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Rhonda Villamia

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I was a volunteer during the 9-month relief effort at the WTC site...initially as a spontaneous volunteer along West Side Highway from Canal St. to Chambers St., then with the Red Cross at St. John's U Respite #1, the Salvation Army "Taj/Bubble" tent, and at St. Paul's Chapel.

In each of these 4 settings, **the disaster relief volunteers were predominately females of all ages**. A number of us were siblings or mother/daughter teams. I myself was part of a sibling pair, and I can think of 3 others on my shift alone, as well as 4 mother/daughter teams. **Aside from the volunteers, females also outnumber males in the survivor and office cleaner cohorts.**

In 2009, I was invited to join the WTC Health Registry Community Advisory Board, representing the disaster relief volunteers. From several 9/11 health-related activities I'd been involved with, inclusive of trips to DC with the FealGood Foundation to lobby for the passing of the Zadroga Act, **I became aware that reproductive abnormalities were being voiced by the majority of the women I encountered**. I was also repeatedly hearing that this data was not being noted in our monitoring and treatment programs...so it appeared these...and other emerging conditions were not being tracked to the degree they should have been.

Though the Registry was conducting a "Birth Outcomes" study to be completed in 2010, I noticed there were no female reproductive health questions up to that point on the Registry survey, so I began advocating for that and reaching out to the volunteers, while Registry Community Advisory Board member Kimberly Flynn did the same with the survivors. We had both heard anecdotal reports of **early menopause, with some cases of sudden cessation of menses, fibroids and cysts, endometriosis, and breast cancer**. In addition, I had heard reports of **infertility, birth defects, low birth weights, and pre-term deliveries**. I myself developed uterine fibroids, as did my sister, and I began menopausal symptoms at age 46. The only study I was aware of at the time was one published September 8<sup>th</sup> 2004 in *Environmental Health Perspectives*, titled "The Effects of World Trade Center Event on Birth Outcomes Among Term Deliveries in Three Lower Manhattan Hospitals".

In the Wave 3 Survey of 2011, the Registry added 4 female reproductive health questions: age at onset of period, confirmation of still having a period, age when period stopped, and reason why period stopped. In the Wave 4 Survey of 2015, these 4 questions were not included, but instead, there were questions about current pregnancy, mammograms, breast cancer, cancers in biological parents, siblings, and other blood relatives...and the opportunity to write in any other condition or cancer not listed.

It is gratifying that the WTC Health Program (WTCHP) has certified breast, ovarian, and certain rare cancers in our female population such as vulva, vaginal, and cervix uteri. **I am here today in support of uterine and endometrial cancer being added to that list of certified conditions.**

**I would request that further research be done on our 9/11-exposed women in view of the conditions indicated in my 4<sup>th</sup> paragraph above.** Have **any** studies been done on these conditions...including women exposed to 9/11 toxins who became pregnant after 9/11?

A WTC volunteer friend...with no family history of any reproductive issues... suffered with fibroids, infertility, and 3 breast tumors while in her 30's. When she finally conceived, the pregnancy ended in the 4<sup>th</sup> month due to Trisomy 18...a/k/a Edwards Syndrome. She shared this with me recently, and I decided to see if Trisomy 18 could be caused by toxic exposure. I found an April 8<sup>th</sup> 2020 *International Journal of Environmental Research and Public Health* abstract titled "Potential Increased Risk of Trisomy 18 Observed After a Fertilizer Warehouse Fire in Brazos County TX". **What we were exposed to on 9/11 is unlike any previously seen combination of toxins, therefore, more research is needed on our female population.**

Before concluding my comment, I'd like to bring to the STAC's attention **other situations** I have personally experienced. Though these may not be within the STAC's purview, I'd like to nevertheless make note of them in the hopes that these will come to the attention of the appropriate decision-making body for consideration.

The first has to do with **mental health coverage**. I'd like to ask that the National Provider Network do its due diligence in insuring treatment is not interrupted as a result of delayed or denied claims payments. I have not had therapy sessions since July 7<sup>th</sup> because claims since September 2020 have not been paid. It was crucial to have been under mental health treatment, especially at this time of year as the countdown to the **20-year milestone of the 9/11 anniversary** began. Further increasing the PTSD was the devastation of the **Surfside building collapse**, which was so reminiscent of the WTC attack that it was a **great trigger** for our 9/11 community. And...the fact that my son and grandchildren live in Surfside...an area I'm very familiar with...added to my trauma.

**This interruption of mental health care created even more PTSD during an already very stressful period.** And mine is not an isolated case. My sister is presently going through the same situation, as are others, per a September 9<sup>th</sup>, 2021 NBC news article titled "I Feel Betrayed: Some 9/11 Responders Still Face Major Health Care Obstacles". This situation must

be remedied so our 9/11 community can have the mental health treatment we need, without interruptions.

Regarding PTSD, **I'd like to ask the WTCHP to please consider covering urticaria as a condition secondary to PTSD.** I have consistently had urticaria eruptions during periods of extreme stress, and despite having medical documentation from dermatologists linking it to my WTC-certified PTSD, my requests for coverage of this condition have twice been denied.

The final situation has to do with **acupuncture coverage.** I have greatly benefitted from this modality over the past 6 years. **I'd like to request the WTCHP please consider approving it as a maintenance treatment for chronic musculoskeletal conditions.** Though it is approved as a complementary long-term plan of care for cancer patients, it is only approved for acute short-term use otherwise, much as physical therapy or chiropractic care would be. Aside from my musculoskeletal issues being managed...since the protocol is **systemic-affecting** ...it has benefitted my other WTC-certified conditions to the point that I have been able to manage my symptoms while seeing fewer specialists. **Acupuncture is of clinical benefit to the patient and of economic benefit to the WTCHP.** It costs less to see fewer specialists and be on fewer medications...and **acupuncture has no side effects that would create secondary conditions that the program would have to cover.**

Therefore, I graciously ask the WTCHP to **consider approving acupuncture** as a maintenance protocol...**at minimum, to the degree Medicare is available...at 20 visits per year.**

And...**I would humbly ask the STAC to consider recommending that the WTCHP fund research on the efficacy of acupuncture in treating multiple WTC conditions.**

Finally, I'd like to end with this point. When the WTCHP was implemented, part of its founding mandate was to have a venue by which our 9/11 community members could have our voices heard by the program leadership. This was done by establishing a Responder Steering Committee and a Survivor Steering Committee.

Though the category of "Responders" includes uniformed first responders, construction industry personnel, disaster relief volunteers, and clean-up workers...the Responder Steering Committee consists of labor union representatives for the uniformed, construction, and other workers.

As I pen these words, I do not know the total number of volunteers that served at the WTC site, but I have begun to make inquiries. What I do know is that aside from our local volunteers who were classified as "long-term volunteers", there were continual 2-week rotations of volunteers coming in from throughout the US and Canada, particularly with the Red Cross and Salvation Army. Also present at the site were the Southern Baptist Disaster Relief teams. In the 9-month relief period, with new people responding every 2 weeks, there was quite a large number exposed to the toxins. And the great majority of these volunteers were women.

We have a **network of volunteers** that has remained in contact these past 20 years, and we are now forming a stakeholder committee. **Going forward, we'd like an opportunity to periodically meet with WTCHP and Registry representatives for input and dialogue.**

In conclusion, I reiterate that **more studies MUST be done on the health of our 9/11-exposed women, perhaps including a study of familial pairs such as siblings or mother/daughters.**

Furthermore, I entreat the WTCHP and Registry to provide **disaster relief volunteers** a venue for dialoguing because **we are a numerically significant portion of the 9/11 community whose voice is not being heard.**

I very gratefully thank the STAC members and the WTCHP leadership for their consideration of all I've shared in my comment.