

## Editorial

# A Call to Action: Advocacy as a Cornerstone of Child Neurology

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In this issue of the *Canadian Journal of Neurological Sciences*, Dr McMillan and colleagues<sup>1</sup> discuss the urgent need in Canada to have provincial payers align with regard to how treatments such as disease-modifying therapy for spinal muscular atrophy are funded. Since the initial trials regarding gene and antisense oligonucleotide therapy in spinal muscular atrophy several years ago,<sup>2,3</sup> there has been an increase in disease-modifying therapy for a number of rare neurogenetic diseases with onset in childhood.<sup>4</sup> While these individual diseases may be rare, taken together, there are more than 7,000 rare genetic diseases in Canada that have a significant impact on one million Canadians and their families: two-thirds of these diseases cause significant disability, and three-quarters affect children.<sup>5</sup>

Although our neuromuscular colleagues are at the forefront of these types of rare disease treatments, very soon all child neurologists will be involved in some way with these genetic treatments. Certainly, we will be involved in determining whether patients are candidates for a particular therapy and, more likely, will be initiating these therapies ourselves. We are entering a brave new world in child neurology and the old axiom of “nothing can be done for pediatric neurology patients” is completely outdated.

Dr McMillan et al. – using the example of patients with four SMN2 copies – emphasize the need to advocate for coverage of expensive therapies for rare disorders to ensure that every child across our nation is treated fairly, despite health care being a provincial mandate in Canada. Thus, the letter in this issue emphasizes the importance of advocacy as a cornerstone in child neurology practice.

### Advocacy for children with neurologic disabilities and a rights-based approach to care

The right to health is a fundamental part of human rights and is upheld in many documents including the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights.<sup>6</sup> As such, a rights-based approach to health is based on the concept that every human being has the right to the highest attainable standard of physical and mental health and that we, as both healthcare providers and community members, have a duty to create health systems and public health measures that improve the underlying social determinants of health.<sup>7</sup>

An intrinsic part of the right to health is the right to nondiscrimination with regard to age, disability, socioeconomic status and geographic location. Children with neurologic disabilities may be at an increased risk of living under structural and systemic inequalities.<sup>6</sup> For example, they are more likely to live in low socioeconomic status, foster care, rural areas or be of aboriginal origin. Children with neurologic disabilities are also at risk for being exposed to heavy financial burdens on families, caretaker burnout (including stress and mental health issues) and the inaccessibility of the community/environment, all of which are social determinants of health.<sup>6</sup> As children with neurologic disabilities live longer, there is a large cost to treating neurologic disabilities across the lifespan. However, these costs can be optimized by ensuring we advocate for a rights-based and evidence-based approach to care of these individuals.<sup>8</sup>

Historically in Canada, these have been legal challenges initiated by patients and families in order to ensure that children received the optimal treatment for their conditions. Shikako-Thomas and Shevell state,<sup>6</sup> however, that healthcare providers can potentially mitigate the need for legal action by advocating for health services and health structures to take into account a rights-based approach to health care from the beginning.

### Advocacy in child neurology training

Advocacy, in and of itself, essentially means endorsing effective solutions for patients and their families. These solutions can range from action being taken at the local community level to national and international efforts.<sup>9</sup> In order to ensure that all child neurologists are adequately prepared in this competency,<sup>10</sup> advocacy should be integrated into postgraduate residency training in child neurology. It has been suggested that advocacy training in residency should include community resource identification and referral, screening for social determinants of health, effective use of medical-legal partnerships and political engagement.<sup>9</sup>

To aid in this, some clinical teachers may also need education in advocacy, as many faculty lack formal training, mentorship or protected time to engage in advocacy work.<sup>9</sup> Advocacy should also be valued by academic promotion committees. All of these steps are necessary to ensure that advocacy is not merely an accreditation requirement, an isolated community immersion experience or a “quality improvement” project with a definitive

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endpoint. It needs to be considered to be part and parcel of what it means to care for patients as a pediatric neurologist in Canada.

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