

Epidemiology

Understanding the trends, prevalence and causes of cerebral palsy across multiple populations



Cerebral Palsy
ALLIANCE

RESEARCH FOUNDATION



Epidemiology literally translates to “the study of people”. It is the branch of medicine and research that studies and analyses the incidence, distribution and causes of a condition in a population. It is a cornerstone of public health, and shapes policy decisions and evidence-based practice. Researchers do this by measuring outcomes following changes in practice, identifying risk factors and causes for a condition and identifying targets for preventive healthcare.

Epidemiology research in cerebral palsy uses large population datasets (CP Registers) to better understand the causes of CP, identify new avenues for prevention, and report trends about the rate and severity of CP over time. This helps us to identify if treatments and prevention strategies are working for a whole population.

Learnings and infrastructure from CP Registers in one population (e.g. Australia) can be used as a platform for other populations (e.g. Low- and Middle-Income Countries).

Current focus areas for epidemiology research in relation to CP:

- Cerebral Palsy Registers
 - reporting trends in Australia and around the globe
- Prevention of cCMV (congenital cytomegalovirus), a known cause of CP
- Identifying new causal pathways to CP, particularly, better understanding of the genetic contribution to CP

Improving outcomes for people with CP around the world

Our epidemiology research priorities to improve the lives of people with cerebral palsy:

1. Ensure the Australian CP Register (ACPR) is complete and ongoing, so we can track trends and identify better ways to prevent and minimise CP severity. Current focus areas include reducing severe CP, CP in Aboriginal and Torres Strait Islander populations, and ensuring equitable access to services for all.
2. Collaborate with registers around the world to improve outcomes for people with CP. We have a particular focus on supporting the registers in Low- and Middle-Income Countries.
3. Continue to build awareness of CMV prevention and other prevention strategies. Includes working with Midwives, Obstetricians, GPs, perinatal infectious diseases specialists and the community to implement public health campaigns to prevent CMV in pregnancy, develop a congenital CMV register and a nation-wide CMV network.
4. Advance genomic research to understand causes and develop opportunities for personalised medicine for CP. Current focus areas include: families with siblings with multiple neurodevelopmental outcomes, launching the CP Commons (an international, centralised resource for genomic and clinical findings), identifying and classifying the evidence of potentially important genes, growing the International CP Genomics Consortium (ICPGC) to increase global collaboration and accelerate the knowledge translation pathway.

What epidemiology research means for people with cerebral palsy

Epidemiology research can significantly change the future of cerebral palsy through:

- Reporting CP trends and severity over time
- Identifying and driving focus areas for prevention strategies
- Measuring treatment changes across the whole population and identifying which treatments are working to prevent and reduce the severity of CP across Australia

Ambitious research goal

The current rate of CP in Australia is 1.4/1000 live births, a 30% decline since the mid-1990s. With further advances in maternal, neonatal and infant care, our goal is for the rate of CP to decline further to 1/1000 live births by 2030.

Family perspective

"I find this very exciting, because 21 years ago, when our daughter was born at 27 weeks, we were told this was just life, and there were no prospects of prevention in the future. Yet here we are today with these fantastic results [30% reduction in CP], that proves research, great care and registers together, make a huge difference."

*Leanne Diviney,
mother of Hannah and member of our CP Register Advisory Group*

Theme Leader



Dr Sarah McIntyre:
BAppSc (Occupational
Therapy) (Hons),
MPS, PhD

"When I first started in this job, there had been no real changes in the rates of CP, but there were some exciting new breakthrough treatments on the horizon. I knew it was important to further understand the causes of CP and to keep measuring and reporting back to families, clinicians and researchers about any small change in rates.

I am thrilled that our team have contributed to identifying causes, are working on prevention strategies, and through the Australian CP Registers are now able to report a real and sustained reduction in CP.

It's a massive team effort across Australia and around the world, and it's an exciting area to be working in. We have a fantastic group of researchers and next gen researchers in the Epi theme, and they are all passionate about high quality data, rigorous research methods, and working with people with CP and their families to ensure we have maximum impact with our work."

Dr Sarah McIntyre



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