

## Introduction to the Special Issue

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# Spina Bifida

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Spina bifida (myelomeningocele) is one of the most complex birth defects compatible with life, with an estimated prevalence of between 3.06 and 3.13 cases per 10,000 live births [1]. People of Hispanic descent have higher rates of spina bifida than non-Hispanic Caucasians [1]. Myelomeningocele is the most common form of “spina bifida”, but other forms of open and closed lesions exist, including lipomyelomeningocele, diastematomyelia, diplomyelia, myelocystocele, myeloschisis, and fatty filum.

With advances in medical care, more individuals with spina bifida are living to adulthood [2]. It is believed that there are now more adults living in the United States with spina bifida than children. Despite spina bifida’s multisystem effects and complexity, relatively little good quality research exists related to spina bifida. In 2003, the Centers for Disease Control and Prevention (CDC), the Agency on Healthcare Research and Quality (AHRQ), the National Institutes of Health Rare Diseases section and the National Institute on Child Health and Human Development and the Department of Education’s National Institute on Disability and Rehabilitation Research sponsored a conference entitled “Evidence Based Practice in Spina Bifida: Developing a Research Agenda”. These national experts in spina bifida invited for the meeting reviewed the existing research in spina bifida care in advance of this meeting, and reviewed the evidence for care, with the express purpose of developing a research agenda and highlighting research priorities in various areas of spina bifida. Information from that meeting indicated that most of the research on treatments in spina bifida were based on studies using relatively weaker study designs or were based on small groups of patients from

single sites [3]. As the Spina Bifida Association is currently in the process to revise the Health Care Guidelines for Spina Bifida, it is clear that, with the notable exception of the Management of Myelomeningocele Study (MoMS), the paucity of high quality research remains true today.

However, many strategies are underway to address this challenge. The first, the Spina Bifida Association (SBA), the only voluntary non-for-profit health agency for people with spina bifida and other neural tube defects, is working to build increasingly robust connections among providers and sites of care and to promote linkages that support patient-centered outcomes research in spina bifida. One of the realizations of SBA was that it was important to provide a multidisciplinary forum for research in spina bifida to be presented. Thus, SBA undertook sponsorship of the Third World Congress on Spina Bifida Research and Care on March 17–19, 2017, as a follow-up to their First and Second World Congress meetings in 2009 and 2012. The most recent meeting had over 370 attendees from 23 countries; 136 oral abstract presentations and 65 poster presentations were accepted for the Third World Congress on Spina Bifida Research and Care. This represents 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.

The Planning Committee of the Third World Congress and the Spina Bifida Association partnered with the *Journal of Pediatric Rehabilitation Medicine* (JPRM) and IOS Press to disseminate research from the World Congress. The journal, supported by ABC Medical Supply and the Division of Pediatric Rehabilitation in the Department of Physical Medicine and Re-

habilitation at the University of Pittsburgh/UPMC did an e-publication of the abstracts and posters selected for presentation [4]. In addition, JPRM and IOS Press agreed to publish a special edition on spina bifida of presented research presented the 3rd World Congress meeting.

As this special double issue related to spina bifida research is going to press, we are celebrating Spina Bifida Awareness month. It is fitting that the theme of Spina Bifida Awareness month this year is “Care About SB Care”. This edition 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. To all the presenters and researchers at the World Congress meeting and to people who submitted manuscripts for publication, whether or not your work is included in this or future editions, thank you for caring about spina bifida care.

We are delighted to include commentaries based on the plenary sessions from the 3rd World Congress. In this edition, eight commentaries are presented which cover important topics in spina bifida care and research. Commentaries of regenerative medicine, and genetics and spina bifida highlight cutting edge research. The commentary on trauma informed care in spina bifida reminds us that with spina bifida’s complexity, patients and their families can experience trauma associated with the care we provide, even when that medical care is necessary, and that we all need to be sensitive to this in the care we provide. Two commentaries discuss self-management from the theoretical to the practical. Finally, three commentaries are presented from colleagues in Latin America. Our Associate Guest Editors for this special edition, Dr Jonathan Castillo and Dr Kathryn Smith, were in charge of working with our Latin American colleagues so that their messages and distinctive viewpoints would be clearly understood.

In addition to the commentaries, this special double issue includes original research articles spanning clinical and health services. This impressive body of work doesn’t include multiple manuscripts that are still in a state of revision and were not able to be completed in time for the publication deadline of this special edition. As a result, PRM will be doing a spina bifida-focused regular edition of the journal to come out in the spring of 2018.

Readers of this special double issue will note that several manuscripts utilized the National Spina Bifida Registry to answer important research questions. The Spina Bifida Association advocated for funding for the development of the National Spina Bifida Program at the CDC after a research summit in 2003. Funding specifically for a National Spina Bifida Patient Registry was granted in 2008. Subsequently the registry has enrolled thousands of individuals with spina bifida across 19 centers in the United States. We are delighted to see how fruitful this partnership has been.

As we look toward the future of spina bifida care and research, we hope that the sponsorship of the 3rd World Congress by the Spina Bifida Association and the opportunity to partner with the *Journal of Pediatric Rehabilitation Medicine* in both the e-publication of the abstracts and this special edition of commentaries and original research will catalyze additional research related to spina bifida.

Finally, having a forum for more research related to spina bifida would not have happened if not for the efforts of Dr Jay Neufeld. As Editor-in-Chief of the journal, he was committed to having this special edition on spina bifida research and care come to fruition. We are saddened by his recent death and will miss his passion and enthusiasm. We thank Dr Jerry Clayton, as acting co-Editor-in-Chief, for responding to our needs as Guest Editors of this special edition and for helping ensure that this special edition could be completed for publication.

## References

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