



For Immediate Release

Refocus Intersex Care Standards

Medical Associations Should Back Moratorium on Unnecessary Surgery

(New York, September 7, 2017) – Two key medical associations should publicly affirm their support to end medically unnecessary surgery on intersex children, Human Rights Watch and interACT said today. The groups sent letters to the medical associations, the <u>Pediatric Endocrine Society</u> and the <u>Societies for Pediatric Urology</u>, urging them to use their upcoming international medical conferences to publicly state this position.

Since the 1960s, doctors in the <u>United States</u> and around the world have routinely performed surgery on intersex infants and children – born with chromosomes, gonads, or genitalia that do not correspond to traditional notions of "male" or "female" – to assign them a sex. These surgeries are medically unnecessary, irreversible, often traumatizing, and carry a risk of lifelong harm.

"Endocrinologists and urologists are critical to intersex health care, and their support for an end to unnecessary and high-risk surgery on children too young to consent is crucial," said Kimberly Zieselman, executive director of <u>interACT</u>. "Despite decades of patient advocates calling for an end to these harmful procedures, some doctors continue to present these surgeries to parents as good options."

The Council of Europe's Committee on Bioethics in 2017 wrote that, "The treatment protocols that emerged from the US-based recommendations were not based on any clinical trials or careful research," and "repeated systematic reviews of evidence have found no quality data confirming their safety and benefits for each affected child."

However as Human Rights Watch and interACT documented in a <u>recent report</u>, despite decades of controversy over the procedures, US doctors continue to operate on children's gonads, internal sex organs, and genitals when the children are too young to participate in the decision. The results are often catastrophic and the supposed benefits largely unproven. For intersex children, it is rare that urgent health considerations require immediate intervention.

Medical protocols in the United States and around the world have evolved over the past two decades. The use of multi-disciplinary teams to work on cases of "Differences of Sex Development" – or DSD – is increasingly common. Most medical practitioners now acknowledge that parents may legitimately prefer to leave their child's body intact. However, the field remains fraught with uneven, inadequate, and piecemeal standards of care. While certain surgical interventions on intersex children are undisputedly medically necessary, some surgeons perform risky and medically unnecessary cosmetic surgery on intersex children, often before they are even able to talk.

The American Academy of Pediatrics <u>welcomed</u> the Human Rights Watch and interACT research and the American Medical Association <u>board of trustees</u> and three former US <u>surgeons-general</u> – including one who was a pediatric urologist – have recommended an end to medically unnecessary surgeries on intersex children.

The AIS-DSD Support Group, the largest US community support group for people and families affected by intersex conditions, <u>endorsed</u>Human Rights Watch and interACT's report recommendations, including the recommendation that the Pediatric Endocrine Society and the Societies for Pediatric Urology support a moratorium on medically unnecessary surgeries on intersex children.

"All doctors swear an oath to 'do no harm,' and the specialists dedicated to DSD care should apply that principle to intersex patients," said Kyle Knight, Human Rights Watch researcher. "Medical professional groups should demonstrate their commitment to the health and human rights of their patients by opposing medically unnecessary surgeries on intersex children too young to consent."

"'I Want to Be Like Nature Made Me': Medically Unnecessary Surgeries on Intersex Children in the US" is available at: https://www.hrw.org/node/306688/
For more information on interACT, please visit: https://interactadvocates.org/
For more information on Human Rights Watch, please visit: www.hrw.org

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