







February 22, 2019

The Honorable Mary Abrams, Co-Chair The Honorable Jonathan Steinberg, Co-Chair Public Health Committee Legislative Office Building, Room 3000 Hartford, CT 06106

RE: Proposed S.B. No. 388, Concerning a person's intersex status or characteristics

Dear Co-Chairs Abrams and Steinberg,

As preeminent organizations representing urologists in the United States, the Connecticut Urology Society (CUS), Societies for Pediatric Urology (SPU), American Association of Clinical Urologists (AACU), and American Urological Association (AUA), appreciate the opportunity to comment on Proposed Senate Bill 388, concerning conditions affecting reproductive development, which has been reserved for a subject matter public hearing.

Collectively, we represent more than 150 urologists in Connecticut and 18,000 nationally who care for patients with conditions affecting the urinary-tract system and reproductive organs. The SPU, in particular, is a non-profit society organized to promote appropriate practice and education in pediatric urology, as well as exchanges between practitioners involved in the treatment of genitourinary disorders in children. These specialists have studied seven to eight years after medical school to acquire expert training in the management of the health of children and adolescents, primarily in children's hospitals and academic medical centers.

As part of the multidisciplinary team that cares for children born with variations of physical sex characteristics, we oppose all forms of prejudice, bias, or discrimination exhibited toward gender and sexual minorities. We likewise affirm the value in celebrating the intersex community a part of the fabric of Connecticut's diversity. The underpinning of this initiative stems from arguments that include multiple inaccuracies, references to outdated medical practices and calls on the state to promote policies that have the potential to hurt vulnerable Connecticut children.

The sponsor's desire to address the needs of the self-identified intersex community who have suffered from "unnecessary surgery" is challenging. Indeed, legislators in two other states considering this issue each sat for several hours of testimony and came to the conclusion that a prohibition on early surgical intervention should not become law. They heard compelling stories from children and families who are overwhelmingly satisfied with the outcomes of surgery, as well as from experts who pointed to peer-reviewed literature attesting to positive results. In the end, the lawmakers found that "unnecessary surgery" could not be defined and any statute would impact vulnerable children who do not identify as intersex.

The American Medical Association recently developed a policy after a deep review of this subject that involved input from all groups including those calling for a moratorium on surgery. They developed an informed consent policy that maintained parental rights, and did not call for a moratorium on surgical procedures.

Several verifiable facts support this position, including:

- Patients with an adrenal disorder that contributes to variations in sex characteristics (congenital adrenal hyperplasia [CAH]) do not identify as intersex.
- Patients with conditions such as hypospadias and chordee, which are the most common variations in sex characteristics, do not experience gender dysphoria at a rate higher than the general population.
- Medical literature confirms that patients who undergo surgery early are overwhelmingly satisfied with the outcome.
- This is a complicated collection of medical problems that requires an individualized approach and multidisciplinary team approach. It would be impossible to develop a legislative solution.
- We provide parents and patients with full information regarding management options and that parents have the right to that information and the right to make medical decision based on all available information. We do not advocate for or against surgery.

Therefore, on behalf of our diverse memberships, we stand strongly in opposition to including any reference to preventing the option for surgery in these children. Senate Bill 388 proponents refer to practices and procedures that where replaced more than 20 years ago. If it progresses, it would fail to acknowledge overwhelming patient satisfaction with early surgical intervention related to variations of physical sex characteristics. We respect a parent's right to be involved in their child's growth, development, and medical care. Calling for limits to their role, as well as treatment options, sets a dangerous precedent.

Sincerely,

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