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Appendix I

October 13, 2016

Dear Dr. XXXX:

I am a researcher at Human Rights Watch, an international non-governmental research and advocacy organization.

Human Rights Watch conducts research on a range of issues in more than 90 countries around the world, including the United States, where we are headquartered. Our research is designed to be objective, and take into account all perspectives so that we can conduct accurate legal and policy analysis.

I am currently undertaking a research project focusing on the experiences of intersex people in the United States. Specifically, we are interested in hearing from practitioners about medical care options available for intersex infants (or infants with DSD) and the advice and information provided to their parents. To better understand the experience of intersex children and their parents, we seek to interview healthcare providers such as yourself about the care and information you and your colleagues provide. We are also interested in interviewing any patients of yours, or their parents, to learn about their experiences living with intersex conditions and seeking care.

We are able to meet with you in person or on the phone at a mutually convenient time. The results of our research projects are public reports that are available in print and online. We are willing to anonymize the information you share with us and if you prefer, we can assure any information you share with Human Rights Watch is featured without any identifying characteristics, including name, location, exact date of the



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interview, and other possibly identifying aspects. We have undertaken the Ethical Review Board process operated by Physicians for Human Rights to ensure this research is carried out with the highest standards of professional care.

We recognize that this can be a polarizing and difficult topic, and our aim is to ensure that our research is objective and that it fully captures the whole range of different perspectives at play.

I am based in New York City, and available to answer any questions you might have in advance of arranging an interview. I can be reached at kyle.knight@hrw.org, or 917-794-6690.

I look forward to hearing from you regarding this meeting.

Sincerely,

A handwritten signature in black ink, appearing to read 'Kyle Knight', with a stylized, overlapping loop structure.

Kyle Knight
Researcher, Human Rights Watch

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Appendix II

January 18, 2017

Dear Dr. XXXX:

We wrote on October 13, 2016 requesting an interview regarding your clinic's practices with patients with disorders of sex development for an ongoing research project, and this letter is a follow up request to provide information in writing.

As mentioned in our previous correspondence, Human Rights Watch is attempting to gain a wide range of perspectives to incorporate into our report—a methodology we apply in all of our research. You can see examples of our research on a range of issues on our website at www.hrw.org.

Two examples of health-specific projects we have recently conducted are *"No Time to Waste" – Evidence-Based Treatment for Drug Dependence at the United States Veterans Administration Department of Veterans Affairs*,¹ and *Care When There Is No Cure – Ensuring the Right to Palliative Care in Mexico*.²

For this project, we are attempting to gather a wide range of perspectives on the following topics, and we would appreciate your responses to the questions below by February 10, 2017:

- What is the process for communicating with parents regarding their child's intersex (DSD) diagnosis and treatment options?
- In addition to speaking with doctors and nurses, what resources exist for parents to learn about their child's condition?

¹ "No Time to Waste" can be found at <https://www.hrw.org/report/2014/06/30/no-time-waste/evidence-based-treatment-drug-dependence-united-states-veterans>

² Care When There Is no Cure can be found at http://features.hrw.org/features/HRW_2014_report/Mexico_Care_When_There_Is_No_Cure/index.html



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- What cases are considered to be candidates for surgery (genital or gonadal)?
- If a child is considered a candidate for surgery, how is the option of surgery presented to parents?
- If parents opt not to have surgery, what advice and resources are provided to them?
- For patients who have undergone surgeries in your clinic, what follow-up is advised and conducted?

If you would prefer to speak on the phone instead, please feel free to contact me to arrange a time.

As mentioned in our prior correspondence, Human Rights Watch is interested in interviewing people with DSDs who have undergone various treatments, in particular related surgeries. This is so that we can establish how the procedures have impacted their lives—including their ability to live openly according to their gender identity, form relationships, establish a positive self-concept, access ongoing healthcare, and engage in employment. We would be happy to have you share our contact information with any of your current and/or former patients who might be interested in speaking with us. We are particularly interested in interviewing individuals with DSDs who are pleased with the surgical interventions they received as children.

As reflected in the reports linked above, all of our interviews, with patients or providers, will be anonymized and are conducted with full informed consent regarding our objectives and methodology. We are keen for our report to contain a wide range of perspectives on these issues, and we understand the topics can be polarizing and challenging. Please consider participating so that your expertise and experience can be reflected in our research.

Sincerely,

A handwritten signature in black ink, appearing to read 'Kyle Knight', with a stylized, overlapping loop structure.

Kyle Knight

Researcher, Human Rights Watch

Appendix III

November 24, 2015

**To: NIH Translational Research Network and NIH Research Coordinating Committee
For Sexual and Gender Minorities**
From: AAN Members
Re: Statement of resignation of some AAN Members from TRN

The original invitation to join the Advocacy Advisory Network (AAN) of the NIH Translational Research Network (TRN) evoked an idealistic vision of patients and clinicians setting aside differences and working together to make life happier and healthier for people living with reproductive difference. Rejoicing at the opportunity to have a voice in major decisions about research and care that affect our community in powerful ways, representatives of multiple peer support and advocacy groups eagerly joined. AAN members include advocates with diverse lived experience, who are affected adults, parents, and children, who are affected by a variety of differences, and who range in life stage from youth to maturity. We bring skills from careers in business, academia, law, social work, conflict resolution, project management, counseling, psychology, genetics, non-profit executive directorship, and medicine. We have decades of combined experience in peer support and leadership. Additionally, for the upcoming Global DSD Update sponsored by Pediatric Endocrine Society, Arlene Baratz is co-chair of the committee on patient perspectives and peer support. Despite our representation of our community and many valuable contributions of expertise and experience since we joined AAN four years ago, we are extremely disappointed that TRN has not lived up to its initial promise.

[Alice Dreger](#) and [Tiger Devore](#) recently announced their resignations from AAN on Alice's blog. We agree with some of their ideas, and would like to clarify our own perspective. AIS-DSD Support Group, Advocates for Informed Choice, and our allies listed below are also withdrawing from AAN because of ongoing miscommunication and lack of meaningful inclusion. At this point, having our names associated with TRN is doing more harm than good because chronic issues with TRN prevent meaningful advocacy input. From its inception, despite our requests, TRN failed to include advocates in the design and goals of the project. Having been denied a presence at the initial meeting of investigators, we hoped that subsequent close involvement in projects could influence the direction of research, but most were already IRB-approved by the time we saw them. Instead of an opportunity to contribute, we have experienced a pattern of misrepresentation in which our involvement and concurrence have been falsely implied. Missed deadlines and absence of key project deliverables also frustrate us.

Let us be clear that our resignation has nothing to do with the TRN clinicians and researchers who devote their lives to caring for and about us. We deeply appreciate your presence at our support group meetings, your availability to our members, and your ability to listen and change. Outside TRN, we are delighted to be involved in ongoing projects whose design and goals reflect successful cooperative relationships. We have found we can be extremely effective in supporting the development of research that meets the needs of our communities when we are involved from the beginning in the design of research goals, when we are able to give input into sensitive language, and when we are engaged to ensure that the specific concerns of this community regarding human research ethics and informed choice are addressed. Examples of successful research we have engaged in include projects on parent experiences with making decisions about genital difference; how young women living with DSD share health information

with peers; and parent experiences with genetic testing. Currently, we are working with TRN clinicians on outside projects investigating language, how medical care is experienced, ways to deliver psychosocial care, and evidence-based best practices in CAIS. We look forward to future opportunities to work with anyone from within or outside TRN who is interested in designing research that is inclusive of community concerns.

Although clinicians may have interacted with Accord Alliance as the designated community representative, we found that indirect transmission was effectively censoring our written and verbal communications. This is disturbing because Accord Alliance was founded in 2006 by Bo Laurent (Cheryl Chase), Katrina Karkazis, Arlene Baratz, and David Sandberg to improve medical care by replacing ISNA's confrontational tactics with a fresh, collaborative approach involving multiple stakeholders. At its closure, ISNA's funds and assets were transferred to Accord Alliance, including the *Handbook for Parents* and *Guidelines for Clinicians*. Accord Alliance hosted a research and quality improvement symposium in 2009, but hasn't sponsored any non-medical events since then, according to its blog. Laurent, Karkazis, and Baratz are no longer involved. Supported in its early days by community donations, Accord Alliance's current major source of funding is the TRN grant, which in turn designates the function of DSD community representative to Accord Alliance. This suggests a major conflict of interest. Reinforcing this impression is TRN's repeated failure to share AAN opinions and concerns about various projects with TRN clinicians. For example, serious and widespread AAN concerns that a proposed photography project posed potential harm to pediatric research subjects were not conveyed accurately to clinicians. When the time came to submit that proposal, clinicians were surprised to learn our opinion. Having further misled clinicians to believe that only a minority of AAN members requested further input on the proposal, TRN circumvented its requirement for AAN support with a letter from Accord Alliance implying our approval. It was an embarrassment to all of us that the proposal was withdrawn after AAN protested the deceptive letter.

Similarly, AAN members were extensively involved for four years in writing and editing numerous drafts of educational material for a TRN family decision support tool. However, ever since we insisted recently that families be made aware of major international human rights policies involving DSD treatment, our contributions are mysteriously absent. Despite our repeated requests, a version of the decision support tool omitting human rights education is already being piloted with families. Ethics and common decency suggest that shared decision-making should include informing families that many international human rights organizations have new statements strongly affirming the right of children with diverse sex characteristics to make their own choices about irreversible interventions. The [UN High Commissioner for Human Rights](#) and the [UN Special Rapporteur on Health](#), working closely with Advocates for Informed Choice (AIC), have both endorsed these as basic human rights. DSD/intersex is increasingly prominent on an international landscape in the midst of tectonic shifts. AIC will continue to advocate for an informed consent process requiring family counseling to include discussion of both social and medical controversies. Otherwise, how will children feel later when they discover that their parents made important decisions about irreversible interventions using decision support tools that consciously excluded vital information on children's human rights? Parents have a right to know just how controversial these procedures are before they make irreversible decisions.

Finally, the original TRN grant proposal included individual letters of support from AAN member organizations. In May, we were asked to draft a new letter jointly supporting a proposal to fund

TRN for the next funding cycle. After requesting changes in the grant to provide AAN more direct involvement as a condition of support, we never saw such a letter. The grant was later submitted, leaving us to wonder if the controversy was resolved by submitting a letter from Accord Alliance without our knowledge. If so, another five years of advocate dissatisfaction and AAN misrepresentation of our constituents concerns are practically guaranteed.

AIS-DSD Support Group's mission is to foster successful stakeholder collaborations that promote community well being through peer support, informed decision-making, and advances in evidence-based care. You see our passionate commitment in the vibrant community of affected people, clinicians, and allies that we nurture. You see it at the annual continuing education meeting we sponsor in partnership with DSD teams around the country. You see it when you attend our support group meetings, hear how people experience treatment, and learn about research that matters to patients. Likewise, AIC's mission is to advocate for the legal and human rights of children born with intersex traits. Neither organization, however, can effectively support or advocate for our constituents through the AAN, and so our consciences dictate that our members must resign.

All of us see how hard you work and how much you care. We know you want to see intersex people thrive as much as we do. The world is already changing because of our mutual dedication. Together, we have the power to transform it and we look forward to further collaborations outside the TRN.

Sincerely,

Arlene B. Baratz, MD
Coordinator of Clinical and Research Affairs AIS-DSD SG
Moderator, AIS-DSD Parents Group
AIC Board of Directors and Medical Adviser

Tiger Devore, PhD
Founding member, past president and vice president, Hypospadias Epispadias Association

Amber Jones
Operations Coordinator, AIS-DSD Support Group
Moderator, AIS-DSD Parents Group
Past member, AIS-DSD SG Board of Directors

Jim Lake
Executive Director, Hypospadias Epispadias Association

Lissa Moran, MPH

Meg Robertson
AIS-DSD SG Board of Directors
Moderator, AIS-DSD Parents Group

Karen Walsh
AIC board of directors

Kimberly Zieselman, JD
Executive Director, Advocates for Informed Choice
AIS-DSD SG Board of Directors

Appendix IV

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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
917 794 6690

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

Kimberly Saviano
President, AIS-DSD Support Group
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