

American Association of Clinical Urologists
www.aacuweb.org

American Association of Pediatric Urologists
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American Urological Association
www.auanet.org

Society for Fetal Urology
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Society for Pediatric Urology
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May 17, 2017

The Honorable Michael Sprinkle
Chair, Health and Human Services Committee
Nevada State Assembly
Legislative Building, Room 3132
Carson City, Nevada 89701

Chairman Sprinkle:

Thank you for the opportunity to comment on Senate Bill 408 on behalf of specialty physicians who comprise part of the multidisciplinary team that oversees the treatment of children born with disorders of sex development (DSD). While acknowledging the well-intentioned objectives of Vice Chair Joiner, Assemblyman Araujo, Senator Parks and the intersex community in proposing this legislation, we must oppose SB 408.

Let us begin by assuring you that treatment of children born with DSD does not automatically include the performance of any surgical procedure. We listen to our families. In the rare situation when parents decide to delay surgery, we abide by that decision. What's more, in the last 20 years a standard of care has emerged among pediatric urologists that infants born with clear chromosomal and gonadal sex and a discordant anatomy are not reassigned to the opposite gender for ease of reconstruction. This is a significant change in practice from the 1980's and 1990's when a male born with an abnormally small phallus would often be reassigned as female.

When early surgery is indicated, but not necessarily required to protect the life of the child, many voices are heard. No one health care provider is making a recommendation on the treatment of DSD in a child. DSD is a complicated collection of medical problems that requires a multidisciplinary team evaluation. This team considers each case as a unique individual, taking into account a long-range developmental view, respecting the rights of parents to represent their child and understanding, in that atmosphere, we need to do our best with imperfect options.

SB 408 inaccurately equates surgery to relocate the urethral meatus with surgical procedures to assign anatomical sex. Anatomic sex is not a determination made with urethral surgery. Rather, this procedure restores function to existing anatomy. The most common condition associated with relocation of the urethral meatus is proximal hypospadias, in which the urethra fails to complete development and opens on the ventral side of the penis, as low as the junction between the penis and scrotum or lower. These boys are otherwise typical, with functioning testes and male genetic and chromosomal make-ups. In the first year of life, they undergo reconstruction to build a urethra to the end of the penis. This reconstruction allows future normal voiding and reproduction. SB 408 restricts such procedures intended to move the opening of the urethra, which are considered standard of care in an otherwise typical male infant.

Legislation that limits health care options and generalizes care for all patients is a disservice and potentially harmful to children. Left undefined, innumerable treatments could be considered a "procedure to assign anatomical sex". Those early surgeries often prevent complications that may not be life threatening until later in life.

SB 408 ignores current practice and ties the hands of multiple licensed experts. The legislation establishes a broad standard of care in a complicated area of medicine that is undergoing rapid re-evaluation. If enacted, the law would limit individualized decision-making and treatment options. In addition to the above-referenced clinical considerations, we maintain that parents and guardians must retain the right to provide consent for a child. We urge you to oppose the bill.

Sincerely,

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