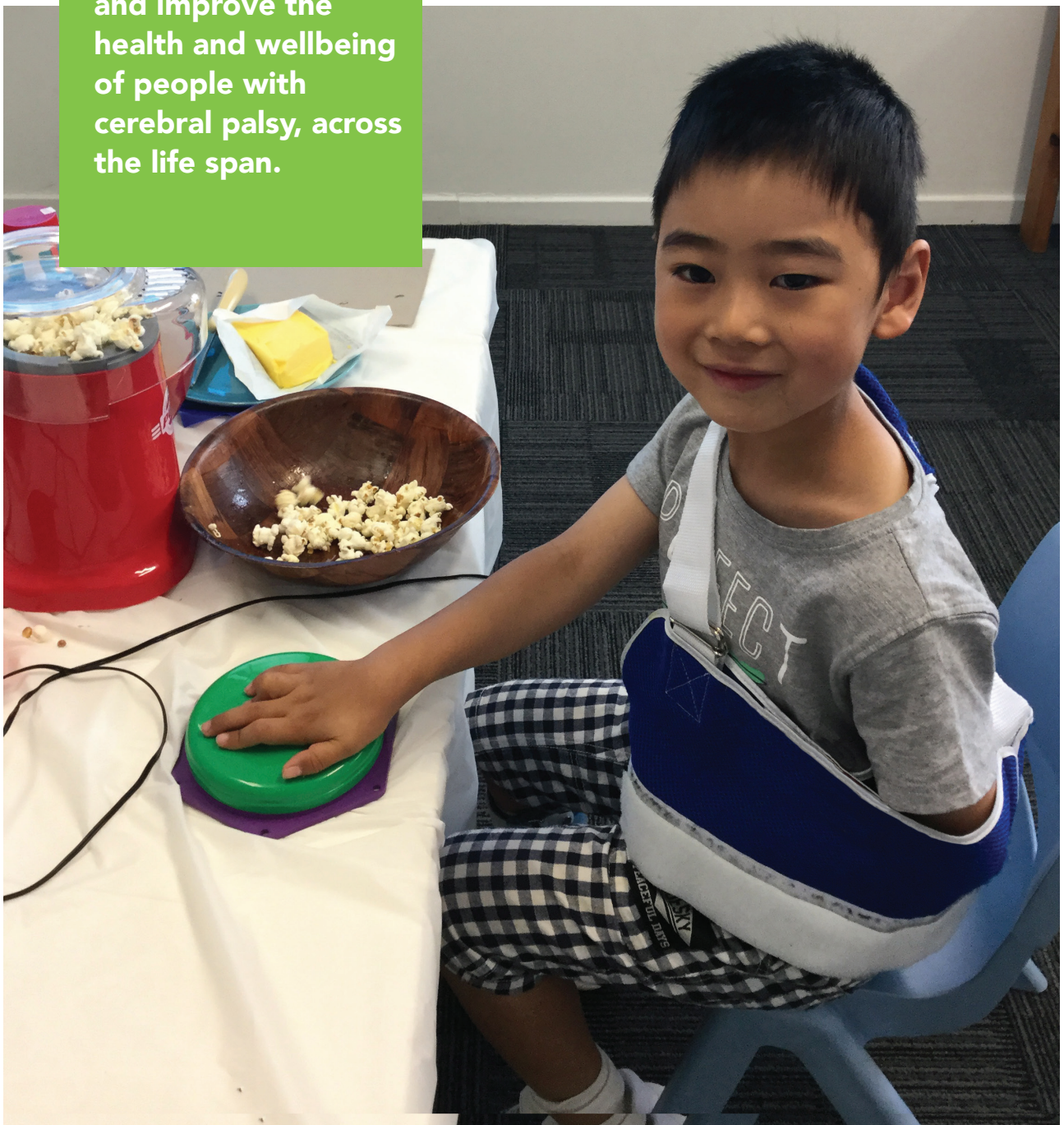
Remarkable is an innovative start-up accelerator made possible by Cerebral Palsy Alliance, committed to developing tech start-ups harnessing the power of technological innovation for driving inclusion of people with disability. Launched in 2016, Remarkable accelerates disability-tech start-ups through a 16-week accelerator program and initiates innovation through events like Remarkable Design-athon. Supporting a total of 41 disability focused start-ups since its launch, including 22 start-ups since 2020.

What Next?

Right now, there is significant opportunity to leverage technological innovation to drive an inclusive future. A total of eight start-ups were supported in 2022, including smart home solutions, navigation technology, fitness applications, and robotic gate technology. Through a total investment of \$29.3m since 2016 in 98 founders and co-founders (18 of which have a disability), Remarkable continues to push boundaries in technological innovation and the disability inclusion.

⁵ Social prescribing programs describe a standardised way for health care professionals to identify patients experiencing unmet social needs (e.g. concerns with food, housing, financials) and link patients to suitable supports and services in the community. These programs can include written resources, referrals, and/or 1:1 navigation support from a person.

We aim to maintain and improve the health and wellbeing of people with cerebral palsy, across the life span.





Assistive Technology - Research into Communication, Cognition and Mobility

Since 2017, Cerebral Palsy Alliance has significantly expanded its technology focus through the appointment of a Chair of Technology for Cerebral Palsy, University of Sydney, the establishment of a research program comprised of 4.5 full-time equivalent research staff at Cerebral Palsy Alliance Research Institute, and through partnering with research collaborators, biomedical engineers and commercial partners. A current focus is on developing new technology solutions for people with cerebral palsy in the areas of communication, cognition and mobility:

Cognition

The 'Cognitive Testing using Eye-Gaze and Switch Technologies- Children' ('CogTEST-C') project is currently underway, with recruitment scheduled to commence in late 2022. CogTEST-C aims to develop and examine accessible cognitive assessment tools for children with speech and/or fine motor impairments, who would not otherwise be able to access assessment.

What Next?

CogTEST-C has limited philanthropic funding. More is needed to expand to adults, accommodate questionnaires, establish license agreements with test publishers and translate to clinical practice.

Communication

Approximately 1 in 4 of people with cerebral palsy have difficulty speaking and need convenient, portable and socially acceptable solutions such as MY Voice Library and Mixed Reality (MR), Eye-Gaze Technology (EGT) and Brain and Computer Interfaces (BCI).

What Next?

Whilst a number of successful individual projects are underway to develop and pilot technology-based communication solutions, a program of research including a virtual space is needed bringing together bioengineers, allied health professionals and people with lived experience.

Mobility

Projects underway include soft robotics for improved standing and walking in infants, the use of neuromodulation techniques to reduce pain and spasticity, and Techtoys; a multi-stakeholder project identifying gaps in the commercial toy market for families with cerebral palsy.

What Next?

In Techtoys, funding is needed to develop prototypes, purchase materials and develop licensing agreements with producers towards establishing a commercialisation pipeline and ongoing invention program. Funding is also needed to support trials to advance the evidence base in soft robotics for children with cerebral palsy and neuromodulation techniques to treat pain and spasticity.



Genomics

On track but not yet complete

The International Cerebral Palsy Genomics Consortium (ICPGC), formed in 2017, now has more than 200 members from academic and medical centres from 29 countries on six continents. Since its inception, the ICPGC and its members have continued to break new ground on what genes can contribute to cerebral palsy. Collectively, genetic findings for more 3,000 people with cerebral palsy are now reported in the scientific literature, with hundreds of genes implicated. This work is vital for clinicians to provide individuals and families with up-to-date information and improve patient care following the identification of a causative genetic variant. Following on from the boom of new knowledge, two working groups have formed that aim to examine the strength of the evidence of these genes:

- A collaboration with Australian Genomics and Australian Panel App, dedicated to evaluating the genes identified in the scientific literature. The group has examined more than 100 genes that have been associated with cerebral palsy, of which 78 have a high level of evidence to support a strong association with causing cerebral palsy.
- In partnership with ClinGen (National Human Genome Research Institute, USA), a National Institute of Health-funded resource has the ambitious goal to curate all the roughly 1,500 genes currently marketed for clinical testing for cerebral palsy.

What Next?

Establish a national advisory group in Australia, where people with cerebral palsy and their families can help shape the future of clinical and research pathways of genomics in cerebral palsy. Together, we will:

- **Identify key communication issues, and major areas of concerns;**
- **Involve families in key clinically relevant questions and programs;**
- **Develop education materials to build awareness to improve genomic literacy and dispel myths that prevent best practice; and,**
- **Advocate for equal access to genomics services.**

We are currently trying to obtain funding to support this next project.

Improved community understanding of cerebral palsy including complex communication

Success Indicator: Australian and New Zealand general public to have an accurate understanding of what cerebral palsy is and how to communicate with people with complex communication needs.

Goal area: Inclusion and Engagement

Inclusion and active participation have been demonstrated to have a range of positive impacts on multiple life areas. Yet people with cerebral palsy continue to face significant barriers to inclusion and participation in all aspects of life. In addition to the physical disability associated with cerebral palsy, approximately one in two people with cerebral palsy have difficulty with communication and one in four are nonverbal. People with complex communication needs face additional barriers participating in society. This is partly due to a lack of community understanding of cerebral palsy and knowledge of how to communicate with people with complex communication needs. Progress made against this success indicator will allow for a more inclusive society by providing opportunities for individuals with cerebral palsy to actively participate, ultimately enhancing their quality of life.

Projects and engagement that address a better understanding of cerebral palsy and complex communication for the wider community:



CPActive is an advocacy platform that brings together people with cerebral palsy and similar disabilities, their families, disability support persons and allies who are passionate about creating positive, lasting change for people with disabilities. Launched in May 2021 by Cerebral Palsy Alliance, CPActive is providing an opportunity for its members 2,500+ supporters, in particular young people, to actively engage in advocacy activities. Key campaigns include Early Identification and Intervention of cerebral palsy; Inclusive Education and Employment; and Accessible Assistive Technology. In addition to activating the wider community, CPActive has recently launched a Youth Lab series which is organising young people with cerebral palsy around issues like education, networking and navigating the transition from school to work. This includes 10 young champions who are already taking an active leadership role in policy discussions, meeting with Minister for the NDIS Bill Shorten and Prime Minister Anthony Albanese at the first NDIS Jobs and Skills Forum in Canberra in August 2022.

What Next?

There is an opportunity for further development and engagement, in increasing membership and expanding the reach of CPActive across Australia.



Inclusion and active participation have been demonstrated to have a range of positive impacts on multiple life areas.



World CP day

Achieved and ongoing

World Cerebral Palsy Day, held annually on 6 October, was created by Cerebral Palsy Alliance in 2012 and now brings together people with cerebral palsy, their families, allies, supporters and organisations across more than 100 countries with the aim of ensuring a future in which children and adults with cerebral palsy have the same rights, access and opportunities as anyone else. The 2021 campaign, 'Millions of Reasons', reached over 73 million people; an increase of 180% on the previous year. The campaign encouraged conversations around cerebral palsy, aiming to educate audiences about the unique factors of cerebral palsy, raise awareness about the changes that could have the most impact on people living with it and build issue engagement. The 2022 campaign focuses on 'Millions of Reasons for Accessible Technology Solutions'; crowdsourcing ideas for the next assistive technology breakthrough. This campaign will shed light on areas that need technology and accessibility improvement whilst engaging with the cerebral palsy community.

What Next?

World CP Day would like to continue to reach more individuals, communities, and organisations internationally, creating lasting impact and awareness around cerebral palsy. Further campaigning and funding of support will enable World CP Day to reach a greater audience bringing together the cerebral palsy community.



CMV awareness

Underway but facing significant barriers

Congenital Cytomegalovirus (cCMV) is a common virus and a major cause of disabilities in newborns, causing an estimated 400 lifelong disabilities annually. A preventable cause of cerebral palsy, CMV is estimated to have a causal link in up to 10% of cerebral palsy cases. In collaboration with CMV Australia, Cerebral Palsy Alliance has led an awareness and prevention campaign to promote hygiene precautions to reduce the risk of CMV in pregnancy. Through the development of eLearning resources, information pamphlets and posters, social media, radio and catch-up television advertisements, Cerebral Palsy Alliance is raising awareness of both CMV prevention strategies and cerebral palsy.

What Next?

Future work should aim to engage the NSW Department of Health, major corporate partners and early childhood centres to further support and fund these initiatives. An eLearning course for general practitioners is also planned, while planning is underway for the next CMV Awareness Month in June 2023.



MY Voice Library

On track but not yet complete

Researchers from Cerebral Palsy Alliance, The University of Sydney, Sydney, University of Bologna, Italy, Scuola Superiore Sant'Anna, Pisa, Italy and a team of national and international collaborators have been awarded \$1.1 million across four years to develop a novel database of voice recordings of children with cerebral palsy. Commencing in 2022, this database will enable real-time communication solutions for children with cerebral palsy. Data collection will be gamified to enable the collection of data in a fun and engaging way for children. Once developed, this resource of 100 voice recordings will lay the foundations for a world-first database hosting the voices of children with cerebral palsy to enable researchers and engineers to build algorithms to gain the understanding they need to build innovative technologies to assist communication.

What Next?

While this project is in the early stages of development, the developed database is expected to enable a host of biomedical engineering projects to develop real-time communication solutions for children with cerebral palsy from the collected voice recordings. It is anticipated that research into automated dysarthria screening to complement clinical assessment will be possible. This will address a significant clinical challenge in dysarthria assessment.



STEPtember

Achieved and ongoing

A Cerebral Palsy Alliance initiative, STEPtember is Australia's leading virtual health and wellness fundraising challenge, encouraging Australians to take 10,000 steps a day their way, for 30 days during the month of September. The funds go directly to support Australians with cerebral palsy, including research into early detection and intervention, identification of babies at risk, telehealth for people cerebral palsy, supporting rural and remote individuals, and youth programs.

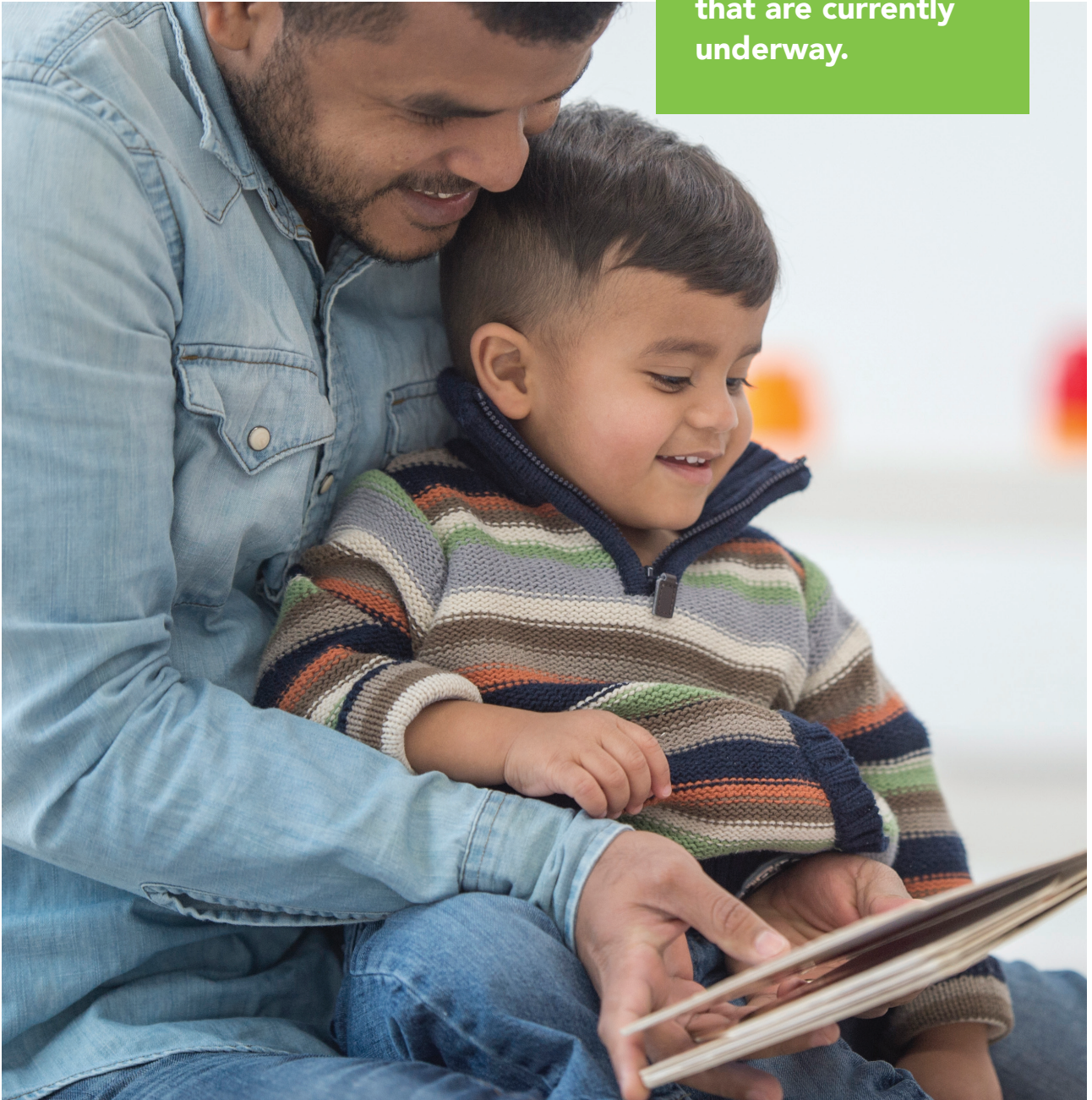
What Next?

STEPtember is continually growing, becoming one of the largest virtual health and wellness campaigns. In 2021, 11 countries participated, raising a total \$21 million. In Australia alone, there were 134,435 participants in 2021, up from 84,099 in 2020. The fundraising campaign aims to continue to reach a greater number of participants, increasing the fundraising capabilities each September whilst raising awareness for the cerebral palsy community.

CPActive is an advocacy platform that brings together people with cerebral palsy and similar disabilities, their families, disability support persons and allies who are passionate about creating positive, lasting change for people with disabilities.



**This Australian
Impact Report 2022
has endeavoured
to map research,
projects, and
opportunities
that are currently
underway.**



Concluding Remarks

Cerebral palsy remains underfunded and under-recognised in the political and social arena in Australia and New Zealand. The Strategy established a pressing need for action across goal areas and priority objectives. By identifying success indicators, it also provided a first step towards developing a Trans-Tasman action plan. This Australian Impact Report 2022 has endeavoured to map research, projects, and opportunities that are currently underway across Australia, within four of the Strategy's success indicators. The recognition of accomplishments to date, work underway, and identification of areas of ongoing need, provides a targeted road map with which to measure progress towards each of these success indicators. Systematic progress within each success indicator will ultimately contribute to achieving the mission and vision of the Strategy.



