#ME ACTION

2019
ANNUAL REPORT

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ME Action Letter

What a year it's been!

With your help, #MEAction has made strides forward in our work towards equitable research funding, access to compassionate and effective medical care for all people with ME, and widespread public awareness.

To accomplish these goals, we're building on all our previous work to build a grassroots, global movement of people with ME and all our allies to leverage the power of technology, community and creativity to push for change. We know that together we are strong enough to bring about the change we need.

We know that our strength rests on the collective shoulders of our incredibly hard-working staff and all of you: so far, over 50,000 activists have taken part in at least one action with us! #MEAction continues to grow, bringing our determination, passion, and our A game to the fight.

And we won't stop pushing until all we achieve health equity for people with ME.

Thousands of activists across the world took part in #MEAction actions this year. U.K. Parliament and U.S. Congress listened to people with ME, as well as to caregivers and fellow politicians. We challenged U.S. federal agencies to accelerate the pace of research and care. We promoted our continuing medical education course to educate our doctors, nurses and health practitioners about ME with Postcards to Doctors. Our #MillionsMissing global protest in May saw participation from nearly 100 cities!

We've got our eyes on the horizon, but before we tackle 2020, let's take a moment to celebrate all of our hard work of 2019. We cannot possibly cover everything but we've highlighted some of the big actions from this year.

Thank you again for all that you do! **Together we will REACH more people, CONNECT the community, EDUCATE medical practitioners, ADVOCATE for research, treatments, and a cure, and INSPIRE new scientists to join the field.**

02

ME Action

2019 Highlights

HIGHLIGHTS

SUPPORTED

#MillionsMissing events in 90 cities on six continents and collected **your stories** for #MillionsMissing 2019.

ORGANIZED

178 advocates to storm the halls of Congress calling for change for ME during **Advocacy Day**. We held a total of 187 meetings with congressional offices!

ACHIEVED

a hard-earned victory: the passing of the bipartisan **U.S. Senate Resolution for ME/CFS**, the first piece of U.S. legislation that has ever been passed for ME/CFS exclusively. The passing of this legislation was the culmination of three years of intense advocacy efforts.

MOBILIZED

thousands of constituents in the UK and collaborated with Members of Parliament to initiate a series of debates, culminating in a **historic House of Commons debate in January**. Forty MPs passed a motion to support biomedical research and care for people with ME.

BUILT

committees of experienced volunteers and staff to develop impactful strategies for advocating for our government agencies to fund research and improve care. We developed our **NIH** and **CDC committees** in the US, and NICE committee in the UK.

SURVEYED AND REPORTED to NICE

on patients' experiences at ME clinics in the UK produced **a response to their request for review** and continued to push for immediate action to ensure that people with ME are not subjected to harmful "treatments" such as GET and CBT.

DEVELOPED

our U.S. State Chapter program, launched with the goal of creating chapters in all fifty states.

REACHED

7.6 million people through social media impressions. We're using online tools to connect, foster conversation, and educate our 76,036 followers.

EDUCATED

hundreds of clinicians, nurses, social workers and medical students through 34 screenings of the ME documentary, ***UNREST***, in 32 cities across the world.

LAUNCHED

our **Postcards to Doctors Initiative** for the community to send postcards to doctors all over the U.S. to educate them about ME. Within one month of launching, we had sent out 3,500 postcards, and we have now reached our year's end goal of **6,000 postcards sent**!

INSPIRED

a new generation of researchers to join the field through our fellowship programs for clinicians and medical students, giving talks at **NIH's Young Investigator's Workshop** and **Stanford's Collaborative Team Meeting** and sending three clinicians to the NIH conference on scholarship.

RELEASED

our **2019 Research Summary** reviewing the most current and important research into ME over the past 10 years. The summary serves as an invaluable resource for clinicians, health officials, government leaders, journalists and the ME community to understand the scientific findings of ME.

03

ME Action

Reach

REACH: PRESS

In 2019, more than 60 press outlets wrote about the #MillionsMissing campaign and the story of people with ME. We made national news, with stories in the BBC, CNN, Evening Times, Daily Mail and National Pain Report.

We received local coverage, too, including major outlets like the Herald Scotland, Lancaster Guardian, The Sheffield Telegraph and Shanghai China News.

Together, we fight stigma against ME!

#MEAction fought back last March when Reuters published an editorial gaslighting the ME community for our stance on the PACE trial, which has been resoundingly criticized for its poor methodology by the research and patient community alike. We published a letter exposing the bias and misinformation in the Reuters editorial, and rallied around our community.

REACH:
SOCIAL MEDIA

#MEAction reaches a community of more than 40,000 people through our social media and communications efforts.

MEpedia, our ME wiki, contains 2,750+ articles and has been viewed more than 16 million times! MEpedia includes not just articles, but links to our primers for journalists, doctors and researchers, patients, and the public.

Thousands of people around the globe took online actions by signing a petition or sharing an action demanding change for people with ME.

REACH:
UNREST
Continuing Medical Education

#MEAction launched its Unrest Continuing Medical Education (CME) course last October to educate doctors, nurses and social workers about ME. Nearly four hundred clinicians have signed up for the Unrest CME thus far, including many who told us that your postcards reached them!

Since Unrest debuted, you have arranged for hundreds of screenings worldwide. This year, you organized 34 screenings in 32 cities! 125 medical students learned about ME at an Unrest screening in Belfast, and Italy held its first Unrest screening in Turin.

Never underestimate the power of the personal. Whether they view Unrest as part of CME or as a stand-alone experience, more clinicians and researchers know about ME than ever. Together we are changing ME care, one clinician at a time.

04

ME Action

Advocate

ADVOCATE:

Over the past year, #MEAction USA has focused on developing our committees to build a stronger foundation for our advocacy work.

We've expanded the work of our NIH committee and launched our CDC committee. These committees bring together experienced staff and volunteers to identify ME policy challenges and opportunities, demand increased agency transparency and meaningful stakeholder engagement, and hold government officials accountable for delivering real outcomes for people living with ME.

ADVOCATE: The National Institutes of Health

In December 2018, we met with NIH Director Francis Collins and called on him to take bold leadership and develop a comprehensive, strategic plan for accelerating research with the goal to deliver the first biomarkers and FDA-approved treatments within five years.

#MEAction representatives accepted invitations to serve on two NIH-led committees: a ME/CFS Conference Planning Committee for a scientific conference at NIH in April 2019, and a yearlong NINDS ME/CFS Working Group of Council that published its recommendations for ME in Sept. 2019. As part of the latter process, #MEAction submitted a 37-page response to NINDS request for information on how best to advance research for myalgic encephalomyelitis. Since the publication of the NINDS Council report, #MEAction has stated that it is far from adequate, and we are launching a campaign to call for the NIH to take real outcomes-driven ACTION for people with ME.

ADVOCATE: Center for Disease Control & Prevention

In August 2018, #MEAction published a petition calling for the CDC to immediately halt its plan to issue a non-competitive (sole-source) contract for conducting a literature review for ME to a vendor who made serious missteps during a previous federal (AHRQ) contract in 2014. More than 8,000 people signed the petition. In Sept. 2018, the CDC re-opened the contract for competitive bid, but only provided a weeklong extension. #MEAction worked with the New York State Department of Health (NYSDOH) AIDS Institute to submit our own bid for the contract, which was ultimately rejected.

In June 2019, we launched dual advocacy actions calling on Congress to increase research funding for ME through the CDC, and we published an open letter to the CDC calling them out for insufficient transparency and accountability in their regular stakeholder engagement calls with the ME community. The CDC later announced future calls would include time dedicated to live question and answers which had been one of our demands.

In July 2019, we formed a formal CDC volunteer committee and, in August, sent the CDC a letter outlining our concerns about the lack of progress on many of the agency's ME/CFS projects, as well as the lack of transparency and engagement with the community regarding these projects. We called on the CDC to act with extreme urgency to educate medical groups and providers about the CDC's recently updated guidelines; and to undertake a large-scale, comprehensive epidemiological study in order to better understand the prevalence and risk factors of ME.

#MEAction calls on the CDC to act with transparency, engage the ME community and step up progress on its ME/CFS initiatives.

ADVOCATE: Congress

#MEAction Congressional Team had an action-packed year advocating Congress to take action on ME.

In November, #MEAction and nine other ME/CFS organizations sent a letter to our champions in the House of Representatives requesting they create legislation for ME/CFS. It was the largest coalition of ME advocates ever to come together to call on Congress to address the ME crisis.

We celebrated with a **big WIN** in December when 42 members of Congress signed a letter about ME to the Department of Health and Human Services. The bipartisan, bicameral letter addressed the sudden termination of the Chronic Fatigue Syndrome Advisory Committee (CFSAC) and other pressing ME issues.

In early 2019, we partnered with the Solve ME/CFS Initiative (SMCI) and MassCFIDS to propose language and specific funding requests for the FY20 Fiscal Year. We had 46 members in the House and 20 members in the Senate sign our appropriations letters and/or support our appropriations requests to the Committees.

ADVOCATE: Congress

In the spring, #MEAction partnered with SMCI to undertake one of the largest Washington, DC ME/CFS Advocacy Day to date! On April 3rd, 178 attendees stormed the halls of Congress calling for change. Advocates held a total of 187 meetings with congressional offices! We also provided tools for people at home to call their senators and advocate via social media.

On May 23rd, by unanimous consent, the United States Senate PASSED Resolution, **S. Res. 225**, “Supporting the goals of International Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Awareness Day”. **The passing of the Resolution is the culmination of three years of intense advocacy efforts and, to our knowledge, the first Senate legislation that has ever passed for ME/CFS.**

#MEAction and SMCI also worked to have the House of Representatives introduce an identical resolution on May 22. While House rules do not allow single disease resolutions to come up for a vote, we were thrilled that four Representatives — 2 Republicans and 2 Democrats — agreed to serve as original co-sponsors.Currently, we have 12 equally bipartisan co-sponsors for H. Res. 399, and we expect to add more as we continue to advocate in the coming months!

ADVOCATE:
State Groups

In the summer of 2019, #MEAction worked to enhance and expand its U.S. State Chapter program with the goal to ensure sustainability and success for years to come. Our vision is to build an advocacy network in all fifty states to more effectively reach our local communities as well as advocate for national legislation.

We rolled out a "Chair Model" with four different roles focused on leadership, advocacy, education and events, and #MillionsMissing. We created a State Chapter Handbook and State Chapter webpages, and plan to create templates for state legislation.

Our State Chapter leaders are truly innovative and exceptional people. They are leading the charge through unique actions that move the needle and engage new advocates. Here are some of their amazing accomplishments over the past year:

ADVOCATE: State Groups

ARIZONA

#MEAction Arizona hosted its annual #MillionsMissing event in Tucson. In support of the House Resolution H.Res 399, #MEAction Arizona has been able to secure four out of nine members of Congress who represent Arizona to co-sponsor the resolution. Their goal is to get all nine!

CALIFORNIA

#MEAction California has set itself the goal of fighting for a statewide Centers of Excellence program to train ME specialists, provide treatment for people with ME, and undertake advanced research. Activists have already met with 24 state legislators across the state to discuss this initiative. Advocates have also attended four Universities of California Board of Regents/Health Services Committee to call for the UC hospitals to provide better care for people with ME, and UC medical schools to educate their doctors about ME.

COLORADO

In February, in response to the federal Chronic Fatigue Syndrome Advisory Committee (CFSAC) being disbanded, Senator Bennet's staff worked with #MEAction Colorado to craft a Colorado-specific letter to HHS. Senator Bennet's office then contacted all Colorado Members of Congress and gained support from 5 of them. Later in the year, #MEAction Colorado worked to support a ME resolution introduced by the Rotary Club International, and also rolled out its monthly newsletter.

GEORGIA

#MEAction Georgia members participated in two #MillionsMissing events in 2019 along with multiple online protests. The team also hosts two monthly calls, one that focuses on advocacy work and the other on support.

FLORIDA

#MEAction Florida hosted a large #MillionsMissing demonstration in Orlando, and received a proclamation signed by Gov. DeSantis recognizing May 12 as Myalgic Encephalomyelitis Day. #MEAction Florida has also been busy sending Unrest postcards to our Senators (Marco Rubio and Rick Scott) as well as to our doctors to educate them about ME!

NEW YORK

In October 2018, #MEAction New York organized a protest outside the conference where Per Fink was presenting on his unscientific theory of Bodily Distress Syndrome, which includes ME and various other diseases. (Medical providers received Continuing Education credit for attending Fink's presentation!) More than 10,000 people signed the #MEAction petition asking Columbia University to uninvite Fink from speaking at the conference.

ADVOCATE: United Kingdom

We mobilized thousands of constituents in the UK and collaborated with Members of Parliament, Forward ME and UK charities to continue the series of debates about ME in the UK Parliament, which started last year. This culminated with an ME debate in the House of Commons in January 2019. Over 40 MPs passed the proposed motion to support biomedical research and care for people with ME in the UK.

#MEAction UK continues to push for immediate action to ensure that people with ME are not subjected to harmful “treatments”. We have also surveyed and reported to NICE on patients’ experiences at ME clinics. Moreover, we produced a response to their request for evidence for the new ME guidelines.

#MEAction Scotland brought a 7,000 signature petition to the Scottish Parliament and ME became a part of a major party platform. The petition continues to make its way through the Scottish Parliament Public Petitions process. As a result, we are now leading on consultations, in collaboration with all major ME stakeholders in Scotland, for a Scottish Government gathering views exercise, the purpose of which is to ascertain what good care for people with ME looks like, in order to inform any future progress.

ADVOCATE: Parliament

#MEAction UK worked hard to secure a historic House of Commons debate on ME in January 2019 with cross-party support. Twenty-seven MPs from across the political divide spoke passionately on behalf of their constituents.

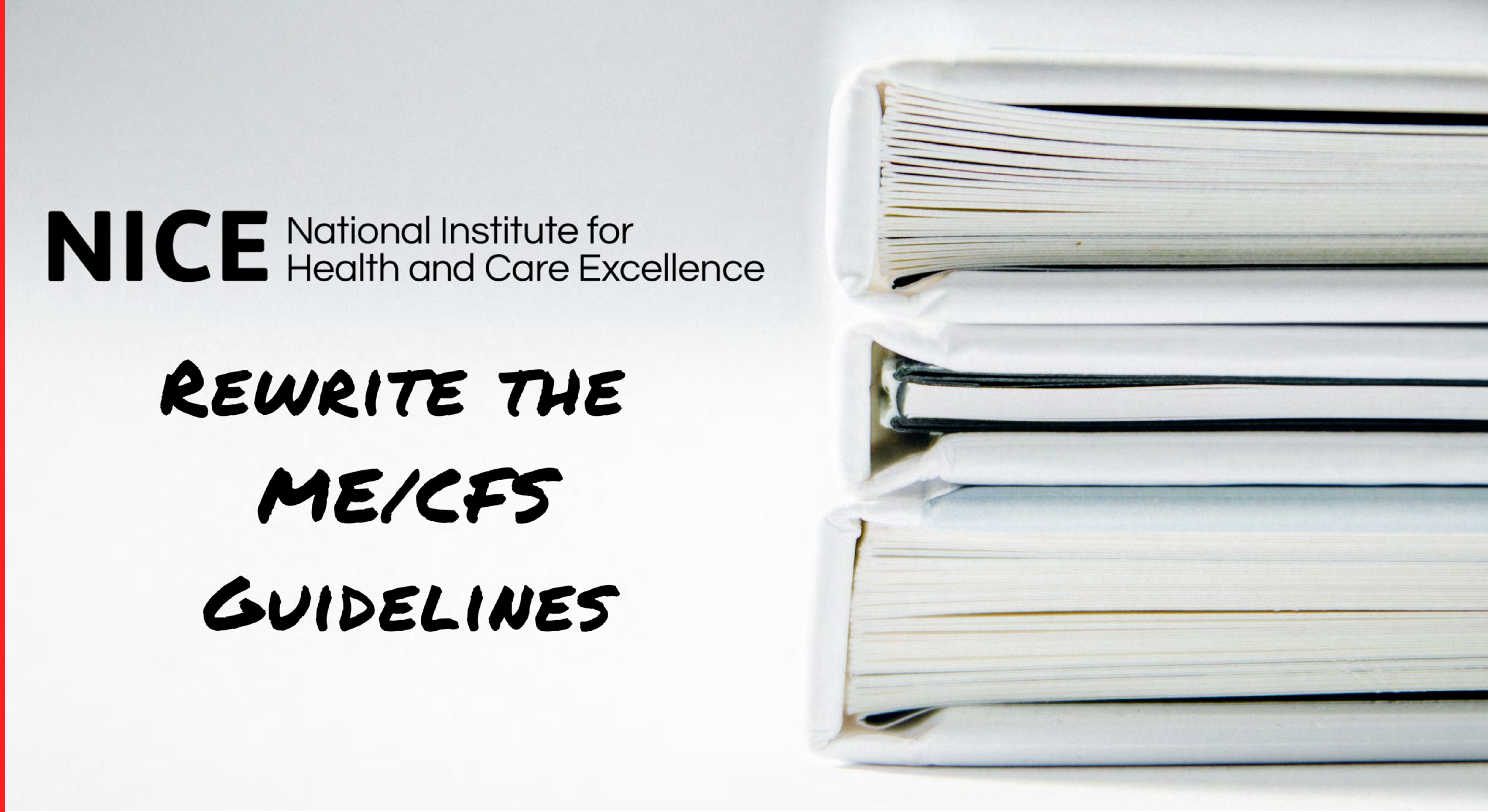
#MEAction UK launched a campaign to encourage MPs to attend the debate with over 3,000 people contacting their MP to urge them to attend.
We also mobilized the global ME community to stage a **virtual demonstration** on the day of the debate. The team also prepared a parliamentary briefing on ME for the debate tailored to the motion that would be discussed and lobbied Members of Parliament.

The motion passed with the support of 40 MPs.
It called for the government to increase biomedical research funding for ME, suspend Graded Exercise Therapy and Cognitive Behaviour Therapy, update the training of GPs to reflect international consensus on best practice, and address the current trend of subjecting ME families to unjustified child protection procedures.

ADVOCATE: NICE Guideline Reform

The National Institute for Health and Care Excellence (NICE) guidelines profoundly shape the way people with ME are diagnosed and treated in the UK. **#MEAction UK continues to push for immediate action to ensure that people with ME are not subjected to harmful "treatments" such as GET and CBT.** We launched a campaign mobilising thousands to warn NICE of the conflicts of interest held by several of the committee members tasked with updated ME guidelines. In collaboration with Forward ME and along with other ME charities, built and distributed a **survey investigating the harms caused by GET and CBT**. In response to NICE's call for evidence on ME, provided **a catalogue of research** showing the harmful effects of GET and CBT, and created, distributed and wrote **a survey and report of ME services** in the UK in which 1,900 respondents participated and which has been submitted to NICE.

#MEAction UK played a key role in producing **a survey with Forward ME Group** investigating the harms caused by Graded Exercise Therapy and Cognitive Behaviour Therapy.



ADVOCATE:
Scotland

#MEAction Scotland's petition continues to make its way through the Scottish Parliament Public Petitions process. As a result, they are now leading on consultations, in collaboration with all major ME stakeholders in Scotland, for a Scottish Government gathering views exercise, the purpose of which is to ascertain what good care for people with ME looks like, in order to inform any future progress

Had meetings with the Scottish Cabinet Secretary for Health and Sport, the Chief Medical Officer for Scotland, and the Scottish Chief Scientist Office. In addition, NHS Education for Scotland has committed to the creation of an ME education module for GPs, and the Scottish Government has pledged to update the Scottish Good Practice Statement (guidance provided to Scottish general practitioners).

05

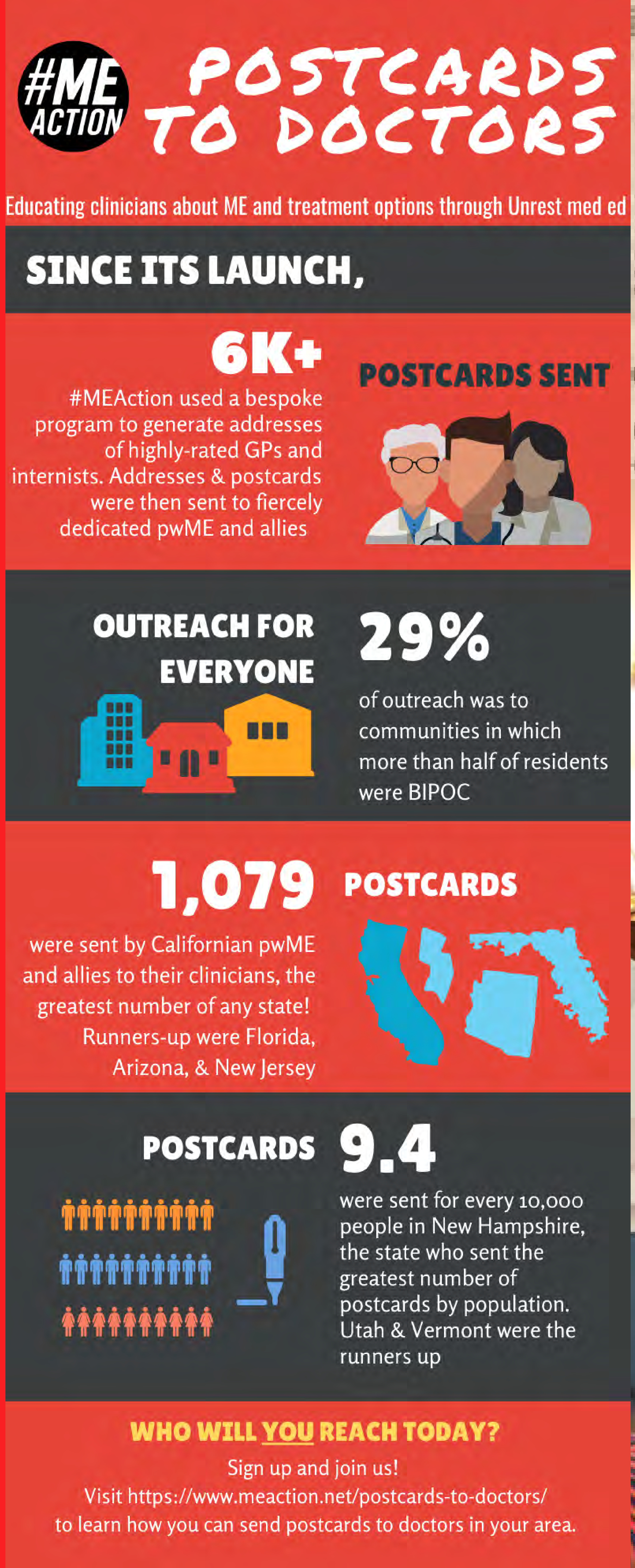
ME Action

Inspire

INSPIRE:

#MEAction launched its Postcards to Doctors Initiative for the community to send postcards to doctors all over the U.S. to educate them about ME. We worked hard to ensure we are targeting a wide range of communities, including minority, rural and veteran communities. Within one month of launching, we had sent out 3,500 postcards!

In the spring, we released our 2019 Research Summary reviewing the most current and important research into ME over the past 10 years. The summary serves as an invaluable resource for clinicians, health officials, government leaders, journalists and the ME community to understand the scientific findings of ME. We also continue to keep the community up-to-date on enrolling ME studies.
Our Director of Scientific and Medical Outreach, Jaime Seltzer, has been active attending conferences on ME across the U.S, including the conference hosted by the NIH in April, and the Stanford Conference in September where she gave a presentation on "big data and ME." #MEAction also sponsored medical students to attend the NIH conference on ME. We have also been participating in the Collaborative Research Centers group.



POSTCARDS TO DOCTORS

Educating clinicians about ME and treatment options through Unrest med ed

SINCE ITS LAUNCH,

6K+ POSTCARDS SENT

#MEAction used a bespoke program to generate addresses of highly-rated GPs and internists. Addresses & postcards were then sent to fiercely dedicated pwME and allies

OUTREACH FOR EVERYONE

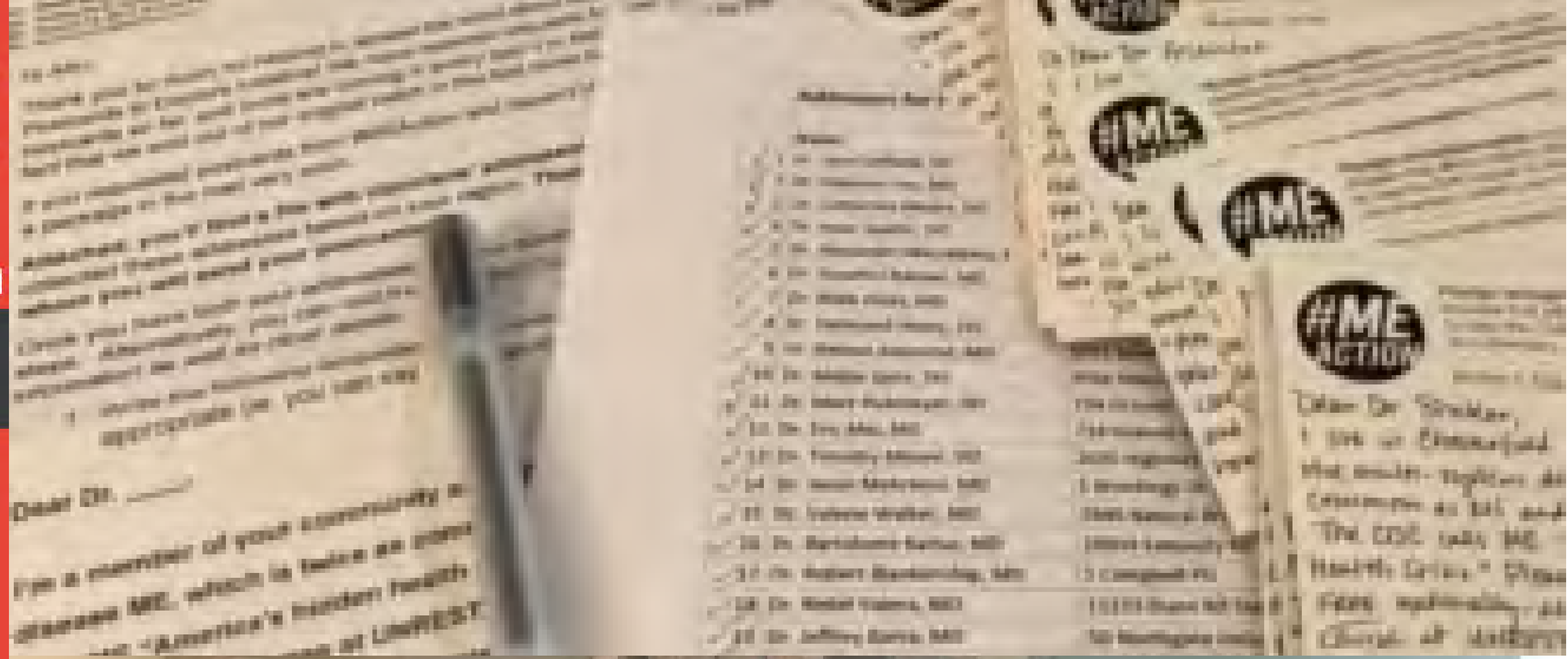
29% of outreach was to communities in which more than half of residents were BIPOC

1,079 POSTCARDS were sent by Californian pwME and allies to their clinicians, the greatest number of any state! Runners-up were Florida, Arizona, & New Jersey

POSTCARDS **9.4** were sent for every 10,000 people in New Hampshire, the state who sent the greatest number of postcards by population. Utah & Vermont were the runners up

WHO WILL YOU REACH TODAY?

Sign up and join us!
Visit https://www.meaction.net/postcards-to-doctors/
to learn how you can send postcards to doctors in your area.



POSTCARDS FOR DOCTORS: CALL FOR ARTISTS!

INSPIRE: Gratitude for our fierce and hard-working volunteers!

#MEAction couldn't continue to push for change in the halls of government, in the hearts and minds of the public, in medical schools and doctors' offices, without you. We're grateful for each and every one of you! Here are some of the amazing volunteers whose work we highlighted this year

IN AUGUST,

we shone a light on the incredible hard work of **our MEpedia volunteers, Innie and Pyrrhus!** Powered by #MEAction, MEpedia is crowdsourcing a knowledge base on the history, science and medicine with the goal to create a literature review so accurate, comprehensive, and technical that it can serve as a launching point for new scientists entering the field, as well as accessible and useful to patients at all levels of exposure to science. Our contributors include patients, allies and researchers within the ME community. MEpedia could never have come so far without our stalwart volunteers. Thank you, Innie and Pyrrhus!

THIS PAST SEPTEMBER,

we highlighted the awe-inspiring **Wilhelmina Jenkins**, who has been fighting for people with ME for four decades. "I started doing advocacy on a small scale right away. These were the days when all we had was snail mail and telephones. I joined every national group that had a newsletter, starting with one of the first groups in Portland, OR. My name and phone number were placed on a contact list the CDC had published and I received calls from all over the country," Jenkins recalls. Today, as an activist with #MEAction, she has been a key organizer with **#MEAction Georgia**, with #MEAction's CDC Committee, and with **#MEAction's People of Color with ME Group**. She also wrote an **excellent article on inclusion** for #MEAction's Values and Policy process. Thank you, Wilhelmina!

NOVEMBER'S VOLUNTEER

is **Claudia Carerra**. Claudia had an epiphany last April while watching the livestream of the National Institutes of Health (NIH) conference on ME/CFS from her bed. Having expected a major advancement, Claudia realized that at the current rate of research, a breakthrough is unlikely to happen anytime soon. "We need 10x the number of researchers investigating ME, if not 100x," she realized. Claudia joined our team of staff and volunteers spearheading our **#NotEnough4ME** campaign, which is escalating pressure on the NIH to take urgent action and address the crisis of ME after 30 years of neglect. She became active in our People of Color with ME group working to address health disparities and develop strategies to reach communities of color. Claudia helped organize a **#MillionsMissing** rally in her home state.

OCTOBER'S VOLUNTEER

of the month was **Malcolm Bailey**. "As a healthy ally I've done everything from editing videos, ordering and distributing 10,000 leaflets, managing the UK social media accounts, acted as general UK coordinator for a short time, to sourcing a pdf of an old obscure German book on polio," Bailey says didn't know much about ME until he met his current partner. "Having come to understand it more, I attended the first #MillionsMissing demonstration in London, partly as a show of solidarity and partly to see what what the levels of support were for pushing advocacy and change in the UK. Although there are many great charities and organisations related to ME/CFS, I decided to volunteer my time with #MEAction [because], being primarily an IT nerd, #MEAction resonated with my skills. As an organisation they 'get' online and social media advocacy. What is being achieved with very limited resources is pretty amazing." Thank you so much, Malcolm!

INSPIRE: Cultivating New Knowledge

We're motivating a new generation of researchers to join the field through our outreach and fellowship programs.

Last year, #MEAction sponsored 3 medical students and clinicians to engage in ME research through our #MEAction Blue Ribbon Fellowship and #MEAction Young Investigators Fellowship.

We published a white paper about the harmful effects of graded exercise therapy and cognitive behavioural therapy on people with ME. Finland has used this document to fight to protect children with ME from being separated from their parents when they refuse to subject their children to these potentially harmful treatments.

Our **MEpedia** resource continues to grow, serving as an online wiki encyclopedia of the science and history of ME and related diseases. To date, our 2,751 articles have been viewed over 16 million times!

This page was created by volunteers like you! Help us make it even better. To learn more about contributing to MEpedia, click here.

Join the movement: Visit #MEAction to find support or take action. Donate today to help us improve and expand this project.

Welcome to MEpedia

MEpedia is a project founded by MEAction, powered by the patient community, and built by volunteers including patients, students, and researchers. We are crowd-sourcing a knowledge base on the history, science and medicine of ME, CFS, and related diseases. Jump in!

About MEpedia | Become an editor

MEpedia's 2,846 articles have been viewed 19,575,386 times.

#MillionsMissing2019

This past May, 2019, an astounding 90 cities held demonstrations across 6 continents, calling on their governments to invest in ME research and medical care. Thousands more protested on social media from their beds. Organized by #MEAction, this is the fifth global #MillionsMissing demonstration in three years.

We will continue to take to the streets until our government addresses the ME crisis.

#MillionsMissing is a joyous, sometimes emotional time for the community, but people with ME are paying the price for the precious energy they gave to organize, support, attend and protest virtually.

Thanks to the efforts of our organizers, the #MillionsMissing were featured by 63 news outlets, including the BBC, CNN, Evening Times, Daily Mail, and many more.

In addition to raising awareness and pressuring governments to take action, #MillionsMissing events are invaluable opportunities to forge local community and reach patients who are undiagnosed.

“When you’re in the middle of it, it’s hard to tell what change looks like,” said #MEAction co-founder, Jennifer Brea. “Well… this is what change looks like. And it’s coming faster and faster every year.”

#MillionsMissing 2019 USA

Cities across the United States showed its heart for ME in beautiful and moving #MillionsMissing demonstrations. Researchers and clinicians turned out to speak about the urgent need to address this crisis with real action. Members of Congress tweeted out their support for people with ME!

A gathering of students took place in **Bayamón, Puerto Rico**. The New York State Department of Health Clinical Education Initiative **tweeted** out its support for the **New York City** protest. **Boston** staged a lie down in the Commons. **Orlando** lit up the iconic Orlando Eye lit up blue for ME.

Tulsa, Oklahoma formed a heart and took a photo via an overhead drone. **Minneapolis** lit up a bridge blue in solidarity. **Atlanta** displayed giant balloons forming the number “5813” to indicate the number of people diagnosed and undiagnosed with ME in Cobb Country where the rally took place.

#MillionsMissing 2019 USA

Austin held a small, indoor rally in solidarity. **Tucson** held an art auction benefiting ME, and the mayor presented a proclamation. **Denver** displayed shoes on the steps of the capitol building. **Salt Lake City** demonstrated at its state capitol.

In California, **San Francisco** demonstrated on the steps of city hall where researchers and clinicians spoke with urgency about the need for the government to step up. **Santa Monica** held a rousing rally. **San Diego** gathered to raise awareness at an indoor mall.

Portland, Oregon hosted a table at the Beaverton City Library and gave out #MillionsMissing bookmarks. **Seattle** gathered in a park, displaying 73 shoes with tags describing the lives of people with ME.


PYLE
MILLIONSMI
ME


#MILLIONS MISSING
FUND RESEARCH
I'M IN Austin TX
#CanyouseeMEnow?


Millions ARE TOO ILL to BE HERE. #MillionsMissing
MISSING


MILLIONS


Campaigning in Southampton for the
Equality, Treatment & Research for M.E.
#MILLIONS MISSING
#ME Action
ME is solitary confinement


I'M MISSING MY
Doctors Ignore M.E. WILL YOU? MEACTION.NET
#NoHope
HEALTH EQUALITY for ME/CFS! Myalgic Encephalomyelitis PATIENTS MATTER!
WE ARE FIGHTING FOR OUR LIVES!
WE ARE THE #MILLIONS MISSING FROM OUR LIVES!
WE BELIEVE IN LIFE BEFORE DEATH
Myalgic Encephalomyelitis
#MillionsMissing
MEDICAL PROVIDERS:
- SHOW COMPASSION
- SCIENCE NOT STIGMA
- BELIEVE US
- LEARN ABOUT ME
Myalgic Encephalomyelitis
#MILLIONSMISSING
www.MEAction.net


#MILLIONS MISSING
FUND RESEARCH
#MILLIONSMISSING
#ME ACTION
DON'T TELL US TO 'GO SLOW'
Stop the HARM
#MILLIONSMISSING
A Campaign for Health Equality
I'M ONLY 31 YEARS OLD AND I'VE ALREADY BEEN SICK FOR 12 YEARS.
BUT IT HASN'T TAKEN MY HOPE OR STRENGTH.
#MILLIONS

#MillionsMissing 2019 UK

2019 was the largest #MillionsMissing protest in the UK with events held in **30 cities** across the country from London to Glasgow, Southampton to Leeds!

The #MillionsMissing hashtag **trended** in the UK. Over twelve MPs spoke at demonstrations. Mass lie downs took place across the country to show solidarity for those with severe ME. Carol Monaghan MP applauded the movement, saying, "I want to pay tribute to all the campaigners here. With enough pressure, governments are forced to put money into research."

Glasgow hosted Stuart Murdoch, lead singer of the group Belle and Sebastian, who has ME. A choir sang at the demonstration in **London.** **Sheffield** lined up hundreds of pairs of empty shoes outside city hall to represent those missing from their lives due to ME. In **Southampton**, around 75 #MEAction volunteers and supporters attended the event and spoke to over 300 members of the public to raise awareness.


#ME ACTION
UNITED KINGDOM
#MILLIONS MISSING
FUND BIOMEDICAL RESEARCH
into myalgic encephalomyelitis
in line with its prevalence and severity
NORWICH City Council
DOWNLOAD


20
MISSING


#MILLIONS MISSING


#MILLIONS MISSING
FUND M.E. RESEARCH NOW!


#MILLIONS MISSING
Equality, Treatment & Research for M.E.
Thorntons
CAN YOU SEE ME


FUND RIGOROUS M.E. RESEARCH
Won't You Come See About ME
CAN YOU SEE ME NOW?
MISSING

#MillionsMissing 2019 Asia Pacific

Australia hosted several #MillionsMissing events throughout the country, including Sydney, Melbourne and Perth. Palm Cove hosted a screening of the ME documentary, Unrest.

Tokyo hosted a #MillionsMissing event where it promoted petitions calling on parliament to fund ME research. A small and mighty group demonstrated in Hong Kong this year!

New Zealand held a **coordinated** country-wide virtual protest.

#MillionsMissing 2019 Europe

#MillionsMissing events across Europe were both big and small, and very creative. From joining hands in **Bilbao** to a large concert in **Berlin**, the #MillionsMissing events in Europe raised the profile of ME.

Italy, France, Germany, Belgium, Spain, Sweden, Czech Republic, Switzerland, Denmark, Norway, and Finland all had visibility actions! New countries participated for the first time, which is thrilling, making ME more visible around the world!

#MillionsMissing 2019 Latin America & Africa

Mexico City and **Santiago** both organized #MillionsMissing demonstrations. #MEAction is so excited to see the #MillionsMissing movement growing strong in Latin America.

Several virtual events took place in **South Africa**.

#MillionsMissing 2019 Virtual

Virtual Actions are the backbone of our work at #MEAction since our community spreads across the world, and is often homebound. Hundreds of community members showed up from their beds in solidarity of the #MillionsMissing protest.

THANK YOU

#ME ACTION