# WINDOW OF OPPORTUNITY

*Don't wait and see. Screen for CP!*

The case for a **national early screening program** to detect cerebral palsy in newborn babies

August 2021

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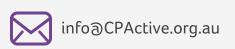CPActive.org.au          info@CPActive.org.au          # WindowOfOpportunity

# What is the
# Window of Opportunity?

**In Australia, a baby is born with cerebral palsy every 20 hours, making it the most common physical disability in childhood, with close to 500 children diagnosed every year.**

Some 34,000 Australians are living with CP, their conditions ranging from relatively mild to severe impairment.

There is a window of opportunity in the first 12 months of a baby's life when neuroplasticity is highest. In that window, diagnosis and treatment for cerebral palsy can make a lifetime of difference.

But in Australia today, average diagnosis typically occurs between 12-24 months of age. This delay means that 75%[1] of newborns are missing out on therapy and intervention when the baby's brain is in its ideal state of high neuroplasticity.

Early interventions from allied health therapists, such as speech, physiotherapy and occupational therapy, provides parents and their babies with the best chance of neurorehabilitation. This is proven to increase a child's chances of moving, eating, communicating and living more independently later in life.

## Neuroplasticity

Put simply, neuroplasticity is the brain's ability to change, adapt and develop new connections.

This ability 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.

> " *Our aim is that every child with cerebral palsy gets an early diagnosis so that they can get early intervention, and their parents can have support during this difficult time in their lives. Most parents say to us, I prefer to know early, and what they are really saying is I want to help my child.*

## Professor
## Iona Novak

*Cerebral Palsy Alliance Chair of Allied Health, University of Sydney, Faculty of Medicine and Health*

# The solution:
# BaMS for BuBS

**Baby Movement Screening (BaMS) is a program that will give every parent the chance to screen their baby for cerebral palsy and related conditions in the first three to four months after birth.**

Cerebral palsy is the most common physical disability in childhood, affecting close to 500 babies every year in Australia. It is a lifelong, chronic disability affecting a person's mobility and posture.

At the age of three months, it is normal for a baby to have certain predictable movements. There are various words used to describe them, such as 'fidgety', 'startles', 'twitches' and 'yawning'. Breathing patterns can also be distinctive.

If a baby does not have these general movements or has unusual patterns of them, then this may indicate some development problem in the central nervous system. European researchers have taken this insight to build the 'General Movements Assessment' to predict with a high level of accuracy the probability of CP in a baby between 12 and 16 weeks old.

The process involves a trained health professional observing an awake infant lying on its back for three to five minutes. This can be done face-to-face, or remotely observing a video of the child.

The screening process allows babies who have positive indicators of CP or other similar conditions to be subjected to more detailed testing through three methods:
- General Movements Assessment,
- Hammersmith Infant Neurological Examination, and
- Neuro-imaging.

Combined, these three tools can predict a high risk of cerebral palsy with **98% accuracy**[2]

# How **BaMS for BuBS** works

**Under our proposal, BaMS would be included in early childhood health checks and embedded in the infant's 'My Health Record' (known for example, in NSW as the "Blue Book") for parents.**



Keep hands and feet in view

At three months of age, parents would be encouraged to take a short video of their child using a smart phone, where it would be uploaded to a secure portal for review by a trained assessor.

Infants identified as at-risk of CP or similar conditions would progress for further neuro-development assessments and, if necessary, would be referred for rapid access of Early Childhood Early Intervention for critical therapy via the NDIS.

## 25%

*Only one-quarter of children with CP are currently diagnosed before the age of six months* [1]

# Opening the
## window of opportunity

**CPA modelling shows that, over a 10-year period, BaMS would identify 3,750 babies whose cerebral palsy would otherwise go undetected until later in life.**

Fast-tracking these babies into therapy and support would deliver a net benefit of around $17 million over the first ten years, a figure that will increase significantly over the life of a person with CP as the accumulated benefits of early detection are realised.

In the long run, the cohorts of children that received early intervention under the scheme would enter the workforce and contribute more due to better mobility outcomes that were secured from the early detection and intervention.

**3,750** **children with cerebral palsy** *will benefit in the first decade of the program*

**10%** **reduction in health costs of CP** *as a result of earlier screening & intervention*

**$1.16** MILLION **lifetime individual benefit** *for each child to receive early diagnosis*[3]

# Family experiences of **early screening**

**Parents who suspect their baby may have cerebral palsy are often told to 'wait and see', meaning many miss the window for crucial early intervention. BaMS for BuBS will provide concerned parents with certainty, ending the stressful cycle of guesswork and confusion that many experience.**

*They were reluctant to diagnose. Subsequently the GP made the neonatal guy tell me that he had cerebral palsy. Before he was diagnosed, I felt awful because I found it really hard to do things like bathe him. I thought it was me being inadequate. After the diagnosis it was easier, because it was acknowledged.*

*It was quite a fight to get somebody to take it seriously. It took a private paediatrician... We're very grateful to him because he said, 'Yes, I can see what you're saying'. Everyone else seemed to think, 'First time mother, she's over-reacting'.*

*When I took him to the baby clinic for his four-month check-up, the nurses noticed that he might have cerebral palsy. Afterwards they said it wasn't their business to tell me, 'It was the doctors' responsibility'. When I asked the neonatologist or paediatrician whether he had cerebral palsy, they said it was too early to tell.*

*When he was two weeks old, I noticed something wrong. He would not stop crying and wouldn't eat. He was sleeping no more than eight hours a day in small blocks. I went to a sleep clinic to try and find out what was wrong, but nothing helped.*

# How you can get involved

Every baby deserves the chance of life-changing early intervention. Our goal is simple: we want every baby born in Australia to be screened for cerebral palsy and similar conditions at three months of age. To achieve this, we need your support!

Together we can open the window of opportunity for children with cerebral palsy. Here's how you can help:

**Sign the petition...**
and ask the Federal Government to open the window of opportunity for all Australians born with cerebral palsy.

**Tell us about your experience with cerebral palsy...**
and how you or your child's diagnosis impacted your family. These are the stories that will make decision-makers sit up and take notice.
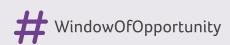
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Connect with us and get involved in our campaigns for change. Visit our website or send us an email for more information.

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2. Morgan C, Romeo DM, Chorna O, et al. The Pooled Diagnostic Accuracy of Neuroimaging, General Movements, and Neurological Examination for Diagnosing Cerebral Palsy Early in High-Risk Infants: A Case Control Study. J Clin Med. 2019;8(11):1879. Published 2019 Nov 5. doi:10.3390/jcm8111879

3. Benchmark Analytics economic analysis conducted on behalf of Cerebral Palsy Alliance, August 2021

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