

## Editorial

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# From autism to zoom<sup>®</sup>: Spina bifida advocacy, care, education, and research in a changing world<sup>1</sup>

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**Abstract.** Whereas legislation mandates for folic acid fortification have been implemented throughout many nations, divergent neural tube defects (NTDs) prevalence rates still remain among the world's populations. In North America, the prevalence estimate is 39 infants per 100,000 live births. Open spina bifida (SB), also known as myelomeningocele, remains the most complex congenital abnormality of the central nervous system compatible with long term survival; this recognized complexity gives rise to emerging comorbidities and interventions. For example, increasing autism spectrum disorder rates have been reported among individuals with SB utilizing a 31,220 subject population-based birth cohort. Along with new clinical observations, telecommunication platforms such as Zoom<sup>®</sup> have evolved as clinical and investigational tools. Historically, society meetings, research conferences, and journals have provided opportunities for professional development and dissemination of up-to-date materials. The *Journal of Pediatric Rehabilitation Medicine* (JPRM) has arisen as an open-access global platform for the dissemination of SB-related inquiry. The journal has also highlighted the research presented at the Spina Bifida Association's previous Spina Bifida World Congresses. At the last congress, which was held in 2017, twenty-three countries were represented; this number is expected to grow by the next convocation in 2023. This congress will provide an opportunity for health care professionals from around the globe to present a broad array of research topics and build collaborations. Concurrently, the JPRM will continue as an open-access platform for SB advocacy, care, education, and investigation, across our fast changing world for the international SB community well into the future.

**Keywords:** Myelomeningocele, autism, telemedicine, international collaboration, global health

Neural tube defects (NTDs) are an important source of morbidity and mortality globally. Though recent legislation mandates of folic acid fortification of staple cereal grains has begun throughout many

nations, divergent NTDs prevalence rates remain among the world's populations [1]. Notably, great variation in these prevalence estimates persist among upper-middle to high-income countries [2]. In North America, the prevalence estimate is 39 infants per 100,000 live births [3]. Open spina bifida (SB) remains the most complex congenital abnormality of the central nervous system compatible with long term survival [4]. The recognized complexity gives rise to well-known comorbidities and interventions, such as executive function impairment and ventriculoperi-

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toneal shunting respectively. However, in this fast changing world, new comorbidities and intervention modalities are also emerging. For example, increasing autism spectrum disorder rates have been reported among individuals with SB utilizing a 31,220 subject population-based birth cohort [5, 6]. Along with new clinical observations, telecommunication platforms such as Zoom® have evolved as SB-related clinical and research tools [7]; from telemedicine to customized electronic medical records, technologies continue to be adapted for service in SB care [8, 9]. To keep pace with the rapid transformations in our changing world, clinicians who serve the SB population must be able to turn to reliable sources of information and continuing medical education. Historically, society meetings and research conferences have provided opportunities for professional development and dissemination of up-to-date materials. Yet, in an interconnected and speedily changing world, open-access medical journals hold promise to further bridge the knowledge gap between clinicians in low and high-income countries [10].

The medical information chasm can be narrowed when journals provide an opportunity, not only of dissemination of current research findings, but also the occasion to underscore the most salient discoveries through condition specific special issues. The *Journal of Pediatric Rehabilitation Medicine* (JPRM) has emerged as an international platform for the dissemination of SB-related research. Through SB-specific special issues, JPRM has aided professionals at home and abroad in keeping abreast of the latest investigational inquiries and their findings from institutions around the globe. This current special issue is no exception, for in its pages the most recent findings in the SB-related care of many comorbidities can be found. From amputations, to scoliosis, to sleep related breathing disorders – the investigational avenues explored are many. Additionally, the journal also previously highlighted much of the innovative research presented at the Spina Bifida Association’s Third Spina Bifida World Congress. At this international congress, which was last held in 2017, twenty-three countries were represented, a number which is expected to grow by the next convocation. The 2023 World Congress on Spina Bifida Research and Care (SBWC 2023) will be held March 22–25, in Tucson, Arizona.

Aware of the growing global community, the SBWC 2023 will offer a *Global Health Symposium* as a pre-conference activity. This symposium will specifically focus on “Assistive Technology and Col-

laboration on Self-Management Promotion,” as well as “Prenatal Surgery Care in a Global Health Context.” During the symposium experts from multiple centers across the globe will share their lived experience and provide state of the art updates in their respective fields of expertise. Along with these presentations by leading experts, plenary sessions, and numerous research breakout sessions, the SBWC 2023 will also offer a number of practical workshops – for example, “The Lifespan Bowel Management Protocol” workshop will be presented. As with other presented workshops, this presentation will include practical recommendations to assist healthcare professionals in making informed treatment decisions with the available scientific data.

As a whole, the SBWC 2023 will provide an opportunity for health care professionals from around the globe to present the latest in basic science, clinical and translational research and build collaborations for future exploration. While the Spina Bifida Association is committed to this population, the JPRM will remain as an open-access platform for SB care, education, and research, across the multidisciplinary SB community well into the future. Furthermore, it can be trusted that the commentaries and original research published through this and future special issues will continue to serve as a catalyst for the broad range of research conducted to improve care around our fast changing world.

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