The possible relationship of Chronic Fatigue Syndrome with problematic buildings has been noted since the beginnings of the history of the disease in the U.S. in the 1980’s. Chester and Levine wrote about the connection of specific early epidemic spots with Sick Building Syndrome in 1994 and 1997, although at the time the role of toxic mold in SBS was not understood by scientists. (1) In April 2013, Brewer et al published a peer-reviewed paper noting that 93% of a sample of patients from a general CFS doctor’s practice had mycotoxins in their urine (compared to 0% of a sample of controls), suggesting that environmental mold toxins might be playing a role in the disease. (2) A number of other CFS physicians also have discussed the possible connection of toxic mold with the disease, observing either that certain species of mold make the sort of inflammatory toxins that would be especially problematic in CFS; that patients anecdotally frequently first get sick or decline precipitously when living or working in moldy buildings; or that some CFS patients insist that careful avoidance of toxic mold has been inordinately beneficial to them.

In addition, many of the specific abnormalities present in CFS are consistent with health effects that have been shown to be produced by trichothecene mycotoxins, such as those made by the building mold \textit{Stachybotrys chartarum}. Some of these effects include (3):

* Damage to the immune system (especially the innate immune system)
* Neurological damage (cognition, emotional stability, processing of sensory information)
* Mitochondrial damage
* Severe oxidative stress and depletion of glutathione
* Gut dysbiosis (mycotoxins kill off a wide range of bacteria)
* Perforations in the blood-brain barrier (potentially allowing toxins, gluten and pathogens that ordinarily would be kept out to enter freely and cause damage)
* Intestinal permeability (contributing to gluten/food sensitivities and other issues)
* Systemwide inflammation (including elevations in IL-1b, IL-6, IL-8, TNF-alpha and N-F-k-b)

A primary question is whether CFS patients are merely reacting negatively to toxic mold as they might to many other stimuli -- or whether the toxic mold is acting as a cause, a risk factor or a progression factor with regard to the overall disease. If toxic mold is merely a trigger, like perfume, then it may be helpful in terms of people’s short-run comfort and functioning for them to avoid it once they are already sick. On the other hand, if exposure to toxic mold is a risk factor for acquiring the disease or a progression factor with regard to people becoming permanently more ill with it, then it is important to know this since it would suggest ways that effective prevention might be achieved.
The goal of the proposed study is to explore this topic by attempting to answer a very simple and limited question: Does living in a particularly problematic home in terms of toxic mold constitute a risk factor for acquiring CFS?

Following are some specifics of the proposed study design.

Subject Population: It is essential here to have a random sample of a well-screened patient population who have been verified by experienced doctors to have actual ME/CFS. Preferably the patients would be moderately severely or severely affected and already would have had specific testing verifying their condition. In addition, since this study is about risk factors for getting the disease, the subjects would need to be living in the same home where they got sick. Provided that enough funding becomes available, a relatively large sample (such as 100 patients) would be preferable, in order for us to be more confident in the results.

Methodology: The determination of whether the patients are living in a problematic residence will be done using the ERMI (Environmental Relative Moldiness Index). This test will have patients use a vacuum cleaner or cloth to obtain a sample of dust from various areas in their home. The sample will be mailed in to a laboratory, which will do a DNA analysis to determine the types and amounts of different molds present in the sample and in the home. The results will be presented as an overall index score that reveals how problematic the home is compared to other homes in the U.S. For instance, a score of -4 suggests that the home is more problematic with regard to toxic mold than 25% of homes. A score of 0 suggests that the home is more problematic than 50% of homes (i.e. at the median). A score of 6 indicates that the home is more problematic than 75% of homes. A score of 17 indicates that the home is more problematic than 95% of homes. (4)

Second-Round Testing: If a patient is living in a home that does not prove to be problematic according to this test, it still may be that toxic mold played a role in the acquisition of the illness due to a workplace or school exposure. If feasible, it would be helpful for patients whose homes do not come up on the test as particularly problematic to get a dust sample for testing from the place where they were working or learning when they got sick, to see if that might have had an influence.

Test Quality: The ERMI was developed by the Environmental Protection Agency (EPA). It has been in widespread use for about six years and has been the subject of a number of peer-reviewed papers showing its accuracy in terms of predicting the presence of asthma and other respiratory ailments. (5) Mold doctors who have used the test with CFS patients (in one instance looking systematically at nearly a thousand patients) report that it is predictive of neuroimmune illness as well, and it has been successfully upheld in court cases for this purpose.

Control Groups: The ERMI has been tested enough that it should be possible to get a good idea about whether subjects are living in particularly toxic homes without running a control group, just by looking at their index scores. However, it is likely that for the study
to be accepted into a peer-reviewed journal, a specific matched control group will be necessary. My inclination would be to wait on doing the control group until we become certain that the sample of CFS sufferers indeed does seem to be living in particularly problematic homes, since at that point raising more funds to make the study publishable might be easier to obtain than if the project is still in the exploratory stages.

Control Group Selection: A key consideration in choosing control group members will be to find patients who are not suffering from anything that is at all related to CFS (such as mild chronic fatigue, mild cognitive issues, depression, gluten intolerance or chemical sensitivities), since these could be preliminary stages of the disease being caused by living in a problematic home for less time than is necessary to cause frank CFS. Clearly healthy subjects, matched for age/gender and living in the same geographic area (though perhaps not the exact same town), would seem appropriate.

Costs: The costs to run the ERMI tests will be about $300 per subject. Insofar as we do workplace/school testing for some subjects, that would be an additional $300 per subject. An IRB apparently is $2500-3000. Additional administrative costs also may be included.

Funding: I am in contact with two separate wealthy entrepreneurs, both of whom obtained CFS after mold exposures and have expressed interest in funding a study such as the one being proposed. Once we determine the amount that our desired study will cost, I will approach them again and find out how much they are willing to contribute.

Thank you very much for considering this study. I am looking forward to discussing it with you further and then seeing the results after it is completed.

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