

International collaborations on advocacy, education, and research: Broad-spectrum thematic diversity catalyzes multidisciplinary spina bifida care

Jonathan Castillo^{a,*}, Judy K. Thibadeau^b, Tim Brei^{b,c} and Heidi Castillo^a

^a*Department of Pediatrics, Developmental and Behavioral Pediatrics, Texas Children's Hospital and the Baylor College of Medicine, Houston, TX, USA*

^b*Spina Bifida Association, Arlington, VA, USA*

^c*Department of Pediatrics, Division of Developmental Medicine, Seattle Children's Hospital and the University of Washington School of Medicine, Seattle, WA, USA*

Abstract. As with the wide range in spina bifida (SB) incidence rates across nations, there is also wide variance in topics encountered by clinicians today. Both the wide variance in SB incidence rates and the wide diversity of topics to be addressed provide the backdrop for any dialogue among professionals serving this population. On the international stage, the World Congress on Spina Bifida Research and Care has been the only conference dedicated solely to research, practical challenges, and real-life solutions for those living with SB, their families, and caregivers. As a conference with a clear sense of the growing global village, the 2023 congress showcased innovative research from junior to preeminent investigators. Topical areas included urology, neurosurgery, global health, prenatal surgery, and transition to adult care amid others. Ultimately, through the dissemination of a compendium of conference abstracts, we hope that professionals will be aided and inspired to continue to improve the education, advocacy, and care among the many communities of individuals affected by SB globally.

Keywords: Myelomeningocele, interdisciplinary collaboration, global health, quantitative and qualitative research, multidisciplinary approach

Autism, bowel continence, cognition, and so forth are part of the lineup of issues demanding attention from clinicians throughout spina bifida (SB) clinics today [1]. Propitiously, stepping up to meet these challenges is a new generation of professionals. They are not only addressing the charge but also engaging in innovative research to improve the outcomes relating to this summons. As with the far-reaching topics encountered by clinicians today, there is also a wide range in SB incidence rates across nations [2].

*Corresponding author: Jonathan Castillo, Department of Pediatrics, Developmental and Behavioral Pediatrics, Texas Children's Hospital and the Baylor College of Medicine, Houston, TX, USA. E-mail: jcporter@texaschildrens.org.

Furthermore, within countries, the outcomes related to various SB comorbidities diverge significantly among distinct segments of the populous. Thus, both the wide variance in SB incidence rates and the wide diversity of topics to be addressed are the backdrop to any dialogue amongst professionals serving this population.

On the world stage, the World Congress on Spina Bifida Research and Care – organized by the Spina Bifida Association – has been the only conference dedicated solely to research, practical challenges, and real-life solutions for those living with SB, their families, and caregivers. Historically, to address gaps and opportunities in SB care, the congress has engaged

experts and thought leaders [3]. Through this conference, the SB international community has been able to network across disciplines and centers to focus on treatment and investigation as well as education and social advocacy of this condition and the plethora of related issues commanding attention today [4].

As a conference with a clear sense of the growing global village, the most recent congress, held in March 2023, showcased innovative research from junior to preeminent investigators. Additionally, a special emphasis on strengthening the professional pipeline created opportunities for learners to attend and develop collaborations with those already in the field. This strategy not only provided the occasion for the wide-ranging research presented in this special issue but also opened the door for developing future agenda-driven investigational projects [5].

As with the presentations at the congress, the abstracts published through this special issue of the *Journal of Pediatric Rehabilitation Medicine (JPRM)* expand a widespread gamut of themes. Topics encompassed included urology, neurosurgery, global health, prenatal surgery, and transition to adult care amid others. With the passage of time and following other congresses, SB care has required fresh approaches to address its many emerging challenges amidst the global community. Concurrently, through the years, *JPRM* has emerged as an international platform for the publication and dissemination of the needed research. Thus, the *Open Access* publication of this compendium of abstracts presented at the 2023 World Congress on Spina Bifida Research and Care is to serve, not only as a repository, but also as a catalyst to continue the international dialogue. We thank

the Spina Bifida Association for their financial support in making this special supplement available as an *Open Access* issue. Ultimately, through the dissemination of this corpus of abstracts, we hope that professionals will be aided and inspired to continue to improve the education, advocacy, and care among the many communities of individuals affected with SB globally [6].

References

- [1] Castillo J, Thibadeau JK, Brei T, Castillo H. From autism to zoom[®]: Spina bifida advocacy, care, education, and research in a changing world. *J Pediatr Rehabil Med.* 2022;15(4):545-7. doi: 10.3233/PRM-220126
- [2] Frey L, Hauser WA. Epidemiology of neural tube defects. *Epilepsia.* 2003;44(Suppl 3):4-13. doi: 10.1046/j.1528-1157.44.s3.2.x
- [3] Sawin KJ, Betz CL, Linroth R. Gaps and opportunities: An agenda for further research, services, and program development in spina bifida. *Pediatr Clin North Am.* 2010;57(4):1041-57. doi: 10.1016/j.pcl.2010.07.020
- [4] Castillo J. Social determinants of health and spina bifida care: Immigrant and minority health in an era of quality of life and multicenter comparative analysis. *J Pediatr Rehabil Med.* 2018;11(4):213-6. doi: 10.3233/PRM-180484
- [5] Struwe S, Thibadeau J, Kelly MS, Widener-Burrows D. Establishing the first community-centered Spina Bifida research agenda. *J Pediatr Urol.* 2022 Dec;18(6):800.e1-800.e7. doi: 10.1016/j.jpuro.2022.06.014
- [6] Gandy K, Castillo H, Rocque BG, Bradko V, Whitehead W, Castillo J. Neurosurgical training and global health education: Systematic review of challenges and benefits of in-country programs in the care of neural tube defects. *Neurosurg Focus.* 2020;48(3):E14. doi: 10.3171/2019.12.FOCUS19448