

Editorial

JPRM cerebral palsy special issue 2023

Heakyung Kim^a, Rachel Byrne^b and Michael Green^c

^a*UT Southwestern, Dallas, TX, USA*

^b*Cerebral Palsy Foundation, New York City, NY, USA*

^c*University of Utah Health, Salt Lake City, UT, USA*

The mission of the Cerebral Palsy Foundation (CPF) is to be a catalyst for creating positive change for the 17 million people with cerebral palsy around the world. This is done by linking people with CP and their care partners to experts and great thinkers in the world of CP. We welcome Rachel Byrne, Executive Director of the Cerebral Palsy Foundation as a guest editor for this Cerebral Palsy Special Edition. Rachel has been working in the field of pediatric rehabilitation and CP research for the past 17 years. She has a background in physical therapy (PT), with a particular interest in neuroplasticity and motor learning. Her early career as a clinician delivering PT services in schools, hospitals, and private practice is underpinned by her research interests focused on implementation science, knowledge translation, and the impact on a person's ability to participate in the community across the lifespan. At the Foundation, she has continued her research pursuits and has been instrumental in implementing early detection of and intervention for CP across the US, promoting inclusion in schools, and steering adult research for CP. As guest editor of the *Journal of Pediatric Rehabilitation Medicine's* (JPRM) Special Edition on Cerebral Palsy, Rachel's contributions enrich this publication by helping to bring the knowledge and expertise contained herein directly to the individuals most impacted by this condition.

Cerebral palsy (CP) is defined as a disorder of movement and posture due to a non-progressive lesion to an immature brain [1]. As such, children with CP may deal with movement problems which are commonly related to spasticity. Because a standardized clinical pathway for managing spasticity does not exist to guide providers toward optimal care for people with CP, there is significant variability in

the care provided to these individuals. This variability also exists partly because no single medication, intervention, or surgery manages spasticity perfectly throughout the lifespan. Additionally, existing surgical and pharmacological treatments come with their own side effects and adverse events, which can sometimes compromise function. These challenges can be exacerbated in child-onset conditions, making spasticity management particularly difficult in individuals with CP.

When individuals are young, it is common to start with conservative/non-invasive treatment such as physical therapy, occupational therapy, or orthoses. As the child grows and their developmental tasks become more nuanced, additional treatment modalities may be needed beyond the therapies and bracing that have already been initiated. However, determining the additional treatment modalities to layer-on can be challenging, since there are not specific guidelines for spasticity management. Thus, clinicians rely on their training and experience rather than a standardized clinical pathway. There's a body of research demonstrating the efficacy of botulinum toxin injections and surgical interventions for spasticity management and little research showing the efficacy of various enteral medications. Despite this, enteral baclofen has been used as a mainstay of spasticity management and was approved by the FDA for the same. Despite its side effects, many clinicians consider baclofen as the first line drug to treat spasticity in children with CP. Given the lack of systematically-collected data, it is extremely important for clinicians to consider experts' experiences and rationales regarding enteral baclofen use when selecting their interventions. We invited three experts on spasticity management to share their experiences and ratio-

nales: one to discuss the mechanisms and methods of baclofen as a treatment of spasticity, a second to discuss the cons of this medication, and a third to share the pros of using baclofen as a treatment for spasticity.

We, the guest editors, sincerely appreciate all contributors' participation in this Special Issue. Your contributions have enriched this issue and deepened the conversation about managing cerebral palsy. Although cerebral palsy is the most common childhood-onset disability, there are very few evidence-based clinical practice guidelines or recommendations. Your commitment to caring for children and adults with cerebral palsy, with the goal of improving research and its translation into evidence-based practice, will improve the care and quality of life for people living with this condition.

As part of this special edition JPRM is proud to be linking efforts with the Cerebral Palsy Foundation. For over 70 years, the Cerebral Palsy Foundation has provided answers for individuals with cerebral palsy and their families through leadership in advocacy, science, research, and medicine. Their commitment to accessibility, representation, inclusion, and a passionate belief in the abilities of all people drive the Foundation to accept nothing less than continued growth, innovation and success.

At the center of their mission is children and adults with cerebral palsy and their families. The Foundation strongly believes that there is a critical difference between obtaining stakeholder feedback and giving stakeholders the real power needed to affect the research process and resulting outcomes. To ensure the latter is achieved, partnerships with continued communication, decision-making abilities, shared vision and change management are essential. In all the work that they do, their goal is to work closely with leaders, to develop, share, invest and provide infrastructure to otherwise underfunded areas. The Foundation uses proven models of implementation and developed research agendas to support deep systems change. (See Editorial Note.)

More than ever, there is an urgent need for dialogue about inclusion of individuals with disabilities in research, medicine and improving healthcare systems. Implementation potential, with translation, education and dissemination will be key to a truly engaged process between stakeholders and researchers.

“Success is not final, failure is not fatal: it is the courage to continue that counts.” -Winston Churchill.

Editor's note: The editorial team is pleased to work with the CPF and other organizations with a shared mission to improve the lives of individuals with disabilities. As a proudly international journal, we also want providers in low-resource settings to be able to access the evidence-based care guidelines and life-changing research we provide. To this end we believe that we can no longer continue to publish research behind a paywall and hope that JPRM will become truly open access so that all the robust medical research will be freely accessible to those with cerebral palsy, their families, and their medical providers.

References

- [1] NIH. Cerebral Palsy [internet]. National Institute of Neurological Disorders and Stroke; [updated 2023 Jan 27; cited 2023 Mar 6]. Available from: <https://www.ninds.nih.gov/health-information/disorders/cerebral-palsy>