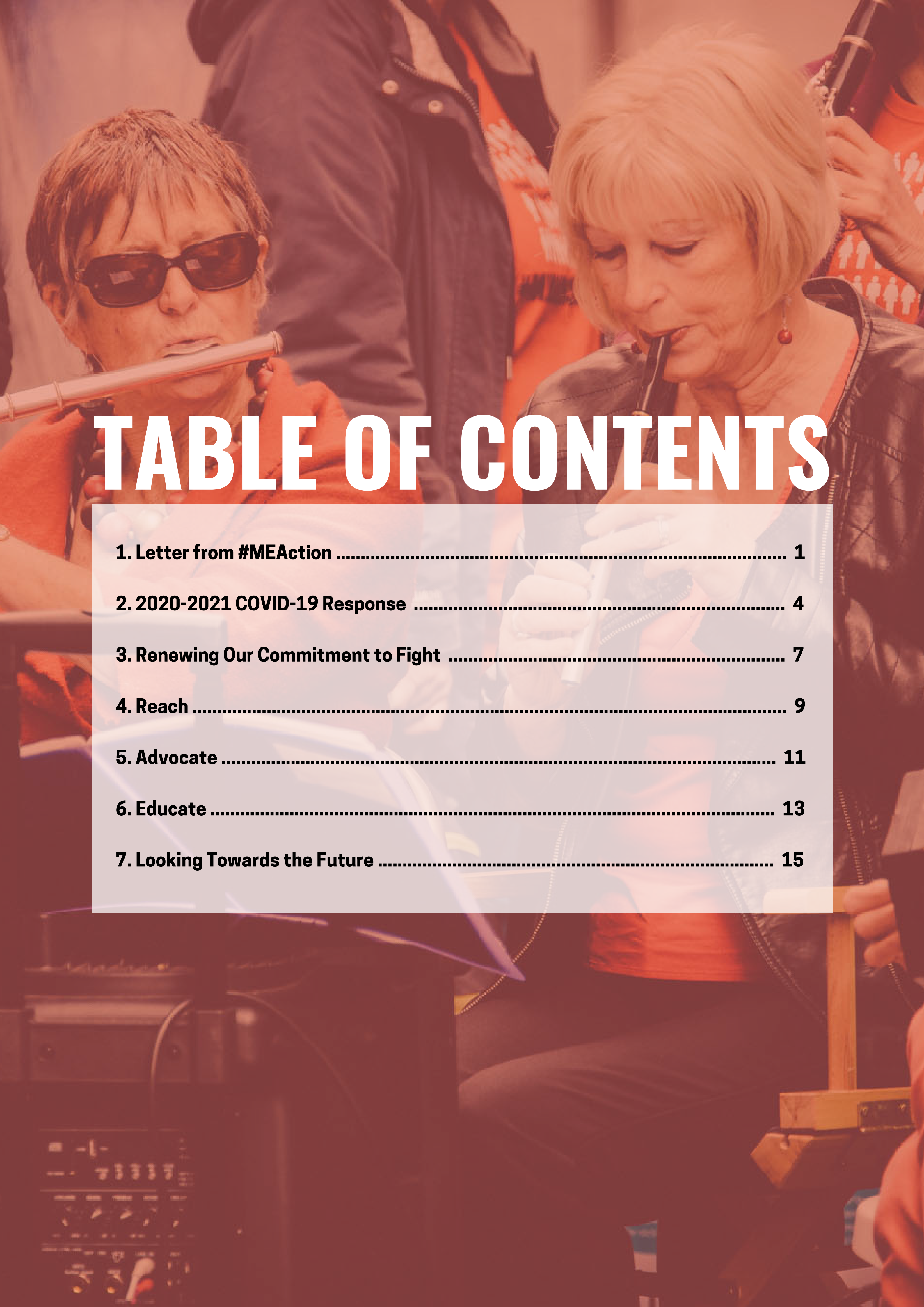
2020
ANNUAL REPORT



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#MEAction

Letter

TO THE ENTIRE #MEACTION COMMUNITY

2019 and 2020 have been years like no other. The global pandemic shook us to the core. We had to urgently respond to the crisis, ensuring people with ME had the access and support needed to weather the storm.

People with ME are the center of all we do. And we understood early that because of COVID-19, the number of people with ME would increase. So we knew we had to both continue to prioritize our community and prepare to welcome more members with new ME symptoms.

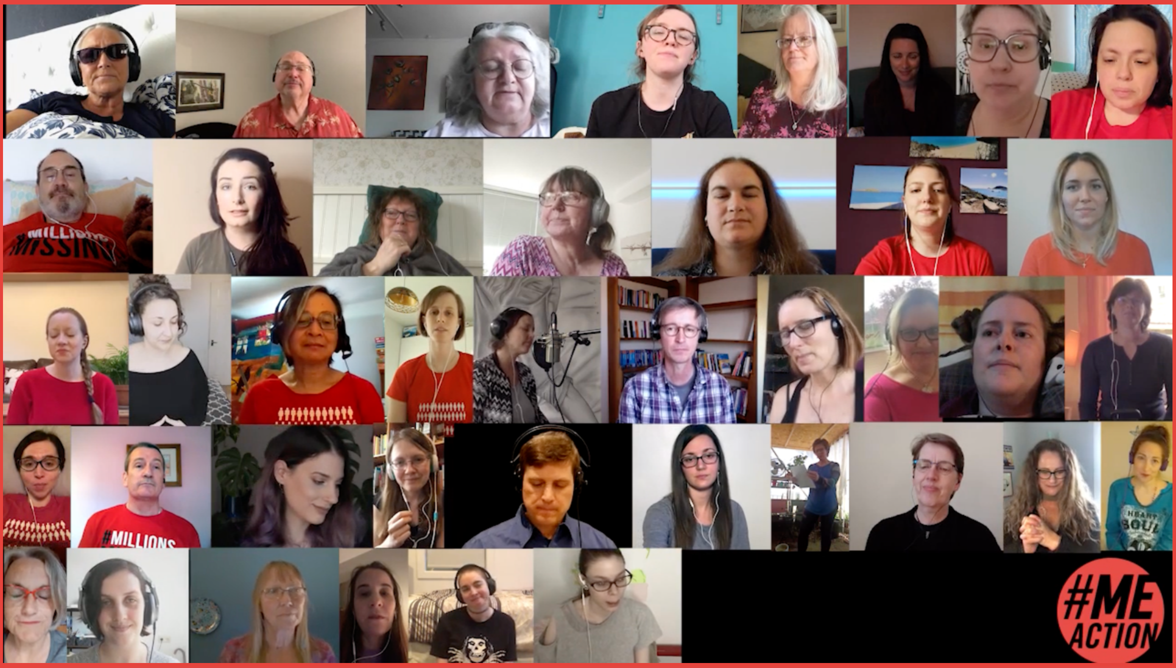
You were there this entire time to encourage people with PEM to Stop. Rest. Pace. You showed up for community events, sent postcards to doctors, challenged federal agencies with us, and advocated for change. You came to our first ever fully-virtual #MillionsMissing. You sang, you shared your stories, you showed each other that we had to continue the fight.

Thank you, thank you, thank you.

Together, we continue to fight for change.

Sincerely,

Laurie Jones, Managing Director &
All of us at #MEAction



#ME ACTION

#MILLIONSMISSING

MAY 12TH 2020

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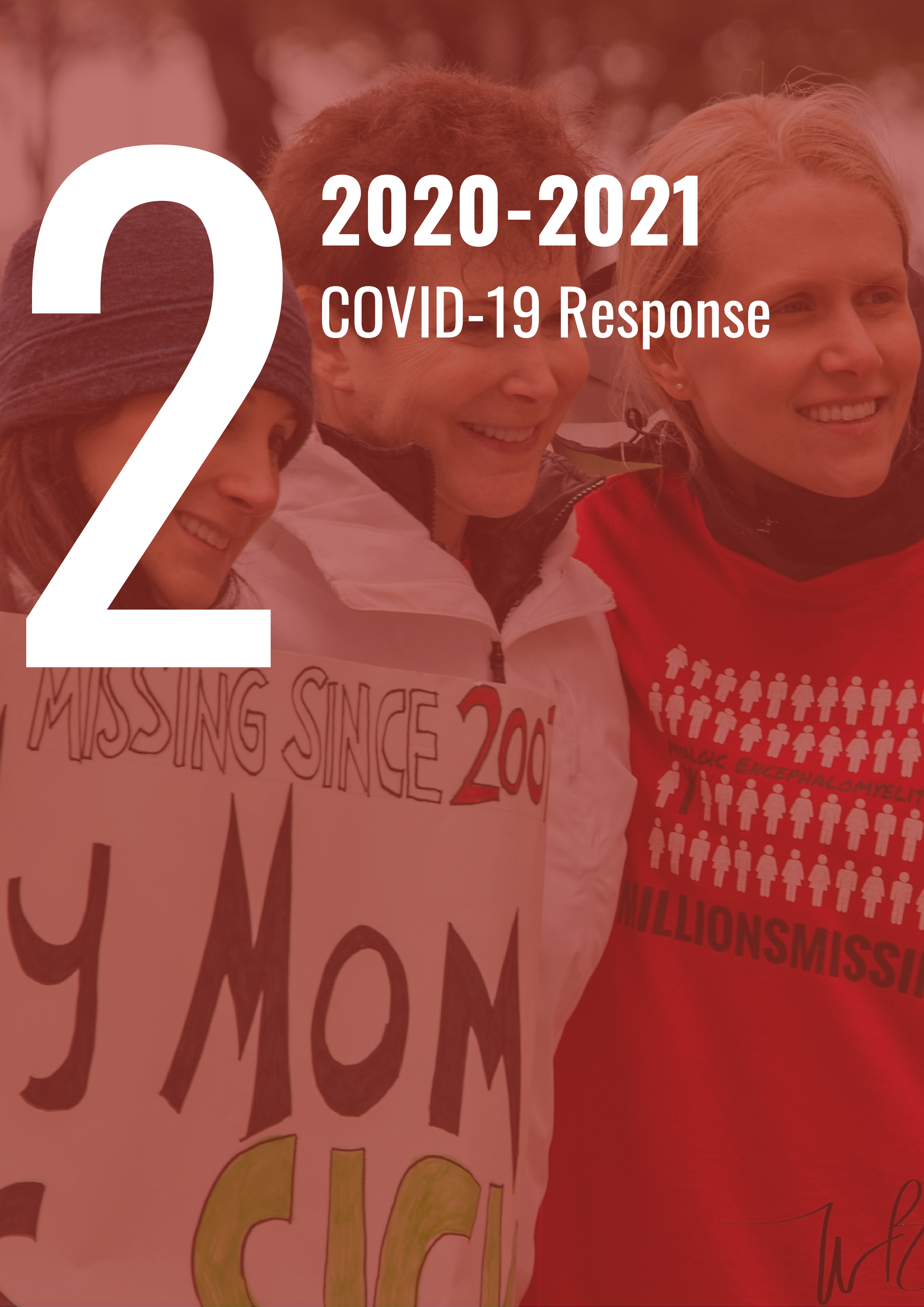
2020-2021

COVID-19 Response



In response to the COVID-19 crisis, during which time more individuals are likely to develop Myalgic Encephalomyelitis after COVID-19, #MEAction took swift action to:

Challenge Institutions

#MEAction demanded more urgent, strategic action from the National Institutes of Health and built a robust campaign to achieve equitable research dollars and take every activist opportunity to move the needle. In the UK, advocates continued to challenge National Institutes for Health and Care Excellence guidelines for people with ME and advocated for continued support in Parliament.

Educate Doctors & Healthcare Professionals

#MEAction hosted 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 said: “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!”

Support People with ME

#MEAction rapidly developed resources for people with ME to take to the hospital during this scary time, including a Hospital Form and Checklist. We stepped up engagement with our 100+ Facebook groups, valuable platforms for connection and support. In Congress, we joined with the #WeAreEssential campaign to recenter the needs of the disability community in COVID-19 relief bills and the Health Care at Home Act. State Groups also worked hard advocating for HR 7057.

Get the Word Out Effectively & Instantly through Press Outreach

From the start of the pandemic, #MEAction pitched stories to major news outlets and was 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.

Support New Individuals with ME Symptoms

#MEAction started a Long COVID group and co-hosted a seminar with Body Politic and the New York COVID-19 Working Group for individuals with Long COVID in the US. Medical professionals, people with ME and Long COVID, and family members participated - sharing personal experiences, asking questions, and building a community of support and understanding.

We 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.”

#MEAction UK issued warnings against Graded-Exercise Therapy for those with Long COVID who may develop ME, and challenged the National Health Service’s posted educational information.

Demand Attention for #MillionsMissing

#MillionsMissing, our biggest advocacy and attention-grabbing annual event, was entirely virtual in 2020. Over 100,000 people were reached each year through social media, virtual workshops, conversations and events, and daily online engagement. Volunteers at #MEAction UK created a video “I’ve got a Virus” that reached thousands of people with personal stories of post-viral ME. From around the world, people participated in #MEAction’s first ever virtual choir, and tens of thousands of people watched our guest artists perform and engaged in Facebook live events.

COVID-19 changed our lives - its effects on those with ME still evolving every day. #MEAction remains dedicated to our cause of equitable treatment and care for all people with ME. Our fight continues.

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RENEWING

Our Commitment to Fight

In times such as these, we are eager to renew our commitment to #MEAction's Mission of building a global movement of patients, families, and allies to fight for research funding, medical education, and public awareness of ME so that one day, our vision of a world where all people with ME have support and access to compassionate and effective care will become a reality.

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REACH

PRESS

#MEAction stepped up press engagement at the start of the COVID-19 pandemic, with Editor Adriane Tillman leading the charge. #MEAction was featured in The Atlantic, The Washington Post, Bustle, CNN, TIME, The Guardian and more!

SOCIAL MEDIA

#MEAction reached a community of more than 40,000 people through social media and communications efforts. Thousands around the globe took online action by signing a petition or sharing an action demanding change for people with ME. MEpedia and our MEwiki articles and primers for journalists, doctors and researchers, patients, and the public reached 2,750+ articles and have now been viewed more than 16 million times! Social Media Manager Holly Latham also prioritized our 5,000 strong Living with ME group, and our creative volunteer endeavors enhanced our reach further - #MillionsMissing 2020's Virtual Choir and #MEAction UK's "I Have A Virus" video reached hundreds of thousands of people across the globe.

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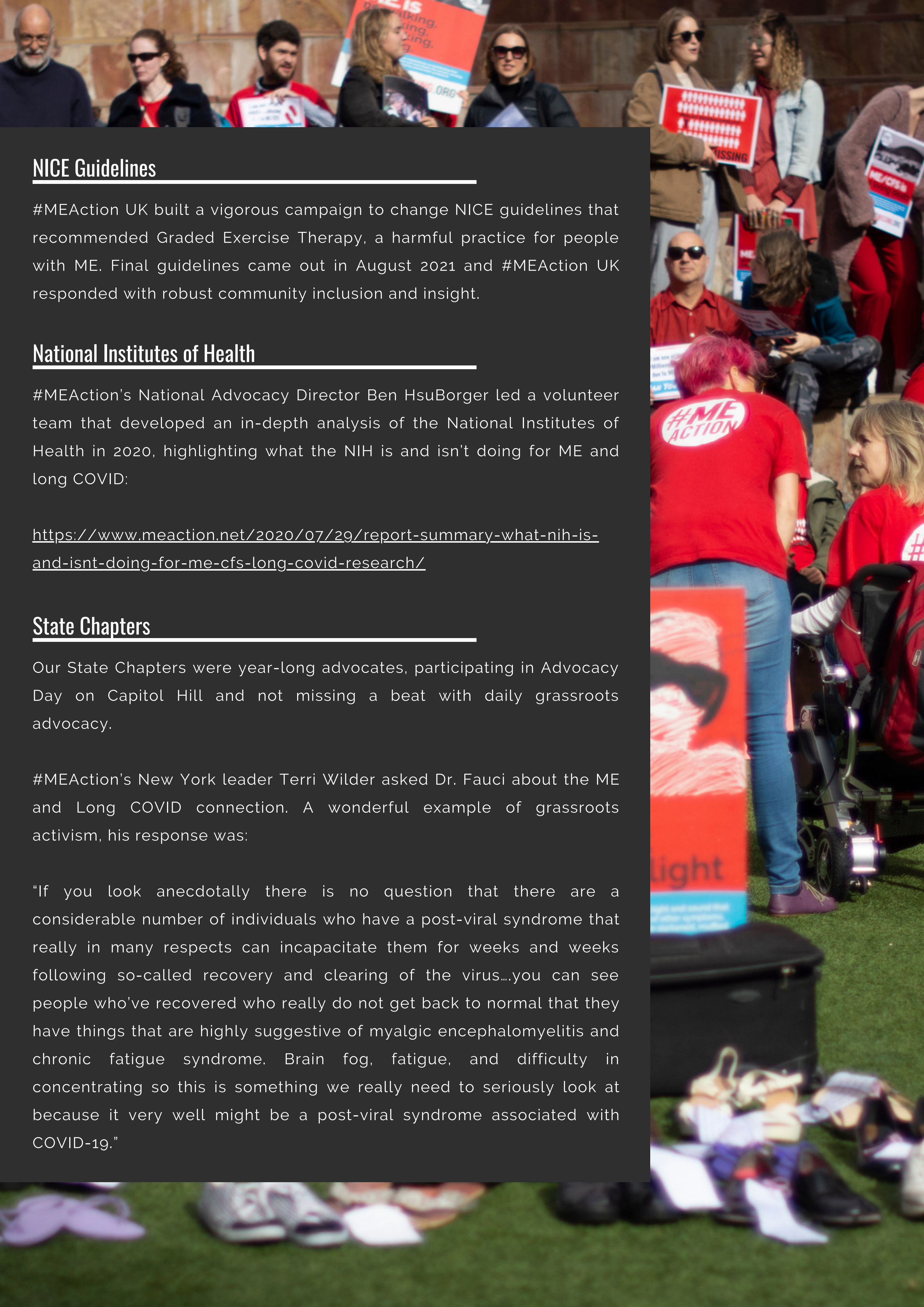
ADVOCATE



NICE Guidelines

#MEAction UK built a vigorous campaign to change NICE guidelines that recommended Graded Exercise Therapy, a harmful practice for people with ME. Final guidelines came out in August 2021 and #MEAction UK responded with robust community inclusion and insight.

National Institutes of Health

#MEAction's National Advocacy Director Ben HsuBorger led a volunteer team that developed an in-depth analysis of the National Institutes of Health in 2020, highlighting what the NIH is and isn't doing for ME and long COVID:

https://www.meaction.net/2020/07/29/report-summary-what-nih-is-and-isnt-doing-for-me-cfs-long-covid-research/

State Chapters

Our State Chapters were year-long advocates, participating in Advocacy Day on Capitol Hill and not missing a beat with daily grassroots advocacy.

#MEAction's New York leader Terri Wilder asked Dr. Fauci about the ME and Long COVID connection. A wonderful example of grassroots activism, his response was:

"If you look anecdotally there is no question that there are a considerable number of individuals who have a post-viral syndrome that really in many respects can incapacitate them for weeks and weeks following so-called recovery and clearing of the virus....you can see people who've recovered who really do not get back to normal that they have things that are highly suggestive of myalgic encephalomyelitis and chronic fatigue syndrome. Brain fog, fatigue, and difficulty in concentrating so this is something we really need to seriously look at because it very well might be a post-viral syndrome associated with COVID-19."

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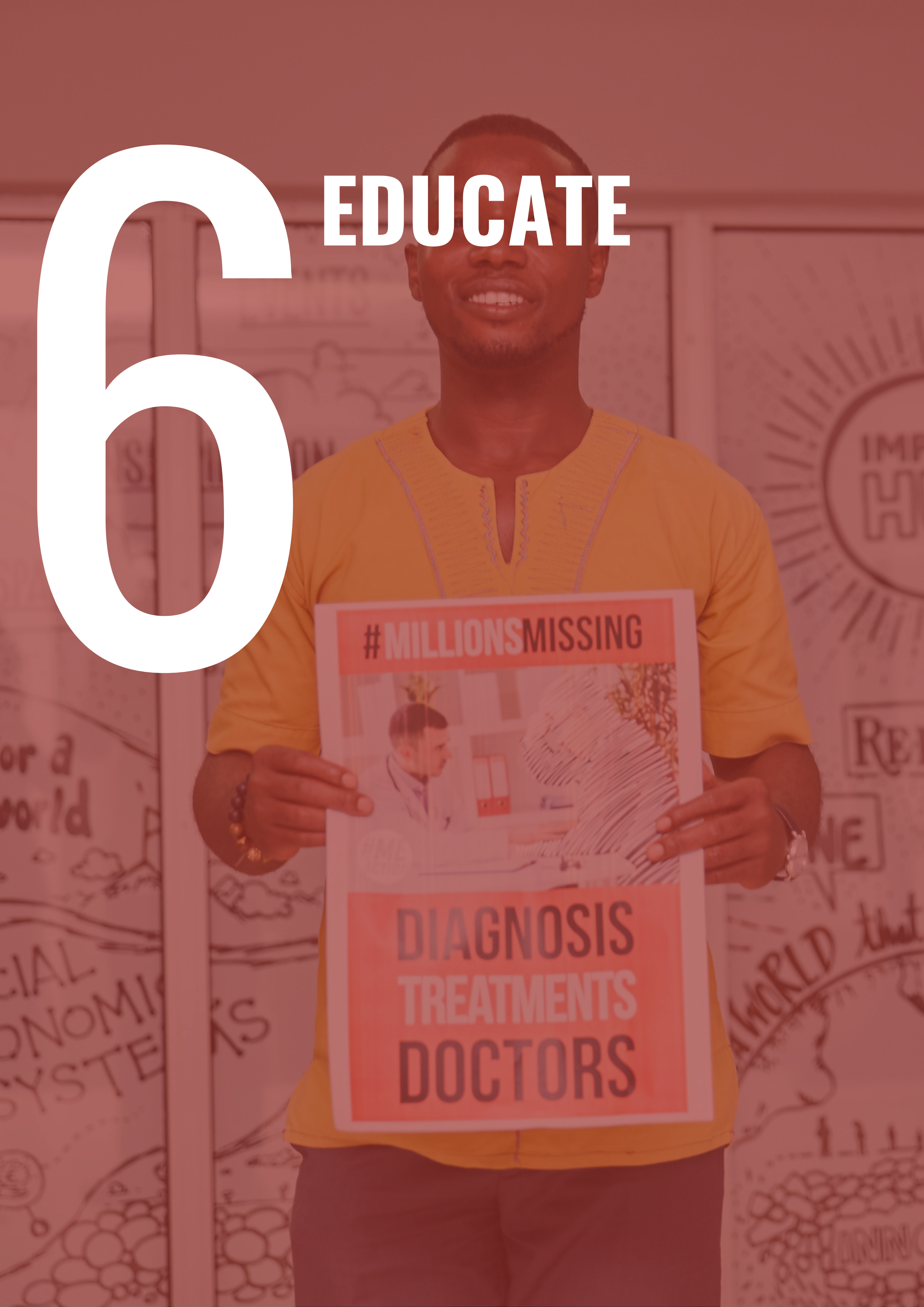
EDUCATE



POSTCARDS TO DOCTORS

The ME community continued to build #MEAction's Postcards to Doctors program by mailing postcards to doctors across the country to encourage their participation in ME-focused Continuing Medical Education through the award-winning documentary, Unrest. You can read the final report here:

https://www.meaction.net/2020/01/28/postcards-returns-2/

CLINICAL SEMINAR

#MEAction's Director of Scientific and Medical Research, Jaime Seltzer, led a clinical seminar on the connection between Long COVID and ME featuring Dr. Lucinda Bateman, Dr. Katherine Rowe, and Dr. Mark VanNess.

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LOOKING Towards the Future

As we look towards the future, we know the people with ME are at the center of all we do. We fight with you and we fight for you all year long.