

Revised comment

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WTC Health Program's Survivors Steering Committee
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Good afternoon, I am Kimberly Flynn and I make these comments on behalf of the WTC Health Program's Survivors Steering Committee, which I chair.

We believe that the rationale presented by Drs. Udasin, Graber, Crowley, Harrison, Moline and Reibman, for adding uterine cancer is sufficient.

They reason:

- That many of the 800 recognized Endocrine Disrupting Chemicals are known constituents of WTC dust and smoke.
- That EDCs have been shown to adversely impact reproductive health across the life cycle.
- That the estrogenic action of many EDCs, including PCBs, TCDD, furans, PFAS, by dysregulation of miRNA expression and other means is plausible evidence of a causal role in uterine cancer.

Furthermore, none of the available studies factor in simultaneous exposure to multiple EDCs, and carcinogens -- a scenario that played a key role in the 2012 cancer deliberation, and was used to justify adding cancers that would not meet the high bar set for uterine cancer currently.

We are between a rock and a hard place with uterine cancer, which is not rare enough to qualify under the rare cancer provision yet not frequent enough to be detected in largely male study cohorts.

Per Dr. Leigh Wilson's comment this morning, about some women walking away from the WTC Health Program when they discover that their health condition is not on the WTC list, I want to point out that of the six responders and survivors with uterine cancer included in public comments, three never made it into the Program. Since uterine cancer is NOT a covered condition, women with this diagnosis may not apply, or may not pursue certification for other conditions that are covered. In addition, four of the six are NOT enrolled in the WTC Health Registry. How many others are similarly off the radar screen?

The STAC should appreciate that although the vast majority of studies glossed in the Scientific Considerations document were underpowered due to very small cohorts of women, it does appear that a collective trend can be seen across a number of these studies suggesting increased uterine cancer among women exposed to EDCs. Focusing exclusively on individual studies can obscure effect trends that would be apparent in a forest plot. For instance, the mortality study of female workers in the Italian asbestos cement factory did show a statistically significant excess mortality of women from cancers of the uterine corpus and cervix, combined. We have emailed the study authors to request data specific to the uterine corpus.

Since cervical cancers make up less than a quarter of all uterine-related carcinomas, there is a good chance that data from this study *would* show a link between asbestos exposure and uterine cancer. The analytical approach used throughout the considerations document, of dismissing all studies whose 95% confidence interval includes an RR of 1.0, erases the opportunity to examine collective trends across multiple studies, employed in meta-studies such as the Cochrane Reviews-

And I want to widen out to the research directions issues which are also part of the charge for this STAC meeting.

The Scientific Considerations document repeatedly observes that most of the studies relevant to environmental exposures with a potential causal link to uterine cancer “have been conducted in occupational cohorts, which included a small number of women or no women at all.” Unfortunately, this statement is mostly true of the entire WTCHP research portfolio, where 78% of research money funds studies of a responder cohort that is 86% male.

While we would agree that the WTCHP research budget is inadequate to address the full range, complexity and persistence of the multi-system health impacts for all populations exposed to 9/11, we do not accept the large disparity in research support.

Most glaring is the lack of support for research on how the WTC disaster affected women, who constitute 50% of survivors, and the health of more than 35,000 9/11-exposed children.

As STAC survivor member Mariama James said on the first day of this meeting, you cannot know how 9/11 exposures are impacting women and children by studying only 50-year old men.

The latest WTCHP research awards cycle may have produced the most unequal results yet – out of 19 awards only two went to survivor studies. Three key survivor program research proposals were denied funding, by study panels that have no directives from NIOSH about the nature of disaster science or the importance to the program and its members of funding studies of survivors.

Given that the WTCHP operates on a “Research to Care” model, research decisions have far-reaching implications. Research gaps become knowledge gaps which in turn become diagnostic and treatment gaps. This is bad science that ultimately translates into denials of care.

The SSC will be updating the STAC in writing on whether the program has followed its 2016 recommendations on Children’s 9/11 Research. The short answer is mostly not. To respond to a comment made by Dr. Sophie Balk, there is no research being done on reproductive health impacts to people exposed as children.

We are also calling on the STAC and the program for a meeting in the next 6 months to start the conversation around health equity and the impact of unequal research.

Finally, we call on the program to review the diagnoses of the women who have come forward in this meeting, several of whom have been struggling for years to figure out whether their individual cancers are “rare” by the program’s definition.

We and they are calling for uterine cancers to be added as a class, but these responders and survivors are entitled to get an authoritative determination from the program now on whether or not WTCHP will certify their cancers as rare.

Thank you for your consideration.

