RELATING TO HEALTH AND SAFETY -- PROTECTION OF CHILDREN -- PHYSICAL SEX CHARACTERISTICS SURGERY ACT

Introduced By: Senator Tiara T. Mack and Representatives Kislak, McNamara, Potter, Felix,

Alzate, Cassar, Cortvriend, Ajello, Donovan, and Henries **Dates Introduced:** March 11, 2021 and March 26, 2021

Referred To: Senate Health & Human Services and House Judiciary

Senate Bill S0593: http://webserver.rilin.state.ri.us/BillText/BillText21/SenateText21/S0593.pdf **House Bill 6171**: http://webserver.rilin.state.ri.us/BillText/BillText21/HouseText21/H6171.pdf

We are writing in committed support for Rhode Island twin Senate / House Bills 0593 and 6171 "Protection of Youth with Variations in Physical Sex Characteristics Act". These bills promote the health of the 1-2% of infants and children under 12 born with physical traits that vary from socially-informed, stereotypical notions regarding the development, appearance or function of sex characteristics. These bills would ban non-consensual, irreversible, medically unnecessary surgeries for cosmetic "normalization" including clitoroplasties, clitoral recessions, vaginoplasties, vaginal exteriorization and similar surgeries. Multiple United Nations treaty committees and expert bodies have condemned these surgeries, some even likening them to a form of torture or ill-treatment. We stand with:

American Academy of Family Physicians World Health Organization Physicians for Human Rights Human Rights Watch Amnesty International Lambda Legal The ACLU

The Trevor Project GLSEN (Gay, Lesbian and Straight Education Network) GLMA (GLMA: Health Professionals Advancing LGBTQ Equality) National Center for Lesbian Rights Equality California

And every intersex-led organization in the world focusing on this population who have condemned non-medically necessary genital surgeries on infants as a human rights violation.

We are in full support of bills S0593 and 6171 for intersex bodily autonomy and an appropriate age of assent and consent in Rhode Island. Consent is a cornerstone of modern medicine, and physicians are bound to respect the ethical principles of beneficence, nonmaleficence and autonomy. Although treatments for children with what is medically diagnosed as "disorders of sex development" are often done with the intent of providing children access to a "normal" childhood development, these surgeries deny children intact genital, urinary, vascular, somatic and autonomic nervous systems and medically enforces societal stigma. Individuals who are intersex are not "abnormal", and operating on infants has definitive consequences. Although intersex conditions can accompany endocrinological medical needs, those aspects of care do not justify non-consensual surgeries. Countless individuals who identify as intersex with conditions such as an androgen insensitivity syndrome and congenital adrenal hyperplasia have spoken out against these surgeries. Patients report pain, stigma, scarring and trauma due to "corrective" procedures, follow-up examinations and research studies endured throughout childhood.

Medicine is advancing, and with it, must the legal systems which uphold the rights of vulnerable populations. Boston Children's Hospital recently made the decision to end the practice of clitoroplasties and vaginoplasties, following the decision by Lurie Children's Hospital to issue a complete moratorium on intersex surgeries. The American Medical Association Board of Trustees also recommends a delay of all procedures unless they are necessary to address a life-threatening risk. Legislation protecting against harmful surgical interventions have been introduced in California, Connecticut and New York. These medico-legal milestones are made with bipartisan support and a commitment to human rights due to the leadership of intersex youth, adults and elders through decades of activism to secure safe medical care for themselves.

Despite claims by supporters of early surgery that patients are satisfied with their outcome, a look at decades of medical, ethical and narrative literature demonstrates both low responses rates for intersex studies carried out by surgeons and consistent complaints made by patients across genders and diagnoses regarding the physical and emotional trauma endured by non-consensual corrective surgeries. A study carried out 2 decades ago showed that out of 44 adolescents with CAH who had surgery in early childhood, 98% required additional surgery to permit penetrative intercourse. In a later study, it was found that 40% CAH individuals who received early surgery always found it impossible to orgasm compared with none of those with CAH who had not received surgery. A subsequent study found that 80% of individuals with CAH who had surgery experienced pain during vaginal penetration, and a 2013 study confirmed that "no matter the technique for vaginoplasty used, vaginal stenosis are quite common, needing surgical revision or vaginal dilations after puberty".

Although physicians often report that operations have advanced and are now "nerve sparing" and thereby allow for optimal sexual functioning, the only significant studies which demonstrated this utilize electromyographic (EMG) responses or a relative elevation in general sensation compared to one's leg. The former technique has been found to not correlate with sexual neurological function, as it measures the presence of any myogenic potentials in the stimulated area, not the smaller diameter fibers which carry the sensory signals of pressure, vibration, heat, cold and pain. A notable example of this faulty correlation is a patient who retained no sensation or orgasm potential after her surgeries, who still demonstrated neuromuscular response over her completely resected clitoris. The second study mentioned has been widely critiqued for "sex testing" on minors as young as 6 years old. These minors were instructed to rate the sensation of vibrational genital stimulation from 0 to 5, and the result of increased vibratory sensation of one's clitoris compared to their leg has been used by some pediatric urologists to inappropriately claim that sexual function is unharmed by childhood genital surgeries. As genital tissue possesses specialized cells which transduce magnified sensation, increased sensation is a finding that would occur unless one's genitalia were completely resected, as was standard of care decades ago. Furthermore, in the contemporary "nerve-sparing clitoral reduction" surgeries the spongy erectile and autonomic nervous system tissue within the clitoral body is completely excised, and the dorsal nerve is transected along its branches, denying patients endocrine and neurologic functions which have been shown to play a role in sexual pleasure, fertility and genitourinary health.

The surgeon critiqued for carrying out genital stimulation testing on minors did not mention on his parent-facing hospital website that in 2013, 6 years after he had published the initial outcomes of his novel nerve-sparing surgeries, the "most common issues" arising in adolescence for girls with congenital adrenal hyperplasia who receive his surgeries are urinary incontinence, clitoral pain, vaginal stenosis, and cosmetic concerns. A direct quote from his paper is "patients who had vaginal surgery in infancy might present in adolescence with several concerns including vaginal stenosis, hairy vaginas, short vaginal length, or incomplete separation of the urogenital sinus." In comparison, on his hospital website, he states that "[the] vaginal incision is carried back far enough to provide for a generous perineal skin flap. It is this aspect of the operation which prevents future vaginal stenosis from occurring". Despite this public claim, a 2018 study found both his practice and similar medical practices have a complication rate of 25% for "feminizing" and 54.5% complication rate for "masculinizing" surgeries. In another paper authored by this provider he stated the "primary goal of the surgery is optimization of genital appearance and function" with continence (the ability to control one's bladder) as a secondary consideration in evaluating surgical success. It is clear these high-risk surgeries are done with the intent of cosmetically altering an infant's genitalia, which is a practice that has been outlawed internationally.

Studies and articles show many parents of intersex children experience delayed regret surrounding the decision to operate on their children in infancy unrelated to complication severity, despite reporting satisfaction with cosmetic outcome soon after surgery. A recurrent theme among parent surveys and narratives is lack of adequate information about their children's conditions and surgeries, and guilt from causing irreparable harm with good intentions. There are parent organizations which promote surgeries, but in the words of a German interdisciplinary cohort of physicians, ethicists, advocates, legal experts, patients, parents and therapists modeled after the UN convention of children's rights, "Parents are only allowed to decide [surgery] on behalf of their child in the case of vital harm and where there is strictly somatic functional or vital medical indication."

The Rhode Island Senate Health and Human Services has an opportunity to move closer to a world in which intersex patients are less likely to experience poor health outcomes due to their differences in sex characteristics. Intersex communities have for too long been hurt by the pathologization of their existence. Unless there is an imperative and detrimental health concern that warrants urgent surgery, we believe that the decision to surgically modify an infant's body should be delayed until the Intersex / DSD individual can play an active role in this decision.

We speak as students and providers who are not anti-surgery, but pro-consent. We hope these bills places power in the hands of those who matter most in medicine: the patient.

For more information on ongoing intersex advocacy, visit:

InterACT: https://interactadvocates.org/

The Intersex Justice Project: https://www.intersexjusticeproject.org/

For a presentation with the citations mentioned in this letter of support: https://docs.google.com/presentation/d/1MjvYF1CmO4T4iDGTBhsKkCExHKI6o3DjKNzndvJtrA4/edit?usp=sharing

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Project LETS

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CAQ Clinic, Vagelos College of Physicians and Surgeons at Columbia University

National Medical Student Associations

American Medical Student Association

Medical Student Pride Alliance

Warren Alpert Medical School of Brown University Student Groups

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