

Kyle Knight

From: Kyle Knight
Sent: Monday, August 23, 2021 7:50 AM
To: [REDACTED]
Subject: RE: Human Rights Watch request for comment on today's protest

Hi [REDACTED] I wanted to follow up on this, just to ensure we have NYP's position reflected accurately. Do you have a sense of when we might receive a response?

My best,
-Kyle

From: Kyle Knight
Sent: Wednesday, August 11, 2021 11:43 AM
To: [REDACTED]
Subject: RE: Human Rights Watch request for comment on today's protest

Dear [REDACTED]

Thank you for sharing NYP's statement regarding the treatment of children born with intersex variations or differences of sex development.

I have some follow up questions. Your answers would help us to have a clear an analysis and accurately reflect NYP's position. We may publish your responses at our discretion and when appropriate, either in full or in part.

You wrote: "As part of our continued efforts to address this important issue, and consistent with our comprehensive approach to the care of patients with DSD, we have a Pediatric Differences in Sex Development (PDSD) committee which includes experts from NewYork-Presbyterian, Columbia University Irving Medical Center, and Weill Cornell Medicine."

DSD committees or teams exist at hospitals across the country and around the world. However research—including [research Human Rights Watch conducted](#)—has shown that they vary in their composition and function. Could you please provide the following information about the NYP PSDS committee:

- Which specialties are represented on the DSD team?
- How often does the team meet?
- What are the team's criteria for determining a child is a candidate for surgery?
- What materials does the team share with families it counsels?
- Which community support groups does the DSD team work with and/or refer families to?

You wrote: "Any new case of DSD at NYP is reviewed by the PSDS Committee, which carefully considers each case individually. Patients and families, as always, are engaged in shared decision-making processes that empower them with knowledge, resources, and support throughout their child's development and life."

Could you please provide the following clarifying information:

- Which shared decision-making protocols or guidelines does the PSDS committee use?

- How does the PDSD committee involve patients in the shared decision-making process, in particular when patients are too young to speak or participate in complex medical decisions?
- What knowledge and resources are shared with patients and families as part of the process? Is referral to a community support group part of the process?
- In providing “support throughout their child’s development and life,” how does NYP work with adolescent medicine specialists and mental health specialists to provide continuous care?

You wrote: **“In all circumstances we will continue to put our individual patients’ life and safety first and we will be guided by what is best to support children and their families. Our patients’ care and well-being is our top priority.”**

- In determining “what is best to support children and their families,” what criteria and policies are used?
- In securing “individual patients’ life and safety,” what safeguards are in place if someone other than the patient themselves elects an intervention that carries significant risk of irreversible harm?

You wrote: **“NYP respects each person’s right to their own unique identity, and that intersex is a sex.”**

A standard definition of “intersex” is along the lines of:

An umbrella term that refers to a range of traits and conditions that cause individuals to be born with chromosomes, gonads, and/or genitals that vary from what is considered typical for female or male bodies. A former medical term, “intersex” has been reclaimed by some as a personal and political identity. Intersex is not the same as transgender, which describes individuals whose gender differs from the sex they were assigned or presumed at birth.

This definition aligns with how [intersex community groups](#) and the [United Nations](#) define the term. In NYP’s statement, the assertion “intersex is a sex” appears to suggest a different understanding, and that “intersex” refers to a third or non-binary sex designation.

- Could you please clarify this so that we might accurately reflect the hospital’s position?
- Could you please clarify which diagnostic codes fall under NYP’s definition of “intersex” or “DSD” for the purposes of treatment and referral?

Thank you for your time and consideration.

-Kyle

From: [REDACTED]
Sent: Monday, August 9, 2021 4:25 PM
To: Kyle Knight [REDACTED]
Subject: RE: Human Rights Watch request for comment on today's protest

[Hi Kyle, please see statement from NYP:](#)

Statement from NewYork-Presbyterian

NewYork-Presbyterian has long recognized the evolving understanding and complexity of medical decision-making for children with Differences in Sex Development (DSD). NYP respects each person’s right to their own unique identity, and that intersex is a sex. As part of our continued efforts to address this important issue, and consistent with our comprehensive approach to the care of patients with DSD, we have a Pediatric Differences in Sex Development (PDSD) committee which includes experts from NewYork-Presbyterian, Columbia University Irving Medical Center, and Weill Cornell Medicine.

Any new case of DSD at NYP is reviewed by the PDSD Committee, which carefully considers each case individually. Patients and families, as always, are engaged in shared decision-making processes that empower them with knowledge, resources, and support throughout their child's development and life.

In all circumstances we will continue to put our individual patients' life and safety first and we will be guided by what is best to support children and their families. Our patients' care and well-being is our top priority.

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From: Kyle Knight [REDACTED]
Sent: Monday, August 9, 2021 11:30 AM
To: [REDACTED]
Subject: [EXTERNAL] FW: Human Rights Watch request for comment on today's protest

Greetings –

Please see the inquiry below from Human Rights Watch, forwarded at the request of [REDACTED]

Regards,
-Kyle

From: [REDACTED]
Sent: Monday, August 9, 2021 11:26 AM
To: Kyle Knight [REDACTED]
Subject: RE: Human Rights Watch request for comment on today's protest

Dear Kyle,

Thank you for reaching out and apologies for missing your note during the weekend. NewYork-Presbyterian is handling all media requests. Please send your request to [REDACTED]

Thanks,

[REDACTED]

[REDACTED]
[REDACTED]
[REDACTED]

[REDACTED]
[REDACTED]
[REDACTED]

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From: Kyle Knight [REDACTED]
Sent: Saturday, August 7, 2021 6:24 PM
To: [REDACTED]
Subject: [PR-WCMC] [EXTERNAL] Human Rights Watch request for comment on today's protest

Dear Weill-Cornell Office of External Affairs:

I am a researcher with Human Rights Watch, an independent non-governmental research and advocacy organization headquartered in New York City.

In 2017, we published a [report](#) on the issue of medically unnecessary surgeries on children born with intersex traits (also know as differences of sex development, or DSD).

At his request, we met with Dr. Dix Poppas of Cornell and discussed his views on the issue. Our follow-up correspondence with Dr. Poppas can be seen [here](#) and his response [here](#).

As you may know, there was a demonstration outside of your facility today regarding the same issue, as covered in the media [here](#).


While HRW did not participate in the demonstration, we will be preparing a statement to publish on Monday regarding the human rights violations the protesters were highlighting.

I would like to request a response from your office regarding the protest, and the issues raised, including:

- What steps has Weill-Cornell taken to end the human rights violations taking place when medically unnecessary surgeries on intersex/DSD children are taking place without their consent?
- Does Weill-Cornell have a policy regarding the use of medically unnecessary risky surgical procedures on pediatric patients?

Thank you for your time and consideration.

Kind regards,
-Kyle

Kyle Knight
Senior Researcher
Human Rights Watch


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