

Leading the Fight to cure ME/CFS

February 8, 2019

To the Editors of *University Times*,

My name is Emily Taylor, and I'm the Advocacy and Community Relations Director for the Solve ME/CFS Initiative (SMCI), the national research and advocacy organization dedicated to accelerating the discovery of safe and effective treatments for Myalgic Encephalomyelitis, formerly known as Chronic Fatigue Syndrome, or ME/CFS.

In addition to research and advocacy, an important part of our work involves debunking fallacies and misinformation about this devastating disease which cause active harm to people with ME/CFS and increase rates of misdiagnosis and mistreatment.

In her article, "An Unhealthy Mind Can Lead to An Unhealthy Brain. Let's Not Forget That," (Feb. 7, 2019) University Times Science and Research Correspondent Yasmine Tadjine, wrote:

The most well-known psychosomatic disorder is probably chronic fatigue syndrome. A lot of controversy surrounds the disorder: how can it be possible that one can become bedridden or experience excruciating pain for "no reason"?

You must issue retraction and correction of this statement. It is factually wrong and a gross mischaracterization of ME/CFS. This is not "psychosomatic" illness. Decades of rigorous scientific research have yielded substantial scientific evidence proving that ME/CFS is indeed a biological illness. As Harvard University's Dr. Anthony Komaroff asserted, OVER 10 YEARS AGO, "There are now thousands of published studies that show underlying biological abnormalities in patients...It's not an illness that people can simply imagine and it's not a psychological illness."

A simple search on pubmed.com or any scientific journal would have yielded this information. I am terribly disappointed that your "Science and Research" correspondent could not even conduct a basic literature review for making a completely false statement like this. Even the Center for Disease Control website, clearly states the biological nature of this disease. This is commonly known and easily accessible information.

Promotion of the incorrect notion that ME/CFS is a "psychosomatic" illness, despite vast quantities of scientific research proving otherwise, causes unnecessary pain and suffering to patients and their families, promotes mistreatment of people with this disease, and contributes to the failure of the medical community to provide proper care to people suffering from significant biological impairments. It also contributes to the continuing misdiagnosis of gravely ill people with the disease. According to the 2015 Institute of Medicine report, between 84-91% of people with ME/CFS are undiagnosed or misdiagnosed.



When trusted media outlets spread false information about ME/CFS, it thwarts the progress made in raising public awareness about the disease, which makes it even more difficult to acquire funding for treatment and research, attract new scientists to the field, and educate medical caregivers about the disease. The human cost of incorrectly labeling ME/CFS as a "psychosomatic disorder," is very real. Your story has actively contributed to harming people with this disease.

Our SMCI website contains a great deal of easily accessible and quantifiable information regarding ME/CFS for journalists like Ms. Tadjine, including:

5 Myths of ME/CFS

https://solvecfs.org/5-myths-of-me-cfs/

FAQs About Me/CFS

https://solvecfs.org/me-cfs-faqs/

And a vast <u>archive of SMCI publications</u> reporting years of scientific breakthroughs in the study of ME/CFS.

Another important resource for your consideration is the **IOM report on ME/CFS**:

Beyond Myalgic Encephalomyelitis/Chronic Fatique Syndrome: Redefining an Illness

Very recent evidence of the physiological/biological causes of the disease can also be found in the work of:

Columbian University's Mailman School of Public Health

https://www.mailman.columbia.edu/public-health-now/news/insights-metabolites-get-us-closer-test-chronic-fatigue-syndrome

Dr. Carmen Scheibenbogen, a researcher at Charité—Universitätsmedizin Berlin in Germany

https://solvecfs.org/recent-autoimmune-therapy-study-from-ramsay-2016-2017-grantee-carmen-scheibenbogen/

Dr. Jarred Younger, Director of the Neuroinflammation, Pain and Fatigue Laboratory at University of Alabama at Birmingham

https://www.youtube.com/watch?v=rxdzaWD5wfU

And countless others by esteemed researchers working in labs around the world and decades of peer-reviewed medical publications.

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www.solvecfs.org



Do a basic online search before making false claims about a debilitating illness. As a journalist, the only correct and responsible course of action is retracting and the article with this false characterization of ME/CFS as a "psychosomatic disorder" and issuing an immediate apology to the international ME/CFS community.

Sincerely,

Emily Taylor

Director of Advocacy and Community Relations

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Solve ME/CFS Initiative

P.S. As the daughter of a person with ME/CFS, I have seen first-hand the damage caused by poor information about this disease. I urge you and your team to be part of the solution, rather than part of the problem.