



Solve M.E.

Dear New Yorker editorial team –

Thank you so much for publishing Mike Mariani's piece, "A Town for People with Chronic-Fatigue Syndrome." (September 3, 2019) and please pass my gratitude to Mr. Mariani as well.

As a caregiver for my mother who has struggled with ME/CFS for over a decade, I share the author's frustration about the lack of public awareness and the damaging lack of knowledge among the majority of health care providers. Proper clinical trials that could lead to FDA-approved treatments (and a cure) are so desperately needed, and I agree that "the fact that we still understand so little about C.F.S. may have helped to foil the trial"-- particularly as this relates to understanding potential *subtypes* of ME/CFS.

After seeing the suffering this disease caused my family, I left my career in autism public policy and I now serve as the Director of Advocacy for the Solve ME/CFS Initiative (Solve M.E.). Solve M.E. is the longest standing ME/CFS organization in the U.S. We're working on multiple fronts to increase understanding about the disease. I am especially optimistic about the upcoming launch of our global, collaborative registry and biobank. In the article, Dr. Ian Lipkin remarked, "*a study that did not parse M.E./C.F.S. by subtype might miss a bona fide treatment response.*" *I truly believe this [Registry](#) could contribute significantly to meeting this need.*

In an effort to improve public acceptance of ME/CFS, we created the [Humans of M.E. \(HoME\)](#) story archive. ME/CFS researchers Dr. Liz Worthey and Dr. Camille Birch (HudsonAlpha Institute) have already begun using the information provided by patients to inform their analysis of whole genome sequencing and ME/CFS.

Raising awareness (as you have by publishing this article), improving our federal government response, improving research funding, and sharing data are the KEY paths forward to unlocking the mysteries of ME/CFS. From my own personal and professional experience, I know that we are making great strides toward a future free of this horrible disease.

Thank you for being an ally in this effort,

Emily Taylor

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