



ISSUE ADVISORY: NOW Foundation Women's Health: Research needed on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Neglected and Misdiagnosed Disease that Strikes Mostly Women

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Rivka's Mysterious Illness - When NOW member Rivka Solomon was 21 years old, she contracted mononucleosis. However, instead of recovering normally, she remained sick and incapacitated for a year. She was forced to withdraw from her social activities, she was unable to leave her home, and she was unable to exert any physical and intellectual energy without experiencing subsequent extreme exhaustion and physical pain.

However, all her medical tests came back negative, and no doctor could find a cause, let alone a cure, for the condition that had devastated Rivka's life. After a few years of spontaneous remission, her symptoms returned and she was once again forced to put her life on hold. As Rivka herself puts it "*my body just collapsed.*"

Unable to Function - Rivka was barely able to complete her Master's degree due to the debilitating effects of the condition. She had to resign from her social activities and quit the women's organization she had founded to raise awareness about sexism in the media.

As she herself states, "*after I graduated, I crawled back to my mom's home and into bed, and I have been tethered to my bed ever since.*"

Diagnosis of ME/CFS - After her condition relapsed, Rivka was diagnosed with a little-known neuro-immune condition called Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS). She has spent decades trying to cope with the devastating and volatile symptoms of her condition.

As Rivka describes it, "*this means that for decades I have lived with exhaustion so debilitating that on any given day it can be hard to find the strength to take a shower or make a meal. It also means constant brain fog, and legs so weak they can refuse to support me.*"

She has had to fear exerting any energy because it could result in a physically and mentally-debilitating crash, new symptoms, and a greater loss of mobility and abilities. She has had to sacrifice a social life and traditional career to this awful illness, noting, "*I have already lost my 30s, 40s and now some of my 50s to ME.*"

Advocacy Needed for Women with ME/CFS - However, Rivka and her mother, long-time NOW member from Contra Costa County, CA, Bobbi Ausubel, have fought back against the illness that devastated Rivka's life by dedicating their time to ME/CFS advocacy. As ME/CFS received minimal attention and funding both within and outside the medical world, Rivka

and Bobbi know that advocacy is the only way to improve the quality of life for women like Rivka.

Awareness Will Help - On May 12, International Awareness Day for ME/CFS, NOW Foundation will be amplifying their story and message, hoping that through raising awareness the suffering of millions of women like Rivka will no longer be overlooked. Events will be held around the country and, in the following week, advocates will visit members of Congress to urge more funding for research.

Millions Affected in U.S. - ME/CFS is a debilitating neuro-immune condition that is estimated to affect up to 2.5 million individuals in the United States. However, because there is no diagnostic test to detect ME/CFS, it is estimated that up to 91% of those suffering from the condition have yet to be properly diagnosed. Symptoms include extreme exhaustion, orthostatic intolerance (collapsing due to temporary low blood pressure), memory loss, joint pain, severe headache, cognitive dysfunction, neurological abnormalities, among a long list of symptoms. Patients are often unable to walk even short distances without a severe worsening of their exhaustion, sometimes for weeks or months. They are sometimes unable to tolerate the touch of a loved one, or the sound of a voice at a normal volume. Twenty-five percent will be home or bed-ridden at some point in their lives, and fifty to seventy-five percent are unable to work even part-time. A recent study shows patients with ME/CFS to have the lowest quality of life scores of any disease tested. Too many patients turn to suicide as a result.

Cause Not Known, No Proven Treatment - If you haven't heard of ME/CFS, you're not alone. It is rarely taught in medical schools, and if it is, it is often steeped in misinformation. There are fewer than 12 ME/CFS specialists in the United States. Recently, the CDC has come under scrutiny for including on their website and in their medical education treatments for ME/CFS that are harmful to patients, such as exercising. In fact exercising can make an ME patient much worse. Despite the fact that the cause of ME/CFS is unknown, and there is no FDA-approved treatment for the disease or a cure for the condition, this disease that affects millions of people receives incredibly little funding and attention. The burden of disease for ME/CFS has never been calculated by the National Institutes of Health (NIH) due to lack of research, so the allocation of resources to combat the disease has never been accurate.

Scant Funding Provided - Currently, ME/CFS is in the lowest 4% of diseases funded by the NIH. As Rivka shares, *"with the federal government dedicating such minimal funding to researching this disease, it is hard to hold on to hope."* The National Institutes of Health, despite repeated pledges to do more, is still dragging its feet on making ME/CFS a priority.

Same Old Story: Women Disbelieved - Why has this disease received so little attention? Gender bias. 75-85% percent of those diagnosed with ME/CFS are women. Many were told that their condition was psychological or that they were exaggerating or making up the symptoms. In fact, the disease continues to be misrepresented by some as psychological. This is not uncommon; 75% of autoimmune patients are women, and many of them have suffered unnecessarily after physicians informed them that they were simply

hypochondriacs or that their conditions were psychological. Today, many in the medical profession still diminish the symptoms and pain of women, and still do not believe their stories, and that needs to be addressed.

It's All in Your Head, Dearie - The medical field has a storied history of neglecting to appropriately treat women's pain and ailments. For centuries, women's health conditions, including brain tumors, multiple sclerosis, epilepsy, and other disorders were inappropriately psychologically categorized by physicians who diminished their pain and invoked centuries-old sexist concepts of hysteria to explain the women's symptoms. Medicine has come a long way to attempt to rectify this history and treat female patients as equals, but there is still enormous amount of work to be done.

Film-maker with ME/CFS Speaks Out - As prominent ME/CFS patient and activist Jennifer Brea has urged, "*we need to think in more nuanced ways about women's health. Our immune systems are just as much a battleground for equality as the rest of our bodies.*" Brea, at one time a Ph.D. student at Harvard University, has made remarkable strides in bringing more awareness to the disease. She founded a global network of people with ME/CFS, #MEAction (www.meaction.net), and gave a widely viewed Ted Talk about her illness. Jen's film, *Unrest*, made while she was bedridden, describes her life after being stricken in 2011. The film was supported by the Sundance Film Institute and the Sundance Film Festival awarded it a jury prize. *Unrest* will be shown on PBS's Independent Lens series in 2018.

ACTION NEEDED: As part of NOW Foundation's effort to lift up NOW members Rivka and Bobbi, and all those suffering from ME/CFS and their families, we enthusiastically support Solve ME/CFS Initiative (SMCI) and #MEAction's [ME/CFS Advocacy Week](#). The week of action will take place from Thursday, May 11 to Thursday, May 18. Events include district meetings, a social media storm, a call-in, a Capitol Hill Storm, and a Capitol Hill briefing, featuring the President of SMCI, Carol Head, a patient and former NOW treasurer, and SMCI's Chief Scientific Officer, Dr. Zaher Nahle, and Jennifer Brea.

Information and dates are listed on SMCI's website (www.solvecfs.org) and we hope that we can count on our wonderful NOW members and supporters to amplify the voices of patients and their families as we lobby Congress to make real strides at combatting this horrible disease. We hope to help bring public awareness to this debilitating disease and help raise a national demand for more adequate funding for ME/CFS research. We hope to signal to ME/CFS patients like Rivka that they are seen, that their suffering is legitimate, and that we are working to help them.

Please Note: At the 2011 National NOW Conference Dr. Nancy Klimas was honored for her work on ME/CFS and other diseases with the special Victoria J. Mastrobuono Women's Health Award. Dr. Klimas, a 36-year member of NOW, was drawn to care for patients with the often maligned and misunderstood illness, ME/CFS. A national and international leader in the treatment and research of ME/CFS, she heads an interdisciplinary research program and has published over 150 scientific articles, 18 book chapters, and three books on the disease. She is past president of the International Association for Chronic Fatigue Syndrome and Myalgic Encephalopathy (ACFS/ME), a professional organization of

clinicians and investigators, and a member of the HHS CFS Advisory Committee. More on Dr. Klimas at <http://www.nova.edu/nim/clinic/dr.-nancy-klimas-bio-page.html>

MORE INFORMATION

Solve ME/CFS Initiative, <http://solvecfs.org/> and advocacy efforts <http://solvecfs.org/2017-mecfs-advocacy-week-information-and-updates/>

MEAction, www.meaction.net

Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome – Redefining an Illness, Institute of Medicine, http://www.nationalacademies.org/hmd/~media/Files/Report%20Files/2015/ME/CFS/ME/CFS_ReportBrief.pdf

April 6, 2017 Letter to House Appropriations Committee leadership, urging progress on research, education and training by Department of Health and Human Services, Centers for Disease Control and National Institutes of Health, signed by 31 members of the House, http://solvecfs.org/wp-content/uploads/2017/05/LHHS_FY18-ME-Chronic-Fatigue-Syndrome-Research_FINAL-SIGNED.pdf

Jennifer Brea's Ted Talk, https://www.ted.com/talks/jen_brea_what_happens_when_you_have_a_disease_doctors_cant_diagnose

Carol Head, SMCI President, past treasurer of the Los Angeles Chapter of NOW, and a long-time activist for women's equality speaks about her experience with ME/CFS <https://youtu.be/kQwUmoAKUic>

Illuminating an Illness without End: Fellows Friday with Jennifer Brea, by Karen Eng, <http://blog.ted.com/illuminating-an-illness-without-end-fellows-friday-with-jennifer-brea/>