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Submitter Name Lila Nordstrom To the members of the STAC,

Thank you for moving forward with discussion about the potential addition of uterine cancer to the list of WTCHP covered conditions.

StuyHealth is an organization that works with young adults in the 9/11 community, and today we are writing to express our deep concerns about the continuing disadvantages women face in the World Trade Center Health Program. The program's lack of coverage for uterine cancer is a symptom, but the omission of coverage for that condition points to a greater flaw in the way the program has been set up – one that disadvantages women and young people and, ultimately, offers us inequitable access to the program's services.

For many years there has been consistent conversation at STAC meetings about the possibility of adding both uterine cancer and autoimmune disorders to the list of WTCHP covered conditions. Both of these primarily or exclusively affect women, which also means both disproportionately affect members of the survivor community, who make up a vast majority of the women exposed to the toxins of the 9/11 clean-up. The fact that these omissions are both conditions that disproportionately affect women is, unfortunately, not an accident.

Officially, the reasoning for the exclusion of women's health coverage from the WTCHP has generally been based on a lack of "sufficient evidence." It easy, of course, to find insufficient evidence of a claim you haven't studied. Given that there is a documented lack of research focusing on female 9/11 survivors and responders, asking for women's reproductive health concerns to meet the same standard of evidence as male reproductive health concerns sets female patients up for failure. A lack of coverage becomes a self-fulfilling prophesy, not a justifiable scientific conclusion.

This logic is particularly vexing because the program's own policies prevent it from gathering meaningful data on women's health. Unlike first responders, who are 90% male, survivors do not have access to proactive monitoring within the WTCHP. Our participation is contingent on a diagnosis with an already covered condition, and inclusion of those conditions has generally been based on data from studies of first responders. These are all studies of disproportionately or exclusively male cohorts. Since proactive monitoring is not available to the vast majority of women in the 9/11 community, the program, by design, does not collect adequate data on women's health concerns. Outside research focusing on women's health has been lacking as well, largely because most research funding to the 9/11 community has focused on first responders. The result is that women – both responder and survivor - are receiving a different, generally lower, standard of care in the World Trade Center Health Program.

Beyond the fact that women (and, it should be noted, children) are nearly absent from 9/11 health research, regular community members face greater obstacles to even finding out about the program in the first place, meaning many sick survivors who would otherwise qualify are not yet in the program and therefore not represented in the monitoring data the program does collect. Survivors have been made to feel undeserving by frequent rhetoric that frames first responder acts of heroism as the qualifying basis for their care when, in fact, it was government disinformation that created the need for this program. Outreach to the community was too little, too late and hasn't reached the entire affected population. This is alarming since survivors actually make up a majority of the 9/11 community.

The coverage conversation is not a scientific puzzle to solve. Real people are sick and suffering in

the present. The difference between covering potentially fatal conditions now and later is literally life or death, especially for younger survivors like myself who lack consistent primary health coverage and have spent our entire adult lives living under the shadow of 9/11 health concerns. It should be enough that every male reproductive cancer, as well as almost all other malignant cancers, are covered by the WTCHP. It is imperative that, given the lack of data on women's health overall, we use the most expansive criteria possible to justify the addition of women's health conditions. We also must create new research cohorts so that we can obtain information about the range of health impacts women and younger victims of 9/11 are likely to experience since they are not being meaningfully captured by the program's monitoring.

We're told again and again that 9/11 was an attack on America, but to some of us that attack was a little more tangible than it was to others. Hundreds of thousands of those Americans who experienced the attacks firsthand were women and children. To wait on providing them equitable care under the WTCHP is unacceptable.

Thank You,

Lila Nordstrom (on behalf of StuyHealth)