



COVID-19 RESPONSE



#MEAAction

is building a global movement to fight for recognition, education and research so that one day, all people with myalgic encephalomyelitis (ME) will have access to compassionate, effective care.



In response to the
Covid-19 crisis, in which
more individuals are
likely to develop
Myalgic Encephalomyelitis
after Covid-19, #MEAction
is taking swift action to:

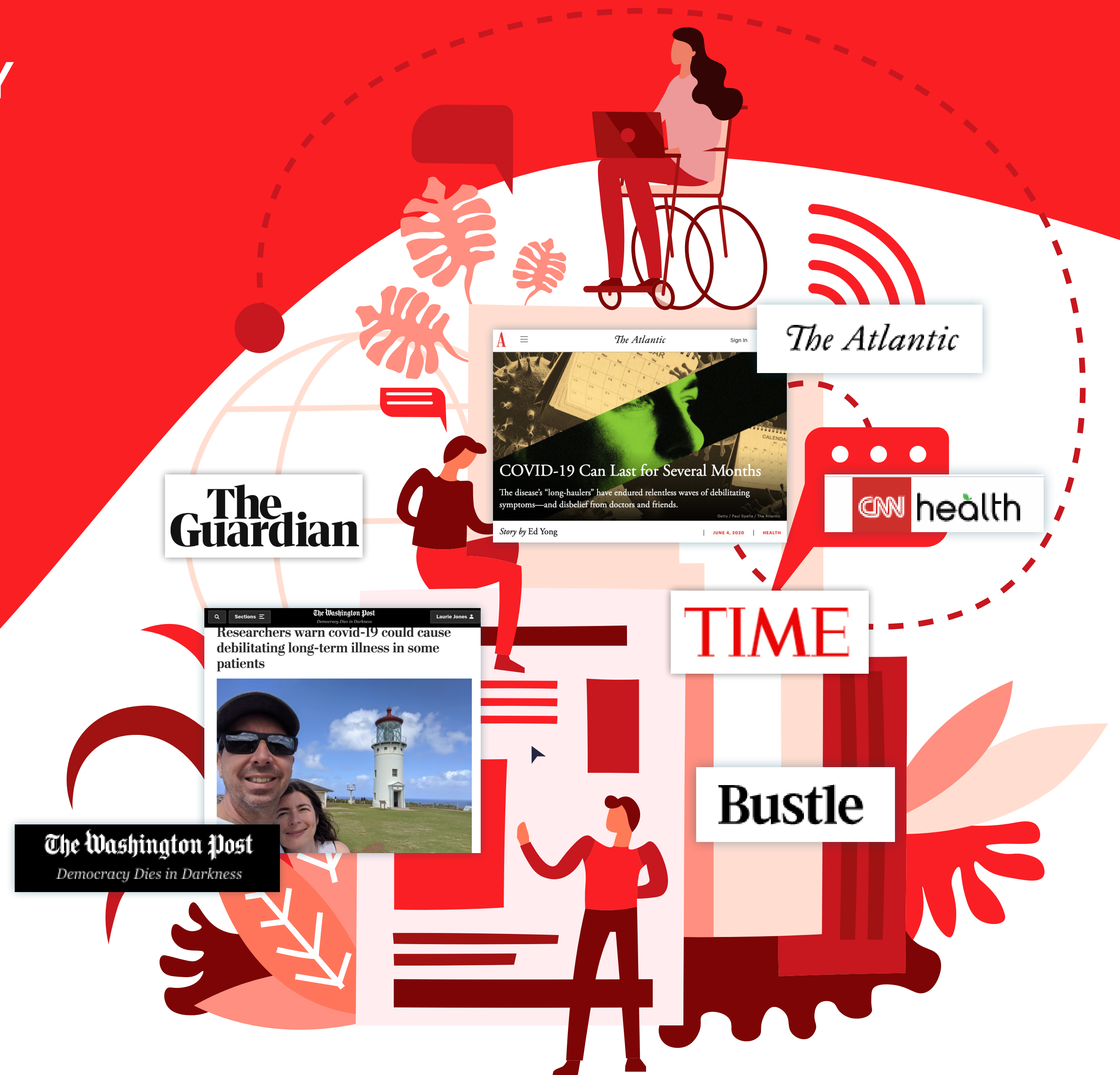


GET THE WORD OUT EFFECTIVELY AND IMMEDIATELY THROUGH PRESS OUTREACH

Since the pandemic hit, #MEAaction has pitched stories to major news outlets and we've been featured in [The Atlantic](#), [The Washington Post](#), [Bustle](#), [CNN](#), [TIME](#), [The Guardian](#) and more!

"Research on ME/CFS, which was neglected for decades, has been gathering momentum in recent years," writes Beth Mazur and Brian Vastag in the Washington Post.

"The research community is hoping that the coronavirus pandemic could wake people up to the long-term effects of ME," writes Bustle journalist, JR Thorpe.



EDUCATE DOCTORS AND OTHER HEALTHCARE PROFESSIONALS

We are hosting clinical seminars in the US, educating clinicians on the connection between COVID-19 and ME, as well as ways to diagnose and treat ME. Clinicians are saying:



DIAGNOSIS & TREATMENT
Dr. Lucinda Bateman, MD
Co-author of ME/CFS diagnostic criteria for adults
Founder and Director of the Bateman Horne Center



PEDIATRICS
Dr. Katherine Rowe, MD
Co-author of ME/CFS pediatric diagnostic criteria
University of Melbourne Royal Children's Hospital, pediatrician



EXERCISE SCIENCE
Dr. Mark VanNess, PhD
Scientific Advisor, Workwell Foundation
Prof of Health & Exercise Science, U. of the Pacific

"Spectacular presentation, thank you all so much for your level expertise and understanding of ME." and "You have packed the best core issues into this brief presentation. Thanks to all of you for what you do!"



SUPPORTING PEOPLE WITH ME

#MEAAction rapidly developed resources for people with ME to take to the hospital during this scary time including: Hospital Form and the Hospital Checklist.

We have maintained the support of our Facebook Groups for connection and support.

In Congress, #MEAAction joined with the #WeAreEssential campaign to recenter the needs of the disability community in the coronavirus relief bills and the Health Care at Home Act and State Groups have worked so hard in advocating for HR 7057.

MYALGIC ENCEPHALOMYELITIS (ME)
HEALTH INFORMATION

#MEA
ACTION

MY MEDICAL INFORMATION

FULL NAME (LAST, FIRST, MIDDLE, SUFFIX)

DATE OF BIRTH

HEIGHT

EMERGENCY CONTACT NAME

EMERGENCY CONTACT NAME

PRONOUNS

WEIGHT

PHONE NUMBER

PHONE NUMBER

ABOUT ME

ALLERGIES

OTHER DIAGNOSES

I HAVE ME/CFS

Symptoms may include:

- Severe fatigue and easy fatigability
- Dizziness/lightheadedness, especially on standing
- Muscle and joint pain
- An exacerbation of symptoms following physical, environmental, or cognitive exertion
- Sensory sensitivity
- Flu-like symptoms

People with ME may have heightened sensitivity to medications. Use the lowest dose and build up slowly over time.

People with ME may have altered immune function. Their body temperature may run low, and they may have serious infection with low or no fever.

The following may be considerations for anesthesia:



SUPPORTING NEW INDIVIDUALS WHO MAY RECEIVE AN ME DIAGNOSIS

#MEAAction started a group for long COVID and also co-hosted a seminar with Body Politic and the NY Covid-19 Working Group for individuals with long COVID in the US with medical professionals and people with ME and COVID to speak from personal experience.

#MEAAction launched the Stop. Rest. Pace. campaign to encourage those with long COVID to not push.

"Great work! Thank you! Stop/Rest/Pace changed my life. I still struggle, but today I know that I don't need to make life harder by ignoring symptoms and making them worse."

#MEAAction UK issued warnings against Graded- Exercise therapy for those with Long Covid who may develop ME and have challenged the NHS's educational information on the subject.



CHALLENGING INSTITUTIONS THAT CAN HELP OR HARM PEOPLE WITH ME

#MEAAction is demanding urgent, strategic action now more than ever from the National Institutes of Health (NIH) and are building a robust campaign to achieve equitable research dollars and taking every activist opportunity to move the needle.

In the UK, advocates continue to challenge NICE guidelines for people with ME, as they have done for years and advocating in Parliament.

#MEAAction developed the campaign *Stop. Rest and Pace.* for those with long COVID.



#MILLIONSMISSING

#MillionsMissing, our biggest advocacy and attention-grabbing annual event, was entirely virtual. Over 100,000 people were reached through efforts of posting and engaging.

Volunteers at #MEAAction UK created a video "I've got a Virus" reaching tens of thousands of people, personally conveying post-viral ME.

From around the world, people participated in #MEAAction's first ever virtual choir, tens of thousands of people watched our guest artists perform and engaged in Facebook lives.



Covid-19 has changed our lives and the effects it will have on those with Myalgic Encephalomyelitis is still evolving every day.

#MEAction remains dedicated to our cause of equitable treatment and care for all people with ME.

Our fight continues.





THANK YOU