

PES **PEDIATRIC ENDOCRINE SOCIETY**

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Dear Senators Wiener, Glazer, and Assemblywoman Limón:

We are writing to you on behalf of the membership of the Pediatric Endocrine Society (PES), the organization that represents North American Pediatric Endocrinologists, and the Endocrine Society, which represents over 18,000 adult and pediatric endocrinologists around the world, to express our concerns regarding SCR-110. As endocrinologists, we are the physicians who are the main care providers for the patients who are affected by the resolution and want to express our perspectives based on our experience working with families and health care teams wrestling with these intimate and critical decisions regarding their children.

It is critical that everyone involved understands that current medical practice eschews surgery for children with minimal differences in genital anatomy, reserving the surgical option for those with anatomy that compromises urological, pubertal, and reproductive development. Additionally, most centers that care for patients with Differences in Sex Development (DSDs) practice a team approach, which includes psychologists and, often, ethicists, to review options and to assist parents with this intimate decision-making. Furthermore, there is consensus that only the most experienced surgeons should perform genital surgery to minimize adverse outcomes that had, admittedly, been more common decades ago.

As endocrinologists who have long studied the course of development in children with a variety of differences in genital anatomy and psychosexual development, we are aware that there is a great deal of individual variation in anatomy and an even greater variation in the ability of the patient and the family to adapt to atypical body parts. These issues are exceedingly complex: On the one hand, leaving children with a congenital difference in external genital anatomy may create stigma and SCR-110, restricting access to early surgery, may be unfair and harmful to these children and their families. On the other hand, some newborns with DSDs may end up with a gender identity that is not aligned with their sex of rearing and early surgery may be unfair and harmful. This arena of medical decision-making is further complicated by consideration of the role of parents.

The most common type of DSD, known as congenital adrenal hyperplasia (CAH), causes varying degrees of masculinization of the external genitals in affected girls. While a minority of these individuals will have a male gender identity as adults, the outcomes in the majority of the female CAH patient population are generally more clearly delineated than other types of DSDs, as these girls have normal internal female genital anatomy with a capacity to bear children. Sometimes these children have or develop vaginal or urethral outlet obstruction, making them prone to infections. These surgeries are much easier from a technical standpoint in younger children.

It is this sort of nuanced, scientific, and evidence-based decision-making that is not reflected in SCR-110, which does not adequately address the needs of several competing constituencies: Furthermore, it is not always clear what constitutes “medical necessity.” There are individuals whose gender identity is ultimately aligned with their sex of rearing and who experience harm having atypical body parts during childhood without access to surgery. Others are found to have a gender identity that is not aligned with their sex of rearing and experience harm as a result of early surgery. Parents of these individuals have traditionally been viewed as having rights in deciding what is in the best interest for their minor offspring, and they rely on experienced healthcare professionals, as well as lay support groups, to make these important decisions.

Given the complexity of medical decision-making in this context, governmental regulation of medical practice does not reflect the individual needs of individual patients in unique circumstances, as well as the advances made by the endocrinology and urology communities in the evidence-based and patient-centered multidisciplinary care of these children. Therefore, we respectfully request that the California legislature reconsider SCR-110.

Sincerely yours,



Philip Zeitler, MD, PhD
President
Pediatric Endocrine Society



Susan Mandel, MD
President
Endocrine Society

