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AIS-DSD Support Group  
PO Box 2148, Duncan, OK 73534  
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August 15, 2017

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American Medical Association (AMA)  
330 N. Wabash Ave. Suite 39300  
Chicago, IL 60611-5885

Dear Dr. Barbe and Dr. Agliano:

We write to share with you the first ever in-depth report on the treatment of intersex youth in the United States. AIS-DSD Support Group wrote to you previously on May 19, 2017, and Human Rights Watch corresponded with the AMA's Physician Engagement Department on July 12, 2017.

As you may know, Human Rights Watch is an international non-governmental research and advocacy organization that works in more than 90 countries and is headquartered in the United States. 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 conditions, also known as Differences of Sex Development (DSD). AIS-DSD Support Group runs an annual conference for the intersex community and creates the curriculum for and co-conducts CME classes for the clinicians (physicians, psychosocial counselors, geneticists, and DSD program coordinators) who attend the conference. AIS-DSD Support Group helped Human Rights Watch connect with affected individuals, families, and doctors to conduct interviews that are included in the report.

This report, the result of 10 months of intensive research by Human Rights Watch, recommends that the American Medical Association, as a matter of urgency, pass the proposed resolution as recommended in the AMA Board of Trustees report 7-I-16, that,

Optimal management of DSD through individualized, multidisciplinary care...: (1) seeks to foster the well-being of the child and 20 the adult he or she will become; (2) respects the rights of the patient to participate in decisions 21 and, except when life-threatening circumstances require emergency intervention, defers 22 medical or surgical intervention until the

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child is able to participate in decision making; and 23 (3) provides psychosocial support to promote patient and family well-being.

Major health and human rights organizations, including the United Nations, the World Health Organization, and Amnesty International, have condemned medically unnecessary surgeries performed without informed consent. In July 2017, three former US Surgeons General, including one who was a pediatric urologist, wrote to oppose this practice because “there is insufficient evidence that growing up with atypical genitalia leads to psychosocial distress,” and “the surgery itself can cause severe and irreversible physical harm and emotional distress.” Every major intersex organization opposes unnecessary surgeries on intersex infants, as does every major LGBT legal organization in the United States. AIS-DSD Support Group endorsed the recommendations of the Human Rights Watch report on July 25, 2017, when it was launched in Chicago.

Human Rights Watch, AIS-DSD, and the AMA share the goals of protecting the human rights of and promoting healthy outcomes for intersex-affected individuals and their families. The nonconsensual medically unnecessary surgeries that are performed today jeopardize the lives, health, and happiness of the intersex community. If the AMA adopts the proposed resolution, we hope that the AIS-DSD Support Group will be able to shift the focus of our support efforts over time away from helping adults, youth and their families recover from medically-induced traumas, and toward support of the physical and psychological health of our members, from birth to old age. Our support will continue to respect individual's rights to physical autonomy, including the right of older children and adults to consent to surgeries; we will also continue to provide support for parents and others who have made decisions for surgeries in the past.

For the well-being of intersex children and their families, we strongly urge the AMA to issue clear, unambiguous guidance recommending a delay of all medically-unnecessary interventions. We would be happy to meet with you—in person or on the telephone—to discuss our recommendations further.

Thank you for your time and consideration.

Kind regards,

A handwritten signature in black ink, appearing to read "Kyle Knight".

Kyle Knight  
Researcher, Human Rights Watch  
[kyle.knight@hrw.org](mailto:kyle.knight@hrw.org)  
917 794 6690

A handwritten signature in black ink, appearing to read "Kimberly Saviano".

Kimberly Saviano  
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