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WTC Health Program's Survivors Steering Committee
Public Comments to WTC STAC
November 18, 2021

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

We fully endorse the STAC's recommendation to add all uterine cancers to the list of WTC conditions. And we thank the STAC Work Group for their excellent work.

This brings me to the larger context and the question that responder and survivor women, especially those with uterine cancer, have been asking: How is it that, for nearly a decade after the 2012 addition of more than 50 cancers, uterine cancer has been the only cancer not added by the WTC Health Program?

The WTCHP's Science Team provided an answer: occupational cohorts, which are the main basis of the research literature linking environmental exposures to cancers, are overwhelmingly male. The same is true of the responder cohorts receiving the lion's share of research support from the WTC Health Program.

So - who is left understudied?

STAC member Mariama James answered at the last meeting when she said, "you cannot know how 9/11 exposures are impacting women and children by studying only 50-year old men."

Because under the Zadroga Act, the WTCHP relies on research for adding new conditions for care, research inequities translate into care inequities. Uterine cancer is today's example, but there are more.

We as Survivors have long raised this issue with the WTCHP. We know that there are scientific complexities around research design, but the Program has run a research funding process where survivor proposals for studies focused on the disaster population of civilians, are placed at a disadvantage. With each funding cycle, survivor proposals are denied funding because they plan to study a so-called "self-referred population."

Unlike responders, survivors do not have a screening program. So the Program punts to the WTC Health Registry to conduct surveillance for emerging conditions in survivors. The STAC has heard why this is problematical in discussions of the Registry's small and disproportionately affluent child cohort. While the Registry continues to publish valuable research, it is a flawed surveillance tool. This is especially true for less common cancers, like uterine cancer. Of the 8 women with uterine cancer who came forward to myself and Rhonda Villamia in the course of the STAC deliberation, at least 5 were not enrolled in the WTC Health Registry. The Registry was not able to introduce its Wave 1 Survey until 2003. Its failure to ask questions about indoor contamination and respirator use sowed mistrust among survivors and responders, leading to lowered enrollments, and in some cases, boycotts.

However, as the STAC Work Group has noticed, the survivor program is developing other approaches that promise to yield useful information. First example is the WTC EHC's Pan Cancer Database (PCBD).

PCDB includes patient demographics and exposure information, site-specific cancer characteristics, cancer molecular profiling and biomarker information. One preliminary study, led by Dr Alan Arslan found "considerable differences in the breast cancer characteristics and distribution of breast cancer intrinsic subtypes in the WTC-exposed civilian population compared to that of the general population." This is important because of the relevance of molecular subtype to breast cancer prognosis and treatment options.

What can we learn from the WTC EHC Pan Cancer Database?

The studies using this database may well have significant translational import, yielding molecular information that could guide targeted treatments including for endometrial cancer, for which current options are often radical. Studies could yield epidemiological information: Will epigenetic analysis of these cancers show a WTC fingerprint, as Dr. Arslan's findings hint? Further, such studies may shed light on links between cancers and environmental exposures beyond WTC. This resource and the studies based on it need research support.

With respect to children (now adults), the STAC recognizes that the developmental age at which exposures occur is critical to the effects of EDCs across the life cycle and the importance of early exposures.

The Work Group cited Dr. Leo Trasande's study finding that blood levels of the EDCs dioxin and furan were significantly higher in WTC-exposed adolescents than a control group. This study needed follow-up, but funding was denied.

Nonetheless, we agree with Dr. Trasande and other experts that it remains critical to investigate a range of endocrine-related conditions, including metabolic syndrome, PCOS, endometriosis, infertility and cancer, as those who were children on 9/11 enter their 30s and 40s. The SSC continues to call for assembling a representative cohort of young people, so that longitudinal surveillance of emerging reproductive health problems, among others, can get underway – much better late than never.

At the last STAC meeting, we heard a “Research Activity Update” from Travis Kubale, the Associate Director: Research Planning and Care Integration

After explaining that 78% of WTCHP funded publications examined responders, he stated:

“Research is needed to better identify at-risk populations, characterize burden, assess health equity, and inform care.”

We would agree, but we don't need research to tell us there is health inequity, we need research to rectify the existing health inequity. We should start with the women who make up half of the survivor population (and half of the 30,000 WTCHP survivor members), and with the 35,000 people exposed to WTC as children.

We believe that the STAC is an important venue for discussion of health inequity with respect to the WTC-affected population, and, crucially, the unintended but ongoing research inequity that has helped to drive it. We now call for the next STAC meeting to engage the “equity analysis” that the Program is proposing. The affected community has often benefited from the public dialogue between experts and stakeholders that happens at STAC meetings, and we are confident that we will do so again.

Thank you.