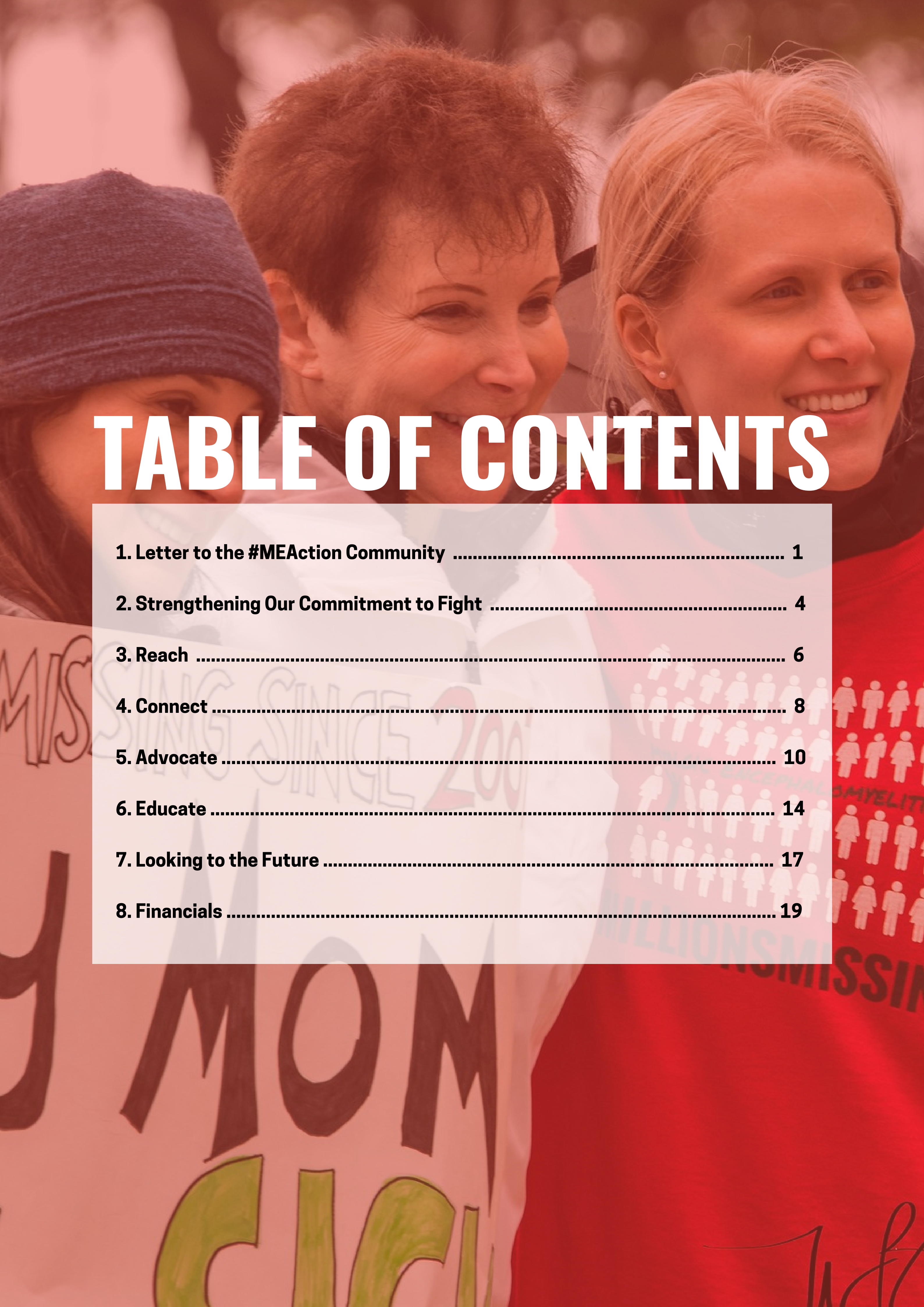
2021

ANNUAL REPORT

#ME ACTION

| WWW.MEACTION.NET |



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Letter to the #MEAction Community

TO THE #MEACTION COMMUNITY

We're delighted to share with you #MEAction's 2021 Annual Report! A year of challenges, transitions, and building for the future, you have been with us every step of the way, and for this, we are truly grateful!

Your confidence in our work has enabled us to:

- Reach 2,000 journalists and put ME on the global map through intense and strategic press engagement.
- Challenge government institutions to fix the coding of ME to improve tracking, disease identification and research, prioritize ME in research initiatives, and acknowledge treatments that are dangerous for people with ME.
- Launch a massive research survey to provide key data that will help generate better care and quicker diagnoses of ME and other similar chronic diseases.
- Deepen our response to an unprecedented pandemic to ensure that people with ME and Long COVID have the access and support needed to navigate their healthy journeys.
- Partner with allied organizations in reaching BIPOC and underserved communities through #MEAction research, awareness, advocacy, and community-building.
- Demand that we are heard at #MillionsMissing events across the globe.
- Support and Mobilize the ME community creatively through Artists Salons, writing groups, and literary interviews, as well as Facebook groups that connect thousands.
- Recruit new Executive Director Julia Miele who is working Jen Brea, staff, the Board of Directors, and the #MEAction community on a five-year strategic plan.

We know that #MEAction's next steps must be bold and decisive. As we emerge from the COVID-19 pandemic and face the realities of its aftermath, we must continue to take every opportunity to change how scientists, doctors, and policymakers understand and address ME and other post-viral illnesses like Long COVID. The next five years have the potential to shape history, and you can help #MEAction meet this moment by investing deeply in our mission of recognition, medical education, and research for ME.

Our 2021 Giving Season Campaign is underway. We must raise US$100,000 (£72,500) by December 31, and we can't do it without you. We need your help to mobilize friends, family, loved ones, and our entire #MEAction community to this cause.

With your investment in our work, we'll be able to strengthen our public outreach, medical education, and global advocacy so that we can continue to be the place where people with ME and their families can come together as a community to find support and to fight for a better future.

There are so many ways you can help. You can donate directly to #MEAction, start a Facebook fundraiser, and share our campaign on social media and with friends and family. We know that this illness has stolen so much, including our livelihoods. Many in our community are not able to give financially, which is why it is so important to give if you can. And if you can't, it is equally important to share our campaign and help spread the word, whether that means writing friends and family, starting an online fundraiser on our behalf, or sharing our campaign on social media.

We know that with your help, we'll meet our goal! Visit www.meaction.net/eoy-2021 to join #MEAction's End-of-Year Giving Adventure!

In solidarity and with gratitude,

All of us at #MEAction
Laurie, Ben, Jaime, Erin, Adriane, Holly, Steven, and Julia

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Strengthening Our Commitment to Fight

We remain deeply committed to #MEAction's Mission of building a global movement of people with ME, families, caregivers, 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.

Carrying out our mission through the strategic pillars of partnership, patient empowerment, supportive communities, community organizing technology, and the voices of patients, volunteers, families, and experts, we focused our efforts in 2021 to:

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REACH


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International
ME/CF
Awareness D
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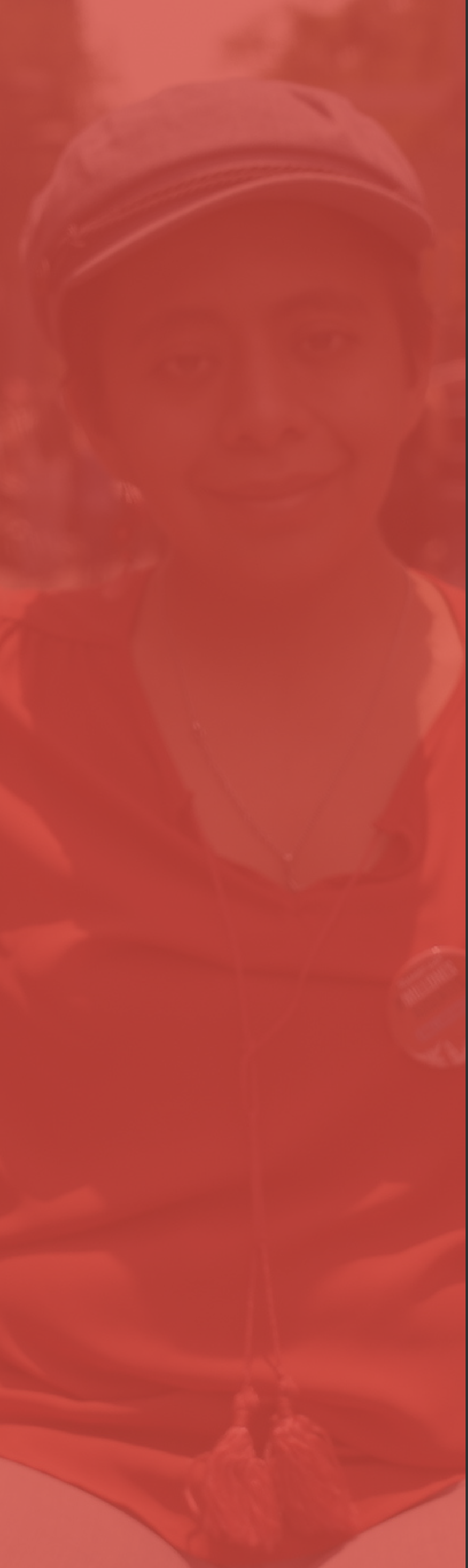

Press

#MEAction staff and volunteers played a lead role in securing the connection between Long COVID and ME with personal outreach to journalists and press outlets - Efforts that culminated in a #MEAction-sponsored press briefing featuring a panel of experts who were uniquely positioned to speak on how Long COVID was being informed by the research on ME. Journalists attended from over 15 press outlets including The New York Times, Fox News, NBC, CNN, and US News & World Report plus international outlets Women's Health UK, Luzerner Zeitung Switzerland, and Carte Blanche South Africa.

Project ECHO

#MEAction forged a new partnership with Project ECHO to support our efforts to better reach rural, underserved, and BIPOC communities. A clinical distance learning project that helps clinicians in hard-to-reach areas learn from disease experts, Project ECHO just received a CDC grant for Long COVID/ME support and outreach and identified #MEAction as a key partner. This new effort will enable us to expand research study recruitment, support group engagement, and educational outreach in communities that have been historically unheard and overlooked.

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 a statement demanding change for people with ME. We prioritized our 5,000+ strong Living with ME group and worked hard to build and grow the many other support groups we offer, like Pregnancy and Parenting with ME, Seniors Connect groups, and Long COVID. Every day of every year, our mandate is to help people find support, build community, and take action knowing that the fight to improve the lives of people with ME is far from over.

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CONNECT


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MILLION
MISSING

Severe ME Artists Salon

In recognition of Severe ME Day on August 8, 180 people with severe ME sent in photos, drawings, writings, and videos of their work to #MEAction's Severe ME Artists Salon. With over 300 pieces submitted, we created the Severe ME Artists Salon to allow those with severe ME to connect with the community about their artwork, share stories about their creative journey, and provide an opportunity to be seen. Severe ME Day of Understanding and Remembrance was started in 2013 by the 25% ME Group as a response to the death of Sophia Mirza from the UK.

#MEAction Membership

We formally launched the #MEAction Membership Program to grow our community and foster stronger connections among members. #MEAction members support a thriving network of patients, caregivers, and allies fighting for recognition, education, and research for ME. Membership also helps us sustain and grow our work for the years to come. #MEAction members have access to virtual social events––from holiday parties to movie nights––and semi-annual member town halls to stay up to date and help us inform our future work. Nearly 400 new members have signed up to date!

Writing, Reading, Supporting, and Connecting

Through #MEAction's support groups, writing groups, and literary series, we continued to find ways to bring the #MEAction community together for conversation, learning, and creative exploration. We featured powerful stories from #MEAction's Writing from Our ME Lives group, chatted with Rachel Riggs about her cookbook, Clean Eating Foodist, whose recipes are designed for food-sensitive people with ME such as herself, and interviewed ME advocate and author Jean Meltzer who released her first novel, The Matzah Ball, which features a protagonist with ME.

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ADVOCATE

Attention for the #MillionsMissing

#MillionsMissing, our biggest advocacy and attention-grabbing annual event, was virtual again in 2021. We received almost 500,000 views on social media alone with 255 participating in our May 12 virtual event. We hosted our first-ever Artists Salon, a beautiful and supportive event where 55 people shared their art - poems, photography, pottery, writing, song, dance - to express their struggles and experiences living with ME. We also gathered over 1,100 signatures on a letter to Surgeon General Dr. Vivek Murthy requesting that he: 1). Tweet out his support of the #MillionsMissing from #MEcfs; and/or 2). Meet with #MEAction to discuss ME, the challenges this community faces, and how he can help us raise awareness and advocate for treatments.

ME and Long COVID

In May, we leaned into the Long COVID space by sending a letter to the Congressional House Subcommittee on Health urging Congress to hold the NIH accountable for expediting treatments to people with ME and Long COVID. This same month, #MEAction UK sent a letter to England National Health Service's Matt Hancock and Member of Parliament Stephen Powis to make them aware of the risk to people with ME in not prioritizing access the COVID-19 vaccine.

CDC's Flawed Systematic Evidence Review

In June, we responded to the CDC's flawed systematic evidence review on ME treatments, which concluded that the controversial and widely-disputed interventions of graded exercise therapy and cognitive behavioral therapy were likely beneficial in treating ME. Over 7,200 ME community members signed on to have their names added to our 40-page response, which offered four key arguments supporting why the CDC's findings were fundamentally flawed and should not be published.

PASC (Long COVID) Initiative

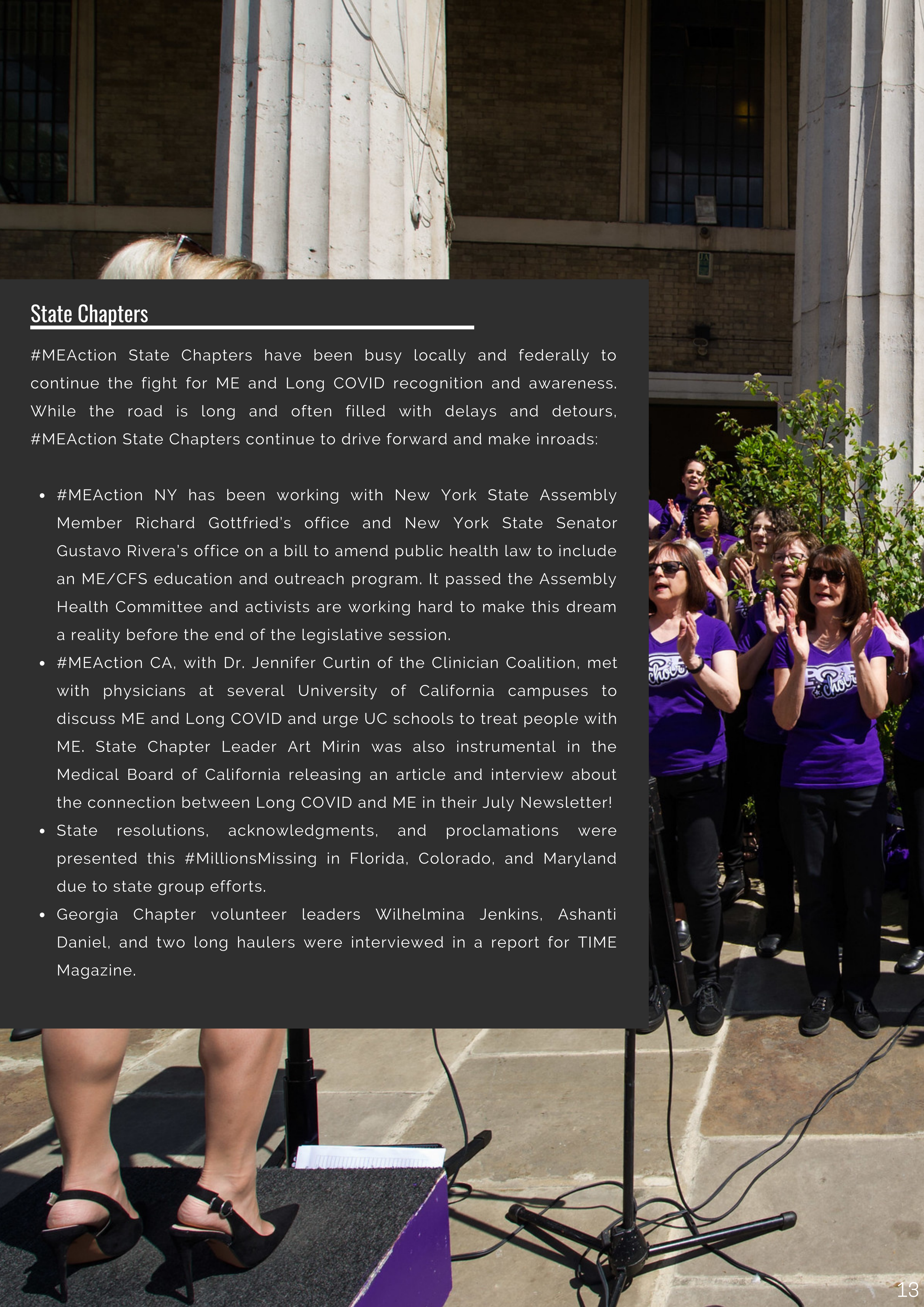
In August, we joined ME researchers, Open Medicine Foundation, and Solve M.E. in writing a joint letter to NIH leadership regarding the research agenda for PASC (Long COVID), including suggestions for the RECOVER Initiative that would shed light on other post-infectious fatigue syndromes and ME/CFS. When our suggestions went unaddressed, we partnered with Solve M.E. in October and sent a list of questions to Walter Koroshetz, MD about ME/CFS research to be addressed in a telebriefing by the Trans-NIH ME/CFS Working Group.

NICE Guideline

#MEAction UK did not miss a beat when the National Institute of Care and Excellence (NICE) paused the publication of a new guideline in August that would remove the harmful practices of Graded Exercise Therapy and Cognitive Behavioral Therapy. Launching a petition calling on NICE to publish the finalized ME guideline in its current form, #MEAction UK collected over 22,000 signatures and delivered the petition in advance of a NICE-initiated Roundtable in October to discuss issues surrounding the delayed guideline. The good news hit just two days following the Roundtable, Professor Gillian Leng, NICE Chief Executive, releasing the statement about the gathering: “We are now confident that the guideline can be effectively implemented across the system, and we will discuss the input from the meeting at our Guidance Executive next week with a view to publish the guideline.” Over 16 publications featured information on NICE because of our outreach. Several articles featured #MEAction UK volunteer Sian Leary.

#CodeUsCountUsCureUs

In September, #MEAction and six other ME/CFS organizations submitted a proposal to the National Center of Health Statistics (NCHS) to fix the coding of ME/CFS in the US International Classification of Diseases (ICD-10-CM). At present, because of ICD-10-CM coding of ME/CFS in the US, it is impossible to track the mortality and morbidity of 1 to 2.5 million Americans with ME/CFS, or to identify ME/CFS cases using ICD codes in electronic health records. This is also a major barrier to any research on this disease, and an urgent issue, especially with the potential tsunami of new ME/CFS cases following COVID-19 infections. The #CodeUsCountUsCureUs petition followed the proposal, and on November 15, we submitted letters of support with over 3,000 petition signatures to NCHS calling for April 2022 implementation to fix the catastrophic lack of ME/CFS tracking in the US.



State Chapters

#MEAction State Chapters have been busy locally and federally to continue the fight for ME and Long COVID recognition and awareness. While the road is long and often filled with delays and detours, #MEAction State Chapters continue to drive forward and make inroads:

- #MEAction NY has been working with New York State Assembly Member Richard Gottfried's office and New York State Senator Gustavo Rivera's office on a bill to amend public health law to include an ME/CFS education and outreach program. It passed the Assembly Health Committee and activists are working hard to make this dream a reality before the end of the legislative session.
- #MEAction CA, with Dr. Jennifer Curtin of the Clinician Coalition, met with physicians at several University of California campuses to discuss ME and Long COVID and urge UC schools to treat people with ME. State Chapter Leader Art Mirin was also instrumental in the Medical Board of California releasing an article and interview about the connection between Long COVID and ME in their July Newsletter!
- State resolutions, acknowledgments, and proclamations were presented this #MillionsMissing in Florida, Colorado, and Maryland due to state group efforts.
- Georgia Chapter volunteer leaders Wilhelmina Jenkins, Ashanti Daniel, and two long haulers were interviewed in a report for TIME Magazine.

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EDUCATE

The Chronic Illness Survey Adventure

During #MillionsMissing, we launched The Chronic Illness Survey Adventure - a massive survey aimed at providing clinicians and researchers with key data that could educate and generate better care for and quicker diagnoses of ME and other similar chronic diseases. Our hope is that the survey will identify aspects of the disease that are well understood by patients, but not as well understood by the clinicians who see them and the researchers who want to learn more. At the writing of this report, over 2,100 people with ME had signed up to take the survey, with new sections opening each month as this exciting year-long research effort unfolds. Section 2 just launched, but you can still take Section 1!

MEpedia Views Surpass 25 MILLION and 3,000 Articles

We created MEpedia as a direct response to the community's need to collect, in one place, all the diverse knowledge scattered throughout the medical, scientific, and patient communities concerning ME, CFS, and related conditions. This crowdsourcing, Wikipedia-style knowledge base is powered by the #MEAction community and built by our tremendous volunteers including patients, students, family members, caregivers, and researchers with access to countless resources. Because of MEpedia, more and more people are looking to #MEAction for guidance and ensuring that accurate information is getting to the public with people with ME at the center.

Activist Camp

Through #MEAction's Activist Camp - a free four-part activism teach-in series for activists in the US - we trained over 50 activists to make our movement smarter and more strategic. Participants become inspired, competent activists and dive into current #MEAction campaigns. With a disability justice and anti-oppression framework, Activist Camp gave participants the opportunity to explore the historical context of social justice movements and contemporary organizing, create effective campaigns and actions, and develop new activist skills.

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. #MEAction also offered access to CME credits through the University of Rochester's course, "Post-Viral ME/CFS: Diagnosing and Treating ME/CFS in the Time of COVID" through April 2021, and "Post-Viral Syndrome and Myalgic Encephalomyelitis: What Every Clinician Needs to Know."

REGAIN Clinical Trial

#MEAction and #MEAction UK teamed up to educate REGAIN Clinical Trial leads on the importance of communicating caution to COVID-19 trial participants when testing two treatments – an online rehabilitation and recovery support group OR a single online session of exercise advice and support. Detailing why exercise is inappropriate and potentially dangerous for people with post-exertional malaise, the #MEAction team noted the need for such people to be screened out of any exercise program that might encourage more physical activity than is safe for one's "energy envelope". Practitioners adopted some of the procedures as a result, with training manuals also amended to include a section on post-exertional malaise.

#StopRestPace

We continue to encourage people with Long COVID to #StopRestPace, and the feedback we have received is so heartening. We want to ensure that people with Long COVID don't feel like they should push past their energy envelope and we know this advice is working for many people who heed it.

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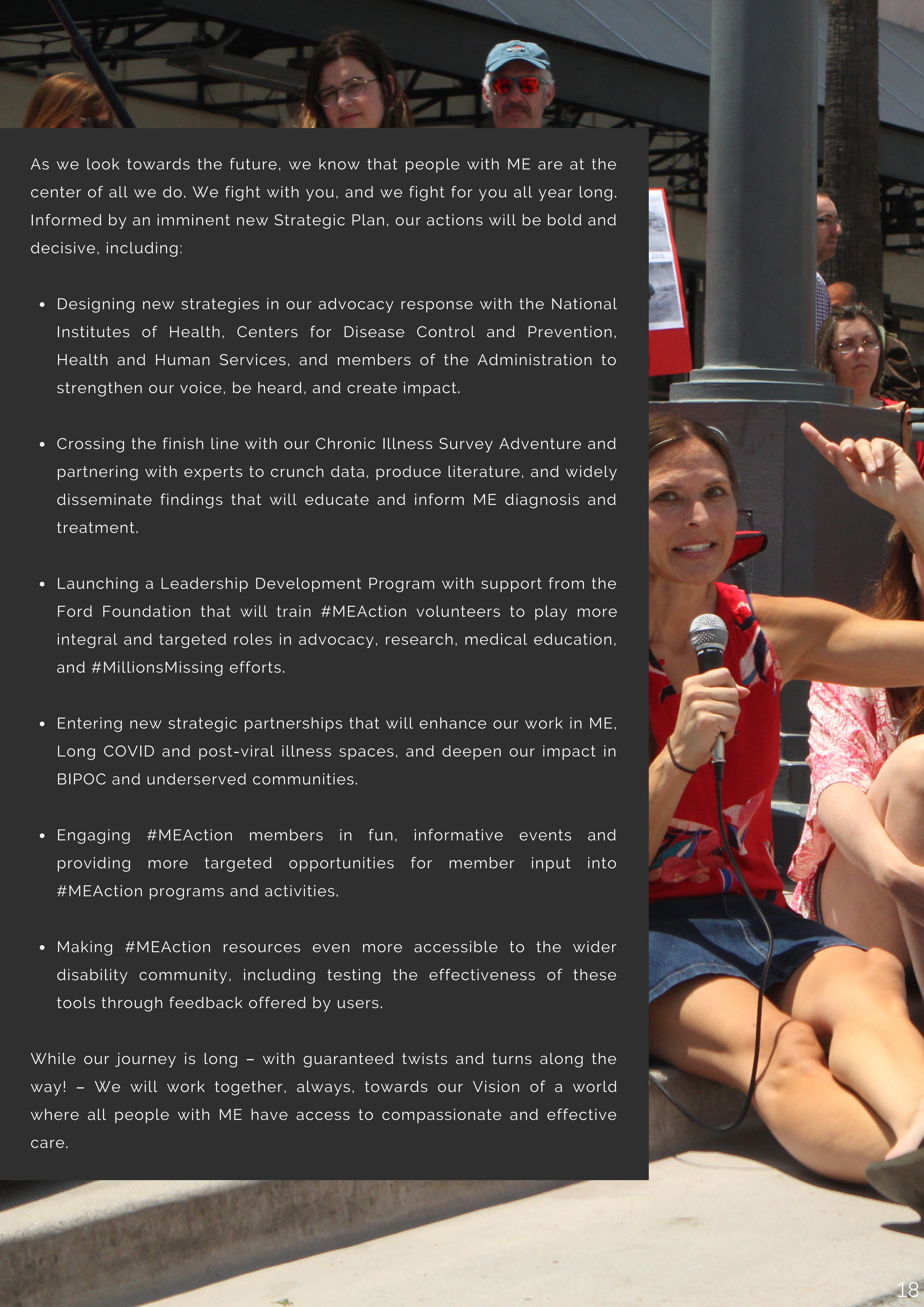
LOOKING

To the Future



As we look towards the future, we know that people with ME are at the center of all we do. We fight with you, and we fight for you all year long. Informed by an imminent new Strategic Plan, our actions will be bold and decisive, including:

- Designing new strategies in our advocacy response with the National Institutes of Health, Centers for Disease Control and Prevention, Health and Human Services, and members of the Administration to strengthen our voice, be heard, and create impact.
- Crossing the finish line with our Chronic Illness Survey Adventure and partnering with experts to crunch data, produce literature, and widely disseminate findings that will educate and inform ME diagnosis and treatment.
- Launching a Leadership Development Program with support from the Ford Foundation that will train #MEAction volunteers to play more integral and targeted roles in advocacy, research, medical education, and #MillionsMissing efforts.
- Entering new strategic partnerships that will enhance our work in ME, Long COVID and post-viral illness spaces, and deepen our impact in BIPOC and underserved communities.
- Engaging #MEAction members in fun, informative events and providing more targeted opportunities for member input into #MEAction programs and activities.
- Making #MEAction resources even more accessible to the wider disability community, including testing the effectiveness of these tools through feedback offered by users.

While our journey is long – with guaranteed twists and turns along the way! – We will work together, always, towards our Vision of a world where all people with ME have access to compassionate and effective care.

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FINANCIALS

We are pleased to share our Yearend September 2020 Audited Financial Statements completed by Moss Adams LLP.

To the Board of Directors
The Myalgic Encephalomyelitis Action Network

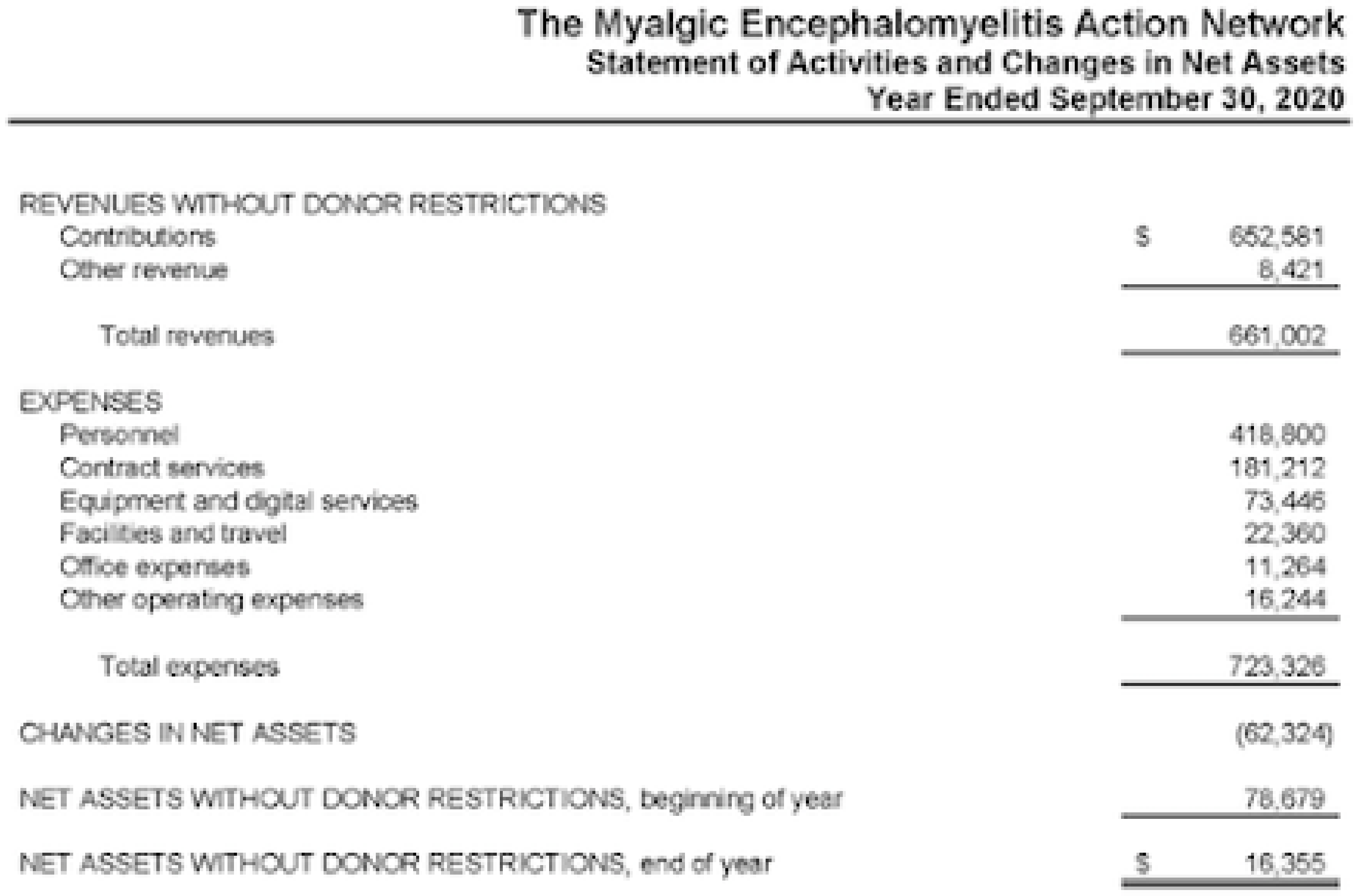
Report on Financial Statements

We have audited the accompanying financial statements of The Myalgic Encephalomyelitis Action Network ("MEAction"), which comprise the statement of financial position as of September 30, 2020, and the related statements of activities and changes in net assets, functional expenses, and cash flows, for the year then ended, and the related notes to the financial statements.

Opinion

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of The Myalgic Encephalomyelitis Action Network as of September 30, 2020, and the changes in its net assets and its cash flows for the year then ended, in accordance with accounting principles generally accepted in the United States of America.

Moss Adams LLP
May 21, 2021 - Sacramento, California



The Myalgic Encephalomyelitis Action Network
Statement of Activities and Changes in Net Assets
Year Ended September 30, 2020

REVENUES WITHOUT DONOR RESTRICTIONS	
Contributions	$ 652,581
Other revenue	8,421
Total revenues	661,002
EXPENSES	
Personnel	418,800
Contract services	181,212
Equipment and digital services	73,446
Facilities and travel	22,360
Office expenses	11,264
Other operating expenses	16,244
Total expenses	723,326
CHANGES IN NET ASSETS	(62,324)
NET ASSETS WITHOUT DONOR RESTRICTIONS, beginning of year	78,679
NET ASSETS WITHOUT DONOR RESTRICTIONS, end of year	$ 16,355

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