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New York, NY 10118-3299
Tel: +1-212-290-4700
Fax: +1-212-736-1300; 917-591-3452

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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



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information you share with Human Rights Watch is featured without any identifying characteristics, including name, location, exact date of the 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, cursive-like script.

Kyle Knight
Researcher, Human Rights Watch

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Appendix II



HRW.org

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

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

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?
- 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, cursive-like script.

Kyle Knight
Researcher, Human Rights Watch

Appendix III

Kyle Knight

From: Kyle Knight
Sent: Thursday, May 11, 2017 7:10 PM
To: Dina Matos
Cc: medicaldirector
Subject: RE: meeting
Attachments: HRW Letter to Dr Poppas.pdf

Dear Dina:

Thank you so much for organizing the meeting with Human Rights Watch last week. We enjoyed the opportunity to learn more about the work and positions of the CARES Foundation. I think we could have continued talking for many more hours!

Due to time constraints, we were unable to ask all of our questions, and receive complete, detailed answers. In order to accurately reflect CARES and Dr. Poppas' information in our report, we are following up with the questions below. It would be great to receive responses by May 22, which will enable us to incorporate your responses in our report.

The questions for Dr. Poppas are attached in a letter—could you kindly forward this to him or share his email address with me? I do not have his contact information.

Kind regards,
Kyle

Questions for CARES:

- As we discussed during the meeting, the CARES Foundation recognizes that there should be some legal limits on the discretion of parents and doctors to decide on and perform surgeries on children's genitals—Female Genital Mutilation being the most obvious example of a practice that should be prohibited. Beyond a specific

prohibition on FGM, what do you think would be the most reasonable approach to define such limits in law more broadly, and identify circumstances where surgeries should be prohibited?

- Part of our discussion focused on how the decision to conduct surgeries on children with CAH was an extremely challenging one for parents. We also acknowledged that the decision-making process is often fraught with overwhelming amounts of information—and with that, the potential for misinformation. Could you please describe the activities the CARES Foundation undertakes to correct misinformation when parents approach CARES with information that is not validated, or incorrect? Are there any common misconceptions parents appear to have?
- Part of our discussion focused on how psycho-social outcomes may be factors in parents' decisions to undertake surgery on their daughters with CAH. Could you please direct us to any medical literature citations CARES uses that demonstrate the psycho-social outcome differentials between girls with CAH who underwent surgery, and those who did not?
- We understand that terminology—both as it relates to identities and health issues—can be complicated and intensely personal. At the moment, the following paragraph is included in our methodology section to reflect the sensitivity you shared with us during our meeting, and the input we gained while interviewing people with CAH and parents with CAH, including those who called us during the CARES Call To Action. Please send us your reactions to the text.

o On February 23, 2017, as Human Rights Watch's research for this report was ongoing, a support group for parents of children with Congenital Adrenal Hyperplasia, The CARES Foundation, launched a "Call To Action" that featured instructions to contact Human Rights Watch. The notification read: "Human Rights Watch is actively fighting parents' rights to make decisions regarding early surgical intervention comparing it to female genital mutilation, a horrendous practice by religious sects to disfigure and disable external genitalia. These entities have not asked how CAH patients and their families feel about these issues and they need to hear from you." As a result of this campaign, Human Rights Watch was contacted by 16 people with expressions of concern. We attempted to contact each of the people who called us, and arranged to interview those we were able to reach and schedule—eight people in total, including five

parents of children with CAH and three adults with CAH. In those interviews, we followed the same methodology as we did with each of the other interviews, and explained that as this was Human Rights Watch's first report dedicated to intersex issues, we had not taken a position on any related item. Some of these interviews are identified in the report as resulting from the calling campaign. Prior to this campaign, Human Rights Watch had interviewed parents of children with CAH and adults with CAH whom we had contacted through our other outreach methods. Similarly, we asked each interviewee how they would like themselves or their children identified in the report, and we have followed through accordingly.

From: Dina Matos [mailto:]
Sent: Monday, May 01, 2017 3:21 PM
To: Kyle Knight <knightk@hrw.org>
Cc: medicaldirector <>
Subject: RE: meeting

Thanks Kyle!

Dina M. Matos
Executive Director
CARES Foundation, Inc.



Website: www.caresfoundation.org

FOLLOW CARES ON [TWITTER](#) & [FACEBOOK](#)!

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Jan Weidner

Appendix IV

May 11, 2017

Dr. Dix Poppas

The Institute for Pediatric Urology

525 East 68th Street

New York, NY 10065



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Dear Dr. Poppas:

Thank you for taking the time to meet with us last week.

As we explained during the meeting, we are keen to present all of the information on this topic accurately. Because of time constraints, we were unable to ask clarifying questions on all of the relevant issues, so we have included them below. We would like to reflect your professional opinion and experience accurately in our report, alongside the accounts we received from 17 other healthcare providers who work in this field.

Please send your responses by May 22, which will enable us to incorporate your responses in our report.

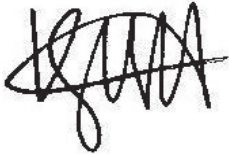
Our questions are as follows:

- During the meeting, you said the “vast majority of surgeries done today are medically necessary.” Could you please help us understand the threshold that distinguishes the medical necessity of the majority, from the medical non-necessity of the minority? We are trying to understand on which criteria such decisions are made, and examples of symptoms that make children candidates for surgery, or not.

- During the meeting, you stated that you believe that clitoral reduction surgeries on children with Partial Androgen Insensitivity Syndrome should never be conducted. However, the same operation on children with CAH was an option. Could you please explain the reasoning behind separating those two categories of patients, with one being excluded from surgery candidature, and one being included?
- During the meeting, you described a surgical technique that recessed the clitoris in a way that allowed for it to be “released” later in life. Can you please tell us: 1) is this the primary/most common form of clitoral surgery currently conducted on girls with CAH, 2) Approximately what percentage of girls who undergo this surgery later choose to “release” their clitoris, and what their outcomes are?
- During the meeting, you described how “a clitoris has to be pretty large for me to recommend surgery.” We were unable to clarify during the meeting what that size threshold, according to the Prader Scale, was. Could you please let us know how large a clitoris has to be in order for you to recommend a reduction surgery? If it is on a case-by-case basis, could you share some examples?
- During the meeting, you cited statistics that 5 percent of girls with CAH transitioned to identifying as male later in life, as opposed to 1 percent of the general population who experience gender dysphoria. Could you please provide us with the citations for those statistics?
- Due to time constraints, we were unable to specifically inquire about the sensitivity tests you reported on in your 2007 *Journal of Urology* paper with Yang and Felsen titled “Nerve Paring Ventral Clitoroplasty: Analysis of Clitoral Sensitivity and Viability.” We understand that this practice has been criticized, and we would like to know your response to that criticism. Also, since that publication, have you continued that kind of test with your pediatric patients? Has the practice changed at all since the 2007 paper? Are you aware of any other surgical provider who conducts such tests on pediatric patients?

- During the meeting, you suggested that conducting genital surgery on girls with AH could contribute to a decreased likelihood that a girl would attempt suicide later in life. Could you please provide any available citation on other evidence for this claim, so that we may understand the risk analysis?

Kind regards,

A handwritten signature in black ink, appearing to read 'Kyle Knight', with a stylized, cursive script.

Kyle Knight
Researcher, Human Rights Watch
kyle.knight@hrw.org
350 5th Avenue, 34th floor
New York, NY 10118

Appendix V

The birth of a newborn with atypical genitalia -- defined as discordance between external genitalia and gonadal and chromosomal sex -- represents a unique set of challenges. Parents question how their early decisions will impact their child's life in the long-term. Often parents of girls born with congenital adrenal hyperplasia (CAH) choose reconstructive surgery for several important reasons: to prevent lifethreatening urogenital infections, to minimize future fertility issues, and to address their child's psychological need for body image parity with their peers.

CARES Foundation is dedicated to respecting the rights of all patients and families and helping them make informed decisions about treatment and care for CAH. While a select group of individuals has worked to limit the surgical treatment options available to CAH patients, CARES Foundation strongly believes that the choices available to parents and patients should not be limited. Deciding how to best treat CAH, including whether a young child should undergo reconstructive surgery due to atypical genitalia and other urological anomalies, is fundamentally a parent's right. CARES' role is to help parents and patients make informed decisions with respect to surgical procedures and all other treatment options for this life-threatening condition. This is accomplished with educational programs and referrals to internationally -- recognized experts in the treatment of all CAH patients.

A parent's right to make a decision for their child, whether it involves making the difficult decision to choose a surgical intervention or the more routine decision about what to feed their child or where to send them to school, should be respected and honored. Medical decisions are difficult enough for parents

without having to contend with the moral and philosophical agendas of certain movements. In children's hospitals all across the globe, parents in conjunction with medical professionals make decisions on behalf of their children every day. Parents of CAH children are no different. Their rights should not be limited.

Therefore, CARES will continue to lead in the effort to improve the lives of CAH patients. We will continue to advocate for the rights of patients and parents and help them make educated decisions about all treatments available to them. Furthermore, we will continue to support research that will lead to better treatments and hopefully a cure for CAH.

Appendix VI

From: Dix P Poppas
Sent: Thursday, June 29, 2017 9:46 AM
To: Kyle Knight
Cc: Dina Matos
Subject: HRW response

Hi Kyle:

In response to your questions, my team has not used clitoral sensory testing to evaluate post procedural outcomes since before 2006. In addition, I do not recall ever commenting on a link between surgery and suicidality in our meeting or at any other time.

Sincerely,

D. Phillip Poppas, M.D., F.A.C.S.

<http://urology.weillcornell.org/dix-p-poppas-md>

Vice Chairman and Professor of Urology
Chief of Pediatric Urology
Rodgers Family Professor of Pediatric Urology
Director of Pediatric Surgical Services
Surgical Director Comprehensive Center for
Congenital Adrenal Hyperplasia

Weill Cornell Medicine

Urology

525 East 68th Street, Box 94
New York, NY 10065
Work: 212.746.5337 Fax: 212.746.8065

Komansky Center for Children's Health



New York Presbyterian Hospital

Appendix VII

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

11/24/15, re: AAN membership

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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

11/24/15, re: AAN membership

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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

11/24/15, re: AAN membership

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Karen Walsh
AIC board of directors

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

11/24/15, re: AAN membership

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