

Stopping unnecessary surgeries on intersex children

Cosmetic surgeries on infants cause lifelong suffering

(Chicago, July 25, 2017) The [AIS-DSD Support Group](#) lauds the 183-page [report](#), “[I Want To Be Like Nature Made Me: Medically Unnecessary Surgeries on Intersex Children in the US](#),” released today by Human Rights Watch in partnership with interACT: Advocates for Intersex Youth, which condemns physicians who continue to perform medically unnecessary and irreversible surgeries on the genitals and gonads of intersex children. Intersex is an umbrella term describing the 1.7 percent of babies who are born with chromosomes, gonads or the internal or external sex traits that differ from societal expectations. These children are typically still subject to unnecessary and irreversible surgeries to force their genitals to conform to the societal norm, risking future fertility, scarring, incontinence, loss of sensation and psychological trauma, and a lifetime on synthetic hormones. This report calls for a new standard of care that allows time for the intersex children to become old enough to participate in and approve decisions about surgery and hormone treatments that will affect their future.

“We are thrilled that we will be able to refocus our support model over time away from ‘damage control’ of the current medically-induced traumas, and onto support of the physical and psychological health of our members, from birth to old age,” said Kimberly Saviano, President of AIS-DSD Support Group. “Further, we support the Human Rights Watch recommendation to wait until the child is old enough to assent or consent to any surgeries they might choose. This fully informed consent from the most important stakeholder, the affected child, has been mostly absent from the current standard of care for intersex children.”

AIS-DSD Support Group’s goal is to “Embrace, Support and Educate” our affected individuals, their families and allies. It has allowed the group to meet families who have been affected by infant surgery, as well as those who have chosen to delay such decisions. “This Human Rights Watch report will go a long way in helping us to achieve more meaningful and practical support for the health and wellbeing of our members,” continued Saviano. “This will include educating parents and allies regarding what is truly medically necessary versus what is cosmetic. Parents need to be able to make these fully informed decisions and to understand that delaying the decision is not harmful.”

AIS-DSD Support Group agrees with the recommendations in the HRW Report. Additionally, we applaud the three former Surgeons General who recently [reported](#) their opinions on the lack of real data supporting the current standard of infant surgeries. “It is about time that intersex children were allowed to make their own decisions when it comes to surgeries which place appearance over the function of their own bodies,” said the parent of a twelve-year old intersex child who is a member of AIS-DSD. “I am glad that we were able to leave her body intact, and so is she.”

AIS-DSD Support Group is the largest organization in the US exclusively dedicated to promoting support, education, and outreach to foster healthy outcomes for adults, youth, children, and families affected by Intersex. We run the largest annual conference for the intersex community, drawing participants from the US and abroad. We also create the curriculum, coordinate and co-conduct annual CME classes for the clinicians (physicians, psychosocial counselors, geneticists, DSD program coordinators) who provide care for intersex individuals and their families. Founded in 1995, AIS-DSD has consistently worked to create an environment for intersex people to share their histories, stories and receive the kind of support and understanding only available through a community of intersex people and their families.

If you would like to set up an interview with a member of the [AIS-DSD](#) Board of Directors, please contact us at media@aisdsd.org.

For information on Human Rights Watch, please see: www.hrw.org.

For information on interACT: Advocates for Intersex Youth, please see: www.interactadvocates.org

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