

## Guest Editorial

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Spina Bifida is one of the most challenging and complex congenital birth defects for health care providers to treat. The care of children with Spina Bifida has moved beyond initial surgical solutions resulting in long stable periods. Consequently, the cutting edge of care now includes a comprehensive team approach and a stronger emphasis on (re)habilitation. We are now focusing on those with Spina Bifida becoming fully participating and contributing adults in society – transitioning from childhood to adolescent to adult care. Incorporating the World Health Organization International Classification of Function (<http://www.who.int/classifications/icf/en/>) provides a more holistic approach compared to the medical model of impairment. This edition of the journal brings together articles by well-known clinicians and researchers on primary care, neurogenic bowel and bladder, neurobehavioral outcomes, barriers to community participation, adolescent development and family functioning, and the development of a bladder protocol program in Kenya. The next issue will address additional issues of the spina bifida population.

Levels of independence, participation rates and employment rates are still much lower in this group than expected. The causes of these differences are only partly understood. Medical advances have addressed some major morbidities, though cures do not exist and individuals with Spina Bifida still require frequent hospitalization and surgery. Therapies have been developed to reduce the time, effort and burden of daily care needs and to facilitate the inclusion of children and adults with Spina Bifida into the community. It is increasingly recognized that the cognitive sequelae of Spina Bifida and difficulties with attention and executive function skills may play a significant role in the development of independence. Additionally, it is evident that family factors and individual beliefs are important in the long-term outcome of persons with Spina Bifida. As accessibility to and options for community activities and fitness improve, we need to encourage families to use and demand opportunities to build skills and develop interests. among youth with disabilities, as they do for all youth

With recent improvements in medical care, over 75% of individuals with SB now live into adulthood. Though the major causes of morbidity and mortality do not “go away”, adults with Spina Bifida additionally face new morbidities, such as pain and pressure ulcers. Issues such as obesity, cardiovascular disease, and cancer become relevant as aging occurs. Among children and adults, the impact of learning difficulties, family influences, beliefs and societal participation all remain significantly understudied.

Although a growing number of people with Spina Bifida are adults, most of the clinical services are provided by pediatric institutions and practitioners. Transition preparedness is now being recognized as a key component of pediatric services to prepare youth for adult care, life roles and responsibility. It behooves us to reach across cultural divides and support our medical and surgical adult counterparts in building and developing interest and expertise in care for adults with congenital conditions such as Spina Bifida. With an aging Spina Bifida population, adult providers will be needed to meet the challenges ahead. Psychiatrists can play a key role in filling this gap.

The Spina Bifida Association and the National Spina Bifida Program at the Centers for Disease Control (CDC) are partnering to support quality improvements in care and increased research to improve the lives of people with Spina Bifida. The “Guidelines for Spina Bifida Health Care Services throughout the Lifespan” have just been revised and are available through the Spina Bifida Association website ([sbaa.org](http://sbaa.org)). This Association also has supported the development of the Spina Bifida Clinical Care Network which provides a foundation to enhance care along with a framework that can ultimately encourage multi-site collaborative research. An initial step in this research initiative is the introduction of the Spina Bifida Database Registry project. This registry will begin enrolling patients soon and collecting data at eight sites around the country. It is hoped that as funding for Spina Bifida research increases, this data base can be expanded and new research questions added.

These and more issues will be discussed at the first World Congress on Spina Bifida care, in Orlando, Florida on March 15–18, 2009. We encourage you to attend, participate, and be active in the conference and in ongoing efforts for this special population.

*Guest Editors*

Tim Brei  
Medical Director, Spina Bifida Program  
James Whitcomb Riley Hospital for Children  
Indiana University School of Medicine

Indianapolis, IN, USA  
Medical Director, Spina Bifida Association  
Washington, DC, USA

Shubhra (Sue) Mukherjee  
Pediatric and Adolescent Rehabilitation  
Rehabilitation Institute of Chicago  
Chicago, IL, USA  
Physical Medicine and Rehabilitation  
Northwestern University Feinberg School of Medicine  
Chicago, IL, USA