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The Importance of Registers in our Understanding of Cerebral Palsy

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Letter to Editor

Manuscript Type: Letter to the editor

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Morgan et al highlight the risk factors, recommended investigations and co-morbidities for the important large group of children with cerebral palsy (CP) born at term.¹ Whilst there has been a recent decline in overall rates, there are still about 700 new cases each year in Australia and 34,000 individuals with CP. Morgan et al describe substantial co-morbidities including pain, sleep disorders and epilepsy.¹ Other work has stressed poor outcomes for adults with CP who have lower educational achievement, reduced employment, lower levels of annual income, and who are more likely to be single and live in the parental home.² CP is a lifelong condition affecting not only individuals but also their families and society. The annual cost of CP in Australia is approximately \$1.5 billion (0.14% of GDP) and lost well-being (as a result of disability and premature death) can be valued at a further \$2.4 billion.³ National Disability Insurance Agency data indicate that people with CP represent 5.2% of those requiring support but need the second highest annualised support package in dollar value (median: ~\$50,000).

As Morgan et al point out,¹ making a correct diagnosis early in life is crucial. It is then important to offer families evidence-based interventions where available. The management of CP also requires a team with the child and their parents at the centre, as important partners every step of the way.

Morgan et al's used prevalence figures from the Australian Cerebral Palsy Register (ACPR).⁴ The ACPR collects information from every state and territory in Australia. Three of the Registers are long-standing: the Western Australian, Victorian and South Australian Registers founded in 1977, 1986 and 1998 respectively. Registers are the foundation of research in CP. Difficult to fund and taking many years to become fruitful, they provide epidemiological information and can also provide cohorts for studying specific aspects of care. For example, the Victorian Register has been the basis for 112 projects and 117 publications have resulted from it, covering diverse areas such as MRI findings, hip management, epilepsy and language outcomes. Substantial further research is needed across all areas of CP aetiology and management to ensure the best evidence is available to guide treatment. The CP Registers provide a good place to start. Let us join together to increase the

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research efforts to achieve optimal participation and quality of life for this important group of people.

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