

To The Editor:

Dr. Barron Lerner's perspective on Spina Bifida ("Playing God With Birth Defects in the Nursery) painted a disturbingly misleading picture. Unfortunately, he chose to focus on the work of two physicians and the comments of two young women to represent the medical community, the disability community, and a highly complex moral issue that is not so easily packaged. I know he was not speaking for the 250,000 members of the Spina Bifida community and tens of thousands of multidisciplinary health professionals who labor tirelessly to provide resources and care.

I prefer to deal with facts. Spina Bifida is the most commonly occurring and permanently disabling birth defect in the United States, today. The reality is that research is extremely limited and woefully under funded. Unfortunately, alluding to statistics regarding meningomyelocele, the most severe form of Spina Bifida, is as misleading as using a broad brush to address the decisions parents must make or the quality of life for those living with Spina Bifida.

As an adult living with Spina Bifida, I would have found his work more compelling had he used his bully pulpit to recognize a national problem that must be addressed. It would have helped had he sought to educate the over 60 million women who are at risk of giving birth to a baby with Spina Bifida. In fact, one of every 8 pregnancies is impacted by Spina Bifida and related birth defects. Women of childbearing age could reduce their risk by as much as 70% by taking a daily multivitamin containing 400 micrograms of folic acid.

Through my work with the Spina Bifida Association of America, the only national voluntary health agency working for people with Spina Bifida and their families, I have seen beyond my own horizons. I have met countless children with dreams, parents with aspirations, and highly educated adults

pursuing rewarding careers no different than any others. Certainly, our challenges are great. However, with the advances of medical technology, an integrated network of resources and services, and hoped for research funding to find answers to highly complex medical challenges, I am loathe to dismiss the value of anyone living with Spina Bifida.

I always knew I was blessed to have loving parents, a supportive family, wonderful friends, terrific health care providers, and a successful career. Dr. Lerner has provided me with a poignant reminder.

Sincerely,

A handwritten signature in black ink, appearing to read 'D. Sorocco', with a vertical red line to its right.

Douglas Sorocco, Esquire
Chair, Spina Bifida Association of America