

International Spina Bifida experts shapes future research, shares insights for practical care

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Spina bifida (myelomeningocele), a serious and complex spinal cord birth defect, has an estimated prevalence of slightly over three cases per 10,000 live births. As medical and surgical interventions have improved, the life expectancy of individuals with spina bifida has increased. However, further research to address the complexities of this multi-system condition more effectively is needed. In order to provide a multidisciplinary forum for research in spina bifida, the Spina Bifida Association (SBA) sponsored the Third World Congress on Spina Bifida Research and Care in 2017. This special issue of the *Journal of Pediatric Rehabilitation Medicine* (JPRM) presents significant contributions from that conference.

One of the primary goals of the SBA is to improve the health and quality of life of individuals with [spina bifida](#), who require healthcare from specialists across many disciplines. Once considered a pediatric condition, it is believed that there are now more adults living in the United States with spina bifida than children. Whether for adults or children, research is still essential to understanding spina bifida, finding better methods to treat people, and improving their health outcomes and quality of life.

Guest Editors Timothy Brei, MD, Professor of Developmental Pediatrics at Seattle Children's Hospital, and Amy Houtrow, MD, MPH, PhD, Director of the Spina Bifida Program at Children's Hospital of Pittsburgh and Associate Professor of Physical Medicine and Rehabilitation and Pediatrics, University of Pittsburgh School of Medicine, note that "this special collection of insightful research and review articles resulting from the last world congress is the culmination of the work by numerous researchers and clinicians who are dedicated to advancing the care of children and adults with spina bifida. It further

supports the goals set forth in during Spina Bifida Awareness month, 'Care About SB Care.'"

Sara Struwe, President and CEO of the Spina Bifida Association, adds, "While the World Congress events are crucial to improving care for people with spina bifida, equally significant is making sure that others know about the research related to their care. This why I'm delighted that the *Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach* is amplifying the research presented at the Third World Congress on Spina Bifida Research and Care."

The Congress represented the single largest and impressive forum of research related to spina bifida and included the breadth of research in the field, from bench to bedside and beyond. Published commentaries cover regenerative medicine, genetics, poverty and how it impacts care available to individuals living with spina bifida worldwide, trauma care for spina bifida patients, and self-management from both practical and theoretical perspectives.

Original research articles covering clinical and health services focus on topics ranging from managing the transition from pediatric to adult care, daily time management in children with spina bifida, bowel and bladder function, and the creation of care networks for patients. These and other articles provide an extensive grounding in the current state of spina bifida research and practical clinical care of spina bifida patients.

"I'm extremely pleased with the publication of this double issue of JPRM and the efforts of Birgit Bogler, our managing editor, to make this happen. This took a tremendous amount of work to bring everything together," comments Elaine L. Pico, MD, UCSF Benioff Children's Hospital Oakland (CA)

and editor-in-chief of JPRM. "It has been almost 10 years since we had consecutive spina bifida issues and this double issue is a landmark event for the journal. We also thank Dr. Houtrow and Dr. Brei for guest editing the special issue.

For those already devoted to spina bifida care, many are familiar with the work of Dr. Jay Neufeld, who recently passed away. This special issue includes professional and personal tributes to "Dr. J.," who launched and for many years served as Editor-In-Chief of the journal and was a major force in driving the field of pediatric rehabilitation. His legacy of dedication, action, and advocacy for children with disabilities and their families will live on.

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