The Singapore Cerebral Palsy Registry: An important new resource for cerebral palsy research

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Cerebral palsy (CP) is a common, lifelong disorder of movement and posture resulting from an insult or maldevelopment of the developing brain. The movement disorders of CP are often accompanied by other associated sensory and cognitive impairments. For the majority of children (about 95% in high income countries), the brain injury responsible for their CP occurs in the pre/perinatal period. The birth prevalence for this group has been estimated to be 1.4 (95% confidence interval 1.3–1.6) children per 1,000 live births.¹ The smaller, post-neonatal CP group refers to those children who acquire a brain injury beyond the neonatal period and before 2 years of age. While there are many well-recognised risk factors for CP, the causal pathways for both pre/perinatally and post-neonatally acquired CP are complex and, in most cases, not fully understood. Understanding these pathways is essential for identifying opportunities for prevention. CP registers, which aim to collect a defined minimum data set for all children with CP at a specific age, within a specified geographic region, can be used to identify aetiological risk factors and map causal pathways.

CP register datasets also provide a means to examine temporal trends in prevalence, clinical profile and severity of disability. In recent years, declines in both birth prevalence and severity of pre/perinatally acquired CP have been reported by CP registers internationally.^{2,3} These declining trends provide further evidence to support the effectiveness of advances in perinatal and neonatal care including but not limited to the use of magnesium sulphate and corticosteroids in anticipated preterm birth.⁴ The Singapore Cerebral Palsy Registry (SingCPR) established in 2017, has now joined the expanding international community of CP registers, committed to both identifying opportunities for prevention of CP and improving the lives of children and adults with CP and their families.

In this edition of the *Annals*, Ng et al. describe 151 children with CP recruited to the SingCPR, outlining the children's clinical profiles (e.g. CP motor type,

functional motor limitations, vision and hearing), pre/perinatal risk factors (e.g. preterm birth, low-birth weight and plurality), known post-neonatal causes (e.g. infection and head injury) and other factors associated with quality of life (e.g. sleep and pain).⁵ The majority of children were recruited to the SingCPR from 2 large tertiary hospitals, including very low birth weight clinics run within these hospitals. Compared with findings from high-income countries where the largest group of children with CP are those born at term,¹⁻³ the SingCPR paper reports unexpectedly high proportions of preterm births (>75%). Similarly, twins (20%), children with either bilateral spastic CP motor type (>65%) or dyskinetic CP motor type (>25%) and severe gross motor function limitations (>40%) are also over-represented. While it is possible that these findings represent country specific differences,⁶ it is more likely that the findings from the SingCPR reflect the profile of preterm children with CP born in the tertiary hospitals and children with more severe disability profiles accessing services at these hospitals. Moving forward, it will be helpful to understand more about the number and profile of individuals who choose to opt out of the SingCPR compared with those who choose to participate. It will also be important to determine whether there are children with CP in Singapore who do not access these hospitals, and are being missed by the current recruitment strategy. By investigating these questions, the SingCPR team will then be well-placed to determine whether the current recruitment process will capture all or nearly all children with CP, or whether it will require adjustment. It will be interesting to see if and how the profile of CP reported by SingCPR changes as the programme becomes more established and recruitment expands.

In addition to clinical, demographic and aetiological risk factors, the SingCPR has included pain and sleep variables within their data collection. While it is not clear what specific questions or questionnaires were used, most families reported that their children had no

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or few difficulties with pain or sleep. This contrasts with previous research from the Netherlands, Australia and Canada, which has identified that difficulties with both pain and sleep are common among children and adults with CP; reported at higher rates than the general population, with estimates of >50% experiencing chronic pain and sleep problems.⁷⁻¹⁰ In recent years, there has been a greater awareness and recognition of the substantial impact these difficulties can have on both the individuals with CP and their families. In response, new toolboxes and resources to guide the management of chronic pain and sleep problems are emerging.¹¹

Beyond the findings of this first paper, the establishment of the SingCPR signals the beginning of an exciting new era for CP research in the region. CP registers are invaluable tools for both clinical and epidemiological CP research. In addition to their usefulness in monitoring temporal trends in prevalence, data from CP registers can inform the development of services, assist in the evaluation of new interventions and be used as a source of recruitment for research studies. Furthermore, when register groups collaborate, they can use their combined de-identified datasets to answer research questions pertaining to small specific subgroups of children, which would otherwise not be possible using other methodologies.¹² As a member of the international CP register community, the SingCPR researchers and clinicians are well positioned to develop links with other CP registers across the world through both informal networks and by contributing to and attending meetings such as the World CP Register and Surveillance Congress within the International Alliance of Academies of Childhood Disabilities Conference. These collaborations between registers and register networks provide opportunities to exchange ideas and knowledge and to develop programmes of collaborative research, ultimately advancing our understanding of CP.

The authors should be congratulated on establishing this exciting new CP register programme in Singapore. To establish and maintain a CP register requires tremendous persistence and the commitment of considerable time and resources by both the researchers

and clinicians involved and the custodian organisation(s) that support them. As the SingCPR dataset continues to develop in the coming years, there is no doubt that it will be a fantastic resource that will support researchers, clinicians and families to better understand CP both in Singapore and beyond.

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