

November 16, 2017

RE: HRW and interACT Report, "I Want to Be Like Nature Made Me"

As physicians who comprise part of the multidisciplinary team that oversees the treatment of children born “intersex,” we have undertaken a thorough review of the Human Rights Watch (HRW) report on surgeries on children in the United States (I Want to Be Like Nature Made Me, July 25, 2017). We feel strong empathy for those who experienced adverse outcomes from childhood procedures. Individual patient data can be instructive and we care for patients one individual at a time; however, it is imperative that we determine the outcomes of our care using research methods that are inclusive of the population of patients we care for as opposed to focusing on isolated patient accounts. As our understanding of this complex condition has rapidly evolved, so has our ability to provide effective and compassionate care. Although we strive to disseminate our progress to our patients and the medical community at large, our progress is incompletely reflected in the Human Rights Watch report.

The majority of the patients documented in the report were treated decades before physicians began to specialize in pediatric urology, and many of the related procedures are no longer being performed. The American Board of Urology first offered pediatric certification in 2008. Professional organizations that promote appropriate practice and education have more recently formed to support further specialized training.

Use of the term “intersex people” implies inclusion of individuals with many different, unrelated diagnoses. With molecular advances, the medical community preferentially references a patient’s specific condition, thus enabling focused therapeutic recommendations. Within the specialty of pediatrics, we focus on genetic, hormonal and environmental factors that contribute to a child's physical, mental and social growth, as well as their overall development. As such, we ascribe to the growing understanding that gender is experienced on a spectrum. In that the estimated incidence of gender dysphoria in the "intersex" population may be higher than the general population, treatment recommendations for children born with these entities do not automatically include a surgical procedure. We respect both parental authority as well as the rights of the child and offer medical, non-surgical, and surgical options, when appropriate, for management in conjunction with multidisciplinary review of each individual case based on treatment standards. These multidisciplinary teams generally include experts in the areas of pediatric and reproductive endocrinology, genetics, urology, gynecology, psychiatry and cytogenetics with close involvement of family members. If surgery is considered, complete informed consent with counseling and support should be provided prior to proceeding with any surgical intervention. As a result of specialized training, surgery is performed in rare situations

and after comprehensive evaluation and consideration of all the available evidence for the patient’s best health and interests. Given the rarity and diversity of these unique conditions, a moratorium on all surgery would be as harmful as recommending surgery for all and would deprive select individuals of the benefit of early intervention not to mention depriving parents of their rights. We are not “for” or “against” early surgery. Rather, we are working tirelessly to better understand the role of surgical intervention and how it impacts patients’ sexual, emotional and social functioning, as well as overall quality of life.

It is unfortunate that a connection is being drawn between medical reconstructive procedures performed by trained professionals and non-medical mutilations. We abhor non-medical alteration of the female genital organs and encourage data collection, prevention and training programs, health services to survivors and public awareness. We would have preferred that the Human Rights Watch report had more carefully defined medical necessity and draw a distinction between extreme cases. A universal ban may very well limit access to beneficial surgery for at-risk individuals.

Each child's diagnosis and treatment options are presented to parents based on best available science. Societal norms and financial incentives do not dictate whether a child may be a candidate for surgery. The American Academy of Pediatrics recently affirmed its commitment "to continued examination and discussion of recommended treatments for children with differences of sex development" rather than provide patients and parents with a single option.

We have worked hand in hand with advocacy organizations, and we continue to encourage patient advocates to use their resources to ensure a high standard of care across the country. This approach is in line with the mission of our specialty organizations, and will help to advance care for all children. Within pediatric urology, we are working diligently to grow the number of fellowship-trained specialists, but there are still thousands of hospitals and some entire states that are not served by our specialty, necessitating travel for expert specialty care.

In addition to offering support for specialized training programs, we welcome participation by advocacy groups in the development of resources that facilitate parental education and accurate informed consent standards. As pointed out in the report, there are little long-term data related to outcomes of patients not receiving any surgery. Supporting well designed, ethically sound studies to evaluate outcomes would be highly beneficial rather than spending resources for non-scientific papers. Likewise, a confidential registry of patients and their treatment would also be helpful.

We recognize the physical and emotional turmoil endured by the ill-affected individuals described in the report, and we do not dismiss this information. Indeed, it is because of their pain, we believe that patient advocacy groups will best serve their constituents by encouraging them to work with us to advance the care of all children. We truly care about getting it right. It is not logical to impose mandatory restrictions on surgery in an area as complicated as this because it could affect patients who require timely, health-improving surgical intervention. Further,

extending the moratorium to other genital surgery not even related to this area is not supported by the information in the HRW report.

At the November 2017 Interim American Medical Association House of Delegates meeting, the Council on Ethics and Judicial Affairs (CEJA) presented recommendations for the management of patients with DSD, however the house of medicine recognized that there were complexities that required further consideration. The report has been referred back for further deliberation and we look forward to constructive discourse and respectful cooperation to achieve satisfaction in a swiftly developing area of medicine and social awareness.

Societies for Pediatric Urology

American Association of Clinical Urologists

American Association of Pediatric Urologists

Pediatric Endocrine Society

Society of Academic Urologists

The Endocrine Society