



For Immediate Release

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Thousands Demonstrate Globally for Health Equality for People with M.E.

More than 75 cities are demonstrating around the world from May 5th to May 12th, calling for our government and health leaders to take *urgent* and comprehensive action for people living with myalgic encephalomyelitis (ME). Hundreds more patients who are too ill to leave their homes will demonstrate from their beds on social media.

We are the [#MillionsMissing](#) who are missing from our lives due to decades of neglect. We are demanding that our federal agencies - the NIH, CDC and HHS - provide equitable research funding, treatments and care for people with ME. *We will be seen, and our story will be told.*

"Sickness doesn't scare me, death doesn't scare me. What scares me is that you can disappear because someone is telling the wrong story about you," said Jennifer Brea in her award-winning documentary, [Unrest](#), that chronicles her journey with ME.

Myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome or ME/CFS, is a devastating disease that causes [dysfunction](#) of the brain, immune system, endocrine system and energy metabolism systems. ME affects a large population of Americans, an [estimated](#) 1- 2.5 million Americans, including men, women and children. ME leaves 25% of patients housebound or bedbound and an estimated 75% unable to work.

People with ME are in crisis.

- We face a **crisis of research funding**: For decades, ME has received around \$5 million annually in research funding from the NIH, which increased to \$13 million last year. Research funding for ME should be at **\$250 million**, [research](#) shows, according to the disease burden (number of people sick and severity of the disease).
- We face a **crisis of clinical care**: Many doctors lack the essential knowledge about how to diagnose and treat ME. Fewer than one-third of medical school curricula and less than half of medical textbooks include information about ME.
- We face a **crisis of treatments**. There are no FDA-approved drugs to treat ME.

#MillionsMissing is a global campaign first launched by [#MEAction](#) in 2016. This is our fourth global protest with demonstrations happening around the world in the UK, Brazil, Japan, Hong Kong, South Africa and across Europe from the Netherlands to France and the Czech Republic.

“This is about more than a disease. This is a social justice issue. We are fighting for the research funding and medical education we need to stop this epidemic. We are fighting for our lives.” – [Jennifer Brea](#), co-founder of #MEAction, and director of the award-winning documentary, [Unrest](#).



About #MEAction: #MEAction is an international network of patients, caregivers and allies empowering each other to fight for health equality for myalgic encephalomyelitis. To learn more, visit: <http://meaction.net> and <http://millionsmissing.org>.

Science summary: <http://bit.ly/me-science> - *download for easier viewing*

Medical summary: <http://bit.ly/mecfs-medical>

Jennifer Brea's TED Talk: <http://bit.ly/2rc9wDX>

Unrest: <https://www.netflix.com/title/80168300>