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Photos available

Before COVID-19 long haulers there were the #MillionsMissing.

The devastating effects of Long COVID are now being realized around the world. Urgent, outcome-driven action needs to be at the forefront to bring treatments to this community as quickly as possible.

There is one community who knows there is nothing new about long-term consequences of a viral infection. Before the COVID-19 “long haulers,” there were the **#MillionsMissing**, made up of millions of Americans who got sick from an infection and never recovered. They went on to develop myalgic encephalomyelitis (ME) or myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), a devastating condition that affects an estimated 1.5 million Americans. And, now experts are [predicting](#) the number of people with ME/CFS will double following COVID-19.

“This is a problem of extreme magnitude that cannot be ignored, especially if the ME community is expected to double.” said Julia Miele, Executive Director of #MEAction.

[#MEAction](#), an organization that fights for the #MillionsMissing from ME, **knew this was coming**. Now, we see the Long COVID community [reporting](#) the same core symptoms as ME/CFS: fatigue, post-exertional malaise - a worsening of symptoms after any kind of exertion - and cognitive dysfunction.

Dr. Anthony Fauci has [emphasized in several interviews](#) that people who are not recovering after contracting COVID-19 are showing symptoms “that are highly suggestive of myalgic encephalomyelitis and chronic fatigue syndrome.”

Dr. Walter Koroshetz, director of NINDS institute at the NIH, has stated that, “The disorders overlap so much, that over time they will become one and the same.”

For years, the ME community has demonstrated in the streets calling for justice from our governments - for research and medical education. *See attached photos*. We became known as the “MillionsMissing.” **The #MillionsMissing will hold a virtual demonstration this Wednesday, May 12th**, calling for governments to urgently respond to the growing crisis of ME, to the #MillionsMore after COVID-19. Our message this year is, *While this crisis is dark, #YouAreNotAlone*. You have a community of warriors fighting with you. Join our main event: [RSVP here](#).

ME/CFS is the most [neglected disease](#) in the NIH's portfolio per disease burden, which is why the #MillionsMissing have been fighting for decades for recognition, research, approved treatments and knowledgeable doctors.

NIH leadership continue to talk about the overlaps between Long COVID and ME/CFS, but the question remains, Will they finally prioritize ME/CFS research at this moment of crisis, as we see the ME/CFS community doubling.

The patient-led Long COVID advocacy group, Body Politic, sent an [open letter](#) to the NIH this past April calling for the NIH to prioritize the knowledge of ME/CFS researchers in its PASC grant awards.

"Researchers with decades of post-infection experience need to be at the forefront of the Long COVID research agenda, or we risk delaying our understanding and treatment of this illness," wrote Body Politic.

Based on evidence from past [viral outbreaks](#), researchers expect that at least 10-12 percent of COVID-19 patients will go on to develop ME/CFS, and coronaviruses like SARS-CoV-2 have had even [higher rates](#) of triggering the disease. Up to [80% of cases](#) of ME are initiated by an infection. It's been well established that viruses cause ME/CFS in patients from common viruses like influenza and Epstein Bar to SARS, Ebola, H1N1, Ross River, West Nile Virus, H5N1, the list goes on. Now, the majority of Covid-19 long haulers are [reporting](#) symptoms that resemble ME/CFS, most notably post-exertional malaise, a worsening of symptoms after exertion.

#MEAction and the #Millionsmissing will not stop fighting until there is action and equity. Now, more than ever, we need results for the Long COVID community, and for all of those with ME/CFS who have been neglected for decades. Anyone can join this fight.

About #MillionsMissing

#MillionsMissing is an international movement fighting for equality for people with ME, spearheaded by #MEAction. This is our fifth global #MillionsMissing demonstration.

<https://millionsmissing.meaction.net/>

Join us on May 12th: <https://www.meaction.net/event/millionsmissing-2021-global-event/>

#MEAction is an international network of patients and allies empowering each other to fight for health equality for ME.

<https://www.meaction.net/>

Stories from the #MillionsMissing:

http://www.meaction.net/wp-content/uploads/2019/03/SMALLFORMAT_98_ProfilesMM2.pdf

I Got A Virus Video

<https://www.youtube.com/watch?v=e3Pd0o-rwrU>

Reference Links:

- Researchers predict the number of people with ME will double following COVID-19:
<https://www.frontiersin.org/articles/10.3389/fmed.2020.606824/full>
- Long haulers are reporting their 3 main are the same core symptoms as ME/CFS:
<https://www.medrxiv.org/content/10.1101/2020.12.24.20248802v2>
- ME/CFS is the most neglected disease in the NIH's portfolio per disease burden:
<https://pubmed.ncbi.nlm.nih.gov/32568148/#:~:text=Results%3A%20We%20find%20the%20disease,that%20commensurate%20with%20disease%20burden.>
- Dr. Fauci's statement about the strikingly similarities between Long COVID and ME/CFS:
<https://www.meaction.net/2020/07/10/dr-anthony-fauci-says-that-post-covid-syndrome-is-highly-suggestive-of-myalgic-encephalomyelitis/>
- NINDS Director, Dr. Walter Koroshetz, wrote this in the chat box at the Trans-NIH ME/CFS Working Group meeting on Feb. 25, 2021: "I think the disorders overlap so much, that over time they will become one and the same. ME/CFS is thought in most cases to be a post-some infectious illness. Only difference here is that we know what virus is driving it in large numbers of persons." Screenshot available.
- Scientific evidence show that chronic illness, including ME/CFS, is common following viral outbreaks:
 - <https://www.tandfonline.com/doi/full/10.1080/21641846.2020.1778227>
 - <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/415378>
 - <https://www.frontiersin.org/articles/10.3389/fmed.2020.606824/full>
 - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7889402/>